NSW Child Death Review Team

Annual Report 2013

nsw cdrt child death review team

October 2014

Ombudsman
New South Wales

ABN 76 325 886 267
Level 24, 580 George Street, Sydney NSW 2000
T 02 9286 1000 | **F** 02 9283 2911
Tollfree 1800 451 524 | **TTY** 02 9264 8050
www.ombo.nsw.gov.au

NSW Child Death Review Team Annual Report 2013 Errata

Errata notice

Errors in the NSW Child Death Review Team's Annual Report 2013 have been identified.

Executive Summary

On page 6 of the Executive Summary, the number of deaths of young people from suicide that were registered in 2013 is reported as 18. The correct number is 19.

Based exclusively on coding, page 6 of the Executive Summary should indicate that the 20 deaths of children from intentional causes were due to suicide (19) and fatal assault (1).

Deaths from external causes

The Team's data analysis is based on the coding of deaths under the International Statistical Classification of Diseases and Related Health Problems (ICD) system. Based on coding, the deaths of 81 children registered in NSW in 2013 were due to external causes. This is reflected in the number of deaths from external causes reported on page 6 of the Executive Summary, and in Chapter 18: Deaths from all external causes. As coded, the 81 external cause deaths are comprised of:

- 30 deaths of children in transport fatalities
- 13 drowning deaths
- 18 deaths from other unintentional external causes
- 19 deaths from suicide, and
- 1 death from fatal assault.

However, our more detailed discussion of the external cause deaths in the subsequent sections and chapters includes slightly different numbers. This is because:

- Three deaths from other unintentional external causes (all 'threats to breathing') are also Sudden Unexpected Death in Infancy (SUDI), and are discussed in detail in Chapter 17. We have therefore not included them in the deaths reported in Chapter 21 on other unintentional external causes.
- We have included the deaths of two children that had not been coded at the time of writing the report. The two matters include one death due to fatal assault (page 98), and one death due to 'threats to breathing' as a result of choking on food (page 129). The two cases have been included in the discussion of those causes of death on the basis of the weight of evidence at hand, and to provide a more complete account of the deaths registered in 2013.

Deaths due to fatal assault

In Chapter 18, the Team notes that two children whose deaths were registered in 2013 died as a result of fatal assault (page 98). There should be a footnote explaining that the two deaths includes one child whose death had not been coded at the time of writing the report.

Other unintentional external causes

In Chapter 21, footnote 176 explains the exclusion of the three unintentional external cause SUDI from table 79 (page 123). There should be a further footnote explaining that table 79 includes the death of one child from 'threats to breathing' that had not been coded at the time of writing the report.

Multiple causes of death

Tables 17 and 18 outline the multiple causes of death in 2013 (pages 30-31) and in the 10-year period 2004-2013 (pages 32-33). Late changes to the coding of two deaths in 2013 were not reflected in these tables:

- One case originally coded as having an underlying cause of death of 'Diseases of the nervous system' was uncoded, and should be removed from the tables.

- One case was originally coded as having an underlying cause of death of 'Diseases of the ear and mastoid process', with a contributory cause of 'Diseases of the nervous system'. The change to coding resulted in diseases of the nervous system becoming the underlying cause of death, and ear and mastoid process diseases becoming the contributory cause.

This results in the following changes to Table 17:

Table 17: Underlying cause of death and contributory causes of death, 2013

Underlying cause of death 'Diseases of the ear and mastoid process'	0
Underlying cause of death 'Diseases of the nervous system' and contributory cause 'Diseases of the ear and mastoid process'	1
Underlying cause of death 'Diseases of the ear and mastoid process' and contributory cause 'Diseases of the nervous system'	0
Total underlying cause of death 'Diseases of the nervous system'	45
Total underlying cause of death 'Diseases of the ear and mastoid process'	0
Underlying cause of death 'Diseases of the nervous system' reported alone	5
Underlying cause of death 'Diseases of the nervous system' percent reported alone	14.7
Total no. of cases	527
Total contributory causes 'Diseases of the nervous system'	38
Total contributory causes 'Diseases of the ear and mastoid process'	1
Total reported alone	121

And the following changes to Table 18:

Table 18: Underlying cause of death and contributory causes of death, 2004-2013

Underlying cause of death 'Diseases of the nervous system' and contributory cause 'Diseases of the ear and mastoid process'	2
Underlying cause of death 'Diseases of the ear and mastoid process' and contributory cause 'Diseases of the nervous system'	0
Total underlying cause of death 'Diseases of the nervous system'	476
Total underlying cause of death 'Diseases of the ear and mastoid process'	1
Underlying cause of death 'Diseases of the nervous system' reported alone	59
Underlying cause of death 'Diseases of the nervous system' percent reported alone	19.2
Total contributory causes 'Diseases of the nervous system'	377
Total contributory causes 'Diseases of the ear and mastoid process'	5
Total reported alone	1,412

Yours sincerely

Bruce Barbour
Convenor, NSW Child Death Review Team
NSW Ombudsman

NSW Child Death Review Team

Annual Report 2013

October 2014

NSW Child Death Review Team
NSW Ombudsman
Level 24, 580 George Street
Sydney NSW 2000

General enquiries: (02) 9286 1000
Toll free (outside Sydney Metro Area, NSW only): 1800 451 524
Facsimile: (02) 9283 2911
Telephone typewriter: (02) 9264 8050

Website: www.ombo.nsw.gov.au

Email: nswombo@ombo.nsw.gov.au

ISSN 1329-640X

ISBN 9978-1-925061-42-0

NSW Government Publication

Foreword

This report is about the 567 children whose deaths were registered in NSW in 2013. The death of any child is a significant loss, and I extend my sincere condolences to their family and friends on behalf of the Child Death Review Team.

The mortality rate of 31.70 deaths per 100,000 children represents the second lowest rate of death in the history of the Team. This report notes the progress that has been made towards reducing the deaths of children from unnatural (external) causes – particularly transport fatalities, including pedestrian and passenger fatalities; and the deaths of children due to drowning and fatal assault.

Reductions in any causes of the deaths of children are positive and, at least in part, reflect the concerted efforts over many years of individuals and agencies to improve safeguards for children and communicate critical prevention messages to children, their carers and the broader community.

However, the increase in the number of deaths of young people due to suicide, and the persistently high rate of sudden and unexpected deaths of infants underscore the need for continued attention and a multifaceted approach to reduce the likelihood of child deaths.

While this report includes 16 recommendations for NSW government and non-government agencies, it also highlights key causes of the deaths of children for which prevention is highly reliant on the awareness and actions of parents and carers. These causes include deaths due to asthma, house fires, choking, drowning, and unsafe sleep environments. In this context, the Team is working to strengthen the communication and reinforcement of our information with families and other carers.

Bruce Barbour

Convenor, Child Death Review Team
NSW Ombudsman

NSW Child Death Review Team

Team members in 2013 - 2014 were:

Statutory members

Mr Bruce Barbour
Convenor
NSW Ombudsman

Ms Kerryn Boland
A/Commissioner for Children and Young People
Children's Guardian

Mr Steve Kinmond
Community and Disability Services Commissioner
Deputy Ombudsman

Agency representatives

Ms Robyn Bale
R/Director, Aboriginal Education and
Community Engagement
Department of Education and Communities

Detective Superintendent Michael Willing
Commander Homicide
NSW Police Force

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

Mr Marcel Savary
Courts Policy Manager
Department of Attorney General and Justice

Mr Maurice Taylor (until December 2013)
Coordinator, Coronial Information and Support Unit
State Coroner's Office

Ms Jane Gladman (from December 2013)
Coordinator of the Coronial Information and Support Program
State Coroner's Office

Professor Les White
NSW Chief Paediatrician
Ministry of Health

Aboriginal representatives

Professor Ngiare Brown
Executive Manager, Research,
National Aboriginal Community Controlled
Health Organisation

Professor Megan Davis
Director, Aboriginal and Torres Strait Islander Law Centre
University of NSW

Independent members

Dr Susan Adams
Director, Division of Surgery and Senior Staff Specialist
Paediatric General Surgeon, Sydney Children's Hospital

Dr Luciano Dalla-Pozza
Head of Department and Senior Staff Specialist (Oncology)
Children's Hospital at Westmead

Dr Jonathan Gillis
Deputy Convenor
NSW Organ and Tissue Donation Service

Dr Bronwyn Gould
General Practitioner

Dr John Howard (until end June 2014)
Senior Lecturer, National Drug and Alcohol Research Centre
University of NSW

Professor Heather Jeffery
International Maternal and Child Health
University of Sydney/ Royal Prince Alfred Hospital

Professor Ilan Katz
Director, Social Policy Research Centre, University of NSW

Dr Helen Somerville
Visiting Medical Officer, Department of Gastroenterology
Children's Hospital at Westmead

Dr Ella Sugo
Paediatric Pathologist
Sydney Children's Hospital

Acknowledgements

The Child Death Review Team extends its appreciation to the NSW state government and other agencies that provided data and other information for this report, including the NSW Registry of Births, Deaths and Marriages; the State Coroner's Office; the Victorian Institute of Forensic Medicine and Victorian Department of Justice (National Coronial Information System); the Department of Family and Community Services; NSW Health; and the NSW Police Force. The Team also appreciates the contribution of information from agencies and child death review committees in other states and territories.

The Team would like to acknowledge Fadwa Al-Yaman and Bernice Cropper from the Australian Institute of Health and Welfare for their provision of expert advice relating to identification and reporting of Aboriginal and Torres Strait Islander status.

Many thanks to Dr Jonathan Gillis, Dr Bronwyn Gould, Dr Dominic Fitzgerald, Dr Michael Fairley, Dr Julie Brown, and Dr Cheryl McIntyre for their review of matters and provision of expert advice.

Finally, the Team would like to thank Maurice Taylor and Dr John Howard for their contribution to the work of the Team over many years, and their invaluable expert advice.

Contents

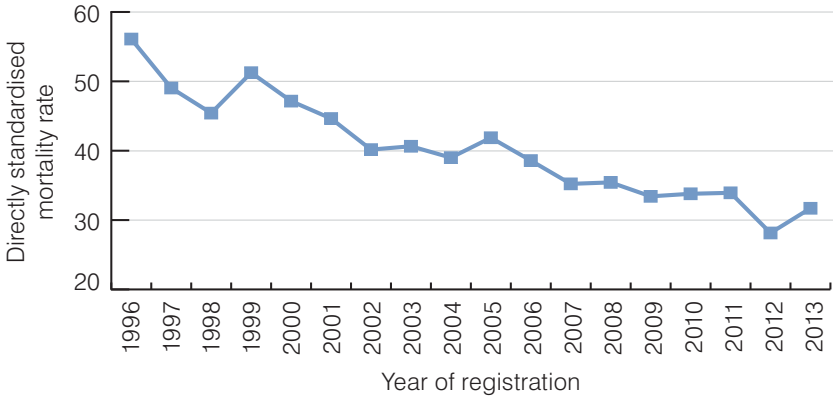
Executive summary

The purpose of the NSW Child Death Review Team is to prevent or reduce the likelihood of child deaths. The Team reports annually on its work, including data, trends and patterns relating to child deaths, and its recommendations to reduce such deaths. This is the Team's 18th annual report, and the fourth since the NSW Ombudsman became Convenor.

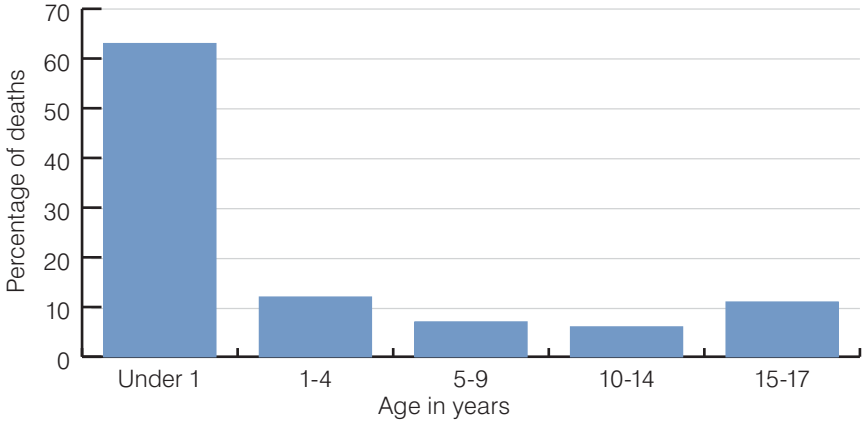
In 2013, the deaths of 567 children were registered in NSW

The directly standardised mortality rate shows the number of children who died out of every 100,000 children living in NSW.

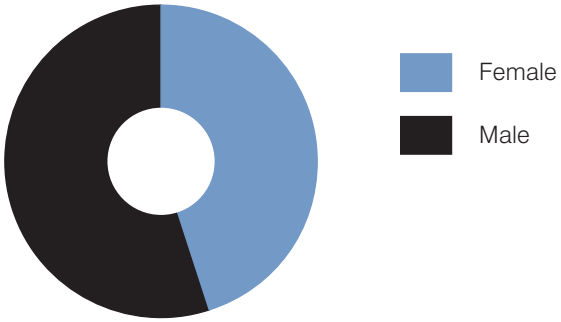
In 2013, the mortality rate was 31.70 per 100,000 children. **This is the second lowest rate of death of children in NSW since the Team began in 1996.**



Most (63%) of the children who died were infants under one year of age.



More males (55%) than females (45%) died.



Consistent with previous years, Aboriginal and Torres Strait Islander children were over-represented in child deaths. Eighty children (14%) were identified as Aboriginal and/or Torres Strait Islander. **The rate of death of Aboriginal children was nearly three times the rate of non-Aboriginal children.**

While most (69%) of the children who died lived in major cities, the mortality rate was highest in very remote areas of NSW. The mortality rate was also highest among children who lived in the most socioeconomically disadvantaged areas.

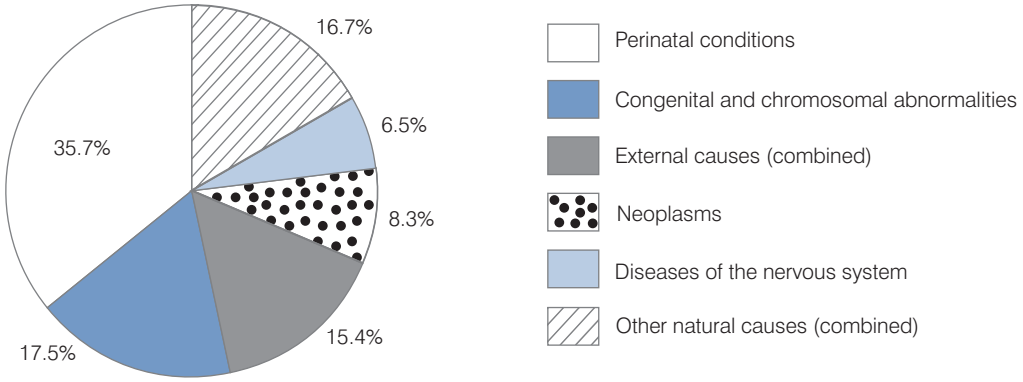
The families of 112 children (20%) had a child protection history.

Leading causes of death in 2013

As the final cause of death of 40 children was unavailable at the time of writing, information and analysis relating to causes of death in the report focuses on 527 children.

Overall, the leading causes of death for children in NSW in 2013 were consistent with previous years. The majority (85%) of deaths were due to natural causes.

Perinatal conditions (36%) and congenital and chromosomal conditions (17%) were responsible for around half of the deaths of children in 2013. External (unnatural) causes were the third leading cause of death (15%).

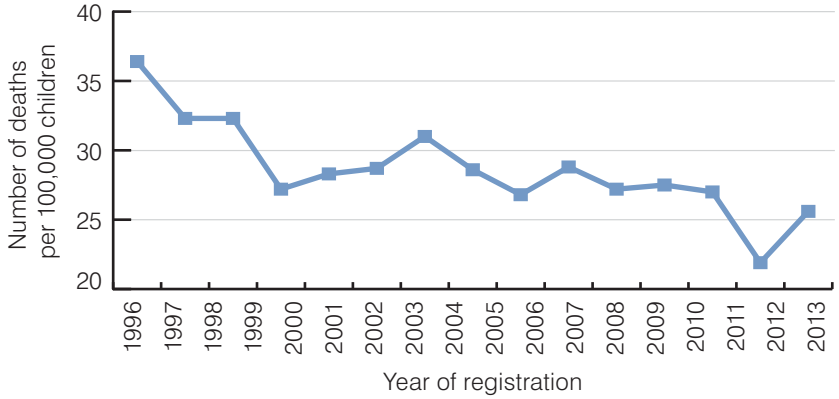


While the leading cause of death of infants was perinatal conditions, the leading cause for children over one year of age was neoplasms (cancers and tumours) (21%), followed by transport fatalities (15%).

For most cause of death categories, more males than females died. Neoplasms were an exception to this pattern – in 2013, over twice as many females died from neoplasms than males.

Natural causes of death (428 deaths)

While both the number and rate of deaths from natural causes increased in comparison to 2012, over the past 15 years there has been a decline in the rate of these deaths. The number of natural cause deaths of children in 2013 was 26% lower than in 1999.



Natural causes accounted for most of the deaths of infants aged less than one year (84%), and children aged 1-4 years (69%), 5-9 years (60%), and 10-14 years (78%). The lowest proportion of deaths from natural causes was amongst children aged 15-17 years (43%).

Conditions arising in the perinatal period

Number of children: 188

Mortality rate: 1.9 per 1,000 live births

Leading causes: complications of pregnancy, labour and delivery; and disorders related to length of gestation and foetal growth, such as prematurity.

Most perinatal deaths occur in the first day of life; over half of these children were less than one day old when they died.

Congenital malformations and chromosomal abnormalities

Number of children: 92 (congenital – 71; chromosomal – 21)

Mortality rate: 5.5 per 100,000 children

Leading causes: congenital malformations of the circulatory system; and chromosomal abnormalities, not elsewhere classified.

The vast majority (75%) of these children were less than one year old; over half of these children died in the first day of life.

Neoplasms

Number of children: 44

Mortality rate: 2.6 per 100,000 children

Leading causes: Malignant brain tumours; and cancers of lymphoid and haematopoietic tissue (affecting blood and bone marrow), mainly leukaemias.

Neoplasms were the leading natural cause of death of children one year of age and older in 2013. The mortality rate was higher than 2012, but consistent with the average mortality rate from this cause over the past 15 years (2.8 per 100,000 children).

Diseases of the nervous system

Number of children: 34

Mortality rate: 2.0 per 100,000 children

Leading causes: congenital myopathies; cerebral palsy; degenerative diseases of the nervous system; and epilepsy.

While the mortality rate in 2013 was the highest since 2006, it was consistent with the NSW average over the past 15 years.

Diseases of the respiratory system

Number of children: 18

Mortality rate: 1.1 per 100,000 children

Leading causes: pneumonia; asthma; acute lower respiratory infections; and influenza.

The mortality rate from respiratory diseases in 2013 was the highest since 2008.

Endocrine, nutritional or metabolic diseases

Number of children: 17

Mortality rate: 1.0 per 100,000 children

Leading causes: Sandhoff disease; I-cell disease; and cystic fibrosis.

The vast majority (16) of the deaths were due to metabolic disorders. There were no deaths due to diabetes or nutritional diseases.

Diseases of the circulatory system

Number of children: 10

Mortality rate: 0.6 per 100,000 children

Leading causes: cardiomyopathy; and cerebrovascular diseases.

The deaths of two of the 10 children who died from circulatory diseases in 2013 were considered to be sudden cardiac deaths.

Infectious or parasitic diseases

Number of children: 9

Mortality rate: 0.54 per 100,000 children.

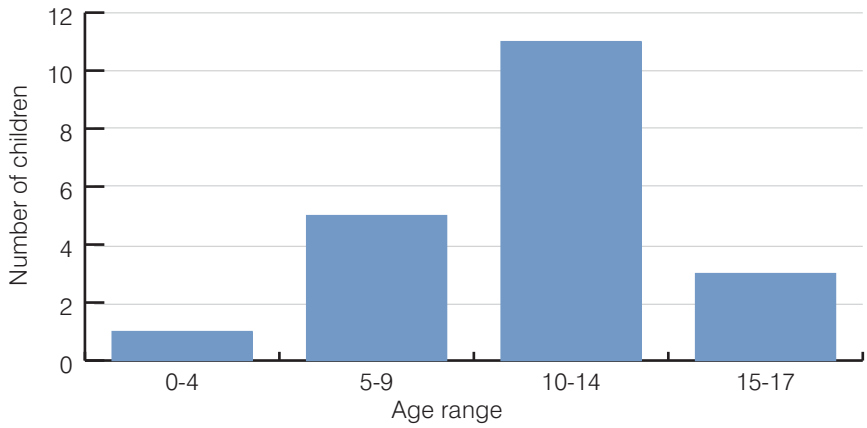
Leading causes: enterovirus infection; and sepsis.

The rate of death from infectious diseases in 2013 was slightly lower than the 15-year average (0.7 per 100,000 children). There were no deaths from parasitic diseases in 2013.

Deaths from asthma 2004 – 2013 (20 deaths)

This year, the Team undertook a 10-year review of the deaths of children due to asthma. Between 2004 and 2013, 20 children in NSW died from asthma. There were more deaths in 2010, 2012 and 2013 than in previous years; half of the deaths in the 10-year period occurred in the last two years.

Over two-thirds (14) of the 20 children who died from asthma were male. The rate of death of boys from asthma was more than twice the rate of girls for the same period.



While the children ranged in age from four to 17 years, more than half (11) were 10-14 years old.

Psychosocial issues were identified for the families of over half (11) of the children who died from asthma. More than one-third (8) had a child protection history.

All of the children were known to have had asthma before their death; most (16) had persistent asthma (symptoms on most days). The majority (18) of the children who died from asthma were allergic or atopic and/or had other triggers for asthma.

Risk factors and prevention

The majority (17) of the 20 children who died from asthma in 2004-2013 had factors that may have increased their risk of death, including:

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

The majority (15) of the children had more than one risk factor. Sub-optimal asthma control was identified in relation to 10 children who had one or more hospital presentations/admissions for asthma in the year before their death and who also had inadequate compliance with their asthma medication.

Insufficient follow-up after a hospital presentation/admission was a factor for eight children who did not visit a doctor or outpatient clinic for review. In several cases, this was despite the hospital offering asthma education and advising the family GP that the child had presented, and, in three cases, either the hospital or GP contacting the family to encourage a follow-up review. For four children, it was unclear who in the family was overseeing the child's asthma management.

For two-thirds of the children, we found that there was scope to improve their asthma care, through more regular/enhanced GP involvement, or through referral to a paediatrician or respiratory paediatrician.

In relation to the fatal asthma attack, in six cases there were indicators that the child or the child's family may not have recognised early signs that asthma symptoms were slowly worsening, or may not have fully appreciated the severity of the child's condition.

Sudden Unexpected Death in Infancy (SUDI) (55 deaths)

Of the 356 infants whose deaths were registered in 2013, 15% were Sudden Unexpected Death in Infancy (SUDI). SUDI is not a cause of death, but a classification to enable the consideration of the deaths of otherwise healthy babies who die suddenly and unexpectedly. It includes Sudden Infant Death Syndrome (SIDS).

Of the 55 SUDI:

- Over half (30) of the infants died in the first three months of life. Eleven infants were less than 28 days old (neonates).
- Most (33) of the infants were male.
- Fifteen infants were Aboriginal. Consistent with previous years, Aboriginal infants were overrepresented in SUDI, comprising 27% of these deaths in 2013.
- One-third (18) of the infants had a parent(s) who was born overseas.
- Young mothers were overrepresented. Five of the mothers were teenagers and 37 (67%) were aged under 30 at the time of death. This is a higher proportion than expected given the age distribution of mothers in the general population of NSW.
- Infants from families with a child protection history were overrepresented in SUDI. Of the 55 families, 23 (42%) had a child protection history. The majority (19) of the 23 infants were in unsafe sleep environments when they died; and the vast majority (21) were exposed to tobacco smoke.

Cause of death

At the time of writing, information on cause of death was available for 26 of the 55 infants:

- The cause of death of nine infants was identified after investigation. The majority (6) of explained SUDI were due to diseases and conditions that were not recognised as life-threatening prior to death, including cardiac conditions and respiratory infections.
- The cause of death of 17 infants remained unexplained after investigation. The cause of death of these infants has generally been classified as ill-defined or unspecified; undetermined in the context of co-sleeping; or consistent with SIDS.

Modifiable risk factors

Modifiable risk factors for SUDI include exposure to tobacco smoke; infants sharing a sleep surface with another person; not placing infants on their back to sleep; infants placed to sleep with loose bedding or other items; infants placed to sleep in bedding that is not infant-specific; and over-heating.

In 2013, the vast majority (51) of the 53 infants in a sleep environment had at least one modifiable risk factor present, and over half (31) had three or more risk factors present. Only five infants who died in a sleep environment had been placed to sleep alone in fixed infant-specific bedding. Of these five, one infant was later found to have died from natural causes.

Prevention messages

Key prevention messages to reduce the risk of SUDI are: to sleep babies on their back in a safe sleeping environment, on their own, with their head and face uncovered, without loose bedding or objects, and in the same room as an adult caregiver; to keep babies smoke free before and after birth; and to breastfeed.

The Team's recommendations have been aimed at:

- improving the response to SUDI, including a comprehensive and multidisciplinary approach to the investigation process
- ensuring that safe sleeping practices are consistently promoted across health services, and
- facilitating improved assessment of risk to infants in families with a child protection history and targeted education to at-risk families.

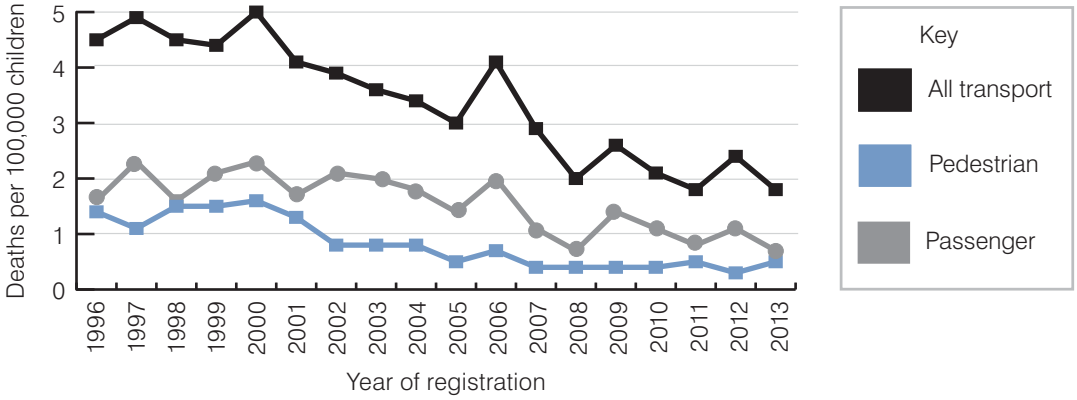
We are continuing to monitor the work of key agencies, including NSW Kids and Families, the Ministry of Health, and the Department of Family and Community Services in relation to these important areas.

External causes of death (81 deaths)

The majority (61) of the external cause deaths of children in 2013 were due to unintentional or accidental causes, mainly related to transport fatalities (30) and drowning (13). The deaths of 20 children were intentional, due to suicide (18)[e] or fatal assault (2).[e]

Transport (30 deaths in 29 incidents)

Consistent with previous years, transport fatalities were the leading external cause of death of children in NSW. The rate of death in 2013 (1.8 per 100,000 children), was the lowest rate for the past 15 years (equal to 2011), and much lower than the average rate over that time (3.1 deaths per 100,000 children).



This was primarily due to a drop in pedestrian fatalities and passenger fatalities:

- the rate of death of child pedestrian fatalities has dropped by two-thirds, and
- the rate of death of child passenger fatalities has halved.

There was also a slight decline in the rate of death of children as drivers of vehicles.

Of the 30 children who died in 2013:

- the majority (70%) were male
- half (15) were aged 15-17 years, and
- Aboriginal children were highly overrepresented, and had a mortality rate more than five times the rate of non-Aboriginal children.

There were 21 motor vehicle fatalities:

- Twelve passengers – nine on public roads; three off-road.
- Nine drivers – all were on public roads and all were single vehicle collisions with stationary objects, including trees.

Contributing factors included drug use by drivers; driver inexperience; no or incorrect use of restraints; and speed.

There were three off-road fatalities:

- all of the children were male and were passengers
- the vehicles were a quad bike, mini-bike and sedan, and
- two of the vehicles rolled over – on a steep incline (quad bike) or while taking a corner at speed (sedan).

Contributing factors: lack of appropriate protective equipment (helmets, seatbelt); having passengers on a quad bike; and excessive speed.

In 2012, the Team reported on its review of 25 child fatalities involving off-road vehicles over a 10-year period. Consistent with that review, the deaths in 2013 highlighted:

- the substantial risks associated with the use of off-road vehicles involving children, including the inherent instability of quad bikes on anything other than flat terrain, and the dangers associated with the inclusion of passengers, and
- the need for greater public awareness of the dangers associated with off-road vehicles involving children.

[e] see errata in the front of this document

There were 9 pedestrian deaths:

- eight children were on foot, and one child was riding a bicycle
- the children were aged 3-17 years
- the majority (7) were male, and
- five children were struck by vehicles travelling above 10km/h, mainly on public roadways. Four children died in low speed vehicle run-over fatalities, mainly on driveways.

Contributing factors: limited visibility; negligent driving; inadequate supervision; and children entering the roadway mistakenly, quickly or while drug-impaired.

Prevention measures

Key factors in the deaths of children in transport fatalities in 2013 included driving under the influence of drugs and/or alcohol, fatigue, distraction, and speeding; driver inexperience; failure to use appropriate safety restraints or other protective equipment; young children entering the road environment without a carer supervising or holding their hand; and young children accessing driveway areas without the knowledge of their carers.

Many of these factors have been identified in targeted prevention measures and behaviour modification strategies by NSW Government agencies and injury prevention organisations, including Transport for NSW campaigns specifically targeting driver factors, use of restraints and the safe drivers course to improve skills of inexperienced drivers.

The Team is continuing to monitor key preventative and community awareness work by the Centre for Road Safety in relation to low-speed vehicle runovers; and the actions of the Department of Premier and Cabinet to address the Team's recommendations to reduce the risk of death and serious injury of children associated with off-road vehicle incidents.

Drowning (13 deaths)

In 2013, drowning was the second most common unnatural unintentional cause of death of children in NSW, and the leading external cause of death for children under five years. The drowning mortality rate of 0.8 deaths per 100,000 children was slightly higher than 2012, but lower than the 15-year average (1.1 deaths per 100,000 children).

Of the 13 children:

- over two-thirds (9) were under five years of age
- the majority (10) were male – the drowning mortality rate of males was three times the rate of females
- three were Aboriginal, and three children were of a culturally and linguistically diverse background, and
- the children drowned in private swimming pools (7); bath tubs (2); a public swimming pool; a beach; a bucket; and floodwater.

Deaths in private swimming pools

The deaths in private swimming pools in 2013 mainly comprised very young children who drowned after falling into the pool. The key factors that contributed to the children drowning in the private swimming pools were inadequate barriers to prevent them accessing the pools, and inadequate carer supervision.

Each of the six pools where young children drowned in 2013 had problems with the child safety barriers:

- one pool was unfenced
- of the five pools that were fenced, two had barrier fence defects, and two had objects that children could climb to access the pool, and
- all of the five pools that were fenced had problems with the gate or latch mechanism that meant they did not self-close.

In five of the six deaths, the children accessed the pool via an open gate – either accidentally left open (4) or intentionally propped open. The other child accessed the pool through gaps in the pool barrier fence.

Shallow Water Blackout

Since 1996, the deaths of three young people have been identified as resulting from shallow water blackout – two of which occurred in 2013.

Both were male, strong swimmers, and had a history of challenging themselves to hold their breath under water for extended periods. Shallow water blackout is a consequence of breath-holding underwater.

In both cases, a supervising adult was present and was unaware the young person was experiencing a problem. During Shallow Water Blackout, people drown quietly underwater without any sign they are experiencing difficulty.

Prevention measures

Royal Life Saving Australia provides information to the public about Shallow Water Blackout, and the risks associated with breath-holding underwater.

In relation to swimming pools, the deaths of young children in private swimming pools in 2013 reinforce the key findings from the Team's review of swimming pool drowning deaths in 2007-2011. Key messages to parents should reinforce that:

- where children have access to swimming pools, adult supervision must be constant and active
- if safety barriers are not effectively child-resistant, even momentary lapses in supervision or diverted attention can result in a drowning death
- clearly designated responsibility for supervising children around pools is essential, and
- 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 latch mechanisms.

The Team continues to monitor the implementation and impact of the changes to the *Swimming Pools Act 1992* introduced by the NSW Government to increase safety around backyard swimming pools and reduce drowning and near-drowning incidents.

Deaths from other unintentional external causes (16 deaths)

Sixteen children died as a result of other unintentional external causes in 2013:

- seven died from threats to their breathing – including three children who died as a result of accidental hanging or strangulation; three children who choked on food or other objects; and one child whose tracheostomy tube was accidentally removed
- three children died in house fires
- the deaths of two young people were drug-related – one died from a suspected overdose, and the other young person died after jumping from a building while under the influence of a synthetic drug, and
- four children and young people died from a range of causes, including as a result of a brain haemorrhage while playing rugby league; being mauled by a dog; being thrown off a horse; and accidentally pulling an object onto their head.

Deaths of children in house fires

Between 2004 and 2013, 35 children died in 27 house fires in NSW over the 10-year period 2004-2013. Three children died in house fires in 2013; the highest number since 2010.

Over half (14) of the 27 fires occurred in regional NSW, mainly inner regional (8) areas. Most (19) of the fires occurred in areas of greatest socioeconomic disadvantage.

Most of the 35 children were male (22), and younger than five years of age (20). Over one-quarter (10) were Aboriginal.

Of the 27 house fires, two-thirds (18) involved families with a child protection history.

The Team's review of the deaths of children in house fires over the 10-year period has highlighted the risks associated with:

- children having access to, and playing with, matches and lighters
- heaters and candles being placed too close to flammable materials and/or being left unattended while in use
- young children being unsupervised or left in the supervision of young teenagers
- smoke alarms not being installed or being disconnected, and
- household members not having adequate means of escaping the premises.

Prevention measures

Fire & Rescue NSW provides information and resources, and delivers education and awareness programs, aimed at reducing fire risks, including those associated with children. One of the programs, the Intervention and Fire Awareness Program, has been designed to help families with children who play with fire, aimed at stopping the behaviour.

While there is a mandatory standard for disposable cigarette lighters relating to child resistance, it is important to note that 'child resistant' lighters are not 'child proof'. It is critical that carers are vigilant and take active steps to ensure that fire-starting materials such as matches and lighters are kept out of reach of children.

In light of the findings of the review, the Team has directed recommendations to the Department of Family and Community Services and Fire & Rescue NSW, aimed at reducing the fire risks of children with a child protection history.

Suicide (19 deaths)

Suicide was the leading external cause of death of young people aged 10-14 years, and the equal leading cause of death of young people aged 15-17 years.

The age of the young people ranged from 13 to 17 years. Most (16) were aged 15 years and older. While just over half (10) were male, the number of females who died from suicide in 2013 was the highest since 1999.

Intent and precipitating factors

Just over half (10) documented their intent to suicide, by a note or letter, text message, online chat forum or a phone call.

Very few of the young people told others of their intent ahead of the event – only three had contacted someone and clearly indicated their intent, either to Lifeline or 000.

Just under half (9) experienced a precipitating event in the month prior to their suicide – including a relationship breakdown with a boy/girlfriend; an argument or relationship breakdown with a parent/s; alleged sexual abuse; distress about school or work; and anxiety related to body image.

Risk factors

There are a range of interrelated risk factors associated with suicidal behaviour. These include: mental health conditions such as depression; previous suicidal behaviour; substance misuse; childhood trauma; interpersonal or personal stressors; and issues related to sexual identity.

For the 19 suicide deaths in 2013:

- The vast majority (18) experienced at least one risk factor associated with suicide. Most (16) experienced multiple risk factors.
- The most common interpersonal or personal stressors were associated with education or school (14) – most of these young people had experienced multiple stressors, including academic failure, bullying, behavioural problems, and peer conflict.
- The majority (13) had experienced mental health issues, either a diagnosed mental illness or undiagnosed mental health problems.
- Ten young people exhibited prior suicidal or self-harming behaviours, or prior suicidal thoughts and/or discussions.

Opportunities for intervention and prevention measures

In considering the circumstances of the young people who died as a result of suicide in 2013, we identified three key groups:

1. young people who had ongoing serious difficulties and complex needs and who had multiple agency and practitioner involvement in relation to addressing these risks (7)
2. young people who had some difficulties/ challenges but who had not necessarily been identified as being at risk (7), and
3. young people who had few risk factors and for whom there were no evident flags that they required assistance (5).

The three groups present very different challenges and opportunities in relation to suicide prevention, and highlight the diversity of young people that suicide. The Team's reviews of the suicide deaths of young people have emphasised:

- the importance of providing multiple avenues and opportunities for young people to obtain help
- opportunities for collaborative and coordinated support

- the importance of school counsellors and other school staff
- the key role of general practitioners
- the need for close monitoring of, and support for, young people prescribed antidepressant medication, and
- the need to support families.

There is a substantial amount of existing and developing work in NSW and across Australia that is aimed at improving the mental health and wellbeing of children and young people and preventing youth suicide. These include activities aimed at facilitating discussions about suicide and other concerns; providing online resources and support for young people; and providing support at school.

The Team has noted that there are multiple services and programs involved in youth mental health and suicide prevention in NSW and nationally, with some overlap and duplication, and it is not clear whether, and how, the activities are being coordinated. Over the next year, the Team will take into account the findings and plans of the NSW and National Mental Health Commissions and the Australian Human Rights Commission and their implications for preventing or reducing youth suicide, and consider whether further recommendations may be required.

Recommendations

Deaths from asthma

Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, and Christian Education National

1. Against the background of the issues raised in this report relating to children with asthma, the Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, 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:

   - identify children with severe asthma who need a health care or other support plan, and
   - ensure that health care or other support plans for children with severe asthma are developed, implemented and regularly reviewed

   (b) how compliance with the policies/ guidance is monitored, and

   (c) any other actions the Department, Authorities, AIS, CSA and CEN intend to take in relation to identifying and supporting students with asthma.

Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, Christian Education National, and the Ministry of Health

2. Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, Christian Education National, and the Ministry of Health 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.

Ministry of Health

3. The Ministry of Health should consider the findings of the Team's review in relation to post-hospitalisation follow-up of children with asthma, and provide 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

NSW Kids and Families

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.

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 *Sudden Infant Death Syndrome (SIDS) and safe sleeping for infants* guidelines and provide guidelines to community-based staff.

NSW Health Pathology

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.

Department of Family and Community Services

7. In relation to the Department of Family and Community Services' 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.

Off-road fatalities

Transport for NSW, the Centre for Road Safety

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.

Department of Premier and Cabinet

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.

Deaths of children in private swimming pools

Office of Local Government

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.

11. OLG should provide advice to the Team on how it will publicly report on swimming pool inspection and compliance activity across NSW.

Department of Family and Community Services, Office of the Children's Guardian and Office of Local Government

12. The Department of Family and Community Services (FACS), Office of the Children's Guardian (OCG) and the Office of Local Government (OLG) should develop arrangements to facilitate:

(a) the identification by FACS, the 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.

Department of Family and Community Services

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.

Office of the Children's Guardian

14. The Office of the Children's Guardian 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.

Association of Children's Welfare Agencies

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.

Deaths of children in house fires

Department of Family and Community Services and Fire & Rescue NSW

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 the Department of Family and Community Services (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 the Department, 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.

Chapter 1. Introduction

Since 1996, the NSW Child Death Review Team ('the Team') has been responsible for reviewing and reporting on all deaths of children[1] in NSW.

This is the Team's 18th report, providing information on 567 children and young people whose deaths were registered in NSW in 2013.

The purpose of the Team

The Team is established under Part 5A of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA), for the purpose of preventing and reducing the likelihood of child deaths in NSW.

The legislation requires the Team to comprise the NSW Ombudsman (Convenor); the Commissioner 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 on page ii.

The functions of the Team are to:

- maintain a register of child deaths 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 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 monitors and reports on the progress that has been made by agencies and others in addressing its recommendations, and the outcomes from the work. Chapter 23 details agencies' progress towards meeting the Team's previous recommendations. The Team's new recommendations are outlined on page 11.

Work of the Team

Over the past year, the Team has met four times. Smaller sub-committees of the Team, including the SUDI and Child Protection sub-committees, have met on other occasions.

In 2013, the Team developed a high-level strategic plan for its work over the next three years. In line with the priorities identified in the plan, the work of the Team over the past year has focused on developing an integrated deaths register; implementing measures to support best practice in identifying and reporting Aboriginal and Torres Strait Islander status; and undertaking a cohort review of deaths of children from asthma over 10 years.

Improving the child death register

The Team's previous reports have outlined the considerable challenges it has faced in relation to the child death register, and the pressing need for a new data system to improve its ability to reliably and consistently extract and analyse information.

A major area of focus over the past year has been the development of an integrated, reliable and sustainable death register that provides for efficient extraction of meaningful data for prevention purposes. The new data system, built by Resolve on a SQL server platform, brings together the data and other information from reviews of the deaths of children in NSW, and the deaths of certain children and people with disability in care that are reviewable by the Ombudsman's office. Following extensive development and user testing, the integrated death register commenced operation in August 2014.

1 For the purposes of the Child Death Review Team, a child is a person under the age of 18 years.

Identifying and reporting the Aboriginal and Torres Strait Islander status of children

Collection of reliable data relating to Aboriginal and Torres Strait Islander identity has been an ongoing concern for the Team. To improve the accuracy of data and the capacity to report on trends, the Team contracted the Australian Institute of Health and Welfare (AIHW) to provide expert advice on how to best collect and report on the Aboriginal and Torres Strait Islander status of children who die in NSW.

The AIHW's advice included that the Team should:

- continue to use its current 'ever-Aboriginal and Torres Strait Islander' method to derive Aboriginal and Torres Strait Islander status, but undertake sensitivity analysis to determine whether the 'ever-Aboriginal and Torres Strait Islander' method or a frequency-based method will provide more meaningful results
- periodically review the quality of Aboriginal and Torres Strait Islander identification in the data sets it uses, and monitor the proportion of children who are identified in more than one data set, in order to decide whether switching to a frequency-based method would be more appropriate[2]
- report the numbers of children identified using at least two data sets and those using only one data set
- ensure that a data quality statement accompanies any data on Aboriginal and Torres Strait Islander child deaths, indicating the quality of Aboriginal and Torres Strait Islander identification from the source data set, and
- report trends from 2005 onwards on children identified in NSW Registry of Births, Deaths and Marriages (BDM) data.[3]

In light of the recommendations of the AIHW, we have modified our processes to, among other things, capture information about the child's Aboriginal and Torres Strait Islander status from all of the available sources; and apply business rules to assign Aboriginal and Torres Strait Islander status. We will also conduct sensitivity analyses to, over time, ascertain the most appropriate identification method. Importantly, and consistent with the recommendations, this year the Team is reporting trends in relation to Aboriginal and Torres Strait Islander children from 2005 onwards.

Reporting on the causes of death of children with a child protection history

As part of its work, the Team may at any time – and at least every three years – report to Parliament on the results of research undertaken in the exercise of its functions.[4]

In April 2014, the Team tabled a special report to Parliament on the findings from its research into the causes of death of children with a child protection history over the 10-year period 2002-2011. Amongst other things, the research identified that children with a child protection history:

- have a higher rate of death (1.4 times the rate) than children without a child protection history, and
- have a much higher rate of death from certain causes, including sudden unexpected death in infancy (9.8 times the mortality rate of children without a child protection history), and unnatural causes, such as fire (23.8 times the rate) and assault (6.3 times the rate).

The research found that child protection history conveys an additional risk beyond factors such as age, gender, Indigenous status, remoteness and area socioeconomic status. Controlling for these variables, child protection history significantly increases the odds of death from fire, assault, suicide, SUDI, accidental poisoning, SIDS and cerebral palsy.

In the report, the Team noted that the analysis underscores the importance of shared agency and broader community responsibility in reducing the deaths of children with and without a child protection history. The information also points to potential opportunities for joint work in the targeting of prevention strategies, such as those focused on:

- families with a child protection history in the context of particular causes of death, and the death of children of certain ages – such as young children and external causes such as fire, assault and drowning, and

2 The AIHW has indicated that this should occur when analysis concludes that the current identification process is approaching completeness or overestimating identification.

3 The AIHW advised that it considers the reporting of trends from 2005 onwards using BDM data is appropriate as at this time birth registration data was used to supplement death registration data by the Team, and the quality of these two data sets is sufficient to allow for trend analysis.

4 Section 34H of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*.

- Aboriginal and Torres Strait Islander families in relation to key causes of death, particularly where Aboriginality carries an additional risk (for example, SUDI).

The Team's annual report includes key points from the research in relevant chapters. Following on from findings in the research, this report also includes an examination of all fire-related deaths of children in the 10-year period 2004-2013, including a comparison of the deaths of children with and without a child protection history and the identification of factors relevant to prevention.

Disclosure of information authorised by the Convenor

CS CRAMA contains strict confidentiality conditions that prevent the disclosure of CDRT information except in specific circumstances. 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 six occasions. Four requests were received from child death review teams in other Australian jurisdictions for de-identified data; one request was from a government agency in relation to the number of deaths involving motorised bicycles; and one was from another child death review body in NSW relating to cause of death coding and Aboriginal and Torres Strait Islander status.

Future work

Priorities for the Team over the next year include exploring ways to enhance its work and effectiveness, including:

- strengthening links and opportunities for collaboration with injury prevention and child safety organisations to communicate key prevention messages
- increasing the Team's access to, and analysis of, relevant injury/morbidity data (such as near-drowning events), and
- exploring data linkage opportunities to facilitate research by the Team and others that is relevant to prevention of child deaths.

To achieve better consistency between the child death review functions and afford increased opportunity to achieve its chief purpose of preventing or reducing the likelihood of child deaths, the Team decided in its March 2014 meeting to seek legislative amendments. In the main, the Team has sought changes 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.

In addition to facilitating greater integration between the child death review functions, the Team has sought the legislative changes to:

- enhance the Team's capacity to undertake key prevention activities
- support greater flexibility for the Team to explore alternative and targeted methods for communicating critical injury and fatality prevention messages, and
- provide to agencies a reasonable period of time in which to implement the Team's recommendations and demonstrate results.

This report

Methodology

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.

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

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

Cause of death

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.'[5] 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.

In the main, the report focuses on underlying cause of death (UCOD), which is the disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury.

Identifying and reporting Aboriginal and Torres Strait Islander status

Individual children are identified as Aboriginal and/or Torres Strait Islander in this report if:

- The child has been identified as Aboriginal and/or Torres Strait Islander on their NSW Births, Deaths and Marriages (BDM) death certificate.
- The child or their parent/s have been identified as Aboriginal and/or Torres Strait Islander on their BDM birth certificate.
- Agency records identify the child as Aboriginal and/or Torres Strait Islander through a number of corroboratory records. Relevant records include the NSW Police Force's Computer Operated Policing System and Community Services' KiDS database, which often hold information that can support Aboriginal and Torres Strait Islander identity. NSW Health and other agency records were also used to assess child and family background.

As noted earlier, and in line with the recommendations of the AIHW, information relating to trends in the deaths of Aboriginal and Torres Strait Islander children is based on identification of Indigenous status in BDM data only, and from 2005 onwards. 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.

5 Australian Bureau of Statistics, 2014, *3303.0 Causes of Death, Australia, 2012 (Explanatory Notes), March 2014 release*, Canberra: ABS.

Chapter 2. All child deaths in 2013

The deaths of 567 children were registered in NSW in 2013, representing a directly standardised mortality rate[6] of 31.70 deaths per 100,000 children. The rate of death of children in 2013 was the second lowest in the history of the Team (after 2012).

Table 1: Deaths of children from all causes – deaths registered, 1999-2013

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval[7]	Directly Standardised Mortality Rate	95% Confidence Interval
1999	1582928	813	51.36	47.83 - 54.89	51.25	47.72 - 54.77
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	31.18 - 36.69
2012	1655685	493	29.78	27.15 - 32.40	28.14	25.65 - 30.62
2013	1672152	567	33.91	31.12 - 36.70	31.70	29.09 - 34.31

6 The directly standardised mortality rate is deaths per 100,000 people under 18 years of age, adjusted for the age structure of the population.
7 The confidence interval estimates the range in which some proportion (95%) of the statistics from all samples will fall (see Appendix 1 for more information).

Demographic and individual characteristics

The following table describes the demographic characteristics of the 567 children whose deaths were registered in 2013.

Table 2: Key demographic and individual characteristics – deaths registered, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio[8]	*p*[9]
Total	**567**	**100**	**33.9**	**31.12 - 36.70**		
Gender						
Female	254	45	31.3	27.42 - 35.11	-	-
Male	313	55	36.4	32.37 - 40.44	1.2	0.04
Age						
Under 1 year	356	63	354.1 (IMR = 3.61)†	317.36 - 390.93	-	-
1-4 years	70	12	18.1	14.10 - 22.85	-	-
5-9 years	42	7	9.0	6.51 - 12.22	-	-
10-14 years	36	6	8.1	5.64 - 11.16	-	-
15-17 years	63	11	23.1	17.72 - 29.50	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	487	86	30.8	28.07 - 33.54	-	-
Aboriginal or Torres Strait Islander	80	14	87.8	69.65 - 109.32	2.9	0
Remoteness*						
Major cities	392	69	32.6	29.35 - 35.80	-	-
Inner regional areas	120	21	36.2	29.73 - 42.69	-	-
Outer regional areas	41	7	38.8	27.81 - 52.57	-	-
Remote areas	3	1	-	-	-	-
Very remote areas	4	1	179.1	48.79 - 458.44	-	-
Socioeconomic status**						
Quintile 5 (highest)	76	13	21.5	16.96 - 26.95	-	-
Quintile 4	73	13	22.2	17.37 - 27.86	-	-
Quintile 3	104	18	32.9	26.59 - 39.24	-	-
Quintile 2	120	21	38.2	31.38 - 45.05	-	-
Quintile 1 (lowest)	185	33	55.1	47.20 - 63.09	-	-

*Remoteness was not calculated in seven cases.
**Socioeconomic status was not calculated for nine cases.
† Infant Mortality Rate[10]

Age and gender

The proportion of deaths in each age group in 2013 is highly consistent with previous years. Infants consistently account for almost two-thirds of all child deaths in NSW. Together, the deaths of children aged 1-4 years and young people aged 15-17 years comprise just under one-quarter of child deaths each year.

The mortality rates for each age group are slightly higher than last year, except for children aged 5-9 years (where it was largely unchanged). Overall, the mortality rates per age group have not substantially changed in recent years.

8 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).
9 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).
10 The Infant Mortality Rate is the rate of death per 1,000 live births.

Males have consistently outnumbered females in child deaths in NSW each year, including 55% of deaths (313) in 2013. As shown in the tables below, the mortality rate for males has consistently been higher than the rate for females. However, the mortality rate for males in 2013 (36.40 deaths per 100,000 children) was the second lowest for the past 15 years. The mortality rate for females has varied over that time.

Table 3: Deaths of male children from all causes – deaths registered, 1999-2013

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval	Directly Standardised Mortality Rate	95% Confidence Interval
1999	810911	463	57.10	51.90 - 62.30	57.28	52.07 - 62.50
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	859836	313	36.40	32.37 - 40.44	34.18	30.40 - 37.97

Table 4: Deaths of female children from all causes – deaths registered, 1999-2013

Year	Population	Deaths	Crude Mortality Rate	95% Confidence Interval	Directly Standardised Mortality Rate	95% Confidence Interval
1999	772017	350	45.34	40.59 - 50.09	44.95	40.24 - 49.66
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	30.38	26.65 - 34.11
2012	804046	200	24.87	21.43 - 28.32	23.49	20.24 - 26.75
2013	812316	254	31.27	27.42 - 35.11	29.10	25.52 - 32.68

Child protection history[11]

As indicated in the table below, the families of 112 children (20%) had a child protection history.

