ACT Children & Young People
Death Review Committee

Annual Report 2014–15

ACT Children and Young People Death Review Committee

Who are we?

The ACT Children and Young People Death Review Committee is established under the *Children and Young People Act 2008* to work towards reducing the number of deaths of ACT children and young people. The committee reports to the Minister for Children and Young People.

The legislation sets out the requirement for the committee members to have experience and expertise in a number of different areas, including paediatrics, education, social work, child safety products and working with Aboriginal and Torres Strait Islander children and young people.

What do we do?

The committee aims to find out what can be learnt from a child's or young person's death to help prevent similar deaths from happening in the future.

To assist with this aim, we keep a register of all the deaths of ACT children and young people who die before they turn 18, and use the information on the register to learn more about why children and young people die in the ACT.

We can make recommendations about changes to legislation, policies, practices and services to both government and non-government organisations.

The committee does not investigate or determine the cause of death of a particular child or young person. We do not place blame or seek to identify underperformance.

What do we do with the information on the register?

The committee provides its annual report to the Minister for Children and Young People and the ACT Legislative Assembly on the deaths of children and young people in the ACT.

We also issue reports and fact sheets on different topics to help raise awareness or to spread prevention messages in the community.

The committee is keen to receive advice and feedback from interested ACT residents

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Foreword

This is the fourth annual report of the ACT Children and Young People Death Review Committee. The data we present in this report throws a light on how well our community protects the lives of our children and young people. It provides an evidence base from which to examine the systems that support our community: these systems underpin the way we live, the way we interact and the way we thrive - individually and collectively.

The ACT is in the interesting position of having a higher education level, higher employment, higher incomes and lower rates of morbidity than other parts of the country. It is perhaps these factors, among others, that shape the view the rest of Australia has of the Territory. And while these factors protect the ACT from some of the worst effects of high morbidity and mortality rates, they are not the whole story of the ACT.

There are many ways we can work to better understand the patterns and trends in the ACT and then build on the strengths of our community to improve our systems. We can look at the distribution of death over age groups, sex, Aboriginal and Torres Strait Islander status and cause of death, and we can pinpoint the need for change. In the chapters that follow there are a number of areas that could benefit from further exploration. The committee will consider these in terms of its established work agenda and the directions the evidence leads us.

The next focus of the committee will be on reviewing the deaths of children aged between 0 and 3 years, given the high mortality rates in that cohort. We will be examining these deaths in light of a range of factors that increase the vulnerability of children and young people.

The upcoming *Retrospective report: 10-year review* will provide a further opportunity to examine trends over the 10 year period and to identify intervention points or system changes that can make a difference.

The Secretariat and members of the Committee have done an outstanding job in preparing this report and in drawing out the messages from the data. Their work demonstrates the growing capacity and maturity of the committee to support the development of systems that help shape our community.

Dr Penny Gregory
Chair, ACT Children and Young People Death Review Committee

ACT Children & Young People Death Review Committee

Letter of transmission

The Minister for Children and Young People
ACT Legislative Assembly
London Circuit
CANBERRA ACT 2601

Dear Minister

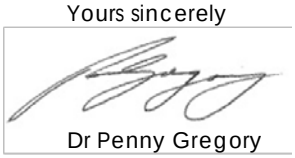
I am pleased to present you with the fourth annual report of the ACT Children and Young People Death Review Committee.

This year, the Committee's report focuses on presenting analyses of the data held on the children and young people deaths register and identifying trends and patterns in relation to those deaths.

While the report is in relation to 2014–15, it also presents information for the 2010–11 to 2014–15 financial years and fulfils the Committee's statutory obligations under Section 727S of the Act.

I commend this report to you, as the fourth in the series and as a foundation of further reports in the future.

Yours sincerely



Dr Penny Gregory
Chair
30 October 2015

The ACT Children and Young People Death Review Committee is established under the *Children and Young People ACT 2008*

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Executive summary

The ACT Children and Young People Death Review Committee (ACTCYPDRC) is established under the *Children and Young People Act 2008* to work towards reducing the number of deaths of children and young people in the Australian Capital Territory. The committee reports to the Minister for Children and Young People.

The committee aims to find out what can be learnt from a child's or young person's death to help prevent similar deaths from happening in the future.

To assist with this aim, we keep a register of all the deaths of ACT children and young people who die before they turn 18, and use the information on the register to learn more about why children and young people die in the ACT.

Chapter 1 provides an introduction to the Children and Young People Death Review. It lays out the legislative requirements of this report and the limitations of the data. It also explains how to use this report, noting some of the changes that have occurred between this and previous reports.

Chapter 2 provides an overview of all deaths of children and young people residing in or visiting the ACT. Taking into account all registered deaths between the years 2004–05 and 2014–15, it describes indicative trends in the deaths of children and young people in the ACT such as the overall decline in the number of deaths and the lower numbers of deaths that occur during the school years. This chapter is a precursor to the ACTCYPDRC's forthcoming 10-year review.

Chapter 3 examines the deaths of ACT resident children and young people from the previous five years. Excluding those children and young people who normally resided interstate or elsewhere, the chapter provides demographic and individual characteristic analysis to determine that the reduction in the death rate for the ACT is most likely levelling off. It shows that in the ACT more males die than females, and that Aboriginal and Torres Strait Islander children and young people are over-represented on most variables.

Chapter 4 is the first of two chapters investigating a specific population group. The first population focus is on neonates and infants. The chapter describes the indicative trends in the cohort, notably that the current Infant Mortality Rate (IMR) is about two-thirds what it was this time 10 years ago, though early indications suggest that the IMR might be rising. It is, as yet, too early to confirm, but the evidence is strong enough to suggest continued monitoring of the IMR.

The final chapter, Chapter 5, focuses on the second population group, vulnerable children and young people. For the purposes of this report, *vulnerability* is determined by engagement with either Children and Young People Protective Services (CYPS) or ACT Policing. We hope that this definition of vulnerability will be broadened in the future. In this chapter it was concluded that, given the higher incidence of female deaths by vulnerability factor than males, there may be the potential for further analysis in terms of the gendered nature of vulnerability and disadvantage. We also note that intentional self-harm is a concerning cause of death for vulnerable young people.

The appendixes provide further helpful information for reading, understanding and interpreting the findings in this report.

Chapter 1 Introduction to the Children and Young People Death Review

This chapter provides an overview of the work of the ACT Children and Young People Death Review Committee. It also notes changes in approach between this report and previous annual reports.

ACT Children and Young People Death Review Committee

The ACTCYPDRC is an independent committee established to review information about the deaths of children and young people in the ACT, identify emerging patterns and undertake research aimed at preventing or reducing the deaths of children.

The committee has an important role: to examine information about all deaths of children and young people under the age of 18 years in the ACT, with the intention of preventing or reducing the number of those deaths. This report is the main vehicle to share the findings of that examination. The committee wishes to share these findings and maintain a dialogue with the public, whose greater awareness of these issues may facilitate the reduction of preventable deaths in the future.

From these analyses the ACTCYPDRC is able to recommend changes to legislation, policies, practices and services that will help to reduce the number of future deaths of children or young people in the ACT.

Information about:

- previous reports
- additional reports on identified issues of concern
- governance and membership of the committee
- legislation underpinning the work of the committee

can all be found on the committee's website: **childdeathcommittee.act.gov.au**

Annual review report

This report will examine the deaths of all children and young people who died in the ACT as well as children and young people who usually reside in the ACT but who died elsewhere in the period 2010–11 to 2014–15, with particular reference to 2014–15. Chapter 2 in particular will provide an overview of all deaths.

Section 727S of the Act requires the ACTCYPDRC to report on the following information about the deaths of children and young people included on its register:

- total number of deaths
- age
- sex
- whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, 'was the subject of a report the director-general decided, under section 360(5), was a child protection report'
- any identified patterns or trends, both generally and also in relation to the child protection reports under section 360(5) of the Act.

The ACTCYPDRC is dedicated to respecting the child, young person and their family's right to privacy. Under section 727S(3) of the Act, the committee must not disclose the identity of a child or young person who has died or allow the identity of a child or young person to be established.

As with previous years, the decision has been taken to review the incidence of death over a five-year period. This is largely in response to the small number of deaths that occur in the jurisdiction each year. Conducting and reporting on analyses over a five-year period brings a level of stability to the data allowing for generalisations to the broader population. It also minimises the risk of breaching the confidentiality

requirements stipulated in the Act whereby the committee must not reveal the identity or make possible the identification of any individual. Although greater rigour may be generated through the analysis of aggregate data, there are limitations and as such caution must be exercised when interpreting results.

Using this report

The annual report is a signature publication for the ACTCYPDRC in that it can provide the catalyst and foundation for further investigations that seek to prevent death. This report adopts approaches that support the committee in that objective—approaches that differ slightly from previous reports in a number of ways. In reporting on the findings of this report it is important to clarify each of these approaches to ensure the findings accurately inform the community and, ultimately, changes to the system. Each will be outlined below.

Age standardisation

Where appropriate, comparisons have been made to the national incidence rates of deaths of children and young people. However, given that the age structure of the ACT is not directly comparable to the same cohort nationally (see Figure 1.1), ages must be standardised to be able to make a valid comparison. In the report where crude mortality rates (CMR) are reported, these refer to the ACT population only. Where standardised mortality rates (SMR) have been reported, these refer to a calculation which smoothes out differences in age structures to allow comparisons between 'apples' and 'apples'. These have been included to benchmark the experiences of the ACT against that of the national experience.

