

# THE FIRST RESEARCH REPORT:

Patterns and trends in mortality of Western Australian infants, children and young people 1980 - 2002.

Advisory Council on the Prevention of Deaths of Children and Young People

Author Dr. J Freemantle





### BABY DREAMING: The importance of children

The infant spirit sleeps snugly in the clouds dreaming about what life may hold for them. Everything needed is held within their crib. The knowledge and experience of ancestral spirits, the gifts of life and creation, the songs and stories to be heard and remembered, and the talents and aspirations to be developed and embraced. Watched over by the earthly and spiritual guardians, the father, mother, grandparents and siblings ever present to ensure the baby's safety. Each has a special gift to give. Black for strength and endurance, white for purity and innocence, grey for compassion and warmth. The father envelops the family in the spirit of hope and protection. The mother holds the family with kindness and nurturance. The ancestors sit with wisdom and guidance. The children dance with joy and playfulness. Everyone gazes upon the infant with love.

The serpent birds travel between earth and sky to guide the baby's journey between worlds at the beginning and end of life. As the day dawns and as the sun sets, the infant dreams about the life that was promised, what should have been, what is yet to come. What would the world be without infant dreams? The promise of the future yet to be realised is a great loss indeed. The world needs infant dreams to remember its own innocence and the need to look after the delicate balance of life. The most important reason of all however, is to be rejuvenated by the immense joy new life brings and the knowledge the future is safe in their soft little hands.

The destiny of the nation will unfold once we can see the potential in all of our children. As parents, as peoples, we are the guardians of the future through infant dreaming. Our greatest assets are our children. Our greatest achievement is bringing about their wellbeing throughout life and development. We can be caught up looking ahead when we should be taking care of the present. Together we must gaze upon the infant with love and understanding, watch the child grow with encouragement and admiration, and stand beside our youth with humility and pride. Above all we must respect their fundamental right to live out their story as it should be. Protected, nurtured yet free to dream dreams and achieve brilliance.

Cover art by Dr Helen Milroy

### The First Research Report: Patterns and Trends in Mortality of Western Australian Infants, Children and Young People 1980-2002

"Children are our future. Our hopes and aspirations as people of this world rest on their shoulders and they will carry us with them as they grow and develop, as they walk the path we have created for them, and in turn they will prepare a place for us on which to rest in our later years. The importance of children however, is far beyond them taking up their place in society. Children keep us grounded. They help us to enjoy the simple things in life and give to us the greatest gift of all, the chance to love and nurture a new little spirit, a little person that will be totally dependant on our care. In turn they will look at us and smile, bring light into our lives and give us the opportunity to experience unfettered joy as they reach out and touch our hearts."

**Dr Helen Milroy** 

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- 1. Telethon Institute for Child Health Research
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## **Chairperson's Foreword**

Of all human rights, the most basic is the "right to survive". Infant survival is increased when the social, economic and cultural environments are optimal for all families in a society. It is for this reason and because it reflects social and economic conditions that infant mortality is widely recognised as one measure of a Nation's overall social prosperity. High infant and child mortality rates in marginalised groups within Australia reflect the stresses and challenges faced by them, not only from birth and in the first year of life, but throughout the entire life cycle. Disparities in infant and child mortality rates between Aboriginal and Torres Strait Islander and non-Aboriginal groups (described in this report) provide an important indicator of the health of Aboriginal and Torres Strait Islander communities and the long term impact that racism, discrimination and dispossession have had and continue to have on them.

The Government of Western Australia established the Advisory Council on the Prevention of Deaths of Children and Young People in June 2003, as part of the recommendations of the Gordon Inquiry.

This is the first Research Report of the Advisory Council and it provides a comprehensive description of the patterns and trends of deaths of Western Australian born infants, children and young people, from 1980 to 2002. This report has established 'how' and 'where' infants, children and young people in Western Australia died and some possible important risk factors. It is now important to determine more definitively 'why' they died, to discover the common pathways to these deaths and thus identify the pathways to prevention.

Dr Helen Milroy, a Psychiatrist and a senior Aboriginal researcher stated "To lose a child at any age is an absolute tragedy, for this to have been preventable is unforgivable. The depth of grief and trauma associated with childhood death can be so overwhelming it is beyond words". On behalf of the Advisory Council, I extend my sympathy to the families and friends of the children who have died. It is the hope of the Advisory Council that this Report will assist in informing policy and strategy that will not only contribute to preventing deaths in infants, children and young people, but also to create better environments for them to live in.

I would like to sincerely thank the members of the Advisory Council for their commitment, energy and generous sharing of their expertise in the first term of this Council and the Minister for her insight in establishing the Advisory Council and her commitment to ensuring its success.

Professor Fiona Stanley AC Chairperson The Advisory Council on the Prevention of Deaths of Children and Young People.

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Ms Samantha Faulkner reviewed the First Research Report.

Ms Catherine Needham prepared the manuscript for submission to the Minister.

### **Executive Summary**

The purpose of the First Research Report (herewith the Report), commissioned by the Advisory Council on the Prevention of Deaths of Children and Young People, is the first of a series to provide a comprehensive resource to inform policy and strategies aimed at preventing deaths in infants, children and young people in Western Australia (WA). The establishment of the Advisory Council arose from recommendations in the Gordon Inquiry and hence the Report focuses on preventable deaths and the disparity between Aboriginal and non-Aboriginal infants, children and young people.

The Report contains total population data describing the maternal and infant demographic and perinatal circumstances, geographical location and the cause of every death which occurred between 1980 and 2002 (inclusive) of Western Australian infants and children and who were born between 1980 and 2001 (inclusive). These deaths do not include stillbirths.

The Report describes all-cause and cause-specific mortality rates between 1980 and 2002, with a particular focus on measuring the disparities in the patterns and trends of mortality of Aboriginal and Torres Strait Islander (hereafter Aboriginal) infants, children and young people and the comparison with their non-Aboriginal peers. The infant mortality rate was expressed as the cumulative mortality rate (CMR) per 1000 live births. The childhood mortality rate was expressed as the CMR per 1000 infant survivors and age-specific mortality as per 10,000 person years, to allow for comparisons of mortality rates over the lives of children and young people up to 23 years.

The development of the WA Infant, Child and Youth Mortality Database provides a unique resource that has the potential for ongoing and strategic research into the prevention of deaths in WA infants children and young people.

The Report was presented to Ms Sheila McHale MLA, Minister for Community Development, Women's Interests, Seniors and Youth in December 2004, by the chair of the Advisory Council Professor Fiona Stanley, AC.

### Key Findings – birth years 1980-2001 inclusive

The findings for Aboriginal infants, children and young people are highlighted.

**Infant mortality** - live born infants who died before reaching their 1<sup>st</sup> birthday.

There were 3713 infant deaths. Of these deaths 58% (n= 2138) were male, 42% (n= 1575) were female, 61% (n=2264) were neonatal (first 4 weeks of age) and 39% (n=1449) postneonatal deaths (4 weeks to 1 year).

Of all infant deaths, 17% (n=629) were Aboriginal. Of these deaths 55% (n=346) were male and 45% (n=283) were female, 47% (n=293) were neonatal and 53% (n=336) were postneonatal. The postneonatal mortality rate was higher than that for the neonatal mortality, a picture seen in poor developing countries.

#### The overall infant mortality rate has fallen

Between 1980 and 2002 the all-cause CMR has decreased from 8.4/1000 live births to 3.7/1000 live births. The most recent CMR observed in WA was lower than the Australian infant mortality rate (IMR) in 2001, which was 5.3/1000 live births (Australian Bureau of Statistics 2002c). Of note, the Australian IMR was the 16<sup>th</sup> highest among 28 OECD countries and significantly worse than countries such as Sweden (3.4) and Iceland (3.0) (National Health Performance Committee 2004).

The Aboriginal all-cause CMR has also fallen, 25.0/1000 live births in 1980-1984 to 16.1/1000 live births in 1998-2001. However, this decrease has been proportionately less than in non-Aboriginal infants and thus the risk of Aboriginal infants dying compared to non-Aboriginal infants has increased to over four-fold. The WA mortality rate was compared to the IMR<sup>1</sup> in South Australia (9.0), Northern Territory (18.9) and Queensland (12.3) in a similar time period.

#### Gender patterns are evident

Over all years studied, the CMR for males was higher (7.8/1000 live births) than for females (5.9/1000 live births). The CMR has fallen significantly for both males and females over past 23 years.

The rate has not fallen as quickly for Aboriginal male and female infants as non-Aboriginal infants and the risk of Aboriginal female and male infants dying compared to non-Aboriginal infants has increased to over four-fold and nearly five-fold respectively.

#### Teenage pregnancies were associated with high mortality rates

The highest overall CMR was among non-Aboriginal teenage mothers (13.3/1000 live births).

29% of Aboriginal births were to teenage mothers. The infant CMR for Aboriginal teenage mothers was 19.6/1000 live births. However, the highest CMR was among Aboriginal infants whose mothers were between 20 and 29 years (21.4/1000 live births).

#### Changes have been observed in rates of post-mortem examinations

29% of non-Aboriginal and 53% of Aboriginal infants underwent forensic post-mortem examination. 64% of Aboriginal and 47% of non-Aboriginal infants who died as a result of infection underwent forensic post-mortem examination. Low percentages of forensic post-mortem examination raise concerns as to the accuracy of the cause of death. There was a significant increase in the number of infant deaths where the cause was identified as "unascertainable" in the most recent years studied making comparisons of cause of death more difficult.

The proportion of "unascertainable" deaths was significantly higher among Aboriginal infants.

<sup>&</sup>lt;sup>1</sup> These states along with WA have reasonably reliable data describing Aboriginal populations from 1998

#### The main causes of infant death differ in Aboriginal and non-Aboriginal populations

The main causes of mortality among non-Aboriginal infants were prematurity (27%) and birth defects (27%) followed by Sudden Infant Death Syndrome (SIDS) (19%) and infection 11%). The CMR for all main causes of death has decreased significantly.

The main causes of mortality among Aboriginal infants were infection (29%), SIDS (27%), prematurity (16%) and birth defects (15%). The CMR due to infection, prematurity and birth defects has decreased but not significantly. However in the most recent years studied: the CMR attributable to SIDS is similar (4.7/1000 live births) to 1980-1984 (4.9/1000 live births). In the most recent years studied, the relative risk compared with non-Aboriginal infants of death due to infection was 9 times higher, the risk of SIDS was nearly 8 times higher and there was an increase in the CMR due to the sequelae of prematurity.

#### **Co-sleeping was identified in a number of infant deaths (1998-2002)**

Co-sleeping was identified in 60% of deaths attributable to SIDS, 20% of "unascertainable" deaths and 15% of deaths due to infection. Of deaths attributable to SIDS, 40% of non-Aboriginal infants were identified as co-sleeping at the time of death.

Of deaths attributable to SIDS, 73% of Aboriginal infants were identified as co-sleeping at the time of death.

NOTE: Co-sleeping cannot be described as a cause of death or assessed as a risk factor for infant mortality until we can identify the prevalence of co-sleeping in the total population and obtain information regarding the frequency and circumstances of co-sleeping in infants who die.

#### Patterns in mortality according to geographical location are evident

There was a significant decrease in all-cause mortality in all geographical locations. The all-cause CMR was highest in remote locations. There was an increase in non-Aboriginal mortality in remote locations in the most recent years studied.

There was a significant decrease in the Aboriginal CMR in metropolitan and remote locations. The highest Aboriginal CMR was in rural and remote locations. There was an increase in the Aboriginal CMR in rural locations in the most recent years studied. The risk of all-cause mortality for Aboriginal infants compared with non-Aboriginal was highest in remote locations ( $3\frac{1}{2}$  times).

#### Rural and remote locations have higher rates of cause specific mortality

The CMR due to infection, the sequelae of prematurity and attributable to SIDS was highest in remote locations. Non-Aboriginal infants living in remote or rural locations were at a significantly increased risk of SIDS and death due to infection compared with non-Aboriginal infants living in metropolitan locations.

Aboriginal infants living in remote locations are significantly more likely to die due to birth defects and infection compared with Aboriginal infants in metropolitan locations.

# Maternal smoking during pregnancy has a negative effect on infant outcome – years 1998-2002 inclusive.

Overall, 20% of non-Aboriginal mothers smoked and in 29% of infant deaths, mothers smoked during pregnancy. The risk of infant mortality among non-Aboriginal mothers who smoked was significantly higher than among non-Aboriginal mothers who didn't smoke. There was a six-fold increase in the risk of SIDS among infants of non-Aboriginal mothers who smoked compared with those of non-Aboriginal mothers who did not smoke.

Overall, 51% of Aboriginal mothers and in 60% of infant deaths, mothers smoked during pregnancy. The risk of SIDS for infants of Aboriginal mothers who smoked was nearly three-fold compared to Aboriginal mothers who did not smoke.

**NOTE**: The association between poor infant outcome and maternal smoking during pregnancy is complex. These data represent descriptive analyses only, and in cause-specific analyses the numbers are quite small. The true measure of a causal association should be tested using multivariate analyses and case-control studies. However, if smoking is causal, 46% of Aboriginal and 50% of non-Aboriginal deaths due to SIDS, and 38% of Aboriginal and 8% of non-Aboriginal infant deaths could be prevented if mothers did not smoke in pregnancy.

**Childhood mortality** – infant survivors who died before reaching their 23<sup>rd</sup> birthday.

There were 1535 deaths in this age group. Of these deaths 61% (n= 941) were male and 39% (n= 594) were female. Non-Aboriginal deaths accounted for 83% (n=1274) of the deaths of which males accounted for 62% and females 38% of deaths.

Of all childhood deaths, 17% (n=261) were Aboriginal. Of these deaths 57% (n=149) were male and 43% (n=112) were female.

#### The main causes of childhood death were preventable

For both populations and in all age groups, road traffic accidents were the most frequent cause of accident and injury related deaths except for non-Aboriginal pre-primary children where drowning was the most frequent cause. Suicide rates increased as children grew older, forming 41% of Aboriginal and 23% of non-Aboriginal deaths in the 17-23 years age group (see below).

Infection was also a major cause of death among Aboriginal children in both the preprimary aged and post school aged children and the risk of death due to infection was  $5\frac{1}{2}$ times and nearly  $6\frac{1}{2}$  higher respectively than non-Aboriginal children.

#### Suicide rates increased with age

Suicide deaths accounted for 20% of Aboriginal and 9% of non-Aboriginal deaths in children aged between 13 and 23 years. More males (76%) than females committed suicide. The predominate mode of non-Aboriginal death was hanging (57%), other methods were also used. Alcohol, cannabis or other illicit drugs were present in 61% of non-Aboriginal deaths due to suicide.

Aboriginal young people aged between 13 and 23 years were over 5 times more likely than non-Aboriginal to commit suicide. The proportion of females committing suicide was higher among Aboriginal young people than non-Aboriginal. Aboriginal females were nearly 7 times and males nearly 5 times more likely to commit suicide compared to their non-Aboriginal peers. Aboriginal female suicides were all as a result of hanging, and males predominately hanging (85%) and gunshot. Alcohol, cannabis or other illicit drugs were present in 69% of Aboriginal deaths due to suicide.

# Evidence of cannabis, alcohol and other illicit drugs were identified in a proportion of deaths due to motor vehicle accidents in young people

Alcohol was present in 33%, cannabis in 22% and other illicit drugs in 16% in non-Aboriginal MVA related deaths. In 49% of non-Aboriginal deaths due to MVAs there was toxicological evidence at post-mortem of the presence of blood/urine alcohol and/or cannabis and/or other illicit drugs.

Alcohol was present in 46%, cannabis in 45% and other illicit drugs in 25% in Aboriginal MVA related deaths. In 58% of Aboriginal deaths due to MVAs there was toxicological evidence at post-mortem of the presence of blood/urine alcohol and/or cannabis and/or other illicit drugs.

### Age-specific and cause-specific mortality

#### **Pre-primary children**

Children aged between 1 and 5 years accounted for 757 of all childhood deaths. Of these deaths, 618 were non-Aboriginal childhood deaths of which 60% were male and 40% were female. The main causes of non-Aboriginal deaths were due to accident and injury with drowning (42%) and pedestrian deaths (58%) being the main causes.

This age group accounted for 139 Aboriginal childhood deaths. Of these 52% were male and 48% female. The main causes of Aboriginal deaths were accident and injury (50%) of which pedestrian deaths accounted for 67%, drowning 20% and fire 13%. Infection accounted for 28% of deaths with the majority due to respiratory infection.

#### **Primary-school aged**

Children aged between 6 and 12 years accounted for 318 childhood deaths. Of these deaths 86% (n=269) were non-Aboriginal, of which 58% were male and 42% were female. Accident and injury (45%) and cancers (25%) were the main causes of death. Motor vehicle accidents (41%) and pedestrian deaths (40%) were the main causes of RTAs. Homicide accounted for 16% and drowning 11% of non-Aboriginal deaths.

Of Aboriginal deaths, 69% (n=34) were male and 31% (n=15) were female. The main causes of death were due to accident and injury (64%). RTAs accounted for 42%, drowning 13%, suicide 10%, fire 6% and homicide 6%.

#### High-school aged

Children aged between 13 and 17 years accounted for 204 the childhood deaths. Of these deaths 19% were Aboriginal (n=38) and 81% (n=166) were non-Aboriginal. Of the non-Aboriginal deaths 61% were males and 39% females. The main causes of accident and injury deaths were RTAs (58%) and suicide (13%). The main causes of RTAs were due to motor vehicle accidents (MVAs)(67%).

Of the Aboriginal deaths, 61% were male and 39% female. Accident and injury were the main causes of death (36%). Of these deaths, RTAs accounted for 45% and suicide 26%. All RTAs were due to MVAs.

#### Post school aged

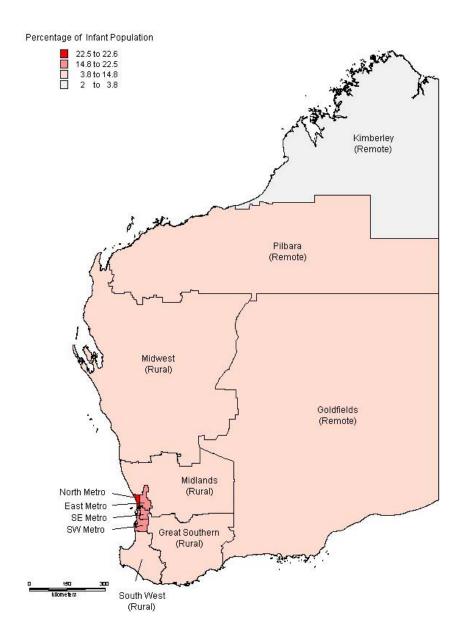
There were 256 deaths in this age group. Of these 14% (n=35) were Aboriginal and 86% (n=221) non-Aboriginal. Males accounted for 76% and females 24% of non-Aboriginal deaths. The main causes of accident and injury (36%) were due to RTAs (54%) and suicide (26%). MVAs (84%) were the main cause of RTAs. Cancers (25%) were the other main cause of death in this age group.

Of the Aboriginal deaths 66% were male and 34% were female. Of the accident and injury deaths 48% were due to RTAs and 41% due to suicide. There were similar numbers of MVAs and pedestrian deaths.

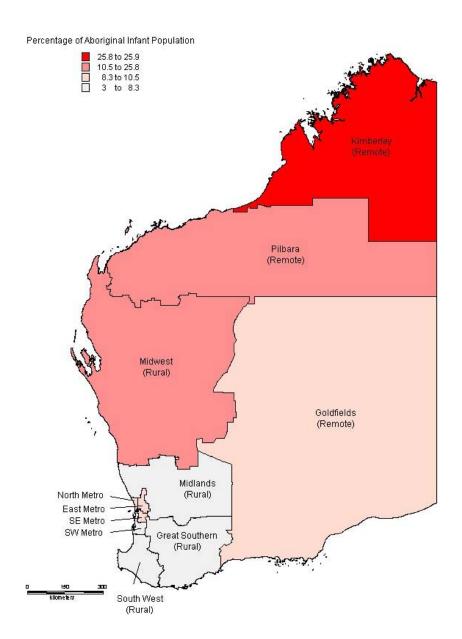
## Recommendations – arising from the First Research Report

Refer to Annual Report of the Advisory Council on the Prevention of Deaths of Children and Young People 2003-2004

## Figure 1 Population of Infants in Western Australia (by Health Zone WA. -Rural, Remote and Metropolitan)



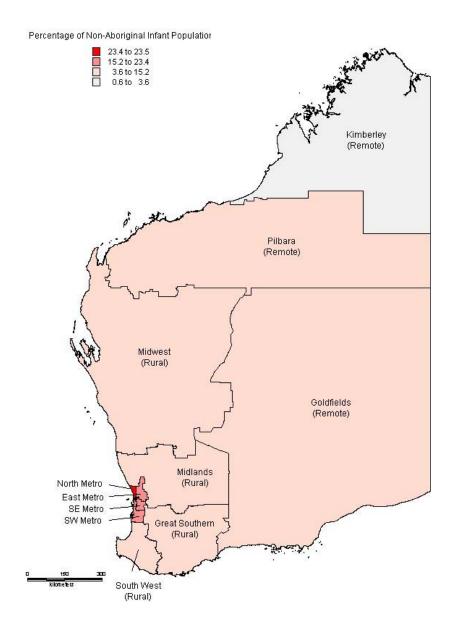
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## Figure 2 Population of Aboriginal Infants in Western Australia (by Health Zone W.A. - Rural, Remote and Metropolitan)

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Figure 3 Population of Non-Aboriginal Infants in Western Australia (by Health Zone W.A. – Rural, Remote and Metropolitan)



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Figure 4Glossary of TermsFigure 4 defines the terms that have been included in this paper

Term	Study definition
Indigenous/Aboriginal	A person who identified as an Aboriginal or Torres Strait
	Islander or is identified as Aboriginal or Torres Strait
	Islander by the community within which he/she lives.
Indigenous/Aboriginal	Born to a mother who identifies as an Aboriginal or Torres
infant/child	Strait Islander or identified as such by responsible person
	on admission to hospital.
Indigenous/Aboriginal	Defining whether a person/child identifies or is identified as
status	Indigenous or non-Indigenous
Non-Aboriginal	Includes all persons other than those who identify as an
	Aboriginal or Torres Strait Islander.
Live birth	The complete expulsion or extraction from its mother of a
	product of conception after 20 weeks gestation or 400 gms
	birthweight which after separation shows signs of life (Gee
	& O'Neill 1998).
Stillbirth	The complete expulsion or extraction from its mother of a
	product of conception of at least 20 weeks gestation or
	400gms birthweight, after which separation does not show
T	any signs of life"(Gee & O'Neill 1998).
Infant death	"The death of a liveborn infant within the first year of life"
Neonatal death	(Gee 1995) includes neonatal or postneonatal deaths;
Neonatal death	"A death occurring within 28 days of birth in an infant whose birthweight was at least 400gms of born after at least
	20 weeks gestation" (Gee & O'Neill 1998).
Postneonatal death	The death of a liveborn infant greater than 28 days and
i usuiconatai ucatii	before their 1 <sup>st</sup> birthday.
Perinatal death	"A stillborn or neonatal death." (Gee & O'Neill 1998).
Relative risk	Or the risk of an occurrence occurring in one population
Keldti ve 115K	relative to the risk of the occurrence in another (occurrence
	could be death/survival)
Person years	Used as the denominator for age-specific mortality rates.
	Calculated as the sum over all children of the time spent in
	each 'cell' of the cross-classification of Aboriginality, sex
	and for years 1980-2002
SIDS	"The sudden death of an infant under the age of one which
	remains unexplained after the performance of a complete
	post-mortem examination, including autopsy and a review of
	the case history" (Beckwith 1970).
Birth Defect	"Any defect probably of prenatal origin" (Bower & Rudy
	2000).
Prematurity	A birth where the gestation is less than 37 completed
	weeks.

Term	Study definition
Birth cohort	The component of the population born during a particular
	period and identified by date of birth so that its
	characteristics ( <i>e.g.</i> causes of death and numbers still
	living) can be ascertained as it enters successive time and
	age periods (Last 2000).
Numerator	The upper portion of a fraction used to calculate a rate or a
	ratio (Last 2000).
Denominator	The lower portion of a fraction used to calculate a rate or a
	ratio (Last 2000).
Mortality rates	Expressed as the cumulative mortality risk, (CMR) which
	is the risk of mortality over a specified number of years and
	expressed per 1,000 births.
	Infant mortality - expressed as per 1,000 live births
	<b>Neonatal mortality</b> – expressed as per 1,000 live births
	<b>Postneonatal mortality</b> – expressed as per 1,000
	neonatal survivors
	Childhood mortality – expressed as per 1,000 infant
	survivors
Age-specific child	The number of deaths in specific age groups defined by the
mortality rates	population at risk of this age group (per 1,000 person
	years). Age-specific rates were calculated for those who
	died after reaching their 1 <sup>st</sup> birthday and before reaching
	their nineteenth birthday.
Birthweight	The first weight, measured to the nearest five grams, of the
	newborn which is usually obtained within the first hour of
	birth" (Gee & O'Neill 1998).
Sex	Gender of the infant/child
Cause-specific death	Major categories of cause of death selected for analysis:
	Infant - Sudden Infant Death Syndrome (SIDS), birth
	defects, infection, and sequelae of prematurity.
	Childhood- birth defects, infection, accidents, and
	cancer and leukaemia.
"Other" causes	Causes included in "other causes" category:
	Infant - maternal causes, intrapartum causes, cancers
	and leukaemias, other specific conditions not included
	under other general classifications, unknown and
	unclassifiable.
	Childhood - SIDS, prematurity, other specific
	conditions not included under other general
	classifications, unknown and unclassifiable.
'Place 'of death	Death occurring in hospital or out of hospital
'Geographical	Metropolitan, rural or remote location of the residence at
location' of	time of birth/death
birth/death	

Term	Study definition
"Residence' at time of	Residence at time of death
death	
Chorioamnionitis	Infection in the placental membranes
Septicaemia	The presence of bacteria in the blood and is often
	associated with severe disease
Road traffic accidents	Deaths due to bicycle, tricycle, motorbike, and deaths due
	to train accidents were also sub-coded under RTAs.
Motor vehicle	Deaths that occurred "inside the structure of a motor
accidents	vehicle" – passenger of driver

#### Figure 5 Abbreviations

Abbreviation	Meaning
Ab.	Aboriginal
Aboriginal	Aboriginal and Torres Strait Islander
<i>c.f.</i>	compared with
CI	Confidence Interval (95%)
CMR	Cumulative mortality rate
<i>e.g.</i>	for example
i.e.	that is
ICD9	International Classification of Diseases, Version 9
ICD10	International Classification of Diseases, Version 10
MCHRDB	Maternal and Child Health Research Database
MNF	Midwives' Notification Form
MVAs	Motor vehicle accidents
Ν	Number of cases in each category or sub-category thereof
NHMRC	National Health and Medical Research Council
NMR	Neonatal mortality rate
NND	Neonatal death
non-Ab.	Non-Aboriginal
NS	Neonatal survivors
PMR	Postneonatal mortality rate
PND	Postneonatal death
Pys	Person years
Relative risk	Relative risk
RG(s)	Registrar-General(s)
RTAs	Road traffic accidents
WA	Western Australia
USA	United States of America

Figure 5 defines the abbreviations that have been used in this paper

## Chapter 1 Background

In November of 2001, the Western Australian Government announced that it would undertake a special inquiry into the response by Government Agencies to complaints of Family Violence and Child Abuse in Aboriginal Communities. This announcement came in response to the release of findings from a Coronial Investigation into the death of a fifteen year old Aboriginal girl, Susan Taylor. The Inquiry was headed by Magistrate Sue Gordon and the report (the Gordon Report) ran to over 640 pages and made 197 findings and recommendations.

The Gordon report recommended that a child death review committee be established: "The child death review committee to be established will have an independent chair and members will be drawn from a range of agencies and organizations. This committee will bring together existing information about child deaths, identify trends, gaps in knowledge and areas for further research. This committee will report its findings publicly." (Gordon 2002)

The Advisory Council on the Prevention of Deaths of Children and Young People was thus established in response to the Gordon Inquiry. The terms of reference of the Advisory Council were:

- Review and analyse data, information and research relating to the causes of deaths of children and young people, identify patterns and trends relating to those deaths and consider pathways to prevention.
- Identify areas that would benefit from further research and consider linkages of data to better inform pathways to prevention.
- Evaluate the effectiveness of interventions designed to reduce or prevent deaths of children and young people, and identify policies, programs and practices that are successful at reducing of preventing deaths of children.
- Formulate recommendations to be implemented by Government and private organizations and by community for the prevention or reduction of deaths of children and young people.
- Undertake other functions relating to the promotion of the health, safety and wellbeing of children as the Minister may direct.

The Advisory Council reports to the Cabinet Standing Committee on Social Policy through the Minister for Community Development as Chair of the Standing Committee on Social Policy.

There was also an undertaking by the Council to provide an annual report and to make the report and the results of the data collection and analysis widely available. To achieve this, a comprehensive review of the epidemiology of all-cause and cause-specific infant and childhood mortality in Western Australia was conducted.

This Report addresses the first term of reference and future reports will work towards identifying pathways to prevention.

A total population mortality database describing Western Australian born children had previously been developed for the years 1980 to 1998 inclusive (Freemantle 2003). This database provided the data to inform a comprehensive analysis of the cause of death, place of death (in or out of hospital), the geographical location of the residence at the time of death (and of birth) and included a number of maternal and infant variables relating to the antenatal and perinatal period. The Council commissioned an extension of this database, enabling the collection and analysis of total population data describing the deaths of children born in Western Australia (WA) from 1998 to 2002 inclusive. As a result of this commission, a comprehensive, total population mortality database describing 23 years of complete mortality data of WA born children has been established.

These data have been analysed and patterns and trends of mortality over this period have been described. Of particular interest given our terms of reference, the disparity between Aboriginal<sup>2</sup> and non-Aboriginal infants and children has been measured with preventable deaths highlighted. The results of this mortality review comprise the First Research Report of the Advisory Council on the Prevention of Deaths of Children and Young People.

<sup>&</sup>lt;sup>2</sup> Aboriginal and Torres Strait Islander people are referred to throughout this document as " Aboriginal".

## **Chapter 2** Introduction

The risks of death for a child are greatest around the time of birth and in the first year of life. For the last 100 years or so, children who survived the first year had a good chance of surviving to adulthood. As the most powerful influences on infant mortality are social and economic, death in infancy is a good indicator of the social progress of a society, country or group of people. Because many of the causes of infants dying are potentially preventable, such as being born too small (due to low birth weight or preterm birth), infections and cot death (SIDS), infant mortality is also an important measure of the effectiveness and availability of health services for mothers and children. Thus, any disparities in infant mortality, as is seen between rich and poor nations or between Aboriginal and non-Aboriginal children in Australia, are indications of inequalities in social and economic status as well as inequalities in the availability of health care.

The excess burden of mortality born by young Aboriginal Australians and the disparity in the rates of infant and childhood mortality that exists between Aboriginal and non-Aboriginal Australians is well known (Moodie 1969), (Moodie 1981), (Thomson 1997), (Moon et al. 1998), (Freemantle 2003). (Eades & Read 1999), (Zubrick et al. 2004), (Briscoe 2003). To determine effective prevention strategies and relevant health and other government policies in order to redress this disparity, a comprehensive and accurate profile of mortality is vital. The role of epidemiology is essential and should include not only the patterns and trends of mortality over time, but also measurements of the indicators that have the potential to contribute to the prevention of infant and child deaths. These include perinatal, maternal and infant indicators, the specific causes of death and the role of the geographical location (particularly important for Aboriginal children). A definitive profile of this nature for this First Report of the Advisory Council for the Prevention of Death in Children and Young People (hitherto called 'The First Report") has been made possible by linking all births in WA to all deaths since 1980 (the WA Infant, Child and Youth Mortality Database; the Maternal and Child Health Research Database (MCHRDB) (Freemantle 2003).

The MCHRDB includes a composite birth record for every child born in WA from 1980 onwards and includes birth and infant, childhood, adolescence and early adulthood life (and death) experiences. The MCHRDB has provided an invaluable resource for over 20 years to describe and investigate the patterns and causes of deaths, illnesses and disabilities in children and youth, and to evaluate the impact of their families, environments, services and changes in society on such mortality and morbidity. Few places in the world have such data, thus the MCHRDB is a unique resource and the comprehensive data in this First Report further demonstrate its usefulness.

Figures 1, 2 and 3 demonstrate the major differences in the distribution of the Aboriginal and non-Aboriginal infant population in WA according to geographical location. Throughout this report the considerable differences in death rates between Aboriginal and non-Aboriginal infants and children are reported. It is vital, therefore, that these populations are considered separately, as outcomes for the Aboriginal population would otherwise be obscured by the outcomes for the total population.

The mortality rates are shown for Aboriginal and non-Aboriginal populations separately. Age-specific rates are calculated for infants (less than one year of age), one year to less than six years, six years to less than 13 years, 13 to less than 17 years and 17 to less than 23 years. These age groups reflect the important transitions in childhood and adolescence.

The place of death (in or out of hospital), and the geographical locations of residence at the times of birth and of death have been identified. The latter provide an opportunity to map the distribution of mortality to geographical location, and may give clues to possible lost opportunities for prevention of deaths.

