# NSW Child Death Review Team Annual Report 2014



October 2015

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# Foreword

This report concerns 485 children whose deaths were registered in NSW in 2014.

The death of a child is a profound loss that is felt in an acutely individual way. The NSW Child Death Review Team extends its deep sympathy to the families and friends of the children and young people who died. Their individual stories are not told in this report, but hopefully the broader picture presented in this report can contribute to a fuller understanding of how we can respond to child deaths.

The rate of child deaths for 2014 – 28.41 deaths per 100,000 children – is the second lowest annual rate since 2000, and continues the significant decline in infant and child mortality rates over the last 15 years. This is a positive sign. This report nevertheless shows that more can be done to prevent child deaths in NSW.

As in previous years, Aboriginal and Torres Strait Islander children were over-represented in child deaths in 2014. The rate of death was 2.6 times that of non-Indigenous children. This indicates a need for further work to identify both targeted and broad-based responses to the vulnerability that Indigenous children face.

The Team also continues to be concerned about Sudden Unexpected Deaths in Infancy. Almost 50 infants die suddenly and unexpectedly each year. While rates have been declining, the figures in this report indicate that the decline may have plateaued. The Team will monitor this closely, with a view to identifying whether and where prevention efforts need to be better targeted. In addition, the proportion of unexpected sudden infant deaths in NSW in which a cause of death is determined is too low. After investigation, there is no recognised cause of death for almost three quarters of sudden unexpected infant deaths. This has consistently been the case since 2000. The NSW Sudden Infant Death Advisory Committee is currently considering the underlying service model to respond to this issue, and the Team keenly awaits the results of this work and the response by NSW Health.

Another key focus for the Team is injury-related deaths. In 2014, almost one in five (80) children died as a result of injury. It is sobering to reflect that over one third of these deaths were caused by intentionally inflicted injury: 22 children and young people died by suicide and nine deaths occurred in circumstances of abuse. Significant initiatives are underway on youth mental health and suicide risk, and the Team will closely follow these developments.

More broadly, the importance of a more comprehensive and better coordinated approach to childhood injury prevention is illustrated in the research report the Team is releasing alongside this annual report. The *Scan of childhood injury and disease prevention infrastructure in New South Wales* is an independent – and initial – review of the networks, initiatives and activities that contribute to this state's efforts to prevent childhood injury and illness. It should assist the Team and injury prevention advocates in the ongoing debate about how to deliver further improvements to the safety and wellbeing of children.

Yours sincerely

**Professor John McMillan Ao** Convenor, Child Death Review Team Acting NSW Ombudsman

# **NSW Child Death Review Team**

Team members in 2014-2015 were:

### **Statutory members**

**Professor John McMillan** (from 3 August 2015) Convenor Acting NSW Ombudsman

**Mr Bruce Barbour** (to 30 June 2015) Convenor NSW Ombudsman

**Mr Chris Wheeler** (1 July – 2 August 2015) Acting Convenor Acting NSW Ombudsman

Mr Steve Kinmond Community and Disability Services Commissioner Deputy Ombudsman

**Ms Kerryn Boland** (to January 2015) Acting Commissioner for Children and Young People Children's Guardian

Mr Andrew Johnson (from January 2015) NSW Advocate for Children and Young People

### Agency representatives

**Ms Kate Alexander** Executive Director, Office of the Senior Practitioner Department of Family and Community Services

**Ms Robyn Bale** Director, Student Engagement and Interagency Partnerships Department of Education

**Ms Christine Callaghan** District Director, Nepean Blue Mountains Department of Family and Community Services

**Ms Jane Gladman** Coordinator of the Coronial Information and Support Program State Coroner's Office

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# Acknowledgements

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Thank you to Dr Jonathan Gillis and Dr Bronwyn Gould for their regular review of matters and provision of expert advice.

Finally, the Team extends its appreciation and thanks to the former Ombudsman and Convenor of the Team, Mr Bruce Barbour, for his leadership and significant contribution to the work of the Team over the past five years.

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# **Executive Summary**

The NSW Child Death Review Team (the Team) maintains a register of child deaths and identifies any patterns or trends arising. The Team undertakes research and makes recommendations about legislation, policies, practices and services that may help to prevent the deaths of children.

# Trends in mortality rates: children in NSW

The deaths of 485 children were registered in NSW in the period 1 January 2014 to 31 December 2014, representing a directly standardised mortality rate<sup>1</sup> of 28.41 deaths per 100,000 children. This is the second lowest annual rate since 2000.

There has been a continual and significant decline in infant and child mortality rates over the 15 years to 2014. Infant mortality rates in NSW have declined considerably over the past 15 years, to a low of 2.95 deaths per 1,000 live births in 2014.

Mortality rates for children in each age group in 2014 were not significantly different from 2013, and have not changed substantially in recent years. Mortality rates decreased in the 5-9 and 10-14 year age groups before rising again in the 15-17 year age group.

While mortality rates for male children have been consistently higher than for females over time, since 2011, female mortality rates appear to have plateaued while male mortality rates have continued to decline.

Over the past 15 years, crude mortality rates for Aboriginal and Torres Strait Islander children have varied considerably from year-to-year. However, Aboriginal and Torres Strait Islander infant mortality rates have decreased since 2000.

# The children who died in 2014

Of the 485 children who died, 254 were male and 231 were female.

The majority of children who died were very young, which is consistent with previous years. Almost two thirds (296; 61%) of the children were infants aged less than 12 months. Three quarters (353; 73%) of the children who died were under five years old.

The families of just under a quarter of the children who died (21%) had a child protection history, a proportion that is consistent with previous years. Thirteen children were in care at the time of their death.

As in previous years, there was a significant difference in mortality rates between Indigenous and non-Indigenous children. The mortality rate for Aboriginal and Torres Strait Islander children in 2014 was 2.6 times the mortality rate for non-Indigenous children.

# **Causes of death**

Information about cause of death was available for 461 of the 485 children (95%):

- 361 children (78%) died as a result of natural causes
- 80 children (17%) died as a result of injury; two thirds (49) were unintentional injury, 22 deaths were due to suicide and nine children died in abuse-related circumstances
- The cause of death for 20 children (4%) remained undetermined following post-mortem investigation; all but one of these deaths were Sudden Unexpected Death in Infancy.

### Leading causes of death

The leading natural cause of death for infants was conditions arising in the perinatal period (late pregnancy, birth and the first 28 days of life). The leading natural cause of death for children in all other age groups was cancers and tumours.

Suicide was the leading injury-related cause of death for children and young people aged 10-14 and 15-17 years. Transport fatalities were the leading injury-related cause of death for children aged 1-4 years; for those aged 5-9 years, transport was the equal leading cause with drowning.

<sup>1</sup> The directly standardised mortality rate is deaths per 100,000 people under 18 years of age, adjusted for the age structure of the population.

# Natural cause deaths

### Conditions arising in the perinatal period

Perinatal conditions originate during pregnancy, or up to 28 days post-partum. They include conditions such as prematurity; respiratory and cardiovascular disorders; maternal factors such as hypertensive disorders; and complications of pregnancy, labour and delivery.

161 children died as a result of perinatal conditions in 2014. All of the children were less than 12 months of age. Consistent with previous years, the leading cause of death from perinatal conditions was related to maternal factors and complications of pregnancy, labour and delivery, which accounted for close to half of all perinatal deaths.

### **Congenital and chromosomal conditions**

Congenital malformations, deformations and chromosomal abnormalities include anatomical defects or developmental disorders that are present at birth.

71 children died as a result of congenital and chromosomal conditions. As has consistently been the case, these conditions were the second leading cause of death in 2014. The two main causes were congenital malformations of the circulatory system; and congenital malformations of the nervous system, including neural tube defects and spina bifida.

### **Neoplasms (cancers and tumours)**

38 children died as a result of cancers and tumours. Consistent with previous years, neoplasms were the leading natural cause of death of children aged one year and over.

Malignant brain tumours were the most common cause of death from neoplasms. Cancers of the lymphoid and haematopoietic tissue (affecting the blood and bone marrow) were the second leading cause, and all but one of these deaths was due to leukaemia, which is the most commonly diagnosed childhood cancer.

### **Respiratory system diseases**

25 children died from respiratory diseases. The mortality rate from this cause (1.49 per 100,000 children) was the highest it has been over the past 15 years.

The most common respiratory diseases that caused the deaths of children were pneumonia, asthma, influenza and aspiration pneumonia.

### Asthma

Four children died as a result of asthma in 2014. The Team's 10-year review of asthma, reported in the CDRT Annual Report 2013, identified opportunities for strengthening policy and practice to improve the identification of and support to children with asthma. The Team made recommendations about this to NSW Health, the Department of Education and Catholic and Independent school authorities.

In response, all of these agencies and schools have provided details of strategies in place or proposed to improve responses to and support of children with asthma. This includes the establishment of a cross-sectoral working party, auspiced by NSW Health, to identify strategies for improving support to school-aged children and young people with asthma and their families.

The Team has asked NSW Health to provide detailed advice on the outcomes of the working party, and processes within Health to provide post-hospitalisation support to children with asthma.

### Endocrine, nutritional or metabolic diseases

13 children died from metabolic disorders. The metabolic disorders causing the deaths of children in NSW in 2014 included cystic fibrosis, Sandhoff disease, glycogen storage disease and lipid storage disorders.

### Diseases of the circulatory system

Eight children died as a result of diseases of the circulatory system. Cardiomyopathy was the most common cause of death of children from circulatory system disease.

The deaths of two of the eight children who died from circulatory system diseases in 2014 were considered to be sudden cardiac deaths. Sudden cardiac death is rare and typically occurs in seemingly healthy young people.

### **Infectious diseases**

6 children died as a result of infectious diseases. Deaths due to infectious disease have declined over the past century largely due to the vaccination program and improvements in public health. Vaccination not only protects the individual, but also protects others in the community by increasing the overall level of immunity in the population and minimising spread of infection. As a result of successful vaccination programs, diseases such as tetanus, diphtheria, Haemophilus influenzae b (Hib) disease and polio are very rare.

In 2015, the Team commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to analyse data held in the Child Death Register in relation to deaths from infectious diseases in NSW.

The NCIRS will review 788 child deaths recorded in the NSW Child Death Register with infectious or parasitic causes of death and classify the likelihood that the deaths were due to a vaccine-preventable disease. More detailed case file analysis will be performed on those triaged as high or moderate likelihood of being related to a vaccine-preventable disease. The outcomes of the NCIRS review will be detailed in the Team's Annual Report in 2016.

# **Sudden Unexpected Death in Infancy**

In 2014, 15 percent of the deaths of infants aged less than 12 months (45) were classified as Sudden Unexpected Death in Infancy (SUDI). SUDI is a classification rather than a cause of death. Most SUDI are attributed to Sudden Infant Death Syndrome (SIDS) or a fatal sleep accident.

While the proportion of SUDI deaths has fluctuated to some degree from year to year, changes over the last 15 years have not been significant. The infant mortality rate for SUDI in 2014 was the lowest rate since 2000. However, the total mortality rate reached a plateau from 2009-2010. This plateau reflects a rise in the mortality rate of neonates, which for 2010-2014 has returned to rates for 2000-2003.

Almost one third (14) of the 45 infants whose deaths were classified as SUDI in NSW were Aboriginal or Aboriginal and Torres Strait Islander children. Families with a child protection history have also been consistently over-represented in SUDI. In 2014, over one third of the families (17) of the 45 infants who died had a child protection history.

### **Explained and unexplained SUDI**

At the time of writing, information regarding cause of death was available for just over half (26) of the 45 infants who died suddenly and unexpectedly. Of the 26, seven deaths were explained; that is, a cause of death was identified. Explained causes of SUDI in 2014 included suffocation, pethidine toxicity, respiratory illness, infectious disease and congenital disorder.

In 19 cases, SUDI were unexplained – a cause of death was unable to be identified. On average, since 2000, a cause of death was able to be determined in only one quarter of SUDI. This is a rate well below what could be considered best practice in the investigation of SUDI. For example, Joint Agency Approaches to SUDI investigation have led to a cause of death being determined for approximately 40 percent of cases in England and Wales.

### **SUDI Prevention measures and the Team's recommendations**

The Team has identified a range of risk and protective factors for SUDI:

- In 2014, almost all of the infants (43) who died suddenly and expectedly were in a sleep environment. The Team's work highlights the need for ongoing education about safe sleeping.
- A thorough and complete investigation of the circumstances surrounding SUDI is critical to establishing, wherever possible, the cause of death. This is critical for families, and for learning to help prevent future deaths.
- It is important to target high risk populations. Infants from Aboriginal and Torres Strait Islander families, and those from families with a child protection history, are at increased risk of SUDI.

The Team's recommendations for 2015 include:

- NSW Health should review the policy directive Newborn Infants with Respiratory Maladaptation to Birth Observation and Management
- FACS and NSW Health should jointly consider initiatives in other jurisdictions that specifically target high risk populations, with a view to considering their applicability to NSW
- NSW Health should provide advice to the Team on the findings of the review *Death Management of Sudden Unexpected Death in Infancy* policy directive, and any action intended as a result of the review
- FACS should provide advice to the Team on recommendations arising from its review of SUDI, which was completed in 2014.

# External cause (injury-related) deaths

The mortality rate for external cause deaths in 2014 of 4.75 per 100,000 children represents the lowest rate since the Team began in 1996.

### **Transport fatalities**

The deaths of 23 children resulted from transport incidents:

- over half (13) of the children died in motor vehicle incidents. All of these occurred on a public road
- nine children died after being struck by a vehicle. Eight children were on foot and one child was riding a bicycle
- one child was a passenger in a light plane.

Over the 15 years to 2014, 711 children have died in transport-related incidents in NSW. The rate of death of children from transport fatalities has declined by 73 percent between 2000 (5.1 per 100,000 children) and 2014 (1.37 per 100,000 children).

### Contributing factors in fatalities involving children as drivers, riders and passengers

Speeding, fatigue and alcohol are key contributing factors in road fatalities and casualties in NSW. In the majority (12) of the 13 passenger, driver and rider fatalities, police determined that driver factors had contributed to the collisions. Of the 12 drivers considered by police to be at fault, seven had relevant driving histories with NSW Police.

The most common driver-related factors were speeding, being substance-affected, and inexperience. The other main driverrelated contributing factors included fatigue, unroadworthy tyres and reckless driving.

### **Pedestrians and cyclists**

Five children were struck by a vehicle travelling at speed. Four children were struck by a vehicle travelling at less than 10km per hour; a 'low speed vehicle run-over'. Police determined that intermittent supervision of the child, restricted vision from the vehicle, and inattention on the part of the driver contributed to the low speed vehicle run-over fatalities.

### Key issues arising from reviews and prevention measures

Reviews of transport deaths registered in 2014 highlighted:

- the contribution of unsafe driver behaviours to transport fatalities, in particular speeding and drivers being affected by drugs or alcohol while driving
- the importance of appropriate use of child restraints, given the number of fatal collisions where children were either not restrained or not restrained appropriately
- the proportion of older vehicles involved in the collisions, noting their lack of advanced safety features compared to more recently manufactured vehicles
- the importance of close and constant adult supervision when small children are around vehicles
- a history of driving infringements or offences for over half of the at fault drivers.

# Deaths due to suffocation and other threats to breathing

In 2014, 10 children died from unintentional asphyxia, broadly defined as any condition that leads to oxygen deprivation in the human body. The deaths occurred in sleep-related circumstances, as a result of choking on food, accidental strangulation, and suffocation after becoming trapped in a confined space.

In 2014, two children died from accidental strangulation involving blind cords fitted close to their cots.

Key prevention messages relating to the dangers of blond cords include:

- keep children away from all cords move furniture, cots and beds away
- check all blind and curtain cords to make sure they are out of the reach of children
- make loose cords safe by using safety devices or cutting the cord loop.

# Drowning

The deaths of nine children were attributed to drowning.

After transport fatalities and accidental threats to breathing (asphyxia), drowning constituted the third leading unintentional injury-related cause of death of children in NSW.

Four children drowned in natural bodies of water, including beaches (2), an inland river and a lake. Two children drowned in private swimming pools, and one child died as a result of injury from near-drowning in a swimming pool eight years previously. One child drowned in a dam, and one child in a bath.

### Trends in drowning deaths of children

Over the 15 years to 2014, the drowning deaths of 245 children were registered in NSW. The largest proportion of drowning deaths occurred in private swimming pools (44%), followed by natural inland bodies of water (16%), bathtubs (14%) and coastal waters (13%).

The mortality rate of children from drowning has declined between 2000 and 2014. The average mortality rate of 0.77 deaths per 100,000 children for the five-year period 2010 to 2014 is lower than the previous five-year periods of 2005-2009 (0.95 per 100,000 children), and 2000-2004 (1.32 per 100,000 children). The decline is overall, and is not attributable to any one circumstance.

### Drowning prevention measures and the Team's recommendations

In line with the Team's findings over a number of years, key prevention messages to parents/carers about drowning risks should reinforce that:

- Supervision of young children in and around water must be constant and active, with supervisory responsibility clearly and appropriately designated.
- If safety barriers are not effectively child-resistant, even momentary lapses in supervision or diverted attention can result in a drowning death.
- Environmental conditions in and around waterways can change rapidly and it is critical that young people and carers of younger children are alert to, and constantly assess, potential dangers and actively supervise children at all times.

### 2015 review of swimming pool barrier requirements

Significant amendments to the *Swimming Pools Act 1992* came into effect in October 2013. These introduced requirements for registration of private swimming pools, and a compliance and inspection regime. Inspections to date indicate that over 90 percent of pools are non-compliant at first inspection.

In July 2015, the Minister for Local Government announced a new regulatory review of swimming pool legislation, in part due to the high level of non-compliance with barrier requirements. The review aims to 'simplify the regulatory framework and encourage greater barrier compliance in order to reduce the incidence of child drownings and near-drownings in private pools'.

The Team agrees with the need for simple, targeted and effective regulation of swimming pools in NSW. In relation to barrier requirements and inspections, the Team's recommendations in recent years have focused on the need for:

- councils to be able to identify properties with swimming pools where young children reside or regularly visit, in order to target or prioritise those premises for inspection
- guidance / model policies for councils to provide for consistency, and to assist them develop and effectively target inspection programs
- annual and public reporting by councils on: the number of inspections; compliance with the *Swimming Pools Act*; orders issued by councils to rectify non-compliance; and whether or not owners have rectified defects within a reasonable period of time, and
- guidance for child protection staff working with vulnerable families to identify drowning risks to young children, including compliance with the Swimming Pools Act.

The Team notes that the review will examine an enforcement framework, including consideration of the Team's recommendations.

# Suicide

### Trends in suicide deaths

The deaths of 22 children and young people were due to suicide, and suicide was the leading external cause of death for children and young people aged 10-14 and 15-17 years. 2014 represents the largest annual number and highest rate of suicide of children and young people since 2000, largely accounted for by a suicide cluster. However, since 2000, there has been no significant change in the suicide mortality rate.

The majority (84%) of young people who died by suicide between 2000 and 2014 were aged 15 years or older; 17-year olds represented over one third of all suicide deaths. Aboriginal and Torres Strait Islander children and young people represented seven percent of all children and young people (17) who died by suicide over that 15-year period.

### Key issues arising from reviews

Suicide is a complex phenomenon generally resulting from a combination of several individual, social and contextual risk factors. Suicide can result from interactions between risk factors across a person's life span.

Reviews of suicide deaths in 2014 identified:

- young people did not always communicate that they needed help, and those that did approached different people in their lives through a range of avenues
- young people often told their friends about their thoughts of self-harm or intent to suicide
- it was not always evident to family, schools or other professionals that a young person was at risk
- effective responses to self-harm and suicide attempts are critical 17 of the 22 young people who died by suicide in 2014 had a history of self-harm, and nine had previously attempted suicide
- many of the young people were receiving support and assistance through a number of avenues. In some cases, this appeared to be well-coordinated; in others, there appeared to be minimal coordination between different support providers.

### Suicide prevention measures and the Team's recommendations

The Team has identified the importance of:

- Ensuring effective postvention programs in schools, and assertive strategies to target young people who have experienced the suicide death of a family member or friend
- Effective identification of, and response to:
  - self-harm and attempted suicide in young people
  - problematic substance use in the context of mental health concerns in young people
- possible contagion, particularly where young people communicate about suicide via electronic media
- The need to ensure coordination of support provided to young people at risk of suicide

- The need for appropriate referral and follow-through for young people at risk of suicide:
  - ensuring school counsellors refer appropriately to specialist mental health services
  - strategies for assertive outreach where there is lack of follow-through by families

There are a number of significant initiatives underway in relation to mental health and suicide prevention in NSW. These include the NSW Mental Health Commission's Living Well – a strategic plan for mental health in NSW 2014-2024 and a number of strategies being implemented by the Department of Education, including development of a postvention resource for schools.

The Team will monitor developments in these and other areas relating to youth suicide prevention against the background of the implementation of the Strategic Plan for Mental Health in NSW.

# **Abuse-related deaths**

The deaths of nine children registered in NSW in 2014 were the result of abuse or alleged abuse; a rate of 0.53 per 100,000 children.

All abuse-related deaths of children and young people are reviewable by the NSW Ombudsman. The Ombudsman reports biennially on reviewable deaths, and the deaths considered in this chapter will be the subject of further analysis by the Ombudsman.

### Factors associated with fatal abuse and prevention measures

The NSW Ombudsman has identified a number of specific contexts within which abuse-related deaths occurred over the decade to 2013:

- In a child abuse context, including cases where there was evidence of prior abuse
- Murder-suicide, with common factors including mental health issues and current or recent family breakdown
- · Where the perpetrator experienced a psychotic episode at the time of the incident
- Where harm was not the intention of an action, primarily where drugs were administered to pacify or sedate children.

The Ombudsman, through reports of reviewable deaths, has made recommendations to government agencies relating to the identification of, and response to, children and families at risk. Most recently, recommendations have included those addressing identification of risk by agencies, and better and more timely information exchange and collaboration between agencies.

# **Child Death Review Team: Annual Report to Parliament 2014-15**

The legislation requires the Team to report to the NSW Parliament on its activities.

The work of the Team for the year ending 30 June 2015 has included:

- convening four formal meetings in 2014-15. Smaller sub-committees of the Team, including the Sudden Unexpected Death in Infancy sub-committee, have met on other occasions
- finalising a review of asthma-related deaths of children and completing the Child Deaths Annual Report 2013
- developing and commissioning projects on deaths from infectious disease, and a scan of childhood injury and disease prevention infrastructure in NSW
- participation in a range of injury prevention initiatives, and
- pursuit of strategies to improve the capacity of the Team to contribute to the prevention of child deaths, including:
- implementing the new child death register
- liaison with injury prevention groups
- negotiating legislative change to enable the Team to report on a biennial basis, in order to achieve consistency between the child death review functions of the Team and those of the Ombudsman, and to increase the opportunity for the Team to progress specific strategies to prevent child deaths.

# **Recommendations**

# Asthma

- As auspice agency of the cross-sectoral working party that has been established to identify strategies for improving school-based support to children with asthma and their families, **NSW Health** should provide detailed advice to the Team on the outcomes of the working party, including any action taken to develop a standard asthma action plan for use in schools.
- 2. **NSW Health** should consider the Team's review of asthma deaths 2004-2013 in relation to post-hospitalisation followup of children with asthma, and provide detailed advice to the Team on the adequacy of processes within Health for:
  - a) identifying children/families who may require more assertive follow-up and asthma education
  - b) facilitating active follow-up of these children/families, and
  - c) monitoring practice and related outcomes in relation to acute management by health services of asthma in children, including links to follow-up support.

# **Sudden Unexpected Death in Infancy**

- 3. **NSW Health** should review the policy directive *Newborn Infants with Respiratory Maladaptation to Birth Observation and Management*, with a view to updating procedures to reflect contemporary observation and monitoring standards for potential opiate overdose.
- 4. The Department of Family and Community Services (FACS) and NSW Health should jointly consider initiatives in other jurisdictions that specifically target high risk populations, with a view to considering their applicability to NSW. This should include consideration of the findings emerging from safe sleep pod programs in New Zealand and Cape York.
- 5. In relation to the review of the *Death Management of Sudden Unexpected Death in Infancy* policy directive and model of response to SUDI, **NSW Health** should provide advice to the Team on:
  - a) the findings of the review, including the outcomes of consideration of the potential for NSW to adopt a more centralised response to SUDI, and a multidisciplinary case review approach to the SUDI investigation process, and
  - b) any action NSW Health intends to take in response to the findings.
- 6. In relation to the promotion of safe sleeping practices, **NSW Health** should provide detailed advice to the Team on:
  - a) the outcome of the audits conducted by Local Health Districts to assess compliance with the Maternity Safer Sleeping Practices for Babies in NSW Public Health Organisations policy directive. The advice should include NSW Health's assessment of:
    - (i) the adequacy of the audits, including the scope and method (such as the use of spot checks)
    - (ii) the findings of the audits regarding compliance with the policy requirements, and
    - (iii) whether there are any systemic issues identified by the audits and, if so, the actions **NSW Health** will take in response.
  - b) the progress of **NSW Health**'s work with SIDS and Kids to review Health's *Sudden Infant Death Syndrome* (*SIDS*) *and safe sleeping for infants* guidelines and provide guidelines to community-based staff.

- 7. In relation to post-mortem examinations following unexpected deaths of infants, **NSW Health** should provide to the Team:
  - a) a copy of the plan developed by the Paediatric Histopathology Working Party to address key issues relating to perinatal and infant post-mortems, and
  - b) advice about progress in implementing the plan.
- 8. In relation to **FACS**' cohort review of SUDI where the infant's family had a child protection history, the agency should provide advice to the Team on:
  - a) progress in the development and publication of an online training package on SUDI
  - b) delivery of training to FACS field staff in relation to work with culturally and linguistically diverse families
  - c) the findings of any audit of training delivery (as above)
  - d) the outcome of discussions between the Office of the Senior Practitioner and the Helpline relating to the current Structured Decision Making tool to better support Helpline staff in identifying risk
  - e) the outcome of meetings with **NSW Health** to establish consistent cross-agency messages on safe sleeping and barriers to this.

# **House fires**

9. Against the background of the high proportion of children with a child protection history who were among those who have died in house fires in the last 10 years; the high proportion of these fires having been started by children playing with matches/lighters; and the previous recommendations of the NSW Coroner, FACS and Fire & Rescue NSW should provide advice to the Team on actions taken, or planned, to reduce fire risks to children with a child protection history.

# **Chapter 1. Introduction**

# 1.1 The NSW Child Death Review Team: role and functions

Since 1996, the NSW Child Death Review Team ('the Team') has been responsible for reviewing and reporting on all deaths of children<sup>2</sup> in NSW.

The Team is required by the *Community Services (Complaints, Reviews and Monitoring) Act* 1993 (CS CRAMA) to prepare two reports, which are presented here together:

- An annual child death review report, consisting of data collected and analysed in relation to child deaths registered in the previous calendar year (section 34G).
- An annual report on the Team's activities, including the extent to which previous recommendations have been accepted (section 34F). This is at chapter 12.

This is the Team's 19th report, providing information on 485 children and young people whose deaths were registered in NSW in 2013.

The Team is established under Part 5A of CS CRAMA for the purpose of preventing and reducing the likelihood of child deaths in NSW.

The Team consists of the NSW Ombudsman (Convenor); the Advocate for Children and Young People; the Community and Disability Services Commissioner; representatives of certain NSW government agencies; experts in health care, research methodology, child development or child protection, or persons who are likely to make a valuable contribution to the work of the Team; and two members who are Aboriginal. The current members of the Team are listed above.

The functions of the Team are to:

- maintain a register of child deaths occurring in NSW
- classify deaths in the register according to cause, demographic criteria and other relevant factors, and to identify trends and patterns relating to those deaths
- undertake, alone or with others, research that aims to help prevent or reduce the likelihood of child deaths, and to identify
  areas requiring further research, and
- make recommendations as to legislation, policies, practices and services for implementation by government and non-government agencies and the community to prevent or reduce the likelihood of child deaths.

The Team is supported and assisted in the exercise of its functions by staff of the Ombudsman's office.

# 1.2 Reviewable child deaths

Separate to the functions of the CDRT, the Ombudsman reviews 'reviewable' child deaths; children who die as a result of abuse or neglect, or in suspicious circumstances, and children who die while in care.

This report includes information about the deaths of children that are reviewable by the Ombudsman.

The most recent report of reviewable child deaths is available at: http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1

# 1.3 Child deaths in 2014: Methodology

The methodology and definitions used in this report are detailed in the appendices.

The information in this report is drawn from the NSW Child Death Register, which is maintained by the Team. The register holds demographic, cause of death, and other relevant information about the children who have died in NSW.

Percentages in the report have been rounded, so may not add to 100.

<sup>2</sup> For the purposes of the Child Death Review Team, a child is a person under the age of 18 years.

# **Cause of death**

At the time of writing, information about the cause of death was available for 461 of the 485 children who died in 2014 (95%).<sup>3</sup>

Reporting of cause of death in this report is by the International Statistical Classification of Diseases and Related Health Problems (ICD) system. The ICD is the international standard health classification published by the World Health Organisation (WHO), and is 'designed to promote international comparability in the collection, processing, classification, and presentation of causes of death statistics.<sup>4</sup> The report presents information by the classification chapters of the ICD system, 10th revision, as modified for Australia (ICD-10-AM). The sources for coding of cause of death are medical certificates of cause of death and, in the case of deaths that are examinable by the Coroner, autopsy reports and coronial certification of cause of death.

Analysis of cause of death in this report relates primarily to underlying cause of death, which is defined as 'disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury'.<sup>5</sup> Historically, and from national and international perspectives, the concept of underlying cause of death is considered the most critical factor for public health reporting purposes in annual mortality statistics.<sup>6</sup>

Where underlying cause of death is the basis for the analysis below, it relates to 461 children.

# Identifying and reporting Aboriginal and Torres Strait Islander status

Since 2012, the Team has used a consistent approach to identifying Aboriginal and Torres Strait Islander status:

- If children are identified as Indigenous in either their death or birth registrations, or their parent(s) are identified as Indigenous in birth registration data, they are coded as Indigenous. If the child is identified as Indigenous in the Perinatal Data Collection only, then the child's case is reviewed before it is coded as Indigenous.
- If the child is not identified as Indigenous in either BDM or perinatal data, but is identified as such in at least one other data source, such as police, coronial, health, or other records, then the child is coded as Indigenous.

Information about Indigenous status for 2014 is based on this approach. However, information relating to trends in the deaths of Aboriginal and Torres Strait Islander children is based on identification of Indigenous status in data from the Registry of Births, Deaths and Marriages (BDM) only. This is because variability in the methods and data sources over the past decades has impeded the Team's ability to accurately report trends, if drawing on sources other than BDM.<sup>7</sup> As such, the trend figures do not include all Aboriginal and Torres Strait Islander child deaths identified by the Team during the relevant period.

Appendix 1 includes a data quality statement, indicating the quality of Indigenous identification from the source data set; and a report on the numbers of children identified using different data sets.

# **Rates of death**

Unless otherwise stated, mortality rates used in this report are Crude Mortality Rates. This is the rate per 100,000 persons (for this report, persons are all those aged under 18 years). Rates are not calculated for numbers less than four because of lack of reliability.

Where discussion is exclusively related to infants,<sup>8</sup> Infant Mortality Rate is used. This is the rate of death per 1,000 live births.

A number of tables use a Directly Standardised Mortality Rate. This is the rate per 100,000 children under 18 years of age, adjusted for the age structure of the population.

# **Report structure**

Chapter 2 is an overview of the deaths of children in 2014, and analysis of relevant trends.

Chapter 3 examines child deaths from natural causes.

Chapter 4 provides information on infectious diseases in childhood.

Chapter 5 is a detailed review of Sudden Unexpected Death in Infancy.

Chapters 6 to 11 present information on child deaths from injury-related causes.

Chapter 12 is the Team's annual report to Parliament, including an assessment of the implementation of recommendations made previously by the Team.

<sup>3</sup> This includes findings of unascertained cause of death.

<sup>4</sup> Australian Bureau of Statistics (2014), 3303.0 Causes of Death, Australia, 2012 (Explanatory Notes), March 2014 release. ABS: Canberra.

<sup>5</sup> World Health Organisation (2008), International Statistical Classification of Diseases and Related Health Problems, 10th revision. WHO: Geneva.

<sup>6</sup> National Centre for Health Information Research and Training (2011), *Review and recommendations for the annual reporting of child deaths in NSW*, prepared for the NSW Ombudsman, unpublished.

<sup>7</sup> Australian Institute of Health and Welfare (2013), Identification and Reporting of Aboriginal and Torres Strait Islander Children by the NSW Child Death Review Team, advisory report prepared for the NSW Ombudsman, unpublished.

<sup>8</sup> Infancy is the period from birth to less than 12 months of age.

# Chapter 2. The deaths of children in NSW: 2014

### **Key facts:**

- The deaths of 485 children were registered in NSW in the period 1 January 2014 to 31 December 2014, representing a
  directly standardised mortality rate<sup>9</sup> of 28.41 deaths per 100,000 children. This is the second lowest annual rate since 2000.
- There has been a continual and significant decline in infant and child mortality rates over the 15 years to 2014.
- Of the 485 children who died, 254 were male and 231 were female.
- The majority of children who died were very young:
  - Almost two thirds (296; 61%) of the children were infants aged less than 12 months
  - Three quarters (353; 73%) of the children who died were under five years old.
- The mortality rate for Aboriginal and Torres Strait Islander children in 2014 was 2.6 times the mortality rate for non-Indigenous children.
- Most children for whom cause of death was available died as a result of natural causes (78 percent):
  - The leading natural cause of death for infants was conditions arising in the perinatal period (late pregnancy, birth and the first 28 days of life). Fifteen percent of infant deaths were Sudden Unexpected Death in Infancy.
  - The leading natural cause of death for children in all other age groups was cancers and tumours.
- Almost one in five children (80) died as a result of injury. Of these deaths, almost two thirds (49) were due to unintentional injury. The deaths of 31 children were intentional; 22 were due to suicide and nine occurred in circumstances of abuse:
  - The leading injury-related cause of death for infants was assault.
  - Suicide was the leading injury-related cause of death for children and young people aged 10-14 and 15-17 years.
  - Transport fatalities were the leading injury-related cause of death for children aged 1-4 years and for those aged 5-9 years, transport was the equal leading cause with drowning.

### How does NSW compare?

In 2012, NSW had the third lowest rate of child deaths in Australia and New Zealand, and the lowest rates of death for children aged 1-4 and 10-14 years (table 14).<sup>10</sup>

# 2.1 Deaths of children in NSW: 2014 and trends

The deaths of 485 children were registered in NSW in the period 1 January 2014 to 31 December 2014, representing a directly standardised mortality rate<sup>11</sup> of 28.41 deaths per 100,000 children. This is the second lowest annual rate since 2000.

As shown in table 1, there has been a continual and significant decline in the rate of child deaths in NSW over the 15 years to 2014.

10 Table 14 draws on information about children who died in 2012 in Australian states and territories and New Zealand. It is reproduced from the Queensland *Family and Child Commission's Annual Report – deaths of children and young people 2013-2014*. Note that 2012 is the most recent information available and crude mortality rates were not reported for Tasmania and the Australian Capital Territory.

The directly standardised mortality rate is deaths per 100,000 people under 18 years of age, adjusted for the age structure of the population.
 Table 14 draws on information about children who died in 2012 in Australian states and territories and New Zealand. It is reproduced from the

<sup>11</sup> The directly standardised mortality rate is deaths per 100,000 people under 18 years of age, adjusted for the age structure of the population.

### Table 1: Deaths of children from all causes – deaths registered, 2000-2014

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval	Directly Standardised Mortality Rate	95% Confidence Interval
2000	1591513	753	47.31	43.93 - 50.69	47.15	43.78 - 50.52
2001	1601789	715	44.64	41.37 - 47.91	44.64	41.37 - 47.91
2002	1600107	636	39.75	36.66 - 42.84	40.16	37.04 - 43.28
2003	1594914	645	40.44	37.32 - 43.56	40.64	37.50 - 43.77
2004	1589345	617	38.82	35.76 - 41.88	39.00	35.92 - 42.08
2005	1588682	668	42.05	38.86 - 45.24	41.87	38.70 - 45.05
2006	1591812	630	39.58	36.49 - 42.67	38.58	35.57 - 41.59
2007	1602269	597	37.26	34.27 - 40.25	35.22	32.40 - 38.05
2008	1612212	607	37.65	34.65 - 40.65	35.43	32.61 - 38.25
2009	1623266	580	35.73	32.82 - 38.64	33.42	30.70 - 36.14
2010	1635207	590	36.08	33.17 - 38.99	33.79	31.06 - 36.52
2011	1641477	582	35.46	32.58 - 38.34	33.93	31.17 - 36.68
2012	1655685	493	29.78	27.15 - 32.40	28.14	25.65 - 30.62
2013	1670997	567	33.93	31.14 - 36.72	31.92	29.29 - 34.54
2014	1682684	485	28.82	26.26 - 31.39	28.41	25.89 - 30.94

The following table describes the demographic characteristics of the 485 children whose deaths were registered in 2014.

Table 2: Key demographic and individua	I characteristics – deaths registered, 2014
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	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio <sup>12</sup>	<b>p</b> <sup>1</sup>
Total	485	100	28.82	26.26 - 31.39	-	-
Gender						
Female	231	48	28.26	24.61 - 31.90	-	-
Male	254	52	29.36	25.75 - 32.97	1.0	0.67
Age						
Under 1 year	296	61	319.38 (IMR = 2.95)†	283.00 - 355.77	-	-
1-4 years	57	12	14.50	10.98 - 18.79	-	-
5-9 years	41	8	8.64	6.20 - 11.73	-	_
10-14 years	38	8	8.47	5.99 - 11.62	-	-
15-17 years	53	11	19.36	14.50 - 25.32	-	-
Aboriginal and Torres Strait Islander sta	itus					
Aboriginal or Torres Strait Islander	63	13	68.87	52.92 - 88.12	2.6	0.00
Not Aboriginal or Torres Strait Islander	422	87	26.52	23.99 - 29.05	-	-
Remoteness*						
Major cities	349	72	28.49	25.50 - 31.48	-	-
Inner regional areas	100	21	30.07	24.18 - 35.97	-	-
Outer regional areas	29	6	27.64	18.51 - 39.70	-	-
Remote areas	5	1	67.28	21.84 - 157.00	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	72	15	18.75	14.67 - 23.61	-	-
Quintile 4	60	12	20.78	15.86 - 26.75	-	-
Quintile 3	77	16	26.62	21.01 - 33.27	-	-
Quintile 2	101	21	31.69	25.51 - 37.88	-	-
Quintile 1 (lowest)	169	35	43.41	36.87 - 49.96	-	_

\*Remoteness was not calculated in 2 cases

\*\*Socioeconomic status was not calculated in 6 cases

†Infant Mortality Rate14

# 2.2 Age and gender

The proportion of deaths in each age group in 2014 is consistent with previous years, with infants accounting for close to two thirds of all child deaths in NSW.

Mortality rates for children in each age group are not significantly different from 2013, and have not changed substantially in recent years. The rate of death for all causes also followed a similar pattern to previous years. That is, mortality rates decreased in the 5-9 and 10-14 year age groups before rising again in the 15-17 year age group.

As shown in tables 3 and 4 below, mortality rates for both male and female children have declined over the last 15 years (from 54.69 to 29.36 for males and from 39.56 to 28.26 for females). The mortality rate for male children in 2014 (29.36 per 100,000 children) was the lowest in 15 years, while the mortality rate for female children (28.26 per 100,000 children) represented the second lowest over the same period. The lowest rate for female children was in 2012.

<sup>12</sup> The Incident Rate Ratio is the ratio of the mortality rates for two exclusive classes of people, such as male and female (see Appendix 1).

<sup>13</sup> The *p*-value is a quantitative measurement of the likelihood that a statistic occurred by chance. All *p*-values noted in this report are statistically significant (see Appendix 1).

<sup>14</sup> The Infant Mortality Rate is the rate of death per 1,000 live births.

Mortality rates for male children have been consistently higher than the rate for females over time. However, male mortality rates have been declining faster than female mortality rates. The difference in male and female standardised mortality rates have reduced – from 15.4 in 2000 to 1.2 in 2014. Since 2011, female mortality rates appear to have plateaued while male mortality rates have continued to decline.

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval	Directly Standardised Mortality Rate	95% Confidence Interval
2000	815442	446	54.69	49.62 - 59.77	54.71	49.63 - 59.79
2001	821353	410	49.92	45.09 - 54.75	49.92	45.09 - 54.75
2002	820192	372	45.36	40.75 - 49.96	45.93	41.26 - 50.60
2003	817513	362	44.28	39.72 - 48.84	44.62	40.02 - 49.21
2004	814752	343	42.10	37.64 - 46.55	42.34	37.86 - 46.82
2005	814880	390	47.86	43.11 - 52.61	47.67	42.94 - 52.40
2006	816277	385	47.17	42.45 - 51.88	46.25	41.63 - 50.87
2007	822163	333	40.50	36.15 - 44.85	38.42	34.29 - 42.54
2008	827582	364	43.98	39.47 - 48.50	41.78	37.48 - 46.07
2009	833860	339	40.65	36.33 - 44.98	38.32	34.25 - 42.40
2010	840132	362	43.09	38.65 - 47.53	40.62	36.43 - 44.80
2011	843998	327	38.74	34.54 - 42.94	37.31	33.27 - 41.35
2012	851639	293	34.40	30.46 - 38.34	32.55	28.82 - 36.27
2013	859298	313	36.43	32.39 - 40.46	34.43	30.61 - 38.24
2014	865191	254	29.36	25.75 - 32.97	29.02	25.45 - 32.59

### Table 3: Deaths of male children from all causes, 2000-2014

### Table 4: Deaths of female children from all causes, 2000-2014

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval	Directly Standardised Mortality Rate	95% Confidence Interval
2000	776071	307	39.56	35.13 - 43.98	39.27	34.87 - 43.66
2001	780436	305	39.08	34.69 - 43.47	39.08	34.69 - 43.47
2002	779915	264	33.85	29.77 - 37.93	34.10	29.99 - 38.21
2003	777401	283	36.40	32.16 - 40.64	36.45	32.20 - 40.70
2004	774593	274	35.37	31.18 - 39.56	35.49	31.29 - 39.70
2005	773802	278	35.93	31.70 - 40.15	35.78	31.57 - 39.98
2006	775535	245	31.59	27.64 - 35.55	30.61	26.77 - 34.44
2007	780106	264	33.84	29.76 - 37.92	31.84	28.00 - 35.69
2008	784630	243	30.97	27.08 - 34.86	28.79	25.17 - 32.41
2009	789406	241	30.53	26.67 - 34.38	28.30	24.72 - 31.87
2010	795075	228	28.68	24.95 - 32.40	26.64	23.19 - 30.10
2011	797479	255	31.98	28.05 - 35.90	30.37	26.64 - 34.10
2012	804046	200	24.87	21.43 - 28.32	23.49	20.24 - 26.75
2013	811699	254	31.29	27.44 - 35.14	29.29	25.69 - 32.90
2014	817493	231	28.26	24.61 - 31.90	27.77	24.19 - 31.36

# 2.3 Aboriginal and Torres Strait Islander status

# Deaths of Aboriginal and Torres Strait Islander children in 2014

In 2014, 63 children (13%) whose deaths were registered in NSW were identified as Aboriginal and/or Torres Strait Islander.<sup>15</sup> The mortality rate for Aboriginal and Torres Strait Islander children and young people in NSW was not significantly different from previous years.

However, as has also been the case over time, there was a significant difference in mortality rates between Indigenous and non-Indigenous children. The mortality rate for Aboriginal and Torres Strait Islander children (68.87 deaths per 100,000 children) in 2014 was 2.6 times the mortality rate for non-Indigenous children.

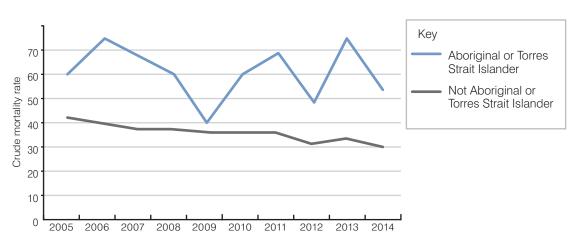
# Trends in deaths of Aboriginal and Torres Strait Islander children in 2014

Nationally, mortality rates for Aboriginal and Torres Strait Islander children recorded a significant decline between 1998 and 2012, particularly for infants, with the national infant mortality rate for Aboriginal and Torres Strait Islander children decreasing by more than half over this period (from 14 to 5 per 1,000 live births).<sup>16</sup>

As detailed in chapter 1, information relating to trends in the deaths of Aboriginal and Torres Strait Islander children is based on identification of Indigenous status in data from the Registry of Births, Deaths and Marriages (BDM) only. This is because variability in the methods and data sources over the past decades has impeded the Team's ability to accurately report trends, if drawing on sources other than BDM.<sup>17</sup> As such, the trend figures do not include all Aboriginal and Torres Strait Islander child deaths identified by the Team during the relevant period.

The NSW Child Death Register shows that over the past 15 years, and limited to BDM identification of Indigenous status, mortality rates for Aboriginal and Torres Strait Islander children have varied considerably from year-to-year, as illustrated in figure 1 below.<sup>18</sup>

As is the case for all child deaths, the majority of the Aboriginal and Torres Strait Islander children whose deaths were registered between 2005 and 2014 were infants, comprising 67 percent of all deaths of Aboriginal and Torres Strait Islander children during the period. Children aged 1-4 years comprised 13 percent of the deaths of Aboriginal and Torres Strait Islander children, followed by young people aged 15-17 years (10%).



### Figure 1: Aboriginal and Torres Strait Islander status, comparative rates 2005-2014

<sup>15</sup> This is based on identification of Aboriginal or Torres Strait Islander status in either the child's death or birth registrations, or parent(s) birth registration, or other data sources, such as police, coronial, health, or other records. See chapter 1 for full details.

<sup>16</sup> Steering Committee for the Review of Government Service Provision (2014), Overcoming Indigenous Disadvantage: Key Indicators 2014. Productivity Commission, Canberra, p. 2.

<sup>17</sup> Australian Institute of Health and Welfare (2013), Advisory Report Identification and Reporting of Aboriginal and Torres Strait Islander Children by the NSW Child Death Review Team. NSW Ombudsman, unpublished.

<sup>18</sup> As detailed in chapter 1, trend information regarding the deaths of Aboriginal and Torres Strait Islander children is limited to identification of Indigenous status in Births, Deaths and Marriages data.

# 2.4 Remoteness and socioeconomic status<sup>19</sup>

In 2014, almost three quarters of the deaths of children in NSW occurred in major cities (349, 72%).

Consistent with previous years, the rate of death of children in remote areas in 2014 (67.28 per 100,000 children) was higher than mortality rates in both inner and outer regional areas, and over twice the rate in major cities.

Consistent with last year, over half (270, 56%) of the children whose deaths were registered in 2014 lived in areas of greatest socioeconomic disadvantage (quintiles 1 and 2). In 2014, the difference in mortality rates between children who lived in areas of greatest socioeconomic disadvantage (quintile 1) and those who lived in areas of least socioeconomic disadvantage (quintile 4 and 5) was significant.

# 2.5 Child protection history

The families of 101 children (21%) had a child protection history, a proportion that is consistent with previous years.<sup>20</sup>

Risk of significant harm reports were made to Community Services in relation to the child who died (56) or a sibling of the child (20). In addition, 25 children and/or their sibling(s) had been the subject of a report to a Child Wellbeing Unit (14), or a report to Community Services that did not meet the risk of significant harm threshold but related to concerns about risk (11).

Thirteen children were in care at the time of their death.21

# 2.6 Deaths of infants

As noted above, infants under the age of 12 months consistently represent the majority of child deaths in NSW. In 2014, the deaths of 296 infants were registered in NSW, accounting for 61 percent of all child deaths.

Consistent with national trends,<sup>22</sup> infant mortality rates in NSW have declined considerably over the past 15 years, to a low of 2.95 deaths per 1,000 live births in 2014.

Forty-five infants died suddenly and unexpectedly. The deaths of these children are examined in detail in chapter 5.

The table below provides an overview of the key demographic characteristics of the infants and their families.

<sup>19</sup> The indicator of the socioeconomic status of a child used in this report is the Index of Relative Social Disadvantage (IRSD) of the areas in which the child usually resided. Quintile 1 represents the relatively most disadvantaged 20%, and quintile 5 the relatively least disadvantaged 20%. Further information is provided in Appendix 1.

<sup>20</sup> A child is reported as being from a family with a child protection history if the child, or their sibling, had been the subject of a report of risk of harm or risk of significant harm to Community Services, or the subject of a report to a Child Wellbeing Unit, within the three years before the child's death.

<sup>21</sup> The definition of a 'child in care' is outlined in Appendix 2, and is consistent with the *Community Services (Complaints, Reviews and Monitoring)* Act 1993.

<sup>22</sup> Australian Bureau of Statistics (2014), 3302.0 – Deaths, Australia, 2013. ABS: Canberra.

Table 5: Key demographic and individual characteristics – deaths of infants from all causes in NSW, 2014
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	Number	Percent	Infant Mortality Rate	95% Confidence Interval	Incident Rate Ratio	p
Total	296	100	2.95	2.61 - 3.28		-
Gender						
Female	142	48	2.92	2.44 - 3.40	-	-
Male	154	52	2.97	2.50 - 3.44	1.0	0.90
Age						
Under 1 year	139	47	1.38	1.15 - 1.61	-	-
1 day – under 1 week	43	15	0.43	0.31 - 0.58	-	-
1 week – under 28 days	35	12	0.35	0.24 - 0.48	-	-
28 days – under 1 year	79	27	0.79	0.62 - 0.98	-	-
Aboriginal and Torres Strait Islander sta	tus					
Aboriginal or Torres Strait Islander	47	16	7.88	5.79 - 10.48	3.0	0.00
Not Aboriginal or Torres Strait Islander	249	84	2.63	2.31 - 2.96	-	-
Remoteness						
Major cities	220	74	2.84	2.46 - 3.21	-	-
Inner regional areas	63	21	3.81	2.93 - 4.87	-	-
Outer regional areas	10	3	1.90	0.91 - 3.49	-	-
Remote areas	3	1	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status*						
Quintile 5 (highest)	39	13	1.86	1.32 - 2.54	-	-
Quintile 4	36	12	2.05	1.43 - 2.83	-	-
Quintile 3	51	17	2.88	2.14 - 3.78	_	_
Quintile 2	59	20	2.96	2.26 - 3.82	-	-
Quintile 1 (lowest)	107	36	4.42	3.58 - 5.26	-	-

\*Socioeconomic status was not calculated in four cases

# Age, gender and Aboriginal and Torres Strait Islander status: infants

In 2014, almost three quarters of the infants (217, 73%) died during the neonatal period (less than 28 days).

As has consistently been the case, males outnumbered females among infant deaths in 2014, comprising just over half (154) of the infants who died. The table below shows that infant mortality rates for males have consistently been higher than for females over the 15 year period.

### Table 6: Infant deaths and mortality rates by gender, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	181	183	159	175	162	187	160	168	166	155	147	162	120	156	142
	(4.30)	(4.46)	(3.77)	(4.19)	(3.90)	(4.22)	(3.60)	(3.58)	(3.38)	(3.24)	(2.98)	(3.37)	(2.51)	(3.21)	(2.92)
Male	252	239	184	194	203	248	242	199	223	213	217	203	183	200	154
	(5.64)	(5.49)	(4.15)	(4.36)	(4.58)	(5.28)	(5.06)	(4.02)	(4.36)	(4.23)	(4.18)	(3.98)	(3.61)	(3.86)	(2.97)
Total	433	422	343	369	365	435	402	367	389	368	364	365	303	356	296
	(4.99)	(4.99)	(3.96)	(4.27)	(4.25)	(4.77)	(4.36)	(3.81)	(3.88)	(3.75)	(3.59)	(3.68)	(3.08)	(3.54)	(2.95)

As shown in table 5 above, of the 296 infants who died in 2014, 47 (16%) were identified as Aboriginal or Torres Strait Islander.<sup>23</sup>

23 This is based on identification of Aboriginal or Torres Strait Islander status in either the child's death or birth registrations, or parent(s) birth registration, or other data sources, such as police, coronial, health, or other records. See chapter 1 for full details.

In terms of trends, while there has been some fluctuation from year to year, Aboriginal and Torres Strait Islander infant mortality rates have decreased since 2000, from 14.71 to 6.37 per 1,000 live births in 2014 (table 7).<sup>24</sup>

Despite this, and as shown in table 7, differences in mortality rates between Indigenous and non-Indigenous infants over the 15-year period have been marked. In 2014, the infant mortality rate for Aboriginal and Torres Strait Islander infants (6.37 per 1,000 live births) was more than twice as high as the rate for non-Indigenous infants.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Aboriginal	44	27	32	34	28	35	40	46	34	17	38	37	27	45	38
Torres Strait Islander	(14.71)	(8.68)	(9.58)	(10.45)	(7.93)	(9.28)	(9.54)	(9.62)	(6.71)	(3.26)	(6.68)	(6.59)	(4.91)	(7.55)	(6.37)
Non- Aboriginal	389	394	311	329	337	398	359	321	354	341	326	328	276	311	258
Torres Strait Islander	(4.64)	(4.84)	(3.74)	(3.96)	(4.09)	(4.55)	(4.08)	(3.51)	(3.72)	(3.67)	(3.41)	(3.51)	(2.97)	(3.29)	(2.73)
unknown	0	1	0	6	0	2	3	0	1	10	0	0	0	0	0
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Total	433	422	343	369	365	435	402	367	389	368	364	365	303	356	296
	(4.99)	(4.99)	(3.96)	(4.27)	(4.25)	(4.77)	(4.36)	(3.81)	(3.88)	(3.75)	(3.59)	(3.68)	(3.08)	(3.54)	(2.95)

### Table 7: Infant deaths by Aboriginal and Torres Strait Islander status, 2000-2014

### Leading causes of infant death: neonatal and post-neonatal

As has consistently been the case, conditions arising in the perinatal period<sup>25</sup> comprised the leading cause of the deaths of infants in NSW in 2014, accounting for the deaths of 161 (54%) infants. Almost all of these deaths (154, 96%) occurred in the neonatal period (less than 28 days). Congenital and chromosomal conditions comprised the second leading cause of death of infants, accounting for the deaths of 61 infants (21%). Over three quarters of these deaths (44) occurred in the neonatal period.

While the leading cause of neonate deaths is perinatal conditions, the leading cause of the deaths of infants aged 28 days or older is Sudden Infant Death Syndrome (SIDS). This is highly consistent with previous years.