Figure 1.1: Population ratios comparing males and females and total population between Australia and the ACT, 2015

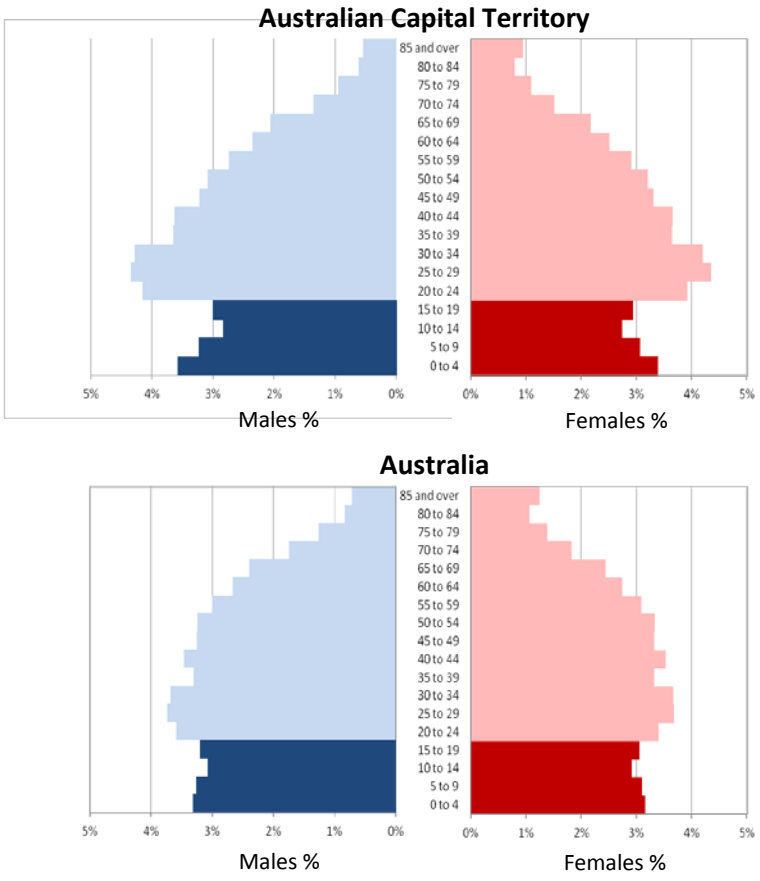


Figure 1.1 shows the differences between the age structures of both the ACT and Australia. The focus of this report are those children and young people under the age of 18 years. This group is highlighted in the bolder colours.

The Australian figure shows a consistent rate through the early years of life for both males and females, with a reduction around 10–14 years for both sexes. The ACT figure presents a sharper taper, indicating a greater change in the population during those years. If the age structures were the same we would expect to see a relatively similar shape across the base of both pyramids. There is some variability, however, which implies the age structures between the ACT and Australia differ and therefore comparisons between populations would be better served through standardisation.

Coronial counts

In previous reports, numbers of deaths being heard by the Coroner have been reported in different ways. This is largely due to the confidentiality concerns arising from the small number of cases and determinations on cause of death. The legislation clearly stipulates that the ACTCYPDRC must not report on the causes of death of those cases that are open in the Coroners court at the time of publishing. However, this stipulation does not exclude the reporting of total numbers of deaths, including those currently being heard by the Coroner. As such, in the early chapters of this report where total numbers are reported, these will include coronial cases

that are open. The number of these will be indicated in brackets next to the total figure. These cases are excluded from subsequent analyses.

International Classification of Diseases

Since the inception of the Children and Young People Death Register (the Register) reporting on main cause of death or leading cause of death has centred largely on indicative causes with reference made to the International Classification of Diseases (ICD). The committee has made the determination to transition to reporting on the ICD framework, in line with World Health Organization standards (WHO 2015). This report will form a transition point between previous reports and subsequent reports—this 2014–15 annual review will report on both the indicative causes of death and the ICD, noting that only the ICD will likely be reported in the future.

Reporting fewer than five cases

Given the small number of incidents in the ACT of deaths of a child or young person and the broad range of causes of those deaths, often there will be only one or two individuals who have died as a result of a particular cause. The ACT is a small community and individuals may be identified through the reporting of numbers and causes of death. Therefore, where the number is fewer than five incidents the symbol • will be used to indicate that deaths have occurred but not how many. In some instances, further data have been suppressed to prevent calculation of figures and subsequent identification of individuals. These numbers will remain included in total figures and aggregated counts over five.

Data sources

Unless otherwise stated all figures reported in this document are sourced from the ACT Children and Young People Deaths Register. The information in this register is compiled from information sourced from ACT Births, Deaths and Marriages (BDM), New South Wales BDM, Northern Territory Office of the Children's Commissioner, Queensland Child Death Review Team, South Australia Child Death and Serious Injury Review Committee, Tasmanian Council of Obstetric and Paediatric Mortality and Morbidity, Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity, Western Australia BDM, and the National Coronial Information System.

Chapter 2 All deaths of children and young people residing in or visiting the Australian Capital Territory

Key messages:

- Overall, the ACT has experienced a decline in the number of annual deaths of children and young people.
- Between July 2004 and June 2015, 383 children and young people under the age of 18 years died in the ACT:
  - 271 were ACT residents
  - 97 normally resided interstate or elsewhere
  - 51 were ACT residents who died interstate or elsewhere
  - 15 have no residential details
  - 7 are currently before the Coroner.
- In 2014–15, 29 children and young people died in the ACT; this is the lowest number of deaths in recent years.
- The average number of deaths is 34.81 deaths per year, with 8.81 deaths of children and young people who normally reside elsewhere.
- Deaths of interstate children and young people comprise one-quarter of all deaths.
- Overall, there are more deaths of males than females.
- Fewer deaths occur during the primary school years (ages 4–14) than in other age years.
- Aboriginal and Torres Strait Islander children are over-represented among deaths of children and young people.
- Overall, the leading causes of death include *Certain conditions originating in the perinatal period*, *Congenital anomalies* and *Neoplasms*.

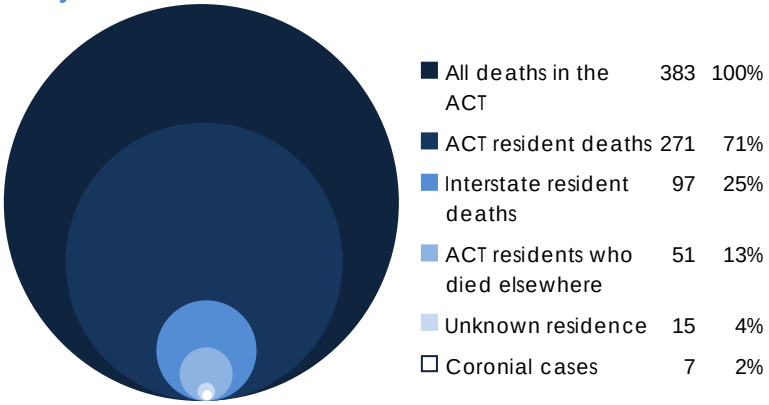
This chapter provides an overview of **all registered deaths** of children and young people that occurred in the ACT or involved ACT residents in the reporting period, with particular reference to the current reporting year 2014–15. Subsequent chapters in this report will focus on the last five years in aggregate; however, this chapter takes a broad overview of all deaths that have occurred, including children and young people from interstate or elsewhere. This chapter is also a precursor to the 10-year review.

Overview

This section will look at the overall incidence of mortality among children and young people in the ACT. Table 2.1 provides a summary of all deaths on the ACT Children and Young People Death Register for the period July 2004 to June 2015.

Figure 2.1 represents the deaths of children and young people who have either died in the ACT or who normally resided in the ACT but died elsewhere. Since July 2004, 383 children and young people have died. ACT residents comprise 71% (n=271) of the deaths, and children and young people who

Figure 2.1: Deaths of children and young people, ACT, July 2004 to June 2015



normally reside elsewhere comprise 25% (n=97) of the deaths. The remainder are children and young people whose deaths are the subject of a coronial case (2%, n=8) or whose residential details are unknown (4%, n=15).

ACT residents and non-residents

Table 2.1 presents a breakdown of all deaths occurring since July 2004 in terms of ACT residents and those children and young people who normally reside interstate or elsewhere.

Table 2.1: Annual deaths of children and young people in the ACT, including ACT residents who died elsewhere, July 2004 to June 2015

YEAR	ALL DEATHS [a,b]		ACT RESIDENTS [c]		INTERSTATE RESIDENTS	
	number	per cent	number	per cent	number	per cent
	383	**100**	**271**	**100**	**97**	**100**
2004–05	44 (-)	11.5	35 (6)	12.9	9	9.3
2005–06	34 (-)	8.9	24 (8)	8.9	9	9.3
2006–07	39 (-)	10.2	24 (3)	8.9	13	13.4
2007–08	37 (-)	9.7	23 (4)	8.5	10	10.3
2008–09	37 (-)	9.7	24 (5)	8.9	11	11.3
2009–10	37 (-)	9.7	24 (5)	8.9	10	10.3
2010–11	31 (-)	8.1	23 (8)	8.5	7	7.2
2011–12	29 (-)	7.6	19 (4)	7.0	8	8.2
2012–13	29 (2)	7.6	24 (3)	8.9	5	5.2
2013–14	37 (2)	9.7	26 (2)	9.6	11	11.3
2014–15	29 (3)	7.6	25 (3)	9.2	•	•

[a] Figures provided in brackets are cases currently before a Coroner and are included in the total figure. However, these cases will not be included in subsequent analyses.

[b] The number of all deaths includes 15 children and young people for whom there is no residential data. These cases have not been included in the residential numbers.

[c] Figures provided in brackets were ACT residents who died outside the ACT. These cases are included in subsequent analyses.

In regard to all deaths (column two), the figures supplied in brackets are currently the subject of a coronial inquest. These cases will be removed from the total number of deaths in subsequent chapters as it is not in the remit of the committee to report on those cases that are subject to ongoing investigations. For the number of ACT residents (column four), the figures shown in brackets are the number of ACT residents who died interstate or elsewhere. The percentages in all named columns (three, five, seven) are the percentage of all deaths in the period July 2004 to June 2015.

Including open coronial cases, 2014–15 recorded the lowest number of year-on-year deaths of children and young people (n=29) whereas the average number of annual deaths was 34.81. The number of children and young people who normally reside in the ACT but died interstate is similarly declining, with the average number of ACT resident deaths at 24.63 and, of those, residents who died outside the ACT number around 4.6. The number of deaths of interstate residents has recorded some volatility, with the average currently sitting at 8.81.

The high number of deaths of interstate residents—in comparison to the number of ACT residents who die elsewhere—may be in some way explained by the manner in which these children and young people died. This observation will be explored further in Chapter 4.

Distribution across characteristics: sex, age, Aboriginal and Torres Strait Islander status, usual place of residence, and cause of death

The following discussion focuses on the key demographic and individual characteristics of the children and young people who died. Examination of these variables allows comparisons between groups and identification of trends within the total population to better inform and advocate for system, service or programmatic change. Examined here are sex, age, Aboriginal and Torres Strait Islander status, usual place of residence, and cause of death.