In the three years before their death, 69 children (12%) had been the subject of a report of risk of harm or risk of significant harm to Community Services. Thirty children (mainly infants) had not themselves been the subject of a report, but had a sibling who had been reported.

Thirteen children were the subject of a report to a Child Wellbeing Unit in the three years before their death, although this did not lead to a report to Community Services. Six children were in care[12] at the time of their death.

Table 5: Age and child protection history, 2013

Age range	No known history		Child subject of a report(s) to Community Services or Child Wellbeing Unit		Sibling only subject of a report(s)		
	Number	Percent	Number	Percent	Number	Percent	Total
Infants (<1 year)	298	83.7	33	9.27	25	7.0	356
1-4 years	51	72.9	16	22.86	3	4.3	70
5-9 years	31	73.8	10	23.81	1	2.4	42
10-14 years	27	75.0	8	22.22	1	2.8	36
15-17 years	48	76.2	15	23.81	0	0.0	63
Total	**455**	**80.2**	**82**	**14.46**	**30**	**5.3**	**567**

As noted in the previous chapter, in April 2014, the Team tabled a special report to Parliament on its analysis of the causes of death of children with a child protection history in the 10-year period, 2002-2011. Among other things, the analysis found that these children had a much higher mortality rate for particular causes of death, including Sudden Unexpected Death in Infancy (SUDI), external causes such as fire and assault, and certain natural causes such as cerebral palsy and meningococcal infection.

Information from the Team's analysis of the causes of death of children with a child protection history has been incorporated into this report.

Aboriginal and Torres Strait Islander status

In 2013, 80 children (14%) were identified as Aboriginal and/or Torres Strait Islander. Of the 80 children, 74 were Aboriginal, and six children were Aboriginal and Torres Strait Islander.

There was a significant difference between the rates of death of Indigenous and non-Indigenous children. The mortality rate for Aboriginal and Torres Strait Islander children in 2013 (87.8 deaths per 100,000 children) was almost three times the mortality rate for non-Indigenous children.

Trends in the deaths of Aboriginal and Torres Strait Islander children 2005-2013

Over the nine-year period 2005-2013, the deaths of 487 Aboriginal and Torres Strait Islander children were registered in NSW.[13] The nine-year average mortality rate of Aboriginal and Torres Strait Islander children (61.1 deaths per 100,000 children) was 1.7 times the rate of non-Indigenous children for the same period (35.5 per 100,000).

As shown in the table below, the mortality rate of Aboriginal and Torres Strait Islander children in 2013 (75.8 deaths per 100,000 children) was the highest for the nine-year period.

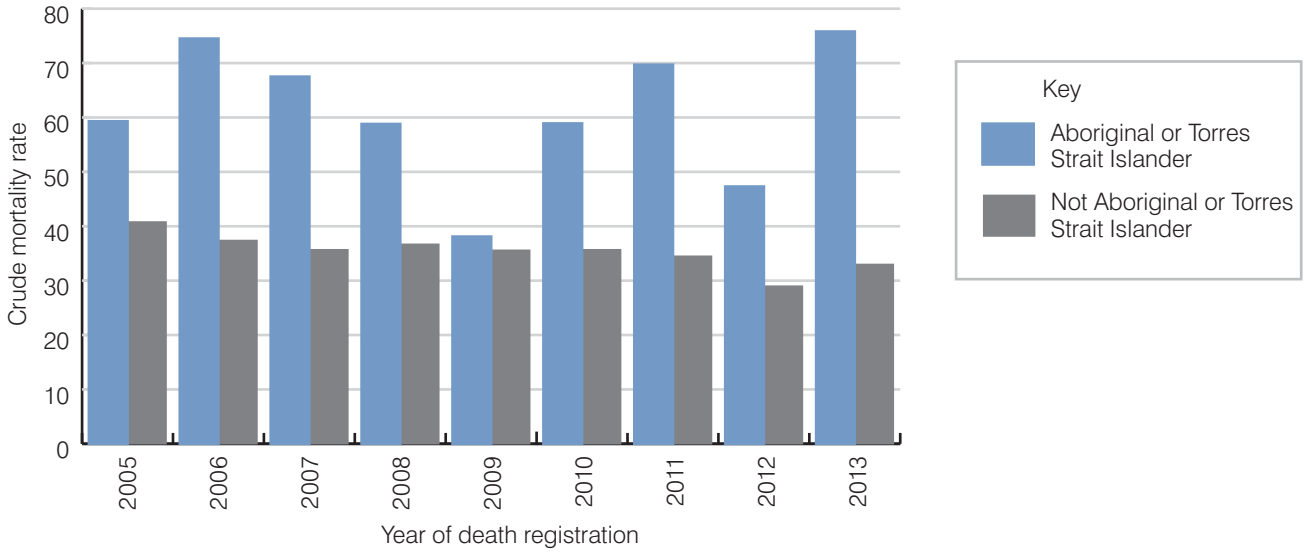
Consistent with broader child deaths, the majority of the Aboriginal and Torres Strait Islander children whose deaths were registered in 2005-2013 were infants under one year of age, comprising 65% of all deaths of Aboriginal and Torres Strait Islander children during that period. Children aged 1-4 years comprised 13% of the deaths of Aboriginal and Torres Strait Islander children, followed by young people aged 15-17 years (11%).

11 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.

12 The definition of 'child in care' is outlined in Appendix 2, and is consistent with the *Community Services (Complaints, Reviews and Monitoring) Act 1993*.

13 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.

Figure 1: Crude mortality rate of children by Aboriginal and Torres Strait Islander status, 2005-2013



Remoteness

Major cities accounted for over two-thirds of the deaths of children in NSW in 2013.

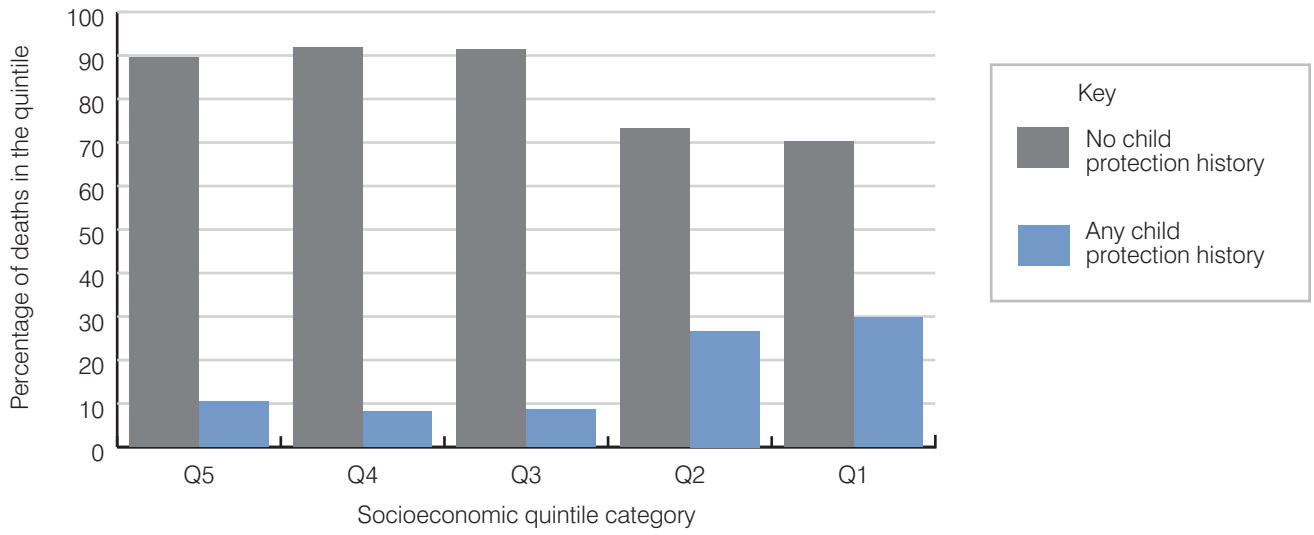
The rate of death of children in very remote areas was over 4.5 times the rate in inner and outer regional areas, and 5.5 times the rate in major cities.

Socioeconomic status[14]

In 2013, just over half (305) of the children whose deaths were registered in NSW lived in areas of greatest socioeconomic disadvantage (quintiles 1 and 2). Overall, a higher proportion of the children who died in 2013 lived in areas of greater socioeconomic disadvantage compared with 2012 and 2011.

As indicated in the figure below, child protection history interacts with socioeconomic status. The children who resided in areas of greatest socioeconomic disadvantage (quintile 1) were almost three times more likely to have a child protection history than those who resided in areas of least socioeconomic disadvantage.

Figure 2: Child protection history by socioeconomic status (IRSD quintiles), 2013



14 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 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.

Chapter 3. Leading causes of death of children in NSW in 2013

At the time of writing, information about the cause of death was available for 527 children (93%). Where underlying cause of death is the basis for the analysis below, it relates to 527 children.

Overview of leading causes of death by age group

The table below provides the total number of deaths for each age group, and identifies the leading natural and external (unnatural) causes of death.

As has consistently been the case, the leading cause of death of infants was certain conditions originating in the perinatal period ('perinatal conditions') – conditions that arise during pregnancy or up to 28 days after birth. The leading natural cause of death of children aged one year and older was neoplasms (cancers and tumours).

The leading external causes of deaths of infants were drowning (3) and threats to breathing (3), including accidental suffocation in bed. While transport fatalities have typically been the leading cause of death of young people, suicide featured as the leading (or equal leading) external cause of death of young people aged 10-17 years in 2013.

Table 6: Frequency, rates and leading natural and external causes of death, 2013

Age group	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	356	63	Perinatal conditions (185 per 100,000)	Drowning & accidental threats to breathing[15] (2.98 per 100,000)
1-4 years	70	12	Neoplasms (4.65 per 100,000)	Drowning (1.55 per 100,000)
5-9 years	42	7	Neoplasms (1.51 per 100,000)	Transport (2.58 per 100,000)
10-14 years	36	6	Neoplasms (2.01 per 100,000)	Suicide (0.67 per 100,000)
15-17 years	63	11	Neoplasm (3.29 per 100,000)	Suicide / Transport (5.49 per 100,000)

The following tables outline the top five leading causes of death by age group for 2010-2013.

Infants – under 1 year

The top three leading causes of death of infants have been highly consistent over time. In 2012 and 2013, nervous system diseases have been the fourth leading cause of death of infants.

15 'Accidental threats to breathing' include accidental suffocation and strangulation; and inhalation and ingestion of food and other objects causing obstruction of respiratory tract.

Table 7: Frequency and mortality rates of the top five leading underlying causes of death for infants aged <1 year, 2010-2013

2013 (IMR = 3.61)		2012 (IMR = 3.06)		2011 (IMR= 3.79)		2010 (IMR = 3.92)	
Perinatal	186 (185)	Perinatal	147 (157.87)	Perinatal	191 (204)	Perinatal	180 (186)
Congenital	75 (74.6)	Congenital	84 (90.21)	Congenital	96 (103)	Congenital	99 (102)
Symptoms/signs	18 (17.91)	Symptoms/signs	16 (17.18)	Symptoms/signs	10 (10.7)	Symptoms/signs	10 (10.3)
Nervous system	17 (16.9)	Nervous system	7 (7.52)	Neoplasms	5 (5.35)	Endocrine	7 (7.2)
Endocrine	5 (5)	Infectious	5 (5.37)	Circulatory	5 (5.35)	Respiratory	6 (6.2)

1-4 years

While cancers and tumours have consistently featured as a leading cause of death of children aged 1-4 years, the rate of death from this cause in 2013 was higher than recent years.

Drowning has consistently been the leading external cause of death of children aged 1-4 years. The rates of death from drowning in this age group in 2012 and 2013 were slightly lower than the rates in the previous two years.

Table 8: Frequency and mortality rates of the top five leading underlying causes of death for children aged 1-4 years, 2010-2013

2013 (CMR = 18.1)		2012 (CMR = 12.83)		2011 (CMR = 17.36)		2010 (CMR = 19.7)	
Neoplasms	18 (4.7)	Congenital	10 (2.62)	Neoplasms	13 (3.53)	Neoplasms	10 (2.7)
Congenital	9 (2.3)	Neoplasms	7 (1.83)	Drowning	9 (2.44)	Drowning	9 (2.5)
Endocrine	6 (1.6)	Drowning	6 (1.57)	Nervous system	7 (1.9)	Congenital	8 (2.2)
Drowning	6 (1.6)	Transport	4 (1.05)	Congenital	5 (1.36)	Nervous system	8 (2.2)
Accidental threats to breathing	4 (1.0)	Nervous system	3 -	Fatal assault	5 (1.36)	Endocrine	4 (1.1)
		Endocrine	3 -			Transport	4 (1.1)

5-9 years

In 2013, neoplasms continued to be the leading natural cause of death of children aged 5-9 years. However, unlike previous years, transport fatalities were the overall leading cause of the deaths of children in this age group.

The number and rate of death due to nervous system diseases has slightly increased in recent years for children aged 5-9 years, to become the third leading cause of death in 2012 and 2013.

Table 9: Frequency and mortality rates of the top five leading underlying causes of death for children aged 5-9 years, 2010-2013

2013 (CMR = 9.0)		2012 (CMR = 9.76)		2011 (CMR = 7.85)		2010 (CMR = 7.7)	
Transport	12 (2.6)	Neoplasms	11 (2.44)	Neoplasms	10 (2.24)	Neoplasms	11 (2.5)
Neoplasms	7 (1.5)	Transport	8 (1.77)	Fatal assault	3 -	Transport	6 (1.4)
Nervous system	6 (1.3)	Nervous system	5 (1.11)	Congenital	3 -	Circulatory	3 -
Congenital	4 (0.9)	Congenital	3 -	Circulatory	3 -	Congenital	3 -
Diseases of the blood	2 -	Respiratory	2 -	Drowning	2 -	Perinatal	2 -
Respiratory	2 -	Endocrine	2 -	Transport	2 -	Drowning	2 -
		Infectious	2 -	Respiratory	2 -		
				Nervous system	2 -		

10-14 years

Consistent with previous years, neoplasms featured as a common cause of death of children aged 10-14 years – being the overall leading cause in 2013. Nervous system diseases and circulatory system diseases have consistently featured in the leading causes of death of children in this age group; there has been no notable change in the mortality rates from these causes.

In 2013, suicide was the leading external cause of death of children aged 10-14 years. Suicide has featured in the top five leading causes of death of children in this age group for the past two years. While transport fatalities have typically featured in the leading causes of death, this was not the case in 2013.

Table 10: Frequency and mortality rates of the top five leading underlying causes of death for children aged 10-14 years, 2010-2013

2013 (CMR = 8.1)		2012 (CMR = 7.92)		2011 (CMR = 10.22)		2010 (CMR = 9.3)	
Neoplasms	9 (2.0)	Transport	9 (2.04)	Neoplasms	15 (3.33)	Neoplasms	11 (2.4)
Nervous system	6 (1.3)	Respiratory	5 (1.13)	Congenital	5 (1.11)	Nervous system	7 (1.6)
Circulatory	4 (0.9)	Nervous system	4 (0.9)	Nervous system	5 (1.11)	Congenital	5 (1.1)
Congenital	3 -	Neoplasms	3 -	Transport	5 (1.11)	Transport	5 (1.1)
Suicide	3 -	Circulatory	2 -	Circulatory	4 (0.89)	Circulatory	3 -
		Endocrine	2 -			Respiratory	3 -
		Suicide	2 -				

15-17 years

Transport fatalities and suicide have consistently featured as the two leading causes of the deaths of young people aged 15-17 years. The suicide mortality rate for young people aged 15-17 years has increased at the same time as the rate of death from transport fatalities has slightly declined.

Neoplasms have consistently featured in the top five leading causes of death in this age group, with no particular trend evident. Unlike previous years, respiratory diseases featured as a leading cause of death of young people aged 15-17 years in 2013, with asthma and pneumonia the main underlying causes.

Table 11: Frequency and mortality rates of the top five leading underlying causes of death for children aged 15-17 years, 2010-2013

2013 (CMR = 23.1)		2012 (CMR = 22.59)		2011 (CMR = 25.73)		2010 (CMR = 27)	
Suicide	15 (5.5)	Transport	17 (6.19)	Transport	18 (6.43)	Transport	18 (6.4)
Transport	15 (5.5)	Suicide	14 (5.10)	Suicide	16 (5)	Suicide	13 (4.6)
Neoplasms	9 (3.3)	Neoplasms	8 (2.91)	Nervous system	7 (2.5)	Neoplasms	10 (3.6)
Endocrine	5 (1.8)	Nervous system	6 (2.19)	Neoplasms	6 (2.14)	Fatal assault	8 (2.8)
Respiratory	5 (1.8)	Congenital	3 -	Endocrine	3 -	Circulatory	5 (1.8)
		Accidental poisoning	3 -				

Underlying causes of death by ICD chapter

The following tables outline the underlying causes of death of children in NSW in 2013 by chapters of the International Statistical Classification of Diseases and Related Health Problems (ICD) system.[16]

Overall, the leading underlying causes of death of children in NSW in 2013 were consistent with previous years, with perinatal conditions and congenital/chromosomal conditions accounting for over half of all child deaths. External (unnatural) causes continued to be the third leading cause of death of children in NSW.

Table 12: Frequency and rates of leading underlying causes of death by ICD chapter and age group, 2013

	Number of deaths (Crude Mortality Rate)					
ICD chapter	**All children**	**Under 1 year**	**1-4 years**	**5-9 years**	**10-14 years**	**15-17 years**
Certain conditions arising in the perinatal period	188 (11.24)	186 (185.0)	0 -	1 -	1 -	0 -
Congenital malformations, deformations and chromosomal abnormalities	92 (5.50)	75 (74.6)	9 (2.33)	4 (0.86)	3 -	1 -
External causes of mortality and morbidity	81 (4.84)	7 (6.96)	16 (4.13)	15 (3.23)	7 (1.57)	36 (13.18)
Neoplasms	44 (2.63)	1 -	18 (4.65)	7 (1.51)	9 (2.01)	9 (3.29)
Diseases of the nervous system	34 (2.03)	17 (16.91)	2 -	6 (1.51)	6 (1.34)	3 -
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	19 (1.14)	18 (17.91)	1 -	0 -	0 -	0 -
Diseases of the respiratory system	18 (1.08)	4 (3.98)	5 (1.29)	2 -	2 -	5 (1.83)
Endocrine, nutritional and metabolic disorders	17 (1.02)	5 (4.97)	6 (1.55)	0 -	1 -	5 (1.83)
Diseases of the circulatory system	10 (0.60)	2 -	1 -	1 -	4 0.90	2 -
Certain infectious and parasitic diseases	9 (0.54)	3 -	5 (1.29)	0 -	0 -	1 -
Diseases of the blood, blood-forming organs and certain disorders of the immune system	8 (0.48)	4 (3.98)	1 -	2 -	1 -	0 -
Diseases of the digestive system	5 (0.30)	3 -	1 -	0 -	0 -	1 -
Mental and behavioural disorders	1 -	0 -	0 -	1 -	0 -	0 -
Diseases of the musculoskeletal system and connective tissue	1 -	0 -	0 -	0 -	1 -	0 -
Total	**527**	**325**	**65**	**39**	**35**	**63**

Age and gender

Tables 12 and 13 provide the leading underlying causes of death by age group and gender.

Natural causes of death accounted for the majority of deaths of children 0-14 years. Most (36) of the 63 deaths of young people aged 15-17 years were due to external (unnatural) causes.

The higher number of deaths in 2013 compared with 2012 is largely due to increases in the deaths of infants due to perinatal conditions (186 compared with 147), deaths due to neoplasms (44 compared with 29), and deaths due to nervous system diseases (34 compared with 25).

Consistent with previous years, boys outnumbered girls in the majority of the leading causes of death. In 2013, girls outnumbered boys in deaths from neoplasms and infectious diseases.

16 Nationally and internationally, morbidity and mortality data are coded according to the ICD system. The ICD is the international standard health classification published by the World Health Organisation (WHO) for coding diseases for statistical aggregation and reporting purposes. The ICD provides structured rules guiding how the underlying cause of death is determined. Use of these rules assists with standardisation of coded data and facilitates comparability with other collections of mortality data.

Table 13: Leading underlying causes of death by ICD chapter and gender, 2013

ICD chapter	All children	Female	Male
Certain conditions arising in the perinatal period	188 (11.24)	82 (10.09)	106 (12.33)
Congenital malformations, deformations and chromosomal abnormalities	92 (5.50)	46 (5.66)	46 (5.35)
External causes of mortality and morbidity	81 (4.84)	29 (3.57)	52 (6.05)
Neoplasms	44 (2.63)	30 (3.69)	14 (1.63)
Diseases of the nervous system	34 (2.03)	17 (2.09)	17 (1.98)
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	19 (1.14)	5 (0.62)	14 (1.63)
Deaths of the respiratory system	18 (1.08)	5 (0.62)	13 (1.51)
Endocrine, nutritional and metabolic disorders	17 (1.02)	8 (0.98)	9 (1.05)
Deaths of the circulatory system	10 (0.60)	4 (0.49)	6 (0.70)
Certain infectious and parasitic diseases	9 (0.54)	5 (0.62)	4 (0.47)
Diseases of the blood, blood-forming organs and certain disorders of the immune system	8 (0.48)	2 -	6 (0.70)
Diseases of the digestive system	5 (0.30)	1 -	4 (0.47)
Mental and behavioural disorders	1 -	1 -	0 -
Diseases of the musculoskeletal system and connective tissue	1 -	0 -	1 -
Total	**527**	**235**	**293**

Aboriginal and Torres Strait Islander status

Consistent with previous years, the main causes of death of Aboriginal and Torres Strait Islander children were perinatal conditions and external causes. In 2013, the mortality rate for perinatal conditions increased for both Indigenous and non-Indigenous children.

The mortality rate of Aboriginal and Torres Strait Islander children increased in relation to congenital and chromosomal conditions (from 7.02 to 8.78 deaths per 100,000 children) and external causes (from 15.45 to 20.86 per 100,000). The mortality rates of non-Indigenous children from these causes declined slightly in 2013.

Table 14: Frequency and rates of leading underlying causes of death by ICD chapter and Aboriginal and Torres Strait Islander status, 2013

	Number of deaths (Crude Mortality Rate)		
ICD chapter	All children	Not Aboriginal or Torres Strait Islander	Aboriginal or Torres Strait Islander
Certain conditions arising in the perinatal period	188 (11.24)	159 (10.06)	29 (31.84)
Congenital malformations, deformations and chromosomal abnormalities	92 (5.50)	84 (5.31)	8 (8.78)
External causes of mortality and morbidity	81 (4.84)	62 (3.92)	19 (20.86)
Neoplasms	44 (2.63)	43 (2.72)	1 -
Diseases of the nervous system	34 (2.03)	33 (2.09)	1 -
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	19 (1.14)	14 (0.89)	5 (5.49)
Diseases of the respiratory system	18 (1.08)	15 (0.95)	3 -
Endocrine, nutritional and metabolic disorders	17 (1.02)	16 (1.01)	1 -
Diseases of the circulatory system	10 (0.60)	9 (0.57)	1 -
Certain infectious and parasitic diseases	9 (0.54)	8 (0.51)	1 -
Diseases of the blood, blood-forming organs and certain disorders of the immune system	8 (0.48)	8 (0.51)	0 -
Diseases of the digestive system	5 (0.30)	4 (0.25)	1 -
Mental and behavioural disorders	1 -	1 -	0 -
Diseases of the musculoskeletal system and connective tissue	1 -	1 -	0 -
Total	**527**	**458**	**70**

Remoteness and socioeconomic status

In 2013, the mortality rate for perinatal conditions increased across most areas (major cities, inner regional and outer regional areas). The mortality rate from external causes declined in outer regional areas by around seven deaths per 100,000 compared with 2012.

The mortality rates for most causes of death increased amongst children residing in areas of greatest socioeconomic disadvantage (quintile 1). The highest mortality rate was associated with perinatal conditions in quintile 1 (17.29 deaths per 100,000 children), with an increase of more than eight deaths per 100,000 children.

Table 15: Frequency and rates of leading underlying causes of death by ICD chapter and remoteness, 2013

	Number of deaths (Crude Mortality Rate)					
ICD chapter	**All children***	**Major Cities**	**Inner Regional**	**Outer Regional**	**Remote**	**Very Remote**
Certain conditions arising in the perinatal period	186 (11.1)	136 (11.30)	37 (11.17)	13 (12.29)	0 -	0 -
Congenital malformations, deformations and chromosomal abnormalities	92 (5.5)	71 (5.90)	17 (5.13)	2 -	1 -	1 -
External causes of morbidity and mortality	80 (4.8)	39 (3.24)	24 (7.24)	13 (12.29)	2 -	2 -
Neoplasms	43 (2.6)	33 (2.74)	8 (2.41)	2 -	0 -	0 -
Diseases of the nervous system	34 (2.0)	29 (2.41)	4 (1.21)	1 -	0 -	0 -
Symptoms, signs and abnormal clinical laboratory findings, not elsewhere classified	19 (1.1)	13 (1.08)	5 (1.51)	0 -	0 -	1 -
Diseases of the respiratory system	18 (1.1)	11 (0.91)	6 (1.81)	1 -	0 -	0 -
Endocrine, nutritional and metabolic disorders	17 (1.0)	12 (1.00)	3 -	2 -	0 -	0 -
Diseases of the circulatory system	10 (0.6)	7 (0.58)	2 -	1 -	0 -	0 -
Certain infectious and parasitic diseases	9 (0.5)	6 (0.50)	2 -	1 -	0 -	0 -
Diseases of the blood, blood-forming organs and certain disorders of the immune system	8 (0.5)	6 (0.50)	1 -	1 -	0 -	0 -
Diseases of the digestive system	5 (0.3)	3 -	2 -	0 -	0 -	0 -
Mental and behavioural disorders	1 -	1 -	0 -	0 -	0 -	0 -
Total	**522**	**368**	**111**	**37**	**3**	**4**

*Remoteness was not calculated in five cases.

Table 16: Frequency and rates of leading underlying causes of death by ICD chapter and Index of Relative Social Disadvantage quintile, 2013

	Number of deaths (Crude Mortality Rate)					
ICD chapter	**All children***	**Quintile 5**	**Quintile 4**	**Quintile 3**	**Quintile 2**	**Quintile 1**
Certain conditions arising in the perinatal period	184 (11.0)	34 (9.63)	25 (7.59)	34 (10.76)	33 (10.51)	58 (17.29)
Congenital malformations, deformations and chromosomal abnormalities	92 (5.5)	13 (3.68)	9 (2.73)	22 (6.96)	16 (5.10)	32 (9.54)
External causes of morbidity and mortality	80 (4.8)	6 (1.70)	9 (2.73)	13 (4.11)	21 (6.69)	31 (9.24)
Neoplasms	43 (2.6)	7 (1.98)	5 (1.52)	10 (3.16)	14 (4.46)	7 (2.09)
Diseases of the nervous system	34 (2.0)	4 (1.13)	8 (2.43)	8 (2.53)	4 (1.27)	10 (2.98)
Symptoms, signs and abnormal clinical laboratory findings, not elsewhere classified	19 (1.1)	2 -	0 -	3 -	7 (2.23)	7 (2.09)
Diseases of the respiratory system	18 (1.1)	2 -	2 -	2 -	5 (1.59)	7 (2.09)
Endocrine, nutritional and metabolic disorders	17 (1.0)	4 (1.13)	5 (1.52)	1 -	4 (1.27)	3 -
Diseases of the circulatory system	10 (0.6)	2 -	1 -	2 -	2 -	3 -
Certain infectious and parasitic diseases	9 (0.5)	0 -	1 -	4 (1.27)	3 -	1 -
Diseases of the blood, blood-forming organs and certain disorders of the immune system	8 (0.5)	0 -	1 -	1 -	2 -	4 (1.19)
Diseases of the digestive system	5 (0.3)	0 -	2 -	1 -	1 -	1 -
Mental and behavioural disorders	1 -	1 -	0 -	0 -	0 -	0 -
Total	**520**	**75**	**68**	**102**	**112**	**164**

*Socioeconomic status was not calculated in seven cases.

Chapter 4. Multiple causes of death

In addition to underlying cause of death, information about contributing and direct causes of death are important for a more complete understanding of what led to a death, and the contribution of diseases to mortality.

Table 17 shows the underlying cause of death and other contributory causes of death ('multiple causes of death') recorded for all deaths of children in 2013, and table 18 shows this for all child deaths in the 10-year period 2004-2013.

The tables show that perinatal conditions were the largest contributory cause of death, contributing to one-third of all deaths as an underlying or associated cause of death. Perinatal conditions have commonly been a contributing factor in the deaths of children from congenital and chromosomal conditions and nervous system diseases. Perinatal conditions as a contributory

Table 17: Underlying cause of death and contributory causes of death, 2013[e]

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)	Ear and Mastoid (H60-H95)
Certain infectious and parasitic diseases (A00-B99)	9	-	-	1	-	1	-	-
Neoplasms (C00 - D48)	44	7	7	5	1	-	5	-
Diseases of the blood, blood-forming organs and certain disorders of the immune system (D50-D89)	8	3	-	2	-	-	1	-
Endocrine, nutritional and metabolic disorders (E00-E90)	17	-	-	-	2	2	3	-
Mental and behavioural disorders (F00 - F99)	1	-	-	-	-	-	-	-
Diseases of the nervous system (G00-G99)	34	-	-	-	-	2	5	-
Diseases of the ear and mastoid process (H60-H95)	1	-	-	-	-	-	1	-
Diseases of the circulatory system (I00 - I99)	10	1	1	-	-	1	2	-
Diseases of the respiratory system (J00-J99)	18	3	-	-	-	3	-	-
Diseases of the digestive system (K00-K93)	5	-	1	-	-	-	2	-
Diseases of the skin and subcutaneous tissue (L00-L99)	0	-	-	-	-	-	-	-
Diseases of the musculoskeletal system and connective tissue (M00-M99)	1	1	-	1	-	-	-	-
Diseases of the genitourinary system (N00 - N99)	0	-	-	-	-	-	-	-
Certain conditions originating in the perinatal period (P00-P96)	188	8	-	-	1	-	5	-
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	92	4	1	1	2	3	9	-
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	19	-	-	-	-	-	1	-
Injury, poisoning and certain other consequences of external causes (S00-T98)	0	-	-	-	-	-	-	-
External causes of morbidity and mortality (V00-Y98)	81	-	-	-	1	1	5	-
Total	**528**	**27**	**10**	**10**	**7**	**13**	**39**	**0**

[e] see errata in the front of this document

cause were most often associated with other perinatal conditions as an underlying cause, showing that a single death can be caused by multiple issues of the same nature.

Other leading contributory causes of death of children were:

- Injury, poisoning and certain other consequences of external causes, which contributed to just under 20% of deaths
- Congenital and chromosomal conditions, which contributed to 11% of deaths, and
- Respiratory diseases, which contributed to 10% of deaths. Respiratory diseases have commonly been a contributing factor in the deaths of children from nervous system diseases (such as cerebral palsy), and from neoplasms (where it tends to be the direct cause of death at the end-stage of the disease).

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)	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	-	3	-	1	11	3	33.3
9	12	3	-	-	2	1	2	8	4	1	67	15	34.1
1	2	2	-	-	-	-	-	2	1	1	15	1	12.5
4	5	2	-	1	-	2	1	1	2	1	26	3	17.6
-	-	-	-	-	-	-	-	-	1	-	1	0	0.0
4	22	1	-	-	-	3	2	5	-	-	44	6	17.6
-	-	-	-	-	-	-	-	-	-	-	1	0	0.0
5	2	-	-	-	2	1	1	2	1	-	19	2	20.0
1	3	-	-	-	1		2	4	1	1	19	7	38.9
1	-	1	-	-	-	1	2	1	1	-	10	1	20.0
-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
-	1	-	-	-	-	-	-	1	-	-	4	0	0.0
-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
5	6	1	-	-	-	132	7	13	-	-	178	45	23.9
17	5	5	-	-	5	40	40	11	4	2	149	16	17.4
1	1	-	-	-	-	1	-	-	-	-	4	18	94.7
-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
1	1	-	-	-	-	-	1	7	75	2	94	5	6.2
49	**62**	**17**	**0**	**1**	**10**	**182**	**58**	**58**	**90**	**9**		**122**	

Table 18: Underlying cause of death and contributory causes of death, 2004-2013[e]

Underlying cause of death (ICD-10 chapter)	No. of cases	Certain infectious and parasitic diseases (A00-B99)	Neoplasms (C00 - D48)	Diseases of the blood, and blood-forming organs and certain disorders involving the immune system (D50-D89)	Endocrine, nutritional, and metabolic diseases (E00-E90)	Mental and behavioural disorders (F00 - F99)	Diseases of the nervous system (G00-G99)	Diseases of the eye and adnexa (H00-H59)	Diseases of the ear and mastoid process (H60-H95)	Diseases of the circulatory system (I00 - I99)
Certain infectious and parasitic diseases (A00-B99)	107	14	5	11	12	3	14	-	-	18
Neoplasms (C00 - D48)	403	53	66	36	7	-	45	-	-	51
Diseases of the blood, blood-forming organs (D50-D89)	50	21	1	15	2	-	4	-	-	9
Endocrine, nutritional, metabolic diseases (E00-E90)	140	8	-	3	15	7	25	-	-	27
Mental and behavioural disorders (F00 - F99)	12	-	-	-	1	-	4	-	-	1
Diseases of the nervous system (G00-G99)	308	9	7	3	9	22	82	1	1	44
Diseases of the eye and adnexa (H00-H59)	1	-	-	1	1	-	-	-	-	1
Diseases of the ear and mastoid process (H60-H95)	1	-	-	-	-	1	1	-	-	-
Diseases of the circulatory system (I00 - I99)	167	9	7	5	10	4	18	-	-	62
Diseases of the respiratory system (J00-J99)	135	17	1	2	2	8	31	-	-	18
Diseases of the digestive system (K00-K93)	53	9	1	4	8	3	8	-	-	10
Diseases of the skin and subcutaneous tissue (L00-L99)		-	-	-	-	-	-	-	-	-
Diseases of the musculoskeletal system and connective tissue (M00-M99)	15	2	-	2	2	1	-	-	-	4
Diseases of the genitourinary system (N00 - N99)	8	1	1	1	2	-	1	-	-	1
Certain conditions arising in the perinatal period (P00-P96)	2,009	29	4	9	8	2	28	-	-	39
Congenital and chromosomal conditions (Q00-Q99)	1,024	38	5	14	20	17	59	2	2	141
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	408	1	-	-	-		2	-	-	2
Injury, poisoning and certain other consequences of external causes (S00-T98)	2	-	-	-	-	-	1	-	1	-
External causes (V00-Y98)	1,025	6	-	3	6	38	55	1	-	37
Total	**5,868**	**217**	**98**	**109**	**105**	**106**	**378**	**4**	**4**	**465**

[e] see errata in the front of this document

iiseases of the respiratory system (J00-J99)	Diseases of the digestive system (K00-K93)	Diseases of the skin and subcutaneous tissue (L00-L99)	Diseases of the musculoskeletal system and connective tissue (M00-M99)	Diseases of the genitourinary system (N00 - N99)	Pregnancy, childbirth, and the puerperium (O00-O99)	Certain conditions arising in the perinatal period (P00-P96)	Congenital and chromosomal conditions (Q00-Q99)	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	Injury, poisoning and certain other consequences of external causes (S00-T98)	External causes (V00-Y98)	Total	Reported alone	Percent reported alone
21	14	1	-	11	-	9	10	18	2	1	164	27	25.2
93	22	1	3	20	-	7	10	43	27	28	512	150	37.2
11	6	-	-	7	-	6	4	12	11	11	120	4	8.0
51	9	-	2	4	-	9	6	23	6	5	200	27	19.3
9	3	-	3	-	-	-	-	1	2	1	25	1	8.3
136	11	-	8	2	-	31	20	44	24	21	475	60	19.5
-	-	-	-	-	-	-	-	-	-	-	3	0	0.0
-	-	-	-	-	-	-	-	-	-	-	2	0	0.0
13	5	-	5	13	-	9	18	16	2	1	197	56	33.5
38	5	1	3	3	-	3	17	16	2	2	169	40	29.6
11	21	-	-	4	-	7	12	10	5	4	117	3	5.7
-	-	-	-	-	-	-	-	-	-	-	0	0	0.0
6	-	-	-	-	-	1	1	3	-	-	22	3	20.0
1	4	-	1	1	-	-	1	-	1	-	16	1	0.0
31	14	-	4	7	1	1,485	127	88	4	5	1,885	447	22.2
122	42	-	6	31	-	416	392	90	24	20	1,441	175	17.1
2	-	-	-	-	-	3	-	2	1	1	14	401	98.3
-	-	-	-	-	-	-	-	1	1	-	4	1	0.0
21	3	-	1	5	1	8	3	25	993	71	1,277	17	1.7
566	**159**	**3**	**36**	**108**	**2**	**1,994**	**621**	**392**	**1,105**	**171**		**1,413**	

Chapter 5. Children who died outside of NSW

Each year, a number of children normally resident in NSW die in another state or territory. In 2012,[17] 24 children from NSW died outside of the state, consistent with the average (23) since the commencement of the CDRT in 1996.[18]

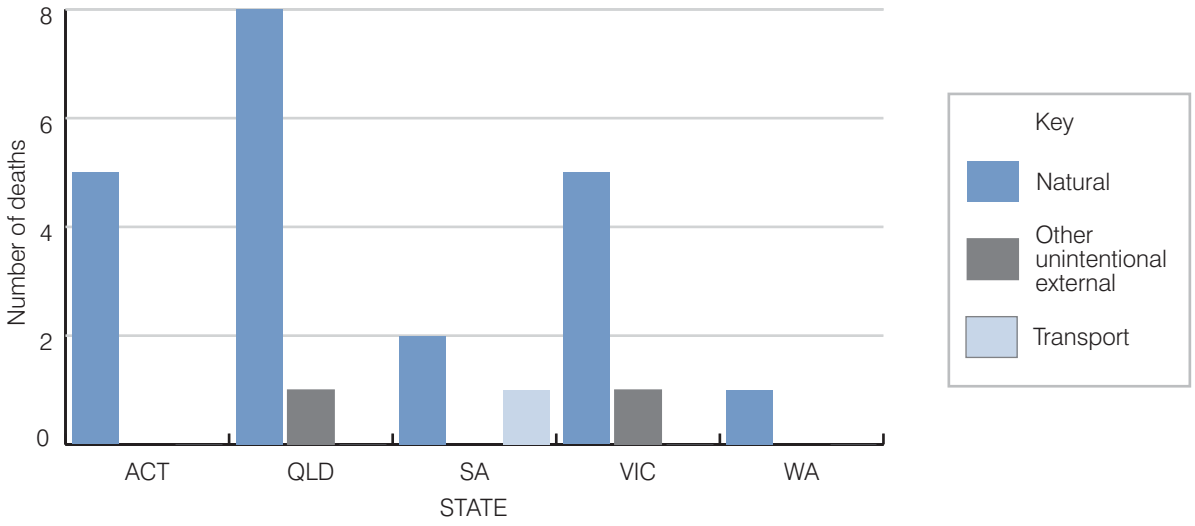
Table 19: Deaths of children resident in NSW registered in another state or territory, 1998-2012

	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
ACT	6	10	7	12	13	7	5	6	11	7	7	9	11	5	5	121
NT	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	2
QLD	7	14	8	8	13	12	5	8	9	14	5	10	14	5	9	141
SA	0	2	1	2	1	2	1	1	1	2	4	1	0	0	3	21
VIC	0	1	3	4	3	1	5	3	2	2	8	9	5	3	6	55
WA	1	0	0	0	1	0	0	0	0	0	1	0	1	0	1	5
TAS	0	0	0	0	0	0	0	1	1	0	0	0	1	1	0	4
Total	**15**	**28**	**19**	**26**	**31**	**22**	**16**	**19**	**24**	**25**	**25**	**29**	**32**	**14**	**24**	**349**

As shown in the figure below, the majority (21) of the 24 children died from natural causes, mainly conditions arising in the perinatal period (10) and congenital and chromosomal conditions (4). The deaths of three children were due to unnatural unintentional causes, including a transport fatality, and a fall.

The 24 children normally resident in NSW who died in another state or territory in 2012 included 12 males and 12 females. Consistent with the main causes of death, most of the children (17) were infants.

Figure 3: Deaths of children resident in NSW registered in another state or territory, 2012, by underlying cause of death



Similarly, some of the deaths registered in NSW are children who were normally resident in another location in Australia or overseas. The 567 children whose deaths were registered in NSW in 2013 include eight children who were normally resident in another state or territory, and two children who were normally resident in another country.

17 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 2012.

18 The Team provides information about the deaths of children outside of NSW separately within the report because its jurisdiction is limited to NSW. While the Team obtains information about children from NSW who die outside of the State from other child death review teams or similar bodies, the information is typically limited to demographic details. No state or territory provides identifying data, which means that no further information can be sought by the Team from agencies within NSW. For this reason, the Team has generally excluded the deaths of children outside of NSW from detailed analysis in its annual report, and has reported the deaths separately within the report.

Chapter 6. Deaths due to natural causes

Consistent with previous years, three-quarters (428) of the children whose deaths were registered in NSW in 2013 died from natural causes.

The deaths of four of the 428 children reported here are also 'reviewable' deaths, and have been reviewed separately by the Ombudsman.[19]

Demographic and individual characteristics

Table 20: Key demographic and individual characteristics – deaths due to natural causes, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**428**	**100**	**25.6**	**23.17 - 28.02**		
Gender						
Female	202	47	24.9	21.44 - 28.30	-	-
Male	226	53	26.3	22.86 - 29.71	1.1	0.28
Age						
Under 1 year	300	70	298.4 (IMR = 3.05)†	264.66 - 332.21	-	-
1-4 years	48	11	12.4	9.14 - 16.44	-	-
5-9 years	25	6	5.4	3.48 - 7.94	-	-
10-14 years	28	7	6.3	4.17 - 9.06	-	-
15-17 years	27	6	9.9	6.51 - 14.38	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	381	89	24.1	21.68 - 26.52	-	-
Aboriginal or Torres Strait Islander	47	11	51.6	37.92 - 68.62	2.1	0
Remoteness*						
Major cities	315	74	26.2	23.29 - 29.07	-	-
Inner regional areas	82	19	24.7	19.68 - 30.71	-	-
Outer regional areas	24	6	22.7	14.53 - 33.75	-	-
Remote areas	1	0	13.3	0.34 - 74.32	-	-
Very remote areas	2	0	89.5	10.84 - 323.40	-	-
Socioeconomic status**						
Quintile 5 (highest)	67	16	19.0	14.71 - 24.10	-	-
Quintile 4	59	14	17.9	13.63 - 23.10	-	-
Quintile 3	85	20	26.9	21.49 - 33.26	-	-
Quintile 2	84	20	26.8	21.34 - 33.12	-	-
Quintile 1 (lowest)	127	30	37.9	31.27 - 44.44	-	-

*Remoteness was not calculated in four cases.
**Socioeconomic status was not calculated in six cases.
† Infant Mortality Rate.

19 Under Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*, the Ombudsman is required to review the deaths of children and adults with disability in care; the deaths of children who died as a result of abuse, neglect, or in suspicious circumstances; and the deaths of children in detention.

Age and gender

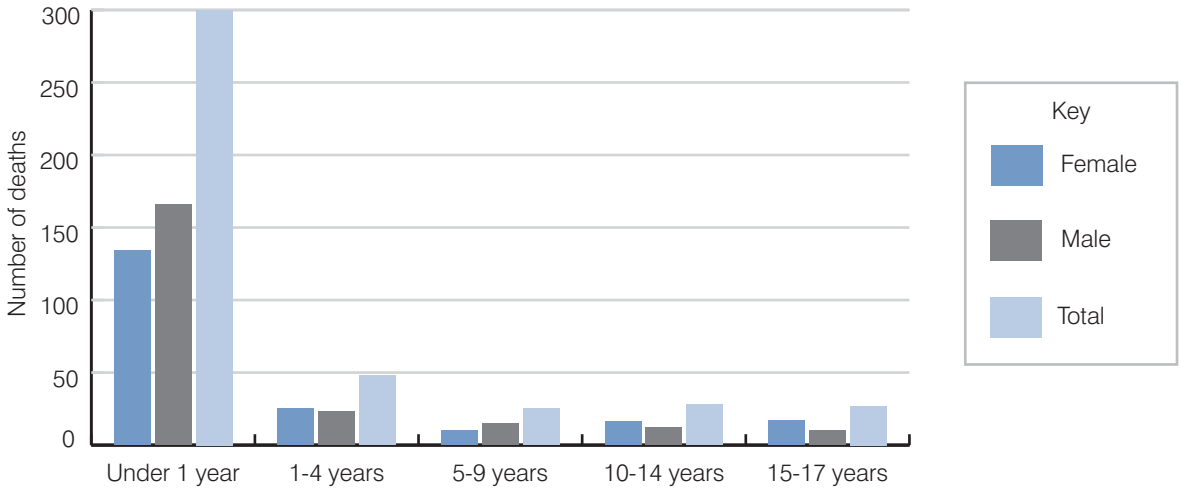
The figure below illustrates the age and gender of the children who died from natural causes in 2013. Consistent with previous years, the majority (70%) of the children who died from natural causes were infants aged less than one year.

Most of the infants who died in 2013, died of natural causes (84%). Natural causes also accounted for most of the deaths of children aged 1-4 years (69%); 5-9 years (60%); and 10-14 years (78%). The lowest proportion of natural cause deaths was amongst young people aged 15-17 years (43%).

Compared with 2012, the natural cause mortality rate increased in 2013 for most of the age groups (except 5-9 years), with the largest increase amongst children aged 1-4 years.

Boys accounted for just over half of the deaths of children from natural causes – a slightly lower proportion than in 2012. Overall, 72% of boys and 80% of girls died from natural causes in 2013, largely consistent with previous years.

Figure 4: Deaths due to natural causes by age and gender, 2013



Aboriginal and Torres Strait Islander status

Forty-seven children who died from natural causes were Aboriginal (44) or Aboriginal and Torres Strait Islander (3). The rate of death of Aboriginal and Torres Strait Islander children from natural causes was more than twice the rate of non-Indigenous children, which is largely consistent with previous years.

Remoteness and socioeconomic status

Three-quarters (315) of the children who died from natural causes resided in major cities; a slightly higher proportion than recent years. Three children resided in remote or very remote areas.

In 2013, half of the children who died from natural causes resided in areas of greatest socioeconomic disadvantage (quintiles 1 and 2).

Child protection history

Of the 428 children whose deaths were due to natural causes, the families of 58 (14%) had a child protection history. In the three years before their death, 31 of the 58 children had been the subject of a report of risk of harm or risk of significant harm to Community Services.

One child was in out-of-home care at the time of their death.

Leading natural causes of death

The following table outlines the top five leading natural causes of death of children in 2013. The leading causes, and their order, are unchanged from 2012. Overall, the top four leading natural causes of death have not changed in recent years.

The leading natural causes of death of children in 2013 are discussed in greater detail in subsequent chapters.

Table 21: Top five leading natural causes of death, 2013

Natural cause of death	Count	Percent	Crude Mortality Rate	95% Confidence Interval
Certain conditions arising in the perinatal period	**188**	**33.2**	**11.24 (1.91) †**	**9.64 - 12.85**
Foetus and newborn affected by maternal factors/complications of pregnancy (P00-P04)	73	12.9	4.37 (0.74)	3.42 - 5.49
Disorders related to length of gestation and foetal growth (P05-P08)	59	10.4	3.53 (0.60)	2.69 - 4.55
Respiratory and cardiovascular disorders (P20-P29)	23	4.1	1.38 (0.23)	0.87 - 2.06
Other perinatal disorders (P90-P96)	11	1.9	0.66 (0.11)	0.33 - 1.18
Haemorrhagic and haematological disorders of foetus and newborn (P50-P61)	9	1.6	0.54 (0.09)	0.25 - 1.02
Digestive system disorders of foetus and newborn (P75-P78)	6	1.1	0.36 (0.06)	0.13 - 0.78
Integument and thermoregulation conditions foetus/newborn (P80-P83)	4	0.7	0.24 (0.04)	0.07 - 0.61
Infections specific to the perinatal period (P35-P39)	3	0.5	0.18	0.04 - 0.52
Congenital malformations, deformations and chromosomal abnormalities	**92**	**16.2**	**5.50**	**4.44 - 6.75**
Malformations of the circulatory system (Q20-Q28)	29	5.1	1.73	1.16 - 2.49
Chromosomal abnormalities, not elsewhere classified (Q90-Q99)	21	3.7	1.26	0.78 - 1.92
Malformations of the nervous system (Q00-Q07)	11	1.9	0.66	0.33 - 1.18
Other congenital malformations (Q80-Q89)	9	1.6	0.54	0.25 - 1.02
Malformations of the respiratory system (Q30-Q34)	8	1.4	0.48	0.21 - 0.94
Malformations and deformations of musculoskeletal system (Q65-Q79)	7	1.2	0.42	0.17 - 0.86
Malformations of the digestive system (Q38-Q45)	5	0.9	0.30	0.10 - 0.70
Malformations of the urinary system (Q60-Q64)	2	0.4	0.12	0.01 - 0.43
Neoplasms	**44**	**7.8**	**2.63**	**1.91 - 3.53**
Malignant neoplasms of eye/brain/other parts of the central nervous system (C69-C72)	16	2.8	0.96	0.55 - 1.55
Malignant neoplasms of lymphoid/haematopoietic tissue (C81-C96)	14	2.5	0.84	0.46 - 1.40
Malignant neoplasms of bone/cartilage (C40-C41)	5	0.9	0.30	0.10 - 0.70
Malignant neoplasms of thyroid and other endocrine glands (C73-C75)	3	0.5	0.18	0.04 - 0.52
Malignant neoplasms of mesothelial and soft tissue (C45-C49)	2	0.4	0.12	0.01 - 0.43
Malignant neoplasms of urinary tract (C64-C68)	2	0.4	0.12	0.01 - 0.43
Malignant neoplasms of digestive organs (C15-C26)	1	0.2	0.06	0.00 - 0.33
Neoplasms of uncertain or unknown behaviour (D37-D48)	1	0.2	0.06	0.00 - 0.33
Diseases of the nervous system	**34**	**6.0**	**2.03**	**1.41 - 2.84**
Diseases of myoneural junction/muscle (G70-G73)	11	1.9	0.66	0.33 - 1.18
Cerebral palsy/other paralytic syndromes (G80-G83)	5	0.9	0.30	0.10 - 0.70
Other degenerative diseases of the central nervous system (G30-G32)	5	0.9	0.30	0.10 - 0.70
Episodic and paroxysmal disorders (G40-G47)	4	0.7	0.24	0.07 - 0.61
Other disorders of the nervous system (G90-G99)	3	0.5	0.18	0.04 - 0.52
Systemic atrophies primarily affecting the central nervous system (G10-G14)	3	0.5	0.18	0.04 - 0.52
Inflammatory diseases of the central nervous system (G00-G09)	2	0.4	0.12	0.01 - 0.43
Extrapyramidal and movement disorders (G20-G26)	1	0.2	0.06	0.00 - 0.33
Diseases of the respiratory system	**18**	**3.2**	**1.08**	**0.64 - 1.70**
Influenza and pneumonia (J09-J18)	7	1.2	0.42	0.17 - 0.86
Acute lower respiratory infections (J20-J22)	4	0.7	0.24	0.07 - 0.61
Chronic lower respiratory diseases (J40-J47)	4	0.7	0.24	0.07 - 0.61
Suppurative and necrotic conditions of lower respiratory tract (J85-J86)	2	0.4	0.12	0.01 - 0.43
Diseases principally affecting the interstitium (J80-J84)	1	0.2	0.06	0.00 - 0.33

† Infant Mortality Rate.