The First Report acknowledges the importance of the voice of children being heard and for children to have a say in shaping and promoting changes that will provide a safer environment in order that preventable deaths are averted. The chapter "Kids *Talk*" includes information gleaned from both the report on activities of the Kids Help Line and the recent 2003 Youth Survey Report undertaken by the Youth Media Committee in conjunction with the Office of Children and Youth.

It is noted that at the time of the writing of this report there was no single body responsible for reviewing ALL infant, child and youth deaths occurring in Western Australia. The main mortality review committees that deal with maternal and infant deaths are mandated by the Health Act 1911: The Anaesthetic Mortality Committee (established in 1978), The WA Maternal Mortality Committee (established in 1960) and The Perinatal and Infant Mortality Committee (established in 1978). The data of these committees is "privileged" under the Health Services (Quality Improvement) Act 1994. There is currently no mandated mortality committee that considers the deaths of ALL children and young people. A number of hospital mortality committees exist e.g. the Princess Margaret Hospital Mortality Review Committee. However, the committees serve as an internal audit function for the hospital and as such do not have a "privilege" status for the protection of committee proceedings. In addition, the various committees act independently and there is no sharing of information or findings. Thus, there has been no potential to report mortality statistics for the total population on a regular basis, to identify patterns and trends of mortality and to identify "black spots" or areas where timely and targeted interventions could contribute to the effective prevention of deaths in infants, children and young people.

The Recommendations have been developed by members of the Advisory Council on the Prevention of Deaths of Children and Young People, based on the information included in this First Report.

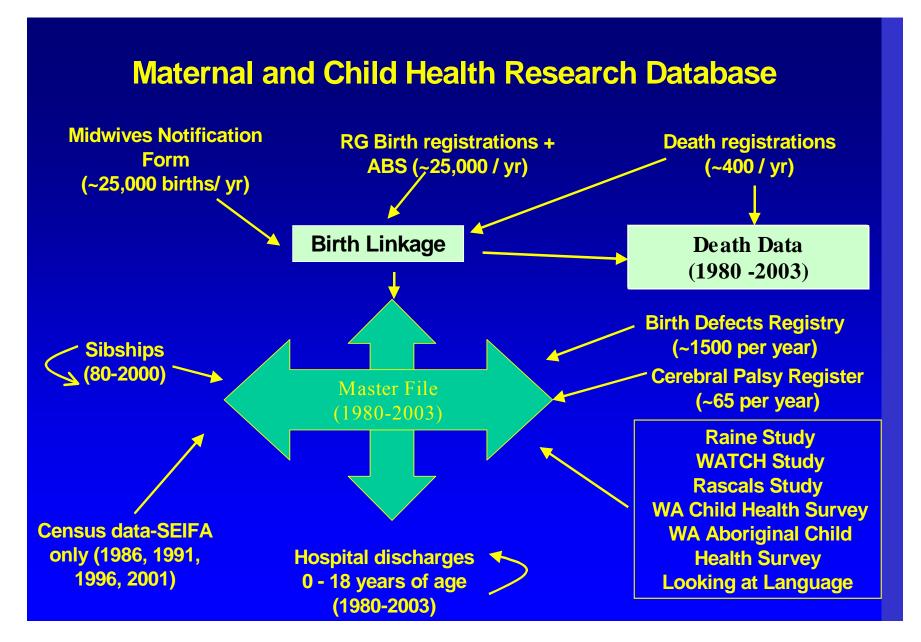
## Chapter 3 Method

The primary source of the data was the WA MCHRDB. These data were supplemented and validated through extensive reviews of descriptive data pertaining to cause of death maintained at the Office of the Registrar-General of WA and autopsy reports held at the Forensic Pathology Department, and hospital inpatient morbidity data. The Linked Database Project, which is a collaborative project of the Centre for Health Services Research at the University of Western Australia (UWA), the Telethon Institute for Child Health Research (TICHR) and the Health Information Centre at the Department of Health WA (DOHWA), also provided supplementary mortality information. The Birth Defects Registry was used to supplement death information for WA born children who died and who had a birth defect. Deaths that were coded as attributable to a birth defect were those deaths where the birth defect had been identified as the likely underlying cause of death in infants and children either by the Coroner or Medical Practitioner. Cases were noted with a separate code where a birth defect was present, but was not given as the major cause of death. Children who had been diagnosed with cerebral palsy and who died were coded in a similar manner.

#### 3.1 Maternal and Child Health Research Database

The WA MCHRDB includes linked birth, death and hospital discharge data, which serve epidemiological monitoring, surveillance and research purposes for the total population of births in WA. The Database was formally established early in the 1980s and is complete for all births in WA from 1980 onwards with new birth cohorts being linked on an annual basis (Stanley et al. 1994). Each case included on the MCHRDB was given its own unique identifying number, the "maternal and child health number".

Figure 3.1 describes the MCHRDB and indicates the linkages that have contributed to each of the composite birth records. Those data sources that have contributed to this report include: the Midwives' Database; Registrar-General's Database; Hospital Inpatient Morbidity Database; (all statutory collections); The Birth Defects Registry of WA; The Cerebral Palsy Registry (latter two collected by active ascertainment); and Coroner's Database (accessed under special privilege granted by the Coroner's Ethics Committee).



#### 3.1.1 Midwives' Notification Form

The Midwives' Notification of Birth system was established in WA in the late 1970s with complete data collected for births from 1980. The Midwives' Notification Form (MNF) includes antenatal and perinatal information, demographic details for both mother and infant, and limited paternal information. Around 25,000 records are added each year (Stanley et al. 1994). Validation studies were completed in 1987 and 1994. These studies identified the accuracy of the data collected on the MNF when compared with information recorded on the mother's medical record and concluded that mother's race was between 90% (Hill 1987) and 96% (Gee & Dawes 1994) accurately recorded on the Form.

Every midwife attending a birth in WA must complete the MNF for births greater than or equal to 400 grams birth weight or greater than or equal to 20 weeks gestation. Completion of the MNF is a statutory requirement under the Health Act and Midwifery Nurses' Regulations. The MNF is forwarded to the DOHWA within 48 hours of the birth and together with the hospital summary admission form provides the information for the Midwives' Notification System (Arturo 1989). The births included on the MNF also include home births. In a validation of the Midwives' Database, it was estimated that 99.9% of all births in WA have a MNF completed (Gee 1992). Information from this form is processed, coded and validated and entered onto a database (Gee 1994).

#### 3.1.2 Birth Registration Forms

It is a statutory requirement to complete a form for all births greater than 20 weeks gestation. The birth registration form of the Registrar-General of WA includes information relating to parents' age, occupation, and country of birth, marital status, date of marriage and the number of previous children (of the mother).

Linkage between births and deaths had commenced in the 1970s. The linkages of the WA Midwives' Notification of Birth system to the Registrar-General's (RGs) birth registrations in WA began in 1985 (Gee 1996). Information collected on the RGs birth registration form supplements missing data routinely collected on the MNF and adds important social and demographic details. A review of the two sources of birth information – the MNF and the RGs birth registrations showed that the most complete data was sourced from the MNF (Read 1999). The residential address of the infant at birth is included on the MCHRDB, which provides the opportunity to map the distribution of disease and mortality to location.

#### 3.1.3 Death certificates

A registered doctor must complete a death certificate for every death that occurs, a special perinatal death certificate is completed for infants dying in the perinatal period. These data and childhood deaths are coded by ABS. Multiple cause history is used on these certificates. The RGs Office in WA collects descriptive data pertaining to the cause of death together with the age at death and place of death from these death certificates.

These data are then forwarded to the ABS, where they are coded according to the International Classification of Disease (ICD). Codes used in this research project relate to the ICD ninth revision (ICD-9) (World Health Organisation 1975). The coded data are then forwarded to the MCHRDB where they are linked to the birth information for each individual child. Annually, there are approximately 460 deaths of infants and children nineteen years and under recorded on the MCHRDB.

#### 3.1.4 Hospital inpatient morbidity data

These data include all inpatient episodes for public and private hospitals in WA. Currently over 50,000 new records per year are received and data are available from 1970 onwards. Data are collected on the DOHWA Inpatient Summary Form (Health Statistics Unit 1987) and are completed for all hospital separations detailing basic demographic information, length of stay, principal condition treated and other conditions present, operations and procedures, outcome, and place to where person is admitted and discharged from, where applicable. These data are linked to the MCHRDB and validated annually. This linkage to the MCHRDB provided a valuable resource through which to validate the place of death (in/out of hospital).

#### 3.2 Additional Death Information

#### 3.2.1 Registrar-General of WA

A description of the death information maintained by the RGs Office is mentioned previously in association with the linkage of data to the MCHRDB. Further examination of the data held at this office was undertaken to supplement the existing computerised data on the MCHRDB where information regarding the place of death and residence at time of death was missing. Death information that came from the RG was minimal for the years 1980 to 1982. Data describing the years 1983 and 1984 were slightly more comprehensive. Data from 1985 onwards were in most cases complete.

#### 3.2.2 Perth Coroner's Office

Post-mortem records since 1986 are held at the State Coroner's Office (in Perth), whereas before this time, the Coroners in the regional areas held the records. These post-mortem reports provide a summary of all information describing the death and include demographic information, cause of death, circumstances surrounding the death, witness statements, police reports and medical records (where available). Autopsy reports provide more explicit information about the cause of death and include pathology details. All Coroner's cases are referred to the Coroner with jurisdictional responsibility associated with the geographical location of the death. The reports of post-mortems authorised by the State Coroner are held either at the Forensic Pathology Department located at the Queen Elizabeth 11 Medical Centre, or in cases where the autopsy has been authorised by a Regional Coroner, the Regional Coroner's Office. The majority of forensic autopsies are carried out at the Western Australian Centre for Pathology and Medical Research (PathCentre).

#### 3.2.3 Data Linkage

As a result of data linkage, a composite birth record for each mother and child pair for each year from 1980 has been created and loaded onto the MCHRDB. These linkages include antenatal, birth, death and hospital discharge records for all children born in WA from 1980 onwards. In the early years the record linkage was done by a deterministic method, that is, two records were linked on a variety of fields only taking into account the information on the two records. More recently the records are linked through a probabilistic method, which includes a weighting system based on the relative frequency of the occurrence of, for example, a surname. For instance the surname of 'Oldhem' would have a higher weight than 'Smith' in the linking procedure.

The process associated with linking two case records is based on the identification of compatible fields in the records. This linkage process commences with the creation of an index. Most often the baby's date of birth is found to be the most successful field on which to create the index. The preliminary pass through the linkage program requires a complete match on most fields common to both files, for example the infant's date of birth, sex, birth weight, hospital of birth, mother's maiden and married name and address. A link file is created as a result of this process and includes the infant's record number from each of the original data files. This process usually captures about 80% of all eventual linkages (Stanley et al. 1994). Subsequent linkage reviews the remaining files for cases where matches exist but between fewer variables. This process is repeated numerous times using different combinations of fields on which to effect a linkage. This stage also involves manual checking of the various values and identifiers in the various fields to identify where there are missing data or obvious errors in recording or in transmitting data from case records and data collections to database. In the final analysis doubtful links may be accepted but are flagged for manual checking. At the completion of this process linkage is usually about 98.5% complete. The 1.5% of cases where doubtful links are acknowledged are manually checked and included or excluded accordingly (Croft 2002).

Probabilistic linkage methods have been employed to create these linkages since 1994. Probabilistic record linkage methods compare a combination of fields from two data sets, giving a separate weight to each field depending on whether it matches or does not match. The weight for a given pair of records (indicating the relative likelihood of the records originating from the same infant/child) is taken to be the sum of these weights. This assumes that the weights for each field are independent (Fellegi & Sunter 1969). However, with a large number of fields there is always some dependence between fields. To achieve maximum discrimination as much data as possible should be included. Methods of combining weights for dependent fields based on unconditional logistic regression are currently being used successfully.

#### 3.2.4 Confidentiality processes

It is imperative that the complete confidentiality of individuals included in the MCHRDB is maintained at all times. Linkage of data is undertaken at the Data Linkage Unit (DLU), Health Department of Western Australia. The linkage process relies on demographic information (including full name and date of birth) provided to a small independent technical linkage group. No clinical or service information is provided to the linkage The linkage team members are the only people with access to demographic team. information from more than one source. The personal identifying information is only available to the nominated linkage officers involved in the linkage process. These personnel have signed legally binding confidentiality agreements. The disparate data sources are linked using a number of key identifiers. Following linkage the sets of linkage keys are held within the DLU. No data are released from the DLU unless ethical approval has been received from a National health and Medical Research Council (NHMRC) accredited ethics committee. Only data that are directly pertinent to the particular study are supplied. All data supplied by the DLU are anonymous except in extraordinary circumstances in which case extra approval for release of data must be obtained. To enable this research, extra permission was obtained for named data in order to access post-mortem case reports. Permission was obtained in conjunction with permission from the Coroner's Ethics Committee. Confidentiality guidelines for access to or release of, named data are strictly enforced. Approval for the use of data from the DLU must also be sought from the statutory body, the Confidentiality of Health Information Committee (CHIC). Linkage of Registers such as Birth Defects and Cerebral Palsy is achieved through a "link/unlink" methodology. This method ensures that individuals are not identified during the linkage process (Kelman 2002). The use of data was governed by strict adherence to the National Privacy Legislation (1995) and the NHMRC Guidelines on Scientific Practice (2003).

#### 3.2.5 Method for coding of death

The method developed to code the cause of death has been rigorous in both approach and validation. The cause of death code permits a consistent coding of death throughout the perinatal period and childhood into early adulthood. The system comprises nine major categories (1<sup>st</sup> digit) each of which could be sub-categorised with the use of a second and third digit for infections and accident and injury. Classification is based on what was the antecedent factor of death (Appendix 1). The system was designed primarily for research purposes, but can be mapped to the perinatal component of the Australian and New Zealand Perinatal Mortality Classifications (National Perinatal Data Development Committee Working Group 2000). The major benefit of this coding is that it allows the same code to be applied throughout the child's life course. The simple classification system can be applied to all deaths of all ages in the birth cohort – from the perinatal period to deaths that occurred into adulthood (Alessandri et al. 2001).

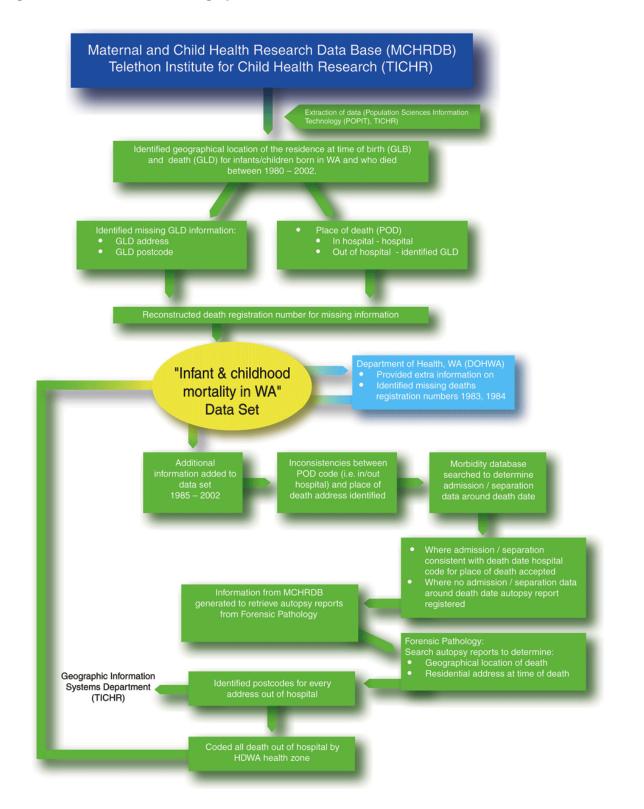
#### Table 3.1Major categories for the classification of death

Code	Description of cause of death
1	Intrapartum causes – sub-categories classify underlying cause of the
	intrapartum problem.
2	Significant birth defects – where a birth defect was described in the death description on the death certificate and was the underlying and sufficient cause of death. In cases where the death was due to another cause, and a birth defect was described on the death description, the death was coded as the underlying cause and the presence of a birth defect noted in a co-
2	joining field.
3	Death as a result of immaturity – where gestational age was <37 completed weeks.
4	Infections - sub-categories provided information regarding the site of infection $(2^{nd} \text{ digit})$ and organism/s responsible where known $(3^{rd} \text{ digit})$ .
5	Accidents - includes non-accidental injury and sub-categories provided information relating to the type $(2^{nd} \text{ digit})$ and the agent $(3^{rd} \text{ digit})$ of the accident <i>e.g.</i> motor vehicle, pool.
6	Cancers - sub - category includes leukaemias.
7	Sudden Infant Death Syndrome.
8	Other specific conditions - not previously noted and sub-categories include
0	cerebral palsy and neurological conditions.
9	Unclassifiable/unknown - Sub-categories include cause unclassifiable in other categories and cause unknown/unascertainable.

Figure 3.2 shows a flowchart describing the process used to determine the cause of death for infants and children, including the sources of data used and the validation process.

The following flow charts have been simplified and modified to reflect activities relevant to the 1<sup>st</sup> report.

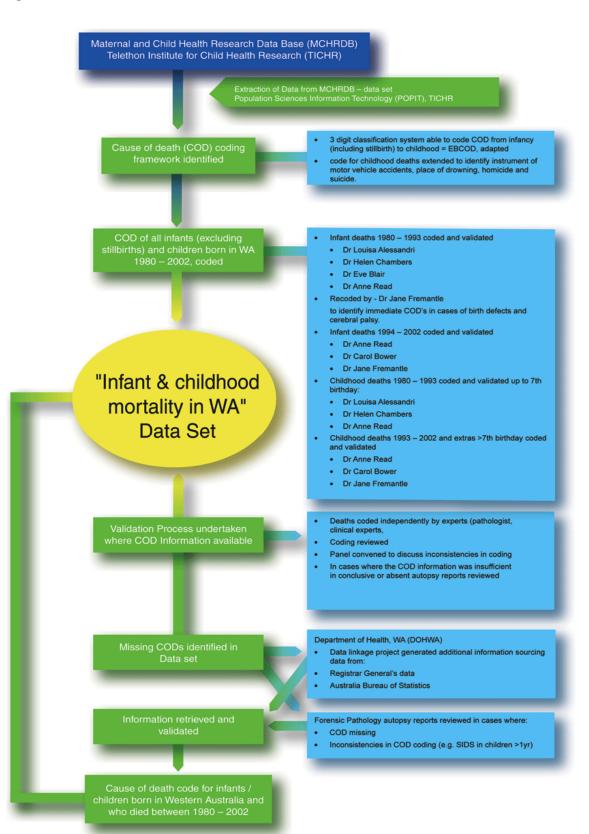
#### Figure 3.3 Place of Death / Geographic Location of Death flowchart



#### 3.3 Place of death and the geographical location

Data were initially retrieved from the MCHRDB regarding place of birth. The place of death was identified through the Registrar-General's database. The Hospital Inpatient Morbidity Database was used to validate existing information on the MCHRDB as to place of death (in or out of hospital). Autopsy case reports were used to establish both the geographical location of the residence at time of death and, if the death occurred out of hospital, the geographical location of the death. Figure 3.3 describes the process undertaken to ensure that the information describing the geographical locations at the time of birth and death was as complete and accurate as possible.

#### Figure 3.2 Cause of death flow chart



#### 3.4 Health zone location at time of birth and time of death

In order to attach health zone locations to the file, postcodes were attached to the address associated with the geographical location of the residence at death. Postcodes were not always included on place of death information, particularly where a child had died in a remote community. Furthermore, the locations of deaths due to motor vehicle accidents were often points on highways. In these cases the addresses of the places of death were referred to the Geographic Information Services Department of the Telethon Institute for Child Health Research. Postcodes were identified for all locations, through a mapping program (MapInfo Professional, Version 6.0 for Windows) (MapInfo Corporation 2000). Where the postcode was still not available contact was made with the nearest shire council to obtain the information. Once postcodes were included, the data were submitted to the mapping program (MapInfo Professional, Version 6.0 for Windows) that automatically appended the health zone to the postcode.

There were 11 health zones as identified by the DOHWA. These health zones and the consequent geographical locations had been defined by Codde and Penman in the mid 1990s (Codde J., Penman. 1994, DOHWA) and were developed by considering the level of isolation and distance from the major regional and metropolitan health care facilities. The geographical locations of the health zone, metropolitan, rural, or remote, were manually added to each case. The following Table 3.2 identifies the health zones used and the corresponding geographical location.

Health zone	Number	<b>Geographical location</b>	Abbreviation
North metro	1	Metropolitan	М
East metro	2	Metropolitan	М
South East metro	11	Metropolitan	Μ
South West metro	12	Metropolitan	М
Kimberley	4	Remote	RM
East Pilbara	5	Remote	RM
Goldfields	8	Remote	RM
Midwest	6	Rural	R
Central	7	Rural	R
Great Southern	9	Rural	R
South West	10	Rural	R

Table 3.2 Health zone and associated geographical location, for Western Australia

#### 3.5 Identification of Aboriginal and Torres Strait Islander People

The Aboriginal status of the child reflected the Aboriginal status of the mother as selfidentified on the Midwives' Notification Form (Gee & O'Neill 2000). It was possible that the mother might choose to identify differently over subsequent pregnancies. To quantify such changes we calculated the change in Aboriginal status over the birth cohort by identifying those mothers who had identified as Aboriginal at the birth of one child and who had also identified as non-Aboriginal at the birth of another child. Using sibship data for the years 1980 to 1995, we calculated that only 8% of Aboriginal mothers had been recorded as non-Aboriginal when giving birth to another child. Thus, mistakes in documenting Aboriginal status are minimal in these data.

#### 3.6 Age and cause specific categories

All cause and cause specific infant mortality rates were generated for those infants who died before reaching their first birthday (365 days). Neonatal deaths are defined as occurring within 28 days of a live birth. Postneonatal deaths are defined as occurring after 28 days and before 365 days. All cause and cause specific, and age specific mortality rates were calculated for infant survivors who died before reaching their nineteenth birthday and were grouped as follows: one year to less than five years, five years to less than 13 years, 13 to less than 17 years and 17 to less than 23 years.

## 3.7 Calculation of mortality rates, relative risk of mortality and confidence intervals

Data were retrieved from the MCHRDB in an SPSS format (SPSS for Windows 2000). SPSS version 10.1 computer software was used to clean and edit the data, for data manipulation, for generating new variables and for obtaining frequencies.

Infant and childhood mortality were expressed as the cumulative risk of mortality (CMR) and calculated for infant (per 1,000 live births), neonatal (per 1,000 live births), postneonatal (per 1,000 neonatal survivors) and childhood deaths (per 1000 infant survivors. The CMR was calculated separately for the Aboriginal and non- Aboriginal populations. The CMRs were calculated for each birth cohort by dividing the number who had died (numerator) by the number of live births in the population at risk of mortality (denominator). The denominator for postneonatal mortality rates was calculated by subtracting the neonatal deaths from the number of live births for each category where the CMR was calculated by subtracting infant deaths from the total number of births in each category of interest (per infant survivors). Age-specific mortality in childhood according to birth year groups was calculated using person years (see below).

It should be noted that the calculation of 'rates' per thousand live births is the usual way of describing infant mortality, as each child is followed for the same amount of time (ie one year) (Lilienfield & Lilienfield 1980). Thus, the rates are comparable with those in the literature. In this Report children aged over one year are followed for varying amounts of time, thus calculations of age specific mortality use person years, are calculated as described below.

Cause-specific infant mortality rates were also calculated using the same procedure for SIDS, birth defects, infection and sequelae of prematurity. Child mortality rates were calculated similarly, however rates for each birth year group and age category were determined using person years as the denominator.

The relative risks of dying of an Aboriginal infant or child compared with a non-Aboriginal infant or child (risk ratio) were calculated. The relative risk was computed as the ratio of risk per thousand live births of an Aboriginal child dying divided by the risk per thousand live births of a non-Aboriginal child dying. This procedure was repeated for each outcome of interest. The Mantel-Haenszel chi square statistic and the relative risk, together with the 95% confidence interval around the estimate, were calculated using the EpiInfo software package (Dean et al. 2000). Where an expected value was less than 5, Fisher's exact test was used to estimate p-value.

Trends in the CMR over the birth year groups were calculated for each variable of interest using logistic regression. The chi-square test for linear trend was used to identify the changes both positive and negative in the CMR over the birth year groups.

For all results, statistically significant results were identified by 'bolding' of the estimates and the 95% confidence interval (CI) in the tables.

#### 3.8 Calculation of the denominator for childhood death rates

To calculate the rate of death during childhood, it was necessary to determine the person years of follow-up for each child (denominator).

Person years were calculated using PAMCOMP version 1.41 – PAMCOMP is a person years and mortality computation program designed at the Institute of Epidemiology at the University of Munster (Teager et al. 2000). In order to calculate person-years using PAMCOMP, it was necessary to calculate an "exit date" for each child. The termination date (or exit date) for each child was either the death date of the child or the last date of follow-up of the cohort (31/12/2002) if the child was still alive.

Person years were calculated as the sum over all children of the time they spent in each "cell" of the cross-classification of Aboriginality, sex and location and for years 1980-2002.

#### 3.9 Migration between location at time of birth and time of death

As discussed previously the coding for the place of death and location at time of death was undertaken for all deaths. Location at time of birth was identified by the postcode of the residence at time of birth as identified on the MCHRDB. Location of death was derived from the RG births and deaths information and also from the case reports held by the Coroner's Office. The residence at time of death was the same as the geographical location of death for both Aboriginal and non-Aboriginal infants in all but one case.

Changes in health zone and in geographical location (metropolitan, rural, remote) were tracked between birth and death for infants and children who had died. To describe the extent of the migration between geographical location between birth and death, a measure of agreement (Kappa) between locations at birth and death was computed for both Aboriginal and non-Aboriginal infants. The measure of agreement was excellent (Kappa 0.92 and 0.95 respectively, p<0.001). Note that a Kappa (*k*) greater than 0.75 denotes "excellent agreement" (Rosner 1986)

Given the excellent agreement between residence at time of birth and residence at time of infant death, the residence at time of birth was used for the cases where the location of death could not be retrieved. In one case the residence at time of birth was identified as New South Wales and no other address was available. This case was treated as missing.

In the childhood analyses there was a negative correlation between the geographical location at time of birth and the geographical location at the time of death for both Aboriginal and non-Aboriginal children: Kappa agreement = -0.83 and -0.64 respectively. The p value of these negative estimates was significant (p<0.001), which indicates that the child was significantly more likely to die in a geographical location that was <u>different</u> to the one in which the child was born. Therefore, mortality in childhood by geographical location referred to the geographical location of the residence at the time of the child's birth (as residential movements were unknown for all children who did not die and this would have been necessary for the calculation of rates).

Information describing the location of death in infancy was poorly recorded for the years 1980 and 1982. The autopsy case reports were not easily accessible for these years and in many cases not available. Five percent of cases where there was no information available regarding residence at time of death were Aboriginal and seven percent were non-Aboriginal infants. The majority of the missing information for Aboriginal infants was for deaths occurring in the years 1980 to 1982 with the remainder between 1982 and 1984. All but two non-Aboriginal infant deaths occurred between 1980 and 1984 (a further one case was in 1985 to 1989 and one in 1990 to 1994). Autopsy case reports for the subsequent years (1995-2002) were reviewed and the data for location of death was complete for these years.

# Chapter 4 Trends and Patterns of Infant Mortality, 1980-2002

### 4.1 Introduction

The data described in this report are based on a birth cohort. The patterns and trends of mortality for WA infants, and children born between 1980 and 2001 inclusive are described separately for infants and for children and young people. The latter groupings are described using age groupings that reflect pre-primary, primary, high school and post-school categories. The post-school age grouping include young people aged seventeen and over to reflect the commencement of their legal entitlement to drive a motor vehicle. These data are described in Chapter 5.

The results describe the total population and also the Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander populations. The 23 years of data are divided into birth year groups: 1980 to 1984; 1985 to 1989; 1990 to 1994; 1995 to 1997; 1998 to 2001 inclusive. Deaths include deaths up to the end of 2002. The mortality data also describe the geographical location at the time of death (infants).

Extra information is provided to further describe the main causes of death. The format for this chapter is as follows:

Trends in infant mortality since 1980

- All-cause infant mortality
  - Neonatal/postneonatal
  - Male and female
  - Maternal age
  - Place of death in /out of hospital
  - Geographical location
- Cause specific infant mortality
  - Place of death in /out of hospital
  - SIDS and infection
  - Smoking effects

Trends in Childhood mortality since 1980 (births) will be discussed in Chapter 5.

The following table provides a summary of the data with regards to the number (and percentage) of births and deaths described by type of death (neonatal, postneonatal and childhood) according Aboriginal status.

	Aboriginal	Non-Aboriginal			Total
	Ν	(%)	Ν	(%)	
BIRTHS	30261	(6)	504661	(94)	534922
Infant deaths	629	(17)	3,084	(83)	3,713
Neonatal	293	(47)*	1.971	(64) †	2,264
Postneonatal	336	(53)*	1,113	(36) †	1,449
Childhood deaths	261	(17)	1,274	(83)	1,535
TOTAL deaths	890		4,358	·	5,248

Table 4.1Number (and %) of births and deaths in Western Australia, 1980-2001inclusive according to Aboriginal status and type of death.

\* % of all Aboriginal infants deaths

<sup>†</sup>% of all non-Aboriginal infant deaths

#### 4.2 All-cause infant mortality – patterns and trends

Aboriginal births account for 6% of the total WA births. However, over the past 22 years, Aboriginal deaths have accounted for 17% of infant deaths and 17% of childhood deaths in WA.

The rate of infant mortality in Western Australia has fallen significantly over the past two decades ( $\chi^2$  test for trend 421.6; p<0.001). Figure 4.1 represents the CMR for Aboriginal and non-Aboriginal infants dying between the birth years 1980 and 2001. The relative risk (RR) of Aboriginal infants dying compared with non-Aboriginal infants in each of the birth year groups is identified below the abscissa. The rate of infant mortality has fallen over the past 22 years in both Aboriginal and non-Aboriginal populations. However, while this decrease has been significant for Aboriginal ( $\chi^2$  test for trend 19.1; p<0.001) and non-Aboriginal infants ( $\chi^2$  test for trend 258.7; p<0.0001), the mortality rate has not fallen as quickly for Aboriginal infants and thus, the relative risk of infant mortality for Aboriginal infants has increased over the years and is now nearly four and a half times the risk for non-Aboriginal infants



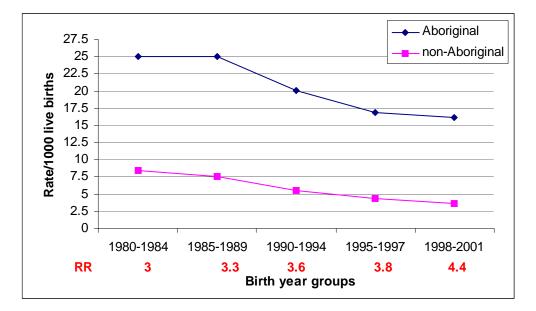
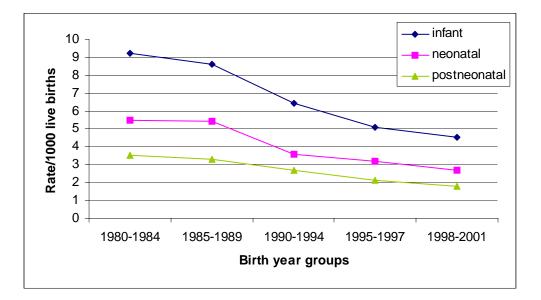


Figure 4.2 represents the infant, neonatal and postneonatal mortality rate for all WA born infants who have died in the first years of life over the past 22 years. The figure shows a higher infant mortality rate in the neonatal period compared with the rate in the postneonatal period. This is the picture that would be expected in developed countries with good maternal and child health services. A significant decrease in the infant, neonatal and postneonatal mortality rate has been observed over the past 22 years when considering the total WA population (Aboriginal and non-Aboriginal infants combined).

## Figure 4.2 CMR for infant, neonatal and postneonatal deaths in the total WA population by birth year groups



Note: The use hereafter of the terms Ab. and non-Ab. as abbreviations in the graphs and tables in this Report were deemed to be acceptable after consultation with Aboriginal researchers in the Kulunga Research Network, Telethon Institute for Child Health Research.

Figure 4.3 represents the CMR for infant, neonatal and postneonatal mortality for Aboriginal and non-Aboriginal infants and shows the different pattern of mortality when the total WA population is considered from an Aboriginal perspective. Unlike the mortality pattern in the non-Aboriginal population, the postneonatal mortality rate in the Aboriginal population is higher than the neonatal mortality rate. This pattern of mortality is most often observed in less developed countries and has been reported among American Indians (Kleinman 1990). The crossover occurred for WA Aboriginal infants in 1985-1989 births.

