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Review of ACT Child Deaths

1992-2003

REVIEW OF ACT CHILD DEATHS

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CONTENTS

ACKNOWLEDGEMENTS	2
EXECUTIVE SUMMARY	4
1 INTRODUCTION	6
1.1 Child Death Review Team.....	6
1.1.1 <i>Functions and activities of the Child Death Review Team</i>	7
1.1.2 <i>Legislation</i>	8
2 METHODOLOGY	9
2.1 Data sources	9
2.2 Data issues.....	9
2.3 Data definitions.....	10
2.3.1 <i>Infant death</i>	10
2.3.2 <i>Year of death and year of death registration</i>	10
2.3.3 <i>Residency status and death registrations</i>	10
2.3.4 <i>Aboriginal and Torres Strait Islander status</i>	10
2.4 Period of analysis	11
2.5 Method of analysis	11
3 TRENDS IN INFANT, CHILDREN AND YOUNG PERSON'S DEATHS, 1992-2003 .	12
3.1 Demographics	12
3.2 Trends in infant deaths.....	13
3.2.1 <i>Causes of infant death</i>	14
3.3 Trends in children and young person's deaths	15
3.3.1 <i>Causes of children and young person's deaths</i>	16
3.3.2 <i>Aboriginal and Torres Strait Islander child deaths</i>	18
4 INFANT DEATHS IN THE ACT, 2000-2003	19
4.1 Demographics	19
4.2 Causes of infant death	20
4.2.1 <i>Neonatal deaths</i>	22
4.2.2 <i>Post-neonatal deaths</i>	23
4.2.3 <i>Sudden unexpected deaths in infancy (SUDI)</i>	23
4.2.4 <i>'External' causes of death</i>	25
5 CHILDREN AND YOUNG PERSON'S DEATHS IN THE ACT, 2000-2003	26
5.1 Demographics	26
5.2 Causes of children and young person's deaths	27
5.2.1 <i>Diseases and morbid conditions</i>	27
5.2.2 <i>'External' causes of death</i>	29
APPENDIX 1: INFANT, CHILDREN AND YOUNG PERSON'S REGISTERED DEATHS, ACT AND AUSTRALIA, 1992 - 2003	32
GLOSSARY	33
REFERENCES	35
LEGISLATION	36

EXECUTIVE SUMMARY

This report has been prepared with guidance from the ACT Child Death Review Team. The primary objective of the Team is to prevent, or reduce, the deaths of infants, children and young persons in the Australian Capital Territory (ACT). The first step in achieving this aim is to identify and understand existing mortality patterns and trends in the ACT.

This report provides descriptive information on the deaths of infants, children and young persons aged from birth to 17 years of age, where the death was registered between January 1992 and December 2003 and the deceased was a resident of the ACT, at the time of death.

KEY FINDINGS

Total deaths between 1992 and 2003

There were 400 death registrations for infants, children and young persons, aged 0-17 years, during the period 1992 to 2003, where the deceased was an ACT resident at the time of death. There were 229 male and 171 female deaths registered during this period. More than 60 per cent of the children who died were less than 12 months of age.

Infant deaths

The ACT infant mortality rate compares favourably with other jurisdictions

The ACT infant mortality rate (4.8 deaths per 1,000 live births) for the period 1992 to 2003 was lower than the rate for Australia (5.6 deaths per 1,000 live births).

In the more recent period from 2000 to 2003, there were 67 infant deaths registered, where the infant was a resident of the ACT at the time of death. The ACT infant mortality rate was 4.1 deaths per 1,000 live births for this period and compares favourably with New South Wales (2003: 4.9 per 1,000 live births) and Australia (2000-2003: 5.1 per 1,000 live births).

ACT infant mortality has decreased over time

Infant mortality for the ACT has declined steadily over time, with an average annual decrease of 0.75 per cent between 1992 and 2003. The ACT infant mortality rate decreased from 5.0 deaths per 1,000 live births between 1992 and 1995, to 4.1 deaths between 2000 and 2003.

The leading causes of infant mortality were conditions arising in the perinatal period, congenital anomalies and sudden unexpected deaths of infants (SUDI)

More than 90 per cent of ACT infant deaths registered between 2000 and 2003 included a disease or morbid condition as the underlying cause of death. More than half of these deaths (55%, or 37 deaths) were attributed to *Certain conditions originating in the perinatal period* (pregnancy and the first 28 days of life), which includes conditions relating to the pregnancy, foetal growth, labour or delivery of the infant. About a fifth (19.4%) were attributed to *Congenital malformations, deformations and chromosomal abnormalities* (congenital anomalies) and about ten per cent were attributed to *Ill defined and unknown causes of mortality*, or sudden unexpected deaths of infants (SUDI).

There has been a decrease in mortality from sudden unexpected deaths of infants (SUDI) over time

The mortality rate for *Ill defined and unknown causes of mortality* (SUDI), decreased from 0.9 deaths per 1,000 live births in the period 1992 to 1995 to 0.7 in the period 2000 to 2003.

Sudden infant death syndrome (SIDS) is a sub-category of SUDI and largely accounts for this decrease in mortality. The mortality rate from SIDS declined from 0.9 deaths per 1,000 live births between 1992 and 1995, to 0.4 deaths between 2000 and 2003.

There was a sex differential in infant mortality

Consistent with other jurisdictions, the ACT infant mortality rate for males was higher than the rate for females. In the period 2000 to 2003, there were 44 male infant deaths registered (mortality rate of 5.3 per 1,000 live births) compared with 23 female infant death registrations (mortality rate of 2.9 per 1,000 live births): a ratio of nearly two male infant deaths to one female infant death. Fifteen of these male deaths occurred in the first day of life, compared to four female infant deaths.

Children and young person's deaths

The ACT children and young person's mortality rate compares favourably to other jurisdictions

The ACT children and young person's (aged 1-17 years) mortality rate (16.8 deaths per 100,000 population) for the period 1992 to 2003 was lower than the rate for Australia (23.5 deaths per 100,000 population).

In the more recent period from 2000 to 2003, the ACT mortality rate for this age group was 13.7 per 100,000 population (41 deaths), which compares favourably with NSW (2003: 18.1 per 100,000 population) and Australia (2000-2003: 20.2 per 100,000 population).

ACT children and young person's mortality has decreased over time

ACT children and young person's mortality has declined steadily over time, with an average annual decrease of 0.13 per cent between 1992 and 2003. The mortality rate for this age group decreased from 19.3 deaths per 100,000 population between 1992 and 1995, to 13.7 deaths between 2000 and 2003.

The leading causes of children and young person's mortality were injury or poisoning, cancers and congenital anomalies

In the period 2000 to 2003, death from *External causes of morbidity and mortality* (injury or poisoning) accounted for nearly a third (31.7%) of all deaths of children and young persons in the age group 1-17 years. *Transport accidents* comprised the largest group in this category, accounting for six of the 13 deaths from *External causes of morbidity and mortality* during this period.

The second leading cause of death for ACT children and young persons in the period 2000 to 2003 was *Neoplasms* (cancers), accounting for 17.1% of all death registrations for children and young persons aged 1-17 years. *Congenital malformations, deformations and chromosomal abnormalities* (congenital anomalies) accounted for 14.6 per cent of death registrations for ACT children and young persons during this period.

There has been a decrease in mortality from injury or poisoning, and cancers over time

The two major causes in the decline of ACT children and young person's mortality rates, from 1992 to 2003, were deaths from *External causes of morbidity and mortality* (injury or poisoning), and *Neoplasms* (cancers). The mortality rate for *External causes of morbidity and mortality* decreased from 9.0 deaths per 100,000 between 1992 and 1995, to 4.3 deaths between 2000 and 2003. The reduction in deaths due to *External causes of morbidity and mortality* is largely due to a decrease in *Accidental drowning and submersion* in younger age groups.

The *Neoplasms* (cancer) mortality rate decreased from 5.1 deaths per 100,000 population between 1992 and 1995, to 2.3 deaths between 2000 and 2003. The greatest reduction in *Neoplasms* mortality was due to a decrease in mortality from leukaemia-type conditions.

There was an age differential in children and young person's mortality

In the period 2000 to 2003, ACT children aged one to four years were the most vulnerable and comprised more than a third (34.1%) of all death registrations for the age group 1-17 years.

1 INTRODUCTION

This is the first statistical report on the deaths of infants, children and young persons in the ACT. It includes deaths of children from birth to 17 years of age, for the period 1992 to 2003. The report has been compiled with guidance from the ACT Child Death Review Team, which was established by the Minister for Health in April 2004.

Any death, particularly that of a child, causes anguish to family and friends. By looking at mortality patterns and trends over time, this report aims to add to the existing body of knowledge to help prevent, or reduce, child deaths in the ACT.

1.1 Child Death Review Team

Dr Paul Dugdale (Chair)	ACT Chief Health Officer, ACT Health.
Dr Wayne Ramsey (Chair: June – Dec 2005)	Clinical Governance Unit, ACT Health.
Ms Vicki Crispe (Secretariat)	Office of the Chief Health Officer, ACT Health.
Ms Jenny Beutel	ACT Chief Nurse, ACT Health.
D/Sgt Peter Budworth	Deputy Chief Police Office, Australian Federal Police – ACT Policing.
Mr Ron Cahill	ACT Chief Magistrate, ACT Law Courts & Tribunals Administration.
Ms Merrie Carling	Child and Adolescent Mental Health, ACT Health.
Supt. Leanne Close	Deputy Chief Police Office, Australian Federal Police – ACT Policing.
Ms Michelle Heidtmann	Coroner's Office, ACT Law Courts & Tribunals.
Mr Chris Killick Moran	Community Policy Division, ACT Health.
Ms Denise Lamb	Maternal and Child Health, ACT Health.
Dr Sue Packer	Child at Risk Assessment Unit, ACT Health.
Mr Shane Paton	Clinical Governance Unit, ACT Health.
Professor Graham Reynolds	Paediatrician, ACT Health.
Mr Alasdair Roy	Child and Youth Advocacy, Office of the Community Advocate.
Ms Catherine Shands	Clinical Governance Unit, ACT Health.
Mr Phil Thompson	Executive Section, ACT Law Courts & Tribunals Administration.