Table 2.2: Key demographic and individual characteristics of all deaths of children and young people in the ACT, July 2014–June 2015 and July 2004–June 2015

CHARACTERISTICS	2014–15 DEATHS		RATIO	2004–05 to 2014–15 DEATHS		RATIO
	number	per cent		number	per cent	
Total						
Persons 0–18 years of age	29	100	-	383	100	-
Sex						
Female	15	51.7	1:0.93	180	47.0	1:1.13
Male	14	48.3	1:1.07	203	53.0	1:0.89
Age						
Under 1 year	23	79.3	-	269	70.2	-
1–4 years	•	3.4	-	38	9.9	-
5–9 years	-	0.0	-	14	3.7	-
10–14 years	•	6.9	-	23	6.0	-
15–18 years	•	10.3	-	39	10.2	-
Aboriginal and Torres Strait Islander status						
Aboriginal and Torres Strait Islander	•	6.9	1:14	29	7.6	1:11.69
Neither Aboriginal nor Torres Strait Islander	27	93.1	1:0.07	339	88.5	1:0.09
No data	-	-	-	11	2.9	-
Usual place of residence						
ACT	25	86.2	-	271	70.8	-
NSW/Vic.	•	•	-	96	25.1	-
Other	-	-	-	•	•	-
No data	-	-	-	15	3.9	-

[a] These cases have been excluded from the calculation of the Incident Ratio

Sex

Table 2.2 shows the number of female and male deaths for the last annual period 2014–15 and all deaths up to June 2015. In the last year an equal distribution was observed between the deaths of males (n=14) and females (n=15), resulting in a ratio of 1.07 females to males. While there were more female deaths to male deaths in 2014–15, overall there have been more recorded male deaths to female deaths, resulting in an incident ratio of 1.13 males to females.

Furthermore, taking a rolling five-year aggregate view of deaths to level out some of the volatility in the annual figures, we again see a higher tendency toward male deaths. In preceding reports, and indeed each year since July 2004, the incidence ratio has been skewed toward a higher incidence of male deaths, ranging between 1.01 (2010–15) and 1.45 (2006–11) male deaths to female deaths. While these findings are not significant it is still interesting to note that there have been more male deaths on average than female deaths. This can in part be explained by those particular years, as noted below, that saw a spike in the number of male deaths.

Age

Figure 2.2 below shows the distribution of the proportion of deaths occurring in each age bracket over the period July 2004 to June 2015. The figure clearly illustrates a trend whereby the number of deaths occurring after infancy dramatically decreases. However, the proportion of deaths further decreases when the child comes of school age, that is, after four years of age. The number of deaths subsequently increases when the young person ages out of the primary school system. A polynomial trend line demonstrates the sharp decrease after infancy through to the subsequent increase in the late teen years. With reliability of 0.87, the trend is a good fit for the data. It is as yet unclear whether the change in the number of deaths is due to protective factors which exist for children and young people during those years or whether it is due to the risks

associated with the other life stages, such as risk-taking behaviour in the teen years. There are potential lessons to be learnt from further exploration.

Figure 2.2: Distribution of deaths by age, July 2004 to June 2015

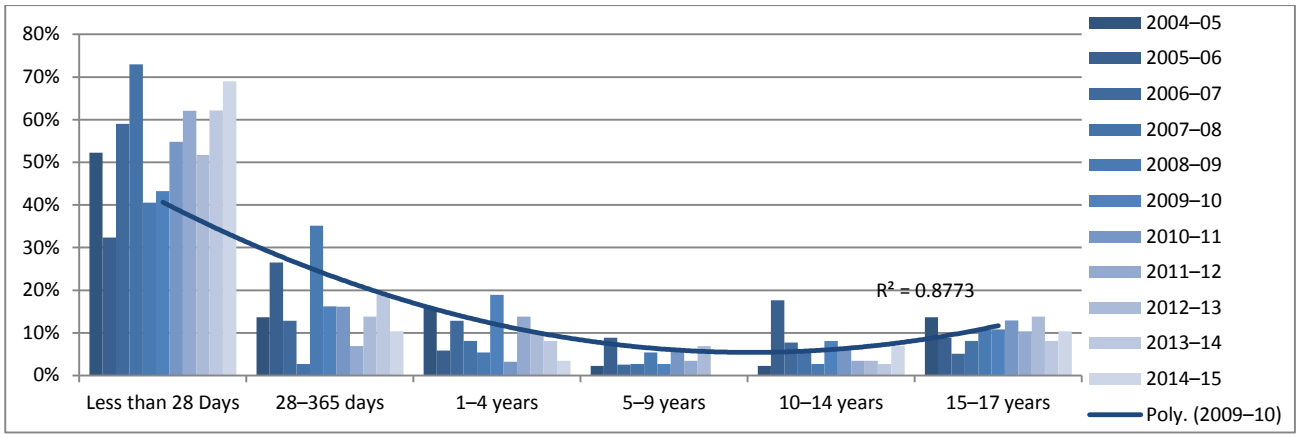


Figure 2.2 also illustrates the remarkably high proportion of deaths occurring in the neonatal period (54.3% of all deaths), which will be touched on in later discussions relating to cause of death.

Aboriginal and Torres Strait Islander status

Table 2.2 presents the number of individuals who have died in the previous year (2014–15) and in all years (July 2004 to June 2015) who were identified as Aboriginal and Torres Strait Islander. The Aboriginal and Torres Strait Islander population in the ACT is considerably smaller than the non-Aboriginal and Torres Strait Islander population. There are a number of constraints that exist which can often result in an undercount of the Aboriginal and Torres Strait Islander population (ABS 2013; AIHW 2015b). Nevertheless, the 2011 Census (ABS 2015) puts the Aboriginal and Torres Strait Islander population at 1.5% of the total ACT population. As a proportion of recorded deaths the proportion for Aboriginal and Torres Strait Islander children and young people deaths in the 11 years to June 2015 was 7.6%, more than five times the expected proportion.

Between July 2014 and June 2015, the incident ratio was one death of an Aboriginal and Torres Strait Islander child or young person to 14 deaths of children and young people who did not identify as Aboriginal and Torres Strait Islander. Although these rates are based on an expected number of deaths per 10 000 individuals and not actual numbers of deaths, a question remains regarding the representation of the Aboriginal and Torres Strait Islander population in the overall mortality rates in the ACT. This question will be examined further in Chapter 3.

Usual place of residence

Table 2.2 presents information on the usual place of residence of those children and young people who either died in the ACT or normally reside in the ACT but who died elsewhere. In the 11 year period up to June 2015 an average of 34.81 children and young people died each year, with 8.81 of those young people normally residing interstate.

As shown in Table 2.1, 2013–14 recorded the highest number of deaths in recent years. The same period recorded the highest number of deaths in terms of both ACT residents (n=26) and interstate visitors (n=11), 37 children and young people in total. In contrast, 2014–15 recorded one of the lowest number of deaths. The lower number recorded in this period is largely the result of the lower than average deaths of interstate residents.

The geographic proximity of the ACT and NSW accounts in some measure for the higher numbers of NSW residents that die in the Territory. On census night in 2011 there were a total of 14 675 visitors to the ACT from interstate and overseas (ABS 2012)—visiting from NSW alone were 6225 individuals, 1819 of which were under the age of 24 years. The ACT's role as a regional hub for the surrounding areas of NSW has the net effect of increasing the population of the Territory and, subsequently, the number of people receiving services from the ACT. In particular, the Tertiary Referral Centre at the Canberra Hospital is a key referral centre for complex and

high-risk perinatal conditions. As will be discussed in the following section, the higher number of deaths of children and young people from NSW and to a lesser extent Victoria (combined n=96) reflects these factors.

Cause of death

Table 2.3 presents the causes of all deaths for the period July 2004 to June 2015. As noted in Chapter 1, the cause of death provided are both the indicative causes and those groups outlined by the International Classification of Diseases (ICD-10). In future years it is likely that the committee will report on these latter groupings only.

The majority of deaths occur in the neonatal period (the first 28 days of life) and are a result of medical causes and extreme prematurity. A more detailed examination of the ICD-10 groupings reveals that *Certain conditions originating in the perinatal period* is the main cause of death, accounting for 40% (n=153) of all deaths.

Medical causes relate to disorders and diseases of the internal systems of the human body. As can be seen from the table it covers all manner of concerns ranging from conditions arising from birth, through to conditions relating to the various internal systems of the human body. According to the ICD-10 classifications, *Congenital anomalies* (n=75) and *Neoplasms* (n=28) make up the remaining two of the top three causes of death in the period July 2004 to June 2015.

Certain conditions originating in the perinatal period	Deaths whose cause originates in that period, even though death may occur later. The perinatal period commences at 22 completed weeks (154 days) of gestation (the time when birth weight is normally 500 g), and ends seven completed days after birth (WHO 2011).
Congenital anomalies	Deaths whose cause was from particular conditions provided there is no indication that they were acquired after birth.
Neoplasm	Any new and abnormal growth, specifically one in which cell multiplication is uncontrolled and progressive. Neoplasms may be benign or malignant (Miller-Keane 2003)

Excluding medical causes and prematurity, the main causes of death for all ages in the period July 2004 to June 2015 are transport accidents (n=16) and intentional self-harm (n=9). The cause of death for 15 children and young people could not be ascertained.

Conclusions and future activities

- Efforts to reduce the overall number of deaths appear to have had some positive impact, with 2014–15 recording one of the lowest incidents of death in the last 10 years.
- There are potential lessons to be learnt in terms of identifying the protective factors that exist for children between the ages of 5 and 14 years and of determining their application to other cohorts.
- The higher proportion of deaths among Aboriginal and Torres Strait Islander children and young people warrants further attention.
- The number of interstate child and young person deaths increases the overall death rates of the ACT.