### Table 8: Top five causes of death: neonates and post-neonates, 2000-2014

Deaths of neonates (birth to <28 days)	N=3960	Percent
Certain conditions arising in the perinatal period	2822	71
Congenital malformations, deformations and chromosomal abnormalities	882	22
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	95	2
Endocrine, nutritional and metabolic disorders	33	1
Diseases of the nervous system	32	1
Deaths of post neonates (28 days to 365 days)	N=1617	Percent
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	521	32
Congenital malformations, deformations and chromosomal abnormalities	353	22
Certain conditions arising in the perinatal period	197	12
Diseases of the nervous system	121	7
External causes of morbidity and mortality	117	7

As trend analysis of the deaths of Aboriginal and Torres Strait Islander children is based on identification of Aboriginal and Torres Strait Islander status in BDM data only, the figures do not include all Aboriginal and Torres Strait Islander child deaths identified by the Team during the period.
 Perinatal conditions arise during pregnancy, or up to 28 days post-partum.

# 2.7 Leading causes of death by age group

At the time of writing, information about the cause of death was available for 461 of the 485 children who died in 2014 (95%).<sup>26</sup>

Natural causes of death accounted for the majority of deaths of children aged 0-14 years, and injury was the leading cause of death for young people aged 15-17. This has been consistent over time.

Table 9 shows the leading natural and external (injury-related) causes of death of children whose deaths were registered in 2014, by age group.

### Natural causes of death by age group

As noted, the leading natural cause of deaths for infants was conditions arising in the perinatal period.

The leading natural cause of death for children aged one year and older was neoplasms (cancers and tumours).

### Leading injury-related deaths by age group

External (injury-related) causes comprised the third leading cause of the deaths of all children in 2014 (80, 17%).

- The equal leading external causes of death of infants were assault and accidental threats to breathing. Drowning and accidental threats to breathing have been the leading external causes for this age group in recent years.
- Drowning has frequently been the leading external cause of death of children aged 1-4 years. By contrast, in 2014, transport incidents represented the leading external cause of death of children in this age group, as rates of drowning decreased slightly over the last two years.
- Transport incidents were also the equal leading cause of death (with drowning) of children in the 5-9 year age group.
- The leading external cause of death for children aged 10-14 years and 15-17 years was suicide. This is different to previous years where transport incidents have either been the leading or equal leading cause of death (with suicide) for young people.

	Total number of deaths	Percentage of total deaths (0-17 years)	Leading natural cause for age category	Leading external cause for age category
<1 year	296	61	Perinatal conditions (1.60 per 1000)†	Assault (0.03 per 100,000)
1-4 years	57	12	Neoplasms (3.05 per 100,000)	Transport (1.53 per 100,000)
5-9 years	41	8	Neoplasms (2.53 per 100,000)	Drowning/Transport (0.63 per 100,000)
10-14 years	38	8	Neoplasms (1.56 per 100,000)	Suicide (1.11 per 100,000)
15-17 years	53	11	Neoplasm (2.19 per 100,000)	Suicide (6.21 per 100,000)

### Table 9: Leading natural and external causes of death, number and rate, 2014

†Infant Mortality Rate

26 This includes findings of unascertained cause of death.

# 2.8 Underlying causes of death by ICD chapter

Table 10 describes the underlying causes of death for children in NSW in 2014 by chapters of the International Statistical Classification of Diseases and Related Health Problems (ICD) system, and Aboriginal and Torres Strait Islander status.

As noted, the leading cause of death for children in NSW in 2014 was perinatal conditions (161 children, 33% of all deaths). The third leading cause of death was congenital malformations, deformations and chromosomal abnormalities ('congenital/ chromosomal causes') (71 children, 15 % of all deaths). Taken together, these leading causes of death accounted for close to half of all child deaths registered in 2014. This is consistent with the Team's previous findings, and reflects the proportion of infants in all child deaths in previous years.

The second most common cause of death in children was 'external causes of mortality and morbidity' ('injury-related causes'), (80 children, 17%). Injury-related deaths tend to peak between the ages of one and three years, drop to a minimum at about nine years, and then rise steadily through the teenage years.

# Aboriginal and Torres Strait Islander children

For Aboriginal and Torres Strait Islander children, perinatal conditions were also the leading cause of death. However, injury was the second most common cause of death, being twice the number of congenital and chromosomal causes, and more than three times the rate for non-Indigenous children. This is consistent with previous years. The third most common cause of death for Aboriginal and Torres Strait Islander children was congenital and chromosomal causes.

# Table 10: Leading underlying causes of death by ICD chapter and Aboriginal and Torres Strait Islander status, number and rate, 2014

ICD chapter	All	children	Not Abo Torres Strait	riginal or Islander	Aboriginal Strait	or Torres Islander
Certain conditions arising in the perinatal period	161	(9.57)	139	(8.74)	22	(24.05)
External causes of morbidity and mortality	80	(4.75)	68	(4.27)	12	(13.12)
Congenital malformations, deformations and chromosomal abnormalities	71	(4.22)	65	(4.08)	6	(6.56)
Neoplasms	38	(2.26)	35	(2.20)	3	-
Diseases of the respiratory system	25	(1.49)	24	(1.51)	1	-
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	24	(1.43)	19	(1.19)	5	(5.47)
Diseases of the nervous system	22	(1.31)	17	(1.07)	5	-
Endocrine, nutritional and metabolic disorders	13	(0.77)	13	(0.82)	0	-
Diseases of the blood, blood-forming organs and certain disorders of the immune system	12	(0.71)	10	(0.63)	2	_
Diseases of the circulatory system	8	(0.48)	8	(0.50)	0	-
Certain infectious and parasitic diseases	6	(0.36)	6	(0.38)	0	-
Diseases of the genitourinary system	3	-	1	_	2	-
Diseases of the digestive system	1	_	1	_	0	_
Mental and behavioural disorders	1	_	1	_	0	_
Total		465		407		58

# 2.9 Multiple causes of death

Analysis of underlying cause is important because this is the point at which preventative actions may best be targeted. However, multiple cause data is also important for a more complete understanding of the association of diseases that contribute to deaths.<sup>27</sup> Multiple causes of death take into account all conditions recorded on a death certificate or coronial finding:

- *Direct cause of death*: the final condition or event that actually produces a death (for example, cardiac arrest or respiratory failure)
- Intervening causes of death: other conditions that may have given rise to the immediate cause of death
- Contributory causes of death: conditions or events that were present during the sequence leading to death, but may not have been necessary influences.

Multiple causes consider the associations between underlying, contributory, intervening and direct causes.

An example of the importance of considering multiple causes is death by drowning where epilepsy may have been a contributing factor. Epileptic seizures are known to be an important risk factor for drowning, and the appearance or omission of this factor can have a profound influence on any inference about risk factors, as most drowning deaths are unobserved. Another example is a death in which the direct cause is a respiratory condition, but the underlying cause is dysphagia (swallowing difficulties) in the context of a disability such as cerebral palsy. In such cases, acknowledging the contribution of the chronic disability by a case analysis of the multiple causes of death is the appropriate way to differentiate this from a respiratory death due to an acute condition.

Table 11 provides a cross-tabulation of causes of death for children whose deaths were registered in 2014. The table shows contributory causes against underlying causes. Table 10 provides this information for the 10-year period 2005-2014.

Some of the salient relationships to emerge from consideration of multiple causes of death for the 10-year period largely reflect the associations for children who died in 2014:

- Conditions arising in the perinatal period and congenital malformations or chromosomal abnormalities are often recorded together, with congenital or chromosomal causes tending to be recorded as the underlying cause of death when this occurs.
- Multiple perinatal causes of death were often recorded, with almost two thirds of these deaths having at least one additional perinatal cause of death as a contributory cause.
- About half of deaths having an underlying cause from the nervous system chapter include a contributory cause from the respiratory chapter. Respiratory conditions are common in children with long term nervous system disabilities such as cerebral palsy or muscular dystrophy. Respiratory conditions were also common in cases where the underlying cause of death was infectious or parasitic disease, disorders of the endocrine or metabolic system, or diseases of the circulatory system.
- As would be expected, the majority of deaths (three quarters) with an underlying external cause of death included at least one contributory cause relating to injury or poisoning.

<sup>27</sup> Australian Institute of Health and Welfare (2012), Multiple Causes of Death. Bulletin 105, AIHW: Canberra.

### Table 11: Underlying cause of death and contributory causes of death, 2014

Underlying cause of death (ICD-10 chapter)	No. of cases	Infectious and Parasitic (A00-B99)	Neoplasms (C00 - D48)	Blood, Blood Forming Organs (D50-D89)	Endocrine, Nutritional, Metabolic (E00-E90)	Mental & Behavioural Disorders (F00 -F99)	Nervous System (G00-G99)	Eye and Adnexa (H00-H69)
Certain infectious and parasitic diseases (A00-B99)	6	3	-	-	1	-	-	-
Neoplasm (C00-D48)	38	2	4	2	-	3	6	-
Diseases of the blood, blood-forming organs and certain disorders of the immune system (D50-D89)	12	3	1	2	-	-	2	1
Endocrine, nutritional and metabolic disorders (E00-E90)	13	-	-	-	1	1	3	-
Mental and behavioural disorders (F00-F99)	1	1	-	-	-	1	-	-
Diseases of the nervous system (G00-G99)	22	1	-	-	1	3	8	-
Diseases of the eye and adnexa (H00-H59)	0	-	-	-	-	-	-	-
Diseases of the ear and mastoid process (H60-H95)	0	-	-	-	_	-	-	-
Diseases of the circulatory system (I00-I99)	8	-	-	-	_	1	-	-
Diseases of the respiratory system (J00-J99)	25	5	-	-	1	2	9	-
Diseases of the digestive system (K00-K93)	1	1	-	-	-	-	-	-
Diseases of the skin and subcutaneous tissue (L00-L99)	0	-	-	-	-	-	-	-
Diseases of the musculoskeletal system and connective tissue (M00-M99)	0	-	-	-	-	-	-	-
Diseases of the genitourinary system (N00-N99)	3	1	-	-	1	1	-	-
Pregnancy, childbirth and the puerperium (O00-O99)	0	-	-	-	-	-	-	-
Certain conditions arising in the perinatal period (P00-P96)	161	5	-	-	1	-	2	-
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	71	2	-	-	1	2	4	-
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	24	-	-	-	-	-	-	-
Injury, poisoning and certain other consequences of external causes (S00-T98)	0	-	-	-	-	-	-	-
External causes of morbidity and mortality (V00-Y98)	80	1	1	-	-	1	10	-
Total	528	27	10	10	7	13	39	0

Ear and Mastoid (H60-H95)	Circulatory (I00 - I99)	Respiratory (J00-J99)	Digestive (K00-K93)	Skin and Subcutaneous Tissue (L00-L99)	Musculoskeletal and Connective Tissue (M00-M99)	Genitourinary System (N00 - N99)	Pregnancy, Childbirth, Puerpertum (000-099)	Perinatal (P00-P96)	Congenital and Chromosomal (Q00-Q99)	Symptoms and Signs NEC (R00-R99)	Injury, Poisoning and External (S00-T98)	External Causes (V00-Y98)	Total	Reported Alone	Percent Reported Alone
-	2	-	-	-	-	-	-	-	2	1	-	-	9	2	33.3
1	6	9	4	-	-	-	-	-	3	4	2	1	47	15	39.5
-	3	5	2	-	-	1	-	1	2	2	3	-	28	1	8.3
_	4	4	1	-	1	-	-	_	1	_	_	-	16	4	30.8
-	-	-	-	-	-	-	-	-	-	-	1	-	3	0	0.0
-	4	11	2	-	2	1	-	-	2	3	-	-	38	3	13.6
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	3	1	-	-	-	-	-	1	3	-	-	-	9	4	50.0
-	5	4	1	-	-	-	-	2	5	6	-	-	40	7	28.0
-	-	-	-	-	-	-	-	-	1	1	-	-	3	0	0.0
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	1	1	-	-	-	-	-	-	1	1	-	-	7	0	0.0
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	4	3	2	-	-	1	-	103	8	8	-	-	137	50	31.1
-	10	8	3	1	1	1	-	30	23	2	-	-	88	17	23.9
-	-	-	-	-	-	-	-	1	-	-	-	-	1	23	95.8
_	_	_	-	_	-	_	_	-	_	-	_	_	0	0	0.0
	3	_	_	_	_	_	_	_	1	1	72	2	92	6	7.5
1	45	46	15	1	4	4	-	138	52	29	78	3		132	

#### Table 12: Underlying cause of death and contributory causes of death, 2005-2014

Underlying cause of death (ICD-10 chapter)	No. of cases	Infectious and Parasitic (A00-B99)	Neoplasms (C00 - D48)	Blood, Blood Forming Organs (D50-D89)	Endocrine, Nutritional, Metabolic (E00-E90)	Mental & Behavioural Disorders (F00 -F99)	Nervous System (G00-G99)	Eye and Adnexa (H00-H59)
Certain infectious and parasitic diseases (A00-B99)	105	14	5	12	12	2	13	-
Neoplasm (C00-D48)	388	46	66	33	6	3	43	-
Diseases of the blood, blood-forming organs and certain disorders of the immune system (D50-D89)	56	20	1	15	2	-	6	1
Endocrine, nutritional and metabolic disorders (E00-E90)	145	8	-	1	16	8	29	-
Mental and behavioural disorders (F00-F99)	12	1	-	-	1	1	3	-
Diseases of the nervous system (G00-G99)	281	8	7	2	8	23	72	1
Diseases of the eye and adnexa (H00-H59)	1	-	-	1	1	_	-	-
Diseases of the ear and mastoid process (H60-H95)	1	-	-	-	-	1	1	-
Diseases of the circulatory system (100-199)	161	7	7	4	7	5	16	-
Diseases of the respiratory system (J00-J99)	145	20	1	2	3	10	36	-
Diseases of the digestive system (K00-K93)	49	9	1	4	7	3	7	-
Diseases of the skin and subcutaneous tissue (L00-L99)	0	-	-	-	-	-	-	-
Diseases of the musculoskeletal system and connective tissue (M00-M99)	14	2	-	2	2	1	-	-
Diseases of the genitourinary system (N00-N99)	9	1	-	1	2	1	1	-
Pregnancy, childbirth and the puerperium (O00-O99)	0	-	-	-	-	-	-	-
Certain conditions arising in the perinatal period (P00-P96)	1988	33	2	6	8	2	25	-
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	990	36	3	12	17	18	61	2
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	427	1	-	-	-	-	3	-
Injury, poisoning and certain other consequences of external causes (S00-T98)	2	-	-	-	-	-	1	-
External causes of morbidity and mortality (V00-Y98)	996	8	1	3	4	30	56	1
Total	5770	214	94	98	96	108	373	5

Ear and Mastoid (H60-H95)	Circulatory (I00 - I99)	Respiratory (J00-J99)	Digestive (K00-K93)	Skin and Subcutaneous Tissue (L00-L99)	Musculoskeletal and Connective Tissue (M00-M99)	Genitourinary System (N00 - N99)	Pregnancy, Childbirth, Puerperium (000-096)	Perinatal (P00-P96)	Congenital and Chromosomal (Q00-Q99)	Symptoms and Signs NEC (R00-R99)	Injury, Poisoning and External (S00-T98)	External Causes (V00-Y98)	Total	Reported Alone	Percent Reported Alone
-	20	19	14	1	-	11	-	7	11	18	2	1	162	27	25.7
1	50	85	26	1	3	19	-	7	12	44	23	21	489	146	37.6
-	12	14	8	-	-	7	-	6	4	14	13	10	133	5	8.9
-	30	49	9	-	3	4	-	9	7	22	6	5	206	29	20.0
-	-	8	2	_	3	-	-	-	-	1	3	1	24	1	8.3
1	39	127	10	-	9	3	-	23	16	43	20	18	430	56	19.9
-	1	-	-	-	-	-	-	-	-	-	-	-	3	0	0.0
-	-	-	-	-	-	-	-	-	-	-	-	-	2	0	0.0
-	55	11	5	-	3	12	-	10	22	15	2	1	182	60	37.3
-	22	37	6	1	3	3	-	5	21	21	2	2	195	42	29.0
-	9	11	20	-	-	4	-	7	12	11	5	4	114	3	6.1
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	4	5	-	-	-	-	-	1	1	3	-	-	21	3	21.4
-	2	2	2	-	1	1	-	-	2	1	1	-	18	1	11.1
-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
	37	30	11	-	4	8	1	1458	115	89	4	5	1838	458	23.0
2	142	118	39	1	7	31	-	409	376	90	24	18	1406	166	16.8
-	2	2	-	-	-	-	-	4	-	2	1	1	16	418	97.9
1	_	_	_	-	_	_	_	_	_	1	1	_	4	1	50.0
_	34	18	2	_	1	3	_	8	4	27	959	57	1216	22	2.2
5	459	536	154	4	37	106	1	1954	603	402	1066	144		1438	

## 2.10 NSW resident children who died outside NSW

Each year, an average of 24 children who were normally resident in NSW die in another state or territory.

Generally, if a person dies in a particular state, their death is registered in that state. This is required by legislation in NSW. Funeral Directors are generally responsible for registering a death to the state registry of births, deaths and marriages.

The Team's jurisdiction is limited to NSW, and it is therefore unable to require agencies in other states or territories to provide information about a child who dies.

Each year, the Team requests information about children from NSW who die outside of the State from other child death review teams or similar bodies, and/or registries of births, deaths and marriages. The information provided is mostly limited to age or age grouping, gender, cause of death, and residential postcode. No state or territory provides identifying data, which means no further information can be sought by the Team from agencies or service providers within NSW.

For this reason, the deaths of children outside of NSW have generally been excluded from detailed analysis in the Team's annual report, and are reported separately within the report.

In 2013,<sup>28</sup> 23 children from NSW died outside of the state, consistent with the average (24) since the commencement of the CDRT in 1996.

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
ACT	10	7	12	13	7	5	6	11	7	7	9	11	5	5	8	123
NT	1	0	0	0	0	0	0	0	0	0	0	0	0	0	N/A <sup>29</sup>	1
QLD	14	8	8	13	12	5	8	9	14	5	10	14	5	9	7	141
SA	2	1	2	1	2	1	1	1	2	4	1	0	0	3	1	22
VIC	1	3	4	3	1	5	3	2	2	8	9	5	3	6	7	62
WA	0	0	0	1	0	0	0	0	0	1	0	1	0	1	0	4
TAS	0	0	0	0	0	0	1	1	0	0	0	1	1	0	0	4
Total	28	19	26	31	22	16	19	24	25	25	29	32	14	24	23	357

#### Table 13: Deaths of children resident in NSW registered in another state or territory, 1999-2013

As in previous years, most of the children (19) died of natural causes.<sup>30</sup> Twelve children died as a result of conditions arising in the perinatal period, six from congenital and chromosomal conditions, and one from infectious disease. Two of the children died from external causes; one from asphyxia in the context of an unsafe sleeping environment and one in a motor vehicle crash.

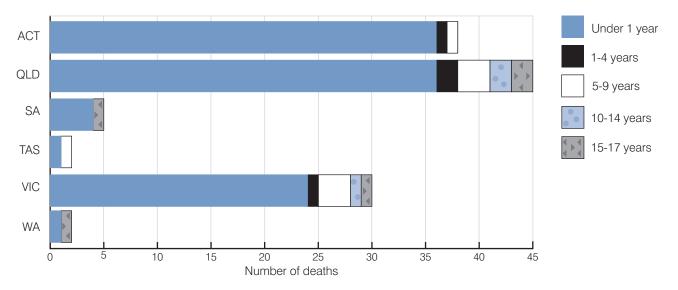
Consistent with previous years, almost all of the children (22) were under the age of one year when they died. As shown in figure 2, most (102) of the children (122) who died outside of NSW within the last five years were under the age of one year. Of the 122 children who died outside NSW, 63 were females and 59 were males.

Paediatric Intensive Care and Neonatal Intensive Care are centralised in Australia, mostly in capital cities and Newcastle and Townsville. Critically ill children and very sick neonates are usually transferred to one of these centres. In northern New South Wales, most critically ill infants would be transferred to Brisbane. Similarly, from Albury, most would be transferred to Melbourne; from Queanbeyan to Canberra, and from Broken Hill, most to Adelaide.

<sup>28</sup> Information about deaths registered interstate is generally not available for the current reporting year. The latest available information relates to deaths registered in other states or territories in 2013.

<sup>29</sup> Northern Territory Child Deaths Review and Prevention Committee was unable to provide this information.

<sup>30</sup> For two of the 23 children, manner of death was unable to be ascertained from the information provided.



#### Figure 2: Deaths of children resident in NSW registered in another state or territory 2009-2013 by age group

# 2.11 Comparative rates of child deaths: NSW, rest of Australia and New Zealand

Table 14 below draws on information from each jurisdiction about children who died in 2012 in Australian states and territories and New Zealand.<sup>31</sup>

The information is drawn from data provided by members of the Australian and New Zealand Child Death Review and Prevention Group, which comprises agencies from Australian and New Zealand jurisdictions that have a child death review function. The Team is a member of the group. The aim of the group is to identify, address and reduce the deaths of children and young people.

Overall, NSW had the third lowest rate of child deaths in Australia and New Zealand (30.7 deaths per 100,000 children). Compared to Australian states and territories that publish this data, NSW had the lowest rates of death for children aged 1-4 and 10-14 years (13.4 deaths per 100,000 children) and 8.1 deaths per 100,000 children respectively).<sup>32</sup>

		Number of d	leaths (Rate per	<sup>.</sup> 100,000)		Total
	Under 1 year	1-4 years	5-9 years	10-14 years	15-19 years	
Queensland	276 (436.5)	55 (22.2)	28 (9.3)	32 (10.8)	48 (26.4)	439 (40.5)
New South Wales	310 (315.7)	51 (13.4)	45 (9.9)	36 (8.1)	67 (24.4)	509 (30.7)
South Australia	63 (311.9)	12 (15.2)	10 (10.4)	8 (8.2)	13 (20.9)	106 (29.8)
Victoria	226 (302.6)	56 (19.6)	32 (9.4)	37 (11.2)	55 (26.4)	406 (32.9)
Tasmania	25 (396.3)	3 (*)	1 (*)	5 (15.4)	6 (29.2)	40 (34.5)
Australian Capital Territory	12 (227.4)	<5ª (-)	<5ª (-)	<5ª (-)	<5ª (-)	20 (24.4)
Northern Territory	22 (554.4)	6 (40.5)	4 (22.6)	4 (23.8)	8 (82.2)	44 (69.9)
	Under 1 year	1-4 years	5-9 years	10-14 years	15-19 years	
New Zealand	276 (446.8)	63 (24.7)	30 (10.3)	46 (15.3)	92 (49.3)	507 (46.2)

#### Table 14: Comparative rates of child deaths, Australia and New Zealand, 2012

Data source: Australian and New Zealand Child Death Review and Prevention Group (2012)

\* Rates have not been calculated for numbers less than 4.

<sup>a</sup> Figure not specified where number of deaths is less than 5.

<sup>31</sup> The table is reproduced from the Queensland *Family and Child Commission's Annual Report – deaths of children and young people 2013-2014*. 2012 is the most recent information available.

<sup>32</sup> Note that the crude mortality rates were not reported for Tasmania and the Australian Capital Territory.

#### Notes:

- 1. Rates are calculated per 100,000 children in each age category in each jurisdiction; Total rates are calculated per 100,000 children aged 0-17 years in each jurisdiction.
- 3. Australian Capital Territory data was not available in some age categories age due to the potential identification of individual cases, and does not include deaths of children and young people awaiting coroner's findings.
- 5. Victorian data in this table are provisional and subject to change. Full data will be available from the Annual Report for the Year 2012 at www.health.vic.gov.au/ccopmm/index.htm.
- 6. Note that caution must be exercised when comparing rates between jurisdictions. Although the rates are based on a population rather than a sample, common practice is to consider death a random event, and hence have an associated sampling error. This is particularly important when comparing rates from low numbers. Current methodology calculates the crude rates for 2012, and should not be used to infer the general probability of death for specific cohorts.

# **Chapter 3. Natural cause deaths**

This chapter provides information about the 361 children who died as a result of natural causes and whose deaths were registered in 2014. More detailed analyses on specific natural causes are are presented in the following.

The deaths of six of the 361 children reported in this chapter are also reviewable deaths, subject to separate review by the Ombudsman.<sup>33</sup>

The table below provides an overview of the key demographic characteristics of the children who died as a result of natural causes in 2014.

#### Table 15: Key demographic and individual characteristics – deaths due to natural causes, 2014

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	p
Total	361	100	21.45	19.24 - 23.67		
Gender						
Female	171	47	20.92	17.78 - 24.05	-	-
Male	190	53	21.96	18.84 - 25.08	1.0	0.65
Age						
Under 1 year	246	68	265.43 (IMR = 2.45)†	232.26 - 298.60	-	-
1-4 years	39	11	9.92	7.05 - 13.56	-	-
5-9 years	29	8	6.11	4.10 - 8.78	-	-
10-14 years	24	7	5.35	3.43 - 7.96	-	-
15-17 years	23	6	8.40	5.32 - 12.60	-	-
Aboriginal and Torres Strait Islander sta	itus					
Aboriginal or Torres Strait Islander	41	11	44.82	32.17 - 60.81	2.2	0.00
Not Aboriginal or Torres Strait Islander	320	89	20.11	17.91 - 22.31	-	-
Remoteness*						
Major cities	270	75	22.04	19.41 - 24.67	-	-
Inner regional areas	73	20	21.95	17.21 - 27.60	-	-
Outer regional areas	13	4	12.39	6.60 - 21.19	-	-
Remote areas	4	1	53.82	14.66 - 137.80	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	53	15	13.80	10.34 - 18.05	-	-
Quintile 4	40	11	13.85	9.90 - 18.86	-	-
Quintile 3	60	17	20.74	15.83 - 26.70	-	-
Quintile 2	77	21	24.16	19.07 - 30.20	-	-
Quintile 1 (lowest)	127	35	32.63	26.95 - 38.30	-	_

\* Remoteness was not calculated in one case

\*\* Socioeconomic status was not calculated in four cases

<sup>33</sup> The Ombudsman is required under section 35 of the Community Services (Complaints, Reviews and Monitoring) Act 1993 to review certain deaths.

## 3.1 All natural causes

#### Age and gender

As noted above, most children who die in NSW are infants less than one year of age, and the large majority of these children die as a result of natural causes. Associated with this, and consistent with previous years, more than two thirds (246, 68%) of all children who died from natural causes were infants.

Natural causes also accounted for most of the deaths of children aged 1-4 years (68%); 5-9 years (71%); and 10-14 years (63%). Also consistent with historical trends, the lowest proportion of natural cause deaths occurred amongst young people aged 15-17 years (43%).

Compared with 2013, the mortality rate for natural causes decreased across all age groups except 5-9 year olds, in which there was a slight increase – from 5.4 deaths per 100,000 children to 6.11 deaths per 100,000 children.

Overall, natural causes accounted for the deaths of 75 percent (190) of males and 74 percent (171) of females who died in 2014.

## Aboriginal and Torres Strait Islander status

Of the 63 Aboriginal and Torres Strait Islander children who died in 2014 and where cause of death was known, 41 (65%) died from natural causes.

The rate of death of Aboriginal and Torres Strait Islander children from natural causes in 2014 (44.82 per 100,000 children) was significantly lower than in 2013 (51.6 per 100,000 children). However, the natural cause mortality rate for Indigenous children was more than twice that of non-Indigenous children (20.3 per 100,000 children).

## **Child protection history**

Of the 361 children whose deaths were due to natural causes, the families of 60 (17%) had a child protection history.

A ten-year comparative analysis of cause of death for children with and without child protection histories prepared for the Team in 2014 found that children with a child protection history had a higher mortality rate for particular causes of death, including certain natural causes:

- cerebral palsy (3.5 times the mortality rate of children without a child protection history)
- meningococcal infection (3.4 times the mortality rate)
- influenza and pneumonia (2.2 times the mortality rate), and
- epilepsy (2 times the mortality rate).<sup>34</sup>

## 3.2 Leading natural causes of death

Table 16 details the top leading natural causes of death of children in 2014, by ICD chapter and condition. Overall, the top five leading causes of death have remained stable in recent years (perinatal conditions, congenital and chromosomal conditions, neoplasms, respiratory diseases and nervous system diseases). However, in some years the order has changed. For example, different from 2013, deaths from nervous system diseases (fourth leading cause) outnumbered deaths from respiratory diseases (fifth leading cause) in 2014.

The leading natural causes of death of children in 2014 are discussed in greater detail in subsequent chapters.

<sup>34</sup> NSW Child Death Review Team (2014), Causes of death of children with a child protection history 2002-2011, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

#### Table 16: Top five leading natural causes of death, 2014

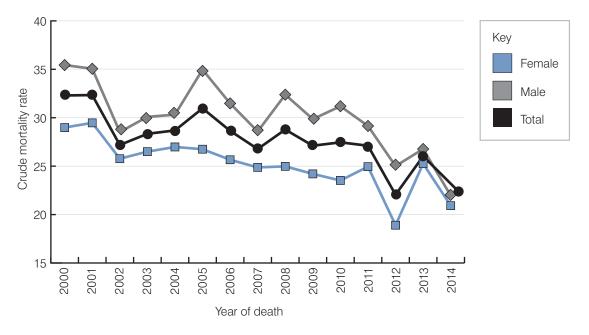
Natural cause of death	Count	Percent	Crude Mortality Rate	95% Confidence Interval
Certain conditions arising in the perinatal period	161	33.2	9.57 (1.60) †	8.09 - 11.05
Fetus and newborn affected by maternal factors/complications of pregnancy (P00-P04)	70	14.4	4.16 (0.70)	3.24 - 5.26
Disorders related to length of gestation and fetal growth (P05-P08)	47	9.7	2.79 (0.47)	2.05 - 3.71
Respiratory and cardiovascular disorders (P20-P29)	19	3.9	1.13 (0.19)	0.68 - 1.76
Other perinatal disorders (P90-P96)	17	3.5	1.01 (0.17)	0.59 - 1.62
Integument and thermoregulation conditions foetus/newborn (P80-P83)	3	0.6	-	-
Infections specific to the perinatal period (P35-P39)	2	0.4	-	-
Digestive system disorders of fetus and newborn (P75-P78)	2	0.4	-	-
Haemorrhagic and haematological disorders of fetus and newborn (P50-P61)	1	0.2	-	-
Congenital malformations, deformations and chromosomal abnormalities	71	14.6	4.22	3.30 - 5.32
Congenital malformations of the circulatory system (Q20-Q28)	19	3.9	1.13	0.68 - 1.76
Congenital malformations the of nervous system (Q00-Q07)	17	3.5	1.01	0.59 - 1.62
Other congenital malformations (Q80-Q89)	9	1.9	0.53	0.24 - 1.02
Chromosomal abnormalities, not elsewhere classified (Q90-Q99)	8	1.6	0.48	0.21 - 0.94
Congenital malformations and deformation of the musculoskeletal system (Q65-Q79)	7	1.4	0.42	0.17 - 0.86
Congenital malformations of the respiratory system (Q30-Q34)	6	1.2	0.36	0.13 - 0.78
Other congenital malformations of the digestive system (Q38-Q45)	3	0.6	-	-
Congenital malformations of the urinary system (Q60-Q64)	2	0.4	-	-
Neoplasms	38	7.8	2.26	1.60 - 3.10
Malignant neoplasm of eye, brain and other part of central nervous system (C69-C72)	15	3.1	0.89	0.50 - 1.47
Malignant neoplasm of lymphoid, haematopoietic and related tissue (C81-C96)	12	2.5	0.71	0.37 - 1.25
Malignant neoplasm of mesothelial and soft tissue (C45-C49)	5	1.0	0.30	0.10 - 0.69
Malignant neoplasm of respiratory and intrathoracic organs (C30-C39)	1	0.2	-	-
Malignant neoplasm of urinary tract (C64-C68)	1	0.2	-	-
Malignant neoplasm of ill-defined, secondary and unspecified sites (C76-C80)	1	0.2	-	-
Malignant neoplasm of lip, oral cavity and pharynx (C00-C14)	1	0.2	-	-
Malignant neoplasm of bone and articular cartilage (C40-C41)	1	0.2	-	-
Malignant neoplasm of digestive organs (C15-C26)	1	0.2	-	-
Diseases of the respiratory system	25	5.2	1.49	0.96 - 2.19
Influenza and pneumonia (J09-J18)	10	2.1	0.59	0.28 - 1.09
Lung diseases due to external agents (J60-J70)	4	0.8	0.24	0.06 - 0.61
Chronic lower respiratory diseases (J40-J47)	4	0.8	0.24	0.06 - 0.61
Other diseases of the respiratory system (J95-J99)	3	0.6	-	-
Other acute lower respiratory infections (J20-J22)	2	0.4	-	-
Other respiratory diseases principally affecting the interstitium (J80-J84)	1	0.2	-	-
Suppurative and necrotic conditions of lower respiratory tract (J85-J86)	1	0.2	-	-
Diseases of the nervous system	22	4.5	1.31	0.82 - 1.98
Cerebral palsy and other paralytic syndromes (G80-G83)	7	1.4	0.42	0.17 - 0.86
Episodic and paroxysmal disorders (G40-G47)	5	1.0	0.30	0.10 - 0.69
Inflammatory diseases of the central nervous system (G00-G09)	3	0.6	-	-
Systemic atrophies primarily affecting the central nervous system (G10-G14)	3	0.6	-	-
Diseases of myoneural junction and muscle (G70-G73)	2	0.4	-	-
Other degenerative diseases of the nervous system (G30-G32)	1	0.2	-	-
Other disorders of the nervous system (G90-G99)	1	0.2	-	-

†Infant Mortality Rate

## 3.3 Trends in deaths of children from natural causes, 2000-2014

Over the past 15 years, there has been a steady decline in the rate of death of children from natural causes, as illustrated in figure 3. The drop in child deaths from natural causes in Australia mostly reflects a decline in infant deaths, which is linked to factors such as advances in medical interventions and reductions in vaccine-preventable diseases through universal immunisation programs.<sup>35</sup>

This trend appears to be continuing. The mortality rate of children who died from natural causes in 2014 was lower than in 2013 (21.45 per 100,000 children compared to 26.03 per 100,000 children).



#### Figure 3: Trends in deaths of children due to natural causes by gender and rate 2000-2014

## 3.4 Conditions arising in the perinatal period

Perinatal conditions originate during pregnancy, or up to 28 days post-partum. They include conditions such as prematurity; respiratory and cardiovascular disorders; maternal factors such as hypertensive disorders; and complications of pregnancy, labour and delivery. While these conditions arise during the perinatal period, they may result in death at a later stage in childhood.

In 2014, 161 children whose deaths were registered in NSW died as a result of perinatal conditions. As shown in table 17, the rate of death from perinatal conditions in 2014 (1.6 per 1,000 live births) was one of the lowest in the last 15 years, and reflects a continued trend of declining mortality rates from this cause. All of the children who died from perinatal conditions in 2014 were less than 12 months of age.

#### Age, gender and Aboriginal and Torres Strait Islander status

Most children who died from perinatal conditions were younger than 28 days when they died (154, 96%); the majority (104) died on the day they were born. This is consistent with previous years.

As the table below shows, there has been an overall decline in infant mortality rates from perinatal conditions over the past 15 years. Rates of death from this cause have generally been higher for males than for females.

<sup>35</sup> Australian Institute of Health and Welfare (2015), *Risk factors, diseases and deaths*, http://www.aihw.gov.au/deaths/age-at-death/, accessed 17 July 2015.

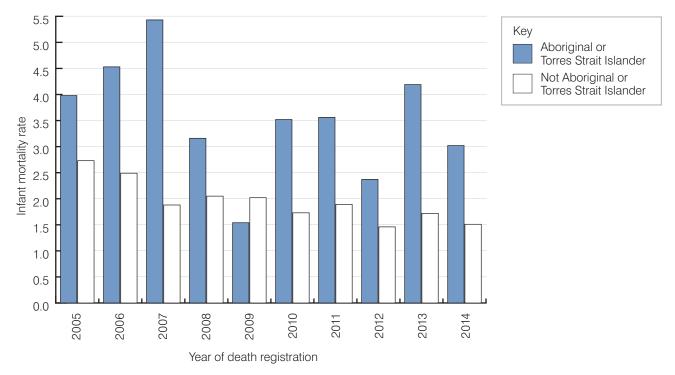
 Table 17: Trends in deaths of children due to perinatal conditions by gender, 2000-2014, number and infant mortality rate

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	107	108	85	99	82	108	94	88	87	84	71	87	57	82	70
	(2.54)	(2.63)	(2.01)	(2.37)	(1.97)	(2.44)	(2.12)	(1.88)	(1.77)	(1.76)	(1.44)	(1.81)	(1.19)	(1.69)	(1.44)
Male	139	136	102	100	101	148	144	110	125	116	114	110	92	106	91
	(3.11)	(3.12)	(2.30)	(2.25)	(2.28)	(3.15)	(3.01)	(2.22)	(2.44)	(2.30)	(2.19)	(2.16)	(1.82)	(2.04)	(1.75)
Total	246	244	187	199	183	256	238	198	212	200	185	197	149	188	161
	(2.84)	(2.88)	(2.16)	(2.30)	(2.13)	(2.81)	(2.58)	(2.05)	(2.11)	(2.04)	(1.83)	(1.99)	(1.51)	(1.87)	(1.60)

Twenty-two of the 161 infants who died from perinatal conditions in 2014 were Aboriginal or Torres Strait Islander. The mortality rate for Aboriginal and Torres Strait Islander children from this cause (3.69 per 1,000 live births) was over twice the rate for non-Indigenous children (1.47 per 1,000 live births).

As shown in figure 4, the rate of perinatal deaths for Aboriginal and Torres Strait Islander children has been higher than the rate for non-Indigenous children for nine of the past 10 years. In 2014, this difference was significant and represented the fourth highest incident rate ratio over the 10-year period.





## Leading causes of death from conditions originating in the perinatal period

Consistent with previous years, the leading cause of death from perinatal conditions in 2014 related to maternal factors and complications of pregnancy, labour and delivery, which accounted for close to half of all perinatal deaths (70, 43%). Of the 70 deaths from this cause:

<sup>36</sup> As trend analysis of the deaths of Aboriginal and Torres Strait Islander children is based on identification of Aboriginal and Torres Strait Islander status in BDM data only, the figures do not include all Aboriginal and Torres Strait Islander child deaths identified by the Team during the period.

- thirty-two were due to maternal complications of pregnancy, mainly related to premature rupture of membranes (15), complex cervix (11) or oligophydramnios<sup>37</sup> (4)
- thirty were due to complications of placenta, cord and membranes, mainly placental separation and haemorrhage (11), chorioamnionitis<sup>38</sup> (8) or compression or prolapse of the umbilical cord (5)
- six were a result of maternal hypertensive disorders, and
- two were a result of complications of labour and delivery.

Disorders related to the length of gestation and foetal growth accounted for just over one quarter of the deaths from perinatal conditions (47, 29%). The majority of these deaths (26) were due to extreme prematurity.

Twelve percent of deaths from perinatal conditions (19) were due to respiratory or cardiovascular disorders; mainly persistent foetal circulation<sup>39</sup> (5), respiratory distress syndrome (4), birth asphyxia (3), and intrauterine hypoxia (3).

As has consistently been the case, a higher proportion of male infants (91, 57%) died from perinatal conditions than did females over the last 15 years. In 2014, the proportion of male infants who died from perinatal conditions associated with extreme prematurity and respiratory and cardiovascular disorders was substantially higher than female infants.

#### Table 18: Leading causes of death due to perinatal conditions, 2014

	Female	Male	Total	Infant Mortality Rate	95% Confidence Interval
Maternal/obstetric factors	36	34	70	0.70	0.54 - 0.88
Length of gestation (prematurity)	18	29	47	0.47	0.34 - 0.62
Respiratory/cardiovascular disorders	7	12	19	0.19	0.11 - 0.30
Other perinatal conditions	4	13	17	0.17	0.10 - 0.27
Disorders of thermoregulation	1	2	3	_	
Infections	2	0	2	_	
Digestive system disorders	2	0	2	_	_
Haemorrhagic/haematological disorders	0	1	1	_	_
Total	70	91	161	-	-

## 3.5 Deaths from congenital and chromosomal conditions

Congenital malformations, deformations and chromosomal abnormalities ('congenital and chromosomal conditions') include anatomical defects or developmental disorders that are present at birth, such as heart and neural tube defects.<sup>40</sup>

In 2014, 71 children whose deaths were registered in NSW died as a result of congenital and chromosomal conditions. As has consistently been the case, these conditions were the second leading cause of death in 2014, accounting for 15 percent of all deaths of children in NSW.

Congenital and chromosomal conditions are one of the overall leading causes of childhood mortality in Australia.<sup>41</sup> In 2014, these conditions were responsible for 21 percent (61) of all deaths of children in NSW aged under one year and for five percent (10) of children aged 1-17 years.

<sup>37</sup> A deficiency of amniotic fluid.

<sup>38</sup> A bacterial infection of the foetal membranes

<sup>39</sup> A condition in which a neonate fails to make the transition from foetal circulation to newborn circulation resulting in insufficient blood flow to the lungs.

<sup>40</sup> Hilder L., Zhichao A., Parker M., Jahan S., Chambers G.M. (2014), *Australia's Mothers and Babies 2012*, Perinatal statistics series no. 30. Cat. No. PER 69. AIHW: Canberra.

<sup>41</sup> Australian Bureau of Statistics (2013), Causes of Death Australia 2013, cat.no.3303.0. ABS: Canberra.

## Age, gender and Aboriginal and Torres Strait Islander status

Reflecting historical trends, a very high proportion (61, 86%) of the children who died from congenital and chromosomal conditions in NSW were less than one year old at the time of their death. Just under two thirds of these 61 infants (44) died in the first 28 days of life. Congenital malformations of the circulatory system and of the nervous system were the two largest contributors, accounting for six and five percent respectively of all infant deaths in 2014.

Six Aboriginal or Torres Strait Islander children died from congenital and chromosomal conditions.

Over the past 15 years, while rates of death of children from congenital and chromosomal conditions have varied, as shown in table 19, they have generally been higher for male children compared to female children each year.

However, in 2014, more girls (40) than boys (31) died from congenital and chromosomal conditions. As shown in table 19, this represents a reversal of the general trend over the past 15 years in which male children have typically outnumbered female children in deaths from this cause.

# Table 19: Trends in deaths of children due to congenital and chromosomal causes by gender,2000-2014, number and rate

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	45	49	47	40	48	40	33	44	53	56	59	48	42	47	40
	(5.80)	(6.28)	(6.03)	(5.15)	(6.20)	(5.17)	(4.26)	(5.64)	(6.75)	(7.09)	(7.42)	(6.02)	(5.22)	(5.79)	(4.89)
Male	59	56	35	46	59	55	43	48	59	59	61	64	60	47	31
	(7.24)	(6.82)	(4.27)	(5.63)	(7.24)	(6.75)	(5.27)	(5.84)	(7.13)	(7.08)	(7.26)	(7.58)	(7.05)	(5.47)	(3.58)
Total	104	105	82	86	107	95	76	92	112	115	120	112	102	94	71
	(6.53)	(6.56)	(5.12)	(5.39)	(6.73)	(5.98)	(4.77)	(5.74)	(6.95)	(7.08)	(7.34)	(6.82)	(6.16)	(5.63)	(4.22)

### Leading causes of death due to congenital and chromosomal conditions

The causes of most congenital malformations and chromosomal abnormalities are largely unknown.<sup>42</sup> Congenital circulatory system conditions are the most commonly occurring congenital malformations in Australia,<sup>43</sup> and have consistently been a leading cause of death of children in NSW.

In 2014, the five leading causes of death of children from congenital and chromosomal conditions were:

- Congenital malformations of the circulatory system (19, 27%) including malformations of the cardiac chambers and connections (10) and the great arteries (3).
- Congenital malformations of the nervous system (17, 23%) congenital malformations of the brain such as neural tube defects (13), spina bifida (2) and Arnold-Chiari syndrome (2).
- Other congenital malformations (9, 12%) including dicephaly (2) and CHARGE syndrome (1)
- Chromosomal abnormalities, not elsewhere classified (8, 11%) including trisomy 18 (Edward's syndrome) (1).

Other deaths of children in 2014 were associated with malformations of the musculoskeletal system (7), respiratory system (6), digestive system (3), and urinary system (2).

As indicated in the table below, infants accounted for most of the leading causes of death from congenital and chromosomal conditions, including those related to the circulatory system (15, 21%), congenital malformations of the nervous system (15, 21%) and chromosomal abnormalities (5, 7%).

<sup>42</sup> Al-Yamen F., Bryant M. & Sargeant H. (2002), Australia's Children: Their Health and Wellbeing 2002. Australian Institute of Health and Welfare, Cat. No. PHE 36. AIHW: Canberra.

<sup>43</sup> Blue G.M., Kirk E.P., Sholler G.F., Harvey R.P. & Winlaw, D.S. (2012), 'Congenital heart disease: current knowledge about causes and inheritance', Medical Journal of Australia, 197(3): pp. 1-5.

Table 20: Leading causes of deaths due to congenital and chromosomal conditions by age, 2014

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Circulatory system 15	Chromosomal 1	Circulatory system 2	Chromosomal 1	Nervous system 1
Nervous system 15	Circulatory system 1	Chromosomal 1	Circulatory system 1	
Other congenital 9	Digestive system 1			
Musculoskeletal system 7	Nervous system 1			
Respiratory system 6				
Chromosomal 5				
Digestive system 2				
Urinary system 2				

## 3.6 Neoplasms (cancers and tumours)

In 2014, 38 children whose deaths were registered in NSW died as a result of neoplasms (cancers and tumours). In line with national trends<sup>44</sup> and consistent with previous years, neoplasms were the leading natural cause of death of children aged one year and over in NSW.

#### Age, gender and Aboriginal and Torres Strait Islander status

While the number of cancer-related deaths of children and young people is low compared to older age groups<sup>45</sup>, in 2014, neoplasms were:

- the overall leading cause of death of children aged 5-9 years, and
- the leading natural cause of death of children aged 1-4 years and 15-17 years.

However, as table 21 shows, deaths of children from this cause have declined in NSW over the past 15 years. The decline is largely due to medical advances in diagnosis and treatment of cancer.<sup>46</sup> The Kids' Cancer Project notes that 50 years ago, only two percent of children survived cancer. Today, the overall survival rate is 80 percent.<sup>47</sup>

In 2014, an equal number of male (19) and female (19) children died from neoplasms. This represents a notable reduction in the number of female children who died from this cause compared to 2013, when more than twice as many females died from neoplasms than males.

Three of the 38 children who died from cancers and tumours in 2014 were Aboriginal.

<sup>44</sup> Australian Institute of Health and Welfare (2014), *Cancer in Australia: an overview 2014*. Cancer series No 90. Cat. No. CAN 88. AIHW: Canberra.. 45 Ibid.

<sup>46</sup> Australian Institute of Health and Welfare (2012), A picture of Australia's children 2012. Cat. No. PHE 167. AIHW: Canberra.

<sup>47</sup> The Oncology Children's Foundation, *The Kids' Cancer Project*, http://www.thekidscancerproject.org.au/about/Childhood-Cancer-Facts.aspx, accessed 17 July 2015.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	26	26	18	19	29	18	18	23	15	11	22	23	15	30	19
	(3.35)	(3.33)	(2.31)	(2.44)	(3.74)	(2.33)	(2.32)	(2.95)	(1.91)	(1.39)	(2.77)	(2.88)	(1.87)	(3.70)	(2.32)
Male	26	33	29	34	25	21	13	24	18	21	22	26	16	14	19
	(3.19)	(4.02)	(3.54)	(4.16)	(3.07)	(2.58)	(1.59)	(2.92)	(2.18)	(2.52)	(2.62)	(3.08)	(1.88)	(1.63)	(2.20)
Total	52	59	47	53	54	39	31	47	33	32	44	49	31	44	38
	(3.27)	(3.68)	(2.94)	(3.32)	(3.40)	(2.45)	(1.95)	(2.93)	(2.05)	(1.97)	(2.69)	(2.99)	(1.87)	(2.63)	(2.26)

Table 21: Trends in deaths of children due to cancers and tumours by gender, 2000-2014, number and rate

#### Leading causes of death due to neoplasms

Table 22 below shows the leading types of cancers and tumours that resulted in the deaths of children in NSW in 2014, by age group.

In 2014, malignant brain tumours were the most common cause of deaths from neoplasms, accounting for the deaths of 14 children. Brain tumours are the second most frequently diagnosed type of childhood cancer in Australia.<sup>48</sup> While the deaths of children from brain tumours occurred across all age groups, the majority of deaths (12) were of children aged less than 10 years.

Cancers of the lymphoid and haematopoietic tissue (affecting the blood and bone marrow) were the second leading cause of death of children in NSW from neoplasms, accounting for the deaths of 12 children. All but one of these deaths was due to leukaemia, which is the most commonly diagnosed childhood cancer.<sup>49</sup> Of the 11 children who died from leukaemia in 2014, most (9) died from acute lymphoblastic leukaemia and two died from acute myeloblastic leukaemia.

Five children died as a result of malignant tumours of soft tissue and a further two children died as a result of bone cancer.

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Brain	Brain	Brain	Leukaemia	Leukaemia
1	5	6	2	2
	Leukaemia	Leukaemia	Accessory sinuses	Brain
	4	3	1	1
	Connective/soft tissue	Connective/soft tissue	Bone	Connective/soft tissue
	1	2	1	1
	Optic nerve	Liver	Brain	Head, face and neck
	1	1	1	1
	Other blood cancer		Kidney	Nasopharynx
	1		1	1
			Nervous system 1	

Table 22: Leading causes of death due to cancers and tumours by age, 2014

## 3.7 Respiratory system diseases

Diseases of the respiratory system include conditions such as pneumonia, influenza,<sup>50</sup> asthma and bronchitis.

Twenty-five children whose deaths were registered in NSW died from respiratory diseases in 2014. The mortality rate from this cause (1.49 per 100,000 children) was the highest it has been over the past 15 years.

 <sup>48</sup> Australian Institute of Health and Welfare (2014), Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. AIHW: Canberra.
 49 Ibid.

<sup>50</sup> Influenza is an infectious disease, however some types of influenza are classified as respiratory diseases under the International Classification of Diseases.

## Age, gender and Aboriginal and Torres Strait Islander Status

In 2014, while the deaths of children from respiratory diseases occurred across all age groups, half (13) were under five years of age. The over-representation of children aged under five years in respiratory deaths is consistent with recent years.

Over two thirds (17) of the children who died from respiratory diseases were male. As shown in the table below, mortality rates of males from this cause have been consistently higher than females over the last 15 years, and in 2014 were the highest since 2000 (1.96 per 100,000 children).

One child who died from a respiratory-related illness was Aboriginal.

 Table 23: Trends in deaths of children due to diseases of the respiratory system by gender and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	5	5	5	7	7	2	3	5	9	4	7	4	8	6	8
	(0.64)	(0.64)	(0.64)	(0.90)	(0.90)	-	-	(0.64)	(1.15)	(0.51)	(0.88)	(0.50)	(0.99)	(0.74)	(0.98)
Male	9	9	11	8	9	5	8	9	10	5	10	4	6	13	17
	(1.10)	(1.10)	(1.34)	(0.98)	(1.10)	(0.61)	(0.98)	(1.09)	(1.21)	(0.60)	(1.19)	(0.47)	(0.70)	(1.51)	(1.96)
Total	14	14	16	15	16	7	11	14	19	9	17	8	14	19	25
	(0.88)	(0.87)	(1.00)	(0.94)	(1.01)	(0.44)	(0.69)	(0.87)	(1.18)	(0.55)	(1.04)	(0.49)	(0.85)	(1.14)	(1.49)

#### Leading causes of death due to respiratory diseases

As illustrated in the table below, the most common respiratory diseases that caused the deaths of children in NSW in 2014 were pneumonia (6), asthma (4), influenza (4) and pneumonitis, or aspiration pneumonia, due to inhalation of food or vomit (4). Each of the children who died from aspiration pneumonia had significant and complex health issues including cerebral palsy, epilepsy/seizure disorders and a history of recurrent respiratory issues.

Of the 10 children who died from pneumonia and influenza, more than half (6) were under five years of age.

Asthma was the cause of death of four children in 2014 who ranged in age from 11 to 17 years.

Two children died from acute lower respiratory infections (bronchitis).

#### Table 24: Leading causes of death due to respiratory diseases by age, 2014

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Alveolar/parietoalveolar conditions 1	Acute bronchitis 2	Human metapneumovirus pneumonia 2	Asthma unspecified 2	Asthma unspecified 1
Chronic respiratory failure 1	Influenza with other manifestations, other influenza virus identified 1	Pneumonitis due to food and vomit 1	Influenza with other manifestations, virus not identified 1	Pneumonitis due to food and vomit 1
Pneumonia unspecified 1	Influenza with other respiratory manifestations, virus not identified 1		Influenza with pneumonia, virus not identified 1	Predominantly allergic asthma 1
	Pneumonia due to Haemophilus influenzae 1		Lobar pneumonia unspecified 1	Pyothorax without fistula 1
	Pneumonia due to other streptococci 1		Pneumonitis due to food and vomit 1	
	Pneumonia due to Streptococcus pneumoniae 1			
	Pneumonitis due to food and vomit 1			
	Respiratory disorder unspecified 1			
	Tracheostomy malfunction 1			

#### Deaths from asthma

Asthma is a chronic respiratory illness that causes episodes of wheezing, breathlessness and chest tightness due to constriction of the airways. Australia has a relatively high prevalence of asthma by international standards, with around one in ten Australian children having been diagnosed with the condition.<sup>51</sup>

In 2014, 13,162 children aged one to 17 years presented to hospital emergency departments in NSW for asthma, accounting for almost two thirds of all asthma presentations across the state.<sup>52</sup>

Deaths from asthma are relatively rare and have declined nationally since the early 1990s.<sup>53</sup> Furthermore, in the decade to 2011, the prevalence of asthma amongst people aged 5 to 34 also declined.<sup>54</sup>

As noted above, four children whose deaths were registered in NSW in 2014 died from asthma. Their ages ranged from 11 to 17 years. All were younger than five when the condition was first diagnosed.

The four children who died had presented and/or been admitted to hospital for the condition on at least one occasion in the five years before the acute episode that resulted in their death. None of the children had presented to hospital for asthma in the 12 months prior to death.

All four children had a written asthma plan. Records indicate that two of the children had persistent asthma (symptoms on most days).<sup>55</sup> The other two children appeared to have infrequent intermittent asthma (symptoms up to once every three weeks on average, with no symptoms between flare-ups). The records also indicate the use of both preventer and reliever medication in all four cases.

All four of the children had health conditions in addition to asthma. Health records for three of the children indicated that they were allergic or atopic<sup>56</sup> and/or had other triggers for asthma. These three children had eczema, including two children for whom eczema was recorded as chronic and/or severe.

Two of the four children also had a history of anaphylaxis related to food allergy and had previously used or had been prescribed an EpiPen (epinephrine). This aligns with research which indicates that up to 80 percent of people who have asthma have co-occurring allergies, that often act as a trigger for asthma.<sup>57</sup>

All four children attended school. However, in each case, the acute episode that led to the death occurred at the child or young person's home.