The Team membership reflects a multi-disciplinary interagency approach to preventing and reducing children and young person's deaths in the ACT. Members include persons recommended (and/or expressions of interest) by an interdepartmental team, experts in health care, research methodology, child development, child protection, and persons by nature of their experience, or qualifications, are likely to make a valuable contribution to the Team. There are currently 17 members in the Team.

The role of the Team is to formulate recommendations for consideration by Government, and to assist policy makers in formulating policies and practices, to help prevent, or reduce, child deaths in the ACT. This is achieved through:

- The provision of recommendations from the interpretation of data trends and patterns derived from validated data sources.
- The undertaking of reviews to demonstrate the extent to which previous recommendations have been incorporated into practice.

1.1.1 Functions and activities of the Child Death Review Team

The functions of the Team are described in the Terms of Reference, and include:

- **Research and surveillance to prevent, or reduce, child deaths in the ACT.**

The members of the Child Death Review Team have access to a number of data sources that provide information on child deaths. These sources include the Australian Bureau of Statistics cause of death data, the National Coronial Information System for deaths referred to the Coroner, and hospitals in the ACT, which generate clinical data.

- **Maintaining a Child Death Register of all child deaths occurring in the ACT, classified according to cause of death, demographic criteria, and other factors, with a view to understanding the causes of child death and preventing these fatalities.**

An agreement has been reached with the NSW Child Death Review Team to obtain a copy of the NSW Child Death Register database to use as a model for the ACT Child Death Register. This will enable the ACT to collect similar data items to NSW and will simplify validations and comparisons between jurisdictions.

- **Undertaking detailed case reviews of child deaths in the ACT.**

The Team has reviewed deaths occurring in the following circumstances:

- Deaths within educational environments (i.e. schools and preschools).
- Children of parents with a mental illness/drug addiction.
- Child suicide.
- Children in care or custody.
- Autopsies especially for suspected deaths from Sudden Infant Death Syndrome (SIDS).

Although very few deaths occur under these circumstances in the ACT each year, the Team will continue to undertake detailed reviews when they do occur and they will continue to be a focus for future reports.

- **Identifying areas requiring further research that will assist in preventing and reducing child deaths in the ACT.**

Research into child deaths requires careful investigation and reporting, especially where the cause of death is not clear. The importance of this was highlighted by the Coroner's recommendations that were made following the death of a young boy from unknown causes. The recommendations included:

- That the International Standardized Autopsy Protocol for Sudden Unexpected Death of an Infant (Krous & Byard 2001) be adopted in the ACT.
- That the ACT adopt the South Australian practice of 'peer review' of all autopsies conducted on children under 6 years of age, who die from unknown causes.
- That Children's Services in the ACT establish a standard to be included in licensing conditions that would mandate child carers to keep appropriate documentation, and to disclose this documentation in circumstances of injury or death of a child.

Members decided to develop an ACT protocol for the investigation of Sudden Unexplained Deaths in Infancy (SUDI) based on the Royal College of Pathologists and the Royal College of Paediatrics and Child Health (2004) report, *Sudden Unexpected Death in Infancy: A multi-agency protocol for care and investigation*.

The protocol will provide direction and guidance for professionals from agencies involved in dealing with sudden unexplained and unexpected death in infancy. Together with principles and a clear definition, the protocol contains general advice and guidance for dealing with SUDI, along with information concerning inter-agency cooperation. This information will assist in the investigation and prevention of sudden infant deaths in the ACT.

1.1.2 Legislation

A need has been identified for appropriate legislation that will underpin the operations of the Child Death Review Team. The ACT Government Department of Disability Housing and Community Services is responsible for development of the legislation. In the interim, the Team has relied on the powers of the ACT Chief Health Officer, under the *Public Health Act 1997*, which provides for the ACT Chief Health Officer to undertake investigation if there is a risk to public health.

2 METHODOLOGY

2.1 Data sources

Data used in this report are derived from a number of sources, including the Australian Bureau of Statistics (ABS) cause of death unit record files and unpublished data requested from the Bureau. These deaths are coded by the ABS to the ninth and tenth revisions of the International Statistical Classification of Diseases (ICD-10 and ICD-9). The tenth revision of the ICD was adopted by Australia for deaths registered from 1 January 1999.

For deaths referred to the Coroner, resulting from 'external' or 'undetermined' causes, additional information relevant to the incident was obtained from the National Coroners Information System (NCIS). The NCIS is maintained by the Monash University National Centre for Coronial Information and is an on-line computerised data storage facility that houses information on deaths reported to Coroners within Australia, from 2000 onwards. Information from police reports, autopsy reports and findings was obtained from this database to gain greater insight into the deaths of the infants, children and young persons included in this report.

2.2 Data issues

A series of issues were identified in analysing the death data presented in this report:

- Information from the Coroner's database was used to validate data from ABS cause of death unit record files. This was to ensure that all deaths on the Coroner's database were registered with the ABS.

There was a discrepancy with one death referred to the Coroner for investigation that did not appear on the ABS cause of death unit record file. That death has now been included in the ABS Mortality Collection. The ABS have advised that 'mortality data published by the ABS are considered the best estimate at the time of release. Any information subsequently received by the ABS that may fall within the already reported time period will be included in the mortality collection but the ABS do not publish revised mortality estimates'.

- Another issue identified was the unavailability of data from post-mortem examinations other than those conducted for the Coroner. There is provision for recording on the death certificate whether the certified cause is based on autopsy results, but this information is not routinely collected.
- A number of deaths recorded as being from 'unknown' or 'external' causes do not appear to have been referred to the Coroner for investigation, as required under the *Coroners ACT 1997*.
- The number of deaths in the ACT is relatively small and subject to fluctuation on an annual basis. This has implications for analysis and interpretation, particularly when a rate or proportional distribution (%) is based on a small number of deaths. This issue should be considered when reading and quoting from this report.

The methods used to address this issue in this report include aggregating several years of data to increase numbers. In most instances, death data have been aggregated into four-year blocks to minimise the degree of fluctuation observed with annual numbers. In general, percentages have only been included where they represent more than 20 per cent of the distribution.

2.3 Data definitions

2.3.1 Infant death

For the purposes of this report, an infant death is defined as a registered death of a live born baby that died within the first year of life (ie before the first birthday: age <12 months). The data exclude stillbirths, which are included in the definition of a perinatal death and are reported elsewhere (ACT Health 2004).

2.3.2 Year of death and year of death registration

The 'year of death' refers to the year in which an infant, child or young person died. The 'year of death registration' is a term referring to the year in which an infant, child or young person's death was registered. A small percentage of deaths, for example, those occurring at the end of each year, are not registered until the year following the death. Delays in death registration can also occur when deaths are subject to the findings of a Coroner. For the purposes of this report, analysis was undertaken according to the year of death registration.

2.3.3 Residency status and death registrations

This report is concerned with deaths where the usual residence of the deceased was the ACT. These data include deaths of ACT residents that occur and are registered interstate (outside the ACT). For example, children transferred to specialist facilities in Sydney who subsequently died are included in the death data provided in this report. Details of these deaths have been provided to the ACT by other States and Territories.

However, because of its geographical location, the ACT has specific cross-border service issues with NSW. Health services in the ACT are not only accessed by ACT residents, but also residents from surrounding NSW areas such as Queanbeyan and Yass. From a policy perspective, it is also important to profile the number of interstate residents (people who usually reside outside the ACT) whose deaths are registered in the ACT.

Table 2.1 shows that between 1992 and 2003, there were 400 deaths of infants, children and young people whose usual State of residence was the ACT (this is the group of interest for this report) and that 55 of these deaths were registered interstate.

Table 2.1: ACT usual residents deaths by State of registration, 1992-2003.

	ACT	NSW	Other	Total
1992-1995	125	22	2	149
1996-1999	132	11	0	143
2000-2003	88	14	6	108
Total	345	47	8	400

Data source: ABS Cause of death unit record file.

Conversely, Table 2.2 shows that over the same period, there were 474 deaths of infants, children and young people registered in the ACT, but 129 of these registrations were for infants, children and young people whose usual State of residence was outside the ACT.

Table 2.2: Deaths registered in the ACT by State of usual residence, 1992-2003.

	ACT	NSW	Other	Total
1992-1995	125	40	1	166
1996-1999	132	35	0	167
2000-2003	88	53	0	141
Total	345	128	1	474

Data source: ABS Cause of death unit record file.

2.3.4 Aboriginal and Torres Strait Islander status

Aboriginal and Torres Strait Islander status is recorded on ACT Registry of Births, Deaths and Marriages death registration forms and there is an identification flag in ABS cause of death unit record files. However, validation studies have shown that this information is substantially under-reported, so the total number and leading causes of death of Aboriginal and Torres Strait Islander ACT residents remains unknown.

2.4 Period of analysis

This report examines the deaths of infants, children and young persons, from birth to 17 years of age, where deaths were registered between 1 January 1992 and 31 December 2003.

2.5 Method of analysis

Data was analysed using Excel and the statistical package SPSS, version 11.5. A descriptive analysis of results has been presented in this report.

Age-specific mortality rates were calculated to facilitate comparisons between age groups. These rates show the number of death registrations per 100,000 children in each age and sex group in the population. Population estimates from the ABS were used to calculate age-specific mortality rates. However, the infant mortality rate is based upon the number of death registrations among infants in the first year of life (aged <12 months) and is expressed as a rate per 1,000 live births. Where possible, rates have been used for comparison between groups as they relate deaths to the population at risk.

Since the observed value of a rate may vary due to chance, even when there is no variation in the underlying value of a rate, 95 per cent confidence intervals have been calculated and presented for comparison of rates between geographical locations. The 95 per cent confidence interval is a computed interval with a 95 per cent chance of containing the true value of a rate. When making comparisons between rates for different geographical locations, if confidence intervals overlap, then there is no statistically significant difference between rates. Alternatively, if confidence intervals do not overlap then there is at least a 95 per cent probability that the difference in rates between locations is greater than would be explained by chance alone (statistically significant).

For the purposes of this report, deaths from *Injury, poisoning and certain other consequences or external causes* and *External causes of morbidity and mortality* include those deaths that were coded to ICD-10 codes S00-Y98. Additional information from Coronial records was reviewed for deaths resulting from 'external causes' or 'undetermined' causes, or those that occurred after an infant was placed in bed to sleep.

