

Chapter 3: Methodology

This chapter explains the methodology used by the Commission to maintain the register of all child deaths in Queensland and to identify patterns and analyse trends in child deaths⁷⁰.

Child deaths register

The Commission has a statutory obligation under the *Commission for Children and Young People and Child Guardian Act 2000* to maintain a register of all deaths of children and young people under 18 that occur in Queensland. It is a requirement that the information in the register be classified according to cause of death, demographic information and other relevant factors. The register contains records of all child deaths from 1 January 2001. In this capacity, the Commission has responsibility for the centralised collection and coding of mortality information for both coronial and non-coronial child deaths.

The Commission analyses information in the child deaths register to identify and report on patterns of child mortality and make recommendations focused on improving policies, procedures and practices that apply to children and reducing risk factors associated with deaths that may have been preventable.

To support the establishment and maintenance of the register, the *Births Deaths and Marriages Registration Act 2003* and the *Coroners Act 2003* impose an obligation on the Registry of Births Deaths and Marriages and the Office of the State Coroner to advise the Commissioner of a child's death.

Registry of Births, Deaths and Marriages

The basis of the register is death registration data from the Queensland Registry of Births, Deaths and Marriages. To assist the Commission in fulfilling its child death functions, the *Births Deaths and Marriages Registration Act* provides that the Registrar must give notice of the registration of all child deaths to the Commissioner⁷¹. The data provided includes the following information:

- the registration number
- the child's name
- the child's date and place of birth
- the child's usual place of residence
- the child's age
- the child's sex
- the child's occupation, if any
- Aboriginal or Torres Strait Islander status
- the duration of the last illness, if any, had by the child
- the date and place of death
- the cause of death, and
- the mode of dying⁷².

To the extent practicable, this information is provided within 30 days after registering the death.

Where the death is a 'natural death' and a Cause of Death Certificate is issued by a general practitioner, only death registration data is available for analysis.

Office of the State Coroner

In cases of 'reportable' child deaths, coronial information is also available⁷³.

Section 8 of the *Coroners Act 2003* defines a 'reportable death' as deaths where:

- the identity of the person is unknown
- the death was violent or unnatural
- the death happened in suspicious circumstances
- the death was not the reasonable expected outcome of a health procedure
- a 'cause of death' certificate was not issued or is not likely to be issued
- the death occurred in care, or
- the death occurred in custody.

A death in care occurs when the person who has died:

- had a disability (as defined under the *Disability Services Act 1992*) and was living in a residential service provided by a government or non-government service provider or a hostel

70 In preparing this chapter, the Commission has adopted the general structure presented in the NSW Child Death Review Team Annual Reports.

71 Section 48A (details of still born children are not included in the information given to the Commission).

72 Section 48B of the *Births, Deaths and Marriages Registration Act 2003* enables the Registrar to enter into an arrangement with the Commissioner to provide additional data. Aboriginal and Torres Strait Islander status, date of birth and mode of dying are provided by administrative arrangement only.

73 Section 8 of the *Coroners Act 2003* defines a 'reportable death' as deaths where the identity of the person is unknown; that occur in violent, unnatural or suspicious circumstances; was not the reasonably expected outcome of a health procedure; a 'cause of death' certificate was not issued nor likely to be issued; or where the death occurred in care or custody.

- had a disability such as an intellectual disability or an acquired brain injury or a psychiatric disability and lived in a private hostel (not an aged-care hostel)
- was being detained, taken to or undergoing treatment in a mental health service, or
- was a child in foster care or under the guardianship of the Department of Child Safety (DChS)⁷⁴.

A death in custody is defined as a death of someone either in custody (including someone in detention under the *Juvenile Justice Act 1992*) escaping from custody or trying to avoid custody⁷⁵.

To assist the Commission in fulfilling its child death research functions, the *Coroners Act* imposes an obligation on the State Coroner to notify the Commissioner of all ‘reportable’ child deaths. The information provided by the State Coroner includes:

- Police Report of Death to a Coroner (Form 1), which includes a narrative providing a summary of the circumstances surrounding the death
- Autopsy and toxicology reports, and
- Coroner’s findings and comments⁷⁶.

