

**Sudden Unexpected Deaths in Infancy:  
the New South Wales Experience**

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## Convenor's foreword

Over the past two decades there has been a marked decline in the number of infant deaths in New South Wales. This decline has been largely due to the determined efforts of a number of services and the community working together. Nevertheless, sudden unexpected infant deaths remain the second largest group of possibly preventable deaths of children and young people under 18 years.

Providing an appropriate response to sudden unexpected infant deaths is complex and presents many challenges for the professionals involved.

This report details the results of several studies undertaken to determine current parental practices regarding known risk factors that contribute to sudden unexpected infant deaths and to describe the policies, guidelines and practices in relation to these deaths.

The results have significant implications for both prevention efforts and the response provided by professionals when a death occurs. The Child Death Review Team has made nine recommendations aimed at refocusing prevention efforts and altering the current response system.

I would like to particularly thank Dr Elisabeth Murphy for her expertise in chairing the sub-committee which oversaw this research and the sub-committee members and Commission staff for their commitment in pursuing this research.

I would also like to thank my colleagues on the Child Death Review Team for the knowledge and skill they have brought to the Team's deliberations.



**Gillian Calvert**

Convenor, Child Death Review Team  
Commissioner for Children and Young People

January 2005

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## Acknowledgements

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## Executive summary

There has been a marked decline in the incidence of sudden unexpected deaths in infancy (SUDI) in New South Wales over the past two decades. This is largely due to the efforts of a number of services working in partnership including NSW Health, other health professionals, sudden infant death syndrome (SIDS) associations and researchers. However, incidents of SUDI still make up a large number of potentially preventable deaths of children under 18 years. On average there were 62 incidents of SUDI in New South Wales during the 2000 to 2002 period. This compares with 68 motor transport fatalities, 18 suicide deaths, and 18 deaths due to drowning over the same period.

The Child Death Review Team (the Team, CDRT) with funding from the NSW Government, undertook a research project into incidents of SUDI to consolidate existing knowledge of unsafe sleeping environments; determine current parental practices in New South Wales in relation to modifiable risk factors that contribute to SUDI; describe current policy and practice in New South Wales when responding to these sudden deaths; and identify SUDI due to assault and neglect.

The study commenced with a comprehensive literature review to examine current research and international practice and protocols relating to SUDI. This review informed the overall design of the study. The study comprised five individual components; an audit of the key information collected; an analysis of NSW agency policies and guidelines; an investigation of worker practice; an analysis of parental practices in relation to modifiable risk factors; and an analysis of SUDI resulting from assault or neglect, or occurring in suspicious circumstances.

### Overview of findings

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#### Audit of the key information collected

This study found that the data generally available for determining cause of death was dependant on the way in which the data was collected. Data on a specific item was more likely to be available if it could be sourced from a standard question or format, rather than opportunistically revealed in an open text section of a document.

The study concluded that the current New South Wales data collection could be improved by standardising documents and using questions specifically related to incidents of SUDI that have been identified in the literature and Australian and international SUDI practice standards, guidelines and protocols.

#### New South Wales SUDI policies and guidelines

This study found that while the roles and responsibilities of the various agencies responding to SUDI were clearly delineated, the response was limited when compared with key aspects identified in the literature. Limitations included: policies and guidelines relating to the support and guidance for parents were less prescriptive than those relating to investigative processes; guidelines and forms available to those responsible for collecting and recording information did not support comprehensive collection; the level of expertise required to undertake tasks was not evident in many of the policies and procedures; multi-agency case reviews occurred opportunistically, limiting the knowledge and skill available for each case and opportunities for continuous improvement; and uncoordinated monitoring and research activities, limiting prevention opportunities.

The study concluded that modifying the policies and guidelines to address the limitations identified would improve the response to SUDI in New South Wales.

### **Practices of New South Wales workers**

This study identified a range of issues experienced by workers in responding to SUDI in New South Wales. Although there was variation in the extent and intensity of issues experienced across participants, three main areas for improvement were identified.

Firstly, responding workers did not always have the knowledge and experience required to undertake stressful roles. Secondly, the information required to undertake the essential tasks of autopsy, attribution, monitoring and research varied in quality and comprehensiveness. Thirdly, continuous improvement in New South Wales was restricted by limitations in the information available and the lack of systems to convey this information to those who required it.

The study concluded that the response to SUDI in New South Wales could be improved. Some workers were placed in situations which they were ill-equipped to handle, leaving them exposed and parents poorly supported, accurate determination of cause of death and prevention efforts were thwarted and the capacity for learning and continuous improvement diminished.

### **Modifiable risk factors and parental practices**

The literature has consistently identified placing infants on their back for sleep, allowing infants to sleep with their heads uncovered, keeping infants smoke-free before and after birth, and not co-sleeping and smoking as safe sleeping practices for infants.

Not surprisingly research demonstrates that the knowledge that parents had of risk factors; information provided by health professionals; printed material distributed by hospitals; the attitudes and behaviours of nurses and midwives; and whether alternative infant settling techniques were provided, all contributed to the decisions parents made.

The results of the analysis of the *NSW Child Death Register* indicated that in almost 90 per cent (86.6%) of SUDI cases modifiable risk factors were present. These included unsafe sleeping positions (40.9%); exposure to tobacco smoke during pregnancy and/or after birth (57.5%); head coverings (59.7%); and co-sleeping in combination with smoking and/or substance use (25.8%).

The analysis of the *NSW Child Health Survey* revealed that 37.7 per cent of infants in New South Wales were put for sleep in unsafe sleeping positions (32.0% on their side, 3.2% face-down, 2.5% in other or multiple positions). In 31.2 per cent of households there was someone who smoked. Among mothers, 12.8 per cent reported smoking in pregnancy. The most consistent relationship found was with mother's level of education, with the likelihood of safe practices increasing with increases in the level of mother's education.

The study concluded that information campaigns may not be reaching some groups and should be modified to target specific groups of the population. In addition benefits would be achieved by refocusing prevention efforts to stop the practice of putting infants for sleep on their sides.

### **Infant deaths and fatal assault and neglect**

The extent and quality of information on the deaths examined in this study severely limited the Team's ability to accurately identify all deaths due to assault or neglect and those that occurred in circumstances suspicious of assault or neglect. Within this limitation, the deaths of three (1.6%) infants were identified as due to assault and

nine (4.9%) from neglect. For a further 50 infants, it was not possible to determine with any confidence whether the deaths were due to assault and neglect or not.

Deficiencies in agency practice were identified in the deaths of infants that occurred as a result of assault or neglect including: failure to recognise and report serious and unstable situations; inadequate risk assessment including overestimating a parent's ability and their capacity to change; inadequate case planning, including providing a suitable sleep environment for infants; and poor interagency collaboration and coordination.

The study concluded that better information gathering and sharing of the information gathered could assist in the investigation of SUDI cases, and reduce the number of these deaths where the cause of death is undetermined.

### Implications and recommendations

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It is clear from the analysis undertaken of parental practices in relation to modifiable risk factors that a substantial number of infants under one year of age continue to be exposed to modifiable risk factors for SIDS and SUDI. The findings suggest that information campaigns highlighting risk factors for SUDI may not be reaching some groups as effectively as others.

**Recommendation 1:** The NSW Government and SIDS and Kids NSW should use prevention strategies that are effective with the high-risk groups identified in this study.

It is noteworthy that this study found that the majority of infants not put on their backs for sleep were put on their sides.

**Recommendation 2:** The NSW Government and SIDS and Kids NSW should place more emphasis on the risk associated with the side-sleeping position in prevention strategies.

Post-implementation evaluation should be undertaken for these two recommendations to assess their success.

The attitudes and behaviours of nurses and midwives influence parental behaviours. The research is clear that if mothers know that a particular behaviour is a risk factor for SUDI they are more likely to refrain from that behaviour.

**Recommendation 3:** NSW Health should monitor safe sleeping practices including the use of the side-sleeping position, used by health professionals in maternity and neonatal wards.

To provide parents with safe and appropriate infant care advice, health care professionals need to have the knowledge, attitudes and practice consistent with the known risk factors for SUDI and the *Reducing the Risk of SIDS* messages. This requires that health professionals have access to the best available evidence and a commitment to best practice, and that agencies impart this information in the most effective way.

**Recommendation 4:** Professional bodies and NSW Health should disseminate information regarding modifiable risk factors for SUDI. This should be preceded by a study which investigates the most effective methods to disseminate this information.

Information is required on sudden and unexpected infant deaths, and on parental practices in relation to modifiable risk factors to assist research efforts and enable patterns and trends to be identified and targeted.

**Recommendation 5:** The New South Wales Health Survey Program should continue to collect information on SUDI and SIDS risk factors and on relevant social and demographic characteristics of parents.

The response to SUDI in New South Wales does not fully achieve important aspects considered necessary for such a response. These aspects include a balance between care and investigation; collection and recording of comprehensive information; involvement of appropriate personnel; multi-agency case review and continual improvement; and monitoring and research.

A shortcoming in New South Wales relates to the information available to the various professionals to enable them to take appropriate actions and make informed decisions, including how parents will be supported.

**Recommendation 6:** The NSW Government should align the information currently collected through the response to SUDI with internationally recognised protocols. It should emphasise multi-agency work, close collaboration and sharing of information, and be gathered by professionals with appropriate training and expertise. The Team believes that this can be achieved by the end of 2006.

Another deficiency is the assignment of the various aspects of the response to SUDI to professional groups which do not necessarily have the skill or experience to undertake them. Without this the investigative, medical and psycho-social aspects of the infant's death are not fully addressed and parents are not adequately supported.

**Recommendation 7:** The NSW Government should make sure that the tasks required are only undertaken by professionals with the appropriate role, knowledge (including up-to-date knowledge of relevant legislation, policies and guidelines) and expertise.

Advances in medical and forensic sciences have increased the ability of pathologists to identify causes of sudden unexpected death in infancy. Successful identification is based on wide and up-to-date knowledge, and considerable experience. Referral to a pathologist with specialist knowledge or experience should therefore be routine practice. Further, the tests considered necessary for the autopsy examination need to be undertaken.

**Recommendation 8:** Pathologists should follow an agreed protocol and make consistent decisions. Post-mortem examinations should only be conducted by pathologists with specialist knowledge or experience, for example paediatric pathologists or forensic pathologists with specific training and expertise in paediatrics. The Team believes that this can be achieved by mid 2006.

Finally, the aspects of multi-agency case review and integration of the response to SUDI need to be addressed. The knowledge of a case is increased when all the available information is brought together.

An integrated system will require identifying the coordinating agency for both the response to SUDI and for the collection and sharing of the SUDI case information between the relevant agencies. The lack of clarity of the coordination role contributed to a number of issues identified in this study including ready access to information necessary to undertake the various tasks, and difficulties in contacting professionals in other agencies. Integration will also require the roles and responsibilities of the various agencies to be clearly stated and a model of response developed and agreed.

**Recommendation 9:** The NSW Government should adopt a multi-agency integrated system of response to sudden and unexpected deaths in infancy. This will involve agreeing on a definition, clearly identifying the tasks of individual agencies and professionals, and developing a model of response. It should reflect the findings from this study and address the key aspects identified, including how to achieve the balance between care and investigation; collection and recording of comprehensive information; involvement of appropriate personnel; multi-agency case review and continual improvement; and monitoring and research. In developing the response the needs of the family should be a central consideration. NSW Health should lead the coordination of this.

The Team believes that this system should be developed by the end of 2006.

## 1.1 Background

The first year of life is more precarious than the later years of childhood and historically has been one of the periods of highest risk of death. The infant mortality rate is commonly used as an indicator of societal health and progress.

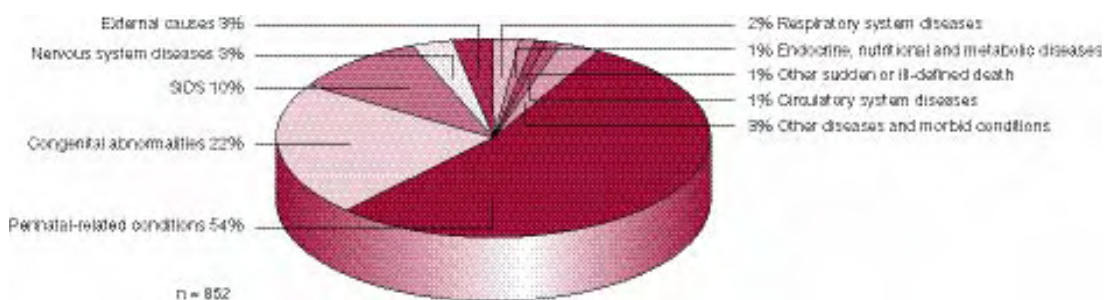
Throughout the 20th century there have been tremendous advances in the understanding of some of the factors associated with infant mortality. These include social and environmental conditions such as improvements to the standard of living, neonatal care, medical technology, surgical knowledge, understanding of the social and environmental risk factors, increases in levels of maternal education and the increased provision of services for infants and their families. The effect of these changes on infant mortality are borne out in greatly reduced infant mortality rates in Australia, from 103 deaths per 1,000 live births in 1900 to 5.2 deaths per 1,000 live births in 2000 (Australian Bureau of Statistics, 2002).

Despite these advances, infants under one year remain the most vulnerable age group of children and young people in relation to death. In New South Wales during the period 2000 to 2002, infants accounted for 57.2 per cent of deaths of children and young people aged 0 to 17 years (CDRT, 2004a). Because such a high proportion of child deaths occur during infancy, the identification of causes and risk factors has potential to make substantial inroads into reducing the overall rate of child deaths. While some factors associated with infant mortality are now well recognised, there are others that are complex and remain poorly understood. Continued improvement of our understanding of these issues offers the potential for additional advances to be made in the prevention of infant deaths.

The main causes of infant death in NSW are shown in Figure 1.1. The two leading causes of infant deaths are conditions that originate in the perinatal period and congenital abnormalities (75.7% of infant deaths when combined).

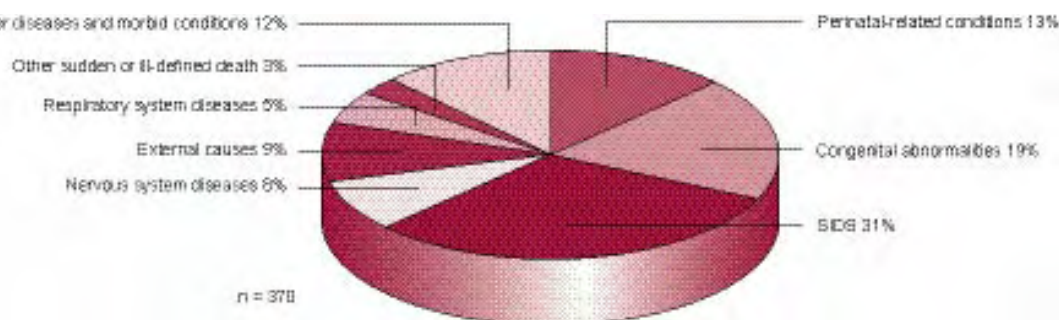
**Figure 1.1:**  
Main categories  
of infant deaths,  
NSW, January  
2000 to December  
2002

*Source:*  
Australian Bureau  
of Statistics,  
Deaths, 2000 to  
2002 (unpublished  
data)



Approximately two-thirds (69.7%) of infant deaths occur before the infant is 28 days old (Australian Bureau of Statistics, 2004). When these neonatal deaths are excluded a different picture emerges. Figure 1.2 shows that SIDS is the leading cause of post-neonatal death, accounting for close to a third of deaths in this age group (31.1%).

**Figure 1.2:** Main categories of post-neonatal infant deaths (death at or after 28 days), NSW, January 2000 to December 2002



Source: Australian Bureau of Statistics, Deaths, 2000 to 2002 (unpublished data)

## 1.2 Sudden and unexpected infant deaths

Over the period 2000 to 2002 deaths that occurred suddenly and unexpectedly accounted for 15.7 per cent of infant deaths (CDRT, 2004a). For some of these deaths a cause may be found after a comprehensive autopsy and examination of the circumstances of the death. For others no clear cause can be determined and many of these are classified as SIDS.

### 1.2.1 Classification of sudden and unexpected infant deaths

The classification of sudden and unexpected deaths in infants has several inherent challenges. Accurate classification of infant deaths can be hampered by an inadequate response to the death, resulting in insufficient information to make a determination of the cause of death and by differences in the application and definition of death classifications.

Determination of cause of death is dependent on: the completeness of the information available, including clinical history and environment and circumstances of the death; resources available to the pathologist; and the expertise of the person undertaking the autopsy. For example, a specialist pathologist with access to the infant's full social and medical history, a thorough death scene investigation report and resources to conduct full histological and microbiological studies as part of the autopsy may ascertain a cause of death that would not have been identified by other pathologists who did not have such detailed information available to them. Therefore, a lack of detailed information may lead a pathologist to incorrectly classify an infant death.

The lack of standard and uniform approaches in the response to and investigation of infant deaths has been documented in Australia (Byard, 2001), the United States (American Academy of Pediatrics, 1999, 2001), the United Kingdom (Fleming, Blair, Bacon, Platt & Berry, 2000; Lancet, 1999) and Europe (Rognum, 1996; Hatton, Bouvier-Colle, Barois, Leroyer, Bouvier & Jouglu, 1995). Experts in the field have increasingly called for the application of international standards and guidelines in these areas (American Academy of Pediatrics, 1999, 2001; Fleming et al., 2000; Centers for Disease Control and Prevention, 1996).

In addition there is disagreement about an appropriate definition for the classification of SIDS. Bacon (2000) argues that the ambiguous definition of SIDS has inevitably led to inconsistencies in the application of the SIDS classification in the certification of death. These inconsistencies exist at international, state and local levels, making comparisons of SIDS data over time and across jurisdictions problematic.



### 1.2.2 Sudden infant death syndrome (SIDS)

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There is currently no universally agreed definition for SIDS. Some of the reasons for the difficulties in achieving an agreed definition result from the different perspectives of the various professions. Epidemiologists, especially when comparing different SIDS rates across countries, exclude autopsy examination from the definition to overcome artificially low rates in some countries. Pathologists usually demand the inclusion of a full autopsy, toxicology, radiology, bacteriology and virology and often insist on a death scene investigation. Paediatric definitions relate to the most likely cause of death. Legal definitions exclude non-accidental injury unless it has been legally proven. The social definition seeks to take account of the impact of a diagnosis on the infant's family.

Over the last few decades numerous definitions have been proposed. The key differences in these definitions relate to:

- the age at time of death;
- an association with sleep;
- the requirement of a death scene investigation;
- the requirement of a review of the clinical history; and
- the requirement of an autopsy.

In 1969, the United States National Institute of Child Health and Human Development (NICHD) held the Second International Conference on Causes of Sudden Death in Infants. The term SIDS was coined and the definition developed by the pathologist Beckwith was disseminated:

*The sudden death of an infant or young child which is unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause of death (Beckwith, 1970).*

In 1989, the NICHD convened an advisory panel to reconsider the definition of SIDS, giving consideration to the research findings of the previous two decades. The revised and more qualified definition, proposed by Willinger in 1991, was as follows:

*The sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including the performance of a complete autopsy, examination of the death scene, and review of the clinical history (Cordner & Willinger, 1995).*

This definition recognised research findings that:

- 90 per cent of SIDS deaths occurred in infants under six months of age and less than two per cent were over one year;
- SIDS infants had a high frequency of infections and cardio-respiratory abnormalities; and
- death scene investigations and analysis of medical and family histories had been vital in determining possible causes of death in some cases that would otherwise have been classified as SIDS.

The Cordner and Willinger definition was endorsed by the American Academy of Pediatrics (American Academy of Pediatrics, 2001).

In 1994, a new definition was proposed at the Third SIDS International Conference in Stavanger, Norway, as a compromise between the Beckwith and Willinger definitions. The new definition, termed the Stavanger definition, required the examination of the circumstances of the death but was less specific than the 1991 Willinger definition:

*Sudden death in infancy unexplained after review of the clinical history, examination of the circumstances of death, and post mortem examination (Rognum & Willinger, 1995).*

The Stavanger definition was proposed for adoption at the Second Global Strategy Meeting in Stavanger in 1994 but failed to gain endorsement. Delegates at the conference adopted the original and broader Beckwith definition.

In January 2004, the SIDS Redefinition Conference in San Diego brought together a group of epidemiologists and paediatric and forensic pathologists to reconsider the definition of SIDS. The forum suggested that the term 'death scene investigation' be changed to 'review of the circumstances of the death' with the aim of encouraging more comprehensive assessments of the events surrounding the deaths (cited in Krous et al., 2004). The forum concluded that a review of the circumstances of the death scene included an examination of the death scene as well as an assessment of all the environments an infant may have been in before and after death<sup>1</sup>. The new definition of SIDS was as follows:

*The sudden and unexpected death of an infant under one year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history (cited in Krous et al., 2004).*

The proposition that the definition of SIDS should include the requirement that the death occur 'apparently during sleep' has added to the definitional difficulties. Alternatives such as 'occurring when unobserved' have been proposed.

Debate concerning the appropriate definition of SIDS continues, with the application of the term becoming increasingly controversial. SIDS remains a diagnosis of exclusion, with some referring to the diagnosis as a 'diagnostic dustbin' (Emery, 1998, cited in SIDS and Kids, 2004). Although the syndrome has several distinctive features, including age distribution and apparent occurrence during sleep, experts have been reluctant to accept a definition that includes these features (Beckwith, 2003).

Differences in the definition and classification of SIDS remain an issue in Australia. The peak national non-government organisation on the syndrome, SIDS and Kids, has adopted the 1969 Beckwith definition. However, there is no current agreement by medical and research professionals across Australian states and territories on the most appropriate definition and classification of SIDS.

In a move to increase standardisation in the classification of SIDS throughout Australia, SIDS and Kids sponsored a national workshop of forensic and paediatric pathologists representing forensic institutions from all Australian states and territories. The workshop held in March 2004

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**Notes:** 1. It is still under discussion whether the definition should refer only to a death scene investigation or also include circumstances of the death.

unanimously endorsed the January 2004 San Diego definition and recommended its national implementation (Krous et al., 2004). The workshop further agreed to use the term ‘unclassified sudden infant death’ (USID) developed in San Diego instead of the currently ill-defined terms ‘unascertained’ and ‘undetermined’.

### 1.2.3 Incidence of SIDS

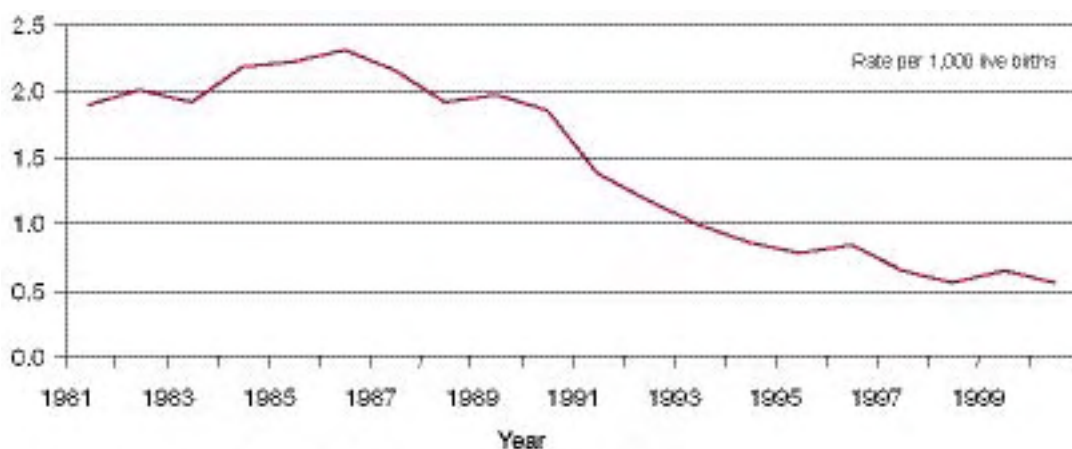
The Australian Bureau of Statistics (ABS) publish national death statistics for all age groups for deaths that occur within Australia. The 10th version of the *International Classification of Diseases* (ICD-10) is currently used by the ABS for coding of deaths. Registration of deaths is the responsibility of the individual state and territory Registrars of Births, Deaths and Marriages. Information on the cause of death is supplied to the registries by the medical practitioner certifying the death or by a coroner. For the ABS to code a death as SIDS, the term SIDS must be stated on the death certificate. Without a national uniform definition of SIDS and autopsy protocol, classification of SIDS by the ABS will be influenced by the practice of individual pathologists and their application of the term SIDS.

In New South Wales, the NSW Child Death Review Team (the Team, CDRT) is charged with reporting on all child deaths registered in the state. Unlike the ABS, the Team has access to a range of documentation in relation to each death, including the police record of death and the final autopsy report, in addition to the information on the medical certificate or information supplied by the coroner. All coronial matters (including all sudden and unexpected deaths of infants) are reviewed by a member of the Team and assigned an ICD-10 code for cause of death. The final cause of death assigned by the Team may differ from that assigned by the coroner as additional information may become available to the Team in the review process. This potential for conflicting classification is particularly relevant to SIDS. Consequently, official reports on the incidence of SIDS in New South Wales may differ depending on the source of the data and the information and criteria used to determine cause of death.

Notwithstanding the difficulties in defining and classifying SIDS, there has been a marked decline in the incidence of SIDS over the past two decades. Figure 1.3 shows the rate of SIDS, as classified by the ABS, in Australia from 1981 to 2000. During this period, the SIDS death rate fell from 1.89 deaths per 1,000 live births in 1981 to 0.55 deaths per 1,000 live births in 2000.

**Figure 1.3:** SIDS by year of occurrence, Australia, 1981 to 2000

**Source:** Australian Bureau of Statistics, *SIDS in Australia 2003*



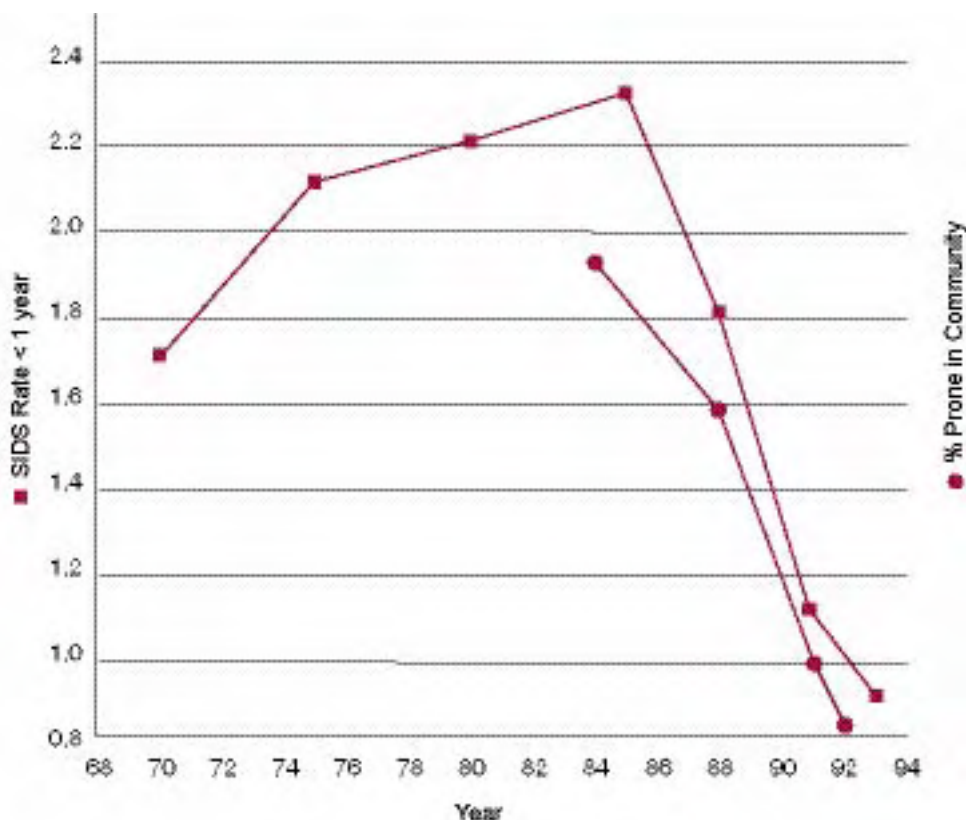
*Note: includes deaths of children aged between 1 and 3 years coded as SIDS.*

This reduction occurred following growing epidemiological evidence that SIDS was associated with placing infants for sleep face-down (Dwyer, Ponsonby, Newman & Gibbons, 1991) and

the introduction of successful public health campaigns aimed at reducing the incidence of SIDS. The association between decline in the SIDS rate and fewer infants being put for sleep face-down (in the prone position) was illustrated in South Australia (Beal, 1995). This is shown in Figure 1.4. Similar reductions in the SIDS death rates were recorded in the Netherlands, New Zealand, Nordic countries and the United States.

**Figure 1.4:**  
incidence of SIDS  
and the face-down  
sleeping position  
in South Australia,  
1995

**Source:**  
Beal, 1995



*Note: Squares indicate SIDS rate per 1,000 live births (infants under one year). Circles indicate prevalence of the face-down position for infant sleep.*

The *Reducing the Risk of SIDS* education campaign commenced in Australia in 1991 and was followed in 1997 with the launch of the *Kids and SIDS: Three Ways to Reduce the Risk* program, recommending that parents place infants on their backs for sleep, allow infants to sleep with their heads uncovered, and keep infants smoke-free before and after birth (Henderson-Smart, Ponsonby & Murphy, 1998). This was followed by a further campaign in 2000, *SIDS and Kids: Safe Sleeping*.

The success of national prevention campaigns has been largely due to partnerships between the community, the SIDS associations, researchers and health professionals. These partnerships have produced sound evidence for decisions, wide participation in programs and the provision of consistent information.

The decrease in SIDS has been largely attributed to a change in child care practices, principally parents placing their infants on their back for sleep (Englebets & de Jonge, 1990; Mitchell, Ford, Taylor, Stewart, Beecroft, Scragg, Barry, Allen, Roberts & Hassall 1992; Mitchell, Brunt & Everard, 1994; Wigfield, Fleming, Berry, Rudd & Golding, 1992; Dwyer, Ponsonby, Blizzard, Newman & Cochrane, 1995; Beal, 1995; L'Hoir, Englebets, Van Well, Westerxs, Mellenbergh, Wolters & Huber, 1998b; Skadberg, Morild & Markestad, 1998; American Academy of Pediatrics, 2000).

#### 1.2.4 Sudden and unexpected deaths of infants (SUDI)

With the ongoing debate and inconsistencies surrounding the definition and classification of SIDS, the use of the broader category of 'sudden and unexpected deaths of infants' (SUDI) for research into sudden and unexpected infant deaths has become more prominent.

The term SUDI usually includes deaths due to SIDS and other undetermined or ill-defined causes. 'Undetermined' is a relatively recent descriptive term used in the literature since the rapid decline of SIDS in most Western countries. The definition has been described by expert pathologists (Mitchell, Krous, Donald & Byard, 2000; Sturner, 1995) as: 'Death where insufficient findings were present to support a particular diagnosis but when sufficient abnormal features in the history or at the scene examination, autopsy, or laboratory work-up were found that were not typical of SIDS'. The term SUDI also includes sudden and unexpected deaths for which a cause is later found.

A death is generally classified as a SUDI if it concerns:

- an infant less than 12 months of age;
- a death that was sudden in nature; and
- a death that was unexpected.

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. Only a small proportion of incidents of SUDI occur when the infant is awake. Of the 623 incidents of SUDI in a study in Quebec, Canada, all but 21 deaths occurred while the infant was asleep, and virtually all were sudden (Cote, Russo & Michaud, 1999). These findings lead the authors to conclude that virtually all such sudden unexplained deaths may be regarded as sleep-related.

The SUDI category has several advantages over SIDS. Firstly, as SIDS remains a diagnosis of exclusion, some cases initially classified as SIDS may be reclassified as due to another cause of death at a later date after more information becomes available. Even after all possible information has been gathered it can still be difficult to distinguish between SIDS and other causes of sudden and unexpected deaths (Bacon, 2000).

Secondly, the maternal, infant and socio-demographic factors are similar in the SIDS and non-SIDS groups. However, these factors are very different in infants who die from causes other than SUDI (Bartholomew, MacArthur & Bain, 1987; L'Hoir et al., 1998b; Leach, Blair, Fleming, Smith, Platt, Berry & Golding, 1999; Fleming, Blair, Bacon, Platt, Smith & Chantler, 2000). Thus similar prevention efforts are required for all SUDI.

Another factor to consider in the selection of the category of SUDI over SIDS for research purposes is the increase in the use of the classification of 'undetermined' in recent years in Australia in relation to infant deaths (ABS, 2003). 'Undetermined' infant deaths account for a growing proportion of sudden and unexplained infant deaths.

The marked decline in the SIDS death rate over the past two decades is another reason to adopt the SUDI category. As the number of SIDS deaths declines, it becomes increasingly important to widen the focus to include explained deaths. Explained sudden and unexpected infant deaths include those associated with unrecognised infection, cardiovascular anomalies, accidents, unsafe sleep environments such as unsafe cots and bedding, rare metabolic diseases and deaths due to non-accidental injury. The benefits of broadening the prevention

and research focus include greater scope for identification of unsafe products, risky parental practices, and families with infants at risk of further harm.

### 1.2.5 Incidence of SUDI

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The classification of infant death is challenging. Not surprisingly, the reported incidence of SUDI also varies according to the classification used.

In New South Wales, the Team uses the SUDI category in its annual reporting of all deaths of children and young people registered in the State. The criteria used by the Team includes cases where the infant's death was sudden in nature and unexpected (the cause of death was not recognised prior to the death). The category is limited to infants found dead after they were placed for sleep. This definition excludes infants who die unexpectedly in misadventures due to external injury (such as transport incidents) and accidental drownings.

The Team has identified an average of 62 sudden and unexpected deaths of infants each year during the period 2000 to 2002, ranging from 56 to 68 deaths. This compares with 68 motor transport fatalities, 18 suicide deaths, and 18 deaths due to drowning over the same period.

This number of SUDI cases equates to a rate of between 0.66 and 0.77 deaths per 1,000 live births. During the period 2000 to 2002, SUDI cases accounted for approximately 12.9 per cent of infant deaths. SUDI account for 2.1 per cent of all deaths in the neonatal period and 37.8 per cent of all deaths in the post-neonatal period (CDRT, 2004a).

### 1.2.6 Causes of SUDI

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

- where infants suffocated whilst sleeping;
- due to faulty or unsafe cots;
- due to suffocation while co-sleeping with adults (some of whom were affected by drugs and/or alcohol or who smoked). (Co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purposes of feeding and settling.)
- due to SIDS;
- which were not expected but after investigation were determined to be homicides (fatal assaults);
- which were not expected but after investigation and forensic analysis were found to be due to disease processes or congenital abnormalities; and
- where the cause was undetermined.

The cause of death of SUDI in New South Wales as determined by forensic pathologists from 2000 to 2002 is presented in Table 1.1.

**Table 1.1:**  
Sudden unexpected  
deaths in infancy  
by cause of death,  
NSW, 2000–2002

Source:  
NSW Child Death  
Review Team, Child  
Death Register,  
2004a

	n	%
<b>Ill-defined and unknown causes of mortality</b>		
Sudden infant death syndrome	110 <sup>a</sup>	59.1
Other sudden death, cause unknown, and undetermined deaths	37	19.9
<b>Subtotal</b>	<b>147</b>	<b>79.0</b>
<b>Accidental threats to breathing</b>		
Accidental suffocation and strangulation	7	3.8
Other accidental threats to breathing	3	1.6
<b>Subtotal</b>	<b>10</b>	<b>5.4</b>
<b>Diseases and morbid conditions</b>		
Diseases of the respiratory system	8	4.3
Other diseases and morbid conditions	14	7.5
<b>Subtotal</b>	<b>22</b>	<b>11.8</b>
<b>Other external causes</b>		
Assault	2	1.1
Other injury, poisoning or external cause	4	2.2
Exposure to excessive heat	1	0.5
<b>Subtotal</b>	<b>7</b>	<b>3.8</b>
<b>Total</b>	<b>186</b>	<b>100.0</b>

Note: a. Fourteen of these deaths were classified as SIDS associated with co-sleeping.

