ACT Children & Young People
Death Review Committee

Annual Report 2019

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* (ACT) to work towards reducing the number of deaths of ACT children and young people. The Committee reports to the Minister for Children, Youth and Families.

The legislation sets out the requirement for Committee members to have experience and expertise in a number of different areas, including paediatrics, education, epidemiology, 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. We 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 of individuals.

What do we do with the information on the register?

The Committee provides its annual report on the deaths of children and young people in the ACT to the Minister for Children, Youth and Families and the ACT Legislative Assembly.

We also issue reports and fact sheets to government, public organisations and the community on different topics to help raise awareness of child safety or to spread child death prevention messages.

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

Foreword

The ACT Children and Young People Death Review Committee (the Committee) is pleased to present its eighth report to the Legislative Assembly. It is presented in line with the requirements of Part 19A.4 of the *Children and Young People Act 2008* (ACT) (the Act), noting its delay due to COVID-19-related resource constraints.

This report is based on information provided to the Committee on the deaths of children and young people that occurred during the calendar year 2019. The number of deaths in 2019 is lower than previous years; however, this result should be interpreted with caution as statistical fluctuations are known to occur with small numbers. As in previous reports, the detailed analysis of the data is based on the aggregation of five years of data (2015–19), thus ensuring individual privacy.

Within the ACT, children die from many different causes, and the numbers of children and young people who die fluctuate over the years. As a small jurisdiction these statistical fluctuations seem more pronounced. The work is, by its very nature, difficult and at times confronting; however, the Committee remains committed to engaging with government and public organisations i to influence change that achieves better outcomes for children.

As required by the Act, the Committee maintains a database of child deaths to which it continually adds information that informs its analyses about rates and patterns of child death in the ACT. This year a focus of the Committee has been to improve data quality. Developing a better understanding of the circumstances and risk factors surrounding the deaths of children and young people provides the greatest opportunities to prevent future deaths. During 2019 I have had the opportunity to meet with many of the individuals and bodies that work tirelessly to improve the safety and wellbeing of children and young people in the ACT. The enthusiasm, skill and expertise of these individuals have contributed to key developments regarding data quality of the Committee. I would like to thank in particular the Co-ordinator General, Mental Health and Wellbeing, Dr Elizabeth Moore, the ACT Coroners Unit and the Emergency Services Agency for their ongoing support of the Committee.

The reviews of all deaths of children who have died in the ACT, both during the 2019 calendar year and cumulatively since the Committee's work began, continue to raise important issues for service planning and delivery and opportunities to improve systems. In 2019 the Committee commenced a review of deaths occurring from intentional self-harm. At a national level there has been a call to reduce the substantial mortality and morbidity burden associated with suicide and suicidal behaviour. The Committee hopes to present the findings of this review to the Minister in 2020.

This year Rebecca Hughes resigned from the Committee and we welcomed the appointment of the Deputy Director-General of the Education Directorate. All members make an invaluable contribution to the work of the Committee and I would like to express my gratitude for the skill and expertise they bring. I was privileged to be appointed for a further three years and I look forward to working with members to effect change that will prevent and reduce child deaths in the ACT. This year we also farewelled Dr Vicky Saunders who over the past three years has provided exceptional, high-quality research and secretariat support to the Committee, enabling the Committee to confidently make recommendations to improve systems and processes for young people. We wish Vicky well in her future career.

The death of any child is a tragedy, and the members of the Committee and I would 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 Children, Youth and Families
ACT Legislative Assembly
London Circuit
CANBERRA ACT 2601

Dear Minister

As chair of the ACT Children and Young People Death Review Committee, I am pleased to present you with the *Children and Young People Death Review Committee 2019 Annual Report*.

This report fulfils the Committee's statutory obligations under s. 727S of the *Children and Young People Act 2008* (ACT).

The timing of this report has been delayed due to COVID-19 impact on secretariat resourcing and related recruitment action.

I hereby present the report for tabling in the Legislative Assembly and request that you make the report public forthwith.

Yours sincerely

M Carmody

Ms Margaret Carmody, PSM
Chair
16 June 2020

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

Executive summary

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

In accordance with s. 727S of the Act, this report provides information on the deaths of 160 children and young people up to the age of 18 years who were included on the Committee's Child and Young Person Deaths Register in the five-year period 2015–2019. Of the 160 deaths across the latest five-year period, eight are awaiting the findings of the Coroner and are therefore not able to be included in this report. The remaining 152 deaths on the register include 27 deaths of children and young people who did not normally reside in the ACT.

Chapter 1 introduces the Children and Young People Death Review Committee. It lays out the legislative requirements of this report and the limitations of the data. It also explains how to use this report.

Chapter 2 provides an overview of all registered deaths of children and young people residing in or visiting the ACT.

Chapter 3 examines the deaths of children and young people who were ACT residents, 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. This chapter focuses on neonates and infants.

Chapter 5 focuses on vulnerable children and young people.

Chapter 6 describes the Committee's activities during 2019 and its continuing work for the next calendar year.

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

Chapter 1 Introduction to the Children and Young People Death Review Committee

This chapter describes the **role of the ACT Children and Young People Death Review Committee** and provides important information on how to read this report.

ACT Children and Young People Death Review Committee

The ACT Children and Young People Death Review Committee is an independent committee established under the *Children and Young People Act 2008* (ACT) (the Act) 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.

This report is the main vehicle to share the findings of that research. From these analyses, the Committee recommends changes to legislation, policies, practices and services. The Committee also wishes to share these findings and maintain a dialogue with the ACT community, whose greater awareness of these issues may help reduce preventable deaths in the future.

Information about previous annual reports and additional reports on identified issues of concern can all be found on the Committee's website: www.childdeathcommittee.act.gov.au

Who we are

Since 2012, the Committee has been responsible for reporting to the ACT Legislative Assembly on all deaths of children and young people under the age of 18 years in the ACT. Membership is prescribed by the Act and requires members to have qualifications, experience or expertise in one or more of the following:

- psychology
- paediatrics
- epidemiology
- child forensic medicine
- public health administration
- education
- engineering and child safety products or systems
- working with Aboriginal and Torres Strait Islander children and young people
- social work
- investigations
- mental health
- child protection or
  -has other qualifications, experience or expertise, or membership of an organisation, relevant to exercising the functions of a committee member or
  -is a police officer with experience in working with children and young people and families.

The Director-General, Community Services Directorate (CSD) and the Commissioner for Children and Young People are ex-officio appointments. Committee members are appointed by the Minister for Children, Youth

and Families, and the Committee must have between eight and ten members in addition to the Chair. The Deputy Chair may undertake some of the roles of the Chair in their absence, including chairing of meetings.

Committee members 2019

Chair

Ms Margaret Carmody PSM
Social policy and strategic human service delivery

Deputy Chair

Mr Eric Chalmers AM CF
Engineering and child safety products or systems

Ex-officio Committee members

Director General, Community Services Directorate	**Ms Rebecca Cross PSM**
Children and Young People Commissioner	**Ms Jodie Griffiths-Cook**

Committee members

Dr Judith Bragg
Paediatrics

Ms Barbara Causon
Working with Aboriginal and Torres Strait Islander children and young people

Dr Amanda Dyson
Paediatrics and Neonatology

Dr Louise Freebairn
Epidemiology

Emeritus Professor Morag McArthur
Social Work and Child Protection

Dr Sue Packer AM
Paediatrics

Dr Catherine Sansum
Child forensic medicine

Ms Rebecca Hughes (Feb 2019 – Sept 2019)
Representative of Education

Ms Meg Brighton (November 2019 – Current)
Deputy Director General, Education

Station Sergeant Dennis Gellatly
ACT Policing – Officer in Charge, Judicial Operations
Police officer with experience in working with children and young people and families

Our functions

The Committee has the following functions:

a) to keep a register of deaths of children and young people under Part 19A.3 of the Act
b) to identify patterns and trends in relation to the deaths of children and young people
c) to undertake research that aims to help prevent or reduce the likelihood of the death of children and young people
d) to identify areas requiring further research, by the Committee or another entity, that arise from the identified patterns and trends in relation to the deaths of children and young people
e) to make recommendations about legislation, policies, practices and services for implementation by the territory and non-government bodies to help prevent or reduce the likelihood of the death of children and young people
f) to monitor the implementation of the Committee's recommendations
g) to report to the Minister under Part 19A.4 of the Act
h) to perform any other function given to the Committee under this chapter.