Figure 4.3 CMR in the neonatal and postneonatal periods for Aboriginal and non-Aboriginal infants by birth year groups

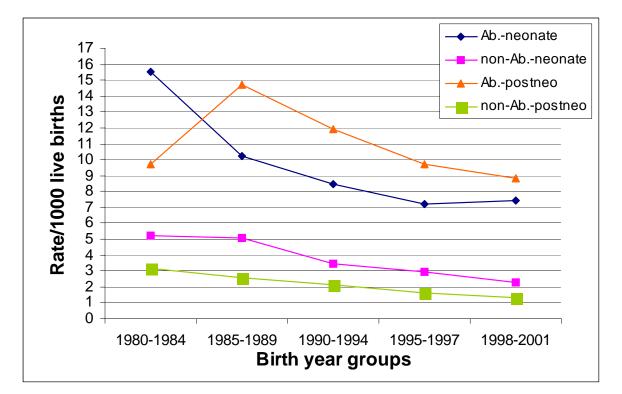
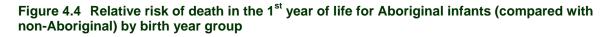
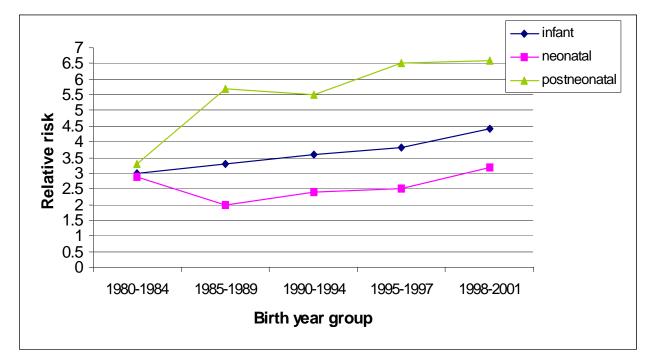


Figure 4.4 shows the increase in the relative risk of death for Aboriginal infants compared with non-Aboriginal in the first year of life, including the neonatal and postneonatal period. The risk of death for Aboriginal infants compared with non-Aboriginal infants has increased over the past 22 years, with the risk of postneonatal death for Aboriginal infants increasing to nearly seven times that of non-Aboriginal infants.





#### 4.2.1.1 Summary

- The rate of infant mortality has fallen significantly (p<0.000) for infants born in Western Australia between 1980 and 2002 inclusive.
- The rate has not fallen as quickly for Aboriginal infants compared to the rate for non-Aboriginal infants.
- The relative risk of infant, neonatal and postneonatal mortality for Aboriginal infants compared to non-Aboriginal infants has increased over the past 23 years in 1998-2001 births, the overall risk of infant mortality for Aboriginal infants was over 4 times and postneonatal mortality nearly 7 times higher than for non-Aboriginal infants.
- Unlike most developed countries, the postneonatal mortality rate is higher than the neonatal mortality rate for Aboriginal infants.

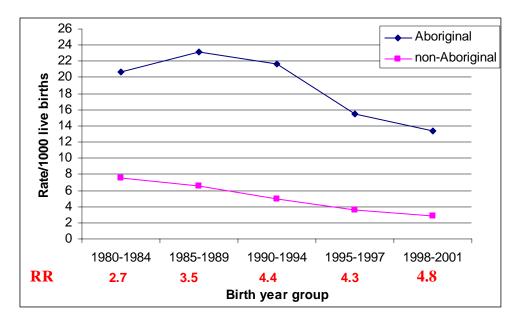
## 4.2.2 Male and female infant deaths

The risk of male infants compared to female infants dying was significantly higher in both Aboriginal (RR= 1.2, 95%CI1.0, 1.4) and non-Aboriginal (RR= 1.3, 95%CI 1.2, 1.4) populations.

The following figures show the patterns and trends of infant mortality according to gender. There was a decrease in the CMR for females between 1980 and 2001 inclusive (figure 4.5).

However, while this decrease has been significant for Aboriginal ( $\chi^2$  test for trend 7.94; p=0.005) and non-Aboriginal infants ( $\chi^2$  test for trend 141.45; p<0.0001), the mortality rate as not fallen as quickly for Aboriginal infants and thus, the relative risk of infant mortality for Aboriginal female infants has increased over the years and was nearly 5 times the risk for non-Aboriginal female infants in the most recent years studied.

Figure 4.5 CMR for female infants according to Aboriginal status and the RR of death for Aboriginal females (compared to non-Aboriginal females), 1980-2002 inclusive



The pattern observed among female infants was similar among male infants (figure 4.6). There was a significant decrease for male Aboriginal ( $\chi^2$  test for trend 11.12; p<0.001) and male non-Aboriginal infants ( $\chi^2$  test for trend 120.56; p<0.0001), the mortality rate has not fallen as quickly for Aboriginal infants and thus, the relative risk of infant mortality for Aboriginal male infants has increased over the years and was over 4 times the risk for non-Aboriginal female infants in the most recent years studied.

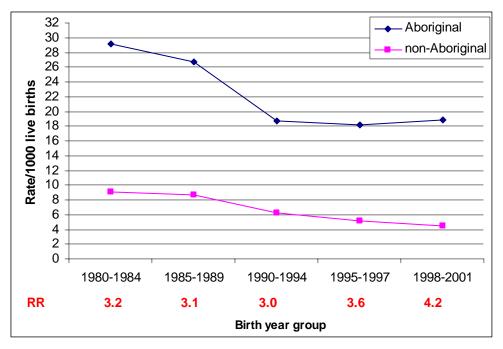


Figure 4.6 CMR for male infants according to Aboriginal status and the RR of death for Aboriginal males (compared to non-Aboriginal males), 1980-2002 inclusive

## 4.2.2.1 Summary

- The rate of infant mortality has fallen significantly (p<0.001) for both male and female infants.
- The rate has not fallen as quickly for male and female Aboriginal infants compared to the rate for non-Aboriginal males and females.
- The relative risk of mortality for male and female Aboriginal infants compared to non-Aboriginal male and female infants has increased over the past 23 years in 1998-2001 births, the overall risk of infant mortality for male Aboriginal infants was over 4 times and for female infants nearly 5 times higher than non-Aboriginal male and female infants respectively.

## 4.2.3 Maternal age at the time of birth

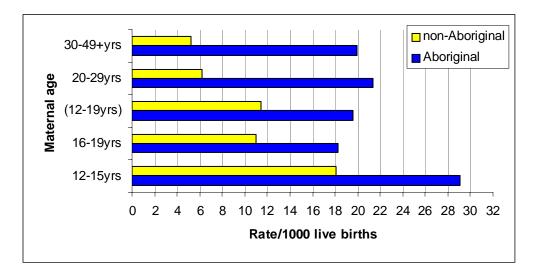
The majority of births for both populations occurred to women who were between 20 and 29 years at the time of the infant's birth. However, 29% of Aboriginal mothers were less than 20 years old at the time of the infant's birth compared with only 5% of non-Aboriginal mothers (table 4.1). Note that CMR and RRs according to maternal ages, refer to the maternal age at the time of the infant's birth.

	Maternal Age (years)							
	12-15 %	16-19 %	20-29 %	30-49+ %				
Aboriginal	3	26	57	14				
Non-Aboriginal	0.1	5	58	37				

Table 4.2Percentage of births for Aboriginal and non-Aboriginal infants according to<br/>maternal age, 1980-2001 inclusive

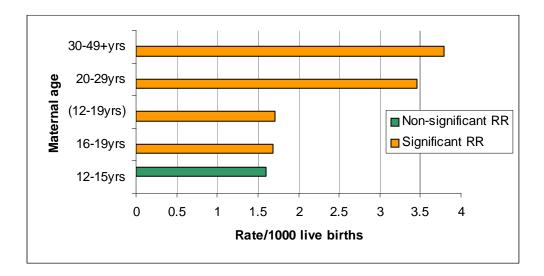
The highest CMR occurred among Aboriginal infants whose mothers were between 12 and 15 years at the time of giving birth (29.1/1000 live births). However, the CMR for Aboriginal infants whose mothers were between 20 and 29 years was 21.4/1000 live births and for non-Aboriginal infants 6.2/1000 live births (Figure 4.7). When the teenage years were combined the CMR for Aboriginal infants was 19.6/1000 live births and for non-Aboriginal infants it was 11.4/1000 live births. The highest RR was among infants whose mothers were 30 years and older (figure 4.7).

# Figure 4.7 CMR for Aboriginal and non-Aboriginal infants according to the maternal age, 1980-2001 inclusive



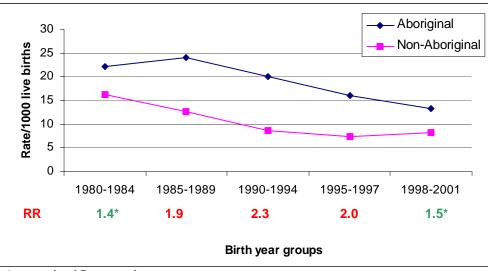
The RR of infant death according to maternal age increased with increasing maternal age groups. Aboriginal infants were at significantly increased risk of death compared with non-Aboriginal infants in all maternal age groups except for mothers aged less than 16 years. These data demonstrate that there are influences other than Aboriginality that affect these excess deaths. The RR of infant death for Aboriginal infants compared with non-Aboriginal infants whose mothers were 30 years or older was nearly 4 times the risk for non-Aboriginal infants whose mothers were of similar age.

## Figure 4.8 The risk of Aboriginal infants (compared with non-Aboriginal) according to maternal age, 1980-2001 inclusive



The following figures show the trends and patterns of infant mortality according to the maternal age (grouped). There has been a significant decrease in the infant mortality rate in all maternal age groups over the past 23 years among Aboriginal ( $\chi^2 < 0.01$ ) and non-Aboriginal infants ( $\chi^2 < 0.001$ ). There was an increase in the CMR for Aboriginal infants whose mothers were older than 30 years in 1998-2001 compared with birth year groups 1995 to 1997. The risk of Aboriginal infants dying in infancy compared with non-Aboriginal infants was significantly higher where mothers were older than 20 years. However the risk of mortality for Aboriginal (compared with non-Aboriginal) infants of teenage mothers was not significantly different in birth year groups 1980 to 1984 and 1998-2001, while significantly increased in birth year groups 1985 to 1989, 1990 to 1994 and 1995 to 1997.





\* non-significant value



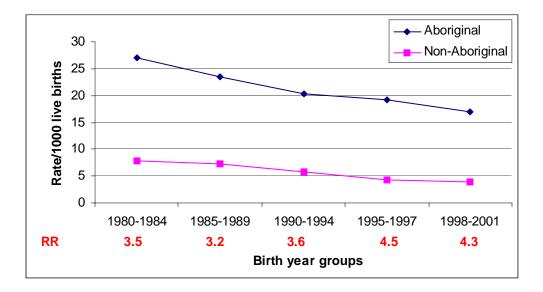
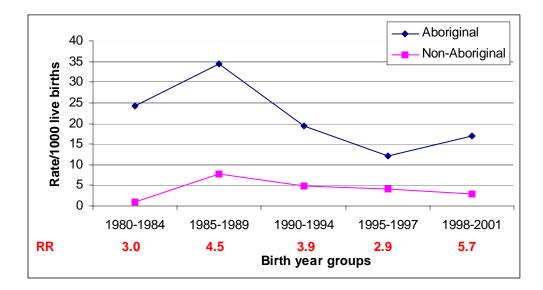


Figure 4.11 CMR for Aboriginal and non-Aboriginal infants and RR for Aboriginal (compared with non-Aboriginal infants) according to a maternal age of over 30 years, 1980-2001 inclusive



### 4.2.3.1 Summary

- There has been a significant decrease in Aboriginal and non-Aboriginal infant mortality in all maternal age groups.
- Twenty-nine percent of Aboriginal births were to teenage mothers (compared with 5% of non-Aboriginal births).
- The highest CMR for non-Aboriginal infants was among teenage mothers.
- The highest Aboriginal CMR was among infants whose mothers were between 20 and 29 years.
- The highest RR for Aboriginal infants was among infants whose mothers were older than 30 years.
- The high rates and relative risks for Aboriginal infants with mothers aged 20-29 years are especially important, as this is the maternal age group where most births occur (57%). In developed countries this is usually the age gap with the lowest risk.
- The highest disparities in mortality between the two populations were also observed among infants with normal birthweight and born greater than 37 completed weeks (data not shown).

## 4.2.4 Place of death – in or out of hospital

The place of death (in or out of hospital) of each infant who died between 1980 and 2002 inclusive was identified. The geographical location in association with the place of death was also identified. The majority of deaths due to sequelae of prematurity occurred in hospital and infant deaths attributable to SIDS occurred out of hospital. However, deaths due to birth defects and as a result of infection, occurred at differing frequencies in and out of hospital for Aboriginal and non-Aboriginal infants. Thus, these causes of deaths were analysed according to the place of death and geographical location of birth for both populations. The relative risk of death within both Aboriginal and non-Aboriginal populations according to geographical location was also determined.

Figure 4.12 describes the percentage of total infant deaths that occur in and out of hospital for Aboriginal and non-Aboriginal infants. Fifty-five percent of Aboriginal and 71% of non-Aboriginal infant deaths occur in hospital.

Figure 4.12 Percentage of total deaths that occur in and out of hospital for Aboriginal and non-Aboriginal infants, 1980-2002 inclusive

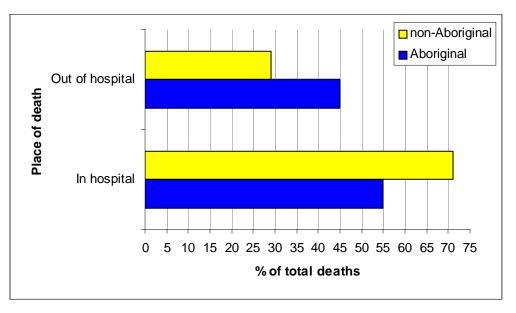
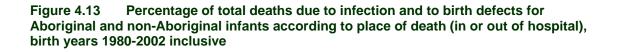


Figure 4.13 identifies the place of death for deaths due to birth defects and infection for Aboriginal and non-Aboriginal infants. The main difference in the two populations was with deaths due to infections with 39% of Aboriginal deaths occurring due to infection take place out of hospital compared with only 21% of non-Aboriginal deaths. Most deaths due to birth defects occur in hospital for Aboriginal (86%) and non-Aboriginal (85%) infants. There were no differences in the percentage of deaths due to birth defects that occurred in hospital or out of hospital in the two populations.



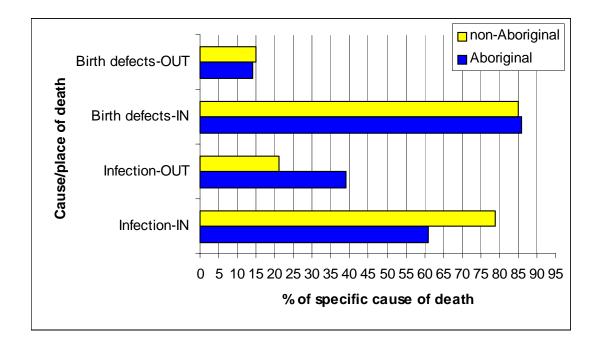


Figure 4.14 shows the percentage of deaths due to infection occurring in and out of hospital according to the geographical location of death. Among infants living in remote locations, a higher percentage of Aboriginal deaths occur in hospital (66%) compared with Aboriginal deaths occurring out of hospital (44%). There was a similar picture for non-Aboriginal infants (69% in hospital, 34% out of hospital). Similar percentages of Aboriginal deaths occur in and out of hospital in metropolitan locations (49% in hospital, 51% out of hospital). This picture differed among non-Aboriginal infants where a high percentage of deaths occurred in hospital (81%). In rural locations higher percentages of deaths occurred in hospital for both Aboriginal (63%) and non-Aboriginal (79%) infants.

Figure 4.14 Percentage of infant deaths due to infection in and out of hospital in each location for Aboriginal and non-Aboriginal infants, birth years 1980 to 2002

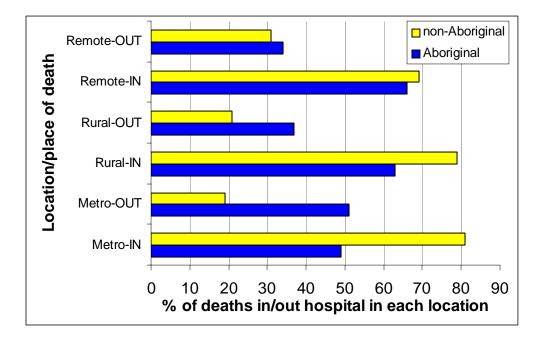


Figure 4.15 shows the CMR due to infection for Aboriginal and non-Aboriginal infants according to the geographical location and place (in or out of hospital).

The CMR due to infection for Aboriginal infants is higher than their non-Aboriginal peers in all locations. However, for deaths occurring both in and out of hospital the CMR is highest for Aboriginal infants in remote locations. There was no significant difference in the risk of dying due to infection out of hospital for Aboriginal infants according to the geographical location. However, the risk of dying in hospital due to infection for Aboriginal infants in a remote location was significantly higher compared with Aboriginal infants in metropolitan, RR= 2.1 (95% CI 1.3, 3.4) and rural RR = 1.7 (95% CI 1.0, 2.8) locations. There was no significant risk of death in hospital due to infection according to location among non-Aboriginal infants. However, non-Aboriginal infants living in a remote, RR= 3.3 (95% CI 1.8, 6.3), and rural, RR = 1.8 (95% CI 1.0, 3.3), location were at a significantly increased risk of death out of hospital due to infection compared with non-Aboriginal infants living in a metropolitan location.

Figure 4.15 CMR due to infection for Aboriginal and non-Aboriginal infants according to location/place of death, birth years 1980 to 2001 inclusive

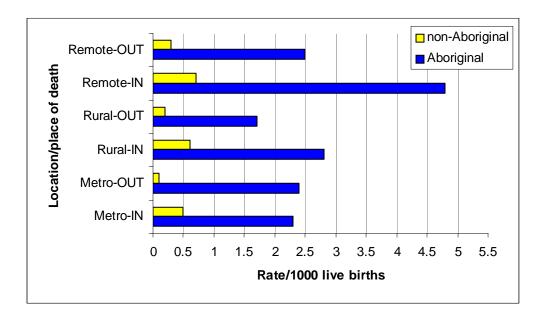


Figure 4.16 describes the CMR due to birth defects for Aboriginal and non-Aboriginal infants according to place of death (in or out of hospital) and location. There was no significant difference in the risk of death due to birth defects according to location of death whether in or out of hospital with the exception of infants who died in hospital living in a remote location, where Aboriginal infants were over twice as likely to die due to birth defects compared with non-Aboriginal infants: RR=2.2 (95%CI 1.5, 3.2). Geographical location did not significantly increase the risk of dying either in or out of hospital due to birth defects for either Aboriginal or non-Aboriginal infants.

## Figure 4.16 CMR due to birth defects according to place and location of death for Aboriginal and non-Aboriginal infants birth years 1980-2001 inclusive

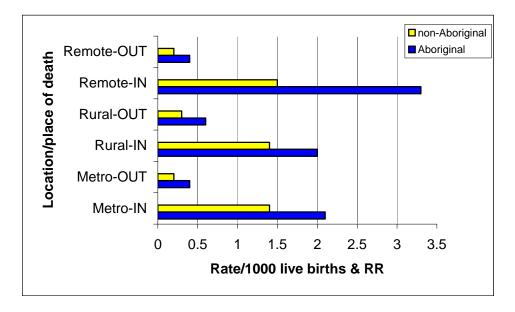
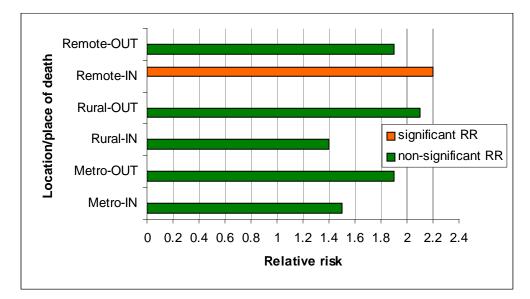


Figure 4.17 RR of death due to birth defects for Aboriginal (compared with non-Aboriginal infants), birth years 1980-2001 inclusive



### 4.2.4.1 Summary

- Forty-five percent of Aboriginal deaths occurred out of hospital compared with 29% of non-Aboriginal infant deaths.
- Overall geographical locations, 39% of Aboriginal deaths due to infection occurred out of hospital compared with 29% of non-Aboriginal infant deaths.
- In the metropolitan area, 51% of Aboriginal infants who died from infection died out of hospital compared with 19% of Aboriginal infants.
- Aboriginal infants living in remote locations were significantly more likely to die in hospital where the cause of death was a birth defect compared to non-Aboriginal infants.
- Of infants living in remote locations who died as a result of infection, similar percentages of Aboriginal (44%) and non-Aboriginal infants (34%) died out of hospital.

## 4.2.5 Geographical location of death

The geographical location was determined from the postcode of the mother's residence at time of birth (which had been identified as being significantly correlated to the geographical location at time of death) and was categorized as metropolitan, rural and remote. The Health Department of WA Health Zone divisions determined these categories. There is the potential to re-analyse the data according to smaller geographical divisions or to apply the ARIA categories to the data. However, for the purposes of this report the data have been analysed using the metropolitan, rural and remote categories.

Between 1980 and 2002, 46% of Aboriginal births occurred to mothers living in a remote location, 24% in rural locations and 29% in metropolitan locations. These percentages compared with 9% of non-Aboriginal mothers living in remote locations, 19% in rural locations and 72% in metropolitan locations. Fifty-three percent of Aboriginal infant deaths occurred among infants living in a remote location, 21% in a rural location and 26% in a metropolitan location whereas non-Aboriginal mortality according to location was similar to the percentages of births: remote 9%, rural 20% and metropolitan 71%. In the birth years between 1998 and 2001 these percentages of births and deaths were similar in the non-Aboriginal population. However, in the Aboriginal population while the percentage remained the same in remote locations, the percentage of deaths increased by 4% in the metropolitan location and decreased accordingly in rural locations.

Figure 4.18 shows the trends in all-cause mortality for all infants according to geographical location. There has been a significant decrease in the CMR between the birth years 1980 and 1997 inclusive in all geographical locations (p<0.001). However, between the birth years 1998 and 2001 inclusive, the CMR has increased in remote locations, remained the same in rural areas and decreased significantly in metropolitan locations (RR = 0.8, 95%CI 0.7, 0.9).

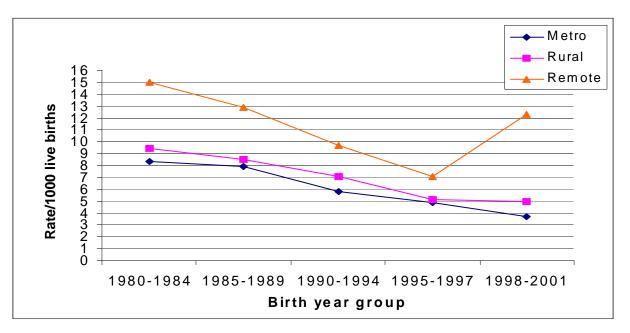


Figure 4.18 CMR for all infants by geographical location at time of death and birth year groups, 1980-2001 inclusive

Figure 4.19 shows the CMR and the relative risk of death for Aboriginal infants (compared with non-Aboriginal) according to the geographical location of their birth over the past 22 years. Over the past 22 years the CMR has been highest in remote locations for both Aboriginal and non-Aboriginal infants. The risk of an Aboriginal infant dying was significantly higher than their non-Aboriginal peers in all geographical locations.

Figure 4.19 CMR of infant deaths between 1980 and 2001 inclusive according to Aboriginal status according to the geographical location of birth

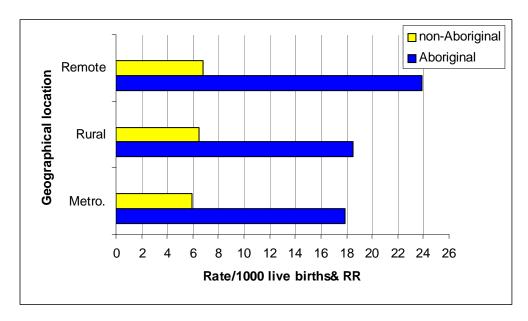


Figure 4.20 RR of deaths for Aboriginal infants (compared with non-Aboriginal) according to the geographical location of birth

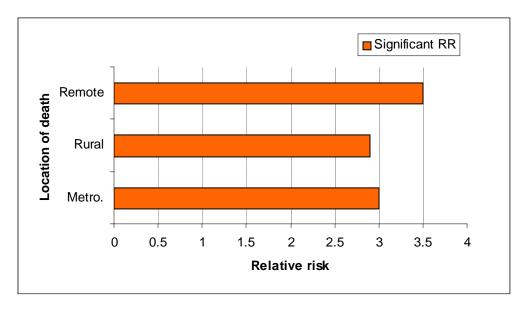
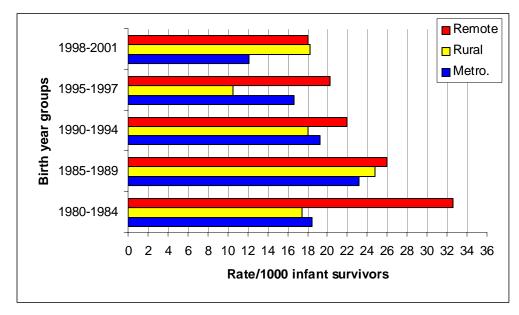
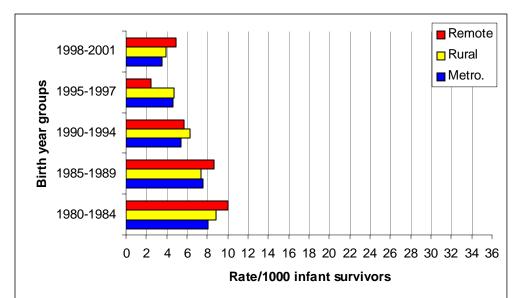


Figure 4.21 and Figure 4.22 shows the trends in all-cause infant mortality according to Aboriginal status and birth year group. There has been a decrease in the CMR among Aboriginal infants in remote and metropolitan locations in the past 22 years. However, there has been an increase in the mortality rate in rural locations and the CMR for Aboriginal infants was similar in rural and remote locations in the birth years 1998-2002 (18 per 1000 live births) (Figure 4.21). The very high mortality rate in remote locations and high rate in metropolitan locations among Aboriginal infants has decreased significantly in the past 23 years (p<0.001 and p=0.03 respectively).

Figure 4.21 CMR of Aboriginal infants, geographical location of birth and birth year group



Over all years studied, there was a significant decrease in non-Aboriginal infant mortality in all geographical locations (p<0.0001). There has also been a significant increase in the CMR for non-Aboriginal infants living in remote locations in the past 5 years (RR = 2.0 95%CI 1.1, 3.7) (Figure 4.22).



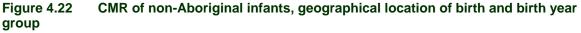
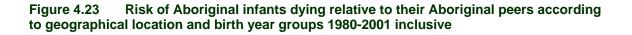
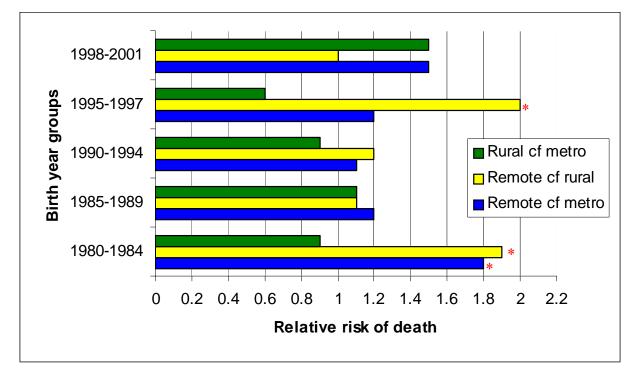


Figure 4.23 shows the relative risk of infant death for Aboriginal infants compared with their peers according to the geographical location by birth year group. There was no significant difference in the risk of infant death for Aboriginal infants according to their location with the exception of the birth years 1980-1984 where there was an increased risk for Aboriginal infants living in remote locations compared with their peers living in rural: RR = 1.9 (05% CI 1.2, 2.9) and metropolitan locations: RR= 1.8 (95% CI 1.1, 2.8). This increased risk for Aboriginal infants living in a remote location compared with their Aboriginal peers living in rural and metropolitan locations was also observed when the cumulative relative risk was calculated for the 22 years: remote *c.f.* rural RR = 1.3 (95% CI 1.1, 1.6); remote *c.f.* metro. RR = 1.3, (95% CI 1.1, 1.6).





\*significant values remote c.f. rural, remote c.f. metro 1980-1984 and remote c.f. rural 1995-1997

Figure 4.24 shows the relative risk of infant death for non-Aboriginal infants compared with their peers according to the geographical location by birth year group. There was no significant difference in the risk of a non-Aboriginal infant dying according to location in any of the birth year groups with the exception of 1995-1997, where a non-Aboriginal infant living in a remote location was significantly less likely to die compared with a non-Aboriginal infant living in a rural: RR = 0.5 (95%CI 0.3, 0.9) or metropolitan location: RR = 0.6 (95% CI 0.3, 0.9). However, when the cumulative relative risk was calculated over the 22 years this picture was reversed and a significantly increased risk of death was observed in non-Aboriginal infants living in a remote: RR= 1.2 (95% CI 1.0, 1.3) and rural location: RR = 1.2 (05% CI 1.0, 1.2) compared with their non-Aboriginal peers in a metropolitan location.

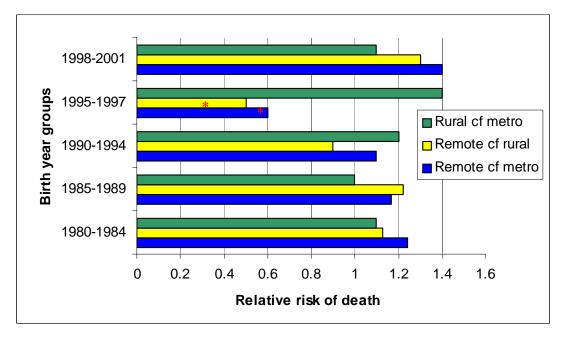


Figure 4.24 Risk of non-Aboriginal infants dying relative to their non-Aboriginal peers according to geographical location and birth year groups 1980-2001 inclusive

\* significant values remote *c.f.* rural, remote *c.f.* metro

### 4.2.5.1 Summary

- There was a significant decrease in the all-cause CMR among infants in metropolitan  $(\chi^2 20.9, p < 0.001)$ , rural  $(\chi^2 29.2, p < 0.001)$  and remote  $(\chi^2 16.0, p < 0.001)$  locations between 1980 and 2001.
- The decrease was significant for non-Aboriginal infants in all locations, and also reached significance for Aboriginal infants living in metropolitan and remote locations.
- For all years studied, the risk of dying was significantly higher for Aboriginal than non-Aboriginal infants in all geographical locations.
- In the past 22 years, the risk of all-cause mortality for Aboriginal infants compared with non-Aboriginal infants was highest in remote locations (3<sup>1</sup>/<sub>2</sub> times).
- For births between 1998 and 2001, there was an increase in the non-Aboriginal infant all-cause CMR in remote locations and Aboriginal infant CMR in rural locations, compared with 1995-1997.
- For births between 1998 and 2001, the all-cause CMR was highest in remote locations for non-Aboriginal infants, and remote and rural for Aboriginal infants.
- However, when considering differences in the risk of infant mortality within each population, the geographical location was found to have no significant influence on the risk of Aboriginal or non-Aboriginal infants dying.

## 4.3 Cause-specific infant mortality – patterns and trends

## 4.3.1 Trends in post-mortems 1998-2002 inclusive

Errors in cause of death information can arise at the time of diagnosis, certification or coding (Cole 1989). Numerous validation studies have concurred that only after autopsy examination together with clinical and laboratory examination can the cause of death be accurately identified (National Centre for Health Statistics 1982). Determining the cause of death of an infant or child serves not only to explain, to a small degree, the tragedy of the death to the parents and family, but also to highlight specific causes that may require special care in future pregnancies or in the perinatal period. The ability to review total population mortality data that spans 23 years enables the development and implementation of strategies to prevent subsequent deaths both at an individual and at a population level.

All sudden and unexpected deaths are by law reported to the State or Regional Coroner and must undergo a post-mortem examination. In most cases this examination includes an autopsy, which includes an examination of organs and associated pathology, toxicology, serology and macro and micro examination of the deceased. In a small number of cases the parents, mostly on cultural grounds, refuse this. Permission to forego an autopsy is determined by a hearing at the Coroner's Court. The post-mortems and autopsies are usually carried out centrally at the Forensic Pathology Department located at the Queen Elizabeth 11 Medical Centre. In cases where the death falls under the jurisdiction of a Regional Coroner, the Regional Coroner determines the place of the autopsy and case reports are held at the Coroner's Office accordingly. Almost all full autopsies are now performed centrally by the Western Australian Centre for Pathology and Medical Research (PathCentre), which is the preferred protocol. In cases where an external examination only is required, these may be performed regionally. Perinatal and infant deaths are often performed by specialist paediatric pathologists at the King Edward and Princess Margaret Memorial Hospital complex.

Since 1990, autopsies of perinatal and infant deaths have been conducted in association with specialised perinatal and paediatric pathologists and have been conducted in one of three tertiary referral centres in Perth with more than 90% of non-coronial autopsies performed in the King Edward and Princess Margaret Memorial Hospital complex (Alessandri et al. 2001).

Between the years 1980 to 1993, autopsies were performed on 56% of Aboriginal and 60% of non-Aboriginal infants (Alessandri et al. 2001).