Nearly four out of five SUDI cases were ill-defined or unknown (79.0%). This group includes cases of SIDS, other sudden deaths and undetermined deaths. SIDS alone accounted for 59.1 per cent of deaths, with undetermined deaths accounting for a further 19.9 per cent. This is similar to Queensland where 52.0 per cent of SUDI were classified as SIDS (Queensland Council for Paediatric Mortality and Morbidity, 2000). The proportion of SUDI classified as SIDS is lower than reported in the literature (Leach et al., 1999; Côté, Russo & Michaud, 1999; Czegledy-Nagy, Cutz & Becker, 1993). Two recent studies, both methodologically rigorous (Leach et al., 1999 and Cote et al., 1999), concur on the major categories of SUDI. Both studies showed that non-SIDS deaths (including accidental threats to breathing, diseases and morbid causes, and other external causes) comprised about 20 per cent to 32 per cent of all SUDI. While some variation would be expected due to the difficulty in accurately diagnosing SIDS the variation is more likely to result from the inadequacy of information available to determine cause of death.

The 186 deaths were explained in 21.0 per cent of cases, with diseases and morbid conditions accounting for 11.8 per cent of the infant deaths.

### 1.3 Background to the study

The Team has a legislative requirement to develop recommendations about policies and practices that can be implemented by government and non-government agencies and the community to prevent or reduce child deaths (*Commission for Children and Young People Act*

1998, section 45N). As part of its function, the Team reports annually on all deaths of children and young people aged 0 to 17 years inclusive whose deaths are registered in New South Wales. In addition, the Team identifies areas where further research is needed to prevent or reduce child deaths in New South Wales.

In its *1999-2000 Annual Report*, the Team reviewed the cases of 35 infants who died suddenly and unexpectedly after they had been placed for sleep. The purpose of reviewing these deaths as a group was to look for trends and make recommendations about systematic issues for the prevention of this category of deaths that may not be apparent when reviewing individual cases. The analysis revealed that these deaths were the second largest group of potentially preventable deaths (after transport fatalities) of children 17 years and under (CDRT, 2000).

Byard and Krous (2001) emphasise that without proper investigation the ability to uncover possible explanations for sudden and unexpected infant deaths is hampered and can lead to the deaths being incorrectly labelled as SIDS. The ramifications of such misclassifications are serious. Rare inherited metabolic diseases such as fatty acid oxidation disorders may not be identified; unrecognised unsafe sleeping environments may result in a dangerous product being left in the marketplace; undetected homicides leave other, or future, children in the family at significant risk; and parents may be wrongfully prosecuted for causing the deaths of their infants. This last outcome has been highlighted in the United Kingdom where a number of mothers were wrongfully convicted of murdering their infants (The Royal College of Pathologists and The Royal College of Paediatrics and Child Health, 2004).

The Team agreed that a research study to investigate incidents of SUDI was considered critical to understanding and prevention and in its *1999-2000 Annual Report* recommended that:

*Government fund the CDRT to undertake a research project to investigate the deaths of infants in bed. This project would include the appointment of a researcher to collect information from bereaved families at the time of the infant's death (CDRT, 2000, Recommendation 4, p. 57).*

The NSW Government responded by funding a study to be undertaken by the Team into incidents of SUDI. It was anticipated that the study would inform efforts to improve the scope and quality of the information available in New South Wales in relation to these deaths.



### 2.1 Informing the study

This study commenced with a comprehensive literature review to examine current research and international practice and protocols in relation to SUDI. The literature review drew upon published and unpublished reports and studies from Australia and overseas. The quality of the research and information reviewed varied; greater weight was placed on studies providing high-quality evidence and methodological rigour. This literature review assisted the Team in identifying priority areas to be investigated by the study and formulating the study design.

### 2.2 Aims of the study

The study aimed to: consolidate existing knowledge of unsafe sleeping environments; determine current parental practices in New South Wales in relation to risk factors that contribute to SUDI; describe current policy and practice in New South Wales when responding to these sudden deaths; and identify SUDI due to assault and neglect.

The key research questions were:

1. What gaps exist in the information collected in New South Wales for diagnostic purposes in relation to incidents of SUDI? What factors influence the availability of the information?
2. What are the strengths and limitations of the SUDI policies and guidelines in New South Wales?
3. What are the practices of New South Wales workers in responding to SUDI?
4. What is known about modifiable risk factors for SUDI? In New South Wales, what are the parental practices in relation to these risk factors among parents of infants generally and among parents of infants who die? Are there any particular groups who engage in these risk behaviours?
5. What is known about SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances?

### 2.3 Components of the study

The study was designed with multiple components:

- an audit of the key information collected to establish cause of death where an infant dies suddenly and unexpectedly;
- an analysis of relevant agency policies and guidelines;
- an investigation of worker practice;
- an analysis of parental practices; and
- an analysis of SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances.

The literature review informed the overall design, the analysis of parental practices, the audit of the key information collected and the analysis of New South Wales agency policies and guidelines. Each of these components, in turn, informed the investigation of worker practice. The final component of the study, the analysis of SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances, was undertaken independently from the other components and in accordance with standard practice employed by the Team for reviewing deaths occurring under these circumstances.

The original recommendation of the Team to include the collection of information from bereaved families at the time of the infant's death was considered unnecessarily intrusive given that the study aims could be achieved by other methods.

A brief description of the research methods employed in each study component is provided in this section. Detailed methods employed within each component of the study are outlined at the beginning of the relevant chapter.

### **2.3.1 Audit of key information**

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An audit of the key information collected to establish cause of death where an infant dies suddenly and unexpectedly was undertaken on documents used routinely in New South Wales data collection and investigation in relation to SUDI and used by forensic pathologists when forming their diagnosis of cause of death. Three documents were included in the analysis: the *Police Report of Death to Coroner (P79A)*; the *Death Scene Investigation Checklist – Sudden Infant Death (P534)*; and the *Final Autopsy Report*.

The data in these three documents were compared with an optimal data collection tool developed from the literature review and an examination of Australian and international data collection protocols. The Team examined a random sample of 81 of the 153 deaths registered between 1 January 2000 and 31 May 2002 and classified as SUDI by the Team. The sample was electronically generated using SPSS (SPSS, 1999) a statistical package, to give a proportionally equal number of cases for each year. For each case, documentation was examined for the presence of each data item in the tool. A descriptive analysis was then conducted for the entire sample for each item in the tool.

This component of the study enabled the Team to identify the scope of current data collection and to ascertain what additional information was required to conduct further research into risk factors and prevention of SUDI. The findings from the audit informed the investigation of worker practice.

This component sought to answer the first research question: What gaps exist in the information collected in New South Wales for diagnostic purposes in relation to incidents of SUDI? What factors influence the availability of the information?

The results of this analysis are reported in Chapter 3.

### **2.3.2 Analysis of relevant agency policies and guidelines.**

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An analysis of current New South Wales policies and guidelines relating to SUDI was used to assist in identifying current practice in the State when responding to SUDI.

Policies and guidelines were sought from relevant government and non-government agencies and from professional associations involved in SUDI. A content analysis of the policies and procedures provided was undertaken.

These policies and guidelines were then compared with aspects considered by the Team as important for a response to SUDI (see Section 2.4). The analysis undertaken was used to identify strengths and weakness in the current system of response to SUDI.

This component sought to answer the second research question: What are the strengths and limitations of the SUDI policies and guidelines in New South Wales?

The results are reported in Chapter 4.

### 2.3.3 Investigation of worker practice

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In addition to the analysis of policies and guidelines, the actual experiences of professionals who have responded to incidents of SUDI were used to identify current practice in relation to SUDI and to identify practice issues for workers involved with these incidents.

Following ethics approval, a researcher from the project team interviewed 45 workers who had been involved in a SUDI case between January 2000 and January 2002. A broad range of professionals were interviewed, including ambulance officers, police officers, pathologists, nurses, doctors, social workers, officers of the State Coroner, counsellors for parents (SIDS and Kids), child protection specialists from the Department of Community Services, and those involved with monitoring, data recording, research and/or education.

Interviews were semi-structured, following a schedule, and were tape-recorded. All interviews were transcribed, then analysed using NVivo (Fraser, 2002), a software package for qualitative data analysis. The content analysis identified recurrent and salient themes.

This component sought to answer the third research question: What are the practices of New South Wales workers in responding to SUDI?

The results are reported in Chapter 5.

### 2.3.4 Analysis of parental practices in relation to modifiable risk factors

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Data for this component of the study was taken from the *NSW Child Death Register* (the Register) and the *NSW Child Health Survey* (CHS) conducted in 2001.

The Register has been maintained by the Child Death Review Team since 1996. It contains records of all deaths of children and young people less than 18 years of age who die in New South Wales. An analysis of all 186 SUDI cases that were registered in the period January 2000 to December 2002 was undertaken to identify risk factors in this population of deaths. Descriptive analyses were undertaken using the statistical package SPSS (SPSS, 1999).

The CHS consisted of a structured telephone interview with parents using computer-assisted telephone interviewing. The survey covered a diverse range of topics on parental practice and child health. Details on the methodology used in the CHS have been published elsewhere (Centre for Epidemiology and Research, NSW Department of Health, 2002). An analysis of all 736 records in the CHS relating to children less than one year of age was undertaken. Three risk factors for SIDS were examined: infant sleep position; household smoking; and

smoking in pregnancy. Variations in parental practices were examined according to social and demographic factors such as the age, geographic location, sex and help-seeking behaviour.

Descriptive and multivariate analyses were undertaken on data obtained from the CHS using the statistical package SPSS (SPSS, 1999). Descriptive analyses comprised cross-tabulations of each of the social and demographic factors with each risk factor. Multivariate analyses included all social and demographic factors in a regression model for each of the risk factors.

This component of the study addresses the fourth research question: What is known about modifiable risk factors for SUDI? In New South Wales, what are the parental practices in relation to these risk factors among parents of infants generally and among parents of infants who die? Are there any particular groups who engage in these risk behaviours?

The results of this analysis are presented in Chapter 6.

### 2.3.5 Analysis of SUDI as a result of assault or neglect, or in suspicious circumstances

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The *NSW Child Death Register* was used to identify the population of all incidents of SUDI registered over a three-year period (1 January 2000 to 31 December 2002). Details of the 186 incidents of SUDI identified were reviewed to identify deaths due to, or possibly indicative of, assault or neglect. Records relating to this subgroup of deaths were further analysed in order to identify: the factors associated with, and the circumstances surrounding, the deaths; the extent of contact the infants' families had with human service agencies; the coronial and criminal outcomes; and avenues for prevention.

The analysis employed a descriptive archival research design and consisted of a case file review of official records from government departments held by the Team. Descriptive statistics were used to create an overall profile of the infants who died as a result of assault or neglect and those who died in circumstances where no clear determination was possible. A logistic regression model was created to examine factors which may differentiate deaths where no clear determination was possible from those where there was clearly no assault or neglect.

This component sought to answer the fifth research question: What is known about SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances? The results of this analysis are reported in Chapter 7.

## 2.4 Administrative structure

The study was directed by the Team. A study subcommittee of the Team provided oversight and guidance. The subcommittee included Team members from NSW Health, NSW Police and the Office of the State Coroner; independent Team experts in the areas of paediatrics and forensic pathology; and two non-Team expert advisers working in the fields of perinatal nursing and neonatal medicine.

## 2.5 Methodological limitations

The study is a multi-component study. The methodology used in each component had its own limitations, which are examined when the findings of each component are discussed.

Overall, with the exception of the worker interviews, the study relied on pre-existing information and is therefore dependent on the accuracy and completeness of the information provided.

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## Chapter 3 | New South Wales: audit of key information

Data currently collected for sudden unexpected deaths in infancy in routine documentation in New South Wales were compared with an optimal data collection tool to assess gaps in information collection and highlight areas for further development.

### 3.1 Introduction

The ability to accurately determine the cause of death in incidents of SUDI is largely dependent on the type and availability of information collected in relation to these deaths. Such information is also necessary for the identification of causes and risk factors for SUDI, for providing appropriate information to parents, for monitoring trends and research, targeting prevention strategies and identifying vulnerable infants.

The Team is not aware of any study to date that has specifically investigated the adequacy of information collected in New South Wales about incidents of SUDI. A pilot study of the role of parental drug abuse and other risk factors undertaken in New South Wales in 2000 by Jeffery and Page identified a lack of data available relating to infant deaths (Jeffery & Page unpublished). Infant death records held on the NSW Institute of Forensic Medicine database were examined for all incidents of SUDI to compare SIDS with non-SIDS on known SIDS risk factors. Deficits in information related to the death scene investigation and individual risk factors were identified through the examination of records.

Research indicates that systematic and detailed collection of information is fundamental to a thorough death scene investigation and for accurate attribution of cause of death (Bacon & Tripp, 2000; Berry, Allibone, Moore, Wright & Flemming, 2000). Currently there is no internationally or nationally accepted protocol for information collection in relation to incidents of SUDI. However, as discussed in the previous chapter, several guidelines and protocols have been developed to encourage systematic investigation and information collection in relation to incidents of SUDI (see Centers for Disease Control and Prevention, 1996; Minnesota Department of Health Maternal and Child Health Section, 2002; Sidebotham & Aldus, 2002; Missouri Department of Social Services, 2003). These guidelines typically were developed in consultation with experts and researchers and workers from a range of agencies experienced in the management and investigation of sudden unexpected deaths of infants.

It is of note that the collection of information does not occur at one time but rather over the span of the response to SUDI which can sometimes be several months. Further, even when expansive information is available there will be some infant deaths where cause of death will remain uncertain.

## 3.2 Aim of this component of the study

This component of the study sought to address Research Question 1:

*What gaps exist in the information collected in New South Wales for diagnostic purposes in relation to incidents of SUDI? What factors influence the availability of the information?*

## 3.3 Research method

### Development of optimal data collection tool

There is currently no internationally endorsed 'best practice' standard for the data requirements in relation to incidents of SUDI. As such, a research tool was developed based on a review of literature and of Australian and international SUDI practice standards, guidelines and protocols. The tool sought to include data considered important to collect throughout the response to SUDI.

The review highlighted the importance of collecting a range of information to inform the diagnosis of cause of death. Information from the death scene included a detailed account of the events leading up to the death, the circumstances in which the death occurred, the previous health of the child and other family members, the family's social and economic background and all samples and tests necessary to establish a correct diagnosis at autopsy.

The research tool developed was the basis against which data from New South Wales SUDI documentation was compared. The tool comprised 246 data items which clustered around five domains:

1. family demographics;
2. death scene investigation;
3. psycho-social information;
4. clinical history; and
5. post-mortem.

Items within each of these five domains were further classified into subgroups, with items relating to similar issues grouped together.

### Sampling procedure

The *NSW Child Death Register* was used to identify a sample of cases for inclusion in this component of the study. The Team maintains the *NSW Child Death Register*, which contains data on all deaths of children aged 0 to 17 years inclusive who have died since 1 January 1996.

To be included in the sample, cases were required to meet the following criteria:

- the death occurred between 1 January 2000 and 31 May 2002;
- the deceased was less than one year of age at the time of death;
- the death was a coronial matter;
- the death was not due to external injury (transport incident) or accidental drowning (ICD-10 code for death); and

- the death was both sudden and unexpected and occurred after the infant was placed for sleep.

Of the 153 infants identified as meeting these criteria, a random sample of 81 cases was reviewed. The sample was electronically generated using the statistical package SPSS to give a proportionally equal number of cases for each year.

#### Documentation reviewed

The study employed an archival research design, reviewing documents made available to the Team under the *Children and Young Persons (Care and Protection) Act 1998*. The extent of documentation available for the Team's infant death files differs from case to case. In order to adopt a systematic approach to the audit, only the three most frequently available documents were reviewed:

- the *Police Report of Death to Coroner* (the P79A);
- the *Death Scene Investigation Checklist – Sudden Infant Death* (the P534); and
- the *Final Autopsy Report*.

These are the documents most consistently used by forensic pathologists when forming a diagnosis in relation to cause and manner of death. The study was not designed to examine either the degree to which these three documents were completed or how expertly they were completed.

The *Police Report of Death to the Coroner* (P79A) is completed by New South Wales police officers attending the death of any person. It contains some structured data fields relating to demographics and time and place of death, and quantitative information on the circumstances under which the death took place. This information is provided in narrative format. The P79A was available for all 81 cases included in the audit. The P79A and the facts to be addressed during completion of the P79A can be found in Appendix 3.1.

The *Police Sudden Infant Death: Death Scene Investigation Checklist* (P534) is completed by New South Wales police officers attending the death scene of any infant where the police officer judges the death to be attributable to SIDS. The checklist was developed by the NSW SIDS Advisory Committee in the early 1990s. (The SIDS Advisory Committee is an interdepartmental committee chaired by the NSW Coroner, involving professionals and consumer representatives. The Committee provides advice on matters concerning sudden unexpected infant death.) The document is a structured checklist including demographic information on the mother and the birth and health of the infant, as well as information on the last sleep and sleep environment. The information placed on the checklist is compiled from interviews with parents. The checklist was provided to the Team for 72 of the 81 cases included in the audit. The P534 can be found in Appendix 3.2.

The *Final Autopsy Report* is completed by a forensic pathologist located in the Departments of Forensic Pathology at Glebe, Westmead or Newcastle. The reports are not standardised documents but generally follow a similar structure and contain cause of death, autopsy, pathology, toxicology and other findings. The *Final Autopsy Report* was available for all 81 cases.

### 3.4 Analysis

Documents were scrutinised for the presence of each data item in the research tool. If data could not be found on any of the three documents it was noted as absent.

The percentage of cases with data present was calculated for each item on the tool. The data availability of each item was classified into one of three categories:

- low (0 to 24% of cases with data present);
- medium (25 to 74% of cases with data present); or
- high (75 to 100% of cases with data present).

No attempt was made to assess the accuracy of the data.

In addition, the source of the data for each item was classified into one of the following three categories:

- A: The source of the data was a standard question appearing on one of the documents reviewed. The question was well defined according to the research tool (e.g. 'Was resuscitation attempted? By: Parent? Ambulance officer? Other? Please specify').
- B: The source of the data was a standardised question, but the question was not defined according to the research tool (e.g. 'Does anyone in the house smoke? Yes/No').
- C: Data did not come from a standard question but was opportunistically revealed (e.g. data obtained from a comment or a narrative section on the document).

### 3.5 Results

#### Sample demographics

Of the 81 SUDI cases included in the sample, a little over half of the infants were female (57%), the age range was hours to one year with a mean age at death of 124 days (standard deviation (SD) 90 days), 63 per cent lived in a major metropolitan centre at the time of death and 22 per cent had the cause of death coded as SIDS by the CDRT.

#### Summary statistics

Two hundred and forty-six data items were identified and included in the research tool. Information on the presence or absence of data on 241 of these items was reviewed (see Appendix 3.3). Five items included in research tool were not included in the analysis of data availability due to an oversight in the development of the tool. None of the documents reviewed contained questions specifically on any of these five data items, which were therefore excluded from the analysis.

#### Data availability

A summary of the availability of data for items in the research tool reviewed is presented in Table 3.1.



**Table 3.1:**  
Availability of data  
items by domain

Domain	Data availability category							
	Low		Medium		High		Total <sup>a</sup>	
	n	%	n	%	n	%	n	%
Family demographics	11	30.6	8	22.2	17	47.2	36	100.0
Death scene investigation	21	25.3	27	32.5	35	42.2	83	100.0
Psycho-social information	17	100.0	0	0.0	0	0.0	17	100.0
Clinical history	39	57.4	14	20.6	15	22.1	68	100.0
Post-mortem	3	8.1	13	35.1	21	56.8	37	100.0
<b>All items</b>	<b>91</b>	<b>37.8</b>	<b>62</b>	<b>25.7</b>	<b>88</b>	<b>36.5</b>	<b>241</b>	<b>100.0</b>

*Note: a. Five items missing from analysis of availability of data excluded from table.*

Data availability was categorised as 'high' for just over one third of the data items (36.5%), as 'medium' for 25.7 per cent and as 'low' for 37.8 per cent of data items.

The 'post-mortem' domain had the highest proportion of items categorised as 'high' availability, with 56.8 per cent of these items meeting the criteria for 'high' availability. The 'psycho-social information' domain had the lowest rating for data availability, with all 17 items categorised as a 'low' availability.

The availability of data items also varies within each of the five domains. Table 3.2 presents data availability for each of the subgroups of the domains.

**Table 3.2:**  
Availability of data  
items by subgroup

Subgroup	Data availability category			
	Low	Medium	High	Total <sup>a</sup>
<b>Family demographics</b>				
Infant	0	0	8	8
Mother	5	2	6	13
Father/other carer	5	3	2	10
Siblings/others in residence	0	2	1	3
Social factors	1	1	0	2
<b>Death scene investigation</b>				
Administrative information	3	6	7	16
Death scene	1	3	11	15
Last feed	0	0	4	4
Last sleep	4	1	6	11
Bedding	2	7	2	11
Co-sleeping	2	4	2	8
Infant clothing	1	1	2	4
Ambient environment	5	3	0	8
Condition of premises	3	2	1	6
<b>Psycho-social information</b>				
Agency history	4	0	0	4
Criminal history	13	0	0	13
<b>Clinical history</b>				
Family alcohol and other drug use	13	2	1	16
Family clinical history	10	2	4	16
Infant clinical history	9	5	2	16
Other risk and protective factors	4	2	2	8
Recent health status of infant	3	3	6	12
<b>Post-mortem</b>				
Administrative information	0	3	4	7
Attribution of death	1	1	2	4
External examination	1	5	5	11
Internal examination	0	1	7	8
Pathology	1	3	3	7

*Note: a. Five items missing from analysis of availability of data excluded from table.*

Within the 'family demographics' domain, data availability is best for items relating to the infant and mother, but often absent for items relating to the father or other carers, other siblings and social factors.

There was considerable variation in the availability of data from items in the ‘death scene investigation’ domain. Availability was greatest for items relating to general administration, the death scene, and the infant’s last feed. However, data was lacking for items relating to co-sleeping and the environment in which the infant was found.

The availability of data for all items relating to the psycho-social history of the infant and family, including criminal histories of the parents or carers and contact with social welfare agencies, rated ‘low’.

The availability of data for items in the ‘clinical history’ domain was generally poor across each of the subgroups. Availability was greatest for items relating to the recent health status of the infant, but only six of the 12 items in this subgroup were classified in the ‘high’ availability category.

Data availability across the ‘post-mortem’ domain was generally consistent. Data availability was best for items relating to the internal examination conducted during the autopsy (seven of the eight data items rated as ‘high’). The remaining four ‘post-mortem’ subgroups each had approximately half the data items classified in the ‘high’ availability category.

**Data source**

The source of each data item was examined. A summary of the sources of data for items in the research tool is presented in Table 3.3.

**Table 3.3:**  
Number and percentage of data items by category of source

Domain	Source classification						Total	
	A (standard and optimal definition)		B (standard and suboptimal definition)		C (opportunistically revealed)			
	n	%	n	%	n	%	n	%
Family demographics	12	31.6	5	13.2	21	55.3	38	100.0
Death scene investigation	22	26.2	15	17.9	47	56.0	84	100.0
Psycho-social information	0	0.0	0	0.0	17	100.0	17	100.0
Clinical history	3	4.4	19	27.9	46	67.6	68	100.0
Post-mortem	0	0.0	0	0.0	39	100.0	39	100.0
<b>Overall</b>	<b>37</b>	<b>15.0</b>	<b>39</b>	<b>15.9</b>	<b>170</b>	<b>69.1</b>	<b>246</b>	<b>100.0</b>

Table 3.3 shows that for the majority (69.1%) of the data items examined, data were opportunistically revealed (source category C). Only 15 per cent of data items were obtained from a standardised question which was well-defined according to the data collection criteria (source category A).

When data sources were examined by domain, items in the ‘family demographics’ domain were most likely to be category A (31.6% of items). The ‘death scene investigation’ domain had the second highest proportion of items with the source of data fitting the definition of category A (26.2%). Less than 5 per cent of ‘clinical history’ domain items were obtained from a category A source. None of the data from items in the ‘psycho-social information’ and ‘post-

mortem' domains was from a category A source. The absence of any category A data sources for 'post-mortem' data is largely due to the reliance on the *Final Autopsy Report* for post-mortem information. This report does not contain standardised questions.

### Relationship between data source and availability

Table 3.4 presents the cross-tabulation of the type of data source by data item availability. The table shows that the availability of data varies according to the source of the data, with availability increasing as the source is standardised. This difference is statistically significant ( $\chi^2 = 88.3$ , 4 df,  $p = 0.00$ ).

**Table 3.4:**  
Percentage and number of items in each source category by items in each availability category

	Availability category							
	Low		Medium		High		Total <sup>a</sup>	
	n	%	n	%	n	%	n	%
Source category								
A standard and optimal definition	0	0.0	2	5.4	35	94.6	37	100.0
B standard and suboptimal definition	4	10.3	16	41.0	19	48.7	39	100.0
C opportunistically revealed	87	52.7	44	26.7	34	20.6	165	100.0

*Note: a. Five items missing from analysis of availability of data excluded from table.*

Table 3.4 shows that, in general, where there is a standard, well-defined question pertaining to an item (source category A), the availability of data was almost always categorised as 'high' (in 94.6% of items). Conversely, when data has to be obtained opportunistically (source category C), data availability is categorised as 'high' for only 20.6 per cent of items.

## 3.6 Conclusion

The audit of the key information collected to establish cause of death where an infant dies suddenly and unexpectedly was undertaken to determine gaps that exist in the information routinely collected in New South Wales in response to incidents of SUDI for diagnostic purposes, and what factors influence the availability of the information. The study did not examine the degree to which the three documents reviewed were completed or how expertly they were completed.

A research tool was developed from the list of data items considered to be optimal in relation to SUDI and was used for comparative purposes. Documentation used in 81 SUDI cases occurring in New South Wales between 1 January 2000 and 31 May 2002 was examined to identify the frequency with which each data item on the tool was collected. An item was recorded as present if it appeared in any one of the three documents examined. The availability of each data item across the sample was classified into three categories: high (75 to 100% of cases with data present); medium (25 to 74% of cases with data present) and low (0 to 24% of cases with data present).

The source for the data obtained for each item was also examined and was classified into three categories which varied according to the level of standardisation of the source.

The analysis revealed substantial variation in data availability across the domains examined. In particular, there appear to be gaps in the current routine data collection in relation to:

- psycho-social information about the infant and the family (including contact with social service agencies and criminal history of parents and carers);
- clinical history of the family and the infant;
- demographic information on the father or other carers and siblings;
- social factors;
- information on co-sleeping; and
- the environment of the room in which the infant was found.

The availability of data was shown to be related to the way in which data was collected. Data on a specific item was more likely to be available if it could be sourced from a standard question or data format, rather than opportunistically revealed in an open text section of a document.

While the findings indicate areas of the current routine data collection in relation to incidents of SUDI that could be improved, the limitations of the methodology and analysis need to be acknowledged. Firstly, this component of the study addressed one aspect of quality data collection, the availability of data items. Assessing the accuracy of the data that is currently collected was beyond the scope of the current study.

Secondly, only data from the three documents most commonly available for diagnosis of cause of death by a forensic pathologist was included in the analysis. Government agencies such as NSW Police, the NSW Department of Community Services and NSW Health may have had other records relating to SUDI cases included in the study. For example, police provide the coroner with a brief of evidence which may contain additional information to that provided to the forensic pathologist. Therefore, it is possible that some of the items in the research tool may have been collected and recorded in documents that were not included in this review. However, these records are not routinely made available to the pathologist when investigating the cause of death.

Finally, the research tool against which the current New South Wales data collection was assessed is subjective. The tool was developed after reviewing data collection systems and the available literature. However, there is currently no internationally endorsed 'best practice' data collection system for responding to incidents of SUDI.

Despite these limitations, the findings suggest that current data collection in New South Wales could be improved by standardising documents and using questions specifically related to the optimal data collection items identified. Such information would potentially increase the number of SUDI that can be explained.

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## Chapter 4 | New South Wales: response to SUDI policies and guidelines

The current policies and guidelines of key government agencies in New South Wales relating to incidents of sudden unexpected deaths in infancy are described and compared with a checklist of important aspects of response identified by the Team. The strengths and limitations of current New South Wales policies and guidelines are highlighted and areas for improvement identified.

### 4.1 Introduction

Policy is a broad term covering the rules set by organisations to govern their operations. Policy is used to set the boundaries for what an organisation or individual can and cannot do. Guidelines are produced from policy and usually contain the rules and procedures to implement the policy, direct action and specify the individuals responsible for such action.

The ability to provide an appropriate response to SUDI is influenced by the policies and guidelines that are set by the various agencies involved and the integration of these across the agencies; they shape and direct the actions of those that provide services.

Nationally and/or internationally agreed upon protocols for responding to SUDI are still lacking, despite considerable work conducted in this area. Some work has been undertaken on the procedures, roles and responsibilities of agencies required for an optimal response to incidents of SUDI, including who will undertake the various aspects of the response, how cause of death will be attributed, and how a balance between investigation and family support will be achieved.

The work undertaken presents information in a variety of ways. Some provide detailed interagency protocols, some are based around data collection forms, others provide guiding principles and some are a combination of the above.

### 4.2 Aim of this component of the study

This component of the study sought to address Research Question 2:

*What are the strengths and limitations of the SUDI policies and guidelines in New South Wales?*

### 4.3 Research method

Current policies and guidelines relevant to the response to SUDI in New South Wales were assessed against a checklist consisting of five important aspects of response for SUDI developed by the Team for this purpose.

The aspects were:

1. balance between care and investigation;
2. collection and recording of comprehensive information;
3. involvement of appropriate personnel;
4. multi-agency case review and continuous improvement; and
5. monitoring and research.

The 'important aspects of response' checklist (the checklist) was based on the review of literature and international protocols undertaken to inform the study. Particular attention was given to the *Confidential Enquiry for Stillbirths and Deaths in Infancy (CESDI)* recommendations, with the information collection requirements drawn from internationally recognised protocols such as the *Sudden Unexplained Infant Death Investigation Report Forms (SUIDIRF)* and the *International Standardised Autopsy Protocol (ISAP)*. While both these protocols require revision to reflect advances made over the preceding years, they remain the protocols supported internationally.

Each of the five aspects of response is discussed in detail in Appendix 4.1. Full details of the development of the checklist is presented in the paper titled *Sudden Unexpected Deaths in Infancy: Aspects of Response*, available at [www.kids.nsw.gov.au/publications/sudi.html](http://www.kids.nsw.gov.au/publications/sudi.html)

#### **Documentation reviewed**

Relevant policies and guidelines were sought from government agencies, non-government agencies and professional associations that had responsibility for any aspect of responding to SUDI. The list of agencies and associations can be found in Appendix 4.2. Policies and guidelines were considered relevant if they related to investigating and responding to a sudden unexpected infant death, researching and monitoring such deaths, educating parents and service providers about preventable risk factors, interacting with parents, liaising with other agencies or training personnel.

Information was received from NSW Police, NSW Health, the Department of Disability, Ageing and Home Care, the Department of Community Services, the Office of the State Coroner, and SIDS and Kids NSW. Documents received from NSW Health included limited information from the Departments of Forensic Medicine; no documents were provided from the NSW Ambulance Service. All professional associations advised that they had no relevant documents. A full list of the policies and guidelines obtained is provided in Appendix 4.3.

Since no information was obtained from professional associations, the analysis is limited to government agencies and SIDS and Kids NSW.

#### **Methodological limitations and cautions**

This study sought to document and analyse the policies and guidelines in operation in New South Wales. The information available for analysis was restricted to the information provided by the organisations. It is possible that not all relevant documents were provided.

The checklist against which the New South Wales policies and guidelines were compared was based on an analysis of the available literature. Other aspects of response may also have been appropriate for comparison.

Further, no conclusions can be drawn from the study findings of the operation of the policies and guidelines.

## 4.4 Analysis

This study consisted of a content analysis of the documents made available to the Team under the *Commission for Children and Young People Act 1998*.

Documents were scrutinised to identify the roles and responsibilities of each agency. The roles and responsibilities of the NSW Ambulance Service and the coroner were inferred from the documentation provided by other agencies. A brief summary of the role of each agency is provided, followed by a list of the responsibilities of each agency grouped into one of the following three categories:

1. service provider;
2. employer; or
3. interagency partner.

Some responsibilities may be included in more than one category.

The overall New South Wales service system was then examined to identify the purpose of, and consistency within, the system. Areas of duplication were also identified.

The policies and guidelines were further examined and compared with the checklist. Each aspect was considered in turn and the consistency of the policies and guidelines with each aspect classified into one of the following three categories:

- does not conform;
- partly conforms; or
- fully conforms.

## 4.5 Results

### 4.5.1 Roles and responsibilities

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The results of the analysis are presented for each agency in turn followed by a description of the overall New South Wales service system.

#### NSW Health

NSW Health has adopted the 1995 Corder and Willinger definition of SIDS: 'The sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history'.

NSW Health has several roles in responding to SUDI. The NSW Ambulance Service provides the initial medical response and may transport the infant to hospital.

Hospitals provide a medical and forensic response. This includes taking a medical history, collecting samples and providing a support service to parents. The hospital response is provided when an infant dies after admission to hospital or presents to an Emergency Department following a death at home.

NSW Health also plays a role in prevention and early intervention, grief counselling, research and surveillance relating to infant deaths and providing information to health professionals and



parents on the risk factors for SIDS. The Departments of Forensic Medicine conduct post-mortem examinations. All NSW Health policies are notified by Circular.

***Responsibilities as a service provider:***

- taking all infants who present at hospital to the Emergency Department;
- nominating a key person to coordinate care for the parents (key persons include the senior nurse on duty, the duty social worker and the paediatrician on call);
- informing the parents when their infant is deemed dead on arrival;
- informing parents about the need for a post-mortem examination;
- providing parents with contact details for SIDS and Kids NSW and for counsellors at the Departments of Forensic Medicine;
- offering practical help to parents, such as arranging transport home and discussing funeral arrangements;
- providing bereavement support;
- informing the hospital or community social worker so that ongoing support can be arranged for parents;
- seeking the names of all health professionals involved in the infant's care so that they can be informed of the death and be involved in the parents' care;
- assessing the extinction of life and certifying death;
- taking a brief medical history including perinatal problems, immediate or continuing health problems, and family history;
- assisting with completing formal identification of the infant before the family leaves the hospital;
- obtaining management advice from a paediatrician if there is a surviving twin;
- minimising handling of the body;
- monitoring the occurrence of SIDS death rates annually and informing on relevant research recommendations of the *Reducing the Risks of SIDS* campaign and the impact of these recommendations; and
- reviewing details of all perinatal morbidities.

***Responsibilities as an employer:***

- involving staff in a maternity service or care of the newborn in regular perinatal morbidity and mortality review with other health practitioners;
- providing staff with guidelines when dealing with cases of sudden unexpected infant death including: *Hospital Protocol for Unexpected Infant Death*; *Guidelines for Nursing Staff and Medical Officers on Coroners' Cases Dying in Hospital*; *Guidelines for Essential Documentation, Management, Storage and Disposal of Health Care Records*; and the *Information Privacy Code of Practice*;
- ensuring that health professionals are informed of SIDS risk factors and their implementation through the distribution of up-to-date information and research findings;
- providing recommendations to health professionals in maternity units concerning positioning of infants for sleep;

- providing guidelines to forensic pathologists regarding what should be included in an autopsy report consistent with the *Australasian SIDS Autopsy Protocol*; and
- contacting the duty forensic pathologist once death is established. (No further examination of the body should be undertaken without permission of the duty forensic pathologist.)