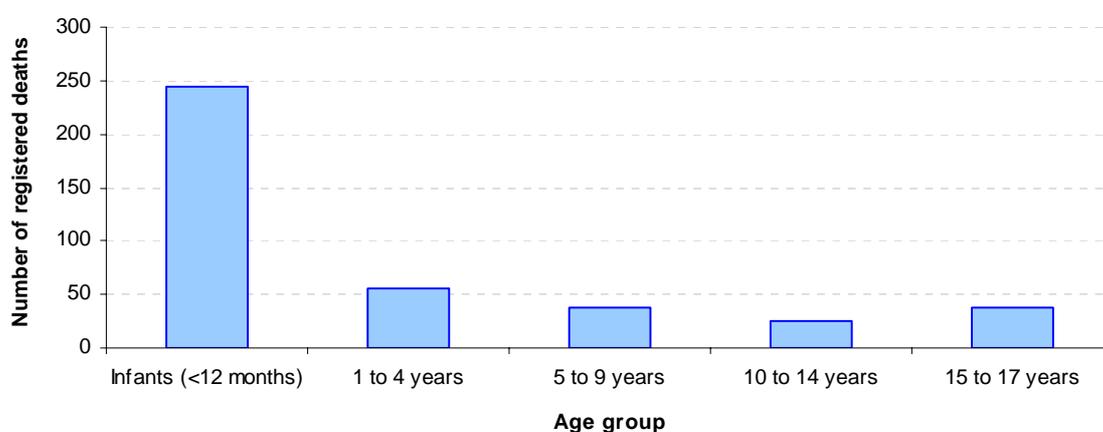
3 TRENDS IN INFANT, CHILDREN AND YOUNG PERSON'S DEATHS, 1992-2003

3.1 Demographics

International comparisons show that mortality rates for Australian children are low and that they have declined steadily over the last two decades, largely due to declines in the infant mortality rate and the child (ages 1-14 years) mortality rate (AIHW 2004; WHO 2006).

Between 1992 and 2003, there were 400 registered deaths for infants, children and young persons, aged 0-17 years, who were ACT residents at the time of their death. There were slightly more male (57.2%; 229) than female (42.8%; 171) deaths registered during this period.

Figure 3.1: ACT resident infant, children and young person's registered deaths by age group, 1992 - 2003^(a).



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all deaths registered between 1992 and 2003, where the infant, child or young person was an ACT resident at the time of their death.

During the period 1992 to 2003, more than 60 per cent of the registered deaths for residents aged 0-17 years, were infants (Figure 3.1). Children aged 1-4 years had the second highest number of registered deaths and young persons aged 10-14 years had the lowest number of registered deaths. In each age group, there were more male than female deaths registered (Table 3.1).

Table 3.1: ACT resident infant, children and young person's registered deaths by age group and sex, 1992-2003^(a).

	Males	Females	Total
Infants (<12 months)	134	111	245
1-4 years	32	23	55
5-9 years	21	16	37
10-14 years	19	7	26
15-17 years	23	14	37
Total	229	171	400

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all deaths registered between 1992 and 2003, where the infant, child or young person was an ACT resident at the time of their death.

3.2 Trends in infant deaths

The infant mortality rate is often used as an indicator of the health of a population because of its sensitivity to health care intervention and the availability of ongoing reliable data. Although there have been changes over time to the way in which perinatal mortality rates are calculated, infant mortality rate definitions and calculations have not changed (ABS 1999). The infant mortality rate is also important from a demographic perspective because of its impact on life expectancy: a low infant mortality rate is a major contributor to increased life expectancy (ABS 2004a).

In spite of declines in infant mortality over the last 30 years, with advances in neonatal care leading to higher survival rates among premature, low birth weight and seriously ill infants, and declines in the number of deaths from sudden infant death syndrome since the early 1990s, infants in the first year of life (aged <12 months) remain a vulnerable group. Between 1992 and 2003, there were 245 ACT resident infant deaths registered, compared to 155 deaths registered for ACT resident children and young persons, 1-17 years of age (Table 3.1).

Although there is considerable variation in infant mortality for the ACT each year (Appendix 1), the ACT has experienced a steady decline over time, with an average annual decrease in mortality of 0.75 per cent between 1992 and 2003.

There were 89 infant deaths registered for the periods 1992 to 1995 and 1996 to 1999, where the infant was an ACT resident at the time of death (Table 3.2). There was a higher infant mortality rate in the latter period because of a lower number of live births in 1996 to 1999 (16,839), compared to the earlier period 1992 to 1995 (17,737).

Table 3.2 shows that the infant mortality rate for the ACT was lower than the rate for Australia, for the period 1992 to 2003. The Territory's infant mortality rate was 5 deaths, compared to 6.2 deaths, per 1,000 live births for all Australian infants for the period 1992 to 1995 (Figure 3.2). For the period 1996 to 1999, the respective rates were 5.3 and 5.4, and for the period 2000 to 2003, the respective rates were 4.1 and 5.1 deaths per 1,000 live births.

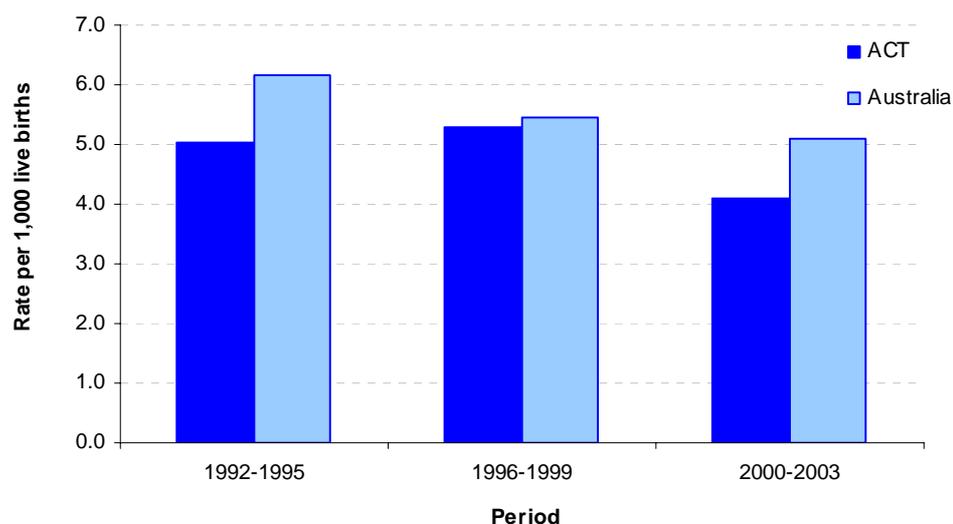
Table 3.2: Infant mortality, ACT and Australia, 1992-2003^(a).

	Number of deaths registered	Infant mortality rate (per 1,000 live births)	95% CI
ACT			
1992 - 1995	89	5	4.0 - 6.1
1996 - 1999	89	5.3	4.2 - 6.4
2000 - 2003	67	4.1	3.1 - 5.1
Total 1992 - 2003	245	4.8	4.2 - 5.4
Australia			
1992 - 1995	6395	6.2	6.0 - 6.3
1996 - 1999	5461	5.4	5.3 - 5.6
2000 - 2003	5062	5.1	5.0 - 5.2
Total 1992 - 2003	16,918	5.6	5.5 - 5.7

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 1992 and 2003, where the infant was either an ACT resident, or Australian resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents, or to all Australian residents, between 1992 and 2003.

Figure 3.2: Infant mortality rate, ACT and Australia, 1992-2003^(a).



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 1992 and 2003, where the infant was either an ACT resident, or Australian resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents, or to all Australian residents, between 1992 and 2003.

3.2.1 Causes of infant death

The leading causes of infant death for the period 1992 to 2003, were *Conditions originating in the perinatal period* (50.6% of all registered infant deaths, where the infant was an ACT resident at the time of death), *Congenital malformations, deformations and chromosomal abnormalities* (24.5%) and *Sudden infant death syndrome (SIDS)* (13.1%).

Table 3.3 shows that there were more registered deaths from *Congenital malformations, deformations and chromosomal abnormalities* between 1996 and 1999 than between 1992 and 1995, or between 2000 and 2003.

Following the 1991 introduction of the National SIDS Council of Australia's public education campaign on the sleeping position of infants, which advised that babies should be placed on their back or on their side in such a way that they cannot roll onto their stomach, the mortality rate from SIDS decreased (AIHW 2004). In the period 1992 to 1995, there were 15 registered infant deaths attributed to SIDS, 11 between 1996 and 1999, and six between 2000 to 2003 (Table 3.3 & Figure 3.3).

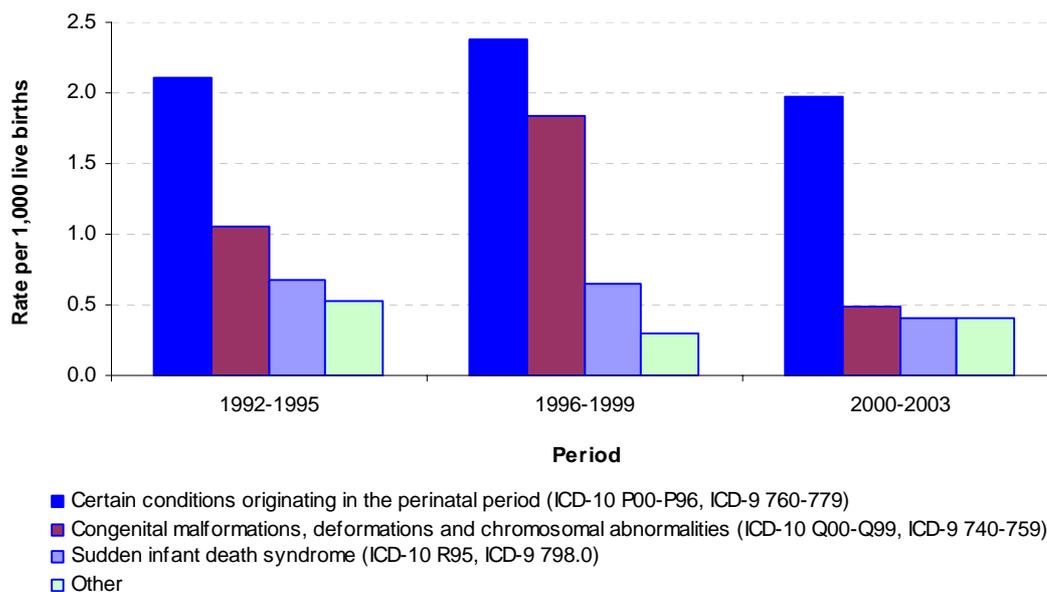
Table 3.3: Causes of infant death, ACT, 1992-2003^(a).