In the following data, post-mortems refer to those conducted as a result of a coroner's enquiry. Non-coronial autopsies were conducted on the number of deaths to identify a physical cause of death. However, the post-mortem includes ideally, not only the physical causes of death but also a number of other forensic and pathology examinations, scene identification and previous medical, clinical and social history in determining the cause of death. This integrated approach to determining the cause of death is imperative if we are to insure that the correct cause of mortality is identified in every case of infant and childhood death.

Between 1998 and 2001, 35% of infants who died had a post-mortem. In this time period, 53% of Aboriginal infant deaths and 29% of non-Aboriginal infant deaths underwent a post-mortem examination (table 4.2). The main causes of infant death among non-Aboriginal infants were birth defects and prematurity where in most cases the deaths are expected (in the former) and explained (in the latter). However, among Aboriginal infants the main causes of infant death were due to infection and attributed to SIDS, which in the main, are unexpected (former) or sudden (the latter). Therefore, the higher percentage of post-mortems performed on Aboriginal infants is perhaps not surprising.

Table 4.3Shows the number and (%) of post-mortems undertaken for infant deathsaccording to the general causes of death and Aboriginal status, for the years 1998-2002inclusive

General cause of death	Aboriginal				Non-Aboriginal			
	PM		no P	M	I	PM	n	o PM
	Ν	(%)	Ν	(%)	Ν	(%)	Ν	(%)
Intrauterine	1	(100)	0	(0)	2	(13)	14	(87)
Birth defects	2	(13)	14	(88)	8	(8)	78	(92)
Prematurity	1	(6)	21	(96)	0	(0)	89	(100)
Infection	16	(64)	9	(36)	20	(47)	23	(53)
Accident/injury	3	(100)	0	(0)	12	(92)	1	(6)
Cancer/leukaemia	0	(0)	0	(0)	0	(0)	1	(6)
SIDS	16	(100)	0	(0)	36 (	(100)	0	(0)
Other specific conditions.	1	(33)	2	(66)	3	(8)	37	(92)
Unascertainable/unknown	13	(93)	1	(7)	20	(90)	2	(10)
TOTAL	53*	(53)	47	(47)	102	(29)	245	(71)

\* 2 cases there was no information as to whether a post-mortem was undertaken

## 4.3.1.1 Summary

- Overall, 53% of Aboriginal infants who died underwent post-mortem, compared with 29% of non-Aboriginal infants.
- Generally this difference could be explained by the variation in the main causes of death for Aboriginal and non-Aboriginal infants.
- Of infants who died as a result of infection, 64% of Aboriginal infants had a postmortem compared with 47% of non-Aboriginal infants.
- Overall, the low percentages of post-mortem raise concerns as to the accuracy of cause of death, particularly in non-Aboriginal infants dying as a result of the sequelae of prematurity.

## 4.3.2 Cause-specific infant mortality

The causes of infant death were identified under nine general categories (table 4.3). The main causes of infant death were identified and analysed by place of death (in/out of hospital) and geographical location of the residence at time of birth. Further analyses were completed for deaths attributable to SIDS and due to infection. Data describing trends in infant mortality due to birth defects and according to geographical location are also presented.

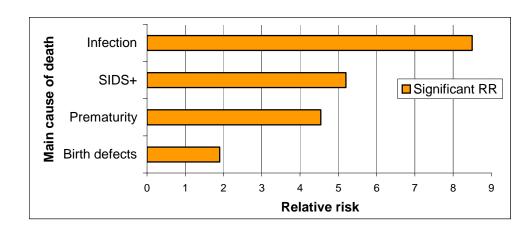
Table 4.3 identifies the nine general categories of infant death and includes the number and percentage of total deaths. The data are also included for Aboriginal and non-Aboriginal populations. Table 4.3 demonstrates the importance of disaggregating total population data in order that specific information describing minority groups may be observed. Table 4.3 identifies that the main causes of death over the past 22 years among Aboriginal infants were infection (29%) and SIDS (27%). These causes of death are potentially preventable. However, the main causes of death among non-Aboriginal infants were prematurity (27%) and birth defects (27%), which are less preventable in the current state of knowledge. If one were to consider the main causes of infant death only for the total population in the determination of health policies and development of disease and mortality prevention strategies, then the needs of the minority and disadvantaged populations would be ignored.

General Cause of infant	Abo	riginal	Non-A	boriginal	Total	
death	Ν	<b>(%</b> )	Ν	%	Ν	%
Infection	179	(29)	348	(11)	527	(14)
SIDS	167	(27)	596	(19)	763	(21)
Prematurity	99	(16)	837	(27)	936	(25)
Birth defects	93	(15)	827	(27)	920	(25)
Intrapartum	19	(3)	149	(5)	168	(5)
Accident and injury	16	(3)	76	(3)	92	(3)
Maternal condition	3	(0.5)	10	(0.3)	13	(0.4)
Cancer/leukaemia	2	(0.3)	14	(0.5)	16	(0.4)
Unknown/unascertainable	30	(5)	40	(1)	70	(2)
Other	21	(3)	187	(6)	208	(5)
Total deaths	629	(100)	3084	(100)	3713	(100)

## Table 4.4Number and (percentage) of infant deaths according to the generalclassification and Aboriginal status, births 1980-2001 inclusive

The main causes of death were identified for both populations and then analysed according to these categories. The main causes of infant death were SIDS, infection, the sequelae of prematurity and birth defects. The other general causes of death were included under 'other' in the main causes categories. However, the trend in the classification of "unascertainable" deaths deserves particular consideration.

The risk of death for Aboriginal infants was significantly higher than the risk for non-Aboriginal infants for all main causes of death. The risk of death due to infection for Aboriginal infants was  $8\frac{1}{2}$  times higher than the risk for non-Aboriginal infants.



# Figure 4.25 Risk of mortality for Aboriginal (compared to non-Aboriginal) infants for the main causes of death, 1980-2001 inclusive

Table 4.4 identifies CMR for the main causes of infant death over the past 23 years. It includes both calculations for SIDS diagnosis and the combining of SIDS diagnoses and deaths where the cause of death was given as "unascertainable". Further, the cause-specific CMR due to the sequelae of prematurity, which decreased in earlier years (4.3 to 1.3/1000 live births) has increased among Aboriginal infants in the most recent birth year group (1.3 to 3.5/1000 live births) (table 4.4).

Table 4.5 identifies the trends in the CMR for the main causes of infant death. The cause-specific CMR has decreased significantly for all main causes of non-Aboriginal infant death. However, for Aboriginal infants, while the overall CMR has fallen significantly, when the main causes of death were analysed separately, the observed falls were not significant.

Cause of death	198	30-1984	1985-1989	199	)-1994	199	95-1997	19	98-2001
	Ab.	non-Ab.	Ab. non-Ab.	Ab.	non-Ab.	Ab.	non-Ab.	Ab.	non-Ab.
	CMR N	CMR N	CMR N CMR N	M CMR N C	CMR N	CMR N	CMR N	CMR N	CMR N
SIDS	4.5 (25)	1.7 (183)	9.0 (60) 1.7 (195)	6.2 (45)	1.1 (135)	4.7 (21)	0.7 (47)	2.5 (16)	0.4 (36)
SIDS +									
unascertainable	4.9 (27)	1.8 (185)	9.9 (66) 1.8 (203)	6.7 (49)	1.2 (140)	5.6 (25)	0.7 (49)	4.7 (30)	0.6 (57)
Infection	6.3 (35)	0.9 (98)	6.5 (43) 0.6 (66)	6.9 (50)	0.8 (93)	5.6 (24)	0.7 (49)	4.1 (26)	0.5 (43)
Birth defects	4.5 (25)	2.2 (230)	3.2 (21) 2.2 (250)	2.5 (18)	1.5 (180)	3.0 (13)	1.1 (80)	2.5 (16)	0.9 (86)
Prematurity	4.3 (24)	2.3 (241)	3.8 (25) 2.3 (258)	1.3 (22)	1.3 (159)	1.3 (6)	1.2 (89)	3.5 (22)	0.9 (92)

 Table 4.5
 CMR for the main causes of infant mortality for Aboriginal and non-Aboriginal infant for the birth year groups 1980-2001

Table 4.6Shows the significance in the trends in the CMR for the main causes of infant mortality for Aboriginal and non-Aboriginalinfants for the birth year groups 1980-2001

Cause of death	Abori	ginal	non-Abo	original
	Chi-square#	p-value	Chi-square#	p-value
SIDS +				
unascertainable	2.5	0.12	88.6	<0.001
Infection	3.2	0.08	10.1	0.002
Birth defects	3.2	0.08	78.1	<0.001
Prematurity	2.3	1.13	80.1	<0.001

\* bolded values reflect statistically significant decreases.

# test for trend

Death in infancy due to infection should in most cases be preventable. Most cases of SIDS are also potentially preventable given the significant reduction in the mortality rate attributable to SIDS in the non-Aboriginal population following the 1991 "Reduce the Risks" campaign. The next section will focus on the patterns and trends of infant mortality according to SIDS and infection. Data describing SIDS deaths will include cases where the cause of death could not be ascertained. The justification for this is described in 4.3.3.

## 4.3.2.1 Summary

- The main causes of Aboriginal infant mortality were deaths due to infection (29%) and deaths attributable to SIDS (27%) both causes are potentially preventable.
- The main causes of non-Aboriginal infant mortality were deaths due to birth defects (27%) and the sequelae of prematurity (27%), which are difficult to prevent in the current state of knowledge.
- Over all the years studied, infant mortality among non-Aboriginal infants decreased significantly in all the main causes of infant death.
- There were no significant decreases in the cause-specific infant mortality of Aboriginal infants over all the years studied.
- The CMR attributable to SIDS was similar in 1998-2001 as in 1980-1984 in Aboriginal infants.
- The risk of death due to infection for Aboriginal infants was 8<sup>1</sup>/<sub>2</sub> times higher than for non-Aboriginal infants.
- In the past 5 years, there has been a significant increase in the number of deaths where the cause was unascertainable by forensic pathology.
- Infant mortality in Aboriginal infants due to the sequelae of prematurity has increased significantly in 1998-2001 compared with 1995-1997 (RR=2.6, 95% CI 1.0, 6.3).

## 4.3.3 Trends in unascertainable deaths

In the past five years an increase in the number of deaths determined as unascertainable was observed. As a result, the autopsy case reports of these cases were re-considered. It is possible that with an increase in the availability of information regarding co-sleeping, alcohol, smoking, consumption of other illicit drugs and improved death scene descriptions that deaths previously identified as SIDS have recently been identified as unascertainable. There were also changes in the number of full autopsies following the changes to the Coroners Act in 1996. These changes included the provision for relatives of a dead infant to appeal to the Coroner against a full autopsy being performed, a 24 hour period between signing permission for an autopsy and the autopsy being performed, and provision to appeal to the Supreme Court in cases where the Coroner had disallowed parental objection to a full autopsy.

Given the significant increase in the numbers of unascertainable deaths in the past 5 years (Table 4.6), all deaths between 1980 and 2002 attributable to SIDS and deaths where a cause was considered to be unascertainable were included together and the data reanalyzed accordingly.

There was a higher percentage of deaths among Aboriginal infants (14%) where the cause was not identified compared to non-Aboriginal deaths (6%) in 1998-2002.

Table 4.7Shows the increase in the number of deaths identified as unascertainablebetween 1980 and 2001

	1980-1984		1980-1984		1980-1984 1985-1989		1990-1994		1995-1997		1998-2001	
	Ab.	non-Ab.	Ab.	non-Ab.	Ab.	non-Ab.	Ab.	non-Ab.	Ab.	non-Ab.		
Unascertainable death	2	2	6	8	4	5	4	2	14	21		

## 4.3.4 Infant mortality due to SIDS

One of the main aims of forensic examination through post-mortem is to identify the cause of death. The identification of cause of death depends not only upon a thorough post mortem examination, but also upon comprehensive assessment of clinical and social factors and the medical history. This approach represents an integrated approach to child death enquiry. A specialised paediatric examination in these cases has the potential to yield more complete and informative data than a non-specialist examination.

The "sudden and unexpected death of an infant or child is one of the worst events to happen to any family" (Fleming 2004). The rate of sudden and unexpected death in infants and children continues to be of concern particular with regards to the Aboriginal population. The importance of seeking to determine the causes behind these deaths cannot be overestimated. Determining the cause of such deaths is predicated on extensive forensic examination in addition to an integrated approach as identified previously.

At a recent meeting in Canberra, forensic and paediatric pathologists from all states and territories met to discuss and determine a national forensic approach to sudden and unexpected death. At this meeting, a nationally consistent protocol for the post mortem and forensic examination of infants and children was achieved. The meeting endorsed the desirability of a joint paediatric and forensic investigative approach to infant and child post mortems. Importantly, the meeting considered a new international definition of SIDS, the uniform national adoption of which is a world first. The workshop was supported and the outcomes were endorsed by, SIDS and Kids (the national peak body representing bereaved parents).

The recommendations and initiatives resulting from the workshop are in line with world best practice. In particular, a joint working party on the Investigation of Sudden Death in Infancy acknowledged the work of Professor Fleming in Bristol where circumstances of death were investigated immediately afterwards by a senior paediatrician and a police officer (British Paediatric Pathology Association 2004). Post mortems were also done by an experienced paediatric pathologist and included input from a number of relevant sources. It was concluded that the benefits of a protocol that included the immediate involvement of a paediatric pathologist in an integrated process enabled optimal categorisation on the basis of such an extensive investigation.

The Foundation for the Study of Deaths and the Report of the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESI SUDI) (Fleming 2000) recommends a comprehensive evaluation of all infant deaths using an integrated, multi-agency approach. Together with the American Academy of Pediatrics, these bodies suggest that such a method of enquiry provides the best opportunity of determining the cause of death. Cote *et al.* also demonstrated that in cases where the post mortem was conducted by a paediatric pathologist, there was significantly less likelihood of a death being classified as "unascertainable" (Cote 1999). Fleming *et al* recommended the use of an integrated approach to forensic investigation including medical and social services staff. This approach was found to better interpret the social, cultural or economic markers of normal patterns of childcare in cases of sudden and unexpected deaths (Fleming et al. 2004).

The current view of SIDS is that it is a multifactorial disorder influenced by developmental, environmental and biological risk factors (Opdal 2004). Research has also suggested "death occurs only when a vulnerable infant is exposed to external stresses during a critical developmental stage " (Filiano 1995).

SIDS is diagnosed on the basis of exclusion. Up to 2004, SIDS had been defined using the 1989 National Institute of Child Health and Human Development Beckwith definition (Willinger 1991). In 2003, Beckwith reintroduced the proposal to include a system of stratification to enable separation of cases into typical and atypical groups (Beckwith 2003). In January 2004, an international expert panel of paediatric and forensic pathologists and paediatricians, proposed a new definition of SIDS and, in consultation with experts in Australia, this definition was formally accepted in July 2004 as the definition for the determination of SIDS. The new definition states that SIDS is "the sudden unexpected death of an infant under one year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and a review of the clinical history" (Krous 2004).

There were also subsets of the general definition to include:

- Category 1A: Classic features of SIDS present and completely documented includes infant deaths that meet the requirements of the general definition and a number of other clinical requirements and circumstances of death (scene examination) and autopsy findings.
- Category 1B SIDS: classic features of SIDS present but incompletely documented.
- Category 11 SIDS: meet category 1 criteria except for selected clinical, circumstances of death and autopsy information.
- Unclassified sudden infant death: includes deaths that do not meet the criteria for category 1 or 11 SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.
- Post-resuscitation cases: infants found *in extremis* who are resuscitated and later die ("temporarily interrupted SIDS") may be included in the above categories, depending on the fulfillment.

The following data describes mortality where the cause of death has been attributed to SIDS or was unascertainable and will be incorporated under the category of SIDS. It is concluded that this method of classification is more suitable when considering deaths over the period 1980 to 2002, as in this report.

Figures 4.26 and 4.27 show the change in the CMR for the cause of death attributable to SIDS and where the cause of death was considered unascertainable for Aboriginal (figure 4.26) and non-Aboriginal infants (figure 4.27). The decrease in the CMR of deaths attributable to SIDS and relative increase in the CMR of deaths that were unascertainable strongly suggests that cases formerly classified as SIDS particularly in Aboriginal infant deaths have more recently been classified as unascertainable.

Figure 4.26 CMR attributable to SIDS and where cause of death was unascertainable for Aboriginal infants, birth years 1980-2001 inclusive

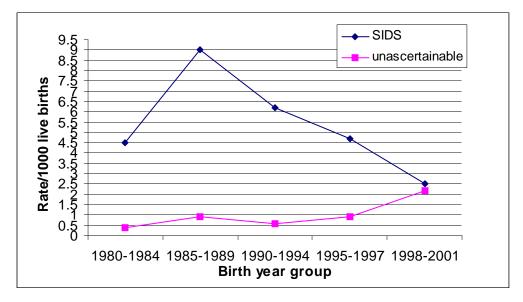
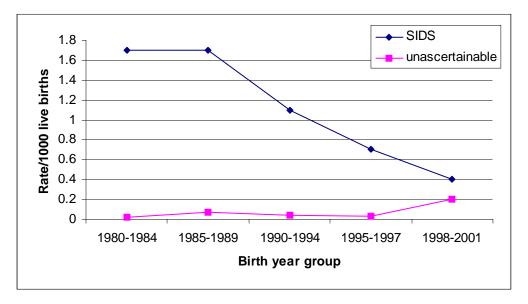
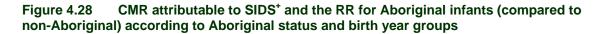
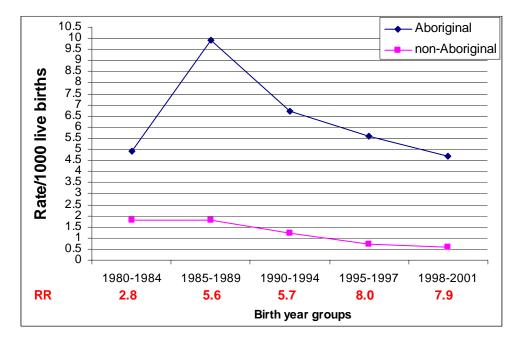


Figure 4.27 CMR attributable to SIDS and where cause of death was unascertainable for non-Aboriginal infants, birth years 1980-2001 inclusive



The following graphs describe the trends of combined rates *i.e.* where deaths were attributed to SIDS and where the cause of death was unascertainable (SIDS<sup>+</sup>) from 1980-2001 inclusive. The CMR attributable to SIDS<sup>+</sup> has decreased significantly over the past 22 years in non-Aboriginal infants ( $\chi^2$  test for trend 88.6; p<0.001), but not in Aboriginal infants ( $\chi^2$  test for trend 2.5; p=0.1). While there was a decrease in the CMR from the birth years 1985-1989 to 1998-2001, it was not significant. In 1998-2001, the risk of an Aboriginal infant dying due to SIDS<sup>+</sup> compared with non-Aboriginal infants was nearly eight times the risk for a non-Aboriginal infant, rising from nearly 3 times in 1980 to 1984 (figure 4.28).





Note in determining the infant mortality rate of cause specific deaths in each of the birth year groups, there were small numbers particularly for Aboriginal infants (range 25-66). While the small numbers of deaths are heartening and one would wish to see this trend continuing, from an epidemiological perspective it is possible that the observed trends are not as clearly robust compared with non-Aboriginal. This also applies when reporting the trends in deaths due to infection (range 24-66) (Figure 4.31).

Between 1980 and 2001, the CMR attributable to  $SIDS^+$  was highest in rural and remote locations for both Aboriginal and non-Aboriginal infants. There was a significantly increased risk  $SIDS^+$  for Aboriginal infants compared with non-Aboriginal infants independent of geographical location and was over four times greater and in the metropolitan location over five times greater. There was no significant difference in the risk of  $SIDS^+$  for Aboriginal infants according to geographical location. However, non-Aboriginal infants living in a remote or rural location were at a significantly increased risk of  $SIDS^+$  compared with non-Aboriginal infants in metropolitan locations.

Figure 4.29 CMR attributable to SIDS<sup>+</sup> according to geographical location, 1980-2001 inclusive

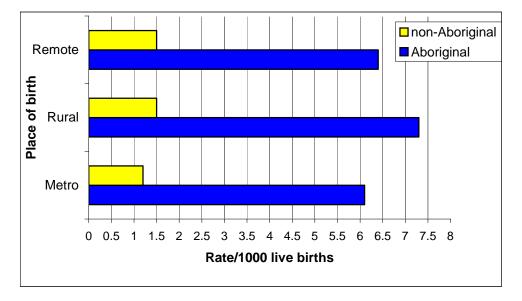
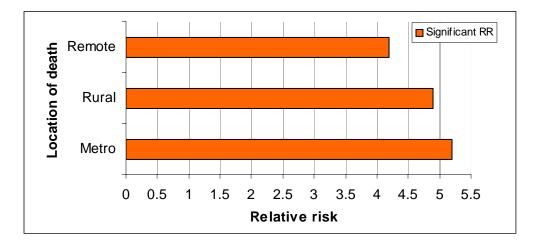


Figure 4.30 RR of SIDS<sup>+</sup> for Aboriginal infants (compared with non-Aboriginal) according to geographical location, birth years 1980-2001 inclusive



## 4.3.5 Co-sleeping

Co-sleeping has been identified as a risk factor associated with SIDS (Fleming 2000). In reviewing the autopsy case reports of deaths occurring between birth years 1998 to 2001 inclusive, information regarding co-sleeping was noted.

In all (n=11) cases where a cause of Aboriginal infant death was given as unascertainable except one – where co-sleeping was not identified- infants were identified as co-sleeping at the time of death. Co-sleeping was identified in 62% (n=8) of non-Aboriginal infant deaths. There were 6 cases where co-sleeping was not stated but would not have been a consideration in the determination of the cause of death.

In cases where the causes of death SIDS and unascertainable were analysed together 38 infants were co-sleeping at the time of death (19 Aboriginal, 19 non-Aboriginal, 27 were not (2 Aboriginal 25 non-Aboriginal) and in 9 cases it was not stated (5 Aboriginal 4 non-Aboriginal).

Information was also gathered in cases where infection was the cause of death and there was a post-mortem co-sleeping was identified in 38 of the cases (10 Aboriginal, non-Aboriginal 3), and no co-sleeping in 5 of the deaths (1 Aboriginal, 4 non-Aboriginal).

Co-sleeping	Unascertainable	$\mathbf{SIDS}^+$	Infection	<b>Birth defects</b>	Other
Yes					
Aboriginal	11	19	10	0	1
Non-Aboriginal	8	19	3	1	1
Sub-Total	19	38	13	1	2
No					
Aboriginal	0	2	1	0	0
Non-Aboriginal	4	25	4	0	4
Sub-Total	4	27	5	0	4
Not stated					
Aboriginal	1	5	0	0	0
Non-Aboriginal	1	4	0	0	0
Sub-Total	2	9	0	0	0
TOTAL	25	74	18	1	6

Table 4.8Cases where there was a post-mortem coroner's case report and<br/>information gathered regarding co-sleeping for the main causes of death, 1998-2002<br/>inclusive

These data must be considered in the context of total population infant mortality data. That is, these data only identify whether the baby was co-sleeping at the time of death. It does not identify whether this was the normal practice or a departure from normal practice, it does not identify how many infants who die from all other causes of death co-slept. As there are no total population data available for the total WA population that describe the number of babies who co-sleep and who do not die, a causal association cannot be assessed between co-sleeping and SIDS. Further, international studies have demonstrated that co-sleeping is only a risk factor for SIDS if the mother is a smoker (Fleming et al. 2003).

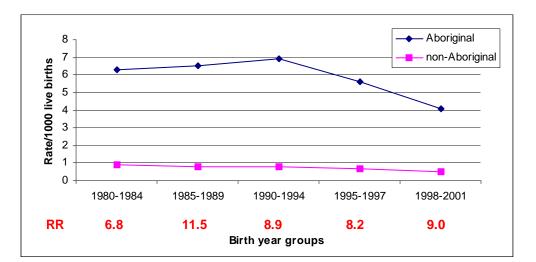
### 4.3.5.1 Summary

- The increasing trend towards "unascertainable" makes trend comparisons of cause of death more difficult.
- Aboriginal infants are more likely than non-Aboriginal to have the cause of death identified as unascertainable.
- When SIDS and unascertainable causes are combined together (SIDS<sup>+</sup>), Aboriginal infants were almost eight times more likely than non-Aboriginal to die from these causes in the 1998-2001 birth years.
- Co-sleeping is not a cause of death and cannot be assessed as a risk factor in these data as total population data on co-sleeping are not available.

### 4.3.6 Infant mortality due to infection

While the rates for deaths due to infection decreased for both Aboriginal and non-Aboriginal infants, the decreases were only significant in non-Aboriginal groups ( $\chi^2$  test for trend 10.1; p<0.01). However, this rate has not fallen as quickly among Aboriginal infants ( $\chi^2$  test for trend 3.2; p=0.08). Thus, the RR remains high and actually increased to a nine-fold difference in 1998-2001 (figure 4.31).

Figure 4.31 CMR due to infection according to Aboriginal status and birth year groups, and RR of infection for Aboriginal infants (compared with non-Aboriginal)



The CMR is higher for Aboriginal infants compared with non-Aboriginal infants independent of the geographical location (figure 4.32). However, the risk of death due to infection for both Aboriginal and non-Aboriginal infants living in remote locations compared with their peers in rural or metropolitan locations is significantly increased. The risk for Aboriginal infants living in remote locations dying as a result of infection is significantly higher than the risk of Aboriginal infants living in metropolitan or rural locations: metro. RR=1.6 (95%CI 1.1, 2.3); rural RR = 1.5 (95% CI 1.0, 2.2). The risk for non-Aboriginal infants living in remote and rural locations dying as a result of infection is significantly higher than the risk of non-Aboriginal infants living in metropolitan locations: remote/metro. RR=1.7 (95%CI 1.2, 2.3); rural/metro RR = 1.3 (95% CI 1.0, 1.7).

Figure 4.32 CMR dying as a result of infection according to Aboriginal status and geographical location, 1980-2001 inclusive

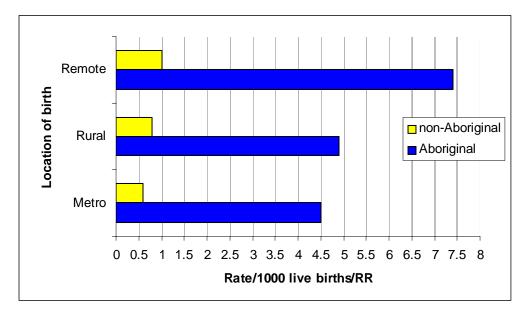
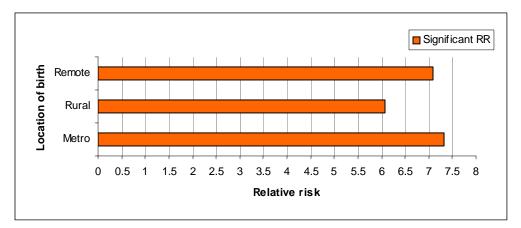


Figure 4.33 The relative risk of an Aboriginal (compared with a non-Aboriginal infant) dying as a result of infection according to geographical location, 1980-2001 inclusive



Over the past 22 years there have been impressive falls in Aboriginal infant deaths due to infection in remote and metropolitan locations. However, in the birth year groups 1998-2001 inclusive Aboriginal infant deaths due to infection increased in rural locations (figure 4.34). Decreases were observed in non-Aboriginal infant deaths due to infection in metropolitan and rural locations, and a slight increase in the birth year group 1998-2001 in remote locations (figure 4.34).

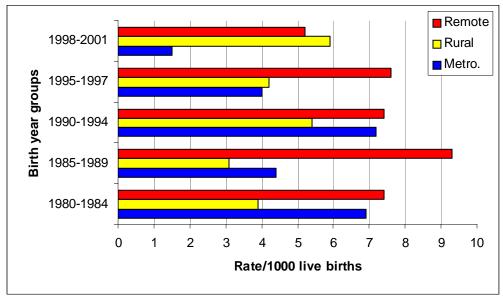
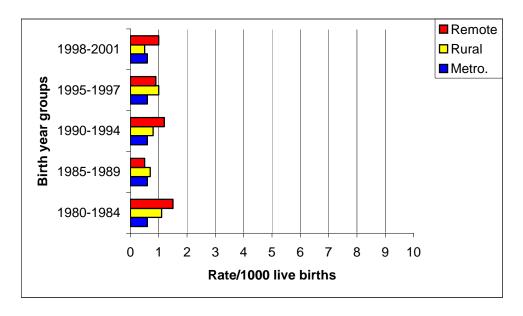
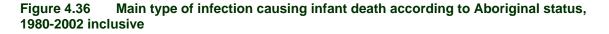


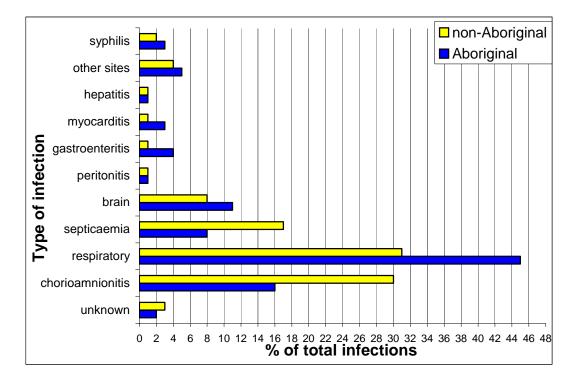
Figure 4.34 CMR due to infection for Aboriginal infants by geographical location and birth year groups





The main causes of deaths due to infection in both Aboriginal and non-Aboriginal infants were respiratory infection followed by chorioamnionitis (infection in the placental membranes). The CMR due to respiratory infection was highest for infants living in remote locations: Aboriginal 3.1/1000 live births; non-Aboriginal (0.5/1000 live births). The CMR due to chorioamnionitis was also highest in remote location for Aboriginal infants (1.2/1000 live births), but was similar in all locations for non-Aboriginal infants (0.2/1000 live births). Note that chorioamnionitis and septicaemia are higher in Aboriginal infants than in non-Aboriginal infants.





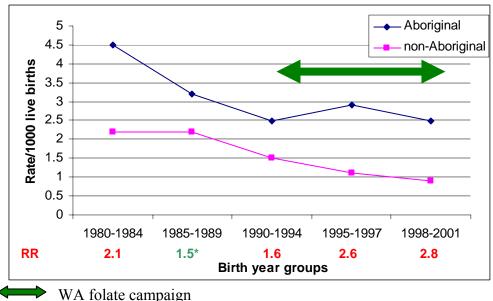
### 4.3.6.1 Summary

- The CMR due to infection has decreased for both Aboriginal and non-Aboriginal infants.
- The risk for Aboriginal infants was nine times higher than for non-Aboriginal infants.
- The risk of death from infection for both Aboriginal and non-Aboriginal infants was significantly increased for those in remote locations compared with rural and metropolitan locations.
- There has been an increase of deaths due to infection for Aboriginal infants in rural locations in 1998-2001 compared with all the other birth years.
- Most infectious deaths were due to respiratory infections followed by chorioamnionitis, septicaemia and meningitis.
- Chorioamnionitis and septicemia were both more prevalent as a cause of death in non-Aboriginal than Aboriginal infants.
- Few deaths were observed from gastro-enteritis, which historically was a major cause of death particularly among Aboriginal infants.
- There were a small number of deaths due to syphilis in both Aboriginal and non-Aboriginal infants.

### 4.3.7 Infant mortality due to birth defects

The rate of mortality due to birth defects has fallen significantly among non-Aboriginal infants ( $\chi^2$  test for trend 78.8; p<0.001). However this pattern has not been observed among Aboriginal infants ( $\chi^2$  test for trend 3.2; p=0.08). The CMR among Aboriginal infants is the same in the most recent birth year groups (1998-2001) as it was in 1990-1994 and, thus, the relative risk of death has increased to nearly three fold. This lack of recent improvement in deaths due to birth defects in Aboriginal infants is of concern because of the proven effectiveness of preconceptional folic acid intake in preventing a significant proportion of neural tube defects (NTDs) such as spina bifida. The WA campaign between 1993 and 1995 aimed at preventing NTDs through periconceptual folic acid supplement use and voluntary fortification of food with folate and is reflected in the non-Aboriginal decrease in birth defects (figure 4.37). However, there is no such decrease observed in the Aboriginal population over the same years. Further, a recent study by Bower et al. identified in 1996-2000 an almost 2-fold prevalence of NTDs in Aboriginal infants compared with non-Aboriginal infants. The paper suggested that although the number of cases of NTDs was small the difference was statistically significant. Figure 4.37 illustrates the significant decrease in the CMR according to birth defects among non-Aboriginal infants since 1985, but no decrease among Aboriginal infants since 1990. Thus, there is a significantly increased relative risk of Aboriginal infants dving due to birth defects compared with non-Aboriginal infants. Between 1990 and 2002, this risk has increased to nearly 3-fold. This pattern suggests that the health promotion messages regarding folate are either not reaching Aboriginal women or not being acted upon. Similarly, the data could also suggest that the intake of folate-fortified food is less among Aboriginal women. This could be due to a lack of access to folatefortified food as well as lack of knowledge of the health benefits.