### ***Responsibilities as an interagency partner:***

- identifying coronial cases and promptly informing police of the death so that an early post-mortem can be conducted;
- arranging for timely collection of information and samples following discussion with the duty forensic pathologist;
- reporting deaths that occur in hospital to the coroner using the *Report of Death of a Patient to the Coroner (Form A)* and/or *Report of Death Associated with Anaesthesia/Sedation (Form B)*;
- liaising with the coroner regarding the removal of organs and tissues for transplantation (if the death is examinable by the coroner, this may only proceed with the explicit agreement of the coroner);
- delivering and collecting medical records from the Coroner's Court;
- providing a discharge summary on request of the coroner;
- liaising with Department of Community Services and other agencies if necessary; and
- convening the NSW SIDS Advisory Committee.

### **NSW Police**

NSW Police conduct an investigation of the death on behalf of the coroner. This includes investigation of the death scene and gathering and recording information concerning the death scene, medical and social information and, if necessary, further information such as child protection history.

### ***Responsibilities as a service provider:***

- urgently attending the scene of a sudden unexpected infant death;
- assigning an experienced investigator to the death scene investigation;
- checking for signs of life;
- establishing a crime scene;
- calling the Forensic Services Group and detectives;
- examining the child and location of death;
- interviewing parents to gather information, including when medical authorities or police were called and arrived, and the environment and circumstances surrounding last sleep, personal details of the infant and others present at the crime scene;
- involving a member of the Joint Investigation Team in the investigation if child abuse is suspected;
- ensuring that a crime scene investigator attends in cases where the death is not thought to be due to natural causes;
- providing next of kin with a copy of the Coroner's Court brochure;

- providing the parents with a clear explanation of the process required to confirm cause of death;
- informing parents that support services such as SIDS and Kids NSW and grief counsellors at the Departments of Forensic Medicine are available;
- responding to family requests to say goodbye to their infant after the consent of an on-call pathologist has been given and after a photographic record of the deceased in situ has been obtained;
- completing a *Death Scene Investigation Checklist – Sudden Infant Death* (P534) if the death is an apparent SIDS concerning a child less than two years of age and forwarding it to the Coroner (see Appendix 3.2 for the P534);
- collecting evidence;
- preparing a brief of evidence for the coroner consisting of a comprehensive report of all the facts and circumstances of the occurrence which resulted in the death;
- taking anything significant to the cause of death to the pathologist;
- ensuring that no interference with the body occurs without the consent of the duty forensic pathologist;
- ensuring that original medical records or hospital notes accompany the body;
- seeking the services of a government contractor to remove the body;
- transporting the body to a mortuary immediately following certification of life extinct;
- attending the mortuary to report the death, identifying the body or consulting with or assisting the forensic pathologist when required by the local coroner; and
- acting in consultation with the local coroner when a death occurs in country areas.

***Responsibilities as an employer:***

- providing support services to police officers; and
- providing training and development for staff concerning coroner's cases and SIDS cases in particular.

***Responsibilities as an interagency partner:***

- reporting deaths that occur in certain circumstances (such as those that occur suddenly, due to unknown causes, or in suspicious or unusual circumstances) to the coroner by submitting the *Police Report of Death to Coroner* (P79A) within 24 hours of the death and in cases of suspected SIDS the *Death Scene Investigation Checklist – Sudden Infant Death* (P534) (see Appendix 3.1 for the P79A);
- promptly reporting deaths that fall under section 13AB of the *Coroner's Act 1980* to the State Coroner, Glebe, or the Deputy State Coroner, Westmead;
- liaising with the forensic pathologist concerning the investigation; and
- liaising with Department of Community Services and other agencies if necessary.

**New South Wales State Coroner**

Coroners enquire into the circumstances surrounding deaths reported to them to determine the manner and cause of death. They are responsible for determining whether an inquest

should be held, and overseeing the inquest if held. Coroners can make recommendations regarding public health and safety and other relevant issues.

### ***Responsibilities as a service provider:***

- properly investigating and concluding all deaths which come under the coroner's jurisdiction;
- determining when an inquest is necessary;
- enquiring into the circumstances surrounding deaths—this includes determining the identity of the person who has died and inquiring into the time, place, cause and manner of death;
- advising next of kin about the time and place of the inquest;
- overseeing the inquest and if necessary calling witnesses to give evidence of their knowledge of the circumstances of the death; and
- sending the coroner's findings to the next of kin.

The following special responsibilities exist for coroners in country areas of New South Wales:

- sending a signed copy of the *Police Report of Death to Coroner (P79A)* and the order for the post-mortem examination with the body to the appropriate morgue office and also promptly faxing the documents;
- ensuring that the police officer in charge of the death obtains any relevant hospital or medical records to accompany the body for the pathologist's information;
- ensuring that the *Death Scene Investigation Checklist – Sudden Infant Death (P534)* is completed by the police officer in charge of the death and that the form accompanies the body; and
- ensuring that prior to its transport the body is not interfered with (that is to say, footprints, handprints or locks of hair are not taken, clothing not removed, and the body not washed or cleaned in any way).

### ***Responsibilities as an interagency partner:***

- referring the matter to the Director of Public Prosecutions if the inquest reveals that a known person has committed a serious criminal offence in connection with the death;
- notifying relevant authorities of any practices, policies or laws which could be changed to prevent similar deaths in the future;
- exposing other matters of public importance; and
- chairing the NSW SIDS Advisory Committee.

The Coroner has no responsibility as an employer in the area of SUDI.

### **Department of Ageing, Disability and Home Care**

The Department of Ageing, Disability and Home Care responds to the deaths of infants who were in a departmental facility. This includes provision of services to parents, carers and families, and assisting with police and coronial investigations.

### ***Responsibilities as a service provider:***

- notifying departmental management of the death;
- supporting other residents during the police interview;

- notifying the family, carer or guardian of the deceased as soon as possible;
- assisting in arrangements to certify the death and transport the deceased to a hospital mortuary;
- assisting family members in organising the funeral;
- referring family members to the Bereavement Care Centre for emotional and practical support;
- considering the appropriateness of other residents attending the funeral; and
- completing an incident report or briefing note of circumstances surrounding the death.

***Responsibilities as an employer:***

- providing crisis counselling to other residents and staff where required;
- supporting staff to attend the funeral; and
- submitting to the Department of Ageing, Disability and Home Care the *Notice of Death of a Person with a Disability Residing or Attending a Service Funded under the Disability Services Act 1993* no later than two weeks after the death.

***Responsibilities as an interagency partner:***

- notifying the relevant authorities of the death of the infant including NSW Police and the Coroner;
- notifying the police immediately in cases of sudden death, to enable the police to establish whether any suspicious circumstances exist;
- assisting the police and/or coroner with enquiries; and
- seeking payment and organisation of the funeral from the Department of Community Services where the infant was under a guardianship order.

**Department of Community Services**

The Department of Community Services may become involved during the course of death investigation by the coroner where the infant died as a result of or in circumstances suspicious of abuse or neglect.

***Responsibilities as a service provider:***

- assessing the risk of harm to any surviving sibling of the deceased infant; and
- responding to information requests under the *Children and Young Persons (Care and Protection) Act 1998*.

***Responsibilities as an employer:***

- activating the Staff Support Team formed when necessary to respond to extraordinary events; and
- informing staff of their responsibilities in relation to sections 248 and 254 of the *Children and Young Persons (Care and Protection) Act 1998* concerning exchange of information.

### ***Responsibilities as an interagency partner:***

- notifying the relevant authorities, including NSW Police or the coroner, of the death of an infant in a Department of Community Services residential care facility and advising the Department's management of the death;
- participating in case discussions if a child is identified at risk of harm;
- providing information to coroners under a *Memorandum of Understanding*;
- providing information to the NSW Ombudsman under the *Community Services (Complaints Reviews and Monitoring) Act 1993* and the *Ombudsman Act 1974*; and
- receiving and responding to police requests for information regarding examinable children, advising NSW Police on whether the death meets the examinable criteria under section 13AB of the *Coroner's Act 1980*. (A death is examinable by the State Coroner or a Deputy State Coroner if it appears to the coroner that the person was, or was reasonably suspected to be, a person referred to in section 13AB of the *Coroner's Act 1980*.)

### **SIDS and Kids NSW**

SIDS and Kids NSW provides counselling for parents, community education and training information for health professionals.

### ***Responsibilities as a service provider:***

- supporting families through a network of trained parents who have previously had a child or infant die, and with professional counsellors, support groups and literature (such as information booklets and newsletters);
- increasing awareness in the community of the care of bereaved parents and the *Reducing the Risk of SIDS* health promotion campaign;
- supporting and promoting research into the causes of sudden infant death syndrome and perinatal death; and
- providing a 24-hour telephone service to support families.

### ***Responsibilities as an employer:***

- providing a *Code of Ethics for SIDS NSW Volunteers* detailing ethical considerations for those volunteering to help bereaved families; and
- providing training resources and policies on a range of subjects including confidentiality guidelines, guidelines for initial contact with the bereaved family, funeral policy, parent supporters' rights and responsibilities, policy on the SIDS and Kids NSW Buddy System, and supervision and debriefing policy.

### ***Responsibilities as an interagency partner:***

- providing resources for health professionals, such as *Appropriate Care for Women and Their Partners when Their Baby Dies*.

### **In summary**

In New South Wales there are several agency-specific policies and guidelines for responding to SUDI. Some of these are very detailed; few reference the policies of other agencies. Policies and guidelines are sometimes specific for SUDI or SIDS, while others cover response to deaths

in general. There is no New South Wales protocol that outlines the role and responsibility of each agency in the response to SUDI.

The policies and guidelines in New South Wales are geared to providing information to the coroner so that manner and cause of death can be attributed, and support and guidance to parents provided. Police are responsible for collection of evidence; ambulance, hospitals and pathologists provide a medical response and a number of services provide support to parents throughout the response.

The New South Wales policies and guidelines are consistent, with no contradictions identified within agencies or between agencies. Only two possible areas of duplication were found. Providing support and guidance to parents is the responsibility of a number of agencies. The policies in this regard did not always refer to each other, leaving open the potential for duplication. The second area relates to the collection of medical and social information from parents. The analysis of police and health policies suggests their collections are similar.

#### 4.5.2 Comparison with the checklist

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The results of the comparison with each aspect of the checklist are presented first, followed by a summary of the New South Wales response.

##### **Balance between care and investigation**

An infant death response requires a balance between care for the family and investigation of the infant's death. The policies and guidelines demonstrate a focus on the investigative process to provide evidence for the coroner. A death scene is established for all SUDI to enable this to occur. However, the review of guidelines and policies also revealed that guidance and support can be provided by a range of personnel in New South Wales throughout the response to SUDI including the police investigation, at certification of death, the post-mortem and after investigation.

NSW Police, NSW Health, the coroner and SIDS and Kids NSW have detailed policies and guidelines outlining their specific responsibilities.

- NSW Police policy requires police officers to provide parents with the Coroner's Court brochure as part of their initial response. This includes the contact number for forensic counsellors. Parents are also given contact details for SIDS and Kids NSW.
- NSW Health policy details the support to be offered to the family if they attend a hospital during certification of death. Practical help such as arranging transport home, discussing funeral arrangements and helping the mother if she had been breastfeeding is to be provided. The policy enables a hospital social worker to provide ongoing support to the family.
- Forensic counsellors provide the family with support and information during the post-mortem process, though the details of this are unclear in the policies and guidelines provided.
- SIDS and Kids NSW provide ongoing support at a parent's request.

With exception of forensic counsellors the support provided is discretionary.

In summary, the policies and guidelines relevant to providing a balance between care and investigation were found to partly conform to this aspect of the checklist.

### Collection and recording of comprehensive information

The policies and guidelines in New South Wales identify the primary purpose of information collection as supporting the coroner's investigation.

New South Wales police officers have the main role in collecting and recording this information. The information collected in New South Wales is limited; it is largely guided by the *Police Report of Death to Coroner (P79A)* and the *Death Scene Investigation Checklist – Sudden Infant Death (P534)*. Additional information is collected by police in preparing the brief of evidence.

While some guidance is provided to police (including the necessity to record in detail the full circumstances of the death, to note the persons present at the scene such as ambulance officers, and to take statements from relevant persons and a summary of any medical reports), the collection of this information is at the discretion of the individual officer. The details of the reports prepared are quality reviewed by the police duty officer.

There are gaps in the current routine data collection in New South Wales, including the collection and recording of: the psycho-social and clinical history of the infant and the family; demographic information on the father or other carers and siblings; family social factors; information on co-sleeping; and the environment of the room in which the infant was found (see Chapter 3 for further details).

The policies and guidelines of NSW Health and the Department of Ageing, Disability and Home Care refer to the collection and recording of information. NSW Health completes a *Report of Death of a Patient to the Coroner (Form A)* in cases where the infant died in hospital. The Department of Ageing, Disability and Home Care receives a *Notice of Death of a Person with a Disability Residing or Attending a Service Funded under the Disability Services Act 1993* when a child dies in a Department of Ageing, Disability and Home Care facility. The Department also reports reviewable deaths of children, young people and adults with a disability to the NSW Coroner, NSW Police and the NSW Ombudsman.

Variation existed regarding post-mortem processes in New South Wales in the correspondence received. It is clear there is no statewide protocol. The Departments of Forensic Medicine noted that the *Australasian SIDS Autopsy Protocol* is followed at Westmead, standardising the collection and recording of information. Glebe use 'standard' sudden infant death autopsy techniques and consider the *Australasian SIDS Autopsy Protocol*. The Newcastle Department of Forensic Medicine provided a *Paediatric Autopsy Report* which is completed for paediatric autopsies.

It is not possible from the correspondence to comment on the extent of standardisation across the three centres providing forensic services.

There was no evidence in the correspondence received from NSW Health that standardised information regarding the medical and psycho-social history of the infant and the family is routinely included in an autopsy report.

In summary, the policies and guidelines relevant to the collection and recording of information were found to partly conform to this aspect of the checklist.



### **Involvement of appropriate personnel**

In New South Wales, designated personnel undertake various tasks but they do not necessarily have the expertise outlined in the checklist.

Ambulance and police officers provide the first response to an infant death. Ambulance officers have medical training, but there are no policies that require specialised designated personnel to respond. NSW Police have investigative training, and policies require that their most experienced officers on duty at the time respond to the incident. As part of their investigative role police officers are required to investigate any suspicious circumstances, to collect information about the death, including medical and social information, and to provide support to parents. It is unclear from the policies and guidelines what kind of experience is required, but there is no mention that officers need to have additional specialised knowledge.

The involvement of NSW Health, including hospital staff and forensic pathologists, follows initial police involvement. If the infant is taken to hospital, NSW Health staff take a brief medical history. It is unclear from the policies which staff are responsible for taking this history.

In 1991 NSW Health implemented the State Coroner's recommendation that all autopsies following unexpected infant deaths be undertaken in Sydney either at the Institute of Forensic Medicine, Glebe, or the Department of Forensic Medicine in the Institute of Clinical Pathology and Medical Research, Westmead. This recommendation recognised that the cause of death can be difficult to establish and that post-mortem examination should be undertaken by a pathologist with extensive experience in infant autopsies. The Newcastle Department of Forensic Medicine was subsequently included.

The correspondence received regarding the knowledge and experience of pathologists undertaking the autopsy examination provided no further information on the skills or expertise required by pathologists.

In summary, the policies and guidelines relevant to the involvement of appropriate personnel were found to partly conform to this aspect of the checklist.

### **Multi-agency case review and continuous improvement**

Multi-agency case reviews are not routinely held in New South Wales. The policies and guidelines indicate that discussion occurs as required between police officers and the forensic pathologists or coroner; between the key person nominated to coordinate the response at the hospital and general practitioners, nurses, midwives and social workers to support parents; between police officers and child protection workers in suspected abuse or neglect cases; and between health professionals and the forensic pathologist when there is a particular health issue. The policies and guidelines do not address any discussion required with other persons by the forensic pathologist before conducting the autopsy examination.

A key function of case review is examination of any errors or deficiencies in professional care. The policies and guidelines in New South Wales make one reference to this. NSW Health requires each maternity service to have a perinatal death review committee for infant deaths that occur up to one month after birth to audit the details of the death as part of quality assurance. Only deaths that occur in hospital are examined. The review process is multi-disciplinary with membership open to midwives and general practitioners involved in the provision of the maternity service, an Aboriginal representative where appropriate, independent midwives accredited to the service and general practitioners with a shared antenatal care

arrangement with the hospital. The review committee is limited to health staff and is therefore not multi-agency. However, the review committee does provide a forum to discuss the cause of death, other adverse outcomes and their determinants. This has immediate benefits for participants in providing feedback and enables identification of possible avoidable factors which may be used to improve local services. Information from the review committee is forwarded to the NSW Maternal and Perinatal Committee to develop policies aimed at reducing maternal and perinatal mortality in New South Wales.

In summary, the policies and guidelines relevant to multi-agency review did not conform to this aspect of the checklist.

### Monitoring and research

The policies and guidelines of the various agencies stipulate how information is to be shared. Most information is shared with a view to keeping others informed of the findings or progress of the case. There is some evidence that information from the response to SUDI is used for monitoring and research in New South Wales.

- Demographic details of the mother and infant and the date of death of the infant are reported to NSW Health by forensic pathologists where the death is classified as SIDS. (SIDS is a notifiable medical condition under the *Public Health Act 1991*.) These deaths are monitored by the SIDS Advisory Committee convened by NSW Health.
- Research into SIDS is undertaken by SIDS and Kids (National Council of Australia Ltd), with support from member organisations. Between 1990 and 1999, a total of 52 projects were funded.
- The Child Death Review Team maintains a register of all deaths of children and young people in New South Wales. Full and unrestricted access to information is provided under the *Commission for Children and Young People Act 1998*. Patterns and trends are identified with a view to reducing or preventing further deaths. The Team also undertakes specific research that can include research into SUDI.
- Information from local perinatal death review committees is forwarded to the NSW Maternal and Perinatal Committee for review.
- The National Coroners Information System provides information to researchers on request.

The quality of the information available on SUDI directly influences the quality of the information available for monitoring or research. As has been demonstrated, this is variable and often incomplete. There is no formal relationship between the various agencies and committees responsible for monitoring and research. This leaves open the possibility for duplication of effort.

In summary, the policies and guidelines relevant to monitoring and research partly conform to this aspect of the checklist.

### In summary

The comparison of the New South Wales system with the key aspects of the checklist is summarised in Table 4.1.

**Table 4.1:**  
Comparison of  
New South Wales  
policies and  
guidelines with  
the checklist

Key aspects	New South Wales policies and guidelines	Classification		
		Does not conform	Partly conforms	Fully conforms
Balance between care and investigation	Aspects of care and investigation evident, but investigation predominates. A range of agencies provide support to family, but there is a chance that only forensic counselling will be accessed.		X	
Collecting and recording of comprehensive information	Information is largely guided by standard forms with some information collected opportunistically.		X	
Involvement of appropriate personnel	Designated personnel undertake tasks. They are not required to have specialist knowledge.		X	
Multi-agency case review and continuous improvement	Multi-agency case discussion does not occur.	X		
Monitoring and research	Monitoring and research occurs to some extent in New South Wales. It is not coordinated.		X	

The policies and guidelines do not fully conform to any aspect of the checklist. Limitations of the current policies and guidelines include the following:

- Policies and guidelines relating to support and guidance for parents are less prescriptive than those relating to investigative processes.
- The guidelines and forms available to those responsible for collecting and recording information do not support comprehensive collection.
- The level of expertise required to undertake tasks is not evident in many of the policies and procedures.
- Multi-agency case reviews occur opportunistically, limiting the knowledge and skill available for each case and opportunities for continuous improvement.
- The monitoring and research activities are uncoordinated, limiting prevention opportunities.

The review examined the strengths and limitations of the SUDI policies and guidelines in New South Wales.

### 4.6 Conclusion

The review examined the strengths and limitations of the SUDI policies and guidelines in New South Wales.

The roles and responsibilities of each agency were identified and the response of the New South Wales service system as a whole was described. The policies and guidelines were then compared with a checklist developed for this research and classified according to their level of conformity with each aspect of the checklist.

The analysis revealed that the response to SUDI in New South Wales is provided by a number of agencies: the NSW Ambulance Service; NSW Health; NSW Police; the Departments of Ageing, Disability and Home Care and Community Services; the NSW Coroner; and SIDS and Kids NSW. The policies and guidelines provided clearly delineated the roles and responsibilities of the various agencies.

The comparison of the New South Wales system with the checklist revealed substantial variation between the two. On four of the five aspects the New South Wales policies and guidelines partly conformed. These four aspects were: a balance between care and investigation, collecting and recording information, involvement of appropriate personnel, and monitoring and research. Multi-agency case review and continuous improvement did not conform. The response to SUDI in New South Wales could be improved by addressing the limitations identified through this study.

Some of the limitations identified are recognised by the agencies. Significantly, the NSW SIDS Advisory Committee is reviewing the *Death Scene Investigation Checklist – Sudden Infant Death* (P534) used by NSW Police to collect information from the death scene, and there are national moves to standardise autopsy practice relating to infant deaths. It is important that these initiatives occur as part of the examination of the statewide response to SUDI and within a multi-agency context.

No conclusions can be drawn from this review regarding the operation of the policies and guidelines. Chapter 5 explores the practical application of the policies and guidelines.

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## Chapter 5 | New South Wales: response to SUDI in operation

Workers responsible for responding to sudden and unexpected deaths in infancy in New South Wales were interviewed in order to understand current practice and obtain their views on the key issues in service delivery and possible solutions.

### 5.1 Introduction

Providing an appropriate response to SUDI is influenced by a number of factors including the policies and guidelines set by the various agencies involved in providing the response, the integration of these across the agencies and how effective these policies and guidelines are in practice. In Chapter 4 the policies and guidelines of the various agencies in New South Wales were examined. Research suggests that it is likely that these policies and guidelines will operate differently within and across locations.

In his examination of public policy development, Lipsky (1980) found that the implementation of policies and guidelines was largely left to individuals who had significant autonomy from the control of their agency and the resources to resist the agency's top-down control or pressure. It is the middle managers and practitioners with direct contact with members of the public who make the policy choices: 'the decisions of the ... bureaucrats, the routines they establish, and the devices they invent to cope with pressure, effectively become the policy [that is] carried out' (Lipsky, 1980, p. xii).

Research has identified a number of factors influencing the operation of policies and guidelines. Work conditions including available resources, demand for services and agency expectations have been shown to have an impact on the actions taken by middle managers and professionals. Sometimes services provided are limited because resources are inadequate, or jobs are redefined thereby reducing workers' experience of conflict and distress.

Also, an individual's theory of social justice influences the judgements they make. Their conception of what is required in any given situation affects how they implement policies, and this can alter policy outcomes. Such effects on outcomes are more likely in agencies where workers have significant levels of discretion (Kelly, 1994).

Other influences on workers' responses include different organisational and political settings, the pressures exerted from the community where a service is located, the leadership of individuals in the service and the culture of the workplace (Weissert, 1994; Carol, 1994).

### 5.2 Aim of this component of the study

This component of the study sought to address Research Question 3:

*What are the practices of New South Wales workers in responding to SUDI?*

## 5.3 Research method

### Sampling procedure

Interviews were undertaken with workers in New South Wales who are responsible for the key aspects identified by the Team in responding to SUDI (see Chapter 4 for details).

In order to reflect rural and urban issues, workers in three urban areas, two rural areas and one remote location were sought. As incidents of SUDI are infrequent, there are few cases in rural areas and remote towns. Towns with more cases were chosen within these areas.

Workers who had responded to at least one SUDI case in the previous three years were identified by their agency. To assist in identifying police officers, the *NSW Child Death Register* was searched from January 2000 to December 2002. (The Child Death Review Team has maintained a register of all deaths of children 0 to 17 years of age inclusive in New South Wales since 1 January 1996.)

Due to difficulties in identifying participants who met the criteria of the study and their availability for interview, only 46 of the 60 planned interviews could be completed. These interviews included: ambulance officers (10), police officers (11), forensic pathologists (5), nurses (5), doctors (5), social workers (3), coroners (2), counsellors for parents (1), child protection officers (2) and those involved with monitoring, data recording, research and/or education (2).

A researcher from the project team contacted workers provided by the agencies to seek their agreement to participate in the study. Participation in the study was voluntary and workers provided written informed consent prior to their participation.

### Interview schedule

An interview schedule was developed to address all aspects of the response process, key issues and proposed solutions. The schedule did not examine the practice of individual workers in individual cases. The schedule was piloted on several participants to test for clarity and identify problems. With the permission of the participants all interviews were recorded.

## 5.4 Analysis

The interviews were transcribed and entered into NVivo (Fraser, 2000), a software package for qualitative data analysis, and a content analysis was performed. This involved three stages. First, categories or themes were developed by reading the interview transcripts and defining the content categories that emerged. Second, each interview was 'coded', which involved assigning relevant sections of the interview to each category or theme. Finally, the themes or categories that emerged were analysed using a variety of techniques such as clustering, counting, comparing and contrasting, factoring and noting relations between variables (Miles & Huberman, 1994).

Demographic information obtained during the interviews was entered into the statistical package SPSS (SPSS, 1999). Descriptive statistics were used to provide a profile of participants.

## 5.5 Results

The results of this study are presented according to four stages of the response to SUDI: initial response; post-mortem examination; attribution of cause of death; and research, monitoring and continuous improvement.

### 5.5.1 Stage 1: Initial response to the death

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Of the professionals that were interviewed, the police officers, ambulance officers and hospital workers are all involved in Stage 1, the initial response to the death. These groups of workers were asked whether their agencies had policies and guidelines for responding to sudden unexpected infant deaths. With the exception of ambulance officers, who do not have specific SUDI policies and guidelines, most workers were aware that their agency had SUDI policies and guidelines, but not all expressed familiarity with their content.

Three themes emerged from the worker interviews in relation to initial response. These were:

- the importance of worker knowledge and expertise;
- working outside areas of expertise; and
- post-response support.

Each of these themes is now explored further.

#### The importance of worker knowledge and expertise

Two main issues were raised by the workers regarding the importance of knowledge and expertise. These centred around:

- gaining knowledge and expertise; and
- the fact that knowledge comes with experience.

**Gaining knowledge and expertise.** Most workers claimed that they did not receive formal training in relation to incidents of SUDI. Workers did, however, report gaining their knowledge and expertise in SUDI in a variety of ways. Some workers reported that knowledge about SUDI could be found in policy manuals. In addition, many workers spoke of attending one-off mandatory lectures throughout their careers:

*'We've got to do mandatory training every year and one particular year the SIDS package was one of the mandatory lectures we had to attend. So all the police throughout the whole State have to do this lecture otherwise they don't get their next pay increment' (police officer).*

*'In my first years training level ... we had people come in from SIDS to give a talk; I don't know whether that happens any more' (ambulance officer).*

Workers also reported relying heavily on their supervisors' knowledge and expertise. For instance, all groups of workers stated that in most SUDI cases either a supervisor, or at the very least an experienced worker, attended death scene investigations.

*'The other process that occurs in almost every case is that one of our supervisors who are senior officers would sort of drive around and supervise road stuff, also attend these cases either at the scene or the hospital depending on the time frame' (ambulance officer).*

Similarly, when one nurse was asked whether she was provided with supervision when responding to a SUDI case, she answered:

*'I'd probably be, like no junior nurse would be left to do one of these on her own' (nurse).*

Although some police and ambulance officers also expressed a reliance on their supervisors' knowledge and expertise, there were clear differences in responses between city and rural officers, with rural officers stating that there were simply insufficient resources available. One city police officer said the following:

*'You've got a mobile supervisor who usually in those sorts of jobs will come out and make sure that everything is going smoothly, that you're doing the right things ... if you've got any questions usually you'll consult with them. The mobile supervisor usually has a fair bit of experience as well. These days they are at least a senior constable which means five years in the job, minimum. They have a fair bit of experience dealing with all sorts of jobs and if you've got any questions you go and ask them and they'll talk it out' (police officer).*

In contrast, the experiences of a rural ambulance officer were quite different:

*'You have the resources here [in the city], you usually have a supervisor go to something of that nature in the city, whereas in [country town] you're it... here [in the city] most jobs are over in 20 to 30 minutes. Five hours for one job out there, you are on your own you have no back-up, most often you don't have communication with you co-ord except via sat phone, you're it, you are out in the middle of nowhere. Here [in the city] you have a mobile phone, radio, other cars, police—you just have to ask for help here as you've got the back-up here, which is a major difference and people that have never worked west of the mountain they don't understand it when you say you don't have the back-up out there' (ambulance officer).*

Some workers identified difficulties in keeping abreast of the knowledge required to undertake their jobs. For example, one ambulance officer expressed confusion about whether or not the parents were allowed to move their infant, believing that rules with respect to this are constantly changing. As a result, officers typically determine this on a case-by-case basis:

*'No it is not clear because we will go to an incident like, and we are not sure sometimes whether we should let [the mother move the infant], the mother will sometimes want to bath the child and we don't know if she'd be allowed to do that. I know about 10 years ago, we as ambulance officers were encouraged to allow the mother to bath the child and dress the child as many times as they wanted to do that and I am not sure if they are allowed to do that today dealing with the police side, their investigation side. I don't feel our role is clearly made to us what we are allowed to do. I have recently done a course where we were told not to arrange anything, if the baby is still in bed leave the baby in bed and you get back out there in a month or so later and you are told that no the parents should be able to pick the baby up and do whatever they want with them' (ambulance officer).*



As a result, this officer felt the need for clearer guidelines regarding the placement of infants prior to police arrival at the scene:

*'Some sort of clarification of just where you are because if the mother asks me can she bathe the child, I would allow that if I didn't see any obvious signs of negligence or neglect of the child around. I would let the mother do that but I am not sure whether I am legally allowed to do that' (ambulance officer).*

While many workers spoke about the ways in which their knowledge and expertise was gained, some workers felt that their knowledge base was inadequate in several areas. The two areas raised were knowledge of how to approach family members about issues relating to the infant's death, and knowledge about SIDS.

*'I can think of another situation where one of my colleagues ... was not as experienced and felt very uncomfortable talking openly to the family that their baby was going to be cut and things, but I think that's part of experience, and it is very uncomfortable ... I mean I see that training for medical staff and social worker staff actually around raising really uncomfortable things with people is always important ... so training in how to approach that' (social worker).*

*'I think perhaps, maybe, you know a specific training, like they do child protection, maybe a specific training on sudden infant death' (nurse).*

*'With SIDS, I would say definitely, at some stage it would not be of any harm to incorporate part of SIDS into a coroners training day or something similar to that effect, once every couple of years. Because I find with any training day, you never absorb everything, every time you go in and if I go to one of our training days and learn one or two things from it, I think that is great. It helps me and it makes my job easier. So in saying that, I think that ongoing training is definitely a necessity for SIDS' (police officer).*

Workers said they required knowledge not only about SUDI generally, but also about the occurrence of SUDI in Aboriginal and culturally and linguistically diverse (CALD) communities. One ambulance officer said, about responding to a SUDI in an Aboriginal community:

*'Our situation becomes a community, and in an Indigenous sense, a tribal situation. So we really need somebody to be able to come in likewise in any other country community and be able to say that this is what we need here and this is what probably would work best for you' (ambulance officer).*

Similar issues were raised with respect to CALD communities:

*'I imagine it would be very difficult to try and explain the process to someone who didn't speak English, especially trying to explain it through an interpreter to the parents' (police officer).*

**Knowledge comes with experience.** Although workers do not currently receive formal training for responding to incidents of SUDI, some did not feel that such training was necessary. The police officers, ambulance officers and hospital workers typically felt that knowledge was obtained with experience on the job, not through a training course.

*'I don't believe that training would prepare them [young officers] ... without experience it would be very difficult to do anything' (ambulance officer).*

*'I mean dealing with family is very difficult but I don't think you can be trained in doing that... I think anyone would have found that traumatic. I don't think there is skill there. In terms of investigation, there is only so much they can teach and then you just have to learn it for yourself. You've just got to pick up on things. So I think, maybe if I'd had a bit more experience I would have been better at it or, I don't know if I'd had any other qualification or any other skills whether I would have been able to do any better. I just think more experience in dealing with traumatic situations and more investigative experience would have helped me more than any other skills or any other qualification or training or whatever' (police officer).*

Participants spoke of how knowledge gained from experience was passed on to other less experienced workers.

*'It's hand-me-downs all the time. We'll pass on our experience to other police and even in the preparation of our briefs of evidence, if there's a junior police doing one, we'll most happily sit down and assist them' (police officer).*

*'Most of us just work in a way that we see it as an obligation we have, that if we learn something just through our experiences we pass it on' (ambulance officer).*

At least two ambulance officers felt that clarity regarding roles and responsibilities often came with experience on the job. One ambulance officer said:

*'Sometimes the new staff obviously haven't been through it before and so, while there might be procedures in place, they may not (a) be fully aware of all the procedures or (b) they may feel nervous in their role, because it is obviously probably one of the most traumatic experiences that they have had to deal with, and so they may be nervous in what they have to do and feel a little bit [word unclear] about what needs to happen' (ambulance officer).*

### **Working outside areas of expertise**

Many workers expressed concern over the need to perform tasks outside their areas of expertise at death scene investigations. Almost always this was related to providing support and counselling to grieving families. For example, one ambulance officer felt that it was important to have someone trained in grief counselling to accompany them to death scenes:

*'One thing that ambulance officers often find difficult is they haven't really received—unless they've changed this in the ambulance training—they haven't really received information about grief counselling ... it's something that we learn as we go along but some people never feel comfortable with, it's not what they're good at, it's not what they feel comfortable with, and to have an extra person there who does know what to do, has a lot of experience at it, would take a lot of pressure off' (ambulance officer).*

Police officers in particular, and some ambulance officers, spoke of the conflict that exists between their investigative role in the death scene and their belief that they should provide care to the families.

*'It's a really difficult role I think, because you're balancing the priority of making sure the process run[s] ... like the necessary questions, the necessary information from everyone involved in terms of what has happened to the child and you're balancing about trying to be supportive and understanding the parents' vulnerable stage, I think it's sort of balancing the two, but at the end of the day I guess the priority is about what's happened to the child' (police officer).*

Other workers expressed concern over the need to make decisions concerning the maltreatment of infants. For example, one ambulance officer said, in relation to whether the infant is allowed to be moved before the police arrive:

*'If you think that the baby has been perhaps assaulted or cruelly handled you would enforce probably a line where you would not have anything moved. If you get there and assess the situation to see that the baby is not—you know there mightn't be any beer cans or any signs of parties from the night before, the house might be well kept, the parents look well groomed, no signs of drugs or anything around the place, you would decrease your suspicion' (ambulance officer).*

As a result, several workers felt that an experienced officer or a supervisor should attend every death scene investigation. Although this is meant to happen, due to limited resources it is not always possible.

*'The only thing I could suggest that would be reasonable is if they had a policy where a supervisor is automatically responded to that case ... I think that would be useful again just to have someone who is experienced who can assist the junior officers to do their best to muddle through the situation' (ambulance officer).*

### **Post-response support**

Three main issues were raised in relation to support for workers following response to the death. These were:

- ways support is received;
- factors affecting use of support structures; and
- usefulness of post-response support.

**Ways support is received.** Workers typically reported receiving informal support after the response to the death. They all agreed that although formal support structures were in place for critical incidents, these were usually reserved for 'more critical' incidents, not for incidents of SUDI.

*'I don't know whether they do that for SIDS deaths ... it's only really with critical incidents that they have them. Like a police shooting or a car crash, something like that, something huge' (police officer).*

Many of the respondents did, however, note that informal support was more common. This involved either discussion with supervisors, or in most cases, with colleagues.

