

**Annual Report 2016**

Covering the period between   
July 2015 to December 2016

# ACT Children and Young People Death Review Committee

## Who are we?

The ACT Children and Young People Death Review Committee (the 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 Disability, Children and Youth.

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***

Enquiries about this publication should be directed to:

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# Foreword

This is the fifth annual report of the ACT Children and Young People Death Review Committee and my first as Chair of the Committee.

In June 2016, Dr Penny Gregory, the second Chair of the Committee, completed the term of her appointment and did not seek re-appointment. I was appointed as Chair in August 2016 for a three year term. Dr Gregory led the Committee during the three years following establishment, working towards the Committee’s core objective to prevent or reduce the likelihood of the death of children and young people in the ACT. During her time as Chair, the Committee commenced individual case reviews, produced three annual reports and advocated on a number of issues of concern, including the prevalence of co-sleeping. The Committee and I extend our gratitude to her for her guidance and stewardship in progressing the Committee’s work.

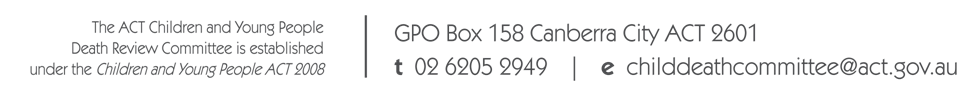
This year saw the Committee release its *Retrospective report: Progress in the ACT between 2004 and 2013* for which it adopted a Social Determinates of Health approach. This assisted the Committee to identify a number of areas where the ACT could be doing better, including future areas of focus for the Committee’s work. The Committee provided several submissions throughout the period, on issues including youth self harm and suicide, information sharing and the system response to family violence in the ACT.

The Committee is currently involved in reviewing the deaths of children aged between 0-3 years, based on the high mortality rates in this age group. These deaths are being examined in light of a range of factors that increase the vulnerability of children and young people.

The Committee will continue to work to improve systems intended to support children, young people and their families and to ensure they are effective at preventing harm.

Finally, I would like to thank the Secretariat and members of the Committee, who have done an outstanding job in preparing this report and in drawing out the key messages from the data. I would also like to extend our sincere condolences to the families, friends and communities who knew and loved the children and young people whose deaths are reported here.

**Ms Margaret Carmody PSM**Chair, ACT Children and Young People Death Review Committee



# Letter of transmission

Minister for Disability, Children and Youth

ACT Legislative Assembly

London Circuit

CANBERRA ACT 2601

Dear Minister

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

This year, the Committee’s report focuses on the period July 2015 to December 2016. This report is unusual in that it encompasses data from an 18 month period. This will be a one off report due to transitioning from financial year reporting to calendar year reporting. As previously, the report focuses primarily on presentation of the data and analysis relating to the deaths, as required by the *Children and Young People Act, 200*8 (the Act), with the contextual information about the Committee and its activities being available and regularly updated on our website (www.childdeathcommittee.act.gov.au).

While the report is in relation to 2015-2016, it also presents data from January 2012 to December 2016 and fulfils the Committee’s statutory obligations under Section 727S of the Act.

Yours sincerely



Ms Margaret Carmody, PSM  
Chair  
30 April 2017



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# Executive summary

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 children and young people in the Australian Capital Territory. The Committee reports to the Minister for Disability, Children and Youth.

In accordance with section 727S of the Act, this report provides information on the deaths of 155 children and young people up to the age of 18 years who were included on the Committee’s Child and Young Person Deaths Register between January 2012 and December 2016. Of the 155 deaths across the latest five year period, 13 are awaiting the findings of the coroner and are therefore not able to be included in this report. The remaining 142 deaths on the register include 33 deaths of children and young people who did not normally reside 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. It provides an overview of all registered deaths between January 2012 and December 2016, with particular reference to the current reporting period: July 2015 to December 2016.

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.

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.

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.

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 describes the **role of the ACT Children and Young People Death Review Committee** and important information for reading this report.

## ACT Children and Young People Death Review Committee

The Committee 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 Committee 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**](http://www.childdeathcommittee.act.gov.au/default.html)

## Annual report

NOTE: This report covers the period July 2015 to December 2016

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 July 2015 to December 2016. This report is unusual in that it encompasses data from an18 month period. This will be a one-off report due to transitioning from financial year reporting to calendar year reporting. Subsequent reports will report on deaths between January and December of any one year. It is customary, due to the fewer deaths that occur in the ACT to also report in five year aggregates. This report will include data from January 2012 to December 2016.

Chapter 19A, Part 19A.4, Section 727S of the *Children and Young People Act 2008* (the Act) requires the Comittee 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 Committee is committed to respecting the child, young person and their family’s right to privacy. As per Chapter 19A, 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 Committee has reported 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 possible 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.

## Report period

To date, the Committee has reported annually on a financial year basis. In 2016, amendments to the Act changed the reporting period to a calendar year resulting in the necessity to produce either a six month or 18 month report. Given that fewer deaths occur in the ACT compared to other jurisdictions the decision was taken to report on an 18 month period for this report in the transition period.

The focus period of this report is July 2015 to December 2016.

Figure 1.1: Population ratios comparing males and females and total population between Australia and the ACT, 2016

## C:\Users\emma higgisson\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.Outlook\JZR6AH0M\PopPyramid_AUSTACT.jpgUsing this report

The annual report is a legislated requirement of the Committee and can be utilised as a catalyst or foundation for further investigations. To facilitate clarity of understanding and enable greater use and reporting on the findings of this report it is important to clarify the methods used.

### Age standardisation

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 slight drop 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 Committee must not report on the causes of death of those cases that are being heard 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 referring to cause of death or population in focus chapters.

### 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 continue the format adopted in the previous report and include both the indicative causes of death and the ICD.

### 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. The same can be true when reporting on other factors, such as vulnerability, where the focus is on a small sub-sample of the cohort. The ACT is a small community and individuals may be identified through the reporting of these low numbers. Therefore, where they number 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. It is important to note that data comparisons with previous annual reports must take into account that coronial findings will have been released thus enabling causes of death to be reported.

### Data quality

The Committee continues to work to improve data quality to better and more accurately identify the contributing factors to deaths reported. Anecdotal information reported by members would indicate that official causes of death do not always reflect the full story. Clearly those cases that have been subject to a coronial inquiry provide excellent information to the Committee. It is only once timely, complete and more reliable information is available that improvements to systems and processes can be identified to prevent or reduce deaths.

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

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 period: July 2015 to December 2016. Subsequent chapters in this report will focus on ACT residents only; however, this chapter takes a broad overview of all deaths that have occurred, including children and young people from interstate or elsewhere.