Annual report

This annual report covers the period 2015 to 2019. It presents the data on 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.

Chapter 19A, Part 19A.4, s. 727S of 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 s. 360(5), was a child protection report'
- any identified patterns or trends, both generally and in relation to the child protection reports under s. 360(5) of the Act.

The Committee respects the child, young person and their family's right to privacy. As per s. 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 the five-year period. This is largely as a result of 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 noted and discussed across the report and, as such, caution must be exercised when interpreting results.

The annual report presents the Committee's activities during 2019 and outlines the continuing work for 2020. Last year, the annual report presented a chapter reviewing the progress on the recommendations made since its establishment. In discussion with Minister Stephen-Smith, the Committee has decided to undertake this activity biennially so that the off-year report may provide a more comprehensive analysis of specific issues, which may be more useful to government and the ACT community.

Using this report

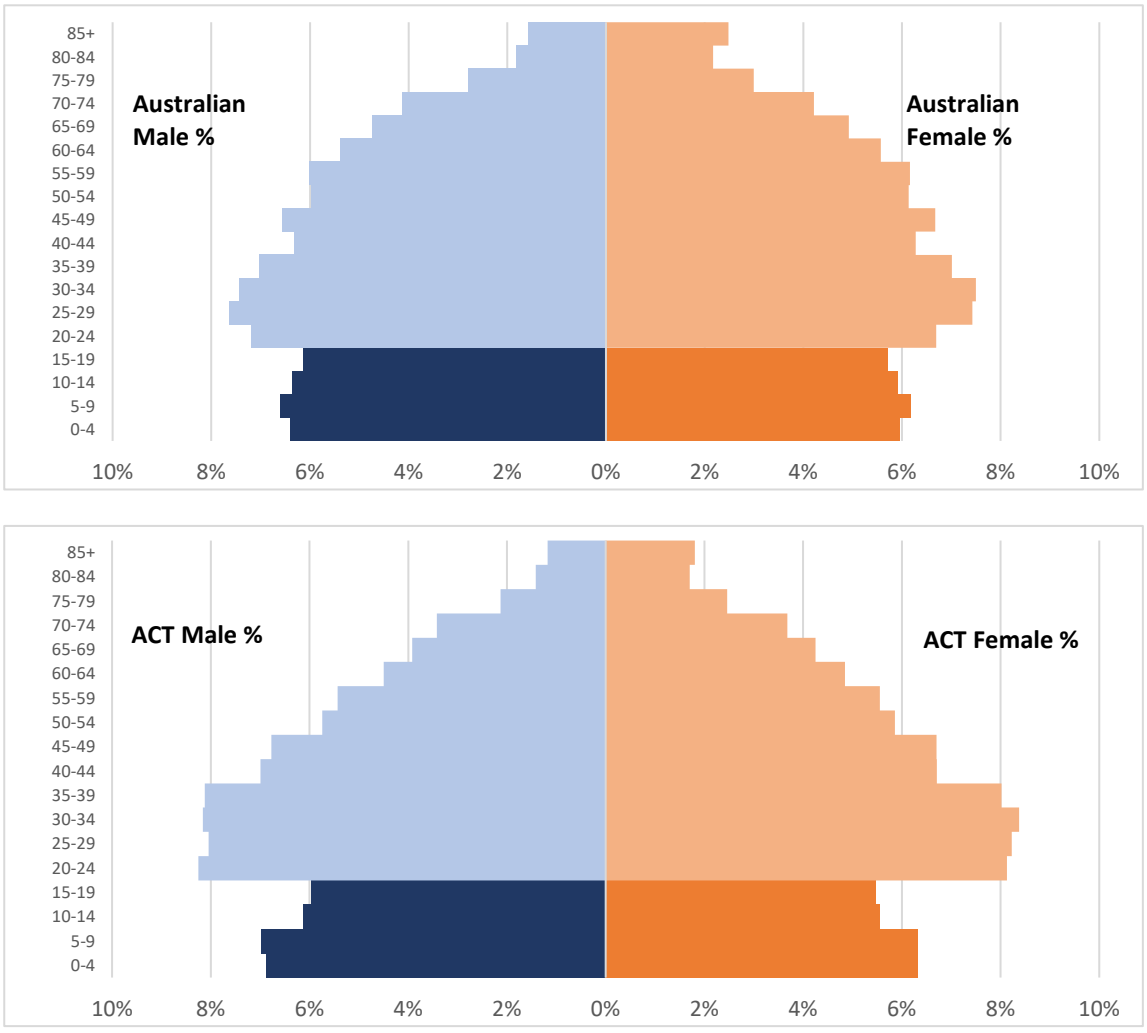
This annual report is a legislated requirement of the Committee and can be used as a catalyst or foundation for further investigations. To increase transparency and to enable greater use and reporting on the findings of this report, it is important to clarify the methods used.

ACT Population

The ACT's population continues to increase, having the third-strongest growth in estimated resident population of all jurisdictions in the three months to 30 June 2019 (ACT Treasury, 2019). The ACT population is currently projected to reach around 450,000 people by 2022. This increase is also seen in children and young people under 19 years of age. Canberra remains 'younger' than the national average, and the number of children and young people is projected to increase by 11% between 2017 and 2022. This age group accounts for around 25% of the total ACT population (ACT Treasury, 2019).

Figure 1.1 shows the differences between the age structures of both the ACT and Australia based on the Australian Bureau of Statistics' (ABS) quarterly population estimates data (ABS, 2019b). The focus of this report is those children and young people under the age of 18 years. This group is highlighted in the bolder colours.

Figure 1.1 Population ratios comparing male and female total population between Australia and the ACT, 2019



Data source: (ABS, 2019b)

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.

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. Reporting on coronial cases by the Committee is also impacted by two factors: the legislative requirement to not comment on open coronial matters and systemic delays in finalising coronial cases.

The legislation clearly stipulates that the Committee must not report on the causes of death of those cases that are being heard in the Coroner's 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 open coronial cases. 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.

In the context of coronial inquests into the deaths of children and young persons, depending on the case, there are two main sources of delay: the need for expert medical and/or forensic investigation or the requirement to 'pause' coronial proceedings where there are related criminal proceedings underway. Where coronial inquests remain open past the five-year reporting period of the Committee's annual report, data about those cases will not be captured. In such circumstances, comment will be made on specific cases in the subsequent years' annual report, noting that information about coronial findings where public hearings have been held is ordinarily in the public domain.

International Classification of Diseases

Since the inception of the Children and Young People Death 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 transitioned to reporting on the ICD framework, in line with World Health Organization standards (WHO, 2016). This report will continue the format adopted in the previous reports and include both the indicative causes of death and the ICD.