#### **Risk factors associated with asthma**

Last year, the Team undertook a 10-year review of the deaths of 20 children in NSW who died from asthma between 2004 and 2013. The review found that most of the 20 children who died during the reporting period had factors that may have increased their risk of death, including:

- sub-optimal level of asthma control
- insufficient follow-up after a hospital presentation/admission for asthma
- lack of a written asthma plan or poor adherence to recommended asthma medication/asthma medication plans, and
- exposure to tobacco smoke.

The Team also identified that for the majority of the children the subject of review, multiple risk factors were evident.

Common triggers for asthma include allergens (particularly pollens, mould, dust and pet dander), tobacco smoke, exercise, air pollutants/particulates, weather patterns/changes and respiratory infections.<sup>58</sup> Research also indicates that food allergies are associated with an increased risk of asthma-related death.<sup>59</sup>

A key message from the Team's 10-year review of asthma deaths is that, even in the absence of a flare-up of symptoms, regular clinical review allows treatment to be stepped up or stepped down as needed, depending on the level of asthma control achieved.

The review is available at: http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/nsw-child-death-review/nsw-child-death-review-team-annual-report-2013

<sup>51</sup> Australian Centre for Asthma Monitoring (2011), Asthma in Australia 2011. AIHW Asthma Series no. 4. Cat no. ACM 22. AIHW: Canberra.

<sup>52</sup> HealthStats NSW, Asthma hospitalisations, http://www.healthstats.nsw.gov.au, accessed 17 July 2015.

<sup>53</sup> Australian Centre for Asthma Monitoring (2011), Asthma in Australia 2017. AIHW Asthma Series no. 4. Cat no. ACM 22. AIHW: Canberra.

<sup>54</sup> Ibid.

<sup>55</sup> Persistent asthma may be mild, moderate or severe.

<sup>56</sup> Atopy is a genetically determined state of hypersensitivity to environmental allergens

<sup>57</sup> Australian Society of Clinical Immunology and Allergy (2010), *About Asthma and Allergy*, Sydney: ASCIA http://www.allergy.org.au/patients/ asthma-and-allergy/about-asthma-and-allergy, accessed 17 July 2015.

<sup>58</sup> Vernon M.K., Wiklund I., Bell J.A., Dale P. & Chapman K.R. (2012), 'What do we know about asthma triggers? A review of the literature', *Journal of Asthma*, 49 (10): 991-998.

<sup>59</sup> Global Institute for Asthma (2014), Global Strategy for Asthma Management and Prevention, GINA: USA: GINA, http://www.ginasthma.org/, accessed 17 July 2015.

#### The Team's recommendations: asthma

#### Improving guidance for health practitioners

The Team's 10-year review of asthma identified opportunities for strengthening policy and practice relating to posthospitalisation follow-up of children with asthma, and recommended that NSW Health advise the Team on the adequacy of processes within Health for:

- identifying children/families who may require more assertive follow-up and asthma medication, and facilitating active follow-up, and
- monitoring practice and outcomes in relation to acute management by health services of asthma in children, including links to follow-up support.

In response, the NSW Government advised in 2015 that it supports the recommendation and that NSW Health will work with NSW Kids and Families, Local Health Districts and specialty networks to progress it. The Team will continue to monitor the action taken by the NSW Health to meet this recommendation.

#### Improving identification and management of asthma in schools

In regard to the 10-year review, the Team reported that half of the school-aged children in the cohort had a written asthma action plan on their school file. In some cases, the Team identified opportunities for improving the level of school-based planning and support provided to students with asthma. The Team recommended that the Department of Education and non-government school authorities review their policies or other guidance for supporting students with asthma and advise the Team on:

- the adequacy of policies/guidance to identify children with severe asthma who need a health care or other support plan;
- the adequacy of policies/guidance to ensure that health care or other support plans for children with severe asthma are developed, implemented and regularly reviewed;
- how compliance with the above policies/guidance is monitored.

The Team also recommended that the Department of Education, relevant non-government school authorities and NSW Health convene a working group to identify specific strategies that may be needed to improve the provision of information to schools by parents and carers and/or their child's treating doctor on the child's asthma diagnosis and management (such as a written asthma action plan, and information regarding recent hospitalisation for asthma).

#### **Public schools**

In relation to the adequacy of policies or other guidance for identifying and supporting children with severe asthma, the NSW Government advised the Team that the Department of Education has undertaken significant work to better support students with significant health conditions, including asthma. Key changes implemented by the Department to policies, procedures and systems for identifying and meeting the health care needs of students include:<sup>60</sup>

- A revised template which enables schools to collect more detailed information from parents/carers about their child's diagnosed health conditions and support needs. The template is included as part of the enrolment process, and for children with diagnosed asthma, allergies and/or anaphylaxis, seeks the provision of a written plan that has been developed in consultation with the child's treating doctor.
- Emphasising with parents/carers the importance of advising the school if their child has been diagnosed with a significant health condition, has presented to hospital for the condition and/or or their health care needs have otherwise changed.
- A new requirement for schools to enter information about individualised health care plans and medication requirements for children with certain conditions (including asthma and anaphylaxis) into the Department's Enrolment Registration Number System. Planned enhancements to this system in 2015 include building capacity for automated emails to be generated, thereby alerting schools to the need for review or other action relating to a child's health care plan.

The Department advised the Team that seeking asthma action plans through enrolment applications, together with reinforcing the importance of parents/carers updating the school if their child is diagnosed with a new or changed health condition, will better equip schools to plan and provide effective health care support to students.<sup>61</sup>

#### Non-government schools

In relation to asthma management in Catholic systemic schools, the Catholic Education Commission advised the Team that there are no overarching state-wide policies or guidelines for asthma management across schools; rather, each individual Diocese implements their own policies and guidelines.

60 Correspondence from NSW Department of Education to NSW Ombudsman, 25 September 2015.

61 Ibid.

Relevant school authorities in each Catholic Diocese reviewed their policies in response to the Team's recommendation and provided advice to the Team on a range of existing and new initiatives to identify, and support children and families, manage significant health conditions, including asthma.<sup>62</sup> These include:

- Most schools require and/or include prompts on enrolment forms for parents/carers to provide information about diagnosed health conditions, medication requirements and any other health-related needs.
- Schools in a number of Dioceses link information contained in individual health care plans to system-wide databases and/or electronic roll marking systems to facilitate awareness amongst staff of action required to manage conditions, and to enable monitoring of schools' compliance with relevant health-related policies and procedures.
- Requiring school staff to undergo training in how to administer asthma medication and provide first aid in the event of an acute asthma episode.
- Issuing newsletters and/or other forms of regular notices to parents that emphasise the importance of communicating to schools any changes in their child's health status.
- A high proportion of schools across the various Dioceses are recognised as 'asthma friendly' schools under the program run by Asthma Australia.

All Dioceses reported that schools are required to develop an individualised plan for children with severe asthma, in consultation with the child's parents and/or treating doctor. A majority of schools across the Dioceses have adopted templates for asthma action plans developed by Asthma Australia or the Sydney Children's Hospital.

Depending on the severity of a child's asthma, individual asthma plans are reviewed on a six or 12 monthly basis. In addition, compliance teams from Catholic Education Offices regularly audit schools' compliance with policies and procedures, which include a focus on whether schools are adequately implementing students' individual health care plans for conditions including asthma.

In relation to non-Catholic independent schools, Christian Education National (CEN), Christian Schools Australia (CSA) and the Association of Independent Schools (AIS) are organisations that support networks of respective member schools in NSW. These organisations advised the Team that an informal survey of member schools identified varying policies and procedures for identifying and supporting children with severe asthma who may need a health care or other support plan. In addition, compliance by school staff with policies and procedures for asthma management are currently monitored at the school level.

To address the Team's recommendations, these organisations are currently developing network-wide policies and procedures for identifying and supporting students with severe asthma. CEN and CSA also advised the Team that they plan to implement a monitoring framework which will involve annual compliance audits by their respective state executive officers.<sup>63</sup>

Additionally, a cross-sectoral working party has been formed to develop strategies for assisting government and non-government schools to better support students with asthma. Chaired by the NSW Ministry of Health, the working party includes representatives from the Department of Education, the NSW Catholic Education Commission, CSA, CEN and AIS.<sup>64</sup>

The Department of Education advised the Team that as a number of different asthma action plan templates currently exist, the working party is considering the need to develop a standard template for use across schools to provide 'concise and easy to follow information for asthma management and treatment of an asthma attack'.<sup>65</sup>

The Department also advised that the working party has identified other potential areas for strengthening support provided to students with asthma and their families to manage the condition at school, including the development of a Child Asthma Care Pathway. It is intended that the Pathway will identify 'an appropriate sequence of care and support steps to assist management of integrated and quality support for children and young people with asthma'. The Department anticipates that the Pathway will provide a basis for identifying the need for amendments to policy or support material for schools.<sup>66</sup>

The Team welcomes the establishment of the working party and will monitor its progress in improving supports for students with asthma.

66 Ibid

<sup>62</sup> Correspondence from Catholic Education Commission NSW to NSW Ombudsman, 26 June 2015; Correspondence from Catholic Education Office Sydney to NSW Ombudsman, 12 June 2015; Letter from Archbishop of Sydney to NSW Ombudsman, 6 June 2015; Correspondence from Bishop of Wilcannia-Forbes Diocese to NSW Ombudsman, 17 June 2015; Correspondence from Catholic Education Diocese of Wollongong to NSW Ombudsman, 19 June 2015; Correspondence from Zimmerman Services, Diocese of Maitland-Newcastle to NSW Ombudsman, 29 June 2015; Correspondence from Bishop of Armidale to NSW Ombudsman, 9 June 2015; Correspondence from Catholic Education Archdiocese of Canberra & Goulburn, 26 June 2015; Correspondence from Catholic Schools Office, Diocese of Lismore to NSW Ombudsman, 15 June 2015.

<sup>63</sup> Correspondence from Christian Education National, Christian Schools Australia and Association of Independent Schools to NSW Ombudsman dated 20 August 2015.

<sup>64</sup> Correspondence from Catholic Education Commission NSW to NSW Ombudsman, 26 June 2015.

<sup>65</sup> Correspondence from NSW Department of Education to NSW Ombudsman, 25 September 2015.

## **Recommendations 2015**

- As auspice agency of the cross-sectoral working party that has been established to identify strategies for improving school-based support to children with asthma and their families, NSW Health should provide detailed advice to the Team on the outcomes of the working party, including any action taken to develop a standard asthma action plan for use in schools.
- 2. NSW Health should consider the Team's review of asthma deaths 2004-2013 in relation to post-hospitalisation followup of children with asthma, and provide detailed advice to the Team on the adequacy of processes within Health for:
  - a) identifying children/families who may require more assertive follow-up and asthma education
  - b) facilitating active follow-up of these children/families, and
  - c) monitoring practice and related outcomes in relation to acute management by health services of asthma in children, including links to follow-up support.

## 3.8 Endocrine, nutritional or metabolic diseases

Endocrine and metabolic diseases include diabetes, cystic fibrosis and rare metabolic disorders.

In 2014, 13 children whose deaths were registered in NSW died from metabolic disorders. No deaths were attributed to endocrine or nutritional diseases.

### Age and gender and Aboriginal and Torres Strait Islander status

In 2014, there was a relatively even distribution of deaths from metabolic causes across all age groups. Most (10) of the children who died were female.

No children who died from this cause in 2014 were identified as Aboriginal or Torres Strait Islander.

As shown in the table below, over the past 15 years mortality rates from endocrine, nutritional and metabolic diseases have remained relatively stable.

# Table 25: Trends in deaths of children due to endocrine, nutritional and metabolic diseases by gender, number and rate 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	7	6	7	5	6	7	5	4	3	12	5	3	7	8	10
	(0.90)	(0.77)	(0.90)	(0.64)	(0.77)	(0.90)	(0.64)	(0.51)	-	(1.52)	(0.63)	-	(0.87)	(0.99)	(1.22)
Male	4	6	11	9	3	8	4	9	16	9	10	8	5	9	3
	(0.49)	(0.73)	(1.34)	(1.10)	-	(0.98)	(0.49)	(1.09)	(1.93)	(1.08)	(1.19)	(0.95)	(0.59)	(1.05)	-
Total	11	12	18	14	9	15	9	13	19	21	15	11	12	17	13
	(0.69)	(0.75)	(1.12)	(0.88)	(0.57)	(0.94)	(0.57)	(0.81)	(1.18)	(1.29)	(0.92)	(0.67)	(0.72)	(1.02)	(0.77)

#### Leading causes of death from endocrine and metabolic diseases

The metabolic disorders causing the deaths of children in NSW in 2014 included cystic fibrosis, Sandhoff disease, glycogen storage disease and lipid storage disorders.

While metabolic disorders are rare, many are associated with reduced life expectancy.<sup>67</sup> Most of the 13 children who died from metabolic disorders in 2014 had related liver, respiratory, circulatory or muscular complications as a result of their condition.

<sup>67</sup> Australian Institute of Health and Welfare (2014). Australia's Health 2014. Australia's health series no. 14. Cat. No. AUS 178. AIHW: Canberra.

Table 26: Leading causes of death due to endocrine, nutritional and metabolic diseases, 2014

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Other metabolic disorders 3	Other metabolic disorders 1	Other sphingolipidosis 2	Other metabolic disorders 2	Cystic fibrosis 2
Glycogen storage disease 1		GM2 gangliosidosis (Sandhoff disease) 1		Type 2 diabetes mellitus without complication 1

## 3.9 Diseases of the circulatory system

Circulatory system diseases comprise a broad range of conditions, including heart diseases, heart failure and cerebrovascular diseases.<sup>68</sup>

In 2014, eight children whose deaths were registered in NSW died as a result of diseases of the circulatory system. The mortality rate from this cause in 2014 (0.48 per 100,000 children) was the lowest since 2000.

### Age and gender and Aboriginal and Torres Strait Islander status

All of the children who died from circulatory system diseases in 2014 were either infants (4) or aged between 1-4 (2) or 15-17 years (2).

Two female and six male children died from this cause in 2014. As indicated in the table below, mortality rates for both genders from circulatory system diseases have fluctuated.

There were no Aboriginal or Torres Strait Islander children who died from circulatory system diseases in 2014.

#### Table 27: Trends in deaths of children due to diseases of the circulatory system by gender, number and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	8	8	11	4	9	8	11	10	8	7	8	8	5	6	2
	(1.03)	(1.03)	(1.41)	(0.51)	(1.16)	(1.03)	(1.42)	(1.28)	(1.02)	(0.89)	(1.01)	(1.00)	(0.62)	(0.74)	-
Male	14	21	10	6	9	11	8	11	8	7	12	10	6	8	6
	(1.72)	(2.56)	(1.22)	(0.73)	(1.10)	(1.35)	(0.98)	(1.34)	(0.97)	(0.84)	(1.43)	(1.18)	(0.70)	(0.93)	(0.69)
Total	22	29	21	10	18	19	19	21	16	14	20	18	11	14	8
	(1.38)	(1.81)	(1.31)	(0.63)	(1.13)	(1.20)	(1.19)	(1.31)	(0.99)	(0.86)	(1.22)	(1.10)	(0.66)	(0.84)	(0.48)

#### Leading causes of death due to diseases of the circulatory system

As demonstrated in the table below, cardiomyopathy was the most common cause of death of children from diseases of the circulatory system in 2014. Cardiomyopathy is a chronic disease in which the heart muscle is abnormally enlarged, thickened and/or stiffened.<sup>69</sup>

Another two children died as a result of congestive heart failure; one child died from cardiac arrhythmia and another from infective myocarditis.

<sup>68</sup> Diseases of the circulatory system do not include congenital malformations of the heart. Deaths due to congenital heart conditions are included in section 3.5.

<sup>69</sup> The Children's Cardiomyopathy Foundation USA, www.childrenscardiomyopathy.org, accessed 17 July 2015.

Table 28: Leading causes of death due to diseases of the circulatory system by age group, 2014

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Cardiomyopathy 2	Cardiac arrhythmia 1			Cardiomyopathy 2
Chronic IHD unspecified 1	Congestive heart failure 1			
Other secondary pulmonary hypertension 1				

#### Sudden cardiac deaths

The deaths of two of the eight children who died from circulatory system diseases in 2014 were considered to be sudden cardiac deaths. Sudden cardiac death is defined as 'an unexplained or presumed arrhythmic sudden death, occurring in a short time (generally within one hour of symptom onset) in a child or young person with previously unknown cardiac disease.<sup>70</sup> Sudden cardiac death is rare and typically occurs in seemingly healthy young people.

## 3.10 Infectious diseases

Infectious diseases are caused by organisms such as bacteria, viruses, parasites or fungi and can be passed directly or indirectly from person to person. Examples include bacterial diseases such as pertussis (whooping cough), meningococcal infection and sepsis; and viral infections such as viral encephalitis, viral meningitis, and measles.

In 2014, the deaths of six children registered in NSW were due to infectious diseases, representing the lowest number of deaths from this cause in the last 15 years.<sup>71</sup>

While infectious diseases are still common in Australia, deaths due to this cause have declined over the past century largely due to the vaccination program and improvements in public health.<sup>72</sup>

In 2015, the Team commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to analyse data held in the Child Death Register in relation to deaths from infectious diseases in NSW. The outcomes of the NCIRS review will be detailed in the Team's next report.

Chapter 11 below provides initial information on infectious diseases in childhood, prepared for the Team by the NCIRS.

#### Age and gender and Aboriginal and Torres Strait Islander status

The six children who died were all aged under five years of age, including two infants; three were female and three male. None of the children were identified as Aboriginal or Torres Strait Islander.

Specific infectious diseases were respiratory syncytial virus, a lower respiratory tract infection; pertussis (whooping cough); meningococcal infection; sepsis associated with pneumococcal infection; and sepsis associated with underlying chronic health conditions.

As shown in table 29, mortality rates of children who died from infectious diseases have varied over the 15-year period. Male children have generally outnumbered females in deaths from this cause.

<sup>70</sup> Commission for Children and Young People and Child Guardian (2012), *Trends and Issues Paper: Child deaths – sudden cardiac deaths,* CCYPCG: Brisbane.

<sup>71</sup> Another three children died from influenza types classified as respiratory disease. See section 3.7.

<sup>72</sup> Australian Institute of Health and Welfare (2012), Australia's Health 2012. Australia's health series no 13. Cat no AUS 156. AIHW: Canberra.

# Table 29: Trends in deaths of children due to infectious and parasitic diseases by gender, number and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	7	2	5	6	2	1	7	6	2	1	2	7	2	4	3
	(0.90)	-	(0.64)	(0.77)	-	-	(0.90)	(0.77)	-	-	-	(0.88)	-	(0.49)	-
Male	5	10	8	8	6	8	12	8	7	7	7	6	8	4	3
	(0.61)	(1.22)	(0.98)	(0.98)	(0.74)	(0.98)	(1.47)	(0.97)	(0.85)	(0.84)	(0.83)	(0.71)	(0.94)	(0.47)	-
Total	12	12	13	14	8	9	19	14	9	8	9	13	10	8	6
	(0.75)	(0.75)	(0.81)	(0.88)	(0.50)	(0.57)	(1.19)	(0.87)	(0.56)	(0.49)	(0.55)	(0.79)	(0.60)	(0.48)	(0.36)

#### Notifiable and vaccine-preventable diseases

Diseases that are defined as communicable (including vaccine-preventable and certain infectious and parasitic diseases) are required to be notified to NSW Health under the *Public Health Act 2010*. Communicable diseases are those that can be transmitted between individuals, and are often preventable through vaccination.

The National Immunisation Program Schedule outlines vaccines that are recommended by age group to protect children from a wide range of vaccine-preventable diseases, many of which are also communicable. Notification of the occurrence of these diseases can assist health authorities to monitor and control outbreaks.

In 2014, three of the diseases that resulted in the death of a child were notifiable diseases<sup>73</sup> – pertussis, meningococcal and invasive pneumococcal disease. Pertussis is vaccine-preventable, as are some types of meningococcal. Meningococcal C vaccine is included under the National Immunisation Program Schedule, and is recommended for children at 12 months. Meningococcal B vaccine has recently become available on the private market, but is not included in the schedule. Pneumococcal vaccine against 13 serotypes is included on the National Immunisation Program for infants at 6 weeks, 4 months and 6 months of age.

<sup>73</sup> The Public Health Act 2010 (NSW) requires that certain medical conditions be notified to NSW Health.

# **Chapter 4. Infectious diseases in childhood**

The following chapter has been prepared by the National Centre for Immunisation Research and Surveillance (NCIRS) for the CDRT as a precursor to an analysis of child deaths from infectious diseases over the 10-year period 2005 to 2014.

The chapter is in two parts:

- An overview of vaccination programs in Australia and sources of data for child deaths from vaccine-preventable diseases
- A literature review of recent trends in child deaths due to vaccine-preventable diseases

## 4.1 Introduction

In Australia, dramatic declines in child deaths due to infectious diseases have occurred as a result of improved living conditions, public health measures and access to healthcare. Despite large reductions in death, infections remain one of the most common acquired causes of death in childhood.

One of the most effective and cost effective measures in reducing rates of childhood infectious diseases has been vaccination. Vaccines work by stimulating the body's immune system, helping to detect and destroy the infection when it is encountered. Vaccination not only protects individuals, but also protects others in the community by increasing overall level of immunity in the population and minimising spread of infection. It is estimated that immunisation programs prevent approximately 2.5 million deaths each year worldwide. In Australia, as a result of successful vaccination programs, diseases such as tetanus, diphtheria, Haemophilus influenzae b (Hib) disease and polio are very rare.

## 4.2 History of vaccination programs in Australia

The first vaccines to be used in Australia were the smallpox, plague and typhoid. These vaccines were mostly used to control outbreaks. In Australia, mass vaccination programs commenced in the 1930s, beginning with the introduction of the diphtheria vaccine, provided to children through infant welfare centres and municipal councils and in school-based campaigns. This was followed by the diphtheria-tetanus-pertussis (DTP) vaccine in 1953. Negotiating a national consensus on scheduling took another 22 years with the commencement of a national, funded infant vaccination schedule in 1975. As shown in table 30, over the subsequent 40 years, a range of vaccines have been added to the schedule.

The current schedule, known as the National Immunisation Program (NIP) protects children against 15 different diseases. Table 31 shows the vaccines funded for all children, protecting against 13 diseases. There are two additional vaccines and one additional dose of a vaccine that are funded for certain groups: the annual influenza vaccine is funded for Indigenous children and children with specified medical conditions; a pneumococcal vaccine booster and hepatitis A vaccine is funded for Indigenous children in the Northern Territory (NT), Queensland (QLD), South Australia (SA) and Western Australia (WA).

#### Table 30: Major milestones in child vaccination programs in Australia<sup>74</sup>

Year	Milestones
1975	First uniform national infant vaccination schedule commences with: Diptheria-tetanus-pertussis vaccine at 3, 4 and 5 months of age; Measles vaccine at 12 months of age; Poliovirus vaccine at 6, 8 and 10 months of age
1982	Measles-mumps (MM) vaccine replaces measles vaccine
1989	Measles-mumps-rubella (MMR) vaccine replaces MM vaccine
1992	Second dose of MMR vaccine funded at 10-14 years
1993	Hib vaccine funded for children at 2, 4, 6, 12, and 18 months of age
1996	Hepatitis B vaccine funded for adolescents through schools and community

<sup>74</sup> National Centre for Immunisation Research & Surveillance, NCIRS vaccination history tables, www.ncirs.edu.au/provider-resources/vaccinationhistory, accessed 5 June 2015.

Year	Milestones
1998	Measles control campaign – one-off school-based catch-up
2000	Hepatitis B vaccine funded for children 0-12 months of age
2001	Pneumococcal vaccine (7vPCV) funded for Aboriginal and Torres Strait Islander children
2003	Meningoccocal C vaccine funded for children aged 12 months
2005	Hepatitis A vaccination funded Aboriginal and Torres Strait Islander children at 12-24 months of age (residing in NT, QLD, SA and WA)
	Pneumococcal vaccine (7vPCV) funded for all children at 2, 4 and 6 months of age
	Varicella vaccine funded for all children at 18 months of age
2007	Human papillomavirus vaccine (HPV) for cervical cancer commences for females through a school based program
	Oral rotavirus vaccine funded for all infants at 2, 4 and 6 months of age
2010	Seasonal influenza vaccine funded for all persons $\geq$ 6 months with risk factors for severe influenza
2011	Expanded pneumococcal vaccine (13vPCV) replaces previous pneumococcal vaccine
2013	Human papillomavirus vaccine commences for males through a school based program
	Measles-mumps-rubella-varicella (MMRV) vaccine replaces the second MMR vaccine and brought forward to 18 months of age
2015	Seasonal influenza vaccine funded for Aboriginal and Torres Strait Islander children aged 6 months to 5 years

#### Table 31: National Immunisation Program Schedule<sup>75</sup>

Age	Vaccine
Birth	Hepatitis B (hepB)
2 months	Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), Haemophilus influenzae type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV) Rotavirus
4 months	Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), Haemophilus influenzae type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV) Rotavirus
6 months	+/- Rotavirus Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), Haemophilus influenzae type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV)
12 months	Haemophilus influenzae type b and meningococcal C (Hib-MenC) Measles, mumps and rubella (MMR)
18 months	Measles, mumps, rubella and varicella (chickenpox) (MMRV)
4 years	Diphtheria, tetanus, acellular pertussis (whooping cough) and inactivated poliomyelitis (polio) (DTPa-IPV) Measles, mumps and rubella (MMR) (to be given only if MMRV vaccine was not given at 18 months)

<sup>75</sup> Australian Technical Advisory Group on Immunisation (2015), *The Australian Immunisation Handbook, 10th edition 2013*. Australian Government Department of Health: Canberra.

The Australian Childhood Immunisation Register (ACIR), established in 1996, recording the details of vaccinations given to children under seven years of age, has enabled the Commonwealth, states and territories to monitor coverage rates to inform program management and targeted immunisation efforts.<sup>76</sup> In 1997, the Immunise Australia 'Seven Point Plan' was launched to increase childhood immunisation coverage from its then level of 53 percent. The plan included incentive payments for parents/ carers and general practice, regular monitoring and evaluation of immunisation targets, and the introduction of school entry requirements. Since the plan was introduced, national immunisation coverage has risen to over 90 percent.<sup>77</sup>

The successful implementation of vaccination programs in Australia has seen dramatic reductions in cases and deaths due to vaccine-preventable diseases. Australia can report a 99 percent decline in deaths due to vaccine-preventable disease overall since the pre-vaccine era despite a three-fold increase in the Australian population over that time.<sup>78</sup>

In addition to the funded vaccines, there are a number of vaccines that have been recommended for children in the 10th edition of the *Australian Immunisation Handbook* and by the Australian Technical Advisory Group and Immunisation (ATAGI). These include the influenza vaccine which is recommended for all children under five years of age, the meningococcal B vaccine which is recommended for young children especially those under 24 months and specific vaccines for travel overseas.

# 4.3 Sources of data for child deaths due to vaccine-preventable diseases in NSW

There are three main sources of data for the monitoring of child deaths due to vaccine-preventable diseases in NSW:

- The vital statistics register of the NSW Registry of Births, Deaths and Marriages (BDM) database records deaths based on coding from death certificates. The child death register maintained by the CDRT is also based on these records.
- The NSW Notifiable Conditions Information Management System (NCIMS) database collects information on cases of notifiable diseases reported to public health authorities.
- The NSW Admitted Patient Data Collection (APDC) records hospitalisations and diagnoses, coded from hospital discharge summaries, and records death as a mode of separation from hospital.<sup>79</sup>

Each source of data has its limitations. For both BDM and APDC records, it is common practice to only report deaths where the disease of interest was recorded as the underlying cause of death. Hence, deaths where the disease of interest is a contributing cause of death are not included. The extent of underestimation due to this limitation varies with different diseases. Secondly, causes of deaths on the BDM and APDC databases are recorded using International Classification of Diseases (ICD) codes. These codes often do not have enough information to indicate whether the disease is vaccine-preventable, for example a death recorded as "Meningococcal septicaemia" is unable to distinguish between disease caused by meningococcal C, for which there is a funded childhood immunisation program and meningococcal B, for which there is not. In contrast, notifications on NCIMS, which are classified using standardised case definitions based on laboratory, clinical and epidemiological criteria, allow for the accurate identification of vaccine-preventable diseases; however recording of death on the database is inconsistent. Studies linking deaths from these different sources have highlighted the potential for data linkage to increase completeness and accuracy of reporting on deaths.<sup>80 81</sup>

## 4.4 Literature review of recent trends in mortality due to vaccinepreventable diseases, Australia

While child deaths due to many vaccine-preventable diseases are rare in Australia, deaths continue to occur due to factors such as: the relatively recent introduction of some vaccines, limitations of the vaccines, disease characteristics and deficiencies in immunisation coverage. The aim of this literature review was to collect, critically appraise and summarise available data on child deaths due to vaccine-preventable diseases in 2005-2014.

<sup>76</sup> Hull B.P., Deeks S.L. & McIntyre P.B. (2009), 'The Australian Childhood Immunisation Register – A model for universal immunisation registers?', *Vaccine*, 27(37): 5054-60.

<sup>77</sup> Ward L., Hull B.P. & Leask J. (2013), 'Financial incentives for childhood immunisation – a unique but changing Australian initiative', *Medical Journal of Australia*, 198(11): 590-2.

<sup>78</sup> Ibid.

<sup>79</sup> Mode of separation is a data element in the NSW Admitted Patient Data Collection which categorises separations as either death, or destination after discharge from hospital.

 <sup>80</sup> Georgousakis M., et al. (2015), Pertussis mortality in Australia – what has changed? Manuscript submitted to Medical Journal of Australia.
 81 Muscatello D.J., et al. (2014), 'Inaccurate ascertainment of morbidity and mortality due to influenza in administrative databases: a population-

based record linkage study', *PLoS One*: 9(5): e98446.

#### Methods

The discussion provided in the report is based on the following type of evidence:

- Evidence from a literature search on deaths due to vaccine-preventable diseases in Australia
- Additional evidence identified by experts at the National Centre for Immunisation Research and Surveillance

A literature search was performed in June 2015 using MEDLINE using combinations of the following MeSH keywords: Death, Australia and Hepatitis, Viral Human, Diphtheria, Whooping cough, Tetanus, Haemophilus influenzae type b, Poliomyelitis, Pneumococcal Infections, Rotavirus, Measles, Mumps, Rubella, Chickenpox, Meningococcal Infections, and Influenza.

Additional evidence provided by experts included disease surveillance reports, unpublished papers (in press), conference presentations and reference texts. Studies were included if they contained data on paediatric deaths in Australia from 2000 onwards. A formal literature review using multiple databases was not completed due to time constraints, but will be completed as part of the final report.

The discussion below focuses on the main diseases covered by vaccines on the NIP that continue to cause child deaths in Australia.

# Vaccine-preventable diseases with vaccines included in the National Immunisation Program

As indicated in table 30, due to the success of immunisation programs, measles, diphtheria, tetanus, *Haemophilus influenzae* type b, and polio now rarely, if ever result in child deaths in Australia.<sup>82 83 84 85 86 87</sup> Mumps, rubella, hepatitis A and B have not been included in the table below, because these conditions, although they can result in serious illness, rarely result in death among children.

 Table 32: Child deaths (< 5 years of age) recorded in death certificates as due to vaccine-preventable diseases in Australia, by five-year intervals<sup>88 89</sup>

Vaccine preventable disease	1993-1997	1998-2002	2003-2006*	2007-2011
Diphtheria	0	0	0	0
Haemophilus influenzae type b disease	13	2	0	0
Influenza	-	15	10	12
Measles	2	0	0	0
Meningococcal disease	-	59	27	20
Pertussis	9	8	2	5
Pneumococcal diseases	25	25	19	16
Poliomyelitis	0	0	0	0
Rotavirus	-	-	0	0
Tetanus	0	0	0	0
Varicella	8	2	4	<5†

\* 4-year interval rather than 5-year interval

† Since 2007, the Australian Bureau of Statistics (ABS) provides ranges when absolute numbers of deaths are low.

82 Chiu C., et al. (2010), 'Vaccine preventable diseases in Australia, 2005 to 2007', Commun Dis Intell Q Rep, Vol 34 Supplement: 1-167.

83 Brotherton J., et al. (2004), 'Vaccine preventable diseases and vaccination coverage in Australia 2001 to 2002', *Commun Dis Intell Q Rep*, Vol 28 Supplement 2: vii-S116.

<sup>84</sup> Brotherton J., et al. (2007), 'Vaccine preventable diseases and vaccination coverage in Australia, 2003 to 2005', *Commun Dis Intell Q Rep*, Vol 31 Supplement: 1-152.

<sup>85</sup> McIntyre P., et al. (2008), Vaccine preventable diseases and vaccination coverage in Australia, 1999 to 2000', *Commun Dis Intell Q Rep*, Vol 26 Supplement: i-xi, 1-111.

<sup>86</sup> Naidu L., et al. (2013), 'Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia 2006-2010', *Commun Dis Intell Q Rep*, Vol 37 Suppl: S1-95.

<sup>87</sup> National Centre for Immunisation Research & Surveillance (2015), Summary of National Surveillance Data on Vaccine Preventable Diseases in Australia, 2008-2011.

<sup>88</sup> For which vaccines are included in the National Immunisation Program.

<sup>89</sup> See footnotes 8, 9, 10, 11, 12 and 13.

#### Influenza

Influenza causes seasonal epidemics of respiratory disease. Although most symptomatic influenza infections are of mild to moderate severity, death in children can result from complications such as secondary bacterial pneumonia and exacerbation of chronic lung disease e.g. asthma. The risk of severe complications from influenza infection is higher at the extremes of age and in people with underlying medical conditions.<sup>90 91 92</sup>

Influenza vaccination is recommended for all children between six months and five years of age. However, the NIP only provides free funded influenza vaccine for Aboriginal and Torres Strait Islander children, and individuals with risk factors for severe disease.<sup>93</sup> Yet, even among children with such risk factors, vaccine coverage for influenza is likely to be low in New South Wales. A study of children attending outpatient clinics in tertiary paediatric hospitals in Sydney reported vaccine coverage rates of 41% in children with high risk conditions and 14 percent among other children.<sup>94</sup>

The exception to this is Western Australia, where after three influenza-related deaths in previously healthy preschool children in 2007, influenza vaccine was funded for all children aged six months to five years of age. This resulted in relatively high rates of vaccine uptake in the 2008 and 2009 influenza seasons; in 2010, however, influenza vaccines were temporarily suspended following an increased incidence of adverse events, resulting in a sustained decline in paediatric influenza vaccine uptake from 40 percent in 2009 to around 5 percent uptake from 2010-2012.<sup>95</sup>

Between 1997 and 2005, death certificate data recorded an average of 2-3 deaths per year due to influenza in children aged 0-4 years in Australia.<sup>96</sup> However, these figures are likely to underestimate the number of deaths due to influenza, since deaths occurring from complications of influenza may not have influenza recorded as the cause of death. A NSW study of influenza deaths in adults and children identified that of the 40 persons who had laboratory confirmed influenza and who died within +/-84 days of specimen collection, only 10 (25%) were recorded as influenza-related deaths. The other deaths were attributed to diagnoses such as pneumonia, other respiratory illness or other or unspecified infection.<sup>97</sup>

Table 33: Influenza deaths, Australia, 1997–2005, in children aged less than five years98

	1997	1998	1999	2000	2001	2002	2003	2004	2005
Influenza deaths 0-4 years	2	6	2	3	2	1	2	3	2

#### **Pneumococcal disease**

*Streptococcus pneumoniae* (pneumococcus) causes a diverse range of diseases from middle ear infection to life-threatening infections such as pneumonia, septicaemia and meningitis. The case fatality rate for invasive pneumococcal disease (IPD), defined by the isolation of pneumococcal bacteria from a normally sterile site such as blood, is around one percent in children.<sup>99</sup>

A nationally funded pneumococcal vaccination program for children was introduced first for children at high risk of IPD in 2001 (Aboriginal and Torres Strait Islander children in northern jurisdictions not including NSW and all children with specified comorbidities under the age of two years) and subsequently for all children in 2005. The vaccine protects against seven serotypes of *Streptococcus pneumoniae* (7vPCV), which together caused 85 percent of invasive pneumococcal disease before the introduction of vaccines. While the overall rate of IPD has declined, the introduction of the vaccine has resulted in a small increase in types not contained in the vaccine, a phenomenon known as 'serotype replacement'.<sup>100</sup> In 2010, a new vaccine covering 13 types of pneumococcal bacteria became available. This replaced the previous vaccine in all states

Owen R., et al. (2008), 'Annual report of the National Influenza Surveillance Scheme, 2007', Commun Dis Intell Q Rep, Vol 32(2): 208-26.

<sup>90</sup> Plotkin S., Orenstein W. & Offit P. (2012), Vaccines 6th Edition, Saunders.

<sup>91</sup> D'Onise K. & Raupach J.C. (2008), 'The burden of influenza in healthy children in South Australia', *Medical Journal of Australia*: 188(9): 510Aust, 2008, Vol 188(9): 510-313.

<sup>92</sup> Khandaker G., et al. (2014), 'Clinical epidemiology and predictors of outcome in children hospitalised with influenza A (H1N1) pdm09 in 2009: a prospective national study', *Influenza and Other Respiratory Viruses*, Vol 8(6): 636-645.

<sup>93</sup> Australian Technical Advisory Group on Immunisation (2015), *The Australian Immunisation Handbook 10th edition 2013*. Australian Government Department of Health: Canberra.

Newcombe J., et al. (2014), 'Prevalence and determinants of influenza vaccine coverage at tertiary pediatric hospitals', *Vaccine*, Vol 32(48): 6364-8.
 Blyth C.C., et al. (2014), 'Effectiveness of trivalent flu vaccine in healthy young children', *Pediatrics*, Vol 133(5): e1218-25.

 <sup>97</sup> Muscatello D.J., et al. (2014), 'Inaccurate ascertainment of morbidity and mortality due to influenza in administrative databases: a populationbased record linkage study', *PLoS One*: 9(5): e98446.

<sup>98</sup> Owen R., et al. (2008), 'Annual report of the National Influenza Surveillance Scheme, 2007', Commun Dis Intell Q Rep, Vol 32(2): 208-26.

<sup>99</sup> Plotkin S. Orenstein W. & Offit, P. (2012) Vaccines 6th Edition, Saunders.

<sup>100</sup> Williams S.R., et al. (2011), 'Changing epidemiology of invasive pneumococcal disease in Australian children after introduction of a 7-valent pneumococcal conjugate vaccine', *Medical Journal of Australia*, Vol 194 (3): 116-20.

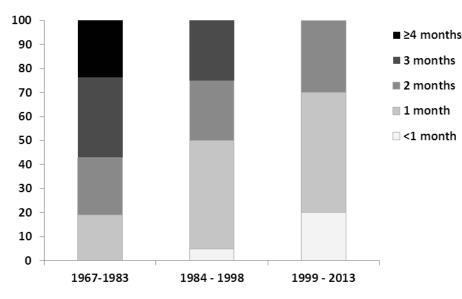
by 2011. Continued monitoring of the types of pneumococcal bacteria causing disease in Australia is important to guide vaccination policy.

From long-term surveillance of pneumococcal disease in metropolitan New South Wales (Sydney, Newcastle, Wollongong) a total of 30 deaths related to IPD (0.42% of all cases under five years of age) were identified between 1998 and 2010. Of these, only three (10%) were identified in the six-year period from 2005 to 2010 compared with 27 in the seven-year period to 2004. None of the deaths from 2005 occurred in children who had received 7vPCV – two deaths were caused by non-vaccine type disease in vaccinated children, the third was caused by vaccine-type disease in a child who was not vaccinated.<sup>101</sup>

#### Pertussis (whooping cough)

Whooping cough is a bacterial illness which causes respiratory infection characterised by paroxysmal cough. Unimmunised children and those less than six months of age who have received fewer than two vaccine doses are at greater risk of complications, such as apnoea (stopping breathing for periods of time), pneumonia, encephalitis (inflammation of the brain), seizures and death.

As shown in figure 5, deaths due to pertussis have decreased significantly since the 1900s. This is in part due to the introduction of pertussis vaccines which have been available since the 1920s in Australia. However, cyclical epidemics continue to occur because the vaccine, which protects well against severe disease, is less effective against mild illness. As immunity is estimated to last on average less than six years, this means pertussis can continue to circulate in the community.<sup>102</sup> In Australia, the primary course of pertussis vaccine in Australia commences from 6 to 8 weeks of age. Between 1967 and 2013, 80 percent of the 76 deaths recorded in death certificates as due to pertussis were of infants under 12 months. During the period 2000 to 2006, when data from death certificates and notifications were both functioning optimally, 2/16 (12.5%) of total deaths were identified only from death certificates, 4 (25%) only from notifications and 10 (62.5%) by both sources.<sup>103</sup> Among infants, the proportion of deaths recorded in children younger than two months of age i.e. in children too young to be eligible for even one vaccine dose, increased from 19% in 1967-1983 to 67% in 2004-2013.





Current strategies to reduce pertussis deaths in infants not yet protected by vaccination are cocooning (vaccination of parents and carers) and maternal immunisation (vaccination of the mother in the third trimester of pregnancy to protect infants directly through transfer of antibodies across the placenta).

<sup>101</sup> Lowbridge C., et al. (2015), 'Long term population impact of seven-valent pneumococcal conjugate vaccine with a "3+0" schedule-How do "2+1" and "3+1" schedules compare?', *Vaccine*, Vol 33(28): 3234-41.

<sup>102</sup> Wendelboe A.M., et al. (2005), 'Duration of immunity against pertussis after natural infection or vaccination', *Journal of Pediatric Infectious Diseases*, Vol 24 (Supplement 5): S58-61.

<sup>103</sup> Georgousakis M., et al. (2015), 'Pertussis mortality in Australia – what has changed?' Manuscript submitted to *Medical Journal of Australia*.. 104 Ibid.

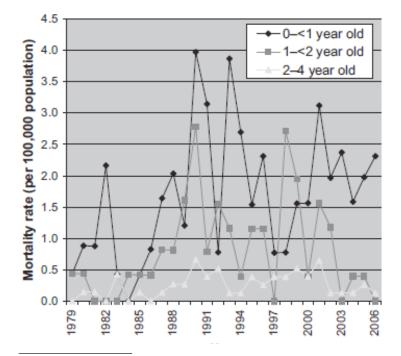
A recent study demonstrated that cocooning, implemented in response to the 2009 pertussis epidemic in NSW, had limited effectiveness, reducing risk of pertussis by 51 percent.<sup>105</sup> New evidence from the United Kingdom following a maternal immunisation program in response to a nationwide epidemic, demonstrated vaccine effectiveness of over 90 percent.<sup>106</sup> This has prompted the introduction of maternal immunisation programs in all states and territories in Australia including NSW which funded cocoon doses from 2009 and recommended vaccine in pregnancy from 2015.

#### Meningococcal disease

Meningococcal bacteria can cause septicaemia and meningitis and have the capacity to cause rapidly fatal disease in previously healthy (and usually young) persons. The case fatality rate is approximately 10-15 percent, despite advances in antibiotic therapy.<sup>107</sup>

In Australia, meningococcal types B and C are the main causes of meningococcal disease. The introduction of the meningococcal C vaccine to the Australian infant immunisation schedule in 2003 has resulted in a sustained decline in serogroup C meningococcal disease.<sup>108</sup> A meningococcal B vaccine became available in Australia in August 2013. In the Immunisation Handbook, it is recommended for infants and young children, particularly those aged less than 24 months; adolescents aged 15-19 years; people with asplenia (lack of a spleen); and laboratory personnel who frequently handle meningococcal specimens, but it has not been funded as part of the infant immunisation schedule.<sup>109</sup>

Between 1990 and 2002, there were large fluctuations in child deaths due to meningococcal disease by year. Meningococcal disease can occur in any age group but a large proportion of cases occur in those under five years of age, with a secondary peak seen in the 15-19 year age group (table 34).<sup>110</sup> In NSW, a data linkage study over an eight-year period (2000-2007) identified 26 deaths recorded on death certificates as due to meningococcal disease among children aged less than 15 years who were born in NSW. All these deaths were identified in notification data but there were four who were not identified as hospitalised, and who may have died before hospital presentation.<sup>111</sup>



#### Figure 6: Age specific death rates, 0-4 years of age, Australia, 1979-2006

105 Quinn H.E., et al. (2014), 'Parental Tdap boosters and infant pertussis: a case-control study', Pediatrics, Vol 134(4): 713-20.

Amirthalingam G., et al. (2014), 'Effectiveness of maternal pertussis vaccination in England: an observational study', *The Lancet*, Vol 384: 1521-8.
Plotkin S., Orenstein W. & Offit P. (2012), *Vaccines 6th Edition*, Saunders.

108 Chiu C., et al. (2010), 'Vaccine preventable diseases in Australia, 2005 to 2007', Commun Dis Intell Q Rep, Vol 34 Supplement: 1-167.

109 Australian Technical Advisory Group on Immunisation (2015), Advice for immunisation providers regarding the use of Bexsero (R) in Australian Technical Advisory Group on Immunisation (ATAGI) Statement. Department of Health: Canberra.

110 Simpkins D., et al. (2009), 'Modern trends in mortality from meningococcal disease in Australia', *Journal of Pediatric Infectious Diseases*, Vol 28 (12): 1119-20.

111 Gibson A., Jorm L. & McIntyre P. (2015), 'Using linked birth, notification, hospital and mortality data to examine false-positive meningococcal disease reporting and adjust disease incidence estimates for children in New South Wales, Australia', *Journal of Epidemiology and Infection*, Vol 143 (12): 1-10.

Table 34: Death rates for meningococcal disease by age group, Australia, 1979-2006<sup>112</sup>

Age group	Average annual death rate <sup>1</sup>
0-<1	1.67
1-<2	0.88
2-4	0.26
5-14	0.09
15-19	0.27
20-24	0.09
25-59	0.05
60+	0.09

1. Per 100,000 population

#### **Rotavirus**

Rotavirus causes gastroenteritis in infants and young children. The disease can range from asymptomatic infection, to mild watery diarrhoea, to severe diarrhoea with fever, dehydration, electrolyte imbalance, shock and death. The case-fatality rate is estimated to be approximately 1 in 200,000 cases of rotavirus gastroenteritis in developed countries like Australia.<sup>113</sup>

Prior to the introduction of the rotavirus vaccine in 2007, death certificates recorded a total of 13 deaths with rotavirus as the principal cause of death between 1990 and 2002 in Australia; an average of around one death per year. The majority of these deaths were in infants (under one year of age): however, three occurred in people over 70 years.<sup>114</sup> From 2006-2010, there were 1-4 deaths due to rotavirus from five jurisdictions (New South Wales, the Northern Territory, Queensland, South Australia and Western Australia). The ABS provides ranges when absolute numbers of deaths are low and the small numbers preclude further age categorisation to avoid possible individual identification.<sup>115</sup>

#### Varicella (chickenpox)

In healthy children, varicella is usually not severe, but can cause complications including secondary bacterial skin infection, pneumonia, or encephalitis. Risk factors for severe varicella include older and younger ages, and impaired immune function. From US studies, the case-fatality rate is reported as 2.6 per 100,000 cases.

In Australia, the varicella vaccine was first recommended for children in 2004; it was not until 2006 that the vaccine was funded as part of the National Immunisation Program as a single dose. Prior to the introduction of varicella vaccination, mortality records reported an average of 5.3 deaths per year from chickenpox between 1971 and 1993 in Australia. In children, deaths were disproportionately high in those younger than nine years, as demonstrated in figure 7 below.<sup>116</sup> In the US, the introduction of a single dose of the varicella vaccine to the infant vaccination program resulted in an 88 percent decline in the deaths due to varicella in all age groups, and 97% decline in deaths among children and young people under 20 years of age.<sup>117</sup> In Australia, active surveillance at four tertiary children's hospitals to determine the impact of the varicella vaccination program did not identify any deaths between 1999 and 2010.<sup>118</sup>

<sup>112</sup> Simpkins D., et al. (2009), 'Modern trends in mortality from meningococcal disease in Australia', *Journal of Pediatric Infectious Diseases*, Vol 28(12): 1119-20.

<sup>113</sup> Plotkin S., Orenstein W. & Offit P. (2012), Vaccines 6th Edition, Saunders.

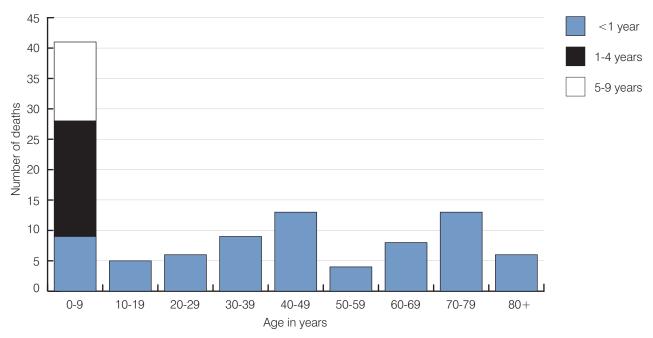
<sup>114</sup> Newall A.T., et al. (2006), 'Burden of severe rotavirus disease in Australia', Journal of Paediatric Child Health, Vol 42(9): 521-7.

<sup>115</sup> Plotkin S., Orenstein W. & Offit P. (2012), Vaccines 6th Edition, Saunders.

<sup>116</sup> Chant K.G., et al. (1998), 'Varicella-zoster virus infection in Australia', Australian and New Zealand Journal of Public Health, Vol 22(4): 413-418.

<sup>117</sup> Marin M., Zhang J.X. & Seward J.F. (2011), 'Near elimination of varicella deaths in the US after implementation of the vaccination program', *Pediatrics*, Vol 128(2): 214-20.

<sup>118</sup> Marshall, H.S., et al. (2013), 'Changes in patterns of hospitalized children with varicella and of associated varicella genotypes after introduction of varicella vaccine in Australia', *Journal of Pediatric Infectious Diseases*, Vol 32(5): 530-7.



#### Figure 7: Chickenpox deaths in Australia by age group, 1971-1993<sup>119</sup>

## 4.5 Child deaths from vaccine-preventable disease 2005-2014

For its next report, the Team has commissioned the NCIRS to:

- describe deaths due to vaccine-preventable diseases by age, gender and Indigenous status
- describe relevant factors contributing to child deaths from vaccine-preventable diseases, including biological, social, environmental and service delivery factors
- identify trends or patterns in deaths related to vaccine-preventable deaths over the period 2005-2014
- determine the validity of cause of death coding in the NSW Child Death Register, for vaccine-preventable diseases
- provide recommendations to prevent child deaths due to vaccine-preventable diseases.

#### Case review

The NCIRS will review 788 child deaths recorded in the NSW Child Death Register with infectious or parasitic causes of death and classify the likelihood (high, moderate, low) that the deaths were due to a vaccine-preventable disease. More detailed case file analysis will be performed on those triaged as high or moderate likelihood of being related to a vaccine-preventable disease.

The case files will be extracted using a standardised form, collecting information about demographics, medical comorbidities, clinical presentation and management. The data will be used to determine whether the death was due to a vaccine-preventable disease and whether preventable or modifiable factors existed on the basis of available details. The process will be overseen by an expert panel of two paediatricians, and a public health physician.

Descriptive statistical analyses of case characteristics and relevant factors will be performed using appropriate statistical packages.

## Additional data sources/data linkage

Additional data on type of organism, date of vaccination, medical contraindications to immunisation, and immune status will be sought from other sources, including the Australian Childhood Immunisation Register (ACIR) and disease notification and hospitalisation data from NSW Health. The additional data will be used to assist with the identification of child deaths due to vaccine-preventable diseases that may have been coded incorrectly and aid in determining whether the child death would have been preventable by vaccination.

These analyses are dependent on the availability and timeliness of access to these databases.

A formal literature review of deaths due to vaccine-preventable diseases in Australia will be completed as part of the final report.

<sup>119</sup> Chant K.G., et al. (1998), 'Varicella-zoster virus infection in Australia', Australia', Australian and New Zealand Journal of Public Health, Vol 22(4): 413-418.

## **Chapter 5. Sudden Unexpected Death in Infancy**

In 2014, 15 percent of infant deaths (45) were classified as Sudden Unexpected Death in Infancy (SUDI).

- While the proportion of SUDI deaths has fluctuated to some degree from year to year (ranging between 12% and 18% of all infant deaths), any changes over the last 15 years have not been significant.
- The deaths of three infants who died suddenly and unexpectedly in 2014 are also reviewable, and have been reviewed separately by the Ombudsman.

## 5.1 Defining Sudden Unexpected Death in Infancy

SUDI is a classification rather than a cause of death. The definition of SUDI varies within Australia and internationally. The Team defines SUDI as:<sup>120</sup>

Where an infant less than one year of age dies suddenly and unexpectedly. Included in SUDI are:

- Deaths that were unexpected and unexplained at autopsy (i.e. those meeting the criteria for Sudden Infant Death Syndrome).
- Deaths occurring in the course of an acute illness that was not recognised by carers and/or health professionals as potentially life threatening.
- Deaths arising from a pre-existing condition that had not been previously recognised by health professionals.
- Deaths resulting from accident, trauma or poisoning where the cause of death was not known at the time of death.

Excluded from this definition are infants who died unexpectedly as a result of injury where the cause of death was known at the time of death (such as transport fatalities and accidental drowning), and deaths that occurred in the course of a known acute illness in a previously healthy infant.

Most SUDI are attributed to Sudden Infant Death Syndrome (SIDS) or a fatal sleep accident. SIDS is a sub-category of SUDI and is a diagnosis of exclusion. The broadly accepted national definition of SIDS is:

The sudden and unexpected death of an infant under 1 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.<sup>121</sup>

## 5.2 Trends in SUDI in NSW

The infant mortality rate for SUDI in 2014 was the lowest rate since 2000. However, the total mortality rate reached a plateau from 2009-2010. This plateau reflects a rise in the mortality rate of neonates, which for 2010-2014 has returned to rates for 2000-2003.

A similar trend has been identified in the United States. The SIDS rate in the US decreased by 53% over the 10 years 1992-2001, linked to a campaign 'Back to Sleep', similar to the Australian SIDS and Kids Safe Sleeping campaign. However, from 2001 to 2006, the rate has remained constant.<sup>122</sup>

Infants who die in the post-neonate period (28 days to under one year) consistently comprise the majority of SUDI. The mortality rates for SUDI neonates and post-neonates are significantly different, with consistently higher rates for post-neonates.

<sup>120</sup> Prior to 2009, the Team restricted the SUDI definition to infants who had been placed for sleep. Since 2009, the Team has included all sudden and unexpected infant deaths. A varying number of SUDI each year occur outside of sleep.

<sup>121</sup> Krous H., et al. (2004), 'Sudden Infant Death Syndrome and Unclassified Sudden Infant Deaths: A Definitional and Diagnostic Approach', Pediatrics, Vol 114 (1):234-238 cited in SIDS and Kids (2004), First Australian SIDS pathology workshop: adoption of a national consensus for the definition of SIDS and autopsy approach to unexpected infant deaths, SIDS and Kids; Canberra.