Figure 4.37 CMR due to birth defects according to Aboriginal status and birth year groups 1980-2001 and RR for Aboriginal infants (compared with non-Aboriginal)



\* non-significant value

The pattern of infant mortality due to birth defects and according to geographical location in figure 4.38 shows that the CMR is highest in remote locations for Aboriginal infants, and in metropolitan locations for non-Aboriginal infants. The risk of Aboriginal death is significantly higher compared to non-Aboriginal infants in remote locations. There is no significant difference in the risk of infant death due to birth defects according to geographical location for Aboriginal (compared with Aboriginal) or non-Aboriginal (compared with non-Aboriginal) infants. However, there is a nearly two-fold (nonsignificant) risk of infant death for Aboriginal infants living in remote location compared with Aboriginal infants living in a metropolitan location: RR = 1.6 (95%CI 1.0, 2.6)

Figure 4.38 CMR due to birth defects according to birth year groups 1980 – 2001 inclusive for Aboriginal and non-Aboriginal infants

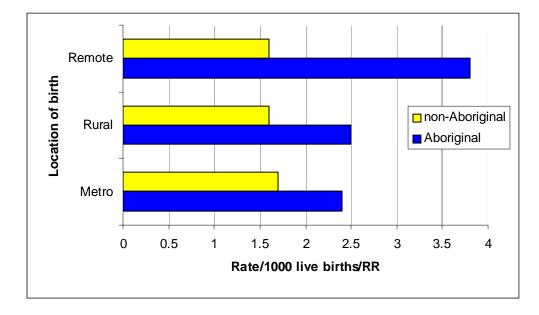
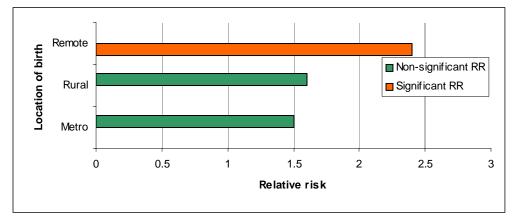


Figure 4.39 RR of death due to birth defects for an Aboriginal infant (compared to a non-Aboriginal) according to birth year groups 1980 – 2001 inclusive



These significantly higher mortality rates of birth defects among Aboriginal infants, particularly in remote locations have a number of possible explanations. Firstly, they could be due to higher prevalence of birth defects among Aboriginal infants. Secondly, the birth defects may be more severe (*i.e.* a higher case fatality rate). Thirdly, Aboriginal infants may have poorer access to clinical services and follow up care. Fourthly, Aboriginal infants born with birth defects may have a number of co-morbidities (eg prematurity, low birthweight) that would compromise their survival under normal circumstances. Finally, all of the above could be contributing to these higher mortality rates due to birth defects among Aboriginal infants. These explanations could all be due to the geographical location of the infant. It is possible to test these hypotheses using the available datasets and research projects are currently being devised to determine the validity of these possible explanations.

### 4.3.7.1 Summary

- Mortality due to birth defects has fallen significantly amongst non-Aboriginal infants but not among Aboriginal infants.
- For birth years 1998-2001, the risk was almost 3 times higher for Aboriginal compared with non-Aboriginal infants.
- Aboriginal infants living in remote locations are significantly more likely to die from birth defects than Aboriginal infants living in metropolitan locations.
- These patterns may be related to differences in the availability and periconceptional intake of folate containing foods between Aboriginal and non-Aboriginal mothers.
- Possible explanations also include differences in access to care particularly in remote locations, and the presence of co-morbidities that compromise the potential for survival of Aboriginal infants born with birth defects.

### 4.4 Maternal smoking during pregnancy

Maternal smoking during pregnancy has been collected on the Midwives' Notification Form since 1997 and thus these data have been analysed for the death years 1998 to 2002 inclusive. As these data are self-reported they are likely to underestimate the true level of smoking. In addition, there is no information on number of cigarettes smoked or nicotine/tar content of the cigarettes (dose-response data). However, the data do provide an indication of the prevalence of maternal smoking and further analysis is possible including case-control studies. In this report, maternal smoking in pregnancy has been briefly investigated, in descriptive analyses, as a risk factor in cause-specific infant mortality.

### 4.4.1 Distribution

Figure 4.40 shows that on average between 1998 and 2002, 51% of Aboriginal women and 20% of non-Aboriginal women smoked during their pregnancy (births). The figure also shows higher percentages of maternal smoking associated with both Aboriginal (60%) and non-Aboriginal (29%) infant deaths.

Figure 4.40 Percentage of total births and deaths according to maternal smoking during pregnancy and Aboriginal status, 1998-2002 inclusive

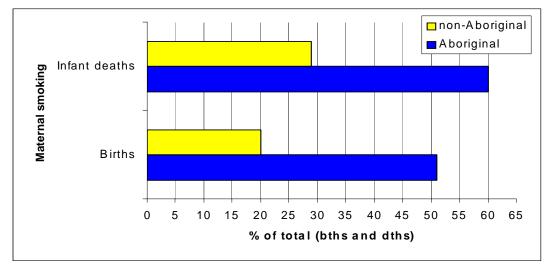
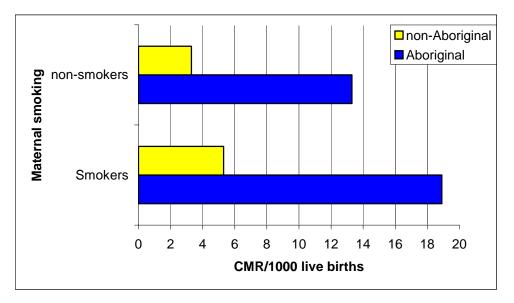


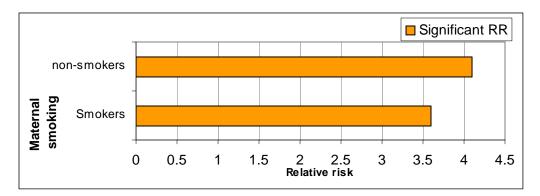
Figure 4.41, the all-cause CMR of Aboriginal infants whose mothers smoked was 18.3/1000 live births and for non-smokers the CMR was 13.2/1000 live births. There was no significant increase in the risk of infant mortality according to maternal smoking among Aboriginal infants (RR=1.4; 95% CI 0.9, 2.1). However the RR was significantly increased for infants of non-Aboriginal mothers who smoked during pregnancy compared with non-Aboriginal mothers who did not smoke (RR=1.6; 95%CI 1.3, 2.1).

# Figure 4.41 CMR according to maternal smoking for all-cause mortality according to Aboriginal status, 1998-2001 inclusive



The risk of infant death of Aboriginal infants compared to non-Aboriginal was significantly higher independent of maternal smoking (Figure 4.42).

# Figure 4.42 RR of all-cause mortality for Aboriginal infants (compared to a non-Aboriginal) according to mother's smoking status in pregnancy 1980 – 2001 inclusive



# 4.4.2 Infant mortality according to maternal smoking/non-smoking during pregnancy

The main causes of infant death according to the smoking status of the mother during pregnancy were analysed separately for smokers and non-smokers according to Aboriginal status and main cause of death. While the CMR was higher for all causes of death among smokers compared to non-smokers (except for birth defects) in both populations, the relative risk of death according to maternal smoking for Aboriginal compared with non-Aboriginal only reached significance for deaths attributable to SIDS. The RR of infant death according to maternal smoking was twice as high among non-Aboriginal infants compared with Aboriginal infants (Table 4.8).

Cause of death	Ab. c.f. Ab.				Non-Ab.c.f. non-Ab.		
Smoking status	CMR	RR	(95%CI)	CMR	RR	(95% CI)	
$\mathbf{SIDS}^+$							
Smoking	6.8	2.6	(1.2, 5.9)	1.9	6.1	(3.6, 10.3)	
Non-smoking	2.6			0.3			
Infection							
Smoking	5.6	2.2	(0.9, 5.0)	0.6	1.4	(0.7, 2.8)	
Non-smoking	2.6			0.4		. ,	
Prematurity							
Smoking	4.3	1.7	(0.7, 4.0)	1.0	1.0	(0.6, 1.7)	
Non-smoking	2.6			0.9		. ,	
<b>Birth Defects</b>							
Smoking	1.6	0.4	(0.2, 1.3)	0.8	0.9	(0.5, 1.5)	
Non-smoking	7.4		/	2.3		· · /	

Table 4.9CMR and RR of cause-specific mortality according to maternal smoking, forAboriginal and non-Aboriginal infants

\* bolded data reflects significant values.

The RR of mortality for Aboriginal infants compared to non-Aboriginal infants was significantly higher independent of mothers' smoking status for all causes of death except for birth defects (smokers) (table 4.9). However, in cases of infant death due to infection and prematurity, the RR (Aboriginal compared to non-Aboriginal) for smokers was higher than the RR for non-smokers. This pattern was reversed for SIDS cases, where the RR was higher in non-smokers. It is important to consider these data as descriptive analyses only. Multivariate analyses would add valuable insight to these data. Further, the numbers of cause-specific deaths are small and as such the results should be interpreted cogniscent of these issues.

Clearly, smoking is a risk factor for infant mortality in both Aboriginal and non-Aboriginal infants. However the difference in the relative risk for Aboriginal and non-Aboriginal infants must be explained by factors other than smoking. These data suggest that there may be more powerful risk factors than smoking to explain the excess infant mortality amongst Aboriginal infants. These could include behavioural factors, poverty and living conditions, including over crowding and poor housing conditions. It should be noted when considering Table 4.9 that these results are exploratory only.

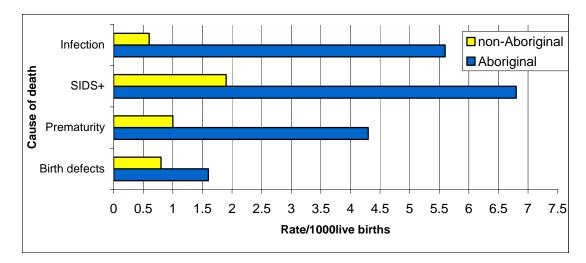
Cause of death Smoking status	Aboriginal N	(%)	Non-Ab N	original (%)	RR Ab. a	(95% CI) c.f. non-Ab.
SIDS <sup>+</sup>						
Smoking	22	(73)	35	(60)	3.7	(2.2, 6.3)
Non-smoking	8	(27)	23	(40)	8.5	(3.8,19.0)
Infection						
Smoking	18	(69)	11	(26)	9.6	(4.5, 20.3)
Non-smoking	8	(31)	31	(74)	6.3	(2.9,13.7)
Prematurity						
Smoking	14	(64)	18	(20)	4.6	(2.3, 9.2)
Non-smoking	8	(36)	71	(80)	2.8	(1.3, 5.72
Birth Defects						
Smoking	5	(31)	15	(17)	2.0	(0.7, 5.4)
Non-smoking	11	(69)	71	(83)	3.8	(2.0,7.1)

Table 4.10The number (%) of Aboriginal and non-Aboriginal infants who died & RR ofAboriginal (compared to non-Aboriginal infants) according to cause of death and maternalsmoking during pregnancy, 1998-2001 inclusive

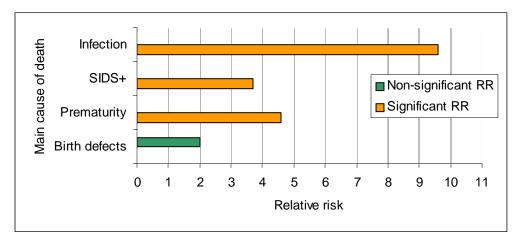
### 4.4.2.1 Maternal smoking and main causes of death

The CMR for Aboriginal infants whose mothers smoked during pregnancy was significantly higher compared with non-Aboriginal infants, for all main causes of death, except for deaths due to birth defects (Figure 4.43 and Figure 4.44). The RR of infant death due to infection was nearly ten times greater for Aboriginal infants compared to non-Aboriginal infants.

Figure 4.43 CMR for infants of mothers who smoked during pregnancy according to the main causes of death, 1980 – 2001 inclusive



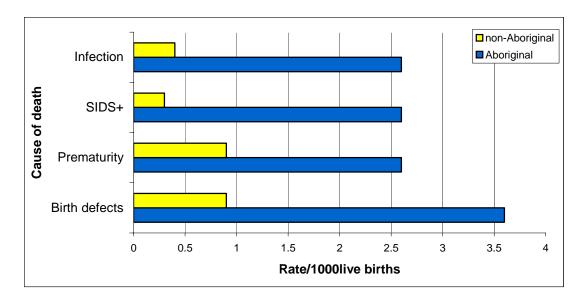


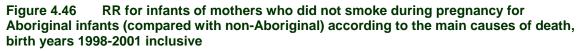


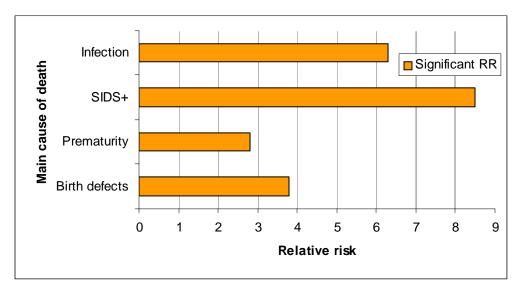
### 4.4.2.2 Maternal non-smoking and main causes of death

The risk of Aboriginal infants dying compared with non-Aboriginal infants whose mother did not smoke during pregnancy was also significantly higher for all main causes of death. The risk of Aboriginal infants dying whose mothers did not smoke as a result of SIDS was over eight times greater compared to non-Aboriginal infants.

# Figure 4.45 CMR for infants of mothers who did not smoke during pregnancy according to the main causes of death, birth years 1998-2001 inclusive







These patterns of mortality by smoking status comparing Aboriginal and non-Aboriginal CMR and relative risks were of considerable interest. For example, the RR of SIDS was much higher (RR=8.5) in non-smokers than in smokers (RR=3.7). Thus factors stronger than smoking must be responsible for the large excess of SIDS in Aboriginal infants. In all other causes of infant death, except birth defects), the RR is higher (or similar) in smokers, suggesting that the very high rates of smoking in Aboriginal women is a major risk factor and further suggests the potential for preventing infant deaths by reducing smoking.

# 4.4.3 Attributable risk: cause specific infant mortality and maternal smoking

While the relative risk used throughout this document is important in suggesting etiological relationships, the attributable risk in many ways is more important in clinical practice and public health. The attributable risk addresses a different question: "how much of the risk (incidence) of disease can we hope to prevent if we are able to limit the exposure (for example smoking) to the population in question - smokers. Therefore, the attributable risk indicates the potential for prevention if the exposure could be limited and if it is truly causal.

This section considers what proportion of cause-specific infant mortality could be attributed to smoking, and (provided that there is a causal association between smoking and the particular cause of death), what proportion of the mortality could be prevented if smoking was eliminated from the population. The population attributable risk calculates what proportion of the cause-specific mortality in the entire population (smokers and non-smokers) can be attributed to smoking. In other words, what would be the total impact of a prevention program on the community? The population attributable risk has been calculated separately for Aboriginal and non-Aboriginal populations.

Table 4.10 shows the proportion of risk attributable to smoking for the main causes of infant death in the Aboriginal and non-Aboriginal populations. Therefore, given a causal association between smoking and the main causes of infant death, if smoking were to be eliminated (and ignoring other risk factors), there is the potential to reduce the mortality rate for the main causes of infant mortality among Aboriginal infants and for deaths attributable to SIDS among non-Aboriginal infants.

	Population attributable risk				
Cause of death	Aboriginal - %	Non-Aboriginal-%			
SIDS+	46	50			
Infection	38	8			
Prematurity	26	0.3			
All causes	18	11			

Table 4.11Population attributable risk according to maternal smoking for the maincauses of infant death

Overall, the interpretation of these data is complex. This section (4.4 Maternal smoking in pregnancy) should be treated with caution, due to the small numbers and possible interactions and effect modification of other variables including behavioural factors, socio-economic status, environmental issues including condition of housing and sleeping arrangements. This current descriptive analysis is not sufficient to describe the causal association between smoking and SIDS, particularly in light of other studies describing SIDS and smoking (Fleming 2000). Case-control or cohort studies using multivariate analysis would be justified using available total population datasets.

The role of smoking in infection-related and other causes of death is less clear and would also benefit from case-control studies that will measure outcomes in the total population and not just among those mothers who smoke and who do not smoke, and whose babies die. Thus, funding of a large and well designed cohort or case-control study undertaken by a team of experienced researchers to determine the true association between maternal smoking and poor infant outcome is recommended.

### 4.4.3.1 Summary

- For the birth years from 1998-2001, 51% of Aboriginal women and 20% of non-Aboriginal women smoked in pregnancy.
- Unlike Aboriginal infants, for non-Aboriginal infants those mothers who smoked during pregnancy, the risk of death was significantly higher.
- Except for birth defects, the risk of death for all causes of death was higher for Aboriginal infants whose mothers smoked than for non-Aboriginal infants whose mothers smoked.
- For non-smoking mothers, the risk of death was higher for Aboriginal than non-Aboriginal infants in all categories of causes of death.
- The percentage of Aboriginal mothers who smoked during pregnancy and whose infants died was significantly higher compared to non-Aboriginal mothers for all main causes of death with the exception of SIDS.
- Assuming that smoking is a causal risk factor, the percentage of infants whose deaths were attributed to SIDS and whose mothers smoked during pregnancy was similar for Aboriginal and non-Aboriginal infants (about 50%); *i.e.* if all mothers ceased smoking during pregnancy the risk of SIDS could potentially be reduced in both Aboriginal (48%) and non-Aboriginal (50%) populations.
- If all mothers ceased smoking during pregnancy the risk of deaths due to infection and prematurity could potentially be reduced in Aboriginal populations by 38% and 26% respectively.
- There has been a decline in infant mortality since 1980 for WA born infants. However, the decline has been slower among Aboriginal infants.
- The risk of an Aboriginal infant dying compared to the risk of a non-Aboriginal infant has increased over the past 22 years and is now over four times higher.
- The CMR in the postneonatal period for Aboriginal infants is higher than the CMR in the neonatal period. This mortality profile is the opposite for non-Aboriginal infants. The former profile is seen in developing countries and other disadvantaged populations including American Indians and many of the First Nations People in Canada.
- The main causes of infant death are infection, SIDS, birth defects and prematurity. However, the picture differs in the two populations. Infection and SIDS are the main causes of infant mortality for Aboriginal infants, these causes of death are potentially preventable. Birth defects and prematurity are the main causes of non-Aboriginal infant death (which are less preventable in the current state of knowledge).

- The infant mortality rate is higher in rural and remote locations.
- The risk of an Aboriginal child dying due to infection is significantly higher compared with non-Aboriginal infants and also compared to Aboriginal infants living in rural or metropolitan locations.
- The risk of an Aboriginal infant dying due to birth defects compared to non-Aboriginal infants is significantly higher in remote locations and nearly twice the risk of an Aboriginal infant living in a metropolitan location.
- The rate of SIDS has fallen significantly among non-Aboriginal infants. The rate has not fallen as quickly among Aboriginal infants and the risk of SIDS has increased. In birth years 1998-2001, the risk was nearly eight times the risk of non-Aboriginal infants.
- Reduction of smoking has the potential to further reduce infant mortality rates in the next 5 years.
- Cohort or case-control studies would further clarify the role of maternal smoking in infant outcome.
- There has been an increase in the number of deaths where the cause of death has been "unascertainable" in the years 1998-2002.

### Chapter 5 Patterns and Trends of Childhood Mortality, 1981-2002

### 5.1 Introduction

This section will present the patterns and trends of mortality among Western Australian children born between 1980 and 2001 inclusive. It will include all-cause childhood deaths. Cause-specific mortality over all years and for combined ages will be shown. In addition, trends in age-specific mortality by grouped year of birth and sex will be presented.

The denominator used in the descriptive analyses for Aboriginal childhood mortality was 29632 infant survivors, and for non-Indigenous childhood mortality, 501577 infant survivors. Childhood mortality will be described as the cumulative mortality risk (CMR) and was calculated per 1,000 infant survivors for the birth years 1980 to 2001 inclusive and for birth year groups 1980 to 1984, 1985 to 1989, 1990 to1994, 1995 to 1997 and 1998 to 2001. Relative rates (RR) and 95% confidence intervals (CI) were calculated to determine the significance of the difference of the rate of death for Indigenous children relative to the rate for non-Indigenous children.

In some categories of childhood mortality, particularly when describing trends in cause– specific childhood mortality, there were small numbers. In these instances interpretation of the data is difficult.

Age-specific mortality rates for children who died after their first birthday and before reaching their 23<sup>rd</sup> birthday were expressed as per 10,000 person years. The age groups for analysis were calculated according to school ages:

- Pre-primary, 1-<5 years
- Primary, 5-<13 years
- High school, 13-<17 years
- Post-school, 17-<23 years

The category of cause of death defined as 'other' causes included intrapartum (one case of death due to chronic respiratory causes that arose in the perinatal period and was associated with oligohydramnios), SIDS (20 cases confirmed by the coroner at autopsy), and unknown or unascertainable deaths (7 non-Aboriginal between 1980 and 1997; 2 Aboriginal and 11 non-Aboriginal between 1998 and 2002).

The format of this chapter is as follows:

Trends in Childhood mortality since 1981

- All-cause childhood mortality
  - Place of death in /out of hospital
    - Due to infection
  - Geographical location
- Age-specific mortality:
  - According to sex
- Cause specific childhood mortality
  - Main causes of death
  - Age specific mortality
    - Due to infection
    - Accident and injury
- Road Traffic Accidents, 1998-2002 inclusive
  - Motor vehicle accidents
    - Passenger/driver
- Deaths resulting from suicide
  - Alcohol and illicit drugs

### 5.2 All-Cause Childhood Mortality, Patterns And Trends

### 5.2.1 Overview

Childhood deaths represented a similar percentage of total deaths (29%) from birth (excluding still births) up to the age of 23 years for both Aboriginal and non-Aboriginal populations, for birth years 1980 to 2001 inclusive (29%). However, 17% of all childhood deaths of WA born children were Aboriginal, but only 6% of total WA births.

The CMR of Aboriginal children was 8.8/1000 infant survivors compared with 2.5/1000 for non-Aboriginal children. The average relative risk over the past 23 years of Aboriginal childhood deaths was nearly four times that of non-Aboriginal children: RR = 3.5 (95%CI 3.0, 4.0).

Sixty-one percent of Aboriginal deaths occurred in children born in remote locations, 18% in rural and 21% in metropolitan. The distribution of Aboriginal births over this period according to geographical location was 46% remote, 24% rural and 29% metropolitan locations. The pattern differed for non-Aboriginal children: deaths of children born in remote locations was 10%, rural 25% and metropolitan 65% which also differed from the distribution of births: remote 9%, rural 19% and metropolitan 72%. These patterns suggest a larger percentage of deaths occurring in remote (Aboriginal) and rural (non-Aboriginal) children compared with their relative distribution of births.

A major influence on childhood deaths was teenage motherhood. Sixty-eight percent of deaths occurred in Aboriginal children whose mothers were less than 20 years old at the time of their child's birth compared with 29% of births occurring among mothers less than 20 years. This pattern was also observed among non-Aboriginal children with 35% of childhood deaths and only 5% of births occurring amongst teenage mothers. These results illustrate the ongoing disadvantage experienced by the infants and children of teenage mothers, whether Aboriginal or not.

### 5.2.2 Place of death – in/out of hospital

The percentage of deaths occurring in and out of hospital was the same for Aboriginal and non-Aboriginal children: 39% in hospital; 61% out of hospital.

Figure 5.1 shows the percentage of all childhood deaths that occurred in hospital by ageand Aboriginal status. There were similar percentages of children dying in hospital in the pre-primary and primary school age groups. The percentage of deaths occurring in hospital (compared with out of hospital) of Aboriginal children decreased from 48% in the pre-primary years to 9% in the post school age group. While there was a similar decreasing trend for non-Aboriginal children, the percentage of deaths occurring in hospital (compared with out of hospital) in the high school years (34%) and post school years (20%) was higher. These percentages probably reflect the causes of death in the specific age categories given that most causes of death in the older Aboriginal children were most likely to be out of hospital *i.e.* due to accident and injury. For non-Aboriginal children, while the main cause of death was also accident and injury, there were also greater percentages of deaths due to birth defects and cancers which would be more likely to occur in hospital (figure 5.1).



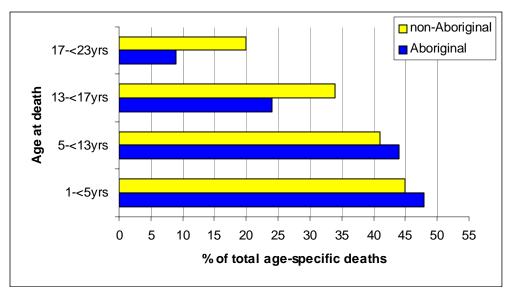


Figure 5.2 shows the percentage of total childhood deaths (for all ages from 1 year to 23 years) in each area of birth by place of death (% of deaths occurring in or out of hospital) for Aboriginal and non-Aboriginal children. In each geographical area, similar percentages of Aboriginal and non-Aboriginal children die in and out of hospital. For example, for children born in remote locations, 61% of Aboriginal children and 66% of non-Aboriginal die out of hospital, while 39% of Aboriginal and 34% of non-Aboriginal children die in hospital.

# Figure 5.2 Percentage of all childhood deaths in each geographical location occurring in and out of hospital, 1981-2002 inclusive by Aboriginal status

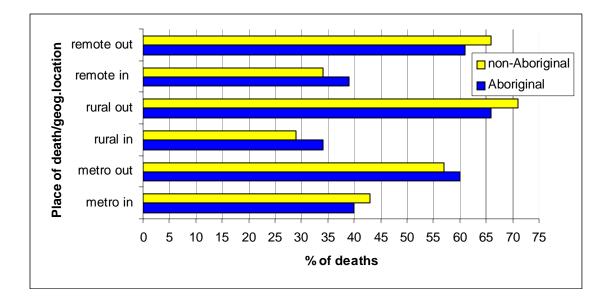


Figure 5.3 shows the percentage of childhood deaths occurring in and out of hospital for each geographical location of birth according to Aboriginal status. Of Aboriginal children dying in hospital, 19% were among Aboriginal children born in metropolitan locations, 15% in rural locations and 67% in remote locations. This compared with the pattern for non-Aboriginal children: 72% in metropolitan locations, 19% in rural locations. Similar percentages to these were observed for out of hospital deaths for Aboriginal children. Similar percentages in and out of hospital were only observed for non-Aboriginal children born in remote locations: 9% in hospital, 10% out of hospital. Generally, the percentages reflect the distribution of the population in the different geographical regions.

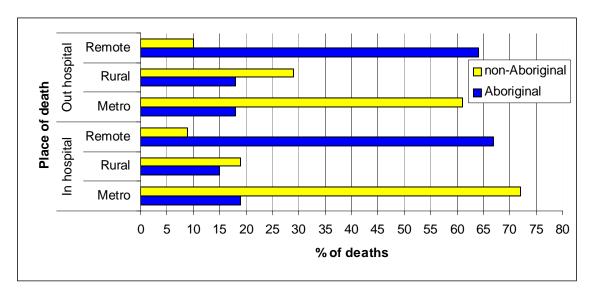
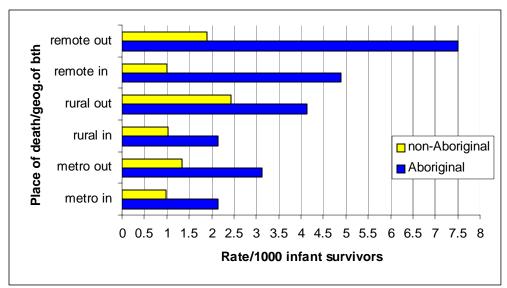


Figure 5.3 Percentage of childhood deaths occurring in and out of hospital in each geographical location, 1981-2002 inclusive

The risk of Aboriginal children dying in the first 23 years of life was significantly higher compared with non-Aboriginal children independent of where they were born or whether they died in or out of hospital. The CMR was highest in children who died out of hospital and were born in a rural or remote location (figure 5.4).

The geographical location of the residence at time of birth of Aboriginal children did not affect their risk of dying out of hospital. However, among Aboriginal children who died in hospital, those born in remote locations were significantly more likely to die compared with Aboriginal children born in rural or metropolitan locations: remote *c.f.* metro. RR=2.3 (95%CI 1.4, 3.8); remote *c.f.* rural, RR=3.3 (95%CI 1.3, 4.0). Conversely, there was no significant difference among non-Aboriginal children who died in hospital according to where they were born. However, the risk of death out of hospital of non-Aboriginal children born in remote and rural locations was significantly higher compared with non-Aboriginal children born in metropolitan locations: remote *c.f.* metro, RR = 1.4 (%% CI 1.1, 1.8); rural *c.f.* metro, RR- 1.8 (95%CI 1.6, 2.1).

Figure 5.4 CMR according to Aboriginal status, place of death and geographical location of birth, 1981-2002 inclusive



Aboriginal children who died in hospital as a result of infection had significantly higher rates of death than non-Aboriginal children, irrespective of where they were born. There was no significant difference in the CMR for Aboriginal compared with non-Aboriginal children born in metropolitan or rural locations who died out of hospital as a result of infection. Overall, there were higher rates of mortality due to infection for Aboriginal children compared to non-Aboriginal children, as would be expected. These rates were particularly so for Aboriginal children born in remote locations dying in hospital: RR = 6.8 (95% CI 3.2, 14.3) and outside of hospital; RR = 5.1 (95% CI 1.9, 14.1). For those dying outside of hospital the RR was not so striking and for non-Aboriginal children born in remote locations. Figure 5.5 also shows that the CMR due to infection among Aboriginal children is higher for deaths occurring in hospital compared with out of hospital.

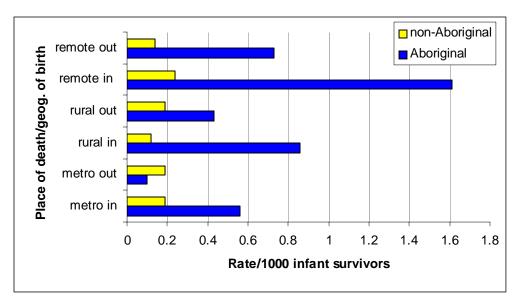


Figure 5.5 CMR for children due to infection according to Aboriginal status, place of death and geographical location of birth, 1981-2002 inclusive

As this is a birth cohort, the data describe rates of death according to the location of the child's birth. Explanations could include Aboriginal children in hospital have more severe infections and thus are at greater risk of death compared with non-Aboriginal children. Aboriginal children dying out of hospital may be due to the type of infection *e.g.* meningococcal infections, which are associated with a rapid deterioration. However, to explain why these patterns occur would need more information and further analyses including other explanatory variables.

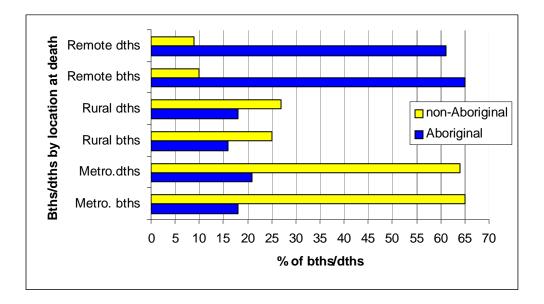
### 5.2.2.1 Summary

- Generally, the geographical location of death and whether the children died in or out of hospital reflect the distribution of the Aboriginal and non-Aboriginal populations and/or the causes of death.
- With regards to dying in hospital, Aboriginal children born in remote locations were significantly more likely to die than Aboriginal children born in rural or metropolitan locations.
- No significant differences in the RR were observed among non-Aboriginal children dying in hospital according to geographical location.
- With regards to dying out of hospital, non-Aboriginal children born in remote or rural locations were significantly more likely to die compared with their peers born in metropolitan locations.
- The data describing children dying from infection are complex and require further analysis, particularly as the rate of death for Aboriginal children born in the metropolitan area and dying out of hospital is less than that for their non-Aboriginal peers.
- Qualitative research would significantly help to interpret these data.

### 5.2.3 Geographical location of death

The distribution of births by geographical location of the residence of the mother at the time of death is similar to the distribution of deaths by geographical location of the residence of the child at the time of deaths for both populations (figure 5.6). For Aboriginal children, the highest percentage of births (65%) and deaths (61%) occur in remote locations and lowest in rural locations (births 16%; deaths 18%). However, for non-Aboriginal children the highest percentage of births (65%) and deaths (64%) occur in metropolitan locations and lowest in remote locations (births 10%; deaths 9%).

# Figure 5.6 Distribution of births and deaths in childhood according to geographical location and Aboriginal status, 1981-2002 inclusive



The highest CMR for Aboriginal children was observed among children born in remote locations and for non-Aboriginal children among those born in rural locations (Figure 5.7). The risk of an Aboriginal child dying compared with a non-Aboriginal child was significantly higher independent of geographical location of birth and was highest in remote locations (figure 5.8).