Reporting fewer than five cases

Given the small number of child or young person deaths in the ACT and the broad range of causes of those deaths, often there will be only one or two individuals who have died in a category. 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 and the individual may be identified, 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. The suppression of further data will not occur when it will significantly impact on the Committee's ability to report population trends. In these instances, calculation of figures may be possible. The identity of a child or young person who has died will not be disclosed or be able to be worked out. The supressed numbers will remain included in total figures and aggregated counts over five years.

Data quality

The Committee continues to work to improve data quality to more accurately identify the factors that contribute to the reported deaths. 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. The Child Death Register database continues to be problematic in that it is complex and sometimes unreliable. The Committee have sought the assistance of CSD to undertake a review of this system and work continues to identify a suitable solution.

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, ACT Coroner's Court, Ombudsman Western Australia, South Australia Child Death and Serious Injury Review Committee, Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity, NSW Ombudsman, Tasmanian Council of Obstetric and Paediatric Mortality and Morbidity, Northern Territory Office of the Coroner, Queensland Child Death Review Team, and the National Coronial Information System. The Committee also has provisions to exchange data with Child Youth and Families, ACT Policing, Emergency Services Agency and the Family Court and Federal Circuit Court of Australia. 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.

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 of 1 January 2015 to 31 December 2019. Subsequent chapters in this report will focus on ACT residents only; however, this chapter takes a broad overview of all deaths that have occurred in the ACT, including children and young people who typically lived interstate or elsewhere.

Overview

This section describes 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 2015 to 2019.

Table 2.1: Deaths of children and young people in the ACT, 2015–2019

Deaths	Number[a]	Per cent
All deaths in the ACT	**160**	
Total ACT resident deaths	131	81.9
Interstate resident deaths	29	18.1
ACT residents who died elsewhere	14	8.8
Open coronial cases	8	5.0

[a] Figures do not sum; coronial cases appear in more than one category.

In total, 160 children and young people died in the five-year period 2015 to 2019. Of these, 131 were children and young people who normally resided in the ACT and 29 usually resided interstate. Of the 131 ACT residents who died, 14 of these deaths occurred elsewhere. There were also 8 cases before the ACT Coroner for the period 2015 to 2019, as at 22 April 2020.

ACT residents and non-residents

The Committee collects information relating to the deaths of all children and young people who die, and 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).

Table 2.2: Annual deaths of children and young people including ACT residents who died elsewhere, 2015–2019

Year	All deaths[a]	ACT residents		From elsewhere	
Jan-Dec	Number	Number	Per cent	Number	Per cent
	160	**131**	**81.9**	**29**	**18.1**
2015	37	29	78.4	8	21.6
2016	32 (1)	27	84.4	5	15.6
2017	31 (1)	23	74.2	8	25.8
2018	41 (6)	36	87.8	5	12.2
2019	19	16	84.2	•	•
Average	**32**	**26.2**		**5.8**	

[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.

Information was not available from South Australia for this report due to the impact of COVID-19 on resourcing; any deaths that are subsequently reported will be included in future reports. In the previous five years covered in this report, no deaths of ACT residents were recorded in South Australia.

In regard to all deaths (Table 2.2), 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 Coronial investigations.

Table 2.2 shows the year-on-year deaths of children and young people, of which the five-year average for 2015 to 2019 is 32. This is a decrease from the average in last year's report of 34. For ACT residents, the five-year average for the number of children and young people who died has also decreased from last year, with the mean moving from 27.4 in 2018 to 26.2 in 2019. While this is a positive trend in 2019, it should be noted that the number of child deaths each year in the ACT fluctuates due to our small population, and the decrease in 2019 should be interpreted with caution. The age-specific mortality rates of ACT residents aged 0–17 years are provided in Chapter 3.

Distribution across characteristics

The following discussion focuses on 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, and Aboriginal and Torres Strait Islander status.

Table 2.3 shows the total deaths of children and young people (not including open coronial cases) in the ACT over the five-year period 2015 to 2019, broken down by key demographic characteristics.

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 an increase again in adolescence and late teens. In the 12-month period to December 2019, deaths which occurred within the first year of life accounted for 53% (n=10). For the five-year aggregate period, deaths in the first year accounted for 65% (n=99) of all deaths.

Table 2.3: Key demographic characteristics of all deaths of children and young people in the ACT, 2015–2019

Characteristics	2015–2019 Deaths[a]	
	Number	Per cent
Total		
Persons 0–17 years of age	152	
Sex		
Female	65	42.8
Male	87	57.2
Age		
Less than 28 days	82	53.9
28-365 days	17	11.2
1–4 years	13	8.6
5–9 years	9	5.9
10–14 years	13	8.6
15–17 years	18	11.8
Aboriginal and Torres Strait Islander status		
Aboriginal and/or Torres Strait Islander	6	4
Neither Aboriginal nor Torres Strait Islander	140	92
Unknown	6	4

[a] Figures do not include open coronial cases.

Table 2.4 shows the total deaths of children and young people in 2019, broken down by key demographic characteristics. Due to small numbers, the age brackets in this table have been aggregated to show deaths of children aged 0–4 years and 5–17 years. The 12-month and five-year data consistently shows a higher incident of male deaths.

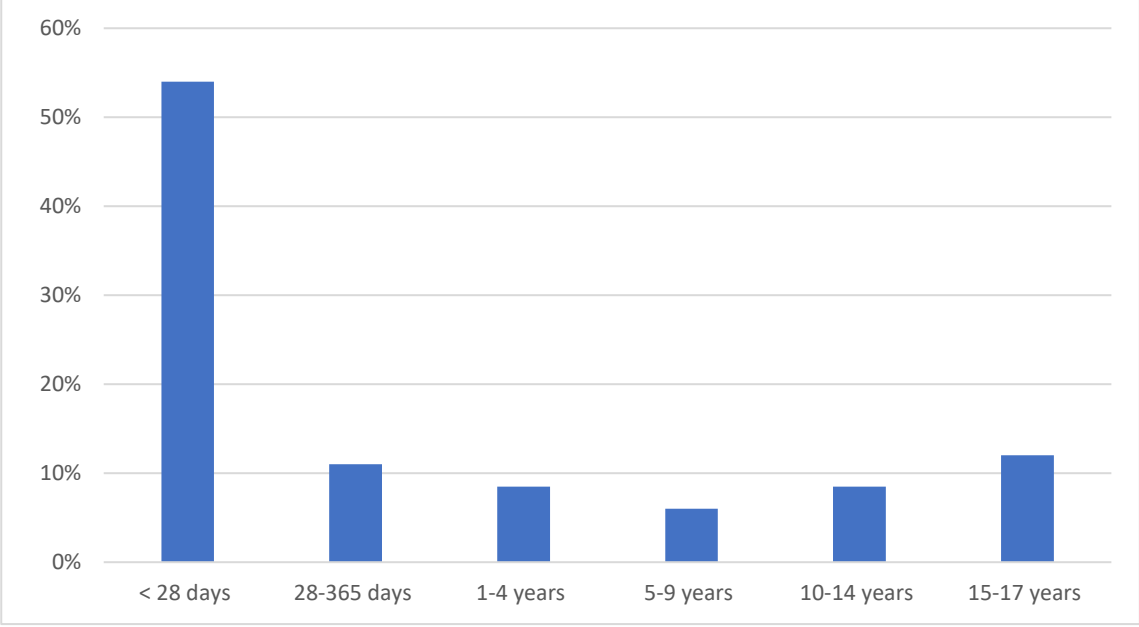
Table 2.4: Key demographic and individual characteristics of all deaths of children and young people in the ACT, 2019

Characteristics	2019 Deaths[a]	
	Number	Per cent
Total		
Persons 0–17 years of age	19	
Sex		
Female	8	42.1
Male	11	57.9
Age		
0–4 years	12	63.2
5–17 years	7	36.4
Aboriginal and Torres Strait Islander status		
Neither Aboriginal nor Torres Strait Islander	17	•
Aboriginal and/or Torres Strait Islander	•	•
Unknown	•	•

[a] Figures do not include open coronial cases.