<sup>122</sup> Moon R.Y. (2011), 'SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment', *Pediatrics*, Vol 128(5): e1341-e1367

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
	9	12	7	12	4	7	7	12	8	5	11	10	13	11	12
Neonates	(0.10)	(0.14)	(0.08)	(0.14)	(0.05)	(0.08)	(0.08)	(0.12)	(0.08)	(0.05)	(0.11)	(0.10)	(0.13)	(0.11)	(0.12)
Post	63	54	54	49	47	47	51	51	45	40	42	38	37	44	33
neonates	(0.73)	(0.64)	(0.62)	(0.57)	(0.55)	(0.52)	(0.55)	(0.53)	(0.45)	(0.41)	(0.41)	(0.38)	(0.38)	(0.44)	(0.33)
Total	72 (0.83)	66 (0.78)	61 (0.70)	61 (0.71)	51 (0.59)	54 (0.59)	58 (0.63)	63 (0.65)	53 (0.53)	45 (0.46)	53 (0.52)	48 (0.48)	50 (0.51)	55 (0.55)	45 (0.45)

#### Table 35: SUDI by neonatal status, infant mortality rate, 2000-2014

However as noted, the infant mortality rate for post-neonates has consistently declined over time, which has not been the case for neonates. As shown below, while the infant mortality rate for neonates declined during the period 2005-2009, during 2010-2014 it has returned to previous levels.

Table 36: Infant mortality rates over five-year intervals by neonatal status, 2000-2014

	Neonates	Post-neonates	Neonates (IMR)	Post-neonates (IMR)
2000-2004	44	267	0.102	0.621
2005-2009	39	234	0.082	0.489
2010-2014	57	194	0.114	0.388

## 5.3 SUDI in 2014

The majority of the SUDI occurred in the infant's own home (36). Another five infants died in the home of a relative, three infants died in hospital and one infant died while in an outdoor environment. The three hospital deaths involved infants who were in hospital following their birth, and who had not yet been discharged home. The babies were born apparently healthy; two infants deteriorated in the hours after birth and were unable to be resuscitated, and one infant was found unresponsive in their crib.

Almost all of the infants (41) were being cared for by their mother and/or father or primary carer in the period immediately preceding their death. Other infants were being cared for by grandparents or by hospital staff.

The table below provides an overview of the main demographic characteristics of infants whose sudden and unexpected deaths were registered in NSW in 2014.

The deaths of three infants classified as SUDI in 2014 are 'reviewable deaths' and have been reviewed separately by the Ombudsman. One of these deaths occurred in circumstances that are suspicious of neglect, one in circumstances that are suspicious of abuse, and one infant was in care at the time of their death.

Table 37: Key demographic and individual characteristics: deaths classified as SUDI, 2014
---

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	p
Total	45	100	0.45	0.33 - 0.60		
Gender						
Female	21	47	0.43	0.27 - 0.66	-	-
Male	24	53	0.46	0.30 - 0.69	1.1	0.82
Age						
Under 1 day	2	4	-	-	-	-
1 day-under 1 week	1	2	-	-	-	-
1 week-under 28 days	9	20	0.09	0.04 - 0.17	-	-
28 days-under 1 year	33	73	0.33	0.23 - 0.46	-	-
Aboriginal and Torres Strait Islander sta	atus					
Not Aboriginal or Torres Strait Islander	31	69	0.33	0.22 - 0.47	-	-
Aboriginal or Torres Strait Islander	14	31	2.35	1.28 - 3.94	7.1	0.00
Remoteness						
Major cities	30	67	0.39	0.26 - 0.55	-	-
Inner regional areas	11	24	0.67	0.33 - 1.19	-	-
Outer regional areas	4	9	0.76	0.21 - 1.94	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status*						
Quintile 5 (highest)	3	7	-	-	-	-
Quintile 4	7	16	0.40	0.16 - 0.82	-	-
Quintile 3	7	16	0.40	0.16 - 0.81	-	-
Quintile 2	8	18	0.40	0.17 - 0.79	-	-
Quintile 1 (lowest)	19	42	0.79	0.47 - 1.23	-	-

\* Socioeconomic status was not calculated in one case.

#### Age and gender

The 45 infants ranged in age from under one day to 11 months. Nearly two thirds (27) died during the first three months of life:

- twelve infants died in the neonatal period; most (8) of these infants were less than two weeks old. As noted above, there has been an increase in the infant mortality rate for neonates in the period 2010-2014
- eighteen infants were aged 1-3 months
- eleven infants were aged 4-6 months, and
- four infants were aged 7-11 months

Just over half (24) the infants were male.

Although there are fluctuations, across the last 15 years SUDI infant mortality rates have been consistently higher for males than females. While the mortality rate has been declining in that period, there is no significant gender difference in the decline.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	28	30	23	27	19	22	20	30	22	16	17	23	22	22	21
	(0.67)	(0.73)	(0.54)	(0.65)	(0.46)	(0.50)	(0.45)	(0.64)	(0.45)	(0.33)	(0.34)	(0.48)	(0.46)	(0.45)	(0.43)
Male	44 (0.98)	36 (0.83)	38 (0.86)	34 (0.76)	32 (0.72)	32 (0.68)	38 (0.80)	33 (0.67)	31 (0.61)	29 (0.58)	36 (0.69)	25 (0.49)	28 (0.55)	33 (0.64)	24 (0.46)
Total	72 (0.83)	66 (0.78)	61 (0.70)	61 (0.71)	51 (0.59)	54 (0.59)	58 (0.63)	63 (0.65)	53 (0.53)	45 (0.46)	53 (0.52)	48 (0.48)	50 (0.51)	55 (0.55)	45 (0.45)

#### Table 38: SUDI by gender, number and rate, 2000-2014

#### Aboriginal and Torres Strait Islander status and cultural background

Aboriginal infants were over-represented in SUDI in 2014. Almost one third (14) of the 45 infants whose deaths were classified as SUDI in NSW were Aboriginal or Aboriginal and Torres Strait Islander children.

In Australia, Aboriginal and Torres Strait Islander babies are significantly more likely than non-Indigenous babies to be born pre-term, of low birth weight, and to die before 12 months of age.<sup>123</sup> Previous research undertaken for the CDRT for the period 2002-2011 identified SIDS as the third leading cause of death for Aboriginal and Torres Strait Islander children, after conditions originating in the perinatal period and external causes. The percentage of deaths of Aboriginal and Torres Strait Islander children due to SIDS was almost twice that of non-Indigenous children.<sup>124</sup>

While Aboriginal and Torres Strait Islander children comprise around five percent of all children under one year of age,<sup>125</sup> over the past 15 years and based on identification through Births, Deaths and Marriages data, they have accounted for an average of 18 percent of all SUDI in NSW.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Aboriginal Torres Strait	13	7	12	15	11	8	12	12	7	4	7	9	8	14	12
Islander	(4.35)	(2.25)	(3.59)	(4.61)	(3.11)	(2.12)	(2.86)	(2.51)	(1.38)	(0.77)	(1.23)	(1.60)	(1.46)	(2.35)	(2.01)
Non- Aboriginal	59	59	49	46	40	46	45	51	46	38	46	39	42	41	33
Torres Strait Islander	(0.70)	(0.72)	(0.59)	(0.55)	(0.49)	(0.53)	(0.51)	(0.56)	(0.48)	(0.41)	(0.48)	(0.42)	(0.45)	(0.43)	(0.35)
not known	0	0	0	0	0	0	1	0	0	3	0	0	0	0	0
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Total	72	66	61	61	51	54	58	63	53	45	53	48	50	55	45
	(0.83)	(0.78)	(0.70)	(0.71)	(0.59)	(0.59)	(0.63)	(0.65)	(0.53)	(0.46)	(0.52)	(0.48)	(0.51)	(0.55)	(0.45)

Table 39: SUDI by Aboriginal and Torres Strait Islander status, number and rate, 2000-2014

Since 2010, there has been a steady increase in the proportion of Aboriginal and Torres Strait Islander infants whose deaths are classified as SUDI, ranging from 18.4 percent in 2010 to 31.6 percent in 2014. The proportion in 2014 is the highest in ten years (31.6%).

Table 40: Proportion of Aboriginal and Torres Strait Islander infant deaths classified as SUDI, 2000-2014
---

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
SUDI	13	7	12	15	11	8	12	12	7	4	7	9	8	14	12
Infants	44	27	32	34	28	35	40	46	34	17	38	37	27	45	38
SUDI percent	29.5	25.9	37.5	44.1	39.3	22.9	30	26.1	20.6	23.5	18.4	24.3	29.6	31.1	31.6

123 Australian Institute of Health and Welfare (2011), Aboriginal and Torres Strait Islander Health Performance Framework 2010: detailed analyses, Cat. No. AIHW 53. AIHW: Canberra.

124 NSW Child Death Review Team (2014), Causes of death of children with a child protection history 2002-2011, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

125 Australian Bureau of Statistics (2013), 3101.0 Australian Demographic Statistics NSW 2013. ABS: Canberra; Australian Bureau of Statistics (2012), Indigenous experimental population projections by age, by sex – Reference period 201. ABS: Canberra.

## **Remoteness and socioeconomic status**

Consistent with previous years, almost all (41) SUDI were infants living in major cities or inner regional areas of NSW.

Most (27) of the families of infants who died suddenly and unexpectedly resided in areas of greatest socioeconomic disadvantage (quintiles 1 and 2).

# Gestational age and birth weight

Prematurity (infants born at less than 37 weeks gestation) and low birth weight (less than 2500 grams) are recognised SIDS risk factors.<sup>126</sup>

Of the 43 infants for whom gestational age was available, almost one quarter (11) were born prematurely. Five infants were born between 31 and 33 weeks, and six infants between 34 and 36 weeks. In NSW, the average proportion of premature births over the period 2008-2012 was 7.4 percent of all births.<sup>127</sup> Most (10) of the infants who were born prematurely were post-neonates when they died,<sup>128</sup> including three twin births where one twin died.

Birth weight was available for 42 of the 45 infants who died suddenly and unexpectedly. Six infants had low birth weight, ranging from 1305 to 2300g. All six infants were also born prematurely.

# Maternal age

Young maternal age has been identified as a factor associated with SIDS.<sup>129</sup>

In 2014, two mothers of infants who died suddenly and unexpectedly were teenagers aged 18 or 19 years. In each case, the infant who died was their first child.

The age of mothers of infants who died suddenly and unexpectedly was markedly skewed towards younger mothers: 37.7% were under the age of 25 whereas only 15.6% of all births are to mothers under the age of 25 years.

## **Seasonal factors**

As shown in the table below, SUDI peak in winter (June – August) with a strong peak in July, and are lowest in summer (January – February). There has been no significant change to this pattern over the three five-year time periods.

	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEPT	ОСТ	NOV	DEC	Total
2014	0	2	5	5	3	1	6	8	5	4	3	3	45
2000-2014	55	64	66	70	57	77	97	81	70	68	58	72	835
2000-2004	17	22	20	28	20	39	30	28	27	28	25	27	311
2005-2009	19	25	24	22	14	25	35	29	21	22	13	24	273
2010-2014	19	17	22	20	23	13	32	24	22	18	20	21	251

#### Table 41: SUDI by month and five-year intervals 2000-2014

# **Child protection history**

For the period 2004-2013, the Team<sup>130</sup> identified that:

- infants with a child protection history were significantly over-represented in SUDI and had a much higher SUDI mortality rate than children without a child protection history (almost 10 times the mortality rate)
- while SUDI mortality rates for children with and without a child protection history have declined over the past decade, the only significant decline in the SUDI mortality rate was for infants without a child protection history, and
- sudden and unexpected deaths of infants with a child protection history were much more likely to have been due to external (unnatural) causes, such as accidental suffocation or strangulation.

<sup>126</sup> Ramirez T. L. & Malloy M.H. (2013), 'Sudden infant death syndrome: are we any closer to identifying which infants will be affected?' *Pediatric Health, Medicine & Therapeutics*, Vol 4: 13-21.

<sup>127</sup> Centre for Epidemiology and Evidence (2014), *NSW Mothers and Babies 2012*. NSW Ministry of Health: Sydney. The proportion of SUDI born prematurely was 9% in 2013; 15% in 2012; 17% in 2011; and 40% in 2010.

<sup>128</sup> Aged 28 days to less than one year.

<sup>129</sup> Moon R.Y. & Fu L. (2012), 'Sudden Infant Death Syndrome: An Update', Pediatrics in Review, Vol 33(7): 314-320.

<sup>130</sup> NSW Child Death Review Team (2014), *Causes of death of children with a child protection history 2002-2011*, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

Families with a child protection history have consistently been over-represented in SUDI. In 2014, over one third of the families (17) of the 45 infants who died had a child protection history. Risk of significant harm reports were made to FACS in relation to eight of the children who died. The siblings of five of the children who died had been the subject of reports to FACS. In addition, four children and/or their sibling had been the subject of a report to a Child Wellbeing Unit, or a report to FACS that did not meet the ROSH threshold but related to concerns about risk.

In 2014, the most frequently reported concerns for the 17 infants and/or their siblings included parent/carer drug and alcohol misuse (13 families); exposure to domestic violence (7); and physical harm (6). Other reported concerns for infants and/or their siblings included neglect, parent/carer mental health, and homelessness or housing issues.

Most (12) of the 17 infants from families with a child protection history were in unsafe (non infant-specific) sleep environments when they died, including infants who were sharing a sleep surface and/or had been placed on, or surrounded by, pillows and other loose items.

#### **Prenatal reports**

NSW child protection legislation<sup>131</sup> provides for the making of risk of significant harm reports about unborn children. The purpose of prenatal reporting is to:

- allow assistance and support to be provided to an expectant parent to reduce the likelihood that the child, when born, will need to be placed in out-of-home care, and
- provide early information that an unborn child may be at risk of significant harm after their birth.

The legislation also makes provision for reports to be made about children after their birth where the mother did not engage successfully with support services to eliminate or minimise the risk factors that gave risk to a prenatal report.

In 2014, seven infants whose deaths were classified as SUDI were the subject of a prenatal report/s. The most frequently reported concerns included maternal drug and/or alcohol abuse (6), lack of/poor antenatal care (3), maternal mental health (2), and transience/homelessness or poor living conditions (2).

FACS assessed prenatal reports for three of the seven infants as not meeting the threshold of risk of significant harm. Prenatal reports for each child included concerns about maternal substance abuse or poly-drug use. Two of the three families had a child protection history relating to siblings of the infant who died. In one case, a subsequent internal review by FACS found the prenatal report should have been prioritised for a response, and that if this had occurred, the report may have been allocated at the Community Services Centre based on the significant history of parental substance misuse.<sup>132</sup>

Caseworkers met face-to-face with two of the other four mothers prior to the child's birth: one matter was closed due to competing priorities following a meeting between the mother and FACS staff at the Community Services Centre; the second case was closed six days after the child's birth when the mother advised caseworkers she did not require support.

High risk birth alerts<sup>133</sup> were issued in relation to two infants. High risk birth alerts are issued in situations where FACS identifies that an unborn child is at high risk and the pregnant woman is unable to be engaged with services due to factors such as drug/ alcohol dependence or mental ill health, and/or is resistant to support intervention, and/or is transient. Birth alerts are issued to relevant health providers to ensure that FACS is advised of a birth where further protective intervention may be required.

In one case, FACS received multiple prenatal reports concerning maternal illicit substance abuse, homelessness, and risktaking behaviour, which resulted in assumption of the child's care at birth because of significant risk. In another case, the birth alert was issued in the context of siblings previously being removed from the family because of significant risk, and the mother's history of alcohol abuse; FACS closed the case due to competing priorities two days prior to the infant's birth. The infant died aged two months, while sharing a sleep surface with the mother, who had consumed alcohol and prescription medication.

NSW Health policy *Child Wellbeing and Child Protection Policies and Procedures for NSW Health*<sup>134</sup> states that its staff are uniquely positioned to identify vulnerabilities in pregnant women so that health services and other supports can be put in place with the aim of preventing the unborn child from being at risk of significant harm when born. A key principle of prenatal reporting is that NSW Health collaborates with FACS to maximise preventative and early intervention strategies to reduce risk

<sup>131</sup> Children and Young Persons (Care and Protection) Act 1998 (NSW), s 25.

<sup>132</sup> Family and Community Services, Office of the Senior Practitioner, Internal Child Death Review, March 2015.

<sup>133</sup> An unborn child high risk birth alert (HRBA) is a procedure which involves the provision of certain information under Chapter 16A of the *Children* and Young Persons (Care and Protection) Act 1998 to NSW Health and/or private health providers to enable health practitioners to make a risk of significant harm report to the FACS Helpline at the birth of a child in accordance with section 27 of the Act. A HRBA gives health providers notice that a prenatal report had been received by FACS and that there may be a risk of significant harm after the child's birth.

<sup>134</sup> NSW Health PD2013 007, Child Wellbeing and Child Protection Policies and Procedures for NSW Health, published April 2013.

of harm to a child when born. According to the policy, each Local Health District/Speciality Network should have a centralised system for the receipt and processing of HRBAs to ensure that accurate, timely and targeted information is available to Health workers providing services to pregnant women.

Records indicate that in one case, NSW Health were closely involved in attempting to stabilise the mother and minimise harm to her unborn child, including providing flexible antenatal care and other specialist services, inpatient and outpatient treatment, and collaborating with other service providers on a regular basis. In the other case, records indicate Health informed FACS of the infant's birth and provided routine post-birth services during the first week of the child's life.

# 5.4 Explained and unexplained SUDI

Deaths classified as SUDI consist of deaths where a cause is found after investigation ('explained' SUDI) and those where the cause remains unidentified after all possible investigations are completed ('unexplained' SUDI).

Identifying a cause of death for SUDI is important for a number of reasons:

- For parents/carers, to understand their loss and to provide information about possible medical or genetic implications for the family
- To identify any possible suspicious deaths
- To learn from untimely deaths and help prevent future deaths.135

Explained SUDI includes deaths from natural causes where an underlying illness or condition was not identified before death, such as undiagnosed infections, cardiovascular anomalies or rare metabolic diseases; accidental deaths associated with unsafe sleep environments; and deaths found to be due to non-accidental injury.

Unexplained SUDI includes deaths that are classified as SIDS and other ill-defined or undetermined causes.

At the time of writing, information regarding cause of death was available for just over half (26) of the 45 infants who died suddenly and unexpectedly and whose deaths were registered in NSW in 2014. Of the 26, seven deaths were explained and 19 were unexplained.

As shown in the table below, the ratio of explained to unexplained SUDI is generally flat: from 2000-2009, 76% of SUDI cases remained unexplained after autopsy. Of SUDI finalised in 2011-2014, 72% remain unexplained.<sup>136</sup> That is, on average, a cause of death was able to be determined in only one quarter of SUDI.

This is a rate well below what could be considered best practice. In examining the range of models for SUDI investigation, Garstang et. al. note that the NSW model of police-led investigation of SUDI does not comply with the best practice standards.<sup>137</sup> In comparison, a Joint Agency Approach generally has a much higher likelihood of determining a cause of death.<sup>138</sup> This approach includes:

- · death scene examination by paediatric specialists as well as police
- the taking of a detailed medical history by appropriately trained paediatric specialists
- mandatory post-mortem undertaken by a paediatric or forensic pathologists with appropriate expertise using an international standardised protocol for pathology, with additional requirements in the cases of sudden unexpected infant death<sup>139</sup>
- a multi-professional review after the post-mortem, and
- · family follow-up.

Joint Agency Approaches to SUDI investigation have led to a cause of death being determined for approximately 40 percent of cases in England and Wales.<sup>140</sup>

<sup>135</sup> Garstang J., Ellis C. & Sidebotham, P. (2015), 'An evidence-based guide to the investigation of sudden unexpected death in infancy', Forensic Science, Medicine and Pathology, Vol 11(3): 345-57.

<sup>136</sup> There were an abnormally low number of unexplained cases in 2010.

<sup>137</sup> Garstang J., Ellis C. & Sidebotham, P. (2015), 'An evidence-based guide to the investigation of sudden unexpected death in infancy', *Forensic Science, Medicine and Pathology*, Vol 11(3): 345-57.

<sup>138</sup> Baroness Helena Kennedy QC (2004), Sudden Unexplained Death in Infancy – a multi-agency protocol for care and investigation: the report of a working group convened by the royal College of Pathologists and the Royal College of Paediatrics and Child Health.

<sup>139</sup> Bajanowski T. et. al. (2007), 'Sudden Infant Death Syndrome (SIDS) – standardised investigations and classifications', Forensic Science International, Vol 165: 129-143.

<sup>140</sup> Garstang J., Ellis C. & Sidebotham, P. (2015), 'An evidence-based guide to the investigation of sudden unexpected death in infancy', *Forensic Science, Medicine and Pathology*, Vol 11(3): 345 -57.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total (%)
Explained	19	20	9	15	17	11	14	15	13	9	22	13	16	12	7	212 (25)
Unexplained	53	46	52	46	34	43	44	48	40	36	30	35	32	36	19	594 (71)
Not finalised	0	0	0	0	0	0	0	0	0	0	1	0	2	7	19	29 (3)
Total	72	66	61	61	51	54	58	63	53	45	53	48	50	55	45	835 (100)

#### Table 42: Explained and unexplained SUDI in NSW, number and rate, 2000-2014

# **Explained SUDI**

At the time of writing, the cause of death of seven of the 45 infants classified as SUDI in 2014 had been identified after investigation.

#### **External cause deaths**

Four infants died as a result of external causes. Three infants suffocated after being placed for sleep in an unsafe sleep environment. One infant died from the toxic effects of pethidine administered during labour.

#### Suffocation

None of the three infants who accidentally asphyxiated were sleeping in infant-specific bedding at the time of their death: two infants were sharing a sleep surface with parents or a parent and siblings; the other infant was placed for sleep on a couch. Loose bedding was noted in all three cases.

The families of the three infants had a child protection history, and social factors were noted for each family. None of the families had contact with health or support services during the weeks immediately prior to the infant's death.

#### **Pethidine toxicity**

Pethidine is a narcotic that can be used for pain relief in labour. Problems with the administration of opioid medication during labour are rare. However, disturbed or delayed physiological transition from the fetal to the neonatal state can be caused by the administration of intramuscular or intravenous opioids to the mother in the four hours prior to birth.<sup>141</sup> Possible problems can include inhibited respiratory drive and activity.<sup>142</sup>

The post-mortem for one infant determined the cause of death as being 'most likely due to the toxic effects of pethidine'. Pethidine was also noted in a second case, where the cause of death for the infant was determined as 'undetermined' following post-mortem. In both cases, pethidine had been administered to the mothers during labour within four hours of the birth.<sup>143</sup> Both cases remain open with the Coroner.

The deaths of both babies were subject to review (Root Cause Analysis – RCA) by the relevant Health Districts. In both cases, the RCA identified issues related to the degree of monitoring of the infant after birth. In circumstances such as the administration of pethidine to a mother within four hours of delivery of a baby, NSW Health policy requires that the infant be observed every 15 minutes for the first hour, then at appropriate intervals to monitor respiratory rate, heart rate, colour and chest recession or retraction.<sup>144</sup> Opportunities for systemic improvements at the Local Health District level were identified in both cases, and recommendations made to facilitate improved practice. In one case, RCA recommendations included a review of the usage and local standing orders of opioids in the birthing units across the Local Health District. The relevant district recently advised the Team that following this review:<sup>145</sup>

• Morphine has been endorsed as the preferred choice of opioid (over pethidine) for pain relief during labour, and the supply of pethidine in birthing units across the district will be discontinued from June 2015. The District advised that pethidine may still be administered in rare circumstances, such as in the event of morphine allergy; however, a recent standing order also endorsed the use of Fentanyl as another alternative in the case of allergy.

<sup>141</sup> NSW Health (2005), Newborn Infants with Respiratory Maladaptation to Birth – Observation and Management, PD2005 256, 27 January 2005.

<sup>142</sup> American Heart Association/American Academy of Pediatrics (2011), *Neonatal Resuscitation Textbook 6th Edition 2011*, Lesson 7, pp. 247-248. 143 NSW Health (2015), *Root Cause Analysis*.

<sup>144</sup> NSW Health (2005), Newborn Infants with Respiratory Maladaptation to Birth – Observation and Management doc PD 2005\_256.

<sup>145</sup> Correspondence from South West Sydney Local Health District to NSW Ombudsman, 28 September 2015.

- The Women's Health Clinical Stream has developed an education program titled '*The first few hours matter Keeping Newborns Safe*'. The program was delivered to clinical staff in all birthing units within the district and includes a focus on monitoring requirements.
- The District has revised the Standard Neonatal Observation Chart audit tool to improve compliance of monitoring newborns at risk, particularly the frequency of observations for infants who have received opioids within four hours of birth.

The Team notes that the NSW Ministry of Health procedure *Newborn Infants with Respiratory Maladaptation to Birth – Observation and Management,* does not appear to have been updated since 2005; it may be timely to revise the policy in light of current monitoring standards.

#### **Diseases and morbid conditions**

Three infants died as a result of natural causes: respiratory illness, infectious disease and congenital disorder.

Of the three infants:

- One infant was identified by their parent to have chronic symptoms of illness, including cough, increased respiratory effort and settling difficulties three weeks prior to their death. Initial investigations, including chest x-ray, failed to detect any significant illness. The infant was subsequently found to have died from pneumonia.
- One 35-week infant had been hospitalised a month prior to their death with Group B streptococcal meningitis. The infant completed a course of antibiotics and was reviewed by a physician a week prior to their death, with no concerns identified. The infant subsequently died as a result of Group B streptococcal late onset meningitis and sepsis, most likely recurrent meningitis.
- One infant died as a consequence of congenital neurological disorder, porencephaly. The child had been seen by a general practitioner a month prior, and a paediatrician in the two weeks prior, both for standard check-ups. No significant concerns were identified.

All three infants who died from natural causes were post-neonates, aged between two and four months.

The table below shows that two thirds (67%) of the explained SUDI in NSW over the past 15 years have been due to diseases and morbid conditions that were not identified or recognised as life-threatening before death. Accidental threats to breathing account for nearly one quarter (24%) of explained SUDI.

#### Table 43: Total number of explained causes of SUDI in NSW, 2000-2014

Cause of death	Number	Percent
Diseases and morbid conditions		
Diseases of the respiratory system	43	20
Congenital and chromosomal conditions	36	17
Other diseases and morbid conditions	24	11
Conditions arising in the perinatal period	15	7
Diseases of the nervous system	12	6
Diseases of the circulatory system	11	5
Subtotal	141	67
Accidental threats to breathing		
Accidental suffocation and strangulation in bed	40	19
Other accidental threats to breathing	11	5
Subtotal	51	24
Other external causes		
Assault	15	7
Other injury, poisoning or external causes	5	2
Subtotal	20	9
Total	212	100

# **Unexplained SUDI**

In 2005, Australia adopted a national consensus for defining SIDS and developed a nationally accepted SIDS autopsy protocol. As noted, SIDS is a classification of exclusion of cause:

the sudden and unexpected death of an infant less than one year of age, with onset of the fatal episode apparently occurring during sleep, which remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.

The cause of death of 19 infants who died suddenly and unexpectedly remained unexplained after comprehensive autopsy and examination of the circumstances of the death.

Appendix 3 provides a detailed explanation of definition of sudden infant death. In summary, the deaths of the 19 infants have been classified as:

- SIDS, as defined above, for one infant.
- SIDS Category 1A for one infant. Category 1A cases meet the requirement of the definition above, and additional features such as normal clinical history and normal growth and development.
- SIDS Category II, for 12 infants. A SIDS II classification generally indicates classic features of SIDS and also the presence of modifiable risk factors where an external cause cannot be determined with certainty, or where there are abnormalities not sufficient to identify an unequivocal cause of death.
- Five infant deaths were classified as 'ill-defined and unspecified causes of mortality'. These deaths are not classified within the SIDS framework.

The table below shows the classification of unexplained SUDI since 2000. Most SUDI are attributed to SIDS. The table does not include the 29 matters that were not yet finalised at the time of writing this report.<sup>146</sup>

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
SIDS	44	31	39	23	15	17	0	1	7	4	6	13	7	4	1	212
SIDS Category IA	0	0	0	0	0	6	4	3	3	4	2	0	0	0	1	23
SIDS Category IB	0	0	0	0	0	2	4	9	3	2	1	1	0	0	0	22
SIDS Category	0	0	0	3	6	13	21	22	18	19	10	10	5	21	12	160
SIDS Unclassified	0	0	0	1	0	1	8	5	2	2	1	1	0	0	0	21
Instantaneous death	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	2
Death <24hrs from onset of symptoms, not otherwise explained	8	7	11	18	8	3	7	3	1	1	0	0	0	0	0	67
Unattanded death	0	0	0	0	1	0	0	1	1	0	0	0	1	0	0	4
Other ill- defined & unspecified causes of mortality	1	8	2	1	2	1	0	4	5	4	10	9	19	11	5	82
Information not available	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
Total	53	46	52	46	34	43	44	48	40	36	30	35	32	36	19	594

#### Table 44: Unexplained SUDI by year, 2000-2014

146 Matters not finalised include one death in 2010, two in 2012, seven in 2013, and 19 deaths in 2014.

# 5.5 Recent illness

More than half (28) of the 45 infants who died suddenly and unexpectedly had exhibited signs of illness in the two weeks before their death. Two of these infants were neonates.

The infants displayed generalised symptoms of being unwell such as reduced appetite, changes in sleep patterns, fever, irritability and problems with settling (15); symptoms of upper respiratory tract infection and/or chesty coughs (13); diarrhoea, vomiting and/or signs of gastroenteritis (3); constipation (3); and other infections or illnesses (3). A number of infants displayed multiple symptoms of illness.

Ten of the 28 infants who exhibited recent signs of illness were seen by a medical professional during the two-week period prior to their death. None of the infants seen by medical professionals were identified as having a life-threatening illness.

Regardless of whether the infant saw a medical professional during the two weeks, just over half (15) were administered prescription or over-the-counter medication to treat illness or signs of illness, including paracetamol, cough medication, 'wind' mixtures, antibiotics, laxatives, nutritional supplements, nasal saline spray, eye ointment and rehydrating fluid.

Of note, two thirds (19) of the 28 infants who exhibited signs of illness in the two weeks before their death were exposed to tobacco smoke, compared with less than half (8) of the 17 infants who did not display any sign of illness prior to their death.

In addition, nearly half (13) the infants who had exhibited signs of illness were in unsafe sleep environments when they died – all were sharing a non-infant specific sleep surface with a parent/s or parent and siblings.

# 5.6 Modifiable risk factors associated with SUDI

Epidemiological evidence has repeatedly shown that most of the risk factors associated with SUDI are modifiable and that the implementation of simple safer sleeping practices can dramatically reduce the incidence of SIDS.<sup>147</sup> One of the key things that families and communities can do to help reduce the risk of sudden unexpected death in infancy is to avoid exposing babies to external factors associated with increased risk of SUDI. These risk factors therefore present a great opportunity for SUDI prevention in primary care.

Modifiable risk factors for SUDI include:

- infants sharing a sleep surface with another person, particularly when additional risk factors such as exposure to tobacco smoke or carer alcohol or drug use are also present. For infants up to 12 weeks, sharing a sleep surface is in itself a risk.
- placing infants in bedding that is not infant-specific
- · loose bedding or other items that can cover the infant's head or restrict breathing
- not placing infants on their back to sleep
- exposing infants to tobacco smoke
- over-heating infants.

Information about modifiable risk factors present in the infant's environment is obtained by reviewing police, health and coronial records in relation to all SUDI. NSW Police attending the death scene complete a narrative and standardised SUDI checklist concerning the circumstances of the infant's death. Hospital medical and social work staff aim to gather SUDI medical history through interviews with the infant's parents and carers.

In 2014, almost all of the infants (43) who died suddenly and expectedly were in a sleep environment. The table below illustrates the modifiable risk factors identified for each of these infants. Noting that some information was not collected, the table shows that the most common modifiable risk factor was loose bedding, followed by infants being placed in inappropriate bedding not designed for an infant, exposure to tobacco smoke, and infants sharing a sleep surface.

Almost three quarters of the infants (30) were exposed to three or more modifiable risk factors.

<sup>147</sup> NSW Health Policy Directive PD2012\_062. Maternity – Safer Sleeping Practices for Babies in NSW Public Health Organisations.

#### Table 45: Presence and frequency of modifiable risk and protective factors for SUDI in a sleep environment, 2014

	Loose bedding	Inappropriate sleep environment	Shared sleep surface	Shared sleep surface with other(s) drug or alcohol affected	Exposure to tobacco smoke	Infant over-heated	Placed for sleep on stomach or side	Total risk factors	Room sharing	Breastfed	Total protective factors
1	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	6		√	1
2	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	n.a.		5		✓	1
3	$\checkmark$	$\checkmark$	$\checkmark$	n.a.	$\checkmark$		$\checkmark$	5		✓	1
4	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	n.a.	$\checkmark$	5			0
5	✓	√	✓	n.a.	✓	n.a.		4			0
6	✓	✓	✓	n.a.		n.a.	n.a.	4		~	1
7	✓ 	✓	√ 			n.a.		4		n.a.	0
8	<ul> <li>✓</li> </ul>	✓	√ 		✓			4			0
9	√ 	✓	√ 	n.a.	✓			4		~	1
10	\[         \]     \[         \[         \]     \[         \[         \]     \[         \[         \]     \[         \[         \]     \[         \[         \]     \[         \[         \[         \[	✓	✓ ✓			n.a.		4			0
11	√ 	✓ ✓		n.a.	√	n.a.		4		~	1
12	✓ ✓	✓ ✓	✓ ✓	n.a.	✓ ✓			4			0
13	✓ ✓	✓ ✓	✓ ✓		v √			4		✓	0
14 15	v √	v ✓	v √		v √	n.a.		4		v √	1
16	v √	v √	•	<b>n</b> 0	v √	n.a. √		4		v	0
17	· ·	· · · · · · · · · · · · · · · · · · ·	$\checkmark$	n.a.	· √	n.a.		4		$\checkmark$	1
18	· ·	· · · · · · · · · · · · · · · · · · ·	· ·		•	n.a.		3		· ~	1
10	· ·	•	•		$\checkmark$	n.a.	$\checkmark$	3			0
20	· √	$\checkmark$			· · · · · · · · · · · · · · · · · · ·	n.a.	-	3			0
21	$\checkmark$				$\checkmark$	n.a.	$\checkmark$	3			0
22	$\checkmark$	$\checkmark$			$\checkmark$	ind.		3			0
23	$\checkmark$	$\checkmark$			✓	n.a.	n.a.	3			0
24	$\checkmark$	$\checkmark$	$\checkmark$					3		$\checkmark$	1
25	$\checkmark$	$\checkmark$	$\checkmark$		n.a.			3			0
26	$\checkmark$	$\checkmark$			$\checkmark$	n.a.		3		$\checkmark$	1
27	$\checkmark$	$\checkmark$	$\checkmark$					3		$\checkmark$	1
28	$\checkmark$	$\checkmark$	$\checkmark$			n.a.		3		$\checkmark$	1
29	n.a.	$\checkmark$	$\checkmark$	$\checkmark$	n.a.	n.a.		3		$\checkmark$	1
30	$\checkmark$				$\checkmark$	n.a.	$\checkmark$	3			0
31	$\checkmark$				$\checkmark$	n.a.		2			0
32	$\checkmark$			n.a.	$\checkmark$	n.a.		2		$\checkmark$	1
33	$\checkmark$					n.a.	$\checkmark$	2	n.a.	$\checkmark$	1
34	$\checkmark$				$\checkmark$			2	$\checkmark$		1
35	$\checkmark$						$\checkmark$	2	$\checkmark$	$\checkmark$	2
36							$\checkmark$	1			0
37	$\checkmark$							1	$\checkmark$	✓	2
38	$\checkmark$							1			0
39	$\checkmark$				n.a.	n.a.		1		n.a.	0
40	$\checkmark$							1		~	1
41	n.a.	$\checkmark$			n.a.	n.a.	n.a.	1		n.a.	0
42						n.a.		0	$\checkmark$	✓	2
43	n.a.							0		~	1
Note: True	38	28	22	2 child was not in a s	27	2	9	a tha alaar	4	22	26

**Note:** Two cases are not listed as one child was not in a sleep environment and in another case the sleep environment was unknown. \* n.a. = information not available

# Sleep environment

#### Key safe sleeping messages:

- Sleep baby with head and face uncovered
- Provide a **safe sleeping environment** night and day
- Sleep baby in their own safe sleeping place in the same room as an adult care-giver<sup>148</sup> for the first six to 12 months

For half (21) of the 43 SUDI in a sleep environment, three key risk factors were present: a sleep surface not designed specifically for an infant; being shared by the infant and one or more others; and with loose items present including blankets, doonas and quilts, adult pillows, soft toys, items of clothing.

Only two infants who died in a sleep environment were placed to sleep in accordance with safe sleeping guidelines – that is, alone and placed on their back, in infant-specific bedding without loose bedding or other items in the cot. One of the infants died in hospital shortly after birth of undetermined causes. The infant had been placed for sleep in a hospital crib. Subsequent Root Cause Analysis by the Health District identified no root cause or contributing factors. The second infant was found deceased in their cot, with no modifiable risk factors identified by investigating police. The infant was later found to have died as a result of pneumonia.

#### Loose bedding

Loose soft items in an infant's sleep environment pose a potential risk of suffocation or over-heating. Pillows, quilts, sheepskins and other soft surfaces have been noted to increase the risk of SIDS five-fold independent of sleep position.<sup>149</sup>

Police recorded the presence of loose bedding or soft objects in the sleep environment of the majority (38) of infants. Nearly two thirds had multiple loose items present in their sleeping environment, including blankets, doonas and quilts, adult pillows, soft toys, items of clothing, comforters and cot bumpers. Where only a single loose item was recorded, it most commonly involved blankets and pillows or toys.

#### **Shared sleep surfaces**

The sharing of sleep surfaces has consistently been identified as a risk factor for SUDI.<sup>150</sup> Sleeping in the same bed as a baby can be unsafe if the infant gets caught under adult bedding or pillows; is trapped between the wall and the bed; falls out of bed; is rolled on by someone who sleeps very deeply or who is affected by drugs or alcohol; is sleeping with a person who smokes; and/or is sleeping with a person who is extremely tired.<sup>151</sup>

Specific bed-sharing situations are considered particularly hazardous. This includes very young age (less than three months), when the infant is placed on very soft surfaces (armchairs and the like), when pillows and blankets are present, where there is more than one other sharing the bed, or when the person sharing the bed has consumed alcohol or drugs.<sup>152</sup>

Nearly half (22) the infants were sharing a sleep surface when they died. In most (16) cases, the shared sleep surface was an adult mattress or bed. Sofas and couches were the other main shared surface. Eight of the infants were less than three weeks old. Of the 22 infants who were sharing a sleep surface:

- Eleven were sharing a sleep surface with one person, either a parent (10) or sibling, and
- Eleven infants were sharing a sleep surface with two or more people, either two adults (4), or adults and other children (7). Four of these infants were sharing a sleep surface with three or four people.

In one of these cases, the adult consumed alcohol while taking prescription antidepressant medication. In addition, in a further four cases, while there was no confirmation the parent/carer had consumed alcohol or drugs at the time of the infant's death, evidence found at the scene or documented in subsequent records suggested possible carer drug use.

<sup>148</sup> SIDS and Kids, http://www.sidsandkids.org/offices/act-region/education/, accessed 17 July 2015.

<sup>149</sup> Moon R.Y. (2011), 'SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment', *Pediatrics*, Vol 128(5): e1341-e1367.

<sup>150 &#</sup>x27;Sharing a sleep surface' includes a person sharing a bed or other surface with an infant with the intention of co-sleeping; bed-sharing for the purpose of feeding or settling the infant where either the adult or the infant has fallen asleep; and persons sleeping with infants on lounges or sofas, whether the person intended to sleep with the infant or accidently fell asleep.

<sup>151</sup> NSW Ministry of Health (2012), *Having a baby*, 2nd edition, http://www.health.nsw.gov.au/Kids/Publications/having-a-baby.pdf, accessed on 17 August 2015.

<sup>152</sup> Moon R.Y. & Fu L. (2012), 'Sudden Infant Death Syndrome: An update', Pediatrics, Vol 33: 316.

Records show that in most (16) of the 22 cases, the adult(s) intended to sleep with the infant. In six cases, the carer's intent is unclear; the infants were all brought to bed or another surface for the purposes of feeding and/or settling and left in situ – either intentionally or unintentionally. In four cases, the carer fell asleep on a couch while breastfeeding or watching television.

Almost half (10) of the 22 families sharing sleep surfaces at the time the infants died were Indigenous.<sup>153</sup> Five families were from non-English speaking cultural backgrounds; one family was both Aboriginal and culturally diverse.

The table below shows that nearly half (45%) of SUDI since 2005 were infants who were sharing a sleep surface with another person or persons. While there has been some fluctuation, the overall proportion has not changed substantially during the 10-year period.

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total (%)
No	26	27	34	29	26	32	26	23	32	21	276 (53)
Yes	25	31	27	19	19	21	22	25	23	22	234 (45)
Other/not known	3	0	2	5	0	0	0	2	0	2	14 (3)
Total	54	58	63	53	45	53	48	50	55	45	524 (100)

#### Table 46: SUDI and shared sleep surface, 2005-2014

#### Infants placed alone in non-infant specific bedding

Placing babies to sleep on surfaces that are not infant-specific, even when the infant is sleeping alone, is a risk factor in SUDI.

Six infants were placed for sleep by themselves on surfaces that were not designed for that purpose. The infants were placed alone on adult beds or mattresses, a sofa/couch, in a pram/stroller,<sup>154</sup> and a fold-out child's foam seat. In all but one of these cases, loose bedding and/or soft objects were also identified in the sleep environment.

#### Infants not placed for sleep

Six of the 45 infants were not placed for sleep, but were in a sleep environment at the time of the fatal incident. All six of the infants died when their parent/s accidentally fell asleep on a couch or in bed after feeding, while trying to settle the infant, or while watching television.

## **Sleep position**

#### Key safe sleeping message:

#### • Sleep **baby on the back** from birth, not on the tummy or side<sup>155</sup>

Information on sleep position was available for 34 of the 37 infants who had been placed for sleep. Almost three quarters of the infants (25) were reportedly placed to sleep on their back and of these, seven were found on their front, and one baby was found on its side.

One quarter of the infants (9) infants were reportedly placed in an unsafe sleeping position:

- Five infants were placed on their side. Three were found on their side and two were on their front.
- Four infants, aged between one and five months, were placed on their front (prone position); all were found on their front.

As shown in the table below, of the SUDI where position placed for sleep was reported in the 10 years to 2014, over 30 percent (123 of 392) were infants who had not been placed for sleep on their back.

<sup>153</sup> Nearly three quarters (10) of the 14 Aboriginal and/or Torres Strait Islander infants who died suddenly and unexpectedly were sharing a sleep surface.

<sup>154</sup> Prams and strollers are not designed as sleeping products. Organisations such as SIDS and Kids and the Australian Competition & Consumer Commission both clearly note that babies should not be left unsupervised if they fall asleep in these devices. See for example, https://www. productsafety.gov.au/content/index.phtml/itemld/975000 and http://www.sidsandkids.org/wp-content/uploads/SafeSleeping\_Brochure.pdf, accessed 17 July 2015.

<sup>155</sup> SIDS and Kids, http://www.sidsandkids.org/offices/act-region/education/, accessed 17 July 2015.

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total (%)
On back	24	35	30	31	21	28	22	22	31	25	269 (51)
On side	7	8	14	6	10	14	8	8	8	5	88 (17)
On front	2	4	4	3	3	2	3	1	3	4	29 (6)
At breast	0	1	0	0	1	0	1	0	0	0	3 (1)
Other	1	0	1	1	0	0	0	0	0	0	3 (1)
Information not available	9	3	9	4	4	4	7	0	5	3	48 (9)
Not placed for sleep	11	7	5	8	6	5	5	11	7	7	72 (14)
Placed for sleep unknown	0	0	0	0	0	0	2	8	1	1	12 (2)
Total	54	58	63	53	45	53	48	50	55	45	524 (100)

#### Table 47: SUDI and position placed for sleep 2005-2014

#### Exposure to tobacco smoke

#### Key safe sleeping message:

#### • Keep baby **smoke free** before birth and after<sup>156</sup>

Maternal smoking during pregnancy and in the infant's environment is a major risk factor for SIDS.<sup>167</sup> Exposure to tobacco smoke has been shown to adversely affect infant arousal, and to increase the risk of premature birth and low birth weight, both of which are risk factors for SIDS. Tobacco smoke exposure is also linked to decreased lung growth and increased rates of respiratory tract infections, otitis media, and childhood asthma, with the severity of these problems increasing with increased exposure.<sup>158</sup>

Information about exposure to tobacco smoke was available for 40 of the 45 infants who died suddenly and unexpectedly and whose deaths were registered in 2014. More than two thirds (27) of the 40 infants where information was available were exposed to tobacco smoke during and/or after pregnancy.<sup>159</sup> Eleven of these infants were Aboriginal.

As shown in the table below, over the 10 years to 2014, over half of all SUDI were infants who had been exposed to tobacco smoke.

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total (%)
No	10	7	12	14	14	17	15	23	16	13	141 (27)
Yes	26	39	38	27	25	29	31	26	39	27	307 (59)
Information not available	18	12	13	12	6	7	2	1	0	5	76 (15)
Total	54	58	63	53	45	53	48	50	55	45	524 (100)

#### Table 48: SUDI and exposure to tobacco smoke, 2005-2014

#### **Protective factors**

#### Breastfeeding

Research has shown that breastfeeding is associated with a reduced risk of SIDS,<sup>160</sup> and helps with infant immunity levels.<sup>161</sup>

<sup>156</sup> Ibid.

<sup>157</sup> Moon R.Y. (2011), 'SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment', *Pediatrics*, Vol 128(5): e1341-e1367.

<sup>158</sup> DiFranza, J.R., Aligne C.A. & Weitzman M. (2004), 'Prenatal and postnatal environmental tobacco smoke exposure and children's health', *Pediatrics*, Vol 113 (Supplement 3): 1007-1015.

<sup>159</sup> The Team has used a definition that includes family members who smoke both inside and outside the family home. Research has shown that cotinine (a metabolite of nicotine) levels in the hair of children of smokers were similar whether the parent smoked inside or outside – see SIDS and Kids (2009), *Information Statement: Smoking*, National SIDS Council of Australia: Melbourne.

SIDS and Kids. National Scientific Advisory Group (NSAG) 2012, *Information Statement: Breastfeeding*. Melbourne: National SIDS Council of Australia.
 Hauck F.R., Thompson J.M., Tanabe K.O., Moon R. & Vennemann M.M. (2011), 'Breastfeeding and reduced risk of sudden infant death syndrome: a meta-analysis', *Pediatrics*, Vol 128(1): 103-110.

An Australian infant feeding survey conducted in 2010 found that breastfeeding rates drop markedly as each month passes in an infant's life. While 90% of women initiate breastfeeding, by the time babies are five months old, less than 20% are still fully breastfed, as recommended. The figure drops to 15% by six months of age.<sup>162</sup>

Information about breastfeeding was available for 41 of the 45 infants. Over half (23) of the infants were reported as being breastfed at the time of death; eight were being fed a combination of breast milk and formula. Just over one third (15) of the infants were exclusively breastfed from birth.

Eighteen infants were being formula-fed at the time they died, including eight infants who had been exclusively formula-fed from birth.

#### **Room sharing**

Room sharing refers to the practice of sleeping an infant in a cot or bassinette next to the parents' bed. Room sharing is recommended for infants less than six months of age and has been found to reduce the risk of sudden unexpected infant death.<sup>163</sup>

The National SIDS Council of Australia has reported that:

'[s]everal studies have shown that when a committed caregiver sleeps in the same room, but not the same bed with their baby, the chance of the baby dying from Sudden Infant Death Syndrome (SIDS) is reduced by 50 percent when compared to babies sleeping in a separate bedroom (solitary sleeping)'.<sup>164</sup>

Room-sharing without bed-sharing allows caregivers to be in close proximity to the infant, facilitating feeding, comforting and monitoring.<sup>165</sup>

In 2014, only four of the 16 infants placed for sleep in infant-specific bedding were sleeping next to their parents' beds.<sup>166</sup> Three of the four infants who were room sharing at the time that they died had been exposed to some form of modifiable risk.<sup>167</sup> These risk factors included loose bedding or other items such as pillows in the cot or bassinette, being placed to sleep on their front (prone position), and exposure to tobacco smoke.

# **5.7 Prevention measures and the Team's recommendations**

Considerable work has been done over many years by a range of agencies to prevent sudden and unexpected deaths of infants in NSW. SIDS and Kids notes the incidence of SUDI has declined markedly since the inception of the SIDS and Safe Sleeping campaign in the early 1990s.<sup>168</sup>

As noted above, the decline in SUDI in NSW has reached a plateau since 2009-10.

As highlighted above, however, certain infants continue to be at higher risk of sudden and unexpected death, including Aboriginal and Torres Strait Islander infants, male infants, infants who are born prematurely and/or with low birth weight, and families with a child protection history.

## Safe sleeping – the importance of clear messages

A critical factor associated with many sudden and unexpected infant deaths is the presence of modifiable risk factors, and in particular, unsafe sleeping practices. The presence of multiple risk factors in the sleeping and living environments of the infants who died in 2014 is notable.

The Team's work highlights the need for ongoing education and the importance of clear messages in relation to safe sleeping, including:

• reinforcement of safe sleeping messages to all new parents and carers, including experienced parents already caring for older children, by child and family health nurses, midwives, and other health practitioners, and

<sup>162</sup> Australian Institute of Health and Welfare (2011), Australian National Infant Feeding Survey: indicator results. AIHW: Canberra.

<sup>163</sup> Moon R.Y. (2011). 'SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment', *Pediatrics*, Vol 128(5): e1341-e1367.

<sup>164</sup> SIDS and Kids. National Scientific Advisory Group (NSAG) (2008), *Information Statement: Room sharing with a baby*. National SIDS Council of Australia: Melbourne.

<sup>165</sup> Moon R.Y. (2011), 'SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment', *Pediatrics*, Vol 128(5): e1341-e1367.

<sup>166</sup> For one infant, the location of infant-specific bedding was not stated.

<sup>167</sup> Investigations into the cause of death of the infant for whom no modifiable SUDI risk factors were identified have not yet been finalised.

<sup>168</sup> SIDS and Kids, http://www.sidsandkids.org/safe-sleeping/about-sids-and-kids-safe-sleeping/, accessed 17 August 2015.

• proactive monitoring of safe sleeping by professionals such as social workers, child protection caseworkers and family support service workers who have at-home contact with families and caregivers caring for infants under one year of age.

NSW Health policy<sup>169</sup> recognises that health professionals who have contact with babies, infants, expectant parents or families with babies or young infants have a significant role in the reduction of the incidence of SUDI by providing and promoting consistent information and modelling safer sleeping practices.

The policy requires Local Health Districts to conduct an annual audit to ensure that practice complies with policy. In 2014, the Team sought advice about the outcome of audits, including their scope and method, findings and any identified systemic issues. The Team also sought information about a review of SIDS and safe sleeping guidelines. In May 2015, the NSW government advised the Team that the NSW Health *Safer Sleep for Babies 2014* audit report is currently being finalised for provision to the NSW Ombudsman, and that NSW Kids and Families will implement the audit recommendations in 2015. Advice also indicated that draft revised SIDS and safe sleeping for infants guidelines were due to be finalised.

At the time of writing, the Team is awaiting further information.

## Improving responses to SUDI

#### Comprehensive and multidisciplinary response

A thorough and complete investigation of the circumstances surrounding SUDI is critical to establishing, wherever possible, the cause of death.

The NSW Health policy directive: *Death – Management of Sudden Unexpected Death in Infancy* was developed in response to the Team's 2005 report on SUDI.<sup>170</sup> The policy directive aims to deliver a coordinated response to SUDI by health professionals, police, ambulance, forensic pathologists and coroners.

The policy directive details a process for managing SUDI from the death of an infant through to coordinated care for the family following post-death investigation. Key aspects include:

- the infant and family transported to hospital emergency department
- the on-call social worker and paediatrician attend, and a key person hands over from police and provides care to the family
- the paediatrician certifies extinction of life, confirms with the key person that there is no objection to a post-mortem and meets the family to inform them of the processes that will take place
- the paediatrician takes a full history from the family, with a social worker present. The history taken includes questions about medical history, the infant's routine, signs of recent illness, sleeping arrangements, and other matters of relevance
- the history and a letter requesting full post-mortem is faxed to the forensic pathologist, and
- ongoing care of the family is coordinated by the paediatrician, social worker and key person.

The Team has previously found low compliance with the policy directive, particularly in relation to the conduct of interviews and the documentation of a full history. In regard to the transfer of babies and families to hospital and psychosocial support for the family, over three quarters of the cases reviewed indicated that this had occurred.<sup>171</sup>

In 2014, a record of the paediatric interview was located for 18 of the 42 deaths which occurred outside of a hospital environment. For the other 24 deaths, there was no record that an interview took place.<sup>172</sup>

The Team has previously recommended that consideration should be given to adopting a multi-disciplinary case review approach to the SUDI investigation process, including the potential for a centralised response to SUDI.

<sup>169</sup> NSW Health PD2012\_062, Maternity – Safer Sleeping Practices for Babies in NSW Public Health Organisations, published November 2012. The policy provides direction to staff on how to reduce the risk of SIDS and SUDI in settings where mothers and babies are accommodated together, and evidence-based information to caregivers on safe infant sleep practices.

<sup>170</sup> NSW Child Death Review Team (2005), Sudden Unexpected Death in Infancy: the NSW experience, NSW Commission for Children and Young People: Sydney.

<sup>171</sup> NSW Child Death Review Team (2012), Report of child deaths in 2011, NSW Ombudsman: Sydney; NSW Child Death Review Team (2013), Report of child deaths in 2012, NSW Ombudsman: Sydney.

<sup>172</sup> In four of the 24 cases, full health records were not available.

#### **NSW Health audit**

In 2013, NSW Kids and Families conducted an audit of files against the policy directive. The findings of the audit reflected the Team's findings in regard to levels of compliance.

The policy directive is currently under review. The NSW Sudden Infant Death Advisory Committee (SIDAC) is overseeing the review, which will include consideration of the underlying service model for SUDI response. The review process has incorporated the commissioning of an international evidence check on SUDI response models, and will include state-wide consultation with relevant health professionals and development of a new interim resource for clinicians to make it clear when the SUDI policy should apply.

In May 2015, the NSW Government advised that:

- a meeting of the SIDAC was convened in November 2014. The committee considered the findings of an independent review of the available evidence on international and best practice responses to the management of SUDI
- a review of the implementation of the SUDI policy directive and consideration of the most appropriate model(s) for the NSW context is underway.