Cause of death	Number of deaths registered			Mortality rate (per 1,000 live births)		
	1992-1995	1996-1999	2000-2003	1992-1995	1996-1999	2000-2003
Certain conditions originating in the perinatal period (ICD-10 P00-P96, ICD-9 760-779)	43	44	37	2.4	2.6	2.3
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99, ICD-9 740-759)	20	28	12	1.1	1.7	0.7
Sudden infant death syndrome (ICD-10 R95, ICD-9 798.0)	15	11	6	0.9	0.7	0.4
Other causes	11	6	12	0.6	0.4	0.7
Total	89	89	67	5.0	5.3	4.1

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 1992 and 2003, where the infant was an ACT resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents between 1992 and 2003.

Figure 3.3: Causes of infant death, ACT, 1992-2003^(a).



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 1992 and 2003, where the infant was an ACT resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents between 1992 and 2003.

3.3 Trends in children and young person's deaths

In Australia, mortality rates are high at birth and decrease rapidly to a minimum at about ten years of age. After the age of ten, they gradually begin to increase with age. In this section, mortality rates for children and young persons between 1-17 years of age are examined. The rates have been calculated by dividing the total number of registered deaths of ACT residents (aged 1-17 years), for each period, by the total population for this age group, for each period. The rates are expressed per 100,000 population.

Table 3.4 shows that the children and young person's mortality rates for the ACT were lower than the rates for Australia. The table shows that the Territory's children and young person's mortality rate was 16.8 deaths per 100,000 population, compared to 26.3 deaths for Australia for the period 1992 to 2003. For the period 1992 to 1995, the respective rates were 19.3 and 26.3 per 100,000 population, 17.6 and 24.3 for 1996 to 1999, and for the period 2000 to 2003, 13.7 and 20.2 per 100,000 population.

There was a decline in the mortality rate for children and young persons (aged 1-17 years) in the ACT and Australia during the period 1992 to 2003 (Table 3.4 & Figure 3.4). The ACT experienced an average annual decrease of 0.13 per cent in children and young person's death registrations, between 1992 and 2003.

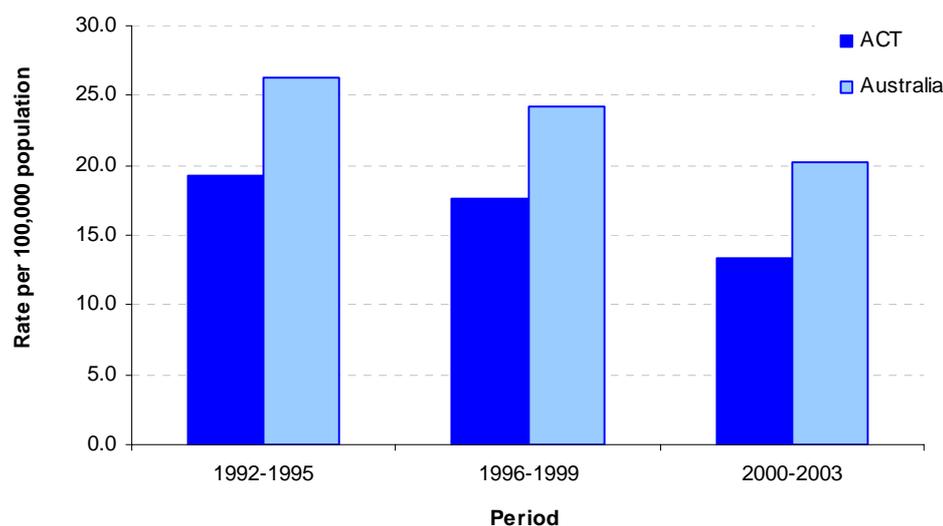
Table 3.4: Children and young person's mortality rate, ACT and Australia, 1992-2003^(a).

	Number of deaths registered	Mortality rate (per 100,000 pop.)	95% CI
ACT			
1992 - 1995	60	19.3	14.4 - 24.1
1996 - 1999	54	17.6	12.9 - 22.3
2000 - 2003	41	13.7	9.5 - 17.9
Total 1992 - 2003	155	16.8	14.1 - 19.5
Australia			
1992 - 1995	4,579	26.3	25.6 - 27.1
1996 - 1999	4,325	24.3	23.5 - 25.0
2000 - 2003	3,665	20.2	19.5 - 20.8
Total 1992 - 2003	12,569	23.5	23.1 - 24.0

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all child and young person's (aged 1-17 years) deaths registered between 1992 and 2003, where the child/young person was either an ACT resident, or Australian resident at the time of their death. The denominators for the mortality rates are the total number of ACT residents, or Australian residents in this age group in each year, between 1992 and 2003.

Figure 3.4: Children and young person's mortality rate, ACT and Australia, 1992-2003^(a).



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all child and young person's (aged 1-17 years) deaths registered between 1992 and 2003, where the child/young person was either an ACT resident, or Australian resident at the time of their death. The denominators for the mortality rates are the total number of ACT residents, or Australian residents in this age group in each year, between 1992 and 2003.

3.3.1 Causes of children and young person's deaths

During the period 1992 to 2003, there were marked decreases in the number of death registrations for children and young persons for *External causes of morbidity and mortality* (injury and poisoning), which are potentially preventable, and *Neoplasms* (cancers) (Table 3.5 & Figure 3.5).

Between 1992 and 1995, there were 28 ACT resident death registrations attributed to *External causes of morbidity and mortality* (injury and poisoning), of which eight, or about 30 per cent, were due to *Accidental drowning and submersion*. These children were aged five years or less – five boys and three girls. The reduction in *External causes of morbidity and mortality* (injury and poisoning) deaths during the reporting period is largely due to a decline in the number of deaths due to *Accidental drowning and submersion*. Three children died from *Accidental drowning and submersion* in the period 2000 to 2003.

The adequacy of pool fencing, and adult supervision around pools, have been identified as important measures that protect children from accidental drowning in houses with private pools (Blum & Shield 2000; Scott 2003). Since 1996, the ACT has adhered to the Building Code of Australia, which requires fencing of domestic swimming pools. Safety fencing is required when the water in a pool is more than 300 mm deep and the pool is used primarily for swimming, wading, paddling or the like, including a bathing or wading pool or spa. The primary purpose of safety fencing is to protect children less than five years of age (ABS 2002).

During the period 1992 to 2003, *Neoplasms* (cancers) were the second leading cause of death for children and young persons aged 1-17 years. The cancer mortality rate declined from 5.1 per 100,000 population for the period 1992 to 1995, to 2.9 for 1996 to 1999 and 2.3 for the period 2000 to 2003. The largest decreases observed in cancer mortality during this period were for leukaemia-type conditions for children in the younger age groups, reflecting advances in cancer treatment over this period.

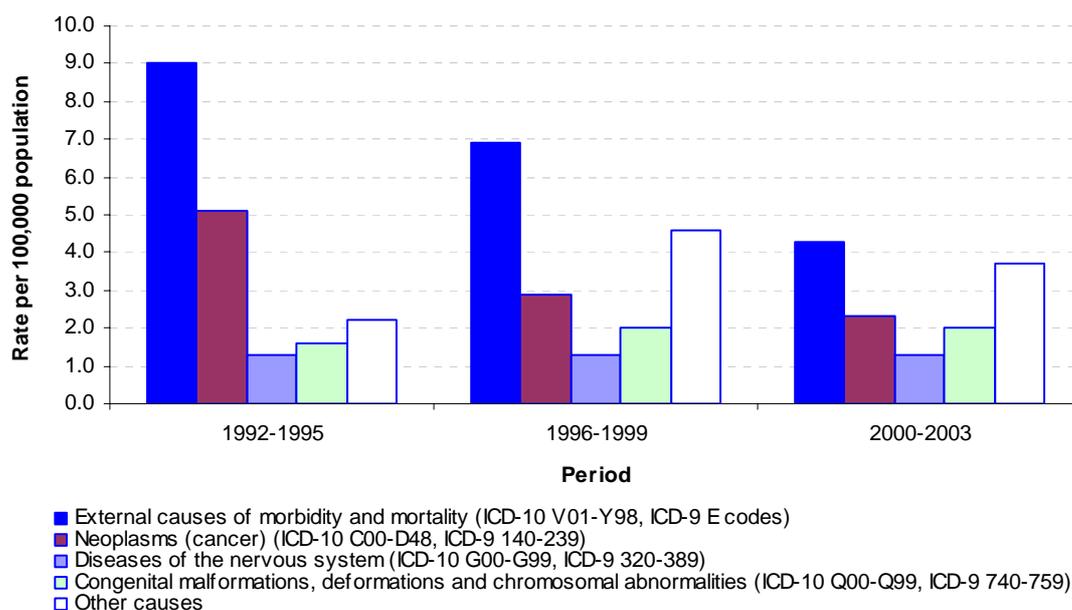
Table 3.5: Causes of children and young person's deaths, ACT, 1992-2003^(a).

Cause of death	Number of deaths registered			Mortality rate (per 100,000 pop.)		
	1992-1995	1996-1999	2000-2003	1992-1995	1996-1999	2000-2003
Neoplasms (ICD-10 C00-D48, ICD-9 140-239)	16	9	7	5.1	2.9	2.3
Diseases of the nervous system (ICD-10 G00-G99, ICD-9 320-389)	4	4	4	1.3	1.3	1.3
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99, ICD-9 740-759)	5	6	6	1.6	2.0	2.0
External causes of morbidity and mortality (ICD-10 V01-Y98, ICD-9 E codes)	28	21	13	9.0	6.9	4.3
Other causes	7	14	11	2.2	4.6	3.7
Total	60	54	41	19.3	17.6	13.7

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (aged 1-17 years) deaths registered between 1992 and 2003, where the child or young person was an ACT resident at the time of their death. The denominators for the mortality rates are the total number of ACT residents in this age group in each year, between 1992 and 2003. Rates expressed per 100,000 population.