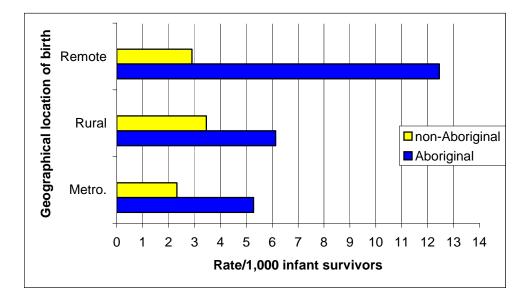
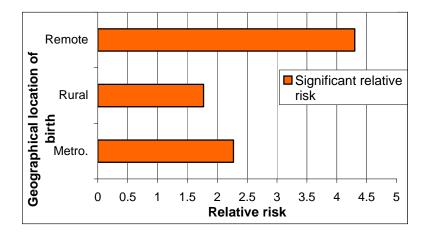
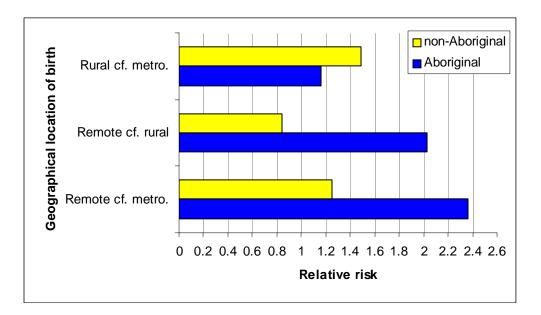


Figure 5.8 RR of Aboriginal (compared with non-Aboriginal) children, according to geographical location of birth 1981-2002



Aboriginal children born in remote locations were significantly more likely to die than Aboriginal children born in rural or metropolitan locations (figure 5.9). Non-Aboriginal children in rural and remote locations were more likely to die than those in metropolitan locations (figure 5.9).





### 5.2.3.1 Summary

- Aboriginal children were significantly more likely to die than non-Aboriginal, independent of geographical location of birth.
- The relative risk of childhood death (Aboriginal compared to non-Aboriginal children) was highest in remote locations.
- Aboriginal children born in remote locations were significantly more likely to die than Aboriginal children born in rural or metropolitan locations.
- Among non-Aboriginal children, those born in rural or remote locations were at a significantly increased risk compared to those born in metropolitan locations.
- Overall, children born in metropolitan locations were at the lowest risk of childhood death.
- Possible explanations for the higher rate of death observed in rural and remote locations could include more children in these areas experiencing illness and/or experiencing more severe illnesses and/or less access to care due to distance and availability.

### 5.2.4 Age-specific all-cause mortality

The figures in this section indicate that the mortality rate of pre-primary aged children has fallen between 1980 and 2001 in both populations.

The CMR has fallen in the pre-primary school aged groups in both populations, and it has fallen more in Aboriginal than non-Aboriginal children with the RR falling from over 4-fold to 3-fold in the most recent years studied (Figure 5.10).

Figure 5.10 Mortality rates for children aged 1 to 4 years dying according to birth year groups

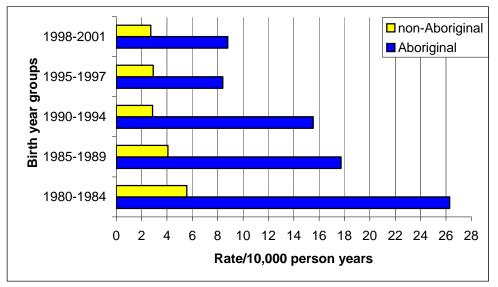
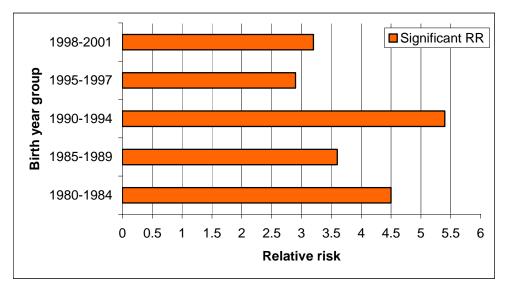


Figure 5.11 The risk of Aboriginal (compared with non-Aboriginal) children aged 1 to 4 years dying by birth year groups



In the primary school age groups (5-12 years) the CMR for Aboriginal children did not improve from 1995-2001 whereas it did decrease in the non-Aboriginal children (figure 5.12). Thus, the RR showed little improvement, and in fact increased from over 2-fold in 1985-1989 to over 3-fold in the most recent years studied (figure 5.12).

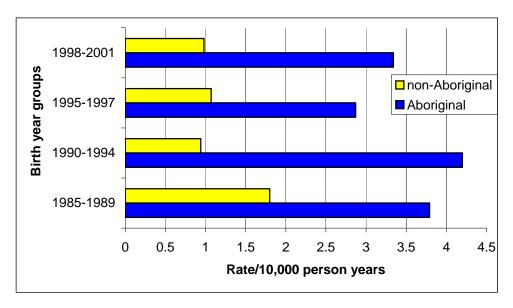
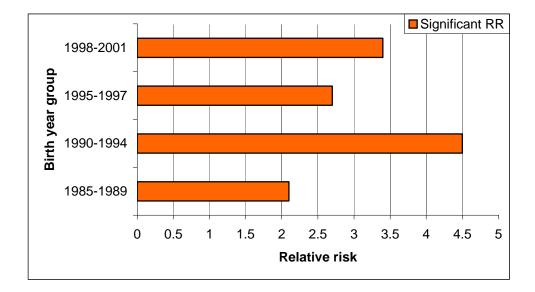


Figure 5.12 Age-specific mortality rate for children aged between 5 and 12 years according to birth year groups

Figure 5.13 The risk of Aboriginal children (compared with non-Aboriginal children) aged between 5 and 12 years, dying according to birth year groups



In high school aged children, there was an increase in the CMR for Aboriginal and a decrease in mortality for non-Aboriginal children (Figure 5.14). Consequently, the RR has risen from one to four-fold over the past seven years (Figure 5.14).

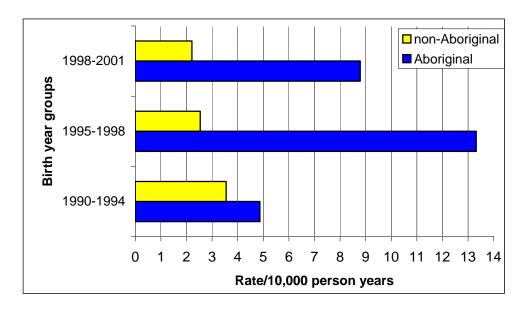
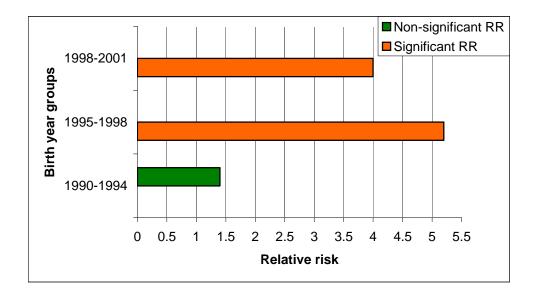


Figure 5.14 Age-specific mortality rate for children aged 13 to 16 years dying, according to birth year groups

Figure 5.15 The risk of an Aboriginal child (compared with a non-Aboriginal child) aged 13-16 years dying according to birth year groups



In the most recent years studied, the CMR is the highest for children aged between 17 and 23 years: Aboriginal 20/10,000 person years; non-Aboriginal 6/10,000 person years (figure 5.16). There was a marked increase in Aboriginal mortality rates in the recent years studied. However, the number of Aboriginal deaths in the 1995-1998 was very small (<5 deaths). The RR of mortality is over three-fold in this age group for Aboriginal children (Figure 5.17).

Figure 5.16 Age-specific mortality rate for children aged between 17 and 23 years dying according to birth year groups

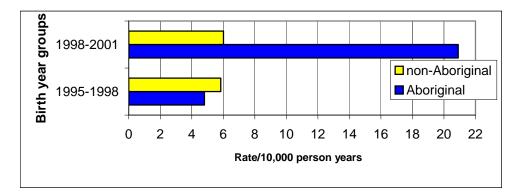
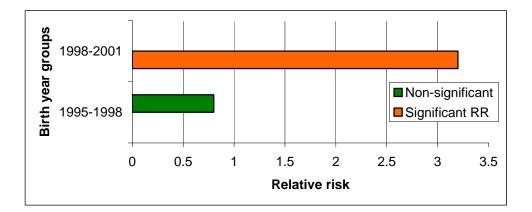


Figure 5.17 The risk of an Aboriginal child (compared with a non-Aboriginal child) aged between 17 and 23 years dying according to birth year groups



### 5.2.4.1 Summary

- Mortality rates have fallen for both Aboriginal and non-Aboriginal children in the youngest age groups studied.
- While there was still disparity between Aboriginal and non-Aboriginal, mortality rates have fallen in both groups in children less than 17 years.
- Mortality rates have increased for young Aboriginal people aged 17 to 23 years.
- These rates are higher than for all other age groups investigated (apart from infancy).

### 5.2.5 Childhood mortality for males and females

The percentage of males and females born between 1980 and 2001 inclusive was similar for both populations: males 51%, females 49%. However, the percentage of males dying in childhood was higher: 57% Aboriginal and 62% non-Aboriginal than the percentage of male births respectively. Aboriginal female deaths were higher than the percentage of female births (43%), but the percentage of non-Aboriginal female deaths was less than that of births (38%). This pattern is illustrated in figure 5.18, which shows that the excess in the percentage of male deaths was particularly obvious in the 5-13 and 17-23 years for Aboriginal children and obvious across all non-Aboriginal age groups.

Figure 5.18 Percentage of total age-specific deaths for Aboriginal children according sex, 1981 – 2002

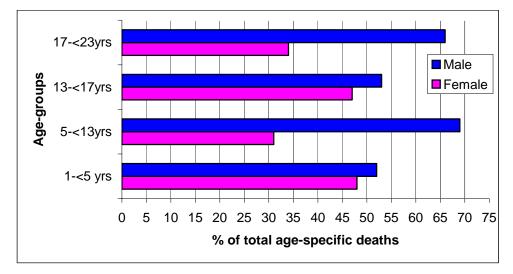
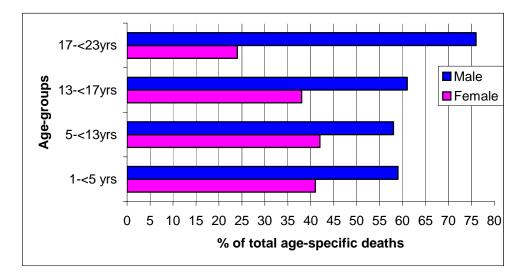


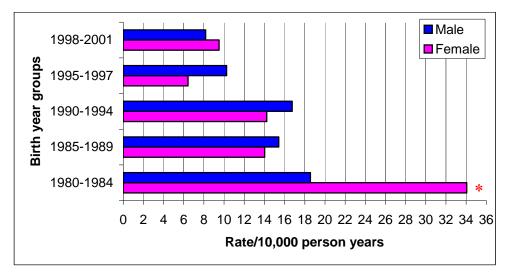
Figure 5.19 Percentage of total age-specific deaths for non-Aboriginal children according sex, 1981 – 2002



The following figures show the patterns and trends of all age-specific cause childhood mortality in males and females for both populations and identifies the risk of Aboriginal children compared with non-Aboriginal children.

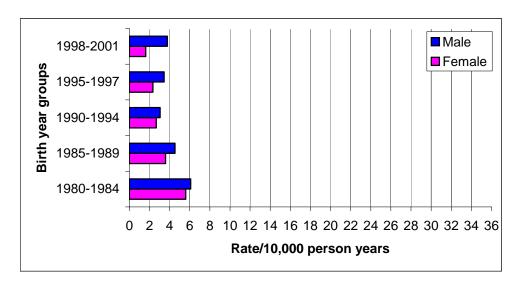
The CMR has fallen in both populations for both males and females in the pre-primary age groups since 1980. The increase observed among Aboriginal females and non-Aboriginal males in the 1998 to 2002 birth years group compared with the previous birth year group was not significant (figure 5.20).

Figure 5.20 Age-specific all-cause CMR for Aboriginal male and female children aged between 1 year and less than 5 years, 1980-2001 inclusive



\* excess number of female deaths

Figure 5.21 Age-specific all-cause CMR for non-Aboriginal male and female children aged between 1 year and less than 5 years, 1980-2001 inclusive



The risk of Aboriginal female children dying compared with non-Aboriginal female children was nearly six-fold in the recent birth year groups. This was similar to the risk in the 1980 to 1984 birth year group. This risk for Aboriginal males compared with non-Aboriginal males has decreased since the birth year groups 1985-1989.

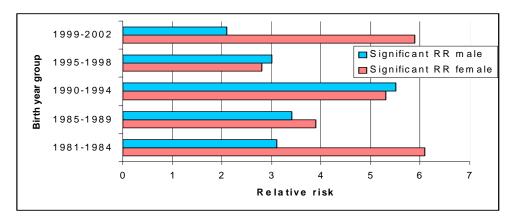


Figure 5.22 Risk of Aboriginal male and female children dying (compared with non-Aboriginal) aged between 1 year and less than 5 years, 1981-2002 inclusive

While the CMR has decreased overall, there was no significant change in the mortality rate among primary school aged male and female children either Aboriginal or non-Aboriginal.

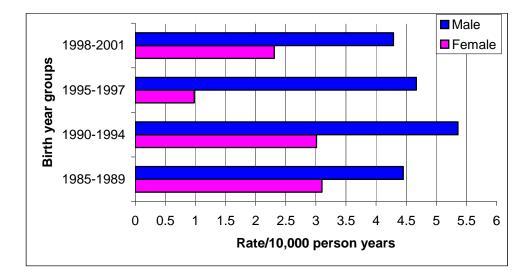
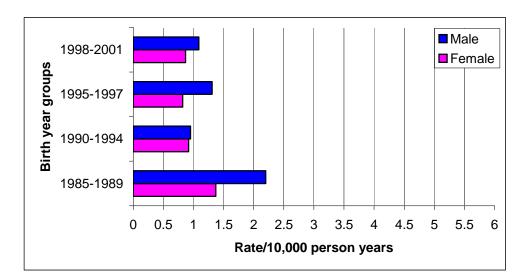


Figure 5.23 Age-specific all-cause CMR for Aboriginal male and female children aged between 6 years and less than 13 years, 1980-2001 inclusive

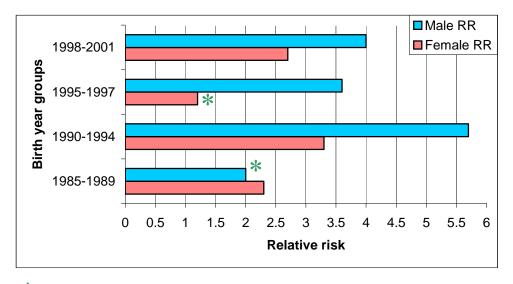
Figure 5.24 Age-specific all-cause CMR for non-Aboriginal male and female children aged between 6 years and less than 13 years, 1980-2001 inclusive



The number of deaths in this age group are small, hence the mortality rates are relatively low in comparison to other age groups.

The risk of death in primary school aged children was significantly higher for Aboriginal children compared with non-Aboriginal for both males and females in all grouped years. These relative risks increased over time for males, but not for females.

# Figure 5.25 Risk of Aboriginal male and female children dying (compared with non-Aboriginal) aged between 6 year and less than 13 years, 1981-2002 inclusive



\*non-significant values

There has been a significant decrease in the CMR for Aboriginal males in the high school years, but remained the same among non-Aboriginal males since birth years 1995 to 1998. The rate has decreased, but not significantly among Aboriginal and non-Aboriginal females.

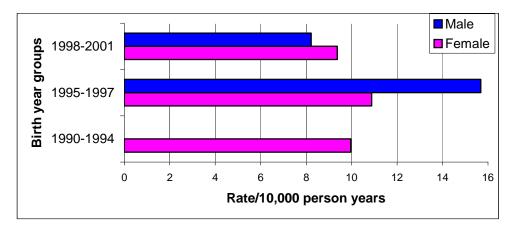
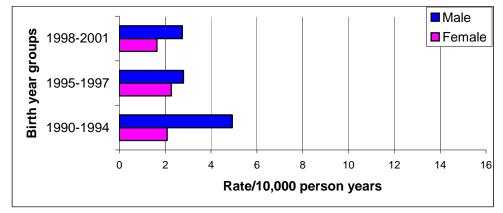


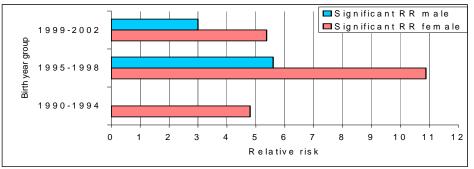
Figure 5.26 Age-specific all-cause CMR for Aboriginal male and female children aged between 13 years and less than 17 years, 1980-2001 inclusive

Figure 5.27 Age-specific all-cause CMR for non-Aboriginal male and female children aged between 13 years and less than 17 years, 1980-2001 inclusive



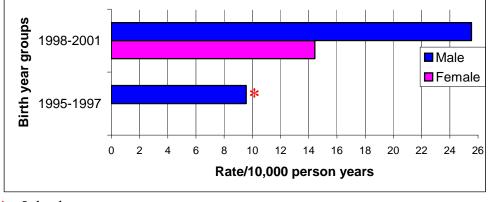
The RR for Aboriginal males and females compared with their non-Aboriginal peers has decreased since birth years 1995 to 1998.

Figure 5.28 Risk of Aboriginal male and female children dying (compared with non-Aboriginal) aged between13 years and less than 17 years, 1981-2002 inclusive



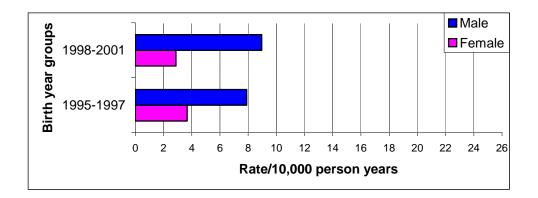
The CMR has increased among Aboriginal and non-Aboriginal males since birth years 1995 to 1998 (not significantly). The CMR has decreased among non-Aboriginal females in this time period. There were no Aboriginal female deaths in 1995 to 1998 in this age group.





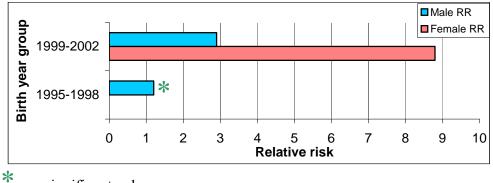
\* <5 deaths





The risk of an Aboriginal female dying among post-school age young people was five times higher compared with non-Aboriginal females and nearly three times higher for Aboriginal males compared with non-Aboriginal males in this age group.

# Figure 5.31 Risk of Aboriginal male and female children dying (compared with non-Aboriginal) aged between 17 years and less than 23 years, 1981-2002 inclusive



<sup>\*</sup>non-significant value

Note: there were no Aboriginal female deaths in 1995-1998.

#### 5.2.5.1 Summary

- For all age groups studied for both populations, males were at higher risk of death than females (except for 13-17 year olds Aboriginal females in the most recent years).
- Generally, this pattern was similar to that found in infant deaths.
- In the first 23 years of life, Aboriginal males were significantly more likely to die than non-Aboriginal males, and Aboriginal females significantly more likely to die compared with non-Aboriginal females.
- Overall, mortality rates have fallen for both male and female children in both populations up to the age of 16 years.
- For both Aboriginal and non-Aboriginal males aged 17-23 years, the mortality rates have increased since 1995-1997.
- Although the rates of death are generally higher in males, the relative differences between Aboriginal and non-Aboriginal children are greater in females than males.
- For high school years and beyond, although the male mortality rate is higher than the female mortality rate in both populations, the RR for Aboriginal compared to non-Aboriginal children was significantly higher for females than males.

### 5.3 Cause-Specific Mortality – Patterns and Trends

Deaths due to accident and injury were responsible for the highest CMRs between the years 1980 to 2001 inclusive. The CMR of these deaths was highest in remote locations for Aboriginal children and in rural locations for non-Aboriginal children. The CMR was highest in remote locations for the main causes of death among Aboriginal childhood and generally higher in rural locations for non-Aboriginal children with the exception of deaths due to infection, which were higher in remote locations (table 5.1).

# Table 5.1CMR according to main causes of death and place of birth for Aboriginal and non-Aboriginal children aged between 1year and 23 years, 1980-2001 inclusive

Cause of death	Aboriginal CMR*					Non-Aboriginal CMR*						
	Metro.		Rural		Remote		Metro.		Rural		Remote	
	CMR	<b>(n)</b>	CMR	<b>(n)</b>	CMR	<b>(n)</b>	CMR	<b>(n)</b>	CMR	<b>(n)</b>	CMR	<b>(n)</b>
Accident/injury	33.7	(30)	35.6	(26)	76.9	(105)	11.8	(420)	22.2	(207)	17.1	(72)
Infection	7.3	(10)	12.8	(9)	20.5	(28)	2.5	(90)	4.0	(37)	3.8	(16)
Birth defects	3.4	(3)	2.9	(2)	8.8	(12)	2.2	(85)	2.2	(15)	1.7	(8)
Cancer	4.5	(4)	2.9	(2)	5.1	(7)	3.5	(125)	4.4	(41)	2.6	(11)

\*per 10,000 infant survivors

Note the small number of deaths on some groups.

#### 5.3.1 Age-specific, cause-specific mortality

The main causes of death in childhood between the ages of one year and 23 years, are identified in figure 5.32. The main cause of childhood death was accident and injury for both populations. Infection was the second main cause of death for Aboriginal children in the first 23 years of life and for non-Aboriginal children, cancer and leukaemia.

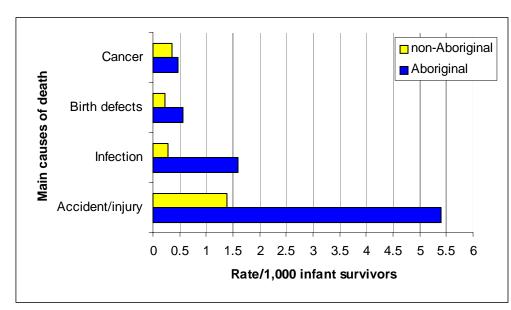
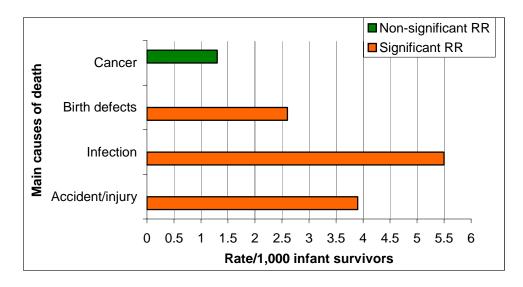


Figure 5.32 Identifies the main causes of childhood death over all age groups, 1980-2001 inclusive

#### Figure 5.33 Risk of childhood death for Aboriginal children (compared with non-Aboriginal) over all age groups for the main causes of childhood death, 1980-2001 inclusive



The main cause of death in childhood (accident and injury) was the same in all age groups, although the CMR of each of the main causes differed according to the different age groups. The following figures present the mortality rates for the main causes of death according to Aboriginal status and the risk of death for Aboriginal children (compared with non-Aboriginal) in each of the age groups.



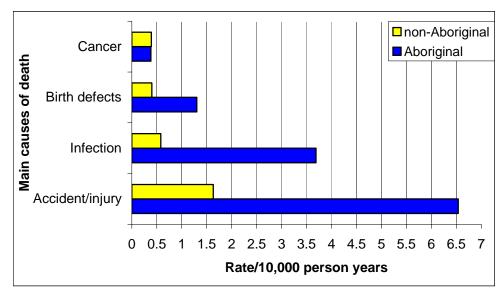


Figure 5.35 Risk of childhood death for Aboriginal children (compared with non-Aboriginal) aged between 1 year and 5 years for the main causes of childhood death, 1980-2001 inclusive

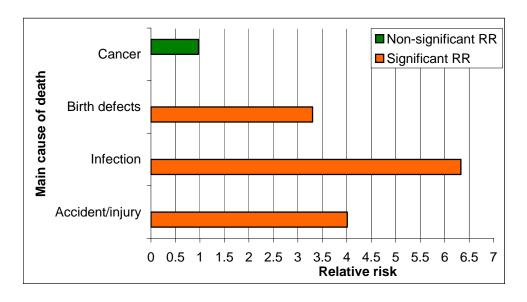


Figure 5.36 CMR for the main causes of death for children aged between 5 years and 13 years according to Aboriginal status, 1980-2001 inclusive

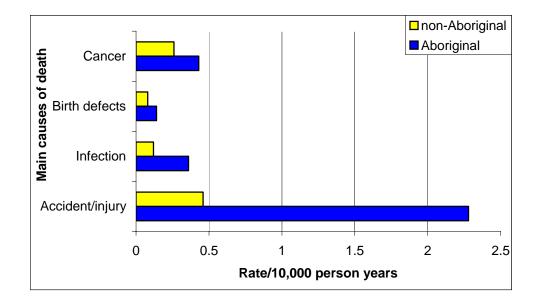


Figure 5.37 Risk of childhood death for Aboriginal children (compared with non-Aboriginal) aged between 5 years and 13 years for the main causes of childhood death, 1980-2001 inclusive

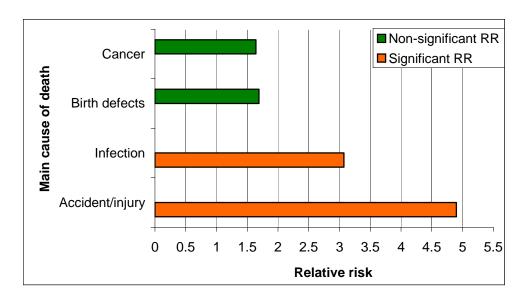


Figure 5.38 CMR for the main causes of death for children aged between 13 years and 17 years according to Aboriginal status, 1980-2001 inclusive

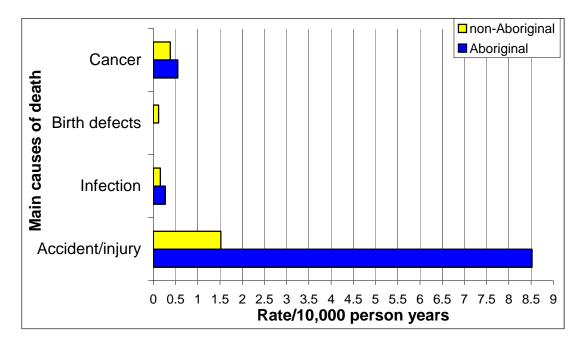


Figure 5.39 Risk of childhood death for Aboriginal children (compared with non-Aboriginal) aged between 13 years and 17 years for the main causes of childhood death, 1981-2002 inclusive

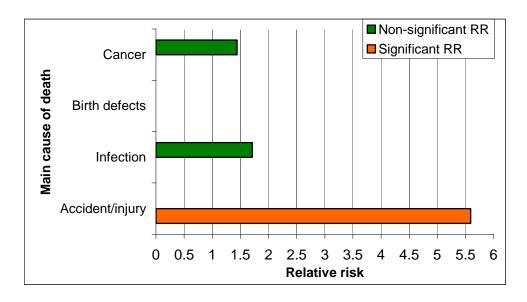


Figure 5.40 CMR for the main causes of death for children aged between 17 years and 23 years according to Aboriginal status, 1981-2002 inclusive

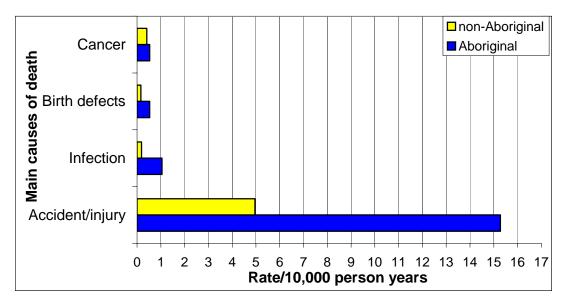
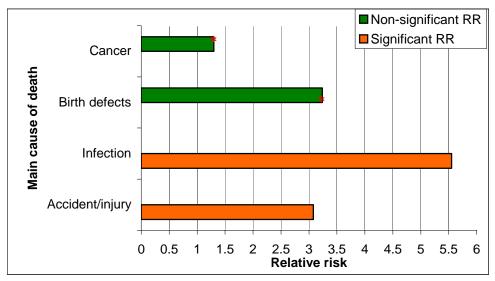


Figure 5.41 Risk of childhood death for Aboriginal children (compared with non-Aboriginal) aged between 17 years and 23 years for the main causes of childhood death, 1981-2002 inclusive



\* small numbers

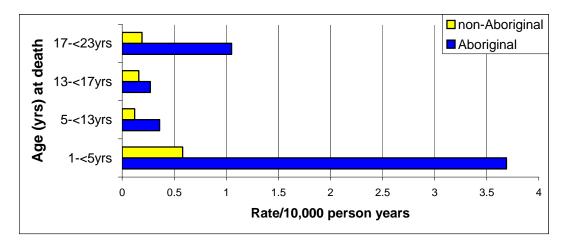
#### 5.3.1.1 Summary

- For all age groups combined, Aboriginal children were at a significantly higher risk of mortality than non-Aboriginal children for all causes of death with the exception of cancer and leukaemia.
- The increased risk was generally seen in all the age groups studied except for birth defects in those aged over 5 years and infection in those aged 13-17 years.
- The high rates of death due to accident and injury for both Aboriginal and non-Aboriginal 17-23 year olds are of major importance and require urgent attention.

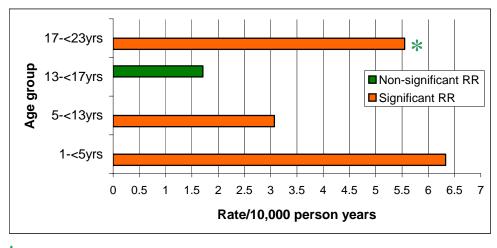
#### 5.3.2 Death due to infection

Deaths due to infections were the second main preventable cause of death among Aboriginal children (and third main highest among non-Aboriginal children. The CMR and the relative risk of death for Aboriginal children were highest in the pre-primary school children, with the second highest rates in the oldest age group in both populations (figure 5.42).

# Figure 5.42 Age specific CMR due to infection according to Aboriginal status, 1980-2001 inclusive







\* small numbers

#### 5.3.2.1 Summary

- The relative risks for Aboriginal children dying from infection compared to non-Aboriginal are similar for the youngest and the oldest age groups.
- It should be noted that there was a small number of cases in the 17-23 year age groups.

#### 5.3.3 Deaths due to accident and injury

As identified in the figures 5.44 and 5.45 the main causes of deaths among children and young people were accidents and injuries with the highest rates of death in the oldest age groups in both populations and the lowest among primary school children.



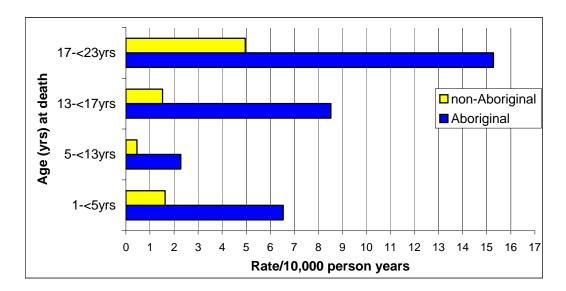
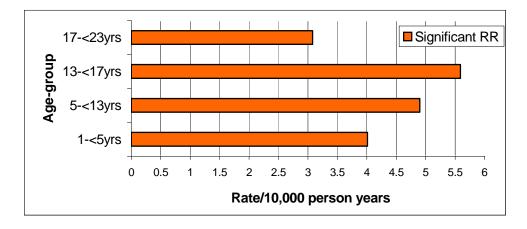
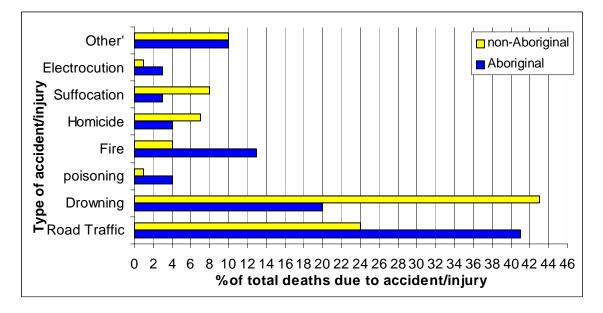


Figure 5.45 The risk of Aboriginal (compared to non-Aboriginal) children dying as a result of accident and injury according to age group, 1980-2001 inclusive



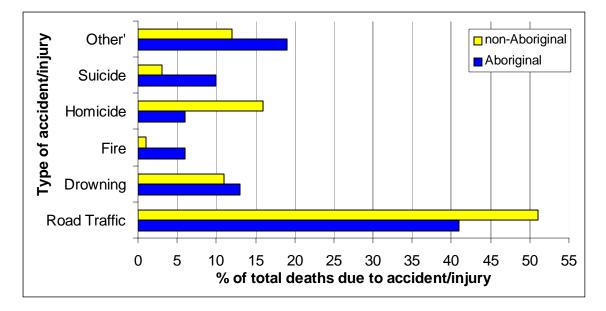
The main types of accident and injury causing death among children and young people varied by the age of the child. The main causes change according to the different age groups. Road traffic accidents (RTAs) were the main cause of death for Aboriginal children in the one to five years age group, while for non-Aboriginal children the main cause of death was due to drowning. Sixty-one percent of the RTAs were pedestrian accidents (Aboriginal 67%, non-Aboriginal 58%), 35% were motor vehicle accidents (MVAs) (Aboriginal 26%, non-Aboriginal 38%). Seventy percent of drownings occurred in a swimming pool (Aboriginal 58%, non-Aboriginal 72%). The remainder occurred in open water. The 13% of deaths due to fire among Aboriginal children occurred predominately in rural and remote locations whereas no fire related deaths occurred in remote locations for non-Aboriginal children.