The Team welcomes the review of the policy directive and its underlying service model, and urges that this process be finalised as soon as possible. This is particularly important in the context of continued low compliance with the requirements of the policy directive in relation to obtaining a comprehensive history, and the high proportion of SUDI that remain unexplained after post-mortem.

The Team notes a recent evidence-based guide to the investigation of SUDI.<sup>173</sup> Garstang et al identified four different models for SUDI investigation:

- Coroner or medical examiner-led models: The Coroner or medical examiner as the lead agency, with initial history from parents taken by police, the death scene examiner or medical examiner.
- *Healthcare-led models*: Health as the lead agency, with initial history from parents taken by a doctor, and the death scene examined by a doctor and police (independently). In this model, there is also multi-disciplinary case review within health.
- *Police-led models*: Police as the lead agency, with initial history from parents taken by police, and the death scene examined by police and a forensic team.
- *The joint agency approach*: Health and police are joint lead agencies, with initial history from the parents taken by a paediatrician and police, and a paediatrician and police jointly examine the death scene. This is the only model where an autopsy is mandatory, and there is also a multi-agency case review.

The authors note that all models, with the exception of police-led models, 'have the potential to reach best practice standards for SUDI investigation.'

#### Post-mortem examinations following unexpected deaths of infants

Determining the cause of the sudden and unexpected deaths of infants can be difficult to establish. As a result, the SUDI policy requires all post-mortems following unexpected deaths of infants to be carried out at the Department of Forensic Medicine (DOFM), where examinations can be done by a pathologist with extensive experience in infant post-mortems at a centre with appropriate facilities for special tests.<sup>174</sup>

In October 2014, the Team recommended that NSW Health Pathology provide the Team with a copy of the plan developed by the Paediatric Histopathology Working Party<sup>175</sup> to address key issues relating to perinatal and infant post-mortems, as well as advice about progress in implementing the plan.

In May 2015, the NSW government advised that it supports the recommendation and that NSW Health Pathology will 'provide an update to the Team in due course'.

<sup>173</sup> Garstang J., Ellis C. & Sidebotham, P. (2015), 'An evidence-based guide to the investigation of sudden unexpected death in infancy', *Forensic Science, Medicine and Pathology*, Vol 11(3): 345-57.

<sup>174</sup> The Team has previously raised concerns about forensic pathology delays at the DOFM in relation to paediatric cases, and the high number of SUDI that remain unexplained after autopsy and investigation. In May 2014, NSW Health advised the Team that the Department of Forensic Medicine had put measures in place to address delays. In September 2015, NSW Health advised that as a result of these measures, the average time for completion of SUDI cases reduced from 148 days in 2013-14 to 101 days in 2014-15.

<sup>175</sup> The working party was established by NSW Health Pathology and Sydney Children's Hospital Network in November 2013.

In September 2015, NSW Health advised the Team that the Paediatric Histopathology Working Party has refined its focus to concentrate on the delivery of perinatal (stillborn) post-mortem services.<sup>176</sup> NSW Health further advised that the working party identified this as its key challenge, given the *'progress made in reducing delayed reporting of paediatric coronial post-mortem cases'*.

In addition, NSW Health Pathology has recently commissioned an external consultant health planner to develop a service model for the delivery of perinatal post-mortem services in NSW and a steering committee has been established to oversee this work.<sup>177</sup>

#### **Targeting high risk populations**

Infants from Aboriginal and Torres Strait Islander families, and those from families with a child protection history, are at increased risk of SUDI. Six of the 17 families with a child protection history in 2014 were also Aboriginal and/or Torres Strait Islander.

Reviews of SUDI in 2014 found there was at least one modifiable risk factor present in the sleep environment of every infant from both groups.

For families with a child protection history, 14 of the 17 infants had three or more modifiable risk factors, including loose bedding (16), exposure to tobacco smoke (16), inappropriate bedding (11), co-sleeping (7) and being placed for sleep on their side or stomach (6); two of the infants were sharing a sleep surface with an adult who was drug or alcohol affected. For most of these infants (11), no protective factors were identified.

Aboriginal and Torres Strait Islander infants had a similar combination of multiple risk factors present. Eleven of the 14 infants had three or more modifiable risk factors, including loose bedding (14), exposure to tobacco smoke (11), inappropriate bedding (10), sharing a sleep surface (10), and being placed for sleep on their side or stomach (3). For almost one third (5) of these infants, no protective factors were identified.

For the six families with a child protection history who were also Aboriginal and/or Torres Strait Islander, the level of risk was higher; multiple risk factors were identified in the sleep environment of every infant, with the combination of loose bedding, a shared/inappropriate sleep surface and exposure to tobacco smoke being the most frequent (4 of the 6 infants).

In 2012, the Team recommended that Community Services conduct a cohort review of SUDI where the infant's family had a child protection history. The Team recommended that the review develop targeted strategies and training resources to assist caseworkers to assess risk for infants and provide casework services to at-risk families.

The review was completed in 2014. In November 2014, Family and Community Services (FACS) published their report *Safe Sleeping: Supporting parents to make safer choices when placing their baby to sleep.* The report included the results of the agency's review of the deaths of 108 infants known to Community Services who died suddenly and unexpectedly in the five-year period 2008-2012.

The review found there was at least one modifiable risk factor known to increase the risk of SUDI in nearly all the deaths reviewed, and three or more modifiable risk factors were identified in over three quarters of the deaths.

The report noted the critical role of field staff in assessing safety in a baby's sleeping environment, and the need for staff to be able to provide parents and carers with well-informed and unambiguous messages about safe sleeping. Current initiatives noted include:

- Development of a one-day training package for Aboriginal caseworkers, managers casework and casework specialists in collaboration with SIDS and Kids NSW and Victoria, which was piloted in 2013 and 2014. The package was intended to enhance the knowledge, skills and confidence of Aboriginal staff to deliver clear and consistent messages about safe sleeping to Aboriginal families and during cultural consultations with non-Aboriginal staff. Following the pilots, a decision was made to revise the training package to a format suitable for delivery to all frontline staff in 2014-15.
- Development of a variety of safe sleeping resources in partnership with NSW Health and the FACS Aboriginal Services Branch in 2013. The resources specifically target risks associated with sharing a sleep surface with a baby when affected by alcohol or other drugs. In June 2014, 150 safe sleeping Aboriginal and general resource kits consisting of posters, door hangers and wallet sized cards were distributed to all CSCs. The kits were also distributed to NGOs and throughout NSW Health districts.

The review resulted in six recommendations which 'aim to support continued learning about SUDI and safe sleeping, and to ensure that field staff are aware of the current information about the issue'. The recommendations focus on distributing learning resources to FACS staff, including the development of an online training package and other training initiatives, and joint work with NSW Health.

<sup>176</sup> Correspondence from NSW Health to NSW Ombudsman, 25 September 2015.

<sup>177</sup> Ibid.

In the context of the high number of SUDI involving co-sleeping in high risk families, the Team notes initiatives in New Zealand and Cape York to provide practical support to prevent SUDI in Indigenous communities.

In New Zealand, Maori infants are over-represented in SUDI. In 2006, a program was established to distribute wahakura – a woven bassinette style flax basket – to Maori mothers who smoked in pregnancy, with the aim of mitigating the risk of bed-sharing. The wahakura is placed within an adult bed, providing a safe a sleeping place for the infant.<sup>178</sup> More recently, polypropylene safe sleep pods,<sup>179</sup> based on the wahakura, are used in the New Zealand sleep pod program. The pods are distributed with a thin mattress and safe sleeping messages to families considered at risk.<sup>180</sup>

A number of evaluations have indicated high levels of acceptability of safe sleep pods, and retention of safe sleeping knowledge and behaviours with such a device.<sup>181</sup>

In late 2013, in the context of Indigenous families often preferring to co-sleep, a safe sleep pod program was established in Cape York by the Apunipima Cape York Health Council. Similar to New Zealand, the program has three elements; the pod to provide a zone of protection for the infant, a 'rules of protection' safety briefing and practical safe sleep information, and 'empowering families'.<sup>182</sup>

# 5.8 Recommendations 2015

The Team recommends:

- 1. **NSW Health** should review the policy directive *Newborn Infants with Respiratory Maladaptation to Birth Observation and Management*, with a view to updating procedures to reflect contemporary observation and monitoring standards for potential opiate overdose.
- 2. **FACS** and **NSW Health** should jointly consider initiatives in other jurisdictions that specifically target high risk populations, with a view to considering their applicability to NSW. This should include consideration of the findings emerging from safe sleep pod programs in New Zealand and Cape York.
- 3. In relation to the review of the *Death Management of Sudden Unexpected Death in Infancy* policy directive and model of response to SUDI, **NSW Health** should provide advice to the Team on:
  - a) the findings of the review, including the outcomes of consideration of the potential for NSW to adopt a more centralised response to SUDI, and a multidisciplinary case review approach to the SUDI investigation process, and
  - b) any action NSW Health intends to take in response to the findings.
- 4. In relation to the promotion of safe sleeping practices, **NSW Health** should provide detailed advice to the Team on:
  - a) the outcome of the audits conducted by Local Health Districts to assess compliance with the *Maternity Safer Sleeping Practices for Babies in NSW Public Health Organisations* policy directive. The advice should include **NSW Health** assessment of:
    - i) the adequacy of the audits, including the scope and method (such as the use of spot-checks)
    - ii) the findings of the audits regarding compliance with the policy requirements, and
    - iii) whether there are any systemic issues identified by the audits and, if so, the actions NSW Health will take in response.
    - iv) the progress of **NSW Health** work with SIDS and Kids to review Health's Sudden Infant Death Syndrome (SIDS) and safe sleeping for infants guidelines and provide guidelines to community-based staff.
- 5. In relation to post-mortem examinations following unexpected deaths of infants, **NSW Health** should provide to the Team:
  - a) a copy of the plan developed by the Paediatric Histopathology Working Party to address key issues relating to perinatal and infant post-mortems, and
  - b) advice about progress in implementing the plan.

181 Ibid.

<sup>178</sup> Abel S. & Tipene-Leach D. (2013), 'SUDI prevention: a review of Maori safe sleep innovations for infants', New Zealand Medical Journal, Vol 126 (1379).

<sup>179</sup> A safe sleep pod is a small bed or pod that can be placed in an adult bed but maintains a safe sleeping space for babies.

<sup>180</sup> Pepi-pod sleep space program, http://www.changeforourchildren.co.nz/pepi\_pod\_programme/home, accessed 17 August 2015.

<sup>182</sup> Cape York Health Council, http://www.apunipima.org.au/news-events/item/487-apunipima-pepi-pod-program-shortlisted-for-nursing-award, accessed 17 August 2015.

- 6. In relation to **FACS**' cohort review of SUDI where the infant's family had a child protection history, the agency should provide advice to the Team on:
  - a) Progress in the development and publication of an online training package on SUDI
  - b) Delivery of training to FACS field staff in relation to work with culturally and linguistically diverse families
  - c) The findings of any audit of training delivery
  - d) The outcome of discussions between the Office of the Senior Practitioner and the Helpline relating to the current Structured Decision Making tool to better support Helpline staff in identifying risk
  - e) The outcome of meetings with **NSW Health** to establish consistent cross-agency messages on safe sleeping and barriers to this.

# **Chapter 6. Injury-related deaths**

In 2014, 80 children died from external (injury-related) causes. Almost two thirds (49) of the deaths were due to unintentional injury. The deaths of 31 children were intentional; 22 were due to suicide and nine occurred in circumstances of abuse.

The mortality rate for external cause deaths in 2014 of 4.75 per 100,000 children represents the lowest rate since the Team began in 1996. The previous lowest mortality rate of 4.97 per 100,000 children was observed in 2013.

This chapter summarises the main features of all deaths from external causes. Subsequent chapters will provide more detailed discussion of specific external causes.

The injury-related deaths of 19 children are 'reviewable' deaths and have been reviewed separately by the Ombudsman, including nine children who died as a result of unintentional injury, one child who died by suicide and nine children who died in circumstances of abuse.

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	p
Total	80	100	4.75	3.77 - 5.92	-	-
Gender						
Female	40	50	4.89	3.50 - 6.66	-	-
Male	40	50	4.62	3.30 - 6.30	0.9	0.80
Age						
Under 1 year	10	13	10.79 (IMR = 0.10) †	5.17 - 19.84	-	-
1-4 years	16	20	4.07	2.33 - 6.61	-	-
5-9 years	11	14	2.32	1.16 - 4.15	-	-
10-14 years	13	16	2.90	1.54 - 4.95	-	-
15-17 years	30	38	10.96	7.30-15.64	-	-
Aboriginal and Torres Strait Islander sta	tus					
Aboriginal or Torres Strait Islander	12	15	13.12	6.78 - 22.92	3.1	0.00
Not Aboriginal or Torres Strait Islander	68	85	4.27	3.32 - 5.42	-	-
Remoteness*						
Major cities	48	60	3.92	2.89 - 5.20	-	-
Inner regional areas	18	23	5.41	3.21 - 8.56	-	-
Outer regional areas	12	15	11.44	5.91 - 19.98	-	-
Remote areas	1	1	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	16	20	4.17	2.38 - 6.77	-	-
Quintile 4	13	16	4.50	2.40 - 7.70	-	-
Quintile 3	11	14	3.80	1.90 - 6.80	-	-
Quintile 2	17	21	5.33	3.11 - 8.54	-	-
Quintile 1 (lowest)	22	28	5.65	3.54 - 8.56	-	-

\*Remoteness was not calculated in one case

\*\*Socioeconomic status was not calculated in one case

† Infant mortality rate

# 6.1 Age, gender and Aboriginal and Torres Strait Islander status

The number of female children who died as a result of external causes in 2014 equalled the number of males. Previously, male deaths in this category have consistently outnumbered those of females. As table 50 shows, the mortality rate for external cause deaths of females in 2014 (4.89 per 100,000 children) also exceeded that for males (4.62 per 100,000 children) for the first time in the period 2000-2014.

Young people aged 15-17 years comprised the largest number (30) of deaths due to external causes, and children aged 1-4 comprised the second largest number of these deaths (16).

Of all 80 deaths, 12 children (15 percent) were identified as Aboriginal and Torres Strait Islander. The mortality rate due to external causes of Indigenous children (13.2 per 100,000 children) was more than three times that of non-Indigenous children (4.27 per 100,000 children).

Table 50: Trends in deaths from all external causes by gender, number and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	58	51	39	47	52	49	27	44	31	34	32	37	29	29	40
	(7.47)	(6.53)	(5.00)	(6.05)	(6.71)	(6.33)	(3.48)	(5.64)	(3.95)	(4.31)	(4.02)	(4.64)	(3.61)	(3.57)	(4.89)
Male	118	94	101	88	65	74	93	69	67	65	70	58	59	54	40
	(14.47)	(11.44)	(12.31)	(10.76)	(7.98)	(9.08)	(11.39)	(8.39)	(8.10)	(7.80)	(8.33)	(6.87)	(6.93)	(6.28)	(4.62)
Total	176 (11.06)	145 (9.05)	140 (8.75)	135 (8.46)	117 (7.36)	123 (7.74)	120 (7.54)	113 (7.05)	98 (6.08)	99 (6.10)	102 (6.24)	95 (5.79)	88 (5.32)	83 (4.97)	80 (4.75)
	(11.06)	(9.05)	(0.75)	(0.40)	(7.30)	(1.14)	(7.54)	(7.05)	(0.08)	(0.10)	(0.24)	(5.79)	(5.32)	(4.97)	(4.75)

# 6.2 Remoteness and socioeconomic status

In 2014, almost all injury-related deaths occurred in major cities or regional areas. Two thirds of injury-related deaths of children in NSW occurred in major cities (48, 60%).

Consistent with previous years, the rate of death of children in outer regional areas in 2014 (11.44 per 100,000 children) was twice the rate of deaths in inner regional areas, and was significantly higher than the rate in major cities.

There was no significant difference in mortality rates between children who lived in areas of greatest socioeconomic disadvantage and those who lived in areas of lowest socioeconomic disadvantage.

# 6.3 Child protection history

Children with a child protection history in NSW have a higher rate of intentional and unintentional injury-related death than children from families with no such history. Drawing on the child death register for the 10-year period from 2002 to 2011, mortality rates from external causes were 2.8 times as high for children with a child protection history.<sup>183</sup> In particular, for children with a child protection history:

- Suicide rates were 4.1 times the mortality rate
- Assault rates were 6.3 times the mortality rate
- Drowning was 2.7 times the mortality rate

This was reflected in 2014; one third of the children (27) who died from injury-related causes had a child protection history. The children died as a result of:

- Unintentional injury: threats to breathing (7), drowning (6), transport (4)
- Suicide: 7
- Abuse-related circumstances: 3

<sup>183</sup> NSW Child Death Review Team (2014), Causes of death of children with a child protection history 2002-2011, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

# 6.4 Unintentional external causes

In NSW in 2014, the registered deaths of 49 children resulted from unintentional injury, a rate of 2.9 per 100,000 children. Injury is also a major cause of hospitalisation for children. For the period 2010-11 to 2012-13, there were about 51,000 hospitalisations of children and young people due to injury and poisonings each year (2,172 per 100,000 population, or 10.5 percent of all hospitalisations).<sup>184</sup>

Children are at greater risk of unintentional injury for a variety of reasons, often strongly associated with their age, stage of development, the types of activities they engage in, and how they interact with their environment. Most childhood injury is preventable.

# Leading injury-related causes of death

Consistent with previous years, the leading external cause of death for children in NSW was transport fatalities (23 children). Ten children died as a result of unintentional suffocation or other threats to breathing, and a further nine children drowned. These deaths are examined in chapters 6, 7 and 8.

# Other unintentional injury

Another seven children died as a result of injury that occurred in diverse circumstances.

- Three of the deaths involved teenagers one young person died from an overdose of illicit drugs whilst engaging in risk-taking behaviour; another was struck by lightning; and one died as a result of medical complications during surgery.<sup>185</sup>
- Two children aged seven to eight years died as a result of accidents at school: one child was struck by a falling tree limb, and one child died after being accidentally knocked over and hitting their head on a hard surface.
- The other two deaths involved infants: one child died in a fall from a height; the other child died shortly after birth from the toxic effects of medication given to the mother during labour. The latter is considered in chapter 5.

Below, we discuss issues arising from two of these cases.

#### Falls from height

Unsafe balconies and decks have been associated with a number of fall-related deaths in NSW and other states.<sup>186</sup> In 2014, one child died after falling from a balcony when the balustrade gave way.

Balconies and decks, like all parts of homes and other buildings, should be subject to regular inspection and maintenance to keep them in good repair and to identify emerging problems. Under NSW tenancy laws, landlords must provide and maintain rented premises in a reasonable state of repair. When a tenancy starts, faults or damage should be noted on the condition report that is completed and signed by both parties. However, routine visual inspections by owners, real estate agents and tenants may not be able to identify underlying structural weaknesses in balconies and decks.

There is currently no requirement for landlords to conduct regular building inspections by a qualified builder or engineer to inform decisions about maintenance.

In May 2014, NSW Fair Trading released a document titled 'Deck and balcony safety: A practical maintenance and safety guide for your home'. This document highlights the need to be particularly conscious of safety with decks and balconies as they are often above ground level, increasing the risk of serious injuries from accidents. The document also provides guidance on common problems that arise with balconies, including damage caused by insects, water and rot, coastal and corrosive effects, and stresses related to heavy loads. The guide notes that decks and balconies must be inspected to identify necessary maintenance or repairs, and recommends inspection by experts such as licensed builders, building inspectors, structural engineers, architects, and building surveyors. The document also provides guidance to those who are renting and about how to seek action from the owner.<sup>187</sup>

<sup>184</sup> Centre for Epidemiology and Evidence (2014), The Health of Children and Young People in NSW: Report of the Chief Health Officer 2014. NSW Ministry of Health: Sydney.

<sup>185</sup> NSW Health completed a root cause analysis in relation to child who died from medical complications during surgery. The analysis did not *...identify any conclusive root causes for the event*', however, noted opportunities for system improvement, including: reviewing of the use of certain medication administered during surgery; reviewing the contents and use of anapylaxis boxes on resuscitation trolleys; reviewing procedures for recording the resuscitation of paediatric patients; and ensuring that reporting to the Therapeutics Goods Administration occurs as required.

<sup>186</sup> NSW Fair Trading (2014), Deck and balcony safety: A practical maintenance and safety guide for your home, http://www.fairtrading.nsw.gov.au/ ftw/About\_us/News\_and\_events/Whats\_new/Deck\_and\_balcony\_safety.page, accessed 17 August 2015.

<sup>187</sup> Ibid.

In addition to balcony maintenance, the case noted above also raises issues in relation to compliance with building consent orders and the need for local councils to have effective monitoring systems to check on the progress of work when construction certificates are issued, and where a final inspection/approval has not been requested.

The Team will consult with the Office of Local Government and undertake further work on this issue.

#### **Tree hazards in schools**

In 2014, a large tree branch fell from a gum tree in the grounds of a primary school, causing the death of one student, and injuring a teacher and two other students.

The Department of Education subsequently engaged a qualified arborist to inspect the tree, and others on the school's grounds; the damaged tree and two other trees were removed. Shortly after this, the Department directed all public school principals to have arborists review all trees overhanging school buildings and areas where students and staff congregated.

At the time of writing, the child's death remains open before the Coroner. The Team will await the outcomes of the coronial inquiry before further consideration of the issues raised in this matter.

# 6.5 Suicide and abuse-related deaths

In NSW in 2014, 22 children and young people died by suicide. These deaths are examined in detail in chapter 10. Another nine children died as a result of abuse or in circumstances suspicious of abuse. These deaths are reviewed in detail by the Ombudsman as 'reviewable' deaths, and are considered in this report at chapter 11.

# Chapter 7. Transport

The deaths of 23 children in transport incidents were registered in 2014.

Transport-related deaths were the leading external cause of death of children aged 1-4 years, and the second leading external cause of children 5-9 years (with drowning) and young people aged 15-17 years.

Of the 23 fatalities:

- over half (13) of the children died in motor vehicle incidents. All of these incidents occurred on a public road:
  - nine of the children were passengers
  - four children were riding or controlling a vehicle at the time of the incident
- · eight children were pedestrians
- one child was riding a bicycle on a public road, and
- one child was a passenger in a light plane.<sup>188</sup>

# 7.1 Trends in transport deaths of children in NSW, 2000-2014

As shown in table 51, over the 15 years to 2014, 711 children and young people have died in transport-related incidents in NSW.

The 23 deaths in 2014 represent the lowest number of deaths and lowest mortality rate of children and young people in transport fatalities in NSW since 2000. The rate of death of children from transport fatalities has declined by 73 percent between 2000 (5.1 per 100,000 children) and 2014 (1.37 per 100,000 children).

Crash data from the NSW Centre for Road Safety shows that 42,832 children under the age of 18 were injured in transportrelated incidents between 1999 and 2013. The data also shows a 45 percent decrease in road transport injuries for children aged 0-17 years over the 15-year period. The most significant decrease occurred for children aged 10-14 years (50 percent) and 15-17 year olds (46 percent).<sup>189</sup>

Historically, the Child Death Register shows that passenger deaths are the single largest grouping of all transport fatalities; however, the overall rate of death has shown significant decline across the past 15 years. Pedestrian deaths have remained constant since 2007, with the mortality rate now approaching that of passenger deaths.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Pedestrian	25 (1.57)	21 (1.31)	13 (0.81)	12 (0.75)	12 (0.76)	8 (0.50)	11 (0.69)	7 (0.44)	6 (0.37)	6 (0.37)	7 (0.43)	8 (0.49)	6 (0.36)	8 (0.48)	8 (0.48)	158
Driver (all vehicles)	12 (0.75)	11 (0.69)	8 (0.50)	11 (0.69)	5 (0.31)	11 (0.69)	12 (0.75)	11 (0.69)	9 (0.56)	9 (0.55)	7 (0.43)	8 (0.49)	9 (0.54)	9 (0.54)	4 (0.24)	136
Passenger	37 (2.32)	27 (1.69)	32 (2.00)	32 (2.01)	28 (1.76)	23 (1.45)	32 (2.01)	17 (1.06)	12 (0.74)	23 (1.42)	18 (1.10)	13 (0.79)	19 (1.15)	12 (0.72)	9 (0.53)	334
Cyclist	2	5 (0.31)	5 (0.31)	1	5 (0.31)	3	2	6 (0.37)	2	2	1 -	0	1	1	1 -	37
Other	4 (0.25)	2	4 (0.25)	2	4 (0.25)	2	8 (0.50)	6 (0.37)	4 (0.25)	2	2	1	4 (0.24)	0	1 -	46
Total	80 (5.03)	66 (4.12)	62 (3.87)	58 (3.64)	54 (3.40)	47 (2.96)	65 (4.08)	47 (2.93)	33 (2.05)	42 (2.59)	35 (2.14)	30 (1.83)	39 (2.36)	30 (1.80)	23 (1.37)	711

 Table 51: Trends in deaths of children due to transport incidents by user type – number and rate, 2000-2014

189 Advice provided by Transport for NSW, the Centre for Road Safety, 8 September 2014.

<sup>188</sup> This matter is the subject of current proceedings and for this reason, consideration of contributory or prevention strategies will be deferred to a later report.

# 7.2 Children who died in 2014

The table below provides an overview of the demographic characteristics of the children who died in transport fatalities, and whose deaths were registered in 2014.

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	p
Total	23	100	1.37	0.87 - 2.05	-	-
Gender						
Female	14	61	1.71	0.94 - 2.87	-	-
Male	9	39	1.04	0.48 - 1.97	0.6	0.24
Age						
Under 1 year	1	4	-	-	-	-
1-4 years	6	26	1.53	0.56 - 3.32	-	-
5-9 years	3	13	-	-	-	-
10-14 years	3	13	-	-	-	-
15-17 years	10	43	3.65	1.75 - 6.72	-	-
Aboriginal and Torres Strait Islander state	s					
Aboriginal or Torres Strait Islander	4	17	4.37	1.19 - 11.20	3.7	0.01
Not Aboriginal or Torres Strait Islander	19	83	1.19	0.72 - 1.86	-	-

#### Table 52: Key demographic and individual characteristics – deaths due to transport incidents, 2014

As indicated in table 53 below, half (11) of the children who died in transport fatalities were teenagers, most of whom (8) were 16 or 17 years of age. The teenagers were primarily passengers and drivers. Children aged 0-4 years comprised almost one third (7) of all transport-related deaths in 2014, and were mainly pedestrians (5).

Table 51 also shows that most (14) of the children who died in transport-related fatalities in 2014 were female. Over half (8) of the females were passengers in either a motor vehicle or aircraft. This is the first time in the last 15 years where females have outnumbered males in transport fatalities; typically, male transport fatalities occur at twice the rate of females.

Age group	Gender	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Under 1	Female	0 -	0 -	0 -	1 -	0 -	2 -	0 -	1 -	1 -	1 -	1 -	0 -	0 -	0 -	1 -
	Male	3 -	0	1 -	1 -	1 -	1 -	2	1 -	0 -	1 -	1 -	1 -	1 -	0 -	0 -
1-4 years	Female	8 (4.72)	3 -	1 -	8 (4.77)	7 (4.19)	3 -	5 (3.01)	5 (2.95)	1 -	5 (2.79)	2 -	3 -	3 -	1 -	3 -
	Male	4 (2.24)	8 (4.48)	8 (4.49)	8 (4.52)	5 (2.84)	3 -	4 (2.28)	4 (2.24)	4 (2.17)	2 -	2 -	1 -	1 -	2	3 -
5-9 years	Female	6 (2.73)	1 -	4 (1.83)	1 -	5 (2.33)	3 -	5 (2.35)	1 -	0 -	3 -	3 -	1 -	3 -	5 (2.22)	1 -
	Male	6 (2.59)	6 (2.59)	1 -	5 (2.20)	4 (1.78)	5 (2.23)	8 (3.58)	2 -	2	1 -	3 -	1 -	5 (2.13)	6 (2.51)	2 -
10-14 years	Female	4 (1.85)	4 (1.82)	2	3	2	0	0	7 (3.20)	0 -	2 -	3 -	2 -	3	0	2 -
	Male	17 (7.49)	8 (3.48)	12 (5.17)	9 (3.86)	7 (3.00)	4 (1.72)	13 (5.63)	5 (2.17)	4 (1.75)	7 (3.06)	2 -	3 -	6 (2.62)	1 -	1 -
15-17 years	Female	11 (8.56)	10 (7.70)	10 (7.64)	8 (6.13)	9 (6.90)	9 (6.86)	5 (3.77)	5 (3.74)	5 (3.74)	6 (4.52)	5 (3.75)	5 (3.76)	4 (3.00)	3	7 (5.26)
	Male	21 (15.63)	26 (19.05)	23 (16.79)	14 (10.27)	14 (10.29)	17 (12.31)	23 (16.41)	16 (11.29)	16 (11.31)	14 (9.94)	13 (9.21)	13 (9.21)	13 (9.20)	12 (8.54)	3 -
Total	Female	29 (3.74)	18 (2.31)	17 (2.18)	21 (2.70)	23 (2.97)	17 (2.20)	15 (1.93)	19 (2.44)	7 (0.89)	17 (2.15)	14 (1.76)	11 (1.38)	13 (1.62)	9 (1.11)	14 (1.71)
	Male	51 (6.25)	48 (5.84)	45 (5.49)	37 (4.53)	31 (3.80)	30 (3.68)	50 (6.13)	28 (3.41)	26 (3.14)	25 (3.00)	21 (2.50)	19 (2.25)	26 (3.05)	21 (2.44)	9 (1.04)

Table 53: Deaths of children due to transport incidents by age and gender, number and rate, 2000-2014

Four children and young people were Aboriginal. There was a significant difference in the rate of death from transport fatalities between Indigenous and non-Indigenous children. As illustrated in the table below, Aboriginal and Torres Strait Islander children are consistently over-represented in transport fatalities. This is also the case for all age groups of Aboriginal people.<sup>190</sup>

 Table 54: Trends in deaths of children due to transport incidents by Aboriginal and Torres Strait

 Islander status, number and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Aboriginal Torres Strait Islander	3	2	2	5 (6.11)	5 (6.02)	4 (4.74)	10 (11.64)	3	3	7 (7.84)	4 (4.44)	5 (5.53)	4 (4.40)	7 (7.69)	3
Non- Aboriginal	77	64	60	53	49	42	54	44	30	35	31	25	35	23	20
Torres Strait Islander	(5.09)	(4.20)	(3.95)	(3.50)	(3.25)	(2.79)	(3.59)	(2.90)	(1.97)	(2.28)	(2.01)	(1.61)	(2.24)	(1.46)	(1.26)
unknown	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
Total	80 (5.03)	66 (4.12)	62 (3.87)	58 (3.64)	54 (3.40)	47 (2.96)	65 (4.08)	47 (2.93)	33 (2.05)	42 (2.59)	35 (2.14)	30 (1.83)	39 (2.36)	30 (1.80)	23 (1.37)

# 7.3 Motor vehicle fatalities

In 2014, over half (13) of the children died in vehicle fatalities; nine children were passengers, three were drivers and one was riding a motorbike.

- The majority (9) of the collisions were single vehicle fatalities, half (5) of which involved collision with a tree. Four involved collision with other vehicles.
- In the majority (11) of cases, the child was travelling in a light vehicle (sedan, utility, or 4WD). One child was riding an off-road vehicle (dirt bike) on a public road and one child was travelling in a truck.

<sup>190</sup> Transport for NSW (2014), NSW Aboriginal Road Safety Action Plan 2014-2017, http://roadsafety.transport.nsw.gov.au/downloads/aboriginal-roadsafety-plan.pdf, accessed 17 August 2015.

# **Passenger fatalities**

Nine children were passengers in motor vehicles travelling on public roads at the time of their death. The ages of the children ranged from less than one year to 17 years.

Eight child passengers were in vehicles being driven by an adult, and one by a peer.

In five cases, the children and drivers were related. All of these drivers held standard NSW drivers licences.

The other four children were driven by unrelated peers, three of whom were adults aged 19, 22 and 24 years. One peer driver held a full licence; one was suspended at the time of the collision and the two others held provisional licences.

Police charged seven people in relation to the collisions, six of whom were driving the child at the time, and another was a driver in a separate vehicle.

Of those charged, three drivers were related to the children and three drivers were peers, two in their teens and one aged in their early twenties. One driver was not known to the child.

In another case, the driver of the child was determined to be at fault but also died in the collision.

# **Driver and rider fatalities**

Four young people died in collisions where they were in control of the vehicle on a public road:

- Two held provisional licences (P1); one held a learner's permit and one young person was unlicensed. One young driver was violating their licence conditions by exceeding the speed limit of their provisional licence. In a separate collision, the learner driver's supervisor was over the legal blood alcohol content limit.<sup>191</sup>
- Three were driving light vehicles (sedans and a utility) and one was riding a dirt bike.
- Two incidents were single vehicle fatalities, involving collisions with trees. The drivers of both vehicles were travelling alone. The other two incidents involved collisions with another vehicle, where police determined one of the young people was at fault.

One child had a child protection history relevant to the circumstances of their death, including adolescent risk taking behaviour.

# Use of safety restraints by drivers and passengers

NSW legislation<sup>192</sup> requires all drivers and passengers of moving or stationary vehicles (not parked) to be appropriately restrained. The restraint is to be either an Australian-approved child restraint suitable for the child's size (mandatory for children up to seven years of age), or a vehicle seatbelt. The child is required to be properly fitted in the child restraint, and the restraint properly fitted to the vehicle.

Table 53 below draws from police and Coronial reports and outlines restraint information relating to the 12 children and young people who were drivers and passengers in vehicles:<sup>193</sup>

- Four children travelling in motor vehicles were appropriately restrained. Intrusion<sup>194</sup> occurred to the child's location in the vehicle for each of these deaths.
- For eight children, restraint problems were either identified or considered possible:
  - four children were unrestrained and all were ejected from the vehicle.
  - significant restraint misuse was evident for one child. This child was not secured into the restraint by the in-built harness.
  - for three children, there were indications that restraints were incorrectly used or inappropriate for the child's height.

<sup>191</sup> The blood alcohol (BAC) limit for a supervisor to a learner driver is under 0.05. See http://www.rms.nsw.gov.au/roads/licence/driver/learner/ supervising-a-learner.html, accessed 17 August 2015.

<sup>192</sup> Road Rules 2008 under the Road Transport (Safety and Traffic Management) Act 1999; Road Amendment (Isabelle Broadhead Child Restraint Measures) Rules 2010 under the Road Transport (Safety and Traffic Management ) Act 1999.

<sup>193</sup> The child riding a dirt-bike has been excluded as no restraints were available for the vehicle.

<sup>194</sup> The vehicle loses structural integrity during the collision and components of the vehicle or other objects in the road environment may intrude into the vehicle's occupant space.

# Table 55: Deaths of child drivers and passengers by age, position in vehicle, restraint type, use, impact type and effect, 2014

	Age	Position in vehicle	Restraint type	Restraint use	Impact type	Effect of collision on child's location
1	Under 1 year	Rear – passenger side	Baby capsule	Incorrect use of restraint - child was not secured into the restraint.	Side impact	Intrusion[1] to child's location in vehicle
2	Under 7 years	Rear – passenger side	Forward facing child seat	Possible incorrect use of restraint – unlikely the child was secured into the restraint.	Vehicle roll-over	Ejected from vehicle
3	7-12 years	Rear – driver side	Adult lap-sash seatbelt	Child was shorter than the recommended height for use of an adult seatbelt. It is unknown if the child met the recommended requirements for optimal positioning and safety when using only an adult seatbelt.[2]	Front and side impact	Intrusion to child's location in vehicle
4	7-12 years	Rear – driver side	Adult lap-sash seatbelt	No issues identified with restraint	Front impact	Intrusion to child's location in vehicle
5	7-12 years	Front passenger	No restraint used	Unrestrained	No impact	Fell from moving vehicle
6	Over 15 years	Front middle	No restraint used	Unrestrained	Vehicle roll-over	Ejected from vehicle
7	Over 15 years	Rear – driver side	Adult lap-sash seatbelt	No issues identified with restraint	The vehicle was airborne and the roof was impacted by a tree.	Intrusion to child's location in vehicle
8	Over 15 years	Front passenger	Adult lap-sash seatbelt	Possible incorrect use of seatbelt. Lap portion of belt was worn. Unknown if sash was also used.	Side & roof impact	Partially ejected from vehicle
9	Over 15 years	Sitting on front passenger window opening	No restraint used	Unrestrained and seating position not for passengers (window opening)	Vehicle roll-over	Ejected from vehicle
10	Over 15 years	Driver	Adult lap-sash seatbelt	No issues identified with restraint	Side impact	Intrusion to child's location in vehicle
11	Over 15 years	Driver	Adult lap-sash seatbelt	No issues identified with restraint	Side impact	Intrusion to child's location in vehicle
12	Over 15 years	Driver	No restraint used	Unrestrained	Side impact	Ejected from vehicle

# Vehicle and safety systems for driver and passenger collisions

The NSW Road Safety Strategy identifies that younger drivers are more likely to drive older, less safe vehicles. The risk of death and serious injury in a crash is lower for later model cars; for example, risk involving a 2007 vehicle is described as about half that of a vehicle produced in 1987.<sup>195</sup>

Eight of the 12 vehicles involved in the fatal incidents were more than 10 years old. The vehicles were manufactured between 1974 and 2003, and were not fitted with vehicle safety systems found in more recently manufactured vehicles, such as electronic stability control, supplementary airbag systems, and anti-lock braking systems. Some vehicles also lacked the improved seat design and seatbelt technologies available in newer models.

Four of the vehicles were manufactured between 2005 and 2010 and were fitted with some vehicle safety systems. In a number of vehicles, however, improved technologies were not available or were faulty:

- Two vehicles did not have electronic stability control, which can assist drivers to control a vehicle and reduce the risk of roll-over.<sup>196</sup> In one case, the driver lost control while attempting to negotiate a curve on the roadway at speed. In the other, a vehicle rolled over after the driver lost control while attempting to make a 90 degree turn on an unsealed road.
- One vehicle was fitted with seatbelt warning lights, but this feature was faulty at the time and the driver was not alerted that the child passenger had released the seatbelt prior to opening the vehicle door and falling onto the roadway.

In half of the 12 cases, the incident included a side impact collision, which resulted in intrusion to the child's location in the vehicle. The risk of injury increases greatly when the passenger compartment is compromised. Neither seatbelts nor frontal airbags offer much protection against doors collapsing inward, or roofs or side pillars bending on impact.<sup>197</sup> The vehicles involved in these collisions were manufactured between 1974 and 2005 and none were fitted with side/curtain airbags.

# Contributing factors in fatalities involving children as drivers, riders and passengers

Speeding, fatigue and alcohol are key contributing factors in road fatalities and injuries in NSW.<sup>198</sup>

In the majority (12) of the 13 passenger, driver and rider fatalities, police determined that driver factors had contributed to the collisions. As indicated in the table below, the most common driver-related factors were speeding, being substance-affected, and inexperience. The other main driver-related contributing factors included fatigue, unroadworthy tyres and reckless driving. Unlike previous years, police did not determine that distraction was a contributing factor in any of these collisions.

While police identified that inexperience was a factor in four fatalities, we note that in another three collisions, the drivers did not hold a standard licence, as they were learner and provisional drivers.

<sup>195</sup> Transport for NSW (2012), NSW Road Safety Strategy 2012-2021, www.roadsafety.transport.nsw.gov.au/downloads/road\_safety\_strategy.pdf, accessed 17 August 2015.

<sup>196</sup> Transport for NSW, Centre for Road Safety, http://roadsafety.transport.nsw.gov.au/stayingsafe/vehiclesafety/esc.html, accessed 17 August 2015.

<sup>197</sup> Chipman, M. (2004), 'Side impact crashes - Factors affecting incidence and severity: Review of the Literature', Traffic Injury Prevention, Vol 5 (67).

<sup>198</sup> Transport for NSW (2013), *Behavioural risk factors in NSW crashes and casualties 2000-2012*, http://roadsafety.transport.nsw.gov.au/downloads/ behavioural-risk-factors.112013.pdf, accessed 17 August 2015.

		Speeding above sign posted limit	Inexperience	hol ent	y/s ent	ənf	Excessive speed for conditions	-a
		Spee abov post	Inex	Alcohol present	Drug/s present	Fatigue	Exce spee conc	Other
	1	✓ Police could not determine speed but assessed as likely well above limit	✓ Provisional licence	✓ 0.105 – 0.128g/100mL				✓ Driver aware of unroadworthy tyres
	2	✓ 38km/h over		✓ 0.177g/100mL		✓ Police considered this was possible		✓ Reckless driving (crossing double unbroken lines)
	3	<ul> <li>✓</li> <li>Police could not determine speed but assessed as over due vehicle damage</li> </ul>	<ul> <li>✓</li> <li>Unfamiliar with vehicle and its operation</li> </ul>	<ul> <li>✓</li> <li>Alcohol</li> <li>present – affect</li> <li>on driving not</li> <li>known</li> </ul>				
	4	√ 10km/h over			✓ Combined effects of cannabis, oxycodone and prescribed methadone	✓ Driver provided a statement of fatigue		
	5	√ 22km/h over	✓ Provisional licence					✓ Reckless driving (unsafe distance from vehicle in front)
	6			√ 0.104g/100mL			$\checkmark$	
	7						V	✓ Driver aware of unroadworthy tyres
	8	✓ 44km/h over	✓ Provisional licence					
	9	✓ 48km/h over						
	10				✓ Cannabis present in system – effect on driving unknown			
	11				<ul> <li>✓</li> <li>Amphetamine and</li> <li>Methylamphetamine</li> </ul>			
	12							✓ Driver allowed vehicle to drift off roadway
Total		7	4	4	3	2	2	4

Of the 12 drivers considered by police to be at fault, seven had relevant driving histories with NSW Police. This included:

- Two drivers who had been given infringement notices for negligent driving within the six months prior to the fatal incident.
- Four drivers who had previously been issued with infringement notices for speeding, including two drivers who were speeding at the time of fatal collision.
- Three drivers who had previously been suspended from driving. One driver had been suspended on five occasions for demerit point allocation and fine defaults. Another driver had their provisional licence suspended twice for mobile phone use and speeding, and another driver had their provisional licence suspended for speeding and transporting an excessive number of passengers.

Police identified that road and environmental conditions possibly contributed to three collisions, including a wet roadway, vegetation at an intersection which may have obstructed the view between vehicles, and one road in poor repair with potholes and an uneven surface.

In addition to the two vehicles noted above as lacking roadworthy tyres, police noted two additional vehicle issues that may have been contributory, including an unroadworthy steering system, and a faulty seatbelt indicator light that the driver had reported to an employer for servicing.

Police charged seven people with offences including negligent driving occasioning death, dangerous driving, and driving under the influence.

# 7.4 Pedestrians and cyclists

In 2014, nine children died after being struck by a vehicle. Eight children were on foot and one child was riding a bicycle.

The children ranged in age from one to 17 years, and five were male.

Five children were struck by a vehicle travelling at speed. Four of the nine children were struck by a vehicle travelling at less than 10km per hour, a 'low speed vehicle run-over'.

#### Low speed vehicle run-over fatalities

The four children who died in low speed vehicle incidents were aged between one and four years. Female and males were evenly represented.

The majority (3) of the low speed vehicle run-over fatalities occurred on a driveway at the child's place of residence.<sup>199</sup> The other fatality occurred on a public road, as the child and their carer crossed the road.

#### The driver and vehicle

In three cases, the driver was a relative of the child. The drivers were aged between 29 and 46 years. One driver was a provisional licence holder.

Of the four vehicles, two were 4WDs, one was a sedan and the other was a wagon. At the time of the incidents:

- three vehicles were exiting a residential property. Two of the vehicles were reversing. The direction of travel of the other vehicle was not known.
- one vehicle was stationary at an intersection prior to moving forward to enter the adjoining road.

#### Contributing factors in the low speed fatalities

Police determined that the following factors contributed to the low speed vehicle run-over fatalities:

- Two children were intermittently supervised at the time that they gained access to driveways without their carer's knowledge. One child was unsupervised and the carer drove the vehicle presuming that the child was inside it.
- Restricted vision was relevant in one incident, as the driver was unable to see the child from the driver's seat, due to the child's height.
- One driver was deemed to be inattentive at the time of the incident by looking in the opposite direction to where the vehicle was travelling.

Police charged two drivers with negligent driving occasioning death.

<sup>199</sup> In one case, police determined that the location of the incident on the driveway fell within the definition of a 'road-related area' in accordance with the *Roads Transport Act 2013.* 

# Other pedestrian and cyclist fatalities

Five children died when they were struck by vehicles travelling above 10km/h. Of these children, three were under eight years of age; two young people were aged 16 and 17 years. Females and males were equally represented.

Most (4) of the fatalities occurred on a public road. One fatality occurred when a vehicle left a public road and mounted a footpath.

#### The driver and vehicle

Most (4) of the drivers were female. The drivers were not known to any of the children. Four drivers held a standard drivers licence and one driver was unlicensed.

The incidents involved light vehicles: 4WDs (3), and sedans (2). All vehicles were travelling forward at the time the child was struck.

Police identified that at the time of the fatality, all vehicles were travelling within the sign-posted speed limit; in each case, this was 50km/h.

#### Contributing factors in at speed transport fatalities

The Coroner and police identified a range of factors that may have been contributory to the at-speed vehicle fatalities in 2014.

In three cases, the actions of the children were considered by police to be contributory. In two separate incidents, a child entered the roadway quickly and unexpectedly from the kerb and from behind a parked vehicle. The drivers had limited chances to react prior to the collision. One child was riding a bicycle on a public road, and failed to stop at an intersection.

On the part of drivers:

- The vision of two drivers was obstructed by the kerb-side A-Pillar<sup>200</sup> in their recently manufactured vehicles.
- One driver had never held a licence, and was also reported to have had no previous driving experience prior to the incident.
- One driver was inattentive at the time of the incident, by looking in the opposite direction to where the vehicle was travelling.

Police charged one driver with dangerous and negligent driving occasioning death and being unlicensed.

# 7.5 Off-road motor vehicle fatalities

In contrast to previous years, there were no driver or passenger deaths that occurred off-road that were registered in 2014. As shown below, over the 10 years 2005-2014, 20 children died in incidents involving off-road vehicles.

#### Table 57: Transport fatalities – off-road vehicles 2005-2014

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Off-road	3	2	1	1	4	1	3	2	3	0	20

In a review of off-road vehicle fatalities between 2003 and 2012, the Team identified strategies to prevent the death and serious injury of children relating to the use of off-road vehicles, including:

- greater public awareness of the dangers of off-road vehicles including risks in the use of quad bikes by children, and vehicle instability
- introduction of engineering controls including crush protection devices/ roll over protective structures on quad bikes; and measures to prevent the operation of the vehicles by children, and
- introduction of administrative controls such as vehicle registration; rider training and licensing; and requirements relating to a minimum age of 16 years, no passengers, and mandatory use of personal protection, such as helmets.<sup>201</sup>

Current initiatives include the Quad Bike Performance Project being run by the University of NSW Transport and Road Safety Research group (TARS), with an aim to develop a consumer safety rating system for quad bikes and side-by-side vehicles

<sup>200</sup> A-Pillar is the structural support that holds both sides of the windscreen in place.

<sup>201</sup> NSW Child Death Review Team (2013), Annual Report 2012, NSW Ombudsman: Sydney.

based on stability, handling and crashworthiness. In June 2015, TARS published the proposed introduction of the Australian *Terrain Vehicle Assessment Program*.<sup>202</sup> Plans for the program's implementation are yet to be announced.

Organisations, including the Australian Competition and Consumer Commission (ACCC), Farmsafe and WorkCover NSW, publish information to raise community awareness about the dangers associated with quad bikes, including risks to children.

The Queensland Coroner recently held an inquest into nine quad bike deaths (including child deaths). In handing down his findings in August 2015, the Coroner made 15 recommendations in relation to the use and safety of quad bikes. These recommendations include regulatory and legislative changes and improvements to education and training initiatives. Later in 2015, the NSW Coroner is expected to give her findings in relation to a current inquest into four child deaths that involved off-road vehicles.

# 7.6 Key issues arising from reviews

Reviews of transport deaths registered in 2014 highlighted key issues, including:

- The contribution of unsafe driver behaviours to transport fatalities, in particular speeding and drivers being affected by drugs or alcohol while driving.
- The importance of appropriate use of child restraints, given the number of fatal collisions where children were either not restrained or not restrained appropriately.
- The proportion of older vehicles involved in the collisions, noting their lack of advanced safety features compared to more recently manufactured vehicles.
- The importance of close and constant adult supervision when small children are around vehicles.
- Histories of driving infringements or offences for over half of the at fault drivers.

# 7.7 Prevention measures

#### Prevention measures – on-road fatalities

As noted above, key factors in the deaths of children in on-road motor vehicle fatalities in 2014 include at fault driver factors such as speeding and driving under the influence of drugs and/or alcohol. Other relevant factors include driver inexperience and the failure to use appropriate safety restraints correctly.

#### Speeding

NSW has three major initiatives to address speeding on public roads. These initiatives are underpinned by the principle that public education conducted in combination with speed enforcement achieves maximum road safety results.<sup>203</sup> The three initiatives in NSW include:

- The Centre for Road Safety's public education campaign titled *Don't Rush*, aimed at raising community awareness about the impact of speed-related crashes. The campaign targets male drivers aged 17 to 49 years
- High visibility policing by the NSW Police Force, including the Enhanced Enforcement Program which has directed additional resources to police operations targeting dangerous driving behaviours. The program also supported the roll out of high visibility road safety message markings on highway patrol vehicles<sup>204</sup>
- Transport for NSW annual speed camera review which monitors the effectiveness of speed cameras on road safety. The 2014 review found that speed cameras in 107 locations continue to deliver positive road safety benefits; including a 42 percent reduction in the number of crashes; 90 percent reduction in deaths and 40 percent reduction in injuries at the camera locations.<sup>205</sup>

<sup>202</sup> Grzebieta R., et. al. (2015), The Australian Terrain Vehicle Assessment Program (ATVAP), Proc. 24th International Conference on the Enhanced Safety of Vehicles (ESV) Gothenburg, Sweden, 8-11 June, http://www.tars.unsw.edu.au/research/Current/Quad-Bike\_Safety/24ESV-000144.pdf, accessed 17 August 2015.

<sup>203</sup> Transport for NSW (2012), A way forward for speed cameras in NSW: The NSW Speed Camera Strategy, http://roadsafety.transport.nsw.gov.au/ downloads/nsw\_speed\_camera\_strategy.pdf, accessed 17 August 2015.

<sup>204</sup> Transport for NSW, Centre for Road Safety (2014), NSW Road Safety Progress Report 2013/14, http://roadsafety.transport.nsw.gov.au/downloads/ road-safety-progress-report-2013-14.pdf, accessed 17 August 2015.

<sup>205</sup> Transport for NSW, Centre for Road Safety (2014), Annual NSW speed camera performance review, http://roadsafety.transport.nsw.gov.au/ downloads/2014-speed-camera-review-appendices.pdf, accessed 17 August 2015.

#### Drug and drink driving

During 2013, roadside drug tests detected the presence of illicit drugs in the saliva of about one in every 40 light vehicle drivers and one in every 76 heavy vehicle drivers. In 2014, targeted enforcement operations resulted in one in every 10 drivers testing positive to the presence of illicit drugs in their saliva.<sup>206</sup>

The Centre for Road Safety has identified drug driving as a serious safety problem. It plans to collect details of the types and use of drugs and develop a new drug driving public education campaign.<sup>207</sup>

The Centre for Road Safety has a range of targeted road safety campaigns in relation to alcohol. These include:

- Plan B drink driving campaign, primarily aimed at young male drivers aged 17-25 years.
- You're in our sights, which supports police operations in relation to three driver behaviours, including drink driving, speeding and unrestrained occupants.

Relevant to the circumstances of death for some children who died in 2014, the Department of Education delivers the *Crossroads* program to students in Years 11 and 12 in public high schools. The program is designed to help senior students address a range of issues relating to health, safety and wellbeing. The program was recently revised to include components to educate about risk associated with drink driving. The Department also established the '*Turning 18: Drugs, alcohol and celebrating safely*' website to educate young people about driving and alcohol, including being a passenger with a driver affected by alcohol. The program explores with young people their rights as a driver and passenger, and how to be assertive about safety.<sup>208</sup>

#### **Driver inexperience**

Consistent with previous years, inexperienced drivers were represented in transport-related deaths of children in 2014.

The NSW Road Safety Strategy identified that novice drivers under 26 years comprise 16 percent of licensed drivers but are involved in around 28 percent of all fatal crashes. This over-representation is considered likely due to a combination of factors, including inexperience, a propensity to take risks, and access to older, less safe vehicles.<sup>209</sup>

The Safer Drivers Course<sup>210</sup> commenced in 2013 and involves a three-hour facilitated group discussion to help learner drivers understand risk and safe driving behaviours, and a two-hour in-vehicle coaching session to help them manage risks on the road.<sup>211</sup> This course is not mandatory for new drivers and costs \$140 to complete. Completing the course credits the learner driver with 20 hours of log book credit.

#### **Restraint systems**

Various agencies provide education to children and adults about the importance of wearing seatbelts. These include:

- Since 2011, the Centre for Road Safety's public education campaign *Clip every trip* has targeted male drivers aged 30-55 years residing in rural areas.
- The Roads and Maritime Services youth website *Geared* provides youth specific information about the risks of injury if not wearing a seatbelt.<sup>212</sup>
- The NSW school curriculum includes road safety messages about seatbelts throughout the later primary years, using the tagline '*Click-Clack front and back*'.<sup>213</sup>

<sup>206</sup> Transport for NSW, Centre for Road Safety (2015), Drug driving fact sheet, http://roadsafety.transport.nsw.gov.au/downloads/drug-driving-f.pdf, accessed 17 August 2015.

<sup>207</sup> Ibid.

<sup>208</sup> NSW Education and Communities (2014), Crossroads, http://www.learning.schools.nsw.edu.au/crossroads/files/2015/03/Final\_ Crossroads\_2March15-1caulki.pdf, accessed 17 August 2015.

<sup>209</sup> Transport for NSW (2012), NSW Road Safety Strategy 2012-2021, http://roadsafety.transport.nsw.gov.au/downloads/road\_safety\_strategy.pdf, accessed 17 August 2015.

<sup>210</sup> Offered by various driving school providers.

<sup>211</sup> NSW Roads and Maritime Services, Safer Drivers Course, http://www.rms.nsw.gov.au/geared/your\_driving\_skills/driving\_skills/safer\_driving\_ course.html, accessed 17 August 2015.

<sup>212</sup> NSW Roads and Maritime Services, What happens to your body in a crash, http://www.rms.nsw.gov.au/geared/your\_driving\_skills/car\_crashes/ anatomy\_of\_a\_crash.html, accessed 17 August 2015.