Coronial information is largely narrative and is not entered into the register.

For the major categories of reportable deaths (which includes deaths from external causes and sudden unexpected deaths in infancy (SUDI)), coronial information is reviewed. The Commission has identified variables relevant to the major categories of reportable deaths and has developed additional databases to capture and analyse this information. For example, in cases of SUDI, coronial information was reviewed for each death in order to extrapolate and record additional information about the circumstances of death such as infant sleep position, shared sleeping arrangements or evidence smoking, drug or alcohol use in the household.

⁷⁴ Section 9 of the *Coroners Act 2003*.

⁷⁵ Section 10 of the *Coroners Act 2003*.

⁷⁶ Section 45 of the *Coroners Act 2003* provides that the Coroner must give written copies of his/her findings relating to child deaths to the Commissioner. Coroner’s findings are the findings of coronial investigations and should confirm the identity of the person, how, when and where the person died and what caused the death. Section 46 provides that in the case of a child death the Coroner must give written copies of his/her comments to the Commissioner. Coroner’s comments may arise from an inquest that relate to public health or safety, or relate to the administration of justice or ways to prevent future deaths.

⁷⁷ The agreement between the Registry of Births Deaths and Marriages and the Commission has been developed in accordance with the provisions of section 48B of the *Births, Deaths and Marriages Registration Act 2000*.

⁷⁸ The agreement between the Office of the State Coroner and the Commission has been developed in accordance with the provisions of section 54A of the *Coroners Act 2003*.

Access to other data sources

Section 89ZG of the *Commission for Children and Young People and Child Guardian Act* enables other government entities to enter into an arrangement with the Commission to provide information or documents reasonably needed for the child death research functions. By providing such information another agency does not contravene any statutory confidentiality provisions.

The Commission has developed agreements with the following agencies:

- Registry of Births Deaths and Marriages⁷⁷
- Office of the State Coroner⁷⁸, and
- Department of Child Safety.

The Commission intends to enter into information sharing arrangements with the following agencies in 2005–06:

- Department of Communities
- Queensland Health
- Disability Services Queensland
- Department of Education and the Arts
- Department of Emergency Services
- Department of Housing, and
- Queensland Police Service.

Access to information held by these agencies will provide valuable insight into the lives of, and circumstances leading to, the deaths of some of Queensland’s most vulnerable children.

Confidentiality

Accompanying the Commission’s privileged access to information is a duty of confidentiality that is specified in legislation. Section 153 (Confidentiality of Other Information) of the *Commission for Children and Young People and Child Guardian Act* states:

If a person gains confidential information through involvement in this Act's administration, the person must not –

- (a) make a record of the information or intentionally disclose the information to anyone, other than under subsection (4)⁷⁹, or
- (b) recklessly disclose the information to anyone.

Coding cause of death

The Commission uses the International Classification of Diseases and Related Health Problems, Revision 10 (ICD-10) to code underlying causes of death. ICD-10 was developed by the World Health Organisation and is designed to promote international comparability in the collection, processing, classification and presentation of morbidity and mortality statistics.

What is the underlying cause of death?

The concept of the underlying cause of death is central to mortality coding and comparable to international mortality reporting⁸⁰. The World Health Organisation has defined the underlying cause of death as:

- the disease or injury which initiated the train of morbid events leading directly to death, or
- the circumstances of the accident or violence which produced the fatal injury.

Stated simply, the underlying cause of death is the condition, event or circumstances without the occurrence of which the person would not have died.

The National Centre for Classification in Health

The National Centre for Classification in Health (Brisbane) (NCCH) is the internationally recognised Australian Centre of expertise in the classification of morbidity and mortality data⁸¹. The NCCH has developed collaborative relationships with several external organisations, including the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) to provide coding, data quality and education expertise.