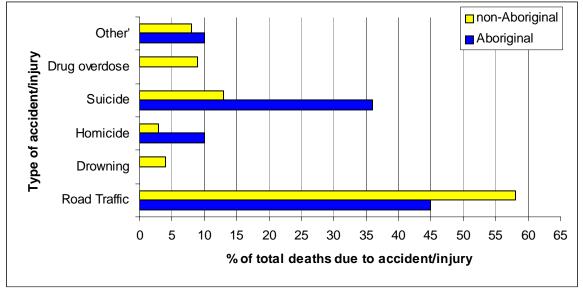
For primary school aged children the main type of accident and injury causing death was RTAs for both Aboriginal (41%) and non-Aboriginal (51%) children. Of these 41% were due to MVAs (Aboriginal 31%, non-Aboriginal 43%) and 40% were pedestrian deaths (Aboriginal 62%, non-Aboriginal 35%). Sixteen percent of deaths in this age group among non-Aboriginal children were due to homicide , but only 6% for Aboriginal children. Thirteen percent of Aboriginal deaths (swimming pools) compared with 11% non-Aboriginal deaths (swimming pools, sea and rivers). More non-Aboriginal children were murdered than died by drowning or suicide. Deaths due to fire among Aboriginal children all occurred in remote locations and among non-Aboriginal children in metropolitan locations. Aboriginal children were living in rural and remote locations, while non-Aboriginal children were living in metropolitan and rural locations.





Deaths that occurred in high school aged children were predominately due to RTAs (Aboriginal 45%, non-Aboriginal 58%). All RTA deaths in these Aboriginal children were due to MVAs (as passengers or drivers). MVAs accounted for 67% of non-Aboriginal deaths, 20% were pedestrian deaths and 13% due to bicycle accidents. Suicide deaths accounted for 36% of Aboriginal and 13% for non-Aboriginal high school aged deaths due to accident/injury. These deaths was fairly evenly distributed between metropolitan, rural and remote locations for Aboriginal young people, but were predominately in metropolitan areas for non-Aboriginal young people. Nine percent of deaths in non-Aboriginal young people were due to drug overdoses, with no fatal drug overdoses documented among Aboriginal young people. There were also no deaths due to drowning among Aboriginal high school aged children.

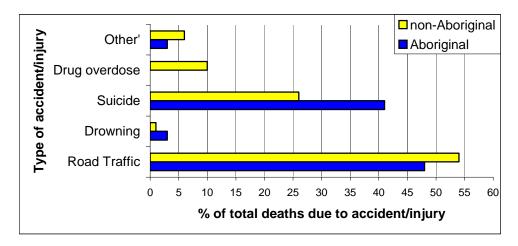




The main type of death in young adults aged between 17 and 23 years was RTAs in both populations (Aboriginal 48%, non-Aboriginal 54% of accident/injury deaths). The number of deaths due to MVAs and pedestrian deaths were similar among young Aboriginal adults. However, among the non-Aboriginal population the majority of deaths due to RTAs were due to MVAs (84%).

Ninety percent of deaths due to RTAs occurred in metropolitan and rural locations. The majority of the MVAs occurred in remote locations, while the majority of pedestrian deaths occurred in metropolitan locations. Forty-one percent of deaths in this age group among Aboriginal young adults was due to suicide (non-Aboriginal 26%). Of the Aboriginal suicide deaths, most occurred in rural and remote locations, while for non-Aboriginal they occurred predominately in metropolitan locations. There were no deaths due to fatal drug overdoses among Aboriginal young adults whereas they accounted for 10% of non-Aboriginal deaths due to accident and injury.

## Figure 5.49 Main types of accident and injury causing death among children aged between 17 and <23 years, 1981-2002 inclusive



#### 5.3.3.1 Summary

- For all age groups, Aboriginal children were at a significantly higher risk of dying from accident and injury than non-Aboriginal children.
- For both populations and in all age groups, road traffic accidents were the most frequent cause of accident and injury related deaths, except for non-Aboriginal children aged 1-5 years, where drowning was the most frequent cause.
- The importance of suicide as a cause of death becomes apparent as children grow older, forming 41% of all deaths for Aboriginal young people aged 17 to 23 years and 26% for non-Aboriginal youth in the same age group.
- Drug overdoses and homicides occurred mostly in non-Aboriginal young people.

#### 5.3.4 **Death due to road traffic accidents**

As shown above, the main cause of death in the first 23 years of life was as a result of accident and injury (A&I) (Figure 5.32). The CMR due to A & I increased according to age and the highest CMRs were observed in the post-school age groups: Aboriginal 15.3/1,000, non-Aboriginal 5.0/1,000 infant survivors. It was also observed that the main cause of A&I deaths was RTAs in all age groups with the exception of non-Aboriginal children aged between 1 year and 5 years, where the main cause of death was drowning. For non-Aboriginal children, of the deaths due to RTAs, in the 5-12 year age group, the numbers of pedestrian (40%) and deaths due to MVAs (40%) were similar. However, the pattern was different among Aboriginal children where 31% of RTAs were due to MVAs and 62% were pedestrian deaths, with 7% due to bicycle accidents: non-Aboriginal MVAs 43%, pedestrian 35%, bicycle 20%. In the subsequent age groups, death due to MVAs were the predominant cause of RTAs in all age groups: Aboriginal 75%, non-Aboriginal 77%.

#### 5.3.4.1 Snapshot of MVAs, 1998-2002 inclusive

The autopsy case reports of the deaths due to MVAs were analysed further to determine more specific information about the nature and location of these deaths. Figure 5.50 shows the % of MVAs according to whether the person was the driver or passenger in Aboriginal and non-Aboriginal young people aged between 13 and 23 years (there were only nine deaths due to MVAs between 1 and 13 years). The driver/passenger percentage ratios were similar in both populations: Aboriginal driver 42%, passenger 58%; non-Aboriginal driver 40%, passenger 58%.

### Figure 5.50 Percentage of deaths in both populations where the deaths due to MVAs occurred to the passenger or driver, 1998-2002 inclusive

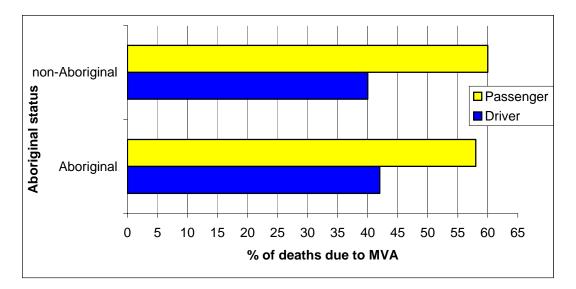


Figure 5.51 shows the driver/passenger percentages for Aboriginal and non-Aboriginal young people according to age. In 13 to 17 year olds, the picture reflects the lower proportion of young people with a valid driver's license. The ratio of driver/passenger deaths in the age group 17 to 23 years is similar for both Aboriginal and non-Aboriginal young people (around 50%).

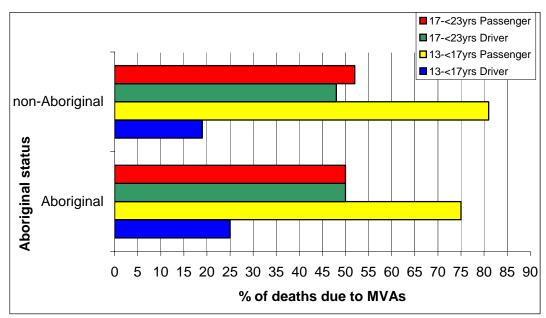


Figure 5.51 Driver/passenger % for Aboriginal and non-Aboriginal children aged 13 to 23 years, 1998-2002 inclusive

There were more passenger than driver deaths in all geographical locations. The ratio (%) of driver to passenger deaths was the same in rural and remote locations. (figure 5.52)



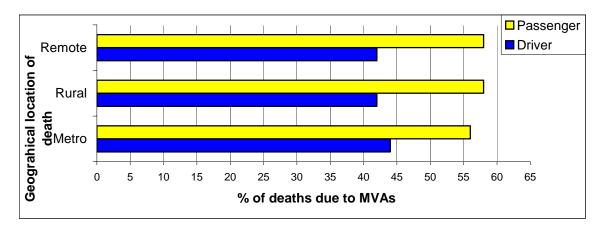
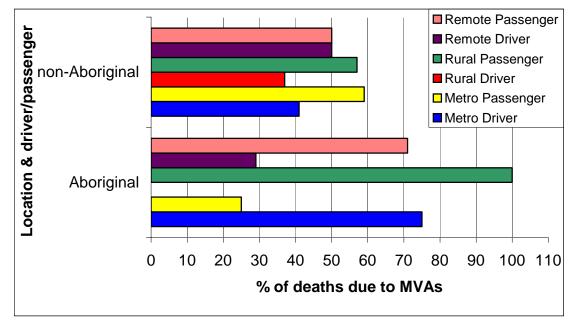


Figure 5.53 shows the ratio (%) of driver/passenger deaths according to the geographical location at the time of death for Aboriginal and non-Aboriginal young people aged between 13 and 23 years. The majority of Aboriginal deaths due to MVAs in the metropolitan location were driver deaths (75%). The opposite picture was observed in remote locations where the majority of deaths were passenger deaths (71%). All Aboriginal deaths in rural locations were passenger deaths. The pattern was different in non-Aboriginal young people. In metropolitan locations, passenger deaths accounted for 59% of non-Aboriginal deaths due to MVAs. There were equal numbers of driver/passenger deaths in remote locations (50%) and there were more passenger deaths (57%) in rural locations than driver (37%).





#### 5.3.4.2 Summary

- Generally, more passengers than drivers died in all geographical locations.
- However, more Aboriginal drivers than passengers died in metropolitan locations.
- Aboriginal children aged between 5 and 7 years were more likely to die as pedestrians than MVA deaths. The opposite was observed among non-Aboriginal children in the same age group.

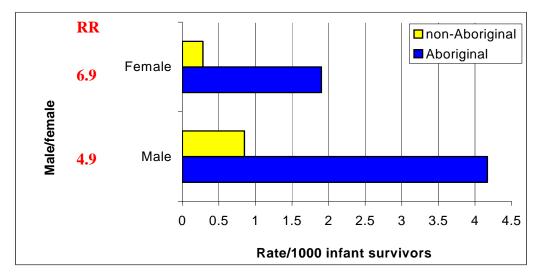
#### 5.3.5 Death due to suicide

The previous sections identify suicide as a cause of death that became increasingly significant in the older age groups. Suicide (and attempted suicide) are the consequences of a complex interaction between environmental, biological and individual risk factors. A report commissioned by the Western Australian Youth Suicide Advisory Committee (YSAC) provided a descriptive and analytical summary of the nature and incidence of suicide in WA between 1986 and 1997 (Hillman 2000). The following figures provide descriptive analyses of the deaths due to suicide occurring in WA born children and young people between 1998 and 2002 inclusive aged between 13 and 23 years and according to mode of suicide and gender.

#### 5.3.5.1 Mortality due to suicide by gender

Twenty-six percent of completed suicides between 1998 and 2002 were among Aboriginal young people. The risk of completed suicide was significantly higher in Aboriginal compared to non-Aboriginal young people (RR=5.3; 95%CI 3.2, 9.0). Males were more likely to complete suicide: Aboriginal 68%, non-Aboriginal 76%. The risk of completed suicide for Aboriginal young people (compared to non-Aboriginal) was significantly higher in both males and females, nearly 5-fold and nearly 7-fold respectively (figure 5.54).

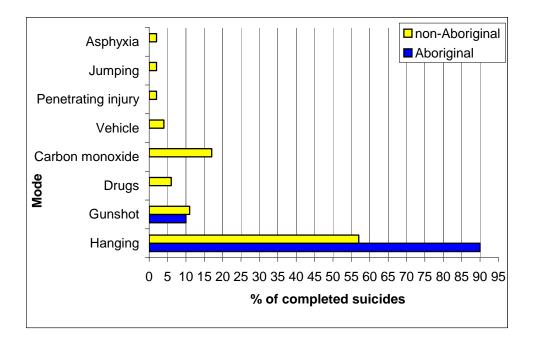
Figure 5.54 CMR of suicide and the RR of Aboriginal young people (compared to non-Aboriginal) according to gender, 1998-2001 inclusive



#### 5.3.5.2 Mode of suicide

The mode of suicide differed between the two populations. Hanging (9%) and gunshot (10%) were the only mode of suicide among Aboriginal young people. While hanging was the predominate mode of suicide among non-Aboriginal young people (57%), a variety of other methods were also used (figure 5.55).

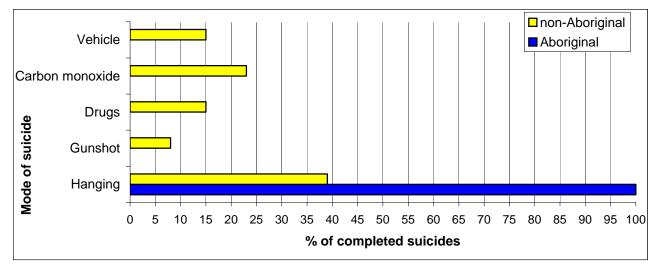
#### Figure 5.55 Mode of suicide (% of completed suicides) for Aboriginal and non-Aboriginal young people, 1998-2002



#### 5.3.5.3 Mode of suicide by gender

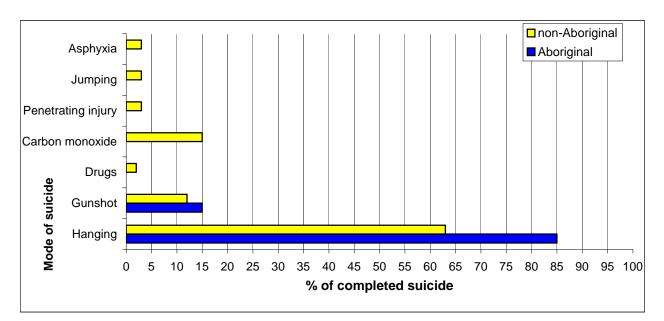
Aboriginal females died as a result of hanging in all cases. Non-Aboriginal females predominately died as a result of hanging (39%), however also used gunshot (8%), drugs (15%), vehicle (15%) and carbon monoxide (23%) (figure 5.56).





Aboriginal males died as a result of hanging (85%) and gunshot (15%). Non-Aboriginal males died as a result of hanging (63%), gunshot (12%), drugs (3%), carbon monoxide (15%), penetrating injury (3%), jumping (3%) and asphyxia (3%).

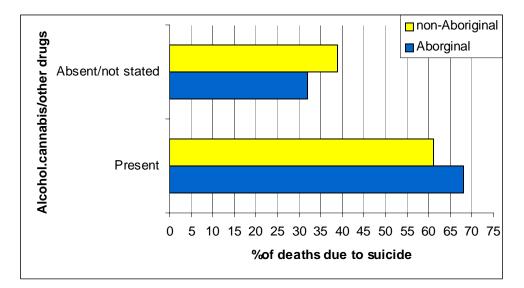




#### 5.3.5.4 Suicide and presence of alcohol, cannabis and other illicit drugs

Documented evidence of the presence of alcohol, cannabis and other illicit drugs on toxicological examination at the time of post-mortem for deaths due to suicide was reviewed for the years 1998-2002. In 68% of Aboriginal and 61% of non-Aboriginal suicides there was evidence of alcohol, cannabis or other illicit drugs.

### Figure 5.58 Evidence of alcohol, cannabis or other illicit drugs at post-mortem for deaths due to suicide according to Aboriginal status 1998-2002



#### 5.3.5.5 Summary

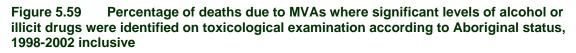
- Aboriginal young people were significantly more likely to commit suicide compared to non-Aboriginal.
- More males than females died as a result of suicide.
- However, the rate of Aboriginal female suicides was higher than non-Aboriginal male suicides.
- Aboriginal females were nearly 7 times and males nearly 5 times more likely to commit suicide compared to their non-Aboriginal peers.
- Aboriginal female suicides were all as a result of hanging and males predominately hanging (85%) and gunshot.
- Non-Aboriginal deaths were due to a number of other methods.
- Alcohol and/or illicit drugs were identified in 69% of Aboriginal and 61% of non-Aboriginal deaths due to suicide.
- Information on alcohol and drugs in this report does not distinguish between the different levels of toxicity found on forensic examination in this report.
- The population prevalence of alcohol or drugs is unknown for this population.

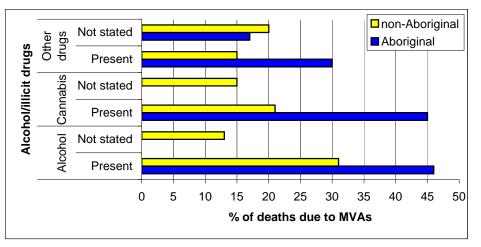
#### 5.3.6 Alcohol, cannabis and other illicit drugs

The presence or absence of toxicological evidence that alcohol, cannabis or other illicit drugs at the time of the MVA<sup>3</sup> was also noted from the information in the autopsy case reports. There is special provision for this information in the autopsy forms. If there was no comment made in the autopsy case report, this was coded as 'not-stated'. The data do not reflect the level of alcohol or drugs in the blood or the urine. As such they are an indication only of the percentage of deaths due to MVAs in which there were drugs and/or alcohol present. Further analyses of the level of alcohol/drugs present, the blood and urine levels, and the population prevalence of alcohol and drugs among drivers and passengers of the same age who have not died would need to be undertaken in order to establish any increased risk of death due to these substances.

Figure 5.59 shows the percentage of Aboriginal and non-Aboriginal people between the ages of 13 and 23 years and years 1998 and 2002 inclusive who died as a result of a MVA and according to the toxicological evidence at post-mortem there was evidence of over the legal limit of blood alcohol, and presence of cannabis and other drugs. Note that the percentages will not add to 100% as there were a small number of MVAs where no toxicology information was available regarding the presence of alcohol (four deaths), cannabis (five deaths), other drugs (six deaths).

The percentage of deaths where alcohol and illicit drugs were <u>not</u> identified at post mortem was greater than deaths where alcohol or illicit drugs were identified. Similar percentages of positive toxicology for alcohol, and cannabis were observed in Aboriginal young people. The percentages of deaths where drugs were identified compared to the percentages where drugs were not identified were higher in Aboriginal young people compared with non-Aboriginal. Toxicological information relating to cannabis and alcohol was included in all autopsy case reports for Aboriginal young people.

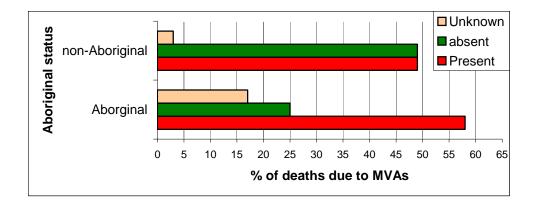




<sup>&</sup>lt;sup>3</sup> Passenger and driver deaths combined

Figure 5.60 shows the percentage of Aboriginal and non-Aboriginal people between the ages of 13 and 23 years and years 1998 and 2002 inclusive, who died as a result of a MVA according to the toxicological evidence at post-mortem of 'all drugs' - alcohol and/or cannabis and/or other drugs. This variable was constructed by identifying any death where toxicological evidence of alcohol or cannabis or other drugs was documented in the post-mortem case reports (there were five cases where there was no information). Considering cases where there was information, there was an equal number of non-Aboriginal deaths due to MVAs where either alcohol or illicit drugs were and were not present. However, in 58% of Aboriginal deaths due to MVAs there was evidence of alcohol or illicit drugs identified on post mortem.

# Figure 5.60 Percentage of Aboriginal and non-Aboriginal people between the ages of 13 and 23 years who died as a result of a MVA according to available toxicological evidence at post-mortem of 'all drugs', 1998-2002 inclusive



#### 5.3.6.1 Summary

- Information on alcohol and drugs in this report does not distinguish between the different levels of toxicity found on forensic examination in this report.
- The population prevalence of driving under the influence of alcohol or drugs is unknown for this population.
- The % of deaths where alcohol or illicit drugs were not identified on postmortem was the same as the % where alcohol or illicit drugs were identified for non-Aboriginal young people.
- The % of deaths where alcohol or illicit drugs were identified on postmortem was higher than the % of deaths where alcohol or illicit drugs were not identified for Aboriginal young people.
- Alcohol and/or illicit drugs were identified in 58% of Aboriginal and 49% of non-Aboriginal deaths resulting from MVAs.
- In 3% of non-Aboriginal and 17% of Aboriginal deaths, there was no toxicology information available in the post-mortem reports.

"Mortality rates among young people in Western Australia are still at unacceptable levels. Additionally, the tragedy that results from the loss of a young person's life is particularly devastating due to the usually preventable nature of such an incident, and the number of potential life years lost."

State Youth Council member

### **Chapter 6 What Kids Say**

### 6.1 Introduction

The purpose of this report is to provide information to guide strategies and policies to prevent deaths in children and young people. The chapter provides a snapshot of "what kids say" about the thoughts, aspirations and concerns of Western Australian children and young people. Information in this chapter is drawn from:

- 2003 Youth Media Survey Results
- Kids Help Line data

Throughout the chapter, statements made by members of the Office for Children and Youth's Children's Advisory Group and State Youth Council are included to highlight issues of significance.

The Kids Help Line data includes information derived from over 44,000 calls received over the past 9 years<sup>4</sup>.

The 2003 Youth Survey information has been compiled from an extensive survey, which elicited responses from over 11,000 Western Australian children aged between 12 and 25 years<sup>5</sup>. For the purposes of this report, the information related to the 12-19 years age group only will be discussed.

It is important to note the difference between the Kids Help Line data and the 2003 Youth Survey data. These differences are borne out in the information collected by the two surveys. The Youth Survey reflected a cross-section of children and young people who 'volunteered (albeit with some incentive) to contribute and, as such, the information tends to be rather more positive. For example, over two-thirds of the respondents expressed "happiness with their family lives" and just over half "with their social lives".

Information derived from the Kids Help Line, on the other hand, provided information derived from children and young people experiencing difficulty and distress. As an example, forty percent of callers to the Kids Help Line were distressed about family relationships.

<sup>&</sup>lt;sup>4</sup> Reference

<sup>&</sup>lt;sup>5</sup> Reference – Ian Thomas, Wendy Reid

This report has identified that accident and injury are the major cause of death among children and young people. Risk taking behaviours underly a significant number of theses deaths, for example, riding on the bonnet of a car or in the tray of a utility vehicle, and excessive alcohol and drug taking in conjunction with motor vehicles. Information derived from initiatives such as the Kids Help Line and the Youth Survey allow us to consider ways, in conjunction with young people, to create a safer, more protective environment in order that these excess deaths may be prevented.

### 6.2 Importance of Participation

The participation of young people in decision making that affects their lives is a fundamental right. The power of listening to the views of young people cannot be underestimated, as such information contributes to a greater understanding and helps shape policy development and program delivery to better inform considerations for effective interventions in the prevention of death in our children and young people.

The findings of the 2003 Youth Survey provide a greater insight into the protective and resilience factors that exist in our young people. These factors should be harnessed and further developed in order that they may permeate more fully throughout the total population, rather than only a part of it.

### 6.3 General Perceptions of Health and Well-Being

In general, young people are healthy and well adjusted with an optimistic view of life. Most young people make informed, responsible decisions for a health, active lifestyle and contribute to family and community life.

In the years between childhood and adulthood, young people become increasingly independent and begin to take more responsibility for their own health and well-being. Young people seek new experiences and may experiment with behaviours and activities which they feel are more adult oriented. For many young people, this may include taking risks which compromise their own health or the health of others. This may involve establishing behaviour patterns which could continue into adulthood with significant consequences for their later health.

Young people are susceptible to influence by peers and the mass media. They may find mainstream services inaccessible or unwelcoming if they perceive that their circumstances and requirements are not fully understood.

While at times, many young people feel invulnerable and may not fully grasp the reality of the risks they are taking, young people are often likely to feel very profoundly the impact of painful events and circumstances in their lives.

Health problems for young people are likely to be related to one or more risk behaviours, including poor nutrition and unhealthy diet, lack of physical activity, consumption of alcohol, tobacco products and other drugs, or unsafe sexual behaviour. The majority of young people do not engage in risk behaviour at a high level, but those who do are likely to combine risks, therefore further compromising their current and future health.

### 6.4 2003 Youth Survey – Key Findings

The 2003 Youth Survey found that Western Australian young people are, in the main, positive and optimistic about their future. They value their education, family and friends and take part in a wide variety of activities.

Overall, the aspect of their lives that young people were the most happy about was their racial/ethnic heritage, with two thirds of young people expressing happiness with their family lives and just over half with their social lives.

Parents and friends remain the major influencers of opinion amongst young people, followed by teachers/lecturers, then other relatives. This finding has significant policy implications.

Young people's perceptions of service provision were largely rated as 'good' particularly in relation to access to youth centres/youth workers, public recreation (such as pools, skateparks and sports centres), health services catering for young people, hassle free places to hang out, and special support services (such as drug and alcohol, mental health and housing support). As would be expected, young people in the country gave consistently lower ratings of the services available to them, especially with regards to public transport and general entertainment.

#### 6.4.1 Information Sources

In keeping with rapid technological changes, the Internet and on-line sources were identified as the most widely used sources of information. Again, this has a significant policy implication.

Information sources varied significantly between age groups. Newspapers and magazines play a much larger role as age increases, as does television and (to a lesser extent) radio and brochures. Younger people are more likely to use CD-ROMS, perhaps reflecting their increased availability within the school system.

Friends and peers are the top choice when it comes to consultation about drug and alcohol abuse problems. However, as young people get older, they are more interested in sourcing information from anonymous references such as written material and the Internet.

To get information, young people use		12-14		15-19			
	Often	Some- times	Never	Often	Some- times	Never	
Internet/on-line	76%	19%	5%	78%	19%	3%	
Books	46%	52%	2%	47%	49%	4%	
Papers/magazines	20%	61%	19%	33%	58%	9%	
Television	32%	50%	18%	36%	51%	13%	
Radio	15%	61%	24%	17%	65%	18%	
Brochures etc	16%	39%	45%	22%	43%	35%	
CD-ROM	25%	48%	27%	20%	51%	29%	
SMS/mobile	9%	22%	69%	16%	30%	54%	
Sample size			1616			2932	

#### Sources of information by age, 2003 Youth Survey respondents

#### 6.4.2 Education

In terms of their opinions about education, 94% of survey respondents said their education had given them valuable skills and knowledge, and 83% said their education had been enjoyable so far. The table below indicates there are minor age and gender differences in young people's perceptions of educational outcomes. Females rated their education experience as more enjoyable, they acknowledged that it taught them to be a team player and helped them to participate in the arts.

#### Opinions of education outcomes by age, 2003 Youth Survey

Young people's education so far has	12-14	15-19
Given them valuable skills and knowledge	94%	95%
Given them skills in literacy & numeracy	90%	94%
Been enjoyable	83%	82%
Helped them to understand their views & those of others	80%	81%
Helped them form their ideas & opinions	81%	79%
Been useful in everyday life	82%	79%
Taught them to be a 'team player'	77%	70%
Helped them to participate in arts activities (eg music, writing, painting, dance, drama, photography etc)	° 82%	72%
Prepared them to leave & find work	69%	69%
Helped them build a network of contacts in their community	58%	59%
Sample size	1670	2988

"Education and jobs (need to be more) available in country areas." 2003 Youth Survey respondent

> "(We need) good education and job opportunities." 2003 Youth Survey respondent

#### 6.4.3 Issues of Concern

Road deaths and injury are worrying factors amongst young people. Along with the environment, these two issues were rated as two of the most important issues facing the community. Drug and alcohol abuse, education/training and crime were also ranked highly. As young people get older, they seem to have less consideration for road deaths and injury, instead being most concerned about the environment and education/training. Twelve to 14 year olds are the group most concerned with road trauma, which is interesting as they are the only group of respondents that cannot drive. Similarly, road trauma is a higher priority for young people in the country than those in the city.

The MOST important issue facing the community	12-14	15-19
The environment	9%	9%
Road deaths & injury	14%	12%
Education & training	6%	7%
Drug & alcohol abuse	9%	11%
Crime	8%	8%
Personal safety	9%	7%
Health	7%	5%
Youth suicide	7%	8%
Poverty	4%	4%
Work and employment	3%	4%
Racism	7%	6%
Immigration / asylum seekers	3%	5%
Family violence	3%	4%
Australia in overseas conflicts	3%	3%
Risks of terrorism in Australia	5%	4%
Aboriginal reconciliation	2%	1%
Protection of personal property	1%	2%
Sample size	1,330	2,614

# 6.4.4 The MOST important issue facing the community by gender, age and location, 2003 Youth Survey

"What would stop me from achieving my goals? Drugs, alcohol and death." Indigenous young person, National Indigenous Youth Leadership Group

"We need to tackle the root causes of the problem (suicide). They can be many and varied such as domestic and family problems, drug addictions, mental health and other health problems as well as social interaction difficulties. These can and often do result in depressed states of mind which I believe in many cases can be prevented by effective counselling and positive encouragement." State Youth Council member

"Deaths on our roads is one of the biggest killers of young people. Advanced driver training should be compulsory for all young people not just when they are getting their licence." State Youth Council member

The fact that they (deaths in young people) still occur suggests either not enough is being done, or what is being done is not sufficiently targeted enough." State Youth Council member

"If we all take part and help when there are accidents, it would not be so hard. Well, people need to know that it is not so hard to help... If you let people know instead of just standing there, lives can be saved because we can handle the problem faster." Children's Advisory Group member

## 6.4.5 Influencers of Opinion

Parents and friends remain the major influencers of opinions amongst young people. 'Teachers/lecturers' and 'other relatives' are the next most influential. Of other influencers, 'newspapers' and 'television/radio personalities' have perhaps the widest influence (if not the most powerful).

Those who don't have friends or are fighting with family could quite easily slip through the cracks..." State Youth Council member

> "My friends and family influence me." 2003 Youth Survey respondent

"My mum and dad influence me in everyway possible." 2003 Youth Survey respondent

Influencers of opinion		2003 Total	
	A lot	Some	None
Parents	54%	40%	6%
Friends	44%	52%	4%
Teachers/lecturers	19%	59%	22%
Other relatives	15%	55%	30%
Sports coaches	13%	31%	56%
Newspapers	9%	59%	32%
Artists/performers	9%	36%	55%
Rock/pop stars	9%	32%	59%
Youth leaders	9%	31%	60%
Sports stars	9%	27%	64%
Religious leaders	9%	24%	67%
Television and radio personalities	8%	47%	45%
Politicians	4%	29%	67%
Sample size	7919		

## 6.4.6 Sport and Exercise

Overall, the majority of young people indicated that they like sport and exercise. This figure was slightly higher for males than females, and young people in the 12-14 year age range. The reasons for enjoying sport and exercise vary considerably, although its capacity to keep people fit and healthy is universally acknowledged.

### 6.4.7 Young people's attitudes towards sport and exercise by age, 2003 Youth Survey

	Male	Female	12-14	15-19	Total
Liking for sport and exercise	90%	84%	93%	86%	87%
Sample size	4028	3914	1688	3003	7991

## 6.4.8 Getting their Voice Heard

Young people are willing to use a wide variety of mechanisms to get their opinions heard. Family and friends remain the most common way that young people get their views heard.

> "There needs to be more avenues to voice WA youths ideas & opinions." 2003 Youth Survey respondent

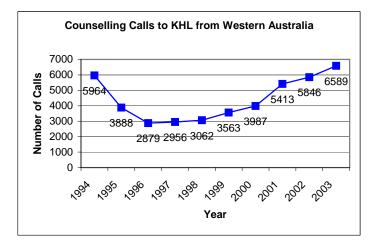
"The government (needs) to understand that the youth does have a voice." 2003 Youth Survey respondent

#### 6.4.9 Mechanisms young people may use to get their views heard, 2003 Youth Survey

To get their views heard, young people use		2003	
	Have used	Would use	Would not use
Family and friends	44%	47%	9%
Voting at an election	34%	43%	23%
Letters to the Editor	11%	56%	33%
School representative body	18%	38%	44%
Start a petition	12%	44%	44%
Contact your Member of Parliament	11%	44%	45%
Public protests or rallies	15%	36%	49%
Council meetings	6%	44%	50%
Youth Advisory Councils	7%	42%	51%
Union	6%	43%	51%
Talk-back radio	5%	40%	55%
Make a painting/drawing/photograph	11%	29%	60%
Write a song/story/poem	13%	24%	63%
Sample size	7,836		

# 6.5 Kids Help Line – West Australian Callers: 1994–2003

Between 1994 and 2003 over 44,000 counselling calls from children and young people residing in Western Australia were responded to by Kids Help Line counsellors.



The majority of these callers were from Perth and the surrounding metropolitan area (73%) with 17% from rural areas and 11% from remote regions of Western Australia. Seventy-five percent of callers were females, compared to 25% males. Just over half of the callers were aged 10 to 14 years (52%) with 42% aged 15 to 18 and 6% aged 5 to 9 years.

Of the 27% of callers for whom ethnicity was recorded, 88% percent were Anglo-Australian while 6% were of Indigenous background. A further 5% were from a non-English speaking background with the remaining 1% of another English speaking background.

#### 6.5.1 Comparison of Metropolitan and Regional Callers

Comparison between callers from metropolitan Western Australia with their rural and remote counterparts revealed a number of key differences.