Table 2.1: Deaths of children and young people in the ACT in the five years between January 2012 and December 2016

| DEATHS | NUMBER | PER CENT |
| --- | --- | --- |
| **All deaths in the ACT** | **155** | **100%** |
| ACT resident deaths | 120 | 77% |
| Interstate resident deaths | 33 | 21% |
| ACT residents who died elsewhere | 6 | 4% |
| Unknown residence | 2 | 1% |
| Coronial cases | 13 | 8% |

## 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 five year period: January 2012 to December 2016.

In total, there were 155 children and young people who died in the period between January 2012 and December 2016. Of these there were 120 deaths of children and young people who were normally resident and six of whom died elsewhere. There were 33 deaths of children and young people who resided interstate and there are two children and young people for whom there is no current residential data. There are also 13 cases currently before the ACT Coroner.

## ACT residents and non-residents

The Committee collects information relating to the deaths of all children and young people who die, or normally reside, in the ACT. This means that information on the Register relating to ACT residents who died outside of the ACT is often provided by similar committees in those jurisdictions. Information is shared between committees to ensure that each jurisdiction has accurate records.

Table 2.2: Annual deaths of children and young people in the ACT, including ACT residents who died elsewhere, January 2012 – December 2016

| YEAR | ALL DEATHS a,b | ACT RESIDENTS c | | INTERSTATE RESIDENTS | |
| --- | --- | --- | --- | --- | --- |
| Jan-Dec | number | number | per cent | number | per cent |
|  | **155** | **120** | **77.4** | **33** | **21.3** |
| 2012 | 30 (1) | 24 (3) | 80.0 | 6 | 20.0 |
| 2013 | 30 (2) | 22 (-) | 73.3 | 8 | 26.7 |
| 2014 | 30 (-) | 22 (1) | 73.3 | 8 | 26.7 |
| 2015 | 38 (5) | 30 (2) | 78.9 | 7 | 18.4 |
| 2016 | 27 (5) | 22 (-) | 81.5 | • | 14.8 |
| **Average** | **31** | **24** |  | **6.6** |  |

1. Figures provided in brackets are cases currently before a Coroner and are included in the total figure. These cases will not be included in subsequent analyses.
2. The number of all deaths includes 2 children and young people for whom there is no residential data. These cases have not been included in the residential numbers.
3. 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 are not included in chapters relating to cause of death or population focus, 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 three), the figures shown in brackets are the number of ACT residents who died interstate or elsewhere.

Table 2.2 shows that the overall pattern of mortality for children and young people is relatively stable. There was a spike in 2015 (n=38) of whom seven were interstate residents. Where there are higher numbers of deaths in the ACT, it is usually expected that there is a correspondingly high number of interstate deaths, however, there was not a corresponding spike in the number of interstate deaths for that year.

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.

The other year-on-year deaths all centre on the average of 31 deaths per year.

The number of ACT residents who die each year is also stable, with an average of 24 deaths each year, drawn up slightly by the higher than average number of deaths in 2015.

The annual figures for 2016 are the lowest in all categories across the five year period.

## Distribution across characteristics: sex, age 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 and cause of death.

Table 2.3: Key demographic and individual characteristics of all deaths of children and young people in the ACT, July 2015 – December 2016 and January 2012 – December 2016

|  | July 2015 – December 2016 (18 months) | | January 2012 – December 2016 (5 years) | |
| --- | --- | --- | --- | --- |
| CHARACTERISTICS | DEATHS | | DEATHS | |
|  | number | per cent | number | per cent |
| **Total** |  |  |  |  |
| Persons 0–17 years of age | 47 | 100 | 155 | 100 |
| **Sex** |  |  |  |  |
| Female | 21 | 44.7 | 79 | 51.0 |
| Male | 26 | 55.3 | 76 | 49.0 |
| **Age** |  |  |  |  |
| Under 1 year | 27 | 57.4 | 109 | 70.3 |
| 1–4 years | • | 8.5 | 13 | 8.4 |
| 5–9 years | 6 | 12.8 | 8 | 5.2 |
| 10–14 years | • | 4.3 | 7 | 4.5 |
| 15–17 years | 8 | 17.0 | 18 | 11.6 |
| **Aboriginal and Torres Strait Islander status** |  |  |  |  |
| Aboriginal and/or Torres Strait Islander | • | 4.3 | 7 | 4.5 |
| Neither Aboriginal nor Torres Strait Islander | 39 | 83.0 | 142 | 91.6 |
| No data | 6 | 12.8 | 6 | 3.9 |

Table 2.3 shows the deaths of children and young people in the ACT or who normally reside in the ACT but died elsewhere broken down by key demographic characteristics. Inherent in the 18-month data are fluctuations that are not necessarily observed in the five year data.

### Sex

An example of variations between the two periods can be seen in the variation between male and female deaths. In the 18-month sample it can be seen that there was a higher incidence of male deaths (55%) but overall, there was minimal difference between sexes, and even shows that females are slightly more prevalent (F=51%, M=49%).

### Age

Age is a consistent predictor of mortality risk. As expected, Table 2.3 shows a higher number of deaths occurring in the early years followed by a substantial reduction through primary years with a subsequent increase again as the young person reaches adolescence and late teens. This pattern is perhaps more pronounced in the five year aggregate data. In the 18 month period deaths which occurred within the first year accounted for 57.4% (n=27), whereas in the five year aggregate period, deaths in the first year were 70.3% (n=109) of all deaths.

Figure 2.1: Distribution of deaths by age in the five years, January 2012 – December 2016

Figure 2.1 shows that by far the greatest mortality risk is for infants aged less than 28 days. Many of the causes of death for these children are related to extreme prematurity and birth defects.

### Cause of death

Table 2.4 presents the causes of all deaths for the five-year period, January 2012 to December 2016. As noted previously, the cause of death provided includes both indicative causes and those categories outlined in the International Classification of Diseases (ICD-10).

Also as noted previously, the majority of deaths occur in the neonatal period and are the result of extreme prematurity and other medical causes. ‘Certain conditions arising in the perinatal period’ are by far the highest cause of death (n=73) followed by ‘chromosomal or congenital anomalies’ (n=18).

| *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. |

Death as a result of suicide or self-harm, on average, impacts one young person a year in the ACT. In 2016 the Committee made a submission to the Standing Committee on Health, Ageing, Community and Social Services Inquiry into Youth Suicide and Self Harm in the ACT this year, demonstrating the common risk factors to young people who had completed suicide in the ACT and highlighting that one of the key risks, and therefore intervention points, is young people who had made a prior attempt.

Deaths that are unascertained continue to present a challenge for the Committee. These deaths can be due to a range of actual causes but there is insufficient evidence to make an accurate determination. These deaths might include deaths ascribed to Sudden Infant Death Syndrome (SIDS) or the sudden unexpected death in infancy (SUDI). They can also include deaths that occurred from co-sleeping but that were inadequately recorded on the death certificate.