Table 2.3: Indicative and ICD-10 cause of death by age bracket, July 2004 to June 2015

CAUSE OF DEATH	<28 days	28–365 days	1–4 years	5–9 years	10–14 years	15–17 years	TOTAL
Total	**208**	**61**	**38**	**14**	**23**	**39**	**383**
Extreme prematurity	**134**	**14**					**148**
Certain conditions originating in the perinatal period	113	11					124
Congenital anomalies	21	•					23
No data		•					•
Medical causes	**67**	**26**	**25**	**11**	**15**	**18**	**162**
Certain conditions originating in the perinatal period	27	•		•			29
Circulatory system diseases	•			•	•	•	7

CAUSE OF DEATH	<28 days	28–365 days	1–4 years	5–9 years	10–14 years	15–17 years	TOTAL
Total	**208**	**61**	**38**	**14**	**23**	**39**	**383**
Complications of medical and surgical care	•					•	•
Congenital anomalies	30	12	6		•	•	52
Diseases of the blood and blood forming organs and immune mechanisms				•			•
Diseases of the circulatory system						•	•
Diseases of the musculoskeletal system and connective tissue	•		•				•
Diseases of the nervous system	•	5	5		•	•	17
Endocrine, nutritional and metabolic disease	•	•	•	•	•	•	10
Infectious and parasitic diseases	•	•					•
Neoplasms		•	11	6	•	•	28
Respiratory diseases		•	•		•	•	7
No data	•						•
SIDS and undetermined	•	•					**5**
Other accidental threats to breathing		•					•
Symptoms, signs not elsewhere classified	•	•					•
SUDI	•	**5**					**6**
Symptoms, signs not elsewhere classified	•	5					6
Unascertained	•	**12**			•		**15**
Symptoms, signs not elsewhere classified	•	12			•		15
Drowning			**6**			•	**7**
Accidental drowning and submersion			6			•	7
Drug overdose						•	•
Accidental poisoning by and exposure to noxious substances						•	•
Fatal assault & neglect	•		•				•
Assault	•		•				•
Natural disaster				•			•
Exposure to forces of nature				•			•
Non-intentional accident/injury					•		•
Exposure to smoke, fire and flames					•		•
Other accidental threats to breathing					•		•
Suicide					•	**9**	**10**
Hanging, strangulation and suffocation, undetermined intent						•	•
Intentional self-harm					•	8	9
Transport		•	•	•	•	**9**	**16**
Transport accidents		•	•	•	•	9	16
Unintentional injury/accident			•				•
Other accidental threats to breathing			•				•
Other external causes of accidental injuries			•				•
No data	•		•		•	•	**6**

Chapter 3 Deaths of ACT resident children and young people: five–year review

Key messages:

- Between July 2010 and June 2015, 155 children and young people under the age of 18 years died in the ACT:
  - 97 were ACT residents who died in the ACT
  - 20 were ACT residents who died interstate or elsewhere
  - 38 normally resided interstate or elsewhere and not subject to further analyses
  - 7 are currently before the Coroner and not subject to further analyses.
- With the exclusion of interstate residents there has been an overall reduction but most likely flattening out of the number of deaths.
- Overall, there are more male deaths to female deaths; in any five-year period there are on average 16 more male deaths than female deaths.
- The proportion of deaths that occur in the primary school years is markedly lower than in other age cohorts.
- Aboriginal and Torres Strait Islander children and young people are over-represented with 12 deaths per 10 000 individuals while non-Aboriginal and Torres Strait Islander children and young people experience 3 deaths per 10 000 individuals.
- Suicide is the cause of death for at least one ACT child or young person per year.

This chapter provides an overview of the registered deaths of children and young people that occurred in the ACT or involved **ACT residents in the last five years** (that is, excluding interstate residents who were included in the previous overview chapter). It will examine the incidence and causes, as well as other demographic and individual characteristics, of those deaths of ACT residents under the age of 18 years that occurred between July 2010 and June 2015.

Overview

In the five years to June 2015 a total of 155 children and young people died in the ACT. Currently there are seven cases before the Coroner and are therefore outside the remit of this report. Findings on these cases will be reported in future years.

In total, 97 ACT residents under the age of 18 years died in the ACT while another 20 ACT residents died elsewhere. A further 38 individuals who normally lived interstate also died in the Territory.

With those children and young people who usually reside elsewhere (n=38) and coronial cases (n=7) removed from these analyses, the following relates to 111 children and young people who were residents of the ACT.

Table 3.1: Breakdown of cases included in analysis, July 2010 to June 2015

DEATHS	NUMBER	PER CENT
Total [b]	**155**	**100**
ACT residents who died in the ACT [a]	97	62.6
ACT residents who died elsewhere [a]	20	12.9
Interstate residents who died in the ACT	38	24.5
Cases before the Coroner	7	4.5

[a] Included in further analyses

[b] These figures do not sum due to coronial cases appearing in two categories.

Data is reported in aggregate five–year periods to bring stability to the data and to protect the privacy of individuals and their families.

As noted in Chapter 1, there are some differences in the analytical approach taken in this report from previous reports. In the following tables particular rates have been noted to indicate trends in death rates. The Crude Mortality Rate (CMR) will be used throughout this report to make comparisons between specific

populations between years for the ACT. The Standardised Mortality Rate (SMR), on the other hand, will be used where appropriate to make comparisons between the ACT and Australian experiences. The SMR accounts for the different age structures of the ACT and Australian populations, as noted in Figure 1.1 on page 3.

Confidence intervals (CI) for both rates are reported at the 95% level, indicating that we are 95% confident that the true rate (affected by number of observations and population size) lies between the upper and lower limits of the range. In interpreting these findings it is important to recall that the ACT experiences low numbers of deaths generally in this jurisdiction as such results may be subject to fluctuations due to chance. Where confidence intervals overlap (an indicator of no significance) further tests for significance have not been applied. It is expected that this will be included in future reports. As a result, findings should be interpreted with caution.

Table 3.2: Standardised mortality rates (per 10 000) of ACT residents under the age of 18 years for the ACT, July 2010 to June 2015

YEAR	POPULATION	DEATHS	ACT CMR	CI	ACT SMR	CI	AUSTRALIA SMR	CI
	≤ 18 years	number	per 10 000	lower–upper	per 10 000	lower–upper	per 10 000	lower–upper
2010–11	81 100	23	2.84	1.68–4.00	3.43	2.03–4.83	3.38	3.23–3.53
2011–12	82 383	19	2.31	1.27–3.34	3.04	1.67–4.40	3.14	3.00–3.28
2012–13	83 578	22	2.63	1.53–3.73	3.03	1.76–4.29	3.17	3.03–3.31
2013–14	84 861	25	2.95	1.79–4.10	3.60	2.19–5.01	n.d	n.d
2014–15	87 447	22	2.52	1.46–3.57	2.83	1.65–4.02	n.d	n.d

Table 3.2 shows the crude and standardised mortality rates for ACT residents who have died within the last five years. It also shows the SMR for Australia. In the last five years a slight reduction in the number of deaths has occurred but most likely a flattening out in the number of deaths of ACT residents under the age of 18 years, annually. Over the period there has been some volatility, with the lowest rate observed in 2011–12. The current CMR for the ACT is 2.52 deaths of children and young people per 10 000 individuals.

It is interesting to note that the SMR for the ACT and Australia are not significantly different, noting that further tests for significance beyond confidence interval testing has not been conducted. Given that the social factors that influence morbidity and mortality are generally more favourable in the ACT compared to the whole of Australia (ACT Health 2014), it was expected that there would be a difference between the two rates.

Distribution across characteristics: sex, age, Aboriginal and Torres Strait Islander status, and cause of death

The following discussion focuses on the key demographic and individual characteristics of the ACT resident population. Examination of these variables allows comparisons between groups and identification of trends within the total population to better inform and advocate for system, service or programmatic change. Examined here are sex, age, Aboriginal and Torres Strait Islander status and cause of death of ACT residents between July 2010 and June 2015.

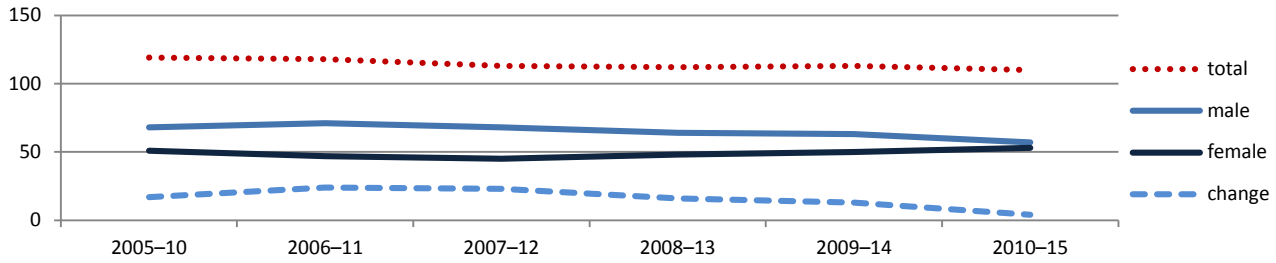
Table 3.3: Key demographic and individual characteristics of deaths of children and young people usually residing in the ACT, not including open coronial cases, July 2010 to June 2015

CHARACTERISTIC	DEATHS		CMR	CI	RATIO
	number	per cent	per 10 000	lower–upper	
Total					
Persons 0–18 years of age	111	100	2.65	2.15–3.14	
Sex					
Female	54	48.6	2.64	1.94–3.35	1:1.06
Male	57	51.8	2.65	1.96–3.34	1:0.95
Age					
Under 1 year	76	68.5	28.18	21.85–34.52	
1–4 years	9	8.2	0.88	0.31–1.45	
5–9 years	5	4.5	0.55	0.07–1.02	
10–14 years	6	5.5	0.56	0.11–1.01	
15–18 years	15	13.6	1.64	0.81–2.47	
Aboriginal and Torres Strait Islander status					
Aboriginal and Torres Strait Islander	8	7.3	0.19	0.06–0.32	1:12.88
Neither Aboriginal nor Torres Strait Islander	103	92.8	2.46	1.98–2.93	1:0.08

Sex

In the five years covered by this report a relatively equal distribution was observed between the deaths of ACT males (n=57) and females (n=54) with a ratio of 1.06. In preceding reports this distribution has been slightly skewed toward a higher incidence of male deaths. Utilising a rolling five-year average, the ACT has recorded 16 more male deaths than female deaths, which is to say that in any given five-year period there were 16 more male deaths than female deaths; however, this difference is not statistically significant.