*'It depends on the circumstances, a lot of nurses tend to debrief just sitting around the tea room and venting that way, a kind of informal debriefing' (nurse).*

*'Think that one of the main ways that ambos cope is just talking with your workmates, whoever you're working with, and that's pretty much a debrief really' (ambulance officer).*

**Factors affecting use of support structures.** The ambulance and police officers, in particular, believed that even when some formalised support was offered, most officers declined.

*'There is a branch now, I think it is just the people who do the counselling in the police service, a lot of times if you go to an incident they will ring us and say I heard you were at this job ... do you want any counselling, and it is just a matter of "no, I'm right", hang up' (police officer).*

*'Even if you do need to, a lot of the police might need a debrief but they say "no I'll be right" (police officer).*

Some respondents claimed that officers declined offers of support because they typically had to organise it themselves, rather than having it arranged for them.

*'Most ambulance officers don't want or accept counselling. I was given a card to go and be debriefed. The supervisor told me but I didn't. So that was very silly of me. I think that probably with that, they should make you have it. They should organise it for you and you would probably turn up. Rather than leaving it up to you' (ambulance officer).*

However, the major reason given for declining support was that counselling or support was simply not a part of the workplace culture for police and ambulance officers.

*'We've got it on paper, like we've got peer debriefers, we've got a couple of chaplains, it looks good on paper ... but in reality I don't think it happens, we still got to act with the mentality if you can't cope, get out' (ambulance officer).*

*'The police service has its own counsellors that you can utilise if you really want to. I don't think too many people take that option up, it's not the done thing. You go to the pub and get pissed, that's about it' (police officer).*

**Usefulness of post-response support.** There were mixed views about the usefulness of support after response to the SUDI incident. Some workers from each professional group did not see this as particularly useful or valuable. For instance, in relation to formal support, one police officer said:

*'The thing with talking to psychiatrists is that what do they know? They haven't been in, done that' (police officer).*

Some of the hospital workers were of the view that formal support after critical incidents was not always effective and that in some cases it could increase distress. Two hospital workers said:

*'We don't do formal debriefing because there's a lot of evidence that it actually increases post-traumatic stress' (doctor).*

*'I've been to ones that have worked really well, I've been to others where I feel like I had to leave because I felt like it was more traumatising' (social worker).*

On the other hand, several workers from all professional groups believed some form of post-response support to be extremely useful. These workers indicated that they would like such support offered as a matter of course after attending to any critical incident. In the words of one ambulance officer:

*'No one likes doing SIDS jobs, no one likes doing any paediatric critical jobs ... to be given 15 or 20 minutes after a job, just to be able to get your thoughts together, sit down and have coffee and chat about it, is all you really need ... so I think that would be good, if they could implement that a bit more, I'm not saying everybody needs it, but sometimes it just becomes too much' (ambulance officer).*

Others felt that whether post-response support was useful depended on the personal circumstances of the individual worker involved. Some workers thought it was necessary for workers with young children.

*'I didn't get any counselling or anything like that afterwards and probably the scary fact with that was that I had a six-month-old myself sort of thing. So that screwed me around a little bit' (police officer).*

*'It is not something that, at this point in time, I need it [support] for ... you never know, it may play on a person's mind later in life. I don't have kids at this point in time either, so it might be a time when I do have children later down the track and it might play on my mind then' (police officer).*

Noting that individual worker's personal circumstances need to be taken into account, one doctor felt that one component of post-response support should seek to identify individual needs:

*'It affects staff in different ways; everyone who is involved is affected differently. Whether it is from previous experience about things going badly, or a child of their own, or a relative who has had it, or all sorts of things. It can awaken all sorts of memories or all sorts of problems and it is surprising how differently it can affect people' (doctor).*

### **In summary**

- Some workers felt that their knowledge and expertise was inadequate in some areas.
- Some workers felt that they were not abreast of the knowledge required to undertake their jobs.
- Knowledge and expertise are gained through experience on the job.
- Some workers were concerned about working outside their areas of expertise.
- Some workers experienced conflict between their various roles.
- Post-response support typically occurred informally.
- There were cultural and practical impediments to workers receiving post-response support.
- Post-response support needs to be tailored to the circumstances of the individual worker.

### 5.5.2 Stage 2: Post-mortem examination

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Forensic pathologists are responsible for conducting post-mortem examinations. Three main issues emerged from the interviews conducted with forensic pathologists. These were:

- information received before performing an autopsy;
- constraints on post-mortem testing; and
- use of SIDS as a diagnosis.

Each of these themes is now explored further.

#### Information received before performing an autopsy

Pathologists spoke about the information they received before undertaking a post-mortem examination. For all cases a *Police Report of Death to the Coroner* (P79A) is received, and in the majority of cases a *Death Scene Investigation Checklist – Sudden Infant Death* (P534) is also received. Pathologists claimed that all information received was highly variable.

Regarding the P79A, several pathologists said that sometimes they were provided with all the required information, other times they were left without sufficient information to fully inform the autopsy.

*'The problem is that some of the police will sort of go at it and they will find out everything they can for you, and others will write the absolute minimum, and that's something we don't have any control over'* (forensic pathologist).

*'I mean some of them do a fantastic job and you get, there's nothing more you want to ask, but some of them ... there are big holes'* (forensic pathologist).

Information mentioned as lacking included medical information and relevant information about the death scene.

*'In fact I've got one at the moment which is a baby who turned out to have a lot of medical problems but I didn't even find out about any of the medical stuff before two days after I'd done the autopsy ... I mean it was obvious from the autopsy, there was a lot of congenital abnormalities with the baby, but you just don't find out and of course then the family want the body before you've got the information that you require to actually, if you need to do more tests ... like the medical records on that particular baby I've got today and I did the autopsy ten days ago'* (forensic pathologist).

One pathologist also mentioned the value of ambulance observations, which they only sometimes receive.

*'I guess most of them have some basic information like when the baby was last seen, how it was found, what location the baby was in, history of drugs in the family, that sort of information we like to get plus medical history, but we often don't'* (forensic pathologist).

Information about Department of Community Services' reports was also mentioned as something that would be useful. One pathologist said the difficulties were related to the logistics of someone making a request to the Department of Community Services, and whether the *Privacy and Personal Information Act 1998* allowed the information to be released.

Several pathologists complained about the recent change in the system whereby police no longer visually identify the body and deliver paperwork in person to the mortuary. The relevant forms are now faxed or emailed, meaning firstly that there is less opportunity for speaking to the police about what they had found, and secondly, whereas in the past they could physically bring medical records with them, they are now reliant on couriers and the post, which has caused big delays.

*'Well we have gone backwards, since they've changed the reporting process, from our point of view, we get a lot less information now than we used to. Now that police don't come in, it's made it a lot more difficult for us, we certainly get less information and it is a lot more difficult to get hold of information and when you have the police there on the spot you can actually say, well can you get us such and such, we need to see the blue book and they say, OK I'll organise that, or I'm not on this week but I will ring the station and get someone to get it ... so now we are sort of it's slow because you've got to wait for them to come back and it is certainly not as streamlined as it used to be from our point of view' (forensic pathologist).*

Some pathologists suggested there would be value in a better trained person attending death scene investigations.

*'Again it would be great to have somebody who is trained to look for both the issues that are important for the investigation of a natural death or an accidental death as well as having somebody who has competence and is clued up to making sure about evidence preservation for those sinister deaths. But I'm not sure that there is such a person that's available to do it. Or if there is such a person whether we frankly can afford them' (forensic pathologist).*

While the pathologists spoke about being reliant on the information they received from police, some police officers also spoke about the difficulties they encountered when attempting to gather information for pathologists. For instance, some police officers claimed that their jobs were often hindered because other agencies were unclear about what information they were allowed to provide to the police. One police officer said:

*'Sometimes you're requesting information and other agencies will say, oh we're not too sure if we can give you that. It's more a case of they're unsure about what information they can provide you due to privacy concerns because everybody seems to be paranoid with privacy concerns and then they just fail to realise in a lot of instances they can give us the information, it's not a problem. At times it can be frustrating for the police because the police know that they can give it to them, but they'll be saying no' (police officer).*

Other workers felt that the inter-agency process for giving and receiving information from different agencies was unclear. One Department of Community Services worker said:

*'As far as the police go, that's a bit more difficult, and I guess it's just because the size of that department, that force and the geographical sort of spread of where they all are, I mean that is a problematic at times. Because they'll often go straight to the local office and sort of request the files and the welfare officer will just hand them over, which is not how it is supposed to happen' (Department of Community Services worker).*

While the pathologists focused on the quality of the information received from other agencies, several workers from other agencies commented on the lack of contact they had with pathologists. One doctor commented that he would like to be able to discuss cases with the pathologists.

*'The feedback from the Coroner is non-existent, and that's a big problem. If you ring the morgue to try and discuss it with the pathologist, you'd be extremely lucky to get on to the pathologist. The feedback is non-existent' (doctor).*

Other workers talked about the need for pathologists to feed back information to the parents. Several hospital staff, for instance, were concerned about whether post-mortem results were being explained to parents.

*'I'm not aware of a system that the State has in place to get people to go through the results, they certainly make it hard. I mean, I would have thought if you were the doctor you fill out the report to the Coroner; I can't see why you can't get a copy [of the post-mortem report] to convey to the family. It's a serious failing in the system' (doctor).*

### Constraints on post-mortem testing

Pathologists spoke at length about the testing they did in SUDI cases. They described the restrictions surrounding what they could do in terms of performing post-mortem examinations in New South Wales. While some pathologists described a process of testing that was generally followed in all SUDI cases, others described the process as more dependent on the particular pathologist and the requirements of the particular case presented.

*'There is a protocol here, or has been for quite a long time, that babies in, shall we say, the SIDS age group have a number of things that are automatically done when they arrive' (forensic pathologist).*

*'We each have our own styles and own views and they're usually based on our own previous experiences. If you get burned in a certain way, you change your practice so that you hopefully never get that event occurring again' (forensic pathologist).*

*'I think that it's hard to apply a protocol ... because cases are different ... Well we have a standard minimum. But the maximum is unlimited, dependent on the case' (forensic pathologist).*

The issues raised in conducting tests in these cases concerned the practicalities of certain testing being done, the resources available, and performing autopsies under the *Coroner's Act 1980*.

**Practicalities.** Pathologists described some of the practical difficulties of undertaking the testing outlined in protocols. For example, some testing requires samples being taken straight away, which is not practical if the infant has been dead for some time.

*'The reality is by the time you do the autopsy it is usually too late to get the specimens for that [metabolic testing] because a lot of them have to be obtained within a few hours of death and often we won't do an autopsy until 12 hours after death, so if a baby dies on a Friday we don't even know about it until Sunday,*



*so you've already lost your chance of getting a lot of the metabolic disorders' (forensic pathologist).*

Another practical issue mentioned was finding places to process the specimens collected.

*'Some places they will refuse to do post-mortem specimens, you get a lot of rubbish growing and it's not worth it. And, the reality is, if you look at it, we rarely get to see anything of clinical significance ... occasionally you do, but it's a fairly poor positive rate on it and so they argue it's not worth doing it, it's too much hassle and they can't see that it's cost effective' (forensic pathologist).*

**Resources.** The issue of resources was mentioned by all pathologists, in particular that some of the testing was very expensive.

*'I can say we should do toxicology on every single post-mortem we do and in real terms, yes you should because somebody who might have heart disease and we diagnose heart disease, but if you don't do toxicology you don't know they haven't been poisoned as well, it's going to be extremely rare, but you've got to do it, but the practicalities are that it would be so incredibly expensive to do, and time-consuming, that you wouldn't get reports out for three or four months so to do it you've got to rationalise and you've got to look at your resources ... not only resources here but the resources in terms of laboratory facilities and so on' (forensic pathologist).*

**Coroner's Act 1980.** The recent changes to the Coroner's Act 1980 were identified as placing constraints on testing.

*'There is a big difference between what our purpose is in terms of the requirements of the Coroner's Act and what could be viewed as an optimal investigation of a death. Now the two are different. The Coroner's Act has requirements. Anything in excess of that is effectively breaking the law because there is no need for it' (forensic pathologist).*

### **Use of SIDS as a diagnosis**

Pathologists had different beliefs about when to use SIDS as a diagnosis. They identified difficulties in determining whether a death was due to SIDS or other factors such as co-sleeping. Some pathologists also spoke about the use of SIDS as a diagnosis to assist families to come to terms with the death.

*'The incidence of SIDS is going to vary depending on who you speak to because one case will be classified as SIDS or a bed-sharing accident, or a co-sleeping accident by different people depending on who you talk to. So there is some problem in terms of definition' (forensic pathologist).*

One pathologist described the considerations in making diagnoses in these cases:

*'The chances are very strong that unless there has been a specific suggestion that there was documented smothering, accidental or otherwise, I would give the cause of death as sudden infant death syndrome. I'm pro-SIDS. It's a good thing because it doesn't apportion blame, there is no evidence really, have you any evidence that lying in the bed with that child on that occasion caused the death.*

*You know, it just makes it a better diagnosis for that family. The kid's not coming back no matter what. So you know in a situation like that where "undetermined" has bad consequences, take your pick on cause of death has bad consequences, I believe that SIDS is the right diagnosis ... Other people will at the slightest suggestion that something having happened, possibly, maybe in the bed, attribute it to that. And then you've got the fence sitters ... undetermined. Now the problem with saying it's undetermined is it effectively forces an inquest. So we're now at the stage that not only have we had police invade the house but you'll end up having to go to court as well' (forensic pathologist).*

It was clear that the feelings of the family were a factor in the diagnosis of cause of death. A SIDS diagnosis was seen as assisting the family to come to terms with the death. Further, some pathologists tried to avoid 'undetermined' as a cause of death, describing pressure from coroners and the belief that it forced an inquest, which was felt not to assist the family.

*'It's supposed to, and that's one of the reasons for using SIDS as a term because it avoids having that public inquest which yes, has some uses in some cases, but in the most part doesn't resolve anything more and is just an opportunity to raise doubts and concerns by families when they probably need to move on to other matters. Yes, if you put out a cause of death as undetermined, the coroner generally will hold an inquest. They will try very hard to get you to change it to something like SIDS or a natural cause of death because that gets them out of the dilemma of having to hold an inquest. It's difficult though because if you start putting things like "overlay" (to suffocate by accidentally lying on top of) it gives an implication of an unnatural death and therefore also is a reason for coroners to consider holding inquests' (forensic pathologist).*

### **In summary**

- The quality of information received by pathologists was variable and sometimes insufficient.
- Feedback to parents and professionals involved in the case did not always occur.
- There were constraints on post-mortem testing that limited the information available to pathologists.
- Pathologists had different beliefs and practices about when and why to use SIDS as a diagnosis.

### **5.5.3 Stage 3: Attribution of cause of death**

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Coroners are responsible for attributing cause of death. Coroners interviewed spoke about the way in which decisions are made concerning cause of death.

Three main issues were raised:

- difficulties in attributing cause of death;
- reliance of coroners on the information presented to them; and
- difficulty of balancing the needs of grieving parents with the requirements of the investigation.

These themes are now explored further.

Determining cause of death in SUDI cases was described by coroners as similar to other deaths, but there were some distinctions made. One coroner spoke about the difficulty in interpreting information due to the limits of the available information concerning infants:

*'I mean one of the things is you're dealing with a situation where there is no input from the deceased. You are dealing with children who cannot communicate; there is nothing in that aspect. Some of the profiles of death, for example suicide, we have the words and the actions from the person themselves but there is absolutely nothing of that oral sort of history as it were. The history is gathered from all other people' (coroner).*

Another coroner stressed the extra investigation and attention to detail given to these cases. Presumably again the extra investigation is undertaken because of the lack of information that can be gained from other sources about the deceased.

*'The only real difference in a SIDS case or baby cases is that there is extra investigation, extra careful investigation done by the police at the scene according to a special protocol which has been devised' (coroner).*

Coroners described the process of making decisions. In general it seemed it was the police investigation together with the pathologists' investigation on which most decisions were based. In certain cases, however, extra information may be requested and in cases where inquests are held, expert witnesses may be called in to assist.

*'I consider the investigation by the police on the one hand and the investigation which includes toxicology by the pathologists on the other, those two would come together with the files ready for me and I decide on that basis. And I should say that that's the same basis on which all coronial matters are dealt with' (coroner).*

*'When you are sitting there you are totally dependent on what people have done and the information combined, the collective information people have about a particular topic and you have to rely on the information coming to you and being able to process it in the context of the case before you' (coroner).*

One of the implications of depending on information from various agencies is that coroners' investigations may be lengthy. A Department of Community Services worker described the difficulty in waiting for the coroner's report in a case where children had been taken from their mother when her child died in suspicious circumstances and could not be returned to her before the release of the final report.

The importance of balancing the requirements of the investigation with the needs of grieving parents was also mentioned as particularly significant in these cases.

*'The other thing to keep in mind is if it is a genuine unexpected death, you've got two grieving parents who are beside themselves with grief and you're tramping through their house with their dead baby there and it's not pleasant for them, so one has to balance the intrusion with proper investigation' (coroner).*

*'You are going to have very bewildered parents ... you have people who don't understand the necessity for ... a post-mortem. They think "we haven't done anything to this child we're in a grieving process"' (coroner).*

### **In summary**

- There were particular difficulties for coroners in attributing cause of death in infants.
- Coroners were reliant on the information available.
- Coroners needed to balance the requirements of the investigation with the needs of grieving parents.

### **5.5.4 Stage 4: Research, monitoring and continuous improvement**

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No epidemiologists were interviewed in this study. As a result, this section focuses more on medical research and less on the need for research and monitoring of parental practices.

One area identified as requiring further research related to the medical aspects of SIDS.

*'We need to get more information to try and identify what the cause is of the condition that is called SIDS. Some of them adhere to overheating, some of them adhere to the view of clostridial infections that were found, some are metabolic diseases that present and end up being called SIDS because they're not identified because they don't show a structural [word unclear] that's identified at post-mortem. So you are not looking at a homogenous group, so it's difficult to legislate or to formulate a plan to prevent it' (forensic pathologist).*

One coroner also endorsed further research being undertaken in this area:

*'I think the more we know about SIDS, the more research that is undertaken, the easier it will make my task' (coroner).*

Other pathologists, however, spoke about the difficulties of doing medical research, given the restrictions in obtaining materials following the recent changes to the *Human Tissues Act 1983* made in response to the *Walker Inquiry into the Glebe Morgue* (2001).

*'To take samples from the body that are considered to be research now requires consent from the family, even the coronial matters... so that's now law with the Human Tissue Act, or changes to the Human Tissue Act, that as long as it is research ... now if they are saying it is a diagnostic procedure, that's a bit of a different thing but it still has to be done with the authority of the coroner, but if there is somebody there who is interested in a particular rare metabolic disorder, and they get a dead baby in there and he takes a sample, not to make a diagnosis, but because he needs samples for research for looking into say ... studying that particular disorder or group of disorders, it has to get written approval from the family or the next of kin' (forensic pathologist).*

Another area that was identified as needing further research was co-sleeping.

*'I think there needs to be more stuff going into the co-bedding because that is not black and white in the guidelines. It sort of says you know there's a neonatal intensive group that with co-bedding with babies they say "oh yes but the evidence is safe". But we don't know whether that is. So I think co-bedding with adults and with siblings and things like that is an important area to still look at' (researcher).*

Finally, one researcher felt that the current focus should not be on research. Rather, this researcher expressed that information collection systems in New South Wales need to be improved so that research can be based on quality data:

*'The information is not good enough, so in fact, the information that we are getting out on the classification of the deaths is very different to the international literature ... so I guess I am saying that you need to have a good audit first and that needs to be a quality and optimal audit, before you can actually generate hypotheses' (researcher).*

The researcher suggested that an 'autonomous group', 'something like a managed network' could be set up with staff responsible for policy, staff responsible for education, and staff responsible for research aspects, with a quality improvement thread across all three strands.

In relation to continuous improvement, several of the workers noted that feedback would be useful for improving their own practice.

*'It is very frustrating not to know what happens ... obviously with confidentiality issues, but still, we can't improve or change anything unless we have any feedback as well' (ambulance officer).*

*'It would be great to hear back from the incident, you like to know that you're on the right track and you're doing the right thing, whether there's been any outcome at the hospital afterwards' (ambulance officer).*

#### **In summary**

- The quality of information available was identified as an impediment to conducting research.
- A need was identified for both medical research and research into professional and parental practices.
- Restrictions in obtaining human tissue samples limited medical research.
- Some workers felt that feedback would be useful for continuous improvement purposes.

## **5.6 Conclusion**

The study into the operation of the response to SUDI in New South Wales obtained the views of key workers: police officers, ambulance officers, hospital workers, forensic pathologists, coroners, Department of Community Services' workers, a SIDS and Kids NSW staff member and researchers. Interviews were conducted in urban, rural and remote locations.

An interview schedule was developed to understand the process of responding to SUDI, key issues and proposed solutions. The schedule did not examine the practice of individual workers in specific cases.

Overall the New South Wales legislation, policies and guidelines of the various agencies as reported in Chapter 4 were not always followed and varied across locations and individual workers. This needs to be taken into account when considering the response to SUDI in New South Wales.

The analysis undertaken across the four stages of the response to SUDI: initial response; post-mortem examination; attribution of cause of death; and research, monitoring and continuous improvement revealed a range of issues by all participants.

Analysis of the initial response stage identified issues including: participants feeling that they worked outside their areas of expertise; conflict between the various roles performed; inadequate knowledge and expertise in some areas; gaining knowledge and expertise through experience on the job; and cultural and practical impediments to receiving post-response support.

The post-mortem process included other issues: variation in the quality and comprehensiveness of information received prior to the post-mortem examination; constraints on post-mortem testing; differences between pathologists' beliefs and practices about when and why to use SIDS as a diagnosis; and lack of appropriate feedback provided to parents and professionals involved in an infant death.

Examination of the attribution of cause of death identified yet other concerns. These included the particular difficulties in attributing cause of death in infants and achieving a balance between the requirements of the investigation and the needs of grieving parents.

Finally, the analysis of the operation of the research, monitoring and continuous improvement stage identified the following as impediments: poor information collection; severely limited opportunities for continuous improvement; and restrictions in obtaining human tissue samples for medical research.

The issues experienced by workers in responding to SUDI provided insights into the challenges faced in New South Wales. Although there was variation in the extent and intensity of issues experienced across participants, three main areas of inadequacy were identified.

First, workers did not always have the knowledge and experience required to undertake stressful roles. Consequently some workers were placed in situations which they were ill-equipped to handle, leaving parents poorly supported. Secondly, the information required to undertake the essential tasks of autopsy, attribution, monitoring and research varied in quality and comprehensiveness. As a result, both accurate determination of cause of death and prevention efforts are thwarted. It is well recognised that it is difficult to gather information after the death of an infant and that specialist skill is required. Thirdly, continuous improvement in New South Wales was restricted by limitations in the information available and the lack of systems to convey this information to those who require it. Consequently the capacity for learning and continuous improvement is diminished.

Some of these issues identified are magnified in non-urban locations. The infrequent incidence of SUDI and the distribution of incidents across the State presents a particular challenge for New South Wales.

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## Chapter 6 | Modifiable risk factors and the New South Wales experience

Risk factors for sudden unexpected deaths in infancy were identified in the national and international literature. The practices of parents in New South Wales in relation to these risk factors were examined among parents of infants generally and among parents of infants who died to determine the prevalence of these factors and implications for prevention.

### 6.1 Introduction

Fundamental to any attempt to reduce the incidence of SUDI in New South Wales is knowledge of associated risk factors. The prevalence of these risk factors amongst the New South Wales population and their associations with population subgroups can highlight where preventative work will have greatest effect.

A considerable body of research on risk factors for SIDS and SUDI has been developed. Little is currently known about the practices of New South Wales parents in relation to these risk factors. The identification of risk factors is dependent on the information available to epidemiologists and researchers. Efforts to identify risk factors in New South Wales have been limited by the information collected and recorded on SUDI cases (see discussion in Chapter 3).

### 6.2 Aim of this component of the study

This component of the study sought to address Research Question 4:

*What is known about modifiable risk factors for SUDI? In New South Wales, what are the parental practices in relation to these risk factors among parents of infants generally and among parents of infants who die? Are there any particular groups who engage in these risk behaviours?*

### 6.3 Risk factors

Many published studies compare the epidemiological characteristics of SIDS with non-SIDS (control) infant populations. These studies have identified socio-demographic and infant characteristics associated with SIDS and have uncovered practices and behaviours associated with a higher risk of SIDS that are amenable to change. While the research in this area has focused predominantly on SIDS, more recent research indicates that the factors associated with SUDI, whatever the cause (SIDS, explained, undetermined), show similar epidemiological profiles (Leach et al., 1999; Fleming, Blair, Platt, Smith & Chantler, 2000).

#### 6.3.1 Socio-demographic and health risk factors

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A range of socio-demographic and infant health characteristics have been found to be associated with a higher risk of SIDS and other SUDI. Among the characteristics that have repeatedly been found to be significantly associated with SIDS are: poor socio-economic status, parental unemployment, young maternal age, higher parity (number of births by

mother); neonatal health problems; and low birth weight (Bartholomew et al., 1987; Taylor & Sanderson, 1995; Fleming, Blair, Platt, Smith & Chantler, 2000; Leach et al., 1999; Arnestad, Andersen, Vege & Rognum, 2001; L'Hoir et al., 1998b; Paris, Remler & Daling, 2001; Alm, Norvenius, Wennergren, Skjaerven, Oyen, Milerad, Wennborg, Kjaerbeck, Helweg-Larsen & Irgens, 2001).

Knowledge of these risk factors can assist health professionals and public health policy makers in targeting infants and families most at risk of SUDI for provision of support, services and education aimed at preventing SUDI.

### 6.3.2 Modifiable risk factors

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Risk factors for SUDI that are potentially amenable to change provide powerful opportunities to reduce the incidence of SUDI. Throughout the past two decades strong research evidence has emerged for several risk factors relating to parental behaviour and the infant's sleep environment. The strongest and most consistent evidence for an association with SIDS has been found for:

- infant's sleeping position;
- exposure to tobacco smoke; and
- head covering.

The evidence for these and other factors are examined in more detail in the following section.

#### Infant sleep position

There is now clear evidence that the back-down position is the safest sleeping position for infants. The face-down position is a risk factor for SIDS, as is placing infants for sleep on their side, as this position is unstable and can result in the infant rolling into the face-down position.

Numerous case-control observational studies have shown that the risk of SIDS is considerably higher when infants sleep face-down. This association is maintained even after adjusting for potentially confounding variables (see Beal & Finch, 1991; Henderson-Smart et al., 1998; Gunn, Gunn & Mitchell, 2000).

The most compelling evidence that face-down sleeping is a risk factor is the significant reduction in SIDS after prevention programs were introduced. The *Reducing the Risk of SIDS* program, encouraging parents to place infant on their backs or on their sides for sleep was introduced in many countries, including Australia, in the early 1990s. Reductions in the rate of SIDS following the implementation of these programs were seen in several countries including Australia, the United States and the Netherlands. Most of the decline can be attributed to the change from the face-down sleeping position (Engelberts & de Jonge, 1990; Mitchell et al., 1992, Mitchell et al., 1994; Wigfield et al., 1992; Dwyer et al., 1995; Beal, 1995; Beal & Byard 1995; L'Hoir et al., 1998b; Skadberg et al., 1998; AAP, 2000).

Importantly, research before and after the implementation of the *Reducing the Risk of SIDS* program indicates that the face-down position remains a risk factor for SIDS. A study of 1,316 SIDS deaths occurring over 30 years (1968 to 1997) in Adelaide, South Australia, reveals that although face-down sleeping for infants in the community decreased to less than one per cent in South Australia, the majority of infants who died of SIDS were still face-down. This was true for all three decades, varying little from 83 to 86 per cent (Beal, 2000).



Numerous other studies conducted after the intervention to reduce SIDS confirmed that face-down sleeping remained a SIDS risk factor (Oyen, Markestad, Skjaerven, Irgens, Helweg-Larsen, Alm, Norvenius & Wennergren, 1997; Willinger, Hoffman, Wu, Hous, Kessler, Ward, Keens & Corwin, 1998; Brooke, Gibson, Tappin & Helen, 1997; Fleming, Blair, Platt, Smith & Chantler, 2000).

Compelling evidence for the risks associated with placing infants for sleep on their sides has emerged since campaigns advising against the face-down position (Fleming, Blair, Bacon, Bensley, Smith, Taylor, Berry, Golding & Tripp, 1996; Mitchell, Thach, Thompson & Williams, 1999). One of the major findings of the *Confidential Enquiry into Sudden Deaths of Infants* (CESDI) study, arguably the most rigorous SUDI research conducted since the intervention, showed a significantly increased risk of SUDI from side-sleeping (Fleming, Blair, Platt, Smith & Chantler, 2000). While the risk of the side-sleeping position was less than for the face-down position, it was significantly higher than for the back-down position. The risk of side-sleeping was related to the risk of the infant rolling into the face-down position.

The findings of the CESDI study are consistent with those found in the US National Infant Sleep Position Study (Willinger et al., 1998). The side-sleeping position was found to be much less stable than the face-down and back-down positions. The risk of side-placed infants rolling on to the face-down position significantly increased with age. Even at an age younger than eight weeks there was a 25 per cent chance the infant would roll from the side position, with the risk increasing to 50 per cent for infants aged 16 weeks.

Additional evidence of the risks of side-sleeping have been reported by the Nordic study (Wennergren, Alm, Oyen, Helweg-Larsen, Milerad, Skjaerven, Norvenius, Lagercrantz, Wennborg, Daltveit, Markestad & Irgens, 1997) and the New Zealand study, which concluded that infants should be placed for sleep on their back only (Mitchell, Tuohy, Brunt, Thompson, Clements, Ford & Taylor, 1997).

### **Exposure to tobacco smoke (during pregnancy and after birth)**

There have been nearly 50 studies into the relationship between smoking and SIDS. This research found not only that maternal smoking during pregnancy increased the risk of SIDS but also that postnatal exposure to tobacco smoke further increased the risk.

The finding of a significant association between exposure to tobacco smoke and SIDS has been maintained over time (before and after risk reduction campaigns) and in many countries including New Zealand, Sweden, Norway, Scotland and the United States (Mitchell et al., 1997; Oyen et al., 1997; Alm, Milerad, Wennergren, Skjaerven, Novenius, Oyen, Helweg-Larsen & Irgens, 1998; Bartholomew et al., 1987; Taylor & Sanderson, 1995). Three recent reviews summarised the relationship between smoking and SIDS (Mitchell & Milerad, 2000; Anderson & Cook, 1997; Golding, 1997). The reviews considered cohort and case-control studies, and after taking into account the methodological problems associated with these studies, all three reviews concurred on the significance of the risk for SIDS of maternal smoking during pregnancy.

The CESDI study also found a strong and independent association between smoking during pregnancy and SUDI. Furthermore, the findings demonstrate a dose-response effect, with the risk increasing with increasing cigarette consumption by the mother (Fleming, Blair, Platt, Smith & Chantler, 2000). Interestingly, the CESDI researchers found a higher prevalence of smoking

during pregnancy for all SUDI than in the control group, but a significantly higher proportion of mothers smoked during pregnancy in the SIDS group than in the explained SUDI group.

There is also some evidence of an increased risk of SIDS with postnatal exposure to smoke. In a review of the international literature, Mitchell and Milerad (2000) noted the methodological difficulties of identifying independent effects on SIDS of postnatal exposure to tobacco smoke by the mother, father and other household members. As most mothers who smoked in the postnatal period also smoked during pregnancy it was difficult to disentangle the effect of one from the other. Similarly, when examining the specific effect of the father's or other household members' smoking on the risk of SIDS it is important to control for maternal smoking. This has been problematic in many studies due to the high correlation between the mother's smoking behaviour and that of other members of the household. Nevertheless, Mitchell and Milerad (2000) concluded that there was a threefold increase in risk of SIDS with maternal smoking and evidence of a small risk of SIDS associated with other household members, particularly fathers, smoking.

The CESDI study also suggested a risk of SUDI from postnatal exposure to tobacco smoke, with the risk increasing with the number of hours infants were exposed to parental tobacco smoke (Fleming, Blair, Platt, Smith & Chantler, 2000).

### **Head coverings**

Head covering carries a high risk for SIDS and is especially associated with loose bedding such as doonas or quilts.

One of the major findings of the CESDI study was a higher risk of SIDS associated with infants found with covers over their heads (Fleming, Blair, Platt, Smith & Chantler, 2000). Doona or quilt use was more common among the SIDS group than among control infants, with a larger proportion of SIDS cases found with covers over their head during their last or reference sleep than the control group (16.2% and 2.9% respectively). In earlier analysis, the magnitude of the association between head covering and SIDS increased after other known risk factors were controlled for (Fleming et al., 1996).

These findings are consistent with previous studies showing that being found with the head covered was a strong risk factor for SIDS (Gilbert, Rudd, Berry, Fleming, Hall, White, Oreffo, James & Evans, 1992; L'Hoir, Englebets, Van Well, Bajamowski, Helweg-Larsen & Huber, 1998a). The majority of the infants that were found covered had moved down or slipped under the covers and were covered by infant doonas or quilts.

Other support for the risks associated with placing infants for sleep in circumstances where their head can become covered comes from cohort and case studies. Beal and Byard (1995) reported that 22 per cent of SIDS infants in South Australia from 1987 to 1993 were found with their head underneath bedclothes or tangled in bedclothes. The NSW Child Death Review Team has repeatedly reported on incidents of SUDI where infants were found with their heads covered by bedding (quilts, blankets or pillows) (CDRT, 2002a, 2003).

Additional support comes from physiological studies that indicate that facial obstruction by soft bedding may obstruct airways completely and lead to accidental suffocation (Galland, Peebles, Bolton & Taylor, 1994; Kemp, Kowalski, Burch, Graham & Thach, 1993).

**Other potentially modifiable factors**

There is some controversy over whether sleeping together with an infant (co-sleeping) is associated with a higher risk of SIDS. (Co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purpose of feeding and settling.) Difficulties in assessing the risk of co-sleeping in itself arise from associations between co-sleeping and other risk factors and the difficulty of defining cause of death under these circumstances. They are often indistinguishable from suffocation due to overlying by another person in the bed and/or entrapment in bed structures and bedding (Flick, White, Vemulapalli, Stulac & Kemp, 2001; Kemp, Unger, Wilkins, Psara, Ledbetter, Graham & Thach, 2000; Beal & Byard, 1995).

A review of six case-control co-sleeping studies by Gunn et al., (2000) concluded that it was unclear whether co-sleeping was a risk factor among infants of non-smoking mothers. The analysis revealed only a small risk of SIDS from co-sleeping by a non-smoking mother, but strong evidence that co-sleeping by mothers who smoked was a major risk factor for SIDS.

A significant risk with mothers who smoke while sleeping with their infants has been found elsewhere (Blair, Fleming, Smith, Bacon, Taylor, Berry, Golding & Tripp, 1996). This study also found an increased risk among infants who shared a sofa with an adult. The authors concluded that it was not co-sleeping in itself that was hazardous but the circumstances in which it occurred. Infants who shared their parents' bed for the purpose of feeding and settling and were then put back in their own cot had no increased risk.

In a recent review of four large case-control studies examining the epidemiology of sudden unexplained infant death, co-sleeping was found to be significant: if the mother smoked, especially in the first weeks of life; if the mother consumed alcohol and the co-sleeping continued throughout the night; and for non-smoking mothers in infants younger than eight weeks (Carpenter, Irgens, Blair et al., 2004) The authors concluded that 'all-night bed-sharing should be discouraged for all mothers who smoke' (p. 190).

