Victorian Aboriginal Child Mortality Study

Patterns, Trends and Disparities in Mortality between Aboriginal and Non-Aboriginal Infants and Children, 1999–2008

Jane Freemantle · Rebecca Ritte · Kristen Smith · Dulce Iskandar · Tess Cutler · Bree Heffernan · Grace Zhong · Fiona Mensah · Anne Read

The Victorian Aboriginal Child Mortality Study, 1988–2008

The overall aim of the Victorian Aboriginal Child Mortality Study (VACMS) is to measure the patterns and trends of Aboriginal infant and child mortality and the disparities between Aboriginal and non-Aboriginal populations for births occurring in Victoria spanning (birth) years 1988–2008, inclusive. In order to calculate mortality rates, a more accurate count of Aboriginal births was an essential first step.

The VACMS is a total population, data linkage, child mortality study being undertaken at Onemda VicHealth Koori Health Unit at The University of Melbourne in conjunction with the Victorian Aboriginal Community Controlled Health Organisation. It is funded by the Australian Research Council, Department of Health Victoria, the Australian Government Department of Prime Minister and Cabinet (formerly Families, Housing, Community Services and Indigenous Affairs), the Lowitja Institute and the R E Ross Trust.

The study has four distinct phases:

Phase 1. Matching of vital statistics datasets containing birth information to obtain a more accurate and complete Indigenous identification for Aboriginal births.

Phase 2. Calculation of an 'ever-never Aboriginal' identifier. Appending of the perinatal information describing all births in Victoria from 1988–2008, inclusive to the matched dataset. Analysis of matched birth dataset and reporting of the patterns and trends of births in Victoria to Aboriginal and/or Torres Strait Islander mothers and/or fathers from 1999–2008, inclusive.

Phase 3. Review of all death information (reported to the Consultative Council on Obstetric & Paediatric Mortality and Morbidity), coding and classification of the death information using a specific cause of death code and validation of the coding and classifications. Development of a comprehensive death dataset (infant and child deaths in Victoria, 1988–2009).

Phase 4. Linking the matched birth dataset with the death dataset. Analysis and preparation of a report that describes the patterns and trends of deaths for Aboriginal and/or Torres Strait Islander compared with non-Aboriginal and/or Torres Strait Islander infants and children (0–11 years), for births from 1999–2008, inclusive.

The six-year study commenced in 2009 and is now complete with the publication of this report.

This report is the fourth and final in a series, with the other reports available from the VACMS website (www.vacms.net.au):

> Heffernan, B., Sheridan, S. & Freemantle, J. 2009, *An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People*, Onemda VicHealth Koori Health Unit, The University of Melbourne, Melbourne.
>
> Heffernan, B., Iskandar, D. & Freemantle, J. 2012, *The History of Indigenous Identification in Victorian Health Datasets, 1980–2011: Initiatives and Policies Reported by Key Informants*, The Lowitja Institute, Melbourne.
>
> Freemantle, C. J., Ritte, R., Heffernan, B., Cutler, T. & Iskandar, D. 2013, *Victorian Aboriginal Child Mortality Study, Phase 1: The Birth Report—Patterns and Trends in Births to Victorian Aboriginal and Torres Strait Islander and Non-Aboriginal and Torres Strait Islander Mothers and/or Fathers 1988–2008 Inclusive*, The Lowitja Institute, Melbourne.

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Patterns, Trends and Disparities in Mortality between Aboriginal and Non-Aboriginal Infants and Children, 1999–2008

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 dependent 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.

Professor Helen Milroy, 2004

Jane Freemantle · Rebecca Ritte · Kristen Smith · Dulce Iskandar
Tess Cutler · Bree Heffernan · Grace Zhong · Fiona Mensah · Anne Read

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A downloadable PDF of this publication is available on the Onemda, VACMS and Lowitja Institute websites, and a CD–ROM of this publication and a Summary Report can also be obtained from:

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This image represents 'connections' and their relevance to health and wellbeing. Our connections with mother earth and the natural world keep us well and our connections with one another through family and community heal us and keep us whole.

Shawana Andrews

An Australian Government Initiative

Foreword

Of all human rights, the most basic is the 'right to survive'. In 1959 the United Nations set down the Declaration of the Rights of the Child, which included in the 10 articles:

> *The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.* (Article 4; see Appendix 4)

It is also a human right to be counted in population statistics in an accurate and timely manner, and people must not be denied the right or opportunity to self-identify as Aboriginal and/or Torres Strait Islander. Without complete and accurate ascertainment of Aboriginal populations in vital statistics, the accuracy of mortality statistics is questionable at best. As infant mortality is a key indicator of effective public health policies and programs, an accurate picture of infant mortality informs a society as to its social progress. Mortality data, particularly the causes of infant and childhood mortality, also reflect a broader set of social, economic, and political issues. If society is unable to care for their most vulnerable, then a nation's overall social prosperity must be brought into question. High infant and child mortality rates in marginalised groups within Australia reflect the stresses and challenges faced by them, not only at 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 provide an important indicator of the health of these communities and suggest the continuing impact of racism, discrimination and dispossession.

This is the fourth and final report of the Victorian Aboriginal Child Mortality Study and it provides a comprehensive description of the patterns and trends of deaths of Aboriginal Victorian-born infants and children from 1999 to 2008. This study reports the causes of Aboriginal infant and child deaths in Victoria and some possible antecedent risk factors. It is now important to discover the common pathways to these deaths and thus identify the pathways to prevention.

This report also describes the mortality gap for Aboriginal compared with non-Aboriginal infants and children between 1999 and 2008. In order to improve, to close the gap, we must systematically collect, analyse and, most importantly, act on these data on a population basis. We must regularly inform the priorities, strategies, access to services and evaluation of programs that are essential if we are to achieve Aboriginal health equality. These data are critical if we are to achieve the consensus priority targets of the Council of Australian Governments to halve Aboriginal infant mortality.

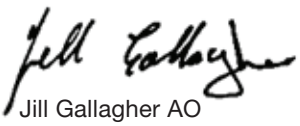
Dr Helen Milroy, a psychiatrist and a senior Aboriginal academic stated:

> *[t]o 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* (Freemantle et al. 2004).

To the families and friends of the infants and children who have died, I extend my sincere sympathy. It is the hope of the research team that this report will assist in informing policy and strategy that will not only contribute to preventing deaths in infants and children, but also to informing optimal environments for them to live in.

I would like to sincerely thank the members of the Victorian Aboriginal Child Mortality Study investigator and research teams for their commitment, energy and generous sharing of their expertise, and their passionate resolve to complete this important work.

Thanking you,



Jill Gallagher AO
Chief Executive Officer
Victorian Aboriginal Community Controlled Health Organisation

Access to the data for this study was provided by the Consultative Council on Obstetric & Paediatric Mortality and Morbidity (CCOPMM). The views expressed in this report are those of the authors and not of the CCOPMM.

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Key Messages and Significance of VACMS

Infant mortality is a key indicator of effective public health policies and programs, and an accurate picture of infant mortality informs a society as to its social progress. However, in Victoria the data describing Aboriginal postneonatal infant and child mortality have not been published to date.

To calculate infant and child mortality, a more accurate ascertainment of the Indigenous status of births and deaths was critical. The Victorian Aboriginal Child Mortality Study (VACMS) has reported the number of births in Victoria where mother and/or father identified as Aboriginal and/or Torres Strait Islander using the Ever-Aboriginal Rule, and the number of infant and child deaths associated with these births.

Key Messages

Births

- Using linked total population data, the VACMS indicated that the previous estimate of the number of births in Victoria to mothers and/or fathers who identified as Aboriginal and/or Torres Strait Islander should be increased by 87%:
  - » 70% of these births were directly due to fathers identifying as Aboriginal and/or Torres Strait Islander in the Registry of Births Deaths and Marriages (RBDM), and 30% to the reassignment of mother's Indigenous status – recorded in the Victorian Perinatal Data Collection (VPDC) – according to the self-identified status in the RBDM.
- Using the ever/never Aboriginal Indigenous identifier, the VACMS reported that between 1999 and 2008, 1.6% of births in Victoria were to mothers and/or fathers who identified as Aboriginal and/or Torres Strait Islander.*
- There was significant regional variation in the under-ascertainment of the Indigenous status of births varying from 269% in the Western Metropolitan region to 33% in the Loddon Mallee region.
- Births to teenage mothers accounted for 17% of Aboriginal births (compared with 3% among the non-Aboriginal teenage population).
- 31% of Aboriginal births were to mothers older than 30 years (compared with 60% among non-Aboriginal mothers).
- 10% of Aboriginal births were preterm compared with 6% among the non-Aboriginal birth population.
- 11% of Aboriginal births were less than 2500 grams compared with 5% of non-Aboriginal births.

Deaths

- Between 1999 and 2008, the Aboriginal infant cumulative mortality rate was 9/1000 live births, which was twice as high as reported in the non-Aboriginal population: there were 48 'excess' Aboriginal infant deaths in the 1999–2009 birth cohort.
- The Aboriginal cumulative infant mortality rate has not changed over the 10 years studied and the risk of death for an Aboriginal child (compared with a non-Aboriginal child) in the first year of life remains significantly higher at two-fold.

*See note on terminology for Aboriginal Australians in Glossary of Terms, p.xvi.

- The neonatal mortality rate (death in the first 28 days of life) for Aboriginal infants decreased from 7/1000 live births to 6/1000 live births: the risk of death in the neonatal period was twice as high for Aboriginal compared with non-Aboriginal infants.
- The postneonatal mortality rate (death between 29 days and within one year of birth) increased from 2/1000 neonatal survivors to 4/1000 neonatal survivors: the risk of death in the postneonatal period was 3 times as high for an Aboriginal compared with a non-Aboriginal infant.
- The risk of death for an Aboriginal infant was significantly higher compared with a non-Aboriginal infant for deaths due to prematurity, infection, injury and SIDS.
- The gap in the risk of death due to SIDS between Aboriginal and non-Aboriginal infants has more than doubled across the birth cohorts.
- An Aboriginal child was nearly 2.5 times more likely to die before his/her 11th birthday compared with a non-Aboriginal child.
- Deaths due to injury (1–<11 years) were the main cause of death for both Aboriginal and non-Aboriginal children.

Significance

- The VACMS demonstrates the value of population data linkage, particularly where the population is small. The knowledge gained through data linkage will increase in proportion to the amount of data that is made available through these linkages.
- A method to determine a more accurate ascertainment of Indigenous status in vital statistics data has been established.
- The VACMS demonstrated the benefit of linking population data through matching (independent) statutory and administrative datasets in order to validate an infant's Indigenous status: birth information collected in the VPDC was matched with the birth registration information collected by the RBDM.
- To date, national mortality rates in Australia for Aboriginal and non-Aboriginal infants and children have excluded Victorian data.
    - » Data generated through the VACMS have the potential to provide the Victorian baseline data that will contribute to measurement of the Australian Government's specific aim 'to halve the gap in mortality rates for Indigenous children under five by 2018'.
- Using linked population data to provide a more complete Indigenous identification of Victorian births and deaths, the VACMS identified 36 infant and child deaths that would have previously been identified as non-Aboriginal.
- The VACMS reports the mortality rates for Victorian-born Aboriginal postneonates, infants and children, 1999–2008; this is the first time these data have been published.
- The Victorian Infant and Child Mortality Database (using information collected by the Consultative Council on Obstetric & Paediatric Mortality and Morbidity) provides a unique resource that has the potential for ongoing and strategic research into the prevention of deaths in Victorian-born Aboriginal children.

Glossary of Terms

Aboriginal	Aboriginal and/or Torres Strait Islander populations are referred to in this report as 'Aboriginal'. The term includes Torres Strait Islander people, and because of the small population living in Victoria, data describing Torres Strait Islander people is not disaggregated. This was deemed to be acceptable on consultation with Onemda VicHealth Group and VACCHO.
Age-specific child mortality rates	The number of deaths in specific age groups defined by the population at risk (per 1000 person-years). Age-specific rates were calculated for those who died after reaching their first birthday and before reaching their nineteenth birthday.
Birth cohort	The component of the population born during a particular period and identified by date of birth so that its characteristics (e.g. causes of death and numbers still living) can be ascertained as it enters successive time and age periods (Last 2000).
Birth defect	Any defect probably of prenatal origin (Bower & Rudy 2000).
Birth weight	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). Categories: • very low birth weight: <1500 grams • low birth weight: 1500–2499 grams • normal birth weight: 2500–4499 grams.
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.
Chorioamnionitis	Infection in the placental membranes.
Denominator	The lower portion of a fraction used to calculate a rate or ratio (Last 2000).
Ever-Aboriginal Rule	A rule used to determine the Indigenous identification of an individual using linkage of multiple population datasets that include information on a person's Indigenous status.
Ever/never-Aboriginal	A person who identified as Aboriginal and/or Torres Strait Islander in one of either the Victorian Perinatal Data Collection or the Registry of Births, Deaths and Marriages (birth registration) (Freemantle et al. 2013).
Excess deaths	Deaths that are the 'excess over statistically expected deaths in a population within a given time frame' (Glossary of Risk Analysis, available online, accessed August 2014).

Geographical location of birth/ death	Metropolitan or regional location of the residence at time of birth/death (categories according to the Department of Human Services health service regions).
Hazard ratio	A measure of how often a particular event happens over time in one group compared to how often it happens in another group. The assumption in proportional hazard models for survival analysis is that the hazard in one group is a constant proportion of the hazard in the other group. This proportion is the hazard ratio (Duerden 2009).
Infant death	The death of a live born infant within the first year of life (Gee 1995); includes neonatal and postneonatal deaths.
Indigenous/ Aboriginal	A person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives (AIHW 2006).
Indigenous/ Aboriginal infant/ child	An infant/child who is born to a mother and/or father who identify as Aboriginal or Torres Strait Islander or is identified as such by a responsible person on admission to hospital.
Indigenous/ Aboriginal status	Defining whether a person/child identifies or is identified as Aboriginal and/or Torres Strait Islander or non-Aboriginal and/or Torres Strait Islander.
JFcode	Coding system for cause of death.
Live birth	The birth of a child who, after delivery, breathes or shows other evidence of life such as a heartbeat (Victorian definition) (CCOPMM 2012).
Mortality rates (all-cause)	Expressed as the cumulative mortality risk for infants (CMR) and for children (ChMR), which is the risk of mortality over a specified number of years and expressed per 1000 live births: • infant mortality—expressed as per 1000 live births • neonatal mortality—expressed as per 1000 live births • postneonatal mortality—expressed as per 1000 neonatal survivors • childhood mortality—expressed as per 1000 infant survivors.
Mortality rates (age-specific)	Expressed as ChMR, which is the risk of mortality over a specified number of person-years expressed per 1000 person-years.
Motor vehicle accidents	Deaths that occurred inside the structure of a motor vehicle (passenger or driver).
Multiparous	A woman who has given birth two or more times.

Neonatal death	A death occurring within 28 days of birth in a live born infant of at least 20 weeks gestation, or if gestation is unknown, weighing at least 400g (CCOPMM 2012).
Non-Aboriginal	Includes all persons other than those who identify as an Aboriginal and/or Torres Strait Islander.
Not in birth cohort	Anyone who was born and/or died outside the prescribed VACMS birth cohort.
Numerator	The upper portion of a fraction used to calculate a rate or ratio (Last 2000).
'Other' categories (location of birth)	Births that occurred in Victoria where mother's usual residence was interstate or overseas.
'Other' causes (of death)	Causes include: • 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.
Perinatal death	A stillbirth or neonatal death (Gee & O'Neill 1998).
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 1999–2009.
Place of death	Death occurring in hospital or out of hospital.
Postneonatal death	Death of a live born baby after 28 days and within one year of birth (Li et al. 2013).
Prematurity/ preterm birth	A birth where the infant's gestation is less than 37 completed weeks.
Primiparous	A woman who has given birth once.
Rate ratio	Relative difference measure to compare the incidence rates of events occurring at any given point in time (occurrence could be death/survival). In this report the rate ratio reports the comparisons between Aboriginal and non-Aboriginal populations.
Stillbirth	The birth of an infant of at least 20 weeks' gestation or, if gestation is unknown, weighing at least 400 grams who shows no signs of life after birth (CCOPMM 2012).
Residence at time of death	Residence of the infant/child at time of death.
Road traffic accidents	Deaths due to bicycle, tricycle, motorbike, and deaths due to train accidents are sub-coded under road traffic accidents.
Septicaemia	The presence of bacteria in the blood (bacteraemia); often associated with severe disease.
Sex	Gender of the infant/child.
Sudden Infant Death Syndrome (SIDS)	The sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history (Krous et al. 2004).

List of Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ARC	Australian Research Council
CCOPMM	Consultative Council on Obstetric & Paediatric Mortality and Morbidity
CCU	Clinical Councils Unit
ChMR	child (cumulative) mortality rate
CI	confidence interval
CMR	cumulative mortality rate
DHS	Department of Human Services (Victorian Government)
GIS	Geographic Information Systems
HR	hazard ratio
ICD	International Classification of Disease
LBW	low birth weight
NMR	neonatal mortality rate
NND	neonatal death
NTD	neural tube defect
PHWB Act	*Public Health and Wellbeing Act 2008* (Vic.)
PNN	postneonatal
PNND	postneonatal death
PNMR	postneonatal mortality rate
PSANZ	Perinatal Society of Australia and New Zealand
PYrs	person-years
RBDM	Registry of Births, Deaths and Marriages
RR	rate ratio
SIDS	Sudden Infant Death Syndrome
SPSS	Statistical Package for the Social Sciences
TOP	termination of pregnancy
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VACMS	Victorian Aboriginal Child Mortality Study
VPDC	Victorian Perinatal Data Collection
VPDCU	Victorian Perinatal Data Collection Unit

Executive Summary

This report, *Victorian Aboriginal Child Mortality Study: Patterns, Trends and Disparities in Mortality between Aboriginal and Non-Aboriginal Infants and Children, 1999–2008* (hereafter the Mortality Report), is the fourth and final report in the series from the Victorian Aboriginal Child Mortality Study (VACMS). The purpose of the Mortality Report is to provide a comprehensive resource to inform policy and strategies aimed at preventing deaths in Aboriginal and Torres Strait Islander infants and children in Victoria.[1] This is the first time that postneonatal infant and child mortality rates have been reported for the Victorian-born Aboriginal population. Data reported for the years 1999–2008 identify the baseline upon which to build a picture of the patterns and trends of Aboriginal mortality into the future.

The Victorian Infant and Child Mortality Database, using data held by the Consultative Council on Obstetric & Paediatric Mortality and Morbidity (CCOPMM), provides a unique resource that has the potential for ongoing and strategic research into the prevention of deaths in Victorian-born Aboriginal infants and children. Specifically, the denominator used in the calculation of the age-specific and cause-specific mortality rates represents matched population data that described births to mothers and/or fathers who identified as Aboriginal and/or Torres Strait Islander. The data derived from two independent statutory population datasets have enabled the validation of the Aboriginal identification of the mother in the perinatal data and the inclusion of additional information describing the mothers' and fathers' self-identified Aboriginal status derived from the Registry of Births Deaths and Marriages.

Individuals may choose to identify themselves differently in varying contexts and at different points in time. However, nationally and internationally it is widely accepted that self-identification is the superlative methodology for statistical measurement of Indigenous status. Accordingly, the Australian Bureau of Statistics (ABS) has adopted this methodology on the basis of (a) its own research exploring self-identification in data collection contexts in Australia; (b) the high levels of support it has been given by the Aboriginal population; and (c) in alignment with international best practice (ABS 2013; AIHW 2010). Currently, Victoria's data describing Aboriginal infant mortality are not included in the national statistics describing Aboriginal infant mortality.

This study uses total population linked data that describe all deaths in Victoria of Aboriginal (and non-Aboriginal) children, 1999 to 2008 inclusive. The denominator used in the calculation of all-cause and cause-specific infant and child mortality rates for Victorian-born children was based on ever/never-Aboriginal (and non-Aboriginal) births using the Ever-Aboriginal Rule reported in the *Victorian Aboriginal Child Mortality Study, Phase 1: The Birth Report* (Freemantle et al. 2013). Advice received from the review of the Birth Report informed the generation of the denominator. The Ever-Aboriginal Rule is based on whether a person self-identifies (or is identified by a third party) as Aboriginal and/or Torres Strait Islander. Although the case files of all infants and children who were born between 1988 and 2008 inclusive and who died in Victoria between the years 1988 to 2009 inclusive were reviewed, the Mortality Report only presents the results of the birth cohort 1999 to 2008 inclusive, based on the integrity of the denominator (Freemantle et al. 2013).

1 See note on terminology for Aboriginal Australians in Glossary of Terms, p.xvi.

Using this method, the VACMS reports a further 36 Aboriginal infant and child deaths that had been previously identified as non-Aboriginal.

The VACMS reports the patterns and trends of mortality for Victorian-born Aboriginal infants compared with non-Aboriginal infants aged from birth to their first birthday. These deaths do not include stillbirths. This report also includes the patterns and trends of mortality for children from their first birthday to their eleventh birthday. In order to report on all data included in the death cohort, the report includes the cause of death and place of birth for infants and children born outside Victoria.

The study uses a coding system for cause of death (JFcode) that enables a consistent coding of death across the perinatal and childhood periods and into early adulthood. The infant mortality rate is expressed as the number of deaths per 1000 live births (described as the cumulative mortality rate, CMR) and the difference between the two populations is expressed as the rate ratio (RR) with 95% confidence intervals (CIs). The child (cumulative) mortality rate (ChMR) is expressed as the ChMR per 1000 infant survivors. The age-specific mortality rate in childhood is reported as per 10,000 person-years to allow for comparisons of mortality rates over the lives of children up to their eleventh birthday. Deaths of infants and children who died in Victoria but who were born outside Victoria are expressed as a percentage of deaths of this cohort.

The draft of the Mortality Report was reviewed by the staff of the Clinical Councils Unit (CCU) at the Department of Health (DoH) Victoria and comments referred to the CCOPMM. It was also reviewed by the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), DoH Victoria's Aboriginal Health Branch, and the VACMS investigators.

Key findings: Birth years 1999–2008 inclusive[2]

The findings for Aboriginal infants and children are highlighted in ochre (non-Aboriginal no highlighting) in the following summaries, and statistically significant results are identified in bold text. The timeframe included all children born in Victoria between 1999 and 2008 inclusive who died in Victoria from 1999 to 2009 inclusive. The two birth cohorts referred to are 1999–2003 and 2004–08. Infant mortality refers to all live born infants who died before reaching their first birthday. The 95% confidence intervals are included as an indication of the stability of the population point estimates. However, of importance is the comparative magnitude of the estimate reported in the Aboriginal population and the direction of the difference when reported according to the two birth cohorts.

It is acknowledged that the results in this report include small numbers of deaths, particularly when the data are disaggregated to report cause-specific deaths for Aboriginal infants and age-specific and cause-specific deaths for Aboriginal children. However, every death of an infant or child is a tragedy and the precise set of circumstances surrounding the loss must be considered in order that such tragedies might be prevented.

The number of 'excess' Aboriginal infant deaths have been calculated and reported as an important indicator as to the burden of mortality experienced within the Aboriginal population. The calculation of excess deaths refers to deaths that are the 'excess over statistically expected deaths in a population within a given time frame' (SfRA 2014). The number of excess deaths is the difference between the number of deaths observed in the Victorian Aboriginal population and the number of deaths that would have occurred in the Victorian Aboriginal population if it had the same infant mortality rate as the Victorian non-Aboriginal population. Excess deaths have also been calculated to relate excess deaths to specific causes.

2 The mortality rates are calculated from a birth cohort: births from 1 January 1999 to 31 December 2008; deaths 1 January 1999 to 31 December 2009.

Summary of all infant deaths

The VACMS team reviewed 3761 deaths (between 1999 and 2009), which represented deaths that had occurred in Victoria and been reported to CCOPMM. Of these deaths, 3025 infant deaths (plus 2 of unknown Indigenous status) are included in this report. Of the infant deaths, 56% (n = 1699) were male, 44% (n = 1321) were female and five were of indeterminate gender; 73% (n = 2217) were neonatal deaths (live born to first 27 days) and 27% (n = 808) were postneonatal deaths (after 28 days but within one year of birth).

The picture of infant mortality is different in the two populations

There were 2932 non-Aboriginal deaths. Of these deaths, 56% (n = 1643) were male and 44% (n = 1284) were female; 74% (n = 2155) were in the neonatal period and 26% (n = 777) were in the postneonatal period.

Of all infant deaths, 3% (n = 93) were Aboriginal. Of these deaths, 60% (n = 56) were male and 40% (n = 37) were female; 67% (n = 62) were neonatal and 33% (n = 31) were postneonatal.

The gap in infant mortality rate has increased

Across the birth cohorts 1999–2003 and 2004–08, the all-cause cumulative mortality rate (CMR) remained similar: 4.7/1000 live births; 4.5/1000 live births.

There were 48 excess Aboriginal infant deaths in the period 1999–2009. The Aboriginal all-cause CMR was similar: 9.1/1000 live births in birth cohort 1999–2003 and 9.4/1000 live births in birth cohort 2004–08. Given the direction of the CMR among Aboriginal and non-Aboriginal infants, the RR changed from 1.9 to 2.1 over the 10 years and thus the risk of Aboriginal infants dying compared to non-Aboriginal infants was more than two-fold in the second birth cohort. The Victorian Aboriginal mortality rate was compared to the Aboriginal CMR in Western Australia (10.6), South Australia (6.9), New South Wales (7.8), the Northern Territory (14.9) and Queensland (9.2) in a similar time period.[3]

The Aboriginal postneonatal mortality rate is higher than the non-Aboriginal neonatal mortality rate

The non-Aboriginal neonatal mortality rate (NMR) was 3.4/1000 live births; the postneonatal mortality rate (PNMR) was 1.2/1000 neonatal survivors. Both rates have decreased over the birth cohorts, although the decrease is not statistically significant.

There were 29 excess deaths in the neonatal period and 19 excess Aboriginal deaths in the postneonatal period for the years 1999–2009.

Over the birth years 1999–2008, the CMR for Aboriginal neonates was 6.2/1000 live births and for postneonates 3.1/1000 neonatal survivors. The risk of death was significantly higher for Aboriginal neonates compared with the non-Aboriginal population. The NMR for Aboriginal infants decreased

3 These States had reasonably reliable data describing Aboriginal populations from early the 1990s (Queensland from 1998 and New South Wales from 2013).

(6.9/1000 live births to 5.7/1000 live births) and the PNMR increased (2.2/1000 neonatal survivors to 3.8/1000 neonatal survivors) in birth cohorts 1999–2003 and 2004–08 respectively.

*The risk of death in the postneonatal period was significantly higher for Aboriginal infants born in the second birth cohort compared with non-Aboriginal infants (**RR = 3.2, p<0.0001**).*

Gender patterns are evident

Over all years studied, the CMR for males was significantly higher (5.0/1000 live births) than for females (4.1/1000 live births) (**p<0.0001**). The CMR decreased for males over the period studied (5.2/1000 live births to 4.8/1000 live births) and increased for females (4.0/1000 live births to 4.2/1000 live births).

There were 31 excess Aboriginal male and 17 excess Aboriginal female infant deaths, 1999–2009.

*The CMR was similar for both Aboriginal male (10.8 to 11.2/1000 live births) and female infants (7.3 to 7.6/1000 live births) over the period studied. The risk of Aboriginal female and male infants dying compared to non-Aboriginal infants was significantly higher (males: **RR = 2.2: CI 1.7–2.9; females RR = 1.8: 95% CI 1.3–2.5**). The risk of infant death for Aboriginal (compared with non-Aboriginal) males increased from RR = 2.1 to RR = 2.4 (p = 0.6) and remained similar for Aboriginal (compared with non-Aboriginal) female infants (RR = 1.8, p = 1.0).*

Teenage pregnancies were associated with high mortality rates

Between 1999 and 2008, 3% of non-Aboriginal infants were born to teenage mothers and 5% of infant deaths were among infants born to teenage mothers. The highest CMR was among infants born to teenage mothers (8.1/1000 live births). The CMR associated with teenage births increased over the two birth cohorts (7.7/1000 live births to 8.6/1000 live births; p interaction = 0.5).

*Between 1999 and 2008, 16.3% of Aboriginal infants were born to teenage mothers and 21% of infant deaths were among infants born to teenage mothers. The highest CMR for Aboriginal infants was among those born to teenage mothers. The CMR for infants born to Aboriginal teenage mothers was 13.8/1000 live births. The CMR was significantly higher compared with the non-Aboriginal population (**RR = 1.7, CI 1.0–2.9, p<0.05**). The CMR increased over the two birth cohorts (7.9/1000 live births to 18.3/1000 live births).*

The CMR of infant mortality decreased with increasing maternal age, but reduced more slowly among Aboriginal infants compared with non-Aboriginal infants and thus the gap in the risk of infant mortality according to maternal age widened according to increased maternal age.

Significant population differences observed among normal birth weights

The CMR for infants with a normal birth weight decreased significantly over the two birth cohorts (1.6/1000 live births to 1.4/1000 live births, p = 0.01).

*An Aboriginal infant born with a normal birth weight was nearly two times more likely to die compared with a non-Aboriginal infant (**RR = 1.9, CI 1.3–2.8**). The CMR for Aboriginal infants born with a normal birth weight increased from 2.2/1000 live births to 3.3/1000 live births over the two birth cohorts (p = 0.5).*

Significant population differences observed associated with gestational age

The CMR for babies born preterm remained the same over the two birth cohorts (RR = 1.0, CI 0.9–1.1), but decreased significantly among term infants (**RR = 0.8, CI 0.7–0.9**).

*The CMR for preterm Aboriginal infants increased from 60.6 to 65.3/1000 live births between the two birth cohorts (RR = 1.1, CI 0.7–1.7) and decreased among term infants; 3.2/1000 live births to 2.7/1000 live births (RR = 0.8, CI 0.4–1.8). The CMR for preterm births was significantly higher among Aboriginal infants compared with their non-Aboriginal counterparts (**RR = 1.5, CI 1.2–1.9**). Similarly, the CMR for full-term births was also significantly higher among Aboriginal infants compared with their non-Aboriginal counterparts (**RR = 1.9, CI 1.3–2.8**).*

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

Between 1999 and 2009 the main causes of mortality among non-Aboriginal infants were significant birth defects (36%), prematurity (30%) and intrapartum incidents (10%). Sudden Infant Death Syndrome accounted for 6% and infection for 5% of infant deaths. The main causes of death remained similar across the two birth cohorts.

There were 24 excess Aboriginal infant deaths due to prematurity, four excess Aboriginal infant deaths attributed to infection and five excess Aboriginal infant deaths attributed to injury, 1999–2009.

The main cause of mortality among Aboriginal infants was prematurity (40%). Significant birth defects (16%), SIDS (15%) and intrapartum causes (10%) were also major causes of infant death. Infection and injury accounted for 7% of infant deaths.[4] There were no cancer/leukaemia deaths during this period.

The CMR for significant birth defects remained stable across the birth cohorts (1.4 to 1.5/1000 live births). There was no significant difference in the risk of death between the Aboriginal and non-Aboriginal infant populations and there were no excess Aboriginal infant deaths attributed to birth defects, 1999–2009.

*In the most recent years studied, the CMR due to injury was five times that for non-Aboriginal infants (**RR = 5.0, CI 2.9–8.6**).*

4 When the infant deaths were disaggregated according to cause of death, the number of deaths was relatively small. However, the magnitude of difference when compared with the non-Aboriginal population was mostly statistically significant.

Significant increased risk of SIDS among Aboriginal infants

The CMR attributed to SIDS was 0.3/1000 live births and decreased among non-Aboriginal infants over the two birth cohorts (RR = 0.9, CI 0.6–1.1).

*Between 1999 and 2008 inclusive, an Aboriginal infant was five times as likely to die due to SIDS compared with a non-Aboriginal infant (**RR = 5.0, CI 2.9–8.6, p<0.0001**). The CMR due to SIDS increased for Aboriginal infants (1.0/1000 live births to 1.7/1000 live births) and remained similar among non-Aboriginal infants across the birth cohorts (0.3/1000 live births). Thus the gap between Aboriginal and non-Aboriginal infant mortality associated with SIDS has more than doubled across the birth cohorts (RR = 3.2 to RR = 6.6).* There were 12 excess Aboriginal infant deaths attributed to SIDS between 1999 and 2009*.*

Co-sleeping and SIDS

There was information in 23% of case files where SIDS was identified as the cause of death. Where information was available regarding 'sleep-place', 36% of Aboriginal infants whose deaths were attributed to SIDS were identified as co-sleeping at the time of death.

NOTE: Co-sleeping cannot be described as a contributing factor to the 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

The all-cause CMR was highest among infants born in regional locations (regional, 4.8; metropolitan, 4.4/1000 live births). Over time there was a significant decrease in all-cause mortality for infants born in regional locations (5.0 to 4.6/1000 live births, p = 0.02). The CMR was similar for infants born in metropolitan locations (4.5 to 4.4/1000 live births, p = 0.6).

The CMR for non-Aboriginal infants born in 'other'[5] geographical locations was 6.7/1000 live births and remained similar between the birth cohorts.

*The CMR was higher for infants born in regional locations compared with those born in metropolitan locations (9.8 to 8.4/1000 live births, p = 0.5). Between the two birth cohorts, there was nearly a two-fold increase in the Aboriginal CMR for infants born in regional locations (6.9 to 11.8/1000 live births, p = 0.08) and a corresponding decrease observed in the metropolitan regions (11.0 to 6.4/1000 live births, p = 0.9). The risk of all-cause mortality for Aboriginal infants compared with non-Aboriginal infants was significantly greater independent of residence at time of birth, but was greatest among infants born in regional areas (**RR = 2.0, CI 1.5–2.7**).*

5 'Other' geographical location refers to infants who were born in Victoria but whose permanent residence was interstate or overseas.

Regional locations had higher rates of cause-specific mortality

A non-Aboriginal infant was nearly twice as likely to die of SIDS if the mother was residing in a regional location at the time of birth, compared to a non-Aboriginal infant born in a metropolitan location (RR = 1.7, CI 1.2–2.3).

The CMR between 1999 and 2008 for Aboriginal infants born in regional locations was higher than the CMR of births in metropolitan locations for deaths due to infection (RR = 1.5, CI 0.2–9.2) and SIDS (RR = 2.2, CI 0.7–7.0), and lower for infants dying as a result of birth defects (RR = 0.4, CI 0.1–1.3).

Maternal smoking during pregnancy

The association between poor infant outcome and maternal smoking during pregnancy has been reported and is complex. The Victorian Perinatal Data Collection recorded maternal smoking in the perinatal record from 2009. Maternal smoking is not reported in this report.

Summary of childhood mortality

When the data to identify deaths in children between their first birthday and before reaching their eleventh birthday were disaggregated according to Indigenous status, the number of deaths within the Aboriginal population was (relatively) small. Therefore, in interpreting these results it is important to note this small (absolute) number of Aboriginal deaths. Given that the main causes of death among this age group are preventable, these data must not be ignored. The RR and hazard ratio (HR) (age-specific mortality) have been reported to indicate the magnitude of the difference and the CIs as an indication of the population numbers. These estimates provide an indication of the direction of the rates and the magnitude of the effect.

All-cause specific child mortality is expressed as the child (cumulative) mortality rate per 1000 infant survivors (all-cause mortality) and per 10,000 infant survivors (cause-specific mortality), and the risk of an Aboriginal child dying compared with a non-Aboriginal child is expressed as a rate ratio (RR). Age-specific mortality rates are expressed as the ChMR per 1000 person-years and the risk of an Aboriginal child dying compared with a non-Aboriginal child is expressed as a HR.

Of the case files collated by the CCOPMM that described the deaths of all children who were born in Victoria and were reviewed by the VACMS research team, a total of 474 deaths were in this age group. Of these deaths, 53% (n = 251) were male and 47% (n = 223) were female.

Higher rates of death among Aboriginal children (1999–2008)

Between 1999 and 2009 inclusive, non-Aboriginal deaths accounted for 97% (n = 458) of the Victorian-born deaths. The ChMR was 0.7/1000 infant survivors.

Of the childhood deaths, 3.4% (n = 16) were Aboriginal. This percentage was more than double the percentage of Aboriginal births. The ChMR for an Aboriginal child was 1.6/1000 infant survivors. An Aboriginal child was nearly two-and-a-half times more likely to die in childhood compared with a non-Aboriginal child (RR = 2.3, CI 1.4–3.8, p<0.0008).

Males were more likely to die during childhood

Non-Aboriginal males accounted for 53% of deaths and females for 47% of deaths. The ChMR according to gender was similar.

*Aboriginal males accounted for 63% (n = 10) of childhood deaths and females for 38% (n = 6). The ChMR was highest among Aboriginal male children and an Aboriginal male was nearly three times more likely to die compared with a non-Aboriginal male (**RR = 2.7: CI 1.5–5.1 p = 0.001**). There was no significant difference in the risk of an Aboriginal female compared with a non-Aboriginal female dying between the first and eleventh birthdays (RR = 1.8: CI 0.8–3.9).*

Regional difference in mortality rates (reflects the residential location at the time of birth)

The percentage of deaths in childhood was higher in metropolitan locations (71%), which reflected the percentage of births that was also higher in metropolitan locations (73%). The ChMR was similar in the metropolitan (0.8/1000 infants survivors) and regional (0.7/1000 infant survivors) locations between 1999 and 2008.

The proportion of deaths was higher in metropolitan areas (50%), reflecting the proportion of births in metropolitan areas (48%). Between 1999 and 2008 the ChMR was higher among children born in metropolitan locations (1.9/1000 infant survivors) than those born in regional locations (1.4/1000 infant survivors) (p = 0.6).

Age-specific mortality[6]

The ChMR was greatest in children aged between 1–2 years at the time of death (0.2/10,000 person-years) and decreased according to increasing age groups.

*The ChMR was greatest in children aged between 1–2 years at the time of death (0.5/1000 person-years), followed by age groups 6–10 years (0.3/1000 person years); the ChMR was least in the 3–5 year age group (0.2/1000 person-years). Aboriginal children aged 6–10 years were almost four times more likely to die than their non-Aboriginal counterparts (**HR = 3.9; CI 1.2–12.4**). Aboriginal females in the 1–2 year age group were more than twice as likely to die (**HR = 2.4, CI 1.1–6.6**) and Aboriginal males in the 6–10 year age group were nearly eight times (**HR = 7.8, CI 2.4–25.5**) more likely to die compared with their non-Aboriginal female and male counterparts (respectively). Although the wide CIs reflect the relatively small number of Aboriginal deaths within the different age groups compared with the non-Aboriginal numbers, the significantly higher risk of death should not be ignored.*

The main causes of childhood death were preventable

For both populations, deaths due to injury were the most frequent cause of deaths (0.2/1000 infant survivors) among children who died before reaching their eleventh birthday. The ChMR was

6 The age cohorts have been determined for the purposes of this report to reflect before pre-school, pre-school and primary school ages.

greatest for deaths due to injury and birth defects (0.2/1000 infant survivors). The ChMR was highest among male children who died as a result of injury (0.3/1000 infant survivors).

*Deaths due to injury were also a major cause of death among Aboriginal children (0.7/1000 infant survivors). The ChMR was highest among male children (0.8/1000 infant survivors). The RR was more than three times greater for Aboriginal compared with non-Aboriginal children (**RR = 3.3, CI 1.6–7.1**).*

Gender patterns are evident

The ChMR for male children was similar to the ChMR for female children (RR = 1.1, CI 0.9–1.3, p = 0.6).

*An Aboriginal male was one-and-a-half times more likely to die compared with an Aboriginal female child (RR = 1.5, p = 0.3). However, a male Aboriginal child was nearly three times more likely to die before reaching his eleventh birthday compared with a non-Aboriginal male child (**RR = 2.7, CI 1.5–5.1, p<0.001**). Although the risk for Aboriginal female children compared with non-Aboriginal female children was nearly twice as high, the estimate was not statistically significant (RR = 1.8, CI 0.8–3.9, p = 0.2).*

Patterns in mortality according to geographical location are evident

The proportion of births and deaths according to mother's geographical location at the time of the child's birth was similar. Although the ChMR was higher among children born in regional locations (0.8/1000 infant survivors) compared with those born in metropolitan locations (0.7/1000 live births), there was no significant statistical difference in the risk of a child dying according to the mother's residential location at birth (RR = 1.2, CI 1.0–1.5, p = 0.6).

The proportions of births and child deaths according to mother's residence at the time of birth among the Aboriginal population differ (metropolitan births 45%, deaths 50%; regional births 48%, deaths 44%). The ChMR was higher among children born in metropolitan locations (1.9/1000 infant survivors) compared with those born in regional locations (1.4/1000 infant survivors) (RR = 1.3, CI 0.4–3.6, p = 0.6).

Summary of Victorian deaths where the residence at birth was interstate or overseas

Between the years 1999 and 2009 inclusive there were 95 infant deaths (39 neonatal deaths (NNDs) and 56 postneonatal deaths (PNNDs)) and 61 child deaths reviewed by CCOPMM where the place of birth was interstate or overseas.

The largest proportion of Victorian infant deaths where the place of residence at birth was interstate or overseas was among infants born in Tasmania (NNDs, 46%; PNDs, 29%), and for childhood deaths the largest proportions were for children born overseas (30%) and in New South Wales (28%).

The highest proportion of infant deaths of interstate or overseas births was due to birth defects (72%), and in childhood the highest proportion was due to injury (36%).

Recommendations Arising from the Victorian Aboriginal Child Mortality Study

This research project has been supported by and included input from, the Victorian Aboriginal Community Controlled Health Organisation and several senior Aboriginal health researchers since its inception. Presentations have been made at various health forums, including meetings for the Aboriginal Community Controlled Health Organisations that form the membership of VACCHO.

Recommendations have been determined in consultation with members of the VACMS Research Advisory Group, the Consultative Council on Obstetric and Paediatric Morbidity and Mortality, the Aboriginal Health Branch (DoH Victoria) and the Victorian Aboriginal Community Controlled Health Organisation, based on the information included in this report. Issues informing these recommendations are found in the Conclusion.

Recommendation 1: There should be continued efforts to improve identification of Aboriginal births and deaths in Victoria to provide evidence for policy, planning and evaluation for State and federal government efforts to 'close the gap' in outcomes for Aboriginal and non-Aboriginal infants and children.

1.1 The Department of Health Victoria can do this through supporting the initiatives aimed at ongoing improvement in the ascertainment of Aboriginal births and deaths by working with the Victorian Registry of Births, Deaths and Marriages as well as continuing to utilise multiple sources of information (such as hospital notes that form part of a case file).

Recommendation 2: The Victorian Government should continue to develop evidence-based policies and programs to reduce morbidity and mortality in Aboriginal and non-Aboriginal infants and children, with special attention to known preventable causes of death that disproportionately affect Aboriginal infants and children.

2.1 Particular consideration should be given to determining evidence-based policies and interventions aimed at reducing the Aboriginal mortality rates in the postneonatal period.

Recommendation 3: The Victorian Government should implement routine linkage of birth and death data to enable the continuing evaluation of the patterns and trends in mortality among the Victorian Aboriginal infant and child populations and the comparison of these outcomes with non-Aboriginal populations.

Recommendation 4: Deaths from Sudden Infant Death Syndrome among the Aboriginal infant populations must be prevented and a greater emphasis should be placed on ensuring that appropriately developed 'Reduce the Risks' (of SIDS) information is available to Aboriginal families.

4.1 This could be achieved through a collaboration of groups including VACCHO, SIDS and Kids (Victoria), and the DoH Victoria that is tasked with developing resources and education programs to reduce the risk of SIDS among Victorian Aboriginal infants.

Recommendation 5: Undertake linkages between population administrative and statutory databases e.g. Victorian Perinatal Data Collection, Victorian Admitted Episodes Data, Victorian Emergency Minimum Dataset, the Registry of Births Deaths and Marriages and the Maternal and Child Health Data to

enable further validation of the Aboriginal status and identification of additional births (and deaths) of children of Aboriginal and/or Torres Strait Islander mothers and/or fathers. The knowledge gained through data linkage will increase in proportion to the amount of data that is made available through these linkages.

Recommendation 6: Efforts and resources should be dedicated to continuing the improvements in achieving accuracy in the identification of Aboriginal and Torres Strait Islander populations (through self-identification) within statutory and administrative data collections.

Recommendation 7: Governance protocols should be developed to enable continued access to the VACMS data by policymakers and researchers while adhering to the relevant legislation and DoH Victoria policies.

Recommendation 8: Legislative review should be undertaken to enable the VACMS de-identified dataset to be made available for ongoing and new research purposes whenever it is in the public interest to do so, but only after obtaining agreement, in writing, from the relevant Human Research Ethics Committee and original data custodians.

Recommendation 9: A process should be developed for the de-identified data to be made available to Aboriginal health services and community controlled organisations to facilitate the development of evidence-based policy and programs within the regions, within the confines of ensuring anonymity and confidentiality of these data.

Specific recommendations determined by VACCHO

Recommendation 10: The Minister of Health should consider the appointment of the Chief Executive Officer of VACCHO (or a delegate) to the CCOPMM.

Recommendation 11: A committee should be formed to oversee the systematic and regular (annual) review of birth and death data for the Aboriginal community.

11.1 An enabling legislative environment is required to facilitate this process.

11.2 This committee could make recommendations to improve the recording and reporting of Aboriginal identifiers, strategies to address disparities in health outcomes, and the evaluation of programs to redress these disparities.

11.3 This committee should include representatives of VACCHO and CCOPMM. It should formally report to VACCHO, the Department of Health Victoria, the Department of Human Services (DHS), the Registry of Births Deaths and Marriages and the Secretaries' Leadership Group on Aboriginal Affairs.

Recommendation 12: The VACMS outcomes should be available to Aboriginal health services and community controlled organisations to inform policy and planning whilst preserving strict individual and family privacy and confidentiality.

Recommendation 13: The VACMS research team should work with VACCHO to ensure appropriate dissemination of this information to the Aboriginal community within Victoria.

Overview of this Report

This report aims to describe the patterns and trends of deaths of Aboriginal infants and children in Victoria. This includes identifying the disparities in mortality rates by:

- age
- gender
- geographical residence
- Aboriginal status.

The report is divided into three chapters. Chapter 1 presents an introduction to the VACMS and outlines the background to the report, including the overall aim of the research, and outlines the four phases of the VACMS. Chapter 2 describes the methods. Chapter 3 is divided into three sections and reports the results of the data analysis of the 10-year birth cohort.

Section 3.1 reports the infant mortality rate (expressed as the cumulative mortality rate, CMR) over the 10 years for Victorian-born infants, further divided into two birth cohorts. These data also include the causes of infant mortality. The estimates (per 1000 live births) for the two populations are compared using the rate ratio (RR: 95% confidence intervals) to measure the difference in the CMR for Aboriginal compared with non-Aboriginal infants.

Section 3.2 presents the cause-specific and age-specific mortality rates for children who die before reaching their eleventh birthday. The child (cumulative) mortality rate, including all ages, was calculated per 1000 infant survivors and differences between the two populations were calculated using a rate ratio (RR: 95% confidence interval). Age-specific mortality was calculated per 1000 (or 10000) person-years. The differences in the age-specific ChMRs are reported using a hazard ratio (HR: 95% confidence interval).

The final section of Chapter 3 (Section 3.3) reports a descriptive analysis of the deaths that occurred in Victoria from 1999 to 2009 of overseas or interstate births. The description includes age-specific (NND, PNND, child) and cause-specific information of these deaths according to gender and geographical location of the residence at the time of birth. Given that the births of these infants and children did not occur in Victoria, the deaths were not able to be linked to the maternal or perinatal data describing the births or to the Indigenous status of the child (as identified through mother and/or father's Indigenous status).