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 congenital anomalies.

Figure 2.1: Distribution of deaths by age, 2015–2019



Cause of death

Tables 2.5 and 2.6 present the causes of all deaths for the five-year period 2015 to 2019. As noted previously, the cause of death provided includes both indicative causes and those categories outlined in the International Classification of Diseases (ICD-10).

Table 2.5 shows that close to half (48%) of the deaths over the five-year period were due to medical reasons. The ICD-10 grouping in Table 2.6 provides some indication of types of medical disorders experienced by children and young people.

Table 2.5: Indicative cause of death, 2015–2019

Indicative cause of death	Number	Per cent
Total	**152**	
Medical causes	73	48.0
Extreme prematurity	49	32.2
Suicide	11	7.2
Unintentional injury/accident (including transport and drowning)	11	7.2
Unascertained	5	3.3
SIDS and or SUDI[a]	•	•

[a] SUDI=sudden unexpected death in infancy; SIDS=sudden infant death syndrome.

The ICD-10 is the tool adopted by the international community to analyse the health of population groups in terms of 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.

Table 2.6: ICD-10 grouping cause of death, 2015–2019

ICD-10 grouping	Number	Per cent
Total	**152**	
Certain conditions originating in the perinatal period	78	51.3
External causes of morbidity and mortality	11	7.2
Neoplasms	10	6.6
Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified	10	6.6
Congenital malformations, deformations and chromosomal abnormalities	9	5.9
Diseases of the circulatory system	7	4.6
Diseases of the respiratory system	6	4.0
Injury, poisoning and certain other consequences of external causes	5	3.3
Other medical disorders[a]	16	17.8

[a] Other medical disorders include the following ICD-10 chapters: Diseases of the nervous system; Other and unspecified effects of external causes; Injury, poisoning and certain other consequences of external causes; Disease of the blood and blood forming organs; Diseases of the Digestive System; External causes of morbidity and mortality; Certain infectious and parasitic diseases; Diseases of the musculoskeletal system and connective tissue; Mental and Behavioural Disorders; Endocrine, nutritional and metabolic disease.

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

This chapter provides an overview of the **registered deaths of ACT resident children and young people that occurred in the ACT or interstate in the last five years** (that is, excluding interstate residents who were included in Chapter 2). 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.

Overview

In the five-year period 2015 to 2019, a total of 131 children and young people who usually resided in the ACT died. Of these cases, six are currently before the Coroner and are therefore outside the scope of the Committee review at this stage.

Table 3.1: Breakdown of cases included in analysis, 2015–2019

Deaths	Number	Per cent
All ACT resident deaths[a]	**131**	
ACT residents who died in the ACT[b]	117	89.3
ACT residents who died elsewhere[b]	14	10.7
Cases before the Coroner	6	4.6

[a] Figures do not sum; interstate deaths are excluded, and coronial cases appear in more than one category.
[b] Included in further analyses.

In total, 117ACT residents under the age of 18 years died in the ACT and 14 ACT residents died elsewhere. The following discussion relates to the **125 children and young people** normally resident in the ACT who died in the last five years and excludes deaths of interstate residents and cases before the Coroner.

Table 3.2 shows the age-specific mortality rate for the ACT across the reporting period. The annual mortality rate for children and young people varied from a low of 1.69 deaths per 10,000 population in 2019 to a high of 3.84 in 2018. The age-specific mortality rate for Australia in 2018 was 2.43 deaths per 10,000 population (ABS, 2019a). In 2018 there was an increase in the deaths of young people caused by suicide in the ACT. In 2019, the Committee commenced a group review of this cohort, and it is anticipated this work will be completed in 2020.

The 2019 mortality rate is lower than previous years, which is positive; however, this annual figure should be interpreted with caution as statistical fluctuations are known to occur with small numbers. The Committee will continue to monitor this trend over time. The age-specific mortality rate for the five-year period 2015 to 2019 was 2.9 per 10,000 ACT children aged less than 18 years.

Table 3.2: Age specific mortality rates (per 10 000) of ACT residents aged 0–17 years 2015-2019

Year	Population	Deaths	ACT ASMR[a]
	0–17 years	Number	Per 10 000
2015	87 650	29	3.30
2016	89 390	27	3.02
2017	91 569	23	2.51
2018	93 681	36	3.84
2019	94 941	16	1.69

[a] The rates in this table are not directly comparable to previous reports.
ASMR = age-specific mortality rate.

Distribution across characteristics

The following discussion focuses on 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 2015 to 2019.

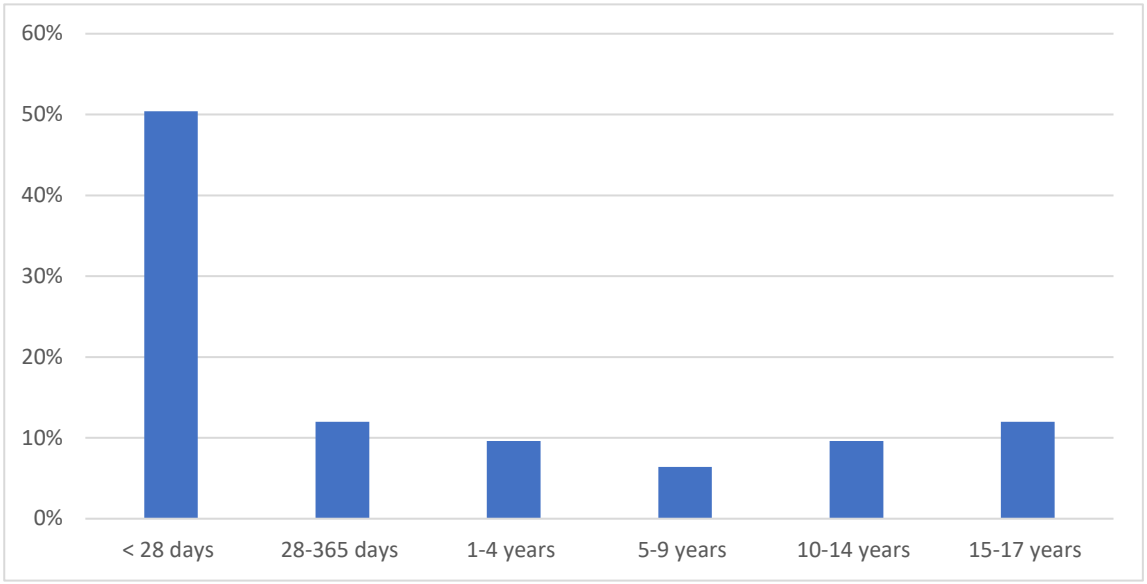
Table 3.3: Demographic characteristics of deaths of ACT resident children and young people, 2015–2019

Characteristic	Deaths	
	Number	Per cent
Total		
Persons 0–17 years of age	125	
Sex		
Female	60	48.0
Male	65	52.0
Age		
< 28 days	63	50.4
28-365 days	15	12.0
1–4 years	12	9.6
5–9 years	8	6.4
10–14 years	12	9.6
15–17 years	15	12.0

In the five years covered by this report, there were 65 deaths of ACT males aged less than 18 years and 60 deaths of ACT females aged less than 18 years.