Callers from metropolitan areas were significantly older (Mean: 17.07 years) than regional callers (Mean: 13.40 years) (Chi Square: 381 df, 1, p < .0001). These findings are consistent with 2001 census data showing a higher proportion of 15 to 18 year olds living in metropolitan Western Australia. This is believed to be due to older adolescents moving away from regional areas to pursue educational and employment opportunities in Perth and other urban areas in the State.

Indigenous callers made 12% of calls from regional areas compared to 2% of calls from metropolitan areas. This is consistent with the population distribution of Indigenous young people living in Western Australia, with the vast majority residing in rural and remote areas of the State. Callers of non-English speaking backgrounds made up a greater proportion of calls from metropolitan areas (5.6%) than from regional areas of Western Australia (2%) (see table below).

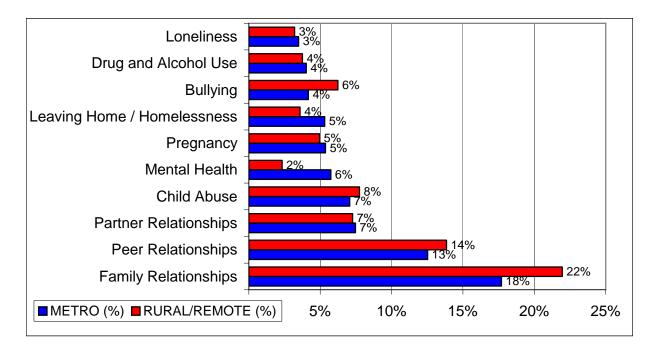
	Metropolitan WA	Rural and Remote WA
Anglo Australian	90.9%	85.1%
Indigenous	2.1%	12.1%
Non-English speaking	5.6%	2.0%
Other English speaking	1.3%	0.8%
TOTAL	100.0%	100.0%

There was very little difference in gender breakdown across regions -75% of metropolitan callers were female, compared with 74% for regional areas.

#### 6.5.2 Types of Calls Received from Western Australia

Regardless of geographical location, relationships with family, peers and partners are the main reasons young people from Western Australia contacted Kids Help Line during the last ten years. However, callers from rural and remote regions were more likely to make contact about peer and family relationships than their metropolitan counterparts. This is consistent with national Kids Help Line data trends and is believed to be due to rural and remote young people placing a greater emphasis on relationships within smaller communities than their metropolitan counterparts. Callers from regional Western Australia were also more likely to call Kids Help Line about child abuse and bullying.

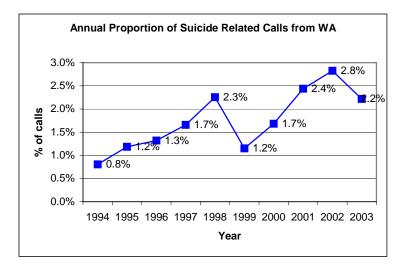
In contrast, callers from metropolitan areas made up a greater proportion of calls about mental health issues, pregnancy and leaving home/homelessness (see figure below).



#### 6.5.3 Suicide Related Calls from Western Australian Young People

Over the past decade, over 800 calls have been received from children and young people in relation to suicide - making this the 16th most common concern for young Western Australians. Overall, calls about suicide have accounted for 1.8% of counselling calls from the State during this time.

The proportion of suicide related calls across time has peaked twice over the past 10 years. One peak occurred in 1998 (2.3%) with a second higher peak in 2002 (2.8%). The 1998 peak is consistent with increased public awareness of youth suicide during this time (see figure below).



Males and females contacted Kids Help Line about suicide in similar proportions to other issues (see table below).

	Suicide Calls	Other Calls
Females	77%	75%
Males	23%	25%
TOTAL	100%	100%

Calls about suicide from West Australian young people were most likely to be come from older adolescents aged 15 to 18 years (76%) with 10 to 14 year olds making the remaining 24% of calls.

	Suicide Related Calls	Other Calls
5 to 9 years	0%	6%
10 to 14 years	24%	53%
15 to 18 years	76%	41%
TOTAL	100%	100%

The proportion of suicide related calls from metropolitan areas of Western Australia (1.7%) was slightly higher than the proportion of calls about suicide from rural and remote areas (1.3%). This may be due to the combined effects of there being a greater proportion of older callers ringing from metropolitan areas, and older callers making a greater proportion of calls about suicide.

### 6.5.4 Nature of Suicide Related Calls from WA

The majority of suicide related calls from young West Australians involved suicidal thoughts or fears (43%). A further 20% of callers reported an immediate intention to suicide, while 7% were making a suicide attempt at the time of making the call to Kids Help Line. The remaining young people were either seeking information (4%) or were concerned for a friend (25%) (see table below).

	Nature of Call (%)*	Nature of Call (n)*
Seeking information	4%	27
Concerned about another person	25%	176
Suicidal thoughts or fears	43%	304
Immediate intention	20%	141
Current attempt at time of call	7%	52
TOTAL	100%	701

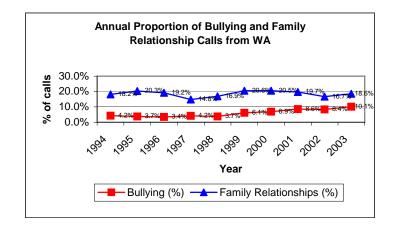
\* Based on data post May 10 1996 due to changes in suicide related data.

## 6.5.5 Family Relationships

Concerns about relationships with family members has consistently been the number one issue for Kids Help Line callers from Western Australia over the past decade, accounting for between 15% and 21% of counselling calls each year (see figure below).

Between 1994 and 2003, over 8100 calls from Western Australian children and young people about family relationships were responded to by Kids Help Line counsellors. Seventy-seven percent of these calls were from females, and 23% from males. The majority of these calls were from 10 to 14 year olds (61%), while 29% were from 15 to 18 year olds and 10% from 5 to 9 year olds.

Callers from rural and remote areas of Western Australia made 33% of calls about family relationships, compared to 27% of all other calls. This is believed to be due to rural and remote young people placing more emphasis on family relationships than their metropolitan counterparts as a result of living in smaller communities.



## 6.5.6 Bullying

Over 2840 calls were received about bullying over the past 10 years, accounting for 6.4% of counselling calls from the State. The proportion of calls about bullying has increased from 3.4% of counselling calls in 1996 to 10.1% of calls in 2003 (see previous figure).

Bullying is now the fourth most common concern for WA callers over the past ten years following family, peer and partner relationships. Males are more likely to contact Kids Help Line in relation to bullying than other issues, with 38% of bullying related calls being from males compared to 24% for all other calls from Western Australia.

Fifteen percent of bullying related calls were from children aged 5 to 9 years making this the second most common concern for this age group, after family relationships (see table below).

	Bullying Calls	Other Calls
5 to 9 years	15%	5%
10 to 14 years	76%	51%
15 to 18 years	9%	44%
TOTAL	100%	100%

There was a much higher proportion of bullying related calls from rural and remote regions of Western Australia over the past 10 years. Thirty-seven percent of bullying related calls came from regional areas of WA, compared to 28% for all other calls. The remaining 63% of calls about bullying came from metropolitan areas.

# 6.5.7 Kids Help Line Caller Data

PROBLEM	WESTERN AUSTRALIA: 1994 - 2003		
RELATIONSHIPS	17989	40.7%	
Family	8194	18.5%	
Friends	6239	14.1%	
Partners	3556	8.0%	
SEX RELATED	3751	8.5%	
Sexual Activity	1167	2.6%	
Contraception	391	0.9%	
Pregnancy	1973	4.5%	
STD	220	0.5%	
ALCOHOL/DRUGS	1679	3.8%	
Alcohol Use	282	0.6%	
Drug Use	1397	3.2%	
SELF CONCEPT	2642	6.0%	
Development	1043	2.4%	
Self Image	1058	2.4%	
Sexual Orientation	541	1.2%	
CHILD ABUSE	2797	6.3%	
Emotional Abuse	219	0.5%	
Neglect	166	0.4%	
Physical Abuse	1385	3.1%	
Sexual Abuse	1027	2.3%	
SCHOOL	4247	9.6%	
Authority	495	1.1%	
Bullying	2844	6.4%	
Study	908	2.1%	
VIOLENCE	1537	3.5%	
Assault/Harassment	491	1.1%	
Domestic	267	0.6%	
Sexual Harassment	284	0.6%	
Sexual Assault	495	1.1%	
HEALTH	2994	6.8%	
Eating Behaviours	238	0.5%	
HIV/AIDS	82	0.2%	
Physical	764	1.7%	
Mental	1910	4.3%	

PROBLEM	WESTEDN AUSTI	RALIA: 1994 - 2003
EMOTIONAL	3700	8.4%
Emotional/Behavioural Management	433	1.0%
Grief	1265	2.9%
Loneliness	1201	2.7%
Suicide	801	1.8%
PRACTICAL	2781	6.3%
Employment/Financial	352	0.8%
Leaving Home/Homelessness	1550	3.5%
Legal	442	1.0%
Life Skills	437	1.0%
MINOR	77	0.2%
Cults/Gangs	65	0.1%
Other	12	0.0%
	44194	100%

## 6.6 Summary

The data from both sources identified the importance of relationships with family and friends as a significant source of support and demonstrated the negative sequelae following the breakdown in these relationships.

The Kids Help Line identified a number of traumatic events (including child abuse, family breakdown leading to homelessness, bullying not being dealt with effectively and social isolation leading to loneliness) as significant traumatic events. These events had the potential to lead to poor mental health outcomes including anxiety and psychoses, drug and alcohol usage and unwanted behaviours. The traumatic events reportedly impact on unwanted pregnancies and risk taking behaviours that led to accidental injury, death and suicide.

Resilience and protective factors including education, strong family relationships, sport and exercise and social participation and connection were identified as important by the respondents of the 2003 Youth Survey. Twenty percent of the respondents believed that education, employment and career would make the biggest impact on their lives in the next ten years.

The 2003 Youth Survey also identified that racial and ethnic heritage was an important factor in their lives.

It is pleasing to note that the 2003 Youth Survey found that Western Australian young people were 'in the main, positive and optimistic about their future".

# 6.7 What Kids Want

Establish a Research Forum examining issues and solutions specific to deaths in children and young people, with a Sub Group comprised of children and young people to ensure their voices have a direct impact.

> "The government needs to take a leadership role in these issues, more than it's currently doing. They're complex problems that need more research to find solutions and keep children and young people alive and safe." State Youth Council member

Develop an online strategy targeting information to children and young people in WA, in an appealing and interactive way.

"More internet services and information." 2003 Youth Survey respondent

Develop an education campaign for parents about 'being a young person in WA', as they are seen as the primary influencers of opinion.

"The biggest positive impact in my life is my family, friends, teachers and parents, especially my mother, my father and my grandparents." 2003 Youth Survey respondent

"(I need) information (to be) given to me by people that are know the situation, like my parents and friends." 2003 Youth Survey respondent

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# **Child Car Restraints**

In WA, legislation requiring infants less than 1 year of age to be restrained in an Australian Standards certified child car restraint was introduced in 1995, some eight years after similar legislation was introduced in other Australian states. WA road traffic regulations allow the minimum requirement of an adult seat belt for children older than 1 year of age as passengers in cars.

# Mortality

Injury data for the period 1985 - 1994 shows a death rate of 6.7 per 100,000 and a hospital admission rate of 142 per 100,000 for children aged 0 - 4 years for Transport related injury.<sup>6</sup>

The death rate for children aged 0 - 4 years as motor vehicle occupants was 3.9 / 100,000 and the hospital admission rate was 47 / 100,000.<sup>7</sup>

Transport related injury death rates for children aged 0 - 14 years, 1985 - 1994 and 1995 - 2000, by age group

	All Tran	sport relate	d injury	Motor vel crashes	nicle occupant	ts / traffic
	0 – 4	5 – 9	10 - 14	0 – 4	5 – 9	10 - 14
1985 -1994	6.7	4.4	5.5	3.9	1.2	2.0
1995 - 2000	5.4	N/A	N/A	N/A	N/A	N/A

# Morbidity

Injury data for the period 1995 - 2000 shows a death rate of 5.4 per 100,000 and a hospitalisation rate of 139.6 per 100,000 for children aged 0 - 4 years for Transport related injury.

For this same time period, the number of deaths for traffic crashes for children aged 0-4 years were too few to be able to calculate a death rate. The hospital admission rate however, increased slightly to 48.8 per 100,000.

<sup>&</sup>lt;sup>6</sup> Ashwell MJS, Pinder T, Thompson N. 1996. An Overview of Injury in Western Australia, 1985 – 1994. Health Department of WA. July 1996

<sup>&</sup>lt;sup>7</sup> Gillam C, Legge M, Stevenson M, Gavin A. 2003. Injury in Western Australia – An Epidemiology of Injury, 1989 to 2000. Injury Research Centre, UWA for WA Department of Health. June 2003

	All transport related injury			Motor vehicle occupants / traffic crashes		
	0-4	5 – 9	10 - 14	0 – 4	5 – 9	10 – 14
1985 - 1994	142	244	410	47	45	60
1995 - 2000	139.6	237.4	413.6	48.8	64.6	83.0

# Transport related injury hospital admission rates for children aged 0 - 14 years, 1985 - 1994 and 1995 - 2000, by age group

It is always difficult to categorically identify any one measure as being responsible for changes in injury statistics over time. Adoption of revisions to ICD codes sometimes affect how injury events are classified, which in turn is reflected in subsequent reporting.

Transport related injury data for the period 1985 – 1994, breaks the category down into Motor Vehicle occupants, Motorcyclist, Bicyclist, Pedestrian, Riding / drawn by an animal and Other/ Unspecified. For the period 1995 – 2000, Transport related injury is broken down to Traffic Crash, Non- traffic crash and Other Transport events.

While the data shows a decrease in death rates for children aged 0 - 4 years of age in car crashes between 1985 and 2000, it also shows a slight increase in hospital admission rates, which may be real, may be an effect of coding changes or other events.

# Drowning

Drowning and near drowning are a significant cause of death and hospitalisation for children under 5 years of age. Backyard swimming pools are frequently the location of drowning deaths and near drowning incidents of young children. There are a number of measures that contribute to preventing drowning deaths and near drowning events in young children.

Adult supervision of young children in and around water is an essential component of downing prevention however the reality is that even the most vigilant of parents can be distracted by any number of valid circumstances. In the short space of time that adult attention is diverted, a young child can quickly and silently gain access to unprotected bodies of water in and around the home. A child can drown in 5 cms of water in 2 minutes in absolute silence.

For the period 1985 - 1994, there were a total 288 drowning deaths in WA and 772 hospital admissions for a near drowning incident. Thirty one percent (n=88) of these deaths and 50% (n=384) of hospital admissions were children aged 0 - 4 years.

For the period 1995 - 2000, there were a total 186 drowning deaths in WA and 475 hospital admissions for a near drowning incident. Twenty four percent (n=45) of these deaths and 51% (N=244) of hospital admissions were children aged 0 - 4 years.

# Number and percent total drowning / near drowning deaths and hospital admissions for children aged 0 – 14 years, 1985 – 1994 and 1995 – 2000, by age group

	Number and % of deaths: Drowning				mber and Drownii		-					
	0	-4	5	-9	10	- 14	0 -	- 4	5.	- 9	10 -	- 14
1985 - 1994	88	31%	9	3%	9	3%	384	50%	34	4%	19	2%
1995 - 2000	45	24%	9	5%	6	3%	244	51%	26	5%	25	5%

The age specific death rates and hospitalisation rates per 100,000 for drowning and near drowning events for the two time periods are shown in the following table.

	Age specific death rates: Drowning				ïc hospitalisat ing / Near Dro	
	0 – 4	5 – 9	10 - 14	0 - 4	5 – 9	10 - 14
1985 - 1994	7.2	0.7	0.7	31	3	2
1995 - 2000	5.9	N/A	N/A	32.1	N/A	N/A

Over time there has been a reduction in the number and rate of drowning deaths of young children in WA. For hospital admissions, however, while the number of hospital admissions has reduced, the percentage and age specific rate for children aged 0-4 years has slightly increased. Backyard swimming pools are still a common location for drowning deaths of children aged less than 5 years.

Comparison against the National Injury Prevention Priority Targets for 2000 for Drowning shows that the Australian target age specific death rate for children aged 0-4 years of 3.0 / 100,000 was exceeded in WA at the year 2000 with a rate of 1.6 / 100,000. However the West Australian hospital admission rate for children aged 0-4 years of 33.5 / 100,000 at the year 2000 was still higher than the Australian target age specific hospital admission rate for children aged 0-4 years of 20.7 / 100,000.

Legislation intended to address the dangers posed to young children by backyard swimming pools was first introduced in Western Australia in 1989. The 1989 legislation was based on the premise that children who drowned in backyard pools were intruders on the property. The legislation required that homes with a swimming pool be perimeter fenced, ie the backyard secured against ready access from the street.

It soon became apparent that young children were still drowning in backyard swimming pools and that almost all of these children were either residents of the house or invited guests to the house. For this reason, fencing that separates the swimming pool from direct access from the house and other parts of the yard is advocated as an essential measure to reduce unintended access by young children and so reduce drowning deaths of young children.

Western Australia has a history of legislative swings with regard to swimming pool fencing requirements. The 1989 legislation required perimeter fencing of new pool installations. The 1992 legislation introduced the requirement for four-sided fencing (commonly known as isolation fencing). This piece of legislation was rescinded six months later by a new State Government and replaced with legislation that permitted self closing, self-locking doors and windows that opened to a maximum 100mm to be classed as part of the barrier around a backyard pool.

In 2000 and 2001, after lobbying from organisations such as Kidsafe WA, West Australian legislation changed again. The 2000 change again required four-sided fencing around new pool installations and the 2001 change requires that all swimming pools constructed prior to 1989 must be brought up to the 1992/93 requirements as a minimum by March 2006.

The introduction of environmental measures such as fencing around swimming pools has contributed to a reduction in deaths and near drowning but there is still more that can be done. In conjunction with these environmental measures, there needs to be ongoing public education and awareness campaigns that offer drowning prevention information and strategies for all child drowning hazards not just swimming pools. Organisations such as Kidsafe WA and Royal Life Saving Society WA need to be properly recognised as leaders in the area and resourced to implement education and awareness campaigns as well as for the provision of their expertise to a variety of Government Departments.

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# Examples of policies introduced to prevent accidents among young children

<b>Table: 1.1</b>	Specific injury	prevention programs '	' Child Safety Preventio	n Program"
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Organisation	Objective
Kimberley	To pilot a Child Safety Prevention Program in
Population	Broome.
Health	
	To raise awareness of child injuries as a health issue,
	and that most injuries are preventable.
	Primary target group (participants) – Aboriginal
	parents and grandparents with children aged 0 to 5
	years.
	Secondary target group (presenters) – Aboriginal
	Health Workers, Child Health Nurses, Community
	Midwives, Child Care Workers, staff from local Child
	Care Centres and Community Organisations working with parents and children.
	Kimberley Population

#### **Project Strategies**

#### Workshop Training

Aimed to educate and train health care providers (Allied and Aboriginal Health) and others in the use of the Child Injury Prevention package.

Implemented because there is a need to increase parents, health workers and social workers knowledge and skills of preventing child injury in the home, and to reduce the number of 0-5 year olds with injury related admissions to hospital and health services.

#### Workshop Objectives

Develop strategies that deal with Child Injury Prevention affecting children 0-5 years old Provide culturally appropriate resources that effectively supports community based injury prevention activities

Distribute culturally appropriate resources to parents/caregivers to prevent childhood injury occurring in the home

Encourage safe practices by improving the access for Aboriginal children 0-5 years old to protective equipment appropriate for their home

>Increase acceptance and support of prevention efforts

The package contains a manual kit and CD rom of the content material. The topics covered in the Child Injury Prevention Program Presenters kit are listed below:

- Poisons
- Fire/Burns/Scalds
- Dogs and Children
- Drowning Prevention

•

Child Car Restraints

SIDS

• Infant First Aid

• Driveway Injury

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#### **Project Outcomes**

Since the workshops, there has been an enormous amount of interest in promoting this project further throughout the Kimberley.

Two other regional child injury prevention training sessions were delivered with the expectation that trained presenters would then conduct one on one or group sessions in their workplace with the primary target group.

The programs activities are ongoing and Community Health Nurses, Women's Groups and young mothers within the Broome community, have requested support to implement the Child Injury Prevention Kit to raise awareness and provide practical strategies that prevent injury to Indigenous children aged 0 to 5 years.

Article about the project has been showcased in a Sydney journal titled RATTLER (issue 70, Winter 2004)

Rattler is a high quality quarterly magazine that includes articles, interviews, reviews, and reports from children services leaders, workers, specialists, parents and others. A magazine which inspires children services.

#### **Quote from June Walley**

This pilot program has been successful in Broome and led to implementation in two other regions in the Kimberley - Derby (situated 220kms north of Broome) and Warmun Community (situated 196kms south from the town of Kununurra).

It is important that these initiatives are extended to other centres in the Kimberley where ther are no Child Safety Programs in place. This project created a very special resource which is utilised by health professionals on a daily basis, therefore in keeping it sustainable I have continued my support in implementing the kit, thus reducing morbidity and mortality rates in the Kimberley.

#### Acknowledgement:

June Walley Aboriginal Health Promotion Officer Kimberley Population Health Unit

Phone: (08) 9192 5333

# Specific injury prevention programs "Safe Kiddies Project – Home Safety Resource Kit"

Project	Organisation	Objective
Safe Kiddies Project – Child Safety Resource Kit	Pilbara Population Health	To increase awareness of child injury prevention and child safety in the home within the Pilbara Indigenous population through the development of a child safety
Funded by Department of Health, Office of		resource package.
Aboriginal Health.		
Project Strategies		

Culturally appropriate child safety resource packages were developed. The resources in the package focussed on four key areas of child injury prevention within the Pilbara – burns, poisons, water safety and supervision.

The child safety resource package contains:

- Posters relating to the four key areas
- A flipchart on safety in and around the home
- An introduction to the resources page
- Home safety checklist
- Useful links page
- The Royal Life saving Societies' 'Watch Out for the Kids' video
- Feedback/evaluation form

Four radio announcements to be aired on the local Indigenous radio station will compliment the resources and address the four key areas of child injury prevention.

#### **Project Outcome**

The resources have recently been developed, are in the process of implementation. Evaluation of the Safe Kiddies Project resources will be conducted at a later date.

#### **Personal Quote:**

"Pilbara Indigenous children in the 0-4 age group are over-represented in terms of hospitalisations due to injury. The goal of the Safe kiddies project is to increase awareness of child injury prevention in the home, within the Pilbara Indigenous population".

#### Acknowledgements:

Pilbara Population Health – Jade Bickley and Amanda Barrett Phone: (08) 9172 0236 and Royal Lifesaving Society of WA, Kidsafe WA

# Specific injury prevention programs "Crossing Aboriginal Pedestrian Road Safety Project"

Project	Organisation	Objective
"Crossing Aboriginal Pedestrian Road Safety Project"	WALGA - Roadwise	To support the reduction in morbidity and mortality of Aboriginal pedestrians.
A Healthway funded project, July 2002 to December 2002.		The project was developed using a collaborative approach with stakeholders and incorporated environmental, community development and mass media strategies.

#### **Project Strategies**

A collaborative approach to implement a combination of strategies to include:

- Environmental
- Community development
- Mass media

Made it possible to achieve improvements in the safety of the walking environment in Fitzroy Crossing.

Sustainable strategies included:

- Installation of streetlights
- Erection of informational street signs

Road crash statistics:

Pre intervention between 1998 and 2001, six pedestrian fatalities and three serious injuries were recorded on roads in the Fitzroy Crossing.

Post intervention, no fatalities/serious injuries have been reported on any roads in Fitzroy Crossing since the project began in July 2002.

The WA Police Road Safety Section and Office of Aboriginal Health have implemented a similar project in Halls Creek modelled on the Fitzroy Crossing intervention.

#### **Project Outcome**

The project won the Community and Road Safety (Rural) category of the 2003 WA Local Government Excellence in Road Safety Awards.

Acknowledgement: Louise Spehr RoadWise Regional Road Safety Officer – Kimberley Broome

Phone: (08) 9191 3456

# Ngunytju Tjitji Pirni Corporation

Ngunytju Tjitji Pirni (NTP) comprises a model program of enhanced antenatal and postnatal care directed, conducted and staffed by Aboriginal women residing in the Eastern Goldfields area of Western Australia. The program was initially developed as a research project in collaboration with the TVW Telethon Institute for Child Health Research and commenced services in early 1993. This report explains the need for such program, describes the intervention, details the first quantitative and qualitative outcomes and explores future directions.

The report includes information on the pregnancies of women enrolled in the program from its commencement to June 1996 (n=142 women), and on the births of their children (n=149 children). Where available, comparative information on all pregnancies and births in the target area has been given. Comparisons are also made between those women who enrolled antenatally and those who enrolled after the birth of the child. More detailed information, including follow-up to the age of one year, is included for a subset of the children. For the purposes of describing outcomes, this subset has been divided into two groups – the 'Full program' group who received optimal follow-up and the 'Part program' group who were followed for varying amounts of time.

Results show that women known to be at high risk were actively recruited by staff and indicate that, for the 'Full program' group of children, morbidity was identified early in the children's illnesses, allowing prompt referral to hospital where necessary. This appeared to avoid some repeated hospital admissions and extended stays. With regard to immunisation, the data indicate that generally children received all their early vaccinations but that the second and third doses of vaccines were not documented as frequently. Of all the children followed to one year of age, 69% definitely completed all their vaccinations scheduled to this age. Important differences were noted in the 'Full program' group compared with the 'Part program' group which underlined the importance of maintaining frequent and regular contact with the children enrolled. For example, 89% of children in the 'Full program' group were documented as having completed their vaccination schedules to one year of age compared with 53% of the 'Part program' group.

Qualitative evaluation incorporated material from the local community, from health professionals including NTP staff and from client histories. Generally, the NTP model and programs were well received by all those surveyed and it was considered that the program fulfils a crucial need in the community. Identified strengths of the program included control of the process and services by Aboriginal women, the holistic nature of the support and services provided, the integration into other services, the advocacy given by NTP staff for the women involved, the home visiting and follow-up aspects, the non-judgemental approach and the fact that NTP caters for all tribal and family groups. The program has also highlighted areas of additional need such as the special needs of young teenagers, which will require further focussed funding.

The success of NTP is such that it is now accepted and funded as a mainstream health care provider. Medical staff are now being recruited who will legitimise particular types of intervention, working with the Aboriginal Health Workers. The boundaries of the program are being extended to include additional towns and communities and the program could be considered as a model for other areas of Australia.

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Ngunytju Tjitji Pirni Aboriginal Corporation. Ngunytju Tjitji Pirni Corporation Evaluation Report. February 1998

# Appendices

Appendix 1Classification System – Coding for Cause of Death......167

# 6.8 Appendix 1

# **Classification System – Coding for Cause of Death**

The classification system used to code the causes of infant, childhood and young persons deaths (the JFcode) was based on a system previously developed by the late Dr Louisa Alessandri, Dr Eve Blair, Dr Helen Chambers and Dr Anne Read. This classification system was developed in order to facilitate a consistent coding of death throughout the perinatal period and childhood into early adulthood. The system comprised nine major categories (1<sup>st</sup> digit) each of which could be sub-categorised with the use of a second and for infections a third digit. Classification is based on what was the antecedent factor of death. The system was designed primarily for research purposes, but can be mapped to the perinatal component of the Australian and New Zealand Perinatal Mortality Classifications (National Perinatal Data Development Committee Working Group 2000). The major benefit of this coding is that it allows the same code to be applied throughout the child's life course. The simple classification system can be applied to all deaths of all ages in the birth cohort – from the perinatal period to deaths that occurred into adulthood.

The following table includes the classifications and codes for still births, although this report does not include still births.

Mortality classification for stillbirths, neonatal, infant and childhood deaths of births >=400g, excluding elective terminations of any gestation or weight.

0		Normally formed fetuses (with recognized sufficient cause of death.
	00	Without significant underlying antepartum condition recognised.
		Normally formed fetuses with the following underlying conditions (see
		also 810-880)
	10	Rhesus iso-immunisation
	20	Severe pre-eclampsia, eclampsia
	30	Maternal essential hypertension.
	40	Maternal Diabetes.
	50	Maternal Lupus related.
	60	Uncomplicated multiple pregnancy (eg. TTT is coded 830)
	70	Maternal epilepsy
	80	Maternal infections without evidence of fetal infection (eg. giving rise
		to VPT birth)
	90	Other or multiple: eg. severe maternal anaemia (203509).

#### 0 Still Born

#### 1 Intrapartum causes

1		Intrapartum causes
	110	Intrapartum fetal distress >25 weeks without recorded sentinel event,:
		includes cord complications NOS, meconium aspiration,
		malpresentations. (= unexplained cause first apparent in labour).
	120	Prematurity: (death due to labour of normally formed, non-infected
		fetus <26 w.)
	130	Intrapartum asphyxia with sentinel event (ruptured uterus N=8, 2h tonic
		spasm (N=1) amniotic fluid embolism (2)), true cord knot (2) traumatic
		exsanguination (88195), cord tightly around neck (346008), vasa
		praevia (336254).
	131	Intrapartum asphyxia without sentinel event
	140	Obstructed labour, specified (not inferred from presentation or BW).
	150	Cord prolapse in birth $> 32$ weeks
	160	Intrapartum complications of multiple delivery
	190	Unattended labour.

#### 2 **Significant Birth Defect(s)**

## 3

**Frank Immaturity of organ systems** (does not apply to stillbirths, see 120 above)

3	300	Frank immaturity of organ systems (does not apply to stillbirths, see
		120 above)
	310	Death from immaturity (<28w) following delivery secondary to APH

## 4 Infection

4		Infection
		2 <sup>nd</sup> digit of 3 digit code denotes site:
	0	unknown
	1	chorioamnionitis (+/- funisitis)
	2	respiratory
	3	blood (septicaemia) and /or multiple sites
	4	brain
	5	peritonitis
	6	gastroenteritis
	7	myocarditis
	8	liver
	9	other eg renal, skeletal, tissue
		3 <sup>rd</sup> digit denotes infectious agent:
	0	unknown
	1	Group B strep
	2	bacterial without a specified code (ie not GBS or listeria)
	3	toxoplasmosis
	4	syphilis
	5	Viral
	6	listeria
	7	Both bacterial and viral
	8	AIDS
	9	other specified agent

## 5 Accidents and Trauma

(Other than birth trauma which is coded as 100-190)

5		Accidents and trauma. (Other than birth trauma which is coded as	
		100-190).	
	510	Road traffic accidents (including antenatal accidents)	
		511 motor vehicle	
		512 motorcycle/pedal bike/trail bike/go kart	
		513 pedestrian/or run over after leaving or falling from	
		vehicle	
	520	Drowning – place not stated	
		521 pool	
		522 dam/water tank/drain/fishpond/lake	
		523 Sea/river	
		525 Bathtub/bucket	
	530 Poisoning		
	540	Fire	
	550	Non-accidental injury	
		551 homicide	
		552 suicide	
	560	Suffocation/asphyxiation not covered in 550 or 540. – includes	
1 5		inhalation/ingestion due to respiratory obstruction/accidental hanging	
Collected from 1998 – 2002			
	561 positional asphyxia		
		562 overlaying	
		Peri-operative accident/following clinical surgical intervention.	
	580 Electrocution		
	590	Accident/trauma NOS, could include NAI where this is questionable,	
		(inc antenatal), includes dehydration/exposure (accidental), including	
		potential manslaughter	
		591 drug overdose	
		592 train runover, slipped	
		/ 11 ~~	

## 6 Cancers & Leukaemias

6 600 Cancers & leukaemias

## 7 700 SIDS 790 Unconfirmed SIDS

# 8 Other Specific Conditions

8		Other specific conditions.
	810	Major APH (before onset of labour) resulting in death before, during or
		after labour.
	820	Acute feto-maternal haemorrhage (will be underascertained - also in
		000).
	830	Lethal complications of twinning not covered elsewhere, eg. twin-twin
		transfusion. (Delivery complications = 160, no recognised complication
		= code 060).
	840	Neurological condition, 1y factor: eg. Status epilepticus, impaired gag
		reflex not known to be due to classifiable cause, CP (DD to aspiration
		pneumonia), febrile convulsion.
	850	Hydrops due to Rhesus iso-immunisation or specific congenital
		anomaly.
	860	Recognised cause of asphyxia or trauma before onset of labour (under-
		estimated).
	870	Asthma
<ul><li>880 PPROM and sequelae</li><li>890 Specific conditions originating not specified above.</li></ul>		1
		Specific conditions originating not specified above.
		891 diabetic related

## 9 Unknown, not classifiable above

9		Unknown, not classifiable above.
	910	Cause(s) not classifiable above.
	990	Cause unknown/unascertainable/undetermined
	991	No coroners report (searched)
	992	Final diagnosis unknown

## Extra Fields

Birth Defects - Major	1
Birth Defects - Minor	2
Cerebral palsy - Major	3
Cerebral palsy - Minor	4

## Co-sleeping field (since 1998 – 2002)

Co-sleeping	1
Not co-sleeping	
Not stated	
Maternal smoking (since 1998 – 2002)	

Yes	1
No	
Not stated	

## Drugs & alcohol (since 1998 – 2002)

Cannabis Alcohol Other drug

Present	1
Not present	
Not stated	

## Motor vehicle accidents

Driver
Passenger
Seat belt
Driveway accident

Present	1
Not present	
Not stated	3

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