

ACT Children & Young People
Death Review Committee

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:
ACT Children and Young People Death Review Committee
GPO Box 158, Canberra ACT 2601
e childdeathcommittee@act.gov.au t 02 6205 2949
ISSN 2205-7250

© Australian Capital Territory, Canberra 2017

This work is copyright. Apart from use permitted under the *Copyright Act 1968*, no part may be reproduced by any process without written permission from the Community Services Directorate, ACT Government, GPO Box 158, Canberra ACT 2601.

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



ACT Children & 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, 2008* (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

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

GPO Box 158 Canberra City ACT 2601

t 02 6205 2949 | e childdeathcommittee@act.gov.au

Contents

ACT Children and Young People Death Review Committee	i
Foreword	i
Letter of transmission	ii
Executive summary	iv
Chapter 1 Introduction to the Children and Young People Death Review	1
Chapter 2 All deaths of children and young people residing in or visiting the Australian Capital Territory	4
Chapter 3 Deaths of ACT resident children and young people: five-year review	8
Chapter 4 Population focus: neonates and infants	11
Chapter 5 Population focus: vulnerable children and young people	13
Chapter 6 Children and Young People Death Review Committee activities	17
References	19
Appendix 1 Media Releases	20
Appendix 2 Population Tables	22
Appendix 3 Methodology	25
Appendix 4 Definition of terms	26

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

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 an 18 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 Committee 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.

Using this report

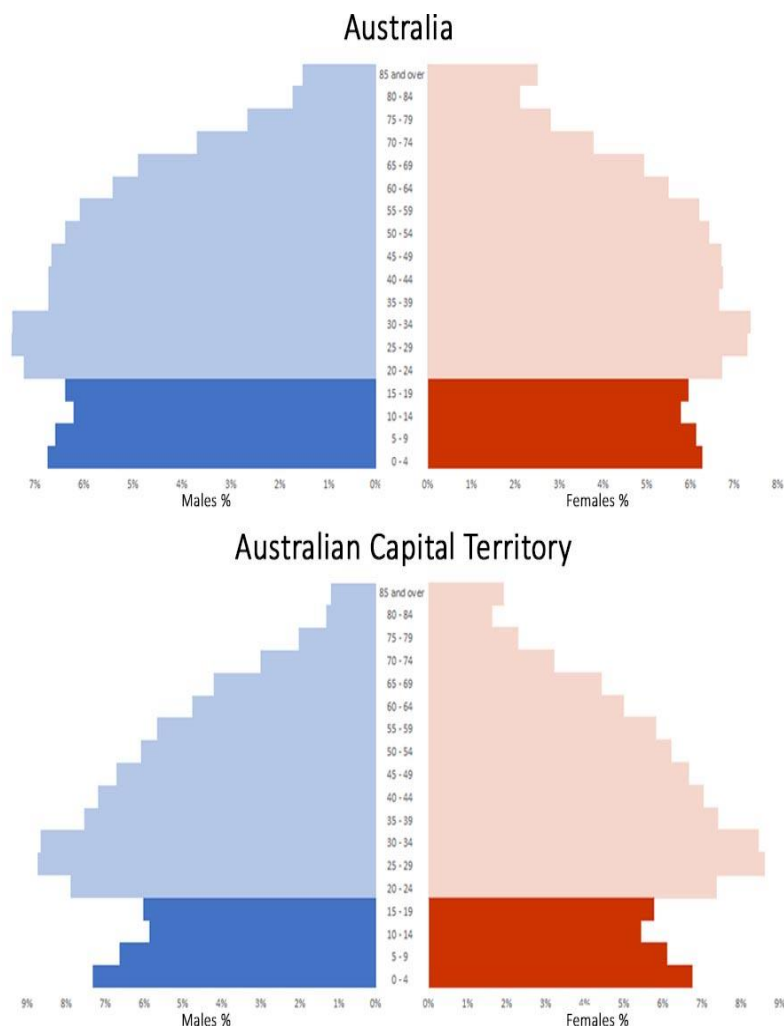
The annual report is a legislated requirement of the Committee and can be utilised as a catalyst or foundation for further investigations. To facilitate clarity of understanding and enable greater use and reporting on the findings of this report it is important to clarify the methods used.