1 Introduction

Importance of this research

Infant mortality is an important measure of economic and social conditions within a society and of overall social prosperity (Freemantle et al. 2014). To date, mortality rates for Victorian-born Aboriginal postneonatal infants (including postneonatal deaths) and children have not been reported. In order to calculate the true rates of infant and child mortality for Aboriginal and non-Aboriginal populations in Australia, we need accurate identification of who identifies as Aboriginal and/or Torres Strait Islander. These data have not been published in Victoria. Mortality rates in Australia for Aboriginal and non-Aboriginal infants and children have excluded Victorian data. National rates have been calculated using data from those States and Territories where it is considered that identification is sufficiently accurate: Western Australia, South Australia, Northern Territory, Queensland and, most recently, New South Wales (COAG 2013).

For this report, major efforts have been made to improve the identification of the Indigenous status of births and infant and child deaths for the Aboriginal population of Victoria. These data, when added to those of Western Australia, South Australia, the Northern Territory, New South Wales and Queensland, will strengthen the findings for national data and enable planners and policymakers to more clearly identify areas where action is required to reduce mortality for Australian Aboriginal infants and children. The findings from Victoria are generally in accordance with other regions in Australia, adding both clinical and statistical significance to the national outcomes.

Data generated through the VACMS have the potential to provide the Victorian baseline data that will contribute to the measurement of the Australian Government's specific aim 'to halve the gap in mortality rates for Indigenous children under five by 2018' (COAG. 2013).

The risk of death for a child is greatest around the time of birth and in the first year of life. For the past one hundred years or so, children who survive the first year have had a good chance of surviving to adulthood. It is well established that the most powerful influences on infant mortality are social and economic (Singh & Kogan 2007). Therefore, death in infancy is an informative indicator of the social progress of a society, country or group of people. Many of the causes of infant death are potentially preventable, such as being born too small (due to low birth weight or preterm birth), infections and 'cot death' or SIDS. Infant mortality is also an important measure of the effectiveness and availability of health services for mothers and children. Accordingly, any disparities in infant mortality, as seen between rich and poor nations or between Aboriginal and non-Aboriginal children in Australia, are indicators of inequalities in social and economic status, as well as inequalities in the availability of health care (Sidebotham et al. 2014).

The high burden of mortality experienced by young Aboriginal Australians and the disparity in the rates of infant and childhood mortality that exist between Aboriginal and non-Aboriginal Australians are well known (Moodie 1981, 1969; Thomson 1997; Moon, Rahman & Bhatia 1998; Freemantle 2003; Eades & Read 1999; Zubrick et al. 2004; Briscoe 2003). To determine effective prevention strategies and relevant government policies to redress this disparity, a comprehensive and accurate profile of mortality is vital. The role of epidemiology is essential and should

include both the patterns and trends of mortality over time, and 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). Such a profile is presented in this report of deaths in Victoria: *Victorian Aboriginal Child Mortality Study: Patterns, Trends and Disparities in Mortality between Aboriginal and Non-Aboriginal Infants and Children, 1999–2008* (or Mortality Report). This has been made possible by linking the matched birth information included in the dataset of Victorian births to the death dataset that included all infant and child deaths up to but not including the eleventh birthday that have occurred in Victoria between 1988 and 2009 inclusive.

Universally, health and vital statistics play an important public health function. They provide a base from which to monitor the incidence and distribution of disease, as well as births and deaths in and between populations. They also provide evidence to inform policy and prevention programs, to clarify government priorities, to monitor service delivery, and to form a base from which to measure the impact of initiatives implemented with the aim of reducing morbidity and mortality (Draper et al. 2009). Better information facilitates better decision making.

The disproportionate health status of Aboriginal and Torres Strait Islander Australians compared to non-Aboriginal and Torres Strait Islander Australians has gained significant political attention in recent years. This has resulted in a strengthened commitment by State, Territory and Commonwealth governments to improve health equity both locally and nationally. This commitment was formalised in the Council of Australian Governments' (COAG) 'Closing the Gap' campaign, which was endorsed by the Commonwealth Government, the Victorian Government and Aboriginal community representatives.

Former Prime Minister Julia Gillard, in her 2011 annual Closing the Gap speech to the Federal Parliament, said:

> *I see 'Closing the Gap' as a way of understanding the problems. It is evidence-based, accountable and transparent. It tells us what needs to be done first and fastest and builds a methodical approach. It allows us to build consensus in support of specific progress, instead of debating abstract ideas. To do what we can, with what we have, where we are… It is a way of making specific, measurable progress… It gives us new information which means we can be sure the government is meeting its responsibilities.* (The Australian 2011)

Although the Closing the Gap initiative has gained increasing political attention, so too have the shortcomings of Aboriginal health data used to measure progress towards the initiative's goals. In response to the 2011 speech, the then Opposition leader Tony Abbott called for 'more rigorous monitoring of efforts to reduce disadvantage and more aggressive targets', commenting that the '2011 Close the Gap' report 'failed to paint a clear picture of how fast things were changing, especially in the target areas of health and education' (Gordon 2011). Abbott commented 'that this is largely because of the inadequacy of existing statistics', a shortcoming Gillard said was 'being addressed' (Gordon 2011).

Accurate and complete Indigenous identification in vital statistics data is mandatory if we are to enable the development and implementation of evidence-based and targeted healthcare, policies and practices. The issue of under-identification of Aboriginal people in statutory and administrative datasets in Victoria has precluded the reporting of Aboriginal infant and child mortality rates, and also the inclusion of Victorian Aboriginal infant mortality statistics in national Aboriginal statistics. A recent Australian Institute of Health and Welfare (AIHW) report stated that:

> *information on Aboriginal deaths is reported for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory combined. Other jurisdictions have a small number of Aboriginal deaths and identification of Indigenous status in the data is poor, making the data less reliable.* (AIHW 2014:301)

The VACMS seeks to address this issue through the development of a robust methodology (which has been successfully implemented in Western Australia) that enables the reporting of age-specific and cause-specific infant and child mortality rates for Victorian-born Aboriginal infants and children.

Background to the Victorian Aboriginal Child Mortality Study

In 2008 a five-year Discovery Project grant was awarded by the Australian Research Council (ARC) to undertake a study, the VACMS, to improve the accuracy and completeness of data describing births in Victoria to Aboriginal and/or Torres Strait Islander (and non-Aboriginal) mothers and/or fathers, thereby determining a more accurate denominator from which age-specific and cause-specific mortality rates could be calculated for this population. As a result, the disparities between the Aboriginal and non-Aboriginal populations could also be calculated for Victoria. Given the complexity of the study methodology, the existing Victorian legislation and regulations governing linking of data between different government jurisdiction and a number of unforseen circumstances associated with accessing and linking these data, the VACMS was extended a further 18 months.

Aim

The aim of the VACMS expressed in the original submission to ARC in 2008 was 'to accurately measure the patterns and trends of Aboriginal infant, child and youth mortality and the disparities between Aboriginal and non-Aboriginal populations for births occurring in Victoria spanning (birth) years, 1988 to 2008 inclusive'. This aim was subsequently amended to 'more accurate and complete', acknowledging that it would be impossible to ensure complete ascertainment of Indigenous status in statutory and administrative datasets. A critical step to enable the calculation of mortality rates was the development of an accurate denominator. The population data matching process that generated the ever/never-Aboriginal identified birth (the denominator) used all births in Victoria between 1988 and 2008 inclusive. The results of this process identified some misclassification in the data describing the Indigenous status of mothers in the perinatal data. The process also reflected mothers and fathers who identified as Aboriginal in the registration of an infant's birth with the Registry of Births, Deaths and Marriages (RBDM) prior to 1999 (Freemantle et al. 2013). Consequently, the aim for the VACMS was further amended:

> *to measure the patterns and trends of Aboriginal infant and child mortality and the disparities between Aboriginal and non-Aboriginal populations for births occurring in Victoria spanning (birth) years, 1999 to 2008 inclusive.*

A total population matched database describing births in Victoria of babies whose mother and/or father self-identified (or were identified) as Aboriginal and/or Torres Strait Islander was established in 2013. These data, which included Victorian births between 1999 and 2008 inclusive, were analysed to establish an ever/never-Aboriginal identifier for these birth years (Freemantle et al. 2013). These data formed the basis for the denominators necessary to calculate mortality rates for this report. This birth cohort has been used in the calculation of mortality rates, therefore only deaths that have occurred from 1 January 1999 to 31 December 2009 are considered.

Further, therefore, only deaths that have occurred before the eleventh birthday are included. The deaths for Aboriginal (and non-Aboriginal) children between 11 years and before their eighteenth birthday have not been included given that the Indigenous status of these children was not able to be identified through the matching process.

A comprehensive description of the method associated with the development of the ever/never-Aboriginal identifier is described in the Birth Report (Freemantle et al. 2013:38–40).

The four VACMS phases

The VACMS has had four distinct phases:

- Phase 1—development of a denominator (births to Aboriginal and non-Aboriginal parent/s for the period 1988–2008 inclusive) using the Ever-Aboriginal Rule; birth information held within the Victorian Perinatal Data Collection (VPDC) was matched with the birth registration data collected by the RBDM (Freemantle et al. 2013)
- Phase 2—analysis of the matched birth dataset to calculate an ever/never-Aboriginal identifier (Freemantle et al. 2013); appending of maternal and perinatal clinical information to the matched data; the matched dataset was analysed and patterns and trends of births to Aboriginal and/or Torres Strait Islander mothers and/or fathers in Victorian 1999–2008 inclusive were reported (Freemantle et al. 2013)
- Phase 3—this phase included the review of all the paper-based case files submitted to the CCOPMM for review of deaths occurring (0–17 completed years according to the birth cohort, 1988 to 2008 inclusive) in Victoria 1988–2009 inclusive (n = 10,961 deaths). Information describing these deaths was collected on hard copy as a function of the CCOPMM. While the CCOPMM maintains additional information in an electronic database for deaths occurring in the more recent years, the VACMS only accessed the paper-based files. The review of the death case files included the recording of the relevant information contained in the files on a data collection sheet and the classification and coding of all deaths that were collected by the CCOPMM. This information was then uploaded onto a database.

  Although all deaths in the 20-year cohort were comprehensively reviewed, only deaths that occurred in the 11 years 1999–2009 are reported in the Mortality Report due to the more complete Aboriginal identification in the associated birth years. The full complement of the death information (all deaths occurring between 11 and 17 completed years) will be utilised in the development of a Preventability Index, which will be undertaken at the conclusion of the VACMS (subject to ethical approvals from data custodians and the DoH Human Research Ethics Committee).

  The cause of death code assigned by reviewers was independently validated for 10% (randomly selected) of deaths in each of the 1999–2008 birth years.

- Phase 4—this phase included the 'building' of a births/deaths database to enable the reporting of age-specific and cause-specific mortality of Victorian infants and children, 1999–2009 inclusive. This database included the context within which the children died. Analysis of the linked birth/death datasets to determine the maternal and perinatal antecedents to poor outcomes for Victorian-born children, 1999–2009 inclusive, was then undertaken. A focused analysis of the patterns and trends of mortality for Victorian-born Aboriginal children who died before reaching their eleventh birthday, and the context within which these children died, was completed. The mortality rates are shown separately for Aboriginal and non-Aboriginal populations.

Age-specific rates are calculated for infants (less than one year), one- and two-year-olds, three- to five-year-olds, and six- to 10-year-olds. The age groups reflect the important transitions from infancy into early adolescence.

This Mortality Report presents the results of phases 3 and 4 of the VACMS, which undertook a comprehensive analysis of the population data (disaggregated into Aboriginal and non-Aboriginal populations) and reported on:

- neonatal, postneonatal, infant and childhood deaths
- a number of maternal and infant variables relating to the antenatal and perinatal period the cause
- place of death (in or out of hospital)
- the geographical location of the residence at the time of death (and of birth)
- (infant and childhood deaths in Victoria of infants and children who were born outside of Victoria).

The VACMS is an additional mortality review cohort to the longstanding and comprehensive CCOPMM death review cohort, which is the Victorian Government's definitive child death review cohort.

As a result of this research, an additional comprehensive population mortality cohort describing 18 years of complete mortality data of Victorian-born children has been established. However, only the death data from the years 1999–2009 inclusive that describe the patterns and trends of mortality for Aboriginal compared with non-Aboriginal Victorian-born infants and children are presented in this report.

The disparity between Aboriginal and non-Aboriginal infants and children, which has been measured with preventable deaths highlighted, is reported. The results of the mortality review comprise the final report of the VACMS.

Identification of Aboriginal and Torres Strait Islander people in population data

Monitoring the numbers of births and the rates and cause/s of mortality for Aboriginal people is made possible through the identification of the Indigenous status (in birth and death collections and registries) of a person or patient. The Indigenous status in perinatal birth reports and birth and death registrations dictates whether an individual's information is aggregated into the 'Indigenous' or 'non-Indigenous' category for monitoring and reporting.

This information is collected from the person or patient using a standard question prescribed by the Australian Bureau of Statistics. This standard prescribes that every Australian-born person admitted to hospital or who gives birth with the assistance of a midwife, or who registers a birth with the RBDM, should be given the opportunity to identify his or her Indigenous status (AIHW 2006). This question should be asked by clerical staff when a person is admitted to hospital, and also by the midwife when completing a perinatal form. The question regarding the Indigenous status of the mother and/or father is self-reported on the birth registration form on behalf of the infant. The question should also be asked of the responsible person when completing the death registration form on behalf of the deceased (Heffernan, Iskandar & Freemantle 2012).

In response to the question, 'Are you [the person] of Aboriginal or Torres Strait Islander origin?' the respondent's answer is recorded as either:

- no
- yes, Aboriginal, and/or
- yes, Torres Strait Islander (AIHW 2006; ABS 1999).

In the AIHW National Health Data Dictionary a more detailed list of responses is documented for datasets (HDSC 2008).

The Commonwealth definition of an Aboriginal and/or Torres Strait Islander person used in many administrative and statutory datasets is based on a High Court judgment in the case of *Commonwealth v Tasmania* (1983) 46 ALR 625:

> *An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives.* (AIHW 2006)

There are three components to the Commonwealth definition:

- descent
- self-identification
- acceptance by the community (AIHW 2006).

However, in practice, for most general purpose statistical and administrative collections it is not feasible to determine whether a person is accepted by his or her community as an Aboriginal person. Therefore, the standard question of Indigenous status in these health datasets relates to descent and self-identification rather than community acceptance, a biological blood quantum or ancestral degree of Aboriginality. There is no requirement to provide 'proof' of descent when identifying in these collections.

The situation is slightly different when registering a birth or death in the VPDC or the RBDM. Although the Commonwealth definition still applies, Indigenous status is not provided by the individual but by a third party, commonly a parent, spouse or family member. Because newborn infants and deceased persons do not have the capacity to answer the question of Indigenous status, the question is answered by the attending parent or next of kin.

Data custodian

The CCOPMM was established in 1962 under the *Health Act 1958* (Vic.), and now functions under section 44 of the *Public Health and Wellbeing Act 2008* (Vic.) (the PHWB Act) and associated regulations. The CCOPMM is the advisory body to the Minister for Health on maternal, perinatal and paediatric mortality and morbidity. Specialist CCOPMM subcommittees review complex or contentious mortality cases. The CCOPMM has statutory responsibility for the administration of the VPDC, which collects information on and in relation to the health of Victorian mothers and babies. The CCOPMM consists of 12 members, including the Chairperson, and is administered within the DoH by the Clinical Councils Unit (CCU) of the Health Service Programs Branch within the Health Service Performance and Programs Division (CCOPMM 2012).

The CCOPMM is able to disclose information obtained in the course of performing its functions, as described in section 38 of the PHWB Act, to the RBDM under section 41(1)(k) of the PHWB Act if it considers it is in the public interest to do so.

Ethics

Given the complexity of this study from a regulatory perspective, numerous ethics applications were required for phases 3 and 4. These were prepared and submitted before the review of the death files commenced. Applications were successfully submitted to The University of Melbourne Human Research Ethics Committee and the DHS Human Research Ethics Committee. An application to the CCOPMM to access its data was also submitted. The ethics approvals remained current throughout the period of data retrieval, review and analysis, and during the linking of the birth registration and death file numbers.

Ethics applications addressed issues relating to the use of health information without individual consent, the lawful use and disclosure of identifiable data, balancing concerns for privacy with public good, and specific consideration for research involving Aboriginal populations.

The specific privacy issues addressed in the ethics applications included and addressed key principles and regulations of the following legislation as they related to privacy, access, use and disclosure of data:

- *Births, Deaths and Marriages Registration Act 1996* (Vic.) (section 48)
- information privacy principles under the *Privacy Act 2000* (Vic.)
- *Health Records Act 2001* (Vic.).

Funding

The VACMS was initially funded by the ARC. Over the life of the VACMS (2008–14) the ARC grant was complemented through further significant funding. Sources of funding included the Aboriginal Health Branch (DoH Victoria), the Australian Government Department of Prime Minister and Cabinet (formerly the Department of Families, Housing, Community Services and Indigenous Affairs), the Lowitja Institute, The University of Melbourne (Melbourne School of Population and Global Health), and the R E Ross Trust.

2 Methods

Clearly, data should be disaggregated on the basis of Indigenousness and non-Indigenousness, but, where possible and appropriate, it should be further disaggregated by gender, age, urban/rural location, and socio-economic status. (Barnsley 2006:48)

At the outset, this chapter explains the cause of death code used in this research (JFcode), comprehensively describing its history and development.

The chapter describes the data sources, acknowledging the data custodians, for the data used in the determination of the final VACMS dataset. Importantly, the chapter reiterates the method used to develop the ever/never-Aboriginal denominator in Phases 1 and 2 of the VACMS (the Birth Report). The chapter describes the determination of the denominator and numerator used in the generation of the mortality rates (the Mortality Report). Reference is made regarding the application of a sensitivity analysis to the data.

The chapter describes the process used to develop the death dataset, including a description of the retrieval of the death information, preparation of the data, coding, and classification and validation of the cause of death. The study used a quantitative framework applied to the matched data linked to the death information provided by the CCOPMM and the chapter explains the methods used to link the birth and death datasets. It also describes the management of data regarding the geographical location of the residence at time of birth (mother) and death. Finally, the chapter details the statistical methods employed in the analyses of these data. The study datasets have undergone a rigorous process of validation and data cleaning to ensure that they are fit for purpose.

The development of the JFCode

The JFcode, a 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 (first digit), each of which could be sub-categorised with the use of a second and third digit for infections 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. This 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).

This code continues to be used in Western Australia through the ongoing Child Mortality Database project at the Telethon Institute for Child Health Research. The Child Mortality Database includes total population validated data describing all Western Australian deaths from 1980 to 2008. The Child Mortality Database is supported by the Western Australian Government Department of Child Protection and Family Support (previously the Department of Community). Three major reports have been published and numerous peer-reviewed journal articles cite this work (Freemantle 2003; Freemantle et al. 2004, 2010; Shepherd et al. 2013).

In the mid-1990s, Dr Louisa Alessandri and colleagues undertook grouped coding of the cause of infant and childhood death. Classification of perinatal deaths was based on the Wigglesworth Classification code for deaths up to and including 28 days and used a code that included a digit followed by a zero (Wigglesworth 1980). A similar numeric configuration was used to code postneonatal and childhood deaths, but some of the numbering was different and coding for accidents used the second digit to identify the type of accident. The original classification codes used by Dr Alessandri (LAcode) for perinatal, postneonatal and childhood deaths are shown in Table 2.1.

Table 2.1: Major categories for the classification of perinatal, postneonatal and childhood death—LAcode

Code	Description of cause of death Perinatal deaths up to and including 28 days
10	Normally formed antepartum stillbirths (unexplained death)
30	Complications of prematurity (NNDs)
40	Asphyxial conditions developing in labour: 41 —without APH (only intrapartum SBs and NNDs) 42 —with APH (intrapartum SBs and NNDs)
50	Other (specific conditions other than above (SBs and NNDs) 51 —SIDS only for NNDs)
60	Unclassifiable on death certificate—includes those with SB unknown (USBs)
10	Perinatal complications
20	Birth defects—including genetic disorders
30	Infections
40	SIDS
50	Accidents and trauma 51—road traffic accidents 52 —drowning 53 —poisoning 54 —fire 55 —non-accidental injury 56—other accidents and injuries 56
60	Cancers and leukaemias
70	Neurological
80	Other specific conditions
90	Unascertainable/unable to categorise

APH: antepartum haemorrhage; NNDs: neonatal deaths; SBs: stillbirths; SIDS: Sudden Infant Death Syndrome; USBs: unknown stillbirths.

The LAcode used a simple and broad classification of death. Under this system, all deaths were classified into major groupings according to the condition determined by the coders to be the underlying cause (Alessandri et al. 1999). Validation of these data was undertaken by review of autopsy reports and post-mortem data by a team including a paediatric pathologist. One drawback of the LAcode was that it did not provide consistent

coding from the perinatal period and infancy throughout childhood and into adolescence and early adulthood. In the late 1990s Dr Eve Blair, Dr Helen Chambers and Dr Anne Read extended the Alessandri classification system (the EBcode) to permit a consistent coding of death throughout the perinatal period and childhood into early adulthood.

The JFcode modified the code used in the EBcode in the classification of perinatal events, and extended the classifications in the areas of infections and accidents. The modification of the original code also introduced a linked field in cases where birth defects were described on the death certificate but not considered to be the major cause of death. The three-digit code can be tracked back to the International Classification of Disease (ICD) version 9 (World Health Organization 1975) and the classification systems developed over the years by the Perinatal Society of Australia and New Zealand (PSANZ). The classifications systems were originally named the Australian and New Zealand Antecedent Classification of Perinatal Mortality, and the Australian and New Zealand Neonatal Death Classification. Following endorsement of this activity as a Special Interest Group of the PSANZ in March 2003, the classifications have been renamed as the Perinatal Society of Australia and New Zealand Perinatal Death Classification and the Perinatal Society of Australia and New Zealand Neonatal Death Classification. Flenady et al. (2009) provide a description of the classification development and the classification system.

Over the evolution of the JFcode, while the nine categories of death remained the same, the sub-groups (second and third digits) included within the JFcode were further expanded through the process of the review of the death information. A VACMS death classification subcommittee was established to oversee the JFcode (Appendix 3).

Table 2.2 identifies the major categories used for the classification of death (the JFcode). The expanded JFcode used to code the cause of death in this report is identified in full in Appendix 1.

Table 2.2: Major categories for the classification of death—JFcode

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-joining field.
3	Death as a result of prematurity of organ systems includes sequelae of prematurity. Also includes death from prematurity (<28 weeks) following delivery secondary to antepartum haemorrhage.
4	Infections—sub-categories provided information regarding the site of infection (second digit) and organism/s responsible where known (third digit).
5	Accidents—includes non-accidental injury and sub-categories, provided information relating to the type (second digit) and the agent (third digit) of the accident (e.g. motor vehicle, pool).
6	Cancers—sub-category includes leukaemias.
7	SIDS.
8	Other specific conditions—not previously noted, sub-categories include Cerebral palsy and neurological conditions.
9	Unknown/unclassifiable/unascertainable—sub-categories include cause unclassifiable in other categories and cause unknown/unascertainable.

Data sources

Consultative Council on Obstetric & Paediatric Mortality and Morbidity or CCOPMM

The primary source of the death information was provided through the death files collated by the CCOPMM, which first reported on the deaths of children in Victoria up to the age of 14 years in 1985. The age remit was extended to include deaths of adolescents, 15 to 17 years, in 2005 and the CCOPMM reports on all deaths in Victoria of children who die before reaching their eighteenth birthday. These comprehensive death files include information requested by the CCOPMM from health services, encompassing obstetricians, midwives and health information officers, that provide confidential medical reports on perinatal deaths and additional information on maternal, perinatal and paediatric deaths (CCOPMM 2012). Information derived from anatomical and forensic pathologists provide critical information necessary to determine causes of death.

The State Coroner's Office and personnel from the Victorian Institute of Forensic Medicine provide information to the CCOPMM on coronial cases under the Public Health and Wellbeing Act. Similarly, the Registrar of Births, Deaths and Marriages provides death certificates to the CCOPMM in accordance with the Births, Deaths and Marriages Registration Act (Heffernan, Sheridan & Freemantle 2009).

Information provided to the CCOPMM is privileged by legislation and (unless it is released by the CCOPMM) is not accessible by any third party, including the courts.

Under the Public Health and Wellbeing Act, CCOPMM (2012:27) is required to:

a. conduct study, research and analysis into the incidence and causes in Victoria of maternal deaths, stillbirths and the deaths of children;
b. conduct study, research and analysis into the incidence and causes of obstetric and paediatric morbidity;
c. conduct a perinatal data collection unit for the purpose of:
    i. collecting, studying, researching and interpreting information on and in relation to births in Victoria;
    ii. identifying and monitoring trends in respect of perinatal health including birth defects and disabilities;
    iii. providing information to the Secretary on the requirements for and the planning of neonatal care units;
    iv. providing information for research into the epidemiology of perinatal health including birth defects and disabilities; and
    v. establishing and maintaining a register of birth defects and disabilities;
d. Provide to health service providers:
    i. information on obstetrics and paediatrics; and
    ii. strategies to improve obstetric and paediatric care;
e. Consider, investigate and report on any other matters in respect of obstetric and paediatric mortality and morbidity referred to the Council by the Minister or the Secretary;
f. Liaise with any other Consultative Council (whether or not prescribed) on any matter relevant to the functions of the Council;
g. Publish an annual report on the research and activities of the Council;
h. Perform any other prescribed function; and
i. Collect information for the purpose of performing its functions as outlined in the Act.

Victorian Perinatal Data Collection

Maternal and perinatal information appended to the death information in the linked births/death datasets was derived from the VPDC.

The Victorian Perinatal Data Collection (VPDC) was established in 1982 by the CCOPMM to collect and analyse data to support its functions under the *Health Act (1958)*. It was established as a population-based surveillance system to collect and analyse information on and in relation to the health of mothers and babies in order to contribute to improvements in their health. The data collected via a birth report contains information on obstetric conditions, procedures and outcomes, neonatal morbidity and birth defects relating to every live birth and stillbirth in Victoria from 20 weeks gestation or, if gestation is unknown, at least 400 grams birth weight. Data regarding the birth are also collected from the hospital and other relevant records. These data are compiled on notification forms and submitted to the CCU for 'data processing, analysis and publication of reports' (Laws & Sullivan 2004:3).

The Indigenous status variable is completed by midwives or clerical staff. Prior to 2009, the birth notification form only included the Indigenous status of the mother and not that of the baby or father. An Indigenous identifier for the baby was added in January 2009, and midwives were required to ask the mother at the time of birth or during antenatal care, 'are you of Aboriginal or Torres Strait Islander origin?' and 'is your baby of Aboriginal or Torres Strait Islander origin?' However, for the period of this study, the Indigenous status in the VPDC only relates to the mother. Every birth reported to the VPDCU that has a gestational age greater than 20 weeks, or if unknown has a birth weight of at least 400 grams, is assigned a birth registration number.

In response to the question of accuracy of Indigenous status data in the VPDC in a 2009 study by Heffernan, Sheridan and Freemantle (2009), the respondent from the VPDC reported that he/she was unsure of the level of accuracy of the Indigenous identifier.

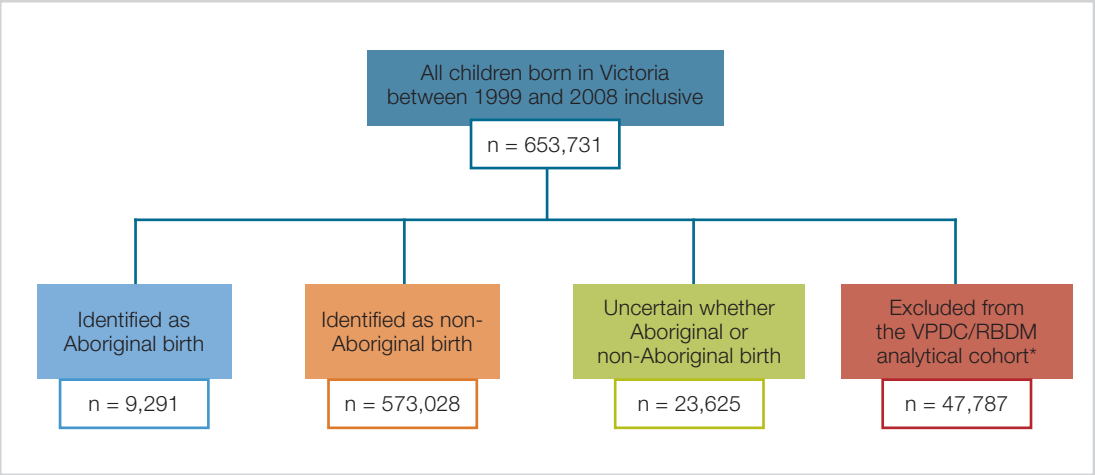
Development of ever/never-Aboriginal variable

Ever/never-Aboriginal denominator (Birth Report)

Phases 1 and 2 of the VACMS used the matching of birth information collected by the VPDC and the RBDM to develop an ever/never-Aboriginal identifier (the denominator) in order to calculate Aboriginal infant and child mortality rates. The ever/never-Aboriginal identifier was appended to the birth registration number (birth dataset) in Phase 2. The method to calculate this replicated previous methodologies and emphasised the importance of the integrity of the Indigenous identifier based on self-identification of one's Indigenous status (Freemantle et al. 2013). Essentially, the Ever-Aboriginal Rule uses independent population data sources to construct an ever/never-Aboriginal identifier based on self-identification (or third-party identification) reported in these data sources.

Figure 2.1 provides a numerical summary of the development of the ever/never-Aboriginal identifier. A detailed description of the figure can be found in the Birth Report (Freemantle et al. 2013:39). Table 2.3 reports the various categories within which the birth files were categorised in the development of the Aboriginal/non-Aboriginal identified variables for birth years 1999–2008 inclusive.

Figure 2.1: Categories of identification as an Aboriginal, non-Aboriginal birth, uncertain and excluded for the years 1999–2008



RBDM: Registry of Births, Deaths and Marriages. VPDC: Victorian Perinatal Data Collection. *Data were excluded if the RBDM data could not be linked to VPDC (n = 632) and if the RBDM data contained more than one possible match to the VPDC (n = * 47,155).

Table 2.3: Categorisation of Indigenous identification derived from the VPDC and RBDM for birth years 1999–2008 inclusive

	1. Aboriginal birth					2. Non-Aboriginal birth		3. Uncertain	
VPDC mother	✓	✓	×	×	✓	×	·	×	·
RBDM mother	✓	·	✓	×/·	×/·	×	×	·	·
RBDM father	✓/×/·	✓	✓/×/·	✓	×/·	×	×	·	·
Total (N)	3,047	140	2,037	3,024	1,043	572,969	59	23,619	6

RBDM: Registry of Births, Deaths and Marriages. VPDC: Victorian Perinatal Data Collection.
✓= Identified as Aboriginal; × = identified as non-Aboriginal; · = missing, unknown, uncertain.

Ever/never-Aboriginal denominator (Mortality Report)

In the final determination of the denominator for the Mortality Report (i.e. the total Aboriginal and/or Torres Strait Islander infants and children born 1999–2008 inclusive) the Indigenous identification of the mother as recorded in the VPDC was used to supplement information in death files where the matching process had identified missing information in the RBDM or multiple links to RBDM-registered births. Using the VPDC supplementary identification, there were 726 additional Aboriginal infants and children (of which 27 died) and 46,416 non-Aboriginal infants and children included in the combined VPDC and RBDM dataset. Conversely, for non-Aboriginal infants and children, we were unable to validate the non-Aboriginal status (n = 46,416) (using the Ever Aboriginal Rule) because of the missing Aboriginal and Torres Strait Islander status information provided from the RBDM. The final denominator used in the calculation of mortality rates for Aboriginal infants was 10,019 live births and for non-Aboriginal infants the figure was 643,693 live births, 1999–2008 inclusive.

Sensitivity analysis

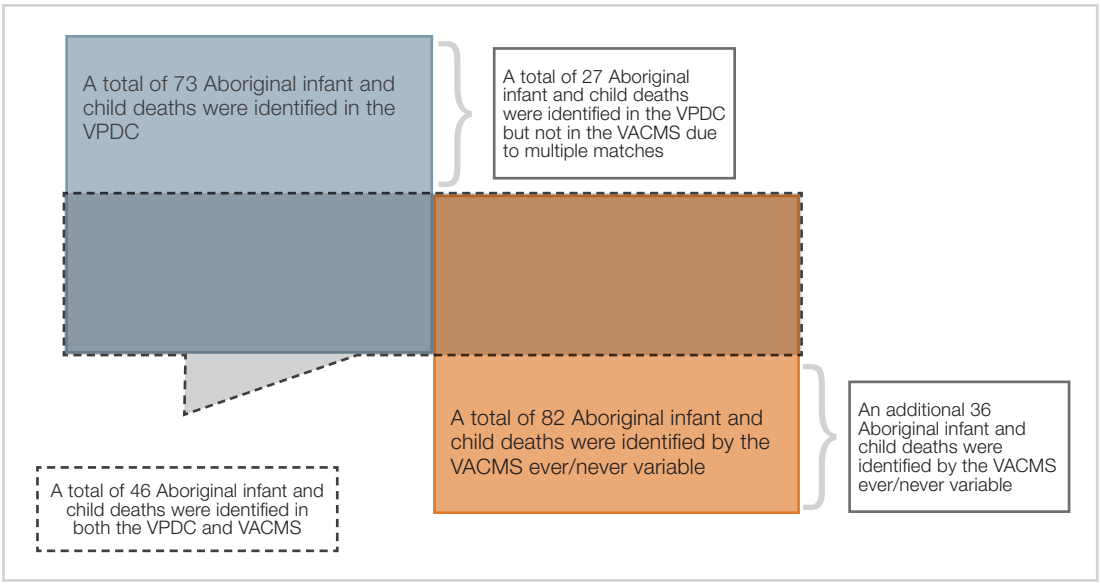
As a result of including the residual information from the VPDC where there was missing information regarding the Aboriginal and/or Torres Strait Islander identification, the total number of Aboriginal and Torres Strait Islander births (n = 10,019) and deaths (n = 109) increased. Therefore, we performed a sensitivity analysis (Table 3.5) restricting the birth–death cohort to the ever/never identified births reported in the Birth Report. We calculated all-cause and cause-specific CMRs and ChMRs. The estimates in the sensitivity analysis describing the primary comparisons of mortality are similar to those presented here in the Mortality Report. Therefore, all available information describing the Indigenous status was used to define the numerator (deaths) and denominator (births) described in the Mortality Report.

Ever/never-Aboriginal numerator

Of the ever/never-Aboriginal births, 93 Aboriginal infants and 16 Aboriginal children died (the numerator). A total of 19 infants and children (of which two infants died) had an unknown/or missing Aboriginal and/or Torres Strait Islander status due to no available information describing their Indigenous identity in either the VPDC or RBDM datasets.

Figure 2.2 describes the identification of the Aboriginal infant and child deaths that occurred in Victoria using the different data sources, 1999–2009 inclusive. There were 46 Aboriginal infant and child deaths where the Indigenous identification was provided by both the VPDC and the RBDM (the ever/never enhanced birth denominator). Indigenous identification was provided by the RBDM in 82 Aboriginal infant and child deaths, and 73 Aboriginal infant and child deaths were informed by the VPDC (mother only identification) (27 of these had not previously be included in the birth dataset due to multiple matches with the RBDM). Thirty-six infant and child deaths were identified in the VACMS as Aboriginal by the generation of the ever/never identifier (previously identified as non-Aboriginal in the VPDC).

Figure 2.2: Identification of the Aboriginal infant and child deaths that occurred in Victoria, using the different data sources, 1999–2009 inclusive



VACMS: Victorian Aboriginal Child Mortality Study; VPDC: Victorian Perinatal Data Collection.

Development of the Mortality Report dataset

Retrieval of the death files

The VACMS research team received full access to the paper-based case files rather than the electronic database (as requested by the research team). The CCU policies and procedures were followed at all times.

To ensure that the VACMS team reviewed all deaths that had been reported to the CCOPMM, a comprehensive tracking system was developed by the VACMS research team utilising a sequential numbering system. The tracking system included the CCOPMM case file number and the relevant file location identification number for each death file. This information was stored electronically on the VACMS secure database. A weekly update of the progress of the retrieval of the death files was undertaken. The progress of the retrieval and review of the death information was provided to CCOPMM meetings and to ministerial subcommittee meetings.

The death dataset includes the CCOPMM case file number appended to each JFcode (cause of death), so this system facilitates the retrieval of specific causes of death through an immediate location of the box number/cabinet hanging file number associated with the cause of death, which enables retrieval of case files.

Process for the review, classification and coding of death information

The death information included in the VACMS was described by a birth cohort and included all live births that occurred between 1 January 1988 and 31 December 2008. Within the birth cohort, deaths to be included in the VACMS included deaths that occurred between 1 January 1988 and 31 December 2009.

However, the case files included *all* deaths in each calendar year (aged <18 years) and were numbered sequentially according to the notification of the death to the CCOPMM.[7] Therefore, the death files included deaths that were not in the VACMS birth cohort. As each death must be accounted for, the reviewers considered all deaths. Once the birth/death date identified that the death did not fall within the VACMS birth cohort, the CCOPMM number was assigned a specific project (numeric) identifier and recorded on a summary review sheet. The case file was then returned to the box/hanging file and no further information was collected. Every CCOPMM death file number was accounted for using the tracking system and the information of only those that were within the birth/death cohort was reviewed and recorded on the data collection sheet. All the information was collected on the data collection sheets and stored electronically.

The data collection sheet was first developed in Western Australia in the establishment of the Child Mortality Database. It has been used to inform the classification and coding of the cause of death and has been described previously (Freemantle 2003; Freemantle et al. 2004, 2010; Shepherd et al. 2013). Throughout the VACMS process of reviewing the death files, additional sub-groups (second and third digit) were added to the data collection sheet. This process was overseen by the VACMS death classification subcommittee (for membership, see Appendix 3). The final data collection sheet (version 60) is provided in Appendix 2.

The information available in each death case file varied in quality (data collected but not reported) and quantity. At a bare minimum, some files contained only a cover sheet identifying the death. Others included comprehensive file notes describing the life course of the infant/child and detailed

7 Stillbirths were identified through a different numbering system and were not reviewed or included in the VACMS and there for not reported in the mortality rates.

the specific context and circumstances of the death. Throughout the process of the death case file review, the data collection sheet was continually revised and updated to reflect the addition of information or amendment to existing information describing the circumstances of the death. Thus, at the conclusion of the review of case files and uploading of the information onto the dataset, it was necessary to revise and, if necessary, add information to data files to reflect the updated data collection sheet. This activity also provided a further validation of the accuracy of the data and was undertaken by a medical doctor and final year graduate medical student. Both these research staff members were granted permission to access the CCOPMM files by the Minister of Health (auspiced through the secretariat to CCOPMM).

The method developed to code the cause of death was rigorous in both approach and validation and replicated the methodology applied in the Western Australian Child Mortality Database in the collection of the information and determination of the cause of death. All death records were reviewed and the information extracted and noted on the data collection sheet by experienced health information coders (Master of Health Information Management graduates).

The Indigenous status of the infant or child death was derived from the linkage of the enhanced birth dataset with the (completed) death dataset. The birth and death datasets were linked after the completion of the coding and classifying of the death information. Any information regarding the Indigenous status of the mother, father, infant or child in the case files was noted on the data collection sheet. The inclusion of this information in the case notes was variable, and its source not identified and therefore not considered reliable. A potential for bias associated with reviewers' knowledge of the Indigenous status in influencing the classification and coding of the death was not considered to be relevant.

The VACMS team met weekly to discuss the coding to identify any concerns or issues and to develop coding rules. The discussions and determinations were collated to ensure consistency in coding (e.g. the determination in the coding of infection associated with deaths in the preterm period). More than 116 variables were collected and included the following information (where available):

- demographics of the child
- Aboriginal status[8]
- location of death
- autopsy
- cause of death (as per the CCOPMM (including CCOPMM 'preventability factor' where noted), the ICD and PSANZ codes, medical certificate, pathologist, coroner)
- maternal and perinatal information, including antenatal visits
- birth defects (where not cause of death)
- forensic toxicology
- disability.

Specific information was collected under four sections:

- SIDS/sudden death in infancy (site of death information based on the national protocol for the collection of information when a child dies suddenly and unexpectedly)
- Infection
- birth defects
- injury (with further comprehensive information on the circumstances and context of accidental and non-accidental injuries).

8 The case files potentially include information on the Indigenous status of the child (by way of mother and/or father self-identification on the medical certificate of cause of death form). This form was not always included in the case files, or the Indigenous identification information completed.

The quality of information contained in the death files was also noted in the death dataset.

A cause of death (the JFcode) was assigned by each coder on the basis of available information and recorded on the data collection sheet. The Chief Investigator reviewed every death file and independently recorded the JFcode. At the completion of the review, classification and coding, the information was uploaded onto an SPSS (Statistical Package for the Social Sciences) computer file. The JFcode for each death was reviewed and where there was inconsistency in the codes, the death files were retrieved and the JFcode discussed and a final JFcode determined. Discrepancies were resolved through discussion and, in a small number of cases, extra information was obtained to assist the determination of the cause of death.

In all cases disagreement was resolved. An expert paediatric epidemiologist who has been working in this area of research for more than 30 years also undertook an external validation on the coding. A random selection of 10% of death files in each year was retrieved and independently reviewed and coded by the independent expert. The research team discussed each of these codes until concordance was noted and the final JFcode agreed upon and added to the death dataset.

Any discrepancies between the VACMS team, JFcode and external JFcode were reviewed and discussed a third time. In all cases disagreement was resolved. To test the inter-rater agreement between the researchers, a test of concordance was performed. There was strong agreement between the external reviewer and principle investigator of the final cause of death code: 95% agreement overall for death cases (range 89%–100%) within major causes of death categories. For the categories with the most disagreement (perinatal causes, infection and other specific conditions), the disagreement was generally a result of disagreement within the details of subcategories rather than the major cause of death.

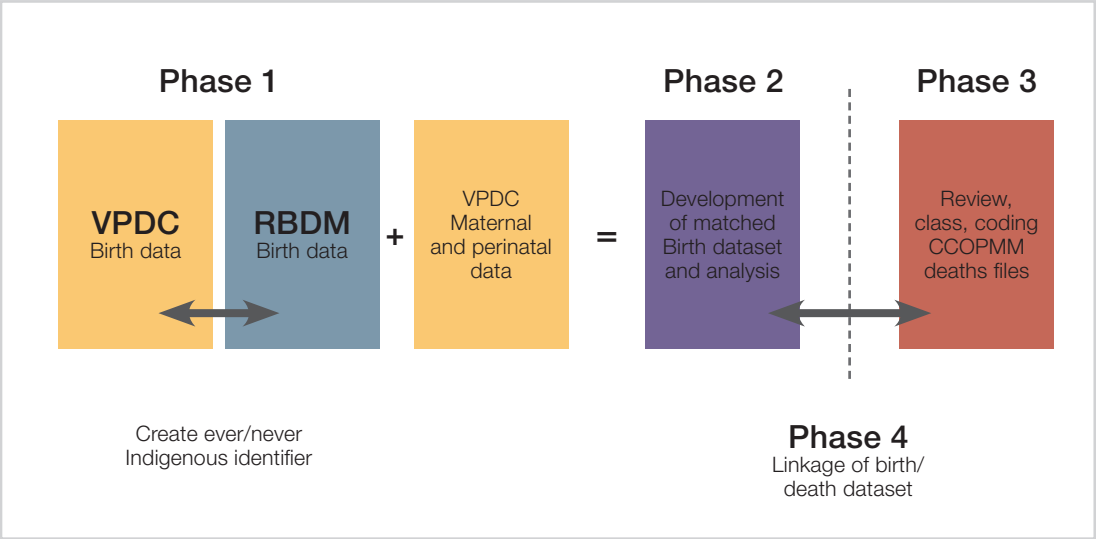
All individual death files were reviewed manually and the context and details of the death recorded on a data extraction sheet. Initially, data were entered into SPSS files; however, as the data files grew, an alternative data management was used. Data initially stored in SPSS files were converted to a Microsoft 2010 Access database for data entry and data cleaning.

The VACMS data linkage process

The ever/never-Aboriginal identifier generated through the matching of the birth information collected by the VPDCU and the RBDM has been described previously (Freemantle et al. 2013).

Figure 2.3 describes the process to achieve linked births/deaths and indicates the matching and linkage process that has generated births/deaths data.

Figure 2.3: Four phases of the VACMS



CCOPMM: Consultative Council on Obstetric & Paediatric Mortality and Morbidity; RBDM: Registry of Births, Deaths and Marriages; VPDC: Victorian Perinatal Data Collection.

Linkage of the birth dataset and death dataset

To enable the calculation of infant and child mortality rates, it was necessary to link the comprehensive death information recorded in the death dataset to the birth dataset. The key linkage variable was the birth registration number (which had an Indigenous identifier generated through the Ever-Aboriginal Rule attached to it). As only births that had occurred in Victoria (included in the VPDC) were able to be linked to the Victorian deaths, a linked CCOPMM death file number to the birth registration number was not available for all deaths in the VACMS birth cohort. To facilitate the linkage of the data, relevant demographic data available in the death files were extracted by the VACMS researchers and recorded in an Excel dataset. Information included mother's first/given name/s, mother's maiden name, mother's surname/s, mother's date of birth, child's first/given name/s, child's surname/s, child's place of birth and child's residence at the time of birth. These data were provided to the CCU to enable the linkage to occur where possible. This process involved a number of iterations since the CCU team had to use various data sources to identify the birth registration number of each death file.

Process for linking birth/death datasets

An important component of the VACMS, was the linking of the death dataset to the matched birth dataset using the birth registration number by the staff in the CCU. During Phase 4, the VACMS birth dataset generated during Phase 2 (which included the ever/never-Aboriginal identifier) was re-linked with the birth registration number in the VPDC by the staff working in the CCU. The ever/never-Aboriginal identifier therefore provided the Indigenous status for each death. Deaths in Victoria that occurred to infants and children who were born outside of Victoria did not have a birth registration number, and there were a number of infant deaths where there was no birth registration number able to be provided

by the CCU. Therefore, the Indigenous status of the infant or child was not able to be determined for 103 deaths (99 infants and four children; Figure 2.5). These deaths were therefore not included in the analysis.

Figure 2.4 (see overleaf) identifies the three deaths' datasets generated through the VACMS. The three datasets were: all deaths that occurred in Victoria, 1988–2009 inclusive (master death dataset); all deaths occurring 1988–1998; all deaths occurring 1999–2009; linked birth/death datasets 1999–2008/9.

The VACMS team reviewed a total of 10,912 death files representing all deaths (of live-born infants) in Victoria that had occurred between 1 January 1988 and 31 December 2009 inclusive. Of these files, 1466 were not in the birth cohort (NIBC)[9] and 38 files were not able to be located (identified through the CCOPMM sequential number system for death files). Of the latter, six files were identified as duplicate cases, 27 were missing with no known reason and five files were 'empty' (front sheet only). As described previously in the Birth Report, the 20-year birth cohort was divided into two birth cohorts (Freemantle et al. 2013). Figure 2.5 reports a schema of all death case files reviewed (1999–2009) and of the development of the analytical cohort for the Mortality Report for the years 1999–2009, and the numbers for all death files. The intensive process to enable the linkage of the birth registration number to the CCOPMM case number has only been undertaken for the 1999 to 2008 birth cohort.