The Commission has a formal secondment arrangement with NCCH, whereby the centre employs a Health Information Manager who is subsequently seconded on a part-time basis to the Commission. The aim of this position is to provide the Commission with contemporary coding expertise.

For each death in the register, the Health Information Manager reviewed all available information and coded the death according to ICD-10 cause of death coding regulations.

Limitations of ICD-10

The Commission recognises ICD-10 carries certain inherent limitations. A classification is used to group conditions, diseases, external causes and health-related problems into homogenous groups to assist with statistical collection and analysis of health information. In the process of grouping and classifying using ICD-10 various specificities in cause or circumstances of death are missed. For example, a case in which a child dies in a car-pedestrian accident while being escorted across the road by an adult is qualitatively different from a case in which a chronically unsupervised child is struck by a car while crossing a busy street alone. For coding purposes the manner and cause of death are the same but the circumstances are distinctly different (Christianson-Wood & Murray, 1999:44).

Additionally, some specific categories of death that are of interest to the Commission are not specified in ICD-10 coding. These are listed below:

- Dam drowning
- Driveway run-overs of toddlers
- Four-wheel motorcycle (quad-bike) accidents.

Consequently, the Commission has developed databases to assist with the capture and analysis of this information.

79 Subsection 4 permits a person to make a record of, or disclose confidential information for this Act, to discharge a function under another law, for a proceeding in a court or tribunal or if authorised under a regulation or another law.

80 In many cases, death certificates only record a single cause of death. These are relatively simple to deal with – the single cause reported is coded using the ICD-10. However, in other cases two or more conditions may have contributed to the death and are all recorded on the death certificate. In such cases, it is necessary to select one of the causes of death for classification purposes. This single cause is usually referred to as the underlying cause of death.

81 The NCCH is also the developer of the Australian modification of the ICD-10 (known as ICD-10-AM). ICD-10-AM is used for morbidity coding only.

Geographical distribution (ARIA)

This report uses the latest version of the Accessibility/Remoteness Index of Australia (ARIA), commonly referred to as ARIA+, to code geographical remoteness.

ARIA+ is a standard distance-based measure of remoteness developed by the National Centre for the Social Applications of Geographic Information Systems (GISCA) and the Commonwealth Department of Health and Aged Care.

It interprets remoteness as access to a range of services; the remoteness of a location is measured in terms of distance travelled by road to reach a centre that provides services⁸².

ARIA+ defines five categories of remoteness:

- Major Cities of Australia⁸³: relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction.
- Inner Regional Australia: some restrictions to accessibility of some goods, services and opportunities for social interaction.
- Outer Regional Australia: significantly restricted accessibility of goods, services and opportunities for social interaction.
- Remote: very restricted accessibility of goods, services and opportunities for social interaction.
- Very Remote: very little accessibility of goods, services and opportunities for social interaction.

All child deaths registered between 1 January 2004 and 30 June 2005 were classified according to the ARIA+ index. The analysis of geographic distribution in this report refers to the child's usual place of residence which may differ from the place of death or incident location.

For the purposes of analysis in this report, ARIA+ categories have been combined into three more general categories:

- Metropolitan: includes major cities of Queensland
- Regional: includes inner and outer regional Queensland
- Remote: includes remote and very remote Queensland.

82 ARIA is a purely geographic measure of remoteness, which excludes any consideration of socio-economic status, rurality and populations size factors (other than the use of natural breaks in the population distribution of Urban Centres to define the service centre categories).

83 These are ABS determined category names. GISCA ARIA+ uses the following category names: highly accessible, accessible, moderately accessible, remote, very remote.

Socioeconomic status (SEIFA)

The Socio-Economic Indexes for Areas (SEIFA) developed by the Australian Bureau of Statistics has been used to code disadvantage. This index provides four measures of the social and economic conditions of geographic areas across Australia:

- Index of Advantage/Disadvantage
- Index of Disadvantage
- Index of Economic Resources
- Index of Education and Occupation.