Figure 3.5: Causes of children and young person's deaths, ACT, 1992-2003^(a).



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (aged 1-17 years) deaths registered between 1992 and 2003, where the child or young person was an ACT resident at the time of their death. The denominators for the mortality rates are the total number of ACT residents in this age group in each year, between 1992 and 2003. Rates expressed per 100,000 population.

3.3.2 Aboriginal and Torres Strait Islander child deaths

As at June 2001, the estimated resident Aboriginal and/or Torres Strait Islander population for the ACT was 3,900, accounting for 1.2% of the total ACT population (ABS 2004b). During the period 1992 to 2003, seven, or 1.75 per cent, of all registered deaths for resident infants, children and young persons were identified as of Indigenous origin.

4 INFANT DEATHS IN THE ACT, 2000-2003

This section of the report focuses on infant death registrations for ACT residents during the four-year period 2000 to 2003. There were 67 ACT resident infant deaths registered during this period. Infant death registrations comprise the largest proportion of death registrations in the age group 0-17 years. However, care should be taken when interpreting, or quoting, these data, particularly when a rate or proportional distribution (%) is based on a small number of death registrations.

4.1 Demographics

There were 67 ACT resident infant deaths registered in the four-year period from 1 January 2000 to 31 December 2003. About two thirds were male (44 deaths) and a third were female (23 deaths), yielding a ratio of almost 2:1 between the sexes.

Table 4.1 divides infant deaths by age at death. The major categories include infants aged less than 1 day at the time of death, infants aged more than a day to less than 28 days, and infants who died in the neonatal and post-neonatal periods. A neonatal death is the death of a live born baby that occurs within 28 days of birth, and a post-neonatal death refers to the death of an infant aged more than 28 days, but less than 365 days (ACT Health 2004).

The ACT neonatal mortality rate was three death registrations per 1,000 live births and the post-neonatal rate was 1.1 per 1,000 live births. More than 70 per cent, or 48 deaths (29 males and 19 females) occurred in the neonatal period (Table 4.1). The neonatal mortality rate for the period 2000 to 2003 was 3.5 for males and 2.4 for females, per 1,000 live births.

The largest sex differentials were observed among infants aged less than one day (15 male compared to 4 female death registrations), and infants in the post-neonatal period (15 male compared to 4 female death registrations) (Table 4.1).

Although more males are born than females, males have a higher rate of early death from conditions such as congenital infections, malformations and abnormalities (AIHW 2004). It may be that males are at a biological disadvantage *in utero* and early infancy, and to a lesser extent in later infancy (Briscoe 1996). The causes of infant death in the ACT and sex differentials are discussed further in following sections.

Table 4.1: Age of infant at death, by sex, ACT^(a), 2000-2003 & NSW^(b), 2003.

Age at death	Number of deaths registered			Mortality rate (/1,000 live births)			% of all deaths	
	Males	Females	Persons	Males	Females	Persons	ACT	NSW
<1 day	15	4	19	1.8	0.5	19.0	28%	25%
1 day to <28 days	14	15	29	1.7	1.9	29.0	44%	35%
28 days to <365 days	15	4	19	1.8	0.5	1.1	28%	40%
Neonatal mortality (<28 days)	29	19	48	3.5	2.4	3.0	72%	60%
Infant mortality (<12 months)	44	23	67	5.3	2.9	4.1	100%	100%

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 2000 and 2003, where the infant was an ACT resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

(b) The NSW percentage distribution is based on registered deaths in 2003.

There was a difference in the distribution of infant deaths in the ACT and NSW by age at death (Table 4.1). A higher proportion of ACT resident infants died in the neonatal period, and by definition, a lower percentage of infants died in the post-neonatal period, compared to NSW. This suggests that more ACT infant deaths were due to circumstances of the confinement, or to pre-natal conditions resulting from disabilities at birth, such as congenital malformations. Whereas, the higher proportion of NSW deaths in the post-neonatal period suggests infants in NSW were more likely to have died from 'external' causes such as infection and injury (Pollard, 1974).

The infant mortality rate for the ACT was 4.1 deaths per 1,000 live births for the period 2000 to 2003, which compares favourably to the rates for Australia and NSW, at 5.1 and 4.9, respectively (Table 4.2).

Table 4.2 Infant mortality rate, ACT & Australia^(a) 2000-2003, NSW^(b) 2003.

	Infant mortality rate (per 1,000 live births)		
	Males	Females	Persons
ACT	5.3	2.9	4.1
NSW	5.3	4.5	4.9
Australia	5.6	4.5	5.1

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 2000 and 2003, where the infant was either an ACT resident, or Australian resident at the time of their death. The denominators for the mortality rates are the total number of live births to ACT residents, or to all Australian residents, between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

(b) The NSW infant mortality rate is based on registered deaths and live births in 2003.

4.2 Causes of infant death

More than 90 per cent of ACT infant death registrations for the period 2000 to 2003 included a disease or morbid condition as the underlying cause of death (Table 4.3 & Figure 4.1). More than half of these deaths (55%, or 37 deaths) were attributed to *Certain conditions originating in the perinatal period* (pregnancy and the first 28 days of life). This ICD-10 chapter includes causes that relate to pregnancy, foetal growth, labour and the delivery of an infant.

About a fifth (19.4%) of all infant deaths were attributed to *Congenital malformations, deformations and chromosomal abnormalities*. These are conditions present at birth that are either hereditary or originating from the pregnancy, including deformities and chromosomal abnormalities.

Almost ten per cent of infant deaths (7 deaths) were from *Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified*. All of these infant deaths was coded to the ICD-10 chapter sub-heading *Ill defined and unknown causes of mortality*, more commonly known as sudden unexpected deaths of infants (SUDI).

The four deaths from 'external' causes were due to *Injury, poisoning and certain other consequences of external causes*, and are analysed further in the neonatal and post-neonatal sections of this chapter.

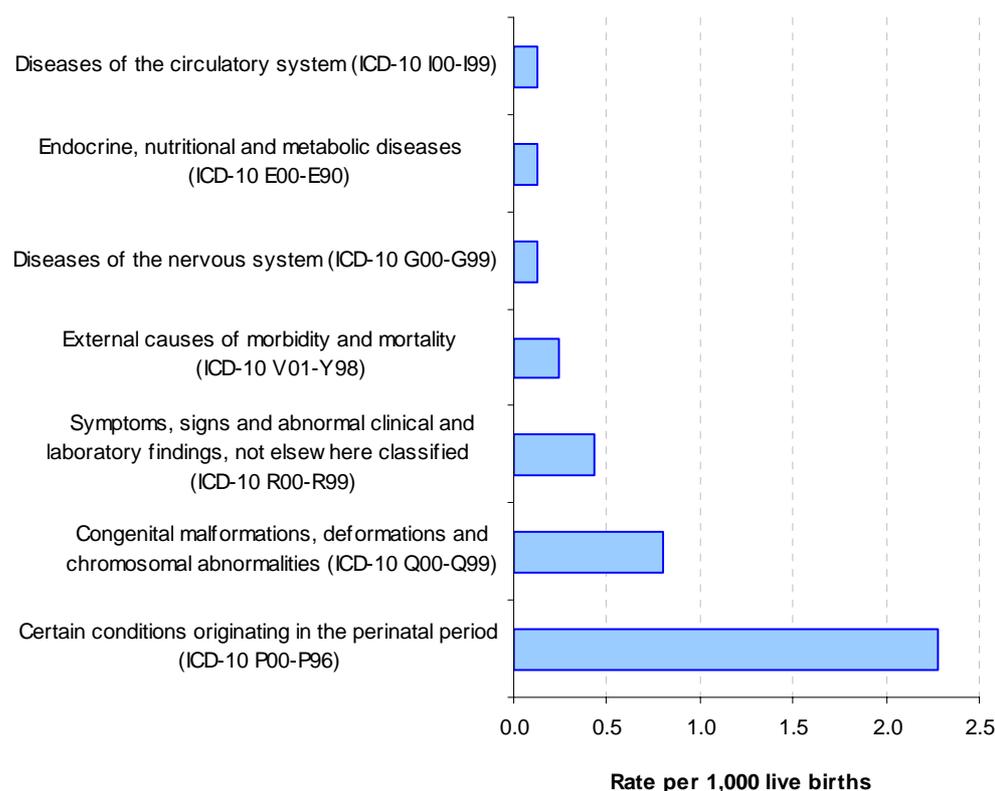
Table 4.3: Causes of infant death by ICD-10 chapter, ACT^(a), 2000-2003.

	Number of deaths registered	Mortality rate (per 1,000 live births)	% of all registered deaths
Diseases of the circulatory system (ICD-10 I00-I99)	2	0.1	3.0
Endocrine, nutritional and metabolic diseases (ICD-10 E00-E90)	2	0.1	3.0
Diseases of the nervous system (ICD-10 G00-G99)	2	0.1	3.0
External causes of morbidity and mortality (ICD-10 V01-Y98)	4	0.2	6.0
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (ICD-10 R00-R99)	7	0.4	10.4
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99)	13	0.8	19.4
Certain conditions originating in the perinatal period (ICD-10 P00-P96)	37	2.3	55.2
Total	67	4.1	100.0

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 2000 and 2003, where the infant was an ACT resident. The denominators for the mortality rates are the total number of live births to ACT residents between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

Figure 4.1: Causes of infant death by ICD-10 chapter, ACT^(a), 2000-2003.



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all infant (<12 months) deaths registered between 2000 and 2003, where the infant was an ACT resident. The denominators for the mortality rates are the total number of live births to ACT residents between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

4.2.1 Neonatal deaths

Deaths in the neonatal period, the first 28 days of life, are more likely to be attributed to circumstances of the confinement or to pre-natal conditions resulting in disabilities existing at birth, such as congenital malformation.

The leading cause of death in the neonatal period was *Certain conditions originating in the perinatal period* (Table 4.4). Within this category, most deaths (20 deaths) were attributed to *Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery*. The largest sex differential was within this category, with 13 male, compared to seven female death registrations.