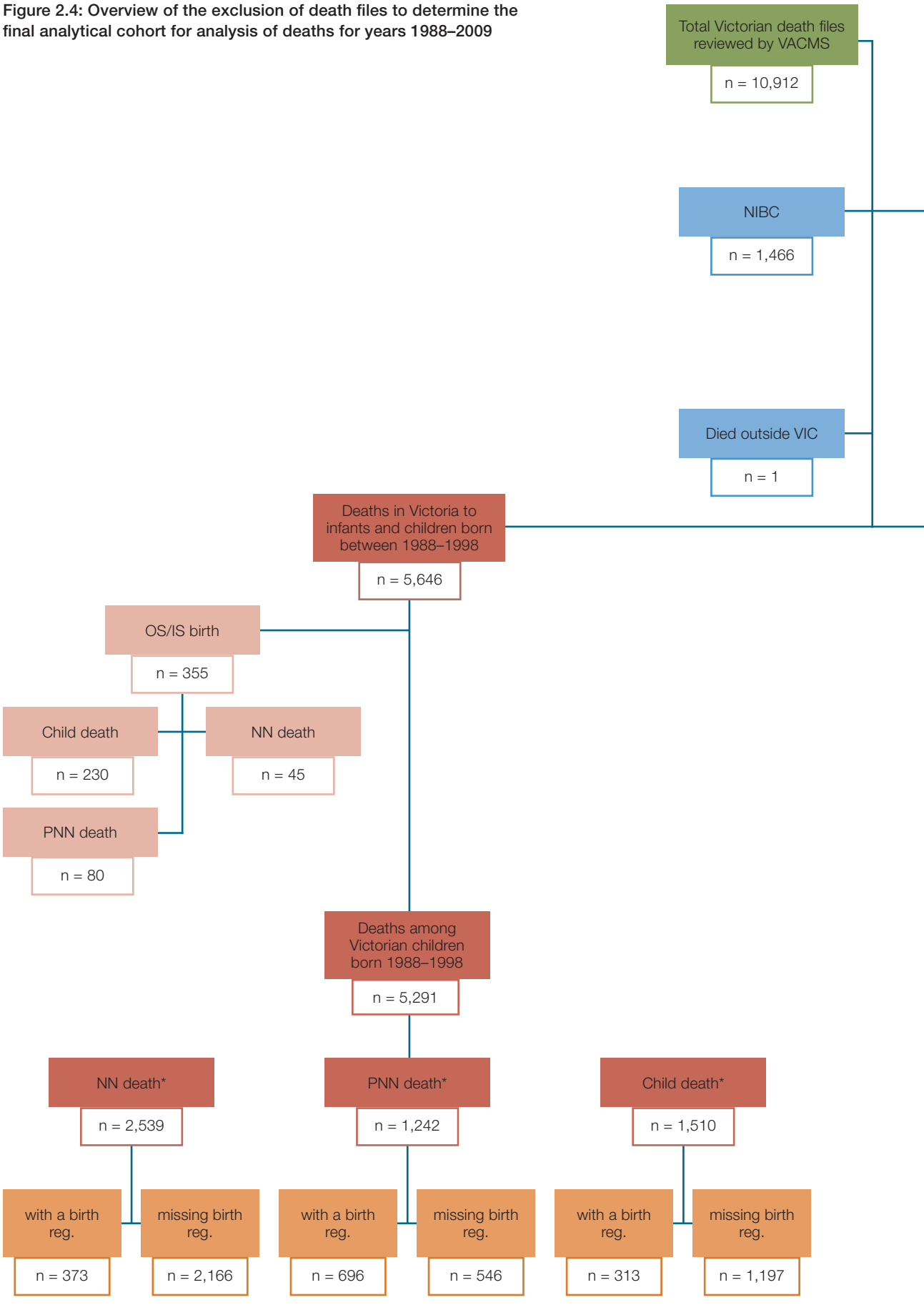
In the 1999 to 2008 birth cohort, 3761 death files were reviewed. Of these, one case was a duplicate, and 156 deaths were overseas or interstate births. Of the latter, 39 were neonatal deaths (NNDs) and 56 were postneonatal deaths (PNDs), and 61 were child deaths. Figure 2.5 (see p.34) focuses on the numbers included in the analytical cohort for 1999–2009 deaths.

A total of 3501 deaths of infants and children who did not reach their eleventh birthday were linked into the birth cohort. These included a total of 2223 neonates, 804 postneonates and 474 children. Of the deaths that occurred in Victoria, a number of deaths were not linked into the birth cohort. These included deaths that occurred to infants and children who were born outside of Victoria and did not have a birth registration number (n = 156). Further, a number of deaths that did have a birth registration number (n = 7 infants; 4 children) were not in the birth cohort. A further 92 live births that were less than 20 weeks gestation and/or where gestation was missing birthweights were less than 400 grams did not have a birth registration number.

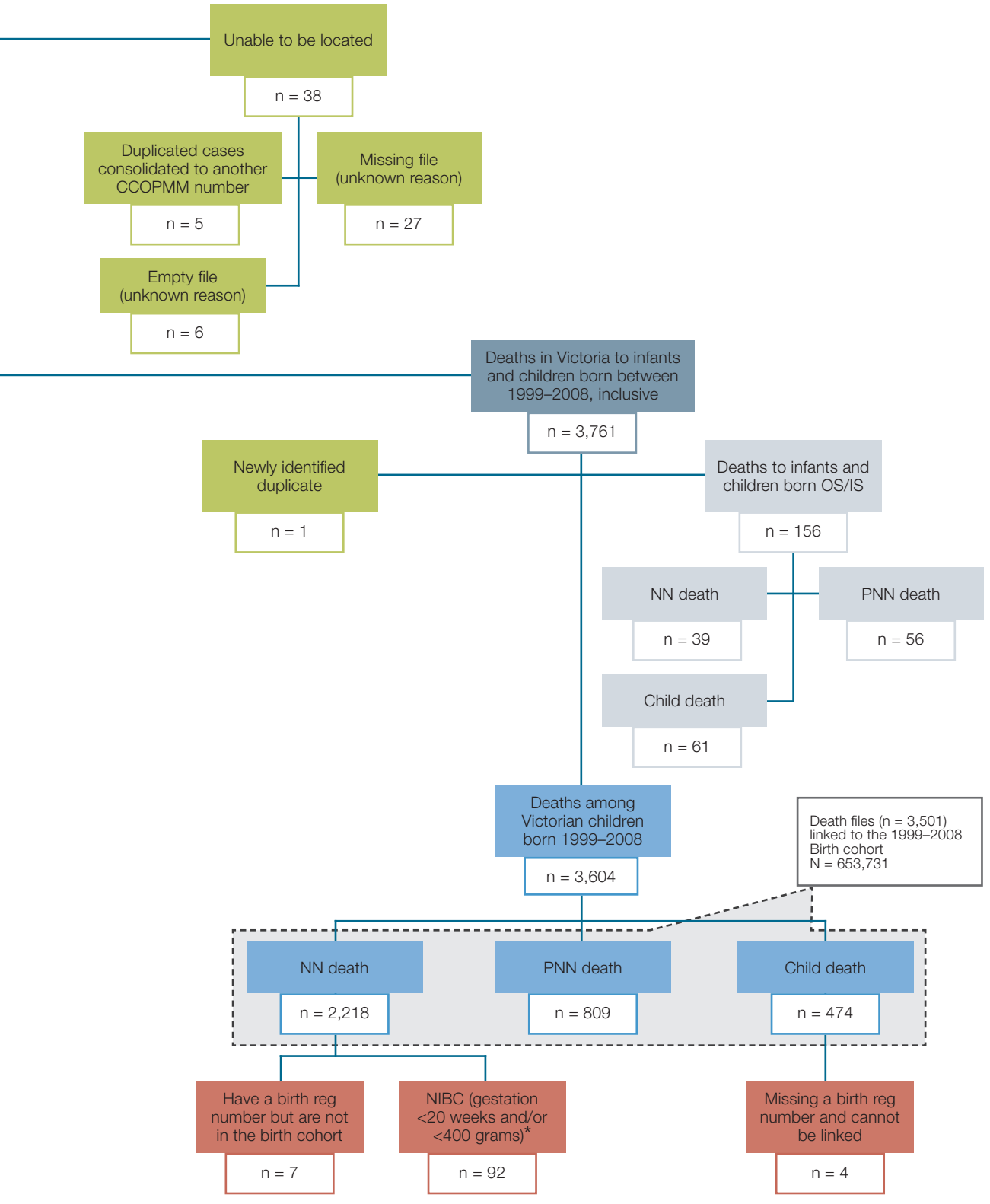
As a result of the process to enable the data linkage, a composite birth (n = 653,731)/death (3501) record for each mother and infant/child pair for each year from 1999 to 2009 for infants and children born in Victoria between 1999 and 2008 inclusive was created.

9 That is, born and/or died outside the prescribed VACMS birth cohort.

Figure 2.4: Overview of the exclusion of death files to determine the final analytical cohort for analysis of deaths for years 1988–2009



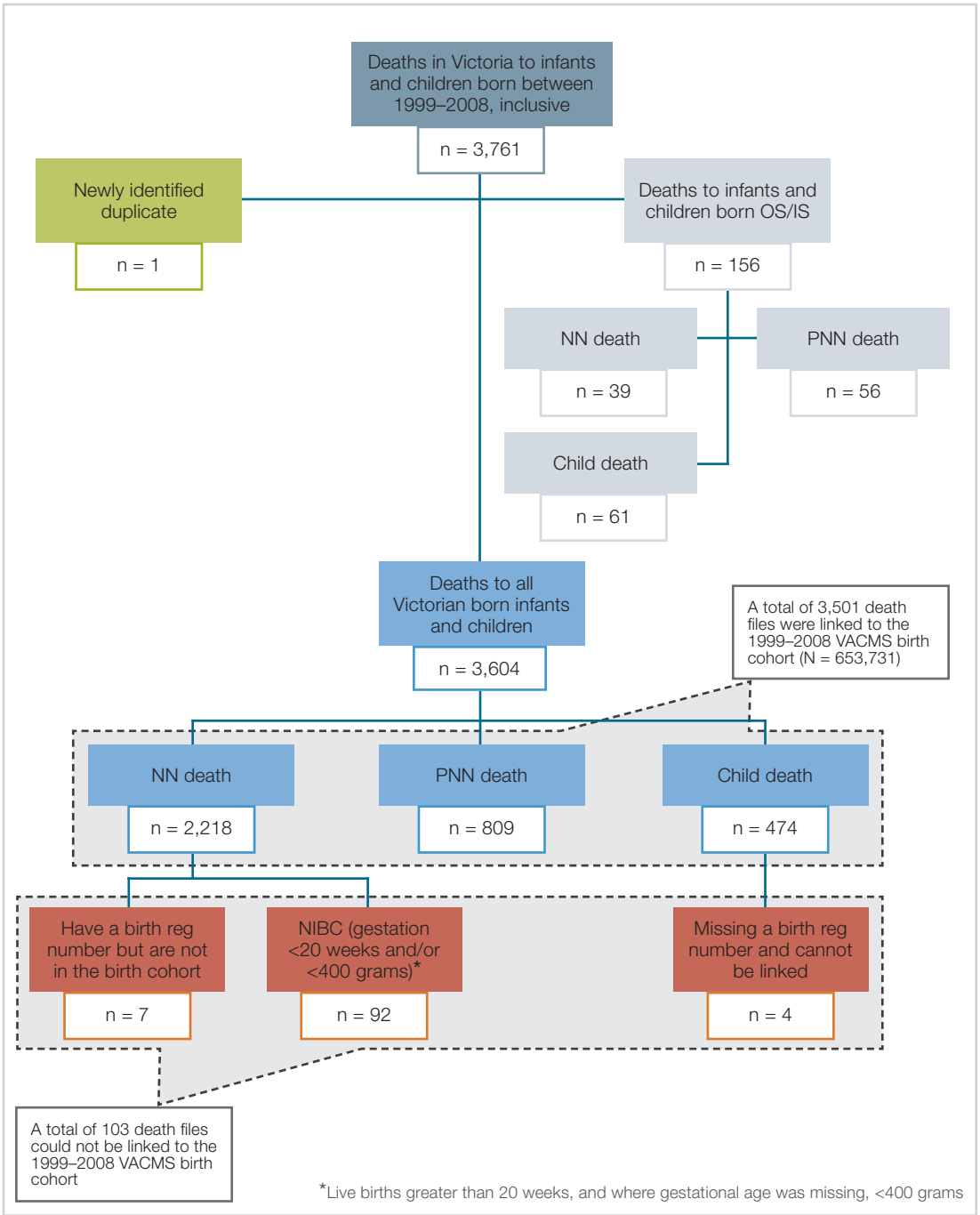
IS: interstate births; NIBC: not in birth cohort; NN: neonatal deaths; OS: overseas births; PNN: postneonatal deaths



*Live births greater than 20 weeks, and where gestational age was missing, <400 grams

Figure 2.5: Overview of the exclusion of death files to determine the final analytical cohort for analysis of deaths for years 1999–2009

IS: interstate births; NN: neonatal deaths; OS: overseas births; PNN: postneonatal deaths; VACMS: Victorian Aboriginal Child Mortality Study



Health services regions at time of birth and time of death

The Geographic Information Systems (GIS), Planning and Products, Strategy and Policy Division of the DoH Victoria provided information to enable the geographical information of the location of births to be identified. The residence at birth was linked to each death.

Over the years, the boundaries of the health services regions have changed. This birth data used the regions defined by the Department of Human Services from 2003/04, but included the separate Northern Metropolitan and Western Metropolitan regions. The DoH Victoria and DHS deliver services through nine geographical regions (four metropolitan regions and five rural regions).

The five rural regions are:

- Barwon – South Western Region
- Loddon Mallee Region
- Grampians Region
- Hume Region
- Gippsland Region.

The four metropolitan regions are:

- Northern Metropolitan Region
- Western Metropolitan Region
- Eastern Metropolitan Region
- Southern Metropolitan Region (Freemantle et al. 2013:19).

Where available, information describing the residence at the time of death was retrieved from the case files. The Department of Health GIS provided a list of postcodes and suburbs according to departmental health zones to enable the correlation of the deaths postcode data into health zones. The mortality data were analysed according to the residential location at the time of birth for both infants and children. The residential location of the child at death was also included in the analysis. Given the (absolute) small number of Aboriginal deaths, the health regions were aggregated into regional and metropolitan categories and other categories.

Given the (absolute) small number of deaths among the Aboriginal population, it was not possible to present the results according to the health regions. This report uses the residential address of the mother at the time of the infant's birth in the calculation of mortality rates when describing the geographical location at the time of death for infant and child deaths. Although studies in Western Australia showed consistency between the location of residence at birth and death for infant deaths, this was not so when calculating childhood deaths according to location. Data that described the population numbers of the health services region within which the child's residence was located at the time of the child's death were not available; therefore, the birth residence at the time of birth was used in the calculation of ChMRs (Freemantle et al. 2004).

Migration between location at time of birth and time of death

Location at time of birth was identified by the postcode of the residence (of mother) at time of birth as identified on the VPDC appended to the matched dataset. The actual location of the death according to postcode and residential location at time of death were collected for all deaths where available. Information on the postcode at the time of birth was also identified in many of the death files. These postcodes were amalgamated into health services regions and then aggregated into metropolitan and regional categories. Comparisons of the residential location between birth and death according to health zone, aggregated into metropolitan or regional categories, were tracked. Information describing the place of death (in/out of hospital) was also collected through the review of the death case files.

Statistical analysis and data management

All-cause and cause-specific infant mortality rates were generated for those infants who died before reaching their first birthday (365 days). Neonatal deaths were defined as occurring within 28 days of a live birth. Postneonatal deaths were defined as occurring after 28 days and before 365 days. Cause-specific infant mortality rates were reported.

Infant mortality was expressed as the cumulative mortality rate (CMR) and calculated for infant (deaths per 1000 live births), neonatal (deaths per 1000 live births), postneonatal (deaths per 1000 neonatal survivors) and childhood deaths (deaths per 1000 infant survivors or per 10,000 person-years). 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 (neonatal survivors). It should be noted that the calculation of CMRs per thousand live births is the usual way of describing infant mortality, as each child is followed for the same amount of time (i.e. one year) (Lilienfield & Lilienfield 1980).

Child (cumulative) mortality rates were abbreviated to ChMR. For child mortality, all-cause and cause-specific mortality rates were calculated for infant survivors who died before reaching their eleventh birthday. The denominator for childhood rates was calculated by excluding infant deaths (n = 3027) from the total number of births in each category of interest (per infant survivor). Age-specific mortality in childhood according to birth year groups was calculated using person-years.

Age-specific mortality rates using person-years were calculated. Ages were grouped as follows: one year to less than three years, three years to less than six years, and six years to less than 11 years. For age-specific childhood mortality rates, the ChMR was calculated for each age group by dividing the number of deaths (numerator) by the number of live births in the population at risk of death and expressed as person-years (denominator).

Person-years for all infant survivors were calculated from the first anniversary of the children's births until they were censored (31 December 2009) or the date of death. To calculate the time at risk for each age time period, age bands were created using left and right censoring for the periods from one to less than three years, greater than three years until six years, and greater than six years and before reaching the eleventh birthday.

Cox regression models were used to calculate hazard ratios and 95% confidence intervals among infant survivors (all infants who survived their first 365 days of life, n = 650,704).

Maternal and perinatal characteristic variables have been described in detail previously in the Birth Report (Freemantle et al. 2013). Briefly, categories used for maternal and perinatal characteristics were predetermined by the VPDC and the aggregated data provided to the VACMS. The maternal and perinatal characteristics reported in the Mortality Report include maternal age (≤19 years, 20–29 years, 30–39, ≥40 years), sex (male, female and indeterminate), birth weight (<1500 grams, 1500–2499 grams, 2500–4499 grams and ≥4500 grams), and gestational age in completed weeks (20–27, 28–31, 32–36, 37–41, >41). Some categories were further collapsed in order to ensure anonymity. The collapsed maternal and perinatal characteristics include maternal age (≤19 years, 20–29 years and ≥30 years), gestational age (preterm, term) and birth weight (<1500 grams, 1500–2499 grams, ≥2500 grams; also <2500 grams and ≥2500 grams).

Comparing Aboriginal and non-Aboriginal mortality rates

Infant mortality rates, rate ratios and 95% confidence intervals between Aboriginal and non-Aboriginal deaths were calculated using computer software (SAS 9.3 and Epi Info). The Mantel-Haenszel chi square statistic and the rate ratio, together with the 95% confidence interval around the estimate, were calculated using Epi Info (Dean et al. 2000).

The rate ratio (RR) reflects the comparison of the CMR of Aboriginal infant deaths with that calculated for the non-Aboriginal infant population. To assess the difference between the RR of Aboriginal and non-Aboriginal deaths for selected variables in the birth cohorts, a Wald test for interaction was performed using an interaction term for birth cohort years (1999–2003, 2004–08) and Aboriginal status.

Statistical tests for significance were reported at the 0.05 level. For all results, statistically significant results were identified in bold text for the estimates and the 95% confidence interval (CI) in the tables.

Reporting the excess deaths observed within the Aboriginal population

The calculation of excess deaths refers to deaths that are the 'excess over statistically expected deaths in a population within a given time frame' (Glossary or Risk Analysis, available on-line, accessed August 2014). The excess death is the difference between the number of deaths observed in the Aboriginal populations and the number of deaths that would have occurred in the Aboriginal population if it had the same infant mortality rate as the non-Aboriginal population. Excess deaths have also been calculated to relate excess deaths to specific causes.

Inter-rater agreement between coding for cause of death

There was strong agreement (95% of overall death cases [range 89%–100% within major causes of death categories]) between the death reviews by the external reviewer and principle investigator. For the categories with the most disagreement (perinatal causes, infection and other specific conditions), the disagreement was generally a result of disagreement within the details of subcategories rather than the major cause of death.

3 Results: Infant and Childhood Mortality, 1999–2008

The 2000 CCOPMM annual report states that 'The Registry of Births, Deaths, and Marriages notifies Council of all perinatal deaths registered in Victoria' (CCOPMM 2003:19). The legal requirements for registration are contained within the Births, Deaths and Marriages Registration Act; for the purpose of registration, the Act dictates that a live birth is the birth of an infant, regardless of maturity or birth weight, who breathes or shows any other signs of life after being born. The definition provided by the CCOPMM states that 'a live birth is the birth of a child who, after delivery, breathes or shows any other evidence of life such as a heartbeat' (CCOPMM 2012:32). All such infants must be registered, and 'if death subsequently occurs within 28 days, the Act dictates that a Perinatal Death Certificate is also required' (CCOPMM 2003:19).

The results in this report are based on the information in the case files describing deaths that have occurred where an infant was live born, as compiled by the CCOPMM through its statutory responsibility. The data were derived from death case files retrieved from archives (deaths 1988–2004) by CCU staff and from hanging files located within the CCU (deaths 2004–09). The Indigenous status attached to each birth generated through phases 1 and 2 of the VACMS was linked to the deaths by CCU staff.

The data described in this report are based on a birth cohort. The all-cause and cause-specific mortality for Victorian infants and children born between 1999 and 2008 inclusive is described. The patterns and trends of mortality for Aboriginal compared to non-Aboriginal infants and children have been identified. The denominator used in the mortality rates reflects a combined ever/never-Aboriginal variables and remaining (non-matched) Aboriginal/non-Aboriginal variable identified in the VPDC (see Chapter 2). These numbers are reported in the Table 3.4.

The classification of death used in this study is a three-digit code, compromising nine major categories, and is based on the antecedent cause of death, the JFcode (Appendix 1; see also 'The development of the JFCode' in Chapter 2). As described in Chapter 2, all CCOPMM case files were independently coded by two experienced coders according to a classification based on the PSANZ Perinatal Death and Neonatal Death Classification, which was extended by Freemantle (Freemantle 2003; Flenady et al. 2009; Freemantle et al. 2006a). The Chief Investigator reviewed these codes. Any inconsistencies in the codes were discussed and relevant case files reviewed. A final code was agreed and recorded in the SPSS database. The coding was submitted to a validation process. Ten per cent of case files in each year were randomly selected and reviewed by an experienced paediatric epidemiologist. The research team reviewed these codes and resolved any inconsistencies through research team discussion and, where necessary, further review of case files.

It is important to note that this coding protocol has been effectively used for more than 15 years. The current method was reported in a doctoral thesis in 2003 (Freemantle 2003). Studies using this coding protocol have been reported in a number of high-impact, peer review journals including the *Lancet, BMJ, Social Inequities in Maternal and Child Health, MJA, Archives of Disease in Childhood,*

Paediatric and Perinatal Epidemiology, and the *Journal of Paediatrics and Child Health*. It has been the basis for three major reports to the Western Australian Government and continues to be used for infant, child and youth mortality studies in Western Australia (Freemantle et al. 2004, 2010; Shepherd et al. 2013).

The results describe Aboriginal and non-Aboriginal infants and children who died in Victoria before reaching their eleventh birthday and who were born between 1999 and 2008 inclusive. In order to analyse trends over time, where appropriate the 11 years of death data were divided into birth year groups (1999–2003 and 2004–08 inclusive). Deaths include deaths up to the end of 2009. The death information also described the geographical location of mother's residence at the time of an infant/child's birth (see 'Migration between location at time of birth and time of death' in Chapter 2).

There is potential for migration flows through changes to the propensity for an individual to identify as Aboriginal (or changes to protocols that govern identification of Indigenous status within the perinatal data), which can alter the size and cohorts over time. These data represent the whole population, but there is always a contingency in the observed data for a different play of chance that could have produced a different pattern (number of deaths) over the past 11 years. Although such migration is likely to be small, the 95% CI has been included as appropriate for comparisons between the two population groups and within the two population groups. The CI enables a broader conclusion about the underlying reality producing this difference between the Aboriginal and non-Aboriginal populations.

As the Indigenous status describing these study data are based on matched data sourced from two administrative records for the entire cohort of Victorian births 1999–2008 inclusive, descriptive statistics on this population data are presented in this report on the assumption that the total population data are presented.

Small numbers of deaths were observed within the Aboriginal cohort when the data were disaggregated by cause of death. These relatively small numbers of deaths potentially compromise the ability to indicate statistical significance between the two populations and the intervals are not necessarily meaningful. Thus, the data were limited in regards to estimating effects associated with the cause of death. However, the calculation of cause-specific CMRs and the relative risk of death for Aboriginal compared with non-Aboriginal infants were of significant public health relevance. The public health relevance of these data was apparent in the calculation of the excess number of deaths (see 'Reporting the excess deaths observed within the Aboriginal population' in Chapter 2). These excess deaths are an indicator of the burden of preventable mortality experienced within the Aboriginal infant population.

While acknowledging the small numbers of deaths, these statistics provide an indication of the direction and magnitude, and therefore the clinical and/or public health significance, of the outcomes. Indeed, for such a relatively small (Aboriginal) population to be at a much higher risk of poor outcomes when compared to a larger (non-Aboriginal) population carries with it significant public health implications. We believe that these data provide an important baseline from which to determine appropriate responses and evaluate interventions aimed at preventing death among infants.

This chapter has three sections: 3.1 Trends and patterns in infant mortality (births); 3.2 Trends and patterns of childhood mortality; and 3.3 All-cause infant and childhood mortality for deaths of children born outside Victoria. The age-specific mortality in 3.2 age groupings reflects pre-primary and primary school categories.

3.1: Trends and patterns in infant mortality (births)

All-cause infant mortality:

- summary of infant mortality for Victorian-born infants 1999–2008 inclusive
- neonatal/postneonatal
- male and female
- maternal age
- birthweight
- gestational age
- parity
- place of death—in/out of hospital
- geographical location

Antecedents to infant outcomes:

- maternal smoking
- antenatal attendance

Cause-specific infant mortality (including geographical residence of mother at time of birth):

- trends in postmortem
- summary of cause specific infant (excess deaths)
- neonatal/postneonatal
- maternal age
- birth Cohorts

Specific case studies:

- SIDS
- infection
- birth defects
- injury.

3.2: Trends and patterns of childhood mortality

All-cause child mortality:

- male and female
- place of death—in/out of hospital
- geographical location

All-cause, age-specific:

- male and female
- place of death—in/out of hospital

Cause-specific:

- postmortems
- male and female
- injury case study

Cause-specific childhood mortality

- postmortems
- main causes of death
- male and female
- mortality due to injury specific causes.

3.3: All-cause infant and childhood mortality for deaths of children born outside Victoria

All-cause mortality:

- neonatal/postneonatal
- child
- male and female

Cause-specific mortality:

- neonatal/postneonatal
- child.

The following tables report the numbers according to the data sources and Indigenous status in the generation of the denominator used in this report (Table 3.1, next page) and the generation of the denominator used in the calculation of the infant mortality rates and basis for the calculation of infant survivors in person years (Tables 3.2, 3.3, 3.4).

Table 3.1: Number of deaths according to the data sources and Indigenous status in the generation of the denominator used in this report, 1999–2009

Matched birth cohort	VPDC Aboriginal status	Ever/never-Aboriginal	Frequency (N)
Yes	Aboriginal	Aboriginal	46
	Non-Aboriginal	Aboriginal	36
	Non-Aboriginal	Non-Aboriginal	2502
	Non-Aboriginal	Unknown	147
	Unknown	Non- Aboriginal	1
Unable to link	Non-Aboriginal	–	3
Multiple matches*	Aboriginal	–	27
	Non-Aboriginal	–	737
	Unknown	–	2
Total			3501

* Refer to Freemantle et al. 2013:135–9.

Table 3.1 reports the numbers of deaths according to Aboriginal status and the VPDC (mother only) and VACMS Birth Report (ever/never mothers and/or fathers, VPDC and RBDM).

Tables 3.2, 3.3 and 3.4 report the generation of the denominator used in the calculation of the infant mortality rates and the basis for the calculation of infant survivors in person years. Taking advice from Professor Marian Knight (author of the External Review of the Birth Report) and Dr Fiona Mensah (independent statistics advisor), it was decided to include the information contained in the VPDC describing mothers' Indigenous status (Table 3.2) in the matched dataset where there was missing information describing mothers' and/or fathers' Indigenous status in the RBDM (Table 3.3). It is important to note that the numbers of deaths according to Indigenous status identified in Table 3.2 and Table 3.3 reflect the different sources of information and are reflected in the final number of deaths according to Indigenous status. The results of the sensitivity analysis comparing the results from using the ever/never-Aboriginal matched data only and the ever/never-Aboriginal data plus information derived from the VPDC are reported in Table 3.5.

Table 3.2 reports the number of live births according to the Indigenous status of the mother recorded by midwives at the time of the birth, 1999–2008 inclusive, and the number of (matched to births) deaths according to infant, neonatal, postneonatal and childhood deaths. The Indigenous status is as recorded in the VPDC at the time of the infant's birth by the midwife.

Table 3.2: Number and proportion of births and deaths recorded in the VPDC in children born in Victoria between 1999 and 2008 inclusive according to Aboriginal* status and type of death**

Type	Non-Aboriginal N (%)	Aboriginal N (%)	Uncertain N (%)	Total N (%)
Births	648,695 (99.2)	4,958 (0.8)	78 (0.0)	653,731 (100.0)
Infant deaths	2,959 (97.8)	65 (2.1)	3 (0.1)	3,027 (100.0)
Neonatal deaths	2,172 (73.4)	44 (67.7)	2 (66.7)	2,218 (73.3)
Postneonatal deaths	787 (26.6)	21 (32.3)	1 (33.3)	809 (26.7)
Childhood deaths	466 (98.3)	8 (1.7)	0	474 (100.0)
Total deaths	3,425 (97.8)	73 (2.1)	3 (0.1)	3,501 (100.0)

VPDC: Victorian Perinatal Data Collection. * VPDC mother only third-party identified Aboriginal variable; ** 'type' of death refers to deaths in the neonatal and postneonatal periods and for deaths between 1 and 11 years.

Table 3.3 reports the number of live births reported in the matched birth dataset of the self-reported information of Indigenous status by the mother and/or father recorded at the time of the infant's birth using the Ever-Aboriginal Rule. It also reports the number of (matched to births) deaths according to infant, neonatal, postneonatal and childhood deaths.

Table 3.3: Number and proportion of births and deaths according to the Ever-Aboriginal Rule in children born in Victoria between 1999 and 2008 inclusive according to Aboriginal* status and type of death

Type	Non-Aboriginal N (%)	Aboriginal N (%)	Uncertain identification (ever/never) N (%)	Multiple matches** N (%)	Total N (%)
Births	573,028 (87.7)	9,291 (1.4)	23,625 (3.6)	47,787 (7.3)	653,731 (100.0)
Infant deaths	2124 (70.2)	66 (2.2)	119 (3.9)	718 (23.7)	3,027 (100.0)
Neonatal deaths	1503 (70.8)	43 (65.2)	84 (70.6)	588 (81.9)	2,218 (73.3)
Postneonatal deaths	621 (29.2)	23 (34.8)	35 (29.4)	130 (18.1)	809 (26.7)
Childhood deaths	379 (80)	16 (3.4)	28 (5.9)	51 (10.8)	474 (100.0)
Total deaths	2,503 (71.5)	82 (2.3)	147 (4.2)	769 (22.0)	3,501 (100.0)

* Ever/never-Aboriginal variable; ** 769 deaths were multiple matches, therefore the non-Aboriginal status in the VPDC was unable to be validated with the ever/never variable.

Table 3.4 reports the combined number of live births in Victoria according to the self-reported information about the Indigenous status of the mother and/or father, combined with additional information on the mother's Indigenous status recorded by the midwives in the VPDC. These numbers formed the denominator for the births and the numerator for the deaths in the mortality rates reported in this report. The table provides a summary of the data regarding the number (and percentage) of births and deaths described by type of death (infant, neonatal, postneonatal and childhood) according Aboriginal status. Infant deaths are, in general, divided into neonatal and postneonatal periods. Deaths in the neonatal period are those occurring in the first 28 days after birth (0–28 days), while postneonatal deaths are those occurring in the remainder of the first year (>28 days to 364 days) (ABS 1998).

Table 3.4: Number and proportion of births and deaths according to the combined ever/never-Aboriginal data and the VPDC mother's Indigenous status in children born in Victoria between 1999 and 2008 inclusive according to Aboriginal* status and type of death

Type	Non-Aboriginal N (%)	Aboriginal N (%)	Uncertain identification (ever/never) N (%)	Total N (%)
Births	643,693 (98.5)	10,019 (1.5)	19 (0.0)	653,731 (100.0)
Infant deaths	2,932 (96.9)	93 (3.1)	2 (0.1)**	3,027 (100.0)
Neonatal deaths	2,155 (73.5)	62 (66.7)	1 (0.50)	2,218 (73.3)
Postneonatal deaths	777 (26.5)	31 (33.3)	1 (0.50)	809 (26.7)
Childhood deaths	458 (96.6)	16 (3.4)	0	474 (100.0)
Total deaths	3,390 (96.8)	109 (3.1)	2 (0.1)	3,501 (100.0)

VPDC: Victorian Perinatal Data Collection.*Combined ever/never-Aboriginal variable and remaining VPDC Aboriginal third-party identified variable.

Sensitivity analysis

The denominator used in these analyses was the ever/never denominator, complemented by the VPDC data in cases where the Indigenous identifier was missing. The VPDC data represented mother's Indigenous status only (see VPDC information in 'Data sources' in Chapter 2). The following table reports the results of the sensitivity analysis. A sensitivity analysis was undertaken to identify whether a bias had been introduced into the results due to the inclusion of the VPDC data describing mother's Indigenous status for those births where the matched data could not determine an ever/never-Aboriginal status. The sensitivity analysis restricted the infant and child mortality rates to the ever/never-Aboriginal status established through phases 1 and 2 of the VACMS (Freemantle et al. 2013). The results indicated that the proportions reported were very similar to those reported in the sensitivity analysis (see Table 3.5 overleaf).

3.1 Trends and patterns in infant mortality (births)

All-cause infant mortality

These data report the deaths of infants born in Victoria between 1999 and 2008 inclusive. The birth cohort has been divided into two cohorts (1999–2003 and 2004–08) to calculate the rate ratio (RR) and significance of change (95% CI) between the two cohorts. Rates are expressed per 1000 live births and the RR is accompanied by the 95% CI. Live born infants <20 weeks gestation are not included in infant mortality calculations (n = 92).

The matched population data in the VACMS Birth Report reported that Aboriginal births account for 1.5% of the Victorian births (birth years 1999–2008 inclusive). However, between 1999 and 2009, Aboriginal infants have accounted for 3.1% of deaths among Victorian-born infants.

The key findings are reported in the Executive Summary of this report.

Table 3.6 (see pp.45–6) reports the summary of the CMR for all Victorian-born infants who died in Victoria between 1999 and 2009 inclusive. It includes maternal information and infant outcomes for selected variables. The data report the total number of births and deaths (n) and percentage (%). The postneonatal mortality rate is calculated per 1000 neonatal survivors. All deaths are disaggregated to identify the population estimates for Aboriginal and non-Aboriginal infants and the RR with the 95% CI for Aboriginal compared with non-Aboriginal infants. The RR for Aboriginal infant mortality compared with non-Aboriginal infants was significantly higher across the majority of categories of maternal and infant outcome variables considered in this analysis. A more comprehensive analysis of each variable is reported in the following section.

Table 3.5: Cumulative mortality rate, and rate ratios of Aboriginal/Torres Strait Islander infants compared to non-Aboriginal/Torres Strait Islander infants born in Victoria between 1999–2008 inclusive according to Ever/never Aboriginal variable (as reported on the Birth Report)

Variable	Denominator births-number	Non-Aboriginal Numerator deaths (%)	CMR /1000 births	Denominator Births-number	Aboriginal Numerator deaths (%)	CMR /1000 births	Rate ratio* (95% CI)	p-value
Infant	573,028	2,124 (100.0)	3.71	9291	66 (100.0)	7.10	1.92 (1.50–2.45)	<0.0001
Neonate	573,028	1,503 (70.8)	2.62	9291	43 (65.2)	4.63	1.85 (1.44–2.39)	<0.0001
Postneonate	571,525	621 (29.2)	1.09**	9248	23 (34.8)	2.49**	2.59 (1.81–3.71)	<0.0001
Gender								
Male	294,208	1,192 (56.1)	4.05	4677	38 (57.6)	8.12	2.23 (1.71–2.92)	<0.0001
Female	278,820	932 (43.9)	3.34	4614	28 (42.4)	6.07	1.83 (1.32–2.53)	0.0003
Indeterminate	0	0	0	0	0	0	0	0
Gender unknown	0	0	0	0	0	0	0	0
Geog. location at birth								
Regional	143,194	565 (26.6)	3.95	4501	32 (48.5)	7.11	1.80 (1.26–2.57)	0.0012
Metropolitan	420,315	1,502 (70.7)	3.57	4144	28 (42.4)	6.76	1.89 (1.30–2.75)	0.0008
Other	9,519	57 (2.7)	5.99	646	6 (9.1)	9.29	1.55 (0.67–3.60)	0.3064
General cause of death								
Perinatal causes	573,028	232 (10.9)	0.40	9291	7 (10.6)	0.75	1.86 (0.88–3.95)	0.1055
Significant birth defects	573,028	831 (39.1)	1.45	9291	13 (19.7)	1.40	0.96 (0.56–1.67)	0.8981
Prematurity	573,028	579 (27.3)	1.01	9291	24 (36.4)	2.58	2.56 (1.70–3.85)	<0.0001
Infection	573,028	115 (5.4)	0.20	9291	5 (7.6)	0.54	2.68 (1.10–6.57)	0.0308
Injury	573,028	55 (2.6)	0.10	9291	3 (4.5)	0.32	3.36 (1.05–10.75)	0.0407
Cancers & leukaemias	573,028	21 (1.0)	0.04	9291	0	0	0	0
SIDS	573,028	140 (6.6)	0.24	9291	9 (13.6)	0.97	3.96 (2.02–7.78)	<0.0001
Other specific conditions	573,028	119 (5.6)	0.21	9291	3 (4.5)	0.32	1.55 (0.49–4.89)	0.4502
Unknown—death not classifiable	573,028	32 (1.5)	0.06	9291	2 (3.0)	0.22	3.85 (0.92–16.08)	0.0641

* the rate ratio reflects the comparison of the CMR/1000 live births for Aboriginal infants compared with the CMR/1000 live births for non-Aboriginal infants.

** CMR per 1,000 neonatal survivors.

Table 3.6: Cumulative mortality rate, and rate ratios of Aboriginal/Torres Strait Islander infants compared with non-Aboriginal/Torres Strait Islander infants in Victoria between birth years 1999–2008 inclusive according to combined Ever/never Aboriginal data and VPDC mothers Indigenous status‡

Variable	Denominator births-number	Non-Aboriginal Numerator deaths (%)	CMR /1000 births	Denominator Births-number	Aboriginal Numerator deaths (%)	CMR /1000 births	Rate ratio* (95% CI)	p-value
Infant	643,693	2,932 (100.0)	4.55	10,019	93 (100.0)	9.28	2.04 (1.66–2.51)	<0.0001
Neonate	643,693	2,155 (73.5)	3.35	10,019	62 (66.7)	6.19	1.85 (1.44–2.38)	<0.0001
Postneonate	641,538	777 (26.5)	1.21**	9,957	31 (33.3)	3.11**	2.57 (1.80–3.68)	<0.0001
Gender								
Male	330,337	1,643 (56.0)	4.97	5,062	56 (60.2)	11.06	2.22 (1.70–2.90)	<0.0001
Female	313,327	1,284 (43.8)	4.10	4,957	37 (39.8)	7.46	1.82 (1.31–2.53)	0.0003
Indeterminate/ unknown	29	5	172.41	0	0	0	0	0
Maternal age (years)***								
< = 19 years	17,632	143 (4.8)	8.11	1,159	16 (21.1)	13.81	1.70 (1.02–2.85)	0.0436
20–29 years	249,562	1,219 (41.3)	4.88	3,736	39 (51.3)	10.44	2.14 (1.55–2.94)	<0.0001
> = 30 years	379,520	1,585 (53.7)	4.18	2,100	21 (27.6)	10.00	2.39 (1.56–3.68)	<0.0001
Unknown	3	2 (0.1)	666.67	0	0		0	0
Parity: prev. births >20 weeks								
0	273,518	1,336 (45.6)	4.88	3,722	33 (35.5)	8.87	1.82 (1.29–2.56)	0.0007
1–2	320,271	1,264 (43.1)	3.95	4,392	34 (36.6)	7.74	1.96 (1.40–2.76)	0.0001
> = 3	49,903	332 (11.3)	6.65	1,905	26 (28.0)	13.65	2.05 (1.38–3.06)	0.0004
Parity (unknown)	1	0	0	0	0	0	0	0
Birth weight (grams)								
<1,500 grams	6,907	1,657 (56.5)	239.90	185	51 (54.8)	275.68	1.15 (0.87–1.52)	0.3282
1,500–2,499 grams	33,350	346 (11.8)	10.37	954	16 (17.2)	16.77	1.62 (0.98–2.67)	0.0603
> = 2,500 grams	603,379	911 (31.1)	1.51	8,879	25 (26.9)	2.82	1.86 (1.25–2.77)	0.0021
Unknown	57	18 (0.6)	315.79	1	1 (1.1)	1000.00	0	0
Gestational age (weeks)								
Preterm	47,058	2,003 (68.3)	42.56	1,057	67 (72.0)	63.39	1.49 (1.17–1.90)	0.0013
Term	596,592	925 (31.5)	1.55	8,959	26 (28.0)	2.90	1.87 (1.27–2.76)	0.0016
Unknown	43	4 (0.1)	93.02	3	0	0	0	0
Geog. location at birth								
Regional	158,716	764 (26.1)	4.81	4,917	48 (51.6)	9.76	2.03 (1.51–2.71)	<0.0001
Metropolitan	472,947	2,087 (71.2)	4.41	4,310	36 (38.7)	8.35	1.89 (1.36–2.63)	0.0001
Other	12,030	81 (2.8)	6.73	792	9 (9.7)	11.36	1.69 (0.85–3.36)	0.1363

‡ Table 3.4

Table 3.6 cont...

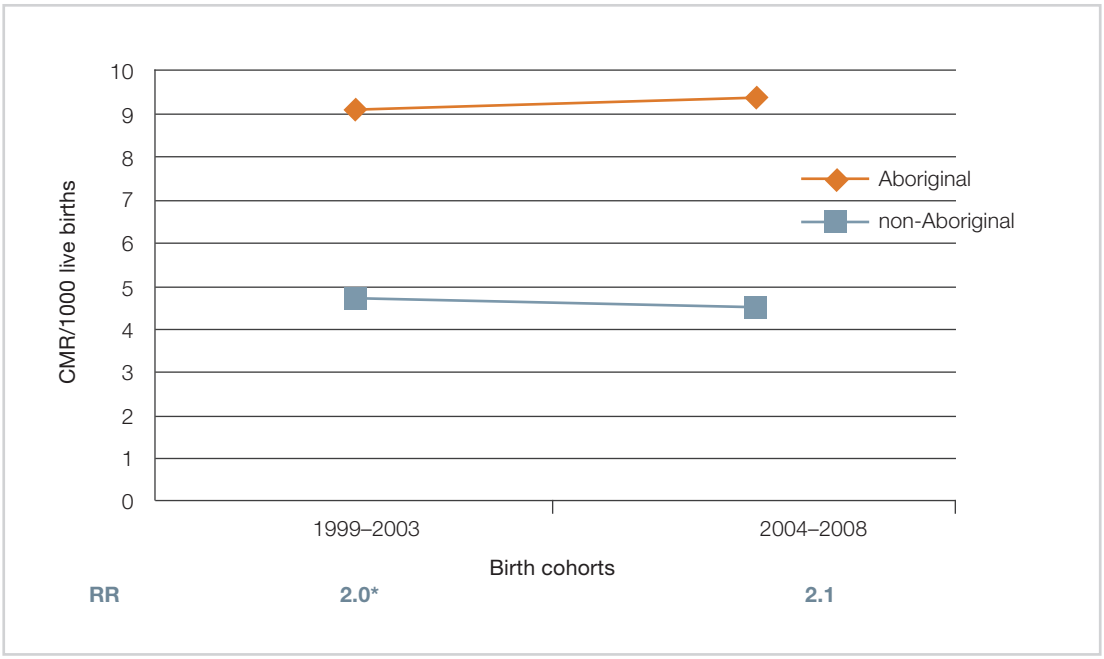
Variable	Denominator births-number	Non-Aboriginal Numerator deaths (%)	CMR /1000 births	Denominator Births-number	Aboriginal Numerator deaths (%)	CMR /1000 births	Rate ratio* (95% CI)	p-value
General cause of death								
Perinatal causes	643,693	298 (10.2)	0.46	10,019	9 (9.7)	0.90	1.94 (1.00–3.77)	0.0501
Significant birth defects	643,693	1,048 (35.7)	1.63	10,019	15 (16.1)	1.50	0.92 (0.55–1.53)	0.7471
Prematurity	643,693	895 (30.5)	1.39	10,019	38 (40.9)	3.79	2.73 (1.97–3.77)	<0.0001
Infection	643,693	157 (5.4)	0.24	10,019	6 (6.5)	0.60	2.46 (1.09–5.55)	0.0308
Injury	643,693	66 (2.3)	0.10	10,019	6 (6.5)	0.60	5.84 (2.53–13.47)	<0.0001
Cancers & leukaemias	643,693	21 (0.7)	0.03	10,019	0	0	0	0
SIDS	643,693	180 (6.1)	0.28	10,019	14 (15.1)	1.40	5.00 (2.90–8.61)	<0.0001
Other specific conditions	643,693	223 (7.6)	0.35	10,019	3 (3.2)	0.30	0.86 (0.28–2.70)	0.8019
Unknown—death not classifiable	643,693	44 (1.5)	0.07	10,019	2 (2.2)	0.20	2.92 (0.71–12.05)	0.1383

Notes: *Rate ratio reflects comparison CMR/1000 live births Aboriginal infants compared with CMR/1000 live births non-Aboriginal infants; **CMR/1000 neonatal survivors; ***mothers only who identified as Aboriginal or non-Aboriginal.

Between 1999 and 2008 birth years inclusive, the cumulative infant mortality in Victoria for all infants was 4.6/1000 live births. The rates were similar in the two birth cohorts (RR = 1.0: CI 0.9–1.0). However, the risk of Aboriginal infants dying before reaching their first birthday compared with non-Aboriginal infants was significantly increased (RR = 2.0: CI 1.7–2.5).

Figure 3.1 (see next page) represents the CMR for Aboriginal and non-Aboriginal infants dying between the birth years 1999 and 2008. The RR of Aboriginal infants dying compared with non-Aboriginal infants in each of the birth year groups is identified below the abscissa. The CMR for Aboriginal infants was similar (9.1/1000, 1999–2003: 9.4/1000, 2004–08; RR = 1.0: 0.7–1.6). The CMR in the non-Aboriginal population was similar across the two birth cohorts (4.7/1000, 1999–2003: 4.5/1000, 2004–08; RR = 1.0: 0.9–1.0). The risk of an Aboriginal infant dying compared with a non-Aboriginal infant was similar across the birth cohorts (1999–2003 **RR = 2.0: CI 1.4–2.7, p<0.0001**; 2004–08 **RR = 2.1: CI 1.6–2.8, p<0.0001**).