Table 2.4: Indicative and ICD-10 cause of death by age bracket in the five years, January 2012 to December 2016

| CAUSE OF DEATH a | < 28 days | 28–365 days | 1–4 years | 5–9 years | 10–14 years | 15–17 years | TOTAL |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Total** | **88** | **20** | **11** | **7** | **6** | **14** | **142** |
| **Extreme prematurity and other medical causes** | **81** | **15** | **9** | **6** | **5** | **7** | **56** |
| Certain conditions originating in the perinatal period | 64 | 9 |  |  |  |  | 73 |
| Chromosomal or congenital anomalies | 12 | • | • |  | • |  | 18 |
| Complications of medical and surgical care | • |  |  |  |  |  | • |
| Diseases of the circulatory system |  |  |  |  |  | • | • |
| Diseases of the musculoskeletal system and connective tissue | • |  |  |  |  |  | • |
| Diseases of the nervous system | • | • | • | • | • | • | 7 |
| Endocrine, nutritional and metabolic disease | • | • |  |  | • | • | • |
| Neoplasms |  |  | 5 | • | • | • | 11 |
| Pervasive developmental disorder |  |  |  |  |  | • | • |
| Respiratory diseases |  |  | • | • |  | • | 5 |
| No data | • |  |  |  |  |  | • |
| **Non-intentional accident/injury** |  |  |  |  | • |  | • |
| Exposure to smoke, fire and flames |  |  |  |  | • |  | • |
| **Suicide** |  |  |  |  | • | • | **5** |
| Hanging, strangulation and suffocation, undetermined intent |  |  |  |  |  | • | • |
| Intentional self harm |  |  |  |  | • | • | • |
| **Transport** |  |  | • |  |  | • | • |
| Transport accidents |  |  | • |  |  | • | • |
| **Unascertained** | • | **5** | • |  |  |  | **9** |
| Symptoms, signs not elsewhere classified | • | 5 | • |  |  |  | 9 |
| **Unintentional injury/accident** |  |  |  |  |  | • | • |
| Other external causes of accidental injuries |  |  |  |  |  | • | • |

1. Cases currently before the Coroner (n=13) are not included in these analyses.

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

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 2012 and 2016.

## Overview

Table 3.1: Breakdown of cases included in analysis,   
January 2012 – December 2016

| DEATHS | NUMBER | PER CENT |
| --- | --- | --- |
| **All deaths b** | **120** |  |
| ACT residents who died in the ACT a | 114 | 95.0 |
| ACT residents who died elsewhere a | 6 | 5.0 |
| No data | 2 | 1.6 |
| Cases before the Coroner | 13 | 10.8 |

1. Included in further analyses
2. Figures do not sum, interstate deaths are excluded and coronial cases appear in more than one category.

In the five years between January 2012 and December 2016 a total of 155 children and young people died in the ACT. Currently there are 13 cases before the Coroner which are outside the scope of this chapter.

In total, 120 ACT residents under the age of 18 years died, with six of those having died elsewhere. Excluding interstate deaths, cases before the Coroner and cases where we do not have residential information, the following discussion relates to the **112 children and young people** normally resident in the ACT who died in the last five years.

As noted in Chapter 1, this report includes some comparisons with the broader Australian population of children and young people. In the following tables the Crude Mortality Rate (CMR) will be used to make comparisons between specific populations between years for the ACT.

Table 3.2: Crude mortality rates (per 10 000) of ACT residents aged 0-17 years for the ACT in the five years between January 2012 and December 2016

| YEAR | POPULATION | DEATHS | ACT CMR |
| --- | --- | --- | --- |
|  | 0-17 years | number | per 10 000 |
| 2012 | 82 120 | 30 | 3.65 |
| 2013 | 83 573 | 30 | 3.59 |
| 2014 | 85 104 | 30 | 3.53 |
| 2015 | 87 073 | 38 | 4.36 |
| 2016 | 88 699 | 27 | 3.04 |

Table 3.2 shows the crude mortality rate for the ACT across years. Ranging between 3.04 and 4.36 deaths per 10 000 children and young people aged 0-17 years in the ACT, the mortality rate for children and young people is relatively stable. Variability between years has not been sufficient to judge a change in the rate of mortality, given the population size.

## Distribution across characteristics: sex, age 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 and cause of death of ACT residents in the five years between January 2012 and December 2016.

Table 3.3: Key demographic and individual characteristics of deaths of children and young people usually residing in the ACT for the five years between January 2012 and December 2016

| CHARACTERISTIC | DEATHS |  |
| --- | --- | --- |
|  | number | per cent |
| **Total** |  |  |
| Persons 0–17 years of age | 112 | 100 |
| **Sex** |  |  |
| Female | 59 | 52.7 |
| Male | 53 | 47.3 |
| **Age** |  |  |
| Under 1 year | 77 | 68.8 |
| 1–4 years | 11 | 9.8 |
| 5–9 years | 7 | 6.3 |
| 10–14 years | 6 | 5.4 |
| 15–18 years | 11 | 9.8 |

In the five years covered by this report a relatively equal distribution was observed between the deaths of ACT males (n=53) and females (n=59). In previous reports the incidence has been slightly skewed toward a higher incidence of male deaths however, as with the previous chapter, female deaths are slightly higher in this period.

### Age

Figure 3.2: Distribution of ACT resident deaths by age, 2012 to 2016

Figure 3.2 shows the distribution of deaths by age for each year. 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 the other age cohorts. In the five years between January 2012 and December 2016, this age bracket accounts for just under 10% of all deaths. This is in keeping with previous periods. Infants under 1 year make up over two thirds of all deaths of ACT residents (70.3%), which is slightly increased from the previous annual report but is consistent with expectations.