Trends in deaths of children from natural causes, 1999-2013

Over the past 15 years, there has been a decline in the rate of death of children from natural causes, as shown in the table below. The number of natural cause deaths of children in 2013 was 26% lower than in 1999.

While the natural cause mortality rate in 2013 was slightly higher than 2012, it remained lower than the 15-year average (28.6 deaths per 100,000 children).

The number of natural cause deaths of boys in 2013 was 30% lower than in 1999; the decrease for girls between 1999 and 2013 was 20%.

Table 22: Trends in deaths of children due to natural causes by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	253 (32.8)	225 (29.0)	230 (29.5)	201 (25.8)	206 (26.5)	209 (27.0)	207 (26.8)	199 (25.7)	194 (24.9)	196 (25.0)	192 (24.3)	187 (23.5)	197 (24.7)	151 (18.8)	202 (24.9)
Male	323 (39.8)	289 (35.4)	288 (35.1)	234 (28.5)	246 (30.1)	247 (30.3)	285 (35.0)	257 (31.5)	235 (28.6)	269 (32.5)	249 (29.9)	262 (31.2)	246 (29.1)	211 (24.8)	226 (26.3)
Both	576 (36.4)	514 (32.3)	518 (32.3)	435 (27.2)	452 (28.3)	456 (28.7)	492 (31.0)	456 (28.6)	429 (26.8)	465 (28.8)	441 (27.2)	449 (27.5)	443 (27.0)	362 (21.9)	428 (25.6)

Chapter 7. Deaths from conditions arising in the perinatal period

In 2013, 188 children whose deaths were registered in NSW died as a result of perinatal conditions. While the rate of death from perinatal conditions in 2013 (1.9 deaths per 1,000 live births) was higher than 2012, it remained lower than the 15-year average (2.3 deaths per 1,000 live births).

Perinatal conditions are those that 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.

Demographic and individual characteristics

The following table provides an overview of the key demographic characteristics of the 188 children who died from perinatal conditions. In this table, mortality rates are represented as Infant Mortality Rates (deaths per 1,000 live births).

Table 23: Key demographic and individual characteristics – deaths due to perinatal conditions, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**188**	**100**	**1.91**	**1.64 - 2.18**		
Gender						
Female	82	44	1.71	1.32 - 2.06	-	-
Male	106	56	2.09	1.69 - 2.49	1.2	0.09
Age						
Under 1 day	113	60	1.15	0.94 - 1.36	-	-
1 day - under 1 week	38	20	0.39	0.27 - 0.52	-	-
1 week - under 28 days	18	10	0.18	0.11 - 0.28	-	-
28 days - under 1 year	17	9	0.17	0.10 - 0.27	-	-
1 year and over	2	1	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	159	85	1.71	1.44 - 1.98	-	-
Aboriginal or Torres Strait Islander	29	15	5.28	3.42 - 7.32	3.1	0
Remoteness*						
Major cities	136	72	1.80	1.49 - 2.10	-	-
Inner regional areas	37	20	2.24	1.50 - 2.94	-	-
Outer regional areas	13	7	2.49	1.19 - 3.83	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	34	18	1.88	1.30 - 2.62	-	-
Quintile 4	25	13	1.34	0.87 - 1.98	-	-
Quintile 3	34	18	1.86	1.29 - 2.59	-	-
Quintile 2	33	18	1.79	1.23 - 2.51	-	-
Quintile 1 (lowest)	58	31	2.98	2.26 - 3.85	-	-

*Remoteness was not calculated in two cases.
**Socioeconomic status was not calculated in four cases.

Age and gender

The vast majority (169) of the children who died from perinatal conditions were younger than 28 days when they died; most (113) died on the day they were born. This is consistent with previous years.

As shown in the following table, over the past 15 years, boys have typically had a higher mortality rate from perinatal conditions than girls. While the mortality rates in 2013 were slightly higher than 2012, they were lower than the 15-year average for both boys (average 2.5 deaths per 1,000 live births) and girls (average 2 deaths per 1,000 live births).

Table 24: Trends in deaths of children due to perinatal conditions by gender, 1999 – 2013, number and (Infant Mortality Rate)

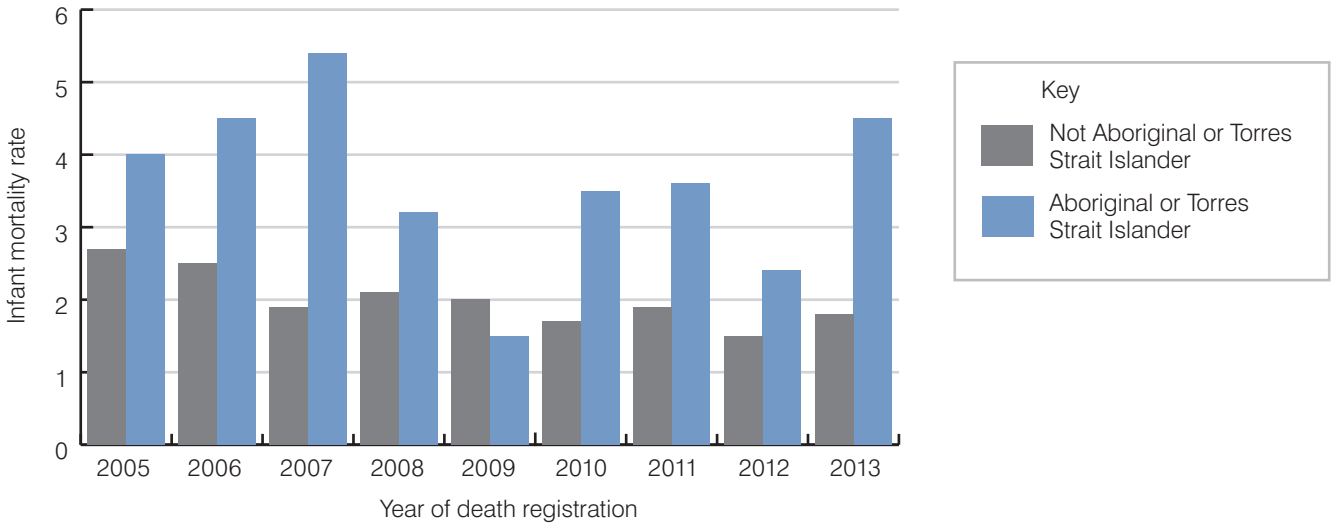
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	102 (2.4)	107 (2.5)	108 (2.6)	85 (2.0)	99 (2.4)	82 (2.0)	108 (2.4)	94 (2.1)	88 (1.9)	88 (1.9)	84 (1.8)	71 (1.4)	86 (1.8)	57 (1.2)	82 (1.7)
Male	149 (3.4)	139 (3.1)	136 (3.1)	102 (2.3)	100 (2.2)	101 (2.3)	148 (3.2)	144 (3.0)	110 (2.2)	125 (2.4)	116 (2.3)	114 (2.2)	110 (2.2)	92 (1.8)	106 (2.1)
Both	251 (2.9)	246 (2.8)	244 (2.9)	187 (2.2)	199 (2.3)	183 (2.1)	256 (2.8)	238 (2.6)	198 (2.1)	212 (2.1)	200 (2.0)	185 (1.8)	196 (2.0)	149 (1.5)	188 (1.9)

Aboriginal and Torres Strait Islander status

Twenty-eight children who died of perinatal conditions were Aboriginal, and one child was Torres Strait Islander. The mortality rate for Aboriginal and Torres Strait Islander children from this cause (5.28 deaths per 1,000 live births) was over three times the rate for non-Indigenous children.

As shown in the figure below, the mortality rate of Aboriginal and Torres Strait Islander children from perinatal conditions has been higher than the rate for non-Aboriginal and Torres Strait Islander children for eight of the past nine years. The difference in the perinatal mortality rate in 2013 was the second highest over that period.

Figure 5: Trends in deaths of children due to perinatal conditions by Aboriginal and Torres Strait Islander status and infant mortality rate, 2005-2013[20]



20 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.

Remoteness and socioeconomic status

While the largest proportion of children who died from perinatal conditions in 2013 resided in major cities, the highest rate of death from this cause was in outer regional areas.

Just under one-third of the children resided in areas of greatest socioeconomic disadvantage (quintile 1). This is different to 2012 and 2011, where the largest proportion resided in areas of greatest socioeconomic advantage (quintile 5).

Leading causes of death from conditions originating in the perinatal period

Consistent with previous years, the leading cause of death from perinatal conditions in 2013 was maternal factors and complications of pregnancy, labour and delivery, accounting for over one-third of all perinatal deaths (73). Of the 73 deaths from this cause:

- half (37) were due to complications of placenta, cord and membranes, mainly chorioamnionitis[21] (17) or placental separation and haemorrhage (11)
- over one-third (28) were due to maternal complications of pregnancy, mainly related to premature rupture of membranes (15), oligohydramnios[22] (6), or incompetent cervix (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 under one-third of deaths from perinatal conditions (59). The majority of these deaths (49) were due to extreme immaturity.

Twelve percent of deaths from perinatal conditions (23) were due to respiratory and cardiovascular disorders; mainly birth asphyxia (8), intrauterine hypoxia (3), and chronic neonatal lung disease (3).

Over the history of the Team, the number of deaths due to chorioamnionitis has increased. The number of deaths from this cause in 2013 (17) was almost double the average (9) over the 18-year period.

Table 25: Leading causes of death from perinatal conditions, 2013

Type	Female	Male	Total	Infant Mortality Rate	95% Confidence Interval
Maternal/obstetric factors	34	39	73	0.74	0.57 - 0.91
Length of gestation (prematurity)	29	30	59	0.60	0.44 - 0.75
Respiratory/cardiovascular disorders	11	12	23	0.23	0.14 - 0.34
Other perinatal conditions	4	7	11	0.11	0.05 - 0.19
Haemorrhagic/haematological disorders	3	6	9	0.09	0.04 - 0.17
Digestive system disorders	0	6	6	0.06	0.02 - 0.13
Disorders of thermoregulation	1	3	4	0.04	0.01 - 0.10
Infections	0	3	3	-	-
Total	**82**	**106**	**188**		

21 Bacterial infection of the foetal membranes.
22 A deficiency of amniotic fluid.

Chapter 8. Deaths from congenital and chromosomal conditions

In 2013, 92 children whose deaths were registered in NSW died as a result of congenital malformations and chromosomal abnormalities ('congenital and chromosomal conditions'). As has consistently been the case, congenital and chromosomal conditions was the second leading cause of death, accounting for 17% of all deaths of children in NSW in 2013.

The majority of deaths (71) were due to congenital factors, such as congenital heart conditions. The deaths of 21 children were due to chromosomal causes, such as trisomy 18 (Edwards syndrome).

Demographic and individual characteristics

The table below provides an overview of the key demographics of the 92 children whose underlying cause of death was congenital and chromosomal conditions.

Table 26: Key demographic and individual characteristics – deaths due to congenital and chromosomal causes, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**92**	**100**	**5.5**	**4.44 - 6.75**		
Gender						
Female	46	50	5.7	4.15 - 7.55	-	-
Male	46	50	5.3	3.92 - 7.14	0.9	0.39
Age						
Under 1 year	75	82	74.6 (IMR = 0.76)†	58.68 - 93.52	-	-
1-4 years	9	10	2.3	1.06 - 4.41	-	-
5-9 years	4	4	0.9	0.23 - 2.20	-	-
10-14 years	3	3	0.7	0.14 - 1.96	-	-
15-17 years	1	1	0.4	0.01 - 2.04	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	84	91	5.3	8.72 - 13.53	-	-
Aboriginal or Torres Strait Islander	8	9	8.8	3.79 - 17.31	1.7	0.09
Remoteness						
Major cities	71	77	5.9	4.61 - 7.44	-	-
Inner regional areas	17	18	5.1	2.99 - 8.21	-	-
Outer regional areas	2	2	1.9	0.23 - 6.83	-	-
Remote areas	1	1	13.3	0.34 - 74.32	-	-
Very remote areas	1	1	44.8	1.13 - 249.40	-	-
Socioeconomic status						
Quintile 5 (highest)	13	14	3.7	1.96 - 6.30	-	-
Quintile 4	9	10	2.7	1.25 - 5.19	-	-
Quintile 3	22	24	7.0	4.36 - 10.54	-	-
Quintile 2	16	17	5.1	2.91 - 8.27	-	-
Quintile 1 (lowest)	32	35	9.5	6.52 - 13.47	-	-

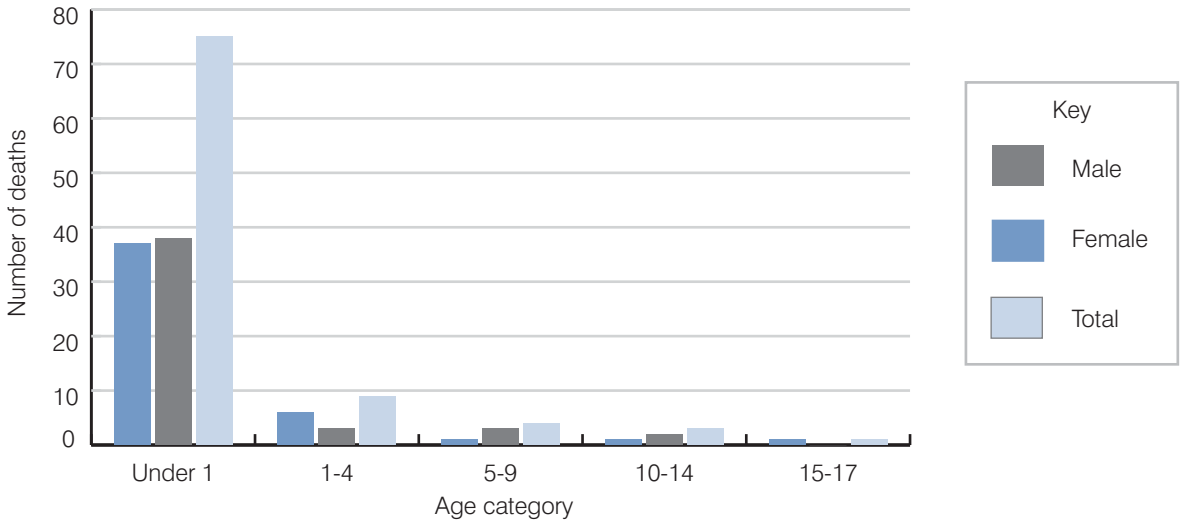
† Infant Mortality Rate.

Age, gender and Aboriginal and Torres Strait Islander status

The vast majority (75) of the children who died from congenital and chromosomal conditions were less than one year of age at the time of their death. Over half of these children (52) died in the first 28 days of life.

Congenital and chromosomal conditions were the second leading cause of death for children aged 0-4 years; the fourth leading cause of death amongst children 5-9 years; and the equal third leading cause of death of children aged 10-14 years.

Figure 6: Deaths due to congenital and chromosomal causes by age and gender, 2013



In 2013, an equal number of boys and girls died as a result of congenital and chromosomal conditions. As indicated in the table below, this has not historically been the case – boys have typically outnumbered girls in deaths from this cause.

Six children who were identified as Aboriginal died of congenital and chromosomal conditions in 2013. The rate of death of Aboriginal and Torres Strait Islander children from this cause in 2013 (6.5 per 100, 000) was slightly higher than that of non-Indigenous children (5.4 per 100 000). This is consistent with previous years.

Table 27: Trends in deaths of children due to congenital and chromosomal causes by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	62 (8.0)	45 (5.8)	49 (5.3)	47 (6.0)	40 (5.1)	48 (6.2)	40 (5.2)	33 (4.3)	44 (5.6)	53 (6.8)	56 (7.1)	59 (7.4)	48 (6.0)	42 (5.2)	46 (5.7)
Male	64 (7.9)	59 (7.2)	56 (6.8)	35 (4.3)	46 (5.6)	59 (7.2)	55 (6.7)	43 (5.3)	48 (5.8)	59 (7.1)	59 (7.1)	61 (7.3)	64 (7.6)	60 (7.0)	46 (5.3)
Both	126 (8.0)	104 (6.5)	105 (6.6)	82 (5.1)	86 (5.4)	107 (6.7)	95 (6.0)	76 (4.8)	92 (5.7)	112 (6.9)	115 (7.1)	120 (7.3)	112 (6.8)	102 (6.2)	92 (5.5)

Leading causes of death due to congenital and chromosomal causes

In 2013, the leading causes of death of children from congenital and chromosomal causes were:

1. **Congenital malformations of the circulatory system** (29, 31%) – mainly other specified congenital malformations of the heart (10), and malformations of the cardiac chambers and connections (5) and the great arteries (5).
2. **Chromosomal abnormalities, not elsewhere classified** (21, 22%) – primarily Edwards and Patau's syndromes (10).

3. **Congenital malformations of the nervous system** (11, 12%) – mainly congenital malformations of the brain such as neural tube defects (7) and spina bifida (2).
4. **Other congenital malformations** (9, 10%) – including Marfan's syndrome (2).
5. **Congenital malformations of the respiratory system** (8, 9%) mainly hypoplasia and dysplasia of the lung (4).

Congenital circulatory system conditions are the most commonly reported congenital conditions in NSW, and have consistently been a leading congenital cause of death of children. The number of deaths of children from this cause in NSW in 2013 was slightly lower than the 15-year average (31).

As indicated in the table below, infants were prevalent in all of the leading causes of deaths from congenital and chromosomal conditions, including those related to the circulatory system (24; 83%), chromosomal abnormalities (18; 86%) and congenital malformations of the nervous system (9; 100%).

Table 28: Leading causes of deaths due to congenital and chromosomal conditions by age, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Circulatory system 24	Nervous system 2	Chromosomal 2	Circulatory system 3	Other congenital 1
Chromosomal 18	Other congenital 2	Circulatory system 1		
Nervous system 9	Circulatory system 1	Musculoskeletal 1		
Other congenital 6	Chromosomal 1			
Respiratory system 7	Respiratory system 1			
Musculoskeletal 6	Digestive system 1			
Digestive system 4	Urinary system 1			
Urinary system 1				

Chapter 9. Deaths from neoplasms

In 2013, 44 children whose deaths were registered in NSW died as a result of neoplasms (cancers and tumours). Consistent with Australia-wide information,[23] neoplasms were the leading natural cause of death of children aged one year and over in NSW.

While the rate of death of children from neoplasms in 2013 (2.6 per 100,000 children) was higher than 2012, it is largely consistent with the average mortality rate from this cause over the past 15 years (2.8 per 100,000 children).

Demographic and individual characteristics

The table below provides an overview of the main demographic characteristics of children who died as a result of neoplasms in 2013.

Table 29: Key demographics and individual characteristics – deaths due to neoplasms, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**44**	**100**	**2.6**	**1.91 - 3.53**		
Gender						
Female	30	68	3.7	2.49 - 5.27	-	-
Male	14	32	1.6	0.89 - 2.73	0.4	0
Age						
Under 1 year	1	2	1.0 (IMR = 0.01)†	0.03 - 5.54	-	-
1-4 years	18	41	4.7	2.76 - 7.35	-	-
5-9 years	7	16	1.5	0.61 - 3.10	-	-
10-14 years	9	20	2.0	0.92 - 3.82	-	-
15-17 years	9	20	3.3	1.51 - 6.25	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	43	98	2.7	4.05 - 7.53	-	-
Aboriginal or Torres Strait Islander	1	2	-	-	-	-
Remoteness*						
Major cities	33	75	2.7	1.89 - 3.85	-	-
Inner regional areas	8	18	2.4	1.04 - 4.76	-	-
Outer regional areas	2	5	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	7	16	2.0	0.80 - 4.09	-	-
Quintile 4	5	11	1.5	0.49 - 3.54	-	-
Quintile 3	10	23	3.2	1.52 - 5.82	-	-
Quintile 2	14	32	4.5	2.44 - 7.48	-	-
Quintile 1 (lowest)	7	16	2.1	0.84 - 4.30	-	-

*Remoteness was not calculated in one case
**Socioeconomic status was not calculated in one case
† Infant Mortality Rate

23 Australian Institute of Health and Welfare 2012, *A picture of Australia's children 2012*. Cat. No. PHW 167. Canberra: AIHW

Age, gender and Aboriginal and Torres Strait Islander status

In 2013, neoplasms were:

- the overall leading cause of death of children aged 1-4 years and 10-14 years, and
- the leading natural cause of death of children aged 5-9 years and 15-17 years.

More than twice as many females (30) died from neoplasms than males (14), and the mortality rate for girls was higher (3.6 per 100 000) than boys (1.6 per 100,000 children). As shown in the table below, the neoplasms mortality rate for boys has generally, but not always, been higher than the mortality rate for girls over the past 15 years.

One of the 44 children who died from neoplasms was Aboriginal.

Table 30: Trends in deaths of children due to neoplasms by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	23 (3.0)	23 (3.4)	26 (3.3)	18 (2.3)	19 (2.4)	29 (3.7)	18 (2.3)	18 (2.3)	23 (2.9)	15 (1.9)	11 (1.4)	22 (2.8)	23 (2.9)	14 (1.7)	13 (3.7)
Male	41 (5.1)	26 (3.2)	33 (4.0)	29 (3.5)	34 (4.2)	25 (3.1)	21 (2.6)	13 (1.6)	24 (2.9)	18 (2.2)	21 (2.5)	22 (2.6)	26 (3.1)	16 (1.9)	14 (1.6)
Both	64 (4.0)	52 (3.3)	59 (3.7)	47 (2.9)	53 (3.3)	54 (3.4)	39 (2.5)	31 (1.9)	47 (2.9)	33 (2.0)	32 (2.0)	44 (2.7)	49 (3.0)	30 (1.8)	44 (2.6)

Leading causes of deaths due to neoplasms

The following table shows the leading types of neoplasms for children whose deaths were registered in NSW in 2013, by age group.

Table 31: Leading causes of death due to neoplasms by age, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Brain 1	Brain 10	Leukaemia 4	Brain 4	Leukaemia 5
	Adrenal gland 2	Adrenal gland 1	Bone 2	Bone 2
	Bone 1	Connective/soft tissue 1	Leukaemia 2	Brain 2
	Connective/soft tissue 1	Kidney 1	Lymphoma 1	
	Kidney 1			
	Leukaemia 1			
	Liver 1			
	Lymphoma 1			
	Pineal gland 1			

In 2013, malignant brain tumours were the most common cause of deaths from neoplasms, accounting for the deaths of 17 children. While the deaths of children from brain tumours occurred across most age groups, the majority (11) of the children were under five years of age.

Approximately 100 children in Australia are diagnosed with malignant brain tumours each year. While they are rare, brain tumours are the second most common cancer in children. The causes of most brain and spinal cord tumours are unknown.[24] The number of deaths of children due to brain tumours in NSW in 2013 was slightly higher than the 15-year average (13). 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 14 children. The vast majority (12) were due to leukaemias – the most common of all childhood cancers.[25] Of the 12 children who died from leukaemias in 2013, half (6) died from acute lymphoblastic leukaemia. Four children died from acute myeloid leukaemia, and two children died from acute leukaemia of unspecified cell type. The number of deaths due to leukaemias in 2013 is consistent with the average over the past 15 years.

Five children died as a result of bone cancer, all of whom were female.

24 Cancer Council NSW, 2011, *Understanding Brain Tumours: A guide for people with brain or spinal cord tumours and their families and friends.* Sydney: Cancer Council NSW.

25 Leukaemia Foundation, 2011, *Blood cancers in children factsheet*. Windsor, QLD: Leukaemia Foundation.

Chapter 10. Deaths from diseases of the nervous system

In 2013, 34 children whose deaths were registered in NSW died from diseases of the nervous system. While the mortality rate from this cause (1.97 per 100,000 children) was the highest since 2006, it was consistent with the average over the past 15 years.

Nervous system diseases include a broad range of conditions, such as epilepsy, cerebral palsy, muscular dystrophy and degenerative diseases of the brain.

Consistent with previous years, nervous system diseases were the fourth leading cause of death of children in 2013.

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of the 33 children whose deaths were due to nervous system diseases in 2013.

Table 32: Key demographic and individual characteristics – deaths due to diseases of the nervous system

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**34**	**100**	**2.0**	**1.41 - 2.84**		
Gender						
Female	17	50	2.1	1.22 - 3.35	-	-
Male	17	50	2.0	1.15 - 3.17	0.9	0.44
Age						
under 1 year	17	50	16.9 (IMR = 0.17)†	9.85 - 27.08	-	-
1-4 years	1	3	-	-	-	-
5-9 years	7	21	1.5	0.61 - 3.10	-	-
10-14 years	6	18	1.3	0.49 - 2.92	-	-
15-17 years	3	9	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	33	97	2.1	2.95 - 6.03	-	-
Aboriginal or Torres Strait Islander	1	3	-	-	-	-
Remoteness						
Major cities	29	85	2.4	1.61 - 3.46	-	-
Inner regional areas	4	12	1.2	0.33 - 3.09	-	-
Outer regional areas	1	3	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	4	12	1.1	0.31 - 2.90	-	-
Quintile 4	8	24	2.4	1.05 - 4.78	-	-
Quintile 3	8	24	2.5	1.09 - 4.99	-	-
Quintile 2	4	12	1.3	0.35 - 3.26	-	-
Quintile 1 (lowest)	10	29	3.0	1.43 - 5.48	-	-

† Infant Mortality Rate.

Age, gender and Aboriginal and Torres Strait Islander status

Half of the 34 children who died from nervous system diseases were infants, including seven children who were less than 28 days old. In 2013, nervous system disease was:

- the fourth leading cause of death for infants
- the third leading cause of children aged 5-9 years, and
- the second leading cause of death of children aged 10-14 years.

Of the 34 children, 17 were female and 17 were male. One child was identified as Aboriginal.

Table 33: Trends in deaths of children due to diseases of the nervous system by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	17 (2.2)	12 (1.5)	21 (2.7)	18 (2.3)	18 (2.3)	21 (2.7)	11 (1.4)	21 (2.7)	9 (1.2)	15 (1.9)	14 (1.8)	10 (1.3)	13 (1.6)	10 (1.2)	17 (2.1)
Male	17 (2.1)	27 (3.3)	15 (1.8)	23 (2.8)	28 (3.4)	26 (3.2)	18 (2.2)	18 (2.2)	8 (1.0)	11 (1.3)	17 (2.0)	18 (2.1)	13 (1.5)	15 (1.8)	17 (2.0)
Both	34 (2.1)	39 (2.5)	36 (2.2)	41 (2.6)	46 (2.9)	47 (3.0)	29 (1.8)	39 (2.5)	17 (1.1)	26 (1.6)	31 (1.9)	28 (1.7)	26 (1.6)	25 (1.5)	34 (2.0)

Remoteness and socioeconomic status

The vast majority of children who died of nervous system diseases (28) lived in major cities in NSW. Just below one-third (10) lived in areas of greater socioeconomic disadvantage.

Leading causes of death due to diseases of the nervous system

As shown in the table below, the leading causes of death from nervous system diseases in 2013 were congenital myopathies[26] (8), cerebral palsy (5), degenerative diseases of the nervous system (5), and epilepsy (4).

The five children who died as a result of cerebral palsy were aged between five and 11 years. All had epilepsy/seizure disorder and recurrent respiratory issues, primarily aspiration pneumonia, and most (4) relied on enteral nutrition via a gastrostomy tube. Two children were receiving palliative care at the time of their death. The number of deaths attributed to cerebral palsy in 2013 was slightly lower than the 15-year average (7).

Respiratory illness, including aspiration pneumonia and acute respiratory tract infections, was a common factor in the deaths of five children from degenerative diseases of the nervous system.

The four children whose deaths were associated with epilepsy ranged in age from 16 months to 16 years. Two of the deaths were sudden and unexpected. All of the children had medical oversight of their epilepsy and were prescribed anticonvulsant medication; in one case, the GP identified problems with the child's compliance with taking the medication. The number of deaths attributed to epilepsy in 2013 was slightly lower than the 15-year average (5).

26 Congenital myopathies are rare, inherited, primary muscle disorders that cause hypotonia and weakness at birth or during the neonatal period. Merck Sharp & Dohme Corp. 2013, *Congenital Myopathies*, http://www.merckmanuals.com/professional/pediatrics/inherited_muscular_disorders/congenital_myopathies.html, accessed 16 July 2014.

Table 34: Leading causes of death from diseases of the nervous system, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Congenital myopathies 8	Status epilepticus 1	Cerebral palsy 4	Epilepsy 2	Epilepsy 1
Spinal muscular atrophy 3		Degenerative diseases of the nervous system 1	Cerebral palsy 1	Degenerative diseases of the nervous system 1
Degenerative diseases of the nervous system 2		Disorder of the central nervous system 1	Degenerative diseases of the nervous system 1	Mitochondrial myopathy 1
Myoneural disorder 1		Streptococcal meningitis 1	Degenerative disease basal ganglia 1	
Myotonic disorder 1			Bacterial meningoencephalitis 1	
Encephalopathy 1				
Other hydrocephalus 1				

Chapter 11. Deaths from diseases of the respiratory system

In 2013, 18 children whose deaths were registered in NSW died from respiratory diseases. The mortality rate from this cause (1.08 per 100,000 children) was the highest since 2008.

Respiratory diseases include conditions such as pneumonia and asthma.

Demographic and individual characteristics

The following table provides an overview of the key demographics of the 18 children who died from respiratory diseases in 2013.

Table 35: Key demographic and individual characteristics – deaths due to respiratory diseases, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
All	**18**	**100**	**1.1**	**0.64 - 1.70**		
Gender						
Female	5	28	0.6	0.20 - 1.44	-	-
Male	13	72	1.5	0.81 - 2.59	2.5	0.04
Age						
under 1 year	4	22	4.0 (IMR = 0.04)†	1.08 - 10.19	-	-
1-4 years	5	28	1.3	0.42 - 3.01	-	-
5-9 years	2	11	-	-	-	-
10-14 years	2	11	-	-	-	-
15-17 years	5	28	1.8	0.59 - 4.27	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	15	83	0.9	1.09 - 3.22	-	-
Aboriginal or Torres Strait Islander	3	17	-	-	-	-
Remoteness						
Major cities	11	61	0.9	0.46 - 1.64	-	-
Inner regional areas	6	33	1.8	0.66 - 3.94	-	-
Outer regional areas	1	6	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	2	11	-	-	-	-
Quintile 4	2	11	-	-	-	-
Quintile 3	2	11	-	-	-	-
Quintile 2	5	28	1.6	0.52 - 3.72	-	-
Quintile 1 (lowest)	7	39	2.1	0.84 - 4.30	-	-

† Infant Mortality Rate.

Age, gender and Aboriginal and Torres Strait Islander status

While deaths of children from respiratory diseases occurred in all age ranges, half (9) of the children were under five years of age.

Almost three-quarters (13) of the children who died from respiratory diseases were male; five children were female. As shown in the table below, the mortality rate of boys from this cause (1.5 per 100,000 children) was the highest since 1999.

In 2013, three of the 18 children who died from respiratory diseases were identified as Aboriginal (2) or Aboriginal and Torres Strait Islander.

Table 36: Trends in deaths of children due to diseases of the respiratory system by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	9 (1.2)	5 (0.6)	5 (0.6)	5 (0.6)	7 (0.9)	7 (0.9)	2 (0.3)	3 (0.4)	5 (0.6)	9 (1.1)	4 (0.5)	7 (0.9)	4 (0.5)	8 (1.0)	5 (0.6)
Male	14 (1.7)	9 (1.1)	9 (1.1)	11 (1.3)	8 (1.0)	9 (1.1)	5 (0.6)	8 (1.0)	9 (1.1)	10 (1.2)	5 (0.6)	10 (1.2)	4 (0.5)	6 (0.7)	13 (1.5)
Both	23 (1.5)	14 (0.9)	14 (0.9)	16 (1.0)	15 (0.9)	16 (1.0)	7 (0.4)	11 (0.7)	14 (0.9)	19 (1.2)	9 (0.6)	17 (1.0)	8 (0.5)	14 (0.8)	18 (1.1)

Remoteness and socioeconomic status

The vast majority of the children lived in major cities (11) or inner regional areas (6) of NSW. Two-thirds (12) of the 18 children who died from respiratory diseases were from the most socioeconomically disadvantaged areas.

Leading causes of death due to respiratory diseases

The most common respiratory diseases that caused the deaths of children in NSW in 2013 were pneumonia (5), asthma (4), acute lower respiratory infections (4), and influenza (2).

Of the seven children who died from pneumonia and influenza, just over half (4) were three years of age and younger. The other three children were aged 13 years and older. Most (5) were male.

Asthma was the cause of death of four children in 2013. All of the children were male, and were aged between eight and 16 years of age. This year, the Team conducted a cohort review of the deaths of children from asthma between 2004 and 2013. Chapter 12 outlines the key data and other information relating to these deaths.

Four children died from acute lower respiratory infections; three of which were due to unspecified pathogens. One child died from acute bronchitis due to echovirus 11.

Table 37: Leading causes of death due to respiratory diseases by age, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Acute bronchitis 1	Acute lower respiratory infection, unspecified 2	Acute lower respiratory infection, unspecified 1	Status asthmaticus 1	Asthma, unspecified 1
Bronchopneumonia unspecified 2	Pneumonia due to staphylococcus 1	Status asthmaticus 1	Parainfluenza virus pneumonia 1	Status asthmaticus 1
Pneumonia due to staphylococcus 1	Influenza 1			Bronchopneumonia unspecified 1
Gangrene and necrosis of lung 1	Pyothorax 1			Pneumonia unspecified 1
				Acute respiratory distress syndrome 1

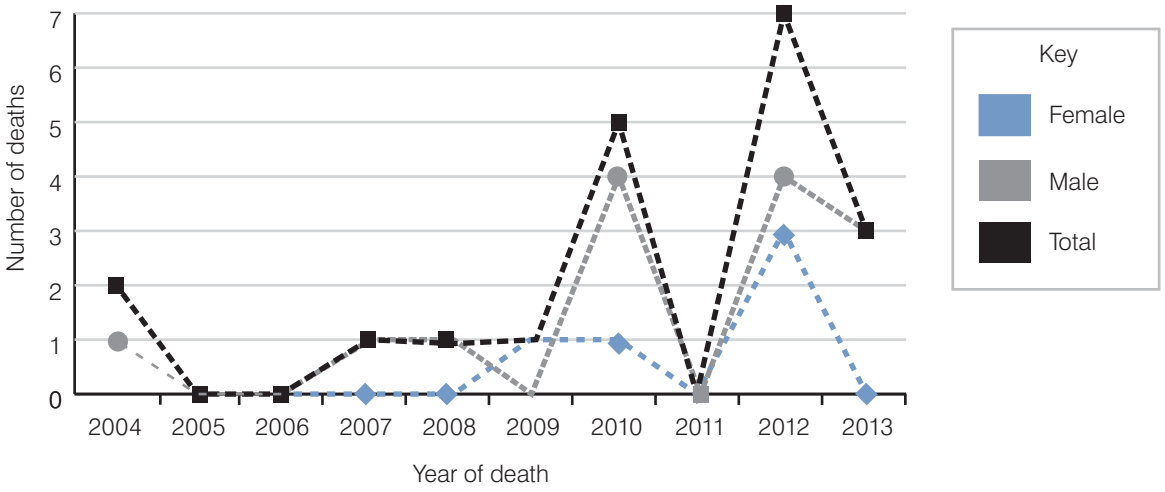
Chapter 12. Deaths from asthma 2004-2013

In the 10 years between 2004 and 2013, 20 children in NSW died from asthma.[27]

Asthma is a common chronic respiratory illness that causes episodes of wheezing, breathlessness and chest tightness due to narrowing of the airways. Australia has a relatively high prevalence of asthma by international standards.[28] Over two million Australians have the condition, including around one in 10 children.[29] More boys than girls have asthma but after the age of 15 years, asthma is more common in females.[30]

Deaths from asthma are uncommon. In Australia, there has been a decline in asthma deaths since the early 1990s and, in the decade to 2011, there was a decrease in asthma prevalence among people aged 5-34 years. However, the Australian death rate from asthma is still high when compared to some other developed countries; including Canada, France, Japan, and Italy.[31] [32]

Figure 7: Trends in deaths of children due to asthma by gender, 2004-2013



While the number of child deaths in NSW from asthma is small, averaging two deaths per year, there were more deaths in 2010, 2012 and 2013 than in previous years. Half of the deaths in the 10-year period occurred in the last two years.

Demographic and individual characteristics

Table 38 provides an overview of the demographic characteristics of the children who died from asthma between 2004 and 2013.

27 Included in this chapter are all children for whom asthma was their underlying cause of death. Two additional deaths with asthma recorded on the death certificate have been excluded following expert advice that asthma was unlikely to have been the underlying cause of death.
28 Australian Centre for Asthma Monitoring 2011. Asthma in Australia 2011. AIHW Asthma Series no. 4. Cat. no. ACM 22 Canberra, AIHW. p21.
29 Ibid. p. vii.
30 Australian Bureau of Statistics 2012, 4364.0.55.001 - *Australian Health Survey: First Results, 2011–12 (Summary) - Australia: Asthma*, October 2012 release, Canberra: ABS.
31 Australian Centre for Asthma Monitoring 2011, op. cit, p51.
32 World Health Rankings, 2011, *Asthma Death Rate per 100,000 population, Age-standardised*, http://www.worldlifeexpectancy.com/cause-of-death/asthma/by-country, accessed 16 July 2014

Table 38: Key demographic and individual characteristics – deaths due to asthma, 2004-2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**20**	**100**	**1.2**	**0.73 - 1.85**		
Gender						
Female	6	30	0.7	0.27 - 1.61	-	-
Male	14	70	1.6	0.89 - 2.73	2.2	0.05
Age						
Under 1 year	0	0	-	-	-	-
1-4 years	1	5	-	-	-	-
5-9 years	5	25	1.1	0.35 - 2.51	-	-
10-14 years	11	55	2.5	1.23 - 4.41	-	-
15-17 years	3	15	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	19	95	1.2	1.49 - 3.86	-	-
Aboriginal or Torres Strait Islander	1	5	-		-	-
Remoteness*						
Major cities	12	60	1.0	0.52 - 1.74	-	-
Inner regional areas	4	20	1.2	0.33 - 3.09	-	-
Outer regional areas	4	20	3.8	1.03 - 9.68	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status*						
Quintile 5 (highest)	3	15	-	-	-	-
Quintile 4	2	10	-	-	-	-
Quintile 3	3	15	-	-	-	-
Quintile 2	5	25	1.6	0.52 - 3.72	-	-
Quintile 1 (lowest)	7	35	2.1	0.84 - 4.30	-	-

* Remoteness and Socioeconomic status were estimated based on the child's postcode of usual residence

Age and gender

Over two-thirds (14) of the 20 children who died from asthma were male. The rate of death of boys from asthma was more than twice the rate of girls for the same period.

While the children ranged in age from four to 17 years, more than half (11) were 10-14 years old.

Aboriginal and Torres Strait Islander status and cultural background

One of the 20 children who died from asthma was Aboriginal. Nine children had culturally and linguistically diverse backgrounds; mainly Asian (4) or Pacific Islander (3) backgrounds.

Remoteness and socioeconomic status

The majority (12) of the children resided in major cities; mainly (10) in suburbs of Sydney. Eight children resided in inner regional (4) or outer regional (4) areas. The regional areas were spread across NSW, with no particular regional patterns. None of the children lived in areas classified as remote or very remote.

Most of the children lived in areas of greatest socioeconomic disadvantage (quintiles 1 and 2).

Child protection history and psychosocial risk factors

Psychosocial issues were identified for the families of more than half (11) of the children who died from asthma. The most common issues were family breakdown, parent/carer substance abuse, domestic violence and neglect.

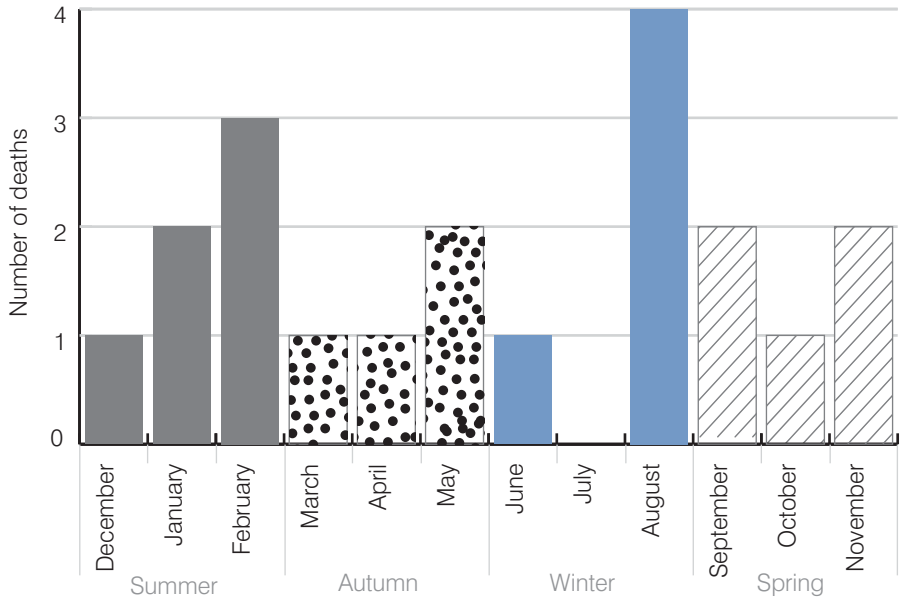
More than one-third (8) of the children who died had a child protection history. In the three years before their death, five children had been the subject of a report of risk of harm or risk of significant harm to Community Services. Three children had not been the subject of a child protection report but had a sibling who had been. One child who had a child protection history was in out-of-home care.

Psychosocial issues were evident for five of the 20 children themselves. The issues were about the child's mental health (3), criminal behaviour (2), education (2) and substance abuse (1). The children were aged 13 to 16 years.

Seasonal factors

No strong seasonal pattern was evident across the 20 deaths. Eleven children died in the warmer months of summer (6) and spring (5). As shown in the figure below, deaths of children from asthma occurred more frequently in August (4) and February (3).

Figure 8: Season and month of death



History of asthma and other health issues

All 20 children were known to have had asthma before their death. For the vast majority (18), asthma had been recorded at least three years beforehand.

Duration and type of asthma

Information about the child's age when asthma was first noted was available for 19 children. All were younger than seven years of age; most (16) were younger than five years when the condition was first noted. The other three children were aged five or six years at the time that asthma was first recorded.

In most cases (13), it was a general practitioner who first recorded that the child had asthma. For four other children, asthma was first recorded by a paediatrician (2) or noted in hospital records (2).[33]

The large majority of the children (16) appear to have had persistent asthma (symptoms on most days).[34] Four children had infrequent intermittent asthma (symptoms up to once every six weeks on average, with no symptoms between flare-ups).

33 For two children, records did not state who first recorded that they had asthma.
34 Persistent asthma may be mild, moderate or severe.

Allergy, atopy[35] and asthma triggers

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.[36] Food allergy has been found to increase the risk of asthma-related death.[37]

Eighteen children (90%) who died from asthma in 2004-2013 were allergic or atopic and/or had other triggers for asthma.[38] This is largely consistent with research, which shows that up to 80% of people who have asthma test positive to allergy.[39]

Two-thirds (13) of the children had a family history of asthma or atopy, including one child whose sibling also died from asthma.

Almost half (9) of the 20 children had eczema, including three children for whom eczema was recorded as chronic or severe. As shown in the table below, rhinitis (hay fever), food, weather/temperature changes and dust mites were the other most commonly occurring factors across the group of children who died from asthma.

Table 39: Atopy, allergy and asthma triggers

Factor	Number of children
Eczema	9
Seasonal or allergic rhinitis (hay fever)	7
Food (nuts, eggs, fish, dairy)	7
Weather/temperature change	7
Dust mites	6
Dogs/cats/other animals	5
Viral upper respiratory tract infection	4
Exercise induced	4
Pollen or grass	4
Other (including mould, cockroach, cotton, dust, cigarette smoke)	6

There was evidence that five children who died from asthma had undergone formal allergy testing (skin prick tests). In each case, testing confirmed that the child was allergic to certain foods (including egg, fish, nuts and dairy) and other substances.

Three children had a history of anaphylaxis and had previously used or been prescribed an EpiPen (epinephrine).

Seven children had a family member (parent or grandparent) who smoked and, in one case, the child also smoked.[40] Cigarette smoke was identified as an asthma trigger for one child.

Hospital presentations

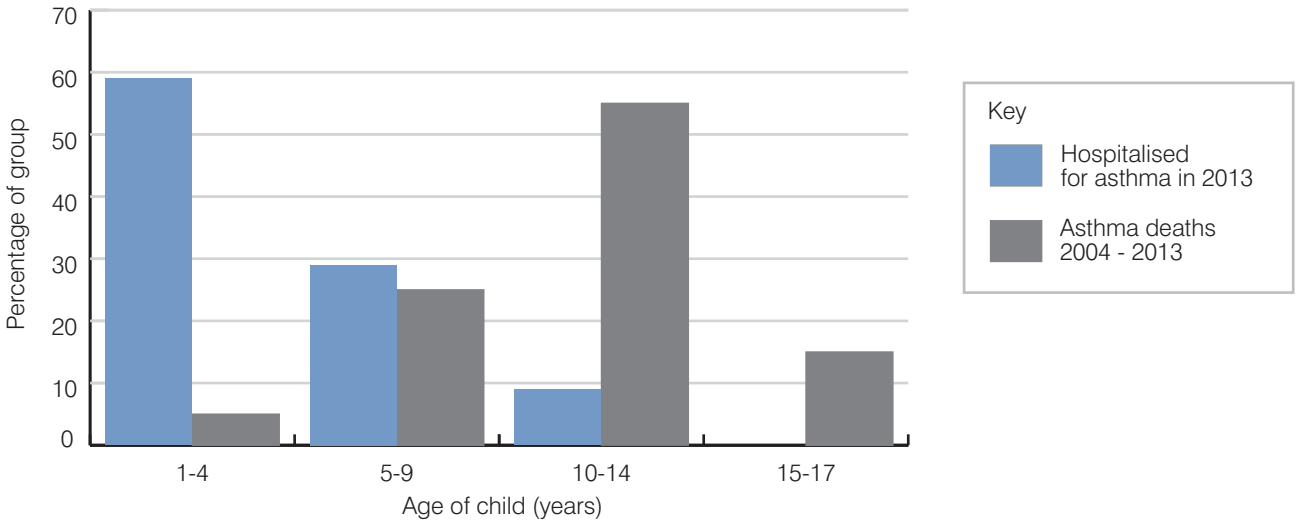
Each year in NSW, more than 6,000 children aged 1-17 years are hospitalised for asthma. In 2013, children in this age range accounted for almost two-thirds of all asthma hospitalisations across the state.[41]

Younger children, particularly children aged under five years, are more likely to be hospitalised for asthma than older children, and boys are more likely to be hospitalised for asthma than girls.[42]

35 Atopy is a genetically determined state of hypersensitivity to environmental allergens.
36 Vernon M. K. Wilund 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.
37 Global Initiative for Asthma 2014, *Global Strategy for Asthma Management and Prevention*, USA: GINA, p59. http://www.ginasthma.org/, accessed 16 July 2014.
38 Information on allergy was missing for one child.
39 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 2 July 2014.
40 For three children, information about exposure to smoking was not available.
41 Where the primary ICD-10 code was J45 (asthma) or J46 (status asthmaticus), and asthma was the primary reason for admission or presentation.
42 NSW Health 2014, *Admitted Patient, Emergency Department Attendance and Death Register, SaPHaRI*, Sydney: NSW Health.

The pattern of hospitalisation in NSW across age groups of children is opposite to the pattern of deaths in this cohort. The figure below shows that, while children aged 10-14 years comprised around 9% of hospitalisations in 2013,[43] they comprised 55% of deaths in this cohort.

Figure 9: Pattern of hospitalisations and pattern of deaths for asthma – NSW children



Three-quarters (15) of the children who died from asthma had a hospital emergency presentation and/or admission for asthma within the past five years.

The table below shows that most (9) of the children stayed in hospital for 2-5 days. However, at either end of the spectrum, one-third (5) were in hospital for one day or less, and one child was in hospital for over 10 days. Four of the children had been admitted to a paediatric intensive care unit (PICU).

Table 40: Hospitalisation for asthma (last five years) – length of stay

Length of stay (last 5 years)	Number of children
1 day or less	5
2-5 days	9
>10 days	1
Total	**15**

Of the 15 children who had been to hospital for asthma within the past five years, most (11) presented/were admitted to hospital for the condition in the year before their death.

The two tables below show the number and duration of presentations/admissions for asthma in the year before death. While the majority (7) of the children had one presentation/ admission, one child had been to hospital in relation to asthma four times in the 12 months. In the main (8), the children were in hospital for up to one day. The maximum length of stay in hospital was 6-10 days.

In six cases, the interval between the child's last presentation/admission to hospital for asthma and their death was less than three months.

43 Hospitalisation patterns were similar across the years 2004-2013.

Table 41: Hospitalisations for asthma – number of stays in the last year

Number of stays in 12 months previous to death	Number of children
1	8
2	2
4	1
Total	**11**

Table 42: Hospitalisation for asthma (last 12 months) – length of stay

Maximum length of stay (last 12 months)	Number of children
1 day or less	5
2-5 days	5
6-10 days	1
Total	**11**

Hospitalisation or emergency care visit for asthma in the past year has been identified as a factor that increases the risk of asthma-related death.[44] In this context, it is important that children who have been to hospital for asthma receive follow-up clinical review and monitoring in the year following discharge.

Almost three-quarters (8) of the 11 children who had a hospital presentation/admission due to asthma in the year before their death did not have a follow-up asthma review with their doctor. All eight children had a history of non-compliance with asthma medications. Three of the children had been to hospital for asthma in the six weeks before their death, and had more than one presentation/admission in the last year.

Other health issues

Four children had diagnosed or suspected mental health concerns, including Attention Deficit Hyperactivity Disorder (ADHD); Oppositional Defiant Disorder, anxiety and ADHD; depression/poor self esteem; and suicidal ideation. All were males aged 11 to 16 years.

Records of height and weight were available for 14 of the 20 children. Of the 14 children, nine were at some time underweight for their age, and two children were overweight.

Information about immunisation status was available for 17 children. Sixteen children were up-to-date with the recommended childhood immunisations. Two children had also been immunised against influenza, but not in the year before their death.

Asthma management

Clinical management and review

Asthma can usually be effectively managed with regular clinical review and tailored treatment and, if well controlled, people with asthma can lead regular, active lives.

The Australian Asthma Handbook, Australia's guidelines for asthma management, provides a framework for managing asthma in children in primary care settings.[45] The framework incorporates asthma diagnosis; symptom assessment; medication review

44 Global Initiative for Asthma 2014, *Global Strategy for Asthma Management and Prevention*, USA: GINA, p59. http://www.ginasthma.org/, accessed 16 July 2014.

45 Australia has had asthma guidelines in place since 1989. The Australian Asthma Handbook is the 7th edition of the guidelines, previously published as the Asthma Management Handbook. The 7th edition was published in April 2014 as a website rather than a printed document. See www.asthmahandbook.org.au. National Asthma Council Australia 2014, *Australia's National Guidelines for Asthma Management*, Victoria: NAC, http:// www.asthmahandbook.org.au, accessed 16 July 2014.

and adjustment; managing co-morbid conditions; engaging and educating parents and children in asthma management; and managing asthma flare-ups. The guidelines recommend that, as a general guide, a child's asthma should be reviewed:

- every three to six months when asthma is stable and well-controlled
- four weeks after increasing the dose or number of medicines to regain control of partially or poorly-controlled asthma, and
- two to four weeks after a visit to an emergency department or a hospital stay due to acute asthma.

The guidelines also recommend that children with asthma be provided with a written asthma action plan and (the child and parent) trained in how to use it. The plan should be reviewed every six months, and whenever asthma control status changes significantly.[46]

General practitioner care and treatment

Information on general practitioner care was available for 19 of the 20 children who died from asthma. For many of the children, it was difficult to ascertain the level of primary care provided for asthma and whether asthma management was sufficient. In a number of cases this was due to poor or limited record-keeping.