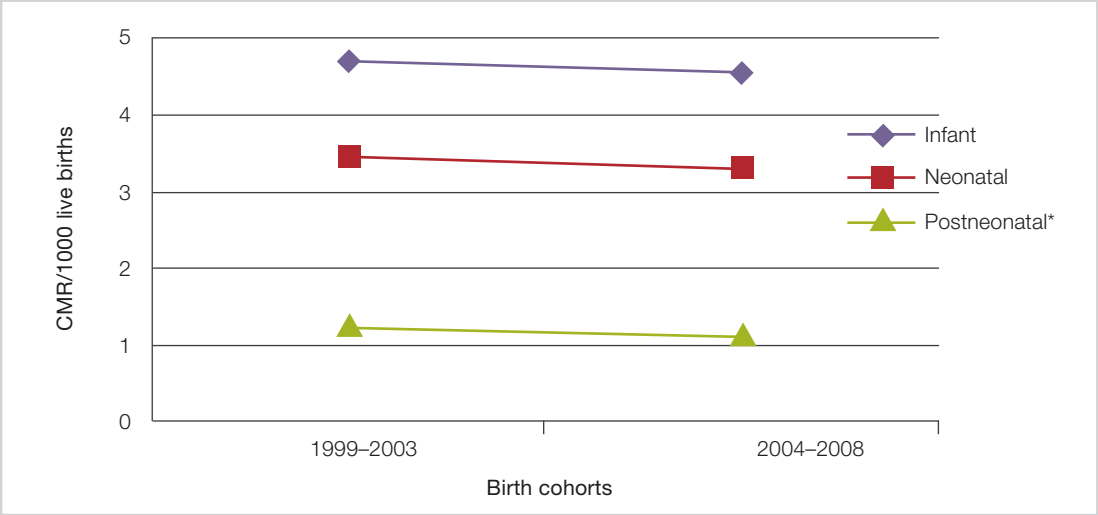
Figure 3.1: CMR for Aboriginal and non-Aboriginal infants by birth year groups, 1999–2008



CMR: cumulative mortality rate; RR: rate ratio; *statistically significant values (refer to text).

Figure 3.2 (see overleaf) represents the infant, neonatal and postneonatal mortality rates for all Victorian-born infants (Aboriginal and non-Aboriginal infants combined) who died in the first year of life between 1999 and 2008 birth years. The figure shows a higher infant mortality rate in the neonatal period compared with the rate in the postneonatal period. This picture would be expected in developed countries with good maternal and child health services. Over the past 10 years, the CMR was similar across the two birth cohorts in the infant (CMR 4.7/1000 live births; 4.6/1000 live births), neonatal (CMR 3.5/1000 live births; 3.3/1000 live births) and postneonatal (CMR 1.3/1000 neonatal survivors; 1.1/1000 neonatal survivors) periods.

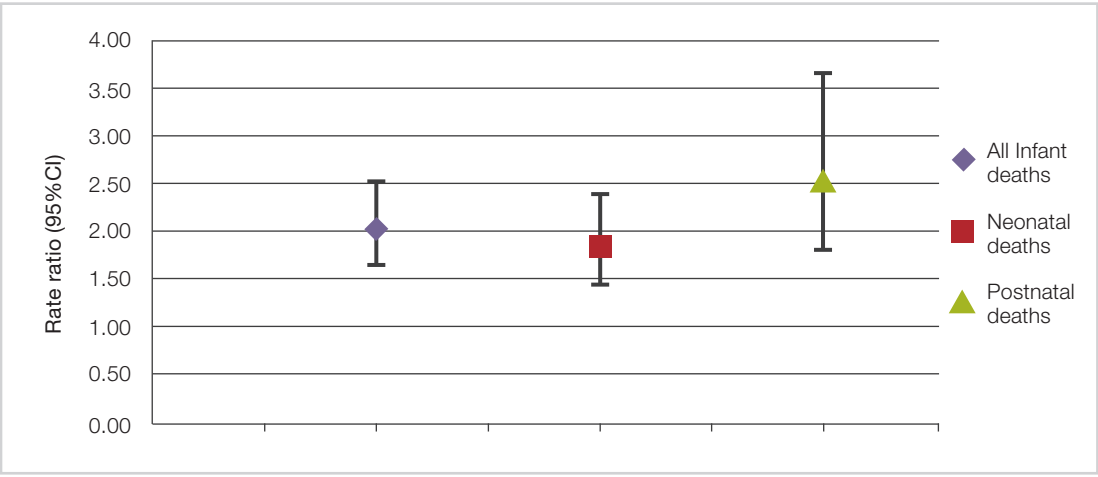
Figure 3.2: CMR for *all* infant, neonatal and postneonatal deaths in the total Victorian population by birth cohorts, 1999–2008



CMR: cumulative mortality rate; *postneonatal CMR/1000 neonatal survivors.

When the population data were disaggregated according to Indigenous status, a different pattern was observed among Aboriginal infant, neonatal and postneonatal mortality compared with their non-Aboriginal peers. Figure 3.3 reports the RR and 95% CI for Aboriginal compared with non-Aboriginal infant, neonatal and postneonatal deaths, 1999–2008 inclusive. The risk of death for Aboriginal infants (compared with non-Aboriginal infants) was significantly higher (RR = 2.0: CI 1.7–2.5) over the 10-year birth cohort. Similarly, the risk of death was significantly increased for Aboriginal neonates (RR = 1.9: CI 1.4–2.4) and postneonates (RR = 2.6: CI 1.8–3.7) when compared with their non-Aboriginal peers.

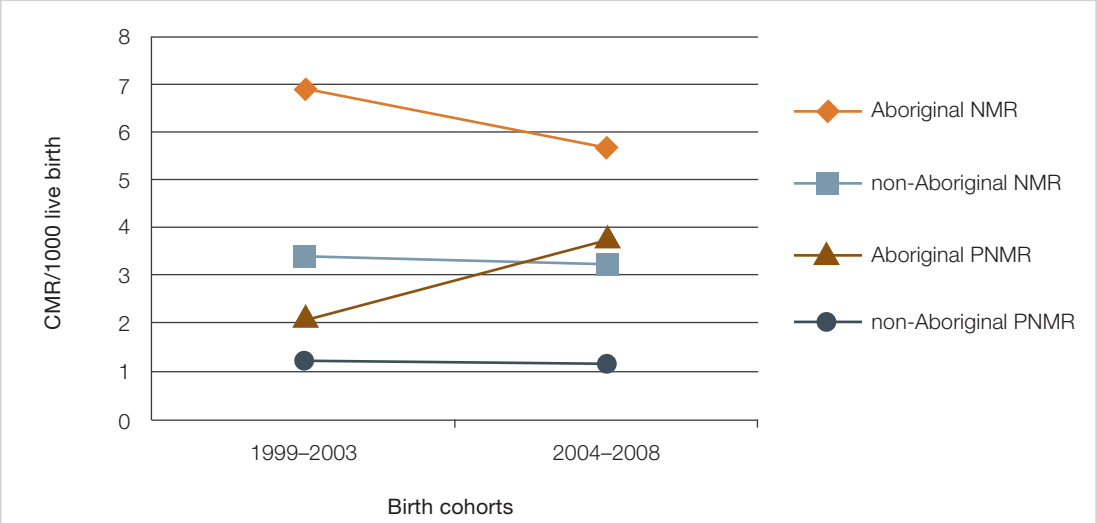
Figure 3.3: RR (95% CI) for infant, neonatal and postneonatal deaths for Aboriginal and non-Aboriginal infants, neonates and postneonates, 1999–2008



CI: confidence interval; RR: rate ratio.

Figure 3.4 represents the CMR for infant, neonatal and postneonatal mortality for Aboriginal and non-Aboriginal infants over the two birth cohorts and shows the different patterns of mortality when the total Victorian population is considered from an Aboriginal perspective. In both populations the neonatal mortality rate (NMR) is higher than the PNMR. However, of note is that the Aboriginal PNMR has increased over the birth cohorts (2.2/1000 neonatal survivors to 3.8/1000 neonatal survivors, p = 0.1). In the 2004–08 birth cohort the Aboriginal PNMR (3.8/1000 neonatal survivors) is higher than the non-Aboriginal NMR (3.3/1000 live births). A higher PNMR than NMR is most often observed in developing countries and has been reported among American Indians (Kleinman 1990).

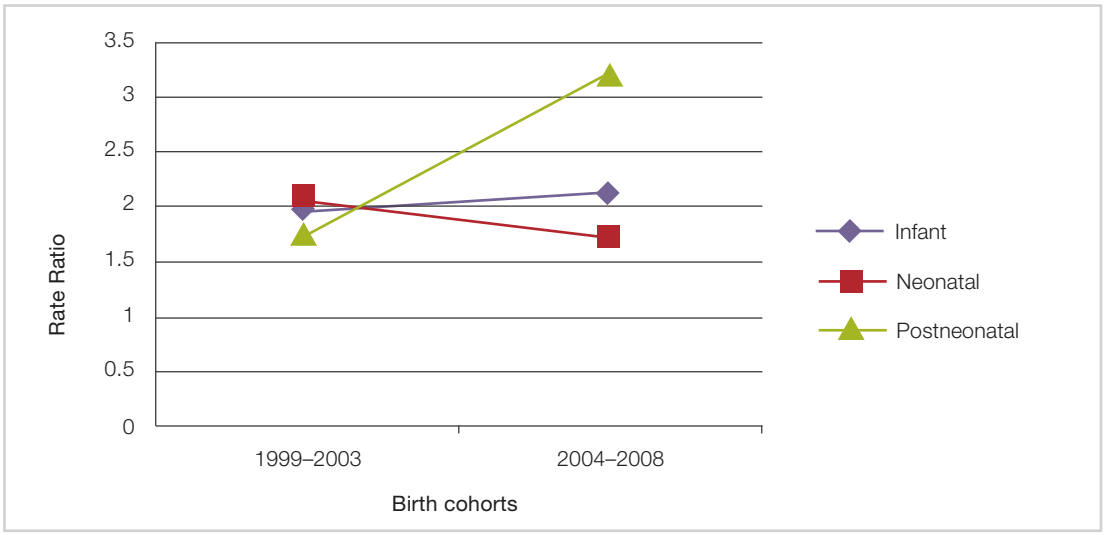
Figure 3.4: CMR for infant, neonatal and postneonatal deaths for Aboriginal and non-Aboriginal infants, neonates and postneonates, birth cohorts 1999–2008



CMR: cumulative mortality rate; NMR: neonatal mortality rate; PNMR: postneonatal mortality rate.

Figure 3.5 (see overleaf) shows the increase in the RR of death for Aboriginal infants compared with non-Aboriginal infants in the first year of life and in the postneonatal period; the RR decreased in the neonatal period but remains statistically significant (RR = 1.7, CI 1.2–2.4). The risk of death in the postneonatal period for Aboriginal infants compared with non-Aboriginal infants increased over the past 10 years between the two birth cohorts (1999–2003 RR = 1.7, CI 0.9–3.4: 2004–08 RR = 3.2: CI 2.1–4.9). The risk of postneonatal death for Aboriginal infants is more than three times that of non-Aboriginal infants in the birth year group 2004–08. This is due to the fact that the non-Aboriginal PNMR remains the same over the birth cohorts (2/1000 neonatal survivors), while PNMR for Aboriginal infants increased from 2.2/1000 neonatal survivors to 3.8/1000 neonatal survivors) across the two birth cohorts.

Figure 3.5: Rate ratio for Aboriginal compared with non-Aboriginal infants in the infant, neonatal and postneonatal periods by birth cohorts



CI: confidence interval; CMR: cumulative mortality rate; RR: rate ratio.

Between the years 1999 and 2009 there were 48 excess Aboriginal infant deaths (29 in the neonatal period and 19 in the postneonatal period; Table 3.7). When these deaths were considered within the two birth cohorts, 19 excess deaths occurred in the 1999–2003 death cohort and 29 occurred in the 2004–09 death cohort. Within the neonatal period there were similar numbers within the two cohorts. However, there was a higher number of excess deaths in the postneonatal period in the 2004–09 cohort (n = 15) compared with the 1999–2003 cohort (n = 4).

Table 3.7: Number and percentage of Aboriginal and non-Aboriginal deaths and excess number of Aboriginal infant deaths, 1999–2009

	Excess deaths				
Death type	Non-Aboriginal		Aboriginal		Excess Aboriginal deaths
	N	(%)	N	(%)	N
Infant	2932	(100)	93	(100)	48
Neonatal death	2155	(74)	62	(67)	29
Postneonatal death	777	(26)	38	(33)	19

Summary

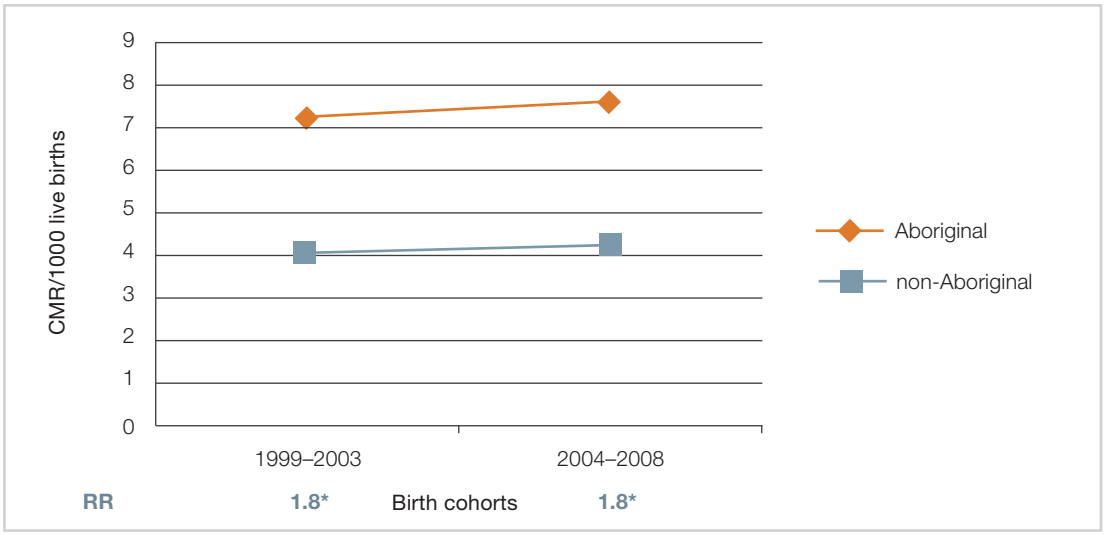
- Between 1999 and 2009 there were 48 excess Aboriginal infant deaths (29 in the neonatal period and 19 in the postneonatal period).
- There were more excess Aboriginal infant and postneonatal deaths in the 2004–09 cohort, but similar numbers of excess Aboriginal neonatal deaths in the two cohorts.
- There has been little change in the infant mortality rate between 1999 and 2008 and a significant gap between the two populations remains.
- Aboriginal infants are more than twice as likely to die in their first year of life as non-Aboriginal infants.
- Although the CMR for Aboriginal infants decreased in the neonatal period across the birth cohorts, the increase in risk of death in the neonatal period compared with non-Aboriginal infants remains statistically significant.
- Although there was no statistically significant difference between Aboriginal and non-Aboriginal infants in the risk of death during the postneonatal period between 1999 and 2003, by birth cohort 2004-2008, Aboriginal infants were more than three times more likely to die than their non-Aboriginal counterparts.
- In the most recent birth cohort, the PNMR for Aboriginal infants is greater than the NMR for non-Aboriginal infants.
- The PNMR is an important indicator of the social and economic circumstances of the environment of an infant. As such, the relatively high CMR reported for the Aboriginal PNMR and the significant increase in the PNMR among Aboriginal infants in the second birth cohort is cause for significant concern.

Male and female infant deaths

The risk of male infants compared to female infants dying was significantly higher in non-Aboriginal populations (RR = 1.2: CI 1.1–1.3, p = <0.001). The risk among Aboriginal males was one-and-a-half times higher than for Aboriginal females (RR = 1.5; CI 1.0–2.2, p = 0.06) over all years.

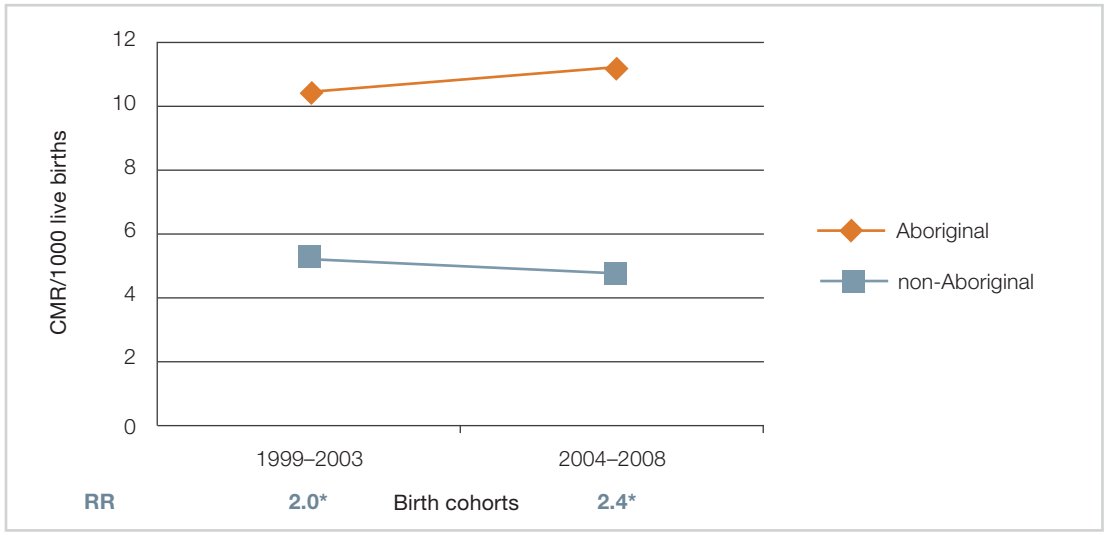
The following figures (see overleaf) show CMR in infants by sex and Indigenous status across the two birth cohorts. Figure 3.6 reports the CMR for female infants by Indigenous status and in each birth cohort. There was little change in the CMR across the birth cohorts for both Aboriginal and non-Aboriginal female infants. The risk of death across all years for Aboriginal females was nearly double that of their non-Aboriginal counterparts (RR = 1.8: CI 1.3–2.5, p<0.0003). When the data were disaggregated according to birth cohort, the risk was significantly higher in both birth cohorts (1999–2003: RR = 1.8: CI 1.1–3.0; 2004–08, p = 0.02: RR = 1.8: CI 1.2–2.8, p<0.05).

Figure 3.6: CMR for female infants according to Aboriginal status and the RR of death for Aboriginal females (compared to non-Aboriginal females), 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio. *statistically significant values (refer to text)

Figure 3.7: CMR for male infants according to Aboriginal status and the RR of death for Aboriginal males (compared to non-Aboriginal males), birth years 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio. *statistically significant values (refer to text)

The pattern observed among female infants differed to the pattern among male infants (Figure 3.7). Although there was a decrease in the rate of death for non-Aboriginal male infants (RR = 0.9; 0.8:1.0), the mortality rate has increased (10.4 to 11.2/1000 live births) for Aboriginal male infants, and thus the RR of infant mortality for Aboriginal compared with non-Aboriginal males increased over the years to 2.4 in the most recent years studied (RR = 2.4: CI 1.7–3.4, p = <0.0001).

Between the years 1999 and 2009, there were 31 excess Aboriginal male deaths and 17 excess female deaths in infancy (Table 3.8).

Table 3.8: Number and percentage of Aboriginal and non-Aboriginal deaths and excess number of Aboriginal infant deaths according to gender 1999–2009

Death type	Excess deaths				
	Non-Aboriginal		Aboriginal		Excess Aboriginal deaths
	N	(%)	N	(%)	N
Male	1,643	(56)	56	(60)	31
Female	1,284	(44)	37	(40)	17

Summary

- Between the years 1999 and 2009 there were 31 excess Aboriginal male deaths and 17 excess female deaths.
- The risk of male infants compared to female infants dying was significantly higher in both populations. However, the risk was significantly higher in non-Aboriginal populations (RR = 1.2: CI 1.1–1.3, p = <0.001) (Aboriginal (RR = 1.5; CI 1.0–2.2, p = 0.06) over all years).
- The risk of death across all years for Aboriginal females was nearly double that of their non-Aboriginal counterparts (RR = 1.8: CI 1.3–2.5, p<0.0003).
- When the data were disaggregated according to birth cohort, the risk of death for Aboriginal female infants was significantly higher than for non-Aboriginal female infants in both birth cohorts (1999–2003, RR = 1.8: CI 1.1–3.0, p = 0.02; 2004–08, RR = 1.8: CI 1.2–2.8, p<0.05).
- The risk of infant mortality for Aboriginal compared with non-Aboriginal males increased over the years to 2.4 (CI 1.7–3.4, p = <0.0001) in the most recent years studied.

Maternal age at the time of birth

The majority of births for Aboriginal populations occurred to women aged between 20 and 29 years (53%) at the time of the infant's birth and in the 30 years or older age group for non-Aboriginal mothers (59%; Table 3.9). Sixteen percent of Aboriginal and 3% of non-Aboriginal mothers were younger than 20 years old at the time of the infant's birth. Thirty-one percent of Aboriginal mothers were older than 29 years.

Note that CMR and RRs according to maternal age refer to the maternal age at the time of the infant's birth (Freemantle et al. 2013).

Table 3.9: Percentage of births for Aboriginal and non-Aboriginal infants according to maternal age, birth years 1999–2008 inclusive

	Maternal age (years)		
	≤19 (%)	20–29 (%)	≥30 (%)
Aboriginal	16	53	31
Non-Aboriginal	3	39	59

Table 3.10 reports the percentages of infant deaths according to maternal age at the time of the infant's birth. The largest percentage of deaths for Aboriginal infants was in the 20–29 maternal age category, and for non-Aboriginal infants the largest percentage of deaths was in the older than 29 years category. Twenty-one percent of Aboriginal and 5% of non-Aboriginal infant deaths were to infants whose mothers were teenagers at the time of birth. As expected, this pattern reflects maternal age at birth of the infant.

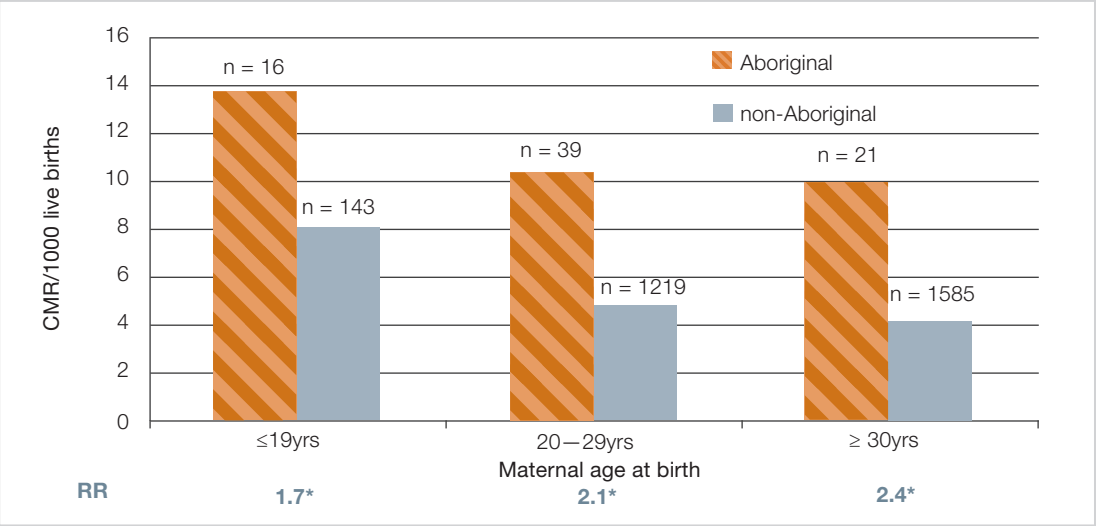
Table 3.10: Percentage of deaths for Aboriginal and non-Aboriginal infants according to maternal age (at birth), birth years 1999–2008 inclusive

	Maternal age (years)		
	≤19 (%)	20–29 (%)	≥30 (%)
Aboriginal	21	51	28
Non-Aboriginal	5	41	54

Figure 3.8 (see next page) shows that the highest CMR occurred among infants of teenage mothers. The CMR for Aboriginal infants was nearly double the CMR for non-Aboriginal infants in this age group (Aboriginal 13.8/1000 live births; non-Aboriginal 8.1/1000 live births; RR = 1.7: CI 1.0–2.9, p<0.05). The CMR of infant death in the maternal age group of ≥30 years was more than twice the CMR for non-Aboriginal infants whose mothers were ≥30 years (RR = 2.4; 1.6:3.7). The CMR for Aboriginal infants (10.4/1000 live births) whose mothers were between 20 and 29 years was also double that reported for non-Aboriginal infants (4.7/1000 live births) and was significantly higher (RR = 2.1: CI 1.6–2.9, p<0.0001). For both Aboriginal and non-Aboriginal infants, the CMR was less among older mothers. The risk of death for Aboriginal compared with non-Aboriginal infants was significantly higher in all maternal age groups and this risk (compared with non-Aboriginal infants) increased according to increased maternal age at the time of birth (≤19 years, RR = 1.7: CI 1.0–2.9 p = 0.4; 20–29 years, RR = 2.1: CI 1.6–2.9 p<0.0001; ≥30 years RR = 2.4: CI 1.6–3.7 p<0.0001). These data demonstrate that there are influences that affect these excess deaths that are not attributed to maternal age and that age (non-teenage) of mother is a protective factor for non-Aboriginal infants but not for Aboriginal infants.

The CMR decreased with increasing age for both Aboriginal and non-Aboriginal infants. However, the decrease in the CMR observed in non-Aboriginal infants was greater (Chi square test for trend,(χ^2) 48.8 p<0.0001) than Aboriginal infants(χ^2 1.0 p = 0.3) and thus the risk of Aboriginal (compared with non-Aboriginal) infant death has increased according to increased maternal age.

Figure 3.8: CMR (n) for Aboriginal and non-Aboriginal infants according to maternal age, and the RR of death for Aboriginal (compared to non-Aboriginal) infants, birth years 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio; *statistically significant values (refer to text).

Table 3.11 reports the CMR for Aboriginal and non-Aboriginal infants by maternal age at the time of the infant's birth for the two birth cohorts. The CMR remained relatively stable among the non-Aboriginal infant population. However, the CMR of Aboriginal infants more than doubled among the teenage maternal age group between the two birth cohorts (RR = 2.3: CI 0.8–7.2) and decreased in the maternal age group ≥30 years (RR = 0.8: CI 0.3:1.8). There was little change in the CMR for Aboriginal infants over time born to Aboriginal mothers aged between 20 to 29 years.

Table 3.11: CMR for Aboriginal and non-Aboriginal infants according to maternal age for two birth cohorts, birth years 1999–2008 inclusive

	Maternal age (years)											
	≤19 (%)				20–29 (%)				≥30 (%)			
	1999–2003		2004–08		1999–2003		2004–08		1999–2003		2004–08	
	(N)	CMR	(N)	CMR	(N)	CMR	(N)	CMR	(N)	CMR	(N)	CMR
Aboriginal	(4)	7.9	(12)	18.4	(17)	10.5	(22)	10.4	(10)	11.6	(11)	8.9
Non-Aboriginal	(70)	4.9	(73)	4.8	(621)	4.9	(598)	4.9	(745)	4.3	(840)	4.1

Summary

- Aboriginal infants were at significantly increased risk of death compared with non-Aboriginal infants in all maternal age groups.
- The CMR by maternal age remained relatively stable among the non-Aboriginal population.
- The CMR in the Aboriginal population more than doubled in the teenage maternal age group between the two birth cohorts (RR = 2.3; 0.8–7.2) and decreased in the maternal age group ≥30 years (RR = 0.8; 0.3:1.8). Although these data did not reach statistical significance, the magnitude of effect and direction of the estimate are of public health relevance.
- Sixteen per cent of Aboriginal births were to teenage mothers (compared with 3% of non-Aboriginal births), and 21% of infant deaths were in the teenage maternal group (compared with 5% of non-Aboriginal deaths).
- The majority of infant deaths were reported in the 20–29 years age group for Aboriginal infants and in the ≥30 years age group among the non-Aboriginal infants, following the pattern of maternal age at birth.
- The highest CMR for Aboriginal and non-Aboriginal infants was among teenage mothers.
- The largest gap between Aboriginal and non-Aboriginal infants in the risk of death occurred in infants born to mothers aged 30 years and older.
- The CMR of infant mortality decreased with increasing maternal age, but reduced more slowly among Aboriginal infants compared with non-Aboriginal infants and thus the gap in the risk of infant mortality according to maternal age widened according to increased maternal age.

Infant mortality according to birth weight

Advances in neonatal medicine have resulted in the increased survival of infants at increasingly lower birth weights. Although these medical success stories highlight the power of medical technology to save many of the tiniest infants at birth, serious questions remain about how these infants will develop and whether they will have normal, productive lives. Low birth weight (LBW) children can be born at term or before term and have varying degrees of social and medical risk. Because LBW children are not a homogeneous group, they have a broad spectrum of growth, health and developmental outcomes. While the vast majority of LBW children have normal outcomes, as a group they generally have higher rates of subnormal growth, illnesses and neurodevelopmental problems. These problems increase as the child's birth weight decreases. With the exception of a small minority of LBW children with mental retardation and/or cerebral palsy, the developmental sequelae for most LBW infants include mild problems in cognition, attention and neuromotor functioning (Hack, Klein & Taylor 1995).

LBW is either caused by preterm birth (commonly defined as younger than 37 weeks of gestation) or the infant being small for gestational age (that is, a slow prenatal growth rate), or a combination of both. Low birth weight is defined as a birth weight of a live born infant of less than 2500 grams regardless of gestational age (WHO 2011). Subcategories include Very Low Birth Weight, which is less than 1500 grams, and Extremely Low Birth Weight, which is less than 1000 grams. Normal weight at term delivery is 2500 grams–4499 grams. In the VACMS, data were analysed for Very Low Birth Weight, LBW, normal weight and ≥4500 grams. The data reported included births <1500 grams, 1500–2999 grams and >2500 grams.

The CMR according to birth weight decreased relative to the increasing birth weight categories in both populations (Table 3.12).

The RR for Aboriginal compared with non-Aboriginal infants in the birth weight category 1500–2499 grams was twice as high in birth year group 1999–2003 (**RR = 2.0: CI 1.1–4.1**). In the birth year group 2004–08, the CMR was nearly two-and-a-half times higher in the normal birth weight category for Aboriginal compared with non-Aboriginal infants (**RR = 2.4: CI 1.6–3.9**). However, the risk for Aboriginal infants with birth weights 1500–2499 grams decreased compared with non-Aboriginal infants. This is an important finding because 'normal' birth weight infants are expected to do well.

Table 3.12: CMR according to birth weight categories for Aboriginal and non-Aboriginal infants, and RR (95% CI) for Aboriginal compared with non-Aboriginal infants over the birth cohorts

Birth weight categories (grams)	1999–2003			2004–2008		
	Non-Aboriginal CMR	Aboriginal CMR	RR (95% CI)	Non-Aboriginal CMR	Aboriginal CMR	RR (95% CI)
<1500	233.9	259.7	1.11 (0.7–1.7)	245.7	287.0	1.1 (0.8–1.7)
1500–2499	11.1	23.6	2.0 **(1.1–4.1)**	9.7	12.4	1.3 (0.6–2.7)
≥2500	1.6	2.1	1.31 (0.6–2.6)	1.4	3.3	2.4 **(1.6–3.8)**

CI: confidence interval; CMR: cumulative mortality rate; RR: rate ratio.

Infant mortality according to gestational age

Infants born preterm are at a substantially increased risk of death in infancy. In birth years 1999–2008, 10% of Aboriginal infants and 6% of non-Aboriginal infants were born preterm, and deaths among infants born at <37 completed weeks accounted for 72% of Aboriginal and 68% of non-Aboriginal infant deaths (Freemantle et al. 2013:57, 60). Similar percentages of deaths in both populations were reported in the 20–31 week gestational age group (57%) and there was no significant difference in the CMR by gestational age in this category (RR = 1.2: CI 0.9–1.5) (Table 3.13). However, in the gestational groups 32–36 weeks and 37–41 weeks, Aboriginal infants were nearly twice as likely to die in the first year of life compared with their non-Aboriginal counterparts (RR = 1.9: CI 1.1–3.3, p = 0.01; RR = 1.9: CI 1.3–2.8, p = 0.001, respectively).

Infant death rates in the Aboriginal population were higher than rates in the non-Aboriginal population at every gestational age, although not significantly so in the gestational age group 20–31 weeks (p = 0.2), but it should be noted that the RR was higher for those born at term 37–41 completed weeks (**RR = 1.9: CI 1.3–2.8**) than those born preterm (**RR = 1.5: CI 1.2–1.9**). This suggests that risk of death associated with being born preterm explains only some of the differences in infant mortality between Aboriginal and non-Aboriginal populations.

Table 3.13: Number and percentage of infant death according to gestational age and the RR for Aboriginal (compared with non-Aboriginal) infants, birth year groups 1999–2008 inclusive

Gestation age groups weeks	Non-Aboriginal N (%)	Aboriginal N (%)	RR	95% CI
20–31	1668 (57)	53 (57)	1.2	0.9 – 1.5
32–36	335 (11)	14 (15)	1.9	1.1 – 3.3
37–41	908 (31)	26 (28)	1.9	1.3 – 2.8
>41	0	0 (0)	0	0
Unknown	4	0	0	0

CI: confidence interval; RR: rate ratio.

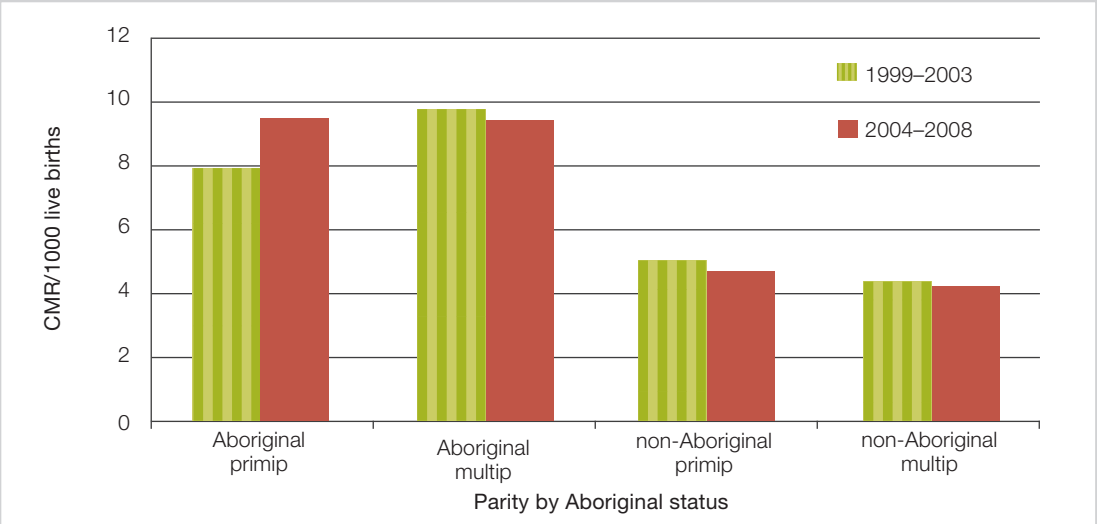
Infant mortality according to parity

Outcomes of previous pregnancies give some indication of the likely outcome and degree of risk with the current pregnancy. The number of previous pregnancies and deliveries will also influence the risks associated with the current pregnancy. Parity is often considered in association with older maternal age in the determination of adverse birth outcomes, specifically stillbirth, neonatal death, preterm birth, small for gestational age and neonatal intensive care unit admission.

The RR of an Aboriginal infant born to a primiparous woman compared to a non-Aboriginal infant born to a primiparous woman was significantly higher (RR = 1.8: CI 1.3–1.5).

Figure 3.9 describes parity according to Aboriginal status in the two birth year groups. The CMR for infants born to Aboriginal primiparous women increased across the birth cohorts (8.0/1000 to 9.5/1000 live births, RR = 1.2, CI 0.6–1.4). The CMR for infants born to multiparous women was similar for both Aboriginal and non-Aboriginal women over the birth year groups. Aboriginal infants were significantly more likely to die compared to non-Aboriginal infants independent of the mother being primiparous or multiparous if born in the second birth cohort.

Figure 3.9: CMR for Aboriginal and non-Aboriginal infants according to parity, birth years 1999–2008 inclusive



CMR: cumulative mortality rate. Note: Multiparous data refers to women who has given birth two or more times

Place of death—in or out of hospital

The place of death (in or out of hospital) of each infant who died between 1999 and 2009 inclusive was identified. Data were determined in accordance with the multiple sources of information in the CCOPMM case files. The geographical location in association with the place of birth according to metropolitan/regional location was also identified. Given the small number of Aboriginal deaths, these data were not disaggregated according to the DHS health region. The majority of deaths due to sequelae of prematurity occurred in hospital, and infant deaths attributable to SIDS occurred out of hospital (data not shown). 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. Percentages of NNDs and postneonatal deaths (PNNDs) for Aboriginal and non-Aboriginal infants are reported according to deaths occurring in or out of hospital.

Figure 3.10 describes the percentages of total infant deaths that occurred in and out of hospital for Aboriginal and non-Aboriginal infants. Seventy-one per cent of Aboriginal and 86% of non-Aboriginal infant deaths occurred in hospital. In 4% of Aboriginal and 3% of non-Aboriginal deaths the information was unknown.

Figure 3.10: Percentage of total deaths that occurred in and out of hospital for Aboriginal and non-Aboriginal infants, 1999–2008 inclusive

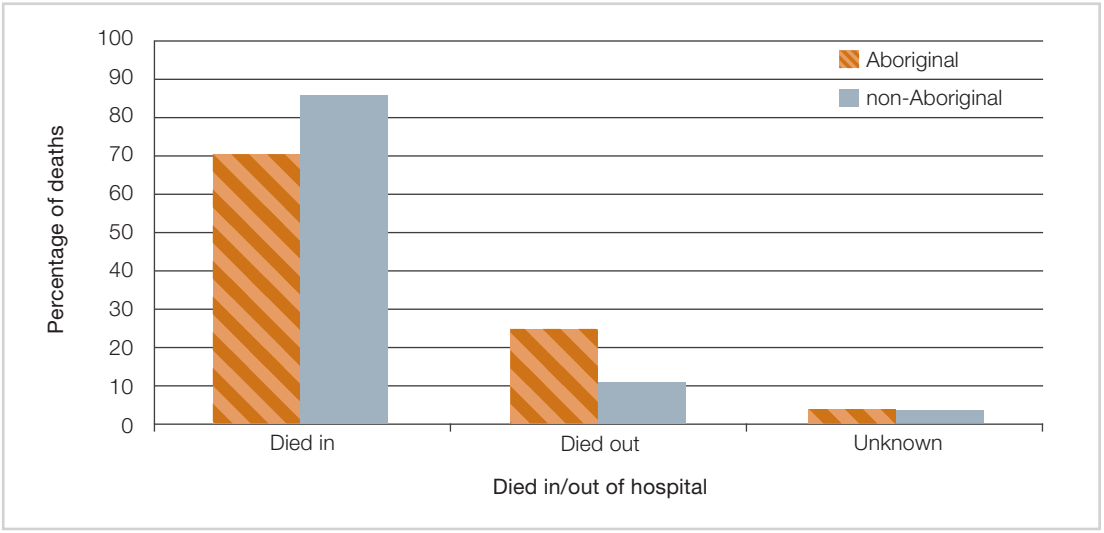


Figure 3.11 (see overleaf) shows the percentage of deaths occurring in and out of hospital according to the geographical location at the time of birth. Among infants born in metropolitan locations, a higher percentage of non-Aboriginal deaths occurred in hospital (87%) compared with Aboriginal deaths (78%). Among Aboriginal infants born in regional areas, 62% of deaths occurred in hospital compared with 81% of non-Aboriginal infants. However, in regional areas the percentage of Aboriginal infants dying out of hospital was almost double the percentage of non-Aboriginal infants.

Figure 3.11: Percentage of infant deaths in and out of hospital according to geographical location at time of birth for Aboriginal and non-Aboriginal infants, birth years 1999 to 2008

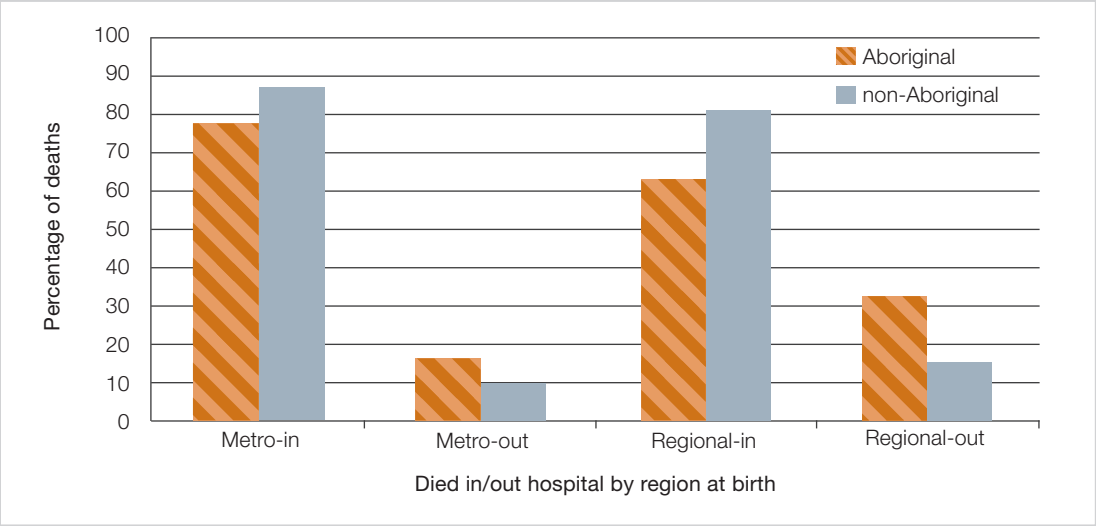
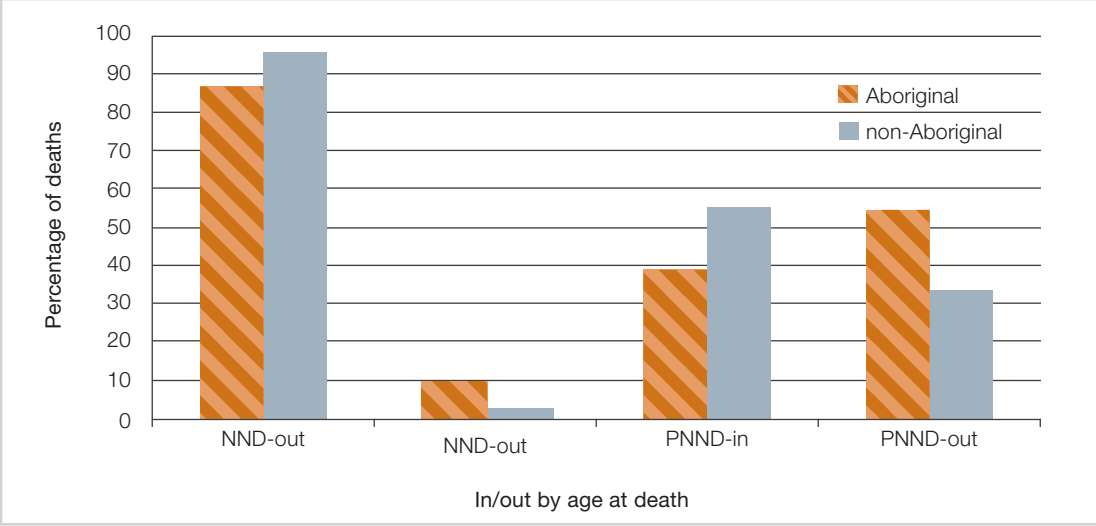


Figure 3.12: Percentage of NNDs and PNNDs for Aboriginal and non-Aboriginal infants according to place of death (in/out hospital), birth years 1999–2008 inclusive

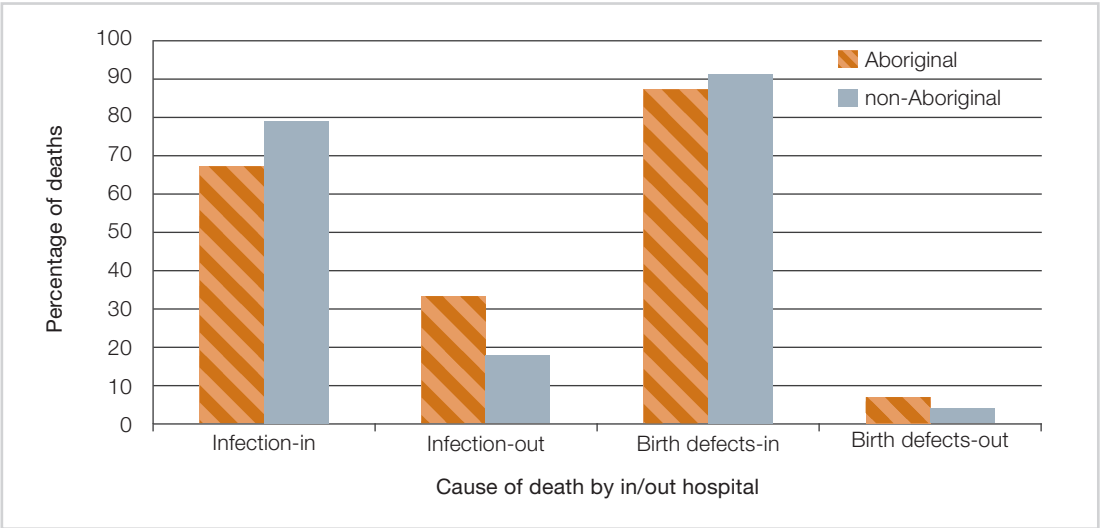


NNDs: neonatal deaths; PNNDs: postneonatal deaths.

Figure 3.12 (see previous page) reports the percentages of NNDs and PNNDs occurring in and out of hospital. A larger percentage of non-Aboriginal NNDs and PNNDs occurred in hospital compared with Aboriginal infant deaths. Eighty-seven per cent of NNDs among the Aboriginal population and 96% among the non-Aboriginal population occurred in hospital, with 10% of Aboriginal and 3% of non-Aboriginal NNDs occurring out of hospital. Thirty-nine per cent of PNNDs among the Aboriginal population and 55% among the non-Aboriginal population occurred in hospital, with 55% and 34% of PNNDs (respectively) occurring outside hospital. There was missing information on the place of NNDs in 3% of Aboriginal deaths and 0.5% of non-Aboriginal deaths. In data collected on place of death for PNNDs, there was missing information in 7% of Aboriginal deaths and 11% of non-Aboriginal deaths.

Figure 3.13 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; 33% of Aboriginal deaths due to infection occurred out of hospital compared with 18% of non-Aboriginal deaths. Most deaths due to birth defects occurred in hospital for Aboriginal (87%) and non-Aboriginal (91%) infants.

Figure 3.13 Percentage of total deaths due to infection and birth defects for Aboriginal and non-Aboriginal infants according to place of death (in/out hospital), birth years 1999–2008 inclusive



Summary

- Twenty-five per cent of Aboriginal infant deaths occurred out of hospital compared with 11% of non-Aboriginal infant deaths.
- For infants born in metropolitan areas, of Aboriginal infants who died, 17% of deaths occurred out of hospital compared with 10% of non-Aboriginal infants.
- For infants born in the regional areas, of Aboriginal infants who died, 33% of deaths occurred out of hospital compared with 16% of non-Aboriginal infants.
- Aboriginal infants were more likely than non-Aboriginal infants to die out of hospital in both the neonatal (10% c.f. 3%) and postneonatal period (55% c.f. 34%).
- Over all geographical locations, 33% of Aboriginal deaths due to infection occurred out of hospital compared with 18% of non-Aboriginal infant deaths.
- Most deaths due to birth defects occurred in hospital for Aboriginal (87%) and non-Aboriginal (91%) infants.

