

## TOWARDS NATIONAL REPORTING

### ***Background***

The aim of the ANZCDRT is to prevent or reduce child deaths by sharing information on issues in the review and reporting of child deaths, and to work collaboratively towards national and international reporting.

At the 2 December 2005 meeting the Australian and New Zealand Child Death Review Teams (ANZCDRT) agreed in principle to a minimum data set (see Attachment 1) and to report nationally on a set of these data items (see Attachment 2).

At this meeting the ANZCDRT set up a *Cause of Death Working Group* with a member nominated by each jurisdiction to develop a core group of deaths for all teams to report against (see Attachment 2). At the March 2008 meeting this *Group* were also asked to consider the definition of SUDI.

Without additional resources it has been difficult for some Australian jurisdictions and New Zealand to undertake the considerable work necessary to achieve the national reporting envisaged. Options for funding have been explored including Minister and Shadow Minister for Health in August 2007, the *Statistical Information Management Committee* in October 2007, and the *Australian Health Ministers' Advisory Council* in December 2007. All options have been unsuccessful.

### ***Discussion:***

Achieving national reporting against all the data items agreed in principle in December 2005 is unlikely to be achieved in the short to medium term without additional funding. An option is to consider reporting against a smaller set of items where definitional issues are not indicated and for the causes of death defined by ICD-10-AM and the SUDI definition agreed by the ANZCDRT in December 2007.

There are two outstanding issues that will require agreement prior to this reporting:

## **1. What to report: underlying, associated, contributory, or all mentions**

This issue has been discussed previously by the ANZCDRT in the context of a presentation on issues in coding, analysing and reporting on multiple causes of death given by Robert van der Hoek at the March 2007 meeting. While no agreement was reached the minutes of the meeting note that “Care needs to be taken in reporting multiple causes of death so that readers do not confuse total number of causes with the total number of deaths”.

The NSW Child Death Review Team has undertaken considerable work in this area in analysing trends in child death. It quickly became clear that apparent trends in death indicated for underlying causes often changed substantially when all mentions of a cause were used, typically moderating or even eliminating the otherwise apparent trend. The reasons for this were probably the result of variation in the likelihood of a code being used as an underlying as opposed to an associated cause, and shifts in coding practice across time. The NSW Team concluded that reporting on the underlying cause only can give incomplete and even misleading information about the importance or salience of particular causes as causes of death overall and now reports all mentions of a cause of death. An excerpt from the NSW Team’s 2007 Annual Report provides further information (Attachment 3).

## **2. What period of time to report**

The period of time reported varies across member teams. For information at hand:

- Australian Capital Territory (have not yet reported)
- NSW report by calendar year according to date of death
- Northern Territory (have not yet reported)
- Queensland report financial years according to date of death registration
- South Australia report by calendar year according to date of death.
- Victoria report by calendar year according to date of death
- Western Australia (no longer report)
- New Zealand report by calendar years according to the date of death

While variation in reporting period across the jurisdictions could be noted in any release of data it would be preferable to report against the same period. If a “majority rules” approach is taken this would mean all teams reporting according to calendar year of death.

A draft reporting template is has been developed by Victoria. This template could be populated and form the basis of national reporting. The ANZCDRT could use the release of this data as an opportunity to request government funding to support its work. Because most of the data is already collected by jurisdictions currently reporting the additional burden is likely to be minimal.

**Suggested action:**

The ANZCDRT agree to:

1. Report annually according to the template tabled at the meeting
2. Report by calendar year of death, using all mentions of a cause of death
3. NSW to collate the data provided by other jurisdictions
4. The first report be released by the ANZCDRT in March 2009 on 2007 data.

### **Minimum data set** (*agreed in-principle*)

- Date of birth
- Date of death
- Date of registration of death
- Sex of child
- Indigenous status of child
- Postcode of child's usual residence
- Postcode of child's death
- Child's country of birth
- Cause of Death (using ICD-10-AM or ICD-10 coding)
- Core groups of death

### ***For coronial matters only***

- Approximate time of incident
- Criminal charge associate with the death (e.g. murder, manslaughter, negligent driving)
- Outcome of criminal charge (e.g. guilty, not guilty)
- Outcome of coronial proceeding (e.g. matters dispensed with, matters terminated, findings given. The categories will require investigation to achieve consistency across jurisdictions)
- Whether a post-mortem was held
- Extent of post mortem held (full, partial, external, or none)
- The collection of 'ethnicity' will be considered at a later time.