As shown in the table below, records showed that all of the children saw a general practitioner about asthma at some point. However, for all except one child, the medical records did not indicate regular review of asthma treatment or assessment of their level of asthma control.

Around one-third (7) of the children did not appear to have a regular or family general practitioner, and some had not seen a general practitioner for a number of years. The vast majority (17) of children seemed to only see a doctor about their asthma when they were unwell, rather than for a planned review.

Three-quarters (14) of the children had consulted a general practitioner about asthma in the year before their death:

- Ten children had visited a general practitioner about their asthma at least once in the six months before their death; however, none of the visits were recorded as asthma reviews. Reasons for the visit(s) were mainly to obtain a prescription (6) and/or due to an exacerbation of asthma symptoms (5).
- Four children had seen a general practitioner about their asthma 6-12 months before their death. The children presented for a routine asthma review; asthma exacerbation; a medication prescription; and a review after hospitalisation for asthma.

Four children had not seen a general practitioner for asthma for an extended period of time, including for almost two years (2), and for more than two years (2).

In addition to asthma, some children saw a general practitioner in relation to managing an allergy or atopy.

Table 43: Frequency and nature of contact with general practitioners

	Length of time since last GP contact		
	within 6 months	>6 to <12 months	>12 months
Number of children (N=19)	11	4	4
Primary reason/s for last contact	• Prescription – asthma medication (5) • Asthma exacerbation (4) • Review following hospital admission for asthma (2) • Respiratory tract infection or cold symptoms (2) • Allergy (1)	• Asthma exacerbation (1) • Asthma review (1) • Review following hospital admission for asthma (1) • Prescription – asthma medication /eczema (1)	• Reason not recorded (2) • Asthma exacerbation (1) • Respiratory tract infection or cold symptoms (1)

46 National Asthma Council Australia 2014, *Providing asthma management education for parents and children*, Victoria: NAC, http:// www.asthmahandbook.org.au/management/children/education, accessed 16 July 2014.

Specialist care and treatment

Information on specialist care and treatment was available for 19 children. Less than half (8) of the children had seen a specialist in relation to asthma, including paediatricians, respiratory paediatricians, and an allergist/immunologist.

Most (5) of the children under the care of a specialist for asthma had not been seen for more than a year before their death; for three children, the last specialist visit in relation to asthma was more than three years ago.

Eleven children had never seen a specialist in relation to asthma.

Table 44: Frequency and nature of contact with specialists for asthma[47]

Type of specialist	Number of children	Length of time since last contact (number of children)			Primary reason for last contact
		within 6 months	>6 to <12 months	>12 months	
Paediatrician	6	0	2	4	• Asthma review (5) • Allergy/Asthma/Eczema review (1)
Allergist/ immunologist	1	1	0	0	• Allergy/Asthma/Eczema review (1)
Respiratory physician	2	0	0	2	• Asthma (2)

Written asthma action plans

A written asthma action plan is a personalised outline on what to do if asthma worsens. Prepared in consultation with a medical professional, the aim of the plan is to help patients stay in control of their asthma by acting early to prevent or reduce the severity of an acute asthma episode.

Written asthma action plans have been associated with a reduction in the risk of death.[48] [49] Research has indicated that asthma plans can empower carers of people with asthma and enhance their capacity to identify changes in symptoms.[50]

While national guidelines for the management of asthma have included written asthma action plans since 1989, less than one-quarter of Australians with asthma in 2007-2008 reported in the National Health Survey that they had a written asthma action plan. In comparison to adults, a relatively high proportion of children with asthma in NSW were reported to have had a plan (51.3%).[51] Responses to the NSW Health Survey 2009-2012 showed similar results, with just over half of the children aged 2-17 years with asthma reported to have a written asthma action plan.[52]

Overall, of the 20 children who died as a result of asthma in 2004-2013, two-thirds (13) had a written asthma action plan. Nine (45%) had a written plan that had been developed in the year before their death; including four children whose plans were written following their presentation to hospital with acute asthma. Four children had older written asthma action plans that had been developed between 16 months and more than three years before their death.

For six children, there was no indication that a written asthma action plan had ever been developed.[53]

47 Information only relates to the eight children who saw specialists in relation to their asthma.
48 Australian Centre for Asthma Monitoring 2011, *Asthma in Australia 2011. AIHW Asthma Series no. 4. Cat. no. ACM 22*, Canberra, AIHW. p.115.
49 Abramson M. Bailey M. Couper F. Driver J. S. Drummer O. H. Forbes A. B. McNeill J. J. Haydn Walters E. Victorian Asthma Mortality Study Group 2001, *Are asthma medications and management related to deaths from asthma*? American Journal of Respiratory and Critical Care Medicine 163:12–18.
50 Buckham L. M. Bailie H. C. 2014, G25 (P) *Asthma action plans: Are they useful?* Archives of Disease in Childhood 99(Suppl 1) : A12-A12.
51 Australian Centre for Asthma Monitoring 2011. op. cit. p 115.
52 NSW Health 2014, *New South Wales Population Health Survey 2009-2012*. Data supplied to order for NSW Ombudsman. Sydney: NSW Health.
53 Information regarding the written asthma action plan was missing for one child.

Managing asthma at school

The majority (16) of the children were attending schools in NSW.[54] Thirteen children attended public schools and three children were at private schools. In most cases (14), the school was aware that the child had asthma.

The NSW Department of Education and Communities encourages (but does not mandate) parents to advise the school if their child has asthma. If a parent formally requests school support, the principal will consider how the request can be met. The Department does not require the parent to provide a written asthma action plan for a child with the condition.

However, the Department does require school principals to develop, in consultation with the child's parent and treating doctor, an individual health care plan for children with 'severe asthma' and to review the plan at least annually.[55]

Written asthma action plans were on the school files for half (7) of the children attending school, and for most (5) children the plan had been developed in the year before their death.

Six of the schools that had a plan for the child were public schools and, in one case, the school had developed an individual health care plan for the child.

In the seven cases where the school was aware the child had asthma but had no written asthma action plan or individual health care plan for the child, records indicate that in five cases the school knew that the child had a history of asthma attacks:

- three children had been treated with asthma medication at school, including one child who had been sent home on numerous occasions due to asthma, and who had been administered asthma medication at school on seven separate days
- one child had numerous school absences recorded due to asthma, and
- school records noted that one child had chronic asthma.

Asthma medication and compliance

There is a wide range of asthma medication available, and recommended treatment depends on the nature and severity of asthma symptoms. Regular asthma review allows treatment to be stepped up or down as needed, depending on the level of asthma control achieved.

The most common asthma medicines are relievers (quick -acting) and preventers (slow-acting), which include combination medications (fairly quick-acting with improvement after continued use) and long-acting beta agonists. Other medications, such as oral corticosteroids, are used to manage asthma flare-ups and asthma that is difficult to treat.

The Australian Asthma Handbook recommends that everyone who has asthma should always carry reliever medication, and indicates that preventer treatment is important for managing persistent asthma. Preventer medicines need to be taken every day, even when symptoms are absent. The Handbook recommends that regular treatment should be considered for children aged two years and over with asthma symptoms more than once every six weeks on average.[56]

The vast majority (19) of the children who died from asthma had prior treatment that included both reliever and preventer medicines. For most (17) children, preventer treatment included an inhaled corticosteroid. Fifteen children were also prescribed a long-acting beta agonist (13) and/or an oral corticosteroid (5).

From the available records, it was not possible to establish with certainty the level of medication compliance for each child, or exactly which asthma medications were being used in the period leading up to their death. In five cases, there had been changes to the child's asthma medication within the last three months, including introducing a preventer (2) or changing the type of preventer medication (3).

For nine children, the records identified occasions when the child and/or the child's carers had not used the asthma medication as recommended. Primarily, this involved the under-use/ intermittent rather than regular use of preventer medicines (8), and irregular use of a reliever (1). The reasons recorded for non-compliance included that the child did not want to take the medication; the family had run out of medication for the child or had not filled prescriptions; and the family needed education on the correct use of preventer medication.

54 School records were missing for one school-aged child, and three children were not at school in NSW (one child had left school, one child had not reached school age, and one child lived interstate).

55 Education & Communities 2005, *Student Health in NSW Public Schools: A summary and consolidation of policy* ref no. PD/2004/0034/V01, Sydney: NSW Government, Education & Communities.

56 National Asthma Council Australia 2014, *Australia's National Guidelines for Asthma Management*, Victoria: NAC, http:// www.asthmahandbook.org.au, accessed 16 July 2014. The recommendation has been updated since the 2006 edition of the handbook, which recommended preventer treatment for children who have asthma symptoms more than three times per week.

Of note, most (8) of the nine children were aged 11-16 years and had a child protection history and/or psychosocial factors within their family. Of these children, the majority (7) had a presentation or admission to hospital for asthma in the year before they died.

In an additional two cases, it was unclear whether the prescribed treatment plan was followed or what medications the child was using at the time of their death. In one case, it appeared the family may have been giving the child medication that had been prescribed for a sibling; and in the other case, the child was reported to have been using reliever medicine excessively due to asthma symptoms, although they had been prescribed a preventer. The two children had also presented or been admitted to hospital for asthma in the year before they died.

Circumstances prior to the fatal asthma episode

Research has shown that 80-85% of people who die from asthma develop progressive symptoms anywhere from 12 hours to several weeks before death (slow onset), with only a small proportion developing symptoms rapidly.[57]

It is important that signs and symptoms of worsening asthma are recognised early so that appropriate medical treatment can be provided as soon as possible. Parents, family, friends, schools and children themselves need (age-appropriate) skills to recognise and respond to the onset of symptoms.

When asthma is well-controlled, there is no night-time (and only occasional day-time) wheezing, coughing or chest tightness; reliever medication is needed only occasionally or before exercise; and usual activities can be completed without getting asthma symptoms.

An asthma attack can come on gradually or quickly. The National Asthma Council identifies that an asthma attack is when symptoms worsen compared to usual and when symptoms don't go away without treatment.

Signs of an asthma attack can include:

- increasing wheezing, cough, chest tightness or shortness of breath
- waking often at night with asthma symptoms, and
- needing to use a reliever again within three hours of taking it.

Warning signs for when to seek emergency treatment include:

- symptoms that get worse very quickly
- severe shortness of breath (can't speak comfortably or lips turn blue), and
- when little or no relief is gained from using a reliever.[58]

Place, onset and possible precipitating factors

Most (16) of the children who died from asthma were at home with their immediate family or at another relative's home when they were identified as being acutely unwell. Three children were at other places, including an afterschool care program, a showground and on a family holiday.[59]

In eight cases, the child had woken in the night or in the morning with asthma symptoms, or had been heard coughing during their night-time sleep.

More than half (11) of the children appear to have had rapid onset of asthma symptoms, (within hours of the death). Most (10) of these children were reportedly well in the days and weeks before their death and had engaged in their usual day-to-day activities, including attending school, sport and leisure pursuits. However, while the onset of the fatal asthma attack appeared rapid, five of the 11 children had presented or been admitted to hospital for asthma in the previous 3-6 weeks.

57 Plaza V. Serrano J. Picado C. Sanchis J. High Risk Asthma Research Group 2002, *Frequency and clinical characteristics of rapid-onset fatal and near-fatal asthma*. European Respiratory Journal 19(5): 846-852.

58 National Asthma Council Australia 2014, *During an Attack*, Victoria: NAC, http://www.nationalasthma.org.au/understanding-asthma/during-an-attack, accessed 16 July 2014.

59 Information about location at time of onset was missing for one child.

Five children appear to have had slow onset of asthma symptoms leading up to their death. Four of the children were known to have been experiencing worsening asthma symptoms, including using reliever medicine more often than usual and waking at night with coughing and/or shortness of breath. One child had shown signs of respiratory illness.

For four children, it was unclear whether the onset of the fatal asthma attack was rapid or slow; two were reportedly unwell with respiratory illness.

In two cases, records suggest that anaphylaxis may have been a precipitating factor in the acute asthma episode.

Emergency response

The emergency response was initiated most often (12) during the evening or night-time hours.

The majority (17) of the children were transported to hospital via ambulance, with ambulance response times ranging from less than 10 minutes (9) to more than 30 minutes in the case of one child who lived in a rural area. The average response time was 12 minutes. Three families took the child directly to a hospital emergency department.

Most (17) of the children were neurologically non-responsive upon arrival at hospital.

Risk factors and prevention

Research has identified various risk factors for poor health outcomes for people with asthma. They include hospitalisation for asthma in the past year; poor adherence to asthma medication and management plans; lack of a written asthma action plan; a disregard for asthma symptoms or severity; poorly-controlled asthma; irregular asthma review; a history of psychosocial factors; allergy; and smoking or exposure to second-hand smoke.[60] [61]

The recent Global Initiative for Asthma (GINA) report[62] indicates that key factors that increase the risk of an asthma-related death include hospital presentation for asthma in the year before death, and poor adherence with asthma medications and/or poor adherence with (or lack of) a written asthma action plan. Similarly, the National Review of Asthma Deaths in the UK identified that potentially avoidable factors in relation to children include poor compliance with medical advice, a lack of an asthma action plan, and inadequate asthma reviews.[63]

The majority (17) of the 20 children who died from asthma in 2004-2013 had factors that may have increased their risk of death,[64] including:

- sub-optimal level of asthma control (poorly or partially controlled asthma)
- presentation/admission to hospital for asthma in the year before death
- insufficient follow-up after a hospital presentation/admission for asthma
- poor adherence to recommended asthma medication/asthma action plans
- lack of a written asthma action plan, and
- exposure to tobacco smoke.

Three-quarters (15) of the children had more than one risk factor, with sub-optimal asthma control being the most common issue (13). While well-controlled asthma can sometimes be difficult to achieve even with good asthma management, the Team identified a number of opportunities for better asthma care among the children who died.[65]

60 Strunk R. C. Mrazek D. A. Wolfson Fuhrmann G. S. LaBrecque J. F. 1985, *Physiologic and psychological characteristics associated with deaths due to asthma in childhood: a case-controlled study,* The Journal of the American Medical Association 254(9) : 1193-1198.

61 Goeman D. P. Abramson M. J. McCarthy E. A. Zubrinich C. M. Douglass J. A. 2013, *Asthma mortality in Australia in the 21st century: a case series analysis* BMJ Open 3(5) : 61.

62 Global Initiative for Asthma 2014, *Global Strategy for Asthma Management and Prevention*, USA: GINA, p59. http://www.ginasthma.org/, accessed 16 July 2014.

63 Royal College of Physicians 2014. *Why asthma still kills: the National Review of Asthma Deaths (NRAD) Confidential Enquiry report*. London: RCP. http://www.rcplondon.ac.uk/projects/national-review-asthma-deaths, accessed 16 July 2014.

64 For one additional child, there was limited information available about the child's history to assess these factors.

65 Opportunities for better asthma care in relation to the children were identified through joint review of each of the deaths by a clinical member of the Team and a specialist clinical adviser to the Team.

Sub-optimal asthma control was identified in relation to 10 children who had one or more hospital presentations/admissions for asthma in the year before their death and who also had inadequate compliance with their asthma medication. The Team identified that six of the children may have benefited from a referral to a paediatrician or respiratory paediatrician about their asthma.

Insufficient follow-up after a hospital presentation/admission was a factor for eight children who did not visit a doctor or outpatient clinic for review. In several cases, this was despite the hospital offering asthma education and advising the family general practitioner that the child had presented, and, in three cases, either the hospital or general practitioner contacting the family by telephone or in writing to encourage a follow-up review.

As shown in the table below, the children who had the highest number of factors tended to be older (aged 10 years and above) and to have psychosocial factors present for either themselves or their family, including a child protection history.[66] This includes four cases in which it was unclear who in the family was overseeing the child's asthma management.

For two-thirds (13) of the 19 children, the Team found that there was scope to improve their asthma care, through more regular/enhanced general practitioner involvement (5), or through referral to a paediatrician (9) or respiratory paediatrician (3).

Table 45: Risk factors, asthma management and psychosocial issues

Age group	Sub-optimal level of asthma control	Child protection history / psychosocial issues	Poor adherence medication or asthma plan	Hospital presentation/ admission in last year	Inadequate follow-up after hospital visit	Exposure to tobacco smoke	No written asthma action plan	Total
10-14 years	✓	✓	✓	✓	✓	✓	✓	7
15-17 years	✓	✓	✓	✓	✓		✓	6
10-14 years	✓	✓	✓	✓	✓	✓		6
10-14 years	✓	✓	✓	✓	✓	✓		6
15-17 years	✓	✓	✓	✓		✓		5
10-14 years	✓	✓	✓	✓	✓			5
10-14 years	✓	✓	✓	✓	✓			5
4-9 years	✓		✓	✓	✓			4
4-9 years	✓		✓	✓	✓			4
10-14 years	unclear			✓		✓	✓	3
4-9 years	✓		✓	✓				3
4-9 years		✓				✓	✓	3
15-17 years	unclear	✓	✓					2
10-14 years		✓					✓	2
10-14 years	✓					✓		2
10-14 years	✓						✓	2
4-9 years	unclear	✓						1
4-9 years	✓							1
10-14 years	unclear	missing	unclear			missing	missing	0
10-14 years								0
Total	**13**	**11**	**11**	**11**	**8**	**7**	**6**	

66 The psychosocial factors included family breakdown, neglect, behaviour management. carer substance abuse and carer or child mental health issues.

In relation to the fatal asthma attack, in six cases there were indicators that the child or the child's family may not have recognised early signs that asthma symptoms were slowly worsening, or may not have fully appreciated the severity of the child's condition.

Current prevention measures

Good asthma management relies on controlling symptoms, taking prescribed medications regularly, having a regular asthma review, and following a personalised asthma action plan when symptoms flare up. Research highlights the importance of education and awareness in management of asthma and the recognition of changes in symptoms.[67] [68] [69]

Education and support for children and their families to manage asthma

There is a wide range of organisations and programs that are targeted at ensuring that people with asthma, including children and their families, have the necessary information and support to understand and effectively manage their asthma.

Asthma Australia provides a range of information and online resources, an information referral service, and training to schools, child care services and health professionals. It also runs the *Asthma Assist* program – a free information and support service, which includes updates about asthma, a regular newsletter and an Asthma Control Pack that contains key prevention strategies and advice about asthma management.[70]

NSW Health has developed the Children's Asthma Resource Pack for parents and carers, which covers asthma medication, treatments and day-to-day management of asthma, and contains helpful tips for coping with asthma, samples of asthma plans and a symptom diary.[71]

The National Asthma Council has developed multiple avenues for children and families to obtain assistance with asthma management, including:

- the *Asthma Buddy* app[72] – the free smartphone app is designed to assist in monitoring of an asthma plan by way of asthma symptoms and medication use, and includes the capacity to email plans to the user or medical staff, and maintain records for monitoring, and
- the 'Kids with Asthma'[73] website provides asthma information about symptoms, diagnosis and management in a design suited to children, including games.

Information and guidance for practitioners

The Australian Asthma Handbook (2014) is the national guideline for asthma management. It includes evidence-based guidelines for health professionals, including diagnostic pathways for adults and children, asthma protocols and information for specific populations, such as adolescents, older adults and Aboriginal and Torres Strait Islander populations. The handbook is available online and is updated frequently.[74]

67 Wesseldine L. J. McCarthy P. Silverman M. 1999, *Structured discharge procedure for children admitted to hospital with acute asthma: a randomised controlled trial of nursing practice*, Archives of disease in childhood 80(2) : 110-114.
68 Britto M. T. Vockell A-L. B. Knopf Munafo J. Schoettker P. J. Wimberg J. A. Pruett R. Yi M. S. Byczkowski T. L. 2014, *Improving outcomes for underserved adolescents with asthma*, Pediatrics 133(2) : e418 - e427.
69 Centers for Disease Control and Prevention 2011, *Vital signs: asthma prevalence, disease characteristics, and self-management education: United States, 2001- 2009* Morbidity and Mortality Weekly Report 60(17): 547-552.
70 Asthma Australia 2014, *Take control of your asthma*, Sydney: Asthma Australia. http://www.asthmaaustralia.org.au/, accessed 16 July 2014.
71 Sydney Children's Hospitals Network 2012, *Children's Asthma Resource Pack for Parents and Carers*, Sydney: SCHN. http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/children039s-asthma-resource-pack-parents-and-carers.pdf, accessed 16 July 2014.
72 National Asthma Council Australia 2014, *Asthma buddy phone apps*, Victoria: NAC http://www.nationalasthma.org.au/asthma-tools/asthma-action-plans/asthmabuddy.
73 National Asthma Council Australia 2014, *kidswithasthma.com.au*, Victoria: NAC http://www.kidswithasthma.com.au, accessed 16 July 2014.
74 National Asthma Council Australia 2014, *Australia's National Guidelines for Asthma Management*, Victoria: NAC, http:// www.asthmahandbook.org.au, accessed 16 July 2014.

The National Asthma Council delivers education workshops for general practitioners, practice nurses and allied health professionals. The Asthma and Respiratory Education Program also provides an education service for primary health care practitioners.[75]

The Practice Incentives Program, administered by Medicare, encourages quality of care and improving outcomes for patients with a moderate to severe level of asthma. Practitioners who qualify are paid an incentive when an asthma 'cycle of care' is delivered over a 12-month period. This must include assessment, treatment planning and the provision of an asthma action plan.[76]

NSW Health's Infants and Children: Acute management of asthma clinical practice guidelines provide guidance to hospital practitioners, including that at the time of discharge all patients/parents should receive a discharge summary, discharge medications (including a spacer), an Asthma Action Plan, information outlining follow-up arrangements, and contact details for any emergency.[77]

School-based programs and support

Various programs are targeted at delivering school-based education and support to children and young people and staff of schools and children's services, including:

- The Asthma Child and Adolescent Program, through which Asthma Australia delivers a free one-hour education session for staff of schools and children's services. The program includes a focus on self-management in adolescents.[78]
- The Triple A (Adolescent Asthma Action) program – a peer education program aimed at improving asthma self-management in young people and creating a supportive school environment for asthma.[79]
- Asthma Australia's Asthma Friendly Schools program – to qualify as asthma friendly, schools must undergo training; have information accessible for staff and parents; have policies that include asthma; and have asthma emergency kits.[80]
- The Aiming for Asthma Improvement in Children Program (AAIC), developed by Sydney Children's Hospital, provides training, education and resources to schools, Out of School Hours care services, and childcare services.[81]

75 Department of Health 2010, *Asthma Management Program*, Canberra: DoH http://www.health.gov.au/internet/main/publishing.nsf/Content/asthma-manage, accessed 16 July 2014.
76 Department of Human Services 2013, *Practice Incentives Program - Asthma Incentive Guidelines*, Canberra: Medicare DoHS, http://www.medicareaustralia.gov.au/forms/4371.pdf, accessed 16 July 2014.
77 NSW Health 2012, *Policy directive – Infants and Children – Acute management of Asthma* Ref: PD2012_056, Sydney: NSW Health
78 Department of Health 2010, op. cit.
79 University of Sydney 2014, *Triple A Program*, Sydney: USyd, http://sydney.edu.au/medicine/public-health/salsa-triple-a/triple-a/index.php, accessed 16 July 2014.
80 Asthma Australia 2014, Asthma Friendly Schools, Sydney: Asthma Australia http://www.asthmaaustralia.org.au/Asthma-Friendly-Schools.aspx, accessed 16 July 2014.
81 NSW Health - South Eastern Sydney Local Health District 2014, Aiming for Asthma Improvement in Children Program (AAIC), Sydney: NSW Health, http://www.seslhd.health.nsw.gov.au/AAIC/, accessed 16 July 2014.

Recommendations

Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, and Christian Education National

1. Against the background of the issues raised in this report relating to children with asthma, the Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, 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:
      - identify children with severe asthma who need a health care or other support plan, and
      - ensure that health care or other support plans for children with severe asthma are developed, implemented and regularly reviewed
   b) how compliance with the policies/guidance is monitored, and
   c) any other actions the Department, Authorities, AIS, CSA and CEN intend to take in relation to identifying and supporting students with asthma.

Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, Christian Education National and Ministry of Health

2. The Department of Education and Communities, Diocesan Catholic Schools Authorities of NSW, Association of Independent Schools, Christian Schools Australia, Christian Education National and the Ministry of Health 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.

Ministry of Health

3. The Ministry of Health should consider the findings of the Team's review in relation to post-hospitalisation follow-up of children with asthma, and provide 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.

Chapter 13. Deaths from endocrine, nutritional or metabolic diseases

In 2013, 17 children whose deaths were registered in NSW died from endocrine or metabolic diseases. The vast majority (16) were metabolic disorders. There were no deaths attributed to nutritional diseases.

Endocrine and metabolic diseases include diabetes, cystic fibrosis and rare metabolic disorders. While some of these conditions are easily treated, others produce lifelong disabilities or can quickly lead to death.

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of the 17 children who died due to endocrine or metabolic diseases in 2013.

Table 46: Key demographic and individual characteristics – deaths due to metabolic and endocrine diseases, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**17**	**100**	**1.0**	**0.59 - 1.63**		
Gender						
Female	8	47	1.0	0.43 - 1.94	-	-
Male	9	53	1.0	0.48 - 1.99	1.1	0.45
Age						
Under 1 year	5	29	5.0 (IMR = 0.05)†	1.62 - 11.61	-	-
1-4 years	6	35	1.6	0.57 - 3.37	-	-
5-9 years	0	0	-	-	-	-
10-14 years	1	6	-	-	-	-
15-17 years	5	29	1.8	0.59 - 4.27	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	16	94	1.0	1.19 - 3.38	-	
Aboriginal or Torres Strait Islander	1	6	-	-	-	
Remoteness						
Major cities	12	71	1.0	0.52 - 1.74	-	-
Inner regional areas	3	18	-	-	-	-
Outer regional areas	2	12	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	4	24	1.1	0.31 - 2.90	-	-
Quintile 4	5	29	1.5	0.49 - 3.54	-	-
Quintile 3	1	6	-	-	-	-
Quintile 2	4	24	1.3	0.35 - 3.26	-	-
Quintile 1 (lowest)	3	18	-	-	-	-

† Infant Mortality Rate

Age, gender and Aboriginal and Torres Strait Islander status

In 2013, endocrine and metabolic diseases were:

- the fifth leading cause of death of infants
- the equal third leading cause of death of children aged 1-4 years, and
- the equal fourth leading cause of death of young people aged 15-17 years.

Nine of the children were male and eight were female. One child who died of a metabolic disorder in 2013 was identified as Aboriginal and Torres Strait Islander.

As indicated in the table below, over the past 15 years there has not been any marked change in the mortality rates from endocrine, nutritional and metabolic diseases.

Table 47: Trends in deaths of children due to endocrine, nutritional and metabolic diseases by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	12 (1.6)	7 (0.9)	6 (0.8)	7 (0.9)	5 (0.6)	6 (0.8)	7 (0.9)	5 (0.6)	4 (0.5)	3 (0.4)	12 (1.5)	5 (0.6)	3 (0.4)	7 (0.9)	8 (1.0)
Male	13 (1.6)	4 (0.5)	6 (0.7)	11 (1.3)	9 (1.1)	3 (0.4)	8 (1.0)	4 (0.5)	9 (1.1)	16 (1.9)	9 (1.1)	9 (1.1)	8 (0.9)	5 (0.6)	9 (1.0)
Both	25 (1.6)	11 (0.7)	12 (0.7)	18 (1.1)	14 (0.9)	9 (0.6)	15 (0.9)	9 (0.6)	13 (0.8)	19 (1.2)	21 (1.3)	14 (0.9)	11 (0.7)	12 (0.7)	17 (1.0)

Leading causes of death from endocrine and metabolic diseases

The metabolic disorders causing the deaths of children in NSW in 2013 included Sandhoff disease (2), I-cell disease (2), cystic fibrosis (2), disorders of urea cycle metabolism (2), Hurler syndrome and Sanfilippo syndrome.

While metabolic disorders are rare, many are associated with reduced life expectancy. Many of the 16 children who died from metabolic disorders in 2013 had related liver, respiratory or circulatory complications as a result of their condition.

One young person's death was due to Allgrove (AAA) syndrome, a rare and severe disorder of the adrenal gland.

Table 48: Leading causes of death from endocrine, nutritional and metabolic diseases, 2013

Under 1 year	1-4 years	10-14 years	15-17 years
Disorders of urea cycle metabolism 2	GM2 gangliosidosis (Sandhoff disease) 2	Mucopolysaccharidosis type I (Hurler disease) 1	Cystic fibrosis 2
Metabolic disorder unspecified 2	Disorders of copper metabolism 1		Mucopolysaccharidoses (Sanfilippo syndrome) 1
Defects in post-translational modification of lysosomal enzymes (I-cell disease) 1	Glycogen storage disease 1		Other metabolic disorders 1
	Defects in post-translational modification of lysosomal enzymes (I-cell disease) 1		Other adrenocortical insufficiency (Allgrove [AAA] syndrome) 1
	Other specified metabolic disorders 1		

Chapter 14. Deaths from diseases of the circulatory system

In 2013, 10 children whose deaths were registered in NSW died as a result of diseases of the circulatory system. Circulatory system diseases comprise a broad range of conditions, including heart diseases, heart failure and cerebrovascular diseases.[82]

On average over the past 15 years, 18 children have died from circulatory system diseases each year. In 2012 and 2013, the number of deaths (10) and mortality rate (0.6 per 100,000 children) from diseases of the circulatory system were notably lower than the 15-year average.

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of the 10 children who died from circulatory diseases in 2013.

Table 49: Key demographic and individual characteristics – deaths due to diseases of the circulatory system, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**10**	**100**	**0.6**	**0.29 - 1.10**		
Gender						
Female	4	40	0.5	0.13 - 1.26	-	-
Male	6	60	0.7	0.26 - 1.52	1.4	0.29
Age						
Under 1 year	2	20	-	-	-	-
1-4 years	1	10	-	-	-	-
5-9 years	1	10	-	-	-	-
10-14 years	4	40	0.9	0.24 - 2.29	-	-
15-17 years	2	20	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	9	90	0.6	0.54 - 2.22	-	-
Aboriginal or Torres Strait Islander	1	10	-	-	-	-
Remoteness						
Major cities	7	70	0.6	0.23 - 1.20	-	-
Inner regional areas	2	20	-	-	-	-
Outer regional areas	1	10	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	2	20	-	-	-	-
Quintile 4	1	10	-	-	-	-
Quintile 3	2	20	-	-	-	-
Quintile 2	2	20	-	-	-	-
Quintile 1 (lowest)	3	30	-	-	-	-

82 Diseases of the circulatory system do not include congenital malformations of the heart. Deaths due to congenital heart conditions are included in the congenital conditions chapter.

Age, gender and Aboriginal and Torres Strait Islander status

The children who died from circulatory system diseases ranged in age from eight months to 17 years. Most (6) were aged 13-17 years.

Slightly more boys (6) than girls (4) died from circulatory system diseases. As noted in the table below, boys have typically, but not always, had a higher rate of death from circulatory system diseases than girls. On average, boys were older at time of death from this cause in 2013 (13 years) than girls (4 years).

One child who died of circulatory system disease was Aboriginal.

Table 50: Trends in deaths of children due to diseases of the circulatory system by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	11 (1.4)	8 (1.0)	8 (1.0)	11 (1.4)	4 (0.5)	9 (1.2)	8 (1.0)	11 (1.4)	10 (1.3)	8 (1.0)	7 (0.9)	8 (1.0)	8 (1.0)	5 (0.6)	4 (0.5)
Male	12 (1.5)	14 (1.7)	21 (2.6)	10 (1.2)	6 (0.7)	9 (1.1)	11 (1.3)	8 (1.0)	11 (1.3)	9 (1.1)	7 (0.8)	12 (1.4)	10 (1.2)	5 (0.6)	6 (0.7)
Both	23 (1.5)	22 (1.4)	29 (1.8)	21 (1.3)	10 (0.6)	18 (1.1)	19 (1.2)	19 (1.2)	21 (1.3)	17 (1.1)	14 (0.9)	20 (1.2)	18 (1.1)	10 (0.6)	10 (0.6)

Leading causes of death due to diseases of the circulatory system

As indicated in the table below, cardiomyopathy was the largest cause of deaths of children from diseases of the circulatory system in 2013, accounting for the deaths of four children. Cardiomyopathy is a chronic disease in which the heart muscle is abnormally enlarged, thickened and/or stiffened.[83] The children who died from cardiomyopathy were either infants, or had additional health conditions that compromised their circulatory system.

Two children died as a result of cerebrovascular diseases, including intracerebral haemorrhage. One of the children was receiving palliative care at the time of their death.

Table 51: Leading causes of deaths due to diseases of the circulatory system by age group, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Cardiomyopathy 2	Cardiac arrhythmia 1	Cardiomyopathy 1	Cerebrovascular disease 1	Cerebrovascular disease 1
			Dissection of thoracic aorta 1	Unexplained cardiac arrest 1
			Cardiomyopathy 1	
			Primary pulmonary hypertension 1	

83 Children's Cardiomyopathy Foundation 2014, The Children's Cardiomyopathy Foundation (CCF), USA: CCF, www.childrenscardiomyopathy.org, accessed 16 July 2014.

Sudden cardiac deaths

In 2013, the deaths of two of the 10 children who died from diseases of the circulatory system were considered to be sudden cardiac deaths. Sudden cardiac death is rare, and involves '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.'[84]

The two sudden cardiac deaths were attributed to cardiac arrhythmia and unexplained cardiac arrest.

84 Commission for Children and Young People and Child Guardian 2012, *Trends and Issues paper: Child deaths – sudden cardiac deaths Number 7* March 2012 Brisbane: CCYPCG

Chapter 15. Deaths from infectious diseases

The deaths of nine children registered in 2013 were due to infectious diseases. The rate of death due to this cause in 2013 (0.54 per 100,000 children) was slightly lower than the 15-year average (0.7 per 100,000 children).

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 whooping cough, meningococcal infection and sepsis; and viral infections such as viral encephalitis, viral meningitis, and measles.

While infectious diseases are still fairly 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.[85]

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of the nine children whose deaths from infectious diseases were registered in 2013.

Table 52: Key demographic and individual characteristics – deaths due to infectious diseases, 2013

	Number	Percent	Infant Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**9**	**100**	**0.54**	**0.25 - 1.02**		
Gender						
Female	5	56	0.62	0.20 - 1.44	-	-
Male	4	44	0.47	0.13 - 1.19	0.76	0.34
Age						
Under 1 year	3	33	-	-	-	-
1-4 years	5	56	1.29	0.42 - 3.01	-	-
5-9 years	0	0	-	-	-	-
10-14 years	0	0	-	-	-	-
15-17 years	1	11	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	8	89	0.51	0.45 - 2.05	-	-
Aboriginal or Torres Strait Islander	1	11	-	-	-	-
Remoteness						
Major cities	6	67	0.5	0.18 - 1.09	-	-
Inner regional areas	2	22	-	-	-	-
Outer regional areas	1	11	-	-	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	0	0	-	-		
Quintile 4	1	11	-	-	-	-
Quintile 3	4	44	1.3	0.34 - 3.24	-	-
Quintile 2	3	33	-	-	-	-
Quintile 1 (lowest)	1	11	-	-	-	-

85 Australian Institute of Health and Welfare 2012, *Australia's Health 2012*. Australia's health series no 13. Cat no AUS 156. Canberra: AIHW.

Age, gender and Aboriginal and Torres Strait Islander status

All but one of the nine children who died from infectious diseases in 2013 were two years of age and younger. The other child was 15 years old.

Just over half (5) of the children were female. As indicated in the table below, the higher proportion of girls in deaths from infectious diseases in 2013 is not consistent with the broader trend. Boys have typically had higher mortality rates from infectious diseases.

One child who died from an infectious disease in 2013 was identified as Aboriginal.

Table 53: Trends in deaths of children due to infectious and parasitic diseases by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	3 (0.4)	7 (0.9)	2	5 (0.6)	6 (0.8)	2	1	7 (0.9)	6 (0.8)	2	1	2 (0.3)	6 (0.6)	2	5 (0.6)
Male	8 (1.0)	5 (0.6)	10 (1.2)	8 (1.0)	8 (1.0)	6 (0.7)	8 (1.0)	12 (1.5)	8 (1.0)	7 (0.8)	7 (0.8)	7 (0.8)	6 (0.7)	7 (0.8)	4 (0.5)
Both	11 (0.7)	12 (0.8)	12 (0.7)	13 (0.8)	14 (0.9)	8 (0.5)	9 (0.6)	19 (1.2)	14 (0.9)	9 (0.6)	8 (0.5)	9 (0.6)	12 (0.7)	9 (0.5)	9 (0.5)

Remoteness and socioeconomic status

Most (6) of the nine children who died from infectious diseases lived in major cities. None of the children lived in remote or very remote areas. The highest proportion of children (44%) lived in areas that comprised the middle tier of socioeconomic status.

Leading causes of death due to infectious diseases

As indicated in the table below, the leading underlying cause of death from infectious diseases in 2013 was enterovirus infection. In total, the deaths of five children were associated with enterovirus, including two children who were identified as having enterovirus 71; one child with enterovirus infection; one child with enterovirus sepsis; and one child with meningoencephalitis that was noted by the Coroner as 'probably due to enterovirus infection'.

The children whose deaths were associated with enterovirus infection were very young, ranging from six days of age to 19 months. Three of the children were male, and two were female. The children were in a range of locations at the time that they became unwell, including the Hunter (2), Sydney metropolitan (2), and Southern NSW (1) areas. Three children died in summer (2) or spring, and two children died in the cooler months of autumn and winter.

In June 2013, NSW Health issued a public health alert on enterovirus, indicating that earlier in the year clinicians on Sydney's Northern Beaches had reported an increase in the number of young children presenting with enterovirus infection, including some children with enterovirus 71. The alert noted that:

- While enterovirus 71 is 'fairly rare' in NSW, general enteroviruses are relatively common, particularly in the warmer months. Illnesses caused by enteroviruses include fevers, rashes, and hand, foot and mouth disease, and 'very rarely' neurological complications.
- There is currently no vaccine for enteroviruses, including enterovirus 71, available in Australia.
- Between 1 January and 9 June 2013, 124 children were admitted to Sydney or Westmead Children's Hospitals with suspected severe enterovirus infection; and 103 of these had been confirmed as being due to enterovirus.
- In March 2013, NSW Health wrote to childcare centres in NSW advising of an increase in enterovirus and hand, foot and mouth disease cases and reminding them to practice routine hygiene.
- The best way to reduce chances of infection is to practice good hand hygiene, 'especially washing hands with soap and water after going to the toilet, before eating, after wiping noses, and after changing nappies or soiled clothing.'

Table 54: Leading causes of deaths due to infectious diseases by age group, 2013

Under 1 year	1-4 years	5-9 years	10-14 years	15-17 years
Enterovirus infection 2	Enterovirus infection 1			Sepsis due to staphylococcus aureus 1
Viral encephalitis 1	Enteroviral encephalitis 1			
	Gastroenteritis 1			
	Sepsis due to pseudomonas 1			
	Respiratory syncytial virus infection 1			

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 2013, only one child died as a result of a notifiable disease – influenza.[86] There were no deaths due to vaccine-preventable diseases.

86 This death is captured in the data relating to diseases of the respiratory system.

Chapter 16. Deaths of infants

In 2013, the deaths of 356 infants aged less than one year were registered in NSW. Consistent with previous years, infants comprised the majority (63%) of all child deaths.

The infant mortality rate has declined over the past 15 years, ranging from 5.6 deaths per 1,000 live births in 1999 to 3.3 deaths per 1,000 live births in 2012. The infant mortality rate in 2013 (3.6 deaths per 1,000 live births) was slightly higher than 2012, but still lower than the 15-year average (4.3 deaths per 1,000 live births).

The trend in NSW reflects the broader national picture. Across Australia, the infant mortality rate declined from 5 deaths per 1,000 live births in 2002 to 3.3 deaths per 1,000 live births in 2012.[87]

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of all infant deaths registered in 2013.

Table 55: Key demographic and individual characteristics – deaths of infants from all causes in NSW, 2013

	Number	Percent	Infant Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**356**	**100**	**3.6**	**3.24 - 3.99**		
Gender						
Female	156	44	3.3	2.75 - 3.77	-	-
Male	200	56	3.9	3.40 - 4.50	1.2	0.04
Age						
Under 1 day	135	38	1.4	1.14 - 1.60	-	-
1 day - under 1 week	59	17	0.6	0.46 - 0.77	-	-
1 week - under 28 days	51	14	0.5	0.39 - 0.68	-	-
28 days - under 1 year	111	31	1.1	0.92 - 1.34	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	304	85	3.3	2.90 - 3.64	-	-
Aboriginal or Torres Strait Islander	52	15	9.5	7.07 - 12.41	2.9	0.00
Remoteness*						
Major cities	258	72	3.4	2.99 - 3.82	-	-
Inner regional areas	71	20	4.3	3.36 - 5.43	-	-
Outer regional areas	21	6	4.0	2.49 - 6.15	-	-
Remote areas	1	0.3	-	-	-	-
Very remote areas	1	0.3	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	52	15	2.9	2.14 - 3.76	-	-
Quintile 4	41	12	2.2	1.58 - 2.98	-	-
Quintile 3	68	19	3.7	2.88 - 4.71	-	-
Quintile 2	61	17	3.3	2.53 - 4.25	-	-
Quintile 1 (lowest)	128	36	6.6	5.43 - 7.71	-	-

*Remoteness was not calculated in four cases.
**Socioeconomic status was not calculated in six cases.

87 Australian Bureau of Statistics 2013, *3302.0 – Deaths, Australia, 2012*, Canberra: ABS.

The deaths of 55 of the 356 infants (15%) in 2013 were classified as Sudden Unexpected Death in Infancy (SUDI). The proportion of infant deaths that have been SUDI has not changed markedly in recent years (ranging between 13% and 17%).

SUDI is not a cause of death, but a classification to enable the consideration of deaths of otherwise healthy babies who die suddenly and unexpectedly. In some cases, a cause of death may be identified through autopsy and examination of the circumstances of the infant's death. For others, no clear cause can be determined, and many of these deaths are classified as Sudden Infant Death Syndrome (SIDS).

The deaths of seven of the 55 infants who died suddenly and unexpectedly in 2013 are also 'reviewable', and have been reviewed separately by the Ombudsman.

Age, gender and Aboriginal and Torres Strait Islander status

In 2013, just over two-thirds of the infants (245) died during the neonatal period (the period from birth to less than 28 days). Males have been consistently over-represented in infant deaths. As indicated in the table below, the deaths in 2013 were consistent with this trend, with males comprising over half (200) of the infants who died.

Of the 356 infants who died in 2013, 52 infants (15%) were Indigenous. The mortality rate of Aboriginal and Torres Strait Islander infants (9.5 deaths per 1,000 live births) was almost three times the rate of non-Indigenous infants.

Table 56: Infant deaths and mortality rates by gender, 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	216 (5.1)	181 (4.3)	183 (4.5)	159 (3.8)	175 (4.2)	162 (3.9)	187 (4.2)	160 (3.6)	168 (3.6)	166 (3.4)	155 (3.2)	147 (3.0)	161 (3.4)	120 (2.5)	156 (3.3)
Male	262 (5.9)	252 (5.6)	239 (5.5)	184 (4.2)	194 (4.4)	203 (4.6)	248 (5.3)	242 (5.1)	199 (4.0)	223 (4.4)	213 (4.2)	217 (4.2)	203 (4.0)	183 (3.6)	200 (4.0)
Both	478 (5.5)	433 (5.0)	422 (5.0)	343 (4.0)	369 (4.3)	365 (4.3)	435 (4.8)	402 (4.4)	367 (3.8)	389 (3.9)	368 (3.8)	364 (3.6)	364 (3.7)	303 (3.1)	356 (3.6)

Remoteness and socioeconomic status

Almost three-quarters of the infants who died in 2013 lived in major cities, a slight increase in the proportion in previous years. However, infants who lived in inner regional areas had the highest mortality rate (4.3 deaths per 1,000 live births).

The largest proportion of the infants who died (36%) lived in the areas of greatest socioeconomic disadvantage.

Leading causes of infant death

As has consistently been the case, conditions arising in the perinatal period comprised the leading cause of the deaths of infants in NSW. As shown in the table below, perinatal conditions accounted for the deaths of 186 infants (52%), the vast majority of whom (169) were neonates.

Congenital and chromosomal conditions comprised the second leading cause of death of infants, accounting for the deaths of 75 infants (21%). Over two-thirds of infants who died from this cause (52) were neonates.

At the time of reporting, the cause of death had not been classified for 31 infants. An additional 18 infant deaths were due to causes that were undetermined or ill-defined, including SIDS.

Table 57: All causes of infant deaths, 2013[88]

Type	Female	Male	Total	Infant Mortality Rate	95% confidence Interval
Certain conditions arising in the perinatal period	81	105	186	1.9	1.62 - 2.16
Congenital malformations, deformations and chromosomal abnormalities	37	38	75	0.8	0.60 - 0.95
Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified	4	14	18	0.2	0.11 - 0.29
Diseases of the nervous system	8	9	17	0.2	0.10 - 0.28
External causes of morbidity and mortality	2	5	7	0.1	0.03 - 0.15
Endocrine, nutritional and metabolic diseases	2	3	5	0.1	0.02 - 0.12
Diseases of the respiratory system	2	2	4	0.0	0.01 - 0.10
Diseases of the blood, blood-forming organs and certain disorders involving the immune mechanism	1	3	4	0.0	0.01 - 0.10
Certain infectious and parasitic diseases	0	3	3	-	-
Diseases of the digestive system	0	3	3	-	-
Diseases of the circulatory system	2	0	2	-	-
Neoplasms	1	0	1	-	-
Diseases of the musculoskeletal system and connective tissue	0	0	0	-	-

Leading causes of neonatal and post-neonatal death

As indicated in the following table, the leading causes of death differ between infants who die in the neonatal period (less than 28 days) and those who die in the post-neonatal period (28 days to 1 year). While the leading cause of death of neonates is perinatal conditions, the leading cause of the death of infants aged 28 days and older is SIDS and other unexplained causes.

Table 58: Top 5 causes of neonatal and post neonatal deaths, 1999-2013

Deaths of neonates (birth to <28 days)	N = 4074	Percent	Deaths of post neonates (28 days to 365 days)	N = 1684	Percent
Certain conditions originating in the perinatal period	2,906	71	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	532	32
Congenital malformations, deformations and chromosomal abnormalities	911	22	Congenital malformations, deformations and chromosomal conditions	364	22
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	92	2	Certain conditions originating in the perinatal period	201	12
Endocrine, nutritional and metabolic diseases	33	1	Diseases of the nervous system	129	8
Diseases of the nervous system	33	1	External causes of mortality and morbidity	118	7

88 The table does not include the 31 infants whose cause of death had not been finalised at the time of writing the report.

Chapter 17. Sudden Unexpected Death in Infancy

Defining Sudden Unexpected Death in Infancy (SUDI)

SUDI is not a cause of death, but a classification of other causes. The following definition of SUDI has been used by the CDRT since 2009:[89]

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 in misadventures due to external 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 sudden 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 clinicial history.[90]

Trends in SUDI in NSW, 1999-2013

In 2013, the deaths of 55 infants were classified as SUDI. The mortality rate in 2013 (0.56 deaths per 1,000 live births) was the highest since 2007. However, it was still lower than the 15-year average (0.62).

As shown in the table below, there has been a slow decline in the overall rate of SUDI in NSW. Over the last 15 years, the average SUDI mortality rate has declined from 0.77 deaths per 1,000 live births in 1999-2003 to 0.51 per 1,000 in 2009-2013.

The trend has differed slightly between infants who died in the neonate period (birth to less than 28 days) and those who died in the post-neonate period (28 days to under one year). Post-neonates have consistently comprised the majority of SUDI. However, while the average number of post-neonate SUDI has declined from 46 per year (1999-2003) to 40 per year (2009-2013), it has not been matched by a similar decline in neonate SUDI. The average number of neonate SUDI has remained at 8-10 per year over the 15-year period.

Table 59: Infant Mortality Rate of SUDI neonatal status, 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Neonates	9	9	12	7	12	4	7	7	12	8	5	11	10	13	11
Post- neonates	64	63	54	54	49	47	47	51	51	45	40	42	38	37	44
Total	**73**	**72**	**66**	**61**	**61**	**51**	**54**	**58**	**63**	**53**	**45**	**53**	**48**	**50**	**55**
IMR	0.85	0.83	0.76	0.70	0.71	0.59	0.59	0.62	0.65	0.53	0.46	0.52	0.48	0.51	0.56

89 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.

90 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*, Canberra: SIDS and Kids; citing Krous H. F. Beckwith B. Byard R. W. Rognum T. O. Bojanowski T. Corey T. Cutz E. Hanzlick R. Keens T. G. Mitchell E. A. 2004, *Sudden Infant Death Syndrome and Unclassified Sudden Infant Deaths: A Definitional and Diagnostic Approach*. Pediatrics 114 (1):234-238.

The deaths of five infants classified as SUDI in 2013 are 'reviewable deaths' and have been reviewed separately by the Ombudsman. Four of these deaths occurred in circumstances of neglect, and one child was in care at the time of their death.

Demographic and individual characteristics

The table below provides an overview of the main demographic characteristics of the 55 infants whose sudden and unexpected deaths were registered in NSW in 2013.

Table 60: Key demographic and individual characteristics of deaths classified as SUDI in NSW, 2013

	Number	Percent	Infant Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**55**	**100**	**0.56**	**0.41 - 0.71**		
Gender						
Female	22	40	0.46	0.28 - 0.68	-	-
Male	33	60	0.65	0.44 - 0.89	1.4	-
Age						
Under 1 day	0	0	-	-	-	-
1 day - under 1 week	1	2	-	-	-	-
1 week - under 28 days	10	18	0.10	0.05 - 0.18	-	-
28 days - under 1 year	44	80	0.45	0.32 - 0.58	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	40	73	0.43	0.30 - 0.57	-	-
Aboriginal or Torres Strait Islander	15	27	2.73	1.48 - 4.35	6.3	-
Remoteness*						
Major cities	33	60	0.44	0.30 - 0.60	-	-
Inner regional areas	17	31	1.03	0.57 - 1.57	-	-
Outer regional areas	4	7	0.77	0.19 - 1.77	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	3	5	-	-	-	-
Quintile 4	4	7	0.21	0.06 - 0.55	-	-
Quintile 3	3	5	-	-	-	-
Quintile 2	14	25	0.76	0.42 - 1.27	-	-
Quintile 1 (lowest)	30	55	1.54	1.04 - 2.20	-	-

*Remoteness was not calculated in one case.
**Socioeconomic status was not calculated in one case.

Age and gender

The 55 infants ranged in age from five days to 11 months. Over half (30) died during the first three months of life:

- eleven infants died in the neonatal period; three of these infants were less than two weeks old
- nineteen infants were aged 1-3 months
- twenty infants were aged 4-6 months, and
- five infants were aged 7-11 months.

Over half (33) of the infants were male. The table below shows that the higher number of male infants who die suddenly and unexpectedly is a pattern that has been consistent over time, regardless of yearly fluctuations in the overall number of SUDI.

Table 61: SUDI by gender, 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
Female	36	28	30	23	27	19	22	20	30	22	16	17	23	22	22	357
Male	37	44	36	38	34	32	32	38	33	31	29	36	25	28	33	506
Total	73	72	66	61	61	51	54	58	63	53	45	53	48	50	55	863

Aboriginal and Torres Strait Islander status and cultural background

In 2013, just over one-quarter (15) of the infants whose deaths were classified as SUDI in NSW were Aboriginal (12) or Aboriginal and Torres Strait Islander (3).

In Australia, Aboriginal and Torres Strait Islander babies are significantly more likely to be born pre-term, of low birth weight, and to die before their first birthday than are non-Indigenous babies.[91] Recent NSW data identifies SIDS (which makes up a large proportion of deaths classified as SUDI) as the third leading cause of death for Aboriginal and Torres Strait Islander children (after conditions originating in the perinatal period and external causes), with the percentage of deaths of Aboriginal and Torres Strait Islander children due to SIDS almost twice that of non-Indigenous children.[92]

While Aboriginal and Torres Strait Islander children comprise around 5% of all children under one year of age,[93] over the past 15 years they have accounted for an average of 17% of all SUDI. In 2013, the number of Aboriginal and Torres Strait Islander infant deaths classified as SUDI represents the highest proportion in 15 years.