Geographical location of death

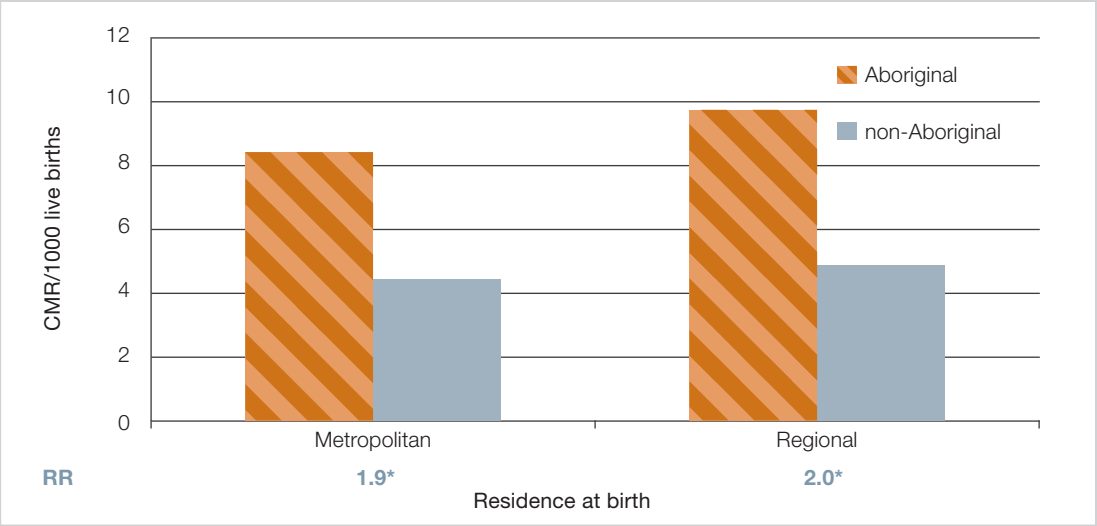
The geographical location was determined from mother's residential postcode at birth recoded into 'metropolitan' or 'regional' (which has been identified as being significantly correlated to the geographical location at time of death) (Freemantle 2003). The information was determined through scrutiny of the available information contained in the death case files. The DHS health regions were aggregated into metropolitan and regional groups because of the relatively small number of Aboriginal deaths. There is the potential to re-analyse the data according to smaller geographical divisions or to apply the Accessibility/Remoteness Index of Australia categories to the data. However, for the purposes of this report the data have been analysed using the metropolitan and regional categories.

There were 25 excess deaths among Aboriginal infants residing in regional locations, 17 excess deaths among Aboriginal infants residing in metropolitan locations, and four excess deaths of infants whose normal residence was interstate, 1999–2008.

Between 1999 and 2008, 48% of Aboriginal births occurred to mothers living in a regional location, and 45% in metropolitan locations (7% of Aboriginal births occurred in Victoria although the usual place of residence was interstate). These percentages compared with 25% of non-Aboriginal mothers living in regional locations, and 73% in metropolitan locations (2% of non-Aboriginal births occurred in Victoria although the usual place of residence was interstate).

Figure 3.14 (see next page) shows the CMR and the RR of death for Aboriginal infants (compared with non-Aboriginal) according to mother's geographical location at the time of birth, 1999–2008. Over the 10 years the CMR has been highest in regional locations for both Aboriginal and non-Aboriginal infants. The risk of an Aboriginal infant dying was significantly higher than non-Aboriginal infants in both locations (metropolitan, RR = 1.9: CI 1.4–2.6; regional, RR = 2.0: CI 1.5–2.7). However, of importance is the widening gap for the risk of death for Aboriginal compared with non-Aboriginal infants born to mothers residing in regional locations. The risk has significantly increased across the two birth cohorts (Wald test for significance p = 0.5).

Figure 3.14: CMR for Aboriginal and non-Aboriginal infants according to mother's residential location, and the RR of death for Aboriginal (compared to non-Aboriginal) infants, birth years 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio; *statistically significant values (refer to text).

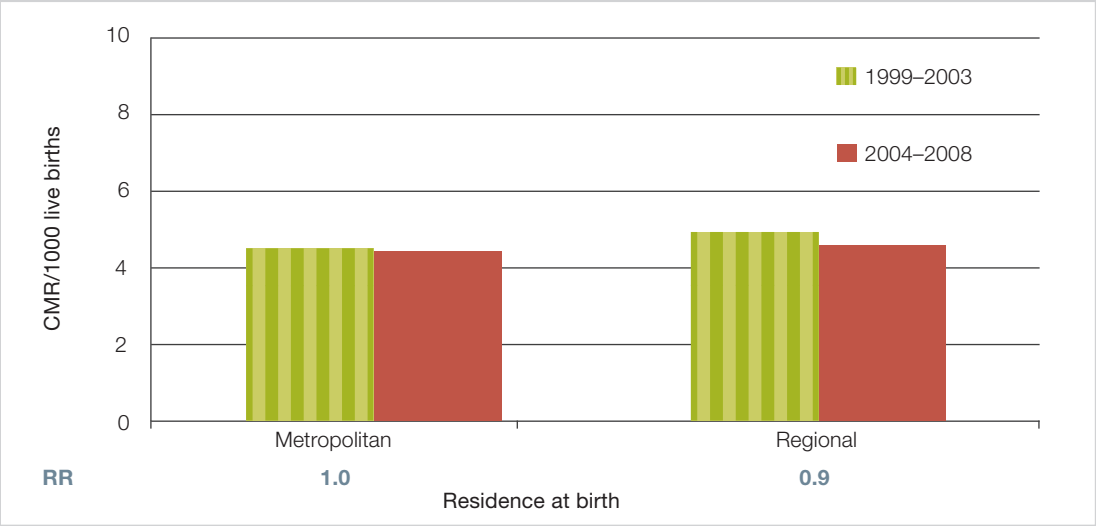
Figure 3.15 shows the risk of infant death for Aboriginal infants compared with their peers according to the geographical location by birth year group. The CMR in the regional areas almost doubled in the second birth cohort (RR = 1.7: CI 0.7–1.5), while halving in the metropolitan locations (RR = 0.6: CI 0.3–1.1) over the years studied.

Figure 3.15: CMR for Aboriginal infants and RR of death for Aboriginal infants according to geographical location and birth year groups, 1999–2008 inclusive

CMR: cumulative mortality rate; RR: rate ratio. Note: RR represents the CMR for birth cohort 2004–08 compared with birth cohort 1999–2003.

Figure 3.16 shows the risk of infant death for non-Aboriginal infants compared with their peers according to the geographical location at birth according to birth year group. There was no difference in the risk of a non-Aboriginal infant dying in metropolitan locations in the birth year groups (RR = 1.0: CI 0.9–1.1). However, the CMR of infant death in regional areas decreased in the second birth cohort (RR = 0.9: CI 0.8–1.1).

Figure 3.16: CMR for non-Aboriginal infants and RR of death for non-Aboriginal infants according to geographical location at birth, birth year groups 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio. Note: RR represents the CMR for birth cohort 2004–08 compared with birth cohort 1999–2003.

Summary

- There were 25 excess deaths among Aboriginal infants residing in regional locations, 17 excess deaths among Aboriginal infants residing in metropolitan locations, and four excess deaths of infants whose normal residence was interstate, 1999–2008.
- The risk of an Aboriginal infant dying was significantly higher than non-Aboriginal infants in both geographical locations.
- The CMR was higher in regional than metropolitan locations for both Aboriginal and non-Aboriginal infants.
- The risk of all-cause mortality for Aboriginal infants compared with non-Aboriginal infants was highest in regional locations.
- The gap between the risk of death for Aboriginal compared with non-Aboriginal infants born in regional locations has widened significantly across the birth year groups.
- For Aboriginal infants, the CMR in the regional areas almost doubled in the second birth cohort, while halving in the metropolitan locations over the years studied.
- There was no difference in the risk of a non-Aboriginal infant dying in metropolitan locations in the two birth cohorts However, the CMR in infant deaths in regional areas decreased over the 10 years.

Antecedents to infant outcomes

Maternal smoking during pregnancy

The 1999 CCOPMM annual report stated that:

> *Maternal smoking is one of the readily identifiable preventable causes of perinatal mortality and morbidity. Appropriate counselling of mothers who smoke has been shown to be effective in reducing smoking and improving outcomes.* (CCOPMM 2001:12)

Maternal self-reported smoking before and after 20 weeks gestation was reported in the Victorian Perinatal Data Collection for the first time in 2009 and thus data provided by the CCU following the matching of the VPDC with the RBDM did not include maternal smoking information; therefore, maternal smoking was not reported in the VACMS (CCOPMM 2012).

Antenatal attendance

A healthy pregnancy is one of the best ways to promote a healthy birth. Early and regular prenatal care improves the chances of a healthy pregnancy:

> *Good care during pregnancy is important for the health of the mother and the development of the unborn baby. Pregnancy is a crucial time to promote healthy behaviours and parenting skills. Good [antenatal care] links the woman and her family with the formal health system, increases the chance of using a skilled attendant at birth and contributes to good health through the life cycle. Inadequate care during this time breaks a critical link in the continuum of care, and effects both women and babies.* (Lincetto et al. 2006:52)

Information describing antenatal care was collected where available in the case files and was available in 63% of the case files where a neonatal death was recorded.

Where antenatal attendance was recorded, information describing the number of visits was available in 43% of case files. The CCOPMM does not collect antenatal attendance for postneonatal infant deaths in most cases. The information regarding antenatal care was therefore available predominately for deaths that occurred in the neonatal period, although there were deaths that occurred early in the postneonatal period where the information was available in the case notes.

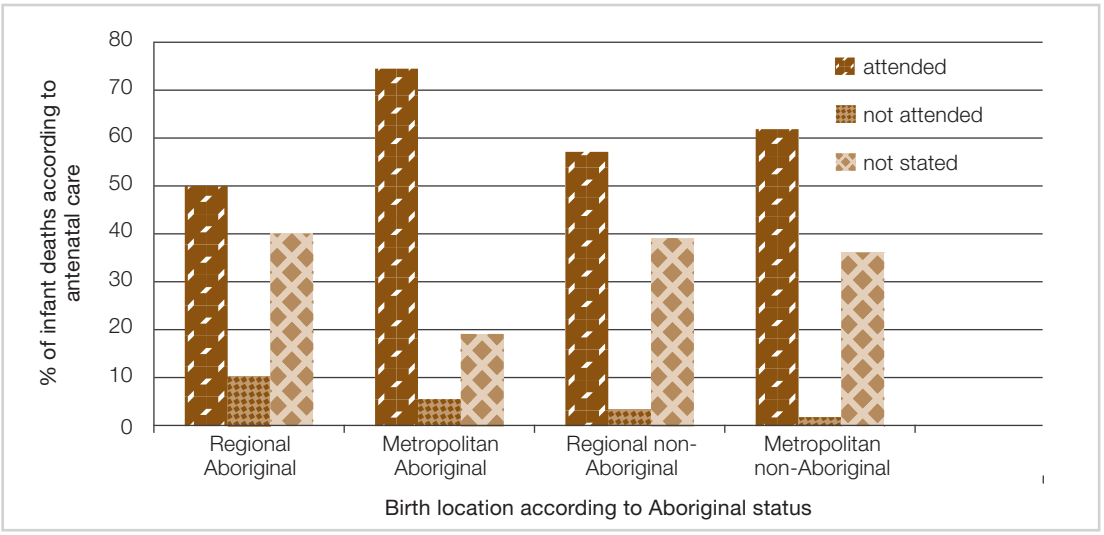
Table 3.14 reports the antenatal attendance and, where available, the number of antenatal visits according to Aboriginal and non-Aboriginal infants who died. In 97% of infant deaths, where information was available in the case files, mothers were reported to have received antenatal care. Although the percentages of (ever) attendance were the same for both population groups (61%), antenatal care was not received in 8% of Aboriginal and 2% of non-Aboriginal mothers. Where information was available regarding the number of visits, 14% of Aboriginal mothers attended between four to five visits, and 12% attended one visit. Fifteen per cent of non-Aboriginal mothers attended two to three visits and 14% attended four to five visits.

Table 3.14: Infant deaths and percentage of antenatal attendance for Aboriginal and non-Aboriginal populations, birth years 1999–2008 inclusive

Antenatal attendance	Outcome	Non-Aboriginal N (%)	Aboriginal N (%)	Unknown N (%)	Total N (%)
Attended	Yes	1,783 (60.8)	57 (61.3)	1 (50.0)	1,841 (60.8)
	No	59 (2.0)	7 (7.5)	0	66 (2.2)
	Unknown/not stated	1,090 (37.2)	29 (31.2)	1 (50.0)	1,120 (37.0)
Number of visits	1 visit	62 (3.5)	7 (12.3)	0	69 (3.7)
	2–3 visits	259 (14.5)	5 (8.8)	0	264 (14.3)
	4–5 visits	253 (14.2)	8 (14.0)	0	261 (14.2)
	6+ visits	196 (11.0)	4 (7.0)	0	200 (10.9)
	Unknown/not stated	1,013 (56.8)	33 (57.9)	1 (100.0)	1,047 (56.9)

Figure 3.17 reports the percentage of infant deaths according to antenatal care, mother's residential location at the time of birth and Aboriginal status for birth years 1999–2008 inclusive. The percentage of mothers accessing antenatal care was highest in the metropolitan regions for Aboriginal (75%) and non-Aboriginal (62%) mothers. Fifty per cent of Aboriginal mothers and 57% of non-Aboriginal mothers residing in regional locations received antenatal care. No information describing antenatal care was available in the case files for similar percentages of Aboriginal and non-Aboriginal mothers residing in regional locations (40%), and for 19% of Aboriginal and 36% of non-Aboriginal mothers residing in metropolitan regions.

Figure 3.17: Infant deaths and percentage of antenatal attendance according to geographical location at birth and Aboriginal status, birth years 1999–2008 inclusive



Trends in post-mortems for birth years 1999–2008 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 10 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, lodge an objection to the post-mortem.

The data in this report do not differentiate between coronial and non-coronial post-mortem examinations. Coronial autopsies are performed if the coroner or police need information for legal reasons about the cause of death. A hospital (or non-coronial) autopsy may be performed if the immediate family gives consent. In this case, the autopsy can help to clarify the reasons why the person died or to offer information to the medical profession on the deceased child's condition (Better Health Channel 2014). The post-mortem ideally includes 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 ensure that the correct cause of mortality is identified in every case of infant and childhood death. In the following data, 'post-mortem' refers to both coronial and non-coronial autopsies.

Between the years 1999 and 2009, where information on autopsies was available in the CCOPMM case file, autopsies were performed on 90% of Aboriginal and 83% of non-Aboriginal infants (Table 3.15). In 10% of Aboriginal and 17% of non-Aboriginal infant deaths, an objection was lodged. The objection was upheld in all objections for Aboriginal infants, and upheld in 95% of non-Aboriginal deaths (3% were over-ruled and in 2% of deaths the outcome to the objection was not stated).

Table 3.15: Proportions of post-mortems with objections by objection outcomes in infants born in Victoria, 1999–2008 inclusive

Antenatal attendance	Outcome	Non-Aboriginal N (%)	Aboriginal N (%)	Unknown N (%)	Total N (%)
With a post-mortem	No	914 (83.0)	35 (89.7)	1 (100.0)	950 (83.3)
	Yes	187 (17.0)	4 (10.3)	1 (100.0)	191 (16.7)
Objection outcome	Not stated	4 (2.1)	0 (0)	0	4 (2.1)
	Overruled	5 (2.7)	0 (0)	0	5 (2.6)
	Upheld	178 (95.2)	4 (100.0)	0	182 (95.3)

Table 3.16 reports the number and percentage of post-mortems undertaken according to cause of death for all Victorian-born infants. Where there was information in the CCOPMM case files, a post-mortem was performed in 38% of deaths due to perinatal causes (information not known in 12% of deaths), in 38% of deaths due to birth defects (information not known in 26% of cases), in 18% of deaths due to diseases of prematurity (information unknown in 18% of deaths), in 45% of deaths attributed to infection (information not available in 34% of cases), in 82% of deaths due to injury (information not available in 8% of deaths), and in 29% of deaths due to cancer and leukaemia (information not available in 67% of deaths). Of the original paper-based files, in all but one death attributed to SIDS, a post-mortem was performed.[10]

Table 3.16: Number and percentage of post-mortems undertaken for *all* infant deaths according to the general causes of death, 1999–2009 inclusive

	All infant deaths		
General cause of infant death	Post-mortem N (%)	No post-mortem N (%)	Unknown N (%)
Perinatal causes	115 (37.5)	156 (50.8)	36 (11.7)
Significant birth defects	402 (37.8)	384 (36.1)	278 (26.1)
Prematurity	168 (18.0)	602 (64.5)	163 (17.5)
Infection	74 (45.4)	34 (20.9)	55 (33.7)
Injury	59 (81.9)	7 (9.7)	6 (8.3)
Cancer & leukaemia	6 (28.6)	1 (4.8)	14 (66.7)
SIDS	191 (98.5)	1 (0.5)	2 (1.0)
Other specific conditions	86 (38.1)	94 (41.6)	46 (20.4)
Unknown	40 (88.9)	2 (4.4)	5 (11.0)
Total	**1,141 (37.7)**	**1,281 (42.3)**	**605 (20.0)**

Table 3.17 (see next page) identifies the causes of death according to whether a post-mortem was held. These data reflect the CCOPMM case files within which information was available. The main causes of infant death among both Aboriginal and non-Aboriginal infants were birth defects and prematurity, where, in most cases, the deaths are expected (in the former) and explained (in the latter). There were low percentages of post-mortems in deaths due to diseases due to prematurity (Aboriginal, 16%; non-Aboriginal, 18%). For Aboriginal populations all deaths attributed to SIDS received a post-mortem and in all but one death in the non-Aboriginal population.

10 This death may not be attributed to SIDS in the current electronic CCOPMM database.

Table 3.17: Number and percentage of general causes of infant death by post-mortem in infants born in Victoria between 1999–2008 inclusive

	Non-Aboriginal infant deaths			Aboriginal infant deaths		
	Post-mortem N (%)	No post-mortem N (%)	Unknown N (%)	Post-mortem N (%)	No post-mortem N (%)	Unknown N (%)
Perinatal causes	113 (37.9)	150 (50.3)	35 (11.7)	2 (22.2)	6 (66.7)	1 (11.1)
Significant birth defects	395 (37.7)	377 (36.0)	276 (26.3)	7 (46.7)	6 (40.0)	2 (13.3)
Prematurity	162 (18.1)	578 (64.6)	155 (17.3)	6 (15.8)	24 (63.2)	8 (21.1)
Infection	70 (44.6)	34 (21.7)	53 (33.8)	4 (66.7)	0	2 (33.3)
Injury	55 (83.3)	7 (10.6)	4 (6.1)	4 (66.7)	0	2 (33.3)
Cancer & leukaemia	6 (28.6)	1 (4.8)	14 (66.7)	0	0	0
SIDS	177 (98.3)	1 (0.6)	2 (1.1)	14 (100.0)	0	0
Other specific conditions	85 (38.1)	92 (41.3)	46 (20.6)	1 (33.3)	2 (66.7)	0
Unknown	38 (88.4)	2 (4.7)	4 (9.0)	1 (100.0)	0	1
Total	1,101 (37.6)	1,242 (42.4)	589 (20.1)	39 (41.9)	38 (40.9)	16 (12.9)

Note: There was one infant death where there was no information in the case file and therefore the cause of death was not able to be determined. Of the two infant deaths of 'unknown' Indigenous identity, one death had a post-mortem and the other death no post-mortem (data not included).

Summary

- Overall, where there was information in the CCOPMM case notes, 90% of Aboriginal infants who died underwent post-mortem examination compared with 83% of non-Aboriginal infants.
- In a significant number of case files, post-mortem information was not available (42% Aboriginal and 36% non-Aboriginal infant deaths).
- In 17% of non-Aboriginal and 10% of Aboriginal deaths an objection to post-mortem examination was lodged.
- Of infants whose deaths were attributed to SIDS, all Aboriginal deaths and all but one non-Aboriginal death underwent a post-mortem—a diagnosis of SIDS can only be confirmed through a full post-mortem.
- There were low percentages of post-mortems in deaths due to prematurity in both populations.
- Overall, the low percentages of post-mortems raise concerns as to the underlying of cause of death for infants dying as a result of the sequelae of prematurity: Aboriginal (16%) and non-Aboriginal (18%).

Cause-specific infant mortality

The all-cause mortality data were disaggregated to report the cause-specific mortality in both populations. Small numbers of deaths were observed when the data were disaggregated by cause of death within the Aboriginal population. Although the main data provide evidence of increased mortality within the Aboriginal population, the cause-specific data provided an indication of the pertinent causes of the excess mortality. The data also provide important information regarding the excess number of infant deaths within the Aboriginal population.

In determining the infant mortality rate of cause-specific deaths in the two birth year groups, there were small numbers, particularly for Aboriginal infants. Although the small numbers of deaths are heartening and one would wish to see this trend continue, from an epidemiological perspective it is possible that the observed trends are not as clearly robust compared with those observed among the non-Aboriginal population. This applies when reporting the trends in deaths due to SIDS, infection and injury (Figures 3.23 and 3.27 respectively, injury trends data not stated).

In acknowledging the small numbers, it is important to note that although the data presented reflect the best possible ascertainment of the identity of the Aboriginal population at the time of the analyses, it is acknowledged that these data are an underestimation of the true number of Aboriginal deaths.

The causes of infant death were identified under nine general categories (Table 3.19) and 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.

The main causes of death were identified for both populations and then analysed to ascertain differences in risk according to these categories. The main causes of infant death were prematurity, birth defects, SIDS (Aboriginal population) and perinatal causes. Infection and injury, both preventable causes of death, have been considered, with deaths due to infection and SIDS considered as separate case studies.

Table 3.18 identifies the excess number of Aboriginal infant deaths according to the main causes of infant death. There were 24 excess infant deaths due to prematurity, 12 deaths attributed to SIDS, five due to perinatal causes and injury, and four due to infection. The calculation of excess deaths is an important public health measure, particularly in populations where small numbers of deaths are reported and for deaths that are potentially preventable (e.g. infection and injury).

Table 3.18: Excess number of Aboriginal infant deaths according to the main causes of infant death, 1999–2009

	All infant deaths		
General cause of infant death	Non-Aboriginal N (%)	Aboriginal N (%)	Excess Aboriginal deaths N
Perinatal causes	298 (10.2)	9 (9.7)	5
Significant birth defects	1,048 (35.7)	15 (16.1)	0
Prematurity	895 (30.5)	38 (40.9)	24
Infection	157 (5.4)	6 (6.5)	4
Injury	66 (2.3)	6 (6.5)	5
Cancer & leukaemias	21 (0.7)	0	0
SIDS	180 (6.1)	14 (15.1)	12
Other specific conditions	223 (7.6)	3 (3.2)	0

Table 3.19 identifies the nine general categories of infant death and includes the number and percentage of total deaths for Aboriginal and non-Aboriginal populations. The results demonstrate the importance of disaggregating total population data in order that specific information describing minority groups may be observed. For example, the magnitude of the percentages within the disaggregated data describing the two populations differs (particularly deaths due to prematurity and birth defects). Importantly, SIDS, a potentially preventable cause of death (considering the known risk factors), accounts for only 6% of infant deaths when considering the combined population data, but is a major cause of death among the Aboriginal infant population.

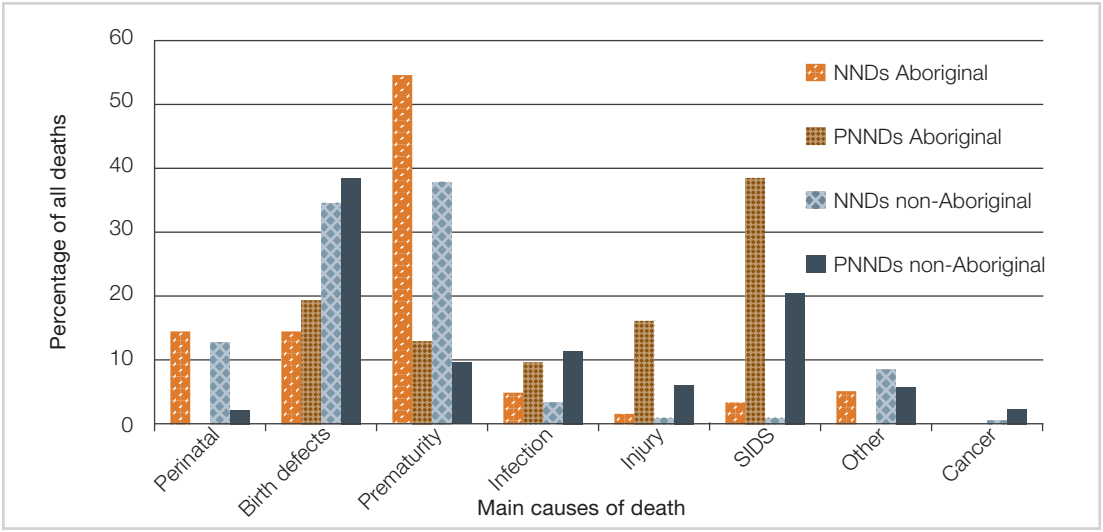
When these data were disaggregated, the main causes of infant death between 1999 and 2009 among Aboriginal infants were prematurity (41%) and significant birth defects (16%). In contrast, the main causes of death among non-Aboriginal infants were significant birth defects (36%) and prematurity (31%). Deaths attributed to SIDS accounted for 15% of Aboriginal infant deaths and 6% of non-Aboriginal infant deaths. Between 1999 and 2009, perinatal causes accounted for 10% of both Aboriginal and non-Aboriginal infant deaths. Deaths due to infection comprised 7% of Aboriginal and 5% of non-Aboriginal infant deaths and deaths due to injury made up 7% of Aboriginal and 2% of the non-Aboriginal infant deaths. There were no deaths attributed to cancer and leukaemia among the Aboriginal infant populations (0.7% of non-Aboriginal deaths). Disaggregating data to identify the minority population is vital if we are to accurately determine the main causes of infant death. Considering only total population cause-specific mortality in the determination of health policies and development of disease and mortality prevention strategies masks the 'true picture' and therefore the specific needs of the Aboriginal populations.

Table 3.19: Number and percentage of infant deaths according to the general classification and Aboriginal status, births 1999–2008 inclusive

	All infant deaths							
General cause of infant death	Non-Aboriginal N	(%)	Aboriginal N	(%)	Unknown N	(%)	Total N	(%)
Perinatal causes	298	(10.2)	9	(9.7)	0		307	(10.1)
Significant birth defects	1,048	(35.7)	15	(16.1)	1	(50.0)	1,064	(35.2)
Prematurity	895	(30.5)	38	(40.9)	0		933	(30.8)
Infection	157	(5.4)	6	(6.5)	0		163	(5.4)
Injury	66	(2.3)	6	(6.5)	0		72	(2.4)
Cancer & leukaemia	21	(0.7)	0		0		21	(0.7)
SIDS	180	(6.1)	14	(15.1)	0		194	(6.4)
Other specific conditions	223	(7.6)	3	(3.2)	0		226	(7.5)
Unknown	44	(1.4)	2	(2.2)	1	(50.0)	47	(2.2)
Total	2,932	(100.0)	93	(100.0)	2	(100.0)	3,027	(100.0)

Figure 3.18 reports the main causes of death according to NND or PNND for both Aboriginal and non-Aboriginal infants for birth years 1999–2008 inclusive. For Aboriginal infants, the largest percentages of deaths in the neonatal period were due to prematurity (55%), followed by birth defects and perinatal causes (15%). Deaths due to prematurity (38%) and birth defects (35%) accounted for the majority of NNDs among non-Aboriginal infants. In the postneonatal period, deaths attributed to SIDS accounted for 39% of Aboriginal infant deaths (21% non-Aboriginal); 19% of Aboriginal infant deaths were due to birth defects (37% non-Aboriginal) and 16% were associated with injury (6% non-Aboriginal). Deaths due to infection in the postneonatal period accounted for 10% of Aboriginal and 11% of non-Aboriginal infant deaths.

Figure 3.18: Main causes of death (%) according to NNDs or PNNDs, birth years 1999–2008

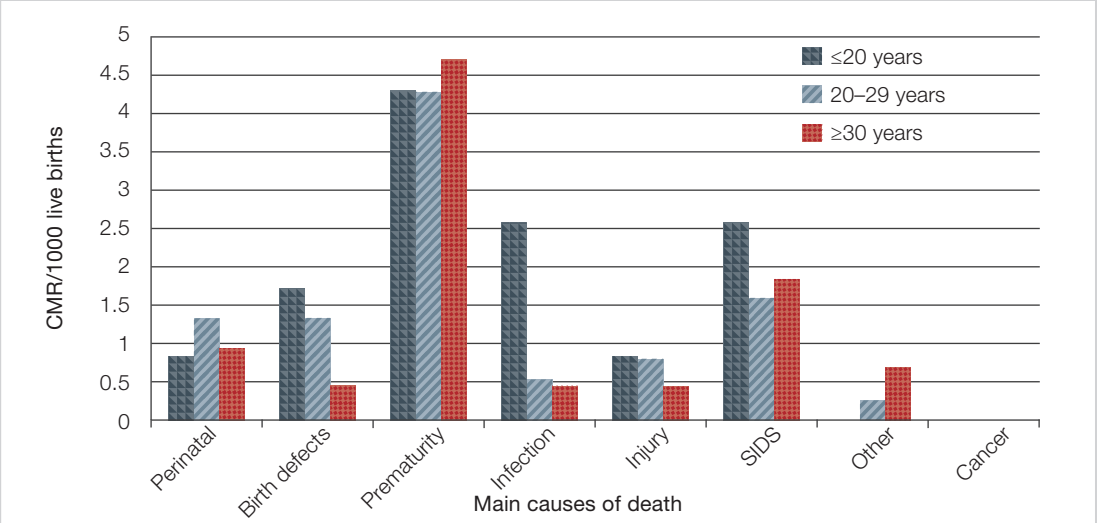


NNDs: neonatal deaths; PNNDs: postneonatal deaths.

Main causes of death according to maternal age

Figures 3.19 (see next page) and 3.20 (see p.74) illustrate the CMR according to maternal age (groups) and the main causes of infant death among Aboriginal and non-Aboriginal infants. For Aboriginal infants, deaths due to prematurity accounted for the highest CMR in all maternal age groups (<20 years and 20–29 years: 4.3/1000 live births; ≥30 years: 4.8/1000 live births). A higher CMR in infants born to teenage mothers was also reported in deaths attributed to SIDS and infection (2.6/1000 live births) and birth defects (1.7/1000 live births) in comparison with the other maternal age groups. A decrease in the CMR associated with increasing maternal age at the time of the infant's birth was reported among deaths due to birth defects, infection and injury. Data describing factors such as socioeconomic status and household composition were not available and therefore not able to be included in a regression analysis.

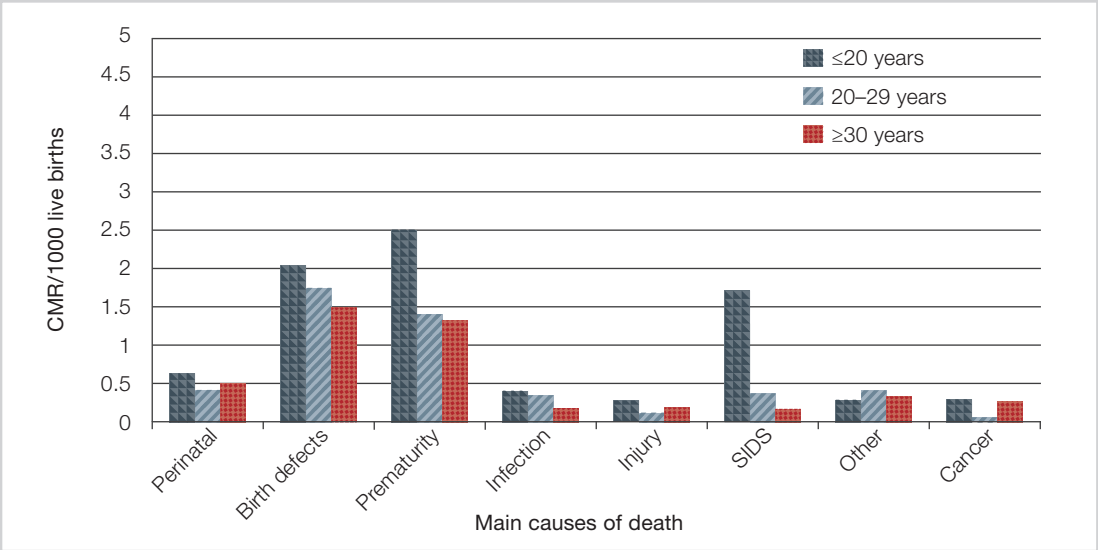
Figure 3.19: CMR/1000 live births according to maternal age (groups) for main causes of death for Aboriginal infants, birth years 1999–2008



CMR: cumulative mortality rate.

For non-Aboriginal infants, the highest CMR was reported among infants born to teenage mothers for deaths due to prematurity (2.5/1000 live births), birth defects (2.0/1000 live births) and deaths attributed to SIDS (1.7/1000 live births). Generally among the non-Aboriginal population, a decrease in the CMR for the main causes of infant death according to increasing maternal age at the time of the infant birth was observed (infant deaths due to birth defects, prematurity, infection and SIDS). This general pattern differed to that observed among Aboriginal infants (except among deaths due to birth defects and infection where a similar decrease according to increasing maternal age was also observed).

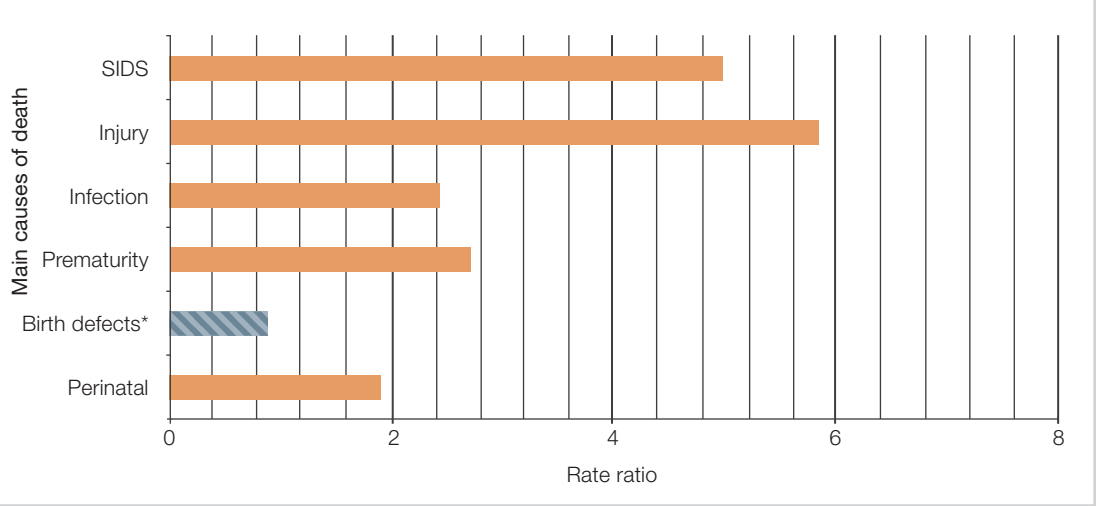
Figure 3.20: CMR/1000 live births according to maternal age (groups) for main causes of death for non-Aboriginal infants, birth years 1999–2008



CMR: cumulative mortality rate.

Figure 3.21 (see next page) reports the RRs associated with the comparison of cause-specific death for Aboriginal compared with non-Aboriginal infants. The risk of death for Aboriginal infants was significantly higher than the risk for non-Aboriginal infants in all main causes of death other than deaths due to birth defects, where an Aboriginal infant was less likely to die (RR = 0.9, CI 0.6–1.5). The risk of death due to injury for Aboriginal infants was nearly six times higher than the risk for non-Aboriginal infants (RR = 5.8: CI 2.5–13.5), five times higher for SIDS (RR = 5.0: CI 2.9–8.6), nearly three times higher for deaths due to prematurity (RR = 2.7: CI 2.0–3.8), two-and-a-half times higher for deaths due to infection (RR = 2.5: CI 1.1–5.6) and nearly twice as high for deaths due to perinatal causes (RR = 1.9: CI 1.5–2.7). It is acknowledged that small numbers of deaths were observed when the data were disaggregated by cause of death. Thus, the data were limited in regards to estimating effects associated with the cause of death, acknowledging the wide confidence intervals. However, in calculation of cause-specific CMRs, the increased risk of death for Aboriginal compared with non-Aboriginal infants is of significant public health relevance.

Figure 3.21: Risk of mortality for Aboriginal (compared to non-Aboriginal) infants for the main causes of death, birth years 1999–2008 inclusive



*Non-statistically significant value.

The all-cause CMR has remained similar for both Aboriginal infants (9.1 to 9.4/1000 live births) and non-Aboriginal infants (4.7 to 4.5/1000 live births) across the two birth cohorts. The all-cause mortality data were then disaggregated to report the cause-specific mortality. Small numbers of deaths were observed when the data were disaggregated by cause of death. Table 3.20 identifies the trends in the CMR for the main causes of infant death across the birth cohorts. When the main causes of death were analysed separately, a slightly different picture was observed in the two populations. There was a decrease in the cause-specific CMR for Aboriginal infants between birth years 2004–08 and 1999–2003 for deaths due to perinatal causes, infection and injury, and an increase in the most recent years for deaths due to birth defects, prematurity and SIDS. The picture was different among the non-Aboriginal population and the cause-specific CMRs were similar across the birth cohorts for all causes of death.

Table 3.20: CMR for the main causes of infant mortality for Aboriginal and non-Aboriginal infants for birth years 1999–2003 and 2004–08

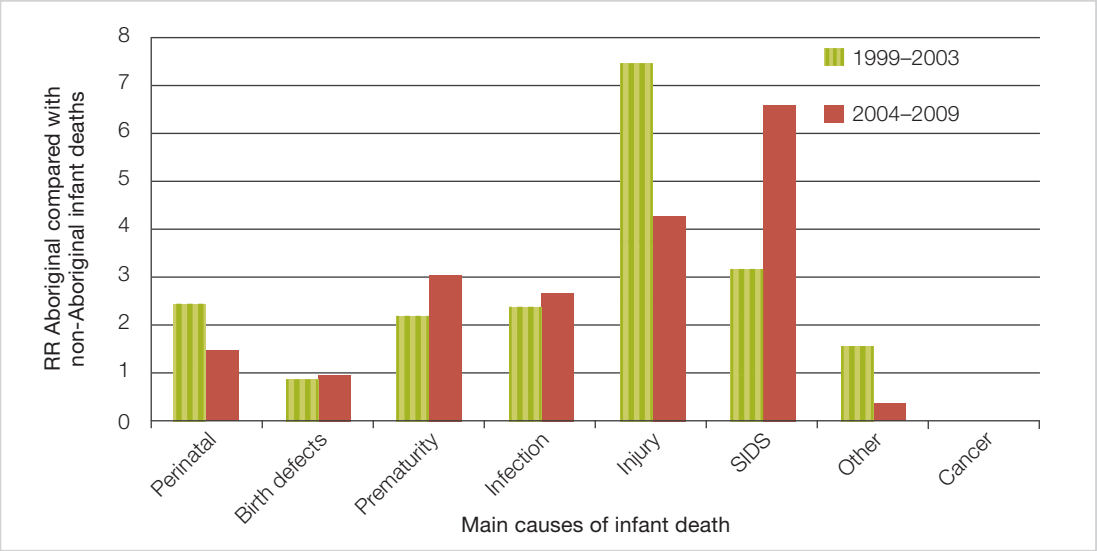
Cause of death	1999–2003			2004–2008		
	Non-Aboriginal CMR*	Aboriginal CMR	RR	Non-Aboriginal CMR	Aboriginal CMR	RR
Perinatal	0.5	1.2	2.5	0.5	0.7	1.5
Birth defects	1.6	1.4	0.9	1.6	1.5	1.0
Prematurity	1.4	3.1	2.2	1.4	4.3	3.1
Infection	0.3	0.7	2.4	0.2	0.5	2.7
Injury	0.1	1.0	7.5	0.1	0.3	4.3
SIDS	0.3	1.0	3.2	0.3	1.7	6.6

CMR: cumulative mortality rate; RR: rate ratio. *CMR/1000 live births.

Figure 3.22 reports the risk of infant mortality for the main causes of death for Aboriginal compared with non-Aboriginal infants, reported for the birth cohorts 1999–2003 and 2004–08. There was a decrease in the risk of death for Aboriginal compared with non-Aboriginal infants between birth years 1999–2003 and 2004–08 for deaths in the perinatal period (1999–2003, RR = 2.5; 2004–08, RR = 1.5) and due to injury (1999–2003, RR = 7.5; 2004–08, RR = 4.3). The risk of death attributed to SIDS more than doubled in the second birth cohort for Aboriginal compared with non-Aboriginal infants (1999–2003, RR = 3.2; 2004–08, RR = 6.6). The p-value did not reach significance when the data were tested for significance across the birth cohorts for all main causes of death (Wald test).

Although statistical significance was not reached (potentially due to the relatively small number of deaths in the Aboriginal population), it is important to note that the RRs between the two populations and between the birth year groups have increased in magnitude for deaths due to SIDS and decreased for deaths due to injury.

Figure 3.22: RR of infant death for birth years 2004–08 compared with 1999–2003 for Aboriginal and non-Aboriginal infants according to cause of death



RR: rate ratio. Note: test for significance (Wald test): the p-value did not reach significance for any of the main causes of death.

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 reported in the non-Aboriginal population following the 1991 'Reduce the Risks' campaign.

Summary

- This section clearly identifies the importance of disaggregating population data so that the needs of minority and disadvantaged populations are not overlooked.
- There were 24 excess deaths due to prematurity, 11 excess deaths due to SIDS, five excess deaths attributed to injury, five excess deaths due to perinatal causes and four excess deaths attributed

to infection among Aboriginal infants, 1999–2009.

- The main causes of Aboriginal infant mortality were prematurity (41% of deaths; CMR: 3.8/1000 live births) and significant birth defects (16% of deaths: 1.5/1000 live births).
- The main causes of death among non-Aboriginal infants were significant birth defects (36% of deaths: 1.6/1000 live births) and prematurity (31% of deaths: 1.4/1000 live births).
- Deaths attributed to SIDS accounted for 15% of Aboriginal infant deaths (CMR 1.4/1000 live births) and 6% of non-Aboriginal infant deaths (CMR 0.3/1000 live births).
- The risk of death was higher for Aboriginal infants compared with non-Aboriginal infants in all main causes of infant death, with the exception of deaths due to significant birth defects, birth years 1999–2008.
- While noting that the number of Aboriginal deaths was small, the risk of death due to injury among Aboriginal infants was nearly six times that for non-Aboriginal infants, birth years 1999–2008 (RR = 5.8: CI 2.5–13.5).
- The risk of SIDS among Aboriginal infants was five times that for non-Aboriginal infants, birth years 1999–2008 (RR = 5.0: CI 2.9–8.6).
- Over all the years studied, infant mortality among non-Aboriginal infants remained the same or decreased in all the main causes of infant death except for deaths due to cancer and leukaemias.
- There were no significant decreases in the cause-specific infant mortality of Aboriginal infants over all the years studied.
- The CMR attributable to SIDS increased nearly two-fold in birth years 2004–08 in Aboriginal infants (1999–2003 0.9/1000 live births; 2004–08 1.7/1000 live births).

The following case studies focus on the patterns and trends of infant mortality according to SIDS, infection, injury and birth defects.

Specific-cause case study: Infant mortality due to SIDS[11]

The 'sudden and unexpected death of an infant or child is one of the worst events to happen to any family' (Fleming et al. 2004: 331). The rate of sudden and unexpected death in infants and children continues to be of concern, particularly with regard to the Aboriginal population. This section provide a comprehensive review of the literature with regards to the definition of SIDS, determination of the diagnosis, risk factors associated with SIDS and some statistics that report rates of SIDS for Aboriginal compared with non-Aboriginal infants.

Definition

The definition of SIDS has changed multiple times since first being described and coded under the International Classification of Disease (ICD-8) for infant deaths in 1965 (Ball & Volpe 2013). The current definition is:

> *the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.* (Krous et al. 2004:17)

This definition, along with five new categories of SIDS with specific criteria, was devised in

11 Prepared in collaboration with Ngaree Blow (fourth-year graduate medical student, The University of Melbourne).

San Diego, California, in 2004 at one of the four major conferences that have resulted in new definitions since 1965. SIDS has also been described and differentiated from 'sudden unexpected death of an infant', or SUDI, which is used as an umbrella term for infant deaths that have not yet been investigated for a cause (Krous et al. 2004).

There has been considerable controversy over the definition of SIDS and many discussions about definitional change. Changes were deemed necessary due to important emerging evidence that altered current understandings in four main areas. These included evolving information about SIDS epidemiological factors, autopsy rates and protocols, investigation techniques and risk factors. Previous definitions had failed to incorporate known demographic features such as age, as with the original definition in 1969 in which the sudden death was that of any infant or young child, without an upper age limit. However, research since the 1960s and 1970s has reported that 95% of SIDS cases are within the age range of one to six months.

It has also been widely understood that both previous and current data have typically reported an infant as asleep prior to death attributed to SIDS (Moon, Horne & Hauck 2007). These two known features of the syndrome (that of age and sleep) were not mutually included until the 2004 definition. Although there is now a universally accepted definition, there continues to be concerns as to the consistent application of the diagnosis of SIDS.

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

SIDS is diagnosed on the basis of exclusion. Until 2004, SIDS was defined using the 1989 National Institute of Child Health and Human Development Beckwith definition (Willinger, James & Catz 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).

There are also subsets of the general definition:

- Category IA: 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 IB SIDS: classic features of SIDS present but incompletely documented.
- Category II SIDS: meet category I 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 I or II 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 fulfilment.

Determining a diagnosis of 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 on a thorough post-mortem examination, but also on a 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 importance of seeking to determine the causes behind these deaths cannot be overestimated. Determining the cause is predicated on extensive forensic examination in addition to an integrated approach as identified previously.

At a meeting in Canberra in 2004, 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. The meeting considered the new international definition of SIDS developed by Krous, the uniform national adoption of which was a world first. The definition was endorsed by SIDS and Kids (the national peak body representing bereaved parents).

The recommendations and initiatives resulting from the Canberra meeting 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 after death by a senior paediatrician and a police officer (Freemantle & Read 2008). Post-mortems were conducted 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.

The Foundation for the Study of Deaths and the report of the Confidential Enquiry into Stillbirths and Deaths in Infancy recommend a comprehensive evaluation of all infant deaths using an integrated, multi-agency approach (Fleming et al. 2000). Together with the American Academy of Pediatrics, these bodies suggest that such a method of enquiry provides the best opportunity to determine the cause of death. Cote, Russo & Michaud (1999) 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'. Fleming et al. (2004) 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.