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.

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



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.

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.

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%

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	
	number	number	per cent	number	per cent
Jan-Dec	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	

a. 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.

b. 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.

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 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

CHARACTERISTICS	July 2015 – December 2016 (18 months)		January 2012 – December 2016 (5 years)	
	DEATHS number	per cent	DEATHS 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

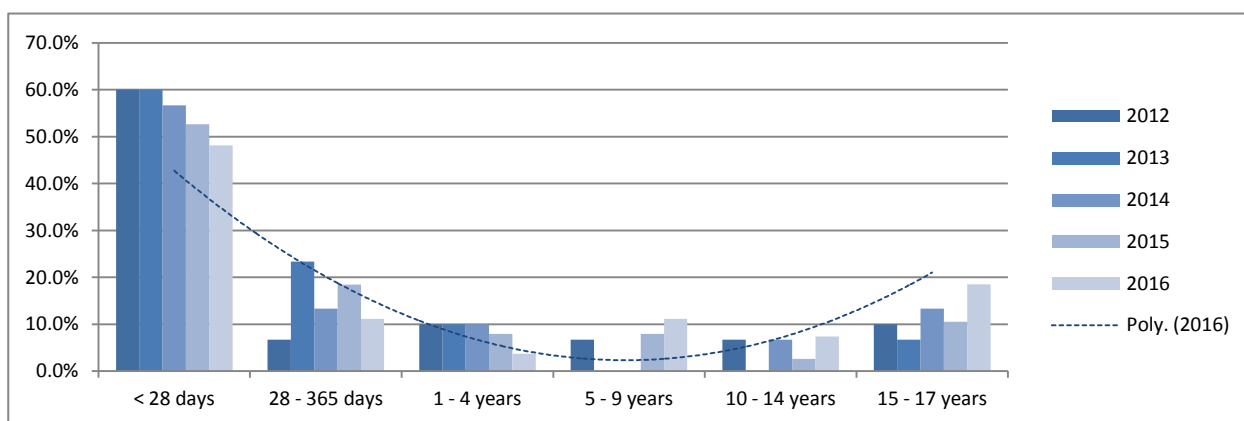


Figure 2.1 shows that by far the greatest mortality risk is for infants aged less than 28 days. Many of the causes of death for these children are related to extreme prematurity and birth defects.

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						•	•

a. 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

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

DEATHS	NUMBER	PER CENT
All deaths ^a	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

a. Included in further analyses

b. Figures do not sum, interstate deaths are excluded and coronial cases appear in more than one category.

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 0-17 years	DEATHS number	ACT CMR 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