One-third (18) of the 55 infants whose deaths were SUDI had a parent/s who were born overseas. Eight families were of Pacific Island background (New Zealand Maori, Tonga, Cook Islands); three families were of Chinese background; and seven families were from diverse cultural backgrounds including Indian, Iraqi, Irish, Khmer, Lebanese, Maltese and South Korean origins.

Remoteness and socioeconomic status

Consistent with previous years, the vast majority (50) of SUDI registered in 2013 were living in major cities or inner regional areas of NSW. The families of 80% of the infants who died suddenly and unexpectedly resided in areas of greatest socioeconomic disadvantage (quintiles 1 and 2). This pattern was also apparent in 2012.

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.[94]

Of the 53 infants for whom gestational age was available, the majority (47) were full-term infants. Five infants were born prematurely between 30 and 36 weeks gestation. The proportion of SUDI in 2013 who were infants born prematurely (9%) is lower than in previous years,[95] however is still just above the NSW average of between 7.0 and 7.5 percent of all births over the 10-year period to 2010.[96]

Birth weight was available for 52 of the 55 infants who died suddenly and unexpectedly. Seven infants had low birth weight, ranging from 1600g to 2480g.

Three infants were born both prematurely and with low birth weight.

91 Australian Institute of Health and Welfare 2011. Aboriginal and Torres Strait Islander Health Performance Framework 2010: detailed analyses. Cat. No. IHW 53. Canberra: AIHW.

92 NSW Child Death Review Team 2014, *Causes of death of children with a child protection history 2002-2011* special report to Parliament, Sydney : NSW Ombudsman.

93 Australian Bureau of Statistics 2013, 3101.0 *Australian Demographic Statistics* (TABLE 51. New South Wales, 2013), Canberra: ABS, and Australian Bureau of Statistics 2012, *Indigenous experimental population projections by age, by sex – Reference period 2011* Canberra: ABS.

94 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 4 : 13-21.

95 The proportion of SUDI born prematurely was 15% in 2012; 17% in 2011; and 40% in 2010.

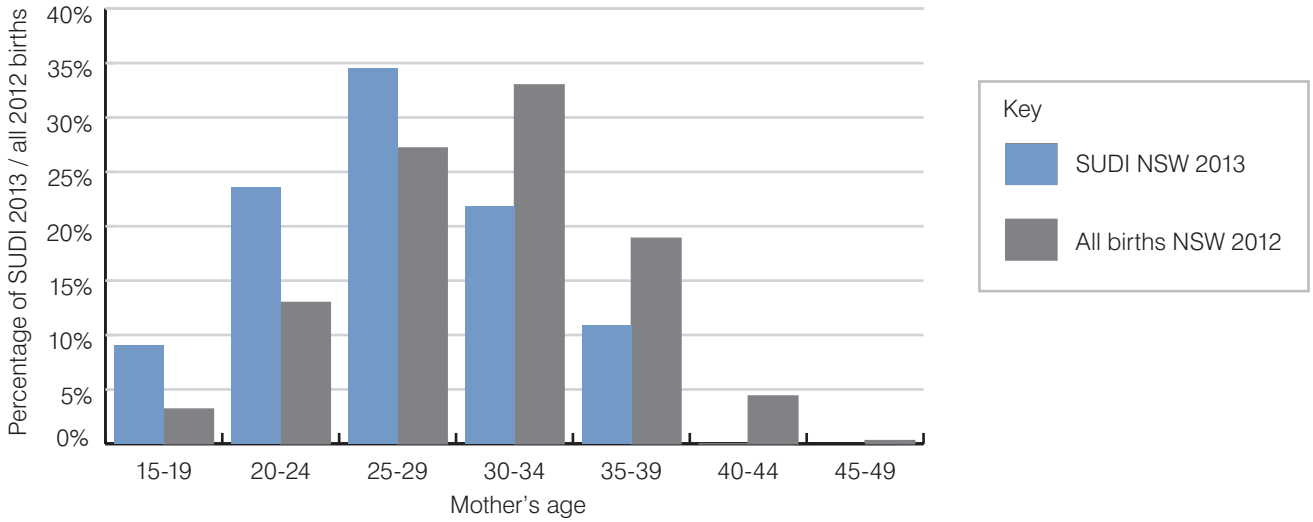
96 Centre for Epidemiology and Evidence 2014. *Health Statistics New South Wales*. Sydney: NSW Ministry of Health. Available at www.healthstats.nsw.gov.au. Accessed 30 June 2014.

Maternal age

Young maternal age has been identified as a factor associated with SIDS.[97] In 2013, five mothers of infants who died suddenly and unexpectedly were teenagers aged between 15 and 19 years. For four of these young mothers, the infant who died was their first child.

The figure below provides the age distribution of the 55 mothers whose infants' deaths were classified as SUDI in 2013, compared with the age distribution of all mothers who gave birth in 2012.[98] The mothers of the infants who died suddenly and unexpectedly were highly represented in the younger age groups – with a higher proportion aged under 30 years than the general NSW population of mothers.

Figure 10: Comparison of maternal age for 2013 SUDI against all NSW births, 2012



Child protection history

In April 2014, the Team tabled a special report to the NSW Parliament that outlined the findings from research undertaken into the causes of death of children with a child protection history over a 10-year period.[99] Amongst other things, the research 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.

In 2013, 23 of the 55 families (42%) had a child protection history. The proportion of SUDI in families with a child protection history in 2013 is higher than 2012 (34%), but consistent with the 10-year average identified in the Team's report to Parliament (43%).

Fourteen of the infants whose deaths in 2013 were classified as SUDI were the subject of a risk of significant harm (ROSH) or contact report about risk issues; with most (10) the subject of a prenatal report.[100] Nine infants had not been the subject of a report, but had a sibling who had been, including one child whose sibling was the subject of a report to a Child Wellbeing Unit.

97 Moon R.Y. Fu L. 2012, *Sudden Infant Death Syndrome: An Update*, Pediatrics in Review 33(7): 314-320.
98 This data is the most recent available from the Australian Bureau of Statistics.
99 NSW Child Death Review Team 2014, *Causes of death of children with a child protection history 2002-2011* special report to Parliament, Sydney : NSW Ombudsman.
100 Prenatal reports may be made to Community Services if there are concerns an unborn infant may be at risk of significant harm after his or her birth.

In 2013, the most frequently reported concerns for the 23 infants and/or their siblings included exposure to domestic violence (13 families); parent/carer drug and alcohol misuse (13); significant neglect (9); inadequate shelter or homelessness (8); and parent/carer mental health (6). Other reported concerns for infants and/or their siblings included parent/carer criminality, physical harm, risk of sexual harm, lack of antenatal care, and carer disability or health issues. Most (16) of the 23 families with a child protection history had reports about two or more risk factors.

The majority (19) of the 23 infants were in unsafe sleep environments when they died, including:

- thirteen infants who were sharing a sleep surface[101] with one or more family members, such as an adult mattress or lounge/sofa – including three who were with a parent who had consumed alcohol or illicit drugs
- four infants who were sleeping alone but propped up, or surrounded, by pillows and other loose items, and
- two infants who were placed for sleep in an inappropriate sleep environment (such as an upturned car seat) or wrapped in overly tight swaddling, causing the infant to overheat.

Notably, 21 of the 23 infants (91%) who had a child protection history were exposed to tobacco smoke. In comparison, 18 of the 32 infants (56%) who did not have a child protection history were exposed to tobacco smoke.

Cause of death

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).

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.

As shown in the table below, around three-quarters of SUDI in NSW remain unexplained after autopsy and comprehensive investigation. This has consistently been the case in the history of the Team, with no substantial change in the proportion of explained SUDI.

At the time of writing, information regarding cause of death was available for 26 of the 55 infants (47%) who died suddenly and unexpectedly and whose deaths were registered in NSW in 2013.

The table below does not identify a substantial change in the proportion of explained SUDI despite the introduction of a government policy in December 2008 aimed at delivering a coordinated response to these deaths.

Table 62: Number and rate of explained and unexplained SUDI in NSW, 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total %
Explained	10	19	20	9	15	17	11	14	15	13	9	22	13	15	9	**211 (24)**
Unexplained	63	53	46	52	46	34	43	44	48	40	36	29	29	27	17	**607 (71)**
Not finalised	0	0	0	0	0	0	0	0	0	0	0	2	6	8	29	**45 (5)**
Total	**73**	**72**	**66**	**61**	**61**	**51**	**54**	**58**	**63**	**53**	**45**	**53**	**48**	**50**	**55**	**863 (100)**

Explained SUDI

At the time of writing, the cause of death of nine of the 55 infants (16%) classified as SUDI in 2013 had been identified after investigation.

The following table shows that two-thirds of explained SUDI in NSW over the past 15 years has been due to diseases and morbid conditions that were not identified or recognised as life-threatening before death.

101 Sharing a sleep surface refers to situations where an infant is sleeping on the same surface as another person, regardless of whether the person intended to sleep with the infant. Surfaces include fixed bedding, mattresses placed on the floor or other surface, couches and sofas, fold-out beds and other surfaces such as bean bags and inflatable mats.

Table 63: Total number of explained causes of SUDI in NSW, 1999-2013

Cause of death	Number	Percent
Diseases and morbid conditions		
Diseases of the respiratory system	44	21
Congenital and chromosomal conditions	36	17
Other diseases and morbid conditions	60	28
Subtotal:	**140**	**66**
Accidental threats to breathing		
Accidental suffocation and strangulation in bed	38	18
Other accidental threats to breathing[102]	12	6
Subtotal:	**50**	**24**
Other external causes		
Assault	16	8
Other injury, poisoning or external cause	4	1
Subtotal:	**20**	**9**
Symptoms and signs involving the circulatory and respiratory systems		
Other symptoms and signs involving the circulatory and respiratory systems	1	<1
Subtotal:	1	<1
Total	**211**	**100**

Diseases and morbid conditions

In 2013, six of the nine infants whose deaths were explained were found to have died from natural causes associated with either undiagnosed cardiovascular anomalies and defects (3) or respiratory infections (3).

Of the six infants:

- two infants were examined by a medical professional in the two weeks before their death as part of routine health checks; neither was identified as having a life threatening condition
- three infants were noted by their parents/carers to have signs of illness (upper respiratory tract infection and/or a general illness) in the two weeks before death, and
- one of the infants who died as a result of a congenital heart defect had previously been identified as having a possible heart murmur that was pending further investigation.

The vast majority (5) of the infants who died from natural causes were post-neonates, aged between one and six months.

External causes

The cause of death for three infants was accidental threats to breathing. All three infants died when they accidentally asphyxiated in an unsafe sleep environment.

None of the infants were sleeping in infant-specific bedding: two infants became wedged between the edge of a mattress and a wall or side railings designed to stop older children falling out of bed; the other infant was sharing a sleep surface with a parent and siblings. Loose bedding was noted in two cases.

Accommodation issues were noted for all three infants, including poor (unhygienic) state of the home (2), homelessness, and inadequate housing – bedrooms too hot to sleep in.

The families of two of the infants had a child protection history in NSW or interstate.

102 Includes inhalation of gastric contents (4); inhale and ingest food causing obstruction to respiration (2); other specified threats to breathing (2); unspecified threats to breathing (2); obstruction of respiration due to inhale and ingest other object; and other accidental hanging and strangulation.

Unexplained SUDI

The cause of death of 17 infants (31%) who died suddenly and unexpectedly and whose deaths were registered in 2013 remains unexplained after a comprehensive autopsy and examination of the circumstances of the death. Two of the infants were aged less than 28 days.

The cause of death of the 17 infants has been classified as:

- other ill-defined and unspecified causes of mortality (7)
- undetermined in the context of co-sleeping, SIDS Category II (7), and
- consistent with SIDS (3).

The table below shows the classification of unexplained SUDI since 1999. There are a number of sub-classifications of SIDS (see Appendix 3 for details). In 2005, Australia adopted a national consensus for defining SIDS and developed a nationally accepted SIDS autopsy protocol. Since that time, a higher proportion of unexplained SUDI has been classified across the SIDS categories. The table does not include the 45 matters that were not yet finalised at the time of writing this report.[103]

Table 64: Unexplained SUDI by year, 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
SIDS	52	44	31	39	23	15	17	0	1	7	4	6	13	7	3	262
SIDS Category IA	0	0	0	0	0	0	6	4	3	3	4	2	0	0	0	22
SIDS Category IB	0	0	0	0	0	0	2	4	9	3	2	1	1	0	0	22
SIDS Category II	0	0	0	0	3	6	13	21	22	18	19	10	9	5	7	133
SIDS Unclassified	1	0	0	0	1	0	1	8	5	2	2	1	1	0	0	22
Instantaneous death	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	2
Death <24hrs from onset of symptoms, not otherwise explained	8	8	7	11	18	8	3	7	3	1	1	0	0	0	0	75
Unattended death	0	0	0	0	0	1	0	0	1	1	0	0	0	1	0	4
Other ill-defined & unspecified causes of mortality	2	1	8	2	1	2	1	0	4	5	4	9	5	13	7	64
Total	**63**	**53**	**46**	**52**	**46**	**34**	**43**	**44**	**48**	**40**	**36**	**29**	**29**	**27**[104]	**17**	**607**

Circumstances of death

Seasonal factors

The distribution of SUDI across the year differs from year to year. For deaths registered in 2013, SUDI occurred throughout the year, with an equal number of deaths during the cooler months of autumn (12) and winter (12), and a slightly higher number of deaths during the warmer months of spring (15) and summer (16). The even distribution of SUDI across the year was also noted in 2012. Prior to this, SUDI was noted to have occurred more often in the winter months of June, July and August.

Table 65: SUDI categorised by month, 2013

Month	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEPT	OCT	NOV	DEC
No. of SUDI	8	3	4	6	2	2	6	4	4	3	8	5

103 As indicated in table 62, the 'not finalised' matters include two deaths in 2010, six in 2011, eight in 2012, and 29 deaths in 2013.
104 The 2012 total does not include one death for which coding has not yet been finalised.

Where the incident occurred

Consistent with previous years, the vast majority (50) of SUDI occurred in the infant's usual home. For five infants, the death incident occurred in other places, including the home of a relative or friend (4), or during a consultation at a doctor's surgery.

Carer at the time of the incident

Almost all (52) of the infants were being cared for by their mother and/or father in the period immediately preceding their death. The other three infants were with grandparents (2) or a family friend.

Recent infant illness

For SUDI registered in 2013, nearly half (25) the infants who died suddenly and unexpectedly had exhibited signs of illness in the two weeks before their death. Four of these infants were neonates.

The infants displayed symptoms of upper respiratory tract infections or bronchiolitis (13); generalised symptoms of being unwell such as fever, reduced appetite, increased crying and problems with settling (7); diarrhoea, vomiting and/or signs of gastro-oesophageal reflux (4); and possible apnoea (1).

Three-quarters (19) of the 25 infants who exhibited recent signs of illness were seen by a medical professional during the two-week period. None of the infants seen by medical professionals were identified as having a life-threatening illness at the time of the health check.

Eleven infants had been treated in the two weeks before their death with prescribed or over-the-counter medication, including antibiotics (3), paracetamol (2), reflux medication (2), nasal saline spray (2), colic or 'wind' medication (2), and a laxative (1).

Other infant illness

Two infants were found after their death to have congenital conditions that had not previously been diagnosed; in one case this condition led to the infant's death. Another five infants had identified conditions that were not associated with their death, including intrauterine growth retardation, gastro-oesophageal reflux disease, haemangioma, neonatal encephalopathy with haemorrhage, and previous episodes of bronchiolitis.

Toxicology

At the time of reporting, post mortem toxicology results were available for 31 infants. For 27 of the 31 infants, toxicology results did not identify the presence of any drugs.

For two infants, low-level prescription or over-the-counter medication was detected, which had no bearing on their death. Another infant was found to have a low level of a medication prescribed to the infant's mother (diazepam); its presence was considered to have had the potential to adversely affect respiration. One further infant was found to have therapeutic levels of medication associated with medical intervention.

Modifiable risk factors associated with SUDI

Modifiable risk factors for SUDI include:

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

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. 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 2013, the vast majority (53) of the 55 infants who died suddenly and expectedly were in a sleep environment. Most (48) were placed or likely to have been placed for sleep; five additional infants were either situated in bed with their parents, placed in non-infant specific bedding next to a sleeping parent, or located on an inappropriate sleep surface after a parent/carer unintentionally fell asleep.

Almost all (51) of the 53 infants in a sleep environment had at least one modifiable risk factor present in their environment, and over half (31) had three or more risk factors present.

Only five 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. Of these five, one infant was later found to have died from natural causes.

The two infants where no modifiable risk factors have been recorded were both neonates. One of these matters is not yet finalised, with information currently unavailable about cause of death; the other death remains unexplained after thorough investigation.

Table 66: Presence and frequency of modifiable risk factors for SUDI in a sleep environment, 2013

	Cause of death	Loose bedding	Exposure to tobacco smoke	Non-infant specific sleep environment	Shared sleep surface	Infant not placed to sleep on their back	Poor ventilation / infant over-heated	Shared sleep surface with person alcohol and/or drug affected	Total
1	Explained: natural	✓	✓	✓	✓	✓	✓		6
2	Unexplained	✓	✓	✓	✓		✓	✓	6
3	Not finalised	✓	✓	✓	✓	✓			5
4	Unexplained	✓	✓	✓	✓		Missing	✓	5
5	Not finalised	✓		✓	✓		✓	✓	5
6	Not finalised	✓		✓	✓	✓	Missing		4
7	Not finalised	✓	✓	✓					4
8	Not finalised	✓	✓	✓	✓				4
9	Not finalised	✓	✓	✓	✓	Missing	Missing		4
10	Unexplained	✓	✓	✓	✓		Missing		4
11	Unexplained	✓		✓	✓	✓			4
12	Unexplained	✓	✓		✓	✓			4
13	Not finalised	✓	✓	✓	✓		Missing		4
14	Not finalised	✓	✓	✓	✓		Missing		4
15	Unexplained	✓	✓			✓	✓		4
16	Explained: Natural	✓	✓	✓	✓		Missing		4
17	Not finalised	✓	✓	✓	✓				4
18	Unexplained	✓	✓	✓	✓	Missing	Missing		4
19	Not finalised	✓	✓				✓		3
20	Not finalised	✓	✓				✓		3
21	Unexplained		✓	✓	✓		Missing		3
22	Not finalised	✓		✓	✓	Missing	Missing		3
23	Explained: External	✓	✓	✓					3
24	Not finalised	✓	✓	✓			Missing		3
25	Unexplained	Missing	✓	✓	✓	Missing			3
26	Not finalised	✓	✓			✓	Missing		3
27	Explained: External	✓	✓	✓			Missing		3
28	Not finalised	✓		✓	✓				3

	Cause of death	Loose bedding	Exposure to tobacco smoke	Non-infant specific sleep environment	Shared sleep surface	Infant not placed to sleep on their back	Poor ventilation / infant over-heated	Shared sleep surface with person alcohol and/or drug affected	Total
29	Not finalised	✓	✓	✓					3
30	Explained: Natural	✓	✓	✓			Missing		3
31	Not finalised	Missing	✓	✓	✓	Missing	Missing		3
32	Not finalised	✓		✓			Missing		2
33	Not finalised	✓	✓				Missing		2
34	Not finalised	✓				✓			2
35	Unexplained	✓	✓						2
36	Not finalised	✓	✓						2
37	Unexplained		✓	✓			Missing		2
38	Not finalised	✓	✓						2
39	Not finalised		✓				✓		2
40	Explained: natural	✓	✓						2
41	Not finalised	✓				✓	Missing		2
42	Unexplained	✓	✓				Missing		2
43	Explained: External	Missing		✓	✓	Missing			2
44	Not finalised	✓	✓				Missing		2
45	Not finalised	✓				✓			2
46	Unexplained			✓					1
47	Unexplained	Missing	✓			Missing	Missing		1
48	Unexplained		✓						1
49	Not finalised	✓							1
50	Unexplained					✓			1
51	Explained: Natural		✓				Missing		1
52	Not finalised						Missing		0
53	Unexplained								0
Total		**40**	**39**	**30**	**23**	**11**	**6**	**3**	

Shared sleep surfaces

The sharing of sleep surfaces has consistently been identified as a risk factor for SUDI. 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.[105]

Twenty-three infants (42%) whose sudden and unexpected deaths were registered in NSW in 2013 were sharing a sleep surface when they died. In most cases (18), the shared sleep surface was an adult mattress or bed. Of the 23 infants who were sharing a sleep surface:

- thirteen were sharing a sleep surface with one person, either a parent (12) or sibling, and
- ten infants were sharing a sleep surface with two or more people, either two adults (7), or adults and children (3).

105 NSW Ministry of Health 2012, *Having a baby.* 2nd edition Sydney: NSW Ministry of Health, p. 113, http://www.health.nsw.gov.au/Kids/Publications/having-a-baby.pdf , accessed on 16 Jul 2014.

Carers who consume drugs, alcohol or sedating medication prior to sharing a sleep surface with a young child can create a hazardous sleep environment that increases the risk of sudden infant death and fatal sleep accidents. Three infants died while sharing a sleep surface with an adult who had consumed alcohol or other drugs. In two of the three cases, the adult/s had also been prescribed methadone and valium, or an opioid pain medication.

Records show that in most (16) of the 23 cases, the adult(s) intended to sleep with the infant. In four 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. For three infants, the carer/s unintentionally fell asleep on a couch after feeding (2) or while lying in bed watching television.

One of the 23 infants was sharing a cot with their twin when they died. The practice of placing twins to sleep together is referred to as 'co-bedding'. Current evidence indicates that the safest way to sleep twins at home is to place each twin separately in their own cot.[106]

Almost three-quarters (17) of the 23 families sharing sleep surfaces at the time the infants died were either Indigenous (10),[107] or from non-English speaking cultural backgrounds (7); one family was both Aboriginal and culturally diverse. Of the eight infants with culturally and linguistically diverse heritage, most (5) were of Islander background.[108]

Five of the 23 infants who died while sharing a sleep surface were less than 28 days old. Most (4) of these infants were of Indigenous or culturally diverse backgrounds.

The table below shows that nearly half (44%) of SUDI since 2004 were infants who were sharing a sleep surface with another person or persons. While there has been some fluctuation, the overall proportion has not substantially changed during the 10-year period.

Table 67: SUDI and shared sleep surface, 2004-2013

Shared sleep surface	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total (%)
No	28	26	27	34	29	26	32	26	23	32	**283 (54)**
Yes	22	25	31	27	19	19	21	22	25	23	**234 (44)**
Other/not known	1	3	-	2	5	-	-	-	2	-	**13 (2)**
Total	**51**	**54**	**58**	**63**	**53**	**45**	**53**	**48**	**50**	**55**	**530 (100)**

Inappropriate sleep surfaces and loose bedding

Placing babies to sleep on surfaces that are not infant-specific, even when the infant is sleeping alone, is also a risk factor in SUDI. In 2013, 10 infants were placed for sleep by themselves on surfaces that were not infant-specific. This included adult beds or mattresses (4), rocker/bouncers (2), fold-out foam seats (2), a portable/carry basket, and an upturned child's car seat.

Police recorded that loose bedding was present in the sleep environment of the majority (40) of the infants.[109] Twenty-three infants placed for sleep had multiple loose items present in their sleeping environment, including blankets, doonas and quilts, adult pillows, soft toys, and folded towels.[110] Where only a single loose item was recorded, it most commonly involved blankets and doonas (8) and adult pillows (6).

106 SIDS and Kids. National Scientific Advisory Group (NSAG), 2010. *Information Statement: Co-bedding twins*. Melbourne: National SIDS Council of Australia.
107 Two-thirds (10) of the 15 Aboriginal and/or Torres Strait Islander infants who died suddenly and unexpectedly were sharing a sleep surface.
108 Including the Cook Islands, New Zealander Maori, and Samoa.
109 Information about the presence of loose bedding was not available in four cases.
110 Pillows, quilts, sheepskins, blankets, doonas and other extra bedding items are hazardous when placed under an infant or left loose in an infant's cot or bassinette. When blankets are used they should be tucked under the mattress in such a way as to ensure they do not cover the infants head or face. Alternative options include infant-specific sleep clothing that is designed keep infants warm without the risk of potential suffocation or over-heating.

Sleep position

Of the 48 infants placed or likely to have been placed for sleep at the time that they died:

- Most (31) were reportedly placed on their back. Over half (18) of these infants were found on their back; eight were found on their front; four on their side; and one in a vertical position.[111]
- Eight infants were placed on their side. Most (5) were found on their side, two were on their front, and one was on their back.
- Three infants aged between one and five months were placed on their front (prone position); all were found on their front.

Positional information was missing for six infants who were placed for sleep.

All of the 11 infants placed for sleep on their side or front were from culturally and/or linguistically diverse (6), Aboriginal (4), or Aboriginal and culturally diverse backgrounds.

In the past 10 years, just under one-third of SUDI were infants who had not been placed for sleep on their back. For SUDI registered in 2013, the proportion (23%) of infants not placed for sleep on their back was lower than the 10-year average (32%).

Table 68: SUDI and position placed for sleep 2004-2013

Position placed to sleep	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total (%)
On back	28	24	36	33	25	22	28	22	22	31	**271 (56)**
On side	9	7	8	14	7	10	14	8	8	8	**93 (19)**
On front	1	1	4	5	2	3	2	3	1	3	**25 (5)**
At breast	-	-	1	-	-	1	-	1	-	-	**3 (<1)**
Information not available	7	10	2	10	5	3	4	9	8	6	**64 (13)**
Not placed for sleep	0	0	0	0	0	0	5	5	11	7	**28 (6)**
Total	**45**	**42**	**51**	**62**	**39**	**39**	**53**	**48**	**50**	**55**	**484 (100)**

*Information in this table prior to 2010 is drawn from previously published Team data.

Infants not placed for sleep

Seven of the 55 infants were not placed for sleep when they died. The circumstances of the infants prior to the incident included:

- four infants died when their parent/s accidentally fell asleep on a couch or in bed after feeding or while relaxing in bed
- two infants died while unsupervised in a bouncer, and
- one infant was being held by a parent while awaiting medical assistance.

Records show that two of the infants were awake when the incident leading to their death occurred. One of the two infants was found to have died from a disease or morbid condition that had not been previously detected. Investigations into the cause of death of the other infant have not been finalised.

Exposure to tobacco smoke

Exposure to tobacco smoke is one of the most important risk factors in SUDI. Research shows maternal smoking during pregnancy is identified as a major risk factor 'in almost every epidemiologic study of SIDS', and that smoke in the infant's environment after birth is just as problematic.[112] 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.[113]

111 The infant was located upside-down between the mattress and wall.

112 Moon, R. Y. 2011, *SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment*. Pediatrics 128(5): e1341-e1367.

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

Nearly three-quarters (39) of the 55 infants who died suddenly and unexpectedly and whose deaths were registered in 2013 were exposed to tobacco smoke during and/or after pregnancy.[114]

As shown in the table below, in the past 10 years, 59% of all SUDI were infants who had been exposed to tobacco smoke. The proportion in 2013 (71%) was much higher than the 10-year average.

Table 69: SUDI and exposure to tobacco smoke 2004-2013

Exposure to tobacco smoke	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total (%)
No	7	10	7	12	14	14	17	15	23	16	**135 (25)**
Yes	32	26	39	38	27	25	29	31	26	39	**312 (59)**
Information not available	12	18	12	13	12	6	7	2	1	0	**83 (16)**
Total	**51**	**54**	**58**	**63**	**53**	**45**	**53**	**48**	**50**	**55**	**530 (100)**

Protective factors

Breastfeeding

Research has shown that breastfeeding is associated with a reduced risk of SIDS,[115] and helps with infant immunity levels.[116]

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.[117] The figure drops to 15% by six months of age.

In 2013, less than half (24) of the infants whose deaths were classified as SUDI were breastfed at the time of death; and nine of these infants were being fed a combination of breast milk and formula. Only 15 of the 55 infants (27%) were exclusively breastfed from birth. One mother was breastfeeding while taking methadone as part of an opioid treatment program.

Most (31) infants were being formula-fed at the time they died, including 11 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.[118]

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)'.[119]

In 2013, 13 of the 21 infants placed for sleep in infant-specific bedding were sleeping next to their parents' beds.[120] All but one of the 13 infants who were room sharing at the time that they died had been exposed to some form of modifiable risk.[121] For most (10), these risk factors were present in the infant's sleep environment and included loose bedding or other items such as pillows or toys in the cot or bassinette (9), being placed to sleep on their side (4), and overheating or hot room temperature (1). Eight infants had also been exposed to tobacco smoke.

114 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. SIDS and Kids 2009, *Information Statement: Smoking*, Melbourne: National SIDS Council of Australia.

115 SIDS and Kids. National Scientific Advisory Group (NSAG) 2012, *Information Statement: Breastfeeding*. Melbourne: National SIDS Council of Australia.

116 Hauck F. R. Thompson J. M. D. Tanabe K. O. Moon R. Y. Vennemann M. M. 2011, *Breastfeeding and reduced risk of sudden infant death syndrome: a meta-analysis*. Pediatrics 128(1): 103-110.

117 Australian Institute of Health and Welfare 2011. *Australian National Infant Feeding Survey: indicator results*. Canberra: AIHW

118 Moon, R. Y. 2011, *SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment*. Pediatrics 128(5): e1341-e1367.

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

120 For one infant, the location of infant-specific bedding was not stated.

121 The infant for whom no modifiable SUDI risk factors were identified was later found to have died from a disease or morbid condition that had not been previously recognised as life-threatening.

Prevention measures

Key organisations such as SIDS and Kids and the NSW Ministry of Health promote six main messages to reduce the risk of sudden unexpected death in infancy, including SIDS and fatal sleep accidents:[122]

- sleep baby on the back from birth, not on the tummy or side
- sleep baby with head and face uncovered
- keep baby smoke free before and after birth
- provide a safe sleeping environment day and night
- sleep baby in their own safe sleeping place in the same room as an adult caregiver for the first six to 12 months, and
- breastfeed baby if you can.

A safe sleeping environment involves safe bedding (no loose bedding, pillows, doonas, lambs-wool, bumpers or soft toys), a safe cot or bassinette (which meets current Australian safety standards), and a safe clean mattress (firm, flat and the right size for the cot).

Observations, themes and issues

Considerable work has been done over many years by a range of agencies to reduce the sudden and unexpected deaths of infants in NSW. Although the national death rate from SIDS has decreased markedly since the introduction of the SIDS education campaign in 1991, certain infants continue to be at higher risk of sudden and unexpected death, including Aboriginal and Torres Strait Islander infants, male infants, infants who weighed less than 2500g at birth, those from areas of lower socioeconomic status, and families with a child protection history.

The Team's work highlights the importance of:

- promoting safer sleeping practices to families of Aboriginal and/or Torres Strait Islander and diverse cultural backgrounds
- current work to develop focused strategies and training resources to assist Community Services caseworkers to better assess risk for infants and provide casework services to at-risk families
- reinforcement by early childhood nurses, midwives and other health practitioners of safe sleeping messages to all new parents and carers, including experienced parents already caring for older children, and
- ensuring families are educated about the risks associated with exposing infants to tobacco smoke, before and after birth.

The Team's recommendations

The Team's recommendations have been aimed at:

- improving the response to sudden unexpected deaths in infancy, including a comprehensive and multidisciplinary approach to the investigation process
- ensuring that safe sleeping practices are consistently promoted across health services, and
- facilitating improved assessment of risk to infants in families with a child protection history and targeted education to at-risk families.

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. In 2008, following the Team's recommendation to adopt a multi-agency integrated system of response to SUDI, Health issued the *Death – Management of Sudden Unexpected Death in Infancy* policy directive. The policy aims to deliver a coordinated response to SUDI by health professionals, police, ambulance, forensic pathologists and coroners.

122 SIDS and Kids. National Scientific Advisory Group (NSAG) 2007, *Information Statement: Sleeping with a baby.* Melbourne: National SIDS Council of Australia.

The Team's reviews have found that overall compliance with the policy has been low, particularly in relation to the requirements to interview parents and take a medical history, to provide follow-up care to the family, and to provide information to the Department of Forensic Medicine. Last year, the Team sought detailed advice from NSW Kids and Families on the outcomes of its file audits to assess compliance with the policy. The findings of Health's audit were consistent with the findings of the Team, and have reinforced the Team's recommendations regarding the need to consider the adequacy of the current model of response to SUDI.

NSW Kids and Families has undertaken substantial work to review and refresh the Sudden Infant Death Advisory Committee (SIDAC), and to commence a review of the SUDI policy and its underlying service model. In relation to the review, the Team has highlighted the importance of considering:

- options for providing a more centralised response to SUDI via a statewide resource that facilitates a consistent and appropriate approach, such as a small skilled expert team that either responds to instances of SUDI itself, or provides detailed guidance and advice to staff in designated agencies to respond at the time of the event, and
- the potential for NSW to adopt a multidisciplinary case review approach to the SUDI investigation process, to ensure that all efforts are made to identify and consider all of the relevant factors in the sudden unexpected deaths of infants.

NSW Kids and Families has indicated that the SIDAC will oversee the review, and anticipates that it will be completed by the end of 2014. The agency has advised that it has progressed considerable work to inform the review, including commissioning an international evidence check on SUDI response models; preparing to undertake statewide consultation with relevant health professionals; and development of a new interim resource for clinicians to make it clear when the SUDI policy should be used.

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.

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. Last year, the Team recommended that the Ministry of Health provide advice on current or planned initiatives to address these issues.

In May 2014, the Ministry advised that DOFM has recently put measures in place to address delays, including defining expected timeframes for completion of reports, and the allocation of forensic pathologists across the service to assist with surges in demand.

In relation to increasing the proportion of SUDI that are explained, the Ministry advised that NSW Health Pathology and Sydney Children's Hospital Network established a Paediatric Histopathology Working Party in November 2013, and discussion has included concerns about perinatal and SUDI post mortem service delivery and quality issues. The working party is currently developing a plan to address key issues relating to perinatal and infant post mortems.

Promoting safe sleeping practices

The importance of safe sleeping practices has been consistently emphasised by the Team and other groups such as SIDS and Kids over an extended period of time. In 2013, less than 10% of infants who died suddenly and unexpectedly and who were in a sleep environment had been placed to sleep in accordance with safe sleeping guidelines (that is, alone and on their back, in infant-specific bedding, and without loose bedding or other items in the cot).

In November 2012, Health released a revised policy on *Maternity – Safer Sleeping Practices for Babies in NSW Public Health Organisatons* to provide 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. The policy requires Local Health Districts to conduct an annual audit to ensure that practice complies with policy. Last year, the Team recommended that NSW Kids and Families provide detailed advice on the outcome of the audits conducted by LHDs. In May 2014, NSW Kids and Families advised that the audit of compliance was progressing on track, and was expected to be completed by 30 June 2014.

In relation to safe sleeping practices, NSW Kids and Families has also:

- been working with SIDS and Kids NSW to review Health's *Sudden Infant Death Syndrome (SIDS) and safe sleeping for infants* guidelines
- worked with Community Services to develop Safe Sleeping resources, and
- commenced work with SIDS and Kids NSW and Victoria to discuss options for providing guidelines to community-based staff in NSW.

Reducing risk for children with a child protection history

In 2012, and against the background of the consistent over-representation in SUDI of infants from families with a child protection history, the Team recommended that Community Services conduct a cohort review of SUDI where the infant's family had a child protection history, for the purpose of developing strategies and training resources to assist caseworkers to assess risk for infants and provide casework services to at-risk families.

In the intervening period, Community Services has been conducting the cohort review, and met with NSW Kids and Families to discuss opportunities and strategies to strengthen the interagency response. Last year, the Team recommended that Community Services should provide detailed advice on the findings of the cohort review, and the actions it will take in response.

In July 2014, Community Services provided a copy of the report from its review, *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; and a survey of current field staff knowledge about SUDI.

Recommendations arising from the review include:

- distribution of the report as a resource for frontline staff
- development of an online training package on SUDI, focusing on modifiable risk factors in the infant's sleeping environment, to be shared with other agencies
- re-development of a one-day training package on SUDI, to include information about working with culturally and linguistically diverse families
- discussions with the Helpline to better support Helpline Caseworkers to identify infants and young children who may be at risk of fatal sleep accidents, and
- interagency meetings with NSW Health to discuss establishing consistent cross-agency messages on safe sleeping and barriers to this.

In the past year, Community Services' Clinical Issues Unit has also worked in partnership with NSW Health and the FACS Aboriginal Services Branch to develop new Aboriginal and non-Aboriginal safe sleeping resources for use by caseworkers, health workers and community members. In June 2014, Community Services distributed 150 safe sleeping Aboriginal and general resource kits (including to NGOs and throughout Health LHDs).[123]

.

123 Department of Family and Community Services, Community Services (2014) *Safe Sleeping: Supporting parents to make safer choices when placing their baby to sleep*, p50

Recommendations

NSW Kids and Families

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.
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 arising from 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 *Sudden Infant Death Syndrome (SIDS) and safe sleeping for infants* guidelines and provide guidelines to community-based staff.

NSW Health Pathology

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.

Department of Family and Community Services

7. In relation to the Department of Family and Community Services' 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.

Chapter 18. Deaths from all external causes

In 2013, the deaths of 81 children (15%) in NSW were due to external (unnatural) causes. As was the case last year, three-quarters (60) of these deaths were due to unintentional (accidental) causes; mainly transport fatalities (30) and drowning (13). The deaths of 21 children were intentional, due to suicide (19) and fatal assault (2).

The mortality rate for external causes in 2013 (4.84 per 100,000 children) represents the lowest rate in the history of the Team. Prior to this year, the mortality rate for external causes ranged from a high of 11.90 per 100,000 children in 1997 to a low of 4.86 per 100,000 children in 2008.

This section summarises the major features of all deaths from external causes. The subsequent chapters provide more detailed analysis of specific external causes.

Key demographic and individual characteristics

Table 70: Key demographic and individual characteristics – deaths from all external causes, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**81**	**100**	**4.84**	**3.85 - 6.02**		
Gender						
Female	29	36	3.57	2.39 - 5.13	-	-
Male	52	64	6.05	4.52 - 7.93	1.69	0.01
Age						
Under 1 year	7	9	6.96 (IMR = 0.07)†	2.80 - 14.35	-	-
1-4 years	16	20	4.13	2.36 - 6.71	-	-
5-9 years	15	19	3.23	1.81 - 5.32	-	-
10-14 years	7	9	1.57	0.63 - 3.23	-	-
15-17 years	36	44	13.18	9.23 - 18.24	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	62	77	3.92	6.18 - 10.34	-	-
Aboriginal or Torres Strait Islander	19	23	20.86	12.56 - 32.58	5.32	0
Remoteness*						
Major cities	39	48	3.24	2.30 - 4.43	-	-
Inner regional areas	24	30	7.24	4.64 - 10.78	-	-
Outer regional areas	13	16	12.29	6.54 - 21.01	-	-
Remote areas	2	2	-	-	-	-
Very remote areas	2	2	-	-	-	-
Socioeconomic status**						
Quintile 5 (highest)	6	7	1.70	0.62 - 3.70	-	-
Quintile 4	9	11	2.73	1.25 - 5.19	-	-
Quintile 3	13	16	4.11	2.19 - 7.04	-	-
Quintile 2	21	26	6.69	4.14 - 10.22	-	-
Quintile 1 (lowest)	31	38	9.24	6.28 - 13.12	-	-

* Remoteness was not calculated in one case.
**Socioeconomic status was not calculated in one case.
† Infant Mortality Rate.

Age and gender

Consistent with previous years, most of the children who died as a result of external causes were boys (52). However, the external cause mortality rate of boys has declined in recent years – ranging from a high of 17.03 per 100,000 children in 1996 to a low of 6.05 per 100,000 children in 2013.

The external cause mortality rate for girls has varied, ranging from 9.12 per 100,000 children in 1999 to 3.28 per 100,000 children in 2008. The external cause mortality rate for girls in 2013 (3.57 per 100,000 children) was the third lowest in the history of the Team.

In 2013, external causes represented:

- over half of the deaths of young people aged 15-17 years (36); mainly suicide (15) and transport fatalities (15)
- over one-third of the deaths of children aged 5-9 years (15); mainly transport fatalities (12), and
- almost one-quarter of the deaths of children aged 1-4 years (16); mainly drowning (6), transport fatalities (3) and choking (3).

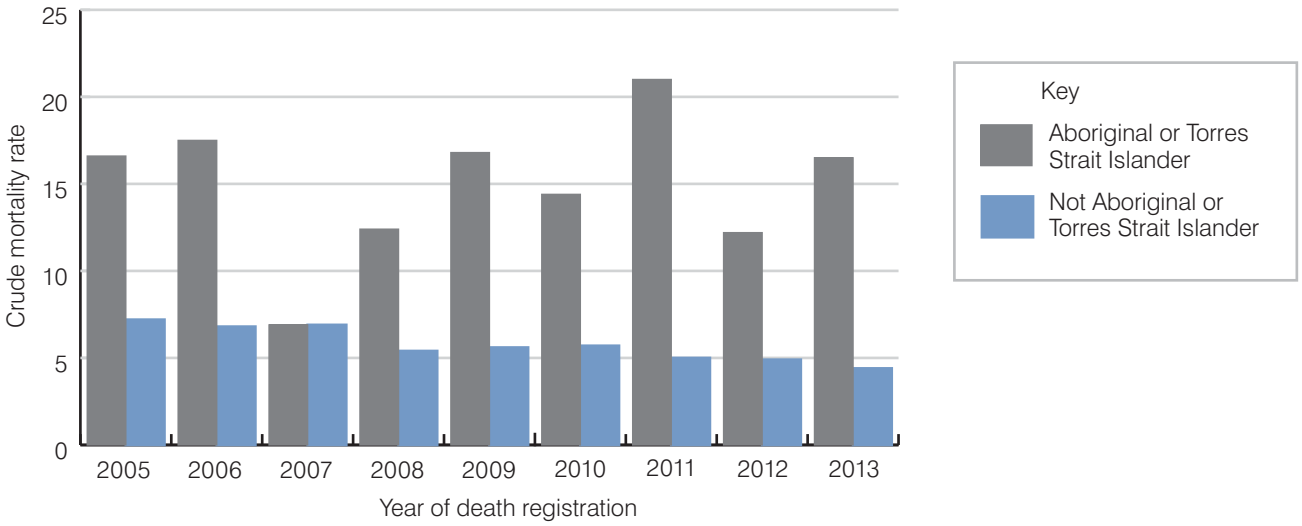
Compared with recent years, the mortality rate for external causes in 2013 declined for children aged 10-14 years.

Aboriginal and Torres Strait Islander status

Aboriginal and Torres Strait Islander children comprised just below one-quarter (19) of the 81 children who died from external causes. Similarly, external causes accounted for one-quarter of the deaths of Aboriginal and Torres Strait Islander children in 2013, mainly deaths due to transport fatalities (7), fire (3) and drowning (3). The external cause mortality rate of Aboriginal and Torres Strait Islander children (20.86 per 100,000 children) was over five times the rate of non-Indigenous children.

As indicated in the figure below, the rate of death of Aboriginal and Torres Strait Islander children from external causes has been higher than the rate for non-Indigenous children for eight of the past nine years. The difference in the external cause mortality rate in 2013 was the second highest over that period.

Figure 11: Trends in the deaths of children from external causes by Aboriginal and Torres Strait Islander status and crude mortality rate, 2005-2013[124]



Remoteness and socioeconomic status

While just under half (39) of the children who died from external causes in 2013 resided in major cities, the rate of death from external causes was highest in outer regional areas. The external cause mortality rate of children who resided in outer regional areas was almost four times the rate of children who resided in major cities.

Consistent with 2012, most of the children who died from external causes in 2013 resided in areas of greatest socioeconomic disadvantage. The external cause mortality rate of children who resided in areas of greatest socioeconomic disadvantage (quintile 1) was over five times the rate of children who resided in areas of least socioeconomic disadvantage (quintile 5).

124 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.

Child protection history

The families of 28 children (35%) who died from external causes had a child protection history, including two children who were in care at the time of their death.

The proportion is consistent with previous years: the Team's recent analysis of causes of death in 2002-2011 identified that 32% of children who died from external causes in the 10-year period had a child protection history. The analysis also found that, while the external cause mortality rate for children with a child protection history was 2.8 times the rate of children without that history, there had been a significant decline (36% reduction) in the rate for children with a child protection history over that time.[125]

Deaths due to fatal assault

Two children whose deaths were registered in NSW in 2013 died as a result of fatal assault.[e] The two deaths comprise the lowest proportion of child deaths from fatal assault in the history of the Team.[126]

This report does not include more detailed data or other information in relation to the two children who died from fatal assault in 2013. In this regard, the Team notes that:

- the very small numbers make it highly likely that the children and their families would be readily identifiable, and
- all deaths of children that occur in the context of assault or circumstances suspicious of assault are reviewed and reported by the Ombudsman's office.

125 NSW Child Death Review Team (April 2014) *Causes of death of children with a child protection history 2002-2011* special report to Parliament

126 However, it is important to note that the number of deaths from fatal assault varies, and caution needs to be exercised in drawing any conclusions. A drop or increase in numbers in any particular year does not necessarily indicate an improvement or worsening; rather, they reflect the erratic nature of such deaths.

[e] see errata in the front of this document

Chapter 19. Transport fatalities

The deaths of 30 children in 29 transport incidents were registered in 2013.

The rate of death of children from transport fatalities in 2013 (1.8 deaths per 100,000 children) was the lowest rate for the past 15 years (equal to 2011), and much lower than the average rate over that time (3.1 deaths per 100,000 children). The 30 deaths in 2013 was substantially lower than the 15-year average of 50 deaths per year.

Most (21) of the children died in motor vehicle fatalities:

- Over half (12) of the children were passengers. The majority (9) of the passenger fatalities occurred on public roads; three occurred off-road.
- Nine children were riding or controlling a vehicle at the time of the fatality. All of the driver fatalities occurred on public roads.

Of the other nine children who died in transport fatalities, eight were pedestrians, and one child was riding a bicycle at the time of their death.

Five of the 30 transport-related deaths in 2013 are 'reviewable deaths' as they occurred in circumstances of neglect, and have been reviewed separately by the Ombudsman.

Trends in transport deaths of children in NSW, 1999-2013

As indicated in the table below, there has been a decline in the number and rate of transport-related deaths of children over the past 15 years.[127] From 1999 to 2013, there has been a 57% drop in the number of deaths.

The rate of death of children from transport fatalities over the past five years, 2009-2013, (2.1 deaths per 100,000 children) is lower than the rates over the previous five-year periods of 2004-2008 (3.1 deaths per 100,000 children) and 1999-2003 (4.2 deaths per 100,000 children).

The reduction in overall transport-related deaths has primarily been due to a drop in pedestrian fatalities and passenger fatalities:

- The rate of death of pedestrian fatalities has dropped by two-thirds; from 1.2 deaths per 100,000 children in 1999-2003 to 0.4 deaths per 100,000 children in 2009-2013.
- The rate of death of passenger fatalities has halved from 2.0 deaths per 100,000 children in 1999-2003 to 1.0 death per 100,000 children in 2009-2013.

There has been a slight decline in the rate of death of children as drivers of vehicles, from 0.6 deaths per 100,000 children in 1999-2003 to 0.5 deaths per 100,000 children in 2009-2013.

Table 71: Trends in deaths of children due to transport incidents by user type – 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
Pedestrian	24 (1.5)	24 (1.5)	21 (1.3)	13 (0.8)	12 (0.8)	12 (0.8)	8 (0.5)	11 (0.7)	7 (0.4)	6 (0.4)	6 (0.4)	7 (0.4)	8 (0.5)	5 (0.3)	8 (0.5)	172
Driver (all vehicles)	9 (0.6)	12 (0.8)	11 (0.7)	8 (0.5)	10 (0.6)	5 (0.3)	11 (0.7)	12 (0.8)	11 (0.7)	9 (0.6)	9 (0.6)	7 (0.4)	8 (0.5)	9 (0.5)	9 (0.5)	140
Passenger	33 (2.1)	37 (2.3)	27 (1.7)	33 (2.1)	32 (2.0)	28 (1.8)	23 (1.4)	32 (2.0)	17 (1.1)	12 (0.7)	23 (1.4)	18 (1.1)	13 (0.8)	19 (1.1)	12 (0.7)	359
Bicyclist	2 -	2 -	5 (0.3)	4 (0.2)	1 -	5 (0.3)	3 -	2 -	6 (0.4)	2 -	2 -	1 -	0 -	1 -	1 -	37
Other[128]	2 -	3 -	2 -	4 (0.2)	2 -	4 (0.3)	2 -	8 (0.5)	6 (0.4)	4 (0.2)	2 -	2 -	1 -	5 (0.3)	0 -	47
Total	**70 (4.4)**	**78 (4.9)**	**66 (4.1)**	**62 (3.9)**	**57 (3.6)**	**54 (3.4)**	**47 (3.0)**	**65 (4.1)**	**47 (2.9)**	**33 (2.0)**	**42 (2.6)**	**35 (2.1)**	**30 (1.8)**	**39 (2.4)**	**30 (1.8)**	**755**

127 Crash data provided by the Centre for Road Safety indicates that casualties among 0-17 year olds have also fallen by 45% over the last 15 years – from 3,734 in 1999 to 2,051 in 2013. In contrast, total casualties decreased by only 19% over the same period. The greatest casualty reduction has been among young people aged 10-14 years (down 50%), and 15-17 years (down 46%). Advice provided by TNSW, the Centre for Road Safety, 8 September 2014.

128 Fatalities in which the child was not a passenger, driver or pedestrian. These fatalities typically involve the child travelling or riding outside the vehicle in a position not intended for passengers.

Demographic and individual characteristics, 2013

The table below provides an overview of the main demographic characteristics of the children who died in transport fatalities in 2013.

Table 72: Key demographic and individual characteristics – deaths due to transport fatalities, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**30**	**100**	**1.8**	**1.21 - 2.56**		
Gender						
Female	9	30	1.1	0.51 - 2.10	-	-
Male	21	70	2.4	1.51 - 3.73	2.2	0.02
Age						
Under 1 year	0	0	-	-	-	-
1-4 years	3	10	-	-	-	-
5-9 years	11	37	2.4	1.18 - 4.24	-	-
10-14 years	1	3	-	-	-	-
15-17 years	15	50	5.5	3.07 - 9.06	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	23	77	1.5	1.90 - 4.49	-	-
Aboriginal or Torres Strait Islander	7	23	7.7	3.09 - 15.84	5.3	0.00
Remoteness*						
Major cities	11	37	0.9	0.46 - 1.64	-	-
Inner regional areas	8	27	2.4	1.04 - 4.76	-	-
Outer regional areas	8	27	7.6	3.26 - 14.90	-	-
Remote areas	0	0	-	-	-	-
Very remote areas	2	7	-	-		
Socioeconomic status**						
Quintile 5 (highest)	1	3	-	-	-	-
Quintile 4	3	10	-	-	-	-
Quintile 3	4	13	1.3	0.34 - 3.24	-	-
Quintile 2	7	23	2.2	0.90 - 4.59	-	-
Quintile 1 (lowest)	14	47	4.2	2.28 - 7.00	-	-

*Remoteness was not calculated in one case
**Socioeconomic status was not calculated in one case

Age, gender and Aboriginal and Torres Strait Islander status

In 2013, transport fatalities were the leading cause of death of children aged 5-9 years and the second leading cause of young people aged 15-17 years.

As indicated in the figure below, just over half (16) of the children who died in transport fatalities were teenagers; most (11) were 17 years of age. The teenagers were primarily drivers (9) or passengers (4).

Children aged 5-9 years comprised over one-third (11) of all transport fatalities in 2013, most of whom were aged five or six years. The children were mainly passengers (7) or pedestrians (3).