Figure 3.1: Number of deaths in rolling five–year aggregates, July 2005 to June 2015

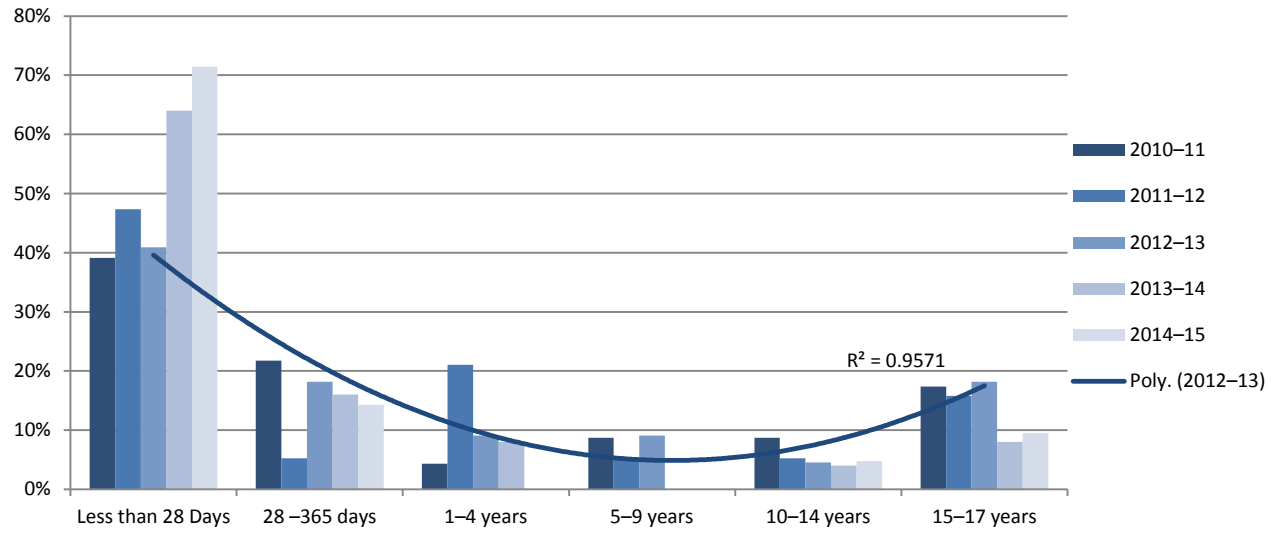


From around 2008–13 the divide between the number of male to female deaths of ACT residents seems to be reducing. Analysing the data in five-year aggregates removes some of the volatility from within the data; however, a trade-off is a lag in determining trends in the most recent observations. Therefore, whether this narrowing between male and female deaths reflects significant change or is an anomaly in the data due to chance cannot yet be determined. Year-on-year analysis of the numbers is inconclusive.

Age

A similar pattern to that shown in Chapter 2 has been repeated whereby the proportion of deaths that occur in the primary school years—that is, between 5 and 14 years of age—is markedly lower than in other age cohorts. In the last five years, this age bracket accounts for 13% of all deaths of ACT children and young people under the age of 18 years, whereas neonates (children who die in the first 28 days of life) account for over half (54%) of ACT resident deaths. The deaths of these children will be discussed in a later chapter.

Figure 3.2: Distribution of ACT resident deaths by age, July 2010 to June 2015



Aboriginal and Torres Strait Islander Status

There were eight children and young people who were identified as Aboriginal and Torres Strait Islander in the reporting period of July 2010 to June 2015. The ratio of ACT residents who died in the last five years was one Aboriginal and Torres Strait Islander child or young person to every 12 non-Aboriginal and Torres Strait Islander people under the age of 18. Given the proportion of Aboriginal and Torres Strait Islander people in the total population we would expect the ratio to be around 1:54. The higher than expected rate is indicative of the structural inequality that Aboriginal and Torres Strait Islander families experience. In the previous chapter we asked how equal is the representation of Aboriginal and Torres Strait Islander to non-Aboriginal and Torres Strait Islander deaths in the ACT. Investigation of the ratio of deaths by own population reveals a stark picture.

Table 3.4: Crude mortality rate by Aboriginal and Torres Strait Islander status per population, July 2010 to June 2015

ABORIGINAL AND TORRES STRAIT ISLANDER STATUS	POPULATION		DEATHS	CMR	CI
	proportion	number	per cent	per 10 000	lower–upper
Aboriginal and Torres Strait Islander	1.5	8	7.2	12.72	3.90–21.53
Neither Aboriginal nor Torres Strait Islander	98.5	102	92.8	2.89	2.33–3.45

Table 3.4 shows the crude mortality rates for ACT residents separated by population. When controlling for the proportion of each population group, that is to say the proportion of Aboriginal and Torres Strait Islander deaths compared to the non-Aboriginal and Torres Strait Islander population, we can see that, similar to other sectors such as health and education, Aboriginal and Torres Strait Islander people are over-represented in the sample. Recall from Table 3.3, the CMR for Aboriginal and Torres Strait Islander children and young people in relation to the total population was 0.19 deaths per 10 000 individuals. Based on similar conditions to the last five years non-Aboriginal and Torres Strait Islander populations might expect around three deaths for every 10 000 children and young people, whereas the Aboriginal and Torres Strait Islander population would expect the deaths of an additional nine to ten children and young people. Note that these figures refer to calculated mortality rates rather than actual deaths and, given the smaller numbers, should be interpreted with caution. However, it still stands that Aboriginal and Torres Strait Islander children are over-represented among the deaths of children and young people, which suggests heightened risk factors and is consistent with national trends (AHMAC 2015).

This issue will be further examined in the ACTCYPDRC 10-year review.

Cause of death

Table 3.5 presents the causes of death, both indicative and by ICD-10 grouping, for ACT residents in the period July 2010 to June 2015. Unsurprisingly, medical causes and extreme prematurity are the lead causes of death (n=49 and n=41 respectively). Again, *Certain conditions originating in the perinatal period* account for the majority of those deaths (n=41 across indicative causes).

Congenital anomalies (n=20) and *Neoplasms* (n=10), round out the leading causes of death of ACT children and young people under the age of 18 years, as they did in the all-inclusive figures noted in Chapter 2.

Certain conditions originating in the perinatal period	Deaths whose cause originates in that period, even though death may occur later. The perinatal period commences at 22 completed weeks (154 days) of gestation (the time when birth weight is normally 500 g), and ends seven completed days after birth (WHO 2011)
Congenital anomalies	Deaths whose cause was from particular conditions provided there is no indication that they were acquired after birth.
Neoplasm	Any new and abnormal growth, specifically one in which cell multiplication is uncontrolled and progressive. Neoplasms may be benign or malignant (Miller-Keane 2003)

Again, if we put aside deaths caused by disorders and diseases of the internal systems of the human body we see a small number of deaths caused by a range of issues. Suicide remains a concern with intentional self-harm resulting in at least one death a year. A notable absence is fatal assault—there have been no fatal assaults in the last five years.

The low numbers observed in the ACT can make it difficult to determine trends in regard to the causes of death and this would be problematic if the quantitative data was the only resource available to the committee. Fortunately, the committee does not examine quantitative data in isolation and has at its disposal a number of avenues to further investigate the deaths of children and young people in the ACT to identify areas and scope for change.

Conclusions and future activities

- Aboriginal and Torres Strait Islander deaths are over-represented in the population. The committee is committed to reducing inequality and Closing the Gap and will actively seek opportunities to share these findings and support broader reconciliation activities.
- The committee is concerned about the level of intentional self-harm leading to death. This issue will be further examined in the 10-year review.

Table 3.5: Indicative and ICD-10 cause of death by age bracket, July 2010 to June 2015

CAUSE OF DEATH	<1 Year	1–4 years	5–9 years	10–14 years	15–17 years	TOTAL
Total	**76**	**9**	**5**	**6**	**15**	**111**
Extreme prematurity	**41**					**41**
Certain conditions originating in the perinatal period	34					34
Congenital anomalies	6					6
No data	•					•
Medical causes	**24**	**8**	**5**	**5**	**7**	**49**
Certain conditions originating in the perinatal period	7					7
Congenital anomalies	•	•		•	•	14
Diseases of the blood and blood forming organs and immune mechanisms			•			•
Diseases of the musculoskeletal system and connective tissue	•					•
Diseases of the nervous system					•	•
Endocrine, nutritional and metabolic disease	•		•	•		•
Neoplasms		5	•	•	•	10
Nervous system disease	•	•		•	•	7
Respiratory diseases					•	•
SIDS and undetermined	•					•
Symptoms, signs not elsewhere classified	•					•
SUDI	•					•
Symptoms, signs not elsewhere classified	•					•
Unascertained	**8**					**8**
Symptoms, signs not elsewhere classified	8					8
Drowning					•	•
Accidental drowning and submersion					•	•
Non-intentional accident/injury				•		•
Exposure to smoke, fire and flames				•		•
Suicide					**6**	**6**
Hanging, strangulation and suffocation, undetermined intent					•	•
Intentional self-harm					•	•
Transport		•			•	•
Transport accidents		•			•	•

Chapter 4 Population focus: neonates and infants

Key messages:

- In 2010–11 to 2014–15, 114 children under the age of one year died in the ACT:
  - 69 were ACT residents who died in the ACT
  - 7 were ACT residents who died interstate or elsewhere
  - 33 normally resided interstate or elsewhere and were not subject to further analyses.
- The current Infant Mortality Rate (IMR) is about two-thirds what it was this time 10 years ago. Early indications suggest that the IMR might be rising but it is too early to tell.
- The leading causes of death for infants include *Certain conditions originating in the perinatal period*, *Congenital anomalies* and *Neoplasms*.

This chapter will examine the incidence and causes, as well as other demographic and individual characteristics, of those deaths of **ACT residents under the age of one year** that occurred in the ACT, with particular reference to the last five years.

Overview

This section will look at the broader incidence of mortality among neonates and infants in the ACT.

In total 69 ACT residents under the age of one year died in the ACT while another seven ACT residents died elsewhere. There were a further 33 infants who normally lived interstate who also died in the Territory.

With those children who usually reside elsewhere (n=33) and coronial cases removed from these analyses, the following relates to 76 children who were residents of the ACT.

Table 4.1: Breakdown of cases included in analysis, July 2010 to June 2015

DEATHS	NUMBER	PER CENT
Total [b]	**114**	**100**
ACT residents who died in the ACT [a]	69	62.2
ACT residents who died elsewhere [a]	7	5.2
Interstate residents who died in the ACT	33	28.9
Cases before the Coroner	•	•

[a] Included in further analyses

[b] These figures do not sum due to coronial cases appearing in two categories.

Distribution across characteristics: sex, Aboriginal and Torres Strait Islander status, and cause of death

The following discussion focuses on the key demographic and individual characteristics of the population in question. Examination of these variables allows comparisons between groups and identification of trends within the total population to better inform and advocate for system, service or programmatic change. Examined here are sex, Aboriginal and Torres Strait Islander status, and cause of death.

Table 4.2 shows the number of deaths occurring between July 2014 and June 2015 reporting periods of children aged less than one year. In 2014–15, 19 ACT residents died in the first year of life. This is higher than the average for the reporting period, which is 15 deaths a year in this age group.