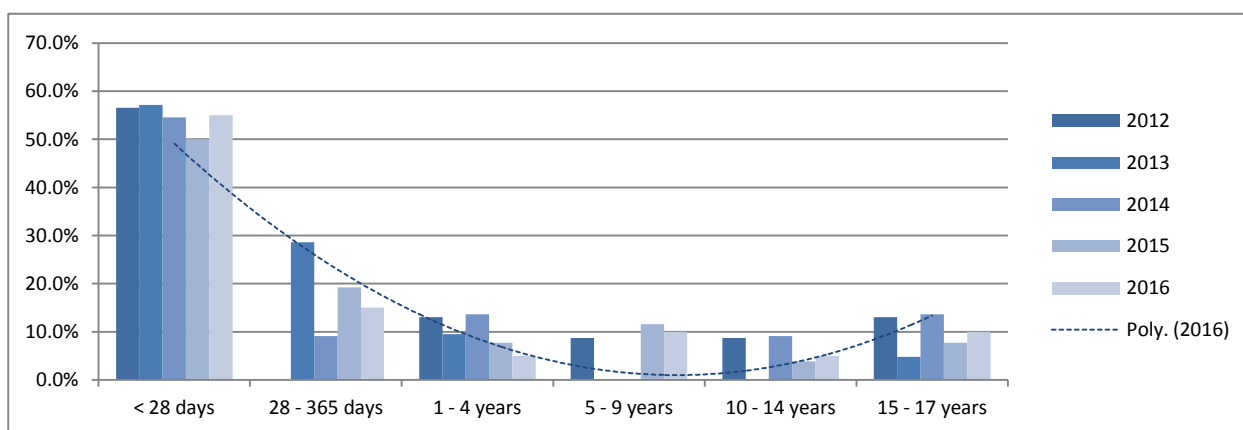


Figure 3.2 shows the distribution of deaths by age for each year. A similar pattern to that shown in Chapter 2 has been repeated whereby the proportion of deaths that occur in the primary school years—that is, between 5 and 14 years of age—is markedly lower than the other age cohorts. In the five years 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

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.

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

a. Included in further analyses

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

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

CHARACTERISTIC	July 2015 – December 2016 (18 months)		January 2012 – December 2016 (5 years)	
	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

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.

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

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

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

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 adult ^a	death incident only	not known
Deaths						
Persons 0–17 years of age ^a	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	TOTAL ^a	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	TOTAL ^a	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.

References

ABS (Australian Bureau of Statistics) 2014. Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Cat. no. 3238.0. Canberra: ABS. Viewed 19 April 2017, <<http://stat.data.abs.gov.au/>>.

Australian Bureau of Statistics, 2016, Quarterly Population Estimates (ERP), by State/Territory, Sex and Age, (Cat no 3101.0), extracted 23 April 2017, <<http://stat.data.abs.gov.au> >AIHW (Australian Institute of Health and Welfare) 2015. Child protection Australia 2013–14. Child welfare series no. 61. Cat. no. CWS 52. Canberra: AIHW. Viewed 27 April 2017, <<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129554513>>.

AIHW (Australian Institute of Health and Welfare) 2012. Indigenous statistics: quality and availability. Canberra: AIHW. Viewed 27 April 2017, <<http://www.aihw.gov.au/indigenous-statistics-quality-availability/>>.

Children and Young People Act 2008 (ACT) (ACT legislation Register)

Miller-Keane (Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health) 2003. Neoplasm. 7th edn. Philadelphia: Saunders. In: The Free Dictionary 2015. Viewed 27 April 2017, <<http://medical-dictionary.thefreedictionary.com/neoplasm>>.

NSW Health (Ministry of Health, NSW) 2010. Policy directive: Critical Care Tertiary Referral Networks (Perinatal). North Sydney: Ministry of Health, NSW. Viewed 27 April 2017, <http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2010_069.pdf>.

WHO 2016. Classification of Diseases. Geneva: WHO. Viewed 27 April 2017, <<http://www.who.int/classifications/icd/en/>>.

WHO 2011. International Statistical Classification of Diseases and Related Health Problems 10th revision: Volume 2 Instruction manual. 2010 edn. Geneva: WHO. Viewed 27 April 2017, <http://apps.who.int/classifications/icd10/browse/Content/statichtml/ICD10Volume2_en_2010.pdf>.

WHO (World Health Organization) 2010. International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10): Version for 2010. Geneva: WHO. Viewed 27 April 2017, <<http://apps.who.int/classifications/icd10/browse/2010/en#!/XVI>>.

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.

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

Age	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	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



Appendixes

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

Age	Australian Capital Territory					Australia				
	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

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 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 –

- 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

Appendixes

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*

GPO Box 158 Canberra City ACT 2601

t 02 6205 2949 | **e** childdeathcommittee@act.gov.au