Table 4.4: Causes of neonatal death by ICD-10 chapter, ACT^(a), 2000-2003.

	No. of deaths registered			Mortality rate (per 1,000 live births)
	Male	Female	Total	
Certain conditions originating in the perinatal period (ICD-10 P00-P96)	20	13	33	2.0
<i>Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery (ICD-10 P00-P04)</i>	13	7	20	
<i>Respiratory and cardiovascular disorders specific to the perinatal period (ICD-10 P20-P29)</i>	3		3	
<i>Infections specific to the perinatal period (ICD-10 P35-P39)</i>	1	3	4	
<i>Haemorrhagic and haematological disorders of fetus and newborn (ICD-10 P50-P61)</i>	1	2	3	
<i>Other perinatal conditions (ICD-10 P05-P15, P70-P96)</i>	2	1	3	
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99)	8	3	11	0.7
External causes of morbidity and mortality (ICD-10 V01-Y98)	1	1	2	0.1
Other causes	0	2	2	0.1
Total	29	19	48	3.0

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all neonatal (<28 days) deaths registered between 2000 and 2003, where the infant was an ACT resident. The denominators for the mortality rates are the total number of live births to ACT residents between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

Since 1997, the Australian Bureau of Statistics has published multiple causes of death data. These data enable users to look at other factors that may have contributed to a particular death. These statistics include all morbid conditions entered on a medical certificate, and those contributing to the morbid sequence of events leading to a death. Extremely low birth weight was the contributing factor in 16 of the neonatal deaths attributed to *Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery*. Twelve of these infants were male and four were female. Seven of these infants were affected by multiple pregnancies, that is, they were triplets or twins.

The cause of death of four infants within the perinatal period was *Infections specific to the perinatal period*. Three of these deaths were due to *Bacterial sepsis of newborn*.

The second leading cause of death in the neonatal period was *Congenital malformations, deformations and chromosomal abnormalities* (11 deaths, 23% of all deaths in the neonatal period) (Table 4.4). Eight of these deaths were male and three female, again reflecting a higher than expected difference between the sexes. Eight of the neonatal deaths within this category were due to *Congenital malformations of the circulatory and musculoskeletal systems*.

Two neonates died from *External causes of morbidity and mortality* (injury and poisoning). Both deaths were as a result of *Other accidental threats to breathing*.

4.2.2 Post-neonatal deaths

A post-neonatal death refers to the death of an infant aged more than 28 days, but less than 365 days. Infants that die after the first 28 days of life are more likely to die from a wider range of causes than those that die in the neonatal period (the first 28 days of life). There were 19 post-neonatal death registrations for ACT residents in the four years from 2000 to 2003. Fifteen of these infants were male and four were female, yielding a ratio of about 3.8:1 between the sexes.

The majority of the infant deaths in this period were due to diseases or morbid conditions. Although the number of deaths for each cause is small, some insight can be gained by a closer look at this group.

All four deaths attributed to *Certain conditions originating in the perinatal period* were due to *Respiratory conditions originating in the perinatal period*. There were two further deaths assigned to *Congenital malformations, deformations and chromosomal abnormalities* that were probably due to congenital conditions. The two infant deaths attributed to *Endocrine, nutritional and metabolic diseases* were both due to metabolic disorders.

Table 4.5: Causes of post-neonatal death by ICD-10 chapter, ACT^(a), 2000-2003.

	No. of deaths registered	Mortality rate (per 1,000 live births)
Endocrine, nutritional and metabolic diseases (ICD-10 E00-E90)	2	0.1
Diseases of the nervous system (ICD-10 G00-G99)	2	0.1
Diseases of the circulatory system (ICD-10 I00-I99)	1	0.1
Certain conditions originating in the perinatal period (ICD-10 P00-P96)	4	0.2
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99)	2	0.1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (ICD-10 R00-R99)	6	0.4
External causes of morbidity and mortality (ICD-10 V01-Y98)	2	0.1
Total	19	1.1

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all post-neonatal (>28 days & <365 days) deaths registered between 2000 and 2003, where the infant was an ACT resident. The denominators for the mortality rates are the total number of live births to ACT residents between 2000 and 2003. All rates are calculated on the basis of deaths per 1,000 live births.

4.2.3 Sudden unexpected deaths in infancy (SUDI)

Sudden unexpected deaths in infancy (SUDI) are those deaths that fall within the ICD-10 category *Ill-defined and unknown causes of mortality*. Within this category, the two major sub categories are *Sudden infant death syndrome (SIDS)* and *Other sudden death, cause unknown*. Although a relatively uncommon event, these deaths comprise the largest group of post-neonatal infant deaths amenable to prevention and occur after the infant is placed in bed to sleep.

The decline in SUDI deaths in Australia has been a major contributor in the recent fall in post-neonatal mortality. Determining the cause of death when an infant dies suddenly and unexpectedly presents several difficulties, as there is no universal definition for a death attributed to this cause. Further difficulties arise from the different perspectives of the various professions involved. However, in January 2004 a group of epidemiologists and paediatric and forensic pathologists came together at a SIDS conference in New South Wales and agreed on a working definition. The conference proposed the following definition:

'The sudden and unexpected death of an infant under one year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.' (Cited in NSW Child Death Review Team 2005).

In spite of recent reductions in the incidence of SUDI, infants in the post-neonatal period remain vulnerable. Between 2000 and 2003, there were six ACT resident post-neonatal infant death registrations with an underlying cause of death attributed to *Ill-defined and unknown causes of mortality*, which includes the sub-categories *Sudden infant death syndrome (SIDS)* and *Other sudden, death, cause unknown*. Three other infants, one aged 15 days, one aged one year and another aged two years are included in this section because their deaths were also attributed to *Ill-defined and unknown causes of mortality*.

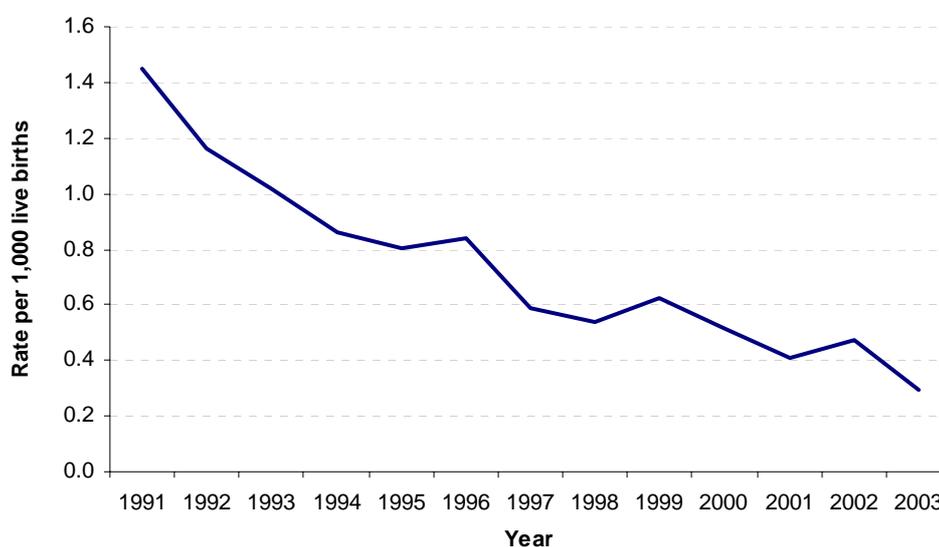
In all, there were nine ACT resident death registrations during the period 2000 to 2003 with an underlying cause of death attributed to SUDI. There was a marked sex differential, with eight males and one female death registration during this period.

SIDS deaths

Analysis of trends over time for SUDI death registrations is difficult in the ACT as there are so few registrations each year. However, it is possible to gain an insight into trends over time by looking at Australia as a whole. Figure 4.2 shows that there was a decrease in SIDS death registrations between the years 1991 and 2003. SIDS deaths comprise the greater proportion (68-80%) and non-SIDS deaths (explained and undetermined) the smaller proportion (20-32%) of all SUDI deaths (NSW Child Death Review Team Report 2004).

Between 1991 and 2003, Australia experienced an average annual decrease of 12.7 per cent a year in SIDS death registrations. During this period, the SIDS mortality rate decreased from 1.4 to 0.3 deaths per 1,000 live births. The actual number of deaths decreased from 373 in 1991 to 73 deaths in 2003. At the same time, the male/female ratio declined from 1.7 to 1.4 male deaths to each female death (AIHW 2005b).

Figure 4.2: Sudden infant death syndrome (SIDS) registration rates^(a), Australia, 1991-2003.



Data source: AIHW State & Territory General Record of Incidence of Mortality (GRIM) Books, 2005b.

(a) Includes all infant (<12 months) SIDS deaths registered between 1991 and 2003, where the infant was an Australian resident at the time of their death. The denominators for the mortality rates are the total number of live births to Australian residents, between 1991 and 2003. SIDS was defined using ICD-10 code 'R95'.

Risk factors

The decrease in SUDI deaths over time is largely attributed to a growing appreciation of the association between SIDS and the sleeping position of infants, exposure to tobacco smoke, and carers' alcohol and drug use. Education about these risk factors has been provided since the early 1990s through a number of successful public health campaigns aimed at reducing the incidence of SIDS in Australia. The campaigns included *Reducing the Risk of SIDS* in 1991, *Kids and SIDS: Three Ways to Reduce the Risk* in 1997, and *SIDS and Kids: Safe Sleeping* in 2000 (NSW Child Death Review Team Report 2004).

Much of the decline in SUDI over the last two decades has been attributed to risk factors related to parental behaviour and the infant's sleeping environment. Several modifiable risk factors have been identified, including:

- Infants sleeping position – caregivers are strongly advised to place infants to sleep on their back. Placing an infant on its side or face down has been identified as a risk factor due to the instability of the position that can result in an infant rolling into the prone position.
- Exposure to tobacco smoke – both maternal smoking during pregnancy and exposure to tobacco smoke after birth are significant risk factors for SIDS.
- Head coverings – carers are strongly advised that loose bedding that can potentially cover the infant's head or slip under is a significant SIDS risk.
- Co-sleeping – co-sleeping can increase the risk of SIDS or SUDI if the caregiver shares a sofa or other inappropriate sleeping environment with an infant (NSW Child Death Review Team Report 2004).

