

ACT Children & Young People  
Death Review Committee

## **Annual Report 2021**



# 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.***

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# Foreword

The ACT Children and Young People Death Review Committee (the Committee) is pleased to present its ninth 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).

This report is based on information provided to the Committee on the deaths of children and young people that occurred during the calendar year 2021. The report focuses on the deaths of children and young people as required by the Act, as well as two population groups: neonates and vulnerable children. As in previous reports, the detailed analysis of the data is based on the aggregation of five years of data (2017–21), thus ensuring individual privacy.

The Committee continues its work to review the circumstances and causes of child deaths in the ACT. Along with meeting its legislated functions, in 2021, the Committee has done a significant amount of work re-evaluating processes to improve the effectiveness of review procedures.

2022 marks the first ten years for the Committee with this being the ninth published report. Since inception the Committee's work has evolved and refined its approach to data and reviews. The Committee has worked with the ACT Epidemiology Division of ACT Health to scope the feasibility of accessing and coding serious injury data of children and young people in the ACT and has revised its review process to better utilise member expertise and knowledge of how the existing system is operating.

The Committee has commenced several specific reviews in 2022 and will make recommendations to Government in line with s.727(b) of the *Children and Young People Act* (2008). Through these reviews the Committee will build on its existing body of research and will be alert to any relevant impacts that COVID-19 restrictions may have had on children, young people and their families' accessing services in the ACT.

The Committee would like to thank the ACT Epidemiology Department for their invaluable contribution to the development of this report and their assistance in establishing a serious injury data set for children and young people in the ACT.

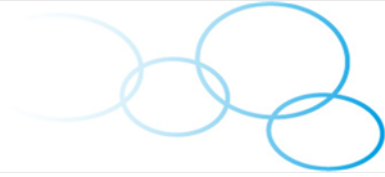
This year has also seen three new members join the Committee. Ms Catherine Rule, Ms Jane Simmons and Dr Bronwen Phillips have all brought great knowledge and enthusiasm to the Committee.

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

Finally, I would like to thank the Secretariat and members of the Committee, who have done an outstanding job throughout the year. 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 Families and Community Services  
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 2021 Annual Report*.

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

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

Yours sincerely

Ms Margaret Carmody, PSM  
Chair  
22 April 2022

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

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# Executive summary

The ACT Children and Young People Death Review Committee 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 157 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 2017–2021. Of the 157 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 149 deaths on the register include 33 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 children and young people identified as vulnerable.

**Chapter 6** describes the Committee's activities during 2021 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](http://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 2021

### 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 Catherine Rule**

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 Bronwen Phillips**

Epidemiology

**Dr Catherine Sansum**

Child forensic medicine

**Mr David Matthews (May 2020 – September 2021)**

Deputy Director General, Education

**Ms Jane Simmons PSM (September 2021 – Current)**

Deputy Director General, Education

**Station Sergeant Sue Smith (August 2020 – July 2021)**

ACT Policing – Officer in Charge, Judicial Operations

**Station Sergeant Dennis Gellatly (July 2021 – Current)**

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 2017 to 2021. 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 their 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 a 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 2021 and outlines the continuing work for 2022. In 2018 for the first time the annual report presented a chapter reviewing the progress on the recommendations made since its establishment. In discussion with Minister Stephen-Smith, the Committee decided to undertake this activity biennially. Last year's report provided an update on the progress of Committee recommendations.

## Using this report

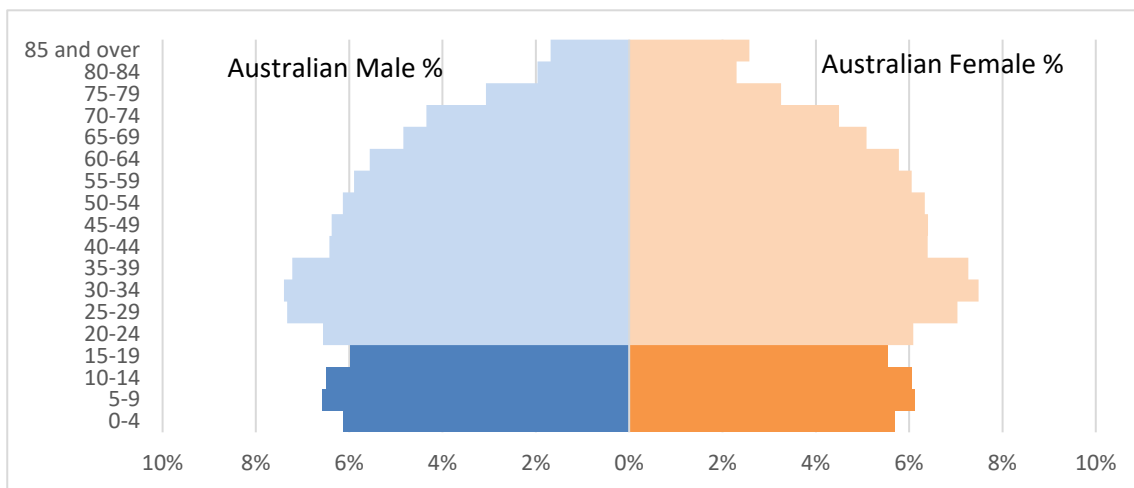
This annual report is a legislated requirement of the Committee and can be used as a catalyst or foundation for further investigations. To increase transparency and to enable greater use and reporting on the findings of this report, it is important to clarify the methods used.