<sup>213</sup> NSW Department of Education, Key road safety messages, http://www.curriculumsupport.education.nsw.gov.au/policies/road/assets/docs/ Key%20messages%20RS%20P-6.pdf, accessed 17 August 2015.

Inappropriate and/or incorrect child restraint use reduces the effectiveness of the restraint in preventing injury.<sup>214</sup> As noted above, sub-optimal restraint use was evident for some children in transport-related deaths in 2014.

In June 2014, Transport for NSW launched the *We're counting on you* child car seat safety campaign, which promotes the correct selection, use and installation of child car seats to reduce child deaths and injuries. The campaign noted that two in every three child passengers are not restrained correctly.<sup>215</sup>

As part of the campaign, Transport for NSW was a partner in establishing an Australia-wide website (www.childcarseats.com. au) that provides consumers with safety and ease of use ratings for many child restraints. Transport for NSW reported that the website received almost 51,000 visits in the six-week period after the campaign launch.

#### Vehicle manufacture

Vehicle safety technology has improved over time. In addition to overall vehicle design improvements, built-in safety features such as airbags, electronic stability control, antilock braking systems, autonomous emergency breaking, lane support systems, seat design and enhanced seat belt technologies all contribute to improved occupant safety.

Many of the children who died in transport-related incidents were travelling in older vehicles that do not feature contemporary safety technologies. Transport for NSW have also identified this problem, noting that the average age of the vehicle in a fatal crash driven by a young driver is three years older than for a middle-aged driver similarly involved.<sup>216</sup> The *NSW Road Safety Strategy 2012-2021* aims to minimise this by promoting consumer awareness and uptake of road safety technologies.

#### **Aboriginal Road Safety Action Plan**

In December 2014, Transport for NSW released an Aboriginal Road Safety Action Plan. Relevant to the child deaths that occurred in 2014, the plan includes use of Aboriginal specific media channels to improve road safety and enhance awareness of driver licensing and other road safety issues for Aboriginal people, and to explore further opportunities to provide professional child restraint installation and fitting demonstrations.

## **Pedestrian deaths**

Key factors in the pedestrian deaths of children in 2014 included young children accessing the driveway of their family home as a vehicle was leaving the premises; children under the age of 10 years entering a road without a carer holding their hand,<sup>217</sup> and driver inattention.

#### Low speed vehicle run-overs

Following a 10-year review of low speed vehicle run-over fatalities in 2012,<sup>218</sup> the Team made a number of recommendations to the Centre for Road Safety. The recommendations aimed to improve the collection, analysis and publication of data on low speed vehicle run-over fatalities; and to enable the development of strategies to reduce the risk of death and injury of children from these incidents.

The Team continues to monitor the progress of work in relation to these recommendations. In June 2015, the NSW government advised that the Centre for Road Safety has established an interagency working group, with a part focus on young children. The group will examine available data, and current programs with the view to identify further countermeasures to prevent low speed vehicle crashes.

The Centre for Road Safety has undertaken a range of activities in relation to their public awareness campaign '*Driveway Safety, They're counting on you*', which focuses on low speed vehicle run-over fatalities. The Centre has partnered with the Georgina Josephine Foundation to produce and distribute an educational video, and other advertising materials on the subject. The Centre for Road Safety will evaluate the campaign's effectiveness in 2015.<sup>219</sup>

219 Correspondence from NSW Premier to NSW Ombudsman, 29 May 2015.

<sup>214</sup> Brown J., Keay L., Hunter K., Bilston J.M. & Ivers R. (2013), 'Increase in best practice child car restraint use for children aged 2-5 years in low socioeconomic areas after introduction of mandatory child restraint laws', *Australian and New Zealand Journal of Public Health*, Vol 37: 272-277.

<sup>215</sup> NSW Strategic Communications (2014), Check your Child's Car Seat, www.advertising.nsw.gov.au/updates/child-restraints, accessed 17 August 2015.

<sup>216</sup> Transport for NSW (2012), NSW Road Safety Strategy 2012-2021, http://roadsafety.transport.nsw.gov.au/downloads/road\_safety\_strategy.pdf, accessed 17 August 2015.

<sup>217</sup> Transport for NSW recommends that children up to eight years of age should have their hand held by a caregiver in environments where cars are or could be, and that children up to 10 years of age be closely supervised by an adult in the same environments.

<sup>218</sup> NSW Child Death Review Team (2012), Annual Report 2011, NSW Ombudsman: Sydney.

#### Other pedestrian deaths

Pedestrian initiatives include:

- The NSW School Road Safety Education Program, which addresses pedestrian safety through early childhood, primary and secondary stages.<sup>220</sup>
- The promotion and use of Safety Town<sup>221</sup> with older primary school children.

NSW Police and local councils also deliver the Community and Road Education Schemes (CARES) program to older primary school students at various bicycle and road safety centres. Among other things, lessons cover safe cycling, road rules and basic riding skills.

#### Prevention measures – off-road fatalities

The Team identified that the lack of any one agency in NSW with responsibility for matters relating to the recreational use of off-road vehicles in an off-road setting (including private property) presents a significant challenge in seeking to address safety issues.<sup>222</sup>

Against this background, the Team directed two recommendations to the Department of Premier and Cabinet (DPC), aimed at bringing together key injury prevention and regulatory agencies to identify whether specific strategies are needed in NSW to reduce the risk of death and injury of children in off-road vehicle incidents.

In 2015, the NSW Government advised the Team that DPC had brought together key injury prevention agencies to consider the recommendations. The government's response noted limitations to regulating the use of recreational vehicles, such as quad bikes and motorcycles on private property, and that changes to legislation may be impractical. The government noted research underway in NSW, including:

- research by the Sydney Children's Hospital and Neuroscience Research Australia which aims to better understand crash and injury causation, including vehicle, human and environmental factors as well as parent/carer perceptions of risk, and
- improved data collection by Transport NSW for off-road incidents.<sup>223</sup>

- 222 NSW Child Death Review Team (2013), Annual Report 2012, NSW Ombudsman: Sydney.
- 223 Correspondence from NSW Premier to NSW Ombudsman, 29 May 2015.

<sup>220</sup> Transport for NSW (2014), Pedestrian Safety Action Plan 2014-2016, http://roadsafety.transport.nsw.gov.au/downloads/ped-safety-plan.pdf, accessed 17 August 2015.

<sup>221</sup> Online interactive resource developed by Transport for NSW and Board of Studies, Education and Teaching Standards for primary school children, their educators and carers on road safety, including pedestrian safety. The resource was developed to complement the current school curriculum.

# Chapter 8. Deaths due to suffocation and other threats to breathing

In 2014, 10 children died from unintentional asphyxia, broadly defined as any condition that leads to oxygen deprivation in the human body.<sup>224</sup> The deaths occurred in sleep-related circumstances, as a result of choking on food, accidental strangulation, and suffocation after becoming trapped in a confined space.

As shown in table 58 below, in NSW each year, an average of seven children and young people die as a result of choking, suffocation and strangulation. The majority of these deaths occur in infants and young children. Household items that are potential suffocation hazards for young children include plastic bags, pillows, bean bags, balloons, bedding, and mattresses. Confined spaces – at home and elsewhere – can also pose a threat to children's breathing.

# 8.1 Age, gender and Aboriginal and Torres Strait Islander status

Of the 10 children who died due to suffocation and other threats to breathing, two were Aboriginal and Torres Strait Islander children, and two were of culturally and linguistically diverse backgrounds.

Seven of those who died were infants and children aged less than four. The predominance of infants and young children in deaths due to suffocation and other threats to breathing is consistent with previous years, as demonstrated in table 58 below. In the period 2000-2015, children under one year of age represented half (55) of the 111 deaths resulting from suffocation and other threats to breathing. Many of these deaths occurred in sleep-related incidents and were classified as SUDI (see chapter 5).

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
	4	4	2	1	3	2	6	5	1	4	7	5	5	3	3
Under 1 year	(4.62)	(4.61)	-	-	-	-	(6.70)	(5.28)	-	(4.12)	(7.16)	(5.27)	(5.09)	-	-
	5	3	2	3	2	2	0	0	0	3	0	4	2	5	4
1-4 years	(1.44)	-	-	-	-	-	-	-	-	-	-	(1.06)	-	(1.29)	(1.02)
E Queoro	1	1	2	0	0	0	0	0	1	0	0	0	0	1	1
5-9 years	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
10.11	0	0	0	0	0	0	1	3	0	1	0	3	0	0	2
10-14 years	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	0	0	1	0	1	0	0	0	1	1	0	0	0	0	0
15-17 years	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	10	8	7	4	6	4	7	8	3	9	7	12	7	9	10
Total	(0.63)	(0.50)	(0.44)	(0.25)	(0.38)	(0.25)	(0.44)	(0.50)		(0.55)	(0.43)	(0.73)	(0.42)	(0.54)	(0.59)

# Table 58: Deaths due to suffocation and other threats to breathing by age group, number and rate, 2000-2014

# 8.2 Deaths in 2014 from suffocation in sleep-related circumstances

In 2014, four children suffocated after being placed for sleep. Three were infants aged seven months or younger;<sup>225</sup> one child was aged five and had very limited mobility as a result of significant disabilities.

In two cases, infants were co-sleeping with either both parents, or a parent and a sibling. The two other children had been placed for sleep alone. All four children died in their family home. In three cases, the children were found face down on soft items beside the bed or couch where they had been placed for sleep.

<sup>224</sup> Richards C. & Wallis D. (2005), 'Asphyxiation: a review', *Trauma*, Vol 7 (1): 37-45.

<sup>225</sup> The deaths of the three infants were classified as SUDI and are considered in chapter 5.

Further detailed information about safe sleeping practices and the other risk factors associated with the sudden and unexpected death of infants is included in Chapter 5.

Older children with significant disabilities are also particularly vulnerable to potential risks in their sleep environment. Safety measures may include the use of bed rails and sleep monitors, as well as relocation of potential hazards such as furniture and soft furnishings in bedrooms.

# **Deaths from choking**

Three children died in 2014 after choking on food. Two of the children were aged between 13 months and 18 months old. The other child was aged 10.

Location of the incidents included a relative's home, a family day care provider and a school. In each case, an adult supervisor was in close proximity to the child at the time of the incident.

Two of the children were seated while eating; one child was standing and moving vigorously at the time of the choking incident.

#### Safe eating habits

Choking on food or a small object can occur at any age; however, young children are particularly vulnerable due to their underdeveloped coughing reflexes, small airways, and the fact that they are still developing their teeth to properly chew and grind food.

The choking deaths of children in 2014 highlight the importance of carers being vigilant about ensuring that the foods provided to young children are appropriate for their developmental stage, and that children are encouraged to sit still while eating.

Organisations such as Kidsafe<sup>226</sup> recommend that carers encourage safe eating habits, such as always sitting down to eat and chewing thoroughly before swallowing.

# 8.3 Deaths from strangulation

In 2014, two children died from accidental strangulation involving blind cords fitted close to their cots.

One of the children was aged 14 months and the other was aged 16 months. In each case, the child had been placed for sleep in the family home.

# Strangulation hazards – blind and curtain cords

Blind and curtain cords can very quickly tangle around a child's neck and cause strangulation. Data indicates that such incidents are rare but persistent; the Australian Competition and Consumer Commission reports that 1-2 Australian children die in this way each year and least 15 such deaths have occurred since 2001.<sup>227</sup>

In 2010, the Federal Government introduced a national mandatory standard for internal window coverings manufactured after December of that year; the standard requires suppliers to provide consumers with warnings on the packaging and the cord about the risks associated with these products; installation instructions; and safety devices when they purchase the products.

The information on the cord must contain these words: 'WARNING: Young children have died by wrapping loose curtain and blind cords or chains around their necks. Secure cords or chains with cord guides or keep them out of reach by winding them around a cleat. Move cots and furniture away from window covering cords or chains. Do not remove this label.'

In March 2014, the Government developed an additional standard following the cord blind strangulation deaths of three children during the preceding six-month period. This new standard took effect on 1 January 2015, and requires commercial installers to prevent cords from forming dangerous loops where they can be reached by children; warning labels or swing tags must also remain attached to the blind cord.

Importantly, the mandatory standards do not reduce the risks associated with blind cords installed before December 2010. Against this background, the Australian Competition and Consumer Commission has urged consumers, and particularly

<sup>226</sup> Kidsafe SA (2010), Prevention of choking, suffocation and strangulation in young children – Information for parents and caregivers, http://www.kidsafesa.com.au/\_\_files/f/3150/4986\_prevention\_of\_choking\_FS\_V2proof.pdf, accessed 17 August 2015.

<sup>227</sup> Australian Competition and Consumer Commission, *Blinds and curtains*, https://www.productsafety.gov.au/content/index.phtml/itemld/974977, accessed 17 August 2015.

parents of babies and young children, to 'take a close look at the cords on their blinds, curtains and fittings and take action to make them safe.<sup>1228</sup>

The websites of organisations, including Product Safety Australia, Kidsafe NSW, and NSW Fair Trading, provide tips on how this can be done. Key messages focus on removing dangers, and include:

- keep children away from all cords move furniture, cots and beds away
- check all blind and curtain cords (at home and when away on holidays) to make sure they are out of the reach of children
- make loose cords safe by using safety devices or cutting the cord loop, and
- check that new blinds and curtains have warning labels and secure the cords out of reach.229

In August 2014, NSW Fair Trading and KidSafe NSW announced an initiative offering free blind cord safety kits to requesting households. They said 10,000 kits were available, suitable for roller blind cords fixed to wooden window frames:

http://www.fairtrading.nsw.gov.au/ftw/Consumers/Product\_and\_service\_safety/General\_products/Blinds\_and\_curtains. page#How\_can\_l\_make\_my\_blind\_cords\_safe?

<sup>228</sup> Australian Competition and Consumer Commission, Product Safety Australia (2014), *Government improves safety standard to protect kids*, http://www.productsafety.gov.au/content/index.phtml/itemld/1006426, accessed 17 August 2015.

<sup>229</sup> NSW Fair Trading (2014), *Blinds and curtains – Child safety guidelines*, http://www.fairtrading.nsw.gov.au/ftw/Consumers/Product\_and\_service\_safety/General\_products/Blinds\_and\_curtains.page, accessed 17 August 2015.

# **Chapter 9. Drowning**

In 2014 in NSW, the registered deaths of nine children were attributed to drowning. Eight deaths occurred in the year, and one child died as a result of a near-drowning that occurred some years prior. After transport fatalities and accidental threats to breathing (asphyxia), drowning constituted the third leading unintentional injury-related cause of death of children in NSW.

Four children drowned in natural bodies of water, including beaches (2), an inland river and a lake. Two children drowned in private swimming pools, and one child died as a result of injury from near-drowning in a swimming pool eight years previously. One child drowned in a dam, and one child in a bath.

# 9.1 Trends in drowning deaths of children in NSW, 2000-2014

Table 59 shows the trends in drowning deaths of children over the 15 years to 2014 by incident location. During this period, the drowning deaths of 245 children were registered in NSW. The largest proportion of drowning deaths occurred in private swimming pools (44%), followed by natural inland bodies of water (16%), bathtubs (14%) and coastal waters (13%).

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Pool (private)	8	4	11	10	7	5	6	13	12	6	6	5	4	7	3	107
	(0.50)	(0.25)	(0.69)	(0.63)	(0.44)	(0.31)	(0.38)	(0.81)	(0.74)	(0.37)	(0.37)	(0.30)	(0.24)	(0.42)	-	
Pool (public)	1	1	0	0	0	3	2	1	0	0	0	0	0	1	0	9
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	
Natural coastal	2	4	5	5	2	0	1	2	2	0	1	3	2	1	2	32
(ocean, beach, estuary)	-	(0.25)	(0.31)	(0.31)	-	-	-	-	-	-	-	-	-	-	-	
Natural inland	5	4	2	2	2	1	3	1	4	4	4	3	2	0	2	39
(river, creek, lake)	(0.31)	(0.25)	-	-	-	-	-	-	(0.25)	(0.25)	(0.24)	-	-	-	-	
Dams	1	3	3	1	1	0	1	0	0	0	1	2	0	0	1	14
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	
Bathtub	2	2	6	4	3	1	2	1	2	1	2	3	2	2	1	34
	-	-	(0.37)	(0.25)	-	-	-	-	-	-	-	-	-	-	-	
Other	1	0	2	0	1	0	0	0	1	1	0	1	1	2	0	10
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	
All	20	18	29	22	16	10	15	18	21	12	14	17	11	13	9	245
	(1.26)	(1.12)	(1.81)	(1.38)	(1.01)	(0.63)	(0.94)	(1.12)	(1.30)	(0.74)	(0.86)	(1.04)	(0.66)	(0.78)	(0.53)	

Table 59: Trends in deaths of children due to drowning by location, number and rate 2000-2014

\* The death of one child in 2014 was the result of a near-drowning incident years prior

Figure 8 below shows that the mortality rate of children from drowning has declined between 2000 and 2014. The average mortality rate of 0.77 deaths per 100,000 children for the five-year period 2010 to 2014 is lower than the previous five-year periods of 2005-2009 (0.95 per 100,000 children), and 2000-2004 (1.32 per 100,000 children). The decline is overall, and is not attributable to any one circumstance.

Despite an evident downward trend in the drowning deaths of children over time, though low, rates of hospitalisation of children in NSW for injury-related incidents (including drowning) have remained relatively stable over the same period.<sup>230</sup>

In relation to young children – who are amongst those most at-risk of drowning – the Australian Institute of Health and Welfare reports that, while hospitalisation rates for drowning / immersion of children under five years is low compared to other causes of injury in this age group, the presentations tend to be more serious in terms of threat to life and lengths of hospital stay.<sup>231</sup> For example, during the reporting period 2011-2012, 193 children aged 0-4 years across Australia were hospitalised as a result

<sup>230</sup> Health Stats NSW, Hospitalisations by cause and age for children aged 0-16 years in NSW, 2001-02 to 2013-14, http://www.healthstats.nsw.gov.au/, accessed 17 August 2015.

<sup>231</sup> Australian Institute of Health and Welfare, Pointer S. (2014). *Hospitalised injury in children and young people 2011-12*. Injury research and statistics series no.91. Cat. No. INJCAT 167. AIHW: Canberra.

of a near-drowning incident, accounting for less than one percent of all hospitalisations for injury amongst this age group. Of the 193 children, 28 were infants and most of the incidents occurred in a bathtub.

Research also indicates that approximately 22 percent of children who survive a near-drowning incident will experience some form of permanent brain damage and require ongoing medical treatment and support.<sup>232</sup>

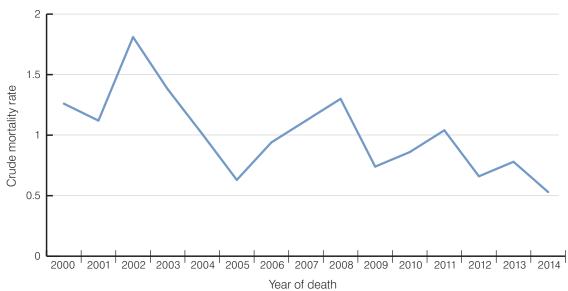


Figure 8: Rate of child deaths due to drowning, 2000-2014

# 9.2 Children who died in 2014

The table below provides an overview of key demographic characteristics of the nine children whose deaths were registered in 2014 and were attributed to drowning.

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	р
Total	9	100	0.53	0.24 - 1.02		-
Gender						
Female	1	11	-	-	-	-
Male	8	89	0.92	0.40 - 1.82	-	-
Age						
Under 1 year	1	11	-	-	-	-
1-4 years	3	33	-	-	-	-
5-9 years	3	33	-	-	-	-
10-14 years	1	11	-	-	-	-
15-17 years	1	11	-	-	-	-
Aboriginal and Torres Strait Islander status						
Aboriginal or Torres Strait Islander	1	11	-	-	-	-
Not Aboriginal or Torres Strait Islander	8	89	0.50	0.22 - 0.99	-	-

Table 60: Key demographic and individual characteristics - deaths due to drowning, 2014

<sup>232</sup> The Children's Hospital Westmead (2013), *Kids can drown without a sound*, http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health. nsw.gov.au/files/attachments/949/report\_inflatable\_and\_portable\_swimming\_pool\_safety\_final.pdf, accessed 17 August 2015.

## Age, gender and Aboriginal and Torres Strait Islander status

Most of the children who died were very young; four were less than five years of age, and four were between five and ten years. One teenager drowned. Nationally, drowning is one of the leading causes of death of children aged one to 14 years.<sup>233</sup>

Eight of the nine children were boys. As shown in the table below, over the 15 years to 2014, 70 percent of drowning deaths have involved males. This gender imbalance is also reflected in national data.<sup>234</sup>

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	3	7	8	5	8	5	3	8	7	6	3	4	2	3	1
	-	(0.90)	(1.03)	(0.64)	(1.03)	(0.65)	-	(1.03)	(0.89)	(0.76)	-	(0.50)	-	-	-
Male	17	11	21	17	8	5	12	10	14	6	11	13	9	10	8
	(2.08)	(1.34)	(2.56)	(2.08)	(0.98)	(0.61)	(1.47)	(1.22)	(1.69)	(0.72)	(1.31)	(1.54)	(1.06)	(1.16)	(0.92)
Total	20	18	29	22	16	10	15	18	21	12	14	17	11	13	9
	(1.26)	(1.12)	(1.81)	(1.38)	(1.01)	(0.63)	(0.94)	(1.12)	(1.30)	(0.74)	(0.86)	(1.04)	(0.66)	(0.78)	(0.53)

#### Table 61: Trends in drowning deaths of children by gender, number and rate, 2000-2014

One child who drowned in 2014 was Aboriginal. Another two children were from a culturally and linguistically diverse background.

# 9.3 Swimming pools

In 2014, two children drowned in private swimming pools; both were less than two years of age. A third child died in 2014 as a result of a near-drowning incident that occurred some years prior, resulting in significant brain injury and disability. The child was under the age of three years at the time of the incident.

As shown in table 62, between 2000 and 2014, 107 children died in private swimming pools in NSW; 78 percent (83 children) were aged between one and three years.

The two children who drowned in 2014 represent the lowest annual number of drowning deaths in swimming pools over this period.

Information about pool type was available for two pools. Both were permanent structures, one in-ground and one above ground. All three pools had barrier fencing and were located at the child's own home. All of the pools were on owner-occupied properties. One child was in care at the time of death and had been placed recently with authorised carers.

As has consistently been the case, the incidents occurred in the context of inadequate barriers to prevent access to the pools, and lapses in carer supervision.

#### Table 62: Drowning deaths of children in private swimming pools by age, 2000-2014

	Age in years																	
under 1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Total
1	39	31	13	6	2	3	2	1	2	1	0	2	0	1	0	2	1	107

### Existence and condition of child safety barriers

While each of the three pools where the children drowned were fenced, records indicate that all had problems with safety barriers.

In two cases, the child accessed the pool though gates that were unintentionally left open. Both of these gates had problems with the latch mechanism that meant they did not self-close. In the third case, the child gained access to the pool through a loose panel in the fence.

For one of the three children, records indicate that the carers were aware of the barrier defect prior to the drowning incident. In the other two cases, it appears that the fault was identified after the incident, with the carers advising relevant authorities that they were not previously aware of the problem.

<sup>233</sup> Australian Bureau of Statistics (2015), 3303.0 – Causes of death Australia, 2013, cat. no. 3303.0, ABS: Canberra.
234 Ibid.

Current pool standards require all pool gates to have a self-closing mechanism that allows the gate to return automatically to a closed position without applying manual force, but requiring manual release to open the gate.

### Supervision of the children

The deaths of the three children in 2014 that were attributed to drowning in swimming pools occurred in the absence of direct adult supervision. The children were left unsupervised for periods ranging from five to ten minutes.

The Team has previously highlighted the increased drowning risks for young children when carers' attention is divided or distracted, and in social gatherings, when incorrect assumptions may be made that someone else is watching the children.

For each of the three children, records show that the supervising adult/s were focused on, or distracted by, other activities and believed that the child was safe in another location in the home.

# 9.4 Natural bodies of water

Around one third of all drowning deaths of children occur in natural bodies such as beaches, rivers and lakes.

Over the past 15 years, 32 children in NSW have drowned in coastal bodies of water (oceans and beach estuaries) and 39 in inland bodies (rivers, creeks, lakes, streams and irrigation channels). Rates of death of children in natural waterways have declined over the 15-year period, in keeping with the overall decline in drowning deaths. The majority of the children who died in natural waterways were either very young, or were teenagers.

In 2014, four children – three aged five years or less and one teenager – drowned in the ocean (2), a lake (1) and a river (1). All were male.

Beaches account for the second largest number of drowning deaths of children aged 5-14 years in Australia.<sup>235</sup>

Environmental conditions contributed to the two drowning deaths that occurred at beach locations in NSW in 2014. Both children were five years of age and were playing with family in shallow water along the shoreline. One child was knocked over and dragged out into deeper waters by a large wave. The other child fell into a channel with a strong outgoing rip current.

In both cases, the beaches were unpatrolled and rescue attempts by supervising adults were hampered by poor swimming ability and environmental conditions including large waves, strong currents and poor visibility. As the Team has previously highlighted, hazardous conditions at beaches can arise and/or escalate rapidly. Risks may be heightened at unpatrolled locations, as swimming conditions are not assessed for safety by lifeguards as part of a life saving service.

Only four percent of Australian beaches are patrolled and they each have varying hazards and associated risk ratings.<sup>236</sup> Surf Life Saving Australia estimates that one in five Australians usually swim at unpatrolled beaches and that swimming ability amongst the general community is relatively low.<sup>237</sup>

In addition, the consultative draft of the Australian Water Council's *Australian Water Safety Strategy 2016-2020* notes that more than 50% of beach drowning deaths occur outside of patrolling times, whether outside of the patrolling season or at a time of day before or after a lifeguard is on active duty.<sup>238</sup> Key prevention measures focus on swimming at patrolled beaches between red and yellow flags, awareness of rips, and what to do if caught in a rip. Royal Life Saving Australia's guidance on beach safety includes the recommendation that caregivers actively supervise young children within arm's reach at the beach.<sup>239</sup>

In 2014, one young child and a teenager drowned in inland bodies of water. The young child accessed a river located across the road from the house. The child's parents were unaware that the child had left the house. The young person who drowned after entering a lake was reportedly not a strong swimmer, the water was deep and the temperature cold.

<sup>235</sup> Surf Life Saving Australia (2014), National Coastal Safety Report 2014, https://sls.com.au/sites/sls.com.au/files/Annual%20Report%202013-14.pdf, accessed 17 August 2015.

<sup>236</sup> Australian Water Safety Council (2015), Australian Water Safety Strategy 2016-20 Consultative Draft, http://watersafety.com.au/Portals/0/ AWSC%20Strategy%202016-20/RLS\_AWSS2016\_ReportV4-Low%20Res%20with%20cover%20letter.pdf, accessed 17 August 2015.

<sup>237</sup> Surf Life Saving Australia (2014), National Coastal Safety Report 2014, http://sls.com.au/sites/sls.com.au/files/NCSR%202014\_101114\_final.pdf, accessed 17 August 2015.

<sup>238</sup> Australian Water Safety Council (2015), Australian Water Safety Strategy 2016-20 Consultative Draft, http://watersafety.com.au/Portals/0/ AWSC%20Strategy%202016-20/RLS\_AWSS2016\_ReportV4-Low%20Res%20with%20cover%20letter.pdf, accessed 17 August 2015.

<sup>239</sup> Royal Life Saving Society Australia (2012), Fact Sheet number 27 – Beach safety, http://www.royallifesaving.com.au/\_\_data/assets/pdf\_ file/0018/3942/KW\_BathTime\_A4toDL\_final.pdf, accessed 17 August 2015.

The Team has previously drawn attention to the potential hazards associated with inland waterways, including currents; crumbling beds; submerged objects; low visibility; and variable water depth and temperature. Seasonal patterns such as flooding can also cause conditions to change rapidly.

								Ag	e in ye	ears								
under 1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Total
0	8	6	8	5	5	1	4	2	3	1	0	0	4	3	4	10	7	71

#### Table 63: Drowning deaths of children in natural bodies of water, 2000-2014

# 9.5 Bathtubs

As shown in table 64, over the past 15 years, 34 children in NSW have drowned in the bath. Almost 60 percent of these deaths occurred in the 6 to 12-month (9) and 12-month to 2 year (11) age groups. This aligns with research findings which indicate that the incidence of drowning deaths and hospitalisations for near-drowning of young children in bathtubs tends to peak around the developmental age at which they are generally able to sit upright.<sup>240</sup>

For the majority of the 25 drowning deaths of children aged less than two years, inadequate supervision was the primary contributing factor. Common circumstances involved the caregiver leaving the child unattended for short periods of time while undertaking other tasks, such as answering the telephone, attending to other children or collecting bathing equipment.

Older children and teenagers accounted for a smaller proportion of bathtub drowning deaths (8) over the 15-year period. In each case, the child either was, or had recently been, unwell; or had epilepsy and/or significant disability.

One child, an infant, died in a bathtub in 2014. At the time of the incident, the infant was placed in a baby bath aid<sup>241</sup> while the carer left the room momentarily to attend to another task.

#### Table 64: Drowning deaths of children in bathtubs by age range, 2000-2014

Age range	Number of children
Under 3 months	4
3 months to under 6 months	1
6 months to under 12 months	9
12 months to under 2 years	11
2-4 years	1
5-9 years	4
10-17 years	4
Total	34

Over the years, the Team's key prevention messages in relation to the drowning deaths of children in bathtubs have focused on the provision of constant and arms length supervision of young children, and restricting access to bathtubs without supervision.

There are a range of organisations and programs that have a similar focus in promoting prevention measures, including publishing resources that provide tips for keeping children safe during bath time. For example:

<sup>240</sup> Australian Institute of Health and Welfare, Pointer S. (2014). *Hospitalised injury in children and young people 2011-12*. Injury research and statistics series no.91. Cat. No. INJCAT 167. AIHW: Canberra.

<sup>241</sup> Baby bath aids are used to support infants in the bath by helping keep their heads up and out of the water while being washed by carers. There are different types of aids, including bath seats, cradles, hammocks, recliners, and rings. Since 2005, baby bath aids must comply with mandatory standards under the Trade Practices (Consumer Product Safety Standard) (Baby Bath Aids) Regulation. The standard includes the need for warning signs about drowning risks to be clearly displayed on products, including that bath aids are not a safety device and that the baby must always be kept within arm's reach of a supervising adult.

- The Royal Life Saving Australia's *Keep Watch* @ *Bath Time* resources provide clear guidance for carers on preventing bathtub drowning deaths. The resources include a checklist of actions carers should take, including having everything ready for bathing before entering the bathroom; and leaving the bathroom with taps turned off, plug removed, bathtub drained and door closed.<sup>242</sup>
- Kidsafe NSW and Royal Life Saving Australia have developed resources specifically aimed at educating carers about the correct use of baby bath aids and the potential dangers, emphasising that children should always be in the presence of arms-length adult supervision as they can easily slip or climb out of the aid and drown.<sup>243 244</sup>

# 9.6 Dams

Drowning on farm dams is the largest single cause of child deaths on Australian farms.<sup>245</sup> Approximately five to six children drown in dams and water bodies located on farms across Australia each year.<sup>246</sup>

Over the 15-year period from 2000-2014, fourteen children drowned in dams in NSW. As shown below, the majority of the children were under five years of age (10). In 2014, one child drowned in a dam on a rural property in NSW.

Royal Life Saving Australia and Farmsafe Australia have developed a range of resources with targeted prevention messages, including suggested strategies for keeping children safe around dams and other water bodies on rural properties. In addition to active supervision, fact sheets developed by both organisations recommend the use of securely fenced 'safe play areas' incorporating child resistant gates and latches to prevent young children from accessing dams on the property.<sup>247 248</sup>

#### Table 65: Drowning deaths of children in dams, 2000-2014

	Age in years																	
under 1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Total
0	4	1	0	3	2	1	2	0	0	0	0	0	0	0	0	0	1	14

# 9.7 Prevention measures and the Team's recommendations

### Key prevention messages and programs

In line with the Team's findings over a number of years, key prevention messages to parents/carers about drowning risks should reinforce that:

- Supervision of young children in and around water must be constant and active, with supervisory responsibility clearly and appropriately designated.
- If safety barriers are not effectively child-resistant, even momentary lapses in supervision or diverted attention can result in a drowning death. Specifically in relation to pools, faulty self-closing or automatic gate latch mechanisms have been the predominant defect in pool safety barriers, indicating the need to ensure pool owners are aware of the need for regular maintenance of gates and latches.
- Environmental conditions in and around waterways can change rapidly and it is critical that young people and carers of younger children are alert to, and constantly assess, potential dangers. It is also essential that young children are actively supervised at all times.

<sup>242</sup> Royal Life Saving Society Australia (2012), Keep Watch @ Bath Time (brochure), http://www.royallifesaving.com.au/\_\_data/assets/pdf\_ file/0018/3942/KW\_BathTime\_A4toDL\_final.pdf, accessed 17 August 2015.

<sup>243</sup> Kidsafe NSW (2013), http://www.kidsafensw.org/newsletter.asp?id=16, accessed 17 August 2015.

<sup>244</sup> Royal Lifesaving Society Australia, *Baby Bath Aids* (brochure), http://www.royallifesaving.com.au/\_\_data/assets/pdf\_file/0019/3943/RLS-and-ACCCBath\_Aid\_Brochure.pdf , accessed 17 August 2015.

<sup>245</sup> University of Sydney, Australian Centre for Agricultural Health and Safety (2009), *Child Safety on Farms: A Practical Guide*, http://www.farmsafe.org.au/resources/document/24-1-, accessed 17 August 2015.

<sup>246</sup> Farmsafe Australia, Safe Play Area (brochure), http://www.farmsafe.org.au/content/safe-play-areas, accessed 17 August 2015.

<sup>247</sup> Royal Life Saving Society Australia, Keep Watch @ The Farm (brochure), http://www.royallifesaving.com.au/families/at-home/toddler-drowningprevention/keep-watch-@-the-farm, accessed 17 August 2015.

<sup>248</sup> Farmsafe Australia, Safe Play Area (brochure), http://www.farmsafe.org.au/content/safe-play-areas, accessed 17 August 2015.

The Team also recognises and supports the work of a range of organisations that deliver education and programs targeting water safety. For example, the Royal Life Saving Society's Keep Watch Program aims to prevent the drowning deaths of children under five years of age in all aquatic locations. The program promotes four key prevention messages:

- **supervise** (close/constant/focused);
- restrict access (fence/gate/maintain);
- water awareness (familiarise/develop/educate); and
- resuscitation (learn/update/act).249

As part of this program, the Royal Life Saving Society have developed a Home Pool Safety Checklist that allows pool owners to complete a self assessment of the pool, and launched a Pool Safety App that includes the checklist.<sup>250 251</sup>

The Australian Water Safety Council<sup>252</sup> has also developed a range of specific strategies to prevent drowning deaths in Australia and aims to achieve a 50 percent national reduction by 2020. The Council has recently issued a consultative draft *Australian Water Safety Strategy 2016-2020*. The strategy includes measures designed to target populations at high risk of drowning (including children aged 0-14) and high risk locations, (including natural bodies of water).

For example, the strategy has a particular focus on coastal waterways and outlines intended actions to reduce drowning deaths at Australian beaches, including identifying non-patrolled beaches with high drowning rates; developing and conducting a national rip awareness program; and expanding surf lifesaving patrols through the use of improved technology and services.<sup>253</sup> Surf Life Saving and NSW CoastSafe are currently in the second phase of a four-year coastal public safety risk assessment for every beach and rock platform in NSW, which will provide a 'blueprint' for NSW to develop a drowning prevention strategy.<sup>254</sup>

## Swimming pools

Following completion of a review of swimming pool legislation in NSW by the (then) Department of Local Government, significant amendments to the *Swimming Pools Act 1992* took effect in October 2013. The review and resulting amendments reflected calls from the Team, the Coroner and pool safety advocacy organisations for further strengthening of the Act.

The amendments are intended to increase safety around backyard swimming pools, and to reduce drowning and neardrowning incidents by including new obligations, responsibilities and accountability for owners of swimming pools, and for councils tasked with ensuring compliance. Key changes include requirements for:

- pool owners to register their pools on an online register, and complete a self-assessment of their pool's compliance with barrier requirements under the Act
- pool owners to include a valid certificate of compliance<sup>255</sup> or a relevant occupant certificate<sup>256</sup> if they sell or lease their property from 29 April 2016, and
- local councils to develop a pool inspection program to monitor compliance with the Act.

Recent advice to the Team from the NSW Government indicates that approximately 95 percent of pools fail to comply with requisite safety standards at first inspection.<sup>257</sup>

<sup>249</sup> Royal Life Saving Society Australia (2012), Keep Watch Actions, http://www.royallifesaving.com.au/families/at-home/toddler-drowning-prevention/ keep-watch-actions, accessed 17 August 2015.

<sup>250</sup> Royal Life Saving Society Australia (2013), Home Pool Safety Checklist, http://www.royallifesaving.com.au/families/at-home/home-pool-safety/ home-pool-safety-checklist, accessed 17 August 2014.

<sup>251</sup> Royal Life Saving Society Australia (2012), Royal Life Saving Society Australia and PoolWerx Launch Home Pool Safety Campaign for 2012, http://www.royallifesaving.com.au/about/news-and-events/news-items/Home-Pool-Safety-Campaign-2012, accessed 17 August 2015.

<sup>252</sup> The Australian Water Safety Council is a consultative forum whose member organisations include major water safety and related government agencies. The Council has a focus on disseminating key water safety messages to governments, industry and the broader community – see http://www.watersafety.com.au/.

<sup>253</sup> Australian Water Safety Council (2015), Consultative Draft Australian Water Safety Strategy 2016-2020, http://www.watersafety.com.au/Portals/0/ AWSC%20Strategy%202016-20/RLS\_AWSS2016\_ReportV4-Low%20Res%20with%20cover%20letter.pdf, accessed 17 August 2015.

<sup>254</sup> Correspondence from NSW Premier to NSW Ombudsman, 29 May 2015.

<sup>255</sup> Pool owners can request the local council or an accredited certifier to inspect the pool for the purpose of obtaining a certificate of compliance. This certificate is valid for three years and states that the swimming pool is registered and complies with the requirements under the Act.

<sup>256</sup> A relevant occupation certificate is an occupation certificate issued under the *Environmental Planning and Assessment Act* 1979 that is less than three years old and that authorises the use of the swimming pool.

<sup>257</sup> Correspondence from NSW Premier to NSW Ombudsman, 29 May 2015.

### 2015 review of swimming pool barrier requirements

In July 2015, the Minister for Local Government announced a new regulatory review of swimming pool legislation, in part due to the high level of non-compliance with barrier requirements.<sup>258</sup> The review aims to 'simplify the regulatory framework and encourage greater barrier compliance in order to reduce the incidence of child drownings and near-drownings in private pools'.<sup>259</sup>

The Terms of Reference for the review require an examination of the inspection and compliance framework (particularly the requirement for compliance certificates for properties sold and leased); the enforcement framework (including relevant recommendations made by the Team and the Coroner); the barrier standards and exemptions framework; and appropriate government arrangements for administering the Act.

The Terms of Reference state that the purpose of the review is to ensure that the regulatory and enforcement framework for swimming pool barriers in NSW:

- is underpinned by swimming pool barrier standards that are simple and effective
- facilitates the application of a uniform standard wherever possible, including to existing swimming pools
- is proportionate to the risk being managed, including consideration of the Guide to Better Regulation principles
- ensures responsibility for maintaining and installing a compliant swimming pool barrier remains with the swimming pool owner, and
- provides an effective enforcement and compliance framework that maximises the likelihood of responsible owner behaviour.

The Team agrees with the need for simple, targeted and effective regulation of swimming pools in NSW and notes that this aligns with key findings from the Team's review of swimming pool drowning over the five-year period 2007-2011. In particular, the Team emphasised that the most at-risk group for drowning in swimming pools are children under five years of age, and pools that present the most risk are located on properties where children live or frequently visit, including rental properties.

In line with the Team's findings from its five-year review of swimming pool drowning deaths and the subsequent introduction of amendments to swimming pool legislation, the Team's recommendations in recent years have focused on the need for:

- councils to be able to identify properties with swimming pools where young children reside or regularly visit, in order to target or prioritise those premises for inspection
- guidance/model policies for councils to provide for consistency, and to assist them develop and effectively target inspection programs
- annual and public reporting by councils on: the number of inspections; compliance with the *Swimming Pools Act;* orders issued by councils to rectify non-compliance; and whether or not owners have rectified defects within a reasonable period of time, and
- guidance for child protection staff working with vulnerable families to identify drowning risks to young children, including compliance with the Swimming Pools Act.

The Team notes that the review will examine an enforcement framework, including consideration of the Team's recommendations.

#### Targeted pool inspection programs and identifying premises with young children

Since October 2013, councils are required under the *Swimming Pools Act* to develop and implement a program for the inspection of swimming pools in their area to ensure compliance with requirements; and to consult with the local community when developing their inspection programs. Given that the amendments to the Act were made with the intention of reducing the drowning deaths and near-drowning of young children in swimming pools, the Team's recommendations have focused on councils effectively identifying premises with swimming pools and young children, and targeting mandatory inspection regimes accordingly.

To help inform council priorities for pool inspections, last year the Team recommended that FACS, the Office of the Children's Guardian (OCG) and the Office of Local Government (OLG) should develop arrangements to facilitate the provision of information to the OLG/local councils about children residing at premises with pools identified by these agencies through the course of their work.

<sup>258</sup> Correspondence from Minister for Local Government to NSW Ombudsman, 6 July 2015.

<sup>259</sup> Office of Local Government, Swimming Pool Barrier Review 2015, https://www.olg.nsw.gov.au/content/swimming-pool-barrier-review-2015, accessed 17 August 2015.

In response, the NSW Government advised that it supports the recommendation and, as lead agency, the OLG will 'organise discussions with FACS, OCG and local councils to determine the feasibility of an arrangement to share and provide this information to local councils'.

The Team notes that the inspection framework is within the scope of the current Swimming Pool Review, and will continue to monitor the targeting of compliance measures in this context.

#### **Reporting on compliance**

There are over 300,000 private swimming pools in NSW. The Team recognises that the amendments to swimming pool legislation have introduced substantial changes for councils and pool owners, and that there are considerable challenges involved in rolling out large scale reform across NSW.

In February 2015, the Office of Local Government announced that the start of the 'sale and lease' provisions of the Act have been postponed until April 2016 in response to high inspection failure rates, challenges in meeting the demand for repairs and upgrades to pool barriers, and associated delays in being able to issue compliance certificates.<sup>260</sup> As noted above, issues relating to non-compliance largely prompted the current review of swimming pool barrier requirements.

Given the significant amendments to swimming pool obligations in recent years, the Team has previously emphasised the importance of ensuring that implementation of the changes is closely monitored by OLG, to enable the early identification and resolution of any barriers to achieving its intended aims of reducing drowning deaths and near-drowning of children. The Team recommended that the OLG provide advice on:

- its analysis of data and other information relating to compliance, including numbers of swimming pools registered and inspected; the proportion of pools considered non-compliant; the main defects identified; and whether or not owners rectified these defects within a reasonable timeframe
- how it will publicly report on swimming pool inspection and compliance activity across NSW.

In response, the NSW Government advised that information currently captured on the swimming pool register enables reporting on the number of pools registered, inspected and considered non-compliant, but that enhancements to the register would need to occur in order to facilitate reporting on the nature of identified defects and remedial action undertaken by owners.<sup>261</sup>

The response further indicates that information currently available on the swimming pools register, including the number of pools deemed non-compliant with barrier requirements, is reported in OLG's annual reports, which can be accessed from OLG's website. The Team has reviewed the information reported in the OLG annual reports and notes that they do not appear to contain this information.

The Team also notes that the swimming pool register includes capacity for authorised officers/accredited certifiers to record the date/time of inspection; whether the pool is compliant or non-compliant; the reasons for non-compliance (gate, fence, window, door, sign, other); and comments/explanation for non-compliance.<sup>262</sup>

• The NSW Government indicated that the OLG is continuing to engage with councils and other stakeholders to 'determine how [the swimming pool register] could be enhanced to improve recording and reporting generally and specifically in relation to [the Team's recommendation]'.

Taking account of the outcomes of the 2015 Swimming Pool Review, the Team will continue to monitor the implementation of regimes for monitoring compliance with legislative requirements relating to private swimming pools and related public reporting.

### Guidance for child protection staff to identify drowning risks

Last year, the Team recommended that FACS, the OCG and the Association of Children's Welfare Agencies (ACWA) advise the Team on:

- the adequacy of risk assessment processes/guidance provided to designated out-of-home care agencies and/or child protection staff to identify drowning risks to young children, including compliance with the *Swimming Pools Act*, and
- intended action to reduce the drowning risks to young children identified through the course of their work.

<sup>260</sup> Office of Local Government, *Circular to Councils 15-20*, dated 26 February 2015, https://www.olg.nsw.gov.au/sites/default/files/15-10.pdf, accessed 17 August 2015.

<sup>261</sup> Correspondence from NSW Premier to NSW Ombudsman, 29 May 2015.

<sup>262</sup> Division of Local Government, Department of Premier and Cabinet (2013), Swimming Pool Register User Guide, http://www.olg.nsw.gov.au/sites/ default/files/Swimming-Pool-Register-User-Guide.pdf, accessed 17 August 2015.

In response, the NSW Government advised that:

- safety and risk assessment tools used by FACS child protection caseworkers when responding to risk of significant harm reports include prompts to identify and assess drowning risks for children
- FACS is progressing work to target drowning risks for children in out-of-home care, including 'strengthening procedures for authorising carers' and links to pool safety resources on FACS' casework practice intranet
- As part of accrediting out-of-home care agencies, OCG assessors review agency records for evidence that they assess and monitor the care environment (including safety risks associated with swimming pools) as required by the NSW Standards for Statutory Out-of-Home Care
- The OCG will incorporate a new requirement into the NSW Standards for Statutory Out-of-Home Care which explicitly requires designated out-of-home care agencies to ensure that swimming pools on premises where children in care reside comply with legislative requirements, and
- The OCG will provide relevant information from the Carers Register<sup>263</sup> to FACS and/or local councils that identifies carer households with pools.

ACWA separately advised that they are committed to working with member agencies (including non-government out-of-home care providers) to communicate the importance of, and implement strategies focused on, the identification of drowning risks for children in care. ACWA also proposes to review its training courses to identify opportunities for a strengthened focus on water safety.<sup>264</sup>

The Team is encouraged by measures aimed at:

- strengthening processes for the exchange of relevant information about premises with pools where young children reside to better enable councils to more effectively target their inspection programs, and
- increased focus on training and dissemination of key water safety messages to staff working with vulnerable families, including in relation to the identification of drowning risks and potentially non-compliant swimming pools.

In the context of the Swimming Pool Review 2015, the Team will continue to monitor how relevant agencies identify and address drowning risks for children, including compliance with swimming pool legislation.

<sup>263</sup> The NSW Carers Register commenced in June 2015 and is administered by the Office of the Children's Guardian. It is centralised database of persons who are authorised, or who apply for authorisation, to provide statutory or supported out-of-home care in NSW.

<sup>264</sup> Correspondence from Association of Children's Welfare Agencies to NSW Ombudsman, 3 June 2015.

# Chapter 10. Suicide

The deaths of 22 children and young people registered in NSW in 2014 were due to suicide, and suicide was the leading external cause of death for children and young people aged 10-14 and 15-17 years.<sup>265</sup> 2014 represents the largest annual number and highest rate of suicide of children and young people since 2000, largely accounted for by a suicide cluster.

This chapter considers the deaths of young people that occurred as a result of suicide or probable suicide. This includes deaths where:

- the Coroner has made a finding that the cause and manner of death was self-harm with fatal intent, or
- the case remains open with the Coroner, or the Coroner has dispensed with an inquest and has not made a finding regarding manner of death, but police have identified the death as suicide, and records examined provide evidence of intent.

The Coroner has determined that five of the 22 deaths were the result of suicide. In nine cases, the Coroner has dispensed with an inquest without recording findings regarding manner of death. At the time of writing, eight cases were still open with the Coroner.

# 10.1 Trends in suicide deaths of young people NSW, 2000-2014

According to the Australian Bureau of Statistics, in 2013 across all states and territories, suicide was the leading cause of death of children and young people aged between five and 17 years. In the period 2009 to 2013, NSW had the lowest suicide rate for children and young people aged 5-17 years of all states and territories in Australia.<sup>266</sup>

As shown in table 66, over the 15 years to 2014, 249 children and young people died by suicide in NSW.<sup>267</sup> The 22 suicide deaths in 2014 represent the highest number and rate of children and young people in NSW over the 15-year period. However, since 2000, there has been no significant change in the suicide mortality rate, with an average of 16 deaths of children and young people in NSW each year.

The table also shows that males are consistently over-represented in suicides. This is also reflected in national data, with male suicide deaths markedly outnumbering female deaths in all age groups.<sup>268</sup> In contrast, national data indicates that females have higher rates of hospitalisation as a result of intentional self-harm, with rates being highest for females aged 15-19 years.<sup>269</sup>

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Female	8 (1.03)	5 (0.64)	6 (0.77)	6 (0.77)	7 (0.90)	6 (0.78)	2	4 (0.51)	5 (0.64)	4 (0.51)	5 (0.63)	4 (0.50)	7 (0.87)	9 (1.11)	9 (1.10)	87
Male	10 (1.23)	12 (1.46)	13 (1.58)	12 (1.47)	9 (1.10)	14 (1.72)	6 (0.74)	10 (1.22)	8 (0.97)	14 (1.68)	9 (1.07)	13 (1.54)	9 (1.06)	10 (1.16)	13 (1.50)	162
Total	18 (1.13)	17 (1.06)	19 (1.19)	18 (1.13)	16 (1.01)	20 (1.26)	8 (0.50)	14 (0.87)	13 (0.81)	18 (1.11)	14 (0.86)	17 (1.04)	16 (0.97)	19 (1.14)	22 (1.31)	249

Table 66: Trends in deaths due to suicide by gender, number and rate, 2000-2014

Note Table 66 was updated on 05/09/2016 due to a labeling error.

Table 67 below shows that the large majority (84 percent) of young people who died by suicide between 2000 and 2014 were aged 15 years or older. Seventeen year olds represented over one third of all suicide deaths over that period.

Drawing on NSW Registry of Births, Deaths and Marriages data, Aboriginal and Torres Strait Islander children and young people represented seven percent of all children and young people (17) who died by suicide over the 15 years from 2000.<sup>270</sup>

266 Australian Bureau of Statistics (2013). Causes of Death Australia, 2013, cat.no.3303.0. ABS: Canberra.

269 Ibid.

<sup>265</sup> This includes cases where the Coroner has determined suicide, and also probable suicide where the Coroner has not confirmed manner of death.

<sup>267</sup> There were no deaths of children aged under 10 years that were recorded as suicide.

<sup>268</sup> Harrison J.E. & Henly G., Australian Institute of Health and Welfare (2014), Suicide and hospitalised self-harm in Australia: trends and analysis. Injury research and statistics no.93. Cat. No. INJCAT 169. AIHW: Canberra.

<sup>270</sup> The CDRT relies on Births, Deaths and Marriages data for trend information for Aboriginal and Torres Strait Islander children. See chapter 1 for details.

The prevalence of mental health problems and suicide among Aboriginal and Torres Strait Islander youth is significantly higher than that of their non-Indigenous counterparts.<sup>271</sup>

The number of suicide deaths of children and young people under the age of 15 is small, but is significant in terms of the proportion of all deaths within this age group.<sup>272</sup> Five children who died by suicide in 2014 were aged between 11 and 14 years of age, the second highest number in any one year since 2000.

#### Table 67: Trends in deaths due to suicide by age, 2000-2014

	Age in years												
	10	11	12	13	14	15	16	17	Total				
Number (%)	1 (<)	3 (1)	3 (1)	12 (5)	20 (8)	46 (18)	69 (28)	95 (38)	249 (100)				

# 10.2 Young people who died in 2014

Table 68 below provides an overview of the demographic characteristics of the 22 children and young people who died by suicide, and whose deaths were registered in 2014.

Three young people were Aboriginal. Five young people were from a culturally and linguistically diverse background.

In the period immediately prior to their deaths, the majority (17) of the young people lived at home with at least one parent. The other five young people were living at the family home of a friend (3), living with extended family (1), and living independently (1).

Over half (12) of the young people died at their usual place of residence. Eight young people died in a public place, and two at the home of a friend or relative.

Most (17) of the young people were enrolled in school. Two had left school and were attending TAFE. Two young people were unemployed at the time of death and one young person was employed full time.

# Table 68: Deaths of young people due to suicide – age, gender and Aboriginal and Torres Strait Islander status, 2014

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	р
Total	22	100	1.31	0.82 - 1.98	-	-
Gender						
Female	9	41	1.10	0.50 - 2.09	-	-
Male	13	59	1.50	0.80 - 2.57	1.4	0.47
Age						
Under 1 year	0	0	-	-	-	-
1-4 years	0	0	-	-	-	-
5-9 years	0	0	-	-	-	-
10-14 years	5	23	1.11	0.36 - 2.60	-	-
15-17 years	17	77	6.21	3.62 - 9.94	-	-
Aboriginal and Torres Strait Islander status						
Aboriginal or Torres Strait Islander	3	14	-	-	-	-
Not Aboriginal or Torres Strait Islander	19	86	1.19	0.72 - 1.86	-	-

<sup>271</sup> McDermott B., Baigent M., Chanen A., Fraser L., Graetz B., Hayman N., Newman L., Parikh N., Peirce B., Proimos J., Smalley T., Spence S.,

Beyondblue Expert Working Committee (2010), *Clinical practice guidelines: depression in adolescents and young adults*. Beyondblue: Melbourne. 272 Australian Bureau of Statistics (2013), *Causes of death, Australia,* cat.no.3303.0. ABS: Canberra.

# **10.3 Indications of intent**

Almost half (10) of the 22 young people who died by suicide had explicitly stated their intent to do so shortly before they died; in most cases within the 24 hours prior to their death. Most often, the person they told was a friend(s), including boyfriends or girlfriends, and in a small number of cases, a counsellor or family member. The messages were mainly conveyed by text message, less often by phone conversation or Facebook, and rarely face-to-face.

Most (9) of the young people who stated their intention to suicide had a history of self-harm, suicide attempt(s), or threats, thoughts or discussion of suicide.

In regard to the 12 young people who did not explicitly state their intent to suicide, eight had some history of self-harm or suicidal thoughts and in three cases, a previous suicide attempt.

Four young people gave no indication of their intent, and had no history to indicate that they were at risk of suicide.

Ten young people left a note or message to be read after their death that confirmed their intent, including five who had not explicitly stated their intention prior to their death.