4.2.4 'External' causes of death

Deaths due to disease or morbid conditions are not usually reviewed in as much detail as other deaths. However, any child whose cause of death appears to be unclear or does not match the normal disease process is usually referred to the Coroner to be fully reviewed, by the attending doctor.

Although the absolute number of deaths decreases in the post-neonatal period, the number of deaths attributed to *External causes of morbidity and mortality* (injury and poisoning) tends to increase proportionally in this period. However, during the period 2000 to 2003, there were too few ACT infant death registrations to test this proposition (two deaths in the post-neonatal period).

5 CHILDREN AND YOUNG PERSON'S DEATHS IN THE ACT, 2000-2003

The focus of this chapter is death registrations for ACT resident children and young persons (aged 1-17 years), during the four-year period 2000 to 2003. There were 41 death registrations for this age group during this period, and similar to infant deaths in Chapter 4, care should be taken when interpreting, or quoting, data from this chapter, particularly when a rate or proportional distribution (%) is based on a small number of death registrations. Percentage distributions in this chapter are limited to categories that are greater, or close to 20 per cent.

5.1 Demographics

There were 41 children and young person's deaths registered in the period from 1 January 2000 to 31 December 2003, where the child or young person was an ACT resident at the time of death (Table 5.1). There were similar numbers of male and female deaths, although the age distribution differed slightly. The mortality rate for males aged 1-17 years was 13.8 per 100,000 population and 13.6 for females.

More than one third (34%) of the death registrations were recorded for children aged 1-4 years (Table 5.1). The lowest proportion of death registrations were recorded for children aged 10-14 years (19.5%). As discussed previously in Chapter 3, the lowest point on a mortality curve in most developed countries is about 10 years of age.

Table 5.1: Age of children and young persons at death, by sex, ACT^(a), 2000-2003.

Age at death	Number of deaths registered			Mortality rate (per 100,000 pop)			% of all death registrations
	Males	Females	Persons	Males	Females	Persons	
1-4 years	8	6	14	23.8	18.2	21.0	34.0
5-9 years	4	6	10	9.0	14.0	11.5	24.5
10-14 years	5	3	8	10.9	6.8	8.9	19.5
15-17 years	4	5	9	14.2	18.4	16.3	22.0
Total	21	20	41	13.8	13.6	13.7	100.0

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (1-17 years) deaths registered between 2000 and 2003, where the child or young person was an ACT resident. The denominators for the mortality rates are the total ACT population in each age group between 2000 and 2003. All rates are calculated on the basis of deaths per 100,000 population.

The ACT mortality rate of 13.7 deaths per 100,000 population for children and young persons compares favourably with both NSW and Australia at 18.1 and 20.7, respectively (Table 5.2). The distribution of deaths is similar in the younger age groups for ACT and NSW, but a greater proportion of NSW death registrations (33%) were reported for young persons aged 15-17 years of age, compared to the ACT (22%).

Table 5.2: Children and young person's mortality rate, ACT^(a) 2000-2003, NSW & Australia^(b) 2003.

	Mortality rate (per 100,000 pop)		
	Males	Females	Persons
ACT	13.8	13.6	13.7
NSW	21.6	14.4	18.1
Australia	22.5	16.2	20.7

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (1-17 years) deaths registered between 2000 and 2003, where the child or young person was an ACT resident at the time of their death. The denominators for the mortality rates are the total ACT population in each sex and age group between 2000 and 2003. All rates are calculated on the basis of deaths per 100,000 population.

(b) The NSW and Australian children and young person's mortality rates are based on registered deaths and age by sex population distributions in 2003.

5.2 Causes of children and young person's deaths

5.2.1 Diseases and morbid conditions

The majority of ACT resident children and young person's (aged 1-17 years) deaths (68.3%, or 28 deaths) were attributed to disease or morbid conditions (Table 5.3 & Figure 5.1). The most common cause of death from disease was *Neoplasms* (cancers), accounting for 17 per cent (seven deaths) of all death registrations in this age group during the period 2000 to 2003. There were three male and four females, between two and 12 years of age, with *Neoplasms* recorded as the underlying cause of death. Three of these deaths were from *Malignant neoplasms of the brain*, and three were from *Lymphoid leukaemia*.

There were six deaths attributed to *Congenital malformations, deformations and chromosomal abnormalities* (Table 5.3). Most deaths from these conditions occur soon after birth or in the first year of life, however, with advances in care some of these conditions do not prove fatal until later on in childhood, or even later on in life. Two thirds, or four children, who died from *Congenital malformations, deformations and chromosomal abnormalities* during the period 2000 to 2003 were aged one year at the time of death.

Of the children and young persons who died from *Congenital malformations, deformations and chromosomal abnormalities*, two died from *Congenital malformations of the circulatory system*, two from *Congenital malformations of the nervous system*, one from *Respiratory malformations* and one from *Digestive malformations*.

Four children died from *Diseases of the nervous system* (Table 5.3), of which three deaths were assigned to *Episodic and paroxysmal disorders*. This category includes epileptic-type conditions.

There were two deaths assigned to the ICD chapter *Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified* (Table 5.3) and the sub-category *Other sudden death, cause unknown*. Both children were less than three years of age at the time of death. Deaths in this sub-category were discussed in greater detail in Chapter 4.

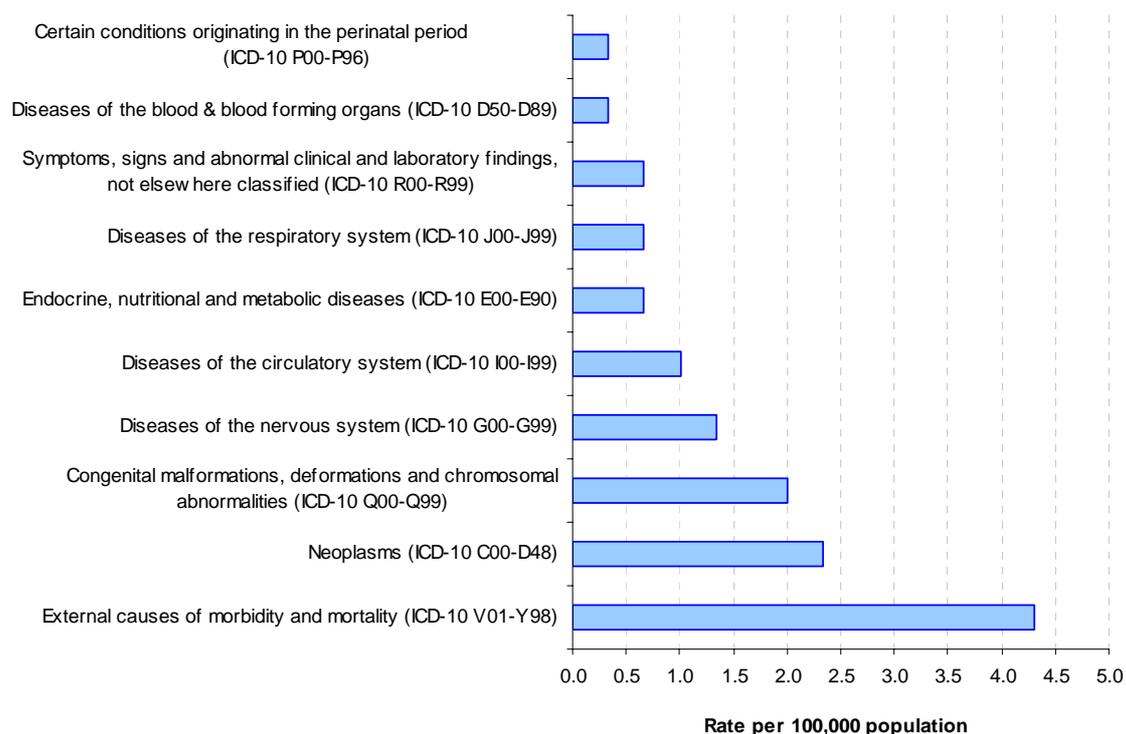
Table 5.3: Causes of children and young person's deaths by ICD-10 chapter, ACT^(a), 2000-2003.

	Number of deaths registered	Mortality rate (/100,000 pop.)	% of all registered deaths
Certain conditions originating in the perinatal period (ICD-10 P00-P96)	1	0.3	2.4
Diseases of the blood & blood forming organs (ICD-10 D50-D89)	1	0.3	2.4
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (ICD-10 R00-R99)	2	0.7	4.9
Diseases of the respiratory system (ICD-10 J00-J99)	2	0.7	4.9
Endocrine, nutritional and metabolic diseases (ICD-10 E00-E90)	2	0.7	4.9
Diseases of the circulatory system (ICD-10 I00-I99)	3	1.0	7.3
Diseases of the nervous system (ICD-10 G00-G99)	4	1.3	9.8
Congenital malformations, deformations and chromosomal abnormalities (ICD-10 Q00-Q99)	6	2.0	14.6
Neoplasms (ICD-10 C00-D48)	7	2.3	17.1
External causes of morbidity and mortality (ICD-10 V01-Y98)	13	4.3	31.7
Total	41	13.7	100.0

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (1-17 years) deaths registered between 2000 and 2003, where the child or young person was an ACT resident at the time of their death. The denominator for the mortality rates is the total

Figure 5.1: Causes of children and young person's deaths by ICD-10 chapter, ACT^(a), 2000-2003.



Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (1-17 years) deaths registered between 2000 and 2003, where the child or young person was an ACT resident at the time of their death. The denominator for the mortality rates is the total ACT population aged 1-17 years, between 2000 and 2003. All rates are calculated on the basis of deaths per 100,000 population.

5.2.2 'External' causes of death

The Australian Bureau of Statistics assigns 'external' causes of death to two ICD-10 chapters: *Injury, poisoning and certain other consequences of external causes* and *External causes of morbidity and mortality* (ICD-10 codes S00-T98 and V01-Y98). These deaths are of particular interest to public health planners and policy makers because they are potentially preventable.

Between 2000 and 2003, there were 13 children and young person's deaths registered, with an 'external' cause of death recorded (Table 5.4). These deaths accounted for nearly a third of all death registrations for ACT resident children and young persons aged 1-17 years. The 'external' cause mortality rate for this age group was 4.3 deaths per 100,000 population.