## Attachment 2

### Data items to report nationally (*agreed in-principle*)

#### **For all deaths**

- Date of registration
- Age at death (<1\*, 1-4, 5-9, 10-14, 15-17 when age categories are reported)
- Sex of child
- Indigenous status of child
- Primary cause of death
- Core group of death
- Month of death
- Socio-economic status (using SEIFA)
- Remoteness (using Accessibility/Remoteness Index of Australia)
- Deaths reported to the coroner

#### **For transport deaths only**

- Place of incident (as categorised in ICD 10-AM)
- Type of transport fatality (as categorised in ICD 10-AM i.e. passenger, pedestrian, pedal cyclist, driver, water transport and other)

#### **For drowning deaths only**

- Place of incident (as categorised in ICD 10-AM)

#### **For suicide deaths only**

- Method of death (as categorised in ICD 10-AM)

#### **For coronial matters only**

- Approximate time of incident
- Criminal proceedings associated with death
- Outcome of criminal charge
- Outcome of coronial proceeding
- Whether a post-mortem was held
- Extent of post mortem

Rate to be reported per 100,000 when reporting children aged 1 to 17 years and per 1,000 live births when reporting rates for infants (<1year).

#### **Reportable cause of death groupings**

**Detailed** reporting for:

- Sudden Unexpected Deaths in Infancy (at the ICD-10-AM 3-characters)
- Deaths due to diseases and morbid conditions
  - Perinatal conditions (P00-P99)
  - Congenital anomalies (Q00-Q99)
  - Infections (A00-B99; G00-G09) – central nervous system infections; J00-J22 – respiratory infections)
  - Neoplasms (C00-D48)
- External causes of death
  - Transport incidents (V01-V99)

Accidental drownings (W65-W74)  
 Suicides (X60-X84)  
 Assaults (X85-Y09)  
 Fires (X00-X09)

The **number** of deaths only for:

ICD-10 Chapter	Cause of Death Group	ICD-10 Codes
I	Certain infections and parasitic diseases	A00-B99
II	Neoplasms	C00-D48
III	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	D50-D89
IV	Endocrine, nutritional and metabolic diseases	E00-E89
V	Mental and behavioural disorders	F00-F99
VI	Diseases of the nervous system	G00-G99
VII	Diseases of the eye and adnexa	H00-H59
VIII	Diseases of the ear and mastoid process	H60-H95
IX	Diseases of the circulatory system	I00-I99
X	Diseases of the respiratory system	J00-J99
XI	Diseases of the digestive system	K00-K93
XII	Diseases of the skin and subcutaneous tissue	L00-L99
XIII	Diseases of the musculoskeletal system and connective tissue	M00-M99
XIV	Diseases of the genitourinary system	N00-N99
XV	Pregnancy, childbirth and the puerperium	O00-O99
XVI	Certain conditions originating in the perinatal period	P00-P99
XVII	Congenital malformations, deformations and chromosomal abnormalities	Q00-Q99
XVIII	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	R00-R99
XX	External causes of morbidity and mortality	
	• Transport accidents	V01-V99
	• Falls	W00-W19
	• Exposure to inanimate mechanical forces	W20-W49
	• Exposure to animate mechanical forces	W50-W64
	• Accidental drowning and submersion	W65-W74
	• Other accidental threats to breathing	W75-W84
	• Exposure to electric current, radiation and extreme ambient air temperature and pressure	W85-W99
	• Exposure to smoke, fire and flames	X00-X09
	• Contact with heat and hot substances	X10-X19
	• Exposure to forces of nature	X30-X39
	• Accidental poisoning by and exposure to noxious substances	X58-X59
	• Overexertion, travel and privation	X50-X57
	• Accidental exposure to other and unspecified factors	X58-X59
	• Intentional self-harm	X60-X84
	• Assault	X85-Y09
	• Event of undetermined intent	Y10-Y34
	• Legal intervention and operations of war	Y35-Y36
	• Complications of medical and surgical care	Y40-Y84

### **Excerpt from the NSW Child Death Review Team's 2007 Annual Report (pgs 270-271)**

#### **Multiple causes and all mentions of a cause**

The annual report now includes more complete information on multiple causes of death. *Multiple cause* usually refers to the consideration of an underlying cause *and* its coded associated causes. For example, leukaemia might be the underlying cause, where the associated causes are Gastrointestinal haemorrhage, unspecified; Pneumonia, unspecified; Failure and rejection of transplanted organs and tissues; and Unintentional cut, puncture, perforation or haemorrhage during surgical and medical care. In this report, contributory factors are included as associated causes.

Some causes of death are rarely coded as an underlying cause yet play critical roles in the causal sequence that leads to death. The underlying cause is "the first in a train of events". The intermediate and immediate causes of death are also important in monitoring deaths and their causes. Importantly, these associated causes may be amenable to treatment as much as the first cause in a causal sequence, and hence may be important in the development of overall preventative strategies. The provision of information on multiple causes across time may help in the identification of trends in common overall patterns of causes for particular types of death.