Table 4.2: Deaths of ACT children under one year of age, July 2010 to June 2015

CHARACTERISTIC	2014–15 DEATHS number	2014–15 DEATHS per cent	2014–15 IMR per 10 000	2014–15 RATIO	2010–15 DEATHS number	2010–15 DEATHS per cent	2010–15 IMR per 10 000	2010–15 RATIO
Total								
Persons 0–1 year of age	19	100	2.17	-	76	100	1.81	-
Sex								
Female	10	52.6	2.35	1:0.90	35	46.1	1.71	1:1.17
Male	9	47.4	2.01	1:1.11	41	53.9	1.91	1:0.85
Aboriginal and Torres Strait Islander status								
Aboriginal and Torres Strait Islander	•	•	•	1:8	6	8	0.12	1:12
Neither Aboriginal nor Torres Strait Islander	17	89.5	1.94	1:0.12	70	92.1	1.67	1:0.09

Sex

In the five years to 2015, 76 children have died in the first year of life with a relatively even split between males and females, slightly skewed toward a higher incidence of male deaths. The 2014–15 period recorded an even distribution of male and female deaths however in relation to their portion of the population, females have a slightly higher mortality rate 2.35 deaths per 10,000 infants compared to 2.01. Over the five-year period however the trend in mortality returns to males having a higher mortality rate 1.91 compared to 1.71 deaths per 10,000 infants. It is unlikely that sex has much of a bearing on the causes of death at this age; however, it is of note that males experience higher mortality rates than females in this age group.

Age

Table 4.3: Infant mortality rates, ACT July 2010 to June 2015

YEAR	DEATHS number	IMR per 10 000	CI lower–upper
Total	**76**		
2010–11	14	28.31	13.48–43.13
2011–12	10	18.95	7.20–30.69
2012–13	13	23.60	10.77–36.43
2013–14	20	35.17	19.75–50.58
2014–15	19	34.25	18.85–49.65

Figure 4.1: Infant mortality rates, ACT 2010–15

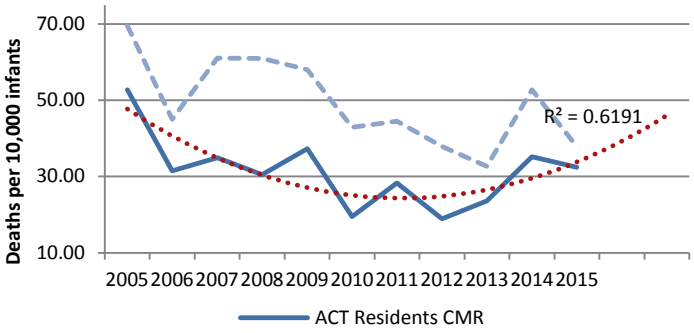


Table 4.3 and Figure 4.1 above show the infant mortality rates (IMR) for the ACT. The IMR, similar to the crude mortality rate, indicates patterns in the number of deaths and allows for comparisons, but instead of a population-level indicator, the age-specific mortality rate takes into account only those individuals falling into the age cohort, in this case neonates and infants under one year of age. From the graph the solid line indicating ACT residents only experienced a decline in mortality. The current rate is about two-thirds what it was this time 10 years ago although the rate has experienced some volatility over that period. The overall rate reached the lowest level around 2011 with 18.95 deaths per 10 000 but has slowly increased since that point to a current age-specific mortality rate of 34.20 deaths of children aged under one year for every 10 000 individuals. While the findings are not significant and the trend line is not a strong fit for the data with reliability around 0.6, there is enough evidence to support the continuation of observing infant mortality rates into the future.

Out of interest, the inclusion of interstate residents who die in the ACT shifts the age-standardised mortality rate (ASMR) considerably, reducing it from a peak level between July 2004 and June 2005 (ASMR=69.56) to the

current rate of 37.86 deaths per 10 000 infants. As noted in Chapter 2, this last year recorded a lower than average number of deaths of interstate residents and, as such, it is expected that this level may increase again in coming years. Of the 97 interstate residents who have died in the ACT, 84.5% were under the age of one year.

Cause of death

The table below presents the main causes of death for the five years to June 2015 of ACT children under the age of one year. As highlighted in a previous chapter, this cohort accounts for a large proportion of all deaths. Of ACT resident deaths in the five-year period to June 2015, children under the age of one year account for 68% of all deaths.

Table 4.3: Causes of death for ACT children under one year of age, July 2010 to June 2015

CAUSE OF DEATH	TOTAL	
	number	per cent
All deaths	**76**	**100**
Persons 0–1 year of age	76	100
Extreme prematurity	**41**	**53.9**
Certain conditions originating in the perinatal period	34	44.7
Congenital anomalies	6	7.9
No data	•	•
Medical causes	**24**	**31.6**
Certain conditions originating in the perinatal period	7	9.2
Congenital anomalies	11	14.5
Diseases of the musculoskeletal system and connective tissue	•	•
Endocrine	•	•
Nervous system disease	•	•
No data	•	•
Other causes	•	•
SIDS and undetermined: Symptoms, signs not elsewhere classified	•	•
SUDI: Symptoms, signs not elsewhere classified	•	•
Unascertained	**8**	**10.5**
Symptoms, signs not elsewhere classified	8	10.5

In keeping with patterns from the broader population, *Certain conditions originating in the perinatal period* (n=41) are the major cause of death for this cohort, followed by *Congenital anomalies* (n=17). Again, eight incidents of death occurred where the cause could not be ascertained (n=11, including those deaths with indicative causes of Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Death in Infancy (SUDI)).

The ICD is the tool adopted by the international community to analyse the health of population groups in terms of studying the incidence and prevalence of morbidity and mortality (WHO 2011). As a classification system, it provides a common framework to report on rates of morbidity and mortality, making it an invaluable tool for states to determine health and population policy. The ICD-10 also serves as an international benchmark, allowing the World Health Organization to develop national and international mortality and morbidity statistics.

The ICD-10 defines the category of *Certain conditions originating in the perinatal period* as deaths whose cause originates in that period, even though death may occur later. These can include but are not limited to complications during labour and delivery, infections specific to the perinatal period, blood disorders and concerns, other internal disorders (such as endocrine or respiratory disorders for example) and temperature regulation (WHO 2010).

Examining the register further reveals that the main cause of death listed for the 41 infants who died in the first month of life was prematurity, extreme prematurity more often than not. Other causes include (Medscape 2015):

Perinatal asphyxia	Clinical and laboratory evidence of acute or subacute brain injury due to asphyxia.
Necrotising enterocolitis	Characterised by variable damage to the intestinal tract, ranging from mucosal injury to full-thickness necrosis and perforation.
Hydrops fetalis	The abnormal accumulation of fluid in body cavities (pleural, pericardial, peritoneal) and soft tissues with a wall thickness of greater than 5 mm.

In Chapter 2, the higher average number of deaths occurring for interstate residents than those deaths that occur for ACT residents who die elsewhere was noted. Also noted in that chapter was the high number of deaths that occur in the first weeks of life. Since July 2004, of the children and young people who normally reside interstate or elsewhere 84.5% were less than one year of age at the time of death. Of those infants, *Certain conditions originating in the perinatal period* and congenital conditions accounted for 65.8% and 24.4% of deaths. Deaths involving a child from interstate are almost three times more likely to be due to complications from or conditions arising through birth.

This finding is largely reflective of agreements such as those between the ACT and NSW regarding Critical Care Tertiary Referral Networks whereby hospitals agree to accept high-risk obstetric and neonatal cases requiring specialised care and facilities (NSW Health 2010). The Canberra Hospital caters to the south-east region of NSW and as such the ACT experiences a higher number of infant deaths as a result.

Conclusions and future activities

- Infant mortality rates are currently stable. However, there is enough evidence to support the continuation of monitoring the IMR in future reports.
- The overall number of deaths in the ACT is increased markedly by the number of infants who die in the ACT and who normally reside elsewhere. Three-quarters of interstate visitors were aged less than one year and this is in large part due to the specialist care provided for complex and high-risk cases through the Tertiary Referral Network agreement with NSW.

Chapter 5 Population focus: vulnerable children and young people

Key messages:

- Between July 2010 and June 2015, 111 residents under the age of 18 years died in the ACT (excluding coronial cases):
  - 23 were known to Child and Youth Protection Services (CYPS) (Child Concern Report or Child Protection Report)
  - 33 were known to ACT Policing (Death incident only or Knowledge of at least one parent)
- Around one-fifth (n=20) of ACT children and young people who died in the last five years were known both to child protection and the police (noting that in regard to police, the majority are through the death incident only).
- Across the board, females seem to be more represented than males in regard to deaths of children known to the protection and justice systems.
- Females are almost twice as likely to be the subject of a Child Protection Report and more than three times as likely to be the subject of a Child Concern Report.
- The number of individuals who were not the subject of a report has increased from 75.2% in the 2009–14 period to 80% in the 2010–15 period.
- The proportion of both Child Concern and Child Protection reports among children and young people who have died has decreased since the last annual review.
- In 10% of all incidents of death in the last five years, at least one parent was known to the police. In less than half of those cases, both parents were known to the police.
- Of the 20 children and young people who were known to both the CYPS and the police there were seven occasions where the police had prior knowledge of at least one parent in terms of a current or previous criminal history.
- Aboriginal and Torres Strait Islander children and young people are over-represented among those who are known to either CYPS or the police, and are almost 1.5 times more likely to have involvement from child protection or police at the time of death than non-Aboriginal and Torres Strait Islander children and young people.

This chapter provides an overview of the registered deaths of children and young people that occurred in the ACT or that involved ACT residents in the **last five years and who had experienced factors of vulnerability (defined below) in the lead-up to their death**. It will examine the incidence and causes, as well as other demographic and individual characteristics, of those deaths of ACT residents under the age of 18 years that occurred between July 2010 and June 2015.

Overview

This section will look at the overall incidence of mortality among children and young people in the ACT who were experiencing particular vulnerability risk factors at the time of death. In this and previous reports the involvement of Children and Youth Protection Services (CYPS) and ACT Policing (the police) were the two proxy indicators of vulnerability. In future reports we hope to look more broadly at other social determinants and vulnerability risk factors.