### 

### Cause of death

Table 3.5: Indicative and ICD-10 cause of death by age bracket for children and young people usually residing in the ACT for the five years between January 2012 and December 2016

| CAUSE OF DEATH | < 28 days | 28 – 365 days | 1-4 years | 5 – 9 years | 10 – 14 years | 15 – 17 years | TOTAL |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Total** |  |  |  |  |  |  | **112** |
| **Medical causes** | **57** | **11** | **9** | **6** | **5** | **6** | **94** |
| Certain conditions originating in the perinatal period | 45 | 7 |  |  |  |  | 52 |
| Chromosomal or congenital anomalies | 9 | • | • |  | • |  | 14 |
| Diseases of the musculoskeletal system and connective tissue | • |  |  |  |  |  | • |
| Diseases of the nervous system | • |  | • | • | • | • | 6 |
| Endocrine, nutritional and metabolic disease | • | • |  |  | • | • | • |
| Neoplasms |  |  | 5 | • | • | • | 11 |
| Pervasive developmental disorder |  |  |  |  |  | • | • |
| Respiratory diseases |  |  | • | • |  | • | 5 |
| **Suicide** |  |  |  |  | • | • | **5** |
| Hanging, strangulation and suffocation, undetermined intent |  |  |  |  |  | • | • |
| Intentional self harm |  |  |  |  | • | • | • |
| **Transport** |  |  |  | • |  | • | • |
| Transport accidents |  |  |  | • |  | • | • |
| **Unascertained** | • | **5** | • |  |  |  | **11** |
| Symptoms, signs not elsewhere classified | • | 5 |  |  |  |  | 8 |
| No data | • |  | • |  |  |  | • |

Table 3.5 presents the causes of death, both indicative and by ICD-10 grouping, for ACT residents in the period January 2012 to December 2016. As expected, medical causes including conditions relating to extreme prematurity are the lead causes of death (n=94). Of these, ‘certain conditions originating in the perinatal period’ account for the majority of those deaths (n=52).

‘Chromosomal or congenital anomalies’ (n=14) and Neoplasms (n=11), 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. |
| *Neoplasms* | Any new and abnormal growth, specifically one in which cell multiplication is uncontrolled and progressive. Neoplasms may be benign or malignant (Miller-Keane 2003) |

In deaths caused by disorders and diseases of the internal systems of the human body we see a small number of deaths due to self-harm and transport accidents. Suicide remains a concern with intentional self-harm resulting in at least one death a year.

# Chapter 4 Population focus: neonates and infants

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

Table 4.1: Breakdown of cases included in analysis, January 2012 to December 2016

| DEATHS | NUMBER | PER CENT |
| --- | --- | --- |
| **Total b** | **109** | **100** |
| ACT residents who died in the ACT a | 82 | 75.2 |
| ACT residents who died elsewhere a | • | 2.8 |
| Interstate residents who died in the ACT | 27 | 24.8 |
| Cases before the Coroner | 5 | 11.9 |

1. Included in further analyses
2. These figures do not sum due to coronial cases appearing in two categories.

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

In total 82 ACT residents under the age of one year died, with three of those having died elsewhere. There were 27 interstate residents who died in the ACT and there are five cases before the Coroner.

With those children who usually reside elsewhere (n=27) and coronial cases (n=5) removed from these analyses, the following analysis relates to 77 children who were residents of the ACT. The Committee is working more closely with the ACT Perinatal Mortality Committee. While these analyses examine the numbers of deaths within this cohort, detailed analyses are available through the reports of the ACT Perinatal Mortality Committee. These can be found on the ACT Health website.

Distribution across characteristics: sex 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 and cause of death.

Table 4.2: Key demographic and individual characteristics of the deaths of children and young people in the ACT under the age of one year, July 2015 – December 2016 and January 2012 – December 2016

|  | July 2015 – December 2016 (18 months) | | January 2012 – December 2016 (5 years) | |
| --- | --- | --- | --- | --- |
| CHARACTERISTIC | DEATHS | | DEATHS | |
|  | number | per cent | number | per cent |
| **Total** |  |  |  |  |
| Persons 0–1 year of age | 20 | 100 | 77 | 100 |
| **Sex** |  |  |  |  |
| Female | 8 | 44.8 | 36 | 46.8 |
| Male | 12 | 55.2 | 41 | 53.2 |

### Sex

In the five years to December 2016, 77 children 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 distribution between male and female deaths in the 18-month period between July 2015 and December 2016 is slightly more skewed toward male deaths but this is likely due to year-on-year fluctuations.

### Cause of death

Table 4.3 below presents the main causes of death for the five years between January 2012 and December 2016 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 December 2016, children under the age of one year account for 70.3% of all ACT deaths.

Table 4.3: Indicative and ICD-10 cause of death of children less than one year of age in the five years, January 2012 to December 2016

| CAUSE OF DEATH | TOTAL | |
| --- | --- | --- |
|  | number | per cent |
| **All deaths** | **77** | **100** |
| Persons 0–1 year of age | 77 | 100 |
| **Extreme prematurity and other medical causes** | **68** | **88.3** |
| Certain conditions originating in the perinatal period | 52 | 67.5 |
| Chromosomal or congenital anomalies | 12 | 15.6 |
| Diseases of the musculoskeletal system and connective tissue | • | 1.3 |
| Diseases of the nervous system | • | 1.3 |
| Endocrine, nutritional and metabolic disease | • | 2.6 |
| **Unascertained** | **9** | **11.7** |
| Symptoms, signs not elsewhere classified | 8 | 10.4 |
| No data | • | 1.3 |

In keeping with patterns from the broader population, ‘certain conditions originating in the perinatal period’ (n=52) are the major cause of death for this cohort, followed by ‘chromosomal or congenital anomalies’ (n=12). There were nine incidents of death where the cause could not be ascertained (including those deaths with indicative causes of SIDS or SUDI, and where there was no data).

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 jurisdictions 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 52 infants who died in the first month of life was prematurity; extreme prematurity more often than not. Other causes included lung disorders and feeding problems.

# Chapter 5 Population focus: vulnerable 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). 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 in the five years between January 2012 and December 2016.

## Overview

Table 5.1: ACT children and young people who have died and were known to CYPS or ACT Policing, January 2012 – December 2016a

| YEAR | TOTAL | KNOWN TO CYPS | KNOWN TO  ACT POLICING |
| --- | --- | --- | --- |
|  | **112** | **21** | **22** |
| 2012 | 23 | • | • |
| 2013 | 21 | 9 | 8 |
| 2014 | 22 | 7 | 5 |
| 2015 | 26 | 0 | • |
| 2016 | 20 | • | • |
| **Average** | **22.4** | **4.2** | **4.4** |

1. Figures include ACT residents only and do not include open coronial cases

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. While the Committee acknowledges that all children and young people are vulnerable and in need of safe environments in which to grow and be nurtured, in this, and previous reports the involvement of Children and Youth Protection Services (CYPS) and/or ACT Policing (the police) were the two proxy indicators of vulnerability. This year, the Committee has also included a focus on Aboriginal and Torres Strait Islander children and young people.

There are several reasons why the Committee focuses on child protective services and the justice system in particular: firstly, it is a requirement of the legislation but more importantly, because these are the systems that often come into play when difficulties arise in a child’s life and therefore are indicators of unusual vulnerability. The over-representation of Aboriginal and Torres Strait Islander children in these systems generally, and in the figures for death rates overall is also an ongoing concern for the Committee.