Table 5.4: Children and young person's 'external' causes of death, ACT^(a), 2000-2003.

	No. of deaths registered	Mortality rate (/100,000 pop.)	Age range
Transport accidents (ICD-10 V01-V99)	6	2	7-16 years
Other external causes of accidental injury (ICD-10 W00-X59)	3	1	6-17 years
Accidental drowning and submersion (ICD-10 W65-W74)	3	1	1-2 years
Intentional self-harm (ICD-10 X60-X84)	1	0.3	17 years
Total	13	4.3	1-17 years

Data sources: ABS cause of death unit record file and ABS unpublished data, available on request.

(a) Includes all children and young person's (1-17 years) deaths registered between 2000 and 2003, where the child or young person was an ACT resident at the time of their death. The denominator for the mortality rates is the total ACT population aged 1-17 years, between 2000 and 2003. All rates are calculated on the basis of deaths per 100,000 population. External causes were defined using ICD-10 codes 'V01-Y98'.

Transport fatalities

In the period 2000 to 2003 there were six death registrations for children and young persons, between the ages of seven and 16 years of age, with a transport related incident recorded as a cause of death (Table 5.4). These deaths accounted for nearly half of all deaths from 'external' causes and included four females and two males.

Three of the children and young persons that died were passengers in cars. One young child was a passenger in a car that was involved in a two-vehicle collision. The collision occurred in daylight as the deceased's mother was exiting from a driveway. The high speed of the second vehicle was considered to be an important factor in the child's death.

The other transport fatalities included: one young person who was a pedestrian; one in which the type of vehicle involved was unspecified; and one as a result of impairment, or disability, from sequelae or 'late effects' of a transport accident which may have occurred a year or more after the original event.

The 2003 NSW Child Death Review Team (2004) annual report states a number of factors are associated with transport fatalities. They include: the correct use and appropriate fitting of seat belts; risk-taking or hazardous driving at high speeds while under the influence of alcohol or other substances, particularly among 16 and 17 year olds; and time of incident, for example during times of reduced visibility, or when the driver is tired or fatigued.

The most important factor with pedestrian traffic accidents involving children is inadequate supervision. Young children are increasingly independent, mobile and curious, but often do not have the developmental capacity to adequately judge risk. Young children often place themselves in dangerous situations without being able to negotiate the dangers, while older children may not have the maturity to adequately supervise younger children (Williamson et al 2002).

Other accidental injury

There were three death registrations assigned to *Other external causes of accidental injury* (Table 5.4). The ages of these children ranged between six and 17 years. Two of these deaths were from falls. The first death occurred at a local picnic spot when a 17-year-old person fell from a ledge 20 metres above ground and died from multiple injuries.

The second death was of a primary school student who fell while swinging on a tree branch and sustained fatal injuries. The accident occurred during school time.

The following policy on tree maintenance within government and non-government schools was obtained from the ACT Department of Education and Training:

Government schools

- In relation to Government schools, comprehensive building condition assessments of all ACT Government schools are undertaken on a three-year rolling program. The condition assessment of trees is part of the comprehensive condition assessment program.
- In cases where trees are deemed to be unsafe and recommended for removal, the Department, or the relevant school arranges for the removal of the unsafe tree(s).
- In addition, Government schools carry out an assessment of the school environment, work and management practices each six months, using the School Safety Checklist. These safety checks are in addition to day-to-day observations made by staff.
- There are two checklist items referring to the tree audit as follows:
 - i. the school has a current tree audit and maintenance report (required every 2 years);
 - ii. trees are maintained in accordance with the recommendations in the tree audit report.

Non-Government schools

- In order for a non-Government school to be registered, it is required to produce evidence of 'procedures for monitoring and managing health and safety features of the buildings, grounds, facilities and equipment of the school with regular training for key staff'. (ACT Department of Education and Training).

The third death of a child, aged 6 years, was attributed to *Accidental exposure to other and unspecified factors*.

Drowning

During the four years from 2000 to 2003 there were three death registrations for ACT resident children that were assigned to *Accidental drowning and submersion* (Table 5.4). The children were all under four years of age at the time of death. The major factor in these deaths was inadequate supervision, as is also found in other jurisdictions. These cases highlight the need for direct adult supervision when children are bathing, swimming or near water (NSW Child Death Review Team Report 2004).

Other factors that may lead to the accidental drowning of a child or young person include: poor maintenance of pool fencing surrounding backyard swimming pools, gates that do not close properly, the use of alcohol or drugs in the case of teenagers and inadequate supervision of the safety of children who have a medical condition, such as epilepsy.

The NSW Child Death Review Team report suggests a number of strategies be put in place to reduce the incidence of drowning fatalities in children and young persons. These include: education on the dangers posed by any body of water; the critical importance of active and constant adult supervision of young children around bodies of water; that safety equipment alone, including fencing, is not enough to protect children; and finally, education on the use of alcohol or drugs by young persons prior to, or during, water activity (NSW Child Death Review Team Report 2004).

Intentional self-harm

Death from intentional self-harm, or suicide, is an untimely or premature death. It has a profound effect on the family and friends of the person involved, especially if the person is a young person (Briscoe 1994). The NSW Child Death Review Team identified three issues that were common threads in suicide and risk-taking deaths in their report. These were: enduring difficulties, pivotal life events and adolescent experimentation (NSW Child Death Review Team Report 2004).

There was one death registration for an ACT resident young person that was attributed to intentional self-harm, or suicide, during the period 2000 to 2003 (Table 5.4). At the time of death the deceased had been receiving professional assistance.

APPENDIX 1: INFANT, CHILDREN AND YOUNG PERSON'S REGISTERED DEATHS, ACT AND AUSTRALIA, 1992 - 2003.

Infants (<12 months)

	ACT	Live births	Mortality rate	Australia	Live births	Mortality rate
1992	28	4,447	6.3	1,843	264,151	7.0
1993	19	4,414	4.3	1,591	260,192	6.1
1994	21	4,461	4.7	1,512	258,051	5.9
1995	21	4,415	4.8	1,449	256,190	5.7
1996	25	4,396	5.7	1,460	253,834	5.8
1997	16	4,208	3.8	1,341	251,842	5.3
1998	24	3,982	6.0	1,252	249,616	5.0
1999	24	4,253	5.6	1,408	248,870	5.7
2000	17	4,065	4.2	1,290	249,300	5.2
2001	12	3,938	3.0	1,309	248,700	5.3
2002	14	4,112	3.4	1,264	247,400	5.1
2003	24	4,128	5.8	1,199	248,000	4.8

Mortality rate per 1,000 live births.

Children and young persons aged 1 to 17 years.

	ACT	Population	Mortality rate	Australia	Population	Mortality rate
1992	17	78,199	21.7	1,180	4,327,878	27.3
1993	12	78,020	15.4	1,156	4,335,712	26.7
1994	16	77,662	20.6	1,137	4,355,452	26.1
1995	15	77,589	19.3	1,106	4,384,886	25.2
1996	19	77,478	24.5	1,112	4,421,539	25.1
1997	13	76,936	16.9	1,106	4,443,855	24.9
1998	9	76,062	11.8	1,080	4,468,055	24.2
1999	13	75,760	17.2	1,027	4,490,245	22.9
2000	14	75,472	18.5	971	4,515,500	21.5
2001	11	75,346	14.6	899	4,545,162	19.8
2002	11	74,609	14.7	911	4,551,971	20.0
2003	4	73,458	5.4	884	4,548,797	19.4

Mortality rate per 100,000 population.

GLOSSARY

An **age-specific mortality rate** is a death rate for a specific age group. The numerator and denominator relate to the same age group.

Birthweight is the first weight of the baby obtained within one hour of the birth

Cause of death information is reported on the death certificate. Each death is assigned an underlying cause of death according to rules and conventions of the International Classification of Diseases (ICD).

A **children and young person's death** refers to the death of a person between one year and 17 years of age.

Confidence intervals are calculated to determine the range of variability in data, within which there is a specified (in this report it is 95%) chance that a calculated estimate is thought to lie.

Congenital is a condition that is recognised at birth, or that is believed to have been present since birth, including inherited conditions or those caused by an environmental factor.

Crude death rates relate to the total number of deaths for specific causes and are the number of deaths for those causes per 100,000 population.

An '**external**' **cause** is the result of an environmental event, circumstance and/or condition as the cause of injury, poisoning or other adverse effect.

ICD refers to the International Classification of Diseases, as developed by the World Health Organisation. – ICD-10 & ICD-9 death data are used in this report

An **infant death** is the death of a child aged less than 12 months.

The **infant mortality rate** is the number of registered deaths in a calendar year of children aged less than 12 months per 1,000 live births in the same calendar year. It comprises neonatal and postneonatal deaths.

A **live birth** is the birth of a child who after delivery, breathes or shows any other evidence of life such as a heartbeat.

Morbidity refers to the ill-health of an individual and to levels of ill-health in a population or group.

Multiple causes of death: All morbid conditions, diseases and injuries are entered on the death certificate. These include those conditions involved in the morbid train of events leading to death which were classified as either the underlying cause, the immediate cause, or any intervening causes and those conditions which contributed to death, but were not related to the disease or condition causing death (ABS 2000). The ABS has published multiple causes of death data since 1997.

A **neonatal death** is the death of an infant within 28 days of birth who, after delivery, breathed or showed any other evidence of life such as a heartbeat.

A **post-neonatal death** is the death of an infant at least 28 days of age and less than 365 days of age.

Perinatal conditions are diseases and conditions that originate during pregnancy or the neonatal period, even though death or morbidity may occur later.

Preventable deaths are those deaths attributed to conditions theoretically considered preventable through early intervention or action.

SIDS refers to *Sudden infant death syndrome* (ICD-10 R95). It is an ICD-10 sub-category of *Ill-defined and unknown causes of mortality* (SUDI).

SUDI refers to sudden unexpected death of an infant (SUDI) and is defined by the ICD-10 category *Ill-defined and unknown causes of mortality* (ICD-10 R95-R99).

A **transport accident** is any accident involving a device designed primarily for, or being used at the time for, conveying persons or goods from one place to another (National Centre for Classification in Health 1998). It is defined by the ICD-10 category *Transport accidents* (ICD-10 V01-V99).

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