Figure 3.2 shows the distribution of deaths by age for the five-year period. The graph shows that the proportion of deaths is highest in the first year of life and lowest between 5 and 9 years of age. In 2015 to 2019, the 5–9 age group accounted for under 6.5% of all deaths. The proportion of deaths increases again during adolescence and is partially explained by an increase in death by suicide during 2018 in the 15–17 and 10–14 age groups. As previously mentioned, the Committee anticipates a thematic review on this group will be completed in 2020.

Figure 3.2: ACT resident deaths by age, 2015–2019



Cause of death

As in Chapter 2, causes of death have been classified by indicative cause of death and those categories outlined in the International Classification of Diseases (ICD-10). While Chapter 2 considered all deaths recorded on the ACT Children and Young People Deaths Register, this section reports specifically on ACT resident children and young people.

Table 3.5 presents the indicative causes of death for ACT resident children and young people during the period 2015–2019, with medical causes accounting for more than half (52%) of all ACT deaths. Table 3.6 presents the ICD-10 grouping, with conditions originating in the perinatal period accounting for 46.6% of all deaths.

Table 3.5: Indicative cause of death, ACT resident children and young people, 2015–2019

Indicative cause of death	Number	Per cent
Total	**125**	
Medical causes	65	52.0
Extreme prematurity	36	28.8
Suicide	11	8.8
Unascertained	5	4.0
Unintentional injury/accident (including transport and drowning)	•	•
SIDS and or SUDI[a]	•	•

[a] SUDI=sudden unexpected death in infancy; SIDS=sudden infant death syndrome.

Table 3.6: ICD-10 grouping cause of death, ACT resident children and young people, 2015–2019

ICD-10 grouping	Number	Per cent
Total	**125**	
Certain conditions originating in the perinatal period	58	46.4
Neoplasms	10	8.0
Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified	10	8.0
Congenital malformations, deformations and chromosomal abnormalities	10	8.0
External causes of morbidity and mortality	7	5.6
Diseases of the circulatory system	7	5.6
Diseases of the respiratory system	6	4.8
Other medical disorders[a]	17	13.6

[a] Other medical disorders include the following ICD-10 chapters: Diseases of the nervous system; Injury, poisoning and certain other consequences of external causes; Other and unspecified effects of external causes; External causes of morbidity and mortality; Disease of the blood and blood forming organs; Diseases of the Digestive System; Certain infectious and parasitic diseases; Endocrine, nutritional and metabolic disease; Mental and Behavioural Disorders.

Chapter 4 Population focus: neonates and infants

This chapter examines the incidence and causes, as well as other demographic and individual characteristics, of **neonatal deaths under 28 days and infant deaths 28–365 days** that occurred in the ACT during 2015–2019.

Overview

This section looks at mortality among neonates and infants in the ACT.

Table 4.1 provides a summary of the deaths of children under one year of age. In total, 99 children were included: 73 ACT infants died within the ACT and five died elsewhere. Health services in the ACT provide care for high-risk pregnancies in the surrounding geographic regions, and 21 interstate infants died in the ACT. There were zero cases before the Coroner as of 22 April 2020.

Table 4.1: Breakdown of infant deaths, 2015–2019

Deaths	Number	Per cent
Total	**99**	
ACT residents who died in the ACT[a]	73	73.7
ACT residents who died elsewhere[a]	5	5.1
Interstate residents who died in the ACT	21	21.2
Cases before the Coroner	0	0

[a] Included in further analyses.

Removing those children who usually reside elsewhere (n=21), and children who died interstate (n=5), the following analysis relates to the 73 children who were resident and died in the ACT during 2015 to 2019. In 2019, six children died under the age of one year. The Committee works closely with the ACT Maternal and Perinatal Mortality Committee to review the cause of deaths that occur in the perinatal period. While the analyses in this report examines the numbers of deaths within this cohort, more detailed analyses are available through the reports of the ACT Maternal and Perinatal Mortality Committee, which can be found on the ACT Health website: www.stats.health.act.gov.au.

The most recent data (2018) indicate that the infant mortality rate (deaths of children aged less than one year) for the ACT was 3.7 per 1,000 live births. This rate is similar to the Australian rate of 3.1 per 1,000 live births (ACT Government, 2019). The ACT has a small number of infant deaths each year, and this means that the infant mortality rate can fluctuate markedly year to year. Between 2014 and 2018 the ACT infant mortality rate ranged from 2.3 to 3.8 per 1,000 live births, whereas the national rate ranged between 3.4 and 3.8 over the same period. The infant mortality rate for 2019 is likely to be well below the national rate, as there were six deaths of ACT children in this age group.

Distribution across characteristics

The following discussion focuses on demographic and individual characteristics of infants 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 and cause of death. Analysis of Aboriginal and Torres Strait Islander infants who died in the period 2015 to 2019 has not been included in this report as the number is below five.

Table 4.2 provides the number of neonatal deaths under 28 days and deaths of infants (defined in the table as 28–365 days). Neonatal deaths account for the majority of deaths in children under one year in the five-year period 2015 to 2019 (n=59) and all deaths for this age group in 2019 (n=6).

Sex

In the five years to December 2019, 73 children died in the first year of life, with a slightly higher incidence of male deaths. The distribution between male and female deaths in 2019 is not able to be reported due to the small number of deaths of children under the age of one year.

Table 4.2: ACT resident infant deaths by age group and sex, 2019 and 2015–2019

Characteristic	1 January 2019 – 31 December 2019 Deaths		January 2015 – December 2019 Deaths	
	Number	Per cent	Number	Per cent
Total	**6**	**100.0**	**73**	
Neonatal deaths under 28 days	6	100.0	59	80.8
Infant deaths 28-365 days	0	0	14	19.2
Sex				
Female	•	•	34	46.6
Male	•	•	39	53.4

Cause of death

Table 4.3 presents the main causes of death of ACT children under the age of one year during 2015 to 2019. As highlighted in Chapter 3, this cohort accounts for a large proportion of all deaths. Of ACT resident deaths in the five-year period, children under one year of age account for 62.4% of all ACT deaths.

Table 4.3: Indicative and ICD-10 cause of death of children less than one year of age, 2015–2019

Cause of death	Number		
	< 28 days	28–365 days	Total
Medical causes and extreme prematurity	**55**	**10**	**65**
Certain conditions originating in the perinatal period	44	7	51
Congenital malformations, deformations and chromosomal abnormalities	•	•	8
Other medical disorders[a]	•	•	6
SIDS & SUDI[b] and unascertained and other causes	•	•	**8**
Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified	•	•	•
Total	**58**	**14**	**73**

[a] Other medical disorders include the following ICD-10 chapters; Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified; Endocrine, nutritional and metabolic disease; Diseases of the musculoskeletal system and connective tissue; Diseases of the Digestive System.
[b] SUDI=sudden unexpected death in infancy; SIDS=sudden infant death syndrome.

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 (e.g. endocrine or respiratory disorders) and temperature regulation (WHO, 2010).

'Certain conditions originating in the perinatal period' (n=51) is the major cause of death for both neonates and infants (aged 28–365 days), followed by 'chromosomal or congenital anomalies' (n=8). There were six deaths caused by other medical disorders. There were fewer than five cases of deaths caused by sudden unexpected death in infancy (SUDI), sudden infant death syndrome (SIDS) or where the cause of death was unascertained.

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.