# 10.4 Risk factors associated with suicide

Suicide Prevention Australia notes that suicide is a complex phenomenon generally resulting from a combination of several individual, social and contextual risk factors:<sup>273</sup>

- Individual risk factors include mental illness, substance abuse, previous suicide attempt and self-harm.
- Social risk factors include childhood adversity, such as a child protection history; bullying and social exclusion; sexual identity issues; and family factors, such as parental loss, divorce or discord and family depression and suicide history.
- Contextual risk factors include socioeconomic disadvantage, suicidality in family or friends, homelessness and detention or contact with police.

Many of these factors are not uncommon among the general population, and suicide among young people has been noted to be sometimes an impulsive act.<sup>274</sup>

For young people, the combination of these factors poses the greatest risk.<sup>275</sup> Risk factors are both proximal (recent stressful events or 'triggers') and distal (factors likely to increase vulnerability over time).<sup>276</sup>

## **Cumulative risk**

Suicide can result from interactions between risk factors across a person's life span.<sup>277</sup> As shown in the table below, most of the young people who died by suicide in 2014 experienced multiple risk factors including psychosocial issues and difficulties associated with family circumstances, education or employment.

Over half of the young people experienced at least one stressful or adverse life event in the month prior to their suicide. The proximal events included significant discord with peers or family members, relationship breakdown with a boyfriend or girlfriend, school or employment pressure, physical assault, bullying, parental separation, the suicide death of a friend or family member, and in one case, a pregnancy miscarriage.

276 Department of Health and Ageing (2008), Life - living is for everyone: A framework for prevention of suicide in Australia,

277 Ibid

<sup>273</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

<sup>274</sup> Standing Committee on Health and Ageing, Federal House of Representatives (2011), Before it's too late: report on early intervention programs aimed at preventing youth suicide, http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&ved=0CCwQFjAD ahUKEwig4va4tq\_IAhXjg6YKHcfODes&url=http%3A%2F%2Fwww.aph.gov.au%2Fparliamentary\_business%2Fcommittees%2Fhouse\_of\_ representatives\_committees%3Furl%3Dhaa%2F.%2Fyouthsuicide%2Freport%2Ffullreport.pdf&usg=AFQjCNHB2-8rVxG6\_I0n6B4uk-qDpqBuSA &sig2=aLE2KBabSx6czbBtHsINjA, accessed 17 August 2015.

<sup>275</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

http://www.livingisforeveryone.com.au/uploads/docs/LIFE\_framework-web.pdf, accessed 17 August 2015.

Table 69: Risk factors	for suicide - individ	ual young people, 2014
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	Diagnosed or undiagnosed mental health conditions	Substance misuse	Previous suicidal thoughts or behaviour and self-harm	Childhood trauma	Difficult family circumstances	Psychosocial issues, self-esteem, body image, social isolation, chronic health issues	Difficulties associated with school, education or employment	Difficult peer relationships, including bullying	Difficult close personal relationships, including relationship breakdown	Suicidality in Family/ Friends	Criminal/anti-social/risk- taking behaviour	Total
1	$\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark\checkmark$	10
2	$\checkmark$	$\checkmark$	$\sqrt{}$		$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$	$\sqrt{}$		$\checkmark$	$\checkmark$	9
3	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$		~	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$			$\checkmark\checkmark$	8
4	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark\checkmark$			$\checkmark$	8
5	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	8
6	$\checkmark\checkmark$		$\checkmark\checkmark$		$\checkmark\checkmark$	$\checkmark$	$\checkmark\checkmark$	$\checkmark\checkmark$				6
7	$\checkmark\checkmark$	$\checkmark$	$\checkmark\checkmark$	$\checkmark$	$\checkmark$					$\checkmark\checkmark$		6
8	$\checkmark\checkmark$	$\checkmark$	$\checkmark\checkmark$				$\checkmark\checkmark$				$\checkmark$	5
9	$\checkmark$		$\checkmark\checkmark$		$\checkmark\checkmark$	$\checkmark$			$\checkmark$			5
10	$\checkmark\checkmark$	$\checkmark$	$\checkmark$				$\checkmark\checkmark$				$\checkmark$	5
11	$\checkmark\checkmark$		$\checkmark\checkmark$				$\checkmark$	$\checkmark$	$\checkmark$			5
12	$\checkmark$		$\checkmark\checkmark$				$\checkmark\checkmark$			$\checkmark$	$\checkmark$	5
13					$\checkmark$	$\checkmark\checkmark$		$\checkmark\checkmark$		$\checkmark$	$\checkmark$	5
14	$\checkmark$		$\checkmark\checkmark$			$\checkmark$			$\checkmark$		$\checkmark$	5
15			$\checkmark\checkmark$		$\checkmark\checkmark$		$\checkmark$	$\checkmark\checkmark$				4
16			$\checkmark\checkmark$		$\checkmark$		$\checkmark$			$\checkmark$		4
17	$\checkmark\checkmark$		$\checkmark\checkmark$					$\checkmark\checkmark$				3
18		$\checkmark$					$\checkmark\checkmark$	$\checkmark\checkmark$				3
19	$\checkmark$				$\checkmark\checkmark$							2
20						$\checkmark$			$\checkmark$			2
21			$\checkmark\checkmark$							$\checkmark$		2
22					$\checkmark\checkmark$							1

✓ Single factor identified

✓✓ Multiple risk factors identified

# **Identified risk**

Table 69 draws from information contained in a range of records. However, the risks noted were not always evident prior to the suicide death of the young person. The majority of the 22 young people were not, at the time of their death, identified as being at high risk by service providers:

Seven had been identified as having chronic difficulties and complex needs. Most of the seven young people were known
to and involved with relevant support agencies, health practitioners or programs to address risks, including risk of suicide.
All seven had a diagnosed mental illness, and six had previously self-harmed and made at least one suicide attempt. Most
of the seven young people had either been reported as a child at risk of harm in the three years prior to their death, and/or
had experienced a traumatic event in their childhood.

- Nine were known to have some difficulties and needs. Some had sought or accessed assistance, but they had not been identified as being at risk of suicide. The main supports accessed by these young people were school counsellors, psychologists, general practitioners and Headspace programs. Six of these young people experienced a proximal stressful or traumatic event in the month prior to their death, including the suicide death of close friend, severe bullying, or significant family conflict.
- Six gave little indication to family or teachers or other professionals that they were at risk. Post-death investigations found
  that a number of these young people had previously indicated sadness or depression to friends, and/or had spoken to their
  friends about suicide. All six young people had experienced a significant proximal event in the month prior to their death.
  These included events commonly experienced in the community and by young people, such as discord with family members,
  relationship breakdown with a boyfriend or girlfriend, and parental separation. Less common triggers for this age group were
  also experienced by a number of young people, including the suicide death of a friend and significant difficulties at work.

## Individual risk factors

### Mental health concerns

#### **Diagnosed mental illness**

Almost half (10) of the 22 young people had been diagnosed with a mental illness. This was mainly depression and/or anxiety, and in three cases, additional diagnoses including personality, attention deficit and conduct disorders.

The majority (7) of the 10 young people with a diagnosed mental illness had previously attempted suicide.

#### Treatment or support for mental health concerns

Nine of the 10 young people with diagnosed conditions received treatment or support from one or more health professionals in the 12 months before their death.<sup>278</sup>

General practitioners are in a key position to provide early support and treatment to young people with mental health concerns, and to make appropriate referrals and linkages to additional, more specialised assistance. General practitioners had prepared a Mental Health Care Plan for seven of the young people. In three cases, these plans had been developed or reviewed within the 12 months prior to their death.

Six of the young people received intervention from a number of professionals in addition to general practitioners. Three had seen private psychiatrists and two a private psychologist. Other sources of support were school counsellor or other personnel, Community Adolescent Mental Health Service (CAMHS), Headspace, Adolescent and Family Service and phone support, such as the Mental Health Line.

Almost all (9) of the 10 young people had been prescribed medication for mental health concerns, primarily depression and/or anxiety, at some point prior to their death.

Records indicate that:

- Four young people had been prescribed selective serotonin reuptake inhibitor (SSRI) antidepressant medication or serotonin and norepinephrine reuptake inhibitors (SNRI) antidepressant medication, but were not taking this at the time of their death. In one case, the prescription had not been filled. In another, the young person was transient and ceased the medication. In the other two cases, it is unclear why the young people were not taking their prescribed medication.
- Three young people had been prescribed, and were taking, medication at the time of their death. Two young people were taking SSRI, including one who had ceased SSRI medication and started SNRI in the week prior to their death. The other young person had taken prescribed beta blockers.
- Two young people had previously been prescribed antidepressant or anti-psychotic medication, but had ceased this some months prior to their death. In both cases, the context was improved mental health and/or other treatment options including counselling.

The NSW Mental Health Commission has noted the challenges in diagnosing mental illness in young people, and that the number of children being treated for mental illness is rising. Following a public submission process in 2014, the NSW Mental Health Commission is currently preparing a paper to outline issues, themes and potential action in relation to medication and mental illness.<sup>279</sup>

<sup>278</sup> There was no evidence in records that one young person had received treatment for mental illness, however as they had resided interstate for some of the year, it is not known whether support was accessed in that state.

<sup>279</sup> Mental Health Commission of New South Wales (2014), *Medication and mental illness issues paper*, http://nswmentalhealthcommission.com.au/sites/default/files/Medication%20and%20mental%20illness%20issues%20paper.pdf, accessed 17 August 2015.

### **Undiagnosed mental health concerns**

In addition to the 10 young people with a diagnosed mental illness, five other young people displayed signs of poor mental health, including physical symptoms of depression, low self-esteem, anxiety, and self-harm behaviour. Two of the young people had accessed support through school counsellors:

- One counsellor made several referrals for the young person, including to a general practitioner and youth worker. The general practitioner had developed a mental health plan in consultation with the young person, and made a referral to a psychologist. The young person had not yet seen the psychologist at the time of their death.
- Another counsellor was of the opinion that a young person was at high risk of suicide and formulated a safety plan with the young person. A safety plan is an agreement between a young person and a health professional/counsellor that involves actions to keep them safe. It consists of a written list of early warnings signs; coping techniques, and sources of support the young person can use to reduce their risk of suicide.<sup>280</sup> The counsellor also advised the parents of risk to the young person and appropriate support services.

#### Substance use

Substance abuse, including cannabis and alcohol, can increase the risk of suicide for young people.<sup>281</sup> Nine of the 22 young people had a recorded history of cannabis use, three of whom also misused alcohol.

Six of the nine young people with problematic substance use had a diagnosed mental illness, mainly depression. All of these young people had previously attempted suicide, four within the 12 months prior to their death.

Service providers were aware of problematic substance use for over half of the young people, however, this was addressed in only two cases:

- one young person underwent detoxification while receiving inpatient care, and
- one young person was provided with a referral for an alcohol and other drugs service, but the referral was not actioned.

Once mental health and drug and alcohol problems have become established, they can perpetuate and exacerbate each other. Drug and alcohol misuse makes it harder to recover from mental health problems. Conversely, mental distress makes dealing with a drug and alcohol problem more challenging. Research has shown that mental health and drug and alcohol problems can be treated together successfully, and that programs that address risky behaviours at the same time are more effective than those that respond separately to different issues in a person's life.<sup>282</sup>

### Previous suicidal behaviour and self-harm

Research suggests that between 7 and 14 percent of adolescents will engage in self-harm, with females over two times more likely to self-harm than males. Although self-harming behaviours generally do not involve suicidal intent, there is evidence to suggest that people who engage in self-harming behaviours have a higher risk of suicide than those who do not.<sup>283</sup> A previous suicide attempt is considered to be a strong predictor of a future suicide attempt or suicide.<sup>284</sup>

As illustrated in table 70 below, 17 of the 22 young people who died by suicide in 2014 had a history of self-harm, suicide attempts and/or had discussed or had thoughts of suicide:

- Almost three quarters (14) of the 22 young people had a history of self-harming behaviour. This ranged from one incident considered to be 'attention seeking' to numerous episodes of self-injury.
- Over half (12) of the young people had previously threatened or discussed suicide. For nine young people this was in the 12 months prior to their death.
- Nine young people had attempted suicide previously, in some cases more than once. The majority of the young people (7) had attempted suicide within the 12 months prior to their death.

284 Ibid.

<sup>280</sup> National Youth and Mental Health Foundation, Headspace, Self-harm and suicidal behaviours, http://headspace.org.au/health-professionals/self-harm-and-suicidal-behaviours/, accessed 17 August 2015.

<sup>281</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

<sup>282</sup> The Mental Health Commission of NSW (2014), Living Well: A strategic plan for mental health in NSW 2014-2024, http://nswmentalhealthcommission.com.au/sites/default/files/141002%20Living%20Well%20-%20A%20Strategic%20Plan%20(1).pdf, accessed 17 August 2015.

<sup>283</sup> Suicide Prevention Australia (2010), *Position statement: youth suicide prevention*, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

In the main, self-harm incidents and suicide attempts resulted in some intervention and referral. Seven of the young people presented to hospital emergency departments, and six were referred on by hospital staff to CAMHS (2), general practitioners (2), alcohol and other drug service (1), and family support service (1), and an adolescent mental health unit. Other young people presented to general practitioners or school counsellors. Referrals were generally followed through by the family and/or the young person, however that was not always the case and a small number of young people did not access any specialised mental health support.

Total	Diagnosed mental illness	Substance use	Suicide threats/discussion	Self-harm	Suicide attempt
1	$\checkmark$		within 12 mths	within 12 mths	
2			No timeframe		
3	$\checkmark$		within 12 mths	within 12 mths	within 12 mths
4	$\checkmark$	$\checkmark$		within 12 mths	within 12 mths
5					
6				within 12 mths	
7	$\checkmark$	$\checkmark$	within 12 mths		within 12 mths
8				within 12 mths	>12 mths
9					
10			within 12 mths	within 12 mths	
11				>12 mths	
12	$\checkmark$	$\checkmark$	No timeframe	within 12 mths	>12 mths
13	$\checkmark$	$\checkmark$	>12 mths	>12 mths	within 12 mths
14					
15			within 12 mths	No timeframe	
16	$\checkmark$		within 12 mths	within 12 mths	
17		$\checkmark$	within 12 mths	within 12 mths	within 12 mths
18	$\checkmark$		within 12 mths		within 12 mths
19					
20					
21	$\checkmark$	$\checkmark$		>12 mths	
22	$\checkmark$	$\checkmark$	within 12 mths	within 12 mths	within 12 mths

Table 70: Risk factors for individual young people, 2014

### Social risk factors

### Education, school and employment issues

Over two thirds (15) of the young people who died by suicide in 2014 had difficulties related to schooling or education:

Fourteen of the young people experienced conflict in their relationships with peers, including as victims of bullying and as
perpetrators of violence. The instances of bullying for nine young people occurred face to-face, covertly and electronically
(cyber bullying).<sup>285</sup> Only four of the young people had advised teachers or school staff of their experiences. One child
attending a public school received ongoing support from the school counsellor to deal with bullying.

<sup>285</sup> Safe and Supportive School Communities Working Group, *Bullying. No Way!* http://www.bullyingnoway.gov.au/teachers/facts/types.html, accessed 17 August 2015.

- Nine of the young people displayed behaviour problems at school. This included disruptive behaviour, non-participation in class, non-completion of school work and disobedience. Eight of the young people were noted for school absences. Half (4) of the young people had substantial school absences for the year prior to their death. Various school personnel supported, monitored or disciplined eight of the nine young people for behaviour and attendance issues. For seven young people, this intervention included short term suspension, and in one case, expulsion. Four young people were receiving direct support from a school counsellor, and all eight had received some targeted school support in the 12 months prior to their deaths.
- Two young people were identified as experiencing long term learning difficulties. One had received learning support from an independent school and had transferred to the public system, where they declined engagement in learning support. One had undergone cognitive assessments and was involved with the Learning Support Team within the public school system.

#### The role of school counsellors and other school staff

The young people who died by suicide in 2014 were often in contact with and supported by teachers and school counsellors; eight young people were receiving targeted assistance. These professionals are well placed to detect risk and should be alert to warning signs.<sup>286</sup>

Beyondblue clinical practice guidelines for responding to depression in adolescents and young adults illustrate how teachers involved with young people can identify and respond to warning signs:

#### A teacher's guide to identifying and supporting students experiencing depressive symptoms<sup>287</sup>

What do teachers need to look for in students?

- Physical signs: Headaches, changes in eating, sleeping and energy levels, tiredness
- Behavioural signs: Changes in behaviour, self-harm, self-neglect, lack of motivation, poor school attendance, poor concentration
- · Cognitive signs: Significant memory gaps, loss of motivation, lower marks, inability to make decisions
- Emotional signs: Depression, withdrawal, agitation, fear, guilt, aggression, anxiety, suicidal thinking, personality changes, reduced self-esteem, feelings of worthlessness

When should teachers consult a person with experience in mental health or consider referral?

- The problem does not seem to be getting any better
- They are uncertain about what the real problem is
- The skills needed are beyond their training/expertise
- They want another opinion
- They don't know what to do

In a small number of cases reviewed, referrals made by the school counsellor were not taken up by the young person or their family.

#### **Family circumstances**

Family conflict, familial discord, parental divorce or separation and family depression have been associated with an increased risk of suicide for young people.<sup>288</sup> In 2014, over half (12) of the young people who died as a result of suicide experienced familial difficulties, including discord or strained relationships with parents or family, parental divorce or separation, or exposure to familial violence. Two young people experienced several of these difficulties.

Family conflict may present as a trigger event in conjunction with other suicide risk factors.<sup>289</sup> For four young people, conflict with a parent or sibling was a proximal event to their suicide.

Seven young people had a family history of mental illness. Six young people had at least one parent with a mental illness.

<sup>286</sup> Australia's National Youth Mental Health Foundation, Headspace (2009), *MythBuster: Suicidal Ideation*, http://headspace.org.au/assets/Uploads/ Resource-library/Health-professionals/suicidal-ideation-mythbusterv2.pdf, accessed 17 August 2015.

<sup>287</sup> McDermott B., Baigent M., Chanen A., Fraser L., Graetz B., Hayman N., Newman. L., Parikh N., Peirce B., Proimos J., Smalley T., Spence S., Beyondblue Expert Working Committee (2010), *Clinical practice guidelines: depression in adolescents and young adults*. Beyondblue: Melbourne.; Headspace: Australia's National Youth Mental Health Foundation (2012), Evidence summary: using SSRI antidepressants to treat depression in young people: what are the issues and what is the evidence?, http://headspace.org.au/assets/Uploads/Resource-library/ Health-professionals/ssri-v2-pdf.pdf, accessed 17 August 2015.

<sup>288</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

<sup>289</sup> Ibid.

### Childhood trauma: abuse and neglect

Adverse and traumatic events in childhood can be precipitating factors in youth suicide attempts or suicides. In particular, physical abuse, sexual abuse and family violence have been associated with suicide attempts.<sup>290</sup> The CDRT has previously identified that over a 10-year period (2002-2011), the suicide mortality rate for young people with a child protection history (6.3 per 100,000) was four times the rate of young people without that history (1.5 per 100,000).<sup>291</sup>

Of the 22 young people who died by suicide in 2014, one third (7) had been the subject of a report of risk of significant harm to Community Services within the three years prior to their death. For four of the young people, the reported risks concerned risk of suicide, intentional self-harm, and/or concerns about their mental health. All reports were closed without assessment. For three of these four young people, Community Services had assessed other services were involved to provide support to the young person. In the other matter, the whereabouts of the young person was not known.

An additional young person had been the subject of a report that was deemed not to have met the threshold for significant harm. The reported concerns were risk of suicide and intentional self-harm. The report was closed at the FACS Helpline, in the context of advice that the young person was receiving ongoing support.

FACS data shows that in the March 2014 quarter, the primary reported issue in 463 risk of significant harm reports was suicide risk. This represented a 19 percent increase from the March 2013 quarter.<sup>292</sup> FACS has noted the challenge in providing effective services and supports to adolescents, and the need to develop an evidence and skill base for working with vulnerable young people and their families.<sup>293</sup>

## **Contextual risk factors**

### Recent suicide death of a peer or family

A family history of suicide is a strong risk factor for suicide and suicide attempt for an individual.<sup>294</sup> In 2014:

- Five young people had experienced the suicide death of a family member, including parents, siblings and extended family. In two cases, the experience was within the 12 months prior to death, and for another two young people, the family members died some years prior.<sup>295</sup>
- Two young people had a parent that had a history of attempting suicide, and one young person's parent had threatened to suicide.
- Six young people who died by suicide in 2014 had experienced the recent suicide death of a peer.
- Four of the young people were members of a suicide cluster, and had attended the same primary school. Three of the four resided in the same local government area (LGA), and records indicate they had maintained some level of connection with each other, through friends or family. The young people died within a four-month period in 2014. The fourth young person had moved away from the Local Government Area but had remained friends with one of the three. This young person's death occurred within the same four-month period noted above.
- Two other young people had experienced the suicide death of a peer. One death occurred the month prior to the young person's death, and the other occurred two years earlier.

A suicide cluster has been defined as 'a group of suicides or acts of deliberate self-harm (or both), that occur closer together in time and space than would normally be expected on the basis of statistical prediction and/or community expectation'.<sup>296</sup>

Records indicate that in each case, Department of Education implemented a plan to provide support to the school and students. Longer-term responses included postvention plans and strategies to promote positive mental health.<sup>297</sup> The Department also provided additional resources for counselling, coordination of postvention measures and additional staff training for suicide risk assessment.<sup>298</sup>

<sup>290</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, Sydney.

<sup>291</sup> NSW Child Death Review Team (2014), Causes of death of children with a child protection history 2002-2011, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

<sup>292</sup> FACS Community Services (March 2014), Community Services quarterly data, http://www.community.nsw.gov.au/docswr/\_assets/main/ documents/docs\_data/quarterly\_report\_mar14.pdf, accessed 17 August 2015.

<sup>293</sup> FACS Community Services (2014), Child deaths 2013 annual report.

<sup>294</sup> Australian Institute for Health and Welfare (2008), Injury among young Australians, Bulletin 60, AIHW: Canberra.

<sup>295</sup> Information was not available in relation to one of the young people.

<sup>296</sup> Centre for Health Policy, Programs and Economics, Melbourne School of Population Health University of Melbourne (2012), *Developing a community plan for preventing and responding to suicide clusters*, http://livingisforeveryone.com.au//uploads/docs//Community%20Plan.pdf, accessed 17 August 2015.

<sup>297</sup> Postvention is the term used to refer to activities to support people bereaved or affected by a suicide.

<sup>298</sup> Advice from the Department of Education to the Coroner 2014.

# 10.5 Key issues arising from reviews

Reviews of suicide deaths of young people in 2014 highlighted several key issues, in particular:

- Ensuring effective postvention programs in schools, and assertive strategies to target young people who have experienced the suicide death of a family member or friend
- Effective identification of, and response to:
  - self-harm and attempted suicide in young people
  - problematic substance use in the context of mental health concerns in young people
  - possible contagion, particularly where young people communicate about suicide via electronic media
- The need to ensure coordination of support provided to young people at risk of suicide
- The need for appropriate referral and follow-through for young people at risk of suicide:
  - ensuring school counsellors refer appropriately to specialist mental health services
  - strategies for assertive outreach where there is lack of follow-through by families

## Avenues of support

The young people who died in 2014 did not always communicate that they needed help, and those that did approached different people in their lives through a range of avenues.

The Team has previously noted the importance of providing a wide range of options and opportunities for young people to seek help.

Health and other professionals who have ongoing contact with young people are often well placed to detect suicide risk. Headspace emphasises the need for professionals to be aware of possible warning signs indicating suicide risk, rather than relying on a young person to spontaneously disclose suicidal thoughts, as young people are unlikely to do so.<sup>299</sup>

Young people are among the least likely to seek professional help for a mental health problem.<sup>300</sup> In a national survey of young people aged 15-19 years, over 60 percent of those with a mental illness were not comfortable seeking information, advice or support from community agencies, online counselling and/or telephone hotlines.<sup>301</sup> The young people with and without a probable mental illness stated they were more comfortable seeking information, advice and support from friends and the internet.<sup>302</sup>

Our reviews also identified that young people often told their friends about their thoughts of self-harm or intent to suicide. If evidence-based and well promoted, strategies that provide young people with tools to recognise and respond effectively to a situation where a friend indicates suicidal thoughts may be of great benefit. The NSW Mental Health Commission and the NSW Youth Advisory Council have established makeamatesday.com.au as one way to assist young people to identify ways to connect with their friends who may be struggling with their mental health.<sup>303</sup>

Reviews also highlighted that it was not always evident to family, schools or other professionals that a young person was at risk. This underscores the importance of a focus on early intervention, and the provision of programs that promote mental wellbeing in young people.

302 Ibid.

<sup>299</sup> Australia's National Youth Mental Health Foundation, Headspace (2009), *MythBuster: Suicidal Ideation*, http://headspace.org.au/assets/Uploads/ Resource-library/Health-professionals/suicidal-ideation-mythbusterv2.pdf, accessed 17 August 2015.

<sup>300</sup> Suicide Prevention Australia (2010), Position statement: youth suicide prevention, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

<sup>301</sup> Mission Australia (2014), Youth Mental Health Report June 2014, Mission Australia in association with Black Dog Institute,

https://www.google.com.au/?gws\_rd=ssl#q=youth+mental+health+report, accessed 17 August 2015.

<sup>303</sup> http://www.makeamatesday.com.au/, accessed 17 August 2015.

# The importance of postvention programs

As noted above, there was evidence that four young people who died by suicide within a short period of time knew, or knew of, each other. In these cases, postvention programs were initiated in relevant schools.

Beyondblue notes:

Some young people, especially those who are already experiencing difficulties and life stresses, may identify with the person who has suicided. This may normalise the behaviour, and contribute to the thinking that suicide is an option. Being exposed to suicide heightens the risk of contagion and therefore postvention services and resources need to be made available for all young people exposed to the suicide – both those directly known to the person who suicided, and also those who may not have known the young person, but who may have heard about the suicide.<sup>304</sup>

However, the Australian Human Rights Commission has noted that systematic evaluation of postvention programs has not occurred in Australia, so there is no evidence to demonstrate their effectiveness. The Commission said evaluation of postvention services must be on the national research agenda for children and young people.<sup>305</sup>

The Black Dog Institute has recommended that urgent research is needed, using new technologies and approaches to understand 'contagion' and to investigate how connectiveness can be used to lower risk and to promote safe communities.<sup>306</sup> The Institute is currently undertaking a study on adolescent grief, to understand the impact of suicide or death on adolescents in order to better help bereaved young people.<sup>307</sup>

The Department of Education, in consultation with the Ministry of Health and Headspace School Support Service, has recently finalised a new postvention resource for schools: *Responding to Student Suicide, Support Guidelines for schools*. The resource has been made available to schools where it is believed students have died by suicide.<sup>308</sup>

The Department of Education has advised that the guidelines provide detailed advice about the response to be made after a student's death by suicide immediately, over the following 24-72 hours and in the longer term. A systemic strategy has been put in place to provide the resource again to a school as soon as it is known that there has been a death which has been reported as suicide or suspected suicide. At this time, a senior staff member provides guidance and support to the principal around the management of the situation at the school level.<sup>309</sup>

The Department of Education has advised that the agency is currently working on a communication and implementation strategy.

# Identifying and responding to self-harm and suicidal behaviour

Seventeen of the 22 young people who died by suicide in 2014 had a history of self-harm, and nine had previously attempted suicide. Our reviews identified postvention actions within schools following the death of a young person, however, responses to self-harm and suicide attempts are also critical. As the Royal Australian and New Zealand College of Psychiatrists noted in a submission to the recent Australian Human Rights Commission Inquiry into intentional self-harm and suicidal behaviour in children:

Disappointingly, most interventions developed to prevent the recurrence of self-harm have been no more effective than treatment as usual (which is of itself often limited)<sup>310</sup>

The Australian Human Rights Commission conducted research into self-harm of young people and noted that when young people present to emergency departments, there is a genuine opportunity to connect with them and facilitate follow-up intervention.<sup>311</sup>

308 Correspondence from NSW Department of Education to NSW Ombudsman, 25 September 2015.

309 Ibid.

<sup>304</sup> Beyondblue submission to the Australian Human Rights Commissioner, June 2014 https://www.humanrights.gov.au/sites/default/files/ Submission%2078%20-%20beyondblue.pdf

<sup>305</sup> Australian Human Rights Commission (2014). Children's Rights Report 2014, https://www.humanrights.gov.au/sites/default/files/document/ publication/Children%27s%20Rights%20Report%202014 2.pdf, accessed 17 August 2015.

<sup>306</sup> Submission by the Black Dog Institute to the Australian Human Rights Commissioner, 2014 https://www.humanrights.gov.au/sites/default/files/ Submission%2088%20-%20Black%20Dog%20Institute.pdfm accessed 17 August 2015.

<sup>307</sup> Black Dog Institute, http://www.blackdoginstitute.org.au/public/research/participateinourresearch/index.cfm, accessed 17 August 2015.

<sup>310</sup> Submission by the Royal Australian and New Zealand College of Psychiatrists to the National Children's Commissioner, 28 May 2014, https://www.humanrights.gov.au/sites/default/files/Submission%2041%20-%20Royal%20Australian%20and%20New%20Zealand%20College%20 of%20Psychiatrists.pdf, accessed 17 August 2015.

<sup>311</sup> Australian Human Rights Commission (2014). Children's Rights Report 2014, https://www.humanrights.gov.au/sites/default/files/document/ publication/Children%27s%20Rights%20Report%202014\_2.pdf, accessed 17 August 2015.

#### Coordination of and access to support

Our reviews identified that many of the young people were receiving support and assistance through a number of avenues. In some cases, this appeared to be well-coordinated; in others, there appeared to be minimal coordination between different support providers.

A range of state and federally funded programs are targeted to suicide prevention, both generally and for young people. However, as the CDRT has previously noted:

There are many government and non-government organisations undertaking work in this area, and it is not always evident whether, and how well, the activities are co-ordinated to minimise duplication of effort and maximise efficacy.<sup>312</sup>

The services targeted to young people in particular are limited. As noted by the NSW Mental Health Commission:

There is a lack of mental health services for children and adolescents – and a lack of mental health workers with special training to work with children. Children and young people, whose need for mental health care is greatest, have some of the lowest access to care.<sup>313</sup>

#### **Dual diagnosis**

Substance abuse is an identified risk factor for suicide, particularly in the context of mental illness.<sup>314</sup> Almost half of the young people who died in 2014 were known to be misusing drugs and/or alcohol.

In most cases, the young people were receiving assistance from professionals. Our reviews indicated that the misuse was directly considered in relation to two of the young people, resulting in action in one case.

In January 2015, the Agency for Clinical Innovation, in partnership with NSW Mental Health Commission and the NSW Ministry of Health, established the Mental Health and Drug and Alcohol Clinical Networks. The Networks bring together a wide range of clinicians, service providers and consumer and carer representatives to improve care through innovation in clinical practice.

# **10.6 Prevention measures**

#### The strategic plan for mental health in NSW

There are a number of significant initiatives underway in relation to mental health and suicide prevention in NSW.

The NSW Mental Health Commission's *Living Well: A strategic plan for mental health in NSW 2014-2024* identifies gaps in the coordination and integration of suicide prevention activities and programs, including on a geographic basis.<sup>315</sup>

In relation to children and young people, the Commission notes that while there are a number of prevention and early intervention services and initiatives involving Commonwealth, state and community-managed organisations, 'these have not been implemented in NSW in a comprehensive way.' For example, while headspace centres are expanding in number and type of service, 'they remain largely disconnected from state-run specialist child and adolescent mental health services.'<sup>316</sup>

The strategic plan delivers a range of actions to address these and other issues. Among other things, the actions include:

- Strengthening prevention and early intervention, with a stronger focus on services for children and young people.
- The establishment of a NSW Suicide Prevention Forum comprising public, industry and community leaders with the aim to strengthen planning, monitoring and coordinating state-wide suicide prevention efforts.
- Preparation of a NSW Suicide Prevention Implementation plan to set evidence-based directions.
- The establishment of a youth alliance, with representation from all sectors. The role of the alliance will be to guide effective targeting of prevention and early intervention efforts by examining risk factors, how the risk is responded to, and how any identified gaps can be eliminated.
- Implementation and further development of the Department of Education Wellbeing Framework for Education.

<sup>312</sup> Submission by the NSW Ombudsman to the National Children's Commissioner, 2 June 2014, https://www.humanrights.gov.au/sites/default/files/ Submission%2063%20-%20Child%20Death%20Review%20Team,%20Ombudsman%20New%20South%20Wales.pdf, accessed 17 August 2015.

<sup>313</sup> The Mental Health Commission of NSW (2014), Living Well: A strategic plan for mental health in NSW 2014-2024, http://nswmentalhealthcommission.com.au/sites/default/files/141002%20Living%20Well%20-%20A%20Strategic%20Plan%20(1).pdf, accessed 17 August 2015.

<sup>314</sup> Suicide Prevention Australia (2010), *Position statement: youth suicide prevention*, http://suicidepreventionaust.org/wp-content/uploads/2012/01/ SPA-Youth-Suicide-Prevention-Position-Statement.pdf, accessed 17 August 2015.

<sup>315</sup> The Mental Health Commission of NSW (2014), Living Well: A strategic plan for mental health in NSW 2014-2024, http://nswmentalhealthcommission.com.au/sites/default/files/141002%20Living%20Well%20-%20A%20Strategic%20Plan%20(1).pdf, accessed

<sup>17</sup> August 2015 316 Ibid.

In December 2014, the NSW Government accepted all actions outlined in the strategic plan, and committed an additional \$115 million to implement the strategy over the next three years.<sup>317</sup>

Since the release of the strategic plan, the NSW Mental Health Commission engaged the National Health and Medical Research Council Centre of Research Excellence in Suicide Prevention to develop a state-wide suicide prevention framework. The draft framework, which was released in August 2015, describes evidence-based strategies that government, non-government organisations and the broader community can implement to lower suicide rates in NSW. It aims to assist agencies plan suicide prevention strategies, crisis interventions and postvention supports.

To progress this work, the NSW Mental Health Commission also plans to establish a Suicide Prevention Forum comprised of industry and community sector leaders and people with lived experience of suicide.<sup>318</sup>

### Initiatives delivered through education

Since 2014, the Department of Education has been progressing the roll out of Networked Specialist Centres to all public schools (to be completed by 2017). The intent of the centres is to draw together expertise of the department, broader government and community managed health and welfare providers in relation to individual young people.<sup>319</sup> Other initiatives in relation to education services and student wellbeing include the:

- 2014 launch of *Safe Schools Hub* which contains supplementary resources to assist schools implement the *National Safe Schools Framework*. The framework provides schools with a vision and a set of guiding principles that assist communities to develop positive and practical student safety and wellbeing policies
- development of the Wellbeing Framework for Education which will set out the role of education within NSW in building and improving wellbeing
- review of the *Crossroads* program which is delivered to all senior students attending a government secondary school. The program aims to prepare and support students in relation to their health, safety and wellbeing
- review of the student welfare policy which will include a focus on resilience, and
- development of a postvention resource for schools titled *Responding to Student Suicide, Support Guidelines for Schools* in consultation with NSW and *headspace*.

# 10.7 The Team's recommendations

As noted above, there are significant current developments that relate directly to the prevention of youth suicide. The Team welcomes these initiatives.

In recent years, the Team's recommendations have focused on making use of new media to deliver prevention services to young people; developing resources to educate young people on the importance of passing on suicide risk concerns about peers; and increasing collaboration between schools and youth mental health services.

In this report, we have highlighted critical issues such as postvention, identification of and response to self-harm and suicide attempts, management of young people with dual diagnosis and coordination of support of young people at risk.

The Team will monitor developments in these and other areas relating to youth suicide prevention against the background of the implementation of the Strategic Plan for Mental Health in NSW.

<sup>317</sup> Premier Mike Baird, Media Release, 22 December 2014, https://www.nsw.gov.au/media-releases-premier/historic-reforms-increase-accesscommunity-based-mental-health-care, accessed 17 August 2015.

<sup>318</sup> Proposed Suicide Prevention Framework for NSW, Prepared by NHMRC Centre for Research Excellence in Suicide Prevention and Black Dog Institute for the NSW Mental Health Commission, http://nswmentalhealthcommission.com.au/sites/default/files/Subfolder/PROPOSED%20 SUICIDE%20PREVENTION%20FRAMEWORK%20FOR%20NSW%202015-2020%204%20Aug%202015.pdf, accessed 15 September 2015.

<sup>319</sup> The Mental Health Commission of NSW (2014), Living Well: A strategic plan for mental health in NSW 2014-2024, http://nswmentalhealthcommission.com.au/sites/default/files/141002%20Living%20Well%20-%20A%20Strategic%20Plan%20(1).pdf, accessed 17 August 2015.

# **10.8 Support and assistance contacts**

### Lifeline

24 hour crisis support and suicide prevention services Phone: 13 11 14 Website: www.lifeline.org.au

### **Mental Health Line**

24-hour telephone service operating 7 days a week across NSW 1800 011 511 Website: www.health.nsw.gov.au

### **Kids Helpline**

telephone and online counselling service specifically for young people aged between 5 and 25 Phone: 1800 55 1800 Website: www.kidshelpline.com.au

### Headspace

National Youth Mental Health Foundation for young people who are going through a tough time – email, chat and speak. For young people aged 12 to 25

Phone: 1800 650 890

Website: www.headspace.org.au

Online/phone support: www.eheadspace.org.au

### Reachout

A web based service that helps young people get through tough times.

Website: www.reachout.com.au

# **Chapter 11. Abuse-related deaths**

The deaths of nine children registered in NSW in 2014 were the result of abuse or alleged abuse; a rate of 0.53 per 100,000 children.<sup>320</sup>

All abuse-related deaths of children and young people are reviewable by the NSW Ombudsman.<sup>321</sup> The Ombudsman reports biennially on reviewable deaths, and the deaths considered in this chapter will be the subject of further analysis by the Ombudsman.

# 11.1 Age, gender and cultural background

Most of the children who died in abuse-related circumstances were very young; six of the children were aged less than five years, including three infants under 12 months of age. The other three children were aged 10 years or less.

The table below shows that, over the 15 years to 2014, abuse-related deaths occurred most commonly among children aged less than five years, with this age group accounting for half of all abuse-related deaths of children.

#### Table 71: Deaths of children in abuse-related circumstances by age group, 2000-2014

	Age in years												
	<1	1-4 5-9		10-14	15-17	Total							
Number (%)	37 (22)	47 (28)	26 (16)	18 (11)	37 (22)	165 (100)							

As illustrated in table 72, males are more likely to die in abuse-related circumstances than females. In 2014, however, this was not the case; six of the nine victims were female. Because the overall number of abuse-related deaths is small, fluctuations are apparent from year to year. Over the 15-year period, males accounted for almost two thirds (61 percent) of fatal assault or abuse-related deaths.

# Table 72: Trends in deaths of children in abuse-related circumstances by gender, number and rate, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Female	6	7	2	10	5	7	1	3	5	2	3	7	0	0	6	64
	(0.77)	(0.90)	-	(1.29)	(0.65)	(0.90)	-	-	(0.64)	-	-	(0.88)	-	-	(0.73)	
Male	10	8	7	10	3	7	11	5	9	7	11	4	4	2	3	101
	(1.23)	(0.97)	(0.85)	(1.22)	-	(0.86)	(1.35)	(0.61)	(1.09)	(0.84)	(1.31)	(0.47)	(0.47)	-	-	
Total	16	15	9	20	8	14	12	8	14	9	14	11	4	2	9	165
	(1.01)	(0.94)	(0.56)	(1.25)	(0.50)	(0.88)	(0.75)	(0.50)	(0.87)	(0.55)	(0.86)	(0.67)	(0.24)	-	(0.53)	

Aboriginal children are over-represented in abuse-related deaths.<sup>322</sup> However, in 2014, none of the children who died were of Aboriginal or Torres Strait Islander background. Two children were identified as being from culturally and/or linguistically diverse backgrounds.

<sup>320</sup> Abuse-related deaths include proven fatal assault and suspicious deaths where criminal justice responses are ongoing.

<sup>321</sup> Part 6 Community Services (Complaints, Reviews and Monitoring) Act 1993.

<sup>322</sup> NSW Ombudsman (2015), Report of reviewable deaths in 2012 and 2013, volume 1: child deaths, NSW Ombudsman: Sydney.

# **11.2 Child protection history**

Children with a child protection history in NSW have a much higher rate of death from fatal assault than children from families with no such history (6.3 times the rate).<sup>323</sup>

In 2014, the families of three of the nine children who died in fatal assault incidents had a child protection history, having been the subject of a report of risk of significant harm to FACS. The nature of reported concerns included unexplained bruising or suspected physical abuse, inadequate supervision, exposure to domestic violence, and parental drug and/or alcohol use.

# 11.3 Context of abuse-related deaths

In 2014, eight of the nine abuse-related deaths of children occurred within a familial context, with most children allegedly killed by a family member or person with whom they resided. Four of the nine children died in two separate incidents of apparent murder-suicide.

As illustrated in table 73, the majority of abuse-related deaths of children in NSW have occurred in a familial or domestic context. Familial homicide includes filicide (custodial and non-custodial parents or step-parents), siblicide and killings by other family members, including extended family.<sup>324</sup> Peer-related homicide generally relates to young people in a context of confrontational violence between friends, acquaintances and strangers.<sup>325</sup> Peers are generally close in age and social status.

The predominance of familial homicide is consistent with national data; in 2010-12 in Australia, approximately 12 percent of homicide victims were aged 17 or younger. The majority of these children were killed by a custodial parent.<sup>326</sup> Nationally, between 2002 and 2012, children comprised the second most frequent group of domestic/family homicides (21 percent of all domestic/family homicides).<sup>327</sup>

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
Familial	10	11	5	14	6	12	11	5	12	8	5	8	3	2	8	120
Peer	2	0	1	4	1	1	1	1	2	1	7	2	1	0	0	24
Other	4	4	3	2	1	1	0	2	0	0	2	1	0	0	1	21
Total	16	15	9	20	8	14	12	8	14	9	14	11	4	2	9	165

Table 73: Trends in deaths of children due to fatal assault by offender relationship to child, 2000-2014

# 11.4 Circumstances of abuse-related deaths

In four of the nine cases in 2014, police have laid charges, including murder and manslaughter, against one or more persons in relation to the death. In two cases where no charges have been laid, the alleged perpetrator also died in the fatal incident. These cases are before the State Coroner. Police investigations are continuing in the remaining matters. At the time of writing, no convictions have been recorded. For this reason, discussion about the circumstances of death is limited.

In relation to the nine deaths:

- Six of the nine children died from injuries allegedly caused by their biological parents. The deaths of two of the nine children were allegedly caused by male defacto partners living in the household. In one case, the person of interest was unrelated to the child. More than one person is implicated in the death of two of the children.
- The children died as a result of blunt force trauma (3), gunshot wounds (3), head injury (1), fire (1) or undetermined causes (1).

<sup>323</sup> NSW Child Death Review Team (2014), Causes of death of children with a child protection history 2002-2011, Special Report to Parliament, NSW Ombudsman: Sydney. Report prepared by the Australian Institute of Health and Welfare.

<sup>324</sup> Strang H. (1996), 'Children as victims of homicide', Trends and Issues in Crime and Criminal Justice, No.53.

<sup>325</sup> Queensland Commission for Children and Young People and Child Guardian (2010), Annual report of deaths of children and young people Queensland 2009-2010, QCCYP: Brisbane.

<sup>326</sup> Australian Institute of Criminology (2015), Homicide in Australia: 2010-2011 to 2011-2012: National homicide monitoring program report, AIC Monitoring reports no. 23, AIC: Canberra.

<sup>327</sup> Australian Institute of Criminology (2015), Domestic/family homicide in Australia, Research in practice no. 38 May 2015. AIC: Canberra.

# 11.5 Factors associated with fatal abuse and prevention measures

Underlying motives for child homicides within families are notably difficult to identify.<sup>328</sup> The NSW Ombudsman has identified a number of specific contexts within which abuse-related deaths occurred over the decade to 2013:<sup>329</sup>

- In a child abuse context, including cases where there was evidence of prior abuse
- Murder-suicide, with common factors including mental health issues and current or recent family breakdown
- Where the perpetrator experienced a psychotic episode at the time of the incident
- Where harm was not the intention of an action, primarily where drugs were administered to pacify or sedate children.

Researchers have also identified motives such as retaliatory intentional killing as a result of anger,<sup>330</sup> and altruistic killing, where the perpetrator believes their actions protect from real or imagined suffering.<sup>331</sup>

The gender of the offender is also of relevance. Mental illness has been identified as a significant factor on the part of mothers who kill their children, whereas men are more commonly associated with abusive and retaliatory deaths.<sup>332</sup>

Because of the difficulty of identifying any family type or circumstance or combination of factors where risk is likely to escalate to fatal abuse, prevention efforts are generally focused on improving and expanding universal services and child protection services.

The Ombudsman, through reports of reviewable deaths, has made recommendations to government agencies relating to the identification of, and response to, children and families at risk.<sup>333</sup> Most recently, recommendations have included those addressing:

- NSW Health strategies to respond to risk to children in the context of parental substance abuse and parental mental illness, and work by NSW Health to improve the identification of and response to children who are presented to hospitals and health services with suspicious injury.
- Better and more timely information exchange and collaboration between the NSWPF and FACS to improve responses to children living with domestic violence, and to enable better assessment of risks to children.
- In the context of risk of significant harm reports, the need for FACS to review strategies that assist caseworkers to consider new partners of birth mothers in assessing risks to children.

The Ombudsman's report of reviewable deaths in 2012 and 2013 can be accessed at: http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1

329 NSW Ombudsman (2015), Report of reviewable deaths in 2012 and 2013, volume 1: child deaths, NSW Ombudsman: Sydney.

333 NSW Ombudsman (2015), Report of reviewable deaths in 2012 and 2013, volume 1: child deaths, NSW Ombudsman: Sydney.

<sup>328</sup> Mouzos J. (2000), Homicidal Encounters: A Study of Homicide in Australia 1989-1999, cat. no. 28, Australian Institute of Criminology: Canberra.

<sup>330</sup> Nielssen N., Large M., Westmore B. & Lackersteen S. (2009), 'Child homicide in New South Wales from 1991 to 2005', *Medical Journal Australia*, Vol 190 (1): 7-11.

<sup>331</sup> Kirkwood D. & Eltringham L. (2012), 'Parents who kill their children in the context of separation', Australian Psychological Society Workshop, APS: Sydney.

<sup>332</sup> Morris B. (2009), 'Deadly dads: men who murder their children', Domestic Violence Resource Centre Quarterly, Vol. 2: 2-9;

Harris G., Hilton Z., Rice M. & Eke A. (2007), 'Children killed by genetic parents versus stepparents', Evolution and Human Behavior, vol. 28:85.

# Chapter 12. Child Death Review Team: Annual Report to Parliament 2014-2015

CS CRAMA requires that the Team report to the NSW Parliament on a financial year basis on:

- The activities of the Team in relation to its functions
- Whether any information has been disclosed by the Convenor in connection with research that is undertaken for the purpose of helping to prevent or reduce the likelihood of deaths of children in NSW
- Details of the extent to which the Team's previous recommendations have been accepted.

Activities and disclosure information is detailed below. Progress in implementing previous recommendations is detailed separately, in chapter 13.

# 12.1 The Team's activities

The work of the Team for the year ending 30 June 2015 has included:

- Convening four formal meetings in 2014-15. Smaller sub-committees of the Team, including the Sudden Unexpected Death in Infancy sub-committee, have met on other occasions.
- Finalising a review of asthma-related deaths of children and completing the Child Deaths Annual Report 2013
- Developing and commissioning projects on:
  - deaths from infectious disease
  - a scan of childhood injury and disease prevention infrastructure in NSW
- Participation in a range of injury prevention initiatives, and
- Pursuit of strategies to improve the capacity of the Team to contribute to the prevention of child deaths, including:
- implementing the new child death register
- liaison with injury prevention groups
- negotiating legislative change

These activities are detailed below.

# Asthma-related deaths of children and the annual report of child deaths in 2013

A review of 20 child deaths resulting from asthma between 2004 and 2013 was undertaken on behalf of the Team by expert adviser, Dr Dominic Fitzgerald and the Team's Deputy Convenor, Dr Jonathan Gillis. The work was completed in 2014, and results reported in the *Annual Report of child deaths in 2013*. The review resulted in a number of recommendations to government, Independent and Catholic schools, and to the Ministry of Health, targeted to improving the identification of and support to children with asthma. Progress in achieving the recommendations is reported in chapter 13.

The Child Deaths Annual Report 2013 was tabled by the Convenor in October 2014.

### Child deaths from infectious disease

In April 2015, the Team commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to produce a report on child deaths from infectious diseases in NSW from 2005 to 2014, focussing on recommendations to prevent or reduce deaths from vaccine-preventable diseases.

In Australia, dramatic declines in child deaths due to infectious diseases have occurred as a result of improved living conditions, public health measures and access to healthcare. Despite large reductions in death, however, infections remain one of the most common acquired causes of death in childhood.

The Team provided the NCIRS with data from the Child Death Register, which will be analysed over the next months. A final report is anticipated by mid 2016, and findings will be reported in the next CDRT annual report. In June, the NCIRS provided the Team with relevant background for the report, including an overview of vaccination programs in Australia and sources of data for child deaths from vaccine-preventable diseases. This is reported above in chapter 4.

## Childhood injury and disease prevention in NSW

The Team has a keen interest in current discussions around the need for childhood injury surveillance and leadership in childhood injury prevention and management in NSW.

### Paediatric injury prevention forum

In September 2014, the Team participated in the paediatric injury and management research forum in August 2014, coordinated by the NSW Research Alliance for Children's Health (RACH), NSW Kids and Families, and the Population Health Research Collaborative (PHRC) of the Sydney Children's Hospital Network. Dr Jonathan Gillis presented to the forum on behalf of the Team. The aims of the forum were to:

- · Identify priorities for research that inform paediatric injury prevention and service development
- · Facilitate communication between clinicians, researchers and planners
- Promote translational research to inform policy and practice.

Following the initial forum, the Team has continued to be represented at subsequent related meetings focusing on current research collaboration.

### Scan of injury and disease prevention infrastructure

In the context of ongoing discussions about the coordination of injury prevention research and activities, the Team commissioned the Centre for Health Service Development at the University of Wollongong to undertake an initial scan of injury and disease prevention infrastructure in NSW.

The scan was completed in June 2015 and is available at http://www.ombo.nsw.gov.au/what-we-do/coordinating-responsibilities/ child-death-review-team.

While the scan does not purport to be a comprehensive and systematic mapping of existing infrastructure, it has demonstrated that:

- there is little overall coordination of effort in childhood injury and disease prevention initiatives in NSW
- significant gaps in prevention initiatives are apparent, and
- the comparability and coordination of several national and state data sources is limited.

The Team considers this work to be a preliminary step to inform a potentially broader gap analysis that analyses the 'Environment-Strategy-Capability Gap'<sup>334</sup> in infrastructure and coordination in childhood injury and disease prevention in NSW.

The report details implications for the work of the Team, which will assist the Team's planning and determination of priorities.

## Improving the capacity of the team to contribute to prevention of child death

### Implementing the integrated deaths register

A revised NSW Child Death Register was developed and built in 2013-14 with funding from the NSW government. The system went online in August 2014.

The new system provides for an integrated register of child deaths, incorporating 'reviewable' deaths subject to review by the Ombudsman. The database provides for improved data capture, capacity and reporting.

At present, data to inform trend analysis is being drawn from the new Register and the legacy system.

The Team's priorities in this area over the next year are to:

- migrate data to the new system
- refine approval processes for authorising access to data for research that is undertaken for the purpose of helping to prevent or reduce the likelihood of deaths of children in NSW.<sup>335</sup>

In the context of ensuring rigour in the data collected and analysed, the Team has engaged the Australian Bureau of Statistics to undertake quality assurance of cause of death coding. Auditing commenced in June 2015.

<sup>334</sup> Hubbard G. et al. (1996), Practical Australian Strategy. Prentice-Hall, Sydney.

<sup>335</sup> Section 34L(1)(b) provides for the Convenor to disclose CDRT information or records for this purpose.

# Liaison with prevention groups

The Team has continued to work with other groups contributing to the prevention or reduction of deaths of children. For example, the Team was represented at:

- a workshop hosted by Suicide Prevention Australia in December 2014 to progress the development of a national minimum data set (NMDS) relating to suicide
- the Australian and New Zealand Child Death Review and Prevention Group annual meeting in April 2015. The focus of the meeting was suicide prevention, and child death review national data. The Team maintains ongoing contact with child death review functions in other States and Territories
- (with observer status) the Children's Hospitals Swimming Pool Safety Working Group

Meetings were also held with relevant agencies to discuss issues arising from the work of the Team, including the NSW Mental Health Commission, NSW Kids and Families, NSW Fire and Rescue, and KidSafe NSW.

## Legislative amendment

In May 2014, the Team's Convenor sought changes to the legislation to extend the reporting period for the CDRT from one year to two years; to change from reporting on the year of death registration to the year the death occurred; and to report as soon as practicable after 30 June rather than within a four-month period.

The rationale for the amendment is to achieve consistency between the child death review functions of the Team and those of the Ombudsman. The change would also increase the opportunity for the Team to progress specific strategies to prevent child deaths, for example:

- by working constructively and effectively with relevant agencies and organisations to address systemic issues which can result in child deaths
- by directing resources to a more timely and focused response to emerging issues which impact on child deaths, and
- by preparing resources and promoting initiatives which are targeted to highlighting and addressing risks which are particularly relevant to child deaths.

The change has been supported by key stakeholders. The Team has been advised that the amendments will be further considered later in 2015.

# **12.2 Disclosure of information authorised by the Convenor**

CS CRAMA contains confidentiality conditions that prevent the disclosure of CDRT information except in specific circumstances.

In regard to external research, section 34L(1)(b) of the legislation provides for the Convenor to authorise the disclosure of information in connection with research that is undertaken for the purpose of helping to prevent or reduce the likelihood of deaths of children in NSW.

Since the last report, the Convenor authorised the disclosure of information pursuant to s34L(1)(b) on three occasions. Data was sought by and authorised for release to:

- The ACT Child Death Review Team, for information relating to the deaths of any ACT-resident child who died in NSW.
- Neuroscience Australia, for details of the number and ages of children who died after falls from balconies and windows in the context of an evaluation of the NSW Health Kids Don't Fly campaign.
- Research on Sudden Unexpected Death in Infancy, associated with the Australian Paediatric Surveillance Unit.

# **Chapter 13. Monitoring recommendations**

In its *Report of Child Deaths in 2013, the* Team made16 recommendations, 15 of which were directed to or included government agencies, and three of which were directed to or included non-government agencies or schools.

This section details the information provided by agencies in relation to the progress made in implementing the recommendations, and the Team's consideration of progress.

In May 2015, the Premier of NSW provided the Team with a NSW Government response to all recommendations directed to government agencies. The response against each recommendation is provided in full below.

Non-government agencies and schools to which the CDRT directed recommendations all provided a response and details of progress. The responses are summarised below.