Risk factors

Although the cause of SIDS is unknown, researchers have been searching for factors to explain sudden unexpected deaths of infants with no apparent cause (Ball & Volpe 2013). There have been links and associations to more than 15 different factors, and the strongest risk factors include prone sleeping, maternal smoking and bed sharing (Byard & Krous 2004). Since epidemiological evidence identified prone sleeping as a risk factor for SIDS in the 1980s, the rate of placing infants in a prone position for sleep has decreased by 50% to 90% (Moon, Horne & Hauck 2007). This decrease has been especially helped along by the introduction of campaigns in which parents and caregivers are advised to place their infant in a supine position to sleep.

Various 'Back to Sleep' campaigns were implemented across the world in the 1980s and 1990s (Krous et al. 2004) and the rate of SIDS decreased by 50% to 90% over this time, particularly among non-Aboriginal infants. Since then, both prone and side-sleeping positions have been considered risk factors, partly because side placement is unstable and infants tend to roll into a prone position, but side placement has also been proven to be a separate risk factor (Mitchell, Hutchison & Stewart 2007).

Maternal smoking is considered a major risk factor that has been shown in almost every epidemiological study of SIDS. It has been suggested that decreased arousal to hypoxia and other stimuli due to the neuroteratogenic effects of nicotine is one of the mechanisms behind this risk (Moon, Horne & Hauck 2007).

Another major risk is bed sharing, especially if the infant is less than two months old. Many major health organisations around the world have advised against infants bed sharing, including the American Academy of Pediatrics and European Medicines Agency (Fleming et al. 2000). Although bed sharing is considered a risk, room sharing without bed sharing has been proven to reduce the risk of SIDS. In many countries it is recommended that infants sleep in a crib or bassinet next to the caregiver's bed, including in Australia, the United States, the United Kingdom and Canada (Moon, Horne & Hauck 2007).

There has been varying evidence for pacifier use and breastfeeding. So far there has been no consistent evidence for the use of a pacifier decreasing the risk of SIDS. In a recent meta-analysis, however, it was established that breastfeeding of any duration is protective against SIDS, and this effect is stronger when breastfeeding is exclusive. It was also assessed that breastfeeding per se reduced the risk of SIDS rather than being an indication of other potentially protective factors such as socio-demographic factors (Hauck et al. 2011).

Many other risk factors have been linked to SIDS with varying results. Infants with medical conditions including prematurity and low birth weight have been shown to have up to four times the risk of SIDS than healthy infants born at term. Other features found in SIDS infants include low socio-economic status, young parental age, and being of a minority ethnicity or being male. There is strong evidence to show that immunisation is not associated with SIDS (Krous et al. 2004; Ball & Volpe 2013; Moon, Horne & Hauck 2007; Byard et al. 2004).

It has also been shown that siblings of SIDS victims have an increased risk for SIDS, but the degree of risk is unclear. Genotypic differences have also been studied in order to investigate vulnerability of infants who died of SIDS. Until now no specific genotypes have been identified, but differences in several gene polymorphisms between infants with and without a SIDS diagnosis have been established. Since these discoveries, the interaction between environmental factors of SIDS, such as prone sleeping, and genetic vulnerability have been investigated. Studies of pathological results have supported the concept that SIDS is associated with abnormalities or prematurity of the autonomic nervous system, immune system and arousal pathways (Moon, Horne & Hauck 2007).

More research is required to explore the antecedents and protective factors associated with SIDS. It is clear that due to a lack of understanding in the causes of SIDS, there is a crucial need to accurately recognise well-established risk and protective factors. However, it is unclear how these risk factors need to be re-evaluated according to the diverse populations across different countries and within a country.

Disparities between Aboriginal and non-Aboriginal SIDS mortality

Rates of SIDS mortality among non-Aboriginal infants in Australia have fallen since the 'Reduce the Risks' campaign was introduced in 1991 (Henderson-Smart, Ponsonby & Murphy 1998). However, the rates remain high within Aboriginal populations (Ball & Volpe 2013; Moon, Horne & Hauck 2007; Byard et al. 2004). In North Queensland the rates for Aboriginal SIDS deaths were approximately three times higher than non-Aboriginal deaths (1.9 compared to 0.66/1000 live births from 1980–98). In Western Australia the rates were three to five times higher in Aboriginal infants (6.5/1000 live births as compared to 1.3/1000 live births for non-Aboriginal infants between

1980–2001) (Panaretto et al. 2002; Freemantle et al. 2006b). Due to the move towards re-classifying SIDS as 'unascertainable' death, data were combined and described as SIDSplus in Western Australia. From grouping these two categories (SIDS and 'unascertainable') it was found that Aboriginal infant mortality did not decrease in response to the 'Reduce the Risks' campaign (in contrast to that observed in non-Aboriginal infants). Several comparable disparities with other epidemiological factors were also discovered.

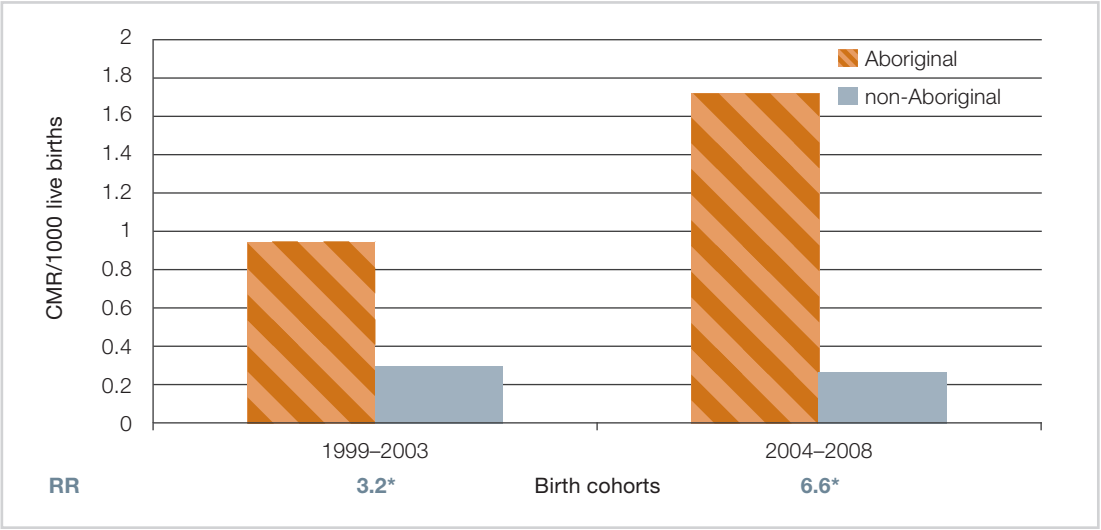
These significant disparities reported between the Aboriginal and non-Aboriginal populations provide a further example for the imperative to disaggregate total populations data in order to 'illuminate' patterns and trends of SIDS and other cause-specific mortality rates among this population and other minority populations.

The following data describe mortality where the cause of death has been attributed to SIDS. Deaths identified as 'unconfirmed SIDS' are noted. The data describing unconfirmed SIDS are not disaggregated as the numbers for Aboriginal infants were very small.

Figure 3.23 reports the CMR attributed to SIDS for Aboriginal and non-Aboriginal infants according to birth year groups, and the RR of deaths for Aboriginal compared with non-Aboriginal infants. The CMR due to SIDS for Victorian-born Aboriginal infants was five times greater than for non-Aboriginal infants, 1999–2008 (RR = 5.0: CI 2.9–8.6, p<0.0001). The CMR attributed to SIDS decreased among the non-Aboriginal infant population (RR = 0.9, 0.6–1.1), but increased nearly two-fold among the Aboriginal population (RR = 1.8, 0.6–5.7). The risk of an Aboriginal infant dying due to SIDS compared with a non-Aboriginal infant was significantly higher and doubled across the birth year groups (1999–2003 RR = 3.2: CI 1.2–8.6; 2004–08 RR = 6.6: 3.5–12.8).

Although the difference between the two cohorts did not reach statistical significance, the direction of the estimates and the magnitude of effect have significant public health relevance, particularly with regards to the relevance and acceptance of the 'Back to Sleep' campaign within the Victorian Aboriginal community.

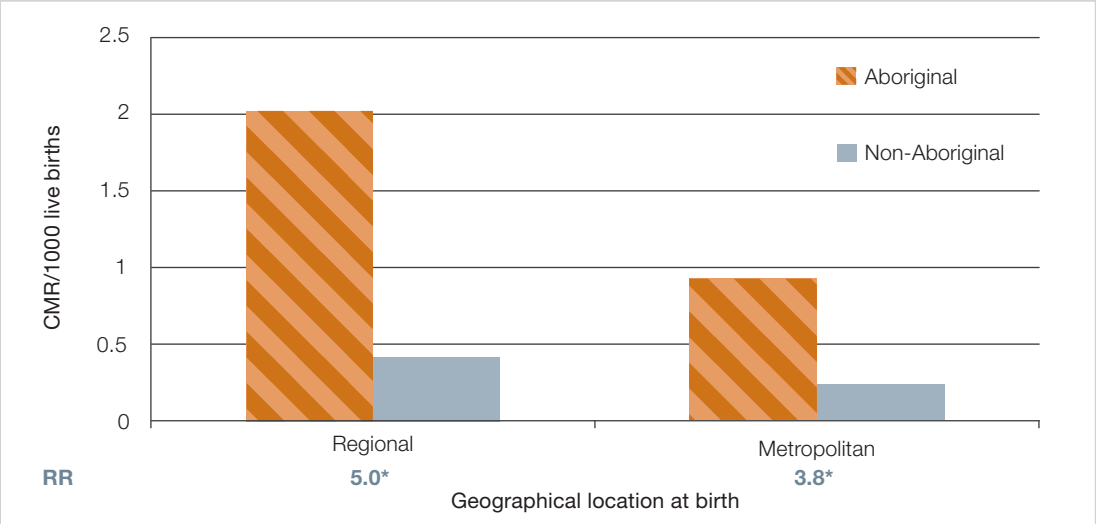
Figure 3.23: CMR attributable to SIDS and risk of death for Aboriginal (compared with non-Aboriginal) infants, birth years 1999–2008 inclusive



RR: rate ratio; SIDS: Sudden Infant Death Syndrome. *Statistically significant values (refer to text).

The following figures report the CMR attributed to SIDS according to Aboriginal status and geographical location of mother at the time of the infant's birth, 1999–2008. Figure 3.24 reports the CMR according to geographical region at the time of birth and the RR of SIDS according to Aboriginal status in the regional and metropolitan regions of birth. An Aboriginal infant was five times more likely to die due to SIDS in the regional locations (RR = 5.0: 2.6–9.7) and nearly four times more likely in the metropolitan regions compared with a non-Aboriginal infant (RR = 3.8: 1.4–10.3).

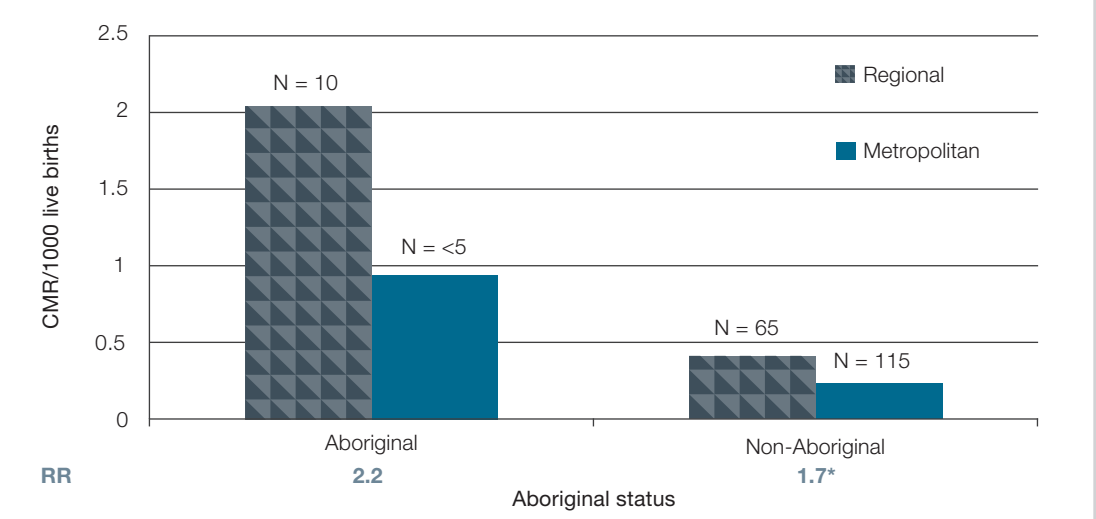
Figure 3.24: CMR attributable to SIDS and the risk of death for Aboriginal infants (compared to non-Aboriginal) according to geographical location at birth, 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio; SIDS: Sudden Infant Death Syndrome. *Statistically significant values (refer to text); RR refers to comparison between the CMR for Aboriginal compared with non-Aboriginal infant deaths.

Figure 3.25 (see next page) reports the CMR according to mother's geographical region at the time of birth and the RR of SIDS according to geographical location at birth for Aboriginal and non-Aboriginal infants. An Aboriginal infant whose mother was residing in a regional location at birth was twice as likely to die due to SIDS as Aboriginal infants whose mothers were residing in metropolitan locations (RR = 2.2, 0.7–7.0). A non-Aboriginal infant was nearly twice as likely to die of SIDS if the mother was residing in a regional location at the time of birth compared to a non-Aboriginal infant born into a metropolitan location (RR = 1.7: CI 1.2–2.3).

Figure 3.25: CMR attributable to SIDS and the RR according to geographical location at birth for Aboriginal and non-Aboriginal infants, 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio; SIDS: Sudden Infant Death Syndrome. *Statistically significant values (refer to text); RR refers to comparison between the CMR observed in the regional and the metropolitan locations at the time of birth.

Co-sleeping

Available information that described the circumstances of a SIDS death and the environment within which the infant was living at the time of death was inconsistent in quality and availability. This research took particular note of co-sleeping in deaths attributed to SIDS. However, in 25% of SIDS cases there was no information identifying whether the infant was co-sleeping at the time of death. Co-sleeping has been identified as a risk factor associated with SIDS (Fleming et al. 2000). In reviewing the autopsy case reports of deaths occurring between birth years 1999 to 2009 inclusive, information regarding co-sleeping was noted.

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, nor does it 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 Victorian 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).

Table 3.21 (see overleaf) reports the number and proportions of SIDS deaths where information describing whether the infant was co-sleeping at the time of death was available. In 44% of Aboriginal infants whose deaths were attributed to SIDS and 23% of non-Aboriginal infants, there was no information regarding co-sleeping. Where information was available, in 36% of SIDS among Aboriginal infants and 44% of non-Aboriginal infants, the infants were reported as co-sleeping (not co-sleeping: Aboriginal, 21%; non-Aboriginal, 32% of infant deaths).

Table 3.21: Frequency and proportions of co-sleeping among SIDS cases in infants born in Victoria, 1999–2008

General cause of infant death	Non-Aboriginal infant deaths			Aboriginal infant deaths			All SIDS deaths		
	Co-sleeping N (%)	No co-sleeping N (%)	Unknown N (%)	Co-sleeping N (%)	No co-sleeping N (%)	Unknown N (%)	Co-sleeping N (%)	No co-sleeping N (%)	Unknown N (%)
All SIDS combined	80 (44.4)	58 (32.2)	42 (23.3)	5 (35.7)	*	6 (42.9)	85 (43.8)	61 (31.4)	48 (24.7)
Confirmed SIDS	75 (42.9)	58 (33.1)	42 (24.0)	*	*	6 (46.2)	79 (42.0)	61 (32.4)	48 (25.5)
Unconfirmed SIDS	5 (100.0)	0	0	*	0	0	6 (100.0)	0	0

* Numbers supressed.

Summary

- There were 11 excess deaths attributed to SIDS among Aboriginal infants, 1999–2008.
- An Aboriginal infant was significantly more likely to die of SIDS compared with a non-Aboriginal infant (RR = 5: CI 2.9–8.6).
- The CMR attributed to SIDS increased among Aboriginal infants and decreased among non-Aboriginal infants across the two birth cohorts.
- The gap between the Aboriginal and non-Aboriginal population of SIDS has more than doubled across the birth year groups.
- The CMR for SIDS was higher in the regional locations of birth compared to infants born into a metropolitan location for both populations, reaching statistical significance among the non-Aboriginal population (RR = 1.7: CI 1.2–2.3).
- Information describing the circumstances and environment in which the infant was living at the time of the death was inconsistent in availability and quality.
- Information describing co-sleeping was not available in 25% of deaths attributed to SIDS deaths.
- The percentage of missing information was significantly higher in case notes describing Aboriginal SIDS (43% compared with 23%).
- 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.

Specific-cause case study: Infant mortality due to infections[12]

This section provides a comprehensive case study of infant mortality attributed to infection for infants born in Victoria between 1999 and 2008 inclusive.[13] It presents data for all infants

12 For infections considered in coding, see Appendix 1 and Appendix 2.

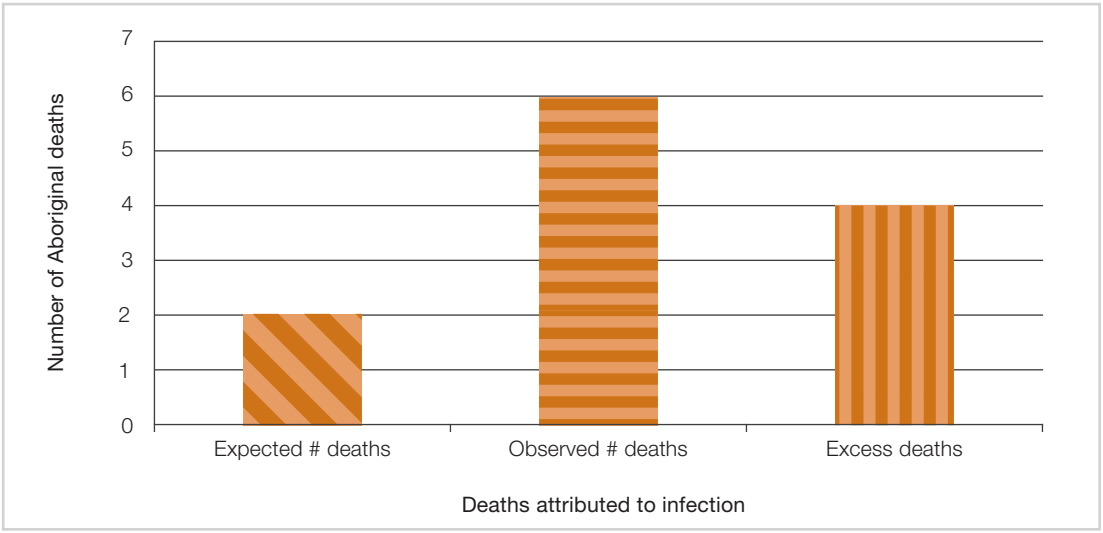
13 Prepared in collaboration with Yolanda Hannigan (4th year graduate medical student, The University of Melbourne).

and describes differences in the patterns and trends for Aboriginal compared with non-Aboriginal infants. It also describes the clinical, public health and statistical significance associated with the estimates. These data are the results of a specific research study undertaken by fourth-year University of Melbourne medical student Yolanda Hannigan through the Scholarly Selective program.

Disparities in health outcomes between Aboriginal and non-Aboriginal populations in Australia are well documented. Research has reported increased infant mortality rates attributed to infection in Aboriginal infants. However, in Victoria limited data have described the mortality rates of Aboriginal infants. This section reports the findings of analysis of the matched birth/death datasets regarding Aboriginal infant mortality rates attributed to infection in Victoria.

It is relevant to note the (absolute) small number of Aboriginal deaths attributed to infection. These relatively small numbers of deaths potentially compromise the ability to indicate statistically significance between the two populations and the intervals are not necessarily meaningful. Thus, the data were limited in regards to estimating effects associated with the cause of death. However, in calculation of cause-specific CMR, the risk of death for Aboriginal compared with non-Aboriginal infants was of significant public health relevance. There were six observed deaths among Aboriginal infants attributed to infection, whereas if the CMR had been the same in both populations, only two would have been expected in the Aboriginal population These excess deaths (n = 4) are an indicator of the burden of infection potentially experienced within the Aboriginal infant population. Although the main data provide evidence of increased mortality within the Aboriginal population, these data provide an indication that infection could be a pertinent cause of the excess mortality. Figure 3.26 reports the excess infant deaths attributed to infection for Aboriginal infants.

Figure 3.26: Expected, observed and excess number of Aboriginal infant deaths attributed to infection, 1999–2008



Infection was reported in 5.6% of all Victorian infant deaths, 1999–2009. The main causes of death due to infection were sepsis and respiratory infection. Over the 10-year period studied, infant mortality rates due to infection decreased significantly (RR = 0.6: CI 0.5–0.9). Risk factors prevalent in infants who died from infection included prematurity, low birth weight, being born to a mother aged less than 20 years, being born to a family with three or more children, and being born in a regional location.

Table 3.22 (see next page) reports the CMR for all infants who died in Vitoria, 1999–2009 inclusive (Aboriginal and non-Aboriginal) and the RR within each variable that reflects risk factors associated with infection reported in the literature. Male infants were significantly more to die due to infection compared with female infants (RR = 1.4: CI 1.0–1.8, p<0.05). Infants of mothers who were older than 30 years at the time of their birth were less likely to die of infection in the first year of life compared with mothers who were between 20 and 29 years at the time of birth (RR = 0. 5: CI 0.4- 0.7, p<0.05). Infants born with a birth weight less than 2500 grams were significantly more likely to die as a result of an infection compared with infants with a birth weight between 2500 and 4999 grams (RR = 19.6: CI 14.3–26.8). Infants born between 32 and 36 weeks gestation were more likely to die due to infection compared with term infants (RR = 4.3: CI 2.6–6.9). Infants whose mothers were residing in a regional location were more likely to die of infection compared with infants living in metropolitan locations (RR = 1.4, CI 1.0:1.9, p = 0.07). Infants who were twins or triplets were more likely to die as a result of infection compared with singleton infants (RR = 3.7: CI 1.9–4.5). (Data not shown in table).

Table 3.22: Risk factors for mortality attributed to infection, all Victorian-born infants, 1999–2008 inclusive

	Number who died from infection	Total number	CMR per 10,000 live births	RR	95% CI
Sex					
Male	97	335,406	2.9	**1.4**	**1.0, 1.9**
Female	66	318,296	2.1	1.00 (ref)	1.00 (ref)
Indeterminate	0	26	0	0	0
Maternal age					
≤19	10	18,793	5.3	1.4	0.8, 3.1
20–29	85	253,307	3.4	1.00 (ref)	1.00 (ref)
30 plus	68	381,627	1.8	0.5	**0.4, 0.7**
Unknown	0	4	0	0	0
Low birth weight					
<1,500	66	7,094	93.0	**82.1**	**58.5, 115.2**
1,500–2,499	28	34,306	8.2	**7.2**	**4.6, 11.2**
2,500–4,499	68	600,310	1.1	1.00 (ref)	1.00 (ref)
4,500 plus	1	11,963	0.8	0.7	0.1, 5.3
Unknown	0	58	0	0	0
Gestational age					
20–27 weeks	48	3,164	151.7	**124.1**	**86.2, 178.6**
28–31 weeks	20	4,630	43.2	**35.3**	**21.5, 57.9**
32–36 weeks	21	40,328	5.2	**4.3**	**2.6, 6.9**
37–41 weeks	73	596,951	1.2	1.00 (ref)	1.00 (ref)
>41 weeks	1	8,611	1.2	0.9	0.1, 6.8
Unknown	0	47	0	0	0
Residence					
Regional	51	163,640	3.1	**1.4**	**1.0, 1.9**
Metropolitan	109	477,267	2.3	1.00(ref)	1.00 (ref)
Other	3	12,824	2.4	1.0	0.3, 3.2
Primiparous	144	631,303	2.3	1	1
Multiparous	19	22,428	8.5	**3.7**	**2.3, 6.0**
Parity					
0	55	277,250	2.0	1	1.00 (ref)
1–2	78	324,670	2.4	1.2	0.9, 1.7
3+	30	51,810	5.8	**3.0**	**1.9, 4.5**
Unknown	0	1	0	0	0

CI: confidence interval; CMR: cumulative mortality rate; RR: rate ratio. CMR/10000 live births; statistically significant values are bolded.

Table 3.23 reports RRs with 95% CIs of infant mortality due to infection reported for all infants associated with the major risk factors. Given the (relatively) small number of deaths due to infection reported among Aboriginal infants, the prevalence of these risk factors within the Aboriginal population have been not been reported. The data indicate that Aboriginal infants were at significantly higher risk of being born with these risk factors compared with non-Aboriginal infants.

Table 3.23: RR and CI of infant mortality due to infection for *all* Victorian-born infants, 1999–2008, and the RR of Aboriginal (compared with non-Aboriginal) infants according to the risk factor at birth

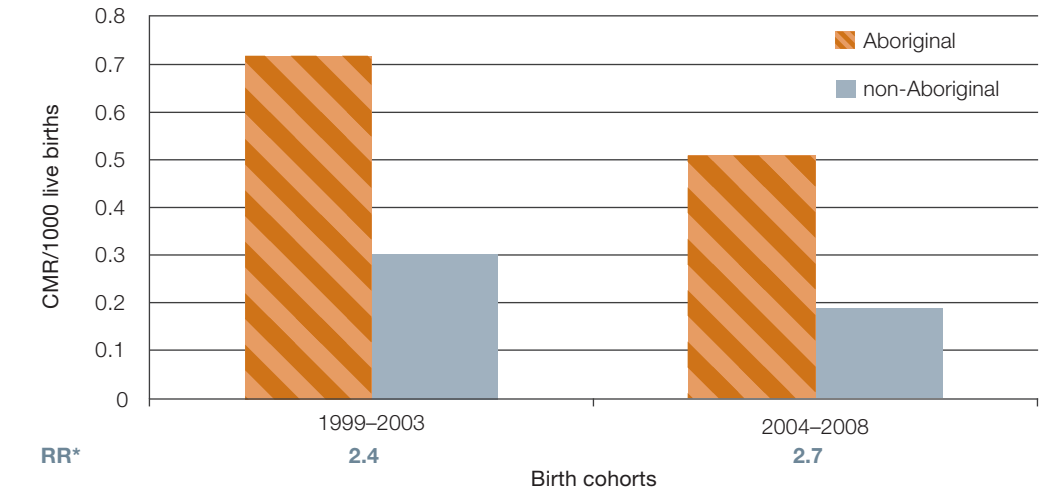
Known risk factor for infection	All infants		Aboriginal compared with non-Aboriginal	
	RR	95% CI	RR	95% CI
Male compared to female	1.4	1.0–1.2		
Male			2.2	1.7–2.9
Female			1.8	1.3–2.
Maternal age (years)				
<20 compared with 20–29	1.4	0.8–3.1		
<20			1.7	1.0–2.9
20–29			2.1	1.6–2.9
Gestational age (weeks)				
Preterm compared with term	15.1	11.1–20.6		
Preterm			1.5	1.2–1.9
Term			1.9	1.3–2.8
Geographical location				
Regional compared with metro.	1.4	1.0–1.9		
Regional			2.0	1.5–2.7
Metropolitan			1.9	1.4–2.6
Parity				
≥3 previous live births compared with no previous births	3.0	1.9–4.5		
No previous pregnancies			1.8	1.3–2.6
≥3 previous births			2.1	1.4–3.1

CI: confidence interval; RR: rate ratio.

Aboriginal infants were two-and-a-half times more likely to die from infection compared with non-Aboriginal infants over the 10 years studied (RR = 2.5: CI 1.1–5.6, p = 0.03). Over the 10 years, the RR remained similar (1999–2003 RR = 2.4: CI 0.8–7.5; 2004–08 RR = 2.7: CI 0.9–8.6). Analysis of the difference in causes and risk factors according to Indigenous status was not undertaken due to the small number of Aboriginal infants who died from infectious causes. However, analysis of the total birth cohort found that Aboriginal infants had higher rates of all the risk factors associated with infection.

Although the CMR for deaths due to infection decreased in the second birth cohort for both Aboriginal and non-Aboriginal infants, the decrease was only significant in non-Aboriginal groups (RR = 0.6: CI 0.5–0.9). The CMR did not reduce as quickly among Aboriginal infants (RR = 0.7: CI 0.2–2.7). Thus the RR of infant deaths according to infection remained high and was nearly three-fold for Aboriginal infants compared with non-Aboriginal in the most recent years studied (Figure 3.27, next page).

Figure 3.27: CMR according to infection for Victorian-born infants and RR for Aboriginal (compared with non-Aboriginal infants) by birth year groups



CMR: cumulative mortality rate; RR: rate ratio; *non-significant RRs (refer to text).

Table 3.24 reports the CMR of deaths for all Victorian-born infants who died of infection in birth years 1999–2008 inclusive according to the location of the mother at the time of birth.

Although the CMR was greater for infants of mothers who were residing in regional areas at the time for the birth, the RR was not statistically significant.

Table 3.24: CMR, number and percentage of deaths due to infection for all Victorian-born infants, 1999–2008 inclusive

	All infants					
Infection	Total births (n)	Total deaths (%**)	CMR/1,000 births	RR	(95% CI)	p-value
Infection	653,712	163 (100.0)	0.24	0	0	
Regional	163,633	51 (31.2)	0.31	1.34	0.63–6.48	0.2383
Metropolitan	477,257	109 (66.9)	0.23	1.00	0	
(Other)*	(12,822)	(3) (1.8)	(0.23)	0	0	

CI: confidence interval; CMR: cumulative mortality rate; RR: rate ratio. * Mother normally resident outside of Victoria, but infant born in Victoria.

The percentage of infants dying as a result of infection according to the mother's residence at the time of the birth was higher in the regional locations for Aboriginal infants (50%) compared with non-Aboriginal infants (31%). These percentages reflect the residential location at birth and were reversed for deaths due to infection in the metropolitan locations (Aboriginal infants, 33%; non-Aboriginal infants, 67%). In contrast, the CMR was higher for both Aboriginal and non-Aboriginal infants in the regional areas, and the risk (two-fold) of an Aboriginal infant dying compared to a non-Aboriginal infant was similar in both locations.

Table 3.25 (see overleaf) reports the CMR and percentage of deaths according to mother's residence at the time of birth and RR for Aboriginal infants (compared with non-Aboriginal infants), birth years 1999–2008.

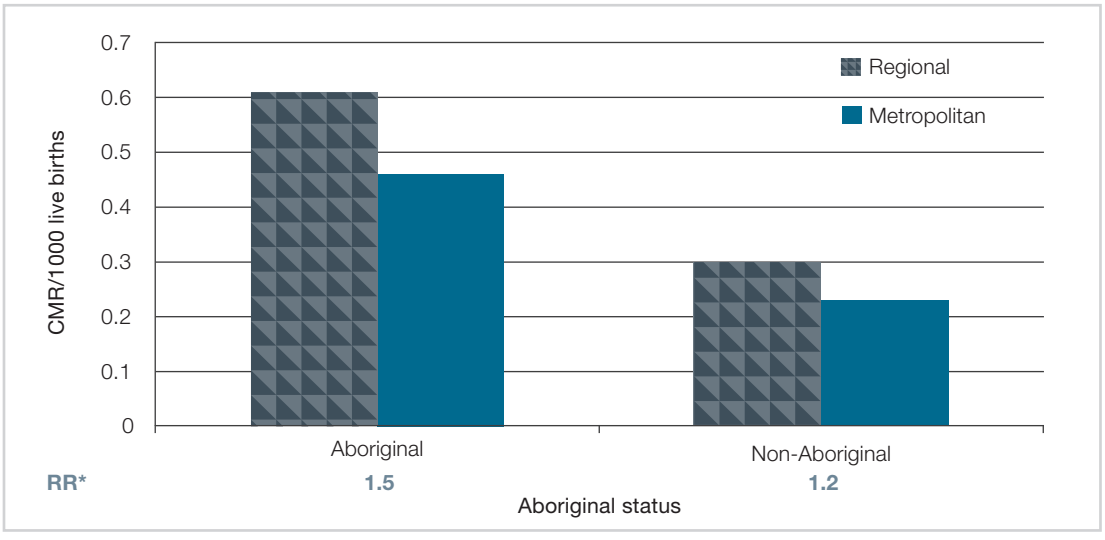
Table 3.25: CMR and percentage of deaths according to mother's residence at the time of birth, and RR for Aboriginal (compared with non-Aboriginal infants), birth years 1999–2008

	Non-Aboriginal		Aboriginal			
Infection	Total deaths (%)	CMR/ 1,000 births	Total deaths (%)	CMR /1,000 births	Rate ratio (95% CI)	p-value
Infection	(100.0)	0.24	(100.0)	0.60	2.46 (1.09–5.55)	0.0308
Regional	(30.6)	0.30	(50.0)	0.61	2.02 (0.63–6.48)	0.2383
Metropolitan	(68.2)	0.23	(33.3)	0.46	2.05 (0.51–8.31)	0.3141
Other*	(1.3)	0.17	(16.7)	1.26	7.59 (0.69–83.76)	0.0978

CI: confidence interval; CMR: cumulative mortality rate; RR: rate ratio * 'other' deaths are deaths occurring in Victoria to Victorian-born infants whose usual residence of birth is interstate or overseas.

Figure 3.28 reports the CMR for Aboriginal and non-Aboriginal infants attributed to infection according to the geographical location at the time of birth and the RR of mortality according to the location of birth. The CMR according to infection was greater for infants born into regional locations compared with metropolitan locations for both Aboriginal and non-Aboriginal infants. The CMR for Aboriginal infants born into regional locations compared with metropolitan locations was one-and-a-half times greater (RR = 1.5: CI 0.7–7.0).

Figure 3.28: CMR attributable to infection and the RR according to geographical location at birth for Aboriginal and non-Aboriginal infants, 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio. * Non-significant RRs (refer to text); RR refers to comparison between the CMR observed in the regional and the metropolitan locations at the time of birth.

Maternal infection at infant's death

The review of case files identified 185 infant deaths where the mother had an infection at the time of death. In 7.4% of infant deaths due to infection, the mother also had an infection. Of the infants who died from prematurity, 8% had a mother who had an infection. Of the infants who died from intrapartum causes, 8.8% had a mother who had an infection. Of the infants who died from accidents, 9% had a mother who had an infection.

In this study, chorioamnionitis, an infection of the uterus in the mother, was considered a maternal complication that can lead to sepsis in the infant and/or prematurity, rather than an infection directly causing death in the infant. Chorioamnionitis is preventable through good antenatal care, a sound clinical history and early diagnosis of uterine infection. The provision of accessible health care services to a community and education as to the importance of seeking early antenatal care, particularly where the mother has experienced previous premature deliveries/stillbirths and/or uterine infection, would contribute to preventing this infection and maternal and perinatal consequences.

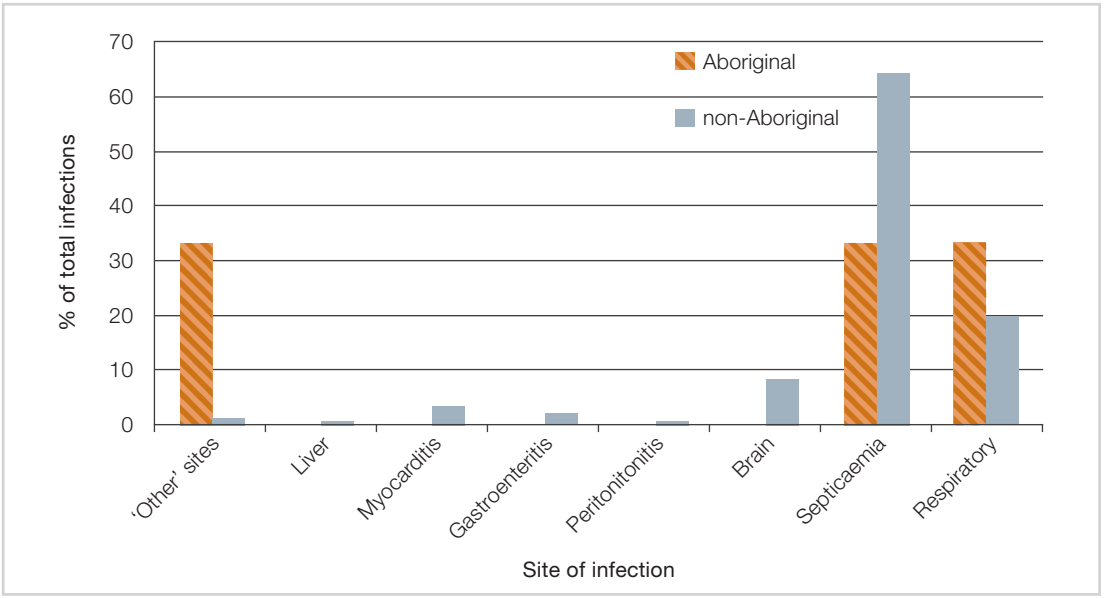
Types of infection

There were higher rates in Aboriginal (2/10,000 sepsis, 2/10,000 respiratory) than non-Aboriginal infants (1.5/10,000 sepsis, 0.4/10,000 respiratory) (data not shown). Deaths due to respiratory infection were four times greater among Aboriginal infants compared with non-Aboriginal infants (data not shown).

Of all the infants who died in the cohort, 273 had a mother who was diagnosed with chorioamnionitis. Of the infants who died from infection, 8% had a mother who had chorioamnionitis (data not shown). Of the infants who died from prematurity, 21.3% had a mother who was diagnosed with chorioamnionitis. Of the infants who died from intrapartum causes, 9.09% had a mother who was diagnosed with chorioamnionitis (data not shown).

Figure 3.29 reports the main types of infection among Aboriginal infants. Infection due to sepsis (63%) and respiratory infections (20%) were the most common causes of mortality for all non-Aboriginal infants. Sepsis, respiratory and 'other' infection each accounted for 33.3% of all Aboriginal deaths due to infection (Figure 3.29).

Figure 3.29: Main type of infection causing infant death according to Aboriginal status, 1999–2008 inclusive



Infection organism

Table 3.26 reports the organism identified in the CCOPMM case files that was detected during the post-mortem process. Given that the number of deaths due to infections was small (n = 6) for Aboriginal infants, the results for all infants are reported. In 18% of deaths due to infection the organism was not identified in the case files. Where information was available, infections where a bacterial infection was noted but the type of bacteria was not specified ('other bacterial') accounted for 44% of infection in infants. Viral organisms accounted for 17% of infections, Group B streptococcus for 10%, and multiple agents and both bacterial and viral, 4% and 5% respectively. Group B streptococcus, unknown agent, 'other bacterial' and viral organisms were identified in the Aboriginal deaths due to infection (data not shown due to small numbers).

Table 3.26: Frequencies and proportions of all infants born in Victoria between 1999–2008 inclusive for deaths by infection organism

Organism	Total N (%)
Organism	163 (100.0)
Unknown agent	30 (18.4)
Group B strep.	16 (9.8)
Other bacterial	71 (43.6)
Toxoplasmosis	1 (0.6)
Syphilis	0
Viral	27 (16.6)
Listeria	2 (1.2)
Both bacterial and viral	8 (4.9)
Multiple agents	7 (4.3)
Other specified agent	1 (0.6)
Parasitic	0

Summary

- There were four excess Aboriginal infant deaths attributed to infection, 1999–2008.
- Among all infants, infection accounted for 5% of deaths in infancy (5% among non-Aboriginal and 7% among Aboriginal infants).
- Over the 10-year period studied, mortality rates for all infants due to infection decreased significantly (RR = 0.6: CI 0.5–0.9 p<0.004).
- Risk factors that were more prevalent in all infants who died from infection included prematurity, low birth weight, being born to a mother aged less than 20 years, being born to a family with three or more children, and being born in a regional location.
- Aboriginal infants were two-and-a-half times more likely to die from infection compared with non-Aboriginal infants over the 10 years studied (RR = 2.5, CI 1.1–5.6, p = 0.03).
- Over the 10 years, the risk of death due to infection for Aboriginal infants compared with non-Aboriginal was similar (1999–2003 RR = 2.5; 2004–08 RR = 2.7).
- The CMR according to infection was higher for infants born into regional locations compared with metropolitan locations for both Aboriginal and non-Aboriginal infants.
- The CMR for Aboriginal infants born into regional locations compared with metropolitan locations was one-and-a-half times greater (RR = 1.5: CI 0.7–7).

- The main causes of death due to infection were sepsis and respiratory infection, with higher rates in Aboriginal (2/10,000 sepsis, 2/10,000 respiratory) than non-Aboriginal infants (1.5/10,000 sepsis, 0.4/10,000 respiratory).
- Deaths due to respiratory infection were four times greater among Aboriginal infants than non-Aboriginal infants.
- Bacterial organisms accounted for the majority of deaths due to infection in infancy in both Aboriginal and non-Aboriginal infants.

Specific-cause case study: Infant mortality due to birth defects

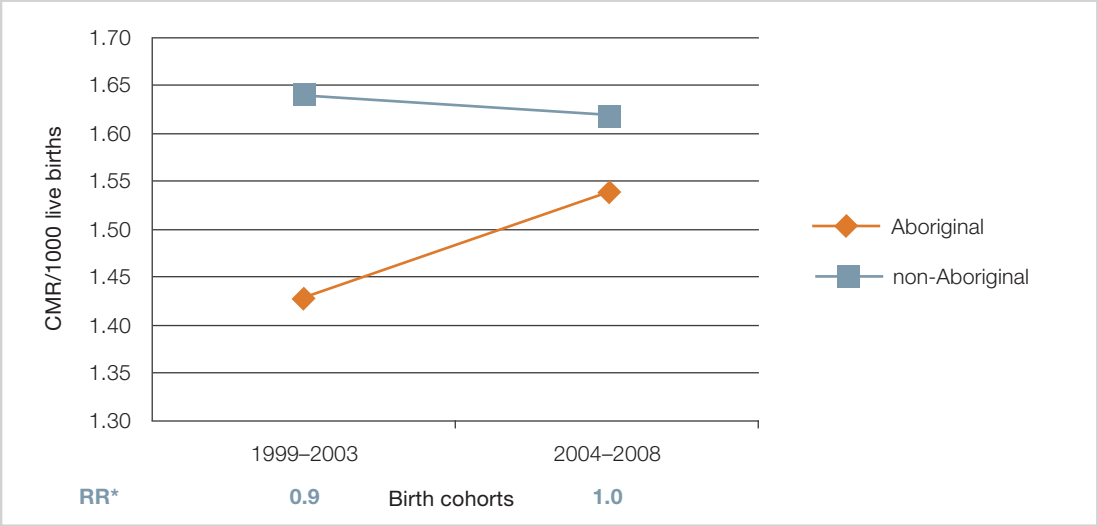
Since voluntary fortification was introduced in 1997, a folate awareness campaign was launched in Victoria in 1999 because of the proven effectiveness of periconceptional folic acid intake in preventing a significant proportion of neural tube defects (NTDs) such as spina bifida. A trial to assess the level of folate awareness in the target population before this campaign reported a baseline level of awareness of 12% (Watson et al. 1999). No further folate awareness strategies have been implemented in Victoria since this time (du Plessis et al. 2008). Mandatory fortification of bread flour was introduced across Australia in September 2009.

The VACMS did not record the particular type of birth defects. Data describing stillbirths were not included in the VACMS and therefore the consideration of stillbirths resulting from termination of pregnancy (TOP) for antenatal diagnosis of neural tube defects was not included in the report. However, notwithstanding the exclusion of stillbirths from these data, it would be of interest to review these data to determine the number of NTDs diagnosed in the two populations over the 10 years, including those diagnosed where a TOP occurred. Further, the VACMS reported that 87% of TOPs was attributed to a prenatal diagnosis of birth defects (87% among non-Aboriginal and 67% among Aboriginal women of all TOPs were due to birth defects). Such information could contribute to discussions as to the efficacy of the 1999 Victorian folate education campaign within the two populations and any ongoing efforts to raise awareness of the importance of folic acid since mandatory fortification began. These data could also contribute to the information describing stillbirths (including TOPs) where a NTD was diagnosed. Combined data could evaluate whether 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 folate-fortified food, as well as lack of knowledge of the health benefits.

Over the 10 years studied, while the CMR associated with birth defects was lower among Aboriginal infants (CMR = 1.5/1000 live births) compared with non-Aboriginal infants (CMR = 1.6), there was no significant difference observed in the risk of infant mortality between the two populations (RR = 0.9: CI 0.6–1.5).

The rate of mortality due to birth defects (Figure 3.30, overleaf) remained similar among non-Aboriginal infants over the two birth cohorts (RR = 1.0: CI 0.9–1.1). However, this pattern has not been observed among Aboriginal infants for whom an increase was evident. The CMR for birth defects for Aboriginal infants was similar over the two birth cohorts (RR = 1.1: CI 0.4–3.0). This lack of recent improvement in deaths due to birth defects in Aboriginal infants is of concern.

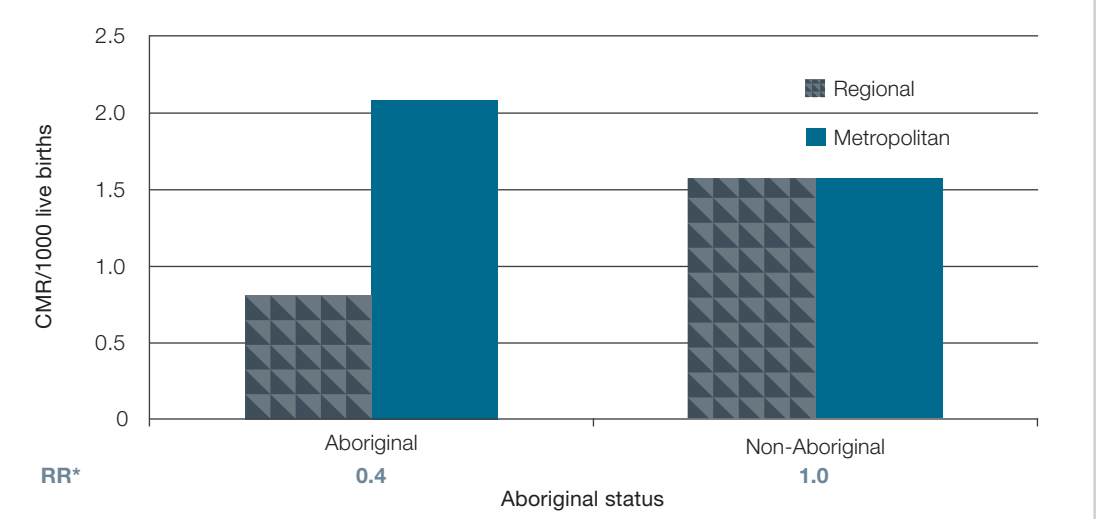
Figure 3.30: CMR due to birth defects according to Aboriginal status and birth year groups 1999–2008 and RR for Aboriginal infants (compared with non-Aboriginal)



CMR: cumulative mortality rate; RR: rate ratio. * Non-significant RRs (refer to text). Note: stillbirths have been excluded; includes all live births.

Figure 3.31 (see next page) reports the CMR due to birth defects and the risk of infant death for Aboriginal compared with non-Aboriginal infants. Although there was no statistical significance according to geographical location in the risk of death for Aboriginal compared with non-Aboriginal infants, the magnitude of the estimate and direction reported over the birth cohorts should be considered. The CMR was less for Aboriginal infants born into regional locations compared with Aboriginal infants born into metropolitan locations (RR = 0.4: CI 0.1–1.3) and also less than non-Aboriginal infants born into regional locations (RR = 0.5: CI 0.2–1.4). The CMR for non-Aboriginal infants was similar whether born into regional or metropolitan locations (RR = 1.0: CI 0.7–2.5), and the CMR was smaller for non-Aboriginal infants born into metropolitan locations when compared to Aboriginal infants (RR = 0.8: CI 0.4–1.5). The CMR for infants who were born and died in Victoria due to birth defects where mother's usual residence was interstate was 2.5/1000 live births for Aboriginal and 4.0/1000 live births for non-Aboriginal infants (RR = 0.63: CI 0.2–2.6). The specific characteristics of these deaths were not scrutinised, although it would be of interest to know the specific cause of the birth defect and whether the Victorian birth was due to a prenatal diagnosis that required corrective surgery in Victoria (which was unsuccessful) following the birth.