## ACT Population

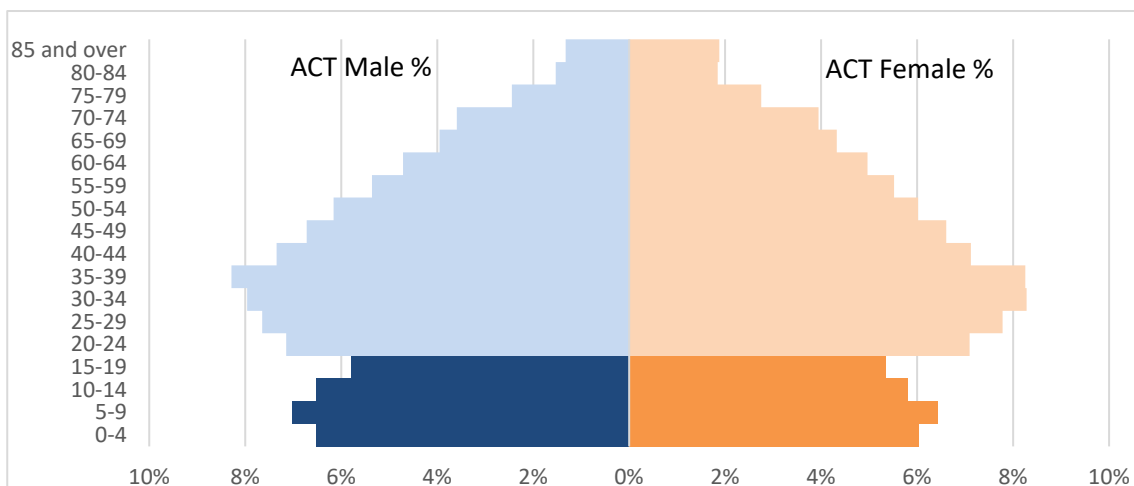
As of 30 June 2021, the ACT's estimated resident population was at 432,266 persons. This represents an increase of 0.24 % over the preceding year (ACT Treasury, 2021). This increase was also seen in children and young people under 19 years of age. Canberra remains 'younger' with the 0-4 and 5-9 age groups higher than the national average. ACT Treasury, in conjunction with the ANU's School of Demography is expected to publish revised projections in the first half of 2022 which will consider the significant effect of COVID-19 on the ACT's population. These revised projections were not available at the time of writing.

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, 2022a). 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, 2021**



Data source: (ABS, 2021b)



## 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 the annual report. In such circumstances, comment will be made on specific cases in the subsequent years' annual report and future relevant thematic reviews, noting that information about coronial findings where public hearings have been held is ordinarily in the public domain. The Committee welcomes the recent appointment of a dedicated Coroner for the ACT.

The Committee acknowledges the significant work undertaken by the Coroners Court in 2021 and supports the recommendations made about better information sharing between agencies in the ACT and renewed training for staff working with vulnerable children. Many of the recommendations made in open coronial matters align with those recommendations made by the Committee since 2012. The Committee will continue to review deaths of vulnerable children and advocate for improvements to systems and processes.

## 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 code(s).

## 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 suppressed 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. The Committee is currently working with the Office of the Coordinator-General for Family Safety to establish if capabilities could be shared with the yet to be established Family Violence Death Review Committee's data system.

## 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 Family and Child Commission, 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 2017 to 31 December 2021. 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 2017 to 2021.

**Table 2.1: Deaths of children and young people in the ACT, 2017–2021**

Deaths	Number <sup>a</sup>	Per cent
<b>All deaths in the ACT</b>	<b>157</b>	
Total ACT resident deaths	124	79.0
Interstate resident deaths	33	21.0
ACT residents who died elsewhere	22	14.0
Open coronial cases	8	5.1

<sup>a</sup> Figures do not sum; coronial cases appear in more than one category.

In total, 157 children and young people died in the five-year period 2017 to 2021. Of these, 124 were children and young people who normally resided in the ACT and 33 usually resided interstate. Of the 124 ACT residents who died, 22 of these deaths occurred elsewhere. As of 1 February 2021, there were also eight cases before the Coroner in the ACT and other jurisdictions for the period 2017 to 2021.

## 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 for their population (Table 2.2).

**Table 2.2: Annual deaths of children and young people including ACT residents who died elsewhere and interstate residents who died in the ACT, 2017–2021**

Year <sup>a</sup>	All deaths <sup>b</sup>	ACT residents		non-ACT residents who died in the ACT	
		Number	Per cent	Number	Per cent
Jan-Dec	<b>157</b>	<b>124</b>		<b>33</b>	
2017	33	25	75.8	8	24.2
2018	41 (2)	36	87.8	5	12.2
2019	19	16	84.2	3	15.8
2020	29 (4)	24	82.8	5	17.2
2021	35 (2)	23	65.7	12	34.3
<b>Average</b>	<b>31.4</b>	<b>24.8</b>		<b>6.6</b>	

<sup>a</sup> Figures not directly comparable to previous reports.

<sup>b</sup> 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.

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 2017 to 2021 is 31.4. This is a similar average to last year's report of 31.0. For ACT residents, the five-year average for the number of children and young people who died was similar to last year, with the mean moving from 25.0 in 2020 to 24.8 in 2021. There was an increase of non-ACT residents who died in the ACT in 2021, of the 33 deaths over the five-year period 12 occurred in 2021. The number of child deaths each year in the ACT fluctuates due to our small population and should be interpreted with caution. The age-specific mortality rates of ACT residents aged 0–17 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 2017 to 2021, broken down by key demographic characteristics.

Age is a consistent predictor of mortality risk. Table 2.3 shows a higher number of deaths occurring in the early years followed by a reduction through primary years, with an increase again in adolescence and late teens. For the five-year aggregate period, deaths in the first year accounted for 66.5% (n=99) of all deaths, this is consistent with previous reports.

**Table 2.3: Key demographic characteristics of all deaths of children and young people in the ACT, 2017–2021**

Characteristics	2017–2021	
	Number	Deaths <sup>a</sup> Per cent
<b>Total</b>		
Persons 0–17 years of age	149	
<b>Sex</b>		
Female	66	44.3
Male	83	55.7
<b>Age<sup>b</sup></b>		
Less than 28 days	84	56.4
28–365 days	15	10.1
1–4 years	11	7.4
5–9 years	8	5.4
10–14 years	13	8.7
15–17 years	18	12.1
<b>Aboriginal and Torres Strait Islander status</b>		
Aboriginal and/or Torres Strait Islander	8	5.4
Neither Aboriginal nor Torres Strait Islander	137	84.9
Unknown	•	•

<sup>a</sup> Figures do not include open coronial cases.