Consistent with the Team's previous findings, the majority (21) of the children who died in transport fatalities were male. Males comprised eight of the nine deaths of drivers; three-quarters of all pedestrian fatalities; and half of the 12 passenger deaths. There was a significant difference between the genders in the rate of death from transport fatalities, with the mortality rate of males from this cause (2.4 deaths per 100,000 children) more than twice the rate of females (1.1 deaths per 100,000 children).

Just under one-quarter (7) of the children were Aboriginal. There was a highly significant difference in the rate of death from transport fatalities between Indigenous and non-Indigenous children, with the mortality rate of Aboriginal and Torres Strait Islander children from this cause (7.7 deaths per 100,000 children) more than five times the rate of non-Aboriginal and Torres Strait Islander children (1.5 deaths per 100,000 children).

Figure 12: Transport deaths of children registered in 2013, by age and gender

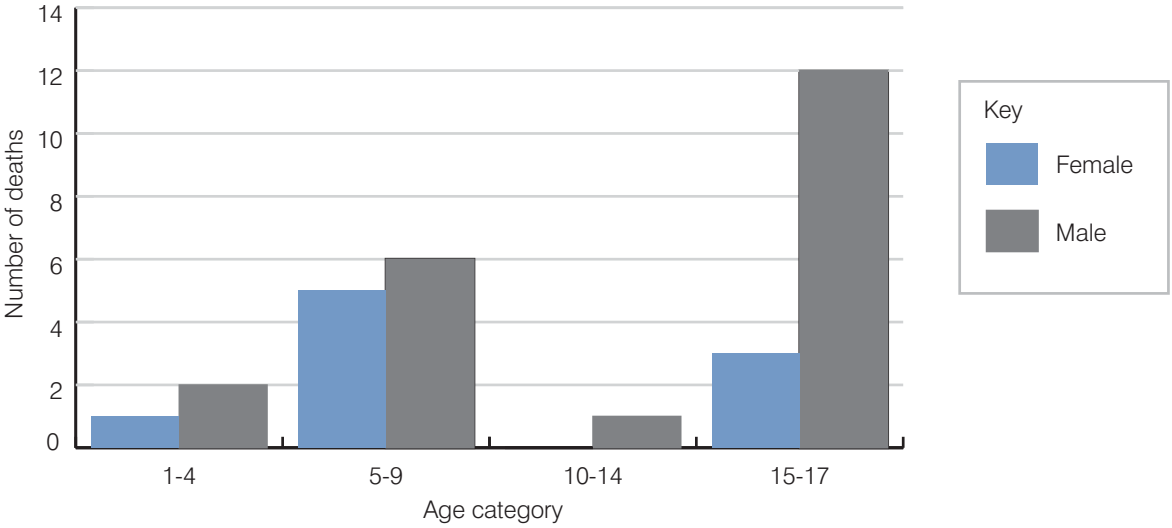


Table 73: Trends in deaths of children due to transport fatalities by gender, 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	28 (3.6)	28 (3.6)	18 (2.3)	17 (2.2)	21 (2.7)	23 (3.0)	17 (2.2)	15 (1.9)	19 (2.4)	7 (0.9)	17 (2.2)	14 (1.8)	11 (1.4)	13 (1.6)	9 (1.1)
Male	42 (5.2)	50 (6.1)	48 (5.8)	45 (5.5)	36 (4.4)	31 (3.8)	30 (3.7)	50 (6.1)	28 (3.4)	26 (3.1)	25 (3.0)	21 (2.5)	19 (2.3)	26 (3.1)	21 (2.4)
Both	70 (4.4)	78 (4.9)	66 (4.1)	62 (3.9)	57 (3.6)	54 (3.4)	47 (3.0)	65 (4.1)	47 (2.9)	33 (2.0)	42 (2.6)	35 (2.1)	30 (1.8)	39 (2.4)	30 (1.8)

Remoteness and socioeconomic status

In 2013, most of the children who died in transport-related fatalities resided:

- outside of major cities in NSW; mainly (16) in inner or outer regional areas, and
- in areas of greatest socioeconomic disadvantage, with almost three-quarters (21) in SEIFA quintiles 1 and 2.

Child protection history

The families of half of the 30 children who died in transport fatalities had a child protection history. In the three years before their death, five of the 15 children had been the subject of a risk of significant harm report to Community Services. For four children, the reported issues were relevant to the circumstances of their deaths, including parental substance abuse (2) and supervision issues (2).

On-road motor vehicle fatalities

In 2013, 17 motor vehicle collisions accounted for the deaths of most (18) of the children; nine were passengers and nine were drivers. One of the collisions resulted in the deaths of two child passengers.

- Over half (10) of the 17 collisions were single vehicle fatalities, most (8) of which involved collision with stationary objects, such as trees, a telegraph pole, or a fence. Seven involved collision with other vehicles.
- In the majority (14) of cases, the child was travelling in a light vehicle (sedan, utility, 4WD or motorbike). Three children were on off-road vehicles (dirt bikes or a bicycle with a petrol engine).

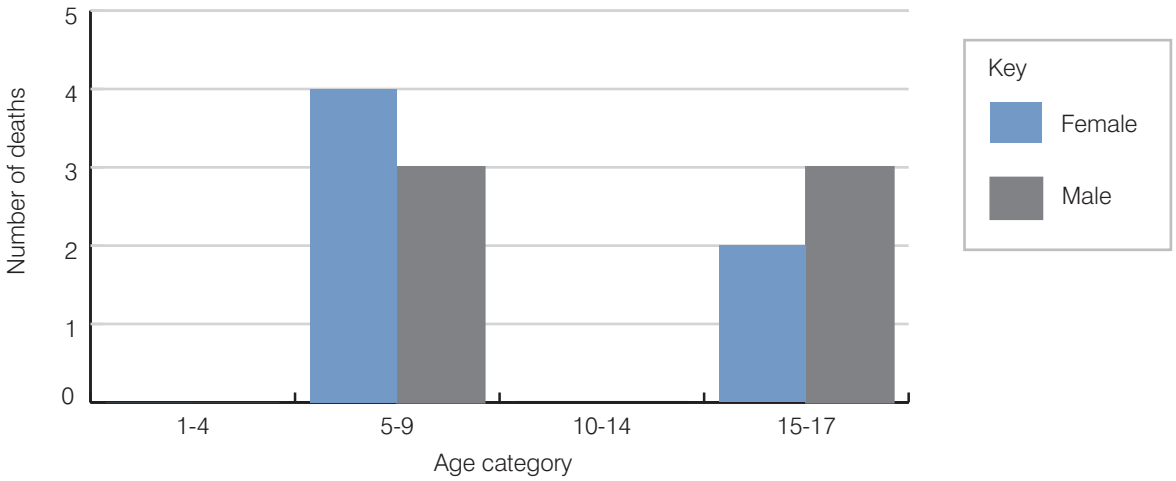
On-road passenger fatalities

Nine children were passengers in eight motor vehicles on public roads at the time of their death.

While all of the drivers were adults, most (5) were provisional licence holders. Two drivers held standard NSW driving licences. In the majority (6) of the cases, the children who died were related to the driver. The other three children were driven by unrelated adult peers.

As seen in the figure below, over half (5) of the children being driven by adults were younger than seven years of age.

Figure 13: Deaths of children as passengers in vehicles with adult drivers on public roads by age of child, 2013



Use of safety restraints in the vehicle

NSW legislation[129] requires all 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.

As shown in the following table and in contrast to passenger fatalities in 2012, no issues were identified with the use of restraints in relation to the majority (6) of the children. In relation to two children under the age of seven years, the restraints had not been used or had been incorrectly used.

The majority (7) of the fatalities involved side impact collisions. Side impacts can result in more severe injuries as there is little structure between the occupant and the impacting vehicle or object. By comparison, it is reported that the front of the vehicle can absorb up to five times the energy of the side structure before injury occurs to the occupants of the vehicle.[130]

129 *NSW Road Rules 2008* and the *Road Amendment (Isabelle Broadhead Child Restraint Measures) Rules 2010*

130 Fildes B.N. Lane J.C. Lenard J. Vulcan A.P 1994. *Passenger cars and occupant injury: side impact crashes*, Report CR 134, Monash University Accident Research Centre Canberra: Federal Office of Road Safety.

Table 74: Deaths of children as passengers in vehicles with adult drivers on public roads by age, position in vehicle, restraint type, use, impact type and effect, 2013

Age	Location in vehicle	Restraint type	Restraint use issue	Impact type	Effect of collision on child's location in vehicle
Under 7 years	Rear – laying across width of vehicle	No restraint used	Child not secured in vehicle by any restraint device	Front and rear impact	Ejected from vehicle
Under 7 years	Location unknown	No restraint used	Vehicle was parked and no seatbelt required by law	Side impact and vehicle roll over	Ejected from vehicle
Under 7 years	Location unknown	No restraint used	Vehicle was parked and no seatbelt required by law	Side impact and vehicle roll over	Ejected from vehicle
Under 7 years	Rear – passenger side	Forward facing child seat	No issues identified with restraint or fit	Front and side impact	Intrusion[131] to child's location in vehicle
Under 7 years	Rear – passenger side	Forward facing child seat	Incorrect use of restraint - likely that seatbelt was not used correctly to secure child in restraint	Front and side impact	Intrusion to child's location in vehicle
Over 15 years	Rear – driver's side	Unknown	Not known if adult seatbelt used	Side impact and vehicle roll over	Intrusion to child's location in vehicle
Over 15 years	Front passenger	Adult lap-sash seatbelt	No issues identified with restraint	Front and side impact	Intrusion to child's location in vehicle
Over 15 years	Front passenger	Adult lap-sash seatbelt	No issues identified with restraint	Side impact and vehicle roll over	Intrusion to child's location in vehicle
Over 15 years	Front passenger	Adult lap-sash seatbelt	No issues identified with restraint	Vehicle roll over	Intrusion to child's location in vehicle

Vehicle and safety systems

Of the eight vehicles transporting the nine children, over half (5) were manufactured between 1994 and 1996 and were not fitted with any of the vehicle safety systems in more recently manufactured vehicles, such as electronic stability control, supplementary airbag systems, anti-lock braking systems and improved structural systems such as seat design and seatbelt technologies.

Three of the vehicles were manufactured between 2006 and 2013 and were fitted with some vehicle safety systems. One vehicle had dual frontal, side and curtain airbags, which deployed during the collision; all unrestrained occupants were ejected from the vehicle. While the other two vehicles had electronic stability control and/or anti-lock braking systems, they were not used during the collision as the brakes were not applied, or the vehicle was not in motion.

Contributing factors in fatalities involving children as passengers with an adult driver on public roads

In the majority (7) of the fatalities, police determined that driver factors contributed to the collision. As indicated in the following table, the most common driver-related factor was drug use, which contributed to four fatalities.

131 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 spaces.

Table 75: Police determined at-fault driver factors that contributed to the collision, 2013

Drug affected	Distracted	Fatigue	Other	Speeding above sign posted limit	Inexperience
✓ Methamphetamine	✓ (Possible – paper map)				✓ (Possible)
✓ Cannabis Methadone Diazepam		✓			
✓ Cannabis			✓ Un-roadworthy tyres		
	✓ Other occupants	✓			
				✓ 13kph over	
			✓ Dangerous driving immediately prior to incident		
	✓ Other occupants				
✓ Cannabis					
4	3	2	2	1	1

The other main driver-related contributing factors included driver distraction, and fatigue – including one matter in which the driver had been the primary driver of the vehicle for approximately 19 hours with insufficient rest breaks. Unlike previous years, excessive speed was only identified as a factor in one fatality.

While police identified that inexperience was a factor in one fatality, we note that in another three fatalities the driver had less than 12 months experience of solo driving.[132] Three fatalities involved the at-fault driver violating the conditions of their licence, including:

- use of illicit substances (3)
- a provisional licence holder who was carrying too many peer passengers for the time of day, and
- a provisional licence holder who had multiple violations, including speeding above the limit imposed on their licence; driving an unregistered vehicle; and driving a manual vehicle when only licensed to drive automatic vehicles.

In one collision that resulted in two fatalities, the at-fault driver had been disqualified from driving for an extended period of years prior to the collision.

Road and environmental conditions contributed to two fatalities, including a slippery road, poor lighting in the area, and the significant presence of wildlife entering the roadway.

In one fatality, the vehicle tyres were deemed to be worn and devoid of roadworthy tread.

Police charged seven people in relation to the deaths of eight children. The charges included negligent driving occasioning death, dangerous driving, and driving under the influence.

On-road driver fatalities

The vast majority (8) of the nine children who were driving a motor vehicle on a public road at the time of their death in 2013 were male.

All were single vehicle fatalities, involving collisions with stationary objects, including trees.

132 Risk that a driver will be involved in a transport incident is highest in the first six to 12 months of solo driving. Centre for Accident Research & Road Safety – Queensland 2013, *State of the road factsheet*, QLD: CARRS-Q, http://www.carrsq.qut.edu.au/publications/corporate/novice_drivers_fs.pdf, accessed 16 July 2014.

Drivers of four-wheeled motor vehicles on a public road

Five children were drivers of light four-wheeled motor vehicles comprising sedans (3) and utility vehicles (2). All were aged 17 years.

The majority (4) of the drivers were the sole occupant of the vehicle. One driver was transporting two peers.

Most (4) held a provisional (P1) licence; one driver had a learner licence. Four of the drivers were violating their licence conditions, including alcohol use, and a lack of appropriate supervision of a learner driver.

Use of safety restraints

Information about the use of restraints was available for four of the five drivers. Most (3) wore an adult lap-sash seatbelt. All three drivers were involved in side impact collisions and had intrusion to their location in the vehicle.

One driver was unrestrained and was ejected from the vehicle.

Vehicle and safety systems

The NSW Road Safety Strategy identifies that younger drivers are more likely to drive older, less safe vehicles; and the risk of death and serious injury in a crash is lower for later model cars, with the risk of a 2007 vehicle about half that of a vehicle produced in 1987.[133]

Three drivers were travelling in vehicles manufactured between 1993 and 1999, which were not fitted with vehicle safety systems present in more recently manufactured vehicles.

Two vehicles were manufactured between 2001 and 2007, and were fitted with driver airbags (2) and an anti-locking braking system (1). Police determined that the fatalities were caused by one driver failing to safely navigate a bend; and the other driver losing control of the vehicle following a quick lane change. Neither of the vehicles was fitted with electronic stability control.[134]

Contributing factors in fatalities involving children as drivers of four-wheeled vehicles on public roads

Police identified that driver factors contributed to three of the five fatalities:

- Excessive speed was a factor in two fatalities. One driver exceeded the sign-posted speed limit by 30km/h.
- Two drivers returned a positive result for alcohol; one also returned a positive result for cannabis.
- One driver reportedly had limited driving experience and another had engaged in dangerous driving immediately prior to the collision.

Road and environmental conditions contributed to two fatalities, including a wet roadway during heavy rain, and wildlife entering the roadway.

The majority (4) of the fatalities occurred within approximately 10 kilometres of the child's usual place of residence. In two cases, the driver was the sole occupant in the vehicle and driving at night, and the vehicle movement prior to the collision was suggestive of fatigue.[135]

Drivers of two-wheeled motor vehicles on a public road

Four children were riding motorised two-wheeled vehicles. All were male, aged 14, 16 or 17 years. None of the children were carrying passengers.

The vehicles included dirt bikes (2), a motorcycle, and a motorised bicycle with a petrol engine. Most (3) of the vehicles were for off-road environments only, and could not be registered for use on public roads. While the motorcycle was registered for on-road use, the rider was unlicensed for that vehicle.

133 Transport for NSW 2012, NSW Road Safety Strategy 2012-2021, Sydney: TNSW, p. 22.

134 Electronic Stability Control (ESC) immediately identifies when a car has deviated from the driver's steered direction and the driver has lost control of the vehicle. As soon as instability, oversteering and understeering are registered, ESC stabilises the vehicle by selectively braking individual wheels and reducing engine torque to bring the vehicle back on course. VicRoads 2013, *Electronic Stability Control*, Melbourne: VicRoads, http://www.vicroads.vic.gov.au/Home/SafetyAndRules/SaferVehicles/BuyingASafeCar/ElectronicStabilityControl.htm, accessed 16 July 2014.

135 Transport for NSW identify fatigue as a contributory factor using specific criteria: the vehicle's controller was described by police as being asleep, drowsy or fatigued and/or the vehicle performed a manoeuvre that suggested loss of concentration of the controller due to fatigue; that is, the vehicle travelled onto the incorrect side of a straight road and was involved in a head-on collision (and was not overtaking another vehicle and no other relevant factor was identified); or the vehicle ran off a straight road or off the road to the outside of a curve and the vehicle was not directly identified as travelling at excessive speed and there was no other relevant factor identified for the manoeuvre. Transport for NSW 2013, *Road Traffic Crashes in New South Wales (Statistical statement for the year ended 31 December 2012*, Sydney: TNSW, p. 14.

Location of incident

Most (3) of the four fatalities occurred outside of the Greater Sydney area. One fatality occurred in metropolitan Sydney.

All occurred on local roads with a sign-posted speed limit of 50km/h. Most (3) occurred on sealed roads.

Use of protective equipment

Of the three riders whose use of protective equipment was known, two were wearing full-face helmets at the time of the collision, including one rider who was also reportedly wearing riding gloves and boots. One rider was not wearing a helmet.

Activity and injury

Most (3) of the children were riding for recreation. One child was riding for transport purposes. It appears that two children riding recreationally were being pursued by police prior to the collision.

Three of the four fatalities involved a collision with another vehicle (2) or a fence. The other fatality occurred when the vehicle's rear tyre lost traction on the road and the child was thrown off.

The majority (3) of the children died as a result of injuries to the chest/thoracic cavity.[136] One rider who had been wearing a full-face helmet sustained a closed head injury.

Contributing factors in fatalities involving children as drivers of two-wheeled vehicles on public roads

Police determined that exceeding the sign-posted speed limit was a factor in one fatality, and that road conditions may have contributed to one death as visibility was affected by dust from an adjoining unsealed road.

Police determined that inexperience was likely to have contributed to one fatality. Two additional riders had limited experience with the vehicles they were using: one child had sourced the vehicle the day before their death, and the other rider had taken the vehicle from a family member on the day of the fatality.

Prevention measures – on-road fatalities

Key factors in the deaths of children in on-road motor vehicle fatalities in 2013 include at-fault driver factors such as driving under the influence of drugs and/or alcohol, fatigue, distraction and speeding. Other relevant factors include driver inexperience and the failure to use appropriate safety restraints or other protective equipment.

The NSW Road Safety Strategy identifies that novice drivers under 26 years are involved in around 28% of all fatal crashes; likely due to a combination of factors, including inexperience, a propensity to take risks, and access to older, less safe vehicles.[137]

At-fault driver factors

The NSW Centre for Road Safety (CRS) has a range of targeted road safety programs and campaigns, focused on many of the factors that were relevant in the on-road deaths of children in 2013, including:

- the *Safe Drivers Course* – helps learner drivers understand more about managing risks on the road, including speed management, gap selection, hazard awareness and safe following distances, to better prepare them for their provisional licence[138]
- *Don't trust your tired self* – targeted at raising awareness about the effects of fatigue on driving, including an interactive test for drivers to see how tired they are,[139] and information on how to recognise the early warning signs when driving
- the *Plan B* drink-driving campaign, primarily aimed at young male drivers aged 17-25 years
- the *Get your hand off it* campaign – mainly targeted at younger drivers aged 17-39, aimed at overcoming the attitudes and societal norms that cause people to use a hand-held phone while driving

136 In one case where a limited autopsy examination was performed, the forensic pathologist considered injuries to the chest/thoracic cavity was considered likely by a forensic pathologist where a limited autopsy examination was performed.

137 Transport for NSW 2012, NSW Road Safety Strategy 2012-2021, Sydney: TNSW, p. 24.

138 The Safe Drivers Course involves a three-hour group discussion with other L platers to learn how to manage risks on the road and a two-hour in-vehicle coaching session with a coach and another learner to enable a learner driver to learn a range of practical safe driving behaviours. As at the end of July 2014, over 11,500 participants had completed the course and progressed to their provisional licence. Advice from TNSW, the Centre for Road Safety, 8 September 2014.

139 Transport for NSW 2012, Test your tired self, Sydney: TNSW, www.testyourtiredself.com.au, accessed 16 July 2014.

- *Don't Rush* – aimed at raising community awareness about the impact of speed-related crashes, and
- the *You're in our sights* campaign, supporting police operations in relation to three main driver behaviours – speeding, drink driving, and non-use of seatbelts.

Since 2007, police have had the power to perform a roadside drug test on any driver in NSW. Relevant to the fatalities that occurred in 2013, cannabis and methylamphetamine can be detected during these tests. CRS has indicated that enforcement actions by the police include approximately 30,000 roadside drug tests each year.[140]

In March 2013, the Joint Standing Committee on Road Safety (Staysafe) released a report from its inquiry into Driver and Road User Distraction. The report identified that non-electronic distractions are difficult to regulate, and noted an imperative for government to conduct regular intensive education programs and safety campaigns.[141] The Government's response in October 2013 indicated that road safety education for school students would be updated to include specific information about distraction, and all educational resources would be available online.[142]

Child restraint systems

Initiatives to prevent sub-optimal restraint use typically involve education of the adults fitting the restraints, and improvements to restraint design to enable appropriate use.

In last year's report, the Team noted the collaboration between Neuroscience Research Australia and Kidsafe Australia to produce *Best Practice guidelines for the safe restraint of children travelling in motor vehicles*. The agencies have since developed a supplementary document for carers, which is promoted through a range of stakeholders, including Kidsafe, restraint manufacturers and the National Roads and Motorists' Association (NRMA).

In June 2014, Transport for NSW launched the *They're counting on you* child car seat safety campaign, which promotes the correct selection, use and fit of child car seats to reduce child deaths and injuries; noting that two in every three child passengers are not restrained correctly.[143] As part of the campaign, Transport for NSW worked with the NRMA, RACV, TAC, VicRoads and RACWA (as part of the Child Restraint Evaluation Program consortium) to develop an Australia-wide website www.childcarseats.com.au.

Driver inexperience

Consistent with previous years, inexperienced drivers were highly represented in transport-related fatalities in 2013.

In 2007, NSW introduced changes to the Graduated Licensing Scheme. These changes aimed to give novice drivers more driving experience prior to them graduating to a full licence.

The P Drivers Project is a partnership of federal and state government and motoring organisations. This project aims to develop a driver education model for inclusion in the graduated licensing scheme. The project has finalised its recruitment of inexperienced NSW and Victorian drivers to be participants in the project (1,600 NSW participants and 25,400 Victorian participants). The research will focus on current behaviour, decision making and risk taking, and aims to promote safe driving behaviour.

The University of New South Wales' Transport and Road Safety Research group is currently researching impulse control in young drivers, and aims to develop a training program that addresses driver immaturity by having inexperienced drivers accelerate the development of brain areas responsible for impulse control.

140 Transport for NSW 2014, Centre for Road Safety - Partners with Police, Sydney: TNSW, http://roadsafety.transport.nsw.gov.au/aboutthecentre/police/index.html , accessed 16 July 2014.
141 Parliament of NSW (March 2013) Joint Standing Committee on Road Safety (Staysafe), *Report on Driver and Road User Distraction*, Report 2/55.
142 NSW Government Response to Staysafe Inquiry into Driver and Road User Distraction, October 2013.
143 NSW Strategic Communications 2014, *Check your Child's Car Seat*, Sydney: Department of Premier and Cabinet, www.advertising.nsw.gov.au/updates/child-restraints, accessed 16 July 2014.

Off-road motor vehicle fatalities

In 2013, all of the three children who died in off-road vehicle fatalities were passengers, and were male. The children were aged five, nine and 15 years of age.

The children were passengers in a light vehicle (sedan), a mini-bike[144] and a quad bike. All were positioned at the front of the vehicle, either in front of the driver (mini-bike and quad bike), or on the front seat (sedan).

Two of the children were being driven by adult drivers. The mini-bike was operated by a 12-year-old peer, and had been acquired on the day of the fatality.

The fatalities occurred on a grassed area for stock agistment, a track on a rural property and a farm.

Activity and injury

All three fatalities were single vehicle collisions: two vehicles rolled over on a steep incline (quad bike) or while the driver attempted to negotiate a corner at speed (sedan); and one collided with a fence at speed (mini-bike). Each of the three children sustained fatal head injuries.

Use of protective equipment

No helmets or protective equipment were worn by the children on the bikes. The child in the sedan had removed the vehicle's seatbelt just before the collision. The vehicle was not fitted with airbags or other vehicle technologies that aim to reduce the likelihood of collision and injury.

Contributing factors in fatalities involving children as passengers and vehicles being driven off-road

Police identified a range of factors that contributed to the fatalities, including:

- excessive speed on an unsealed road
- consumption of alcohol that was likely to have affected the driver's capacity to operate the vehicle
- reckless driving preceding the collision, and
- mechanical faults, including the accelerator and braking systems.

Other relevant factors in the deaths of the children included not following warnings about the dangers of carrying passengers or the dangers of riding in a particular area, and not wearing safety equipment.

Prevention measures

Last year, the Team reported on its review of the deaths of 25 children over a 10-year period from fatalities involving off-road vehicles. Consistent with the findings in the review, the deaths of children in off-road vehicle fatalities in 2013 have highlighted:

- the substantial risks associated with the use of off-road vehicles involving children, including the inherent instability of quad bikes on anything other than flat terrain, and the dangers associated with the inclusion of passengers, and
- the need for greater public awareness of the dangers associated with off-road vehicles involving children.

The other key areas that have been identified as necessary to prevent death and serious injury of children relating to the use of off-road vehicles include:

- introduction of engineering controls – including fitment of crush protection devices/ roll over protective structures to 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.

144 Mini bikes are replicas of motorcycles scaled down to about half the size. They are usually powered by petrol driven motors and are capable of speeds of up to 80 km/h. They cannot be driven on public roads, and are for recreational purposes only. Product Safety Australia 2014, *Mini / monkey bikes*, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/itemId/974443/fromItemId/971517, accessed 16 July 2014.

Current initiatives include the Quad Bike Performance Project being run by UNSW TARS, which aims to develop a consumer safety rating system for quad bikes based on stability, handling and crashworthiness. The final report from the project is expected in the first half of 2014.

A range of organisations, including the ACCC, Farmsafe and WorkCover NSW, publish information to raise community awareness about the dangers associated with quad bikes, including risks to children.

The Team's recommendations

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 the issues.

Against this background, in 2013 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 response, DPC indicated that it would engage with injury prevention and regulatory agencies by November 2014, and would advise the Team of the outcomes.

In March 2014, the NSW Parliament Joint Standing Committee on Road Safety (Staysafe) released the final report from its inquiry into Non-Registered Motorised Vehicles. The report noted the Team's information and recommendations; indicated that '[s]ignificant support was also expressed for the registration of non-registered motorcycles and quad bikes'; and noted that UNSW Transport and Road Safety Research (TARS) 'supported further regulation of quad bikes, involving registration and licensing', with a minimum age limit of 16 for drivers/riders; a requirement that no passengers should be permitted on quad bikes; and the mandatory use of helmets. The inquiry report also noted support for a public awareness campaign on quad bike dangers, including risks to children.

However, the recommendations in the inquiry report relating to off-road vehicles such as quad bikes are focused on:

- the NSW Government giving consideration to mandating the use of safety equipment, such as helmets and protective clothing, when operating a quad bike
- the NSW Government reviewing the WorkCover project on quad bike safety with a view to implementing a star rating system for quad bikes, if this proves feasible, and
- Transport for NSW and WorkCover NSW designing specific road safety campaigns to increase community awareness of different classes of non-registered motorised vehicles and the importance of skills and competency based training.

The Government response to the report is due in September 2014.

Pedestrians

In 2013, nine of the children who died were in a pedestrian environment. Eight were on foot and one child was riding a bicycle.

They ranged in age from three to 17 years, and the majority (7) 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 – known as 'low-speed vehicle run-overs'.

Low-speed vehicle run-over fatalities

The four children who died in low-speed vehicle run-over fatalities were aged between three and six years. Most (3) were male.

The majority (3) of the low-speed vehicle run-over fatalities occurred on a driveway. In one case, police determined that the driveway fell within the definition of a 'road-related area'.[145] The other fatality occurred on a public road, shortly after the child left the footpath.

145 In accordance with the *Roads Transport Act 2013*, the driveway was deemed to be an area that is open to or used by the public for driving, riding or parking vehicles.

Half of the incidents occurred at the child's place of residence. In both cases, the carer was unaware that the child had gained access to the driveway. The other two fatalities occurred as the child was walking to school. In both cases, the child was holding the carer's hand at the time of the fatality.

The driver and vehicle

Most (3) of the drivers were female. Two of the fatalities involved drivers who were not known to the child. In the other two cases, the driver was a relative or neighbour of the child.

Of the four vehicles, three were 4WDs, and one was a sedan. At the time of the fatalities:

- two of the vehicles were reversing out of a driveway to exit the property
- one vehicle was stationary at an intersection prior to moving forward to enter the adjoining road, and
- one vehicle was driven into a driveway to perform a three-point turn.

Contributing factors in the low-speed vehicle run-over fatalities

Police determined that the following factors contributed to the low-speed vehicle run-over fatalities:

- Restricted vision contributed to two fatalities, with the child entering the path of the vehicle in the driver's blind spot, or under the vehicle at the time that the driver attempted to exit the property.
- Two drivers were deemed to have been inattentive at the time of the collision. One driver was looking in the opposite direction to where the vehicle was travelling, and another driver was unaware which gear (and subsequently which direction) the vehicle was in before accelerating.
- In two of the fatalities, the children were intermittently supervised at the time that they gained access to the driveways without the carer's knowledge. One of the children had a history of gaining access to the driveway and vehicle when intermittently supervised.
- In one case, the local school had previously advised the school community not to drive onto the location where the child was struck due to safety concerns.

Information relating to the fatalities suggests that restricted vision may have been a factor in another case, as the child's height matched the rear height of the vehicle; and that footpath repair works may have influenced a carer's decision to cross at the spot where the child was struck.

Police charged two drivers with negligent driving occasioning death.

Other pedestrian fatalities

Five children died when they were struck by vehicles travelling above 10km/h. Most (3) were under 10 years of age; two young people were aged 16 and 17 years. The vast majority (4) of the children were male.

Most (4) of the fatalities occurred on a public roadway. One fatality occurred on a train track.

The driver and vehicle

Most (3) of the drivers were male. The majority (4) of the drivers were not known to the child; in one case, the driver was a relative.

Four drivers held a standard drivers licence. One driver was disqualified at the time of the incident.

The vast majority of the fatalities (4) involved light vehicles: 4WDs (2), a utility, and a van. One fatality involved a suburban commuter train. All of the vehicles were travelling forward at the time the child was struck.

At the time of the fatality, all of the road vehicles were travelling within the sign-posted speed limits; either 40-50km/h (3) or 80km/h. The commuter train was travelling at approximately 110km/h.

Contributing factors in the other pedestrian incidents

Police identified a range of factors that contributed to the at-speed vehicle fatalities in 2013, including:

- In two cases, the child quickly entered the roadway between parked vehicles, providing insufficient time for the driver to apply the brakes. The children died in the course of crossing a road to get to a carer waiting in a vehicle on the opposite side; and attempting to retrieve a ball that had entered the roadway.

- One child died after mistakenly entering the roadway after hearing an audible crossing tone for a different pedestrian crossing in the vicinity. The child did not appear to check for the green pedestrian light before entering the roadway.
- One child entered the path of a moving vehicle while significantly impaired by a synthetic drug. There was no street lighting in the area and the vehicle's low beam lights were on. The driver had insufficient warning to apply the brakes.
- One child riding a bicycle was not wearing a helmet and had not dismounted their bicycle before crossing the road at a crossing.[146]
- One child had walked onto train tracks in order to join others on another platform. The child was wearing headphones at the time and did not hear warnings from other commuters that a train was approaching.

Police charged one driver with driving a motor vehicle during a disqualification period.

Prevention measures

Key factors in the pedestrian deaths of children in 2013 included children aged under 10 years entering the road environment without a carer providing direct supervision or holding their hand,[147] driver inattention, and children accessing driveway areas without the knowledge of their carers. Current initiatives in relation to pedestrian safety include:

- Transport for NSW provides funding for the NSW School Road Safety Education Program, which addresses pedestrian safety through early childhood, primary and secondary stages.[148]
- Transport for NSW engaged the Board of Studies, Education and Teaching Standards to develop *Safety Town*, an online interactive resource for primary school children, their educators and carers on road safety, including pedestrian safety. The resource was developed to complement the current school curriculum.
- The Centre for Road Safety has developed a new guide for principals, parents and members of school communities about road safety issues around schools.
- The Pedestrian Council of Australia continues to raise awareness of pedestrian safety, including its *Don't Tune Out* campaign aimed at pedestrians who use electronic mobile devices and earphones when crossing the road, and its National Walk Safely to School Day.

The Team's recommendations

In the past 15 years, the Team has conducted two reviews of low-speed vehicle run-over fatalities, including a 2012 review of the deaths of 24 children in the 10-year period 2002-2011. Arising from that review, the Team directed recommendations to the Centre for Road Safety aimed at improving the collection, analysis and publication of data on low-speed vehicle run-over fatalities; and enabling 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 its recommendations. The Centre for Road Safety has undertaken a range of important activities to improve data collection and community awareness of the issues, including the 'Check, See – Turn the Key' media campaign, workshops and a driveway safety resource for families and carers that was distributed to over 3,460 early childhood centres and some hospitals. In May 2014, Transport for NSW advised that:

- it implemented a new crash database in January 2014, and is undertaking a detailed data review of all low-speed run-overs (on road and off road, when reported to the police)
- following detailed analysis of the data, Transport for NSW will convene a stakeholder committee to determine further countermeasures to prevent these incidents
- Transport NSW will support an implementation study, project managed by the Commonwealth Department of Infrastructure and Regional Development, to analyse data to further quantify the benefits of reversing technology in vehicles, and to establish a path for implementation into the Australian Design Rules, and
- the Centre for Road Safety, in consultation with the Georgina Josephine Foundation, is developing a new driveway safety public awareness campaign, including a film targeting high school students in grades 9-12 that will promote low-speed run-over safety messages.

146 The *NSW Road Rules 2008* state that riders must not ride across a road at a pedestrian crossing.
147 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.
148 Transport for NSW 2014, *Pedestrian Safety Action Plan 2012-2014*, Sydney: TNSW, p. 8.

Recommendations

Transport for NSW, the Centre for Road Safety

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.

Department of Premier and Cabinet

9. In the context of the Department of Premier and Cabinet's (DPC) plans to convene 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 such vehicles on private property, including licensing, registration, and requirements relating to safety equipment such as helmets.
   (b) how the identified strategies will be progressed.

Chapter 20. Drowning

In 2013, the drowning deaths of 13 children were registered in NSW. The drowning mortality rate of 0.8 deaths per 100,000 children was slightly higher than 2012, but lower than the 15-year average (1.1 deaths per 100,000 children).

Drowning was the second most common unintentional external cause of death of children in NSW. It was the leading external cause of death for children under five years of age.

The 13 children drowned in:

- private swimming pools (7)
- bathtubs (2)
- a public swimming pool
- a beach
- a bucket, and
- floodwater.

The drowning deaths of two of the 13 children are also 'reviewable' deaths, and have been reviewed separately by the Ombudsman. The deaths of the two children are reviewable by the Ombudsman as one child was in care at the time of death, and the other child's death occurred in circumstances suspicious of neglect.

Trends in drowning deaths of children in NSW

There has been an overall decline in the rate of death of children from drowning over the past 15 years. The average mortality rate over the last five years (2009-2013) of 0.82 per 100,000 is lower than the previous five-year periods of 2004-2008 (0.98 per 100,000) and 1999-2003 (1.5 per 100,000).

In the last 15 years, the drowning deaths of 268 children were registered in NSW. As shown in the table below, the greatest proportion of the drowning deaths occurred in private swimming pools (42%), followed by natural inland bodies of water (17%) and bathtubs (14%). While this has consistently been the case, 2013 marks the first year in which there were no deaths of children in natural inland bodies of water.

Table 76: Trends in deaths of children due to drowning by location – deaths registered 1999-2013, number and (Crude Mortality Rate)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Pool (private)	8 (0.5)	8 (0.5)	4 (0.2)	11 (0.7)	10 (0.6)	7 (0.4)	5 (0.3)	6 (0.4)	13 (0.8)	12 (0.7)	6 (0.4)	6 (0.4)	5 (0.3)	4 (0.2)	7 (0.4)
Pool (public)	1	1	1	0	0	0	3	2	1	0	0	0	0	0	1
Natural coastal (ocean, beach, estuary)	5 (0.3)	2	4 (0.2)	5 (0.3)	5 (0.3)	2	0	1	2	2	0	1	3	2	1
Natural inland (river, creek, lake)	10 (0.6)	5 (0.3)	4 (0.2)	2	2	2	1	3	1	4 (0.2)	4 (0.2)	4 (0.2)	2	2	0
Dams	2	1	3	3	1	1	0	1	0	0	0	1	2	0	0
Bathtub	4 (0.2)	2	2	6 (0.4)	4 (0.2)	3	1	2	1	2	1	2	3	2	2
Other[149]	2	1	0	2	0	1	0	0	0	1	1	0	2	1	2
All	**32 (1.9)**	**20 (1.2)**	**18 (1.1)**	**29 (1.7)**	**22 (1.3)**	**16 (1.0)**	**10 (0.6)**	**15 (0.9)**	**18 (1.1)**	**21 (1.3)**	**12 (0.7)**	**14 (0.8)**	**17 (1.0)**	**11 (0.7)**	**13 (0.8)**

149 Other includes drains, toilets, culverts, sewers, troughs, buckets, etc

Demographic and individual characteristics

The table below provides an overview of the key demographic characteristics of the 13 children who drowned and whose deaths were registered in 2013.

Table 77: Key demographic and individual characteristics – deaths of children due to drowning, 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**13**	**100**	**0.8**	**0.41 - 1.33**		
Gender						
Female	3	23	-	-	-	-
Male	10	77	1.2	0.56 - 2.14	3.1	0.03
Age						
Under 1 year	3	23	-	-	-	-
1-4 years	6	46	1.6	0.57 - 3.37	-	-
5-9 years	1	8	-	-	-	-
10-14 years	1	8	-	-	-	-
15-17 years	2	15	0.7	0.09 - 2.64	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	10	77	0.6	0.62 - 2.39	-	-
Aboriginal or Torres Strait Islander	3	23	-	-	-	-
Remoteness						
Major cities	6	46	0.5	0.18 - 1.09		
Inner regional areas	5	38	1.5	0.49 - 3.52	-	-
Outer regional areas	2	15	-	-	-	-
Remote	0	0	-	-	-	-
Very remote	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	2	15	-	-	-	-
Quintile 4	0	0	-	-	-	-
Quintile 3	4	31	1.3	0.34 - 3.24	-	-
Quintile 2	2	15	-	-	-	-
Quintile 1 (lowest)	5	38	1.5	0.48 - 3.48	-	-

Age, gender and cultural background

In 2013, the rate of death of boys from drowning was significantly higher than that of girls (three times the drowning mortality rate of girls). The over-representation of boys in drowning deaths has been consistent over the history of the Team.

Three of the children who drowned were Aboriginal, comprising just under one-quarter of all drowning deaths in 2013. Three children who drowned were reported as being of a culturally and linguistically diverse background, including Arabic, Samoan and New Zealand backgrounds.

Most (4) of the six children identified as being Aboriginal or having a culturally and linguistically diverse background died in private swimming pools.

Table 78: Trends in drowning deaths of children by gender, 1999-2013, number and (Crude Mortality Rate)

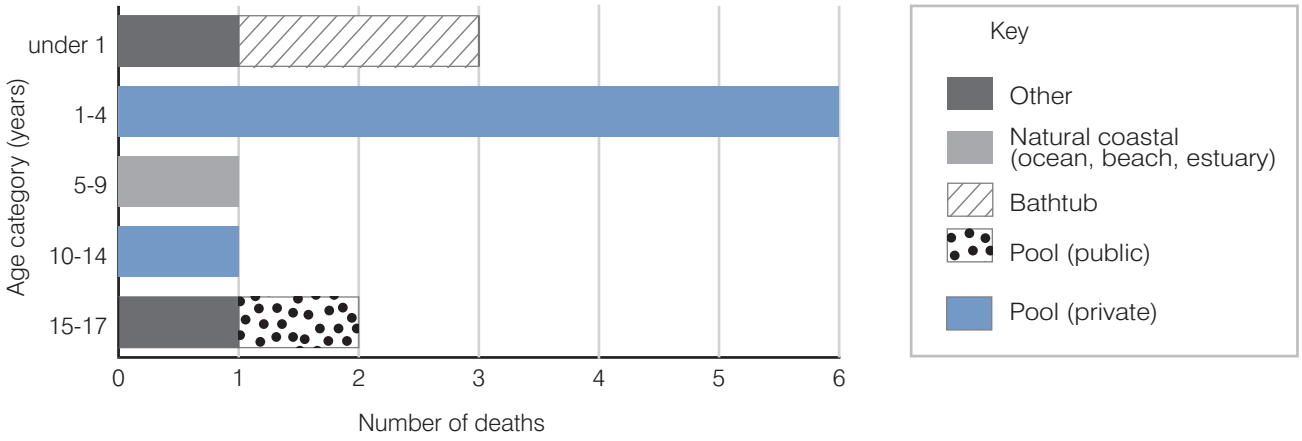
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Female	9 (1.1)	3	7 (0.9)	8 (1.0)	5 (0.6)	8 (1.0)	5 (0.6)	3	8 (1.0)	7 (0.9)	6 (0.7)	3	4 (0.5)	2	3
Male	23 (2.7)	17 (2.0)	11 (1.3)	21 (2.4)	17 (2.0)	8 (0.9)	5 (0.6)	12 (1.4)	10 (1.2)	14 (1.6)	6 (0.7)	11 (1.3)	13 (1.5)	9 (1.0)	10 (1.2)
Both	32 (1.9)	20 (1.2)	18 (1.1)	29 (1.7)	22 (1.3)	16 (1.0)	10 (0.6)	15 (0.9)	18 (1.1)	21 (1.3)	12 (0.7)	14 (0.8)	17 (1.0)	11 (0.7)	13 (0.8)

As shown in the figure below, the majority of the children who drowned in 2013 were very young. This has been a consistent trend. Over two-thirds (9) were two years of age or younger, including three children who were aged less than one year.

Consistent with previous years, very young children dominated drowning deaths in private swimming pools and bathtubs. Six of the seven children who died in private swimming pools were younger than two years, and both of the children who drowned in bathtubs were aged less than one year.

Three of the young people who drowned were aged 12-17 years. Each of the deaths occurred in the context of risk-taking: two young people drowned in swimming pools as a result of breath-holding, and one young person drowned after entering a flood-swollen dam to search for golf balls and being pulled into a drainpipe by the force of the water.

Figure 14: Location of drowning by age, 2013



Remoteness and socioeconomic status

In 2013, the majority of deaths occurred in a major city (6) or inner regional areas (5). Just over half (7) of the children who drowned resided in areas of greatest socioeconomic disadvantage (quintiles 1 and 2).

Child protection history

The families of just under half (6) of the 13 children who drowned had a child protection history. In the three years before their death, two of the children and their siblings were reported to Community Services as being at risk of significant harm; two other children had not been reported to Community Services, but their siblings had been. One child was in care. The reported concerns were not relevant to the circumstances of the deaths.

Inadequate supervision was a factor in the deaths of five of the children. In one case, the young person was self-supervising.

Of the six children with a child protection history, most (4) drowned in private swimming pools.

Deaths in swimming pools

In 2013, eight children died in swimming pools. The vast majority (7) occurred in private swimming pools; one young person died in a public swimming pool.

Private swimming pools

Over the past 15 years, 112 children have died in private swimming pools in NSW. The average rate of death of children in private swimming pools over the 15-year period was 0.5 deaths per 100,000 children. There has been a slight decline in the mortality rate in the last five years.

While the seven deaths in 2013 was highest number since 2008, it was consistent with the 15-year average (7).

The seven children who drowned in private swimming pools were aged between one and 16 years of age. The vast majority (6) of the seven children were two years of age or younger. In total, swimming pools accounted for the deaths of six of the nine children under five years of age who drowned in 2013. This proportion is consistent with national data – in 2012/13, swimming pools accounted for 61% of all drowning deaths in children under five.[150]

Of the seven drowning deaths in private swimming pools:

- Most (4) were permanent in-ground pools; two were above-ground pools.[151]
- The majority (6) occurred at the child's own home. One child drowned at a family friend's residence during a party.
- Most (5) occurred during the warmer months of summer (4) and spring (1). Two deaths occurred during autumn.

Factors involved in drowning deaths in private swimming pools

The deaths in private swimming pools in 2013 mainly comprised very young children who drowned after falling into the pool. The death of one young person in a private swimming pool was due to breath-holding activity, and is discussed separately at the end of this section.

The key factors that contributed to the young children drowning in the private swimming pools were inadequate barriers to prevent them accessing the pools, and inadequate carer supervision.

Existence and condition of child safety barriers

Each of the six pools where young children drowned in 2013 had problems with the child safety barriers:

- One pool was unfenced.
- Of the five pools that were fenced, two had barrier fence defects, such as gaps in chicken wire; and two had objects that children could climb to access the pool, including chairs, pot plants, and a cross-brace on an adjacent fence.
- Pool standards require all pool gates to have a self-closing mechanism that allows the gate to return automatically to a closed position without manual force, and that requires manual release to open the gate. All of the five pools that were fenced had problems with the gate or latch mechanism that meant they did not self-close. In two cases, the pool users had put a chain or an elastic strap on the gate to try to secure it manually.

In five of the six deaths, the children accessed the pool via an open gate – either accidentally left open (4) or intentionally propped open. The other child accessed the pool through gaps in the pool barrier fence.

Supervision of the children

All of the drowning deaths of young children in private swimming pools in 2013 occurred in the absence of adult supervision. The children were left unsupervised for varying periods of time: between four and 10 minutes (2 children), 10 minutes (2), and between 10 and 15 minutes (1).[152]

Royal Life Saving Australia has highlighted the increased drowning risks for toddlers when carers' attention is divided/ carers are distracted; and in social gatherings, when incorrect assumptions may be made that someone else is watching the children.[153]

150 Royal Life Saving Society Australia 2013, *National Drowning Report 2013*, Sydney: RLSSA, p19 http://www.royallifesaving.com.au/__data/assets/pdf_file/0003/9759/RLS_NationalDrowningReport_2013.pdf, accessed 10 June 2014.
151 In one case, information on the type of pool was not recorded.
152 In one case, information about the length of time the child was unsupervised was not recorded.
153 Royal Life Saving Society Australia 2012, *Fact sheet 7 – Home water safety*, Sydney: RLSSA, http://www.royallifesaving.com.au/__data/assets/pdf_file/0003/3963/7.-Home-Water-Safety.pdf , accessed 16 July 2014.

In relation to the six drowning deaths of young children in private swimming pools in 2013:

- in respect to most (4) of the children, the supervising adult/s were focused on/ distracted by other activities; in three of the four cases, the carers believed the child was safe in another location in the home, and
- two young children drowned during social events in which numerous people were at the premises.

Shallow Water Blackout

Royal Life Saving Australia describes 'Shallow Water Blackout' as 'a loss of consciousness under water caused by a lack of oxygen to the brain following breath-holding'.[154] Shallow Water Blackout is extremely dangerous and can occur at any depth.

Since the start of the child death register in NSW, the deaths of three young people have been identified as resulting from Shallow Water Blackout – two of which occurred in 2013.

Both of the young people who died from Shallow Water Blackout in 2013 were male, aged 12 and 17 years. One drowned in the swimming pool at his family home; the other young person died in a public swimming pool. Both drowned while breath-holding underwater.

In both cases, a supervising adult was present and was unaware the young person was experiencing a problem. Importantly, during Shallow Water Blackout people drown quietly underwater, without any sign they are experiencing difficulty.

Both of the young people were known to be strong swimmers, and had a history of challenging themselves to hold their breath for extended periods under water. Both had previously been cautioned by their caregivers to stop engaging in the activity.

Factors associated with swimming pool drowning and prevention measures

Swimming pools

The circumstances of the drowning deaths of young children in private swimming pools in 2013 reinforce the key findings from the Team's review of swimming pool drowning deaths in 2007-2011. In particular, the Team has consistently 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 at properties where children live or frequently visit.

Consistent with the Team's findings, the key messages to parents should reinforce that:

- where children have access to swimming pools, adult supervision must be constant and active
- if safety barriers are not effectively child-resistant, even momentary lapses in supervision or diverted attention can result in a drowning death
- clearly designated responsibility for supervising children around pools is essential, and
- 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 latch mechanisms.

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 drowning prevention messages: Supervise (close/constant/focused); Restrict Access (fence/gate/ maintain); Water Awareness (familiarise/develop/educate); and Resuscitation (learn/ update/act).[155]

As part of the *Keep Watch* program, Royal Life Saving has developed a Home Pool Safety Checklist that allows pool owners to complete a self assessment of the pool and its surrounds; and launched a Pool Safety App for pool owners to use as a checklist.[156] [157]

154 Royal Life Saving Society Australia 2012, *Fact Sheet number 23 – Shallow water blackout*, Sydney: RLSSA, http://www.royallifesaving.com.au/__data/assets/pdf_file/0009/4005/RLS_FactSheet_23HR.pdf, accessed 6 June 2014 .

155 Royal Life Saving Society Australia 2012, *Keep Watch actions*, Sydney: RLSSA, http://www.royallifesaving.com.au/families/at-home/toddler-drowning-prevention/keep-watch-actions, accessed 30 June 2014.

156 Royal Life Saving Society Australia 2013, *Home Pool Safety Checklist*, Sydney: RLSSA, http://www.royallifesaving.com.au/families/at-home/home-pool-safety/home-pool-safety-checklist, accessed 30 June 2014.

157 Royal Life Saving Society Australia, 2012, *Royal Life Saving Society Australia and PoolWerx launch Home Pool Safety Campaign for 2012*, Sydney: RLSSA, http://www.royallifesaving.com.au/about/news-and-events/news-items/Home-Pool-Safety-Campaign-2012, accessed 30 June 2014.

Following amendments to the *Swimming Pools Act 1992*, all pool owners are now required to register their pools on an online register, and to include a valid certificate of compliance[158] or a relevant occupant certificate[159] if they sell or lease their property (from 29 April 2015). Local councils are also required to develop a pool inspection program to ensure compliance with the legislation.

Royal Life Saving has developed the *Be Pool Safe* campaign to ensure the public understand their responsibilities under the Swimming Pools Act, including the need to register private swimming pools and spas.

Shallow Water Blackout

Royal Life Saving Australia provides information to the public about Shallow Water Blackout and the risks associated with breath-holding underwater. Its recommendations for reducing the risks include that individuals should:

- avoid taking a series of faster and deeper breaths prior to swimming underwater
- limit all competitive, repetitive or continuous breath-holding activities
- be aware that repeated hyperventilation together with repeated breath-holding activities increases the risk
- avoid pushing endurance limits in underwater swimming
- leave the water if you are experiencing a shortness of breath or dizziness, and
- always swim with someone that can assist should the need arise.[160]

The Team's recommendations

In recent years, and against the background of our review of swimming pool drowning deaths of children over a five-year period and the subsequent introduction of amendments to swimming pool legislation, the Team's recommendations 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 prioritise those premises for inspection
- guidance for councils to assist them to develop their pool 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
- a comprehensive education and awareness campaign to accompany the amendments to the legislation, including strategies targeting lessees of rental properties.

Mandatory pool inspection program and identifying premises with young children

The legislation requires councils to develop and adopt a program (by 29 April 2013) for the inspection of swimming pools in their area to ensure compliance with requirements; and to consult with the local community when developing its inspection program. Given that the amendments to the Act were made with the intent to reduce the drowning deaths and near-drowning of young children in swimming pools, the Team's recommendations have been aimed at ensuring that councils are able to effectively identify premises with swimming pools and young children, and receive sufficient guidance to develop their inspection program.