## Distribution across characteristics: sex, age and cause of death by engagement with protective services

Table 5.1 outlines the number of children and young people or their families who were known to CYPS or ACT Policing. In the five years between January 2012 and December 2016, 112 residents of the ACT under the age of 18 years died. Overall, 21 children and young people were known to child protective services and 22 were known to police. It is important to note that these broad figures do not account for the extent to which the child or their family was involved with these protective systems.

Table 5.2 below 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 between January 2012 and December 2016. 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 in eight (n=13) 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). Over two-thirds of all children and young people (n=82) were known neither by CYPS nor the police.

Table 5.2: Number of deaths by system engagement risk factors and age for the five years between January 2012 and December 2016

|  | 0–1 YEARS | 1–4 YEARS | 5–9 YEARS | 10–14 YEARS | 15–17 YEARS | TOTAL |
| --- | --- | --- | --- | --- | --- | --- |
| **Known to CYPS** | **13** | • |  | • | • | **21** |
| Police involved | 8 | • |  |  | • | 13 |
| Police not involved | 5 | • |  | • |  | 8 |
| **Not known to CYPS** | **64** | **7** | **7** | **5** | **8** | **91** |
| Police involved | • |  | • | • | • | 9 |
| Police not involved | 60 | 7 | 6 | • | 5 | 82 |
| **TOTAL** | **77** | **11** | **7** | **6** | **11** | **112** |

*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 conducts 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 the Committee 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.

### 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.

Table 5.3: ACT children and young people who have died by child protection reports, police involvement and by sex for the five years between January 2012 and December 2016

|  | CHILD &YOUTH PROTECTION SERVICES | | | ACT POLICING | | |
| --- | --- | --- | --- | --- | --- | --- |
|  | concern | protection | no report | significant adulta | death incident only | not known |
| **Deaths** |  |  |  |  |  |  |
| Persons 0–17 years of agea | 11 | 9 | 92 | 10 | 16 | 81 |
| **Sex** |  |  |  |  |  |  |
| Female | 8 | 5 | 46 | 7 | 7 | 42 |
| Male | • | • | 46 | • | 9 | 39 |

a There is one case where the child was known to CYPS but no data exists on what type of report was made. This child is counted under ’no report’ in this table.

Across the board, females experienced higher representation 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=9) than females (n=7). This is consistent with the pattern reported in previous reports.

Females are almost three times more frequently cited than males in relation to child concern reports. The distribution of Protection reports, the distribution is roughly even, noting the different definitions above. Females were twice as likely to have a significant adult in their life, known to the police. This could be one or both parents, or a close relative.

### 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, noting the different definitions above. The number of individuals who were not the subject of a report was at 82.1%, up from previous reports. The proportion of Child Concern reports has increased slightly from previous reports (up from 8.1% in 2014-15) and Child Protection reports have decreased since the last annual review (down from 11.7% in 2014-15). Given the already low numbers in the ACT these changes are likely due to normal fluctuations.

Table 5.4: Number of ACT notification reports of children who have died by age in the five years between January 2012 and December 2016

| CHILD NOTIFICATION | <1 YEAR | 1–4 YEARS | 5–9 YEARS | 10–14 YEARS | 15–17 YEARS | TOTALa | PER CENT |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Total** | **77** | **11** | **7** | **6** | **11** | **112** | **100** |
| Child Concern Report | 6 | • |  | • | • | 11 | 9.8 |
| Child Protection Report | 7 | • |  |  |  | 9 | 8.0 |
| No report | 64 | 7 | 7 | 5 | 9 | 92 | 82.1 |

a There is one case where the child was known to CYPS but no data exists on what type of report was made. This child is counted under ‘No report’ in this table.

The majority of all 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 five and 14 years of age) seems to be replicated here with fewer reports made on children in the same age bracket.

The Australian Institute of Health and Welfare, in its *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).

Vulnerability was a factor that was considered as part of the Committee’s *Retrospective: Progress in the ACT between 2004 and 2013*. In that review, it was determined that child and youth mortality, as indicated by vulnerability, is generally unchanged in the ACT as a proportion of its broader population.

Table 5.5: Number of ACT child deaths known to ACT Policing by age in the five years between January 2012 and December 2016

| KNOWN TO POLICE | <1 YEAR | 1–4 YEARS | 5–9 YEARS | 10–14 YEARS | 15–17 YEARS | TOTALa | PER CENT |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Level of involvement** |  |  |  |  |  |  |  |
| Involvement in death incident | 12 | • | • | • | 6 | 22 | 19.6 |
| Involvement in death incident only | 8 | • |  | • | 5 | 16 | 14.3 |
| No involvement |  |  |  |  |  | 90 | 80.4 |
| **Previously known** |  |  |  |  |  |  |  |
| Significant adult | 11 |  | • |  |  | 13 | 11.6 |

a Figures do not sum as cases can be included in more than one row

Table 5.5 shows the number of deaths of children and young people who were known—or not—to ACT Policing. One-fifth of all children who died in the five years to December 2016 were 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 or other significant adult was known to the police. In less than half of those cases, both parents were known to the police.

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

There were fewer than five children and young people who were identified as Aboriginal and Torres Strait Islander that died in the five years between January 2012 and December 2016. It is generally accepted that there are complexities in ensuring accurate representation in census data of Aboriginal and Torres Strait Islander people (AIHW 2012). Across the ACT, the 2011 Census calculates Aboriginal and Torres Strait Islander people as comprising 1.5% of the total population. However, utilising moderate projections on Aboriginal and Torres Strait Islander population growth from census data as a proportion of mid-year resident population data over the five years between January 2012 and December 2016, the proportion of children and young people under the age of 18 years and who are of Aboriginal and Torres Strait Islander background is closer to 4% (ABS, 2014).

Table 5.6: Crude mortality rate by Aboriginal and Torres Strait Islander status per population in the five years between January 2012 and December 2016

| ABORIGINAL AND TORRES STRAIT ISLANDER STATUS | POPULATION | DEATHS | CMR | CI |
| --- | --- | --- | --- | --- |
|  | Proportion a | per cent | per 10 000 | lower–upper b |
| Aboriginal and Torres Strait Islander | 3.7 | 3.6 | 0.09 | 0.00-0.19 |
| Neither Aboriginal nor Torres Strait Islander | 96.3 | 92.9 | 2.44 | 1.97-2.91 |
| No data |  | 3.6 |  |  |

a – Based on moderate population projections of children and young people 0-17 years.

b – Confidence intervals that don’t overlap indicate a significant result at the 95% interval.