Table 5.1: ACT children and young people known to CYPS or ACT Policing, July 2010 to June 2015

YEAR	TOTAL	KNOWN TO CYPS	KNOWN TO ACT POLICING
	111	**23**	**33**
2010–11	23	•	7
2011–12	19	•	•
2012–13	22	6	8
2013–14	25	7	•
2014–15	22	•	7

There are several reasons why the committee focuses

on child protective services and the justice system in particular: first and foremost as a requirement of the legislation but also because these are the systems that come into play when difficulties arise in the child's life and therefore are indicators of vulnerability. In terms of accessing data, the relationships between the committee and the relevant agencies are strong.

Table 5.1 outlines the number of children and young people or their families who were known to CYPS or ACT Policing. These figures will be broken down in later sections to look at the level of engagement with the protective services.

In the five years to June 2015, 111 residents of the ACT under the age of 18 years died. Overall, 23 children and young people were known to child protective services and 33 were known to police. It is important to note that these broad figures do not account for the level of that knowledge or involvement.

Table 5.2: Number of deaths by vulnerability risk factor and age, July 2010 to June 2015

	0–1 YEARS	1–4 YEARS	5–9 YEARS	10–14 YEARS	15–17 YEARS	TOTAL
Known to CYPS						•
Police involved	13	•		•	•	20
Police not involved	•			•	•	•
Not known to CYPS						**88**
Police involved	7			•	5	13
Police not involved	55	•	5	•	•	75
TOTAL						**111**

Table 5.2 above shows the number of children and young people under the age of 18 years who normally reside in the ACT and who died in the five years to June 2015. It also shows the number of those children and young people who were known to either—or both—CYPS and ACT Policing by age.

Around one-fifth (n=20) of ACT children and young people who died in the last five years were known both to child protection and the police (noting that in regard to police, the majority are through the death incident only). This is the first year these particular analyses have been conducted and trends are not yet able to be determined. This will establish a baseline from which to make comparisons in future reports. Two-thirds of all children and young people (n=75) were known neither by CYPS nor the police.

Known to CYPS When a report is initially made to CYPS it is known as a 'Child Concern Report', which is a record of information regarding the child or young person made by either a voluntary or mandatory reporter. CYPS then conduct an initial assessment of the issues raised in the Child Concern Report and if this assessment allows the Director-General to form a reasonable belief that a child or young person is in need of protection then a 'Child Protection Report' is recorded in accordance with section 360(5) of the legislation. It is under this same legislation that ACTCYPDRC is required to provide this report to the Minister each financial year about the deaths of children and young people with particular demographic and individual characteristics and trends relating to such (s727S).

Police involved Not all deaths of children and young people require the involvement of police. Where a child or young person clearly dies as a result of medical causes in a setting where professionals are able to make a determination of death, such as a hospital, police are not necessarily informed or called. Police often become involved in a death where people aware of the death call emergency services, where the coroner makes a determination that further inquiries are required or where the individual or persons associated with the individual have current or previous histories with police.

Distribution across characteristics: sex, age, Aboriginal and Torres Strait Islander status, and cause of death

The following discussion focuses on the key demographic and individual characteristics of the population in question. Examination of these variables allows comparisons between groups and trends within the total population to be identified. As a result, the committee and other interested professionals or members of the public may be better informed to advocate for system, service or programmatic change. Examined here are sex, age, Aboriginal and Torres Strait Islander status, and cause of death.

Sex

Table 5.3 shows the number of children and young people who were known to CYPS or ACT Policing broken down by sex and level of knowledge of the child or young person by the relevant agency.

Across the board, females seem to be more represented than males in regard to deaths of children known to the protection and justice systems. The only exception to this pattern in this period is the police involvement in death incidents only, which is higher for males (n=15) than females (n=7) by 50%. This is unusual: in previous sections the incidence of male deaths by selected variables is usually higher.

Females are one and a half times as likely to be the subject of a Child Protection Report and more than three times as likely to be the subject of a Child Concern Report, noting the different definitions above. Females are also two to three times as likely to have at least one parent known to the police.

Table 5.3: ACT child protection reports and police involvement by sex, July 2010 to June 2015

	CHILD YOUTH PROTECTION SERVICES			ACT POLICING		
	concern	protection	no report	at least one parent	death incident only	not known
Deaths						
All persons <18 years of age	9	12	90	11	22	77
Sex						
Male	•	5	50	•	15	39
Female	•	7	40	•	7	39
Incident ratio (m:f)	**1:3.50**	**1:1.40**	**1:0.80**	**1:2.67**	**1:0.47**	**1:1**

Age

Table 5.4 presents the number of children and young people who died that were also the subject of a Child Concern or Child Protection report during their life, noting the different definitions above. The number of individuals who were not the subject of a report has increased from 75.2% between July 2009 and June 2014 to 80% between July 2010 and June 2015 period. Both the proportion of Child Concern and Child Protection reports have decreased since the last annual review, with Concern reports reducing from 11.0% to 8.2% and Protection reports reducing from 13.8% to 11.8%. Given the already low numbers in the ACT these changes may be due to normal fluctuations and trends will have to be viewed over a longer period.

Table 5.4: Number of ACT child protection reports by age, July 2010 to June 2015

CHILD NOTIFICATION	<1 YEAR	1–4 YEARS	5–9 YEARS	10–14 YEARS	15–17 YEARS	TOTAL	PER CENT
Child Notification	**76**	**9**	**5**	**6**	**15**	**111**	100
Child Concern Report	5			•	•	9	8.1
Child Protection Report	8	•		•	•	13	11.7
No report	63	•	5	•	10	88	79.3

The majority of substantiated reports are received within the first year of life (n=13). It is interesting to note, however, the pattern highlighted in previous chapters (where there were fewer deaths of those aged between four and 14 years of age) seems to be replicated here in terms of reports made on children in the

same age bracket. Also of interest in this table are the five substantiated reports for 15–17 year olds. Generally young people between the ages of 15 and 17 are the least likely to be receiving child protection services across Australia (AIHW 2015a). The Australian Institute of Health and Welfare, in its latest *Child protection Australia* report posit that younger children are regarded as the most vulnerable, and most jurisdictions have specific policies and procedures in place to protect them. There has also been an increased focus nationally on early intervention and the provision of services early in a child's life to improve long-term outcomes and reduce the negative impacts of trauma and harm (AIHW 2015a). This is potentially an issue to look at in terms of the 10-year review.

Table 5.5: Number of child deaths known to ACT Policing by age, July 2010 to June 2015

KNOWN TO POLICE	<1 YEAR	1–4 YEARS	5–9 YEARS	10–14 YEARS	15–17 YEARS	TOTAL	PER CENT
Known to police	**76**	**9**	**5**	**6**	**15**	**111**	100
At least one parent known	9				•	11	9.9
Death incident only	11	•		•	8	22	19.8
Not known	56	•	5	•	•	77	69.4

Table 5.5 shows the number of deaths of children and young people who were known—or not—to ACT Policing. Two-thirds of all children who died in the five years to June 2015 were not known to the police. This correlates with the high number of deaths that occur in the first weeks of a child's life from *Conditions originating in the perinatal period*. One-fifth of those children or young people who died were known to the police through the death incident only. In 10% of instances (n=11) at least one of their parents was known to the police. In less than half of those cases, both parents were known to the police.

Of the 20 children and young people who were known to both the CYPS and ACT Policing there were seven occasions where the police had prior knowledge of at least one parent in terms of a current or previous criminal history. In two of those cases the police had information on the criminal histories of both parents. In all but one of the seven cases the child was less than one year of age and in five of the cases the child was the subject of a Child Protection Report.

Aboriginal and Torres Strait Islander status

Table 5.6: Number of child deaths known to Child Youth Protective Services and ACT Policing by Aboriginal and Torres Strait Islander status, July 2010 to June 2015

CHILD NOTIFICATION	NO REPORT			CHILD CONCERN REPORT			CHILD PROTECTION REPORT			TOTAL
known to police	at least one parent	death incident only	no police	at least one parent	death incident only	no police	at least one parent	death incident only	no police	
Indigenous status	•	**11**	**73**	•	**5**	•	**5**	**6**	•	**111**
Aboriginal and TSI	•		•			•		•		8
Neither Aboriginal or TSI	•	11	69	•	5	•	5	5	•	103
Incident ratio	**1:1**	**-**	**1:17.25**	**-**	**-**	**1:1**	**-**	**1:5**	**-**	**1:12.88**

Similarly to previous chapters, the ratio of Aboriginal and Torres Strait Islander children and young people to non-Aboriginal and Torres Strait Islander people is high. On the face of it, a 1 to 1 ratio would seem a relatively even split. However, as noted in previous chapters, Aboriginal and Torres Strait Islander people account for only 1.5% of the total ACT population. With that view, a 1 to 1 ratio is disproportionately high. Similarly, where there is no involvement from protection or law enforcement agencies the ratio shifts to a lower incidence. This indicates that Aboriginal and Torres Strait Islander children and young people are almost 1.5 times more likely to have involvement from child protection or the police at the time of death than non-Aboriginal and Torres Strait Islander children and young people.

Cause of death

Table 5.7 outlines the causes of death for all children and young people who normally resided in the ACT in the between the years July 2010 and June 2015. It also shows the number of deaths of children who were known to CYPS and ACT Policing.

Because of the number of variables in this table and because of the small numbers of deaths in the ACT, many of the numbers are fewer than five deaths. The table has been included simply to give an idea to members of the community of the types of causes of death that occur for children and young people who are known to child protection and the police. For the purposes of this table, police knowledge of previous criminal history and involvement in the death incident only have been combined to facilitate the publishing of numbers where possible.

For children who were known to both CYPS and ACT Policing, the main cause of death could not be ascertained (n=9). For some children and young people who were the subject of Child Concern Reports Intentional self-harm leading to death was also a concern. As expected, for those deaths that were neither subject to any police involvement nor any child protection notifications, the main causes of death were *Certain conditions originating in the perinatal period* (n=35) and *Congenital anomalies* (n>12).

Conclusions and future activities

- Females have a higher incidence of death by vulnerability factor than males. There is potential for further analysis here in terms of the gendered nature of vulnerability and disadvantage.
- It is difficult to determine trends in terms of deaths of vulnerable children and young people. While the numbers have decreased from the last period this may be due to normal fluctuations.
- The finding in this report that Aboriginal and Torres Strait Islander children and young people who died were more likely to have involvement from police or protective services warrants further investigation.
- Intentional self-harm is a concerning cause of death for vulnerable young people.