<sup>b</sup> Percentages do not total 100 due to rounding



Table 2.4 shows the total deaths of children and young people in 2021, 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. There is a higher number of Aboriginal and Torres Strait Islander deaths than in previous years. The Committee plans to consider this increase in future review work.

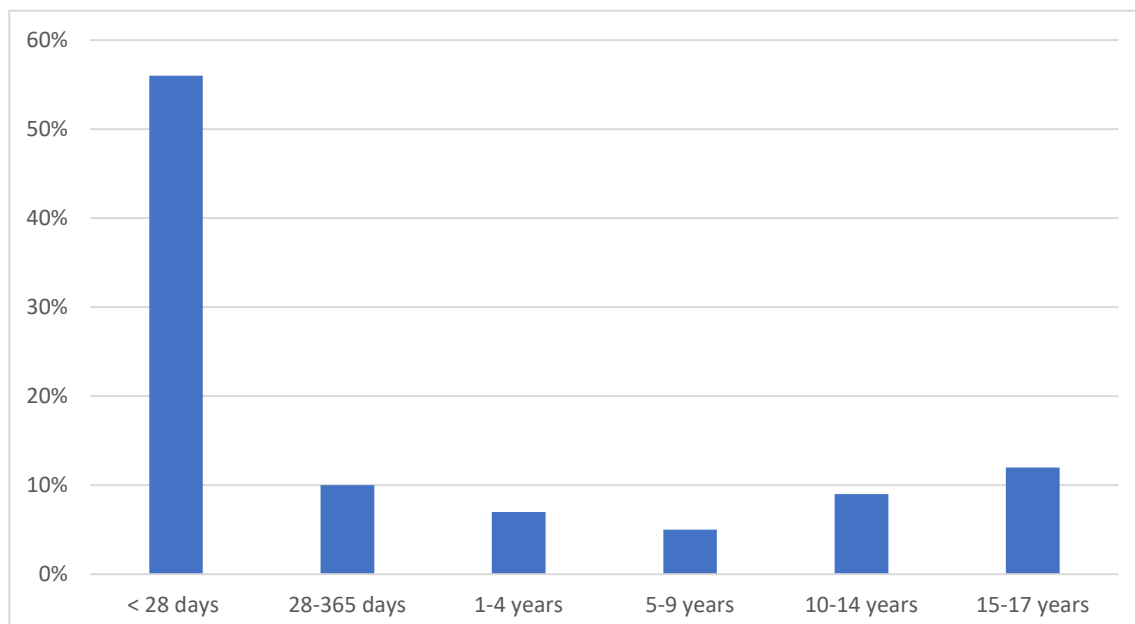
**Table 2.4: Key demographic and individual characteristics of all deaths of children and young people in the ACT, 2021**

Characteristics	2021 Deaths <sup>a</sup>	
	Number	Per cent
<b>Total</b>		
Persons 0–17 years of age	33	
<b>Sex</b>		
Female	15	45.6
Male	18	54.4
<b>Age</b>		
0–4 years	28	84.9
5–17 years	5	15.2
<b>Aboriginal and Torres Strait Islander status</b>		
Aboriginal and/or Torres Strait Islander	5	15.2
Neither Aboriginal nor Torres Strait Islander	28	84.9
Unknown	0	0.0

<sup>a</sup> 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, 2017–2021**



## Cause of death

Tables 2.5 and 2.6 present the causes of all deaths for the five-year period 2017 to 2021. 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 more than half (54.3%) 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, 2017–2021**

Indicative cause of death		
	Number	Per cent
<b>Total</b>	<b>149</b>	
Medical causes	81	54.3
Extreme prematurity	39	26.2
Suicide	14	9.4
Unintentional injury/accident (including transport and drowning)	8	5.4
Unascertained	•	•
Fatal assault	•	•
SIDS and or SUDI <sup>a</sup>	•	•

<sup>a</sup>SUDI=sudden unexpected death in infancy; SIDS=sudden infant death syndrome.

The ICD-10 is the classification system 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, 2017–2021**

ICD-10 grouping		
	Number	Per cent
<b>Total</b>	<b>149</b>	
Certain conditions originating in the perinatal period	77	51.7
Injury, poisoning and certain other consequences of external causes	16	10.7
Congenital malformations, deformations and chromosomal abnormalities	11	7.4
Neoplasms	9	6.0
Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified	8	5.4
Diseases of the circulatory system	8	5.4
External causes of morbidity and mortality	7	4.7
Diseases of the nervous system	6	4.0
Other medical disorders <sup>a</sup>	7	4.7

<sup>a</sup>Other medical disorders include the following ICD-10 chapters: Diseases of the respiratory system; Disease of the blood and blood forming organs; Certain infectious and parasitic diseases; Diseases of the musculoskeletal system; Endocrine, nutritional and metabolic diseases.

# 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 2017 to 2021, a total of 124 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.

In total, 102 ACT residents under the age of 18 years died in the ACT and 22 ACT residents died elsewhere. The following discussion relates to the **118 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 1.7 deaths per 10,000 population in 2019 to a high of 3.9 in 2018.

The annual figure should be interpreted with caution as statistical fluctuations are known to occur with small numbers. The Committee will continue to monitor trends over time. The mean age-specific mortality rate for the five-year period 2017 to 2021 was 2.6 per 10,000 ACT children aged less than 18 years.

**Table 3.1: Breakdown of cases included in analysis, 2017–2021**

Deaths	Number	Per cent
<b>All ACT resident deaths<sup>a</sup></b>	<b>124</b>	
ACT residents who died in the ACT <sup>b</sup>	102	82.3
ACT residents who died elsewhere <sup>b</sup>	22	17.7
Open coronial cases	6	6.5

<sup>a</sup> Figures do not sum; interstate deaths are excluded, and coronial cases appear in more than one category.

<sup>b</sup> Included in further analyses.

**Table 3.2: Age specific mortality rates (per 10 000) of ACT residents aged 0–17 years 2017–2021**

Year	Population	Deaths	ACT ASMR <sup>a</sup>
	0–17 years	Number	Per 10 000
2017 <sup>b</sup>	91 569	25	2.7
2018	93 352	36	3.9
2019	94 715	16	1.7
2020	96 332	24	2.5
2021	96 936	23	2.4

<sup>a</sup> The rates in this table are not directly comparable to previous reports.