Figure 3.31: CMR due to birth defects and the RR according to geographical location at birth for Aboriginal and non-Aboriginal infants, 1999–2008 inclusive



CMR: cumulative mortality rate; RR: rate ratio. * Non-significant RRs (refer to text above). Note: stillbirths have been excluded; includes all live births. RR refers to comparison between the CMR observed in the regional and the metropolitan locations at the time of birth.

Summary

- There were no excess deaths due to birth defects among Aboriginal infants, 1999–2008.
- In light of no statistical significance according to geographical location in the risk of death for Aboriginal compared with non-Aboriginal infants, the magnitude of the estimate and direction reported over the birth cohorts should be considered.
- The CMR associated with birth defects was lower among Aboriginal infants (CMR = 1.5) compared with non-Aboriginal infants (CMR = 1.6).
- There was no significant difference observed in the risk of infant mortality due to birth defects between the two populations.
- The rate of mortality due to birth defects remained similar among non-Aboriginal infants over the two birth cohorts and increased among Aboriginal infants over the two birth cohorts. These differences were not significant and numbers were very small.
- The CMR due to birth defects for Aboriginal infants born into regional locations was less than the CMR for metropolitan locations.
- The CMR according to location of birth for non-Aboriginal infants was similar.

Specific-cause case study: Infant mortality due to injury

The number of deaths due to injury among Aboriginal infants, 1999–2009, was relatively small and mortality due to injury was more common in childhood than in infancy. There were five excess deaths due to injury among Aboriginal infants, 1999–2008. Deaths in the first year of life due to injury accounted for 7% of Aboriginal (n = 6) and 2% of non-Aboriginal (n = 66) deaths. The causes of these deaths among Aboriginal infants were due to positional asphyxia, car accident, pedestrian death and a death in the post-operative period. For non-Aboriginal infants the main causes of death included drowning, perioperative death, positional asphyxia, suffocation and 'other'

asphyxia, fire, motor vehicle accidents, non-accidental injury and homicide, and injury not otherwise specified (Appendix 1).

Sixty-six per cent of Aboriginal infant deaths and 32% of non-Aboriginal infant deaths occurred in regional locations (location of infants' births); 33% of Aboriginal and 65% of non-Aboriginal infant deaths occurred in metropolitan regions (location of infants' births).

There were five excess Aboriginal infant deaths due to injury between 1999 and 2009.

3.2 Trends and patterns of childhood mortality

This section presents the patterns and trends of mortality among Victorian-born children born between 1999 and 2008 inclusive. It includes all-cause childhood deaths. Cause-specific mortality over all years and for combined ages are shown. In addition, trends in age-specific mortality by grouped year of birth and sex are presented.

The denominator used in the descriptive analyses for Aboriginal childhood mortality is 44,189 infant survivors, and 3,105,101 non-Aboriginal childhood mortality infant survivors, expressed in person-years. Childhood mortality is described as the child (cumulative) mortality rate. The age-specific ChMR was calculated per 1000 person-years for the birth years 1999 to 2008 inclusive. Given the small number of deaths, the data were not divided into birth year groups. The hazard ratio (HR) and 95% confidence intervals (CI) were calculated to determine the significance of the difference of the (age-specific) rate of death for Aboriginal children relative to the rate for non-Aboriginal children.

The number of deaths of Victorian-born Aboriginal children was small (n = 16). However, while the absolute numbers were small, the rate ratio (expressed as a hazard ratio) was significant for some variables and for others the magnitude of the HR and the direction of the HR should be noted. Given the small numbers reported in the Aboriginal population, particularly when describing trends in cause-specific childhood mortality, it was difficult to determine meaningful statistical significance and in these instances interpretation of the data is difficult.

However, for a small population to be at a much higher risk than the larger population in itself is of public health and clinical significance.

It is important to re-emphasise that these data potentially underestimate the true Aboriginal child population. Previous research indicated the underestimation of Aboriginal births due to misclassification of Aboriginal mothers and non-inclusion of information describing Aboriginal fathers (Freemantle et al. 2013). Therefore, we would expect that there would be a small number of additional deaths classified as non-Aboriginal that would, indeed, be Aboriginal. These births and deaths could be identified through population data linkage to additional data (e.g. the Victorian Admitted Episodes Dataset).

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

- early years, 1–2 years
- pre-primary, 3–5 years
- primary school, 6–<11 years.

All-cause childhood mortality

Between 1999 and 2009 birth years, there were 16 Aboriginal deaths and 458 non-Aboriginal deaths in Victoria among children who died between their first and eleventh birthdays. Aboriginal deaths accounted for 3.5% of all childhood deaths reported to

the CCOPMM. However, it is important to consider this percentage within the context of the percentage of Aboriginal births (1.6% of total Victorian births).

The ChMR of Aboriginal children was 1.6/1000 infant survivors compared with 0.7/1000 for non-Aboriginal children. The RR over the 10 years of Aboriginal childhood deaths was more than twice that of non-Aboriginal children (RR = 2.3: CI 1.4–3.8).[14]

Male children were more likely to die in both populations compared with female children. An Aboriginal male was significantly more likely to die in childhood compared with a non-Aboriginal male child (RR = 2.7: CI 1.5–5.1).

Over the 10 years studied, the main cause of death in childhood was injury in both populations (Aboriginal, 44%; non-Aboriginal, 30%). Birth defects accounted for 27% of non-Aboriginal child deaths and 19% of Aboriginal child deaths.

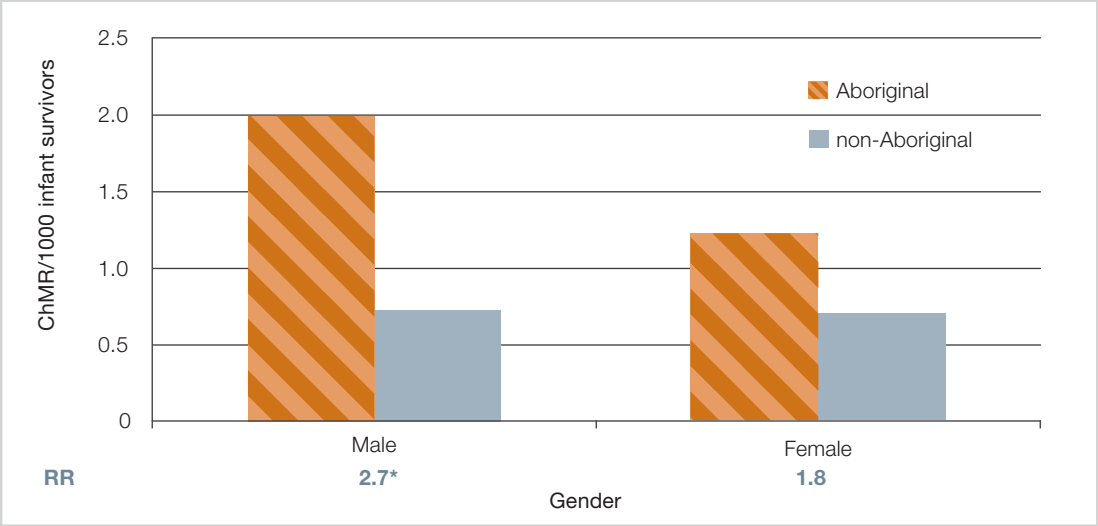
Forty-four per cent of Aboriginal deaths occurred in children born in regional locations, and 50% for those born in metropolitan locations (for 6% who died in Victoria, their normal residence was interstate or, in a few cases, overseas). These percentages are similar to the birth data: between 1999 and 2008, 48% of Aboriginal births occurred to mothers living in a regional location, and 45% in metropolitan locations (7% of Aboriginal births in Victoria were to mothers whose usual place of residence was interstate). For non-Aboriginal children, 29% of the deaths occurred among infants who were born in regional locations and 71% in metropolitan (for 1% of those who died in Victoria their normal residence was interstate or overseas). As for Aboriginal children, these percentages are similar to those for birth data.

Childhood mortality according to gender

Figure 3.32 (see overleaf) reports the all-cause ChMR/1000 infant survivors for Aboriginal and non-Aboriginal male and female children. The ChMR was highest among Aboriginal male children and was significantly higher when compared with non-Aboriginal males (RR = 2.7, CI 1.5—5.1). The ChMR for female children was nearly twice as high when compared with non-Aboriginal female children (RR = 1.8: CI 0.8–3.9).

14 When calculating the mortality rate for all age groups, the ChMR/1000 infant survivors was used and a RR (95% CI) calculated. When calculating age-specific mortality for deaths between one year and before reaching the eleventh birthday, the ChMR/10,000 person-years was calculated. The risk of death for Aboriginal and non-Aboriginal children is expressed as a HR (95% CI).

Figure 3.32: ChMR/1000 infant survivors for males and females according to Aboriginal status and RR for Aboriginal compared with non-Aboriginal children, 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; RR: rate ratio; *statistically significant values (refer to text).

Geographical location of death according to residence at time of birth

Figure 3.33 (see next page) describes the percentages of births and deaths according to residence of the mother at the time of birth. However, migration of individuals across locations is not reported. Therefore, the percentages reported here do not reflect the individual migration across locations.

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 death for both populations. For Aboriginal children, the highest percentage of births occurred in regional locations (48%) and deaths in metropolitan locations (50%). However, for non-Aboriginal children the highest percentage of births (73%) and deaths (71%) occurred in metropolitan locations.

The highest ChMR for Aboriginal children was observed among children born in metropolitan locations and for non-Aboriginal children among those born in regional locations (Figure 3.34, next page). Although an Aboriginal child born in a regional location was less likely to die compared with an Aboriginal child born in a metropolitan location (RR = 0.8, CI 0.3–2.1), there was no statistically significant difference in the risk of a child dying associated with location of birth within both the Aboriginal and non-Aboriginal child populations. However, the risk of an Aboriginal child dying compared with a non-Aboriginal child was higher independent of geographical location of birth and was significantly so for those born in metropolitan locations (RR = 2.7, CI 1.4–5.5). There is therefore a higher risk of death for Aboriginal compared with non-Aboriginal children for those born in metropolitan locations.

Figure 3.33: Distribution of births and deaths in childhood according to geographical location (of birth) and Aboriginal status, 1999–2008 inclusive

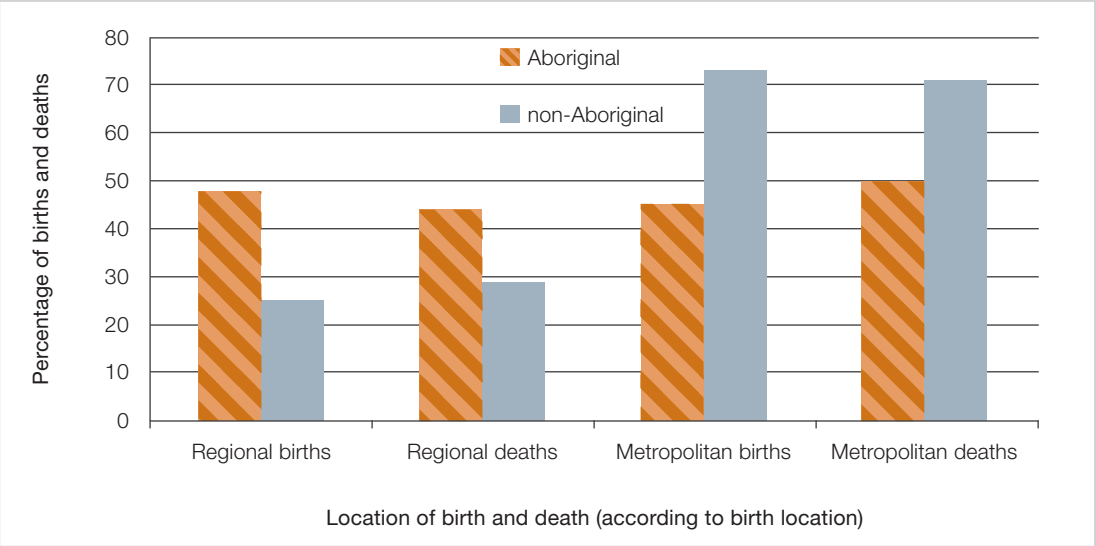
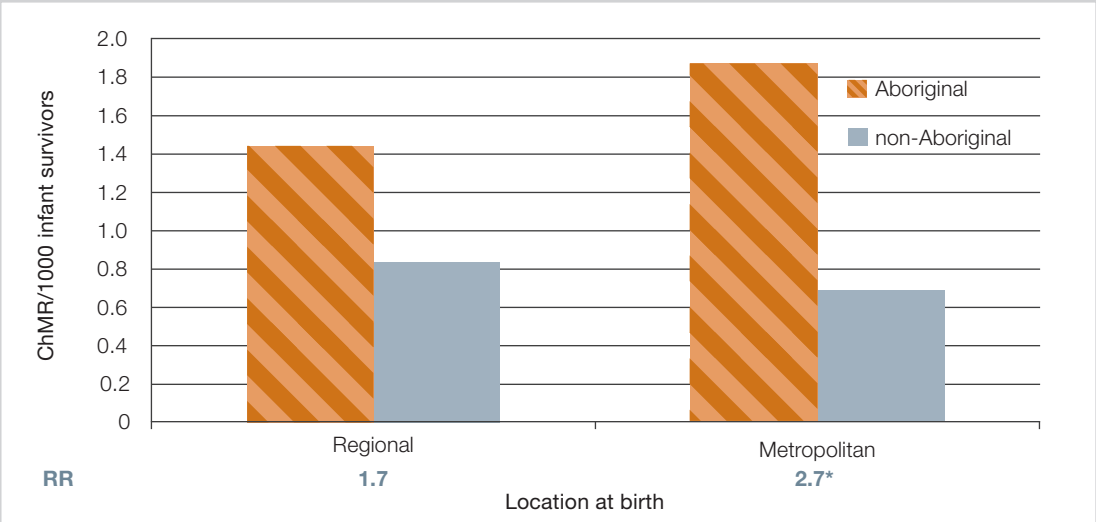


Figure 3.34: ChMR according to geographical location of birth and the RR of Aboriginal (compared with non-Aboriginal) children, 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; RR: rate ratio; *statistically significant values (refer to text).

Geographical location of death according to residence at time of death

Figure 3.35 describes the percentage of deaths according to residence of the child at the time of death for Aboriginal and non-Aboriginal children. Sixty-three per cent of Aboriginal child deaths occurred to children residing in regional locations, and 38% in metropolitan locations. All Aboriginal deaths occurred among children whose residence was in Victoria. The picture differed among the non-Aboriginal child population, where 31% of child deaths occurred among children living in regional locations and 68% among children living in metropolitan regions. Only one non-Aboriginal death occurred where the child's normal residence was interstate or overseas.

Figure 3.36 (see next page) reports the distribution of mother's residence at birth and child's residence at death. Among Aboriginal children, the geographical locations of the residence of mother at the time of the child's birth were similar (regional births 48%, metropolitan births 45% of all Aboriginal births). However, the percentage of Aboriginal child deaths in regional locations was almost double the percentage of deaths in metropolitan locations (regional, 63%; metropolitan, 38%). The percentage of Aboriginal child deaths in metropolitan locations (38%) was less than the percentage of Aboriginal births (45%) to mothers living in the metropolitan locations at the time of the birth. Among non-Aboriginal children the percentage of deaths in regional locations was higher (31%) than the percentage of births to mothers living in regional areas at the time of the birth (25%). The percentage of non-Aboriginal deaths among children living in metropolitan locations (68%) was less than the percentage of births to non-Aboriginal mothers in metropolitan locations (73%).

In summary, in the metropolitan locations, the percentage of Aboriginal deaths is lower than the percentage of births, whereas percentages of non-Aboriginal births and deaths within the metropolitan locations are similar. In regional Victoria, proportions of births and deaths among the Aboriginal and non-Aboriginal populations follow a similar pattern. However, the magnitude of difference is much wider for Aboriginal births and deaths.

Figure 3.35: Percentage of deaths according to geographical residence of the child at time of death for Aboriginal and non-Aboriginal children, 1999–2009

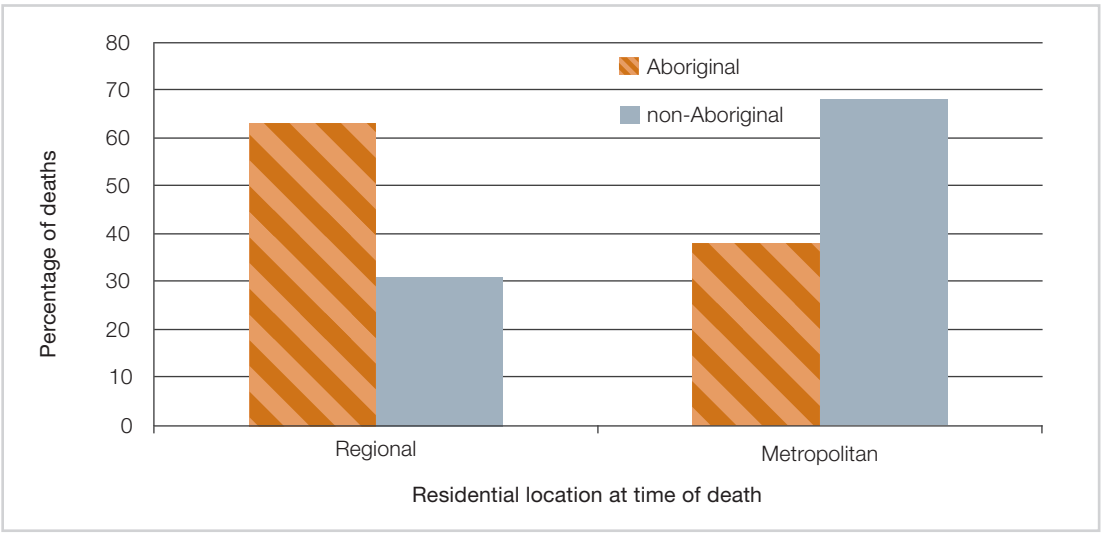
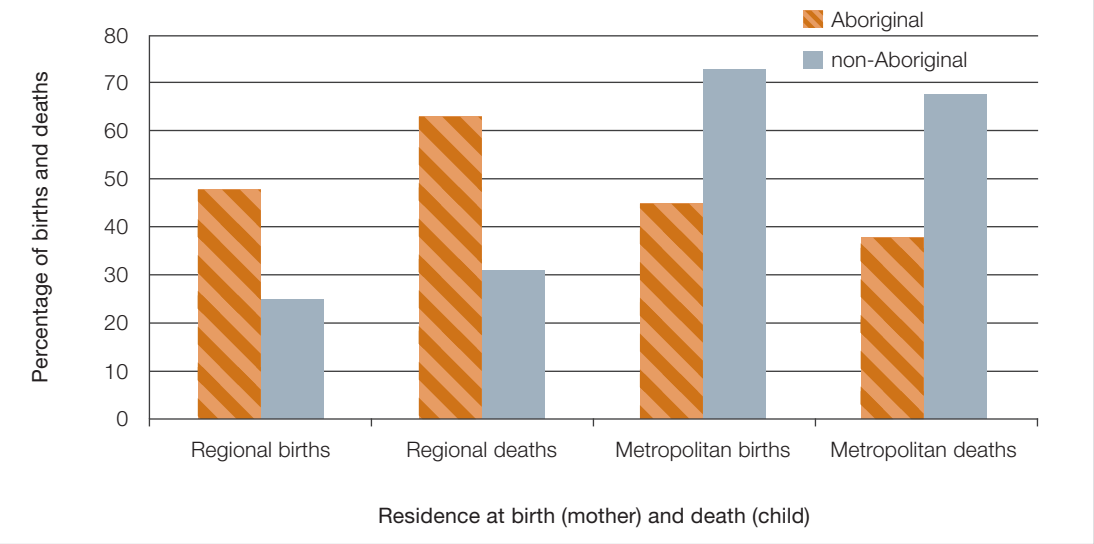


Figure 3.36 Distribution of deaths in childhood according to geographical location and Aboriginal status, 1999–2009 inclusive



Summary

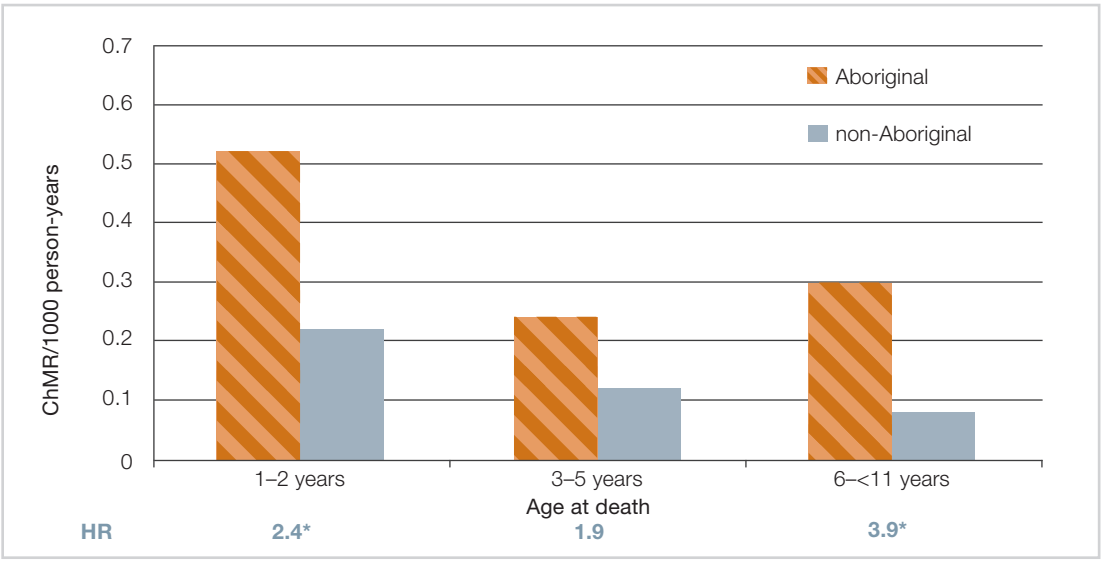
- Male children were more likely to die in childhood compared with females.
- A male Aboriginal child was significantly more likely to die between the first and eleventh birthday compared with a non-Aboriginal child.
- There was no significant statistical difference within both populations in the risk of a child dying according to mother's residential location at birth.
- There was a higher risk of death for Aboriginal compared to non-Aboriginal children born in metropolitan locations.
- Although the percentage of Aboriginal births is similar in regional and metropolitan locations, the percentage of Aboriginal child deaths in regional locations is nearly double the percentage of deaths in metropolitan locations.
- Although the proportions of births and deaths among Aboriginal and non-Aboriginal children follow a similar pattern, the magnitude of difference is much wider for Aboriginal births and deaths.

All-cause age-specific mortality

The figures in this section (see overleaf) describe the all-cause age-specific mortality rate in both populations for age groups 1–2 years, 3–5 years and 6–10 years. A person-years (PYrs) calculation reports a ChMR and the difference between the Aboriginal and non-Aboriginal population is reported as a HR and 95% CIs indicate statistical significance.

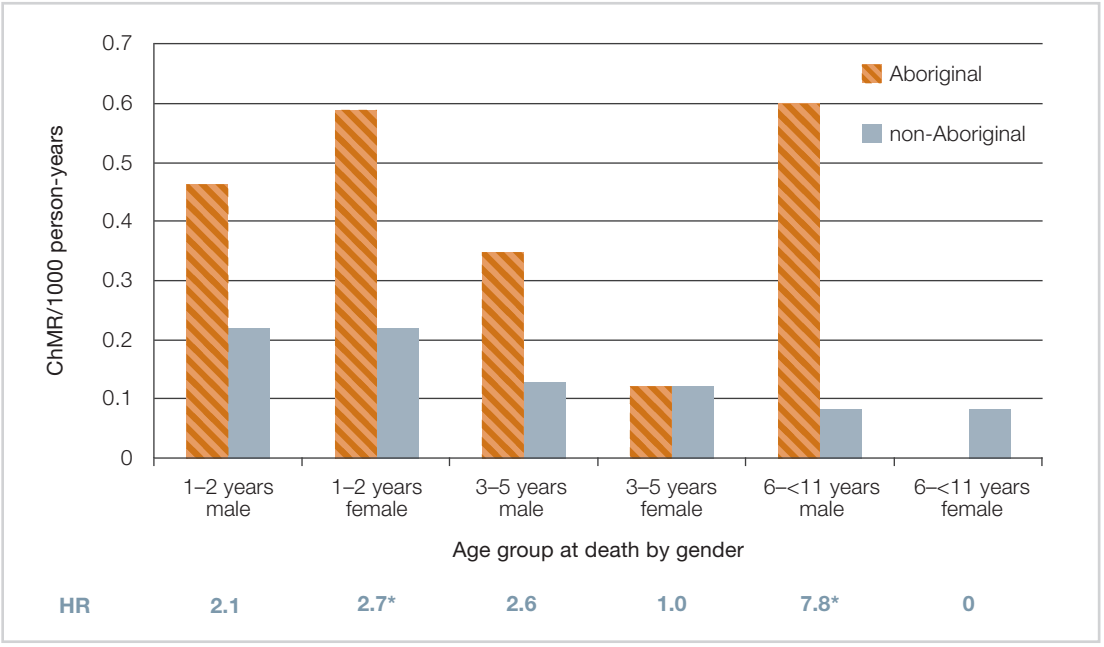
The ChMR was greatest in the 1–2 year age group in both populations (Aboriginal, 0.52/1000 PYrs; non-Aboriginal, 0.22/1000 PYrs) (Figure 3.37). An Aboriginal child in this age group was nearly two-and-a-half times as likely to die in this age group compared with a non-Aboriginal child (HR = 2.4, CI 1.2–4.6). An Aboriginal child was nearly twice as likely to die in the 3–5 year age group compared with a non-Aboriginal child (HR = 1.9, CI, 0.7–5.1). Accepting that the number of Aboriginal deaths was relatively small, the data reported that an Aboriginal child was nearly four times as likely to die in the 6–10 year age groups compared with a non-Aboriginal child (HR 3.9, CI 1.2–12.4).

Figure 3.37: All-cause ChMR for children according to age group, and HR for Aboriginal compared with non-Aboriginal children, 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; HR: hazard ratio; *statistically significant values (refer to text).

Figure 3.38: All-cause, age-specific ChMR according to gender and the HR for Aboriginal compared with non-Aboriginal children, 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; HR: hazard ratio; *statistically significant values (refer to text).

Male and female

The all-cause ChMR/1000 PYrs was greatest among Aboriginal male and female children in all age groups except 3–5-year-old females, where the ChMR was comparable with non-Aboriginal children (HR = 1.0, CI 0.1–7.4). The ChMR was highest in male Aboriginal children 6–10 years (Figure 3.38). The ChMR was significantly higher among Aboriginal compared with non-Aboriginal female children in the 1–2 year age group (HR = 2.7: CI 1.1–6.6) and also Aboriginal compared with non-Aboriginal male children in the 6–10 year age group (HR = 7.8: CI 2.4–25.5). There were no case files reporting Aboriginal female deaths between the ages 6–10 years. Note the wide CIs, which indicate the small total numbers in these age groups and therefore the instability of the estimate.

Mortality in/out of hospital

Data describing the place of death (i.e. in or out of hospital) were recorded and analysed. However, due to the small numbers and percentage of missing data describing where the child death occurred, the results have not been included in this report.

Summary

- The ChMR was highest among children aged between 1–2 years in both populations.
- An Aboriginal child was nearly four times as likely to die in the 6–10 year age group (note small number of Aboriginal deaths).
- The ChMR for non-Aboriginal children in the 6–10 year age group was higher than the non-Aboriginal ChMR in the 3–5 year age groups.
- The ChMR was higher for male and female Aboriginal children compared with their non-Aboriginal peers in all age groups except for the female 3–5 year age group, where there was no difference between the two populations.
- There were no case files reporting Aboriginal female deaths in the 6–10 year age group.

Cause-specific mortality

Trends in post-mortems

Information identifying that a post-mortem had been undertaken was missing in 40% of case files (Aboriginal, 25%; non-Aboriginal, 41%).

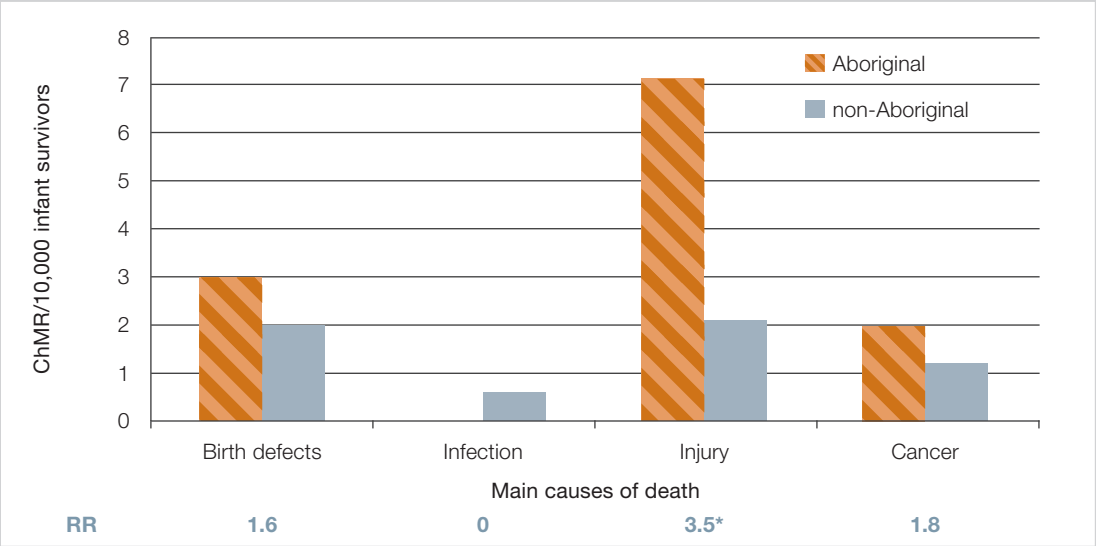
Where information was available, 48% of children who died had a post-mortem and 12% did not. Of the deaths where there was a post-mortem, 24% had an objection lodged (Aboriginal, 30%; non-Aboriginal, 24%). All objections were upheld for Aboriginal deaths, and 96% in the non-Aboriginal deaths. All Aboriginal deaths and 76% of non-Aboriginal deaths due to injury had post-mortems. Post-mortems were conducted on 60% of Aboriginal children and 26% of non-Aboriginal children who died due to birth defects, and all Aboriginal children and 4% of non-Aboriginal children who died due to cancer or leukaemia.

Main causes of mortality

Although the number of deaths within the Aboriginal population was relatively small, it is important to note that the magnitude of the risk of death for an Aboriginal child compared with a non-Aboriginal child was higher in all general causes of death (aside from deaths due to infection for females, where no deaths were reported for Aboriginal children).

Deaths due to injury were responsible for the highest CMRs in both populations (Aboriginal, 7.1/10,000 infant survivors; non-Aboriginal, 2.1/10,000 infant survivors) between birth years 1999–2008 inclusive (Figure 3.39, overleaf). However, an Aboriginal child was more than one-and-a-half times as likely to die between the first and eleventh birthdays due to birth defects (HR = 1.6: CI 0.5–4.9), more than three times as likely to die due to injury (RR = 3.5: CI 1.6–7.4), and nearly twice as likely to die due to cancer and leukaemia (RR = 1.8: CI 0.4–7.2) compared with a non-Aboriginal child.

Figure 3.39: CMR/10,000 infant survivors of the main causes of childhood death and RR for Aboriginal compared with non-Aboriginal children, birth years 1999–2008



CMR: cumulative mortality rate; RR: rate ratio; *statistically significant values (refer to text).

Mortality according to gender

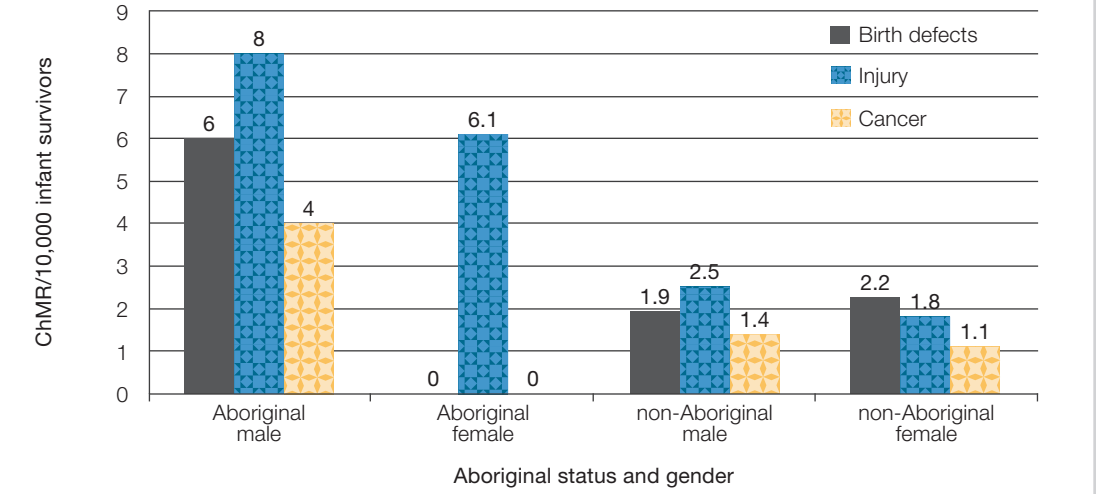
Although the number of Aboriginal child deaths was relatively small, it is important to note the magnitude of difference between the two populations and increased risk of death. For a small population to be at an increased risk of death, particularly for preventable causes, is of immense importance and is of much public health and clinical significance.

Between the birth years 1999 and 2008 inclusive, the main causes of death for both Aboriginal and non-Aboriginal Victorian-born male children was injury (Aboriginal, 40%; non-Aboriginal, 34%) and deaths due to birth defects (Aboriginal, 30%; non-Aboriginal, 26%). Deaths due to cancers and leukaemia accounted for 20% of Aboriginal and 19% of non-Aboriginal childhood deaths. There were no male Aboriginal deaths reported due to infection (12% of non-Aboriginal child deaths). For Victorian-born females, the main causes of death for Aboriginal children were injury (50%) and 'other specific conditions' (33%), and for non-Aboriginal children the main causes of death were birth defects (31%), followed by injury (26%), cancer and leukaemia (16%), and 'other specific conditions' (11%) (Appendix 2).

Figure 3.40 (see next page) reports the ChMR/10,000 infant survivors for the main causes of infant death for Aboriginal and non-Aboriginal children according to gender for Victorian-born children, 1999–2008. The highest ChMR observed among Aboriginal males and females was due to injury (Figure 3.40). The ChMR due to birth defects among Aboriginal males was 6/10,000 infant survivors (there were no Aboriginal deaths due to birth defects or cancer and leukaemia reported among Aboriginal female children). Deaths due to birth defects accounted for 2.2/10,000 female and 1.9/10,000 male non-Aboriginal infant survivors. The risk of dying due to birth defects was three times higher for male Aboriginal children (compared with non-Aboriginal males) (RR = 3.1: CI 1.0–9.9).

Among non-Aboriginal children, the ChMR due to cancer and leukaemia was 1.4/10,000 male infant survivors and 1.1 female infant survivors; the risk for Aboriginal compared with non-Aboriginal males was nearly three times greater (HR = 2.9, CI 0.5–10.1).

Figure 3.40: ChMR/10,000 infant survivors for main causes of death according to gender for Aboriginal compared with non-Aboriginal children, birth years 1999–2008 inclusive



ChMR: child (cumulative) mortality rate.

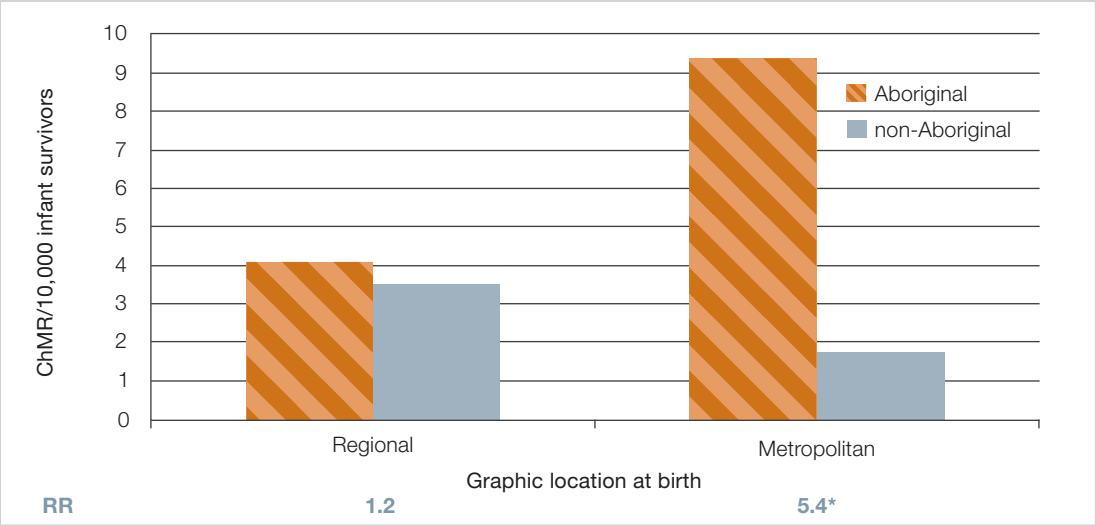
Child deaths due to injury

The number of deaths due to injury among Aboriginal children was small (n = 7) and the CIs are generally wide, therefore the estimates should be interpreted with caution. Raw numbers have not been reported when data have been disaggregated.

The highest ChMR observed among Aboriginal males and females was due to injury (Aboriginal males, 8/10,000; Aboriginal females, 6/10,000 infant survivors). There was more than a three-fold risk of death due to injury among Aboriginal male children when compared with non-Aboriginal male children (RR = 3.2: CI 1.2–8.8). Although the deaths due to injury were small among Aboriginal females, the risk was also significantly higher compared with non-Aboriginal females (RR = 3.3: CI 1.1–10.7).

The ChMR of these deaths was highest in children born in metropolitan locations for Aboriginal children and in regional locations for non-Aboriginal children (Figure 3.41, overleaf). An Aboriginal child born in a metropolitan location was more than five times as likely to die due to injury compared with a non-Aboriginal child (RR = 5.4: CI 2.0–14.5). The risk of a child born in regional areas dying as a result of injury was similar in both populations (RR = 1.2: CI 0.3–4.8).

Figure 3.41: ChMR/10,000 infant survivors due to injury according to location at birth, and RR for Aboriginal compared with non-Aboriginal children, birth years 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; RR: rate ratio; *statistically significant values (refer to text).

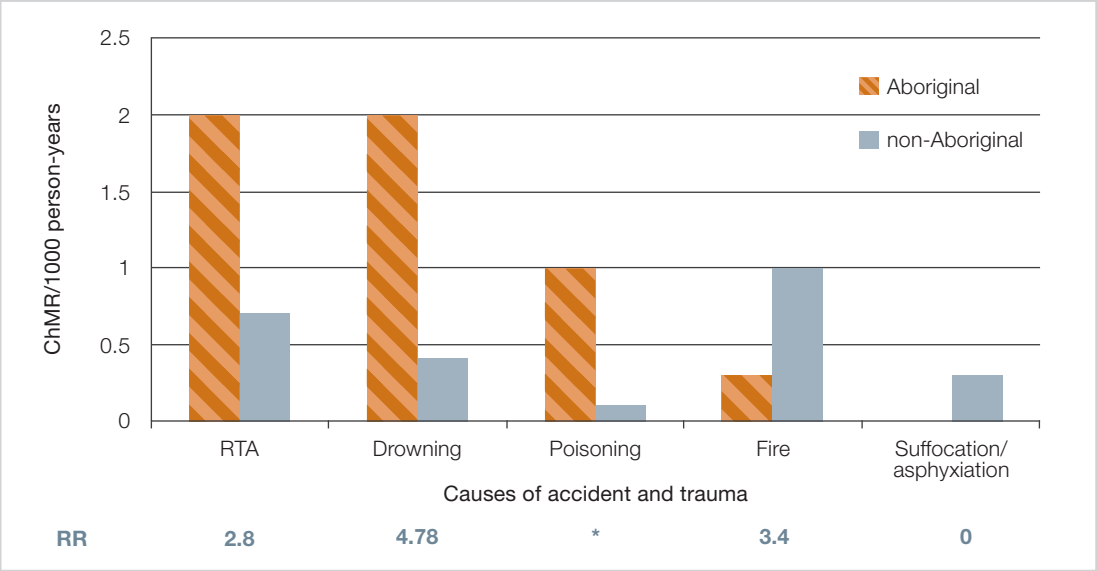
Specific causes of injury

The wide CIs indicate the small number of deaths in these categories. The small numbers do not enable a test for statistical significance to be meaningful. However, the RR provides an indicator of the direction of the estimates and therefore can indicate clinical and public health significance.

The highest percentage of deaths due to injury was due to road traffic accidents and drowning for Aboriginal children (29%) and for non-Aboriginal children the highest percentages were observed in road traffic accidents (34%) and drowning (20%). Other causes included fire and effects of fire (14%, Aboriginal; 14%, non-Aboriginal children) and poisoning (Aboriginal, 14%; non-Aboriginal, 0.7%). Suffocations/asphyxiation accounted for 12% of non-Aboriginal deaths due to injury.

The highest CMR/10,000 infant survivors for both populations in injury deaths was due to road traffic accidents and the risk of an Aboriginal (compared with a non-Aboriginal) child dying as a result of a road traffic accident was nearly three times greater (RR = 2.8: CI 0.7–11.3) (Figure 3.42, next page). The ChMR due to drowning for Aboriginal children was nearly five times greater compared with non-Aboriginal children (HR = 4.8: CI 0.8–17.1). Deaths due to fire or the effect of fire were more than three times greater for Aboriginal compared with non-Aboriginal children (RR = 3.4: CI 0.5–25.4). There were no deaths reported among Aboriginal children due to suffocation/asphyxiation.

Figure 3.42: ChMR/10,000 infant survivors due to main causes of injury and RR for Aboriginal compared with non-Aboriginal children, birth years 1999–2008 inclusive



ChMR: child (cumulative) mortality rate; RR: rate ratio; *very small numbers.

Summary

- The rate of death due to injury was highest in both Aboriginal and non-Aboriginal child populations.
- An Aboriginal child was more than three times as likely to die due to injury compared with a non-Aboriginal child.
- The main cause of death for Aboriginal male and female children was injury (note relatively small numbers).
- The main cause of non-Aboriginal child death for males was injury and, for females, deaths due to birth defects.
- The largest percentage of injury deaths occurred in the regional areas for both populations (data not shown).
- Road traffic accidents and drowning were the main causes of injury deaths in both populations.
- An Aboriginal child was nearly five times as likely to die as a result of drowning and nearly three times as likely to die due to a road traffic accident compared with a non-Aboriginal child.
- A non-Aboriginal child was more than three times as likely to die due to the effects of fire compared with an Aboriginal child.

3.3 All-cause infant and childhood mortality for deaths of children born outside Victoria

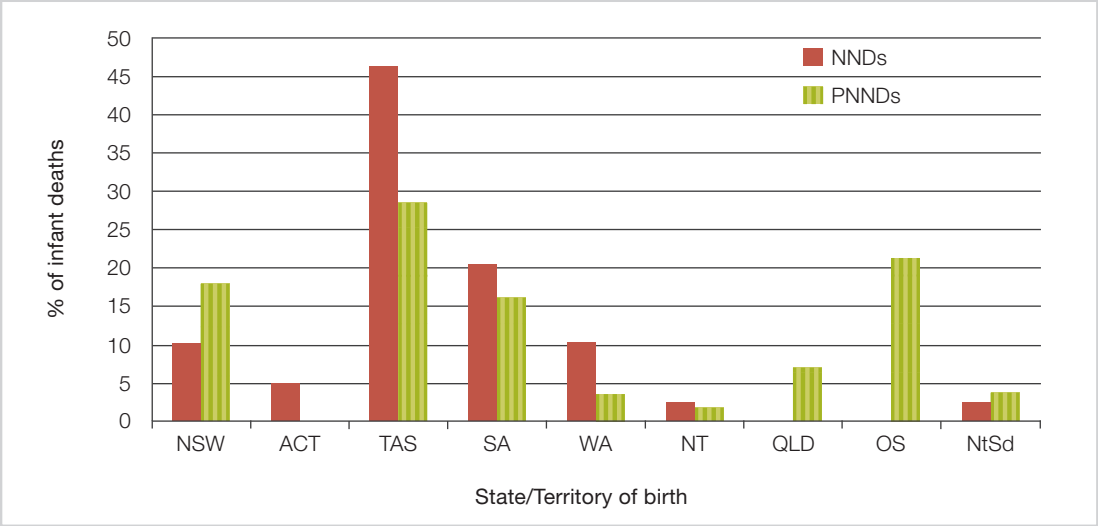
The case files compiled by the CCOPMM of all children who died in Victoria before reaching their eleventh birthday were reviewed. This section briefly describes the percentages of children who died in Victoria between 1999 and 2009, but who were born outside Victoria between 1999 and 2008 inclusive. Given that there were no data available as to maternal or birth outcomes, nor data to indicate the child's Aboriginal status, the causes of death and the place of birth only have been reported as a percentage of the total number of deaths for this sub-group.

Between 1999 and 2009 there were a total of 156 deaths reviewed by the CCOPMM where the infant was born interstate or overseas. The data are not disaggregated by Aboriginal status nor are there any data describing maternal or infant variables as these deaths were not able to be linked to the birth information or information describing their Aboriginal status. Of these deaths, 39 were in the neonatal period, 56 were in the postneonatal period and 61 were child deaths.

The largest proportion of Victorian deaths occurring among infants born interstate or overseas was among infants born in Tasmania (NNDs, 46%; PNNDs, 28.6%). Infants born overseas accounted for 12.6% of infant deaths (Figure 3.43).

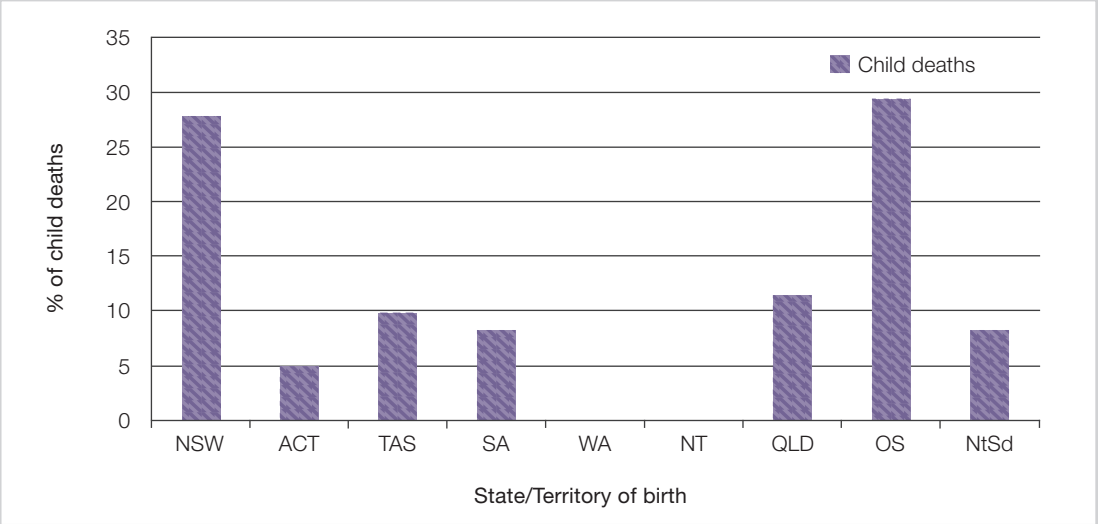
Figure 3.44 (see next page) reports the percentage of deaths occurring in Victoria of children who were born interstate or overseas. The largest percentages of child deaths were among children born overseas (30%) and in New South Wales (28%). Queensland births accounted for 12%, Tasmanian births for 10% and South Australian births for 8% of deaths that occurred in Victoria between 1999 and 2008. There was no information on the place of birth in the case files for 6% of the deaths.