The Office of Local Government (OLG) has advised that:

- councils have a wealth of information available to them (including internal and external data) to enable them to target their inspection programs to localities and developments that are deemed higher risk, such as areas with a higher proportion of children under the age of five years, and
- rather than issuing a prescriptive guideline document, it is engaging directly with councils via regionally-based forums/ education sessions, and promoting good practice examples of programs already developed by certain councils.

158 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

159 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.

160 Royal Life Saving Society Australia 2013, *National Drowning Report 2013*, Sydney: RLSSA, p. 13 http://www.royallifesaving.com.au/__data/assets/pdf_file/0003/9759/RLS_NationalDrowningReport_2013.pdf, accessed 10 June 2014.

There is substantial merit in the OLG providing guidance to councils via face-to-face forums and linking them to good practice examples to use as model inspection programs. The Team welcomes the OLG's advice that it will monitor the implementation of the changes to the Act, and has sought further information in this regard.

While the Team appreciates OLG's advice about the ability of local councils to potentially identify properties with swimming pools where young children reside or regularly visit, it will be important for councils to be supported in this work by other agencies who hold relevant information. In this regard, the Department of Family and Community Services obtains information in the course of its work that would enable the identification of premises with swimming pools and young children. This includes information obtained through assessment of prospective foster carers of young children (Community Services); risk and support needs assessments of families with young children, including those with disability (Community Services and Ageing, Disability and Home Care), and management of social housing (Housing). Similarly, the Office of the Children's Guardian and non-government designated agencies obtain information relating to children in out-of-home care that would assist councils in identifying premises for priority inspections.

Reporting on compliance

In relation to public annual reporting by councils on swimming pool inspections (and related activity), OLG advised the Team in 2014 that it no longer considers it necessary to issue prescriptive regulations for this purpose, and the Swimming Pools Register includes a facility for the OLG and councils to generate inspection and compliance activity reports.

The Team notes that the Register includes facility 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 of any non-compliance. However, while OLG has advised that it will monitor the implementation of the changes to the Act, it is not clear to what extent OLG will publicly report on swimming pools inspection and compliance activity across NSW. The Team has sought advice in this regard, and an initial progress report.

Education and awareness

The Team notes the extensive work that OLG and Royal Life Saving have undertaken to date to raise awareness and educate councils and the broader community about the changes to the Swimming Pools Act and their responsibilities under the legislation. The *Be Pool Safe*. campaign provides clear information across a variety of formats, targeted to a wide cross-section of individuals and organisations.

The Team recognises that the amended swimming pools legislation has introduced substantial change for councils and pool owners, and that there are considerable challenges involved in rolling out large scale reform across NSW. The OLG has provided advice that the start of the 'sale and lease provisions' of the Act has been postponed by 12 months 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.

It is imperative that implementation of the legislative changes is closely monitored by OLG, to enable the early identification and resolution of any barriers to achieving its intended aims of reducing the drowning deaths and near-drowning of children. Noting that the changes to the legislation started on 29 October 2012, the Team is keen to gain a sound understanding of progress to date.

Recommendations

Office of Local Government

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) key current challenges in implementation, and any actions that OLG has identified to address them.

11. OLG should provide advice to the Team on how it will publicly report on swimming pool inspection and compliance activity across NSW.

Department of Family and Community Services, Office of the Children's Guardian and Office of Local Government

12. The Department of Family and Community Services (FACS), Office of the Children's Guardian (OCG) and the Office of Local Government (OLG) should develop arrangements to facilitate:
    (a) the identification by FACS, the 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.

Department of Family and Community Services

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.

Office of the Children's Guardian

14. The Office of the Children's Guardian 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.

Association of Children's Welfare Agencies

15. The Association of Children's Welfare Agencies (ACWA) should consult its member agencies and provide advice to the Team on:
    (c) 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
    (d) any action it intends to take to assist member agencies to reduce the drowning risks to young children, such as training initiatives.

Natural bodies of water

In 2013, one child drowned at a beach while snorkelling with a young person.

Over the past 15 years, 35 children have drowned in natural coastal bodies of water, including ocean, beaches and estuaries. The average number of deaths in coastal waters has declined over that period, from 4.2 deaths per year (1999-2003) to 1.4 deaths per year (2009-2013).

The beach at which a child drowned in 2013 is rated as a moderately hazardous beach that is known to have permanent rips. At the time of the child's death, the beach was not patrolled and there was no adult supervision.

Factors associated with drowning in natural bodies of water and prevention measures

Royal Life Saving Australia reports beaches were the location of the second highest number of drowning deaths nationally for children aged 5-14 years.[161] Only 4% of Australian beaches are patrolled and they all have varying hazards and associated risk ratings.[162]

Prevention measures focus on swimming at patrolled beaches between the 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 children within arm's reach at the beach.[163]

The *Australian Water Safety Strategy 2012-15* notes that more than 50% of beach drowning deaths occur outside of normal patrolling times, whether outside of the normal patrolling season or at a time of day before or after a lifeguard/lifesaving service is on active duty.[164] The Strategy 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.[165]

Surf Life Saving NSW and CoastSafe are currently undertaking 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.[166] [167]

Bathtubs

In 2013, two children drowned in bathtubs.

Over the past 15 years, 37 children have drowned in baths. There has been a slight reduction in the bathtub drowning deaths of children over that period; the number of deaths in 2013 just below the 15-year average of 2.5 deaths per year.

The two children who drowned in bathtubs in 2013 were 11 months of age and dependent on adults for care. Both had been placed in the bathtub by a carer and left unsupervised for up to five minutes. One of the children was placed in the bathtub with their four-year-old sibling.

The caregivers had left the room to undertake other activities, including locating another child for bathing and locating some paperwork. One of the carers had left the child unsupervised in the bathtub on a previous occasion.

Factors associated with bathtub drowning and prevention measures

The factors involved in the drowning deaths of young children in bathtubs in 2013 are consistent with the Team's previous findings. The key prevention measures involve the provision of constant and arms-length adult supervision of young children, and restricting access to bathtubs without supervision.

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.[168]

Other water hazards

The other two drowning deaths of children in 2013 highlight the risks associated with floodwater, and the high drowning risks faced by very young children around any source of water.

161 Royal Life Saving Society Australia 2013, *National Drowning Report 2013*, Sydney: RLSSA, p. 11.
162 Australian Water Safety Council 2012, *Australian Water Safety Strategy 2012-2015*, Sydney: Australian Water Safety Council, pp. 24-25.
163 Royal Life Saving Society Australia 2012, *Fact Sheet number 27 – Beach safety*, Sydney: RLSSA http://www.royallifesaving.com.au/__data/assets/pdf_file/0013/4009/27.-Beach-Safety.pdf, accessed 25 June 2014.
164 Australian Water Safety Council 2012, op. cit., p. 24.
165 Ibid.
166 Australian CoastSafe 2009, *Project Blueprint*, Sydney: Surf Life Saving Australia, http://www.coastsafe.org.au/blueprint, accessed 25 June 2014.
167 Surf Life Saving NSW 2013, *Annual Report 2012-2013*, Sydney: SLSNSW, p. 25.
168 Royal Life Saving Society Australia 2012, *Keep watch @ Bath Time* (brochure), Sydney: RLSSA, http://www.royallifesaving.com.au/__data/assets/pdf_file/0018/3942/KW_BathTime_A4toDL_final.pdf , accessed 16 July 2014.

A young child under one year of age drowned after falling into a mop bucket containing around 10cm of water. The child was unsupervised for a very short period of time, and accessed the bucket while family members were distracted by other activities.

Over the past 15 years, 12 children have drowned in a range of similar water hazards in and around the home, including buckets, eskies, toilets, and fish ponds. Importantly, children can drown in as little as 5cm of water when left unsupervised, even for very short periods.[169]

Floodwater can swell existing waterways and create strong water flows in drains and culverts. One death in 2013 involved a young person who drowned in floodwater while retrieving golf balls. The young person had entered a rain-swollen dam and was pulled into a drainpipe by the force of the floodwater.

Factors associated with other water hazards and preventative measures

Water hazards around the home

Products around the home that contain water can create a drowning hazard and children have drowned in containers carrying very small amounts of water. A range of organisations, including Product Safety Australia, Royal Life Saving, and Kidsafe, provide information about the risks to young children of many drowning hazards around the home, and tips for caregivers to prevent such deaths, including to:

- never leave containers of water unattended in places that very small children can reach
- empty the bathtub, identify water hazards such as open drains, empty inflatable pools, buckets and eskies and store them out of reach of children
- establish a child safe play area, and
- provide constant and arms-length supervision of young children when in or near water.[170] [171] [172]

Floodwaters

The Royal Life Saving Society and NSW State Emergency Service (SES) highlight the dangers and increased risk of drowning in floodwaters associated with quickly changing conditions, rising water levels, strong currents, changing water visibility, and debris washed into the water. Both agencies stress that individuals should avoid entering floodwater.[173] [174]

Following floodwater-related deaths in 2011, the Team recommended that the SES provide advice about the nature and scope of strategies in place or planned to promote to children and their parents and carers the risks associated with, and safety strategies around, floodwater and flooded waterways. The SES advised that it has three targeted education programs for children and their parents on this topic: StormSafe, FloodSafe and TsunamiSafe. The programs include key safety messaging about never playing in floodwater and staying clear of hazardous watercourses such as drains, gutters, stormwater channels, creeks and rivers.

The SES' 'I'm a StormSafe Kid' and 'I'm a FloodSafe Kid' programs are aimed at empowering young people to help take appropriate responsibility for the preparedness of their family and friends, including encouraging safer behaviour from their peers.

In June, the SES launched FloodSafe Month to raise awareness about the dangers of floodwater and what to do before, during, and after flooding.[175]

169 Kidsafe NSW 2009, *Swimming Pool Safety fact sheet*, Sydney: Kidsafe NSW Inc. http://www.kidsafensw.org/imagesDB/wysiwyg/SwimmingPoolSafetyKL2009_2.pdf

170 Product Safety Australia 2014, *Water hazards*, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/itemId/972487;www.royallifesaving.com.au/__data/assets/pdf_file/0003/3963/7.-Home-Water-Safety.pdf; and Kidsafe NSW, Water safety indoors, www.kidsafensw.org/water-safety/water-safety-indoors/

171 Royal Life Saving Society Australia 2012, *Fact sheet 7: Home water safety*, http://www.royallifesaving.com.au/__data/assets/pdf_file/0003/3963/7.-Home-Water-Safety.pdf, accessed 16 July 2014.

172 Kidsafe NSW, *Water safety indoors*, http://www.kidsafensw.org/water-safety/water-safety-indoors/

173 Royal Life Saving Society Australia 2012, *Fact sheet 25: Flooding*, Sydney: RLSSA.

174 NSW State Emergency Service 2014, *Floodwater dangers*, Wollongong, NSW: NSW SES, http://www.floodsafe.com.au/learn-more-about-floods/floodwater-dangers, accessed 16 July 2014

175 NSW State Emergency Service 2014, *FloodSafe month*, Wollongong, NSW: NSW SES, http://www.ses.nsw.gov.au/floodsafemonth, accessed 16 July 2014.

Chapter 21. Deaths from other unintentional external causes

Together, transport fatalities and drowning deaths accounted for most of the 61 deaths of children due to unintentional external causes in 2013. This chapter provides information about the 16 children[176] whose deaths were due to other unintentional external causes, such as fires, choking, and accidental poisoning.

The table below provides an overview of the key demographic characteristics of the 16 children who died as a result of other unintentional external causes in 2013.

Table 79: Key demographic and individual characteristics – deaths due to other unintentional external causes, 2013[e]

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**16**	**100**	**0.96**	**0.55 - 1.55**		
Gender						
Female	8	50	0.98	0.43 - 1.94	-	-
Male	8	50	0.93	0.40 - 1.83	0.94	0.46
Age						
Under 1 year	1	6	-	-	-	-
1-4 years	8	50	2.07	0.89 - 4.07	-	-
5-9 years	2	13	-	-	-	-
10-14 years	2	13	-	-	-	-
15-17 years	3	19	-	-	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	10	63	0.63	0.62 - 2.39		
Aboriginal or Torres Strait Islander	6	38	6.59	2.42 - 14.34	10.42	0.00
Remoteness						
Major cities	8	50	0.66	0.29 - 1.31	-	-
Inner regional areas	5	31	1.51	0.49 - 3.52	-	-
Outer regional areas	2	13	-	-	-	-
Remote areas	1	6	-	-	-	-
Very remote areas	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	0	0	-	-	-	-
Quintile 4	1	6	-	-	-	-
Quintile 3	2	13	-	-	-	-
Quintile 2	9	56	2.87	1.31 - 5.44	-	-
Quintile 1 (lowest)	4	25	1.19	0.32 - 3.05	-	-

176 The 16 deaths reported for 2013 do not include three deaths of infants less than one year of age who died suddenly and unexpectedly from unintentional external causes, which have also been classified as explained SUDI. These deaths are discussed in detail in Chapter 17.

[e] see errata in the front of this document

Of the 16 children whose deaths were due to unintentional external causes in 2013:

- seven children died from threats to their breathing, including three children who died as a result of accidental hanging or strangulation; three children who choked on food or other objects; and one child whose tracheostomy tube was accidentally removed
- three children died in house fires
- the deaths of two young people were drug-related – one died from a suspected overdose, and the other young person died after jumping from a building while under the influence of a synthetic drug
- one young person died from a brain haemorrhage while playing rugby league
- one child died after being mauled by a dog
- one child was thrown off a horse, and
- one infant died after accidentally pulling an object onto their head.

The death of one of the children is a 'reviewable death' as it is considered to have occurred in circumstances of neglect, and has been reviewed separately by the Ombudsman.

Demographic and individual characteristics

Age, gender and Aboriginal and Torres Strait Islander status

The largest proportion of children who died from other unintentional external causes were aged 1-4 years, comprising half (8) of the 16 deaths. The causes of their deaths reflected the overall vulnerability of young children, particularly as they investigate and experiment with their surroundings. Their causes of death included choking on food or other objects that they had picked up; becoming unable to breathe when caught in blind cords; and being attacked by a dog.

Five children who died from unintentional external causes were aged 14-17 years. The causes of their deaths largely reflected risk-taking behaviour amongst young people, including experimentation with drugs.

Over one-third of children (6) who died from unintentional external causes were identified as Aboriginal. The mortality rate of Aboriginal and Torres Strait Islander children from other unintentional external causes (6.59 deaths per 100,000 children) was significantly higher than that of non-Indigenous children from these causes – over 10 times the rate. The deaths of half of the Aboriginal and Torres Strait Islander children from other unintentional external causes were due to house fires, comprising all deaths from that cause in 2013.

Remoteness and socioeconomic status

Half of the children whose deaths were due to other unintentional external causes lived in major cities in NSW.

The majority of the children who died from unintentional external causes lived in areas of greater socioeconomic disadvantage.

Child protection history

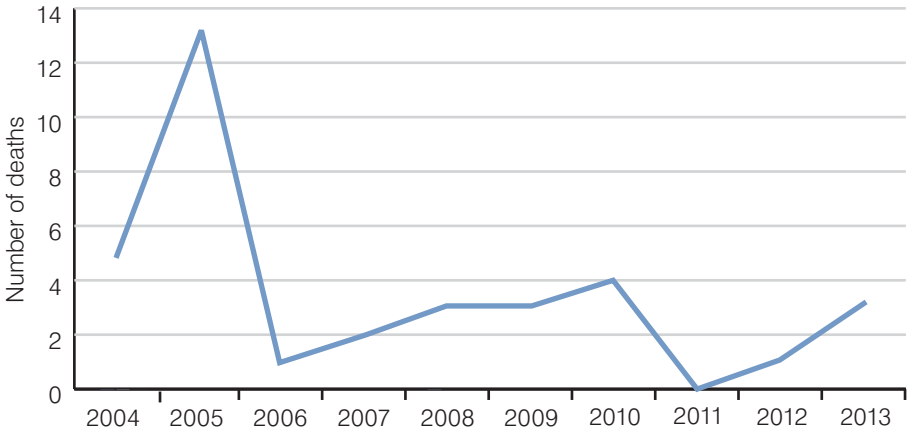
The families of six children who died from other unintentional external causes had a child protection history. One child was in care at the time of their death.

Deaths of children in house fires 2004-2013

In the 10-year period between 2004 and 2013, 35 children died in 27 house fires in NSW. In four fires, multiple children died (involving two to four children at each location).

As shown in the chart below, the highest proportion of children died in house fires in 2005, with seven fires that accounted for the deaths of 13 children. Three children died in house fires in 2013; the highest number since 2010.

Figure 15: Number of deaths of children in house fires, 2004-2013

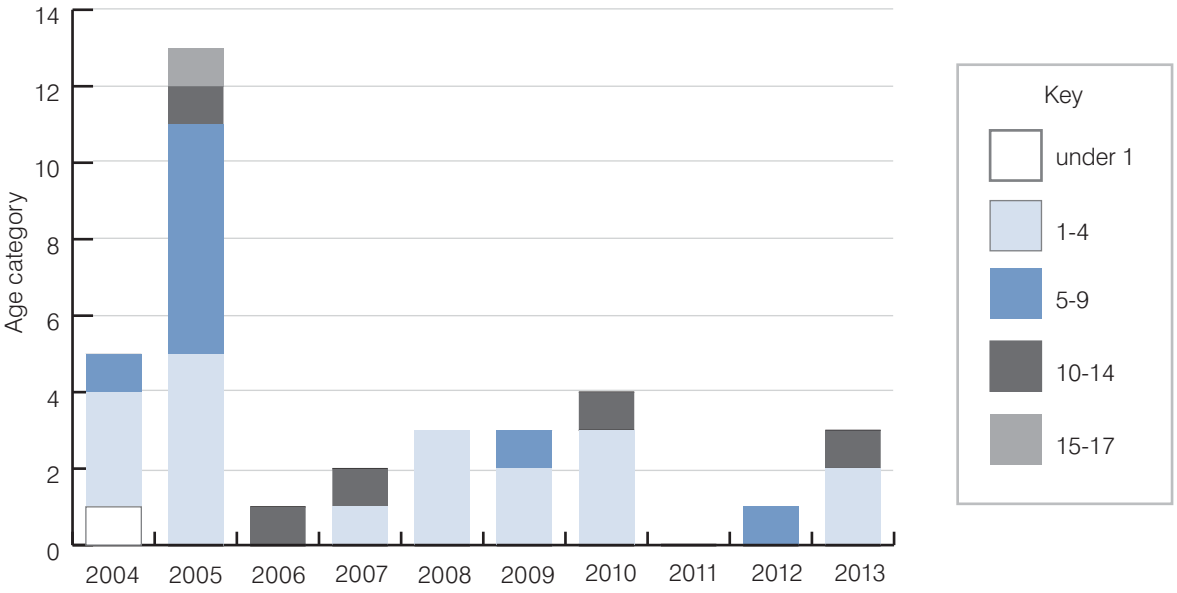


Age, gender and Aboriginal and Torres Strait Islander status

As shown in the following chart, most (20) of the 35 children were younger than five years of age. Just under two-thirds (22) of the children who died in house fires were male.

Ten children (29%) were identified as Indigenous.

Figure 16: Trends in deaths of children due to house fires, 2004-2013, number and age group



Remoteness and socioeconomic status[177]

Over half (14) of the 27 fires occurred in regional NSW, mainly inner regional (8) areas. The fires primarily occurred in the Western, Central West, and Hunter regions of NSW. Twelve of the fires occurred in major cities; four of which were in metropolitan Sydney. One fire was in a remote area of NSW.

Most (19) of the fires occurred in areas of greatest socioeconomic disadvantage (quintiles 1 and 2). There were only two fires in the least socioeconomically disadvantaged areas (quintiles 5 and 4).

177 Remoteness and SEIFA based on the postcode of the child's usual residence/location of the fire

Type of premises

Information about the premises in which the fires occurred was available for all but one of the cases. The vast majority of the premises were houses or townhouses (23); three fires occurred in caravans.

Eight of the premises were identified as Housing NSW or community housing properties; 12 were known to be privately owned or rented premises/caravans; and one was a farmhouse occupied as part of an employment arrangement. Of the 18 houses or townhouses where the number of storeys was known, half were single storey, and half had two or more storeys.

Circumstances of the deaths

In the majority (24) of the 27 fires, the cause was able to be determined to a reasonable level of certainty:

- just under half (11) of the fires were caused by children playing with matches or cigarette lighters
- six fires were caused by materials (including bedding, cushions and clothing) catching alight on heaters
- three fires were caused by candles (including via proximity to pillows, blankets and other materials)
- three fires were due to electrical issues, including an overloaded powerboard, tampering with a fuse in the switchboard, and a possible electrical fault, and
- one fire was related to the surrounding of a chimney.

Just over half (15) of the fires occurred in the cooler months of autumn (8) and winter (7). Of the 13 fires in autumn or winter where the cause was able to be determined, eight (62%) were related to heaters or heating. Fire & Rescue NSW statistics show that the winter months account for around 30% of residential fires in NSW each year, and 43% of all fire fatalities.[178] [179]

Of the 11 fires in spring or summer where the cause was able to be determined, just over half (6) were due to children playing with matches or lighters.

Smoke alarms

Information about the use of smoke alarms was available for 18 of the 27 fires. In 61% (11) of the cases, smoke alarms had not been installed or were not operational. This included where the carer/s had removed or disconnected the smoke alarm/s to stop the sensors from activating. Five of the 11 cases pre-dated the mandatory smoke alarm requirements.

Barriers to escape

Information about any barriers that may have affected the ability of the child/other inhabitants to escape from the premises was available for all but one of the fires. Barriers to escape were present in 42% (11) of the cases, including deadlocked or padlocked doors; security grilles on windows; smoke/fire preventing access to stairs in double-storey premises; and Perspex windows.

Supervision and contributory behaviour

Supervision issues were evident in just under two-thirds (17) of the 27 fires. The supervision issues included multiple young children being left at home in the care of an older sibling; young children being left at home alone (asleep) while the carer/s went out for a period of time; and young children left unsupervised during the day while the carer/s slept.

The behaviour of the children and/or the carer/s was contributory in three-quarters (20) of the 27 fires. The behaviour included children playing with matches/lighters; carers smoking in bed and leaving heaters in close proximity to flammable material; using a candle to read in bed; overloading a powerboard; carer alcohol/ other drug use; and leaving a burning candle unattended.

Children playing with matches or lighters

The 11 fires that were caused by children playing with matches or lighters resulted in the deaths of 13 children. Twelve of the 13 children who died were aged six years and younger. Of the 11 fires:

- Fifteen children were playing with matches/lighters in a bedroom or lounge room at the time of the fires. All of the children were aged between two and six years; the majority (13) were three to five years old. In four cases, the deceased child was not the one who had been playing with the matches/lighters; it was their sibling/s.

178 Fire & Rescue NSW 2013, *Winter fire safety checklist*, Sydney: Fire & Rescue NSW, http://www.fire.nsw.gov.au/gallery/files/pdf/factsheets/13_winter_checklist.pdf, accessed 16 July 2014.

179 Fire & Rescue NSW 2013, *Winter fire safety*, Sydney: Fire & Rescue NSW, http://www.fire.nsw.gov.au/page.php?id=320, accessed 16 July 2014.

- In the majority (9) of the fires, inadequate supervision of the child(ren) was a factor. This included five fires that were started during the day by children who were unsupervised while the carer/s slept.
- In most (8) of the cases, the children who started the fire had a history of playing with matches/ lighters or starting fires, and this was known by their carer/s.
- In all of the cases, the children gained access to matches and lighters that had been left out by the carer/s or were easily accessible (such as in a kitchen drawer or a handbag).

Families with a child protection history comprised the majority (9) of the fires started by children playing with matches or lighters. The child protection reports in the three years prior to the fires included risks associated with carer drug use (6) and inadequate supervision (5).

Child protection history

In April 2014, the Team tabled a special report to Parliament on its analysis of the causes of death of children with a child protection history in 2002-2011. In relation to fires, the analysis identified that:

- the rate of death of children with a child protection history from fires was 23.8 times the rate of children without that history, and
- child protection history significantly increased the odds that a child's death was due to fire, particularly children aged 1-4 years.

In light of this information, the Team indicated in the report that it would examine all fire-related deaths of children in the 10-year period 2004-2013, including comparison of the deaths of children with and without a child protection history, and identification of factors relevant to prevention.

Of the 27 house fires in 2004-2013, two-thirds (18) involved families with a child protection history. Families with a child protection history comprised the majority of fires caused by:

- children playing with matches or lighters (9; 82%), and
- materials catching alight on heaters (4; 67%).

The most common child protection risks reported in relation to the 18 families in the three years before the fires related to carer substance abuse (13); inadequate supervision (10); domestic violence (10); physical harm (7); homelessness (7); and neglect (5).

However, there was no difference between families with or without a child protection history in relation to key factors, including the proportion of fires in which: the child/carer's behaviour was contributory; smoke alarms were not installed or not operational; or there were barriers to escape.

In addition, supervision issues were slightly less prevalent in the fires involving families with a child protection history. Supervision was a factor in over half (10) of the deaths of children with a child protection history, and three-quarters (7) of the deaths of children without this history.

Factors associated with house fires and prevention measures

The Team's review of the deaths of children in house fires over the 10-year period has highlighted the risks associated with:

- children having access to, and playing with, matches and lighters
- heaters and candles being placed too close to flammable materials and/or being left unattended while in use
- young children being unsupervised or left in the supervision of young teenagers
- smoke alarms not being installed or being disconnected, and
- household members not having adequate means of escaping the premises.

Legislation requires all NSW residents to have at least one working smoke alarm installed on each level of their home – including owner occupied, rental properties, relocatable homes, caravans and campervans or any other residential building where people sleep.[180] The legislation requires the smoke alarms to be operational, and that persons do not remove or interfere with their operation. Requirements for residential and certain shared accommodation commenced in 2006; those relating to moveable dwellings started in 2011.

180 Fire & Rescue NSW 2012, *Smoke alarms*, Sydney: Fire & Rescue NSW, http://www.fire.nsw.gov.au/page.php?id=80, accessed 16 July 2014.

Fire & Rescue NSW (FRNSW) has a range of resources and tools on its website that are aimed at assisting the community to identify and address fire risks, including its Home Fire Safety Audit – an easy-to-use online self-assessment tool (www.homefiresafetyaudit.com.au).

FRNSW estimates that at least 3,000 fires a year (nearly 10% of all fires in NSW) are believed to be started by children.[181] To help reduce fire risks associated with children, FRNSW has developed the Intervention and Fire Awareness Program (IFAP) to help families with children who play with fire, aimed at stopping the behaviour. FRNSW also delivers Pre ED and Fire ED programs in NSW preschools and primary schools (targeted at kindergarten and year 2 students).

A mandatory standard for disposable cigarette lighters came into effect on 1 March 1997. Disposable cigarette lighters include all disposable cigarette lighters, novelty lighters, and cheap refillable lighters with an import value of less than $5. There is also a permanent ban on toy-like novelty cigarette lighters.[182] In relation to child safety, the requirements include that:

- lighters must have a device that stops small children from accidentally operating the lighter (such as a button, release catch or metal guard that makes it difficult for small children to operate the lighter)
- lighters must be permanently marked with the phrase, 'KEEP AWAY FROM CHILDREN' or 'KEEP OUT OF REACH OF CHILDREN', and
- prior to importing into Australia, disposable cigarette lighters must have certification of compliance for child resistance issued in accordance with the American Standard.

However, it is important to note that 'child-resistant' lighters are not 'child-proof'. It is critical that carers are vigilant and take active steps to ensure that fire-starting materials such as matches and lighters are kept out of the reach of children.

FRNSW recommends a balance between home security and home safety, noting that security measures such as deadlocks on doors, security grilles and bars on windows or security screen doors, and keyed locks or roller shutters on windows, can present barriers to escaping a fire. FRNSW emphasises the importance of households having a fire escape plan; making sure all windows and doors can be quickly opened if and when required; and ensuring that keys to all locked doors are readily accessible.[183]

Every Housing NSW home has at least one hard-wired smoke alarm with battery back-up. FACS is also currently undertaking a Fire Safety Program in Housing NSW properties, focused initially on walk-up units and other multi-unit developments, including townhouses. The program includes carrying out inspections and undertaking maintenance work; such as installing smoke seals around entry doorways, fitting fire-rated doors and painting using fire-resistant paint.[184]

The State Coroner held inquests into the deaths of 10 children in three house fires in 2004 and 2005. Recommendations arising from the inquests were targeted at the need for promotion in public awareness campaigns of:

- adults ensuring that cigarette lighters are not accessible to children
- all persons being evacuated from the premises before attempting to combat the fire
- occupants ensuring that all doors and windows can be opened in the event of an emergency
- informing householders that lounges and polyurethane furnishings are highly flammable, and
- every home having an evacuation plan.

The Coroner also recommended that Community Services caseworkers be trained in the recognition of fire hazards such as radiant heaters and polyurethane lounges to facilitate their recognition of potential physical risks to children.

The Home Inspection Checklist that is conducted in relation to Community Services' foster carer applicants includes fire safety checks, including whether smoke detectors are installed and working, and whether access doors and windows can be easily opened in the event of a fire. The high proportion of fires involving families with a child protection history warrants consideration of broader opportunities for targeted prevention activities.

181 Fire & Rescue NSW 2012, *Intervention & Fire Awareness Program* (IFAP), Sydney: Fire & Rescue NSW. http://www.fire.nsw.gov.au/page.php?id=222, accessed 16 July 2014.

182 Product Safety Australia 2014, Toy-like novelty cigarette lighters, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/itemId/973479, accessed 16 July 2014.

183 Fire & Rescue NSW 2009, *Home Security and Fire Safety, fact sheet 22*, Sydney: Fire & Rescue NSW,http://www.fire.nsw.gov.au/gallery/files/pdf/factsheets/22_home_security.pdf, accessed 16 July 2014.

184 Family & Community Services 2014, *Fire Safety Program fact sheet*, Sydney: Community Services, http://www.housing.nsw.gov.au/NR/rdonlyres/8E3272F9-099A-4520-9E6B-78CF3B09F89C/0/FireSafetyProgram.pdf, accessed 16 July 2014.

Recommendations

Department of Family and Community Services and Fire & Rescue NSW

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 the Department of Family and Community Services (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 the Department, 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.

Deaths from threats to breathing

In 2013, seven children died from unintentional asphyxia. The children were aged between one and 15 years; the vast majority (6) were younger than five years of age. Of the seven children:

- three children died as a result of accidental strangulation, through becoming caught in a blind cord; wedged in a vehicle window; or risk-taking behaviour involving depriving the flow of blood to their brain
- three children died from choking on a small item or food, and
- one child accidentally removed their tracheotomy tube during sleep.

Deaths from choking

The three children who died in 2013 as a result of choking were aged between one and four years of age. Two choked on food (a jelly bean and a whole grape), and one choked on a fridge magnet.

Two of the children picked up and put the item in their mouth without their carer/s seeing it; one child was provided with the whole grape by the carer, based on the child's prior demonstrated ability to eat the food safely.

Choking hazards and prevention measures

The choking deaths of children in 2013 highlight the importance of carers being vigilant about keeping small objects out of the reach of young children, and ensuring that the foods provided to them are appropriate for their developmental stage.

Young children aged 0-4 years are vulnerable to choking due to their underdeveloped coughing reflexes, small airways, and the fact that they are still developing their teeth to properly chew and grind food. Young children also commonly place small objects in their mouth as a means of exploring the world around them, including buttons, batteries, coins, toy parts, marbles, and pen tops.[185]

Consistent with deaths that occurred in 2013, the most common types of food that young children choke on are nuts, popcorn, corn chips, whole grapes, hard or sticky lollies, foods that have small and hard pieces (such as raw carrot, celery or apple), foods with tough skin such as sausages and hotdogs, and stringy meats such as chicken and steak.[186] [187]

Kidsafe advises carers of young children to stay with the child while they eat; and to avoid giving the above-listed foods, or to ensure that the food is cut up into small pieces with the skin removed. Carers are also advised to ensure that small objects are kept well out of reach of small children.[188]

185 KidsafeSA 2010, *Prevention of choking, suffocation and strangulation in young children – Information for parents and caregivers*, Sydney: Kidsafe NSW Inc., http://www.kidsafesa.com.au/__files/f/3150/4986_prevention_of_choking_FS_V2proof.pdf, accessed 16 Jul 2014.
186 Ibid.
187 Congiu M, Cassell E & Clapperton A. 2005. *Unintentional asphyxia (choking, suffocation and strangulation) in children aged 0-14 years*. Hazard: Victorian Injury Surveillance & Applied Research.
188 KidsafeSA 2010, op. cit.

The NSW Ministry of Health personal health record (also known as the 'Blue Book')[189] is distributed to the carers of all children born in NSW. The current version[190] of the book provides carers with some information of risks for children at certain developmental stages. It notes that infants and toddlers are at risk of choking on small items and unsuitable foods.[191]

Product Safety Australia has developed the 'Choke Check' – a DIY safety tool for carers to use to identify toys and other objects that can pose choking or ingestion hazards for children under three years of age. The Choke Check cylinder mimics the size and shape of a child's throat up to three years of age, and shows how easily an object can block an airway.[192]

Deaths from blind cords

Between 1996 and 2013, the deaths of four children in NSW were due to accidental strangulation associated with window blind cords. Most (3) of the children were 18 months of age or younger; one child was three years old. In each case, the children had been placed to sleep in a cot or bed that was within reach of the window/ blind cords.

At the time of writing, blind cords were implicated in the deaths of a further three children in 2014.

The ACCC indicates that 1-2 Australian children die each year after being strangled by blind or curtain cords; with at least 11 deaths nationwide between 2001 and 2008 (the majority of which were children under three years of age).[193]

Blind cord hazards and prevention measures

Blind and curtain cords can very quickly tangle around a child's neck and cause strangulation.[194] In 2010, a national mandatory standard for corded internal window coverings was introduced in Australia to reduce the incidence of, and potential for, death and injury to young children. The mandatory standard requires suppliers of corded window coverings (after December 2010) 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 warning on the cord must contain the 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, following additional deaths of young children, the Federal Government developed a further mandatory standard for commercial installers of corded window coverings, to complement the 2010 standard. The standard will take effect on 1 January 2015, and requires installation to be done in a way that prevents cords from forming dangerous loops where they can be reached by children; and warning labels or swing tags to remain attached to the blind cord.

Most (5) of the seven deaths of children in NSW that have been linked to strangulation by blind cords occurred post-2010 and the introduction of the mandatory standard. Importantly, the mandatory standard(s) do not reduce the risks associated with blind cords installed pre-2010. Against this background, the ACCC has urged consumers, and particularly 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.'[195] The websites of a range of organisations, including Product Safety Australia, Kidsafe NSW, and NSW Fair Trading, provide tips on how this can be done. Key messages 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.[196]

189 The blue book documents health and developmental checks along with immunisation details.
190 Revised in 2012/2013.
191 In 2012, an e-Blue Book pilot commenced in Western Sydney. The functionality of the accompanying mobile device application enables the continuation of information provision about risks to children of different developmental ages.
192 Product Safety Australia 2014, Choke Check – the DIY safety tool for choking and ingestion hazards, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/tag/chokecheck, accessed 16 July 2014.
193 Product Safety Australia 2014, *Blinds & curtains*, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/itemId/974977, accessed 16 July 2014.
194 Ibid.
195 Product Safety Australia 2014, *Government improves safety standard to protect kids*, Canberra: Australian Competition and Consumer Commission, http://www.productsafety.gov.au/content/index.phtml/itemId/1006426 , accessed 16 Jul 2014
196 Fair Trading NSW 2014, *Blinds and curtains – Child safety guidelines*, Sydney: Fair trading NSW, http://www.fairtrading.nsw.gov.au/ftw/Consumers/Product_and_service_safety/General_products/Blinds_and_curtains.page , accessed 16 July 2014

Deaths associated with drug use

The deaths of three young people in 2013 were associated with the use of illicit substances, including two deaths linked to the use of synthetic drugs. The young people were aged between 14 and 17 years.

The deaths of the three young people were associated with risk-taking behaviour, including:

- consumption of oxycodone,[197] beer and cannabis with other people, resulting in death from oxycodone toxicity
- ingestion of a synthetic substance, 25I-NBOMe, resulting in death after jumping off a balcony, and
- consumption of a synthetic substance, 25C-NBOMe,[198] and cannabis, resulting in death after running onto a road and being struck by a vehicle.[199]

Synthetic drug use hazards and prevention measures

Including one death in 2012, there have been three deaths of young people in NSW associated with the use of synthetic drugs – all variants of NBOMe. The NBOMe compounds can cause confusion and difficulty focusing, scrambled communication, vascular constriction, shaking, nausea and/or vomiting, paranoia, fear and panic, out of control behaviour and possible seizures.[200]

On 7 October 2013, the NSW Government amended the *Drug Misuse and Trafficking Act 1985* and the *Poisons and Therapeutic Goods Act 1966* to prohibit the manufacture, supply, sale and advertising of psychoactive substances;[201] and to prohibit the manufacture, supply, sale or possession of certain poisons and therapeutic goods (Schedule 9 substances). As a result of the amendments, NBOMe is a prohibited substance in NSW.

197 A narcotic analgesic used to relieve moderate to severe pain
198 25I-NBOMe and 25C-NBOMe are potent hallucinogenic substances that can mimic the effects of LSD
199 The death of this young person has been included in the numbers of deaths due to transport fatalities (Chapter 19)
200 NSW Health 2013, Safety information 003/13, Sydney: NSW Ministry of Health
201 Psychoactive (also known as psychotropic) substances primarily act on the central nervous system, resulting in hallucinations or a significant disturbance in, or significant change to, motor function, thinking, behaviour, perception, awareness or mood.

Chapter 22. Suicide

The deaths of 19 young people registered in NSW in 2013 were due to suicide.

Suicide was the leading external cause of death of young people aged 10-14 years, and the overall equal leading cause of death of young people aged 15-17 years.

This chapter considers the deaths of young people that occurred as a result of suicide and probable suicide. Included are suicide deaths where the State Coroner has determined the cause and manner of death to be self-harm with fatal intent, and deaths where records indicate that suicide was the probable manner of death. Probable suicide deaths include those where police identify the death as suicide and the indicators include evidence of prior suicide attempts, expressions of suicidal ideation and/or a history of self-harming behaviour. The Team has consistently used this approach in reporting suicide.

Of the 19 deaths of young people reported here, the Coroner has determined that nine were the result of suicide. In three cases, the Coroner has dispensed with an inquest without recording findings regarding manner of death. In one case, the Coroner dispensed with an inquest and recorded manner as misadventure. At the time of writing, six cases were still open with the Coroner.

The suicide of one young person is also a 'reviewable' death as the young person was in care, and has been reviewed separately by the Ombudsman.

Trends in suicide deaths of young people in NSW

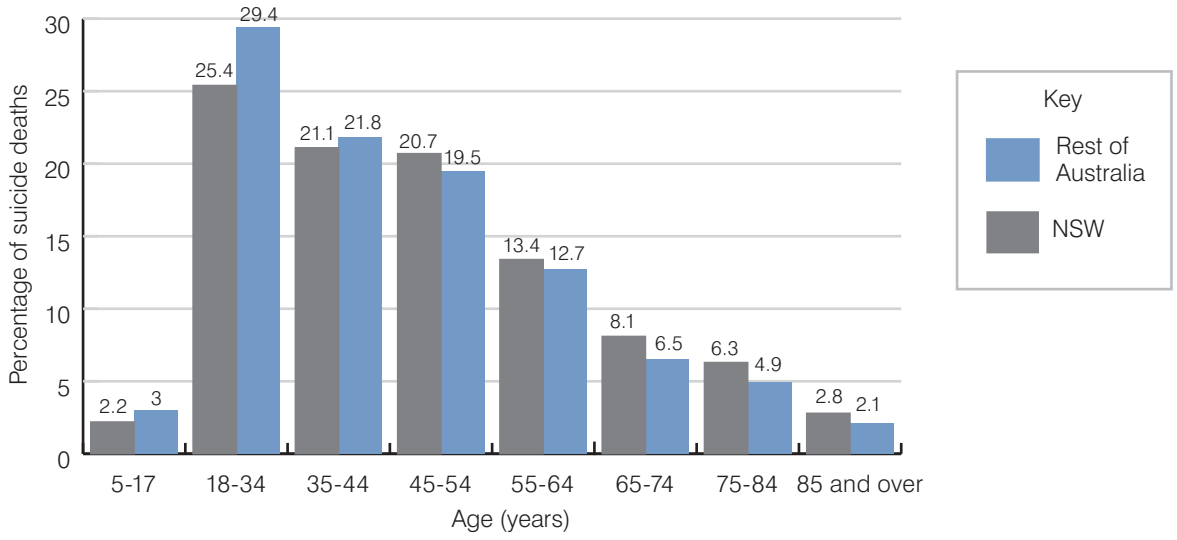
Youth suicide in context

Death by suicide is an infrequent event. In Australia in 2012, 1.7% of all deaths were due to suicide. However, while suicide was the 14th most common cause of death of Australians in 2012, it was the leading cause of death for males and females aged between 15 and 24 years.[202]

In the five-year period 2008-2012, young people aged 5-17 years comprised 2.8% of all suicide deaths. People aged 18-34 years comprised over one-quarter of all suicide deaths in that period (28.3%), with the proportion decreasing with increasing age.[203]

Overall, NSW had the highest proportion of all suicide deaths in Australia in 2008-2012 (27%). As shown in the figure below, the only age groups where the proportion of suicide deaths in NSW was lower than the rest of Australia was amongst the youngest age groups: 5-17, 18-34, and 35-44 years. In the five-year period, the suicide deaths of children and young people aged 5-17 years comprised 2.2% of all suicide deaths in NSW, and 3% of suicide deaths in the rest of Australia.

Figure 17: Suicide deaths by age, NSW and Rest of Australia, 2008-2012[204]



202 Australian Bureau of Statistics 2014, 3303.0 - Causes of Death, Australia, 2012, Canberra: ABS.
203 Australian Bureau of Statistics 2014, *Suicide deaths by sex and age, NSW and Rest of Australia, 2008-2012,* Causes of Death, Customised Report. Canberra: ABS.
204 Based on ABS data, *Suicide deaths by sex and age, NSW and Rest of Australia, 2008-2012*, Causes of Death, Customised Report, 2014. Canberra: ABS.

However, NSW Health estimates that for each suicide in NSW, there are 30 to 40 hospitalisations following suicide attempts each year. This information is based on hospital admissions only, and it is likely there are many more suicide attempts that are excluded from this calculation.[205]

As indicated in the table below, over the 15 years between 1999 and 2013, there have been 248 deaths of young people in NSW from suicide. The number of deaths from suicide in 2013 was the highest since 2005.

The suicide mortality rate in 2013 (1.1 deaths per 100,000 children) was largely consistent with the 15-year average (1.03 per 100,000).

Table 80: Trends in deaths due to suicide by gender – number and (Crude Mortality Rate), 1999-2013

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
Male	8 (1.0)	10 (1.2)	12 (1.5)	13 (1.6)	12 (1.5)	9 (1.1)	14 (1.7)	6 (0.7)	10 (1.2)	8 (1.0)	14 (1.7)	9 (1.1)	13 (1.5)	9 (1.1)	10 (1.2)	**157**
Female	13 (1.7)	8 (1.0)	5 (0.6)	6 (0.8)	6 (0.8)	7 (0.9)	6 (0.8)	2 -	4 (0.5)	5 (0.6)	4 (0.5)	5 (0.6)	4 (0.5)	7 (0.9)	9 (1.1)	**91**
Total	**21 (1.3)**	**18 (1.1)**	**17 (1.1)**	**19 (1.2)**	**18 (1.1)**	**16 (1.0)**	**20 (1.3)**	**8 (0.5)**	**14 (0.9)**	**13 (0.8)**	**18 (1.1)**	**14 (0.9)**	**17 (1.0)**	**16 (1.0)**	**19 (1.1)**	**248**

Demographic and individual characteristics

The table below provides an overview of the main demographic characteristics of the 19 young people who died as a result of suicide, and whose deaths were registered in 2013.

Table 81: Key demographic and individual characteristics – deaths of young people due to suicide in 2013

	Number	Percent	Crude Mortality Rate	95% Confidence Interval	Incident Rate Ratio	*p*
Total	**19**	**100**	**1.14**	**0.68 - 1.77**		
Gender						
Female	9	47	1.11	0.51 - 2.10	-	-
Male	10	53	1.16	0.56 - 2.14	1.05	0.46
Age						
Under 1 year	0	0	-	-	-	-
1-4 years	0	0	-	-	-	-
5-9 years	0	0	-	-	-	-
10-14 years	3	16	-	-	-	-
15-17 years	16	84	5.86	3.35 - 9.51	-	-
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	17	89	1.08	1.29 - 3.54	-	-
Aboriginal or Torres Strait Islander	2	11	-	-	-	-
Remoteness						
Major cities	14	74	1.16	0.64 - 1.95	-	-
Inner regional areas	4	21	1.21	0.33 - 3.09	-	-
Outer regional areas	0	0	-	-	-	-
Remote	1	5	-	-	-	-
Very remote	0	0	-	-	-	-
Socioeconomic status						
Quintile 5 (highest)	2	11	-	-	-	-
Quintile 4	5	26	1.52	0.49 - 3.54	-	-
Quintile 3	4	21	1.27	0.34 - 3.24	-	-
Quintile 2	2	11	-	-	-	-
Quintile 1 (lowest)	6	32	1.79	0.66 - 3.89	-	-

205 NSW Department of Health 2010, *NSW Suicide Prevention Strategy 2010-15*,Sydney: NSWDH, p10.

Age and gender

As indicated in table 81, just over half (10) of the 19 suicide deaths registered in NSW in 2013 were male. While males have typically had a higher suicide mortality rate than females, the number of females who died from suicide in 2013 (9) was the highest since 1999.

The prevalence of males amongst youth suicide deaths in NSW is consistent with broader national suicide statistics. Males dominate the numbers of deaths from suicide, in NSW and the rest of Australia, at all ages.[206]

The majority (16) of the young people who died from suicide in 2013 were aged 15 years and older. As shown in the table below, the number of deaths from youth suicide increases as age increases. Over the past 15 years, almost two-thirds of young people who died from suicide were aged 16 or 17 years.

Three young people who died from suicide in 2013 were 13 or 14 years of age. The proportion of young people aged 10-14 years who died from suicide in 2013 (16%) is consistent with the 15-year average.

Table 82: Trends in suicide deaths of young people by age, 1999-2013 – number and per cent

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Number (%)
10 years	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1 (<1)
11 years	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	2 (<1)
12 years	0	0	1	0	0	1	0	1	0	0	0	0	0	0	0	3 (1)
13 years	1	1	1	0	1	0	1	1	2	0	0	0	0	1	2	11 (4)
14 years	4	1	0	2	2	4	0	0	0	3	0	1	3	1	1	22 (9)
15 years	5	3	3	2	1	2	4	0	3	1	3	3	7	4	7	48 (19)
16 years	3	5	6	6	6	6	3	3	2	5	7	3	5	3	3	66 (27)
17 years	8	8	6	9	7	2	11	3	7	4	8	7	2	7	6	95 (38)
Total	**21**	**18**	**17**	**19**	**18**	**16**	**20**	**8**	**14**	**13**	**18**	**14**	**17**	**16**	**19**	**248 (100)**

Aboriginal and Torres Strait Islander status and cultural background

Two of the young people who died from suicide in 2013 were Aboriginal.

Just over half (10) of the young people had a culturally and linguistically diverse background, including South East Asian (3), African (2), European (2), South American, East Asian and Asian (unspecified) backgrounds.

Remoteness and socioeconomic status

Unlike recent years, a much higher proportion of the young people who died from suicide in 2013 resided in major cities in NSW (74%), and in areas of greatest socioeconomic disadvantage (32%).

Child protection history

In April 2014, the Team tabled a special report to Parliament on its analysis of the causes of death of children with a child protection history in 2002-2011. In relation to suicide deaths, the analysis identified that:

- the suicide mortality rate for young people with a child protection history over the decade (6.3 per 100,000) was four times the rate of young people without that history (1.5 per 100,000)
- there had been a significant decline in suicide mortality rates for young people with a child protection history, while there had been a non-significant decline for young people without that history, leading to a significant decrease in the gap between young people with and without a child protection history, and

206 Australian Bureau of Statistics 2014, *Suicide deaths by sex and age, NSW and Rest of Australia, 2008-2012*, Causes of Death, Customised Report. Canberra: ABS.

- there is a complex relationship between the socioeconomic status of the area in which the young people lived, child protection history and suicide. The highest proportion of young people without a child protection history who suicided were from the least socioeconomically disadvantaged areas, while the highest proportion of suicide deaths among young people with a child protection history was in the middle SEIFA quintile.[207]

Of the 19 young people who died as a result of suicide in 2013, the families of six (32%) had a child protection history. While this is a much lower proportion than 2012, when the families of 11 young people (69%) had a child protection history, it is only slightly lower than the 10-year average (38%).

Of the six young people, four had been the subject of a report of risk of significant harm to Community Services within the three years before their death; and one young person was the subject of a child protection report to Community Services that was assessed as not meeting the threshold of risk of significant harm. For three of the young people, the reported risks concerned risk of suicide, intentional self-harm, and/or concerns about their mental health.

One other young person was the subject of a report to a Child Wellbeing Unit only.

Education and employment circumstances

Most (15) of the 19 young people were enrolled in school. One of these young people had been suspended from school, and another two were enrolled in distance education. Two young people had left school, one of whom was employed. One additional young person was not in enrolled in school but had been due to re-enrol at the time of their death.

Almost three-quarters (14) experienced stress associated with education. Common stressors included academic failure and bullying.

Usual residence and place of death

The vast majority (17) of the young people lived at home with at least one birth parent; one young person was living with other relatives. The other young person was living in emergency/temporary accommodation.

Most (16) of the young people died at their usual place of residence; three young people died in public places.

Intent and precipitating factors

Stated, inferred intent or undetermined intent

Of the 19 young people:

- Just over half (10) documented their intent to suicide. The most common documentation was a note or a letter (5). Other documentation included sent text messages or messages/memos composed on a mobile phone; an online chat forum and a phone call. Often, the young person used more than one medium of communication.
- The suicide intent of an additional nine young people was inferred from their behaviour, including suicidal ideation, making suicide threats or attempts, researching the suicide method, engaging in self-harming behaviour; and/or their chosen method of suicide.

Very few of the young people told others of their intent ahead of the event. Only three had contacted someone and clearly indicated their intent, either to Lifeline (2) or 000. Three other young people had sent text messages to their boy/girlfriend (2) or posted a message on Facebook shortly before death that were not clearly indicative of suicide intent at the time.

207 NSW Child Death Review Team 2014, *Causes of death of children with a child protection history 2002-2011* special report to Parliament, Sydney : NSW Ombudsman, p. 21.

Precipitating events

Research indicates that stressful and traumatic events, including interpersonal conflict, can serve as tipping points for young people already experiencing other risk factors of suicide.[208]

In 2013, just under half (9) of the young people experienced a precipitating event in the month prior to their suicide. The precipitating events included a relationship breakdown with a boy/girlfriend (5), an argument or relationship breakdown with a parent/s (4), alleged sexual abuse, distress about school or work, and anxiety related to body image.

This proportion is largely consistent with the Team's previous findings, in which half to just over half of the young people experienced precipitating events ahead of their suicide.[209]

Risk factors associated with suicide

There are a range of interrelated biological, social and psychological risk factors associated with suicidal behaviour. These include:

- mental health conditions, such as depression, anxiety disorders, personality disorders and behavioural disorders;[210]
- history of suicidal behaviour;[211] [212]
- substance misuse;[213]
- childhood trauma, including abuse or neglect;[214]
- adverse circumstantial factors, primarily interpersonal or personal stressors;[215] and
- issues related to sexual identity, particularly social experience of sexual identity.[216]

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.[217] Suicide Prevention Australia notes that suicide is complex, and generally results from a combination of several individual, social and contextual risk factors; and for young people the grouping of these factors poses the greatest risk.[218]

As shown in table 83, the vast majority (18) of the 19 young people who died as a result of suicide in 2013 experienced risk factors associated with suicide. Most (16) experienced multiple risk factors, mainly psychosocial issues, and difficulties associated with family circumstances, education and employment.