ASMR = age-specific mortality rate.

Data Source - <https://explore.data.abs.gov.au/> (Quarterly Population Estimates (ERP), by State/Territory, Sex and Age)

## Distribution across characteristics

The following discussion focuses on demographic and individual characteristics for ACT resident children and young people who died between 2017 to 2021. 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 2017 to 2021.

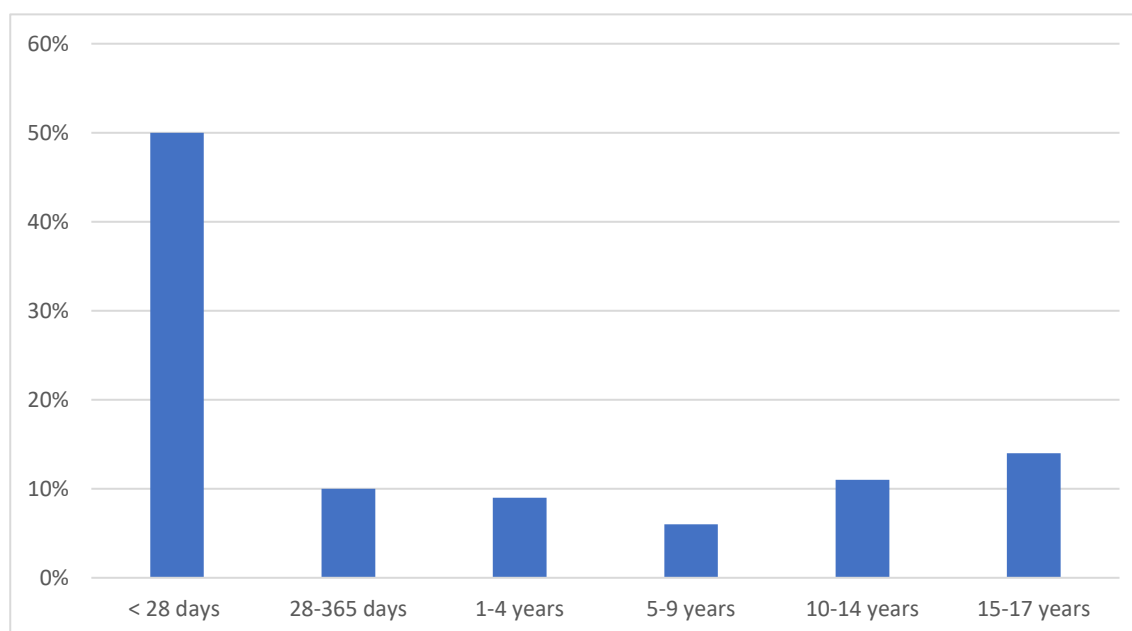
**Table 3.3: Demographic characteristics of ACT resident children and young people who died, 2017–2021**

Characteristic	Deaths	
	Number	Per cent
<b>Total</b>		
Persons 0–17 years of age	118	
<b>Sex</b>		
Female	53	44.9
Male	65	55.1
<b>Age</b>		
< 28 days	59	50.0
28–365 days	12	10.2
1–4 years	11	9.3
5–9 years	7	5.9
10–14 years	13	11.0
15–17 years	16	13.6

In the five years covered by this report, there were 53 deaths of ACT females aged less than 18 years and 65 deaths of ACT males 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 2017 to 2021, the 5–9 age group accounted for 5.9% of all deaths. The proportion of deaths increases again during adolescence and is partially explained by an increase in death by suicide in the 15–17 and 10–14 age groups. The Committee plans to continue to review deaths by suicide to add to the research conducted in 2020.

**Figure 3.2: ACT resident deaths by age, 2017–2021**



## 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 3.4 presents the indicative causes of death for ACT resident children and young people during the period 2017–2021, with medical causes accounting for more than half (53.4%) of all ACT deaths. Suicide is the third most common indicative cause of death accounting for 10.2% of all ACT deaths. Table 3.5 presents the ICD-10 grouping, with conditions originating in the perinatal period accounting for 43.2% of all deaths.

**Table 3.4: Indicative cause of death, ACT resident children and young people, 2017–2021**

Indicative cause of death	Number	Per cent
<b>Total</b>		
Medical causes	63	53.4
Extreme prematurity	29	24.6
Suicide	12	10.2
Unintentional injury/accident (including transport and drowning)	7	5.9
Unascertained	•	•
Fatal assault	•	•
SIDS and or SUDI <sup>a</sup>	•	•

<sup>a</sup>SUDI=sudden unexpected death in infancy; SIDS=sudden infant death syndrome.

**Table 3.5: ICD-10 grouping cause of death, ACT resident children and young people, 2017–2021**

ICD-10 grouping	Number	Per cent
<b>Total</b>	<b>118</b>	
Certain conditions originating in the perinatal period	51	43.2
Injury poisoning and certain other consequences of external causes	13	11.0
Congenital malformations, deformations and chromosomal abnormalities	10	8.5
Neoplasms	9	7.6
Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified	8	6.8
Diseases of the circulatory system	8	6.8
External causes of morbidity and mortality	7	5.9
Diseases of the nervous system	6	5.1
Other medical disorders <sup>a</sup>	6	5.1

<sup>a</sup>Other medical disorders include the following ICD-10 chapters: Diseases of the respiratory system; Disease of the blood and blood forming organs; Certain infectious and parasitic diseases; Endocrine, nutritional and metabolic diseases.

The Committee notes that the number of deaths attributed to 'Congenital malformations, deformations, and chromosomal abnormalities' appears lower than members expected. The Committee plans to undertake a review with the ACT Maternal and Perinatal Maternal Mortality Committee to establish if this is due to ICD-10 coding protocols. An update on this work will be provided in the Committee's 2022 annual report.

# 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 2017–2021.

## 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: 61 ACT infants died within the ACT and 10 died elsewhere. Health services in the ACT provide care for high-risk pregnancies in the surrounding geographic regions, and 28 interstate infants died in the ACT. There were less than five neonate and infant cases before the Coroner as of 15 February 2022.