Table 5.6 shows the crude mortality rates for ACT residents separated by population. Using the higher proportion of population, the data shows that the deaths among children of Aboriginal and Torres Strait Islander descent and children who identify as non-indigenous are evenly distributed. In previous reports, the Committee reported an over-representation of Aboriginal and Torres Strait Islander children, however these reports utilised a larger sample. The low numbers in the ACT are subject to year-on-year fluctuations.

In the Retrospective review for example, the over-representation of Aboriginal and Torres Strait Islander children was found to be concerning and the Committee undertook to engage with the Aboriginal and Torres Strait Islander Elected Body to report findings to that committee.

# Chapter 6 Children and Young People Death Review Committee activities

This chapter provides an overview of the activities of the Children and Young People Death Review Committee throughout 2016. The Committee 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.

## 2016 work program

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 Committee 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.

In 2016, the Committee met quarterly and engaged in a broad range of activities, including submissions and the development of a key report.

**Input to System Review of Family Violence Response in the ACT**

Committee members met with the Review team and provided a submission to the review compiled from evidence generated through in-depth analysis of individual cases.

**Submission to** **Standing Committee on Health, Ageing, Community and Social Services Inquiry into Youth Suicide and Self Harm in the ACT**

A submission prepared for the Standing Committee on Health, Ageing, Community and Social Services Inquiry into Youth Suicide and Self Harm in the ACT and a public version of the submission was distributed to the relevant Directorates and entities, seeking input from those stakeholders on the efforts undertaken to respond to young people with suicidal ideation.

**Submission to Justice and Community Safety Directorate, Family Safety Hub Issues Paper: Information Sharing to Improve the Response to Family Violence in the ACT**

A submission prepared for the consultation undertaken by the Office of the Coordinator General for Family Safety. The submission covered the key themes highlighted in reviews completed by the Committee. These included information sharing and the challenges that a high number of services engaged with a family with complex needs can pose.

***Retrospective: Progress in the ACT between 2004 and 2013***

A report on the changes in death rates in the ACT over the period from 2004 through to 2013 through the lens of social determinants of health; submission and communication/translation strategy. This report was released by the Minister for Disability, Children and Youth in March 2017.

## Continuing work

**Group Review: 0-3 years**

A review of the sociological risk factors that surround and potentially contribute to the death of an infant. This review is underway.

**Data quality**

Monitoring of data quality issues in relation to death certificates and identification of data sources to enhance the quality of data held on the Children and Young People Death Register.

**Information sharing**

Ongoing monitoring of information sharing processes that impact on the safety and wellbeing of children and young people.

**The ACT Perspective**

Given the small size and compact nature of the ACT; our specific population parameters; and the distribution of health and community services, the Committee is in a unique position to review and monitor both trends and the impact of the systems on small groups of families, as well as individual cases. This and the involvement of the committee members in the various parts of the system allow us to identify and advocate for areas for improvement in the Territory’s support for children and young people.

The Committee continues to develop its capacity in both these fields of investigation, including monitoring areas where the incidence of cases indicates significantly lower levels of deaths, such as from unintentional injuries.

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# Appendix 1 Media Releases

Friday, 19 February 2016

Systems review warranted with focus on cross-agency information sharing as key

The ACT Community is understandably shocked by the news this week of the death of an eight year old boy in Canberra’s north. The ACT Children and Young People Death Review Committee actively supports the announcement today of Attorney-General Simon Corbell regarding a systems review into the incident.

Dr Penny Gregory, Chair of the CYPDRC has said that there are so few deaths in the ACT from fatal assault that each one rocks the community. It can be difficult to understand how this could have occurred, especially for people who lived near the family.

“Every death of a child is a tragedy and it is particularly abhorrent when the circumstances involve family violence.“ Dr Gregory said today.

“We do not have all the information on the circumstances of this tragedy and it is important to understand exactly what happened for this family so that we can prevent it from happening again in the future.

“We are pleased to see a focus on cross-agency information sharing which has been identified as a potential area for improving preventable deaths in a number of cases reviewed by the committee.

“Our thoughts are with the family and friends impacted by this tragic event and the committee will support this review in the ways in which we are able.

Tuesday, 08 March 2016

Information sharing key to intervention and prevention

The ACT Children and Young People Death Review Committee met yesterday with Mr Laurie Glanfield to provide its input into the review of ACT system responses to incidents of family violence.

Chair of the Committee, Dr Penny Gregory, said that “The review is an important component of the greater task of ensuring that all ACT crisis and social justice systems work the way they are meant to and create the best environment to support children and their families to get the best help when they need it.

“Too often in the reviews this Committee carries out we see the need for a greater ability to share information between the high numbers of agencies engaged with families in need. This improved communication could have been the key to minimising or preventing harm.

“The often high number of agencies involved with individuals or families experiencing complex situations can mean that no one has complete oversight of what’s happening and sadly, the child’s experience and needs can become invisible as a result.

“Each agency is often operating with a small piece of the picture and in this way, things get missed or the signs that people need help or that a situation is escalating aren’t recognised.

“This is something we can do better.

“The rates of preventable deaths of children and young people in the ACT have been improving in recent years and are on par with other jurisdictions. We are a small jurisdiction and we are making progress in terms of efficient and effective service provision. Yet we still see children who are harmed through violence, poverty, or poor health where this may be aggravated by the system’s difficulty in finding a way through the reticence of many to share vital information when it comes to perceived privacy constraints.

“Ensuring child safety and well-being ought to be the common purpose that brings this community together to better support families before they reach crisis point. In this way we will better minimise and hopefully prevent harm to children and young people.

“The issue of ensuring that the child’s rights and needs are the central focus was a key element of the discussion. We discussed it both in terms of parental rights to privacy overriding the child’s rights for information to be shared for their safety and also in terms of parent rights vs child rights in decisions regarding removing a child.

“The committee shared these views with Mr Glanfield and encouraged him to take a long-term view regarding his recommendations.

“We’re keen to see the outcome of this work and join it with our own reviews of how the system responses might be improved so that there are stronger and more effective mechanisms for early intervention and prevention.