In general there is agreement that the potential for accidental death is increased by co-sleeping. If infants sleep with parents, safe sleeping conditions for the infant are needed (Beal & Byard, 2000; AAP, 2000; Kemp et al., 2000). Infants should sleep in the back-down position on a firm surface without pillows and immobilised in some way to prevent them sliding down under the bedclothes or becoming wedged. The American Academy of Pediatrics also suggest that parents who choose to co-sleep with their infants should not smoke or use other substances such as alcohol or drugs that may impair arousal. As an alternative to co-sleeping they suggest that parents place the infant's crib near their bed to allow for more convenient feeding and parent contact.

Another potentially modifiable risk factor identified by the CESDI study was recognition of infant illness. The study found that more SIDS than control infants were reported by parents to be in poor health. Significantly more SIDS infants were unwell and needed a doctor's assessment (10% compared with 4% for controls) or needed medical attention (5% compared with 1% for controls). The study repeatedly found that parents and health professionals underestimated the severity of illness in infants. Health professionals' failure to recognise the severity of an infant's illness was a frequent factor contributing to suboptimal care. Health professionals included general practitioners, paediatricians, health visitors, nurses, midwives and obstetricians. The authors concluded that improvement in the ability of both parents and health professionals to recognise features of illness in babies and subsequently seek or provide medical attention would reduce SUDI (Fleming, Blair, Bacon, Platt & Berry, 2000).

### 6.3.3 Summary of risk factors

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The epidemiological profile of infant deaths classified as SIDS and explained SUDI are similar to each other and differ substantially from control group infants. The common risk factors shared among SIDS and explained SUDI cases include low social status, economic disadvantage and neonatal problems in general.

Several modifiable risk factors for SUDI have been identified. The strongest evidence has been provided for:

- **sleeping position.** The back-down position is the safest sleeping position for infants. 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.
- **exposure to tobacco smoke.** Both maternal smoking during pregnancy and exposure to tobacco smoke after birth are significant risk factors for SIDS.
- **bed coverings.** Loose bedding that can cover an infant's head is associated with a high risk of SIDS. The risk is particularly associated with the use of bedding such as doonas or quilts which infants can slip under during sleep.
- **co-sleeping and smoking.** Co-sleeping can increase the risk of SIDS if the mother smokes or the caregiver shares a sofa or other inappropriate sleep environment with the infant.

## 6.4 Parental practices to modifiable risk factors evident in infant deaths

This analysis reviewed information on parental practices for the SUDI population in relation to modifiable risk factors identified from the literature.

### 6.4.1 Research method

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#### Data source

The *NSW Child Death Register* (the Register) was identified as an appropriate data source. The Register is maintained by the Child Death Review Team and contains details of all deaths of children and young people less than 18 years of age in New South Wales since 1996. The Register is based on death registration data from the NSW Registry of Births, Deaths and Marriages. Details include date of birth, date of death, date of registration of the death, cause of death noted on the death certificate, age of the child, last known residence, parents' names, place and country of birth, Aboriginal and Torres Strait Islander status and sex. For each coronial case additional information is sought.

#### Identification of cases

A death was included in this analysis if it met the definition of SUDI used by the CDRT. This definition was applied to all infant deaths registered between 1 January 2000 and 31 December 2002 that were referred to the coroner. One hundred and eighty-six deaths were identified.

### 6.4.2 Analysis

All sudden and unexpected infant deaths registered between 1 January 2000 and 31 December 2002 were analysed. The analysis of the deaths was undertaken according to the date of registration of the death. This is in line with other national data sets managed by the Australian Bureau of Statistics and National Injury Surveillance Unit.

Descriptive analyses were undertaken using the statistical package SPSS (SPSS, 1999). The analyses revealed that the information available on these deaths was incomplete and the extent of the information was variable. This limited the analyses that could be undertaken on some variables.

### 6.4.3 Results

Over the three-year period, 186 infants died suddenly and unexpectedly after being placed for sleep. Based on the available information known risk factors were evident in 86.6 per cent (161 of 186) of the deaths.

- Forty-one per cent were placed for sleep in unsafe positions (13 face-down; 63 on their side).
- Fifty-eight per cent were exposed to tobacco smoke during pregnancy and/or after birth (71 during pregnancy; 88 after birth).
- Head coverings were evident in 59.7 per cent of cases (78 had pillows; 73 had doonas, quilts and/or blankets).
- Co-sleeping in combination with smoking or substance use was evident in 25.8 per cent of deaths (24.7% were exposed to tobacco smoke during pregnancy and/or after birth; 9.7% of carers had consumed alcohol or other drugs prior to co-sleeping).

These findings concur with international literature (Leach et al., 1999).

## 6.5 Parental practices to modifiable risk factors evident in the New South Wales population

### 6.5.1 Background to parental practices analysis in the New South Wales population

This analysis reviewed information on parental practices for the New South Wales population in relation to modifiable risk factors. The *Child Health Survey 2001* (CHS) was identified as an appropriate data source for this purpose. Because the analysis was undertaken after the study took place, only three SIDS/SUDI risk factors could be examined.

### 6.5.2 Research method

#### Data source

The CHS, a cross-sectional population-based survey, was conducted by the NSW Department of Health using computer-assisted telephone interviewing (CATI). The target sample comprised at least 500 New South Wales children up to 13 years from each of the 17 health areas. One eligible child was selected from each household, using random numbers generated by the CATI system. A parent or carer of the selected child was interviewed. The survey questionnaire and a detailed description of the survey methods are published elsewhere (Centre for Epidemiology and Research, NSW Department of Health, 2002).

A total of 9,933 interviews were conducted, with a response rate of 84.9 per cent. There were 736 records relating to children less than one year of age in the CHS. Data from these records was used to investigate the social and demographic characteristics of infants and parents on three risk factors. This analysis was carried out by the Centre for Epidemiology and Research, NSW Department of Health.

### Outcome measures

The risk factors used as outcome measures for the study were:

- infant sleeping position;
- household smoking; and
- smoking during pregnancy.

Information on parental practices in relation to bed coverings could not be included in the analysis as it was not collected in the CHS and was therefore not available for analysis.

The survey question of relevance to infant sleeping position was: 'What position did you put [child] to sleep in from birth?' Responses for infant sleeping position were classified as (1) on back and (2) in other position (includes responses such as on side, on stomach, in more than one position and any other position).

The survey question of relevance to household smoking was: 'Which of the following best describes your household? Myself and others in the household smoke; I smoke, but no one else does; I don't smoke, but others in the household do'. Household smoking outcome was categorised dichotomously (yes or no).

The survey question of relevance to smoking in pregnancy was: 'When you were pregnant with [child], did you ever smoke cigarettes, cigars, pipes or other tobacco products?' Smoking in pregnancy was categorised dichotomously (yes or no).

These outcomes were examined for association with a range of social and demographic characteristics collected in the CHS and identified in the literature as associated with the outcomes:

- mother's age;
- sex of child;
- child health rating;
- parents' education;
- parents' employment status;
- country of birth of mother, father and child;
- language spoken at home;
- Aboriginal or Torres Strait Islander status of mother and father;
- contact with a baby health or early childhood nurse;
- age of first contact with baby health or early childhood nurse;
- having a personal health record;

- usual consultant for child's general health problems (local doctor, hospital or medical centre<sup>2</sup>);
- whether infant ever breastfed;
- current breastfeeding;
- total duration of breastfeeding in months;
- geographical remoteness based on the Accessibility/Remoteness Index for Australia;
- relative disadvantage based on Socio-Economic Indexes for Areas; and
- number of children in household.

### 6.5.3 Analysis

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The following analyses were carried out for each of the three risk factors on records relating to children less than one year of age.

1. The risk factors were cross-tabulated with the social and demographic characteristics previously listed.
2. Crude (unadjusted) prevalence rate ratios (PRRs) were calculated for each risk factor. The PRR is analogous in concept to relative risk, which is the incidence rate ratio used as a measure of effect in follow-up studies. As the CHS is a cross-sectional survey, it is not possible to determine cause and effect or incidence, as in a follow-up study. Instead the prevalence rates of (in this case) a risk factor for SIDS in different groups were compared. For example, if the prevalence rate of back-sleeping position for group 1 is 50 per cent and for group 2 (the reference group) is 25 per cent, then the PRR for group 1 compared to group 2 is  $50/25 = 2.0$ . In other words, the prevalence rate of back-sleeping position for group 1 is twice that of group 2. A PRR of 1.0 for group 1 means the prevalence of back back-sleeping for group 1 is the same as that of group 2. A PRR of 1.4 means the prevalence of back-sleeping position in group 1 is 40 per cent higher than in group 2, and a PRR of 0.6 means the prevalence of back-sleeping position in group 1 is 40 per cent lower than in group 2. Group 2, the reference or comparison group, has a PRR of 1.0 as it is being compared to itself.
3. Multivariate analysis was carried out for social and demographic characteristics that on crude analysis had a statistically significant association with the risk factor to obtain adjusted PRRs. Plausible interactions between the explanatory variables were assessed for effect modification.

Descriptive analyses were carried out using SAS version 8.022 (SAS Institute, 2001) and prevalence rate ratios (PRRs) were derived using Stata for Windows 3 (StataCorp, 2001).

Analyses were design-based. (In a design-based analysis, features of the survey design – sampling weights, post-stratification weight, clustering and stratification – are taken into account.) The survey sample was weighted to adjust for differences in the probabilities of selection among respondents, according to the number of eligible respondents in the household and the number of residential telephone lines for the household. Post-stratification weights were used to adjust for the differing rates of non-response among males and females, and among persons of different ages. The weights were adjusted for differences between the child's age and sex structure of the survey sample and the Australian Bureau of Statistics 2000 mid-year population estimates for each health area.

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**Notes:** 2. A medical centre is usually open long hours seven days a week and provides other services such as x-rays.

For the multivariate analysis, Cox's regression procedure was used to fit a generalised linear model to obtain adjusted prevalence rate ratios (PRRs) (Lee & Chia, 1993; Hosmer & Lemeshow, 1999). Constant follow-up time (time to event = 1) was specified and the analysis was weighted to account for sampling design effects.

Reference groups for the risk factors were selected to calculate PRRs. For the association with infant sleeping position, infants placed to sleep in other than the back-down position were made the reference group for the outcome. For household smoking those who reported no household smoking were the reference group. For smoking in pregnancy, the reference group was mothers who did not smoke during pregnancy.

In the preliminary analysis, all the variables of interest were included in the models. However a high degree of correlation was found between some socio-economic variables, so the multivariate models were built using the variables that were significant in the crude analysis. The approach to model building was to find a parsimonious model that still explained the data (Hosmer & Lemeshow, 2000). Two significance tests were applied in the model-building strategy. First was the likelihood ratio test, an overall test of the model. The second was the Wald test to assess the significance of single variables. The choice of variables to include in the models was based on the  $p = 0.05$  criterion for main effects.

### 6.5.4 Results

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#### Descriptive results

There were 736 records relating to children less than one year of age in the CHS. The socio-economic and health characteristics of the group are detailed in Appendix 6.1.

The majority of infants (62.3%) were put on their back for sleep from birth, 32.0 per cent were put on their side, 3.2 per cent were put face-down, and 2.5 per cent were put in other or multiple positions.

In 68.7 per cent of households, there was no one who smoked. In 10.5 per cent of records the mother and others in the household smoked, in 8.9 per cent only the mother smoked and in 11.8 per cent the mother did not smoke but others in the household did. The question on smoking in pregnancy was asked only when the respondent was the mother. Among mothers who were respondents, 12.8 per cent reported smoking in pregnancy. The question was not asked in 12.4 per cent of cases.

A small proportion of households (29 respondents, 3.3%) reported having all three risk factors. Households with two risk factors were also reported as follows:

- smoking in pregnancy and current household smoking (10.7% of households);
- smoking in pregnancy and infant sleeping position other than back-down (4.3% of households); and
- household smoking and infant sleeping position other than back-down (13.2% of households).

A small proportion of mothers (8.3%) did not smoke in pregnancy but reported smoking at the time of the survey. Conversely, 3.9 per cent of mothers smoked in pregnancy and reported not smoking at the time of the survey.



### Crude prevalence rate ratios

The relationship between infant sleeping position, household smoking and smoking in pregnancy and the socio-demographic characteristics was examined. Because multiple comparisons were carried out, it is likely that some associations would appear significant at  $p < 0.05$  by chance alone. For the purpose of this analysis, only associations with  $p < 0.01$  were considered significant.

On crude analysis, the following characteristics were not associated with any of the three risk factors examined: sex of child, child health rating, father's country of birth, child's country of birth, language spoken at home, Aboriginal or Torres Strait Islander father, mother's employment status, ever having had contact with a baby health or early childhood nurse, age of first contact with baby health or early childhood nurse, or having a personal health record.

Mother's and father's level of education were the only characteristics significantly associated ( $p < 0.01$ ) with all three risk factors.

### *Infants' sleeping position*

*Parent's level of education.* Mother's and father's level of education and the child's status in the household (one child or more than one child) were the only factors significantly ( $p < 0.01$ ) associated with infant sleeping position. Results for these characteristics are shown in Table 6.1.

If the mother had a tertiary degree or higher, infants were 47 per cent more likely to be put for sleep on their backs than if the mother had not completed high school (70% compared with 48%). Similarly for a father with a tertiary degree or higher, infants were 51 per cent more likely to be put for sleep on their backs (74% compared with 49%). There was no difference in the rates of back position sleeping between mothers or fathers who had completed high school and those who had not completed high school.

*Number of children in household.* Households with one child were more likely to place the child in the back-sleeping position than were households with more than one child (73% compared with 56%).

**Table 6.1**  
Crude associations  
between socio-  
demographic  
characteristics and  
infant sleeping  
position

Categorical variables	Infant sleeping position			
	On back %	Other %	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	49.2	50.8	1.00	
Completed high school	63.2	36.8	1.283	0.983–0.675
TAFE certificate or diploma	64.9	35.1	1.318*	1.027–1.691
Tertiary degree or higher	74.2	25.8	1.508***	1.207–1.883
<b>Mother's education</b>				
Not completed high school	48.0	52.0	1.00	
Completed high school	61.0	39.0	1.271	0.983–1.644
TAFE certificate or diploma	69.8	30.2	1.456**	1.130–1.876
Tertiary degree or higher	70.3	29.7	1.465**	1.159–1.852
<b>Number of children in household</b>				
More than one child	55.7	44.3	1.00	
One child	72.5	27.5	1.301***	1.123–1.507

*Note:*

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### **Household smoking**

The picture for household smoking was more complex, with significant associations at  $p < 0.01$  found for numerous characteristics: mother's level of education; father's level of education; father's employment status; mother Aboriginal or Torres Strait Islander; usual consultant for child's health; ever breastfed; currently breastfed; accessibility/remoteness category; and socio-economic area category. The results of this analysis are shown in Table 6.2.

*Parents' levels of education.* The prevalence rate of household smoking decreased with increasing level of education for both mothers and fathers. Mothers or fathers who had a tertiary degree or higher reported about 80 per cent lower rates of household smoking than mothers or fathers who had not completed high school (12% compared with 56% for mothers and 11% compared with 53% for fathers). In contrast to infant sleeping position, both mothers and fathers who had completed high school were less likely to report household smoking than those who had not completed high school (31% compared with 56% for mothers and 31% compared with 53% for fathers).

*Father's employment status.* Households where the father was employed were 44 per cent less likely to report household smoking than households where the father was unemployed (28% compared with 51%).

*Aboriginal or Torres Strait Islander mother.* Households where the mother was Aboriginal or Torres Strait Islander were about twice as likely to report household smoking as households where the mother was not Aboriginal or Torres Strait Islander (61% compared with 31%).

*Usual consultant for child's health.* Respondents who usually consulted a general practitioner or local doctor for the child's health were about 42 per cent less likely to report household smoking than those who usually consulted a doctor in a medical centre (28% compared with 49%).

*Breastfeeding.* Household smoking was 58 per cent less common in households where infants had ever been breastfed than in households where they had not been breastfed (28% compared with 65%). Household smoking was 48 per cent less common in households where infants were currently being breastfed than in households where they were currently not being breastfed (21% compared with 40%).

*Accessibility/Remoteness Index for Australia category.* The prevalence rate of household smoking increased with increasing remoteness, with 30 per cent of survey respondents who lived in highly accessible areas reporting household smoking compared with 56 per cent of those in remote or very remote areas.

*Socio-Economic Index for Areas disadvantage category.* The prevalence rate of household smoking also increased with increasing social disadvantage, with 19 per cent of survey respondents who were least disadvantaged reporting household smoking compared with 40 per cent of those who were most disadvantaged.

**Table 6.2**  
Crude associations  
between socio-  
demographic  
characteristics  
and household  
smoking

Categorical variables	Household smoking			
	Yes (%)	No (%)	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	52.6	47.4	1.00	
Completed high school	30.8	69.2	0.587**	0.396–0.870
TAFE certificate or diploma	36.1	63.9	0.687*	0.490–0.962
Tertiary degree or higher	10.5	89.5	0.199**	0.117–0.340
<b>Mother's education</b>				
Not completed high school	55.6	44.4	1.00	
Completed high school	31.4	68.6	0.564**	0.405–0.786
TAFE certificate or diploma	30.8	69.2	0.554**	0.379–0.809
Tertiary degree or higher	12.1	87.9	0.219**	0.136–0.351
<b>Father's employment status</b>				
Unemployed	50.6	49.4	1.00	
Home duties/extended leave	56.6 <sup>a</sup>	43.4 <sup>a</sup>	1.118	0.459–2.721
Employed	27.6	72.4	0.545**	0.358–0.828
<b>Aboriginal/Torres Strait Islander mother</b>				
Yes	61.4 <sup>a</sup>	38.6 <sup>a</sup>	1.00	
No	30.5	69.5	0.496**	0.293–0.840
<b>Usual consultant for child's health</b>				
A doctor in a medical centre	48.6	51.4	1.00	
GP or local doctor	28.0	72.0	0.575**	0.417–0.794
Doctor at a hospital	41.9 <sup>a</sup>	58.1 <sup>a</sup>	0.861	0.353–2.100
Someone else	24.5	75.5	0.504*	0.255–0.998
<b>Ever breastfed</b>				
No	65.1	34.9	1.00	
Yes	27.5	72.5	0.422***	0.314–0.568
<b>Currently breastfeeding</b>				
No	39.6	60.4	1.00	
Yes	20.5	79.5	0.517***	0.378–0.707
<b>Area category</b>				
Remote/very remote	55.6	44.4	1.00	
Moderately accessible	43.4	56.6	0.782	0.432–1.413
Accessible	38.1	61.9	0.686	0.451–1.045
Highly accessible	29.7	70.3	0.535**	0.362–0.792
<b>Area socio-economic quintile</b>				
Most disadvantaged 5th quintile	40.4	59.6	1.00	
4th quintile	33.2	66.8	0.821	0.530–1.271
3rd quintile	32.5	67.5	0.804	0.532–1.214
2nd quintile	29.8	70.2	0.738	0.478–1.140
Least disadvantaged 1st quintile	19.0 <sup>a</sup>	81.0	0.470**	0.268–0.823

Note: Results shown only for factors with at least one level significant at  $p < 0.01$

<sup>a</sup> Unweighted count is less than 20

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### **Smoking in pregnancy**

Several characteristics were found to be associated with smoking in pregnancy on crude analysis. These associations include: father's education; mother's education; father's employment status; mother's country of birth; Aboriginal or Torres Strait Islander mother; usual consultant for child's health; ever breastfed; mother's age; and total duration of breastfeeding. However, as smoking in pregnancy was reported for only 14.6 per cent of mothers, many of the associations found were in groups with fewer than 20 survey respondents. The results for significant associations ( $p < 0.01$ ) are shown in Table 6.3.

*Parent's level of education.* Mothers or fathers who had a tertiary degree or higher reported substantially lower rates of the mother smoking in pregnancy than mothers or fathers who had not completed high school (3% compared with 32% for mothers and 4% compared with 24% for fathers).

*Father's employment status.* Households where the father was employed were 68 per cent less likely to report smoking in pregnancy than households where the father was unemployed (11% compared with 33%).

*Mother's country of birth.* Smoking in pregnancy was over four times more common among Australian-born mothers than among overseas-born mothers (18% compared with 4%).

*Aboriginal or Torres Strait Islander mother.* Mothers who were Aboriginal or Torres Strait Islander were three times more likely to smoke in pregnancy compared with non-Aboriginal or Torres Strait Islander mothers (49% compared with 15%)

*Usual consultant for child's health.* Smoking in pregnancy was 54 per cent less likely when a general practitioner or local doctor was usually consulted for the child's health than when a doctor in a medical centre was usually consulted (12% compared with 26%).

*Breastfeeding.* Smoking in pregnancy was 75 per cent less common when infants had ever been breastfed than when they had not (11% compared with 43%). There was no association between smoking in pregnancy and current breastfeeding, but a significant association was found with total duration of breastfeeding. The prevalence rate of smoking in pregnancy decreased by 15 per cent for each additional month of reported duration of breastfeeding.

*Mother's age.* Of the three risk factors examined, a significant association with mother's age was found only for smoking in pregnancy, with younger mothers more likely to smoke in pregnancy than older mothers. The prevalence rate of smoking in pregnancy increased by 8 per cent for each one-year decrease in mother's age.

**Table 6.3**  
Crude associations  
between socio-  
demographic  
characteristics and  
smoking in  
pregnancy

Categorical variables	Smoking in pregnancy			
	Yes (%)	No (%)	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	24.3	75.7	1.00	
Completed high school	13.4 <sup>a</sup>	86.6	0.550	0.251–1.208
TAFE certificate or diploma	17.0 <sup>a</sup>	83.0	0.686	0.337–1.395
Tertiary degree or higher	3.7 <sup>a</sup>	96.3	0.144 <sup>***</sup>	0.065–0.319
<b>Mother's education</b>				
Not completed high school	32.3	67.7	1.00	
Completed high school	10.0	90.0	0.302 <sup>***</sup>	0.166–0.549
TAFE certificate or diploma	13.4 <sup>a</sup>	86.6	0.437 <sup>*</sup>	0.216–0.883
Tertiary degree or higher	3.0 <sup>a</sup>	97.0	0.089 <sup>***</sup>	0.035–0.227
<b>Father's employment status</b>				
Unemployed	33.2 <sup>a</sup>	66.8	1.00	
Home duties/extended leave	81.9 <sup>a</sup>	18.1 <sup>a</sup>	1.787	0.650–4.912
Employed	11.4	88.6	0.321 <sup>**</sup>	0.157–0.654
<b>Mother's country of birth</b>				
Other countries	4.4 <sup>a</sup>	95.6	1.00	
Australia	17.6	82.4	4.330 <sup>**</sup>	1.879–9.976
<b>Aboriginal or Torres Strait Islander mother</b>				
Yes	48.5 <sup>a</sup>	51.5 <sup>a</sup>	1.00	
No	14.5	85.5	0.314 <sup>**</sup>	0.134–0.734
<b>Usual consultant for child's health</b>				
Doctor in a medical centre	25.9	74.1	1.00	
GP or local doctor	12.0	88.0	0.458 <sup>**</sup>	0.258–0.814
Doctor at a hospital	24.6 <sup>a</sup>	75.4 <sup>a</sup>	1.084	0.307–3.832
Someone else	15.3 <sup>a</sup>	84.7	0.643	0.232–1.777
<b>Ever breastfed</b>				
No	43.3	56.7	1.00	
Yes	11.4	88.6	0.248 <sup>***</sup>	0.142–0.432
<b>Variables on a continuous scale</b>				
	Mean	Mean	Crude prevalence rate ratio	95% confidence interval
Mother's age in years	28.2	31.1	0.920 <sup>***</sup>	0.883–0.959
Total duration of breastfeeding in months	2.84	4.63	0.850 <sup>**</sup>	0.769–0.938

Note: Results shown only for factors with at least one level significant at  $p < 0.01$ .

<sup>a</sup> Unweighted count is less than 20

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### Adjusted prevalence rate ratios

Most of the characteristics that were significant in the crude analysis were not significant after adjustment for other variables (significance was set at  $p < 0.05$  for adjusted prevalence rate ratios). The only factor that was found to have a significant association with all three risk factors was mother's level of education. No significant interactions were found.

### Infant sleeping position

For infant sleeping position, after taking other factors into account, significant associations were found with mother's level of education and the Socio-Economic Index for Areas disadvantage level. Significant associations for infant sleeping position found on multivariate analysis are shown in Table 6.4.

*Mother's level of education.* After taking other factors into account, putting a child for sleep on its back from birth was 40 to 45 per cent more likely when the mother had a TAFE certificate or diploma, or a tertiary degree or higher.

*Socio-Economic Index for Areas disadvantage category.* The prevalence rate of back-sleeping position decreased with social disadvantage. Infants in households in the least disadvantaged areas were 32 per cent more likely to be put on their backs for sleep from birth than infants in households in the most disadvantaged areas.

**Table 6.4**  
Adjusted prevalence rate ratios for characteristics associated with infant sleeping position

Significant variables	Infant back-sleeping position	
	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	1.233	0.958–1.587
TAFE certificate or diploma	1.450**	1.135–1.853
Tertiary degree or higher	1.405**	1.118–1.765
<b>Socio-Economic Index for Areas quintiles</b>		
Most disadvantaged 5th quintile	1.00	
4th quintile	1.120	0.852–1.472
3rd quintile	1.137	0.871–1.485
2nd quintile	1.115	0.847–1.469
Least disadvantaged 1st quintile	1.321*	1.013–1.722

*Note: Results shown only for factors with at least one level significant at  $p < 0.05$*

\*  $p < 0.05$

\*\*  $p < 0.01$

### Household smoking

For household smoking, after taking other factors into account, significant associations remained with mother's and father's level of education and current breastfeeding, as shown in Table 6.5.

*Parents' levels of education.* The likelihood of household smoking decreased with increasing level of education for both mothers and fathers. Mothers who had a tertiary degree or higher

reported about 50 per cent lower rates of household smoking than mothers who had not completed high school. For fathers with a tertiary degree or higher, the reduction was 68 per cent. However, the associations did not achieve statistical significance for parents who had completed high school or had a TAFE certificate or diploma.

*Current breastfeeding.* Household smoking was 31 per cent less common in households where infants were currently being breastfed than in households where they were currently not being breastfed.

**Table 6.5**  
Adjusted prevalence rate ratios for factors associated with household smoking

Household smoking		
Significant variables	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	0.755	0.540–0.055
TAFE certificate or diploma	0.794	0.521–1.211
Tertiary degree or higher	0.501**	0.299–0.837
<b>Father's education</b>		
Not completed high school	1.00	
Completed high school	0.654*	0.435–0.984
TAFE certificate or diploma	0.776	0.540–1.115
Tertiary degree or higher	0.315***	0.179–0.557
<b>Currently breastfeeding</b>		
No	1.00	
Yes	0.687*	0.506–0.934

*Note: Results shown only for factors with at least one level significant at  $p < 0.05$*

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### Smoking in pregnancy

For smoking in pregnancy, after taking other factors into account, significant associations ( $p < 0.05$ ) were found with mother's level of education, father's employment status, and whether the child had ever been breastfed. These results are shown in Table 6.6.

*Mother's level of education.* The likelihood of smoking in pregnancy decreased with increasing level of mother's education. Mothers who had a tertiary degree were 81 per cent less likely to report smoking in pregnancy than mothers who had not completed high school.

*Father's employment status.* Households where the father was employed were 66 per cent less likely to report smoking in pregnancy than households where the father was unemployed.

*Breastfeeding.* Smoking in pregnancy was 69 per cent less likely when infants had ever been breastfed than when they had not.



**Table 6.6**  
Adjusted prevalence rate ratios for characteristics associated with smoking in pregnancy

Smoking in pregnancy		
Significant variables	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	0.454*	0.238–0.865
TAFE certificate or diploma	0.702	0.344–1.432
Tertiary degree or higher	0.178***	0.069–0.461
<b>Father's employment status</b>		
Unemployed	1.00	
Home duties or extended leave	0.807	0.308–2.117
Employed	0.341**	0.163–0.716
<b>Ever breastfed</b>		
No	1.00	
Yes	0.305***	0.173–0.536

Note: Results shown only for factors with at least one level significant at  $p < 0.05$

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

## 6.6 Discussion

The results of the analysis of the *NSW Child Death Register* indicate that in almost 90 per cent (86.6%) of SUDI cases modifiable risk factors were present including unsafe sleeping positions (40.9%), exposure to tobacco smoke during pregnancy and/or after birth (57.5%), head coverings (59.7%) and co-sleeping in combination with smoking and/or substance use (25.8%). The extent and quality of information available on these deaths limits any further comment.

Results of the *NSW Child Health Survey (CHS)* indicate that a substantial number of infants under one year of age continue to be exposed to risk factors for SIDS and SUDI. Nearly 38 per cent of infants were placed in a position other than on their backs to sleep from birth. The majority of these infants were put on their sides (32.0%), and 3.2 per cent were put face-down. In relation to other risk factors, at least one person smoked in 31.2 per cent of households, and 12.8 per cent of mothers reported that they smoked during pregnancy.

The most striking result of the analysis of the CHS is the consistent relationship between mother's level of education and risk factors for SIDS and SUDI. In both the crude and multivariate analysis the likelihood of beneficial behaviours (putting infant for sleep on their backs, no household smoking and no smoking in pregnancy) increased with increasing level of mother's education. The association was strongest with the highest level of education (tertiary degree or higher). While the associations with lower levels of education (completed high school or TAFE certificate or diploma) were for the most part not found to be statistically significant, the crude and adjusted PRRs showed a clear trend of increasing rates of beneficial behaviours with increasing levels of mother's education. This suggests that the level of statistical significance found for the relationship between the middle levels of education (completed high

school or TAFE certificate or diploma) is probably related to the sample size of the survey, rather than to the true lack of an association.

The CHS found the following factors were not associated with any of the three outcomes (infant sleeping position, household smoking, and smoking during pregnancy): sex of child, child health rating, father's country of birth, child's country of birth, language spoken at home, Aboriginal or Torres Strait Islander father, mother's employment status, ever having had contact with a baby health or early childhood nurse, age of first contact with baby health or early childhood nurse, or having a personal health record. Some of these findings may be due to the small numbers of infants reported with these characteristics. For example, only five infants were born overseas.

As the CHS is a cross-sectional data collection it is possible to describe associations, but not cause and effect. The crude PRRs indicate population subgroups that have relatively higher rates of risk factors for SUDI. Prevention programs could be targeted towards these specific sub-populations. For infant sleeping position, it would be appropriate to target parents with lower levels of education and families with more than one child. It is notable that maternal age, country of birth, Aboriginality, and living in remote areas in New South Wales were not associated with infant sleeping position.

It is also noteworthy that the majority of infants not put on their backs for sleep were put on their sides, with infants put face-down making up only 3.2 per cent of the survey sample.

The finding of an association for two socio-demographic variables – higher levels of parental education and first-time parents – with use of the back-down position are supported in other studies. A United States cohort study of over 7,000 women found face-down sleeping at one month to be associated with maternal education and parity, with mothers with less than 12 years education and more than one child more likely to engage in this risk behaviour (Lesko, Corwin, Hunt, Vezina, Mandell, McClain, Heeren, Timothy & Allen, 1998). Further evidence of an association between parents with more than one child and face-down sleeping was found in a comprehensive British study (Rose, Murphy, Macfarlane, Sefi, Shribman & Hales, 1998) and a nationally representative study conducted in Ireland (Cullen, Kiberd, McDonnell, Mehanni, Matthews & O'Regan, 2000).

The international literature has identified additional socio-demographic characteristics with high-risk sleep practices that were not identified as significant in the CHS. Numerous studies have identified young mothers as more likely than older mothers to place their infants in the face-down position (Lesko et al., 1998; Taylor & Davis, 1996; Willinger et al., 1998). Similarly, socio-economic disadvantage has been found to be associated with a higher risk of placing infants for sleep face-down (Shrivastava, Davis & Davies, 1997; Brenner, Simons-Morton, Bhaskar, Mehta, Melnick, Revenis, Berendes & Clemens, 1998). The main measure of socio-economic disadvantage used in CHS (the Socio-Economic Index for Areas) was not found to be a factor in the crude analysis of the CHS but was found to be significant in the multivariate analysis.

The results of the CHS indicate that programs aimed at reducing household smoking would best target families who are socio-economically disadvantaged, families with lower levels of parental education, where the father is unemployed, and families living in socio-economically disadvantaged areas. Mothers who are Aboriginal or Torres Strait Islander and families living in rural and remote areas should also be targeted.

In relation to interventions specifically aimed at reducing smoking in pregnancy, younger mothers, Aboriginal and Torres Strait Islander mothers, parents with lower levels of education, and families where the father is unemployed should be targeted.

The findings of a higher incidence of household smoking and smoking during pregnancy for Aboriginal and Torres Strait Islander mothers is supported by findings of other Australian studies. A Western Australian cohort study found that Aboriginal mothers were more than twice as likely to smoke and their infants were four times as likely to be exposed to smoke (Eades, Read & Bibbulung-Gnarneep Team, 1999). Furthermore, New South Wales data suggests that Aboriginal women were three times as likely to smoke at some time during their pregnancy (61%) compared with non-Aboriginal women (21%) (McDermott, Russell & Dobson, 2002). The association of household smoking and smoking in pregnancy with lower rates of infant breastfeeding found in this study suggest that families and mothers tend to engage in healthy or unhealthy behaviours in a consistent way.

The results of CHS analysis indicate that families speaking a language other than English at home or where the parents were born overseas did not engage in significantly riskier parental practices than other families. However, this does not negate the need to provide information and education campaigns on risk factors of SUDI in a range of community languages.

On multivariate analysis the relationships between smoking in pregnancy and maternal age, father's level of education, maternal country of birth and maternal Aboriginality became non-significant, but the relationship with mother's level of education and father's employment status remained significant. This indicates that the associations between smoking in pregnancy and maternal age, father's level of education, maternal country of birth and maternal Aboriginality can be largely explained by mother's level of education and father's employment. In other words, variations in the level of smoking in pregnancy among different community groups are largely explained by socio-economic factors. The conclusion is the same for infant sleeping position and household smoking.

The strength of the associations found between risk factors for SUDI and the various factors examined in this study are generally moderate. For example, mothers with a tertiary degree or higher were 51 per cent more likely (approximately one and a half times as likely) to put infants to sleep on their backs than mothers who had not completed high school. There was one quite strong association – the relationship between smoking in pregnancy and country of birth: Australian-born mothers were over four times more likely to smoke during pregnancy than overseas-born mothers. This association became non-significant on multivariate analysis, indicating that the difference between Australian-born and overseas-born mothers could be accounted for by mother's level of education and father's employment.

Considerable research has been undertaken to examine why parents refrain from or engage in modifiable risks to SIDS, in particular their choice of infant sleeping position. The findings of the studies undertaken in this area are strikingly similar despite methodological differences.

Not surprisingly, if mothers know that a particular behaviour is a risk factor for SIDS they are more likely to refrain from that behaviour (Ponsonby, Dwyer, Kasl, Couper & Cochrane, 1995). Researchers have examined differences between mothers in their knowledge of SIDS risk factors. A higher proportion of first-time mothers and mothers with higher socio-demographic status were able to recall receiving instruction on risk factors for SIDS (Colson, Stille, Payton, Bernstein & Dworkin, 2000; Rose et al., 1998).

The findings of some studies suggest that information campaigns highlighting risk factors for SIDS may not be reaching some cultural groups as effectively as others. A Queensland study found Aboriginal and Torres Strait Islander women were less able to identify a risk factor for SIDS (Douglas, Buettner & Whitehall, 2001). Factors associated with a lack of awareness of SIDS risk factors in a New Zealand study included ethnicity (Pacific Island-born, Samoan and Cook Islander), poor English language ability, low level of maternal education and not attending antenatal classes (Paterson, Tukuitonga, Butler & Williams, 2002).