Interpersonal and personal stressors

Education, school and employment issues

Most (10) of the 14 young people who had difficulties with schooling or education had experienced multiple stressors, including academic failure (7), bullying (7), behavioural problems (6), peer problems/conflict (2), and recent change of school (1). One young person was unable to attend face-to-face lessons due to a high level of anxiety and depression.

Half (7) of the 14 young people with schooling/education problems were chronically absent from school in the 12 months before their death, including one young person who had been recently suspended:

- Three of the young people had substantial school absences in the months before their death related to health and/or mental health concerns, for which medical certificates were provided to school staff. However, records indicate that in relation to two of the three young people, the general practitioners providing the medical certificates had minimal contact with them, including one case in which the young person did not appear to have attended the consultation/s.

208 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney; SPA, p. 3.
209 See for example, the Team's previous study of suicide and risk taking deaths of children and young people in 1996-2000; and the Team's annual reports of deaths in 2011 and 2012.
210 NSW Department of Health 2010, *NSW suicide prevention strategy 2010-15*, Sydney: NSWDH, p. 13.
211 History of suicidal behaviour refers to a previous suicide attempt and non-suicidal self-harm.
212 NSW Department of Health 2010, *NSW suicide prevention strategy 2010-15*, Sydney: NSWDH, p. 14.
213 Suicide Prevention Australia 2011, *Position statement: alcohol, drugs and suicide prevention*, Sydney: SPA.
214 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 5.
215 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 5.
216 Plöderl M. Wagenmakers E. J. Tremblay P. Ramsay R. Kralovec K. Fartacek C. & Fartacek R. 2013, *Suicide Risk and Sexual Orientation: A Critical Review*. Archives of Sexual Behavior, 42(5):715-727
217 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*, Canberra: SCHA, p. 13.
218 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney; SPA, p4

Table 83: Risk factors for suicide, 2013

	Difficulties associated with school, education or employment	Diagnosed or undiagnosed mental health conditions	Psychosocial issues,self-esteem, body image, social isolation, chronic health issues	Difficult family circumstances	Previous suicidal behaviour and self-harm	Difficult close personal relationships, incl relationship breakdown	Difficult peer relationships, incl bullying	Childhood trauma	Criminal/anti-socia/risk-taking behaviour incl excessive computer and/or internet	Substance misuse	Sexual identity	Total
1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		9
2	✓	✓		✓	✓	✓		✓	✓	✓		8
3	✓	✓	✓	✓	✓	✓	✓				✓	8
4	✓	✓	✓	✓	✓				✓		✓	7
5	✓	✓	✓	✓	✓	✓	✓					7
6	✓	✓	✓	✓	✓	✓	✓					7
7	✓	✓	✓	✓	✓			✓				7
8		✓		✓	✓	✓		✓		✓		6
9	✓	✓	✓	✓			✓					6
10	✓	✓	✓						✓			6
11	✓				✓	✓	✓					4
12	✓	✓	✓	✓								4
13		✓			✓	✓						3
14	✓			✓			✓					3
15	✓	✓	✓									3
16	✓					✓						2
17			✓									1
18			✓									1
19												0
Total	**14**	**13**	**12**	**11**	**10**	**9**	**7**	**4**	**4**	**3**	**2**	

- School counsellors (3) or a Home School Liaison Officer (1) were involved with the other four young people who were chronically absent from school.

Research indicates that young people affected by bullying are at increased risk of suicide, and young people with multiple roles (victim, bully, and bystander) are significantly more likely to experience suicidal thoughts.[219] Social networking and cyber-bullying is an emerging issue for young people.[220] While there are many positive supports and influences for young people online and through social networking sites, there are also challenges associated with online bullying and trolling.[221]

Six young people were subject to bullying; and one young person was noted as a perpetrator of bullying. All six victims were bullied within the school environment, with two of the young people also bullied over the internet. Records indicate that school counsellors were involved with two young people in relation to strategies to manage bullying.

Nine young people who died as a result of suicide in 2013 had contact with a school counsellor or independent school psychologist in relation to their mental health, school attendance, learning difficulties, behavioural issues and/or bullying. For three young people, the school counsellor/psychologist was involved in relation to the young person's mental health; and in two cases, the school counsellor liaised with mental health services that were also involved with the young person. For another three young people, school staff were aware of the young person's mental health issues and liaised with mental health services that were involved.

Family circumstances

Family conflict, familial discord and parental divorce or separation has been associated with an increased risk of suicide for young people.[222] [223] In 2013, 11 young people who died as a result of suicide experienced familial difficulties, including arguments or strained relationships with parents/carers, and parental divorce/separation.

Family conflict may present as a trigger event in conjunction with other suicide risk factors.[224] Each of the 11 young people experienced additional interpersonal or personal stressors in conjunction with family difficulties. For four young people, conflict or a relationship breakdown with a parent was a precipitating event to their suicide.

Mental health concerns

Diagnosed mental illness

Ten of the 19 young people had been diagnosed with a mental illness, mainly depression (7) and/or anxiety (5). All had multiple mental health diagnoses. Other diagnosed conditions included personality disorders, attention deficit and conduct disorders, and eating disorders.

Seven of the 10 young people with a diagnosed mental illness had previously engaged in self-harming behaviour, including six who had previously attempted suicide.

Treatment

Nine of the 10 young people with a mental illness received treatment from one or more health professionals in the 12 months before their death:

- six saw a health practitioner, such as a general practitioner, psychologist, psychiatrist, paediatrician, counsellor, Child and Adolescent Mental Health Services, and other community mental health providers
- six had been prescribed selective serotonin reuptake inhibitor (SSRI) antidepressant medication
- five attended hospital emergency departments on one or more occasions in relation to self-harm and concerns for their mental health, including three who presented after suicide attempts, and
- two received inpatient mental health treatment.

219 Rivers I. & Noret N. 2010, *Participant roles in bullying behaviour and their association with thoughts of ending one's life*, Crisis. 31(3):143-148.
220 Queensland Commission for Children and Young People 2011, *Reducing Youth Suicide in Queensland Final Report*, The State of Queensland (Commission for Children and Young People and Child Guardian, Brisbane, p. 20.
221 Queensland Commission for Children and Young People 2011, *Reducing Youth Suicide in Queensland Final Report*, The State of Queensland (Commission for Children and Young People and Child Guardian, Brisbane, p. 20.
222 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 6.
223 Australian Institute of Health and Welfare 2011, *Young Australians: Their health and wellbeing 2011*, cat. no. PHE 140, Canberra:AIHW, p. 33.
224 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p6.

One young person with a diagnosed mental illness who did not receive mental health support in the year before their death had disrupted living arrangements during that time.

Six young people saw a GP in relation to their mental illness; half of them had a GP Mental Health Treatment Plan, including referral to a psychologist or paediatrician (3) and prescription of antidepressant medication (2). In another case, the GP prescribed antidepressant medication and liaised with mental health services that were already involved with the young person. In relation to the other two young people, one refused to engage with the GP; and records indicate that the other young person was prescribed antidepressant medication with no evident follow-up or referral to psychological support.

Undiagnosed mental health concerns

In addition to the nine young people with a diagnosed mental illness, three young people displayed signs of poor mental health, including depression, low self-esteem, anxiety, suicide threats, self-harming behaviour and social isolation.

One of the three young people had contact with a school counsellor in relation to their mental health in the 12 months before their death. The other two young people did not have any contact with a health professional about their mental health in that period.

While one of the three young people had been prescribed antidepressant medication by the family's GP, it did not appear that the young person had attended the consultation in person. There is no indication that the young person took the prescribed medication.

Previous suicidal behaviour and self-harm

Ten of the 19 young people had a history of suicidal behaviour (7) and/or self-harm (8). A previous suicide attempt is considered to be the strongest predictor of a future suicide attempt or suicide.[225]

Of the seven young people who had previously attempted suicide:

- six had also engaged in self-harming behaviour
- at least five had previously attempted suicide on more than one occasion
- most (5) had contact with hospital emergency departments or other agencies including police in relation to a suicide attempt, and
- three had also previously made suicide threats or discussed suicide.

Self-harming behaviour is frequently related to stress reduction, inflicting self-punishment or the signalling of personal distress to others; and there may be no suicidal intent.[226] However, research indicates that people who engage in self-harming behaviours are at higher risk of suicide than those who do not,[227] and deliberate self-harm is one of the strongest predictors of completed suicide.[228] In addition, young people brought into emergency departments in relation to suicide attempts and other self-inflicted injuries have been found to be at risk of further suicide attempts, with more lethal methods.[229]

Of the eight young people who had engaged in deliberate self-harm, all had also previously attempted suicide (6) or made suicide threats (2).

Childhood trauma

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.[230]

From the available information, four young people had experienced childhood trauma, including exposure to family violence, the death of a parent and emotional neglect.

225 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 5.
226 Wilkinson P. & Goodyer I. 2011, *Non-suicidal self-injury*, European child and adolescent psychiatry, 20(2):103-108.
227 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney; SPA, p. 5.
228 Cooper J. Kapur N. Webb R. Lawlor M. Guthrie E. Mackway-Jones K. & Appleby L. 2005, *Suicide after deliberate self-harm: a 4-year cohort study*, American Journal of Psychiatry 162(2):297-303.
229 Hughes J. & Asarnow J. 2013, *Enhanced mental health interventions in the emergency department: Suicide and suicide attempt prevention*, Clinical Pediatric Emergency Medicine 14(1):28-34.
230 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 5.

Substance use

Substance abuse can increase the risk of suicide for young people. Research indicates that cannabis use has been linked to suicidal behaviour; and depression with alcohol abuse has been associated with increased suicidal behaviour.[231]

In 2013, three of the 19 young people had a history of substance use. This was considerably less than in 2012, when almost half of the young people who died as a result of suicide had a history of substance use. Each of the three young people had a history of cannabis use, in combination with other substance use including alcohol, prescription medication and amphetamines.

None of the young people received any assessment or treatment in relation to their substance use.

Each of the young people who had a history of substance use had also been diagnosed with depression, and had displayed prior self-harming and/or suicidal behaviour. Two of the young people received mental health treatment in the 12 months before their death.

Key issues and opportunities for intervention

While there are well-known risk factors for suicide, the circumstances of the young people and the reasons they ended their lives are highly varied. To examine these differences more closely, the Team considered the circumstances of all 35 young people who died as a result of suicide in 2012 and 2013. Three key groups were identified:

- young people who had ongoing serious difficulties and complex needs and who had multiple agency and practitioner involvement in relation to addressing these risks
- young people who had some difficulties/challenges but who had not necessarily been identified as being at risk, and
- young people who had few risk factors and for whom there were no evident flags that they required assistance.

Young people with ongoing serious difficulties and complex needs

Young people with serious chronic difficulties and complex needs comprised 40% (14) of youth suicide deaths in the two-year period, including seven of the 19 deaths in 2013. These young people had well-known, long-standing and chronic problems, and presented substantial and ongoing challenges to agencies and individuals seeking to help them to reduce their ongoing high risk of self-harm and suicide.

The key characteristics of the young people included that they had chronic mental health concerns (14), mainly depression; had typically previously attempted suicide on at least one occasion (12); and had engaged in other self-harming behaviour (12). Most had also previously threatened suicide (9); had families with a child protection history (9); and had experienced childhood trauma (8), such as exposure to domestic violence.

The young people had significant involvement with multiple agencies and service providers, primarily health practitioners and school staff. Most of the young people had contact with community mental health services (11) and hospitals (9) (including emergency departments and inpatient admissions) in relation to suicide attempts or mental health concerns. Nine of the young people had school counsellor involvement, and seven had contact with a general practitioner. Just under half of the young people (6) had contact with police, and four had been the subject of child protection reports. A smaller number had contact with private psychologists (3), paediatricians (3), and Juvenile Justice (3).

There was a precipitating event to the suicide deaths of half of the 14 young people with ongoing serious difficulties.

Young people with some difficulties but not necessarily identified as being at risk

Over one-third (13) of the youth suicide deaths in 2012 and 2013 comprised young people who had some difficulties/challenges but who had not necessarily been identified as being at risk, including seven of the 19 young people who died from suicide in 2013.

Most of the young people had mental health concerns (12), mainly diagnosed conditions including depression, anxiety and conduct disorder. Many (9) experienced problems at school, such as bullying, and were chronically absent.

While some had engaged in self-harm (5), attempted suicide (3), and/or made suicide threats (3), it was a much lower proportion than the young people with ongoing serious difficulties. Similarly, the proportion whose families had a child protection history (4) or who had experienced childhood trauma (1) was much smaller.

231 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney; SPA, p 4.

In the main, the problems the young people were experiencing had been recognised by at least one agency or practitioner. The main contacts were school counsellors (6) and other school staff (8), general practitioners (7), and private counsellors/psychologists (4). However, the young people had not been identified as being at significant risk, and they did not tend to receive intensive or coordinated support.

There was a precipitating event to the suicide deaths of just over half (7) of the 13 young people.

Young people who had few risk factors and for whom there were no flags that they required assistance

For just under one-quarter (8) of the young people who died as a result of suicide in 2012 and 2013, there was little indication from the documentation that they were at risk of suicide or required assistance, including five of the 19 deaths in 2013. None of the young people had any evident mental health concerns, or had previously attempted or threatened suicide. One young person had engaged in self-harm, one had experienced bullying, and two young people had families with a child protection history.

However, overall, the young people were not on the radar of services or practitioners as being at risk or needing help.

There was a precipitating event to the suicide deaths of half of these eight young people.

Issues arising from reviews of the suicide deaths of young people

The three groups present very different challenges and opportunities in relation to suicide prevention, and highlight the diversity of young people that suicide. While the young people with ongoing serious difficulties were well known to multiple agencies and practitioners, and had been identified as being at risk of suicide and self-harm, from the available documentation this did not appear to be the case for most young people who died as a result of suicide.

The Team's reviews of the suicide deaths of young people have emphasised:

The importance of providing multiple avenues and opportunities for young people to obtain help

The young people were highly diverse in whether, and how, they communicated that they needed help. The reviews highlighted the importance of providing a wide range of options and multiple opportunities for young people to seek help. In this regard, we note that:

- most of the young people had not been identified as being at risk of suicide, or having concerns that warranted intensive intervention – while some of these young people had contact with services or practitioners, this was generally initiated by others (such as family members and school staff) rather than by the young people themselves
- outside of the young people with serious ongoing difficulties, few of the young people were noted to have talked about suicide
- very few of the young people told someone of their intent to suicide in advance, and
- precipitating events were a factor for around half of all young people, regardless of whether they had long-standing and well-known risk factors or not.

Research indicates that young people are among the least likely to seek professional help for a mental health problem.[232] In a recent national survey of young people aged 15-19 years, over 60% of those with a probable serious mental illness were not comfortable seeking information, advice or support from professional services including telephone or online counselling and/or community agencies.[233] 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.[234]

Opportunities for collaborative and coordinated support

The multiple service provider involvement with the young people with ongoing serious difficulties presents opportunities for intervention, with potential for cooperative and collaborative work between the agencies and practitioners to support the young people and their families – particularly across mental health and hospital emergency department services, and between mental health and education staff.

232 Suicide Prevention Australia 2010, *Position statement: youth suicide prevention*, Sydney: SPA, p. 5.
233 Mission Australia 2014, *Youth Mental Health Report* June 2014, Mission Australia in association with Black Dog Institute, Sydney, p3.
234 Ibid.

However, the reviews identified difficulties relating to retaining and sustaining the engagement of the young people; effectively coordinating support across services and practitioners; and managing the high risks/ meeting the intensive ongoing support needs of the young people.

The importance of school counsellors and other school staff

Many of the young people had contact with school counsellors, including almost two-thirds of the young people with ongoing serious difficulties and just under half of the young people with some difficulties. In 2013, almost half of the young people who died as a result of suicide had contact with a school counsellor.

Importantly, for some young people, school counsellors and other school staff were the only service/s involved with them. The reviews identified the key role that school counsellors and other school staff can play in:

- early identification and intervention
- providing a practical and reliable option for the young people to talk about their ongoing or emerging concerns and obtain help, and
- facilitating the involvement of necessary services and support, including mental health services and other psychological support.

The key role of general practitioners

General practitioners are in a key position to provide early support and treatment to young people with mental health and other concerns, and to make appropriate referrals and linkages to additional, more specialised assistance. The reviews identified that general practitioners were also one of the main contacts for families seeking assistance for their children.

Just under half of the young people who died from suicide in 2012 and 2013 had contact with a general practitioner in relation to depression and other mental health concerns. For some of the young people with difficulties who had not been identified as being at risk, the general practitioner was one of the only service providers with whom they had contact.

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.[235]

Ensuring close monitoring of, and support for, young people prescribed antidepressant medication

Research and guidelines emphasise the importance of ensuring that the prescription of SSRI antidepressant medication to young people occurs in the context of 'an ongoing therapeutic relationship and management plan', with close monitoring of symptoms or adverse effects (including the possibility of emergence or escalations of suicidal thinking).[236]

In 2013, three of the seven young people who had been prescribed SSRI antidepressant medication in the year before their death had not been linked in with mental health support or follow-up. In each case, a general practitioner had prescribed the medication. Of the three young people:

- one refused to continue to engage with the general practitioner who had prescribed the medication
- one did not appear to receive any follow-up by the prescribing general practitioner, and had not been referred for other support, and
- a general practitioner wrote a prescription for the medication to be given to one young person they had not seen for an extended period of time and who was not present at the consultation. There is no evidence that the young person took the prescribed medication or had any follow-up with the general practitioner.

The need to support families

The Team's reviews of the suicide deaths of young people have emphasised the importance of ensuring that families receive constructive support – particularly those families supporting children who have been identified as being at high risk of suicide and/or self-harm.

In relation to the young people with chronic serious difficulties, numerous reviews identified that parents had told mental health and other services that they were finding it increasingly difficult and stressful trying to support their child to prevent them from harming themselves. Parents sought additional psychiatric reviews, medication increases, and inpatient admissions to find

235 Headspace: Australia's National Youth Mental Health Foundation 2009, *MythBuster: Suicidal Ideation*, Melbourne:Headspace p1.

236 Beyondblue: The National Depression Initiative 2010, *Clinical practice guidelines: depression in adolescents and young adults*, Beyondblue, Melbourne, p. 57; and 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?*, Version 2, Headspace, Melbourne.

options to reduce the risks to their child. Reviews indicated that parents tended to carry a heavy responsibility, with constant parental oversight of the young people a key aspect of some of the mental health care plans.

However, family members of the young people who had not been identified as being at risk were also seeking advice on how best to help their child, including approaching their general practitioner for help and treatment options.

Prevention measures

There is a substantial amount of existing and developing work in NSW and across Australia that is aimed at improving the mental health and wellbeing of children and young people and preventing youth suicide. Key areas of focus include activities aimed at:

Facilitating discussions about suicide and other concerns

In the past year, a number of websites and associated resources have been launched that have a focus on helping people (including young people) to talk with peers and others about suicide, mental health and other concerns. Recent initiatives include the Conversations Matter[237] and makeamatesday[238] websites, and the Check-in app.[239]

The NSW Mental Health Commission has worked with Suicide Prevention Australia to develop a toolkit to support local communities, particularly small towns, to progress conversations and interest in suicide prevention into activities that reflect local priorities and needs.

Providing online resources and support for young people

Numerous organisations have undertaken or are progressing work to increase the options for young people to seek help, in ways that work best for them. There is increasing focus on making it easier for young people to access information, advice and support online. Current activities include:

- trials by Young and Well of an Online Wellbeing Centre and LINK,[240] and development of an online clinic (with the Brain and Mind Research Institute), and
- trials by the Black Dog Institute of online tools to help people improve their mental health and manage suicidal thoughts, including the Healthy Thinking Study (online self-help program) and a tablet-based app.[241]

School support

There is a range of programs and initiatives that recognise the critical role schools play in helping young people with their mental health and other concerns – within the school environment, and in liaison with families and external support services.

The NSW School-Link initiative between NSW Health and the Department of Education and Communities (started in 1999) is aimed at improving the mental health of children and young people through: strengthening links between schools/ school counsellors and mental health services; training mental health workers and school counsellors; and mental health promotion and prevention programs.

School-based mental health promotion and prevention programs include MindMatters,[242] KidsMatter Primary,[243] headspace School Support,[244] and *beyondblue* school-based programs.[245]

237 Developed by the Hunter Institute of Mental Health as part of the *NSW Suicide Prevention Strategy 2010-2015*, and launched in November 2013. *Conversations Matter* has been developed for communities and professionals to guide discussion about suicide, and includes information on risk factors and warning signs. www.conversationsmatter.com.au

238 the Makeamatesday website has been developed by the NSW Youth Advisory Council and the NSW Mental Health Commission, and was launched in April 2014. The website aims to help young people to identify ways to connect with their friends who may be struggling with mental health issues, and includes key information relating to Look, Listen, Talk, Seek Help. www.makeamatesday.com.au

239 The Check-in App was introduced by *beyondblue* in June 2014 to make it easier for young people to have conversations with friends who may be experiencing depression or anxiety. www.beyondblue.org.au/about-us/programs/youth-program-youthbeyondblue/the-check-in-app

240 LINK is an online triage service to help young people get the right support for them at the right time. The trial is expected to be completed in 2015.

241 www.blackdoginstitute.org.au/public/research/participateinourresearch/index.cfm

242 MindMatters aims to promote mental health, prevent problems and enable early intervention. It provides training for schools; assists secondary schools and health services to work more closely together; encourages secondary school and families to work more closely together; and provides resources for young people, families, teachers and schools. www.mindmatters.edu.au

243 KidsMatter Primary is targeted at improving children's mental health and wellbeing in primary schools. The program includes information sheets to assist parents and carers who have specific questions about issues related to children's mental health. www.kidsmatter.edu.au/primary

244 headspace School Support provides localised support to secondary schools affected by suicide, working with relevant education bodies, local headspace centres and other service providers.

245 *beyondblue* is involved in school-based programs that equip youth to deal with life stressors and encourage awareness of mental health issues; and is working to re-develop the MindMatters program.

The Department of Education and Communities is developing 20 Networked Specialist Centres across the state to support and provide expertise to schools with children and young people with challenging/ complex needs. The Department is also:

- developing a Wellbeing Framework for Schools
- reviewing its welfare policy, including a focus on resilience, and
- developing a new resource for schools, *Responding to Student Suicide, Support Guidelines for Schools* – a postvention resource that is being developed in close collaboration with the Ministry of Health and headspace School Support.

Providing resources to assist professionals working with young people

Conversations Matter, School-Link, MindMatters and KidsMatter Primary provide resources for professionals (such as school counsellors, teachers, mental health staff and others) to support young people experiencing difficulties, and their families/friends.

beyondblue has developed the *Clinical practice guidelines: Depression in adolescents and young adults*, which comes with companion documents for ease of use by clinicians (such as general practitioners, psychiatrists, psychologists, teachers).

Providing help for families

Key in-school support programs such as MindMatters and KidsMatter Primary include aims to support children and young people and their families/carers, and to assist schools and families to work more closely together to support young people.

The Team's recommendations

The *NSW Suicide Prevention Strategy 2010-2015* details the NSW Government's directions and proposed outcomes for suicide prevention. The strategy aligns with the national suicide prevention framework, and includes actions aimed at continuing to develop and implement early childhood and school-based programs promoting resilience and providing support for children and young people (such as School-Link); and developing multimedia resources for young people. The August 2012 progress report in relation to the strategy noted new School-Link initiatives, including a strategic review of the program and a School-Link DVD training program aimed at enhancing skills in the recognition, intervention planning, treatment, support and prevention of mental health problems in children and young people.

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 2013, the Team's recommendation to Health was aimed at monitoring the progress of work to develop resources to support safe and effective discussion of suicide. *Conversations Matter* was launched in November 2013, and Hunter Institute of Mental Health is liaising with other youth partners in relation to specific resources for young people.

2015 signals the end point of the current *NSW Suicide Prevention Strategy*. At the same time, the Team has identified that there are multiple services and programs involved in youth mental health and suicide prevention in NSW and nationally, with some overlap and duplication, and it is not clear whether, and how, the activities are being coordinated. In this regard, the Team notes the importance of current work by the NSW and National Mental Health Commissions, and the Australian Human Rights Commission:

- The Mental Health Commission's draft *Strategic Plan for Mental Health in NSW* has been submitted to the Government, and is expected to provide a vision for mental health reform over the next 10 years. We recognise that the plan is likely to include many of the critical factors that are relevant to suicide prevention.
- The National Mental Health Commission is undertaking a *Review of Mental Health Services and Programmes* across the government, private and non-government sectors, including those that have as a main objective the prevention of suicide. Amongst other things, the review will consider the efficacy and cost-effectiveness of programmes, services and treatments; and duplication in current services and programmes. The Commission's final report is due to the Government by 30 November 2014.
- The Australian Human Rights Commission is examining how children and young people under 18 years can be better protected from intentional self-harm and suicidal behaviour. The findings from this work will be included in the National Children's Commissioner's statutory report to Parliament, anticipated to be tabled in November 2014.

Against this background, over the next year, the Team will take into account the findings and plans of the Mental Health Commissions and the Australian Human Rights Commission and their implications for preventing or reducing youth suicide, and consider whether further recommendations may be required.

Chapter 23. Monitoring recommendations

The following section outlines the recommendations the Team directed to agencies in its previous report; and details the information provided by the agencies on the action they have taken in response.

Sudden Unexpected Death in Infancy (SUDI)

NSW Kids and Families	
Recommendation 1	**NSW Kids and Families' response 2014**
In relation to NSW Kids and Families' file audits to assess compliance with the Death – *Management of Sudden Unexpected Death in Infancy* policy directive, the agency should provide detailed advice to the Team on: (a) the scope and method of the audits (b) the findings of the audits, and (c) any action NSW Kids and Families intends to take in response to the findings.	In February 2014, NSW Kids and Families advised the Team that the audit of hospital files to assess compliance with the *Death – Management of Sudden Unexpected Death in Infancy* policy directive had been completed, and provided a copy of the audit report. The audit reviewed the files of 45 presentations of SUDI over three years across four metropolitan and two regional facilities, and involved assessments of electronic and hardcopy files for compliance with the policy, and thematic analyses by the audit teams. The audit found that, where the policy directive was complied with, the two aspects of management of the SUDI response within Health (the diagnosis of the cause of death, and the support of the surviving family members) were done thoroughly and well. This audit reviewed the files of 45 presentations of SUDI over three years across four metropolitan and two regional facilities, and involved assessments of electronic and hardcopy files for compliance with the policy, and thematic analyses by the audit teams. The audit findings emphasised the importance of: • *The multiagency response* – the audit identified the association between the quality of key relationships (such as between health workers and police) on the quality of the response to SUDI; and emphasised the importance of a local team of health professionals being involved in the initial response and coordination of follow-up care. • *Therapeutic history taking* – the review findings demonstrated the critical need for staff with the right skill set to provide the response to SUDI; and identified that the combination of medical and social work expertise in conducting the health history interview with the parents is an important aspect of the approach. • *Documentation, record keeping and good practice in the management and use of patient files as tools in patient care* – the review identified the importance of a clear and easily navigable structure for electronic medical records; summary notes being easily available to inform emergency care and follow-up; and staff being appropriately skilled in using the local file system(s) and being well versed in the documentation requirements. The report made 12 recommendations, focused on review of the content of the policy, and the requirements of Local Health Districts. NSW Kids and Families informed the Team that it would convene an advisory group to oversee a full review of the policy (see recommendation 2 below), and refer the first nine recommendations to be dealt with in the course of that review. As at May 2014, NSW Kids and Families advised that, in relation to the final three recommendation of the report: • Recommendation 10, regarding the presence of incomplete documentation that did not meet the necessary standard, has been referred to Strategic Relations and Communications Branch • the findings regarding the functionality of electronic medical records have been referred to the Chief Information Officer, and • letters are being drafted to Local Health Districts to provide them with feedback from the audit process and to inform local quality assurance activities.

Recommendation 2	NSW Kids and Families' response 2014
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: (a) provide advice to the Team on the terms of reference and timeframes of the review, and (b) include consideration of the potential for NSW to adopt a multi-disciplinary case review approach to the SUDI investigation process, and the potential for a more centralised response to SUDI.	NSW Kids and Families advised that the review of the policy directive and model of response to SUDI is a major project that it is undertaking in collaboration with a range of stakeholders in 2014, and is being overseen by the NSW Sudden Infant Death Advisory Committee (SIDAC). As at May 2014, NSW Kids and Families advised that an extraordinary meeting of the SIDAC in June would include review of the project plan for the policy review and progress to date. In the meantime, significant work has been progressed to inform the policy review, including: • an independent, international evidence check on SUDI response models has been commissioned from the SAX Institute • a request for a quote is being prepared to engage an external firm to undertake statewide consultation with the relevant health professionals in Local Health Districts about the policy model and implementation issues to inform the review, and ensure that key staff are appropriately engaged in developing and implementing the SUDI management response, and • to improve compliance in the interim, NSW Kids and Families is ensuring that the new resource for clinicians currently being developed through the Chief Paediatrician on managing all deaths of children is clear on when the SUDI policy should be used, and that staff will be advised on how to access to SUDI policy directive.

The Team's response

NSW Kids and Families has undertaken substantial work to complete file audits to assess compliance with Health's SUDI policy, review and refresh the Sudden Infant Death Advisory Committee, and commence a review of the policy and its underlying service model. The results of the file audits were consistent with the findings of the Team, and reinforce the Team's recommendations regarding the need to consider the adequacy of the current model of response to SUDI.

The Team will continue to monitor the important work of NSW Kids and Families to improve the response to, and investigation of, the sudden and unexpected deaths of infants.

Recommendation 3	NSW Kids and Families' response 2014
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 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 arising from the audits and, if so, the actions NSW Kids and Families will take in response.	In May 2014, NSW Kids and Families advised that the audit of compliance with the Maternity – Safer Sleeping Practices for Babies in NSW Public Health Organisations is progressing on track. The audit tool was developed in consultation with the Clinical Excellence Commission, and is being piloted in Murrumbidgee and Sydney Local Health Districts (LHDs). The projected date of completion of the statewide audit for this year remains 30 June 2014. Once the audit reports from LHDs have been submitted, NSW Kids and Families will complete a centralised analysis assessing adequacy, methodology, scope and evaluation of compliance with the policy directive. By the end of July 2014, any systemic issues identified will be addressed and appropriate actions, responsibilities and timeframes allocated. In relation to consultation with SIDS and Kids and Community Services, NSW Kids and Families advised that: • it has also been working with SIDS and Kids NSW to review the Sudden Infant Death Syndrome (SIDS) and safe sleeping for infants guidelines, with a draft revised version due to be distributed to SIDAC members for comment before its June meeting, and • it has worked in collaboration with Community Services to develop Safe Sleeping resources that align with the key education messages for mothers and caregivers present in the policy directive and SIDS and Kids resources.

(b) The outcome of NSW Kids and Families' consultation with SIDS and Kids and Community Services regarding the available education resources and online packages for staff.	NSW Kids and Families advised that it has commenced work with SIDS and Kids NSW and Victoria to discuss options for providing guidelines to community-based staff in NSW. The Team was advised that NSW Kids and Families would also obtain further information on SIDS and Kids' project to update and nationalise its e-learning health professional education package, which had been put on hold.

The Team's response

The Team welcomes NSW Kids and Families' advice that the audits are on track, and notes the work it is undertaking with other agencies to improve guidance and awareness of safe sleeping practices. The Team will continue to monitor the progress and outcomes of this work.

Ministry of Health

Recommendation 4	Ministry of Health's response 2014
In relation to post mortem examinations following unexpected deaths of infants, the Ministry of Health should provide advice to the Team on current or planned initiatives to: (a) reduce forensic pathology delays, and (b) increase the proportion of SUDI that are explained.	**Reducing forensic pathology delays** In relation to reducing forensic pathology delays, the Ministry advised that the Department of Forensic Medicine (DOFM) has put measures in place to address delays in providing reports to families, which include defining expected timeframes for completion of reports and the allocation of forensic pathologists across the service to assist with surges in demand. The Ministry advised that further clarification of NSW Health policy requirements for neuropathology examinations also has potential to reduce delays and will be pursued. In September 2014, NSW Health Pathology indicated that, since the beginning of the year, DOFM has decreased the turn-around times of autopsy reports from over 12 months to less than nine months, with an expected further reduction to less than six months by the end of the 2014/15 financial year. In addition, neuropathology reports have achieved a substantial reduction in report turn-around times to below six months. Focused case management of outstanding cases and reports will continue for all cases greater than six months. **Increasing the proportion of SUDI that are explained** In relation to increasing the proportion of SUDI that are explained, the Ministry told us that: • NSW Health Pathology and Sydney Children's Hospital Network established a Paediatric Histopathology Working Party in November 2013 with terms of reference to review current paediatric anatomical pathology service delivery models and resourcing. Major items of discussion have been concerns about perinatal and SUDI post mortem service delivery and quality issues. Discussion has included the need for infant post mortems to be undertaken by a pathologist with requisite experience and the related workforce challenges this gives rise to. • The Working Party is currently developing a plan to improve support, collaboration and coordination across the various service providers involved, aimed at addressing key issues relating to perinatal and infant post mortems. In September 2014, NSW Health Pathology advised that DOFM will address this recommendation by establishing improved access to paediatric pathology consultancy services early in the post mortem examination for complex cases as well as consultation between the Child Health group and Forensic Pathology to ensure consistent interpretation and application of the post mortem outcome classification. Information on national and international benchmarks will also be sought to establish DOFM performance.

The Team's Response

The Team has raised concerns about forensic pathology delays over an extended period of time, and welcomes the Ministry's advice about measures that DOFM has instituted to address the issue. We will monitor the outcomes from this work.

Noting the continuing lack of substantial change in the proportion of SUDI that are explained after investigation, the Team appreciates the actions taken by NSW Health Pathology and Sydney Children's Hospital Network to look at some of the factors underpinning this issue. We will be keen to see the plan that the working party develops to provide a constructive way forward, and will monitor the progress of this work.

Department of Family and Community Services, Community Services	
Recommendation 5	**Community Services' response 2014**
In relation to Community Services' cohort review of SUDI where the infant's family had a child protection history, the agency should provide detailed advice to the Team on: (a) the findings of the review (b) the strategies and training resources that Community Services will develop to assist caseworkers to assess risk for infants and provide casework services and targeted education to at-risk families, and (c) how the agency will audit or otherwise measure practice and related outcomes.	Community Services advised that the SUDI cohort review was expected to be completed by the end of April 2014, and available for external distribution in mid-June 2014. In July 2014, Community Services provided a copy of the report from its review, *Safe Sleeping: Supporting parents to make safer choices when placing their baby to sleep*. The report includes 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; and a survey of current field staff knowledge about SUDI. Recommendations arising from the review include: • distribution of the report as a resource for frontline staff • development of an online training package on SUDI, focusing on modifiable risk factors in the infant's sleeping environment, to be shared with other agencies • re-development of a one-day training package on SUDI, to include information about working with culturally and linguistically diverse families • discussions with Helpline to better support Helpline Caseworkers to identify infants and young children who may be at risk of fatal sleep accidents, and • interagency meetings with NSW Health to discuss establishing consistent cross-agency messages on safe sleeping and barriers to this. Community Services advised that it would provide information about its plans for implementing additional learning strategies, and details about how the agency intends to audit or otherwise measure practice and related outcomes, after finalisation of the review.
The Team's response	
The Team notes the substantial work Community Services has undertaken in relation to the SUDI cohort review and broader actions to develop targeted resources and training packages for staff. The results of the cohort review align with the Team's findings, and reinforce the importance of developing focused strategies and training resources to support caseworkers to better assess risk for infants and provide casework services to at-risk families. The Team will monitor the progress of Community Services' actions to implement the review recommendations, and has sought further advice as to how the agency will audit or otherwise measure practice and related outcomes.	

Off-road fatalities

The Centre for Road Safety	
Recommendation 6	**The Centre for Road Safety's response 2014**
In the context of the Centre for Road Safety's (CRS) analysis of data relating to low speed vehicle run-over incidents and its plans to convene key injury prevention agencies to determine further countermeasures to address such incidents, CRS should provide advice to the Team on: (a) key findings or results from the data analysis, and b) the outcomes of the consultations/forum with relevant agencies, including any areas of (further work to prevent low speed vehicle run over fatalities.	In response to the recommendations, Transport for NSW advised that: • it implemented a new crash database in January 2014, and the Centre for Road Safety is undertaking a detailed data review of all low-speed vehicle run-overs (on road and off road, where reported to police), and • once the detailed analysis of the data has been completed, Transport for NSW will convene a stakeholder committee to determine further countermeasures to address low-speed vehicle run-overs – planned to occur in the second half of 2014. The Centre for Road Safety also told us that, in consultation with the Georgina Josephine Foundation, it is developing a public awareness campaign promoting slow speed run-over safety messages, including a film targeting high school students in grades 9-12. In addition, the Commonwealth Department of Infrastructure and Regional Development completed a study on the road safety benefits of reversing technology, following the NSW Minister for Roads and Ports raising the issue. Transport for NSW will support an implementation study, project managed by the Commonwealth, to analyse a broader set of data (ie: all low-speed run-overs), 'further quantify benefits, and establish a path for implementation into national standards for vehicle safety through the Australian Design Rules'. Transport for NSW advised that it will continue with efforts to prevent death and serious injuries from low speed run-overs, and will keep the Team informed of its progress.

The Team's response

The Team notes the important work the Centre for Road Safety is undertaking to prevent serious injuries and fatalities from low-speed vehicle run-overs, and has sought an update on the progress of key aspects of this work.

Department of Premier and Cabinet	
Recommendation 7	**Department of Premier and Cabinet's response 2014**
The Department of Premier and Cabinet (DPC) should bring together key injury prevention and regulatory agencies to consider the findings of this report to identify whether specific strategies are needed in NSW to reduce the risk of death and injury to children in relation to off-road vehicle incidents. In particular, DPC, with agencies, should consider: (a) existing or planned initiatives within NSW and at the national level (b) the need for targeted research, including environmental and vehicle design elements of prevention and attitudinal research relating to parent and carer perceptions of risk (c) the need for public awareness strategies, including print and electronic media resources that recognise the behavioural, environmental and vehicle design elements of prevention, and (d) the need for regulation of the recreational use of such vehicles on private property, including licensing, registration, and requirements relating to safety equipment such as helmets.	In May 2014, DPC advised that it would engage with key injury prevention and regulatory agencies within the next six months to consider the report and appropriate approaches to reduce the risk of death and injury of children in relation to off-road vehicle incidents. DPC told us that it would keep the Team informed about the progress and outcomes of this work.
Recommendation 8	
DPC should provide detailed advice to the Team on the outcomes of this work, including identified strategies and how they will be progressed.	

The Team's response

The Team welcomes DPC's acceptance of the recommendations, and looks forward to the Department's advice about the outcomes of its discussions with key stakeholders/ leaders in injury prevention and regulatory agencies to reduce the risk of death and injury to children in relation to off-road vehicle incidents. Given the importance of this work, the Team will continue to monitor progress.

Private swimming pools

Office of Local Government	
Recommendation 9	**Office of Local Government's response 2014**
In relation to targeting swimming pool inspection programs to pools at premises where children, particularly those under five years of age, reside or regularly visit, the Division of Local Government should: (a) provide detailed advice to the Team as to the demographic information available to Councils that will enable them to identify and prioritise the inspection of the pools of these premises, and how the Division encourages Councils to target resources towards swimming pools used by young children, and (b) provide a copy of the Division's guidelines to assist Councils to develop their pool inspection programs.	In response to the recommendations, OLG advised that: (a) NSW Councils can access demographic information through the Australian Bureau of Statistics; their own internal data relating to local development and planning; and all data for all registered pools in their local government area from the NSW Swimming Pools Register to enable them to target and prioritise properties for inspection. The reports include property address, type of pool (spa, outdoor), a description (in-ground or above-ground), the type of property (waterfront, small or large property), and inspection and compliance status. This information can be used by Councils to inform the targeting of their inspection programs to localities and developments that are deemed higher risk, which could include areas with a higher proportion of children under the age of five. A Council's information and knowledge of their local government area impacts their resource allocation decisions and they are best placed to determine where they allocate their resources to meet their responsibilities under the *Swimming Pools Act 1992*.

(b) The OLG does not produce a prescriptive guideline document to assist Councils to develop their pool inspection programs. Evidence over time is that guidelines by themselves do not target Council officers effectively, and the OLG is therefore looking to engage more directly with Councils through regionally-based forums.

In 2013, the OLG conducted a state-wide education program for Council officers on the changes to the Act, including the development of Backyard Swimming Pool and Spa Barrier Inspection programs. Over 400 Council officers have attended 28 education sessions held across NSW, and the OLG is monitoring progress on implementation. Further regional visits will be held in 2014.

Recommendation 10	Office of Local Government's response 2014
The Division of Local Government should advise the Team of the timeframe for issuing the Swimming Pool Regulations.	The OLG has advised that, while it previously considered prescribing reporting requirements by issuing Swimming Pool Regulations, it subsequently decided that issuing prescriptive regulations is not necessary for swimming pool inspection and compliance. Compliance is facilitated through a Council's Annual Report, which must include its progress in implementing its Delivery Program and Operational Plan. This will include its regulatory enforcement activities, including the inspection of backyard swimming pools. The NSW Swimming Pools Register also includes a facility for the OLG and Councils to generate inspection and compliance activity reports. The OLG told us that this approach to monitoring the performance of Councils in implementing the changes to the swimming pools legislation is considered more effective than adding red tape through changes to regulations. However, the OLG will monitor the implementation of the changes to the Act, and will amend the regulations where necessary.
Recommendation 11	**Office of Local Government's response 2014**
In relation to the development of targeted educational resources on the Swimming Pools Act amendments and safety requirements, the Division of Local Government should provide detailed advice to the Team on progress with: (a) the education and awareness campaign it is conducting with Royal Life Saving Australia (NSW) and other stakeholder agencies, and (b) the development of specific resources for lessees of rental properties on the legal and safety requirements for installing an above-ground or inflatable pool at rented premises.	The OLG advised that Royal Life Saving has conducted an education and awareness campaign in partnership with the NSW Government to support changes to the Act and commencement of the NSW Swimming Pools Register, including: • a local print and broadcast media campaign, with 2-3 phases • a social media campaign • community fact sheets, provided to 152 Councils, and • a local print and broadcast media campaign with multiple phases, including the involvement of the Minister for Local Government. The OLG advised that a 'Be Pool Safe' campaign will be developed with Royal Life Saving Australia, targeting all backyard swimming pools including above-ground and inflatable pools in rented premises, and highlighting the commencement of the sale and lease provisions on 29 April 2015. The campaign will include distribution of fact sheets on leasing or selling a property with a swimming pool or spa pool. The OLG advised that the Government extended the date for commencement of the 'sale and lease' provisions of the legislation by 12 months (to 29 April 2015) as: • Councils with high numbers of swimming pools raised concerns that high inspection failure rates have increased the time and resources required to conduct the necessary follow-up inspections before issuing compliance certificates. The OLG advised that it is 'not uncommon for it to take three months from first inspection to then issue a compliance certificate.'

- Pool industry and real estate industry representatives had indicated that pool trades and services are 'under pressure to meet the current demand for repairs and upgrades to swimming pool barriers', and requested more time to prepare properties and obtain a certificate of compliance before selling or leasing a property.

The OLG also told the Team that it continues to work with local Councils, the Department of Fair Trading and other stakeholders including the Law Society, Real Estate Industry peak bodies and tenancy groups to promote awareness of swimming pool laws and the importance of providing a safe environment around swimming pools.

The Team's response

The Team notes OLG's advice about the information available to local councils to enable them to identify properties with swimming pools where young children reside, and the direct work it is undertaking with councils to provide guidance and good practice examples in relation to model inspection programs. The Team also welcomes the extensive work that OLG and Royal Life Saving have undertaken to date to raise awareness and educate councils and the broader community about the changes to the Act and their related responsibilities.

It is imperative that implementation of the legislative changes is closely monitored by OLG, to enable the early identification and resolution of any barriers to achieving its intended aims of reducing the drowning deaths and near-drowning of children. The Team's further recommendations are aimed at gaining a sound understanding of progress to date, and advice as to public reporting on inspection and compliance activities.

Suicide

Ministry of Health	
Recommendation 12	**Ministry of Health's response 2014**
The Ministry of Health should provide detailed advice to the Team on the progress of the project to develop resources to support safe and effective discussion of suicide, *Conversations Matter*. The advice should include information about the intended approach of the project in relation to children and young people, and timeframes for completion.	The Ministry advised that the Minister for Mental Health launched *Conversations Matter* on 14 November 2013, and the NSW Mental Health Commission has assumed responsibility for the ongoing development and implementation of the resource. In May 2014, the Ministry advised that specific resources for young people are being developed by the Hunter Institute of Mental Health, through a robust review and consultation process. The resources are being developed to ensure suitability and relevance to the specific target group (young people and professionals working within the youth space), and will replicate the format of the existing suite of resources to include a downloadable fact sheet, audio podcast and online presentation easily accessible on the Conversations Matter website. Dissemination of the new resources for young people is planned in the latter half of 2014. The Ministry advised that the resources will aim to target the types of conversations young people are having about suicide, where these conversations are occurring, as well as supporting the professionals and community members who are engaging with young people in these spaces. Resources will be developed in agreement with the core principles and feedback provided by the consultation groups and experts. Professional development and training sessions are to be rolled out across NSW in the next few months specifically for organisations and communities working with young people. In September 2014, the NSW Mental Health Commission advised that, while the Hunter Institute had initially hoped to have the youth resources developed between January and June 2014, this has been delayed due to their Conversations Matter project capacity being fully occupied to complete resources for Aboriginal communities. The Institute is now liaising with other youth partners to further scope the youth resources and to explore additional funding.

The Team's response

The Team notes the progress that has been made to date in relation to *Conversations Matter*, and welcomes the advice about the specific resources that are intended to be developed for young people.

Appendix 1: Methods

Base-line 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.[246]
- 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.[247] The most recent figures available were for 2012.
- Infant mortality rates were calculated from the number of live births in NSW in 2012,[248] 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.[249]
- 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.[250]

Remoteness

Remoteness was measured using the Aria-Plus index,[251] a measure of access to services using proxy measures of distance to the five nearest centres of defined populations. The breakdown of population by age categories in the six ARIA categories as of 30 March 2012 was supplied by the ABS to order.

The product supplied by the ABS contains estimates of the resident populations (ERPs) by 2006 Census Collection Districts (CDs) or CD-derived areas of Australia, produced by the ABS. These estimates correspond with preliminary 30 June 2011 ERP by Statistical Local Area as released on 30 March 2012 in Regional Population Growth, Australia, 2010-11 (cat. no. 3218.0). The CD and CD-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.

Because the ABS has updated its underlying geographic spatial structures from Australian Standard Geographical Classification (ASGC) to Australian Statistical Geography Standard (ASGS), this is the first year that data listed by ASGS has been used in this report. Addresses that were assigned to a given area in the ASGC may be grouped slightly differently under the ASGS and, consequently, geographic patterns may have changed slightly compared with previous reports. While it is likely that the changes are minimal at the higher level of remoteness grouping, caution should be applied when analysing and interpreting changes through time.

For the majority of children whose deaths were registered in 2013, 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. For special analyses of groups over time – such as cohort reviews of deaths of children from asthma and house fires – the deaths that occurred before 2013 had been classified

246 Australian Bureau of Statistics, 2014, *3101.0 Australian Demographic Statistics (TABLE 51. New South Wales)*, Sept 2013 release, Canberra: ABS.
247 Australian Bureau of Statistics, 2014, 2011-2012 *Estimated Resident Population, by selected age groups, sex, remoteness areas and socioeconomic factors* Canberra: ABS.
248 Australian Bureau of Statistics, 2013, *3301.0 Births, Australia, 2012* Canberra: ABS
249 Australian Bureau of Statistics, 2014, *2011-2012 Estimated Resident Population, by selected age groups, sex, remoteness areas and socioeconomic factors* Canberra: ABS.
250 Australian Bureau of Statistics, 2014, *3238.0 Estimates and Projections, Aboriginal and Torres Strait Islander Australians*, 2001 to 2026 Canberra: ABS.
251 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 11 July 2014.

by the old ASGC and, in some cases, different groupings of remoteness and socioeconomic status (e.g. low/high instead of quintiles). In order to compare across the groups, ASGS information was derived for the whole cohort by mapping postcodes. It was not possible to translate directly from latitude and longitude for all deaths in these groups.

The remoteness (ARIA) scores were missing in 2013 for seven children: three were usually resident overseas, one was usually resident interstate, and three did not have sufficient information to geocode their place of usual residence.

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. Nine children did not have an IRSD score – the seven children who did not have ARIA scores, plus an additional two children for whom information on their address was insufficient to categorise the socioeconomic status.

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 Service 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.

The Perinatal Data Collection also provides an additional source of information in identifying a child as Aboriginal or Torres Strait Islander.[252]

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 2013 Aboriginal and Torres Strait Islander status and mortality rates are therefore subject to change.

Changes in 2013

In line with recommendations by the Australian Institute of Health and Welfare (AIHW), 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.

252 The NSW Perinatal Data Collection is a state-wide surveillance system that monitors patterns of pregnancy care, services and pregnancy outcomes. The perinatal data collection was not available for deaths in 2013.

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 reporting on deaths 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.

However, 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.

List of sources

BDM death
National Coronial Information System (NCIS)
Police databases (COPS/PODS)
Education records
Community Services KiDS person summary
CWU database – Wellnet
GP/Private practitioner records
Other sources
BDM birth
Other coronial records
Other police records
NSW Health records
Other Community Services records
Other CWU records
NGO records

Sources of Aboriginal and Torres Strait Islander identification of deaths in 2013

As indicated in the table below, of the 80 children who were identified as Aboriginal and/or Torres Strait Islander in 2013, 56 (70%) were identified by two or more sources. The remaining 24 children were identified as Aboriginal and/or Torres Strait Islander by only one source.

Sixty-nine of the 80 children (86%) were identified in BDM records; most (49) of whom were identified in both birth and death records. BDM information (birth and/or death) was the only source of identification for 21 children, most (18) of whom were identified using a single BDM source (birth or death). Eleven children were identified as Aboriginal and/or Torres Strait Islander only by sources other than BDM.

Table 84: Sources of Aboriginal and Torres Strait Islander identification, 2013

Decision	BDM birth or death	Total sources	BDM only	Number of children
ATSI	BDM	1	Y	18
		2	Y	3
			N	9
		3	N	10
		4	N	12
		5	N	5
		6	N	5
		7	N	2
		8	N	5
	Other source only	1		6
		2		1
		3		2
		4		1
		5		1
non-ATSI	Other source only			487

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 in SQL or Excel 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 2013 was (567/1672152 x 100000) = 33.91.

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). Calculation of DSMR and associated confidence intervals was done in Excel.

Infant Mortality Rates (IMR) were 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 2013 were not available at the time of writing this report, 2012 birth figures were used. For example, in 2013 the IMR for infants (under 1 year) whose cause of death was a disease of the nervous system was (17/98508 x 1,000) = 0.2. These calculations were performed in Excel.

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.[253] When the number of cases was 100 or more, the normal approximation was used to calculate the confidence intervals. The equation applied was: ($\pm$1.96 x *(CMR or appropriate rate)*/$\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, with the remainder of the analysis and all illustrations done in Microsoft Excel.

253 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.[254]

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.

Natural causes of death

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.	I00-I99
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.[255] 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

254 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

255 World Health Organisation 2011, *Infectious Diseases*, Geneva: WHO. http://www.who.int/topics/infectious_diseases/en/, accessed 16 July 2013.

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 3 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 s. 135A 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 s. 149 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.[256]

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.

256 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 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

NSW Child Death Review Team
NSW Ombudsman
Level 24, 580 George Street
Sydney NSW 2000

General enquiries: (02) 9286 1000
Toll free (outside Sydney Metro Area, NSW only): 1800 451 524
Facsimile: (02) 9283 2911

Email: nswombo@ombo.nsw.gov.au

www.ombo.nsw.gov.au