# Appendix 2 Population Tables

**Quarterly Population Estimates (ERP), by State/Territory, Sex and Age: ACT**

|  | June 2012 | | | June 2013 | | | June 2014 | | | June 2015 | | | June 2016 | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Age | **Person** | **Male** | **Female** | **Person** | **Male** | **Female** | **Person** | **Male** | **Female** | **Person** | **Male** | **Female** | **Person** | **Male** | **Female** |
| <1yr | **5278** | **2743** | **2535** | **5508** | **2774** | **2734** | **5575** | **2890** | **2685** | **5614** | **2890** | **2724** | **5477** | **2828** | **2649** |
| 0 | 5278 | 2743 | 2535 | 5508 | 2774 | 2734 | 5575 | 2890 | 2685 | 5614 | 2890 | 2724 | 5477 | 2828 | 2649 |
| 1-4 | **19917** | **10295** | **9622** | **20585** | **10671** | **9914** | **21132** | **10834** | **10298** | **21725** | **11190** | **10535** | **22339** | **11484** | **10855** |
| 1 | 5055 | 2627 | 2428 | 5319 | 2788 | 2531 | 5494 | 2755 | 2739 | 5607 | 2898 | 2709 | 5596 | 2874 | 2722 |
| 2 | 5139 | 2606 | 2533 | 5106 | 2658 | 2448 | 5310 | 2779 | 2531 | 5577 | 2796 | 2781 | 5660 | 2940 | 2720 |
| 3 | 4983 | 2598 | 2385 | 5164 | 2617 | 2547 | 5126 | 2671 | 2455 | 5335 | 2786 | 2549 | 5669 | 2845 | 2824 |
| 4 | 4740 | 2464 | 2276 | 4996 | 2608 | 2388 | 5202 | 2629 | 2573 | 5206 | 2710 | 2496 | 5414 | 2825 | 2589 |
| 5 - 9 | **22507** | **11621** | **10886** | **23102** | **11931** | **11171** | **23760** | **12330** | **11430** | **24659** | **12662** | **11997** | **25156** | **12967** | **12189** |
| 5 | 4647 | 2405 | 2242 | 4790 | 2479 | 2311 | 5013 | 2618 | 2395 | 5242 | 2643 | 2599 | 5270 | 2747 | 2523 |
| 6 | 4773 | 2465 | 2308 | 4687 | 2420 | 2267 | 4783 | 2480 | 2303 | 5001 | 2595 | 2406 | 5276 | 2670 | 2606 |
| 7 | 4472 | 2293 | 2179 | 4796 | 2481 | 2315 | 4700 | 2431 | 2269 | 4814 | 2482 | 2332 | 5035 | 2623 | 2412 |
| 8 | 4342 | 2233 | 2109 | 4456 | 2316 | 2140 | 4806 | 2484 | 2322 | 4755 | 2442 | 2313 | 4814 | 2475 | 2339 |
| 9 | 4273 | 2225 | 2048 | 4373 | 2235 | 2138 | 4458 | 2317 | 2141 | 4847 | 2500 | 2347 | 4761 | 2452 | 2309 |
| 10 - 14 | **21139** | **10717** | **10422** | **21278** | **10765** | **10513** | **21464** | **10885** | **10579** | **21785** | **11128** | **10657** | **22303** | **11457** | **10846** |
| 10 | 4108 | 2074 | 2034 | 4304 | 2208 | 2096 | 4398 | 2260 | 2138 | 4493 | 2327 | 2166 | 4843 | 2516 | 2327 |
| 11 | 4214 | 2129 | 2085 | 4150 | 2092 | 2058 | 4321 | 2221 | 2100 | 4434 | 2273 | 2161 | 4481 | 2321 | 2160 |
| 12 | 4282 | 2165 | 2117 | 4254 | 2130 | 2124 | 4163 | 2086 | 2077 | 4347 | 2237 | 2110 | 4440 | 2270 | 2170 |
| 13 | 4300 | 2180 | 2120 | 4284 | 2162 | 2122 | 4263 | 2144 | 2119 | 4212 | 2123 | 2089 | 4340 | 2232 | 2108 |
| 14 | 4235 | 2169 | 2066 | 4286 | 2173 | 2113 | 4319 | 2174 | 2145 | 4299 | 2168 | 2131 | 4199 | 2118 | 2081 |
| 15 - 17 | **13279** | **6849** | **6430** | **13100** | **6685** | **6415** | **13173** | **6714** | **6459** | **13290** | **6729** | **6561** | **13424** | **6797** | **6627** |
| 15 | 4307 | 2223 | 2084 | 4254 | 2169 | 2085 | 4321 | 2188 | 2133 | 4390 | 2215 | 2175 | 4380 | 2217 | 2163 |
| 16 | 4363 | 2208 | 2155 | 4386 | 2268 | 2118 | 4353 | 2209 | 2144 | 4425 | 2248 | 2177 | 4493 | 2270 | 2223 |
| 17 | 4609 | 2418 | 2191 | 4460 | 2248 | 2212 | 4499 | 2317 | 2182 | 4475 | 2266 | 2209 | 4551 | 2310 | 2241 |
| TOTAL | **62203** | **31930** | **30273** | **62988** | **32155** | **30833** | **63972** | **32819** | **31153** | **65348** | **33409** | **31939** | **66360** | **34049** | **32311** |