The SEIFA Index of Advantage/Disadvantage is used in this report. This index aims to rank geographical areas to reflect both advantage and disadvantage at the same time, effectively measuring a net effect of social and economic conditions.

Variables associated with advantage include the proportion of families with high incomes, the proportion of persons with a degree or higher and the proportion of persons with skilled occupations. Variables associated with disadvantage include the proportion of families with low incomes, the proportion of persons with relatively low levels of education and the proportion of persons with low-skilled occupations.

The Index of Advantage/Disadvantage is used more frequently by the Queensland State Government than other SEIFA indexes.

To determine the level of advantage and disadvantage the child's usual place of residence was used for coding the geographic area. As such, measures of socioeconomic status used in this report are measures of the status of the areas in which children and young people reside, not the socioeconomic status of each individual child or their family.

Aboriginal and Torres Strait Islander status

The identification of Aboriginal and Torres Strait Islander peoples continues to be less than satisfactory in many administrative collections. While the identification of the deaths of Aboriginal and Torres Strait Islander peoples has improved considerably in recent years, it is not known

how many Indigenous deaths are not identified. Therefore, the number of deaths registered as Aboriginal or Torres Strait Islanders in a given year is expected to be an undercount of the actual number of deaths of Indigenous people (ABS, 2002).

Aboriginal and Torres Strait Islander status is recorded on both the Registry of Births Deaths and Marriages death registration data and the Police Report of Death to a Coroner (Form 1). However, it is probable that these sources undercount the number of Aboriginal and Torres Strait Islander child deaths.

The Commission recognises that in Queensland, Aboriginal and Torres Strait Islander children and young people aged from birth to 17 years comprise approximately 46.5% of the Aboriginal and Torres Strait Islander populations (Commission for Children and Young People and Child Guardian, 2005:7) and as such the Commission is pursuing means to improve the undercounting of Aboriginal and Torres Strait Islander child deaths⁸⁴.

Disability status

There are difficulties in defining disability status due to the differing working definitions of disability. Disability Services Queensland, Education Queensland and Queensland Health define disability differently. The Department of Child Safety (DChS) does not systematically collect information in relation to disability and the Queensland Police Service and Registry of Births, Deaths and Marriages only note a disability on official records if the child's disability is seen to be relevant to the cause or mode of death.

Due to the paucity and inconsistency of information available on the disability status of the children and young people who have died, it has not been possible for the Commission to code a child's disability status. As such the deaths of children and young people with disabilities have not been analysed in this report.

Analysis and reporting

Analysis period

The register was analysed according to date of death registration (rather than date of death). This is in accordance with national datasets managed by the Australian Bureau of Statistics (ABS) and the child deaths data managed by the New South Wales Child Death Review Team.

Reporting period

This report examines the deaths of 693 children and young people from birth to 17 years, registered between 1 January 2004 and 30 June 2005⁸⁵.

Incidence

This report uses age and gender specific death rates, calculated using ABS population projections for 2003. These rates show the number of deaths per 100,000 children in each age and/or gender group in the population. For infants under one year, rates per 1000 live births were also calculated. Rates allow comparisons over time, across states and internationally.

Indigenous child death rates

The ABS has published experimental estimates and projections of the Indigenous population. However, identifying children and young people under the age of 18 is problematic due to the age groupings used by the ABS. For this report, Indigenous populations were estimated for children and young people under the age of 18 by combining 2001 Census Indigenous Profile with ABS experimental projections for 2003⁸⁶. Specifically, the 2001 Census Indigenous Profile was used to calculate the proportion of children in each single year age group (i.e. <1, 2, 3 years). These proportions were then applied to the 2003 experimental projections to estimate the Indigenous populations for each age category (eg. <1, 1–4, 5–9 years).

Rates were not calculated on less than four cases due to the unreliability of such calculations.

84 In New South Wales, for example, when an Aboriginal member of the Child Death Review Team can identify the family as an Aboriginal family, the child is coded as Aboriginal (NSW Child Death Review Team, 2001:23).