Figure 3.43: Percentage of NNDs and PNNDs occurring in Victoria according to State/Territory of birth, 1999–2008



NNDs: neonatal deaths; PNNDs: postneonatal deaths; NtSd: not stated.

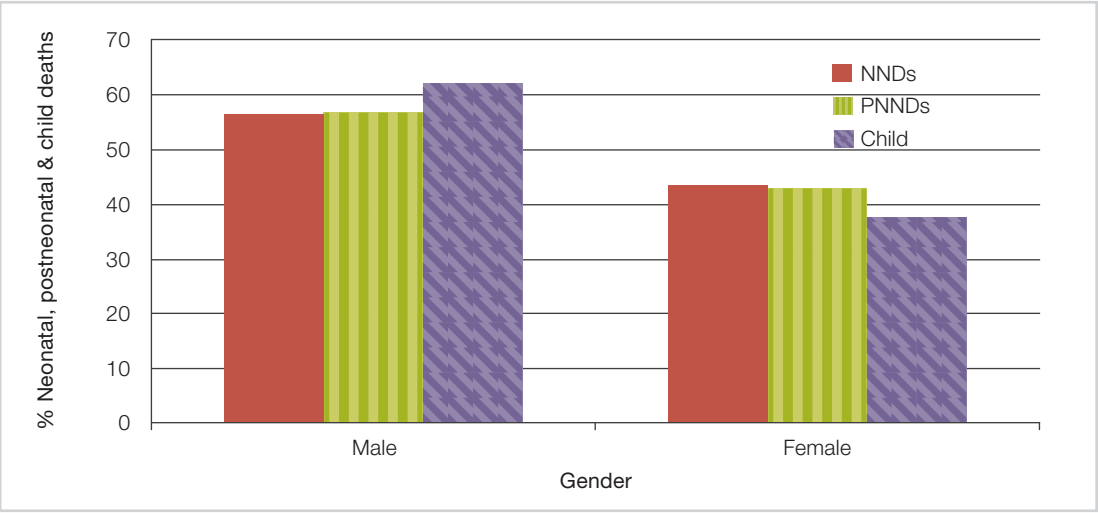
Figure 3.44: Percentage of deaths for births occurring interstate or overseas



OS: overseas; NtSd: not stated.

Figure 3.45 reports the percentage of neonatal, postneonatal and child deaths of interstate or overseas births according to gender. The proportion of male deaths of interstate or overseas births was greater than female deaths born interstate or overseas.

Figure 3.45: Percentage of NNDs, PNNDs and child deaths in Victoria according to interstate and overseas births

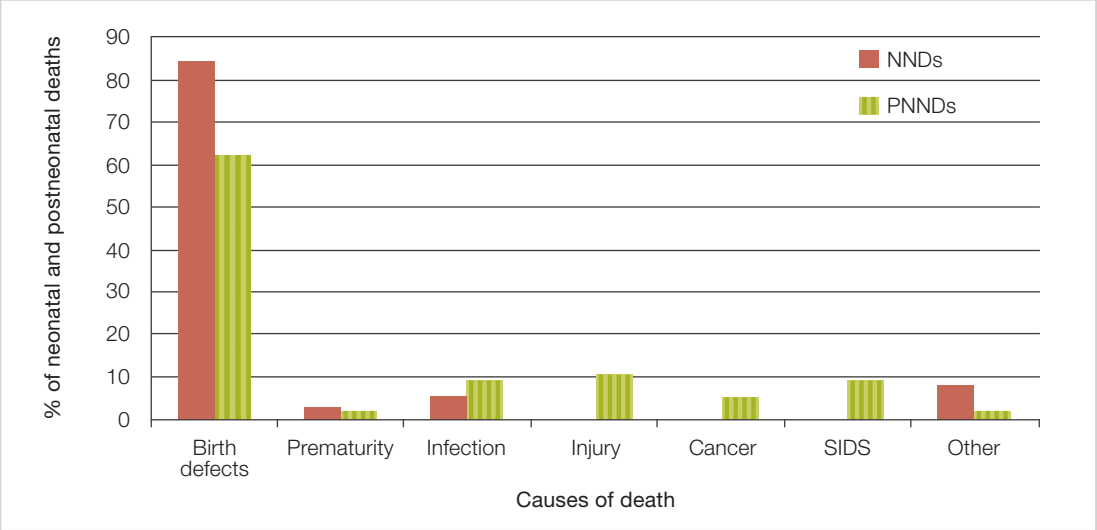


NNDs: neonatal deaths; PNNDs: postneonatal deaths.

Cause-specific infant and child deaths

Figure 3.46 describes the main cause of death in Victoria for infants born interstate or overseas according to cause of death. Birth defects accounted for the largest proportion of infant deaths occurring in Victoria for both neonatal and postneonatal deaths (NND, 85%; PNND, 61%). In the neonatal period for interstate or overseas births, males accounted for 55% of deaths due to birth defects (females 45%). In the postneonatal period the proportions of deaths according to gender due to birth defects were similar (54%, males; 46%, females).

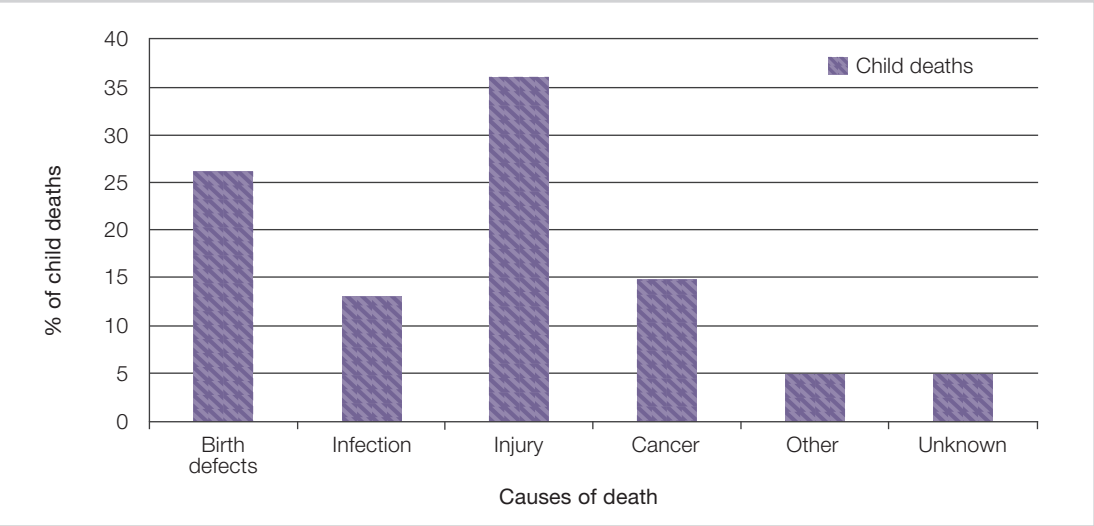
Figure 3.46: Main causes of Victorian deaths of infants born interstate or overseas according to NNDs and PNNDs, 1999–2008 inclusive



NNDs: neonatal deaths; PNNDs: postneonatal deaths.

Figure 3.47 (see next page) describes the cause of death of children who were born interstate or overseas and who died in Victoria between 1999 and 2009. Injury accounted for the largest proportion of childhood deaths for children who were born outside of Victoria (36%), followed by birth defects (26%).

Figure 3.47: Percentage of causes of child deaths in Victoria of overseas or interstate-born children, 1999–2008



Summary

- Between 1999 and 2009 there were 156 infant and child deaths that occurred in Victoria where the residence of birth was recorded as being interstate or overseas.
- The largest proportion of Victorian infant deaths where the place of residence at birth was interstate or overseas was among infants born in Tasmania (NNDs, 46%; PNNDs, 29%) and for childhood deaths the largest proportions were for children born overseas (30%) and in New South Wales (28%).
- The highest proportion of infant deaths of interstate or overseas births was due to birth defects, and in childhood the highest proportion of deaths was due to injury.

Conclusion

Recommendations arising from the Victorian Aboriginal Child Mortality Study fall into two categories:

- Recommendations arising from study findings with input from key stakeholders
- Specific recommendations determined by VACCHO.

Aboriginal community consultation

The VACMS research project has been supported by, and has included input from, the Victorian Aboriginal Community Controlled Health Organisation and several senior Aboriginal health researchers since its inception. Presentations have been made at various health forums, including meetings for the Aboriginal Community Controlled Health Organisations that form the membership of VACCHO.

Recommendations have been determined in consultation with members of the VACMS Research Advisory Group, the Consultative Council on Obstetric & Paediatric Mortality and Morbidity, and the Victorian Aboriginal Community Controlled Health Organisation based on the information in this report.

Infant mortality and the importance of reporting data

Infant mortality is an important measure of economic and social conditions within a society, and of social prosperity overall. To date, mortality rates for Victorian-born Aboriginal infants (including postneonatal deaths) and children have not been published due to inadequate ascertainment of Indigenous status. The VACMS reports that rates of Aboriginal infant mortality were significantly higher compared with their non-Aboriginal counterparts and the rate for Aboriginal infants did not decrease between 1999 and 2008. Rates of postneonatal mortality which are an important measure of the social and economic environment of an infant have increased among Aboriginal infants over the 10 years and the gap between Aboriginal and non-Aboriginal mortality has increased significantly.

Recommendation 1: There should be continued efforts to improve identification of Aboriginal births and deaths in Victoria to provide evidence for policy, planning and evaluation for State and federal government efforts to 'close the gap' in outcomes for Aboriginal and non-Aboriginal infants and children.

1.1 The Department of Health Victoria can do this through supporting initiatives aimed at ongoing improvement in the ascertainment of Aboriginal births and deaths by working with the Victorian Registry of Births, Deaths and Marriages as well as continuing to utilise multiple sources of information (such as hospital notes that form part of a case file).

Recommendation 2: The Victorian Government should continue to develop evidence-based policies and programs to reduce morbidity and mortality in Aboriginal and non-Aboriginal infants and children, with special attention to known preventable causes of death that disproportionately affect the Aboriginal population.

2.1 Particular consideration should be given to determining evidence-based policies and interventions aimed at reducing the Aboriginal mortality rates in the postneonatal period.

Recommendation 3: The Victorian Government should implement routine linkage of birth and death data to enable the continuing evaluation of the patterns and trends in mortality among the Victorian Aboriginal infant and child populations and the comparison of these outcomes with non-Aboriginal populations.

Sudden Infant Death Syndrome

The greatest difference between Aboriginal and non-Aboriginal infant mortality can be attributed to preventable causes, including SIDS. An Aboriginal infant was five times more likely to die due to SIDS compared with a non-Aboriginal infant. There were 12 excess Aboriginal deaths attributed to SIDS between 1999 and 2009.

Recommendation 4: Deaths from SIDS among the Aboriginal infant populations must be prevented and a greater emphasis should be placed on ensuring that appropriate measures that will reduce SIDS are available to Aboriginal families, e.g. 'Reduce the Risks' information.

4.1 This could be achieved through a collaboration of groups including the Victorian Aboriginal Community Controlled Health Organisation, SIDS and Kids (Victoria), and the Department of Health Victoria, that is tasked with developing resources and education programs to reduce the risk of SIDS among Victorian Aboriginal infants.

Accurate self-identification and population data linkage

The VACMS identified 36 Aboriginal infant and child deaths that had been previously reported as non-Aboriginal in the years 1999–2008. The method to determine the reclassification of the Indigenous status was based on population data linkage of statutory and administrative datasets to validate Indigenous status. These data show the value of population data linkage, particularly where the population at risk is small. The number of deaths of Victorian-born Aboriginal children reported in the VACMS was (relatively) small, and the number is believed to be an underestimation of the true number of Victorian Aboriginal child deaths.

Recommendation 5: The Victorian Perinatal Data Collection to undertake linkages with other population and administrative databases (e.g. Victorian Admitted Episodes Data, Victorian Emergency Minimum Dataset, and the Maternal and Child Health Data). These linkages would enable further validation of the Aboriginal status and identification of additional births (and deaths) of children of Aboriginal and/or Torres Strait Islander mothers and/or fathers. The knowledge gained through data linkage will increase in proportion to the amount of data that is made available through these linkages.

Recommendation 6: Efforts and resources should be dedicated to continuing the improvements in the achieving accuracy in the identification of Aboriginal and Torres Strait Islander populations (through self-identification) within statutory and administrative data collections.

Dataset availability

The VACMS has developed a total population validated dataset that describes the birth of every Victorian-born Aboriginal child, and a comprehensive description of all Victorian Aboriginal deaths for children aged between 0 and 11 years. This is a unique dataset that provides a baseline from which to evaluate initiatives and strategies implemented to close the gap on Aboriginal disadvantage.

Recommendation 7: Governance protocols should be developed to enable continued access to the VACMS data by policymakers and researchers while adhering to the relevant legislation and DoH Victoria policies

Recommendation 8: Legislative review should be undertaken to enable the VACMS de-identified dataset to be made available for ongoing and new research purposes whenever it is in the public interest to do so, but only after obtaining agreement, in writing, from the relevant Human Research Ethics Committee and original data custodians.

Recommendation 9: A process should be developed for the de-identified data to be made available to Aboriginal health services and community controlled organisations to facilitate the development of evidence-based policy and programs within the regions, within the confines of ensuring anonymity and confidentiality of these data.

Specific recommendations determined by VACCHO

Recommendation 10: The Minister of Health should consider the appointment of the Chief Executive Officer of VACCHO (or a delegate) to the CCOPMM.

Recommendation 11: A committee should be formed to oversee the systemic and regular (annual) review of birth and death data for the Aboriginal community.

11.1 An enabling legislative environment is required to facilitate this process.

11.2 This committee could make recommendations to improve the recording and reporting of Aboriginal identifiers, strategies to address disparities in health outcomes, and the evaluation of programs to redress these disparities.

11.3 This committee should include representatives of VACCHO and the CCOPMM. It should formally report to VACCHO, the Department of Health Victoria, the Department of Human Services, the Registry of Births Deaths and Marriages and the Secretaries' Leadership Group on Aboriginal Affairs.

Recommendation 12: The VACMS data should be available to Aboriginal health services and community controlled organisations to inform policy and planning whilst preserving strict individual and family privacy and confidentiality.

Recommendation 13: The VACMS research team should work with VACCHO to ensure appropriate dissemination of this information to the Aboriginal community within Victoria.

Appendix 1:

Classification system—coding for cause of death

'JFCODE' 3-digit coding sheet

The JFCODE system comprises nine major categories (first digit), each of which can be sub-categorised with the use of a second and third digit to describe more contextual information.

For example, a death due to infection will have a first digit of 4, with a second digit for the type of infection (e.g. respiratory = 2) and a third digit for the responsible organism (e.g. bacteria = 2). In this example the JFcode would be 422.

Similarly, an injury would have a first code of 5, with a second digit for the type of injury (e.g. non-accidental = 5) and a third digit for the cause (e.g. suicide = 2); therefore, the JFcode would be 552.

3 digit Code			
1			Perinatal causes
1	1	0	Intrapartum foetal distress >25 weeks with recorded sentinel event: includes cord complications Not otherwise specified, meconium aspiration, malpresentations (= unexplained cause first apparent in labour)
1	2	0	Prematurity (death due to labour of normally formed, non-infected foetus <26 weeks)
1	3	0	Intrapartum/birth asphyxia with sentinel event (ruptured uterus N = 8, 2h tonic spasm (N = 1), amniotic fluid embolism (3), true cord knot (3), traumatic exsanguination (88195), cord tightly around neck (346008), vasa praevia (336254), abruption, placental failure, Antepartum haemorrhage
1	3	1	Intrapartum/birth asphyxia without sentinel event
1	4	0	Obstructed labour, specified (not inferred from presentation or BW), birth trauma
1	5	0	Cord prolapse in birth >32 weeks
1	6	0	Intrapartum complications of multiple delivery
1	9	0	Unattended labour
2			Significant Birth Defect(s)
2	0	0	Significant birth defect(s) – genetic condition/cardiac/older child
2	5	0	Birth defects insufficient to cause death (previously coded 00 – unexplained but not normally formed)
3			Prematurity
3	0	0	Frank prematurity of organ systems (does not apply to stillbirths, see 120) includes sequelae of prematurity (<28 weeks underdeveloped)
3	1	0	Death from prematurity (<28 weeks) following delivery secondary to Ante Partum Haemorrhage
4			Infection:
			2nd digit denotes site
4	0		unknown
4	1		chorioamnionitis (+/– funisitis)
4	2		respiratory

4	3		blood (septicaemia) and/or multiple sites
4	4		brain
4	5		peritonitis
4	6		gastroenteritis
4	7		myocarditis
4	8		liver
4	9		Other, e.g. renal, skeletal, tissue
			3rd digit denotes infectious agent
		0	Unknown agent
		1	Group B strep.
		2	Other bacterial
		3	Toxoplasmosis
		4	Syphilis
		5	Viral (includes vaccine preventable and not vaccine preventable)
		6	Listeria
		7	Both bacterial and viral (multiple organisms)
		8	Multiple agents
		9	Other specified agent
		10	Parasitic
5			Accidents and trauma (other than birth trauma (100–190))
5	1	0	Road traffic accidents (unspecified mode/vehicle type)
5	1	1	Motor vehicle
5	1	2	Motorcycle/pedal bike/trail bike/go cart/rollerblades/skateboard
5	1	3	Pedestrian
5	1	4	Antenatal accidents
5	1	5	Exited from vehicle not involved in crash (e.g. fell from vehicle)
5	1	6	Boat accident – not drowned
5	1	7	Train/tram/bus (public transport)
5	1	8	Sport-related accident
5	2	0	Drowning – place not stated
5	2	1	Pool/spa
5	2	2	Dam/water tank/drain/fishpond/lake/waterhole
5	2	3	Sea/river
5	2	5	Bathtub/bucket /shower recess
5	3	0	Poisoning
5	3	1	Snake Bite
5	4	0	Fire/effects of fire/burns and/or asphyxiation due to smoke inhalation
5	5	0	Non-accidental injury
5	5	1	Homicide
5	5	2	Suicide
5	6	0	Suffocation/asphyxiation not covered in 550 or 540. Includes inhalation/ingestion due to respiratory obstruction; industrial accident; accidental hanging; mechanical asphyxiation

5	6	1	Positional asphyxia
5	6	2	Overlaying
5	7	0	Peri-operative accident/following clinical surgical intervention
5	8	0	Electrocution
5	9	0	Accident/trauma Not otherwise specified; could include Non-accidental injury where this is questionable, (including antenatal), includes dehydration/exposure (accidental), including potential manslaughter; scalding
5	9	1	Drug overdose/substance misuse
5	9	2	Drug toxicity
5	9	3	Accidental fall
5	9	4	Sporting injury
5	9	5	Crushing injury
6			Cancers & Leukaemias
6	0	0	Cancers
6	1	2	Leukaemia
7			SIDS
7	0	0	SIDS
7	9	0	Unconfirmed SIDS
8			Other specific conditions
8	1	0	Major Antepartum haemorrhage (before onset of labour) resulting in death before, during or after labour
8	2	0	Acute foeto-maternal haemorrhage (will be under-ascertained – also in 000)
8	3	0	Lethal complications of twinning not covered elsewhere, e.g. twin-twin transfusion. (Delivery complications = 160)
8	4	0	Neurological condition, 1y factor: e.g. Status epilepticus, impaired gag reflex not known to be due to classifiable cause, CP (DD to aspiration pneumonia), febrile convulsion
8	5	0	Hydrops due to Rhesus iso-immunisation or specific congenital anomaly
8	6	0	Recognised cause of asphyxia or trauma before onset of labour (under-estimated)
8	7	0	Asthma
8	8	0	Specific conditions originating before 28 days of life. e.g. hydrops of unknown aetiology and diseases of prematurity. Preterm premature rupture of membranes (preterm, pre-labour rupture of membranes) and sequelae
8	9	0	Specific conditions originating not specified above originating after 28 days of life
8	9	1	Diabetes related
9			Unknown, not classifiable above
9	1	0	Cause(s) not classifiable above
9	2	0	Sudden unexpected death in child >1 year
9	9	0	Cause unknown/unascertainable
9	9	1	No coroner's report (searched)
9	9	2	Final diagnosis unknown
9	9	3	Awaiting coronial outcome

Appendix 2:

Data collection sheet

SECTION 1 (complete for all cases)

1. CCOPMM #_____ 2. Birth regnum: _____ (99=unkn, 98=bth interstate/OS)

3. Place of bth:

☐ 1=Vic ☐ 2=NSW ☐ 3=ACT ☐ 4=Tas ☐ 5=SA

☐ 6=WA ☐ 7=NT ☐ 8=Qld ☐ 9=O/S ☐ 10=NS

4. Sex (1=M, 2=F, 3=Ind, 4=NS): _____

5. Indigenous status: Mother: ☐ 1=Indig ☐ 2=Non-Indig ☐ 3=NS

6. Father: ☐ 1=Indig ☐ 2=Non-Indig ☐ 3=NS

7. Baby/Child: ☐ 1=Indig ☐ 2=Non-Indig ☐ 3=NS

7a. Is new (post-1997) Med. Cert. of COPD in file? ☐ 1=Yes ☐ 2=No

7b. If yes, has Q.B Aboriginality been answered? Mother: ☐ 1=Yes ☐ 2=No

7c. Father: ☐ 1=Yes ☐ 2=No

8. Postcode of usual residence at time of death:_____

9. Res. suburb at dth: _____

10. Postcode of fatal incident*_____ 11. Incident suburb:_____

(*if accident/SIDS incident & died later in hospital, record incident location. If disease/defect and died in hospital, record hospital location)

12. DOB:_____ 13. DOD:_____ 14. If DOB unkn, age:_____d/w/m/y

15. Did incident occur at usual residence: ☐ 1=Yes ☐ 2=No ☐ 3=Not Stated

16. Location of death: ☐ 1=In hospital ☐ 2=Out of hospital ☐ 3=Not Stated

17. Was autopsy performed: ☐ 1=Yes ☐ 2=No

☐ 3=No, unable to perform (burns) ☐ 4=Unk/no record

18. If yes, autopsy type:

☐ 1=Full ☐ 2=External ☐ 3=Unknown/NS ☐ 4=Partial

18a. If partial autopsy, which organ(s)/cavities were autopsied (record all):

☐ 1=Brain ☐ 2=Liver ☐ 3=Heart ☐ 4=Lungs

☐ 5=Spleen ☐ 6=Pancreas ☐ 7=Kidney ☐ 8=Reproductive

☐ 9=Abdominal cavity ☐ 10=Thoracic cavity ☐ 11= Cranium cavity ☐ 12=Other

19. Any autopsy objection: ☐ 1=Yes ☐ 2=No

20. If objection noted, outcome: ☐ 1=Overruled ☐ 2=Upheld ☐ 3=Not Stated

CCOPMM COD	ICD codes (x5)	PSANZ (x2)	CCOPMM clas
1.			
2.			
3.			
4.			

28. CCOPMM 'factor'/prevent: _____

_____

SECTION 1 (complete for all cases) (cont.)

Pathologist COD:

1a._____

1b._____

2. _____

Coroner COD:

1a._____

1b._____

2. _____

Medical Certificate Cause of Death COD:

1a._____

1b._____

2. _____

ANTENATAL/BIRTH FACTORS:

29. Gestation (if noted):_____

29a. Were there any maternal complications?

☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

29b. If yes, type of complication (record all):

☐ 1=Hypertension/pre-eclampsia ☐ 2=Chorioamnionitis

☐ 3=Incompetent cervix/failed suture ☐ 4=Accident/injury ☐ 5=Other

☐ 6=Asthma ☐ 7=Unk/NS/Unclear ☐ 8=Polyhydramnios ☐ 9=Drug use

☐ 10=Alcohol ☐ 11=Smoking ☐ 12=Infection

☐ 13= Diabetes (pre-existing) ☐ 14=Gest. diabetes ☐ 15=Epilepsy

☐ 16=Hepatitis (A/B/C e.g. 16A)

29c. Was there a termination of pregnancy?

☐ 1=Yes ☐ 2=No ☐ 3=NS/NA/Unk

30. Birth weight (if noted): ☐ 1=<2500g ☐ 2=≥2500g

31. Did mother attend antenatal care?

☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS ☐ 4=Poor

31a. If yes, month started (if noted):_____ 31b. No. of visits (if noted):_____

32. If neonatal death, was there a patent ductus arteriosus and/or patent foramen ovale:

☐ 1= ≥37wks ☐ 2= <37wks ☐ 3= NA/Unk/No

32a. If infant or child death, was there a patent ductus arteriosus and/or patent foramen ovale:

☐ 1=Yes ☐ 2=No ☐ 3=NS/Unk

33. Diagnosed birth defect/s:

☐ 1=Yes ☐ 2=No (not detected in autopsy) ☐ 3=NS/no mention/no autopsy

34. If yes, major or minor:

☐ 1=Major ☐ 2=Minor ☐ 3=Not Stated

35. If yes, was condition Cerebral Palsy:

☐ 1=Yes ☐ 2=No ☐ 3=Not Stated

36. Location of birth:

☐ 1=Hospital ☐ 2=Home ☐ 3=Other ☐ 4=Not Stated/NA

SECTION 1 (complete for all cases) (cont.)

37. Was birth unattended:

☐ 1=Yes ☐ 2=No ☐ 3=Unknown/Not Stated/NA

DRUG/ALCOHOL/CHEMICAL TOXICOLOGY:

38. Was smoking reported during pregnancy? ☐ 1=Yes ☐ 2=No ☐ 3=NS/Unk

39. If yes, no._____ (99unk)

40. Did record contain a toxicology report? ☐ 1=Yes ☐ 2=No

41. If yes, drugs detected: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS/Not tested

42. Any drugs detected illicit and/or outside therapeutic range:

☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

Type of drug/s detected:

Drug/medication name	Location of sample (eg. blood, vitreous humour)	Concentration	Prescribed to deceased? Y/N/NA/NS	Within therapeutic range? Y/N/NA/NS	Clinical/ICU admin? Y/N

43. Alcohol detected: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS/Not tested

44. Blood alcohol level:_____ (99=Unknown)

45. Urine alcohol level:_____ (99=Unknown)

46. Chemical substances detected (eg. pesticide/chemical/noxious substance):

☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS/Not tested

Type detected (list one or more):

Chemical name	Location of sample (eg. blood, vitreous humour)	Concentration/level

INFECTION:

47. Infection detected in deceased (in path, CCOPMM or medical cert):

☐ 1=Yes ☐ 2=No ☐ 3=NS/not tested ☐ 4=Yes, in mother

48. If yes, type of infection (tick one):

☐ 1=Respiratory ☐ 2=Blood (septicaemia) ☐ 3=Brain & nervous system (Meninges)

☐ 4=Peritonitis ☐ 5=Gastroenteritis ☐ 6=Cardiac ☐ 7=Liver

☐ 8=Other (eg. renal, bone, tissue) ☐ 9= Multiple sites ☐ 10=Unknown/NS

49. Was there an ear infection? ☐ 1=Yes ☐ 2=No ☐ 3=Not Stated

50. Primary organism responsible for infection type in Qn 26 (tick one):

Viral:

☐ 1=Influenza (Flu) ☐ 2=Measles, mumps or rubella ☐ 3=Varicella (chickenpox)

☐ 4=Hepatitis A/B/C (record 4A, 4B or 4C) ☐ 5=Rotavirus ☐ 6=Viral: other/unspecified

SECTION 1 (complete for all cases) (cont.)

Bacterial:

- ☐ 7=HIB (Haemophilus influenzae)
- ☐ 8=Group B Streptococcus
- ☐ 9=Toxoplasmosis
- ☐ 10=Syphilis
- ☐ 11=Listeria
- ☐ 12=Pertussis (Whooping cough)
- ☐ 13=Meningococcal (leading cause of bact. meningitis)
- ☐ 14=Tetanus (Lockjaw)
- ☐ 15=Pneumococcal
- ☐ 16=Bacterial other/unspecified
- ☐ 20=Staphylococcus

Other:

- ☐ 17=Multiple: bacterial &/or viral &/or fungal
- ☐ 18=Organism unkn/NS
- ☐ 19=Fungal
- ☐ 21=Parasitic

CAREGIVER AT TIME OF DEATH:

51. Who was the caregiver at the time of incident leading to death (tick one):
    - ☐ 1=Mother
    - ☐ 2=Father
    - ☐ 3=Parents
    - ☐ 4=Sibling
    - ☐ 5=Extended family
    - ☐ 6=Step-parent/defacto
    - ☐ 7=Babysitter
    - ☐ 8=Home (caregiver not stated)
    - ☐ 9=Other (not family)
    - ☐ 10=Ward of state (Gov't appointed institution or foster care)
    - ☐ 11=Hospital
    - ☐ 12=No caregiver
    - ☐ 13=Unk/NS
    - ☐ 14=N/A (eg. Adolescent)
52. Did the caregiver have a history of drug/alcohol use? (select an option 1-3 if SIDS or accident/injury COD)
    - ☐ 1=Yes
    - ☐ 2=No
    - ☐ 3=Unkn/NS
    - ☐ 4= N/A: if no caregiver, adolescent death, death in hospital, or birth defect/infection/cancer COD.
53. Was the caregiver affected by drugs/alcohol around the child's time of death: (1-3 if SIDS or A/I COD)
    - ☐ 1=Yes
    - ☐ 2=No
    - ☐ 3= Unkn/NS
    - ☐ 4=N/A (as per Qn. 47)

If COD is not sudden/unexplained infant/child death or accident/injury COD (pages 1-3):

Reviewer'scomments:_____

_____

_____

54. Was COD sudden unexplained death of infant (SUDI) <1 year
    - ☐ 1=Yes
    - ☐ 2=No
    - ☐ 3= Unkn/NS
55. Availability of information in the case file about the circumstance/context death (inc. perinatal):
    - ☐ 1=None
    - ☐ 2=Insufficient
    - ☐ 3= Missing
    - ☐ 4= Sufficient

114. Reviewer's initials:_____(115: reviewer's JFCODE recorded on spreadsheet only)

116. Chief Investigator's JFCODE:_____

117. Final JFCODE:_____(included in SPSS file)

SECTION 2 – Accident/injury

If Accident/injury COD:

56. Was the deceased person in eyeshot of the caregiver at the time of the incident?

☐ 1=Yes ☐ 2=No ☐ 3=Unkn/NS

☐ 4=N/A (ie. deceased ≥16y/old)

57. Accident type:

☐ 1=Transport accident ☐ 2=Non-transport (eg. Homicide, drowning, burns, suicide, or accidental injury from machinery, overdose or poisoning)

Transport accidents:

58. Time of accident (to nearest hour):_____(eg. 2100 [99=unk])

59. Traffic or non-traffic vehicle accident:

☐ 1=Traffic (originating on, terminating on or involving a vehicle partially on, a gazetted road)

☐ 2=Non-traffic (a vehicle accident that occurred entirely in any place other than a gazetted road eg. Residential or commercial property, off-road track) ☐ 3=Unk/NS

60. What position was the deceased (tick one):

☐ 1=Driver/operator ☐ 2=Passenger front ☐ 3=Passenger rear ☐ 4=Passenger (unkn position)

☐ 5=Outside on (eg. bumper/boot/roof/ute tray) ☐ 6=Pillion (passenger on bike)

☐ 7=External to vehicle ☐ 8=Unk/NS

61. Was speed a contributing factor:

☐ 1=Yes ☐ 2=No ☐ 3=Unknown/NS

If deceased was in/on a vehicle (excludes pedestrians):

62. What was the type of vehicle (tick one):

☐ 1=Motor vehicle (car, truck, van, minibus, go cart) ☐ 2=Motorbike/3-wheeled motor vehicle

☐ 3=Bicycle/tricycle ☐ 4=Other devise (skateboard, scooter, rollerblades, skis, baby carriage etc)

☐ 5=Boat (drowned) ☐ 6=Boat (didn't drown) ☐ 7=Trailer/caravan

☐ 8=Railway or streetcar (train/tram) or bus

☐ 9=Agricultural, industrial, special-terrain or construction vehicle (forklift, harvester, tractor/trailer, farm machinery, bulldozer, snowmobile etc)

☐ 10=Not stated ☐ 10=Other

63. Number other occupants in/on the vehicle:_____(99=Unk/NS)

64. Where was the deceased seated:

☐ 1=centre seat ☐ 2=side seat ☐ 3=other ☐ 4=unk/NS

65. Was a seatbelt/restraint worn:

☐ 1=Yes ☐ 2=No ☐ 3=No belt in pos'n ☐ 4=Unk/NS

66. If yes, type of restraint:

☐ 1=Lap belt ☐ 2=Three-point belt (lap & sash)

☐ 3=Harness (lap belt with shoulder straps (eg. infant capsule, child seat) ☐ 4=Other

☐ 5=Unk/NS

67. If yes, was it stated that the devise was operated/installed correctly:

☐ 1=Yes, correct ☐ 2=No, stated as not correct ☐ 3=No, stated as unknown

☐ 4=No, no mention

68. Any comments regarding safety devise/restraint: _____

_____

69. If the deceased was a passenger was the driver reported to be affected by drugs and/or alcohol:

☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

SECTION 2 – Accident/injury (cont.)

70. If in a motor vehicle/cycle, what was the licence status of driver/operator:

☐ 1=Full ☐ 2=Probation ☐ 3=Licensed (status unk) ☐ 4=Learner
☐ 5=Suspended ☐ 6=Unlicensed ☐ 7=Unk/NS

If deceased was on a motor, quad or pedal bike, skateboard, go-cart or scooter:

71. Was a helmet worn: ☐ 1=Yes ☐ 2=No ☐ 3=Unknown/NS

If deceased was a pedestrian:

72. Model of vehicle collided with or in-contact with pedestrian:

☐ 1=Car: SUV/4WD/People mover/utility ☐ 2=Car: sedan/station wagon
☐ 3=Car: Unk model ☐ 4=Oth motorized veh (truck, minibus, go-cart)
☐ 5=Motorcycle or 3-wheeled motorbike
☐ 6=Non-motorized pedestrian devise (skateboard, ice-skate, scooter, skis) ☐ 7=Bicycle/tricycle
☐ 8=Boat ☐ 9=Trailer/caravan ☐ 10=Railway or streetcar vehicle (train/tram) or bus
☐ 11=Agricultural, industrial, special-terrain or construction vehicle (forklift, harvester, tractor (and trailer), bulldozer, digger, snowmobile etc) ☐ 12=NS

73. Was the vehicle reversing: ☐ 1=Yes ☐ 2=No ☐ 3=Unknown/NS

74. Did the incident occur in a driveway:

☐ 1=Yes ☐ 2=No ☐ 3=Unknown/NS

Homicide/intentional injury/assault:

75. Was death the result of a homicide, suspected homicide or intentional harm:

☐ 1=Homicide ☐ 2=Suspected homicidal intent
☐ 3=Intentional harm, not intentional death (manslaughter)
☐ 4=Inflicted injury, intent unknown/undetermined

76. Method:

☐ 1=Firearm ☐ 2=Stabbing/penetration ☐ 3=Bodily force (fists/feet)
☐ 4=Strangulation/asphyxia ☐ 5=Poisoning
☐ 6=Gas/vapours ☐ 7=Burns (fire/acid/water)
☐ 8=Motor vehicle ☐ 9=Drowning ☐ 10=Shaken baby
☐ 11=Multiple ☐ 12=Other ☐ 13=Unknown/NS

Accidental injury (not transport or drowning related)

77. Was the injury inflicted by the deceased, a third party or object:

☐ 1=Deceased ☐ 2=Third party ☐ 3=Object/animal ☐ 4=NS

78. Device/exposure:

☐ 1=Firearm ☐ 2=Piercing/penetration ☐ 3=Asphyxiation ☐ 4=Crushing/dragging
☐ 5=Poisoning (drug, alcohol, chemical) ☐ 6=Gas/vapours ☐ 7=Burns (explosive/fire/acid)
☐ 8=Electrocution ☐ 9=Fall ☐ 10=Multiple ☐ 11=Other
☐ 12=Unk/NS ☐ 13=Overlaying ☐ 14=Perioperative

SECTION 2 – Accident/injury (cont.)

Suicide or suspected suicide:

79. Suicide the COD: ☐ 1=Definitive yes ☐ 2=Potential yes ☐ 3=Unclear

80. Method of suicide: ☐ 1=Drowning ☐ 2=Hanging ☐ 3=Firearm
☐ 4=Vehicle (driver) ☐ 5=Gas & vapours ☐ 6=Stabbing ☐ 7=Jumping
☐ 8=Asphyxiation ☐ 9=Fire ☐ 10=Drugs ☐ 11=Alcohol
☐ 12=Poisoning (not drug/alc) ☐ 13=Multiple methods
☐ 14=Pedestrian (with rail/road veh.) ☐ 15=Other ☐ 16=Unk/NS

81. Was a suicide note left (including social media):
☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

82. Was there any mention that the deceased experienced bullying?
☐ 1=Yes ☐ 2=No

Drowning:

83. What was the location:
☐ 1=Sea/bay ☐ 2=River/Creek ☐ 3=Dam/waterhole/lake
☐ 4=Drain/irrigation channel ☐ 5=Pool ☐ 6=Outdoor spa
☐ 7=Bathtub/spa bath ☐ 8=Water tank ☐ 9=Fish pond ☐ 10= Bucket
☐ 11=Other ☐ 12=Unknown/NS

84. Was there a fence/barrier: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS/NA(eg.lake)

85. If so, was the fence operational:
☐ 1=Operational ☐ 2=Not op. ☐ 3=NS

Burns:

86. What was the location of the fire:
☐ 1=Home/flat/caravan ☐ 2=Workplace ☐ 3=Bush ☐ 4=Other
☐ 5=Unkn/NS ☐ 6=Caravan

DISABILITY PRESENT AT TIME OF DEATH:

87. Was there any mention that the deceased suffered from a disability?
☐ 1=Yes ☐ 2=No

88. If yes, what type:
☐ 1=Visual ☐ 2=Auditory ☐ 3=Emotional/Psychological
☐ 4=Physical ☐ 5=Multiple ☐ 6=Unkn/NS ☐ 7=Neurodevelopmental

If COD is accident/injury related (pages 1-7):

Reviewer's comments:_____

_____

_____

_____

114. Reviewer's initials:_____(115: reviewer's JFCODE recorded on spreadsheet only)

116. Chief Investigator's JFCODE:_____

SECTION 3 – SIDS/SUDI/SUD/SUDC

117. Final JFCODE:_____(included in SPSS file)

If Sudden/unexplained death or positional asphyxia is COD:

89. Place of fatal event: ☐ 1=Bassinette ☐ 2=Cot ☐ 3=Bed ☐ 4=Couch ☐ 5=Other ☐ 6=NS ☐ 7=Pram

90. Did the child die after being put to bed: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

91. At time of death, was the child sharing a sleep surface: ☐ 1=Yes ☐ 2=No ☐ 3=Unknown/NS/NA

92. If yes, who with: ☐ 1=Parent/s ☐ 2=Carer ☐ 3=Sibling/family oth. ☐ 4=Animal ☐ 5=Other ☐ 6=NS

93. Did the child usually share a sleep surface: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

93a. Was there any suggestion of the possibility of overlaying (in path, CCOPMM or medical cert)? ☐ 1=Yes ☐ 2=No ☐ 3=NS

94. Were the infant's sleeping arrangements changed in the last 24hrs: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

95. Was there a plastic sheet covering the mattress/base: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

96. Was the mattress/base well-fitting: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS/NA

97. What was the Infant's position when discovered: ☐ 1=On stomach ☐ 2=On back ☐ 3=Seated upright ☐ 4=Left side ☐ 5=Right side ☐ 6=Side (unspecified) ☐ 7=Unk/NS ☐ 8=Other

98. What was the infant's position when put to sleep: ☐ 1=On stomach ☐ 2=On back ☐ 3=Seated upright ☐ 4=Left side ☐ 5=Right side ☐ 6=Side (unspecified) ☐ 7=Unk/NS ☐ 8=Other ☐ 9=Not relevant (not put to slp)

99. Were any items on/over the infant's head/face when found? ☐ 1=Yes, blankets/covers ☐ 2=Yes, other (toys, bib etc) ☐ 3=No ☐ 4=NS

100. Was room temperature/ventilation reported to be an issue: ☐ 1=Yes ☐ 2=No ☐ 3=Unclear

101. Did residents usually smoke inside: ☐ 1=Yes ☐ 2=No ☐ 3=NS

102. What was the cleanliness of the room/house environment: ☐ 1=Clean ☐ 2=Not clean ☐ 3=NS

103. Did the deceased usually use a dummy: ☐ 1=Yes ☐ 2=No ☐ 3=NS

104. If stated, what were the routine feeding patterns of the infant: ☐ 1=Breast ☐ 2=Breast/formula ☐ 3=Formula ☐ 4=Solids ☐ 5=Solids and milk ☐ 6=NS ☐ 7=Other (soy milk/cow's milk/goat's milk)

105. Had the infant's feeding arrangements changed in the last 48hrs: ☐ 1=Yes ☐ 2=No ☐ 3=Unk/NS

SECTION 3 – SIDS/SUDI/SUD/SUDC (cont.)

106. Any evidence of recent illness in deceased?

☐ 1=Yes ☐ 2=No ☐ 3=NS

107. If yes, type of illness/symptom?

☐ 1=Diarrhoea ☐ 2=Vomiting ☐ 3=Respiratory infection

☐ 4=Bronchitis ☐ 5=Wheezing ☐ 6=Fever ☐ 7=Other

☐ 8=Multiple

108. Any mention of fatty liver change? ☐ 1=Yes ☐ 2=No

109. Any mention of recent vaccination: ☐ 1=Yes ☐ 2=No

109b. If yes, type (record all):

☐ 1=MMR ☐ 2=Polio ☐ 3=tetanus ☐ 4=HIB

☐ 5=Pertussis ☐ 6=Chickenpox ☐ 7=Other ☐ 8=Unknown/NS

110. Infection in the family at time of death:

☐ 1=Yes ☐ 2=No ☐ 3=Unkn/NS

111. Any mention of previous sibling unexplained deaths: ☐ 1=Yes ☐ 2=No

112. If yes, how many:_____ (99=unkn/NS)

113. How many stated ≤1yr/old:_____ (99=unkn/NS)

Reviewer's comments:_____

114. Reviewer's initials:_____(115: reviewer's JFCODE recorded on spreadsheet only)

116. Chief Investigator's JFCODE:_____

117. Final JFCODE:_____(included in SPSS file)

Appendix 3:

Membership of VACMS death classification subcommittee

Membership of the VACMS death classification subcommittee has changed over the six years of the study.

Reviewing, classification and coding of deaths working group

Convener: Jane Freemantle (Onemda)

Membership: Bree Heffernan; Joan Ozanne–Smith (Victorian Institute of Forensic Medicine); Vicki Winship (Victorian Institute of Forensic Medicine); Jessica Pearse (National Coroners Information System); Jane Halliday (Murdoch Child Research Institute); Sharon Goldfield (Royal Children's Hospital , Centre for Community Child Health); Mary Sullivan (Aboriginal Health Branch, Department of Health, Victoria); Kristen Smith (VACMS); Dulce Iskandar (VACMS); Anne Read (Telethon Institute for Child Health Research); Mary-Ann Davey (Victorian Perinatal Data Collection); Olaf Drummer (Victorian Institute of Forensic Medicine); Glen Peters (Aboriginal Funeral Service); Nadia Lusis (Victorian Aboriginal Community Controlled Health Organisation).

Responsibilities:

- develop protocols and a framework for the review of CCOPMM case files
- review the classification and coding protocols for review of CCOPMM death files (infant, child and youth >18 years)
- advise and ensure that privacy and confidentiality protocols are adhered to
- oversee the classification and coding of death information
- contribute to the validation of the classification and coding of the data.

Appendix 4:

United Nations Declaration of the Rights of the Child

In 1959 the United Nations General Assembly adopted the Declaration of the Rights of the Child. It marked the first major international consensus on the fundamental principles of children's rights.

DECLARATION OF THE RIGHTS OF THE CHILD

Adopted by UN General Assembly Resolution 1386 (XIV) of 10 December 1959

WHEREAS the peoples of the United Nations have, in the Charter, reaffirmed their faith in fundamental human rights and in the dignity and worth of the human person, and have determined to promote social progress and better standards of life in larger freedom,

WHEREAS the United Nations has, in the Universal Declaration of Human Rights, proclaimed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status,

WHEREAS the child, by reason of his physical and mental prematurity, needs special safeguards and care, including appropriate legal protection, before as well as after birth,

WHEREAS the need for such special safeguards has been stated in the Geneva Declaration of the Rights of the Child of 1924, and recognized in the Universal Declaration of Human Rights and in the statutes of specialized agencies and international organizations concerned with the welfare of children,

WHEREAS mankind owes to the child the best it has to give,

Now, therefore, the General Assembly Proclaims

THIS DECLARATION OF THE RIGHTS OF THE CHILD to the end that he may have a happy childhood and enjoy for his own good and for the good of society the rights and freedoms herein set forth, and calls upon parents, upon men and women as individuals, and upon voluntary organizations, local authorities and national Governments to recognize these rights and strive for their observance by legislative and other measures progressively taken in accordance with the following principles:

1 The child shall enjoy all the rights set forth in this Declaration. Every child, without any exception whatsoever, shall be entitled to these rights, without distinction or discrimination on account of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, whether of himself or of his family.

2 The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.

3 The child shall be entitled from his birth to a name and a nationality.

4 The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.

5 The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.

6 The child, for the full and harmonious development of his personality, needs love and understanding. He shall, wherever possible, grow up in the care and under the responsibility

of his parents, and, in any case, in an atmosphere of affection and of moral and material security; a child of tender years shall not, save in exceptional circumstances, be separated from his mother. Society and the public authorities shall have the duty to extend particular care to children without a family and to those without adequate means of support. Payment of State and other assistance towards the maintenance of children of large families is desirable.

7 The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society.

The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with his parents.

The child shall have full opportunity for play and recreation, which should be directed to the same purposes as education; society and the public authorities shall endeavour to promote the enjoyment of this right.

8 The child shall in all circumstances be among the first to receive protection and relief.

9 The child shall be protected against all forms of neglect, cruelty and exploitation. He shall not be the subject of traffic, in any form.

The child shall not be admitted to employment before an appropriate minimum age; he shall in no case be caused or permitted to engage in any occupation or employment which would prejudice his health or education, or interfere with his physical, mental or moral development.

10 The child shall be protected from practices which may foster racial, religious and any other form of discrimination. He shall be brought up in a spirit of understanding, tolerance, friendship among peoples, peace and universal brotherhood, and in full consciousness that his energy and talents should be devoted to the service of his fellow man.

(United Nations 1959)

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