**Quarterly Population Estimates (ERP), by State/Territory, Sex and Age: Australia**

|  | June 2012 | | | June 2013 | | | June 2014 | | | June 2015 | | | June 2016 | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Person | Male | Female | Person | Male | Female | Person | Male | Female | Person | Male | Female | Person | Male | Female |
| <1yr | 305017 | 156883 | 148134 | 310144 | 159526 | 150618 | 305827 | 156949 | 148878 | 306715 | 157510 | 149205 | 314988 | 161866 | 153122 |
| 0 | 305017 | 156883 | 148134 | 310144 | 159526 | 150618 | 305827 | 156949 | 148878 | 306715 | 157510 | 149205 | 314988 | 161866 | 153122 |
| 1-4 | 1184328 | 607672 | 576656 | 1207029 | 619849 | 587180 | 1227280 | 630472 | 596808 | 1238114 | 636011 | 602103 | 1251341 | 642835 | 608506 |
| 1 | 293110 | 150370 | 142740 | 307681 | 158218 | 149463 | 311858 | 160337 | 151521 | 307328 | 157700 | 149628 | 308446 | 158399 | 150047 |
| 2 | 298598 | 153338 | 145260 | 296896 | 152313 | 144583 | 310714 | 159700 | 151014 | 314579 | 161786 | 152793 | 309744 | 158955 | 150789 |
| 3 | 296772 | 152289 | 144483 | 302133 | 155199 | 146934 | 299641 | 153732 | 145909 | 313642 | 161296 | 152346 | 317214 | 163062 | 154152 |
| 4 | 295848 | 151675 | 144173 | 300319 | 154119 | 146200 | 305067 | 156703 | 148364 | 302565 | 155229 | 147336 | 315937 | 162419 | 153518 |
| 5 - 9 | 1419580 | 729260 | 690320 | 1455007 | 747686 | 707321 | 1487155 | 764060 | 723095 | 1515041 | 777997 | 737044 | 1530266 | 785601 | 744665 |
| 5 | 291773 | 149989 | 141784 | 299296 | 153485 | 145811 | 303290 | 155684 | 147606 | 307840 | 158182 | 149658 | 305459 | 156717 | 148742 |
| 6 | 291900 | 149914 | 141986 | 294898 | 151612 | 143286 | 301819 | 154833 | 146986 | 305497 | 156807 | 148690 | 310284 | 159413 | 150871 |
| 7 | 282830 | 145552 | 137278 | 294677 | 151350 | 143327 | 297305 | 152840 | 144465 | 303859 | 155870 | 147989 | 307558 | 157872 | 149686 |
| 8 | 277990 | 142903 | 135087 | 285547 | 146990 | 138557 | 296954 | 152509 | 144445 | 299098 | 153689 | 145409 | 305920 | 156889 | 149031 |
| 9 | 275087 | 140902 | 134185 | 280589 | 144249 | 136340 | 287787 | 148194 | 139593 | 298747 | 153449 | 145298 | 301045 | 154710 | 146335 |
| 10 - 14 | 1391602 | 713342 | 678260 | 1398678 | 716616 | 682062 | 1407357 | 721694 | 685663 | 1420565 | 729500 | 691065 | 1442650 | 740776 | 701874 |
| 10 | 274393 | 140506 | 133887 | 277671 | 142202 | 135469 | 282680 | 145384 | 137296 | 289633 | 149096 | 140537 | 300505 | 154349 | 146156 |
| 11 | 278277 | 142824 | 135453 | 276622 | 141696 | 134926 | 279770 | 143328 | 136442 | 284385 | 146265 | 138120 | 291322 | 149988 | 141334 |
| 12 | 279028 | 142729 | 136299 | 280696 | 144111 | 136585 | 278532 | 142718 | 135814 | 281533 | 144290 | 137243 | 285978 | 147079 | 138899 |
| 13 | 279960 | 143374 | 136586 | 281418 | 143949 | 137469 | 282793 | 145215 | 137578 | 280239 | 143575 | 136664 | 283028 | 145028 | 138000 |
| 14 | 279944 | 143909 | 136035 | 282271 | 144658 | 137613 | 283582 | 145049 | 138533 | 284775 | 146274 | 138501 | 281817 | 144332 | 137485 |
| 15 - 17 | 863831 | 444329 | 419502 | 861120 | 442820 | 418300 | 862803 | 442712 | 420091 | 865200 | 443332 | 421868 | 872056 | 446425 | 425631 |
| 15 | 283757 | 145591 | 138166 | 282711 | 145376 | 137335 | 284731 | 145897 | 138834 | 286432 | 146468 | 139964 | 288195 | 147970 | 140225 |
| 16 | 286262 | 147350 | 138912 | 287649 | 147619 | 140030 | 286193 | 147119 | 139074 | 288283 | 147707 | 140576 | 290615 | 148481 | 142134 |
| 17 | 293812 | 151388 | 142424 | 290760 | 149825 | 140935 | 291879 | 149696 | 142183 | 290485 | 149157 | 141328 | 293246 | 149974 | 143272 |
| TOTAL | 5164358 | 2651486 | 2512872 | 5231978 | 2686497 | 2545481 | 5290422 | 2715887 | 2574535 | 5345635 | 2744350 | 2601285 | 5411301 | 2777503 | 2633798 |

**Estimated and projected Aboriginal and Torres Strait Islander population, Series B(a), Single year of age, Australian Capital Territory and Australia**

|  |  | Australian Capital Territory | | | | | Australia | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Age |  | **2012** | **2013** | **2014** | **2015** | **2016** | **2012** | **2013** | **2014** | **2015** | **2016** |
| 0 | no. | 152 | 157 | 166 | 172 | 178 | 8,574 | 8,814 | 9,064 | 9,323 | 9,585 |
| 1 | no. | 163 | 155 | 160 | 169 | 175 | 8,163 | 8,564 | 8,804 | 9,054 | 9,313 |
| 2 | no. | 149 | 161 | 154 | 159 | 169 | 8,567 | 8,160 | 8,561 | 8,801 | 9,051 |
| 3 | no. | 141 | 148 | 159 | 152 | 158 | 8,592 | 8,564 | 8,157 | 8,558 | 8,798 |
| 4 | no. | 121 | 138 | 145 | 155 | 148 | 8,437 | 8,589 | 8,562 | 8,155 | 8,556 |
| 5 | no. | 121 | 119 | 135 | 141 | 150 | 8,419 | 8,435 | 8,587 | 8,560 | 8,153 |
| 6 | no. | 133 | 118 | 116 | 131 | 136 | 8,467 | 8,417 | 8,433 | 8,585 | 8,558 |
| 7 | no. | 118 | 129 | 115 | 114 | 128 | 8,206 | 8,465 | 8,415 | 8,431 | 8,583 |
| 8 | no. | 142 | 117 | 127 | 114 | 114 | 7,978 | 8,205 | 8,464 | 8,414 | 8,430 |
| 9 | no. | 126 | 141 | 118 | 128 | 115 | 7,906 | 7,977 | 8,204 | 8,463 | 8,413 |
| 10 | no. | 121 | 127 | 141 | 120 | 129 | 8,044 | 7,905 | 7,976 | 8,203 | 8,462 |
| 11 | no. | 117 | 121 | 127 | 141 | 120 | 8,114 | 8,043 | 7,904 | 7,975 | 8,202 |
| 12 | no. | 143 | 118 | 121 | 126 | 141 | 7,906 | 8,113 | 8,042 | 7,903 | 7,974 |
| 13 | no. | 121 | 138 | 115 | 118 | 123 | 7,826 | 7,904 | 8,111 | 8,040 | 7,901 |
| 14 | no. | 139 | 117 | 134 | 112 | 115 | 8,031 | 7,824 | 7,902 | 8,109 | 8,038 |
| 15 | no. | 127 | 136 | 115 | 132 | 111 | 7,949 | 8,028 | 7,821 | 7,899 | 8,106 |
| 16 | no. | 118 | 129 | 138 | 117 | 134 | 7,919 | 7,945 | 8,024 | 7,817 | 7,895 |
| 17 | no. | 158 | 127 | 138 | 146 | 126 | 7,938 | 7,914 | 7,941 | 8,020 | 7,813 |
| Total | no. | 2,410 | 2,396 | 2,424 | 2,447 | 2,470 | 147,036 | 147,866 | 148,972 | 150,310 | 151,831 |
| (a) Projection Series B (moderate growth) has been used for the period 2012-2026. | | | | | | | | | | | |

# Appendix 3 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**

Thepopulation 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 2016.

Rates are calculated using child death data contained in the register and both ABS estimated (2009 to 2014) and projected (2016) 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 4 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 –

1. is a descendant of an Aboriginal person or Torres Strait Islander person; and
2. identifies as an Aboriginal person or Torres Strait Islander person; and
3. 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 theinitiative 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.