Printed material was also found to be associated with use of the non face-down position, though not as strongly as the recommendations provided by health professionals (Lesko et al., 1998; Brenner et al., 1998; O'Brien, Oxman, Haynes, Davis, Fremantle & Harvey 2002; Willinger, Hoffman, Kessler & Corwin, 2000). There is some evidence to suggest that exposure to information on SIDS risk factors in different media has an additive effect (Willinger et al., 2000).

Numerous studies have pointed to the importance of the provision of information on safe sleeping by health professionals. Parents who place their infant for sleep on their backs are most likely to cite recommendations from a health professional as the primary reason for choosing that particular sleep position.

There is both theoretical and educational evidence that because people learn through observation, modelling by health care providers can be a powerful influence on behaviour (Bandura, 1986; O'Brien et al., 2002). Lesko et al., (1998) suggest that observed sleep position may modify maternal intentions and ultimately the choice of a particular sleep position. The authors conclude that health care professionals have a considerable role to play in influencing mother's knowledge of, and practice in relation to, modifiable risk factors. Likewise modelling non-smoking behaviour by health professionals in maternity hospitals may be important in modifying the smoking behaviour of carers.

While health care professionals (childbirth educators, physicians, nurses and hospital nursery staff) are in an excellent position to change parental practice, research evidence indicates that not all professionals have taken the *Reducing the Risk of SIDS* messages into their practice (Bacon & Tripp, 2000). Health professionals may know the current and major *Reducing the Risk of SIDS* recommendations but may not advise parents correctly or practise the recommendations in a hospital setting.

There is little current information on health professionals' knowledge, attitudes and practices to SIDS risk factors in New South Wales. In the one survey of all nurse unit managers in maternity hospitals in New South Wales undertaken in 2002 it was found that one third of nurses reported placing healthy term and near-term infants on their sides to sleep while in hospital, citing fear of aspiration as their primary reason (Jeffery, Reid & Kent-Biggs, 2003, cited in Jeffery, 2004).

A recent study undertaken in Queensland into the effectiveness of educational intervention in changing the attitudes of nurses and midwives to the current *Reducing the Risk of SIDS* messages and known risk factors concluded that the attitudes of nurses and midwives were inconsistent with the messages. Further, these attitudes influenced the advice that they provided to parents (Young & O'Rourke, 2003). The authors found that providing an education session and accompanying literature addressing SIDS, risk factors and the *Reducing the Risk of SIDS* messages significantly influenced several attitudes that directly related to the *Reducing*

*the Risk of SIDS* messages, with some participants changing their practice to be in line with current knowledge.

A commonly cited reason for not placing infants on their backs is parents' fear of the infant choking in this position (Willinger et al., 2000; Colson et al., 2000). For parents who have more than one child, their experience with previous children is a strong influence on their use of face-down position for subsequent infants (Lesko et al., 1998; Chessare, Hunt & Bourguigon, 1995). The main reasons parents cite for placing their infant face-down are primarily related to a belief that it is the infant's preferred sleeping position and that the infant is most settled in the face-down position (Ponsonby et al., 1995; Lesko et al., 1998; Brenner et al., 1998; Ottolini, Davis, Patel, Sachs, Gershon & Moon, 1999; Willinger et al., 2000; Gibson, Cullen, Spinner, Kate & Spitzer, 1995; Gibson, Dembofsky, Rubin & Greenspan, 2000).

The previous research provides some direction in relation to changing parents' use of high-risk sleep positions. It suggests that clear guidance to parents by health care professionals is required. To be successful this guidance must emphasise the safety of the back-down position and the instability of side-sleeping, address fears of choking and provide alternative settling techniques.

Changing parental practice in relation to maternal and household smoking may be more problematic. While the addictive nature of smoking makes it a behaviour that is resistant to change, Lumley, Oliver and Waters (2002) demonstrated that interventions for smoking cessation during pregnancy are successful.

The findings of the CHS and what is known from the international literature on risk factors, parents' knowledge, attitudes and practice in relation to modifiable risk factors provide information to further reduce the incidence of SUDI. Clear information on risk factors to parents and health professionals is required. Furthermore, the findings suggest that subgroups of the population may need specifically targeted prevention and information campaigns on risk factors.

Sudden unexpected deaths in infancy that resulted from assault or neglect or that occurred in circumstances suspicious of assault and neglect are examined to identify the factors associated with, and the circumstances surrounding, the deaths; the extent of contact the infants' families had with human service agencies, the coronial and criminal outcomes and avenues for prevention.

### 7.1 Introduction

The Child Death Review Team had a unique and specialised function in relation to deaths due to abuse or neglect. The Team was mandated to identify the deaths of children that were due to or suspicious of abuse or neglect and undertook a detailed review of the information concerning these deaths, with a view to prevention. This function was transferred to the NSW Ombudsman in December 2002.

As the reviews are completed, the findings are usually reported in the Annual Reports of the CDRT. For the 2003 year the Team decided to report incidents of SUDI that occurred in circumstances of abuse or neglect within this study. In doing so an important part of the picture of SUDI in New South Wales is presented.

Research undertaken into the fatal assault of children and young people in New South Wales identified infants as having the highest rate of fatal assault, with 5.8 deaths per 100,000 population for this age group. By comparison the rate of fatal assault for all children 0 to 17 years inclusive in New South Wales is just over 1 death per 100,000 (CDRT, 2004b). Across Australia, children under one year of age are also reported to be at greatest risk of fatal assault; for females the rate of fatal assault in infancy is the highest across their entire life course (Mouzos, 2002; cited in CDRT, 2002b).

The Child Death Review Team's research (CDRT, 2002b) examining the deaths of all children who died from fatal assault established that 18 of the 60 assault deaths identified over a three-and-a-half-year period involved infants less than one year of age. Thirteen of these 18 fatalities were associated with non-accidental injury and five with the mental illness of the mother.

This pattern is reflected in international studies. For instance, in England and Wales a person is four times more likely to be a victim of homicide in the first year of life than at any subsequent age (Bacon & Tripp, 2000).

Fatal non-accidental infant deaths among SUDI cases have been examined in two large and reliable studies undertaken in the United Kingdom (Leach et al., 1999; Bacon & Tripp, 2000). Leach et al., (1999) concluded that fatal non-accidental injury occurred in 4.5 per cent of all incidents of SUDI. Non-accidental injury as a cause of explained death was second only to infection and equal to or greater than cardiovascular anomalies in contribution.

Bacon and Tripp (2000) found that of the 417 SUDI cases studied, there was suggestion of maltreatment in 17 per cent, ranging from criminal prosecution to suspicion by an expert group. Overall there was concern of maltreatment, extending from deliberate action such as smothering to negligence and extremely poor care, in 14.5 per cent of SIDS and 9.9 per cent of explained SUDI.

The features that raise concern of maltreatment in the history and initial examination, summarised from three recent sources, include:

- a family with previous unexplained infant death or non-accidental injuries.
- a parent with a history of being assaulted as a child followed by personality disorder and self-harm.
- a baby with previous injuries or episodes of sudden illness, such as apnoeic attacks that were inadequately explained and occurred in the presence of the same carer.
- death outside the usual age range for SIDS, although unnatural deaths are most common in children younger than eight months.
- death in the afternoon or evening, after recent admission to hospital, or where the dead infant came from a family in which a previous child had died unexpectedly, especially if under the care of the same person (Reece, 1993; Bacon & Tripp, 2000; AAP, 2001).

In addition, the Child Death Review Team (2002b) identified the following associations: family violence; mental health; substance use; suicidal mother; financial difficulty; and criminal arrest.

Infant deaths are difficult situations for both investigating police and forensic pathologists. In its study into fatal assault the Team found no recorded witnesses to any fatal assault that occurred in the infant's home (CDRT, 2002b).

Forensic pathologists face challenges in establishing cause of death as it is challenging to distinguish at autopsy between SIDS and accidental or deliberate asphyxiation with a soft object (Valdes-Dapena, 1992, cited in Levene & Bacon, 2004). Deliberate suffocation may leave no external signs and no clear post-mortem evidence. Eliciting a history of possible intentional suffocation in particular circumstances is essential (AAP, 2001).

To establish fatal assault as the cause for apparent SUDI and determine incidents of SUDI associated with fatal neglect, it is essential to undertake a death scene investigation, a careful complete autopsy, and a case review of all available medical, hospital, social service information including mental health, child protection and social circumstances (AAP, 2001).

## 7.2 Aim of this component of the study

This component of the study sought to address Research Question 5:

*What is known about SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances?*

## 7.3 Research method

### Access to data

Section 45T of the *Commission for Children and Young People Act 1998* imposes a duty on departments, agencies and individuals to provide the Team with 'full and unrestricted access'

to records that the Team reasonably requires for the purpose of exercising its functions. The institutions and organisations affected include: all government departments, statutory bodies and local authorities; the Commissioner of Police; the State Coroner; medical practitioners or health care professionals or heads of bodies that deliver health services to children; persons who, or the heads of bodies that, deliver welfare services to children (including family support services, children's services, foster care or residential out-of-home care, and disability services); and principals of non-government schools (within the meaning of the *Education Act 1990*).

### The Child Death Register

Since 1996 the NSW Child Death Review Team has maintained a *Child Death Register* (the Register) of all deaths of children and young people less than 18 years of age who die in New South Wales. The Register is based on death registration data from the NSW Registry of Births, Deaths and Marriages. Information includes date of birth, date of death, date of registration of the death, cause of death noted on the death certificate, age of the child, last known residence, parents' names, place and country of birth, Aboriginal and Torres Strait Islander status and sex.

For each coronial case additional information is sought, including: the *Police Report of Death to Coroner* (P79A, which includes a narrative of the circumstances of the death); the *Death Scene Investigation Checklist – Sudden Infant Death* (P534, completed by police for cases suspected of SIDS); and a final post-mortem report (including autopsy, pathology and toxicology findings).

### Identification of cases for study

**Identifying cases of sudden and unexpected death in infancy.** A death was included in this study if it met the Child Death Review Team's definition for SUDI. This definition was applied to all infant deaths registered between 1 January 2000 and 31 December 2002 that were referred to the Coroner. One hundred and eighty six deaths were identified.

**Identifying cases of assault or neglect or suspicious of assault or neglect.** The CDRT identified and reviewed child deaths caused by assault or neglect or deaths that were suspicious of assault or neglect from January 1996 until December 2002. To assist with accuracy, the Team developed its own set of definitions (see Appendix 7.1) and screening procedures.

The screening procedure consisted of two stages:

1. initial screening of cases; and
2. further screening of cases with additional information.

Screening was undertaken by representatives of the CDRT including a paediatrician and others with child protection experience. To inform the screening decision information was sought from the Department of Housing and NSW Health. Further information was obtained from NSW Police, Department of Community Services and the NSW Coroner. Full details of the screening process can be found in Appendix 7.2.

Of the 186 incidents of SUDI, 12 deaths were identified during the screening process as due to assault or neglect. Based on the information available it was not possible to determine with any confidence whether a further 50 deaths were due to assault or neglect or not. In these 50 cases there was some information to raise concern of possible maltreatment but not sufficient



evidence to indicate that assault or neglect caused the death. Similar difficulties arising from a lack of adequate information have also been identified as a factor in the determination of cases of maltreatment in other studies (Department of Health, 1996). Notwithstanding data inadequacies, for the remaining 124 cases the information available did not raise concern of maltreatment.

## **7.4 Analysis**

### **Analysis period**

All sudden unexpected infant deaths registered between 1 January 2000 and 31 December 2002 were analysed. (Nineteen cases previously reviewed and reported by the Team were included.) The analysis of the deaths was undertaken according to the date of registration of the death. This is in line with other national data sets managed by the Australian Bureau of Statistics and National Injury Surveillance Unit.

### **Case review tool**

The case review tool developed by the Team to review assault and neglect deaths or those that occurred in suspicious circumstances was modified to include information specific to sudden unexpected infant deaths. The tool consisted of variables clustered around the following domains: demographics; circumstances of the death; individual circumstances; family background; prior agency involvement; and experiences related to childcare, education and employment. This tool was completed for each case by child protection consultants by means of a case file review of government records obtained from NSW Police, the NSW Coroner, NSW Health, the Department of Community Services and the Department of Housing.

Descriptive analyses were undertaken using the statistical package SPSS (SPSS, 1999). An overall profile was created of the infants who died as a result of assault or neglect and those who died in circumstances where no clear determination was possible.

A logistic regression model was created to examine factors which may differentiate the 50 deaths where no clear determination was possible from those where there was clearly no assault or neglect. Logistic regression is a technique used to examine which variables are useful in predicting an outcome (SPSS, 1999). Several variables of interest could not be examined because of the severe limitations of the information available (for example, carer substance use) and the rarity of some events (for example, previous incident of SUDI in the family). The variables examined were:

- infant age at death;
- vulnerability to harm;
- domestic violence;
- diagnosed mental health conditions of carers; and
- adult offending by carers.

### **Methodological limitations and cautions**

The Register provides information on all child deaths registered in New South Wales. As with all data sets that rely on administrative data sources, the extent of information contained in the records was highly variable. In addition, there may be omissions of information and a small

number of errors. The validity and reliability of the information recorded for the Register has not been formally verified. For all coronial cases the reliability and validity of the data is improved by access to several different data sources.

All cases were reviewed by representatives of the Team who used available information to arrive at a shared opinion as to whether a death was caused by assault or neglect. However, without a coronial or criminal finding of fatal assault the Team's conclusions are subjective judgements.

## 7.5 Results

Over the three-year period from January 2000 to December 2002, 186 infants died suddenly and unexpectedly after being placed for sleep.

Table 7.1 shows that 12 of these infants died as a result of assault (3) or neglect (9). No clear determination was possible for 50 infant deaths.

**Table 7.1**  
Category of death

Category	Total	
	n	%
Not assault or neglect	124	66.7
No clear determination possible	50	26.9
Assault	3	1.6
Neglect	9	4.8
<b>Total</b>	<b>186</b>	<b>100.0</b>

### Fatal assault

Deaths from fatal assault were rare among the 186 infant deaths during the three-year period from January 2000 to December 2002: three infants died as a result of assault. The small number of deaths and the absence of available data limit the conclusions that can be drawn about these deaths.

The three causes of death as determined by forensic pathologists were: undetermined; multiple injuries; and consistent with smothering.

The three infants (two males, one female) were aged six months, seven months and 10 months. Two were living with both biological parents and one was living with one biological parent. Perpetrators were identified in two cases: the biological mother in one case and the mother's de facto in the second case. In the third case no perpetrator was identified.

All three infant deaths were categorised by the CDRT<sup>3</sup> as non-accidental injury, meaning that the injuries resulted from either a series of assaults or one fatal assault. In one case, a carer's mental health condition may also have played a role.

All three families had experienced disadvantage in relation to health and well-being, violence, crime or social and economic factors. These were parental mental health problems (1 family),

**Notes:** 3. The *Fatal Assault of Children and Young People* report (CDRT, 2002), identified four categories of fatal assault: non-accidental injuries, assaults by parents affected by mental illness, assaults related to family breakdown, and killings of teenagers.

suicide attempts (2 families), parental substance use (2 families), parental criminal behaviour (3 families), domestic violence (2 families) and financial difficulties (2 families). Carers in two families had also been victims of child abuse and neglect.

All three infants came from families that had prior agency involvement. Agencies involved with the families were the Department of Community Services (3), NSW Police (3), NSW Health (3), the Department of Housing (3), the Department of Corrective Services (1), and private health practitioners (3). Extensive involvement with the Department of Community Services, NSW Police and NSW Health was evident for all three families.

The three infants had all been reported to be at risk of harm to the Department of Community Services. One infant had been the subject of four prior reports, one infant had two prior reports and one infant had one prior report—a total of seven reports. Assessments and investigations commenced for six of the seven reports made. Siblings of the infant had also been reported to the Department of Community Services in all three families.

In responding to two of the three families, workers appeared to underestimate the level of risk the infant was exposed to while living in their family environment. The high level of risk associated with clusters of multiple indicators was not recognised, and the two infants remained in high-risk situations. Intervention in two cases was crisis-driven rather than proactive, and there appeared to be limited understanding of how to intervene to modify or lower risk.

NSW Health was also involved with all three families. In two cases, in different Area Health Services, the infant was taken to the same Hospital Emergency Department on repeated occasions.

Health professionals within the NSW Health system appeared to underestimate the risk for infants in dangerous family environments and did not recognise escalating presentations as indicative of increasing risk.

NSW Police were also involved with all three families. There was evidence that NSW Police reported risk of harm to the Department of Community Services appropriately.

A coordinated interagency approach was lacking in all three cases. In two cases, a coordinated interagency approach may have assisted in identifying the high risk present by combining the information held by each agency. While individual services were well delivered at times, they lacked coordination. In the third case, while an interagency approach may have resulted in a greater understanding of the dynamics operating in the family, it may not have prevented the infant's death.

Coronial proceedings commenced for all three cases. In one case an inquest was held and a finding of the cause of death as 'Not determined' was given. In two cases the inquest was terminated and charges were laid. In one case the infant's mother's de facto was charged with murder; he was found guilty of manslaughter and sentenced to 11 years imprisonment. In the second case, the infant's mother, who was found to be suffering from the effects of postnatal depression at the time of the death, was charged with murder. She was sentenced to four years supervision.

### Fatal neglect

Nine (4.8%) of the 186 infants died as a result of neglect during the three-year period January 2000 to December 2002. There were five males and four females, and the age of infants ranged from nine days to seven months. One of the nine infants was Aboriginal. The small number of deaths and the absence of available data for some variables limit the conclusions that can be drawn about these deaths.

The causes of death as determined by forensic pathologists were sudden infant death syndrome (2); sudden infant death syndrome associated with co-sleeping (1); undetermined (3); positional asphyxia (1); combined effects of positional asphyxia associated with co-sleeping and acute on-chronic aspiration (1); and bronchopneumonia (1).

The nine infant deaths assessed as fatal neglect showed characteristics similar to the category of inadequate supervision by a carer previously identified by the CDRT.<sup>4</sup> They involved impaired parenting capacity as a result of drugs, alcohol, mental illness, physical illness, immaturity or impaired intellectual ability.

Five infants died in circumstances in which their carer or carers were affected by alcohol and/or drugs. Three infants died when co-sleeping with parents who were affected by alcohol and/or drugs. (Co-sleeping is distinguished from bed-sharing. The term bed-sharing is used to describe circumstances where a carer and infant share a bed for the purpose of feeding and settling.) A fourth infant was found dead after not having been fed or checked for 14 hours.

Four infants died in diverse circumstances when carers made inappropriate decisions relating to their care. One infant died from accidental suffocation while co-sleeping with a parent who was a heavy smoker. A second infant died as a result of accidental hanging after being placed for sleep in a stroller without the restraint secured. The third infant died as a result of undiagnosed bronchopneumonia. The infant's carer had recently experienced a stressful life event and may not have recognised the signs of illness in the infant. The fourth infant died after being placed face-down for sleep in a cot. The infant's carers had previously been advised that this was not a safe position for the infant.

**Family circumstances.** Five of the nine infants were living with both biological parents and four were living with one biological parent. The ages of the primary carer ranged from 16 to 32 years (mean 24.4, SD 5.7). The secondary carers were typically older, with ages ranging from 24 to 41 years (mean 30.1, SD 6.6).

The fatal neglect of these nine infants all occurred in the context of family stress. All nine families experienced disadvantage: problems with health and well-being, violence, crime, or social or economic disadvantage. There were parental mental health problems (4), parental physical health problems (1), parental substance use (7), domestic violence (8), parental criminal behaviour (7), changes in family composition (1), financial difficulties (2) and accommodation difficulties (6). One carer had been the victim of child abuse and neglect.

The stressors experienced by these carers may have affected the standard of care they were able to provide for these infants. Accommodation difficulties, mental health problems, and drug and alcohol use were identified as impacting on their parenting capacity.

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**Notes:** 4. The *Fatal Assault and Neglect of Children and Young People* report (CDRT, 2003), identified three categories of neglect deaths; deaths due to inadequate supervision by a carer, negligent driving by a carer, and failure by a carer to provide medical care.

Domestic violence was identified in eight of the nine families. Two carers had recently moved to escape domestic violence, with one carer returning to a violent situation shortly before the infant's death. While ongoing domestic violence was not directly linked to the deaths of these nine infants, it may have affected the capacity of carers to attend to the needs of their infant.

Accommodation difficulties were noted for six of the nine families. Issues included the poor physical state of homes, inadequate heating, and overcrowding. Two families were living in Department of Housing accommodation, two families were living in caravans, one family was living with extended family and one family was staying temporarily with friends. Three families had recently moved, with one family having moved several times within a few months. Two families experienced financial difficulties. Accommodation and financial difficulties may have limited carers' options in providing safe sleeping environments for infants; four infants died when co-sleeping with adults and one died after being placed for sleep in a pram.

A history of substance use was noted in seven of the nine families: in three families use of both alcohol and drugs was noted; in three families use of alcohol only; and in one family use of drugs only. Drugs used by carers included marijuana, amphetamines and methadone. The deaths of five of the nine infants occurred while carers were affected by alcohol and/or drugs.

Mental health problems had been diagnosed in carers in four of the nine families. Diagnoses included depression (2); post-traumatic stress disorder (1); and previous episodes of paranoid delusions (1). Postnatal depression was suspected but not diagnosed in one additional carer.

Eight of the nine families experienced three or more stress factors. For example, in five families issues of substance use were present together with domestic violence and adult offending. In four of these families, problems were further exacerbated by mental health problems (2) and/or accommodation and financial difficulties (3). Greater understanding of how these multiple factors interact is needed.

**Agency involvement.** The nine infants came from families that had prior agency involvement. The agencies involved with the families were NSW Health (9), NSW Police (6), the Department of Community Services (5), the Department of Housing (3) and non-government organisations (2).

Three of the nine infants had been reported as at risk of harm to the Department of Community Services. In total, the infants had been the subject of seven reports (one, two and four reports respectively). Assessments and investigations commenced for five of the seven reports.

Responses to these three infants and their families showed a tendency to minimise the risk factors present in the infant's family environment. The Department of Community Services failed to undertake full risk assessments and relied on other agencies to monitor the infant's situation. One case was closed after an unsuccessful home visit with questions raised concerning the mother's capacity to parent not addressed.

While infants had not been reported at risk of harm to the Department of Community Services in two families, these families had been involved with the Department prior to the infant's birth as a result of reports regarding siblings. In one family no risk assessment was undertaken following concerns expressed by a health professional providing services to the mother. The Department of Community Services had prior knowledge of the family removing other children from the mother's care before the infant's birth.

In two cases where neither infants nor their siblings had been reported to the Department of Community Services, information on file indicated that there was sufficient information for a report to be made by police or health professionals.

NSW Police were involved with six of the families. While there was evidence of police fulfilling their mandatory reporting obligations in some cases, there was also evidence of failure to recognise and report serious and unstable situations to the Department of Community Services in three cases. Failure to report these infants highlights missed opportunities for intervention with families that were clearly experiencing difficulties.

NSW Health was involved with the nine families. Infants and their families attend health services for a range of reasons often presenting opportunities for health professionals to identify infants who may be at risk and to take appropriate action. There was evidence that health practitioners failed to identify risk when infants were born and to report concerns for the infant to the Department of Community Services.

In one case, the brief psycho-social assessment undertaken in hospital failed to identify the impact that the mother's circumstances may have had on her capacity to care for her infant. Following discharge from hospital, there was evidence in three cases that health professionals providing home-visiting services to the mother failed to recognise or report concerns of increasing violence and concerns about the infant's failure to gain weight to the Department of Community Services.

In cases where multiple agencies were involved, there was little evidence of a coordinated interagency response to these families. Such an approach may have identified the multiple risk factors present in some of these families and possibly led to increased intervention.

Inquests were dispensed with by coroners in eight of the nine cases. In the one case where an inquest was held the cause of death remained undetermined.

### **No clear determination possible**

In just over a quarter of the 186 infant deaths (50, 26.9%), it was not possible to determine whether the death was due to assault or neglect or not. The information available on these infants was insufficient to raise concern of possible maltreatment but not sufficient for the Team to make a clear determination.

The infants ranged in age from less than one week to nine months, with deaths peaking at two months of age (30 were male; 20 were female). Thirteen of the infants were identified as Aboriginal or Torres Strait Islander. Seven infants were born to mothers who were born outside Australia.

Almost all of the deaths occurred within the infant's home (45; 90.0%). One death occurred in a foster home, one in a women's and children's refuge, one in institutional care and one in the home of relatives.

Table 7.2 shows the causes of death for the 50 infants as determined by forensic pathologists. A diagnosis of SIDS was given in 26 cases (52.0%); 19 deaths were identified as due to undetermined causes (38.0%) and in five cases a specified cause was given.

**Table 7.2**  
Cause of death

	n	%
Sudden infant death syndrome <sup>a</sup>	26	52.0
Undetermined	19	38.0
Diseases and morbid conditions	3	6.0
External causes of injury	1	2.0
Injury	1	2.0
<b>Total</b>	<b>50</b>	<b>100.0</b>

*Note: a Six cases were diagnosed as SIDS associated with co-sleeping*

An analysis was undertaken of these 50 infant deaths to identify the presence of factors identified in the literature as raising concern of maltreatment (Reece, 1993; Bacon & Tripp, 2000; AAP, 2001; Block, 2002; Levene & Bacon, 2003; CDRT, 2002b, 2003). Due to the lack of information available on these deaths only some of these factors could be examined and of those, fewer still could be examined in detail.

**Death outside the usual age range for SIDS.** Nine of the 50 infants were outside the usual age range (eight were under one month and one was over six months).

**Previous unexplained infant death.** A previous incident of sudden unexpected infant death was positively identified in the immediate family in two cases. In a third case, there was such an incident in the extended family living in the same location. Previous research has identified that a previous sudden unexpected infant death can arise from natural causes (Levene & Bacon, 2004).

**Recent hospital attendance or multiple presentations to hospital.** Eleven of the 50 infants had presented to hospital following birth. Reasons included failure to thrive (2); episodes of apnoea (2); bronchiolitis (1) or bronchitis (2); fever, nausea, vomiting and/or constipation (2); urinary tract infection (1); flu symptoms (1); and following a fall (1). Multiple presentations to hospital were seen in three cases. A further two infants died within 48 hours of being discharged from hospital following birth.

**Signs of injury and physical signs of neglect at autopsy.** Signs of injury were present at autopsy in five of the 50 infants. Signs of injury included: recent and healing fractures of ribs and arms; subarachnoid, subdural and retinal haemorrhages; detached retinas; bruising to the head, trunk, and arms or legs; and injuries to the frenulum. Signs of neglect were present at autopsy in nine of the infants; four infants showed evidence of failure to thrive; four infants had failed to gain weight appropriately; and one infant appeared malnourished.

**Vulnerability of the infant.** There was no accepted measure of vulnerability to death known to the Team. As a result, the Team employed a proxy measure of vulnerability. An infant was considered vulnerable if any child of the family had been reported to the Department of Community Services as at risk of harm prior to the infant's death. Using this measure 35 infants (70.0%) were assessed as vulnerable.

**Previous offending behaviour by carer.** Carers in 30 families (60.0%) had a record of offending behaviour as an adult. Charges related to theft, offences against the person, driving offences, drug offences, offences against good order, offences against justice procedures and property damage. Carers in these families had received between one and 37 charges, with 16

carers being charged with offences in the six months preceding the infant's death. Two carers were on probation at the time of the infant's death.

**Domestic violence.** Domestic violence was present in 31 families (62.0%). Perpetrators of domestic violence were identified in 23 families (46.0%) and victims in 30 families (60.0%).

**Substance use.** Carers in 21 families (42.0%) had consumed alcohol and/or other substances in the period immediately preceding the infant's death. Carers were using methadone in 14 families and smoking marijuana in two families, and in one family the carer's drug use was not specified. Methadone was also detected in infants at autopsy in four of these families.

A history suggesting use of alcohol was evident in 16 families (32.0%) and use of other substances in 27 families (54.0%). Substances used included methadone, heroin, cocaine, amphetamines, benzodiazepines and marijuana.

**Mental health.** The carers in 19 families (38.0%) had been diagnosed with mental health problems prior to the infant's death. Diagnoses included Depression, Postnatal Depression, Bipolar Disorder, Schizophrenia, eating disorders, Attention Deficit Hyperactivity Disorder and anxiety disorders.

A logistic regression model was created to examine factors which may differentiate these 50 deaths from those where there was clearly no assault or neglect. The variables available for this analysis were restricted due to the severe limitations of the information available and the rarity of some events.

The variables examined were infant age at death, vulnerability of the infant, domestic violence, diagnosed mental health conditions of carers, and adult offending by carers.

The analysis revealed two factors as significant in differentiating between the groups. These factors were:

- vulnerable infants;
- diagnosed mental health conditions of carers.

Deaths where infants were identified as vulnerable were almost 11 times more likely to be assigned to the 'no clear determination possible' group ( $\text{Exp}(B) = 10.988$ ;  $p < 0.001$ ) when all other variables were held constant. This result is not unexpected, given that deaths that occurred in the context of a documented history of abuse or neglect (but where the cause of death was not clearly abuse or neglect) were assigned to the 'no clear determination possible' group.

Infants from families where carers had a history of diagnosed mental health condition were almost three times more likely to be assigned to the 'no clear determination possible' group ( $\text{Exp}(B) = 2.829$ ;  $p = 0.031$ ) when all other variables were held constant.

## 7.6 Conclusion

This component of the study reviewed the deaths of 186 infants over the three-year period 2000 to 2002 who died suddenly and unexpectedly after they were placed for sleep.

The extent and quality of information on the deaths examined in this study severely limited the Team's ability to accurately identify all deaths due to assault or neglect and those that occurred



in circumstances suspicious of assault and neglect. Within this limitation, the deaths of three (1.6%) infants were identified as due to assault and nine (4.9%) from neglect. For a further 50 infants, it was not possible to determine with any confidence whether the deaths were due to assault and neglect or not. It is therefore difficult to draw comparisons between the proportions of deaths due to assault found in this study with results from other studies.

This study found that two factors—infant vulnerability and care by a person with a diagnosed mental health condition—were significant in differentiating between the group of infants where there was clearly no assault or neglect and the group where it was not possible to determine with any confidence whether or not the deaths occurred in circumstances suspicious of assault or neglect.

While classification of assault, neglect or suspicious deaths always involves some subjective judgement, the failure to identify the cause of these deaths may leave other or future children in the family at significant risk. Alternatively the misclassification of a death as assault may result in wrongful accusation.

The information available on these deaths needs to be improved. Responding agencies are in the best position to obtain information on the death, and agencies with previous involvement with the infant or infant's family are an important source of historical information. Bacon and Tripp (2000) have argued that the best way to improve the information required to make an assessment of whether the death resulted from maltreatment is through a thorough investigation of the death and consultation and discussion with all professionals involved with the case.

The lack of information available on assault and neglect deaths limited the Team's ability to identify areas for prevention. Notwithstanding, the following deficiencies were identified: failure to recognise and report serious and unstable situations; inadequate risk assessment, including overestimation of a parent's ability and capacity to change; inadequate case planning, including provision of a suitable sleep environment for infants; and poor interagency collaboration and coordination.

All these issues have been identified by the Team in previous reports and recommendations made to address them.

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## Chapter 8 | Summary of findings and implications

The study aimed to: consolidate existing knowledge of unsafe sleeping environments; determine current parental practices in New South Wales in relation to modifiable risk factors that contribute to SUDI; describe current policy and practice in New South Wales when responding to these sudden deaths; and identify SUDI due to assault and neglect.

The study sought to identify:

- the gaps that exist in the information routinely collected in New South Wales for diagnostic purposes in relation to incidents of SUDI and the factors that influence the availability of the information;
- the strengths and limitations of SUDI policies and guidelines in New South Wales;
- the practices of New South Wales workers in responding to SUDI;
- the practices of parents in New South Wales in relation to modifiable risk factors, looking at parents of infants generally and parents of infants who died;
- what is known about SUDI cases where the infants have died as a result of abuse or neglect or in suspicious circumstances.

The rate of deaths determined as SIDS has fallen from 1.89 deaths per 1,000 live births in 1981 to 0.55 deaths per 1,000 live births in 2002. This change was largely due to the efforts of a number of services working in partnership including NSW Health, other health professionals, the SIDS associations and researchers.

However SUDI remains the second largest group (following transport fatalities) of potentially preventable deaths of children under 18 years of age. During the period 2000 to 2002 the Team identified an average of 62 SUDI cases. These deaths impact considerably on the parents of the infant and their families and the professionals involved in responding to the death. They represent a significant cost to the community not only in terms of a life cut short but also in resourcing the response.

The Team believes that more can be done to prevent these infant deaths and considers that action is required by the NSW Government to effect the necessary change.

This final chapter discusses the findings with respect to each of the study aims and recommends avenues for prevention. The recommendations are presented within a context of either prevention of or response to SUDI.

### 8.1 Summary of findings

#### Audit of the key information collected

An audit of the key information collected to establish cause of death where an infant dies suddenly and unexpectedly was undertaken of documents used routinely in New South Wales. Three documents were included in the analysis: the *Police Report of Death to Coroner* (P79A);

the *Death Scene Investigation Checklist – Sudden Infant Death (P534)*; and the *Final Autopsy Report*.

The analysis revealed substantial variation in data availability across the domains examined. In particular, there appeared to be gaps in the current routine data collection in relation to:

- psycho-social information about infants and their families (including contact with social service agencies and criminal history of parents and carers);
- clinical history of the family and infant;
- demographic information on the father or other carers and siblings;
- information on co-sleeping (co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purpose of feeding and settling); and
- the environment of the room in which the infant was found.

The study found data availability to be related to the way in which the data was collected. Data on a specific item was more likely to be available if it could be sourced from a standard question or format, rather than opportunistically revealed in an open text section of a document.

The study indicated that the current New South Wales data collection could be improved by standardising documents and using questions specifically related to incidents of SUDI that have been identified in the literature and Australian and international SUDI practice standards, guidelines and protocols.

### **New South Wales SUDI policies and guidelines**

An examination of the policies and guidelines in use in the agencies that respond to SUDI was undertaken.

The analysis revealed that the response to SUDI in New South Wales is provided by a number of agencies: the NSW Police, NSW Ambulance Service, NSW Health, the Department of Ageing, Disability and Home Care, the Department of Community Services, the NSW Coroner and SIDS and Kids NSW.

The study found that while the roles and responsibilities of the various agencies were clearly delineated, there were limitations in the response when compared with the key aspects of response identified in the literature including:

- Policies and guidelines relating to the support and guidance for parents were less prescriptive than those relating to investigative processes.
- The guidelines and forms available to those responsible for collecting and recording information do not support comprehensive collection.
- The level of expertise required to undertake tasks was not evident in many of the policies and procedures.
- Multi-agency case reviews occurred opportunistically, limiting the knowledge and skill available for each case and opportunities for continuous improvement.
- The monitoring and research activities are uncoordinated limiting prevention opportunities.

The study concluded that updating the policies and guidelines to address the limitations identified would improve the response to SUDI in New South Wales.

### Practices of New South Wales workers

The study into the operation of the response to SUDI in New South Wales obtained the views of police officers, ambulance officers, hospital workers, forensic pathologists, coroners, Department of Community Services workers, a SIDS and Kids NSW staff member and researchers. Interviews were conducted in urban, rural and remote locations.

Analysis was undertaken across four stages of the response to SUDI: initial response; post-mortem examination; attribution of cause of death; and research, monitoring and continuous improvement.

A range of issues were identified in the initial response stage including: participants feeling that they worked outside their areas of expertise; conflict between the various roles performed; inadequate knowledge and expertise in some areas; gaining knowledge and expertise through experience on the job; and cultural and practical impediments to receiving post-response support.