Table 5.1: ACT children and young people who have died and were known to CYPS or ACT Policing, 2015–2019

Total[a]	Known to CYPS	Known to ACT Policing
125	**14**	**40**

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

Overview

This section outlines the overall incidence of mortality among children and young people in the ACT who were experiencing identified 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 increased vulnerability.

There are two reasons why the Committee focuses on child protective services and the justice system in particular. First, it is a requirement of the legislation. But more importantly, these are the systems that are often involved when difficulties arise in a child's life and therefore are indicators of vulnerability.

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 2015 to 2019, 125 residents of the ACT under the age of 18 years died in the ACT or elsewhere. Overall, 14 children and young people and/or their families were known to CYPS and 40 were known to police. These broad figures do not account for the extent to which the child or their family was involved with these systems; this will be discussed later.

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, a 'child protection report' is recorded in accordance with s. 360(5) of the Act. It is under this same legislation that the Committee is required to provide this report to the Minister each calendar year about the deaths of children and young people with particular demographic and individual characteristics and trends relating to such (s. 727S).
Police involved	Not all deaths of children and young people require the involvement of police. Where a child or young person clearly dies as a result of medical causes in a setting where professionals are able to make a determination of death, such as a hospital, police are not necessarily informed or called. Police often become involved in a death where people aware of the death call emergency services, where the Coroner makes a determination that further inquiries are required or where the individual or persons associated with the individual have current or previous histories with police.

Distribution across characteristics

Table 5.2 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 2015 to 2019. It also shows the number of those children and young people who were known to either—or both—CYPS and ACT Policing, by age.

Table 5.2: Number of deaths by system engagement and age, 2015–2019

System engagement	0-4 years	5-17 years	Total
Total	90	35	125
Not known to CYPS	**85**	**24**	**109**
Police involved	17	13	30
Known to CYPS	•	**10**	•
Police involved	•	7	•

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

More females than males were known to the protection and justice systems. The only exception to this pattern is the police involvement in death incidents only, which is higher for males (n=20) than females (n=11). This is consistent with the pattern reported in previous reports that looked at previous periods.

Table 5.3: ACT children and young people deaths by child protection reports and police involvement and by sex, 2015–2019

	Child &Youth Protection Services		ACT Policing		
	Known to CYPS	Children with Siblings known to CYPS	Current or previous police involvement[a]	Death incident only	Not known to Police
Deaths					
Persons 0–17 years of age	14	9	14	26	85
Sex					
Female	10	5	8	11	41
Male	•	•	6	15	44

[a] Current or previous criminal history related to family member including grandparents, parents or child or young person.

Children known to CYPS may have experienced a range of risk factors within their life, including domestic and family violence, parental substance misuse, mental illness and involvement with the criminal justice system. As shown in Table 5.4, five of the children had only child concern reports recorded (any report made to CYPS) and eight children had child protection reports recorded (a second stage of assessment conducted by CYPS to establish if there is a reasonable belief that a child is in need of care and protection).

In addition, fewer than five children had prenatal reports recorded. Fewer than five children who had died had not received any reports; however, it was recorded that their siblings had received either child protection and/or child concern reports within three years of the child dying.

Table 5.4: Number of ACT notification reports of children who have died, 2015–2019

Child notification	Total[a]	Per cent
Child concern report only	5	4.0
Child protection report	8	6.4
Not known to CYPS	109	87.2

[a] Numbers do not add up as not all children known to CYPS received reports and fewer than five children received both child protection and concern reports.

Table 5.5 shows the number of ACT children and young people who were known to CYPS or ACT Policing broken down by indicative cause of death classification groupings. Most deaths of ACT children and young people occur due to medical causes; all other causes have been grouped together under 'other than medical causes.'

In the five-year period 2015 to 2019, a higher proportion of children and young people who died from classifications other than medical causes (13.3%) were known to CYPS than children who died of medical causes (9.2%).

When considering police involvement, a lower proportion of children and young people who died of classifications other than medical causes were known to police (8.3%) compared with deaths classified as medical causes (13.8%). Police involvement due only to death investigation was higher in classifications other than medical causes. As identified previously, Police may be less likely to become involved in a death of a child or young person as a result of medical causes in a setting where professionals are able to make a determination of death.

Table 5.5: Number of ACT children known to CYPS and ACT Policing, indicative cause of death, 2015–2019

	Total	Known to CYPS	Known to Police	Police Involvement Death Incident only
Other than medical causes[a]	60	8	5	18
Medical causes	65	6	9	8

[a] Other than medical causes include indicative cause of death classifications: Extreme prematurity; Suicide; Transport; Drowning; SIDS and undetermined; Unascertained; Unintentional injury/accident.

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 2019.

Continuing work

Review into youth suicide

Youth suicide is an increasingly prevalent concern for modern society. Despite the research pinpointing the risk factors leading to suicide, more young people are taking their lives each year. In both developed and developing nations, suicide is among the leading causes of death for young people. Within Australia suicide remains the leading cause of death for children aged between 5 and 17 years of age. Inextricably linked to mental health, suicide and self-harm remain a critical challenge for services and programs supporting young people. In 2019, the Committee commenced a group review of the deaths of young people in the ACT caused by suicide. It is anticipated this work will be completed in 2020.

The ACT context

Planning for a growing population has led to considerable residential development occurring in the ACT, particularly in areas located close to the city centre, town and group centres and along key transit corridors. The Committee is particularly interested in the changes that are occurring for families, such as the increase in the number of parents raising children in high-rise and medium-density accommodation. With the rise of apartment living for families (ABS, 2016), the Committee emphasises the need for developers and city planners to design for more child-friendly living environments. Each year, around 50 children fall from windows or balconies in Australia, with research in Sydney showing an increase in children presenting at The Children's Hospital at Westmead with serious injuries due to falling from apartment windows and balconies (Children's Hospital at Westmead, 2011). While many suffer serious injuries, these falls can also be fatal. Windows that open from the floor up (enabling children to crawl out), unsafe balconies, traffic at the front door and car parks are all dangers for children. Over the next year, the Committee will continue to increase public awareness about these and other issues that affect the health and safety of children and young people in the ACT.

Domestic and family violence

Domestic and family violence claims the lives of more than 100 people in Australia every year and causes enduring damage to individuals and society. The first and only ACT Family Violence Death Review was published in May 2016. It summarised key issues and themes from an analysis of 14 deaths which occurred in a family violence context in the ACT between 1 June 2000 and 30 June 2012.

At the end of 2019, the ACT Government indicated that they were committed to introducing a family violence death review scheme (FVDR) for the ACT. All jurisdictions, except Tasmania and the ACT, have an FVDR function. The aim of an FVDR scheme would be to analyse information relating to specific family violence deaths and make recommendations for system-wide improvements to services, to help prevent similar deaths occurring in the future.

There is a strong intersection between a number of the functions and processes currently undertaken by the Committee and those to be undertaken by the proposed FVDR scheme. The Committee has provided a

submission into the development of the FVDR in the ACT and we look forward to working with our ACT colleagues in 2020 in the further development of a family and domestic violence death review process.

Data quality

The Committee will continue to work with our colleagues across jurisdictions to improve the quality of data held on the Children and Young People Death Register. In particular, the Committee is seeking support for an enhanced database system to improve accuracy and access to data by the Committee.