**Table 4.1: Breakdown of infant deaths, 2017–2021**

Deaths	Number	Per cent
<b>Total</b>	<b>99</b>	
ACT residents who died in the ACT	61	61.6
ACT residents who died elsewhere	10	10.1
Interstate residents who died in the ACT	28	28.3
Cases before the Coroner	•	•

Removing those children who usually reside elsewhere (n=28), children who died interstate (n=10) and coronial cases, the following analysis relates to the 61 children who were resident and died in the ACT during 2017 to 2021. In 2021, 15 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: <https://health.act.gov.au/about-our-health-system/data-and-publications>

There was an increase in the number of neonatal deaths in the 2021 reporting period. As the ACT is a small jurisdiction, numbers can vary from year to year and the Committee will continue to monitor this trend in coming years. A neonatal death is one that occurs in a baby born at any gestational age with signs of life and within the first 28 completed days of life. Some neonatal deaths occur in babies who are born before they are mature enough to survive outside the womb even with intensive care support. In 2021 the gestational age of viability at which babies could be offered intensive care support in the ACT was 23 completed weeks of pregnancy. Unfortunately, despite receiving medical care a few babies die each year because of the complications of extreme prematurity or other medical conditions. The proportion of babies in this group has not changed significantly from previous years.

Some neonatal deaths occurred in babies with severe and life limiting congenital anomalies. Changes in service provision and state border closures during the COVID-19 epidemic have meant that more families from regional NSW travelled to and birthed in the ACT to access specialist medical care. The committee believes that the increased numbers of neonatal deaths reported in 2021 are predominantly related to changes in service provision, rather than to an increased risk of neonatal death in the ACT, however this will continue to be monitored closely.

The most recent data (2020) indicate that the infant mortality rate (deaths of children aged less than one year) for the ACT was 3.5 per 1,000 live births. This rate is similar to the Australian rate of 3.2 per 1,000 live births (ABS, 2021a). 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 2016 and 2020 the ACT infant mortality rate ranged from 0.9 to 3.7 per 1,000 live births, whereas the national rate ranged between 3.1 and 3.3 over the same period.

## 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 2017 to 2021 has not been separately identified 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 (approx. 90%) of deaths in children under one year in the five-year period 2017 to 2021 (n=54). In 2021, neonatal deaths account for 93.3% of deaths in children under one year.

### Sex

In the five years to December 2021, 61 children died in the first year of life, with a higher incidence of male deaths. In 2021 15 children died of whom 66.7% were male.

**Table 4.2: ACT resident infant deaths by age group and sex, 2021 and 2017–2021**

January 2017 – December 2021		
Characteristic	Deaths	
	Number	Per cent
<b>Total</b>	<b>61</b>	
Neonatal deaths under 28 days	54	88.5
Infant deaths 28-365 days	7	11.5
<b>Sex</b>		
Female	27	44.3
Male	34	55.7

### Cause of death

Table 4.3 presents the main causes of death of ACT children under the age of one year during 2017 to 2021. 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 60.2% of all ACT resident deaths.

**Table 4.3: Indicative and ICD-10 cause of death of children less than one year of age, 2017–2021**

Cause of death	Total
<b>Medical causes and extreme prematurity</b>	<b>55</b>
Certain conditions originating in the perinatal period	48
Congenital malformations, deformations and chromosomal abnormalities	7
<b>SIDS &amp; SUDI<sup>b</sup> and unascertained and other causes<sup>a</sup></b>	<b>6</b>
<b>Total</b>	<b>61</b>

<sup>a</sup> Other causes include the ICD-10 chapter; Injury, poisoning and certain other consequences of external causes, Symptoms, signs and abnormal clinical and laboratory finds, not elsewhere classified.

<sup>b</sup> 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).

Most deaths of ACT children under the age of one over the 5 years to 2021 occurred during the neonatal period. 'Certain conditions originating in the perinatal period' (n=48) is the major cause of death for both neonates and infants (aged 28–365 days), followed by 'chromosomal or congenital anomalies' (n=7). There were six cases of deaths caused by either sudden unexpected death in infancy (SUDI), sudden infant death syndrome (SIDS), injury, poisoning and certain other consequences of external causes 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 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, 2017–2021**

Total <sup>a</sup>	Known to CYPS	Known to ACT Policing
118	20	34

<sup>a</sup> 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 are therefore 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 2017 to 2021, 118 residents of the ACT under the age of 18 years died in the ACT or elsewhere. Overall, 20 (17%) children and young people and/or their families were known to CYPS and 34 (28.8%) 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' (CCR), which is a record of information regarding the child or young person made by either a voluntary or mandatory reporter. In the ACT where the person contacting the Directorate believes that a child is at risk, this is classified as a notification. 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' (CPR) is recorded in accordance with s. 360(5) of the Act. A second stage of assessment is then undertaken and if it is believed that a child may be in need of care and protection CYPS determines if further involvement is necessary which may include a care and protection appraisal (a planned process of enquiry into a family situation).

### *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. Police involvement does not include where a family member was a complainant.

## 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 2017 to 2021. 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, 2017–2021**

System engagement	0-4 years	5-17 years	Total
Total	82	36	118
<b>Not known to CYPS</b>	<b>74</b>	<b>24</b>	<b>98</b>
Police involved	11	13	24
<b>Known to CYPS</b>	<b>8</b>	<b>12</b>	<b>20</b>
Police involved	5	5	10

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=12) than females (n=5). This is consistent with the pattern repeated 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, 2017–2021**

	Child & Youth Protection Services		ACT Policing		
	Known to CYPS	Children with Siblings known to CYPS	Current or previous police involvement <sup>a</sup>	Death incident only	Not known to Police
<b>Deaths</b>					
Persons 0–17 years of age	20	14	34	17	84
<b>Sex</b>					
Female	11	8	12	5	41
Male	9	6	22	12	43

<sup>a</sup> Current or previous known status 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, 15 of the children had child concern reports recorded (any report made to CYPS) and five 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, of the 20 children and young people who died who were known to child protection, fewer than five had an appraisal (a planned process of enquiry into a family situation) conducted, and fewer than five had prenatal reports recorded. Fewer than five children who had died were not the subject of reports themselves; 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, 2017–2021**

Child notification	Total <sup>a</sup>	Per cent
Child concern report only	15	12.7
Child protection report	5	4.2
Not known to CYPS	98	83.0

<sup>a</sup> Percentage does not sum due to rounding.