Issues identified in the post-mortem process, included variation in the quality and comprehensiveness of information received prior to the post-mortem examination; constraints on post-mortem testing; differences between pathologists' beliefs and practices regarding when and why to use SIDS as a diagnosis; and lack of appropriate feedback provided to parents and professionals involved in an infant death.

Other concerns were identified when attributing cause of death including the particular difficulties in attributing cause of death in infants and achieving a balance between the requirements of the investigation and the needs of grieving parents.

Finally, the analysis of the operation of the research, monitoring and continuous improvement stage identified the following impediments: poor information collection; severely limited opportunities for continuous improvement; and restrictions in obtaining human tissue samples for medical research.

Although there was variation in the extent and intensity of issues experienced across participants, three main areas of inadequacy were identified.

Firstly, responding workers did not always have the knowledge and experience required to undertake stressful roles. Secondly, the information required to undertake the essential tasks of autopsy, attribution, monitoring and research varied in quality and comprehensiveness. Thirdly, continuous improvement in New South Wales was restricted by limitations in the information available and the lack of systems to convey this information to those who required it.

Some of the issues identified were magnified in non-urban locations. The infrequent incidence of SUDI and their spread across the State presents a particular challenge for New South Wales.

The study concluded that the New South Wales policies and guidelines relevant to the response to SUDI were not consistently followed and varied across location and individual workers. Some workers were placed in situations which they were ill-equipped to handle, leaving them exposed and parents poorly supported. Accurate determination of cause of death and prevention efforts are thwarted and the capacity for learning and continuous improvement diminished.

### Modifiable risk factors and parental practices

A review of the national and international literature revealed strong research evidence for several risk factors relating to parental behaviour and the infant's sleep environment. The strongest and most consistent evidence for an association with SUDI has been found for:

- **sleeping position.** The back-down position is the safest sleeping position for infants. 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.
- **exposure to tobacco smoke.** Both maternal smoking during pregnancy and infant exposure to tobacco smoke after birth are significant risk factors for SIDS.
- **bed coverings.** Loose bedding that can cover an infant's head is associated with a high risk of SIDS. The risk is particularly associated with the use of bedding such as doonas or quilts which infants can slip under during sleep.
- **co-sleeping and smoking.** Co-sleeping can increase the risk of SIDS if the mother smokes or the caregiver shares a sofa or other inappropriate sleep environment with the infant.

To determine current parental practice in cases of SUDI the *NSW Child Death Register* was analysed to identify known risk factors. The results of the analysis indicate that in almost 90 per cent (86.6%) of SUDI cases modifiable risk factors were present including unsafe sleeping positions (40.9%), exposure to tobacco smoke during pregnancy and/or after birth (57.5%), head coverings (59.7%) and co-sleeping in combination with smoking and/or substance use (25.8%).

To determine current parental practices in the New South Wales population, information available through the *NSW Child Health Survey* was analysed. The analysis revealed that the majority of infants (62.3%) were put on their back for sleep from birth. However, 37.7 per cent were put for sleep in unsafe sleeping positions: 32.0 per cent were put on their side, 3.2 per cent were put face-down and 2.5 per cent were put in other or multiple positions. In 31.2 per cent of households at least one person smoked. Among mothers who responded to the survey, 12.8 per cent reported smoking in pregnancy.

The most consistent relationship found was with the mother's level of education. The likelihood of beneficial behaviours (putting a child for sleep on his/her back, no household smoking and no smoking in pregnancy) increased with increasing level of mother's education. The association was strongest with the highest level of education (tertiary degree or higher).

The study concluded that information campaigns may not be reaching some groups and should be modified to target specific subgroups. In addition benefits would be achieved by refocusing prevention efforts to stop the practice of putting infants for sleep on their sides.

### Infant deaths and fatal assault and neglect

The deaths of 186 infants over the three-year period 2000 to 2002 who died suddenly and unexpectedly after they were placed for sleep were reviewed to identify those that were due to, or suspicious of, assault or neglect. The extent and quality of information on the deaths severely limited the Team's ability to accurately identify these deaths.

Within this limitation the deaths of three (1.6%) infants were identified as due to assault and nine (4.9%) to neglect. For a further 50 infants, it was not possible to determine with any confidence whether the deaths were due to assault and neglect or not.

The study found that the categories of vulnerable infants and infants in the care of a person with a diagnosed mental health condition were significant in differentiating between the group where it was not possible to determine with any confidence whether the deaths were due to assault or neglect or not and the group where there was definitely no assault or neglect.

Deficiencies in agency practice were identified in the deaths of infants that occurred as a result of assault or neglect. Issues identified included: failure to recognise and report serious and unstable situations; inadequate risk assessment including overestimating a parent's ability and their capacity to change; inadequate case planning, including providing for a suitable sleep environment for infants; and poor interagency collaboration and coordination. All deficiencies have been identified by the Team in previous reports and recommendations made to address them.

The study concluded that better information gathering and sharing of the information gathered could assist in the investigation of incidents of SUDI and reduce the number of these deaths where the cause of death is undetermined.

## 8.2 Prevention of sudden unexpected infant deaths

Sudden unexpected deaths of infants are amenable to prevention. It is clear from the analysis undertaken of parental practices in New South Wales in relation to modifiable risk factors that a substantial number of infants under one year of age continue to be exposed to risk factors for SIDS and SUDI.

Considerable research has been undertaken to examine why parents refrain from or engage in risky practices, in particular their choice of infant sleeping position. This research demonstrates that the knowledge that parents had of risk factors for SIDS or SUDI, information provided by health professionals, information in printed material distributed by hospitals (such as magazines, newspapers and pamphlets), the attitudes and behaviours of nurses and midwives and whether alternative infant settling techniques were provided all contributed to the decisions parents made. Not surprisingly, if mothers knew that a particular behaviour was a risk factor they were more likely to refrain from that behaviour.

The findings of the analysis of parental practices in New South Wales suggest that information campaigns highlighting risk factors for SIDS and SUDI may not be reaching some groups as effectively as others. In relation to infant sleeping position it would be appropriate to select prevention interventions that target and work with parents with lower levels of education and families with more than one child.

To address household smoking prevention the findings suggest it would be appropriate to target families who are socio-economically disadvantaged, families with lower levels of parental education, where the father is unemployed and families living in socio-economically disadvantaged areas. Mothers who are Aboriginal or Torres Strait Islander and families living in rural and remote areas should also be targeted.

Preventions aimed at reducing smoking in pregnancy should target younger mothers, Aboriginal or Torres Strait Islander mothers, parents with lower levels of education and families where the father is unemployed.

**Recommendation 1:** The NSW Government and SIDS and Kids NSW should use prevention strategies that are effective with the high-risk groups identified in this study.

It is noteworthy that this study found that the majority of infants not put on their backs for sleep were put on their sides.

**Recommendation 2:** The NSW Government and SIDS and Kids NSW should place more emphasis on the risk associated with the side-sleeping position in prevention strategies.

Post-implementation evaluation should be undertaken for these two recommendations to assess their success.

**Recommendation 3:** NSW Health should monitor safe sleeping practices, including the use of the side-sleeping position, used by health professionals in maternity and neonatal wards.

There was ample evidence that because people learn through observation, modelling by health care professionals can have a powerful influence on parental behaviours. To provide parents with safe and appropriate infant care advice, health care professionals need to have the knowledge, attitudes and practice consistent with the known risk factors for SIDS and the *Reducing the Risk of SIDS* messages. This requires that health professionals have access to the best available evidence and a commitment to best practice and that agencies impart this information in the most effective way.

**Recommendation 4:** Professional bodies and NSW Health should disseminate information regarding modifiable risk factors for SUDI. This should be preceded by a study which investigates the most effective methods to disseminate this information.

In New South Wales SIDS and SUDI are monitored by the NSW Health SIDS Advisory Committee. All infant deaths are monitored and reported by the NSW Child Death Review Team. The National Coroners Information System makes available information on child deaths to researchers.

Information is required by these groups on SUDI and on unsafe parental practices. This information assists research efforts, enabling patterns and trends to be identified and targeted. The *NSW Child Health Survey* undertaken by NSW Health in 2001 included information on three of the known risk factors for SIDS and SUDI. The survey has been incorporated into the ongoing NSW Health Survey Program which is conducted year-round in New South Wales. It is important that this survey collects information on all risk factors for SUDI.

**Recommendation 5:** The New South Wales Health Survey Program should continue to collect information on SUDI and SIDS risk factors and on relevant social and demographic characteristics of parents.

### 8.3 The response following a sudden unexpected infant death

In responding to SUDI, several parallel functions must be served. Many studies have found the response to SUDI to be inadequate and in need of review (Centers for Disease Control and Prevention, 1996; Fleming et al., 2000).

A multi-agency integrated approach that describes the service system as a whole has gained considerable support. This approach acknowledges the diversity of specialist skills required, enables all aims of the response to SUDI to be met and guards against key aspects of the response being duplicated or omitted.

Five aspects of response have been consistently identified in the literature as important:

1. balance between care and investigation;
2. collection and recording of comprehensive information;
3. involvement of appropriate personnel;
4. multi-agency case review and continual improvement; and
5. monitoring and research.

Results from this study indicate that the response to SUDI in New South Wales fails to fully achieve these important aspects. The findings of the study and what is known from the international literature provide information to improve the development of the existing response.

One of the most obvious shortcomings relates to the collection and recording of comprehensive information to allow the various professionals to take appropriate actions and make informed decisions, including how parents will be supported. To achieve this, the information collected needs to be consistent with internationally recognised protocols such as the *Sudden Unexplained Infant Death Investigation Report*, the *International Standardised Autopsy Protocol* and the recent *Sudden Unexpected Death in Infancy – a Multi-Agency Protocol for Care and Investigation*. The Team believes that changing the information requirements would resolve this shortcoming. The Team notes that the NSW SIDS Advisory Committee intends to review the *Death Scene Investigation Checklist – Sudden Infant Death (P534)* used to collect information from the death scene and there are national moves to standardise autopsy practice relating to infant deaths. It is important that these initiatives occur as part of the examination of the statewide response to SUDI, within a multi-agency context and conform to international standards.

**Recommendation 6:** The NSW Government should align the information currently collected through the response to SUDI with internationally recognised protocols. It should emphasise multi-agency work, close collaboration and sharing of information and be gathered by professionals with appropriate training and expertise.

The Team believes that this can be achieved by the end of 2006.

Another shortcoming of the current response is the assignment of various aspects of the response to SUDI to professional groups which do not necessarily have the skill and experience to undertake them. The literature is clear that senior health professionals, including paediatricians, general practitioners or specially trained health visitors with knowledge of disease in childhood and bereavement, are best placed to obtain information from parents in the first instance. The *Confidential Enquiry for Stillbirths and Deaths in Infancy (CESDI)* argues that as the majority of SUDI do not result from unlawful actions it is inappropriate that the initial collection of information be normally or only carried out by a police officer as is the case in New South Wales. The examination undertaken in this study of SUDI resulting from assault or neglect supports this position.



Where information is obtained by professionals with expertise in the particular area of interest the information collection is enhanced. This is confirmed by the audit of key information undertaken as part of this study. Information obtained from the initial response had the highest availability for the death scene investigation domain and the lowest for the family demographic and psycho-social domains. This is not surprising given that this information is collected by police officers.

Where professionals undertake tasks within their area of expertise, the investigative, medical and psycho-social aspects of the infant's death are addressed and parents are supported. Further, the stress experienced by professionals without the necessary skill and experience in providing services outside their expertise is reduced. The findings from the interviews undertaken with police and ambulance officers establish this as an issue in the New South Wales response. This approach enables the balance between care and investigation to be achieved. Achieving this balance has been identified as one of the key aspects to a successful response to SUDI.

In considering how professionals with the necessary expertise provide the response in New South Wales, the infrequent incidence of SUDI cases and the geography and population distribution of the State need to be taken into account. With the exception of the autopsy examination, the New South Wales response is currently provided locally, with no particular agency personnel designated to provide the response. The result is that any worker within an organisation may be called upon to respond. While policies aim to provide the most senior staff to these deaths, the worker interviews undertaken in this study indicate that this is not always possible in practice, with inexperienced staff sometimes being called upon to attend cases beyond their abilities. Given that any individual will respond to a SUDI infrequently and the possibility of random assignment of staff, a comprehensive response cannot be guaranteed. The worker interviews suggest that this may result in inadequate information collection, death scene investigation, attribution of death and care and support for families.

**Recommendation 7:** The NSW Government should make sure that the tasks required are only undertaken by professionals with the appropriate role, knowledge (including up-to-date knowledge of relevant legislation, policies and guidelines) and expertise.

Advances in medical and forensic sciences have increased the ability of pathologists to identify metabolic and other medical causes of sudden unexpected death in infancy. Successful identification is based on wide and up-to-date knowledge and considerable experience in identifying the specific patterns of presentation of different conditions (The Royal College of Pathologists and The Royal College of Paediatrics and Child Health, 2004). The infrequent incidence of SUDI in New South Wales means that such knowledge and expertise is difficult to develop through generalist practice. Referral to a pathologist with specialist knowledge or experience should therefore be routine practice.

Further, pathologists do not always have the information considered necessary for the autopsy examination. Pathologists interviewed for this study indicated that they did not always undertake the tests they require to complete their autopsy examination because of the costs associated with obtaining the tests and the willingness of laboratories to undertake them. A further issue raised in the literature is the need to provide a result expediently. Others have suggested that it would be better to provide a preliminary diagnosis and follow this by a final one when all information and testing is complete. The possibility for this exists in New South Wales.

**Recommendation 8:** Pathologists should follow an agreed protocol and make consistent decisions. Post-mortem examinations should only be conducted by pathologists with specialist knowledge or experience, for example paediatric pathologists or forensic pathologists with specific training and expertise in paediatrics.

The Team believes that this can be achieved by mid 2006. This work will assist in allocating the various professionals' responsibilities in the response to SUDI.

Finally, the aspect of multi-agency case review needs to be addressed. Pathologists and coroners need to be supported in their tasks. Before commencing an autopsy pathologists require full briefing on the history and circumstances of the infant's death by the person who interviewed the parents and collected the initial information (Berry et al., 2000). Further, the pathologists interviewed in this study identified the absence of a full briefing as an issue in successfully undertaking their work. The policies and guidelines of the various agencies do not require such a briefing to occur.

The knowledge of a case is enhanced when all the available information is brought together. While the true facts of a case may never be determined, there is a greater possibility of this when all concerned with a particular case are able to contribute their piece of the puzzle. This is one of the main reasons for the CESDI recommendation that a multi-disciplinary case discussion be held locally after every sudden unexpected death in infancy. This practice is not required by any of the policies reviewed. Health professionals interviewed in this study indicated a clear desire to actively contribute to discussion of cases they were involved in and to provide the future care for the family identified through this process.

There is no central coordinator or coordinating body responsible for a uniform system response covering ambulance, police, hospital, forensic medicine and coroner's services and community services such as Department of Community Services, NSW Health (Community Health program) and non-government organisations such as SIDS and Kids NSW. The Team considers that the agency responsible for coordination of the response to SUDI and for the collection and sharing of the SUDI case information between all the relevant agencies needs to be identified.

The findings of both the policies and guidelines analysis and the worker interviews indicate that the New South Wales system is directed towards providing information to coroners to enable the manner and cause of death to be determined. Despite the belief by several workers that the coroner is responsible for coordination of the response, this is not the case. This confusion about the coordination role contributed to a number of issues identified by workers. These included the lack of ready access to information required to undertake their tasks and difficulties in contacting professionals in other agencies. Incidents of SUDI are largely preventable and the most relevant to general health prevention strategies. The Team considers that coordination by NSW Health is appropriate.

**Recommendation 9:** The NSW Government should adopt a multi-agency integrated system of response to sudden and unexpected deaths in infancy. This will involve agreeing on a definition, clearly identifying the tasks of individual agencies and professionals and developing a model of response. It should reflect the findings from this study and address the key aspects identified, including how to achieve the balance between care and investigation; collection and recording of comprehensive information; involvement of appropriate personnel; multi-agency case review and continual improvement; and monitoring and research. In developing the

response the needs of the family should be an essential consideration. NSW Health should lead the coordination of this.

The Team believes that this system should be developed by the end of 2006.

## 8.4 Conclusion

This research study consolidated existing knowledge of unsafe sleeping environments; determined current parental practices in New South Wales in relation to modifiable risk factors that contribute to SUDI; described current policy and practice in New South Wales when responding to these sudden deaths and identified SUDI cases where infants died as a result of assault and neglect.

The findings inform efforts to improve the scope and quality of information available in New South Wales in relation to infant deaths that occur suddenly and unexpectedly and in so doing maximise prevention efforts.

The analysis of parental practices and SUDI risk factors undertaken in the study indicated that information campaigns may not be reaching some groups and could be modified to target specific subpopulations. In addition benefits would be achieved by refocusing prevention efforts to address the practice of putting infants for sleep on their sides.

To assist in research efforts and identification of patterns and trends, information on parental practices needs to be collected continuously. The NSW Health Survey Program provides the means to achieve this.

International literature and professionals in the field have defined the key aspects of response to SUDI. In New South Wales these aspects are, at best, only partially addressed.

An integrated response is required, with the roles of all participants clearly stated and well delineated. The various aims of the response need to be identified and each adequately addressed. Focusing on some aspects of response to the exclusion of others leads to a disjointed system that does not achieve the main purposes outlined above. As stated earlier this can have far-reaching consequences, including rare inherited metabolic diseases not being identified, unsafe sleeping environments not being recognised, homicides not being detected leaving other children or future children in the family at significant risk and parents being wrongfully convicted of murdering their infants.

In developing the New South Wales response, consideration must be given to:

- which agency will coordinate the response;
- whether the response will be provided using a central, regional or local model;
- how a balance between care and investigation will be achieved;
- what information will be collected and recorded;
- how appropriate personnel will be involved in the various aspects of the response;
- the capacity for multi-disciplinary case review; and
- the various aspects of monitoring, evaluation, continuous improvement and research.

An updated, relevant and instructional model in New South Wales would have benefits for bereaved parents, for professionals, policy makers, researchers and for current and future infants.

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Appendix 3.1 | Police Report of Death to Coroner (the P79A)

NSW POLICE SERVICE  
**Report of Death to Coroner**

P 79A

**NOTE**  
 (1) This form should be prepared in quadruplicate in all cases where a death is reported to the Coroner. The original and two copies should be forwarded to the Coroner. All statements in duplicate should be lodged with the Coroner no later than 28 days after receipt of inquest notice.  
 (2) The full name and address of all persons and the registered number of all motor vehicles concerned should be indicated.

\_\_\_\_\_ Police Station  
 \_\_\_\_\_ Region  
 \_\_\_\_\_ 20 \_\_\_\_\_

The Coroner,  
 \_\_\_\_\_

Death of \_\_\_\_\_ (Christian Name) \_\_\_\_\_ (Surname) Sex: \_\_\_\_\_ Age: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
 \_\_\_\_\_ Morgue Register/Book No. \_\_\_\_\_

Address \_\_\_\_\_ Marital State \_\_\_\_\_

Time and Date of Death \_\_\_\_\_

Place of Death \_\_\_\_\_

By whom found \_\_\_\_\_ Address \_\_\_\_\_

By whom reported to Police \_\_\_\_\_ Address \_\_\_\_\_

By whom last seen alive \_\_\_\_\_ Address \_\_\_\_\_

When last seen alive \_\_\_\_\_

Time and date reported to Police \_\_\_\_\_

Deceased a native of (Country) \_\_\_\_\_

Occupation \_\_\_\_\_  
 (If pensioner state type and authorities informed)

Name and Address and Telephone No. of nearest relative \_\_\_\_\_  
 \_\_\_\_\_ Relationship to Deceased \_\_\_\_\_

Name and Address of identifying person \_\_\_\_\_

Method of Identification (Visual, Dental, F/prints) \_\_\_\_\_

Chain of Identification [i.e. Relative or Friend (name) to Police (name) to other Police (name)] \_\_\_\_\_

Criminal Charges Preferred (Yes/No) - Details \_\_\_\_\_

Property and clothing found on and with deceased \_\_\_\_\_

Miscellaneous Property Book Reference \_\_\_\_\_

How Property and clothing disposed of and on whose authority \_\_\_\_\_

Narrative of circumstances under which death took place.

If any previous illness, and deceased seen by doctor, particulars should be given. Where treated by a doctor a note should be obtained giving particulars of treatment of such doctor. If died within 24 hours of Anaesthetic - Forms A and B required from hospital and indicated at the start of the Narrative.

Signature: \_\_\_\_\_

Rank: \_\_\_\_\_

Annual leave: \_\_\_\_\_

Continued Overleaf

CAT. 81053 (1-97)

**POISONING -**

- (a) Was death apparently from (i) poison, (ii) drug: \_\_\_\_\_
- (b) Name poison or drug (if known): \_\_\_\_\_
- (c) Apparently administered by whom: Name: \_\_\_\_\_ Address: \_\_\_\_\_
- (d) Date and time: \_\_\_\_/\_\_\_\_/20\_\_\_\_. at \_\_\_\_\_ am. / pm.
- (e) When symptoms first showed \_\_\_\_/\_\_\_\_/20\_\_\_\_. at \_\_\_\_\_ am. / pm.
- (f) Detail symptoms: \_\_\_\_\_
- (g) State recently prescribed medicine: \_\_\_\_\_
- (h) Prescribing Doctor: Name: \_\_\_\_\_ Address: \_\_\_\_\_
- (i) When prescribed: \_\_\_\_/\_\_\_\_/20\_\_\_\_. (j) Quantity prescribed: \_\_\_\_\_
- (k) How much remains now: \_\_\_\_\_ (l) Dispensing chemist: \_\_\_\_\_
- Name and address: \_\_\_\_\_

**GAS POISONING -**

- (a) Did gas come from coal-gas supply, brazier, or car: \_\_\_\_\_
- (b) Where in building/car was body found: \_\_\_\_\_
- (c) In what position was body found: \_\_\_\_\_
- (d) State appliance gas had escaped from: \_\_\_\_\_
- (e) Was gas still escaping: \_\_\_\_\_
- (f) If room sealed, how: \_\_\_\_\_
- (g) Was food being prepared: \_\_\_\_\_
- (h) Who in Gas Company notified: Name: \_\_\_\_\_

**ELECTROCUTION -**

- (a) What caused shock: \_\_\_\_\_
- (b) Where in building was body found: \_\_\_\_\_ (c) Position \_\_\_\_\_
- (d) State appliance "shock" received from: \_\_\_\_\_
- (e) Was appliance still "alive": \_\_\_\_\_
- (f) Detail any burns: \_\_\_\_\_
- (g) Who in Electricity Commission of supplying Authority notified: \_\_\_\_\_

**UNIDENTIFIED CASES (the following information should be furnished)-**

Sex, Age, Height, Building, Complexion, Hair, Eyes, Nose, Face: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 Peculiarities, marks, scars, tattoos, deformities, etc.: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

What steps have been taken to establish identification (Department file reference No.: \_\_\_\_\_)  
 \_\_\_\_\_  
 \_\_\_\_\_

**REPORT OF INQUEST (or Magisterial Inquiry)**

Date and place of Inquest: \_\_\_\_\_  
 Name of Coroner or Magistrate: \_\_\_\_\_  
**VERDICT:**  
 \_\_\_\_\_

**INQUEST NOT HELD**

Inquest disposed of on: \_\_\_\_\_  
 By whom: \_\_\_\_\_  
 Cause of death: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_  
 Rank: \_\_\_\_\_ Reg'd No.: \_\_\_\_\_

## Facts to be addressed during completion of the P79A

### Cases will not be commenced without this information.

---

- Police body tag number.
- Full, complete and correct name of deceased.
- Quality review by DUTY OFFICER.
- Does the senior next of kin have any objection to post-mortem?
- Do police request post-mortem, if so detail reasons in narrative.
- In cases of unidentified deceased, prepare report addressing issues detailed in separate checklist provided on this intranet site.

### Medical information.

- Attendance by ambulance, what treatment?
- Was deceased suffering from any infectious diseases?
- Last doctor's visit, medications?
- Request made to forward medical records?

### Information required in relation to ALL DEATHS.

---

- Is any medical attendee prepared to issue a Certificate of Cause of Death? Or ...Reason for non-issue?
- Any recent hospital admissions – details?
- Any recent unnatural incidents that may have impacted on death, e.g. fight, domestic violence?
- Details of collapse, if witnessed, including any complaints of pain, faintness, dizziness, shortness of breath?
- If recently overseas, how long back in Australia and location of overseas destination. General health since return?
- Location and position of body.
- Distinguishing marks, body features and tattoos.

### Special Natural Deaths:

---

#### Epilepsy:

- Frequency of fits?
- History of medication?

#### Asthma:

- Previous hospitalisation?
- Nature of medication?
- Any known allergies?
- Any evidence of attempt to reach medication?

**Vomiting of Blood:**

---

- Any recent medication?
- Alcohol history?
- History of black faeces?
- Abdominal pain?

**Post Surgery**

- Underlying medical condition?
- Any complaint or report of surgical mistake?

**Hospital or Aged Care Facility:**

---

- Any complaints about management?

**Suicide:**

---

- Any suicide note? (Supply to Coroner)
- Possible reason (relationship, medical, depression etc.)
- Any psychiatric admissions, diagnosis or treatment?
- If prescribed medication, was it being taken?
- Drug history?
- Any previous suicide attempts?

**Hanging:**

---

- Height of suspension point?
- Nature of ligature (Note – send ligature with body)
- If ligature removed, how was it applied?
- Any chair/stool etc. to allow victim to reach suspension point?
- Were feet touching the ground?

**Shooting:**

---

- Type of firearm, ownership?
- Calibre and description?
- Source of ammunition?
- Location of firearm in relation to body?
- Location of cartridge cases if any?

**Motor Vehicle Crash:**

---

- Details of collision, speed, direction etc.?
- Any traffic offences committed?
- Seat belts worn?



- Presence and deployment of air bags?
- Any involvement of alcohol or drugs?
- Helmet worn in motorcycle collision?

### **Drowning:**

---

- Location and type of pool and water?
- Use of alcohol or drugs?
- Presence and condition of fence and/or gate?
- Any evidence of injury?
- Any nearby electrical appliances or electrical fault?
- Could deceased swim?
- If child, what level of supervision?
- Could child walk or crawl?
- Any resuscitation efforts?
- Use of scuba equipment – testing of equipment?

### **Electrocution:**

---

- Nature of electrical source?
- Was electrocution witnessed?
- How long after contact did collapse occur?
- What part of the body made contact with source?
- Any water present?
- Has appliance/equipment been tested. If so was fault detected?
- Use of alcohol or drugs?
- Fall in Hospital/Aged Care Facility?
- Witnessed?
- Any other person involved?
- Complaint of pain after fall?
- Management or treatment after fall?

### **Child Death:**

---

- Circumstances and location of discovery of body?
- Previous medical history including medications?
- Any DoCS involvement with family?
- Was delivery normal, if not supply details?
- Any previous infant deaths in family?
- Family Medical History?
- Any chance of co-sleeping, if so were adults affected by alcohol/drugs. Were they obese?

- Anything covering face?
- Was SIDS Checklist completed (if under two years)

#### **Apparent Drug-Related Death:**

---

- Full drug history (including number of tablets missing from available supply) and alcohol?
- Any previous overdoses?
- Is the source of the drug known-prescribed or illicit?
- Method of administration?
- Alcohol abuse?
- Degree of previous use?

#### **Fire/Burn Related Death:**

---

- Source of fire?
- Where there accelerants present?
- Likely duration of survival in fire?
- Was there any explosion?
- Location of deceased in fire site.
- Materials present in fire site.

#### **Carbon Monoxide:**

---

- Drug/alcohol history?
- Was car still running?
- Ignition on?
- Cabin sealed?
- Type of pipe, vehicle, engine?

#### **Falls/Jumps:**

---

- Height?
- Impact surface?
- Accessibility of origin point?
- Witnesses?
- Weather conditions, rain, temperature?

#### **Decomposed:**

---

- When last seen/heard from?
- Presence of heat source?
- Access for insects?
- Medication or evidence of relevant medical history. Especially previous surgery, implants or x-rays.

- Name of dentist, doctor, fingerprint records, missing person file?

**Asphyxia:**

---

- Plastic bag over head? (Take photo before removal and supply bag)
- Obstruction of airway by food – History of alcohol/dementia?
- Crushing Asphyxia – Compressing object?  
– Part of body squashed?

**Stab/Incised:**

---

- Weapon used?
- Was victim right or left handed?

**Train:**

---

- Position of victim prior to impact? (Lying, standing etc.)
- Speed of train?

**Aircraft Crash:**

---

- Position of victim?
- Nature of impact?

Appendix 3.2 | Death Scene Investigation Checklist – Sudden Infant Death (P534)



NSW POLICE

P534

Version 1.1 (04/04)

**Death Scene Investigation Checklist - Sudden Infant Death**

(Sudden deaths of children up to two years of age are notifiable)

TELEPHONE  
INTERPRETER  
SERVICE:  
131 450 (24HRS)

1. When inquiring into the circumstances of the death of a child two years and younger, this form is to be completed and forwarded to the Coroner with completed form P.79A.
2. Contact the Duty Forensic Pathologist immediately on: Glebe 9660 5977 or Westmead: 9845 6244

Carefully explain to the parents, family or carer the need to fully explore the circumstances in an attempt to establish the cause of death. Do not hurry the interview.

**INFANT'S DETAILS**

Surname: ..... Place of Birth: .....  
Hospital/Town

First name/s: ..... Date of Birth: ..... (D/M/Y)

Male  Female  Usual address: No. and Street .....

Suburb: ..... State ..... Postcode .....

Place of death: No. and Street .....

Suburb ..... State ..... Postcode .....

**MOTHER'S DETAILS**

Surname: .....

First name/s: ..... Date of Birth: ..... (D/M/Y)

Residential address at time of birth of infant: No. and Street: .....

Suburb: ..... State: ..... Postcode: .....

**MEDICAL INFORMATION**

- |   |   |
|---|---|
| • Weight at birth: ..... g/lbs  | • Premature birth? Yes <input type="checkbox"/> No <input type="checkbox"/>           |
| • Does the infant have brothers/sisters? Yes <input type="checkbox"/> No <input type="checkbox"/> | • Has he/she been immunised? Yes <input type="checkbox"/> No <input type="checkbox"/> |
| • Normal delivery? Yes <input type="checkbox"/> No <input type="checkbox"/>                       | eg Triple Antigen (or DPT), Polio (Sabin)   |
| Comments: .....   | .....   |

• Is there a past history of unexpected Infant Death in the family?  
 If yes, names: .....

• Was the infant previously healthy? Yes  No  Comments: .....

• Did the infant have any illnesses or changes in behaviour in the past two weeks especially in the last 24 hours?  
 Colds  Cough  Fever  Diarrhoea  Other  (specify) .....

• Had the infant received any prescription or over-the-counter medication? Yes  No   
 If yes, type: ..... Amount: ..... Time of last dose: ..... am / ..... pm

• Did the infant have any falls or sustain any injury recently? Yes  No   
 Comments: .....

• How was the infant being fed?  
 Breastmilk/formula: brand ..... /solids / Other: .....

• Were there any feeding problems? Yes  No  Describe: .....

• When was the infant last fed? ..... am / ..... pm

• Name and address of local doctor: .....

• Location of Early Childhood Centre attended: .....

REQUEST THE "PERSONAL HEALTH RECORD" (BLUE BOOK) OF THE INFANT. EXPLAIN TO THE PARENTS THAT IT IS REQUIRED BY THE MEDICAL OFFICER TO ASSIST WITH REGARD TO THE CAUSE OF DEATH AND WILL BE RETURNED ONCE THE CORONER HAS HAD THE OPPORTUNITY TO CONSIDER THE MATTER FULLY.

- Are there any illnesses in the family? Yes  No  Describe:.....
- Is any family member taking medication? Yes  No  Comment:.....
- Does anyone in the household smoke? Yes  No
- How many people live with the infant? .....

- Who found the infant? ..... Time: ..... am / ..... pm
- How did the infant come to be found?  
Random check  noise  specify: .....
- Was any resuscitation attempted?  
Parent  ambulance officer  Other  (specify): .....
- **Where was the infant when found?**  
Adult Bed  cot  cradle\*  unknown  Other  (specify): .....  
\* was locking pin in place?
- **Were there any other objects in the cot/bed:** eg, Pillow, soft toys: Indicate type .....  
If pillow used, indicate shape: eg, adult, child, horse-shoe:.....
- **Type of mattress:** Foam  fabric covered foam  innerspring  water  unknown  Other   
(specify): .....
- **Type of Bedding:** Sheet  Blanket  Doona  Other  (specify): .....
- Were there items covering the infant's head? Yes  No  List the item/s: .....
- Was the infant sleeping alone? Yes  No  With whom: .....
- **Position of infant when put down:** On back  on stomach  side  head to left side   
head to right side  unknown
- **Position of infant when found:** On back  on stomach  side  head to left side   
head to right side  head face down  unknown
- Were there any recent changes in sleeping pattern? Yes  No   
Describe: .....
- Was the infant found in an unusual sleeping position? Yes  No   
Describe: .....
- What clothing was the infant wearing at the time?  
Describe: .....

**SUPPORT ORGANISATIONS**

The Grief Counselling Service available through the NSW Institute of Forensic Medicine, Glebe, (02) 9660 5977 (24 hours), including the Counselling Service, Westmead Coroners Office and the Sudden Infant Death Association SIDA 1 800 651 186 (24 hours) and in the Hunter Region, Tel. (02) 4969 3171 are available to assist parents and families in the event of sudden infant death. Refer next of kin to these organisations or contact them on the family's behalf.

Name of Officer:  Rank:   
 Location:  Phone:  Date:

**Investigating Officer to complete this section with own observations:**

- Is there any evidence of drug/alcohol abuse? Comment: .....
- What is the general condition of the premises? Describe: .....
- Specify which room the infant was found: .....
- Room temperature: Comfortable/Other: ..... Ventilation: Comfortable/Other: .....
- General Comments:** .....