Table 5.7: Causes of death of children and young people and level of engagement with Child Youth Protective Services and ACT Policing, 2010–15

CHILD NOTIFICATION	NO REPORT		CHILD CONCERN REPORT		CHILD PROTECTION REPORT		TOTAL
police involvement	police	no police	police	no police	police	no police	
Drowning					•		•
Accidental drowning and submersion					•		•
Extreme prematurity	•	**34**	•	•	•		**41**
Certain conditions originating in the perinatal period	•	30	•	•			34
Congenital anomalies	•	•			•		6
No data		•					•
Medical causes	**5**	**38**		•	•		**49**
Certain conditions originating in the perinatal period	•	5					7
Congenital anomalies	•	12		•			14
Diseases of the blood and blood forming organs and immune mechanisms		•					•
Diseases of the musculoskeletal system and connective tissue		•					•
Diseases of the nervous system	•	•			•		**9**
Endocrine		•			•		•
Neoplasms		9			•		10
Respiratory diseases	•						•
Non-intentional accident/injury	•						•
Exposure to smoke, fire and flames	•						•
Other causes in infancy	•		•		•		•
SIDS and undetermined: Symptoms, signs not elsewhere classified			•		•		•
SUDI: Symptoms, signs not elsewhere classified	•						•
Suicide	•		•			•	**6**
Hanging, strangulation and suffocation, undetermined intent	•						•
Intentional self-harm	•		•			•	5
Transport	•	•					•
Transport accidents	•	•					•
Unascertained	•		•		•	•	**9**
Symptoms, signs not elsewhere classified	•		•		•	•	9
Total	**15**	**73**	**7**	•	**11**	•	**111**

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Appendix 1 Methodology

Date of death reporting for the register

For the purpose of this report, the committee has determined it will recognise the actual date of death of each child or young person in the ACT, rather than the registered date of death. This will provide an actual number of child and young person deaths for the reported five-year period and allow for a more accurate reflection of what was occurring at the time of the child or young person's death, namely the circumstances, risk factors, relevant agencies' policies and practices, and the political environment at that time. The time between the actual date of death and the registered date of death may be significant and, in that time, there may have been changes in the aforementioned circumstances. However, there may need to be adjustments if additional deaths of children and young people are registered at a later time.

As the committee is using the actual date of death rather than the registered date of death, there may be discrepancies between the information in this report and the information reported by the ACT BDM and other Australian jurisdictions.

Less than five total deaths

When a particular cohort of children and young people has fewer than five total deaths, the exact number of deaths will not be reported. This will ensure that the committee complies with section 727S(3) of the Act and does not disclose the identity of a child or young person who has died or allow the identity of a child or young person who has died to be worked out. The number of deaths will be reported as •, which means the number of children and young people who died is less than five but greater than zero.

When a cause of death has fewer than five deaths, this report will not provide more detailed information about this cohort. This is not only to ensure the committee's compliance with section 727S(3) of the Act, but to ensure the child, young person and family's right to privacy is maintained.

Population estimates and rates

The population estimates of the ACT and Aboriginal and Torres Strait Islander children and young people are taken from the latest Australian Bureau of Statistics' (ABS) release of estimated resident populations, which provides the estimated resident population as at 30 June 2014 and a projected resident population at 30 June 2015.

Rates are calculated using child death data contained in the register and both ABS estimated (2009 to 2014) and projected (2015) statistics of the ACT population. These rates are calculated per 10 000 children and young people by dividing the total number of deaths by the total population in each age group.

Appendix 2 Definition of terms

'**Aboriginal and Torres Strait Islander'**

In the *Children and Young People Act 2008:*

> ***Aboriginal or Torres Strait Islander person*** means a person who –
>
> (a) is a descendant of an Aboriginal person or Torres Strait Islander person; and
>
> (b) identifies as an Aboriginal person or Torres Strait Islander person; and
>
> (c) is accepted as an Aboriginal person or Torres Strait Islander person by an Aboriginal community or Torres Strait islander community.

'Child'

In the *Children and Young People Act 2008*:

> ***child*** means a person who is under 12 years old.

The *Children and Young People Act 2008* does not provide guidance on when an individual becomes a 'child'. In accordance with common law, a child is a person who has been born alive, which means the child must be living outside its mother's body by virtue of the functioning of its own organs and indicated by breathing, beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles. The term 'a child born alive' does not include stillbirths or other fetal deaths.

'Child Concern Report'

A Child Concern Report is a report made to Care and Protection Services in accordance with section 359 of the *Children and Young People Act 2008* and can be made by either a voluntary or a mandated reporter. A Child Concern Report is a record of information regarding the needs of a child or young person or is about a child or young person's safety or wellbeing (CSD definition).

'Child Protection Report'/ Report under section 360(5) of the Act

If the Director-General suspects, on reasonable grounds, that a child or young person subject to a Child Concern Report may be in need of care and protection, the Director-General must decide that the Child Concern Report is a Child Protection Report. Section 345 of the *Children and Young People Act 2008* defines that a child or young person is in need of care and protection if the child or young person has been abused or neglected, is being abused or neglected or is at risk of abuse and neglect AND no-one with parental responsibility for the child or young person is willing and able to protect the child or young person from the abuse or neglect or risk of abuse or neglect.

'**Coroner'**

Refers to a coroner for the ACT appointed under the *Coroners Act 1997.*

'Infant'

Refers to the period from birth to one year of age.

'National Coronial Information System'

Refers to the initiative of the Australasian Coroners Society that is managed by the Victorian Department of Justice on behalf of the Australian Government and the states and territories. Information about every death subject to a coronial inquiry in Australia is stored in the system, providing a valuable hazard identification and death prevention tool for researchers, including state and territory death review committees (NCIS definition).

‘Neonatal’

Refers to the period from birth to 28 days of age.

‘Parent’

Refers to a birth, step, de facto or adoptive parent of a child or young person as identified by the committee from information obtained as part of its functions.

‘Perinatal’

Refers to the period from 20 weeks gestation to 28 days of age.

‘Register’

Refers to the register of all deaths of children and young people in the ACT that is used by the committee.

‘Review by the ACT’

These reviews are undertaken in the ACT and may include: a coronial inquest into the manner and cause of death of a person who dies in circumstances set out in the *Coroners Act 1997;* a Clinical Health Review Committee; an internal review by the Office for Children, Youth and Family Support; or a joint ACT Health and Office for Children, Youth and Family Support review.

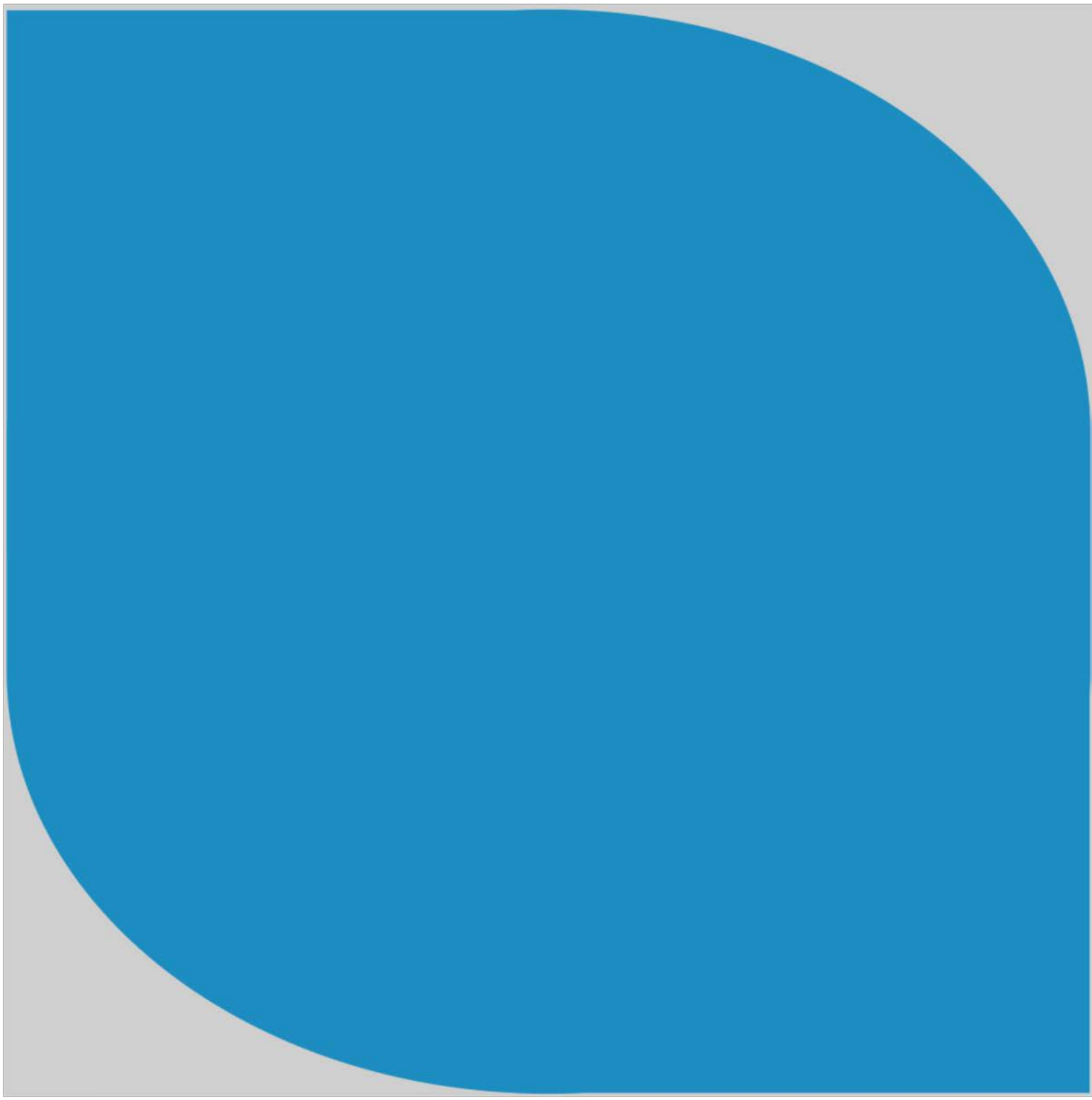
‘Sibling’

Refers to all biological, half, step and adoptive siblings as identified by the committee from information obtained as part of its functions.

‘Young people’

In the *Children and Young People Act 2008*:

> ***young people*** means young persons over the age of 12 years who are not yet 18 years.



The ACT Children and Young People
Death Review Committee is established
under the *Children and Young People ACT 2008*

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