85 The deaths of 656 children occurred during this period. Thirty occurred in December 2003, six in November 2003 and one in October 2003.

86 The ABS has published experimental estimates and projections of the Indigenous population. These statistics are regarded as experimental in that the standard approach to population estimation is not possible because satisfactory data on births, deaths and internal migration are not generally available. As such, it is important to note that much of what is reported may represent under-estimates of numbers of Aboriginal and Torres Strait Islander peoples. It is increasingly recognised that there is a need for good quality information concerning Aboriginal and Torres Strait Islander peoples (Australian Bureau of Statistics, 2003).

Recommendations

Under section 89ZE(c) of the *Commission for Children and Young People and Child Guardian Act*, the Commissioner is required to make recommendations about laws, policies and practices to help reduce the likelihood of child deaths.

Section 89ZF(e) further requires that the Commission for Children and Young People and Child Guardian Annual Report of all Queensland Child Deaths report on the extent to which previous recommendations have been implemented.

In 2005–06 all agencies to which recommendations have been directed will be asked to provide progress reports on the extent to which the recommendations have been implemented, strategies and timeframes for continued implementation, as well as reasons for any alternative action and/or non-implementation.

Improving data collection

Police Report of Death to a Coroner

One of the key data sources used in the Commission's child death research is the Police Report of Death to a Coroner (Form 1).

The Form 1 was developed to a Queensland Police Service and the Office of the State Coroner to improve the type and consistency of initial information provided to assist the pathologist in determining the cause of death⁸⁷. The Office of the State Coroner and the Queensland Police Service should be commended for the successful implementation of the Form 1, which is a rich qualitative and quantitative data source used extensively by the Commission in analysing the deaths of children and young people in Queensland.

The Commission acknowledges that completion of the Form 1s is an administrative task that police officers undertake sensitively when interviewing a family grieving the loss of a child. However, as with all administrative data collections used for research purposes, areas for improvement may be identified. For example, in relation to the investigation of infant deaths the Form 1 identifies whether there

were was “any evidence of alcohol or drug use at [the] location of [the] event”. However, it does not require officers to record the extent of alcohol or drug use and as such unless stated in the form's ‘Summary of Circumstances’ the extent is not clear. Improvements in such areas will assist to clarify current ambiguities thereby improving the utility of the data for research purposes.

The Commission plans to work collaboratively with the Office of the State Coroner and the Queensland Police Service to identify areas that may potentially improve the information captured on Form 1s in future years.

Indigenous status

During the reporting period, the Commission received notification from the Office of the State Coroner of three Indigenous deaths which did not appear to have been registered with the Registry of Births Deaths and Marriages (the Registry). In cases where a death does not appear to have been registered after three months, the Commission has agreed to liaise with the Registry to enable follow up or death registration as appropriate. It is hoped that it will assist the Registry to improve Indigenous death registration.

In addition, the Registry employs a range of strategies to increase the registration of Indigenous births and deaths in Queensland, including targeted media campaigns, postal requests and liaison with funeral directors, Centrelink and chairpersons and council clerks in Deeds of Grant in Trust Communities⁸⁸. The Registry report that improving Indigenous birth registration is more ‘tangible’ than death registration due to the need for a certificate for identity⁸⁹. Encouraging death registration in Indigenous communities is more problematic because of cultural issues.

Disability status

The Commission will work with Disability Services Queensland, the Department of Child Safety, the Queensland Police Service and the Registry of Births, Deaths and Marriages to improve the systematic collection of this data in future years.

87 The former ‘*Report concerning death by a member of the Police Service*’ (Form 4) used by police officers to notify a coroner of a death, did not contain a death scene examination. The Form 4 served only to identify the deceased and provide a brief summary of circumstances of the death. The Form 1 introduced in conjunction with the new Coroners Act 2003 in December 2003.

88 Deeds of Grant in Trust.

89 Information contained in email from the Registry of Births, Deaths and Marriages dated 5 July 2005