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 2017 to 2021, a higher proportion of children and young people who died from classifications other than medical causes (23.6%) were known to CYPS than children who died of medical causes (11.1%).

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, 2017–2021**

	Total	Known to CYPS		Known to Police	
		CCR only	CPR	Involvement	Death Incident only
<b>Other than medical causes<sup>a</sup></b>	55	13	5	12	11
<b>Medical causes</b>	63	7	0	5	6

<sup>a</sup> Other than medical causes include indicative cause of death classifications: Extreme prematurity; Suicide; Transport; Drowning; SIDS & SUDI and undetermined; Unascertained; Unintentional injury/accident; fatal assault.

The Committee is interested in understanding how the child protection system and other service systems interact and share information. The Committee is aware of the increase in reporting to CYPS which impacts on resourcing. Half of the children and young people who died of suicide in the five-year period were known to the child protection system. The Committee's 2020 review of ACT children and young people who died of intentional self-harm would indicate that other services may have been aware of risks for the child or young person. The Committee plans to undertake specific reviews in 2022 that will consider how in the ACT information is shared when there are known risks in a child or young persons life.

# 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 2021.

## Committee Matters 2021

The Committee reports to the Minister for Families and Community Services who has responsibility for the administration of the *Children and Young People Act 2008*.

The Committee's administrative, financial and human resource management is overseen by the Community Services Directorate. The Committee is supported by one Senior Research and Review Officer.

The Committee met four times in 2021. Due to COVID-19 restrictions these meetings occurred online.

In 2021, the Committee reviewed its processes to ensure it is meeting the legislated functions and considered how to improve its own effectiveness in reducing the likelihood of preventable deaths of children and young people. The Committee has worked with the ACT Epidemiology Division of ACT Health to scope the feasibility of accessing and coding serious injury data of children and young people from The Canberra Hospital. The Committee hopes to include serious injury data in both specific reviews and broader commentary of patterns and trends in child mortality.

The Committee has considered the role of in-depth individual and small cohort reviews in its work. The Committee has developed a process to undertake in-depth reviews once other review processes within the ACT have been completed. It is envisaged that this process will better utilise member expertise and knowledge of how the existing system is operating. The Committee plans to undertake several specific reviews in 2022 and make recommendations to Government in line with s.727(b) of the *Children and Young People Act (2008)*.

The Committee continued to work across the following areas:

- The timely and accurate collection of information about the circumstances and causes of death for children and young people in the ACT.
- Contributing through its Annual Report, to Government and community, knowledge and understanding of the causes and circumstances of children and young people's deaths.
- Actively promoting the Committee's work with relevant ACT agencies and individuals to offer informed views aimed at preventing or reducing deaths.
- Maintaining links with interstate and national bodies undertaking similar work.

## Committee Membership

The Committee welcomed three new members in 2021, Dr Bronwen Phillips, Ms Catherine Rule and Ms Jane Simmons. Dr Phillips is a research fellow, Aboriginal and Torres Strait Islander Health Program at the Australian National University Research School of Population Health. Ms Rule and Ms Simmons are appointed to the Committee through their positions as Community Services Directorate Director General and ACT Education Directorate Deputy-Director General respectively.

## Continuing work

Given the small size 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 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 monitoring the safety and wellbeing of children and young people through the following activities:

### **Improving data quality**

Monitoring of data quality issues in relation to cause of death and death certificates, with particular regard to suicide and disability.

Identifying and investigating opportunities for data sharing to enhance the quality of data held on the Register and an improved data system solution.

### **Monitoring the implementation of recommendations**

The Committee continues to monitor the implementation of recommendations including those about strengthening supports systems for children under the care of the child protection system; information sharing to enhance supports for children and young people at risk; and safety around the home. The Committee plans to engage with relevant directorates in 2022 to address outstanding recommendations.

### **Ongoing in-depth reviews**

The Committee will continue to undertake in-depth and thematic reviews and provide these to Government with relevant recommendations to improve legislation, systems and processes that aim to reduce deaths of children and young people in the ACT. The Committee will look at undertaking reviews into those deaths which are likely to provide significant insights or learnings. A focus of reviews for the Committee in 2022 will be deaths by external causes including suicide, which is the third most common indicative cause of death after medical causes and extreme prematurity accounting for 10.2% of all ACT deaths in those aged 0-17.

### **Promote understanding of the cause and impact of child deaths in the ACT**

The Committee will continue to increase public awareness and advocate for the issues that affect the health and safety of children and young people in the ACT by disseminating information through its Annual Report, the Committee's website and through the Committee's involvement at a national level with the Australian and New Zealand Child Death Review and Prevention Group.

## 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 2021 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 2021, we provided information to the Queensland Family

and Child Commission on the number of deaths of children in the 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, 2017–2018*.

- The NSW child death register includes children who normally live in NSW, but whose death occurred in the ACT. In August 2021 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).