## Appendix 3.3 | Analysis of data items reviewed

		Question rating	Percentage of cases with data
<b>Family demographics</b>			
<b>Infant</b>	Full name	A	100.0
	Date birth	A	96.3
	Birth weight	A	79.0
	Birth hospital	A	82.7
	Residence at birth (name and postcode)	A	91.4
	Sex	A	100.0
	Indigenous status	A	96.3
	Address at death	A	98.8
<b>Mother</b>	Full name	A	97.5
	Date birth	A	80.2
	Address (suburb and postcode)	A	98.8
	Address at time of birth of infant	A	90.1
	Relationship to child (e.g. biological or adoptive)	C	100.0
	Pension type	C	0.0
	Employment status	C	0.0
	Last or current occupation	C	2.4
	Highest level education completed	C	0.0
	Living with child at time of death	C	98.8
	Marital status	C	63.0
	Cultural background	C	40.7
	Religion	C	1.2
	Home and work phone numbers	C	not reviewed
	<b>Father or other carer</b>	Full name	C
Date of birth		C	0.0
Address (suburb and postcode)		B	72.8
Relation to child (e.g. biological or adoptive)		B	92.6

		Question rating	Percentage of cases with data
<b>Family demographics (continued)</b>			
<b>Father or other carer (continued)</b>	Pension type	C	2.5
	Employment status	C	2.5
	Last or current occupation	C	1.2
	Highest level education completed	C	1.2
	Living with child at time of death	B	86.4
	Marital status	C	56.8
	Home and work phone numbers	C	not reviewed
	<b>Siblings or others in residence</b>	Siblings (age and sex of each)	B
Siblings at home at death (number and which siblings)		C	65.8
Relationship of other people in the house to child		C	88.2
<b>Social factors</b>	Home ownership status	C	7.4
	Home composition	B	69.1
<b>Death scene investigation</b>			
<b>Administrative information</b>	Time ambulance called	C	66.7
	Time ambulance arrived	C	50.7
	Who called ambulance	C	69.3
	Time ambulance notified police	C	0.0
	Time and date police were called recorded	A	77.8
	Time and date police arrived recorded	C	40.7
	Time first investigator at scene	C	30.9
	Police names recorded	A	88.9
	If detective(s) attended and name(s)	A	95.1
	If crime scene investigator(s) attended and name(s)	A	93.8
	Phone numbers of investigator(s)	C	4.4
	Time and date last investigator left scene recorded	C	3.7
	Date and time certification	C	76.5

		Question rating	Percentage of cases with data
<b>Death scene investigation (continued)</b>			
<b>Administrative information (continued)</b>	Date reported to Coroner	A	91.4
	Name and address of usual general practitioner	A	79.0
	Address of Early Childhood Centre	A	34.4
<b>Death scene</b>	Place of death (e.g. home, childcare centre)	B	96.3
	Time found unresponsive	A	98.8
	How did infant come to be found (noise, random check, routine check)	C	98.8
	Person finding infant unresponsive (relationship to infant)	A	100.0
	Person last saw infant alive (relationship to infant)	A	98.8
	Last seen alive (date and time)	A	93.8
	Condition of infant when found	C	98.8
	Debris, vomitus or object in infant's mouth	C	49.5
	Presence of blood in nose or mouth	C	43.2
	If resuscitation attempted and by whom	A	95.1
	Core body temperature	C	0.0
	Whether infant moved from time found to arrival of official responder	C	71.6
	Items at scene moved or disturbed prior to police or health professional arrival	C	not reviewed
	Usual caregiver (relationship to infant)	A	98.8
	Suspicious death noted	A	97.5
	Criminal charges preferred	A	95.1
	<b>Last feed</b>	Time last fed	A
Who last fed		C	95.1
Type of last feed		B	87.7
Feeding problems noted		B	91.3



		Question rating	Percentage of cases with data	
<b>Death scene investigation (continued)</b>				
<b>Information on last sleep</b>	Person last placed infant for sleep	C	95.1	
	Time infant placed for last sleep	C	91.4	
	Hours since last checked before found	C	96.3	
	Position placed last sleep	B	90.1	
	Position found	B	86.3	
	Face position when found	C	0.0	
	Unusual position found	A	80.5	
	Child can roll to face-down position (prone)	C	6.5	
	Draw position or re-enact when found	C	2.5	
	Whether video recording was made	C	13.6	
	Items collected from scene by police	C	45.7	
	<b>Bedding</b>	Number of pillows in bed	C	55.6
		Information on pillows (type and stuffing)	C	40.5
Type of mattress		A	77.5	
Type of coverings over infant		B	59.3	
Type of coverings under infant		B	33.3	
Whether coverings were loose		C	38.3	
Number of coverings		B	40.7	
Number of objects in cot		C	24.7	
Type of objects in cot		C	39.4	
Sleep surface		B	98.8	
Broken or faulty sleeping equipment recorded		C	12.3	
<b>Co-sleeping</b>	Whether infant was sleeping alone	A	97.5	
	Persons with whom infant was sleeping	A	100.0	
	Frequency of co-sleeping (nights per week)	C	19.4	
	Frequency of co-sleeping (hours)	C	0.0	

		Question rating	Percentage of cases with data
<b>Death scene investigation (continued)</b>			
Co-sleeping (continued)	Physical contact with adult in bed	C	29.0
	Position of infant in relation to others in bed	B	74.2
	Position placed in co-sleeping	B	74.2
	Position when found co-sleeping	B	64.5
Infant clothing	Clothing worn by infant	B	97.5
	Clothing changed since death	C	8.9
	Sleeping bag used	C	55.6
	Head covering (e.g. bed covers over head)	A	81.5
Ambient environment	Room temperature where found (degrees)	B	60.5
	Type of weather outside	C	9.9
	Maximum and minimum temperature on day of death	C	0.0
	Humidity	C	2.5
	Ventilation where found	B	71.8
	Type of heating on	C	8.6
	Heating on all night	C	7.4
	Cooling sources	C	28.4
Condition of premises	Dwelling type	A	32.5
	Comments on condition of dwelling	C	75.3
	Number of persons per bedroom	C	37.2
	Availability of food, clothing and bedding	C	8.6
	Odours, fumes, peeling paint, mould, dampness	C	3.8
	Pets in household	C	2.5
<b>Psycho-social information</b>			
Criminal history	Criminal record of mother	C	4.9
	Criminal record of father or other carer	C	2.5
	Prior charges or convictions for child offences, mother or other carer	C	3.7

		Question rating	Percentage of cases with data
<b>Psycho-social information (continued)</b>			
<b>Criminal history (continued)</b>	Prior charges or convictions for child offences, father or other carer	C	1.2
	Prior charges or convictions for offences against a person, mother	C	0.0
	Prior charges or convictions for offences against the person, father or other carer	C	0.0
	Prior charges or convictions for drug offences, mother	C	2.5
	Prior charges or convictions for drug offences, father or other carer	C	1.2
	Documented history of violence, mother	C	1.2
	Documented history of violence, father or other carer	C	2.5
	Domestic violence charges, AVOs, convictions	C	1.2
	History of child abuse or neglect, mother	C	0.0
	History of child abuse or neglect, father or other carer	C	0.0
	<b>Agency history</b>	Child or sibling as victims of recorded abuse (e.g. DoCS protection order)	C
Children history of suspicious physical or medical problems		C	3.7
Family involved with human agencies (e.g. DoCS, Health, Police, Juvenile Justice, Housing, Corrective Services, NGOs)		C	8.8
Whether DoCS or Child Protection contacted		C	0.0
<b>Clinical history</b>			
<b>Infant clinical history</b>	Maternal illness or complications during pregnancy	C	32.1
	Infant singleton or twin	B	98.8
	Apgar score	C	0.0
	Gestational age at birth	B	82.7

		Question rating	Percentage of cases with data
<b>Clinical history (continued)</b>			
<b>Infant clinical history (continued)</b>	Type of delivery and problems during delivery	B	34.6
	Resuscitation at delivery	C	12.0
	Ever admitted to neonatal intensive care unit	C	21.0
	Health problems in neonatal period	B	44.4
	History of intrauterine growth retardation	C	51.9
	History of failure to thrive or malnourishment	C	57.1
	History of developmental delay	C	10.0
	Number of child health attendances	C	4.9
	Known allergies	C	2.5
	Born drug-dependent (type of drug)	C	19.8
	Opiate replacement program at birth	C	2.7
	Opiate replacement at death	C	18.5
	<b>Other risk and protective factors</b>	Immunisation types received	B
Immunisation dates		C	18.8
Infection exposure		C	10.0
Recent travel		C	6.7
Using dummy last sleep		C	7.4
Type of milk currently being fed		B	88.9
Ever breastfed		C	44.4
Duration of breastfeeding		C	42.0
<b>Recent health status of infant</b>	Illness in past two weeks	B	80.2
	Recent injury or accident type	A	88.9
	Saw health professional in past two weeks	C	26.0
	Type of professional seen	C	37.5
	Diagnosis	C	77.8
	Treatment given	C	77.8
	Days since seen	C	11.1

		Question rating	Percentage of cases with data
<b>Clinical history (continued)</b>			
Recent health status of infant (continued)	Change in health status or behaviour in past 24 hours	B	91.3
	Over-the-counter medications given in past 24 hours	A	86.4
	Over-the-counter medications given in past two weeks	C	38.3
	Illicit drugs (including methadone) in past 24 hours	C	3.8
	Illicit drugs (including methadone) in past two weeks	C	2.5
Family clinical history	Number of mother's live births	C	61.7
	Previous stillbirth	C	7.4
	Other sleep deaths in family	B	94.4
	Previous infant or sibling death (including age and cause)	B	33.3
	Previous injuries in siblings	C	8.6
	Previous injuries in deceased	B	7.4
	Current family illness	B	87.7
	Current family medications	B	82.7
	Family history of asthma	C	21.3
	Intellectual disability of mother	C	3.7
	Intellectual disability of father or other carer	C	2.5
	Physical disability of mother	C	3.7
	Physical disability of father or other carer	C	2.5
	Mental health history, mother	C	3.7
	Mental health history, father or other carer	C	0.0
Evidence of drug or alcohol use in environment	A	83.3	
Family alcohol and other drug use	Alcohol: usual frequency and amount, mother	C	0.0
	Alcohol: usual frequency and amount, father or other carer	C	1.2

		Question rating	Percentage of cases with data
<b>Clinical history (continued)</b>			
Family alcohol and other drug use (continued)	Alcohol in past 24 hours, mother	C	0.0
	Alcohol in past 24 hours, father or other carer	C	0.0
	Over-the-counter medication taken by mother in past 24 hours	B	23.5
	Other drugs used in household	B	0.0
	Illicit drug use in past 24 hours, mother	C	2.5
	Illicit drug use in past 24 hours, father	C	0.0
	Mother on methadone program	C	13.6
	Father or other carers on methadone program	C	7.4
	Number in household who smoke	B	50.6
	Mother smokes currently	B	71.6
	Mother smoked during pregnancy	B	9.9
	Father smokes currently	B	98.8
	Father smoked during mother's pregnancy	C	11.1
	Number of people in dwelling who used marijuana in past 24 hours	C	1.2
	<b>Post-mortem</b>		
Administrative information	Date and time of autopsy	C	100.0
	Name of pathologist	C	100.0
	Qualifications of pathologist	C	100.0
	Place where autopsy conducted	C	100.0
	Time interval before body released for burial noted	C	48.1
	Time interval before inquest dispensed	C	61.7
	Sources of information available to pathologist noted on autopsy report	C	47.5
	List of samples retained	C	not reviewed

		Question rating	Percentage of cases with data
<b>Post-mortem (continued)</b>			
<b>Administrative information (continued)</b>	Photographs or video of body and environment	C	not reviewed
<b>External examination</b>	Post-mortem changes when found documented (lividity, rigidity, other)	C	53.1
	Medical interventions noted	C	76.5
	Post-mortem changes when found	C	53.1
	Full external examination ≥6 areas reported on	C	100.0
	Presence or absence of petechiae noted	C	90.1
	Trauma and distinguishing marks noted	C	98.8
	Full body radiology undertaken	C	72.8
	Congenital abnormalities noted	C	100.0
	Length percentiles	C	33.3
	Birth weight percentiles	C	0.0
	Death weight percentiles	C	34.6
	<b>Internal examination</b>	Investigation of mortal lesions (report on central nervous system, cardiovascular, respiratory, mouth and gastrointestinal tract, reticulo-endothelial system, genito-urinary system)	C
Macroscopy of brain after fixing		C	71.6
Full central nervous system examination (report on at least 12)		C	98.8
Respiratory system examination		C	100.0
Cardiovascular examination		C	100.0
Mouth, neck and abdominal examination		C	100.0
Reticulo-endothelial examination		C	92.6
Genito-urinary examination		C	100.0

		Question rating	Percentage of cases with data
<b>Post-mortem (continued)</b>			
<b>Pathology</b>	Full microbiology (bacteriology and virology of lungs and blood as minimum, liver, trachea, stool and myocardium)	C	79.0
	Full histopathology (includes up to 36 sections and 12 discretionary sections)	C	96.3
	Blood culture	C	44.4
	Exclusion of metabolic disorders	C	8.6
	Serology	C	27.2
	Biochemistry	C	33.3
	Toxicology at levels of detection appropriate to infants	C	97.5
<b>Attribution of death</b>	Direct cause of death noted	C	100.0
	Antecedent causes or morbid conditions described	C	71.6
	Other conditions possibly contributing to death	C	81.7
	Cause of death ICD-10 coding	C	0.0



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## Appendix 4.1 | Sudden unexpected infant deaths: important aspects of response

A checklist of important aspects of SUDI response (the checklist) was developed by the Team to allow comparisons with current New South Wales policies and guidelines. The checklist consisted of five aspects considered important in providing any response:

1. balance between care and investigation;
2. collection and recording of comprehensive information;
3. involvement of appropriate personnel;
4. multi-agency case review and continuous improvement; and
5. monitoring and research.

These aspects of response are based on the review of literature and international protocols undertaken to inform the New South Wales SUDI study. Particular focus is given to the *Confidential Enquiry into Sudden Deaths of Infants* (CESDI) recommendations, with the information collection requirements drawn from internationally recognised protocols such as the *Sudden Unexplained Infant Death Investigation Report Forms* (SUIDIRF) and the *International Standardised Autopsy Protocol* (ISAP). The SUIDIRF is currently being reviewed by the National Center for Chronic Disease Prevention and Health Promotion (US) to make it more user-friendly. A copy of the SUIDIRF and the ISAP are available at [www.kids.nsw.gov.au/publications/sudi.html](http://www.kids.nsw.gov.au/publications/sudi.html). Each of the five aspects is discussed in further detail.

### **Balance between care and investigation**

Many countries focus their response to SUDI on the investigation of death and identification of the cause of death and contributory factors, including abuse and neglect. The provision of care and support to the bereaved family is commonly not the primary responsibility of the investigating agencies (Fleming, Blair, Sidebotham & Hayler, 2004)

The CESDI case-control study challenges this position. Following examination of social, medical, economic and environmental factors, post-mortem examination and review by a multi-professional committee, no suspicion of maltreatment arose as a cause or contributory factor in the death in over 90 per cent of cases (Fleming et al., 2004).

Thorough investigation of the cause of infant death is of value to bereaved families. It can identify medical conditions that may have genetic implications for other family members and uncover factors that contributed to the infant's death that may have implications for prevention. However, the findings of a lack of criminal involvement in the vast majority of cases give weight to the call for an emphasis to be placed on supporting bereaved families. Even when the death is a result of abuse or neglect the members of the family need support. Such care assists them to come to terms with the death of their infant by keeping them informed about what is happening throughout the process and addressing any practical or social issues that may arise.

This said, an investigation of the incident is also required to identify the relatively small proportion of incidents of SUDI that are found to be due to non-accidental injury or

maltreatment. The seriousness of the incident and the potential risks for other siblings require that all cases be investigated. A sensitive balance between these two aspects of the response is required.

### **Collection and recording of comprehensive information**

Any SUDI response system needs to provide for comprehensive collection of information and standardised recording. A lack of information severely limits the ability to monitor incidents of SUDI with a view to reduction or prevention (Byard, 2001; CDRT, 2000).

A range of information collected from a variety of sources (including parents, general practitioners, medical staff, maternity and hospital records and human services agencies) is required to provide a comprehensive picture of the death of an infant. Information required includes birth history, medical history, social history, health and events preceding death, exact circumstances of death including details of any suspicious circumstances and autopsy results. The specifics of the information required should be drawn from internationally recognised practice such as the SUIDIRF, ISAP and the Centers for Disease Control, Atlanta Death Scene Investigation. The information collected and the results of the investigation need to be clearly documented. This includes a summary and discussion of the results of the investigation. The documentation presents the evidence, allows for discussion and verification of findings, and supports the monitoring of and research into these deaths.

It follows that the information collected and recorded be appropriately shared. An effective information sharing system keeps parents informed throughout the process; enables the pathologist to be fully briefed prior to autopsy; keeps other agencies involved in the case informed; provides information to continuously improve practice; and enables incidents of SUDI to be monitored.

### **Involvement of appropriate personnel**

Responding to an infant death involves a number of interrelated processes and tasks. Tasks include the collection of information from the death scene, collection of medical and social history, identification of suspicious circumstances, post-mortem examination, provision of guidance and support to parents and attribution of cause of death. These are specialised tasks requiring not only a sympathetic and well-informed approach but professionals with the appropriate expertise (Fleming et al., 2000).

The death scene investigation requires both a forensic and support focus. Identifying infant deaths that occur in suspicious circumstances is most appropriately undertaken by police officers with child protection experience. Experienced health care professionals are best placed to collect information from parents: their experience in child care, disease in childhood and bereavement is critical. This approach promotes comprehensive and accurate information collection and assists the family to come to terms with what has happened as early as possible.

The pathological processes that lead to deaths in infants are often not straight forward and have 'poorly understood underlying mechanisms. These difficulties are magnified if investigations and interpretations are inadequate' (Byard, 2004). Pathologists with paediatric experience or a general pathologist with special training and expertise are in the best position to undertake post-mortem examinations (Fleming, Blair, Bacon, Platt & Berry, 2000; The Royal College of Pathologists and The Royal College of Paediatrics and Child Health, 2004).

### **Multi-agency case review and continuous improvement**

The case discussion enables all information and expertise available from all professionals involved in the investigation and support of the parents to be shared. The importance of compulsory case reviews in cases of sudden infant death is supported by several leaders in the field (Fleming, Blair, Bacon, Platt & Berry, 2000; Rognum, 2000; Byard, MacKenzie & Beal, 1997).

The case review has several functions including:

- reviews details of the death in order to consider the most likely cause and contributory factors. This information is provided to the coroner to inform attribution of cause and manner of death;
- examines any issues in relation to child protection and if necessary determines appropriate action to be taken;
- identifies errors or deficiencies in professional care and if necessary develops a plan to feed back learning and development into the service system;
- assesses the parents' or carers' need for additional guidance and support regarding bereavement, child care practices and future pregnancies, and if so puts a plan in place; and
- identifies public health threats and unsafe health practices so that preventive strategies can be developed.

### **Monitoring and research**

No response system would be complete without a monitoring and research function. Information collected needs to be used by agencies and researchers to assist in identifying patterns and trends so that prevention strategies are well targeted. Further, the dissemination of ongoing research is essential in keeping the professionals and the community informed on cause, risk factors and best practice behaviours in relation to SUDI.

The checklist proposed by the Team provides some aspects of a response to SUDI that are considered essential for all cases and jurisdictions. The broadness of the criteria provides flexibility for adaptation of protocols and procedures to best suit local circumstances and individual differences relating to each SUDI case.

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## Appendix 4.2 | Policies and guidelines sought

Policy and guideline documents were sought from the following government and non-government agencies and professional associations:

### **Government agencies**

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Ambulance Service of NSW  
Department of Ageing, Disability and Home Care  
Department of Community Services  
Departments of Forensic Medicine  
NSW Health  
NSW Police  
Office of the State Coroner

### **Non-government agency**

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SIDS and Kids NSW

### **Professional associations**

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Alliance of NSW Divisions  
Association for Australian Rural Nurses  
Association of Neonatal Nurses NSW  
Australasian College of Emergency Medicine  
Australian Association of Social Workers  
Australian College of Midwives  
Australian Confederation of Paediatric and Child Health Nurses  
Council of Remote Area Nurses of Australia  
Emergency Nurses Association NSW  
NSW Midwives Association  
Royal Australasian College of Physicians  
Royal Australian College of General Practitioners  
Royal College of Pathologists of Australia  
Rural Doctors Network

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## Appendix 4.3 | Policies and guidelines examined

### NSW Police

NSW Police have both general policies relating to investigating death and particular instructions for dealing with SIDS cases. The relevant information to assist NSW Police in investigating these deaths is contained in an extract from the *NSW Police Commissioner's Handbook* entitled 'Coroners' Matters' and in an extract from a NSW Police mandatory training package entitled 'Coronial Investigation' (March 2004).

The policies and guidelines provided to the Team were:

- an extract from the *NSW Police Commissioner's Handbook* entitled 'Coroners' Matters'
- extracts from a NSW Police mandatory training package entitled 'Coronial Investigation' (1998)
- P79A form *Report of Death to the Coroner*
- P534 form *Death Scene Investigation Checklist – Sudden Infant Death*
- Joint Investigation Response Team (JIRT) document
- NSW Police Forensic Services Group *Deceased Person Exam Notes*
- changes to the *Coroner's Act 1980* due to the *Community Services Amendment Act 2002: Information Package* (2003)
- *Six Minute Intensive Training IN016: Coronial Investigations/Sudden Infant Death Syndrome* (2003).

### NSW Health

NSW Health policies are largely contained in administrative circulars provided to NSW Health staff. The policies and guidelines provided to the Team were:

- *National SIDS Autopsy Protocol* (1992)
- *Circular No. 2002/52: Hospital Protocol for Unexpected Infant Death* (2002)
- *Circular No. 92/82: Notification of Sudden Infant Death Syndrome* (1992)
- *Circular No. 95/57: Assessment of the Extinction of Life and the Certification of Death* (1995)
- *Circular No. 96/53: Discharge Type Summaries for Coronial Cases in Hospitals* (1996)
- *Circular No. 99/57: Coroners' Cases and Amendment to Coroner's Act 1980* (1999)
- *Circular No. 99/92: Assessment of the Extinction of Life and the Certification of Death* (supersedes Circular 95/57) (1999)
- *Information Bulletin 03/17: Sudden Infant Death Syndrome and Safe-sleeping for Infants*
- *Circular No. 97/45: Coroners' Cases and Amendments to Coroner's Act 1980* (1997)
- *Information Bulletin: 97/15 Documentation, Management, Storage and Disposal of Health Care Records* (1997)

- *Guide to the post-mortem examination: brief notes for parents and families who have lost an infant in pregnancy and infancy* (1998)
- Section 12.1: *Protocol for Sudden Infant Death* (excerpt from the manual of the Department of Forensic Medicine in the Institute of Clinical Pathology and Medical Research, Westmead)
- *Circular No. 99/18: NSW Health Information Privacy Code of Practice* (1999)
- *Circular No. 02/6: Hospital Procedures for Review and Reporting of Perinatal Deaths* (2002)
- *Pieces of the Puzzle: Index of Research Projects funded through National SIDS Council of Australia*
- *Circular No. 00/98 Organ Donation—Coronial Cases* (2000)
- *NCIS Minimum Data Set* (June 2001)
- Newcastle Department of Forensic Medicine: *Paediatric Autopsy Report*
- *The Start of Good Health: Improving the Health of Children in NSW* (1999)
- *When a baby dies* (NSW HealthNet, 1998)
- Bereavement care: General bereavement support information for staff (2003).

### Office of the State Coroner

The policies and guidelines provided to the Team were:

- P534 form *Death Scene Investigation Checklist – Sudden Infant Death*
- *Protocol for SIDS*.

Further information regarding the operation of the Office of the State Coroner was accessed from a Coroner's Court brochure provided by NSW Health.

### Department of Ageing, Disability and Home Care

The Department of Ageing, Disability and Home Care does not have specific policies relating to infant deaths. However, there are policies and guidelines relating more broadly to client deaths for services funded or directly provided by the Department.

For disability services provided by the Department of Ageing, Disability and Home Care relevant procedures are outlined in 'Response to the Death of a Consumer' from the manual *Policies for Working with People with Disabilities*. For funded non-government services, *Notification of Deaths of Service Users from Standards in Action* is relevant.

The policies and guidelines provided to the Team were:

- Policy 6.9 'Response to the Death of a Consumer' from the manual *Policies for Working with People with Disabilities* (1996)
- *Standard 4.3 Notification of Deaths of Service Users from Standards in Action*.

### Department of Community Services

The Department of Community Services does not have specific policies relating to infant deaths. However, the Department's legislative base, policies and guidelines are relevant to SUDI.

The policies and guidelines provided to the Team were:

- *Risk of Harm Assessment* (2002)
- *Secondary Risk of Harm Assessment* (2002)
- Sections 248 and 254 of the *Children and Young Persons (Care and Protection) Act 1998*
- *Memorandum of Understanding with the NSW Coroner's Court* (2000)
- *Memorandum of Understanding with NSW Police* (2002)
- *Memorandum of Understanding with the NSW Ombudsman* (2003)
- Department of Community Services case-planning procedures (2000)
- Procedures for case meetings (2001)
- Staff support team (2002).

### **SIDS and Kids NSW**

SIDS and Kids NSW policies and procedures were contained in the resources developed to support their volunteer parent supporters and in their resource package for health and allied professionals, Appropriate care for women and their partners when their baby dies.

The policies and guidelines provided to the Team were:

- Resource kit: *Appropriate care for women and their partners when their baby dies*;
- Internal policies:
  - The model of self help SIDS and Kids NSW follows
  - Confidentiality guidelines (2001)
  - Details about accreditation
  - SIDS grievance procedures
  - Role descriptions for parent supporters (2001)
  - Guidelines for initial contact with the bereaved family (2001)
  - Funeral policy (2001)
  - Policy for linking a bereaved parent with a parent supporter (2001)
  - Parent supporters' rights and responsibilities (2001)
  - Policy on the SIDS and Kids NSW buddy system (2001)
  - Supervision and debriefing policy (2001)
  - SIDS and Kids NSW coffee morning policy and guidelines (2001)
  - Support group rules.

## Appendix 6.1 | Socio-economic and health characteristics

Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Mother's age</b>		
15–19	25	2.0
20–24	95	9.9
25–29	201	23.2
30–34	200	31.3
35–39	108	18.3
40–44	18	3.3
Not stated	89	12.0
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Sex of child</b>		
Males	386	51.2
Females	350	48.8
Persons	736	100.0
<b>Child health rating</b>		
Excellent	517	66.9
Very good	165	25.3
Good	40	4.6
Fair	11	2.5
Poor	2	0.4
Don't know	1	0.4
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Parents' education</b>		
<b>Mother</b>		
Never attended school	1	0.1
Some high school	26	4.1
Completed Year 10 or equivalent	186	24.0
Completed Year 12 or equivalent	160	18.1
TAFE certificate or diploma	134	18.1
Tertiary institute degree or higher	227	35.3
Not stated	2	0.2
<b>Total</b>	<b>736</b>	<b>100.0</b>



Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Parents' education (continued)</b>		
<b>Father</b>		
Some high school	27	3.0
Completed Year 10 or equivalent	175	19.9
Completed Year 12 or equivalent	104	11.8
TAFE certificate or diploma	155	20.4
Tertiary institute degree or higher	219	37.0
Not stated	56	7.9
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Parents' employment status</b>		
<b>Mother</b>		
Employed full-time	54	5.5
Casual	24	2.5
On extended leave	78	11.4
Employed part-time	156	21.3
Unemployed	19	2.1
Home duties	383	54.2
Student and working	4	0.5
Student and not working	11	1.2
Unable to work due to health problems	1	0.1
Other	5	1.0
Not stated	1	0.2
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Father</b>		
Employed full-time	577	80.1
Casual	6	0.4
On extended leave	1	0.2
Employed part-time	18	2.1
Unemployed	48	5.3
Home duties	8	0.7
Student and working	10	3.0
Student and not working	9	1.1
Retired	1	0.0
Unable to work due to health problems	9	2.0
Other	1	0.0
Not stated	48	4.9
<b>Total</b>	<b>736</b>	<b>100.0</b>

Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Country of birth</b>		
<b>Mother</b>		
Australia	605	75.6
United Kingdom	28	4.2
New Zealand	13	1.6
China	8	1.1
Lebanon	8	2.8
Philippines	8	1.9
Other countries	65	12.5
Not stated	1	0.2
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Father</b>		
Australia	561	69.9
United Kingdom	19	3.8
New Zealand	14	1.9
India	7	0.7
China	6	0.6
Germany	6	0.6
Philippines	6	1.8
Other countries	65	13.2
Not stated	52	7.6
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Child</b>		
Australia	731	98.9
Other countries	5	1.1
<b>Total</b>	<b>736</b>	<b>100.0</b>
<b>Language spoken at home</b>		
English	626	78.0
Italian	15	2.2
Arabic	13	4.1
Greek	11	2.3
Filipino/Tagalog	5	1.6
Hindi	5	0.6
Other languages	61	11.2
<b>Total</b>	<b>736</b>	<b>100.0</b>

Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Aboriginal or Torres Strait Islander status of parents</b>		
<b>Mother</b>		
Aboriginal but not Torres Strait Islander	26	2.6
Not Aboriginal or Torres Strait Islander	695	92.7
Not asked	15	4.8
Total	736	100.0
<b>Father</b>		
Aboriginal but not Torres Strait Islander	18	1.7
Aboriginal and Torres Strait Islander	1	0.0
Not Aboriginal or Torres Strait Islander	694	93.1
Not asked	23	5.2
Total	736	100.0
<b>Child ever had contact with baby health or early childhood nurse</b>		
Yes	685	88.6
No	42	9.9
Has not yet attended first appointment	8	1.4
Don't know	1	0.1
Total	736	100.0
<b>Age of child at first contact with baby health or early childhood nurse</b>		
Has never attended	42	9.9
Less than 1 month	523	68.8
1 month	119	14.6
2 months	27	3.2
3 months	10	1.1
4+ months	3	0.5
Not stated	12	2.0
Total	736	100.0
<b>Child has personal health record</b>		
Yes	731	99.3
No	5	0.7
Total	736	100.0
<b>Person usually consulted about child's general health problems</b>		
Doctor at a medical centre	127	16.2
GP or local doctor	533	75.6
Doctor at hospital	15	1.4
Someone else	52	5.6
Not stated	9	1.2
Total	736	100.0

Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Child ever breastfed</b>		
Yes	666	89.7
No	62	9.5
Don't know	1	0.0
Not asked	7	0.8
Total	736	100.0
<b>Child currently being breastfed</b>		
Yes	326	44.3
No	402	54.9
Not asked	8	0.9
Total	736	100.0
<b>Duration of breastfeeding</b>		
Never breastfed	62	9.5
Less than 1 month	115	16.2
1 month	77	9.8
2 months	88	12.7
3 months	77	9.6
4 months	57	8.9
5 months	59	7.5
6 months	42	6.3
7 months	38	5.0
8 months	37	4.5
9 months	26	3.2
10 months	24	2.5
11–18 months	26	3.4
Not asked	8	0.9
Total	736	100.0
<b>Accessibility/Remoteness Index of Areas</b>		
Highly accessible	484	85.4
Accessible	162	11.6
Moderately accessible	37	1.8
Remote	39	1.0
Very remote	12	0.2
Missing	2	0.0
All NSW	736	100.0

Characteristic	Number of respondents (unweighted)	% (weighted)
<b>Socio-Economic Index for Areas</b>		
1st quintile (least disadvantaged)	96	18.1
2nd quintile	147	20.9
3rd quintile	170	20.4
4th quintile	138	19.1
5th quintile (most disadvantaged)	181	21.3
Missing	4	0.1
All NSW	736	100.0
<b>Child's status in household</b>		
Only child	433	39.2
Not only child	303	60.8
Total	736	100.0

*Note: Estimates based on 736 responses for children aged less than one year.*

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## Appendix 7.1 | Definitions of fatal assault and neglect

The CDRT developed its own set of definitions and screening procedures. A review of the literature indicated that other researchers also found difficulties in defining assault and neglect that resulted in the death of a child and no universal definition was evident.

The definitions and guidelines developed were based on the expertise of the Team and their experience in screening deaths. In developing the definitions, the Team reviewed the *NSW Interagency Guidelines for Child Protection Intervention* (2000), the North Carolina Child Advocacy Institute's *Child Maltreatment Fatalities: Guidelines for Response* (2000) and the US *Study of National Incidence and Prevalence of Child Assault and Neglect* (1988).

### Fatal assault

Fatal assault occurs where a child is fatally injured by beating, burning, shaking, stabbing, shooting, poisoning, suffocation, strangulation or other physical means. Fatal assault includes homicides and murder-suicides. The relationship between the child and the perpetrator is not significant to this definition.

### Fatal neglect

Fatal neglect results from an act of omission by a parent or carer that involves: refusal or delay in providing medical care; failure to provide basic needs such as food, liquids, clothing or shelter; abandonment; or inadequate supervision. The relationship between the child and the perpetrator is significant. A carer can be any person responsible for the child, or in loco parentis for any period of time. The act or omission by a parent or carer can be conscious or deliberate, or unconscious or not deliberate. Infants are particularly at risk of fatal neglect due to their physical vulnerability and complete dependence on carers.

Rosenberg (1994) defines inadequate supervision as the failure of parents or carers to carry out their duties to their children, that is 'a failure to provide attendance, guidance and protection to children who, lacking experience and knowledge, cannot comprehend or anticipate dangerous situations' (p. 39).

It is difficult to define inadequate supervision in more specific terms. Firstly, it is often difficult to establish a causal relationship between the child's death and a parental act of omission, especially when reviews are based on administrative records. Secondly, it is difficult to state exactly what is meant by parental (or carer) duties. Parental or carer duty is not defined by law; rather it is determined by unwritten standards in the community. Generally, the community disapproves of parents who act irresponsibly, yet the community does not expect parents to be able to prevent all deaths. The CDRT plays an important role in representing the opinions of the general community and in helping to define what is acceptable in the community.

Rosenberg (1994) suggested that incidents in which a child has died as a result of inadequate supervision may also include instances in which the parents' capacity was impaired as a result of drugs, alcohol, mental illness, physical illness, immaturity or low intelligence. Also included

were: deaths that occurred when older siblings were left to supervise younger siblings; deaths due to fires, falls, drownings or poisoning when children were left unsupervised; and deaths when children were left unattended in cars.

The Team developed a rigorous screening procedure to address the difficulties associated with determining the cause of death by neglect and in particular, inadequate supervision.

The following questions, as outlined by Rosenberg (1994), were considered by the Team when examining the context of deaths relating to neglect:

- the age and developmental stage of the child;
- the period of time that the child was left unsupervised;
- the circumstances in which the child was unsupervised, an assessment of the potential hazard and how obvious the danger was to a carer;
- the physical and mental condition of the carer;
- any previous history of chronic supervision neglect;
- the acceptability of the specific parental behaviour in his or her ethnic group; and
- whether the supervision neglect was causal or related to any coexisting poverty (Rosenberg, 1994, pp. 38–39).

### **Suspicious deaths**

Suspicious deaths are deaths where there is insufficient evidence or information in the post-mortem to determine whether the cause of death was or was not clearly due to assault or neglect. Deaths were considered suspicious if there was a history of child abuse and neglect in the child's family background or other concerning circumstances in the context of the death incident.

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## Appendix 7.2 | Screening process to identify deaths due to, or suspicious of assault and neglect

The Child Death Review Team screened sudden and unexpected infant deaths to identify deaths caused by assault, neglect or suspicious of assault and neglect.

The screening procedure consisted of two stages:

- Stage One – initial assessment of cases of sudden and unexpected infant deaths by representatives of the Team including a paediatrician and others with child protection experience;
- Stage Two – further assessment by these Team members with additional information.

### **Stage One: Initial assessment of sudden unexpected deaths of infants**

Representative Team members assessed each sudden unexpected death of an infant to determine whether it was due to, or suspicious of assault or neglect. Cases were assigned to this group where the death resulted from child assault or neglect or where this is suspected but there is not enough evidence to make a clear determination, for example, where the autopsy cause of death was ‘unascertained’ or ‘not determined’ but the forensic pathologist had noted that it was possible that the child was suffocated or smothered.

In assessing cases, Team members examined information from the *Police Report of Death to Coroner* (P79A), which includes a narrative of the circumstances of the death, the final autopsy report and information from the NSW Department of Community Services’ KIDS System. For the majority of cases this information was not sufficient to make a decision and additional information was sought. This group of infants were further assessed in stage two.

### **Stage Two: Further assessment of sudden unexpected deaths of infants with additional information**

Further information and data was sought from the following organisations for all infants assessed in this stage:

- NSW Police: records regarding the child; criminal records of parents, non-related partners and/or suspects; history of domestic violence incidents involving either or both parents during the course of the child's life, including non-related partners.
- NSW Coroner: records regarding the child including inquest transcripts and police briefs of evidence.
- The Department of Community Services: records regarding the child, their siblings and parents.

In addition, information was sought from:

- NSW Health: birth records of the child; general medical records including admissions to hospital and mental health records of the child and their parents.
- Department of Housing: information indicating whether the child's family was in Department of Housing accommodation during the course of the child's life.



## Appendix 7.2 Screening process to identify deaths due to, or suspicious of assault and neglect

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Independent child protection consultants and researchers at the Commission for Children and Young People reviewed this additional information and data. The results of this review, along with the additional information and data were provided to the representative Team members to assist in their further assessment of the case.