Disclosure of information

Under s. 727P of the Act, the Committee may exchange information with an entity that exercises a function under a law of state that corresponds or substantially corresponds to a function of the Committee. In 2019 the Committee provided information to entities in Queensland and NSW:

- Queensland provides high-level data from all state and territory child death review committees to provide a basic national data set. In August 2019, we provided information to the Queensland Family and Child Commission on the number of deaths of children in ACT by age, sex, Aboriginal status and broad cause of death. This was reported in the *Annual Report: Deaths of Children and Young People, Queensland, 2016–2017*.
- The NSW child death register includes children who normally live in NSW, but whose death occurred the ACT. In August 2019 we provided the NSW Child Death Review team with information about the deaths of NSW resident children who died in the ACT. In June 2019 the ACT signed an information exchange agreement with the NSW Child Death Review Team under s. 34D(3) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (NSW).

References

ABS (Australian Bureau of Statistics) (2015). Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Cat. no. 3238.0. Canberra: ABS. Viewed 6 March 2019, http://stat.data.abs.gov.au/

ABS (Australian Bureau of Statistics) (2016). 2071.0 - Census of Population and Housing: Reflecting Australia - Stories from the Census, 2016. Retrieved from: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Apartment%20Living~20

ABS (Australian Bureau of Statistics) (2019a). Deaths, Australia 2018, ABS Cat. No. 3302.0. Retrieved from: https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/3302.0Explanatory%20Notes12018?OpenDocument

ABS (Australian Bureau of Statistics) (2019b). Quarterly Population Estimates (ERP), by State/Territory, Sex and Age, ABS. Cat. No 3101.0. Extracted 6 March 2019, http://stat.data.abs.gov.au/index.aspx?DatasetCode=ERP_QUARTERLY

ACT Government (2019). Infant Mortality. Retrieved from: https://www.data.act.gov.au/Health/Infant-mortality/um8s-3c6w

ACT Treasury (2019). Estimated Resident Population — September Quarter 2019 ABS Cat. No. 3101.0. Retrieved from: https://apps.treasury.act.gov.au/__data/assets/pdf_file/0008/644813/ERP.pdf/_recache

Children's Hospital at Westmead (2011). Working Party for the Prevention of Children Falling from Residential Buildings Outcomes Report. Retrieved from http://www.chw.edu.au/parents/kidshealth/building_falls/

Children and Young People Act 2008 (ACT) (ACT legislation Register). Retrieved from: https://www.legislation.act.gov.au/a/2008-19/

WHO (World Health Organization) (2010). International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10): Version for 2010. Geneva: WHO. Viewed 6 March 2019, http://apps.who.int/classifications/icd10/browse/2010/en#!/XVI

WHO (World Health Organization) (2011). International Statistical Classification of Diseases and Related Health Problems 10th revision: Volume 2 Instruction manual. 2010 edn. Geneva: WHO. Viewed 6 March 2019, http://apps.who.int/classifications/icd10/browse/Content/statichtml/ICD10Volume2_en_2010.pdf

WHO (World Health Organization) (2016). Classification of Diseases. Geneva: WHO. Viewed 2 February 2019, http://www.who.int/classifications/icd/en/

Appendix A Population tables

ACT Quarterly population estimates (ERP)[a]

Age	June 2015			June 2016			June 2017			June 2018			June 2019		
	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females
0–4	**27384**	**14181**	**13203**	**28054**	**14556**	**13498**	**28411**	**14702**	**13709**	**28178**	**14585**	**13593**	**28138**	**14497**	**13641**
0	5652	2920	2732	5696	2954	2742	5600	2904	2696	5335	2738	2597	5436	2817	2619
1	5526	2877	2649	5694	2945	2749	5733	2967	2766	5612	2918	2694	5321	2727	2594
2	5518	2798	2720	5556	2913	2643	5790	2993	2797	5775	2974	2801	5637	2918	2719
3	5394	2830	2564	5603	2857	2746	5613	2930	2683	5842	3025	2817	5838	2982	2856
4	5294	2756	2538	5505	2887	2618	5675	2908	2767	5614	2930	2684	5906	3053	2853
5–9	**25037**	**12927**	**12110**	**25767**	**13404**	**12363**	**26810**	**13948**	**12862**	**27766**	**14418**	**13348**	**28336**	**14707**	**13629**
5	5365	2756	2609	5391	2819	2572	5606	2931	2675	5781	2972	2809	5701	2958	2743
6	5084	2634	2450	5432	2823	2609	5461	2850	2611	5680	2973	2707	5836	3005	2831
7	4943	2567	2376	5139	2677	2462	5492	2830	2662	5507	2861	2646	5664	2962	2702
8	4805	2484	2321	4981	2585	2396	5206	2702	2504	5548	2878	2670	5561	2891	2670
9	4840	2486	2354	4824	2500	2324	5045	2635	2410	5250	2734	2516	5574	2891	2683
10–14	**21583**	**11057**	**10526**	**22170**	**11384**	**10786**	**23012**	**11891**	**11121**	**23942**	**12374**	**11568**	**24905**	**12915**	**11990**
10	4480	2286	2194	4842	2503	2339	4883	2531	2352	5083	2650	2433	5284	2754	2530
11	4341	2249	2092	4472	2276	2196	4872	2511	2361	4951	2565	2386	5132	2681	2451
12	4301	2236	2065	4355	2250	2105	4530	2315	2215	4887	2524	2363	4988	2603	2385
13	4214	2119	2095	4295	2238	2057	4389	2275	2114	4580	2327	2253	4921	2542	2379
14	4247	2167	2080	4206	2117	2089	4338	2259	2079	4441	2308	2133	4580	2335	2245
15–17	**13646**	**6896**	**6750**	**13399**	**6814**	**6585**	**13336**	**6757**	**6579**	**13466**	**6926**	**6540**	**13535**	**6983**	**6552**
15	4309	2176	2133	4306	2208	2098	4291	2156	2135	4410	2295	2115	4491	2339	2152
16	4479	2274	2205	4384	2220	2164	4421	2260	2161	4400	2225	2175	4500	2346	2154
17	4858	2446	2412	4709	2386	2323	4624	2341	2283	4656	2406	2250	4544	2298	2246
Total	**87650**	**45061**	**42589**	**89390**	**46158**	**43232**	**91569**	**47298**	**44271**	**93681**	**48501**	**45108**	**94914**	**49102**	**45812**

[a] (ABS. Stat, 2019b) By state/territory, sex and age: ACT

Australia Quarterly Population Estimates (ERP)[a]