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# Appendix A Population tables

ACT Quarterly population estimates (ERP)<sup>a</sup>

	2017-Q2			2018-Q2			2019-Q2			2020-Q2			2021-Q2		
Age	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total
<b>0-4</b>	<b>14,702</b>	<b>13,709</b>	<b>28,411</b>	<b>14,585</b>	<b>13,593</b>	<b>28,178</b>	<b>14,383</b>	<b>13,625</b>	<b>28,008</b>	<b>14,267</b>	<b>13,489</b>	<b>27,756</b>	<b>13,914</b>	<b>13,207</b>	<b>27,121</b>
0	2,904	2,696	5,600	2,738	2,597	5,335	2,719	2,613	5,332	2,835	2,633	5,468	2,725	2,633	5,358
1	2,967	2,766	5,733	2,918	2,694	5,612	2,727	2,598	5,325	2,739	2,615	5,354	2,790	2,617	5,407
2	2,993	2,797	5,790	2,974	2,801	5,775	2,914	2,712	5,626	2,745	2,641	5,386	2,723	2,587	5,310
3	2,930	2,683	5,613	3,025	2,817	5,842	2,977	2,857	5,834	2,952	2,734	5,686	2,756	2,630	5,386
4	2,908	2,767	5,675	2,930	2,684	5,614	3,046	2,845	5,891	2,996	2,866	5,862	2,920	2,740	5,660
<b>5-9</b>	<b>13,948</b>	<b>12,862</b>	<b>26,810</b>	<b>14,418</b>	<b>13,348</b>	<b>27,766</b>	<b>14,688</b>	<b>13,624</b>	<b>28,312</b>	<b>14,945</b>	<b>13,911</b>	<b>28,856</b>	<b>14,944</b>	<b>14,099</b>	<b>29,043</b>
5	2,931	2,675	5,606	2,972	2,809	5,781	2,949	2,746	5,695	3,066	2,882	5,948	2,970	2,872	5,842
6	2,850	2,611	5,461	2,973	2,707	5,680	3,005	2,832	5,837	2,971	2,786	5,757	3,066	2,879	5,945
7	2,830	2,662	5,492	2,861	2,646	5,507	2,960	2,701	5,661	3,025	2,831	5,856	2,948	2,767	5,715
8	2,702	2,504	5,206	2,878	2,670	5,548	2,885	2,663	5,548	2,976	2,728	5,704	3,013	2,855	5,868
9	2,635	2,410	5,045	2,734	2,516	5,250	2,889	2,682	5,571	2,907	2,684	5,591	2,947	2,726	5,673
<b>10-14</b>	<b>11,891</b>	<b>11,121</b>	<b>23,012</b>	<b>12,374</b>	<b>11,568</b>	<b>23,942</b>	<b>12,920</b>	<b>11,955</b>	<b>24,875</b>	<b>13,540</b>	<b>12,465</b>	<b>26,005</b>	<b>13,876</b>	<b>12,730</b>	<b>26,606</b>
10	2,531	2,352	4,883	2,650	2,433	5,083	2,757	2,524	5,281	2,907	2,698	5,605	2,900	2,693	5,593
11	2,511	2,361	4,872	2,565	2,386	4,951	2,688	2,443	5,131	2,760	2,546	5,306	2,884	2,687	5,571
12	2,315	2,215	4,530	2,524	2,363	4,887	2,603	2,376	4,979	2,697	2,463	5,160	2,785	2,527	5,312
13	2,275	2,114	4,389	2,327	2,253	4,580	2,540	2,369	4,909	2,620	2,377	4,997	2,692	2,446	5,138
14	2,259	2,079	4,338	2,308	2,133	4,441	2,332	2,243	4,575	2,556	2,381	4,937	2,615	2,377	4,992
<b>15-17</b>	<b>6,757</b>	<b>6,579</b>	<b>13,336</b>	<b>6,926</b>	<b>6,540</b>	<b>13,466</b>	<b>6,977</b>	<b>6,543</b>	<b>13,520</b>	<b>7,088</b>	<b>6,627</b>	<b>13,715</b>	<b>7,318</b>	<b>6,848</b>	<b>14,166</b>
15	2,156	2,135	4,291	2,295	2,115	4,410	2,337	2,150	4,487	2,336	2,258	4,594	2,592	2,367	4,959
16	2,260	2,161	4,421	2,225	2,175	4,400	2,348	2,148	4,496	2,344	2,166	4,510	2,351	2,261	4,612
17	2,341	2,283	4,624	2,406	2,250	4,656	2,292	2,245	4,537	2,408	2,203	4,611	2,375	2,220	4,595
<b>Total</b>	<b>47,298</b>	<b>44,271</b>	<b>91,569</b>	<b>48,303</b>	<b>45,049</b>	<b>93,352</b>	<b>48,968</b>	<b>45,747</b>	<b>94,715</b>	<b>49,840</b>	<b>46,492</b>	<b>96,332</b>	<b>50,052</b>	<b>46,884</b>	<b>96,936</b>