# 13.1 Asthma

### **Recommendation 1**

Against the background of the issues raised in this report relating to children with asthma, the Department of Education and Communities (DEC), Diocesan Catholic Schools Authorities of NSW (DCSA), the Association of Independent Schools (AIS), Christian Schools Australia (CSA), and Christian Education National (CEN) should review their policies or other guidance on supporting students with asthma and provide advice to the Team on:

- a) the adequacy of the policies/guidance for enabling its schools to:
- b) identify children with severe asthma who need a health care or other support plan, and
- c) ensure that health care or other support plans for children with severe asthma are developed, implemented and regularly reviewed
- d) how compliance with the policies/guidance is monitored, and
- e) any other actions the department, DCSA, AIS, CSA and CEN intend to take in relation to identifying and supporting students with asthma.

#### **Recommendation 2**

DEC, DCSA, AIS, CSA, CEN, and the Ministry of Health (MoH) should convene a working group to:

- a) identify the specific strategies that may be needed to improve the provision of information to schools by parents and carers and/or their child's treating doctor on the child's asthma diagnosis and management (such as a written asthma action plan, and information regarding recent hospitalisation for asthma), and
- b) discuss the ways in which the strategies will be progressed, separately or together.

### NSW Government response

a) Between 2013 and 2015 DEC undertook significant work to better support students with specific health care needs, including schools gathering information from parents and/or carers about their child's health at the point of enrolment or where a child's health condition changes.

Specifically:

- In 2013 a new, more detailed template was developed and provided to public schools to collect updated health information from parents and carers where their child has a known diagnosed high risk health condition such as anaphylaxis, severe asthma, diabetes, and epilepsy.
- In 2014 this template was included as part of the *Application to Enrol in a Public School*, enabling a child's health information to be collected at the point of enrolment. The template also requires a documented action plan from the child's treating doctor where a child has diagnosed asthma, an allergy, or anaphylaxis.

• Parents or carers are now requested to provide updated information to the school when the health care needs of their child change, where their child has a newly diagnosed health condition, or where their child has had a hospitalisation related to their health condition.

The information enables schools to commence health care planning so that the child can be well supported as they move into the school setting and/or between schools. It also assists schools during the health care planning process.

b) In 2014, to coincide with the updated application to enrol in a public school, DEC introduced a new process to enable schools to monitor compliance with student health requirements through the Enrolment Registration Number (ERN) system. Schools are required to enter information into ERN, including information in relation to health care planning and medication for conditions such as anaphylaxis that may be required during the school day (including the expiry dates of an epipen).

This year the ERN system is being updated to generate automated emails to the school principal or their nominee when the health care plan is due for review and/or if the epipen is about to expire. This automated email will be activated based on information already entered in ERN by the school and will alert the principal (or their nominee) to the need for review or other action at the school level.

c) DEC has commenced discussions with the AIS and CEC around this recommendation. DEC also has a well-established working relationship with the Ministry of Health (MoH), in particular as it relates to student health and both are having discussions to consider ways in which this recommendation can be progressed.

#### In relation to recommendation 2:

The NSW Government welcomes this recommendation as it will require relevant agencies to work together and identify the ways in which the information flow can be improved. Schools currently rely on information provided by parents/carers in relation to a child's health conditions and the information is not always readily provided.

DEC has commenced initial discussions with MoH, AIS and CEN to consider ways in which this recommendation can be progressed.

In addition, a cross-sectoral working party has been formed to develop strategies for assisting government and non-government schools to better support students with asthma. Chaired by the NSW Ministry of Health, the working party includes representatives from the Department of Education, the NSW Catholic Education Commission, CSA, CEN and AIS.<sup>336</sup>

The Department of Education advised the Team that as a number of different asthma action plan templates currently exist, the working party is considering the need to develop a standard template for use across schools to provide 'concise and easy to follow information for asthma management and treatment of an asthma attack'.<sup>337</sup>

The Department also advised that the working party has identified other potential areas for strengthening support provided to students with asthma and their families to manage the condition at school, including the development of a Child Asthma Care Pathway. It is intended that the Pathway will identify 'an appropriate sequence of care and support steps to assist management of integrated and quality support for children and young people with asthma'. The Department anticipates that the Pathway will provide a basis for identifying the need for amendments to policy or support material for schools.<sup>338</sup>

The Team welcomes the establishment of the working party and will monitor its progress in improving strategies for supporting students with asthma.

### Non-government agency responses

#### In relation to recommendation 1:

In relation to asthma management in Catholic systemic schools, the Catholic Education Commission advised the Team that there are no overarching state-wide policies or guidelines for asthma management across schools; rather, each individual Diocese implements their own policies and guidelines.

Relevant school authorities in each Catholic Diocese reviewed their policies in response to this recommendation and provided advice to the Team on a range of existing and new initiatives to identify, and support children and families manage, significant health conditions including asthma. These include:

• Most schools requiring and/or including prompts on enrolment forms for parents/carers to provide information about their child's diagnosed health conditions, medication requirements and any other health-related needs.

<sup>336</sup> Correspondence from the Catholic Education Commission NSW to NSW Ombudsman, 26 June 2015

<sup>337</sup> Correspondence from NSW Department of Education to NSW Ombudsman, 25 September 2015.

<sup>338</sup> Ibid.

- Schools in a number of Dioceses link information contained in individual health care plans to system-wide databases and/or electronic roll marking systems to facilitate awareness amongst staff of the actions required to manage health conditions, and to enable monitoring of schools' compliance with relevant health-related policies and procedures.
- Requiring school staff to undergo training in how to administer asthma medication and provide first aid in the event of an acute asthma episode.
- Issuing newsletters and/or other forms of regular notices to parents that emphasise the importance of communicating to schools any changes in their child's health status.
- A high proportion of schools across the various Dioceses are recognised as 'asthma friendly' schools under the program run by Asthma Australia.

All Dioceses reported that schools are required to develop an individualised plan for children with severe asthma, in consultation with the child's parents and/or treating doctor. A majority of schools across the Dioceses have adopted templates for asthma action plans developed by Asthma Australia or the Sydney Children's Hospital.

Depending on the severity of a child's asthma, individual asthma plans are reviewed on a six or 12 monthly basis. In addition, compliance teams from Catholic Education Offices regularly audit schools' compliance with policies and procedures, which include a focus on whether schools are adequately implementing students' individual health care plans for conditions including asthma.

In relation to non-Catholic independent schools, Christian Education National (CEN), Christian Schools Australia (CSA) and the Association of Independent Schools (AIS) advised the Team that an informal survey of member schools identified varying policies and procedures amongst schools for identifying and supporting children with severe asthma who may need a health care or other support plan. In addition, compliance by school staff with policies and procedures for asthma management are currently monitored at the school level.

To address the Team's recommendations, these organisations are currently developing network-wide policies and procedures for identifying and supporting students with severe asthma. CEN and CSA also advised the Team that they plan to implement a monitoring framework which will involve annual compliance audits by their respective state executive officers.<sup>339</sup>

#### In relation to recommendation 2:

The Catholic Education Commission advised the Team that a cross-sectoral working party has been formed to develop strategies for improving asthma management across public and private schools. The working party is chaired by the NSW Ministry of Health and includes representatives from the Department of Education and Communities, the NSW Catholic Education Commission, Christian Education National, Christian Schools Australia and the Association of Independent Schools.

#### The Team's response

Substantial work has been undertaken to address recommendations 1 and 2 by the Ministry of Health, Department of Education, Catholic Education Commission (CEC), Australian Independent Schools (AIS), Christian Education National (CEN), Christian Schools Australia (CSA), and government and non-government Catholic and Independent schools. This work has included reviewing the adequacy of policies/guidance to schools in relation to identifying and supporting students with asthma to appropriately manage the condition.

As noted above, the Team acknowledges that schools generally have a range of measures in place to encourage parents/ carers – and treating health practitioners – to provide relevant information about children with asthma; develop and implement personalised asthma action plans; and train staff and equip schools with the resources required to respond in the event of an acute asthma episode.

Following reviews of policies/guidance to schools conducted by the above bodies, the Team welcomes resulting amendments to policies, procedures and practices aimed at further strengthening the support provided to students with asthma and their families to manage the condition at school.

The Team also supports the establishment of a cross-sectoral working group that plans to identify and implement improved strategies for asthma management in schools. The Team will continue to monitor the progress of the working party in this regard.

<sup>339</sup> Correspondence from Christian Education National, Christian Schools Australia and Association of Independent Schools to NSW Ombudsman dated 20 August 2015.

#### **Recommendation 3**

The Ministry of Health should consider the findings of the Team's review in relation to post-hospitalisation followup of children with asthma, and provide advice to the Team on the adequacy of processes within MoH for:

- a) identifying children/families who may require more assertive follow-up and asthma education
- b) facilitating active follow-up of these children/families
- c) monitoring practice and related outcomes in relation to acute management by health services of asthma in children, including links to follow-up support.

### **NSW Government response**

The NSW Government supports this recommendation, and the MoH will work with NSW Kids and Families, Local Health Districts and Specialty Networks to progress it.

#### The Team's response

The Team notes the NSW Government's advice that the Ministry of Health will work with NSW KiDS and Families, Local Health Districts and specialty networks to progress this recommendation. The Team has retained this recommendation pending further advice.

# **13.2 Sudden Unexpected Death in Infancy**

#### **Recommendation 4**

In relation to the review of the *Death – Management of Sudden Unexpected Death in Infancy* policy directive and model of response to SUDI, NSW Kids and Families should provide advice to the Team on:

- a) the findings of the review, including the outcomes of consideration of the potential for NSW to adopt a more centralised response to SUDI, and a multidisciplinary case review approach to the SUDI investigation process, and
- b) any action NSW Kids and Families intends to take in response to the findings.

### **NSW Government response**

In response to the recommendation, a meeting of the NSW Sudden Infant Death Advisory Committee (the SUDI Advisory Committee) was convened in November 2014. The committee considered the findings of an independent review of the available evidence on international and best practice responses to the management of SUDI.

A review of the implementation of the SUDI policy directive and consideration of the most appropriate model(s) for the NSW context is underway. The results of this review will be reported to the Team in due course.

#### The Team's response

The Team notes the NSW Government's advice that a review of the SUDI policy directive is underway. In this context, the Team notes the recent evidence-based guide to the investigation of SUDI developed by Garstang et al.<sup>340</sup>

The Team has retained this recommendation pending further advice.

<sup>340</sup> Garstang J., Ellis C., Sidebotham P. (2015), 'An evidence-based guide to the investigation of sudden unexpected death in infancy', in *Forensic Science, Medicine and Pathology*, Vol 11(3): 345-57.

#### **Recommendation 5**

In relation to the promotion of safe sleeping practices, NSW Kids and Families should provide detailed advice to the Team on:

- a) the outcome of the audits conducted by Local Health Districts to assess compliance with the Maternity Safer Sleeping Practices for Babies in NSW Public Health Organisations policy directive. The advice should include NSW Kids and Families' assessment of:
  - i) the adequacy of the audits, including the scope and method (such as the use of spot-checks)
  - II) the findings of the audits regarding compliance with the policy requirements, and
  - III) whether there are any systemic issues identified by the audits and, if so, the actions NSW Kids and Families will take in response.
- b) the progress of NSW Kids and Families' work with SIDS and Kids to review Health's SIDS and safe sleeping for infants guidelines and provide guidelines to community-based staff.

### **NSW Government response**

- a) The Safer Sleep for Babies 2014 audit report is currently being finalised for provision to the NSW Ombudsman. It addresses all three aspects of this recommendation. NSW Kids and Families will implement the audit recommendations in 2015.
- b) Draft revised guidelines were developed in consultation with SIDS and Kids NSW and Victoria, and were presented to the SUDI Advisory Committee in November 2014 for comment. The draft is about to be finalised for release to Local Health Districts.

A later meeting of the SUDI Advisory Committee occurred in March 2015 to progress further work required to address recommendation 5. An update on progress will be provided to the Team in due course.

### The Team's response

The Team notes the NSW Government's advice that the *Safer Sleep for Babies* audit report is currently being finalised, that draft guidelines were developed and will be finalised for release to Local Health Districts, and that an update on progress will be provided to the Team in due course.

The Team has retained this recommendation pending further advice.

#### **Recommendation 6**

In relation to post-mortem examinations following unexpected deaths of infants, NSW Health Pathology should provide to the Team:

- a) a copy of the plan developed by the Paediatric Histopathology Working Party to address key issues relating to perinatal and infant post-mortems, and
- b) advice about progress in implementing the plan.

### **NSW Government response**

The NSW Government supports the recommendation, which is a continuation of work being progressed from 2013. NSW Health Pathology will provide an update to the Team in due course.

In September 2015, NSW Health advised the Team that the Paediatric Histopathology Working Party has refined its focus to concentrate on the delivery of perinatal (stillborn) post-mortem services.<sup>341</sup> NSW Health further advised that the working party identified this as its key challenge, given the *'progress made in reducing delayed reporting of paediatric coronial post-mortem cases'*.

In addition, NSW Health Pathology has recently commissioned an external consultant health planner to develop a service model for the delivery of perinatal post-mortem services in NSW and a steering committee has been established to oversee this work.<sup>342</sup>

341 Correspondence from NSW Health to NSW Ombudsman, 25 September 2015.342 Ibid.

### The Team's response

The Team notes the NSW Government's advice that it supports the recommendation and will continue to monitor NSW Health's progress in implementing it.

The Team has retained this recommendation pending further advice.

#### **Recommendation 7**

In relation to the Department of Family and Community Services' (FACS) cohort review of SUDI where the infant's family had a child protection history, the agency should provide advice to the Team on:

- a) progress in implementing the recommendations arising from the review, and
- b) how the agency will audit or otherwise measure practice and related outcomes.

# **NSW Government response**

For recommendation 7(a), progress against implementation of the recommendations from the FACS cohort review is below.

Recommendation from cohort review	Progress
To distribute copies of the Safe Sleeping report across FACS	Copies of the Safe Sleeping report were distributed to FACS frontline staff and management in January 2015. A briefing package was also developed.
	The Safe Sleeping report and FACS Child Deaths 2013 annual report were distributed to Community Services Centre (CSC) managers. Briefings have been delivered to CSCs.
	The Safe Sleeping report was also distributed to non- government organisations (NGOs) in December 2014.
To publish abridged version of Safe Sleeping report in FACS Child Deaths 2013 annual report	An abridged version of this report was published in the FACS Child Deaths 2013 annual report. A seminar on the annual report and this content was presented to field staff at the FACS Annual Practice Conference in 2014.
To scope development of an online training package on SUDI focusing on modifiable risk factors and share resource with other agencies	In progress, will be completed in 2015.
Office of Senior Practitioner (OSP) to broaden training package developed by its Clinical Issues Unit to include information about work with culturally and linguistically diverse families and collaborate with Districts to deliver it to field staff in 2014-15	In progress and on track for delivery in 2014-15.
OSP Child Deaths Critical response team to progress discussions with the Helpline about the current SDM tool to better support HL caseworkers to identify risk	Will be actioned.
OSP to reconvene meetings with MoH review findings and discuss establishing consistent cross-agency messages on safe sleeping and barriers to this	In progress.

In terms of recommendation 7(b), it will be implemented after auditing of training delivery (which will occur after the revised, integrated OSP package has been developed and delivered to staff).

#### The Team's response

The Team notes actions to distribute the Safe Sleeping report to FACS staff, and the publication of an abridged version of the report within the FACS *Child Deaths 2013* report. The Team has updated the recommendation to reflect the progress indicated.

# Low speed vehicle run-overs

#### **Recommendation 8**

In 2015, the Centre for Road Safety should provide the Team with an update on the progress of its work in relation to low speed vehicle run-over incidents, including:

- a) stakeholder committee discussions to determine further countermeasures to prevent low speed vehicle run-overs, and
- b) implementation of the new driveway safety public awareness campaign.

# **NSW Government response**

- a) The Centre for Road Safety has established an interagency low speed pedestrian crashes working group with a particular focus on young children and older road users. The inaugural meeting of the working group occurred in February 2015. The terms of reference for the working group are to:
  - examine the available data and evidence to identify key issues and causes for low speed vehicle crashes
  - review existing relevant programs and strategies
  - identify and develop further countermeasures for low speed vehicle crashes.

It is expected that the recommendations and findings of the working group will be reported back to the Team via the usual Transport for NSW (TfNSW) reporting channel and will also be considered by TfNSW as part of delivery of NSW Road Safety Strategy and NSW Pedestrian Safety Action Plan.

- b) In October 2014, the Centre for Road Safety released a new 'Driveway Safety, They're Counting on You' campaign featuring television personality Scott Cam. The campaign was developed in partnership with the Georgina Josephine Foundation. The campaign, which includes TV advertising, online advertising, radio advertising and a YouTube educational video, aims to:
  - raise awareness of the safety risks that driveway environments pose to young children
  - facilitate use of strategies and countermeasures to help prevent driveway safety incidents
  - discourage the use of driveways as play areas.

Though it is early days, the response from the community has been positive since the launch. Transport for NSW has also received positive feedback from other Australian jurisdictions. An evaluation of the campaign effectiveness is planned for 2015.

#### The Team's response

The Team welcomes the establishment of the interagency working group and note the established terms of reference. The Team will monitor the progress and outcome of this work.

# Off-road vehicle fatalities

#### **Recommendation 9**

In the context of the Department of Premier and Cabinet's (DPC) plans to consult key injury prevention agencies to determine whether specific strategies are needed in NSW to reduce the risk of death and injury in relation to off-road vehicle incidents, DPC should provide detailed advice to the Team on:

- a) the outcomes of the consultations/forum with relevant agencies, including in relation to:
  - i) existing or planned initiatives within NSW and at the national level
  - ii) the need for targeted research, including environmental and vehicle design elements of prevention and attitudinal research relating to parent and carer perceptions of risk
  - iii) the need for public awareness strategies, including print and electronic media resources, that recognise the behavioural, environmental and vehicle design elements of prevention, and
  - iv) the need for regulation of the recreational use of off-road vehicles on private property, including licensing, registration, and requirements relating to safety equipment such as helmets.
- b) how the identified strategies will be progressed.

# **NSW Government response**

DPC has brought together key injury prevention agencies to consider this recommendation and to discuss and determine any specific strategies to reduce the risk of death and injury in relation to off-road vehicle incidents. Participants included:

- Centre for Road Safety, TfNSW
- NSW Fair Trading
- Ministry of Police and Emergency Services
- WorkCover NSW
- National Parks and Wildlife Services, Office of Environment and Heritage
- Motor Accidents Authority
- FACS
- Sydney Children's Hospitals Network (Randwick and Westmead).

It is acknowledged that there are limitations to regulating the use of recreational vehicles, such as quad bikes and motorcycles on private property. Changes to legislation may be impractical as it would be difficult for police to enter private land to enforce any licencing or registration scheme. Roads legislation addresses activities that occur on public roads and road-related areas, including national parks and reserves. Any changes to the application of legislation to incidents on private property would involve significant changes to the law.

However, there are initiatives and research underway in NSW that seek alternative options to address the risk of death or injury from off-road vehicle incidents to children.

The Sydney Children's Hospitals Network and Neuroscience Research Australia are collecting data to help understand crash and injury causation from off-road vehicle incidents. This includes human, vehicle and environmental factors associated with motorcycle and quad bike incidents, as well as research into parent and carer perceptions of risk. Multiple stakeholders, such as engineers, patients and their families are involved.

Through its CrashLink database, TfNSW also seeks to capture some information on off-road incidents reported to NSW Police. TfNSW is working with government agencies such as NSW Police and NSW Health to improve data collection and research on injuries and deaths by non-registered motorised vehicles. TfNSW will be convening an interagency working group to examine policy options to reduce low speed pedestrian fatalities that may occur off-road in areas such as driveways (see response to recommendation 8).

In addition, WorkCover NSW is working with the University of NSW on the Quad Bike Performance Project to help develop a consumer safety rating system. Whilst not specific to child injuries, the research aims to develop a consumer safety rating system for quad bikes. As part of a Heads of Workplace Safety Authorities industry strategy, the project intends to help inform Australian safety regulators on vehicle design and testing, operator protection devices, as well as helmet use and training. Once finalised, the NSW Government will review the project's findings, with a view to implementing safety measures to vehicle design and use.

Guidance materials have also been developed by WorkCover NSW to promote child safety on farms, and to address the risks from off-road vehicles, such as quad bikes. The national Primary Industries Health and Safety Partnership has developed material to address child safety on farms. A national safety campaign has also been launched by the Australian Competition and Consumer Commission, warning of the dangers of quad bikes to children. The Sydney Children's Hospitals Network also intends to run awareness campaigns once data analysis of its research study has concluded. It is likely that this research will inform other public awareness strategies in the future.

#### The Team's response

The Team acknowledges the Government's advice that an interagency meeting was convened with key injury prevention agencies, and the view that regulation was seen to have limitations and legislative change may be impractical.

The Team notes a recent comprehensive phase 2 inquest relating to quad bike deaths by the Queensland Coroner, in which the Coroner made 15 recommendations in relation to the use of and safety related to quad bikes. These recommendations included regulatory and legislative change and improvements to education and training and initiatives. The NSW Coroner is currently holding an inquest (at the time of writing) in relation to a number of deaths also involving off-road vehicles. Both inquests included examination of a number of child deaths.

The Team will continue to monitor the findings and/or recommendations from the NSW Coronial inquest, and any government response.

# 13.3 Swimming pool drowning

#### **Recommendation 10**

The Office of Local Government (OLG) should provide a progress report to the Team on the implementation of changes to the *Swimming Pools Act*, including:

- a) its analysis of data and other information relating to compliance with the amendments, including but not limited to:
  - i) the number of swimming pools registered
  - ii) the number of swimming pools that have been inspected
  - iii) the proportion of inspected swimming pools that were deemed non-compliant with the Act at the time of inspection
  - iv) the main defects identified at the time of inspection, and
  - v) whether or not owners have rectified defects within a reasonable period of time.
- b) major challenges in implementing the Act, and any actions that OLG has identified to address these challenges.

# **NSW Government response**

OLG will continue to directly provide updates to the Team on implementation of amendments to the *Swimming Pools Act 1992,* including in relation to challenges and actions identified to address them.

In terms of the data sought, the NSW Swimming Pools Register is currently the best source of information and will need enhancements if it is to provide a fuller range of information. OLG's current role is to maintain the register. The register currently contains information that will support reporting against items (a)(i) and (iii), but not others. The register is reliant on self-reported information from pool owners and local councils. OLG is continuing to engage with local councils and other stakeholders to determine how this register could be enhanced to improve recording and reporting generally and specifically in relation to (a) above.

OLG will continue to provide updates to the Team on implementation challenges and its response to those challenges as well as any opportunities that may arise.

#### The Team's response

In July 2015, the Minister for Local Government announced a new regulatory review of swimming pool legislation. The review aims to 'simplify the regulatory framework and encourage greater barrier compliance in order to reduce the incidence of child drownings and near-drownings in private pools'.<sup>343</sup>

The Team agrees with the need for simple, targeted and effective regulation of swimming pools in NSW and notes that this aligns with key findings from the Team's review of swimming pool drowning over the five-year period 2007-2011. In particular, the Team emphasised that the most at-risk group for drowning in swimming pools are children under five years of age, and pools that present the most risk are located on properties where children live or frequently visit, including rental properties.

The terms of reference for the review require an examination of an inspection and enforcement frameworks, including consideration of the Team's recommendations in this regard. Given that these areas are within the scope of the review, the Team will continue to monitor the targeting of swimming pool compliance measures in this context.

#### **Recommendation 11**

OLG should provide advice to the Team on how it will publicly report on swimming pool inspection and compliance activity across NSW.

# **NSW Government response**

Information on swimming pool inspection and compliance activity that OLG collects can be readily accessed on OLG's annual report, available at www.olg.nsw.gov.au.

As the information which can be publicly reported is limited by the information that OLG collects, currently the public information released by OLG relates to items (a)(i) and (iii) [of recommendation 10].

Once any enhancements to the NSW Swimming Pools Register are approved and implemented, OLG can publicly report on a fuller range of relevant information.

#### The Team's response

The Team has reviewed the information reported in OLG's public annual reports and notes that they do not appear to report numbers of pools inspected and considered non-compliant, as indicated in the Government's response.

The Team also notes that the swimming pool register includes capacity for authorised officers/accredited certifiers to record the date/time of inspection; whether the pool is compliant or non-compliant; the reasons for non-compliance (gate, fence, window, door, sign, other); and comments/explanation for non-compliance.<sup>344</sup>

In the context of the 2015 Swimming Pool Review, the Team will continue to monitor the implementation of regimes for monitoring compliance with legislative requirements relating to private swimming pools and related public reporting.

<sup>343</sup> Office of Local Government, Swimming Pool Barrier Review 2015, https://www.olg.nsw.gov.au/content/swimming-pool-barrier-review-2015, accessed 17 August 2015.

<sup>344</sup> Division of Local Government, Department of Premier and Cabinet (2013), Swimming Pool Register User Guide, http://www.olg.nsw.gov.au/sites/ default/files/Swimming-Pool-Register-User-Guide.pdf, accessed 17 August 2015.

#### **Recommendation 12**

FACS, Office of the Children's Guardian (OCG) and OLG should develop arrangements to facilitate:

- a) the identification by FACS, OCG and designated agencies, in the course of their work, of premises with swimming pools where young children reside, and
- b) the provision of information about the location of these premises to OLG/local councils to enable these pools to be:
  - i) checked for registration, and
  - ii) prioritised for inspection by relevant local councils.

# **NSW Government response**

The NSW Government supports the development of an arrangement between these organisations that identifies premises with swimming pools where young people in care reside, and provides the information to local councils.

OLG will lead actioning of this recommendation, and will organise discussions with FACS, OCG and local councils to determine the feasibility of an arrangement to share and provide this information to local councils.

#### The Team's response

The Team acknowledges the work undertaken by FACS, OCG and OLG to strengthen processes for the exchange of relevant information about premises with pools where young children reside.

The Team notes that the terms of reference for the Swimming Pool Review 2015 require examination of inspection and enforcement frameworks. Given that these areas are within the scope of the review, the Team will continue to monitor the targeting of swimming pool compliance measures in this context.

#### **Recommendation 13**

FACS should provide advice to the Team on:

- a) the adequacy of its current risk assessment and other processes for identifying drowning risks to young children, including compliance with the Swimming Pools Act, and
- b) any action it intends to take to reduce the drowning risks to young children known to the Department, such as training of caseworkers and other relevant staff.

#### **Recommendation 14**

OCG should provide advice to the Team on:

- a) the adequacy of the risk assessment and other processes of designated agencies for identifying drowning risks to young children, including compliance with the Swimming Pools Act, and
- b) any action it intends to take to reduce the drowning risks to young children in out-of-home care, such as issuing guidance to designated agencies and monitoring their supervisory responsibilities.

# **NSW Government response**

In relation to recommendation 13:

For children under the domain of FACS (i.e. those at risk of significant harm), any risks associated with non-compliant swimming pools should be adequately identified using the FACS safety, risk assessment and re-assessment tools.

FACS is continuing to progress work to reduce the risks for children in out of home care (OOHC). This work includes strengthening FACS procedures for authorising carers, improving FACS' casework practice sites with links for caseworkers to pool safety resources (e.g. Kidsafe, Royal Lifesaving) and information about the regulation of swimming pools to the *Home Inspection Checklist* requirements within the authorised carers procedure. FACS will continue to promote pool safety messages through carer support publications and other activities with carers.

In relation to recommendation 14:

a) OCG is responsible for the accreditation and monitoring of designated agencies in NSW. Designated agencies are currently accredited against the NSW Standards for Statutory Out-of-Home Care, which require these agencies to assess the care environment (including outdoor spaces) for safety and suitability prior to placement commencing for children and young people in OOHC.

The standards also require designated agencies to undertake ongoing monitoring of the care environment and to report, record and manage critical incidents (for example, accidents around a pool).

Aside from the standards, policies and procedures for designated agencies include a requirement for regular home visits – these usually occur monthly. If a pool is not fenced, designated agencies will require the pool to be fenced before children are placed. This is also required in circumstances where the *Local Government Act* would not normally require the pool to be fenced (for example for pools installed prior to the Act).

Agencies conduct home safety inspections prior to authorisation of a carer, again around the time of the carer's annual review and also when an authorised carer moves residence.

OCG assessors review agency records for evidence that swimming pool safety is assessed during home safety inspections and that safety issues identified in the care environment are addressed appropriately.

b) The OCG has recently developed a single set of standards, bringing together the NSW Standards for Statutory Outof-Home Care and the Adoption Standards. This will create a more streamlined accreditation system for agencies providing both OOHC and adoption services. The revised standards are currently in draft form and have been circulated for feedback to the sector (standards may be finalised by July 2015).

The OCG will incorporate a requirement into the standards that home safety inspections include an assessment to ensure that swimming pools comply with relevant legislation and guidelines. There could be information to accompany the revised standards about swimming pool safety with a link to relevant legislation, resources and local government information. As supervision is a critical issue for reducing drowning risks to children, the issue of carer support, including adequate respite for carers, is a key issue. The OCG is considering including a requirement in the revised standards that, where an agency determines that respite is required, but refused, a review of the carer and each placement be undertaken.

Additionally the OCG will soon be administering a Carers Register. The register will ensure that agencies have completed the requirements for authorisation of carers, including home inspections. As the Carers Register will record authorised carers including the residential address, OCG will provide this information to FACS so that FACS can provide a report to local councils to enable the identification of carer households that have a pool to prioritise a council check.

#### The Team's response

The Team acknowledges the work by FACS to develop policies, resources and training to assist staff identify and address drowning risks for children. The Team is also pleased that accreditation and monitoring of designated out-of-home care agencies by the OCG includes a focus on ensuring that agencies identify and appropriately address safety risks in the care environment, including drowning risks to children.

The Team also welcomes changes to the *Out-of-Home Care Standards* for designated out-of-home care agencies to specifically require agencies to assess swimming pools as part of the broader requirements relating to home safety inspections of out-of-home care environments.

In the context of the Swimming Pool Review 2015, the Team will continue to monitor how relevant agencies identify and address drowning risks for children, including compliance with swimming pool legislation.

#### **Recommendation 15**

The Association of Children's Welfare Agencies (ACWA) should consult its member agencies and provide advice to the Team on:

- a) the adequacy of the guidance for non-government staff working with vulnerable families to identify drowning risks
  - to young children, including compliance with the Swimming Pools Act, and
- b) any action it intends to take to assist member agencies to reduce the drowning risks to young children, such as training initiatives.
- c) This recommendation relates to an independent community services association.

# **ACWA response**

ACWA advised that they are committed to working with member agencies (including non-government out-of-home care providers) to communicate the importance of, and implement strategies focused on, the identification of drowning risks for children in care. ACWA also proposes to review its training courses to identify opportunities for a strengthened focus on water safety.

#### The Team's response

The Team is encouraged by the increased focus on training and dissemination of water safety messages to staff of non-government agencies, including in relation to the identification of drowning risks and potentially non-compliant swimming pools.

In the context of the Swimming Pool Review 2015, the Team will continue to monitor how relevant agencies identify and address drowning risks for children, including compliance with swimming pool legislation.

# **House fires**

#### **Recommendation 16**

Against the background of the high proportion of children with a child protection history who were among those who have died in house fires in the last 10 years; the high proportion of these fires having been started by children playing with matches/lighters; and the previous recommendations of the NSW Coroner, representatives of FACS and Fire & Rescue NSW should:

- a) meet to discuss the issues raised in this report and opportunities for collaborative work to reduce the fire risks of children known to FACS, and
- b) provide advice to the Team on any action they intend to take to reduce these risks, such as through targeted prevention resources and activities.

#### **NSW Government response**

Similar to swimming pools (recommendation 13), fire hazards should be adequately identified using FACS' safety, risk assessment and re-assessment tools for children deemed to be at risk of significant harm.

Reducing these fire risks requires collaboration with Fire and Rescue NSW, which has a longstanding community education program, well developed prevention resources, and targeted programs for specific groups. FACS and Fire and Rescue NSW met in December 2014 to discuss this recommendation and identify opportunities for collaborative work to reduce fire risks to children and young people, leveraging on Fire and Rescue NSW's existing expertise. These discussions will continue in 2015.

#### The Team's response

The Team notes that FACS and Fire and Rescue NSW have commenced discussions to progress the recommendation.

The Team will seek further advice on specific action the two agencies intend to take to reduce fire risks to children and young people with a child protection history.

# **Recommendations 2015**

As noted above, the Team will carry-over a number of recommendations relating to Sudden Unexpected Death in Infancy, pending further advice. These recommendations are detailed in chapter 5.

In regard to house-fires, the Team recommends:

9. Against the background of the high proportion of children with a child protection history who were among those who have died in house fires in the last 10 years; the high proportion of these fires having been started by children playing with matches/lighters; and the previous recommendations of the NSW Coroner, FACS and Fire & Rescue NSW should provide advice to the Team on actions taken, or planned, to reduce fire risks to children with a child protection history.

# **Appendix 1: Methods**

#### **Baseline measurements**

The report methodology is underpinned by survey data and estimates produced by the Australian Bureau of Statistics (ABS).

#### **Population estimates**

The comparative population size for the Mortality Rate calculations are sourced from a range of ABS reports, including tables supplied by ABS to order:

- The base populations of children in NSW were taken from a current release of the ABS Australian Demographic Statistics publication by sex and single year of age.<sup>345</sup>
- The base populations by Remoteness Area and Socio Economic Index (SEIFA) as Index of Relative Disadvantage (IRSD) quintiles were taken from a table supplied to order by ABS.<sup>346</sup> The most recent figures available were for 2013.
- Infant mortality rates were calculated from the number of live births in NSW in 2013,<sup>347</sup> including breakdowns for Aboriginal and Torres Strait Islander births, and births by Remoteness Area. The estimated population of children below one year of age by socioeconomic quintile (IRSD) was used as a proxy for number of births by quintile. This was sourced from a table supplied to order by ABS.<sup>348</sup>
- Population estimates for all Aboriginal and Torres Strait Islander children were sourced from the ABS publication 'Estimates of Aboriginal and Torres Strait Islander Australians' which has been based on data from the 2011 census.<sup>349</sup>

#### Remoteness

The breakdown of population by age categories and by Remoteness Areas as of 30 June 2013 was supplied by the ABS to order. The delimitation criteria for Remoteness Areas are based on the Accessibility/Remoteness Index of Australia (ARIA+).<sup>350</sup> The Aria+ Index,<sup>351</sup> is a measure of access to services using proxy measures of distance to the five nearest centres of defined populations.

The product supplied by the ABS contains estimates of the resident populations (ERPs) by 2011 Statistical Area Level 1 (SA1) derived areas of Australia, produced by the ABS. These estimates correspond with the preliminary 30 June 2013 ERP as released on 27 March 2014 in Australian Demographic Statistics, Sep 2013 (cat. no. 3101.0). The SA1 and SA1-based ERPs are not standard ABS output, but rather are customised data available for purchase as an information consultancy. Thus, these estimates are not published on the ABS website.

The ABS changes the boundaries of its underlying geographic spatial structures over time. With the 2011 census there was a major change from the Australian Standard Geographical Classification (ASGC) to the Australian Statistical Geography Standard (ASGS). Consequently, geographic patterns may have changed slightly across time and from previous reports. While it is likely that the changes are minimal at the level of remoteness grouping (a high level of grouping), caution should be applied when analysing and interpreting changes through time.

For the majority of children whose deaths were registered in 2014, categorisation of remoteness areas and socioeconomic groupings was done through direct translation of the latitude and longitude coordinates of the address of usual residence. This enables the most accurate categorisation of usual residence using the ASGS.

<sup>345</sup> Australian Bureau of Statistics, 2015, 3101.0 Australian Demographic Statistics (TABLE 51. New South Wales), Sept 2014 release, Canberra: ABS.

<sup>346</sup> Australian Bureau of Statistics, 2015, 2013 Estimated Resident Population, by selected age groups, sex, remoteness areas and socioeconomic factors, Canberra: ABS.

<sup>347</sup> Australian Bureau of Statistics, 2014, 3301.0 Births, Australia, 2013, Canberra: ABS.

<sup>348</sup> Australian Bureau of Statistics, 2015, 2013 Estimated Resident Population, by selected age groups, sex, remoteness areas and socioeconomic factors, Canberra: ABS.

<sup>349</sup> Australian Bureau of Statistics, 2014, 3238.0 Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026, Canberra: ABS.

<sup>350</sup> Australian Bureau of Statistics, 2013, 1270.0.55.005 Australian Statistical Geography Standard (ASGS): Volume 5 – Remoteness Structure Australia July 2011, Canberra: ABS.

<sup>351</sup> Australian Population and Migration Research Centre, 2013, ARIA (Accessibility/Remoteness Index of Australia), Adelaide: APMRC. http://www.adelaide.edu.au/apmrc/research/projects/category/about\_aria.html, accessed 7 August 2015.

#### Relative socioeconomic status

Socioeconomic status refers to the relative access to material resources of an individual or group. The indicator of the socioeconomic status of a child used in this report is the Index of Relative Social Disadvantage (IRSD) of the area in which a child usually resided.

Socioeconomic status is reported in quintiles. Quintile 1 represents the relatively most disadvantaged 20%, and quintile 5 represents the relatively least disadvantaged 20%.

In this report, socioeconomic status is not included in calculations for children whose usual residence was outside of the state or overseas, or for those where insufficient information was available for their usual place of residence. Six children did not have an IRSD score and two children did not have ARIA score.

#### Identification of Aboriginal and Torres Strait Islander children

Individual children are identified as Aboriginal or Torres Strait Islander if:

- The child has been identified as either Aboriginal or Torres Strait Islander on their NSW Births Deaths and Marriages death certificate.
- The child or their parent/s have been identified as either Aboriginal or Torres Strait Islander on their NSW Births Deaths and Marriages birth certificate.
- Agency records identify the child as Aboriginal or Torres Strait Islander through a number of records, which are corroborative. Records used to do this include the NSW Police Computer Operated Policing System and Community Services' KIDS client database, which often hold information that can support Aboriginal or Torres Strait Islander identity. NSW Health and other agency records were also used to assess the child and family background.

### **Data description**

The child death register records information on all children whose deaths have been registered in NSW, including whether any of the children were Aboriginal or Torres Strait Islander Australians.

Data on Aboriginal and Torres Strait Islander status is compiled from a range of sources. The number and source of the records is partially dependent on the cause of death for each child. Some sources in the list below are requested for every child, and some are only requested where applicable.

Record requests can take some time after a death has been registered, and information is added as it becomes available. Data published in this report for 2014 Aboriginal and Torres Strait Islander status and mortality rates are therefore subject to change.

### Changes since 2013

In line with recommendations by the Australian Institute of Health and Welfare (AIHW),<sup>352</sup> the Team's process for collecting Aboriginal and Torres Strait Islander status for the register changed in 2013. Previously, information from BDM was used as the primary source, with other sources taken into account where other records clearly indicated the child was Aboriginal or Torres Strait Islander. Identification of the child's Indigenous status was based on expert assessment of the information. However, information from sources other than BDM was not held in the register; reporting was based on a single data field that contained the final decision.

For deaths registered from 2013 onwards, information about a child's Aboriginal or Torres Strait Islander status has been collected from all sources available for each case. Business rules have been applied to assign Aboriginal and Torres Strait Islander status for each child. For eporting on deaths in 2014 (as in 2013), an 'ever-Indigenous' rule has been used. That is, where a child has been identified as Indigenous in any source collected by the Team in the course of the case review, the child has been nominated as Aboriginal and/or Torres Strait Islander in the register and the case reported as such.

For reporting on trends in deaths over time, only BDM birth and death data has been used. BDM data is the primary source for Indigenous status, and should be used exclusively to analyse trends to avoid compounding errors from differences in accuracy of secondary data sources through time. BDM data has been used for reporting all trends in deaths over time.

<sup>352</sup> Australian Institute of Health and Welfare, 2013, *Identification and reporting of Aboriginal and Torres Strait Islander Children by the New South Wales Child Death Review Team, Advisory Report,* Canberra; AIHW.

List of sources	
BDM death	BDM birth
National Coronial Information System (NCIS)	Other coronial records
Police databases (COPS/PODS)	Other police records
Education records	NSW Health records
Community Services KiDS person summary	Other Community Services records
CWU database – Wellnet	Other CWU records
GP/Private practitioner records	NGO records
Other sources	

# Sources of Aboriginal and Torres Strait Islander identification of deaths in 2014

As indicated in the table below, of the 63 children who were identified as Aboriginal and/or Torres Strait Islander in 2014, 42 (67%) were identified by two or more sources. The remaining 21 children were identified as Aboriginal and/or Torres Strait Islander by only one source.

Forty-eight of the 63 children (76%) were identified in BDM and other records. BDM information (birth and/or death) was the only source of identification for 18 children, most (12) of whom were identified using a single BDM source (birth or death). Fifteen children were identified as Aboriginal and/or Torres Strait Islander only by sources other than BDM.

Table 74: Sources of	Aboriginal	and Torres	Strait Islander	identification.	2014
	Aboligiliai		otiaitioiailaoi	identification,	LUIT

Decision	BDM birth or death	Total sources	Number of children
Aboriginal Torres Strait Islander BD	BDM Birth only	1	5
	BDM Death only	1	7
	BDM Birth & BDM Death only	2	6
	BDM & other sources	2	5
		3	10
		4	6
		5	2
		6	6
		7	0
	Other source(s) only	8	0
		9	1
		1	9
		2	3
		3	1
		4	2
			63
Non-Aboriginal Torres Strait Islander	BDM & other sources		422
Total			485

# **Classification of cases**

In relation to cause of death, individual cases are, with the exception of Sudden Unexpected Death in Infancy (SUDI), reported against a specific category within the report. SUDI is not a cause of death. For this reason, SUDI cases with known underlying causes of death are reported in the sections pertaining to those underlying causes.

For natural cause deaths, reporting categories align with chapter levels of the International Statistical Classification of Diseases and Related Health Problems (ICD). This is also generally (but not always) the case for external cause deaths, where precedence may be determined according to the most appropriate category for considering prevention.

# Calculations

# **Mortality rates**

The Crude Mortality Rates (CMR) were calculated as rates per 100,000 persons. This was done by dividing the number of deaths in a given category by the population that was appropriate for the category. For example, the CMR for deaths of children from all causes in 2014 was  $(485/1682684 \times 10000) = 28.8$ .

Directly Standardised Mortality Rates (DSMR) were also calculated as rates per 100,000 persons. The DSMR differs from the CMR in that it is adjusted for the difference in the age structure of the current population compared with a standard population (in this case, 2001). The adjustment allows comparison between years.

Here, the age-adjustment method used the number of deaths in each year age category for each year and the population in each year age category for each year (and number of deaths and populations separately by gender where appropriate).

Infant Mortality Rates (IMR) are calculated as rates per 1,000 live births. The number of infant deaths in a given category is divided by the total number of live births for the year and multiplied by 1,000. As data on live births in 2014 were not available at the time of writing this report, 2013 birth figures were used. For example, in 2014 the IMR for infants (under 1 year) (296/100462 x 1,000) = 2.95. Where reporting infant deaths IMR are reported unless otherwise stated.

Mortality rates were not calculated where there were less than four deaths.

# **Confidence intervals**

If the number of observed cases was less than 100, confidence intervals were calculated directly from the Poisson distribution, as recommended by the Washington State Department of Health.<sup>353</sup> When the number of cases was 100 or more, the normal approximation was used to calculate the confidence intervals. The equation applied was:  $(\pm 1.96 \times (CMR \text{ or appropriate rate}) / \sqrt{(number of deaths))}$ .

# **Incident rate ratios**

Incident rate ratios are a pairwise comparison of mortality rates. In this report, they were calculated to compare male with female rates and Aboriginal/Torres Strait Islander with Non-Aboriginal/Torres Strait Islander rates. Where the ratio is equal to one, rates were equal. Where the ratio was greater than one, male or Aboriginal/Torres Strait Islander rates were higher. Where they were less than one, female or Non-Aboriginal/Torres Strait Islander rates were higher.

# p values

A test procedure called the two-proportion z-test was used to assess the significance of differences between males and females and Aboriginal/Torres Strait Islander and Non-Aboriginal/Torres Strait Islander populations. Rates and *p* values were not calculated where there were less than four deaths in either category, due to unreliability of estimates for very small numbers. Where *p* is less than 0.05, male or Aboriginal/Torres Strait Islander rates were *significantly* higher than female or Non-Aboriginal/Torres Strait Islander rates. The lower the *p* value below 0.05, the more significant the difference. A *p* value of <0.001 indicates a very significant difference.

#### Software

Much of the data extraction and summarisation was done using Microsoft SQL Server 2012 and Tableau from Tableau Software.

<sup>353</sup> Washington State Department of Health 2012, *Guidelines for Using Confidence Intervals for Public Health Assessment*, Olympia, WA: DOH http://www.doh.wa.gov/Portals/1/Documents/5500/ConfIntGuide.pdf, accessed 11 July 2014.

# **Appendix 2: Definitions**

#### Causes of death

ICD-10 is the International Statistical Classification of Diseases and Related Health Problems, 10th revision (World Health Organization). The ICD-10 has more than 12,000 unique codes in more than 2,000 categories. The highest level classification is the chapter level (22 chapters). ICD-10-AM is the Australian modification of ICD-10.

Underlying cause of death is defined by the World Health Organisation as the 'disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury'. Unless otherwise indicated, in this report the cause of death relates to underlying cause. The underlying cause of death is recognised as the single most essential element to understanding causes of death.<sup>354</sup>

Direct cause of death is the final condition or event that results in death. Intervening causes of death are other conditions that may have given rise to the immediate cause of death. Contributory causes of death are conditions or events that were present during the sequence leading to death, but may not have been necessary influences.

Name	Description	ICD codes
Certain conditions originating in the perinatal period	Includes conditions such as prematurity; complications of labour, including hypertension and maternal haemorrhage; and disorders associated with foetal growth. It may also include certain respiratory, cardiovascular and infectious diseases associated with the perinatal period, such as aspiration of meconium and respiratory distress of the newborn.	P00-P96
Congenital malformations and chromosomal abnormalities	Includes a range of conditions, including congenital hydrocephalus, trisomy 18 (Edwards syndrome), and Down syndrome.	Q00-Q99
Neoplasms	Cancers and tumours.	C00-D48
Diseases of the nervous system	Includes disorders such as epilepsy, cerebral palsy and muscular dystrophy, as well as inflammatory and degenerative conditions.	G00-G99
Diseases of the respiratory system	Includes conditions such as pneumonia, influenza and asthma.	J00-J99
Endocrine, nutritional and metabolic diseases	Includes conditions such as diabetes, malnutrition and Cushing's syndrome.	E00-E89
Diseases of the circulatory system	Includes conditions such as cardiac and blood vessel malformations and disorders of metabolism that lead to blocking of blood vessels.	100-199
Certain infectious and parasitic diseases	Infectious diseases are caused by organisms such as bacteria, viruses, parasites or fungi, and can be passed directly or indirectly from person to person. <sup>331</sup> Examples include influenza, gastroenteritis and meningococcal disease.	A00-B99
Other diseases/ morbid conditions	Includes: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism; Mental and behavioural disorders; Diseases of the eye and adnexa; Diseases of the ear and mastoid process; Diseases of the digestive system; Diseases of the skin and subcutaneous tissue; Diseases of the genitourinary system; and Pregnancy, childbirth and the puerperium.	D50-D89, F00-F99, H00-H59, H60-H95, K00-K93, L00-L99, N00-N99, O00-O99

### Natural causes of death

355 World Health Organisation 2011, Infectious Diseases, Geneva: WHO. http://www.who.int/topics/infectious\_diseases/en/, accessed 16 July 2013.

<sup>354</sup> National Centre for Health Information Research and Training 2011 *Review and recommendations for the annual reporting of child deaths in NSW.* Sydney: NSW Ombudsman. Unpublished.

### External causes of death

Name	Notable inclusions	ICD code
Drowning		W65-W74, Y21
Fatal assault	Assault involving drowning (X92) or a motor vehicle (Y02-Y03) would be included with deaths from fatal assault.	X85-Y09
Suicide	Includes intentional crashing of a vehicle and intentional self-harm by drowning.	X60-X84
Transport		V01-V99, Y31-Y32
Other unintentional external cause death	A number of unintentional external cause deaths occur that are not due to transport fatalities, assault, suicide or drowning. Due to the small number and great variety of these deaths, they are described in one section of the report.	

# Sudden Unexpected Death in Infancy (SUDI)

In this report, SUDI is defined as: where an infant less than one year of age dies suddenly and unexpectedly. Included in SUDI are:

- deaths that were unexpected and unexplained at autopsy (i.e. those meeting the criteria for Sudden Infant Death Syndrome)
- deaths occurring in the course of an acute illness that was not recognised by carers and/or by health professionals as potentially life threatening
- deaths arising from a pre-existing condition that had not been previously recognised by health professionals, and
- deaths resulting from accident, trauma or poisoning where the cause of death was not known at the time of death.

# Sudden Infant Death Syndrome (SIDS)

SIDS is a category of SUDI and is a diagnosis of exclusion. In this report, SIDS is defined as:

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.

As noted, there are a number of sub-classifications of SIDS (see Appendix 2 for sub-classifications).

# **Definitions – other**

Child – a person under the age of 18 years.

Child in care – a child or young person under the age of 18 years:

- who is under the parental responsibility of the Minister administering the Children and Young Persons (Care and Protection) Act 1998, or
- for whom the Secretary of the Department of Family and Community Services or a designated agency has the care responsibility under s49 of the *Children and Young Persons (Care and Protection) Act 1998*, or
- who is a protected person within the meaning of s135A of the Children and Young Persons (Care and Protection) Act 1998, or
- who is the subject of an out-of-home care arrangement under the Children and Young Persons (Care and Protection) Act 1998, or
- who is the subject of a sole parental responsibility order under s149 of the *Children and Young Persons (Care and Protection)* Act 1998, or
- who is otherwise in the care of a service provider.

**Child protection history** – a child is reported as being from a family with a child protection history if the child, or their sibling, had been the subject of a report(s) of risk of harm or risk of significant harm to Community Services, or the subject of a report to a Child Wellbeing Unit, within the three years before the child's death.

**Co-sleeping** – a child or children sleeping with an adult on a shared surface such as a bed, sofa or mattress.

**Confidence interval** – a confidence interval is a quantitative estimate of the uncertainty of a statistic. It is used in this report primarily for the Crude Mortality Rate (see below). Although we know the number of children who died and lived in 2013, the numbers are not static, with children being born, dying and having birthdays throughout the year. This means that the Crude Mortality Rate is a measurement of a sample population, with all other intervals of one year being alternative sample populations (e.g., a year starting on 1 May, rather than 1 January). The confidence interval estimates the range within which 95% of all possible sample populations would occur.

**Crude Mortality Rate (CMR)** – the rate per 100,000 persons (for this report, persons are all those aged under 18 years). In this report, rates are not calculated for numbers less than four because of lack of reliability.

**Directly Standardised Mortality Rate (DSMR)** – the rate per 100,000 children under 18 years of age, adjusted for the age structure of the population. In this report, rates are not calculated for numbers less than four because of lack of reliability.

Incident Rate Ratio - the ratio of the mortality rates for two exclusive classes of people, such as male and female.

Infant - a child less than one year old.

Infant Mortality Rate – the rate of death per 1,000 live births. In this report, rates are not calculated for numbers less than four because of lack of reliability.

**International Classification of Diseases (ICD)** – the ICD is the international standard health classification published by the World Health Organisation (WHO) for coding diseases for statistical aggregation and reporting purposes.<sup>356</sup>

**International Classification of Diseases – Australian Modification** – the ICD-10-AM contains additional codes that are useful in the Australian setting, but is otherwise equivalent to the ICD-10.

**Natural body of water** – oceans, lakes, rivers, creeks, lagoons and other permanent or temporary bodies of water formed by natural processes.

Neonatal period - the period from birth to less than 28 days.

**Other bodies of water** – reservoirs, dams, artificial channels, drainage or sewerage works and any other permanent or temporary body of water not formed by natural processes.

Perinatal period - the period inclusive of late pregnancy, birth and the first 28 days of life.

Post neonatal period - the period from 28 days to less than 365 days.

**P-value** – a quantitative measurement of the likelihood that a statistic occurred by chance. A *p*-value of 0.05 means that there is only a 5% probability that the result obtained was due to a chance variation. A *p*-value of 0.05 is the conventional level for statistical significance. *P*-values are valid only when the distribution of the observation is the same as, or very close to, the theoretical distribution used to calculate the statistic. All *p*-values noted in this report are statistically significant.

**Remoteness** – a measure of distance from services. There are five levels of remoteness specified in this report: highly accessible (major cities), accessible (inner regional), moderately accessible (outer regional), remote and very remote.

Socioeconomic status - a measure of the relative material resources of an individual or group.

Young person – a person aged 16 or 17 years.

<sup>356</sup> World Health Organization, 2010, International Statistical Classification of Diseases and Related Health Problems, 10th Revision. Geneva: WHO.

# Appendix 3: Definitional approach to Sudden Infant Death

The following is sourced from: Krous Henry et al, 'Sudden Infant Death Syndrome and Unclassified Sudden Infant deaths: A definitional and diagnostic approach', *Pediatrics* 2004; 114-234.

# **General definition of SIDS**

SIDS is defined as the sudden unexpected death of an infant below one year of age, with onset of the fatal episode apparently occurring during sleep, which remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

# Category IA SIDS: Classic features of SIDS present and completely documented

Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements:

#### Clinical

- more than 21 days and less than nine months of age
- normal clinical history, including term pregnancy (gestational age of ≥37 weeks)
- normal growth and development, and
- no similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.

#### **Circumstances of death**

Investigation of the various scenes where incidents leading to death might have occurred, and determination that they do not provide an explanation for the death. Found in a safe sleeping environment, with no evidence of accidental death.

#### Autopsy

Absence of potentially fatal **pathologic** findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.

No evidence of unexplained trauma, abuse, neglect or unintentional injury.

No evidence of substantial thymic stress effect (thymic weight of <15g and/or moderate/severe cortical lymphocyte depletion). Occasional 'starry sky' macrophages or minor cortical depletion is acceptable.

Negative results of toxicologic, microbiologic, radiologic, vitreous chemistry and metabolic screening studies.

### Category IB SIDS: Classic features of SIDS present but incompletely documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and/or  $\geq 1$  of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies.

### **Category II SIDS**

Category II includes infant deaths that meet Category I criteria except for ≥1 of the following:

### Clinical

Age range outside that of Category 1A or 1B (that is, 0-21 days or 270 days [9 months] through first birthday).

Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders.

Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death.

## **Circumstances of death**

Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

## **Autopsy**

Abnormal growth and development not thought to have contributed to death.

Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.

## **Unclassified Sudden Infant Death**

The unclassified category includes deaths that do not meet the criteria for Category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.

### **Post-resuscitation cases**

Infants found in extremis who are resuscitated and later die ('temporarily interrupted SIDS') may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

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