Age	June 2015			June 2016			June 2017			June 2018			June 2019		
	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females
0–4	**1552567**	**797038**	**755529**	**1573626**	**807893**	**765733**	**1578994**	**811093**	**767901**	**1572293**	**807995**	**764298**	**1567163**	**805787**	**761376**
0	308446	158281	150165	318860	164034	154826	306802	157886	148916	303407	156125	147282	302684	155741	146943
1	308292	158130	150162	312044	160005	152039	321129	165223	155906	308459	158682	149777	304818	156842	147976
2	313848	161280	152568	311507	159736	151771	315373	161762	153611	323809	166552	157257	311200	160091	151109
3	312136	160379	151757	316679	162613	154066	315183	161549	153634	318292	163366	154926	326896	168085	158811
4	309845	158968	150877	314536	161505	153031	320507	164673	155834	318326	163270	155056	321565	165028	156537
5–9	**1536262**	**788647**	**747615**	**1567281**	**804219**	**763062**	**1586851**	**814019**	**772832**	**1604540**	**823433**	**781107**	**1618647**	**830339**	**788308**
5	313171	160578	152593	314636	161432	153204	318322	163475	154847	324001	166389	157612	321643	164962	156681
6	309529	158970	150559	316919	162362	154557	317926	163075	154851	321028	164791	156237	326729	167757	158972
7	309540	158801	150739	312612	160540	152072	319654	163743	155911	320255	164301	155954	323562	166046	157516
8	306360	157422	148938	313041	160537	152504	315298	161885	153413	321787	164888	156899	322648	165537	157111
9	297662	152876	144786	310073	159348	150725	315651	161841	153810	317469	163064	154405	324065	166037	158028
10–14	**1410688**	**724624**	**686064**	**1431690**	**735448**	**696242**	**1473263**	**757231**	**716032**	**1515917**	**779271**	**736646**	**1555737**	**799102**	**756635**
10	286621	147431	139190	299311	153699	145612	312546	160619	151927	317746	162883	154863	319703	164252	155451
11	282621	145602	137019	287662	148006	139656	301572	154859	146713	314444	161611	152833	319972	163986	155986
12	279297	143147	136150	283993	146382	137611	290029	149268	140761	303530	155889	147641	316523	162653	153870
13	278682	142825	135857	280529	143766	136763	286183	147532	138651	292012	150341	141671	305472	156879	148593
14	283467	145619	137848	280195	143595	136600	282933	144953	137980	288185	148547	139638	294067	151332	142735
15–17	**861342**	**441200**	**420142**	**866346**	**444110**	**422236**	**868020**	**444755**	**423265**	**866825**	**444498**	**422327**	**869528**	**446241**	**423287**
15	285508	146014	139494	286211	147017	139194	283296	145231	138065	285577	146286	139291	290601	149726	140875
16	286762	147119	139643	289244	147904	141340	290389	149167	141222	286559	146922	139637	288611	147763	140848
17	289072	148067	141005	290891	149189	141702	294335	150357	143978	294689	151290	143399	290316	148752	141564
Total	**5360859**	**2751509**	**2609350**	**5438943**	**2791670**	**2647273**	**5507128**	**2827098**	**2680030**	**5559575**	**2855197**	**2704378**	**5611075**	**2881469**	**2729606**

[a] (ABS. Stat, 2019b) By state/territory, sex and age: Australia

Estimated and projected Aboriginal and Torres Strait Islander population[a]

Age	ACT					Australia				
	2015	**2015**	**2016**	**2017**	**2019**	**2015**	**2015**	**2016**	**2017**	**2019**
0	166	172	178	185	195	17,654	18,161	18,671	19,172	19,662
1	160	169	175	181	189	17,149	17,635	18,142	18,652	19,153
2	154	159	169	175	180	16,676	17,143	17,629	18,136	18,646
3	159	152	158	168	174	16,176	16,670	17,137	17,623	18,130
4	145	155	148	154	164	16,714	16,172	16,666	17,133	17,619
5	135	141	150	144	149	16,773	16,710	16,168	16,662	17,129
6	116	131	136	145	139	16,543	16,769	16,706	16,164	16,658
7	115	114	128	132	141	16,556	16,540	16,766	16,702	16,162
8	127	114	114	127	131	16,735	16,554	16,538	16,764	16,700
9	118	128	115	116	127	16,131	16,733	16,552	16,536	16,762
10	141	120	129	117	117	15,505	16,129	16,731	16,550	16,534
11	127	141	120	130	119	15,516	15,503	16,127	16,729	16,548
12	121	126	141	120	131	15,620	15,514	15,501	16,125	16,727
13	115	118	123	136	118	15,874	15,617	15,510	15,497	16,121
14	134	112	115	120	132	15,599	15,870	15,613	15,506	15,493
15	115	132	111	114	118	15,525	15,593	15,864	15,607	15,500
16	138	117	134	114	117	15,584	15,517	15,586	15,857	15,601
17	138	146	126	142	123	15,576	15,576	15,509	15,578	15,849

[a] (ABS, 2015) Single year of age, Australian Capital Territory and Australia

Appendix B 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 Births, Deaths and Marriages and other Australian jurisdictions.

Fewer 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 s. 727S(3) of the Act and does not disclose the identity of a child or young person who has died or allow a child or young person who has died to be identified. The number of deaths will be reported as •, which means the number of children and young people who died is fewer 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 s. 727S(3) of the Act but also to ensure the child's, young person's and family's right to privacy is maintained.

In some instances, further data have been suppressed to prevent calculation of figures. The suppression of further data will not occur when it will significantly impact on the Committee's ability to report population trends. In these instances, calculation of figures may be possible but the identity of a child or young person who has died will not be disclosed or be able to be worked out.

Population estimates and rates

ACT and Aboriginal and Torres Strait Islander children and young people populations are taken from the latest Australian Bureau of Statistics' estimated resident populations as at 30 June.

Rates are calculated using child death data contained in the register and both ABS estimated and projected 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 C Glossary

Aboriginal and Torres Strait Islander

In the *Children and Young People Act 2008* (ACT):

> *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.

Certain conditions originating in the perinatal period

Refers to 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 500g) and ends seven completed days after birth (WHO, 2011). The ACT definition differs in that the perinatal period begins from 20 weeks gestation and 400 grams in birthweight.

Child

In the *Children and Young People Act 2008* (ACT):

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

The *Children and Young People Act 2008* (ACT) 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 foetal deaths.

Child Concern Report

Refers to a report made to Care and Protection Services in accordance with s. 359 of the *Children and Young People Act 2008* (ACT) 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.

Child Protection Report/ Report under s. 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* (ACT) 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.

Congenital anomalies

Includes deformities and chromosomal abnormalities and refers to physical and mental conditions present at birth that are either hereditary or caused by environmental factors and where there is no indication that they were acquired after birth.

Coroner

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

Infant

In this report, refers to the period from 28 days to one year of age.

National Coronial Information System

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

Neonatal period

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

Neoplasm

An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Neoplasms may be benign (not cancer) or malignant (cancer). Also called tumours (definition from the National Cancer Institute).

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

Refers to reviews undertaken in the ACT which 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.

SIDS

Refers to Sudden Infant Death Syndrome. Category of SUDI (see below) that has four categories: 1a, 1b, 2 and unclassified.

SIDS 1a	• An infant aged over 21 days but under 9 months of age. • Gestational age of equal to or over 37 weeks. • Normal clinical history, including during pregnancy. • Normal growth and development. • No similar deaths among siblings, close relatives or other infants in the custody of the carer. • The scene where incident leading to the death occurred does not provide an explanation of the death. • Absence of potentially fatal pathological findings. • No evidence of unexplained trauma, abuse, neglect or unintentional injury. • No evidence of substantial thymic stress effect and • Negative result in other tests (e.g. toxicology).
SIDS 1b	As with SIDS 1a but: • an investigation of the scene where the incident leading to the death occurred was not performed, or • one of the following tests/screens was not performed: o toxicology o radiologic o microbiologic o vitreous chemistry, or o metabolic screening studies.
SIDS 2	As with SIDS 1 except for at least one of the following: • age outside of range • similar deaths among siblings, close relatives or other children cared for by the carer not considered infanticide or recognised genetic disorder • neonatal or peri-natal conditions that have resolved at the time of death • mechanical asphyxia or suffocation caused by overlaying not determined with certainty • abnormal growth and development not thought to have contributed to the death, and/or • marked inflammatory changes/abnormalities not sufficient to be unequivocal (certain) cause of death.
SIDS Unclassified	• Did not meet the criteria for SIDS 1 or 2, and • Alternative diagnosis or natural or unnatural conditions are equivocal (uncertain), including cases for which an autopsy was not performed.

SUDI

Refers to Sudden Unexpected Death in Infancy, which is the death of an infant aged less than 12 months that is sudden and unexpected and where the cause was not immediately apparent at the time of death.

Young people

In the *Children and Young People Act 2008* (ACT):

> *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