<sup>a</sup> (ABS. Stat, 2021b) By state/territory, sex and age: ACT



Australia Quarterly Population Estimates (ERP)<sup>a</sup>

	2017-Q2			2018-Q2			2019-Q2			2020-Q2			2021-Q2		
Age	Males	Females	Total	Males	Females	Total	Males	Females	Persons	Males	Females	Persons	Males	Females	Total
<b>0-4</b>	<b>811,093</b>	<b>767,901</b>	<b>1,578,994</b>	<b>807,995</b>	<b>764,298</b>	<b>1,572,293</b>	<b>806,625</b>	<b>761,580</b>	<b>1,568,205</b>	<b>798,252</b>	<b>753,661</b>	<b>1,551,913</b>	<b>782,554</b>	<b>738,368</b>	<b>1,520,922</b>
0	157,886	148,916	306,802	156,125	147,282	303,407	156,573	147,120	303,693	153,082	145,048	298,130	152,904	143,987	296,891
1	165,223	155,906	321,129	158,682	149,777	308,459	156,924	148,081	305,005	156,907	147,531	304,438	153,039	145,049	298,088
2	161,762	153,611	315,373	166,552	157,257	323,809	160,022	151,110	311,132	157,817	148,921	306,738	157,184	147,784	304,968
3	161,549	153,634	315,183	163,366	154,926	318,292	168,037	158,766	326,803	161,072	152,110	313,182	157,977	149,110	307,087
4	164,673	155,834	320,507	163,270	155,056	318,326	165,069	156,503	321,572	169,374	160,051	329,425	161,450	152,438	313,888
<b>5-9</b>	<b>814,019</b>	<b>772,832</b>	<b>1,586,851</b>	<b>823,433</b>	<b>781,107</b>	<b>1,604,540</b>	<b>830,275</b>	<b>788,307</b>	<b>1,618,582</b>	<b>835,686</b>	<b>792,665</b>	<b>1,628,351</b>	<b>840,134</b>	<b>795,832</b>	<b>1,635,966</b>
5	163,475	154,847	318,322	166,389	157,612	324,001	164,961	156,664	321,625	166,642	157,920	324,562	169,801	160,366	330,167
6	163,075	154,851	317,926	164,791	156,237	321,028	167,759	158,966	326,725	166,370	157,937	324,307	167,002	158,187	325,189
7	163,743	155,911	319,654	164,301	155,954	320,255	166,023	157,544	323,567	168,925	160,013	328,938	166,659	158,099	324,758
8	161,885	153,413	315,298	164,888	156,899	321,787	165,501	157,095	322,596	167,143	158,678	325,821	169,235	160,276	329,511
9	161,841	153,810	315,651	163,064	154,405	317,469	166,031	158,038	324,069	166,606	158,117	324,723	167,437	158,904	326,341
<b>10-14</b>	<b>757,231</b>	<b>716,032</b>	<b>1,473,263</b>	<b>779,271</b>	<b>736,646</b>	<b>1,515,917</b>	<b>799,164</b>	<b>756,676</b>	<b>1,555,840</b>	<b>818,977</b>	<b>776,691</b>	<b>1,595,668</b>	<b>829,144</b>	<b>786,620</b>	<b>1,615,764</b>
10	160,619	151,927	312,546	162,883	154,863	317,746	164,240	155,455	319,695	167,108	159,110	326,218	166,919	158,412	325,331
11	154,859	146,713	301,572	161,611	152,833	314,444	163,997	155,976	319,973	165,363	156,408	321,771	167,370	159,394	326,764
12	149,268	140,761	290,029	155,889	147,641	303,530	162,687	153,892	316,579	164,980	156,911	321,891	165,702	156,710	322,412
13	147,532	138,651	286,183	150,341	141,671	292,012	156,881	148,573	305,454	163,631	154,724	318,355	165,219	157,145	322,364
14	144,953	137,980	282,933	148,547	139,638	288,185	151,359	142,780	294,139	157,895	149,538	307,433	163,934	154,959	318,893
<b>15-17</b>	<b>444,755</b>	<b>423,265</b>	<b>868,020</b>	<b>444,498</b>	<b>422,327</b>	<b>866,825</b>	<b>446,196</b>	<b>423,187</b>	<b>869,383</b>	<b>452,003</b>	<b>427,792</b>	<b>879,795</b>	<b>461,621</b>	<b>436,086</b>	<b>897,707</b>
15	145,231	138,065	283,296	146,286	139,291	285,577	149,774	140,916	290,690	152,342	143,834	296,176	158,152	149,744	307,896
16	149,167	141,222	290,389	146,922	139,637	286,559	147,794	140,843	288,637	150,860	142,084	292,944	152,504	144,106	296,610
17	150,357	143,978	294,335	151,290	143,399	294,689	148,628	141,428	290,056	148,801	141,874	290,675	150,965	142,236	293,201
<b>Total</b>	<b>889,510</b>	<b>846,530</b>	<b>1,736,040</b>	<b>888,996</b>	<b>844,654</b>	<b>1,733,650</b>	<b>892,392</b>	<b>846,374</b>	<b>1,738,766</b>	<b>904,006</b>	<b>855,584</b>	<b>1,759,590</b>	<b>923,242</b>	<b>872,172</b>	<b>1,795,414</b>

<sup>a</sup> (ABS. Stat, 2021b) By state/territory, sex and age: Australia

Estimated and projected Aboriginal and Torres Strait Islander population<sup>a</sup>

Age	Australia					Australian Capital Territory				
	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021
0 - 4	93,985	94,555	96,116	98,035	100,586	901	882	893	913	947
5 - 9	93,853	93,927	93,592	93,602	93,741	817	866	872	850	850
10 - 14	88,189	89,951	91,773	93,333	93,803	696	697	722	776	792
15 - 19	83,089	84,427	85,124	85,530	86,517	788	783	766	747	763

<sup>a</sup> (ABS, 2016) 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 where this would otherwise identify a child. 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	<ul style="list-style-type: none"><li>• An infant aged over 21 days but under 9 months of age.</li><li>• Gestational age of equal to or over 37 weeks.</li><li>• Normal clinical history, including during pregnancy.</li><li>• Normal growth and development.</li><li>• No similar deaths among siblings, close relatives or other infants in the custody of the carer.</li><li>• The scene where incident leading to the death occurred does not provide an explanation of the death.</li><li>• Absence of potentially fatal pathological findings.</li><li>• No evidence of unexplained trauma, abuse, neglect or unintentional injury.</li><li>• No evidence of substantial thymic stress effect and</li><li>• Negative result in other tests (e.g. toxicology).</li></ul>
SIDS 1b	As with SIDS 1a but: <ul style="list-style-type: none"><li>• an investigation of the scene where the incident leading to the death occurred was not performed, or</li><li>• one of the following tests/screens was not performed:<ul style="list-style-type: none"><li>○ toxicology</li><li>○ radiologic</li><li>○ microbiologic</li><li>○ vitreous chemistry, or</li><li>○ metabolic screening studies.</li></ul></li></ul>
SIDS 2	As with SIDS 1 except for at least one of the following: <ul style="list-style-type: none"><li>• age outside of range</li><li>• similar deaths among siblings, close relatives or other children cared for by the carer not considered infanticide or recognised genetic disorder</li><li>• neonatal or peri-natal conditions that have resolved at the time of death</li><li>• mechanical asphyxia or suffocation caused by overlaying not determined with certainty</li><li>• abnormal growth and development not thought to have contributed to the death, and/or</li><li>• marked inflammatory changes/abnormalities not sufficient to be unequivocal (certain) cause of death.</li></ul>
SIDS Unclassified	<ul style="list-style-type: none"><li>• Did not meet the criteria for SIDS 1 or 2, and</li><li>• Alternative diagnosis or natural or unnatural conditions are equivocal (uncertain), including cases for which an autopsy was not performed.</li></ul>

## 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*

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