Because causes of death vary in their likelihood of being coded as an underlying as opposed to an associated cause, and these variations in likelihood can shift with coding practice across time, following only a cause of death when it is coded as the underlying cause can give incomplete and even misleading information about the importance or salience of particular causes as causes of death overall. Reporting *all mentions* of a cause of death overcomes this problem, and includes reporting a cause when it is an underlying cause as well as when it is an associated cause.

The ABS (2003) argues that "[Underlying causes of death] provide a somewhat limited picture of mortality and health of the population. In particular, it does not provide complete information about conditions which frequently appear as a multiple cause of death, but which rarely appear as an underlying cause."

It is becoming increasingly common in monitoring deaths to identify where a cause of death has been coded as either an underlying or an additional cause of death (referred to as total or all mentions, e.g., Wing and Monton, 1981; Wilkins, Wysocki, Morin and Wood, 1997; Eberstein, Nam and Heyman, 2005).

In preparing the report on trends in child death across the period 1996-2005 (CDRT, 2008), analysis commenced with the traditional focus on the underlying cause of

death. It quickly became apparent, however, that apparent trends in death indicated for underlying causes often changed substantially when all mentions of a cause were used -- typically moderating or even eliminating the otherwise apparent trend. Examples of this can be found throughout the diseases and morbid conditions chapters of that report. Further, there were substantial variations in these differences by such factors as age, socioeconomic background and geographic remoteness. A decline in deaths due to a particular underlying cause, then, may reflect only a shift in coding practice towards coding that cause as an associated cause. Whether a cause is coded as an underlying or an associated cause may be influenced by such things as the demographic characteristics of the deceased.

As a result of this finding, this report only reports all mentions of a cause, along with all the other coded causes (multiple causes) related to those all mentions.

## References

- Australian Bureau of Statistics 2003. *Multiple Cause of Death Analysis, 1997-2001*. Canberra: Australian Bureau of Statistics, 3319.0.55.001
- Eberstein, I. W., Nam, C. B., and Heyman, K. M., 2005. *Comparing Underlying and Multiple Causes of Death in Analysing Mortality among the Elderly: United States, 1986-1997*. Paper presented in Session 27, "Mortality and causes of death in elderly populations in high income countries: of the International Union for the Scientific Study of Population, International Population Conference, Tours, France, July 18-23, 2005.
- Wilkins, K., Wysocki, M., Morin, C., and Wood, P. 2005. Multiple causes of death. *Health Reports*, Autumn 1997, vol. 9, No. 2.
- Wing, S. & Manton, K.G. (1981). A multiple cause of death analysis of hypertension-related mortality in North Carolina, 1968-1977 *American Journal of Public Health*, 71(8), 823-830

## Draft Reporting Template

## 2006 Total Deaths: Age Group by State

Age group	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Australia Total
<1 year								311		
1-4 years								35		
5-9 years								27		
10 -14 years								28		
15-17 years								48		
17-19 years								NA		
>20 years								NA		
<b>TOTAL</b>								<b>449</b>		

**2006 Total Deaths: ICD-10 Chapter by State**

ICD Chapter	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC*		WA	Australia Total
								M	F		
<b>1 Certain infectious and parasitic diseases (A00-B99)</b>								3	3		
<b>2 Neoplasms (C00-D48)</b>											
Malignant neoplasms C00-C96								15	9		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	2		
<b>3 Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism (D50-D89)</b>								2	0		
<b>4 Endocrine, nutritional and metabolic diseases (E00-E89)</b>								4	4		
<b>5 Mental and behavioural disorders (F00-F99)</b>								0	1		
<b>6 Diseases of the nervous system (G00-G99)</b>								12	8		
<b>7 Diseases of the eye and adnexa (H00-H59)</b>								0	0		
<b>8 Diseases of the ear and mastoid (H60-H95)</b>								0	0		
<b>9 Diseases of the circulatory system (I00-I99)</b>								6	3		
<b>10 Diseases of the respiratory system (J00-J99)</b>								6	5		
<b>11 Diseases of the digestive system (K00-K93)</b>								1	2		
<b>12 Diseases of the skin and subcutaneous tissues (L00-L99)</b>								0	0		

13	Diseases of the musculoskeletal system and connective tissue (M00-M99)	0	1
14	Diseases of the genitourinary system (N00-N99)	2	0
15	Pregnancy, childbirth and the puerperium (O00-O99)	0	0
16	Certain conditions arising in the perinatal period (P00-P96)	12	8
17	Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	16	13
18	Symptoms, signs and abnormal clinical and lab findings, not elsewhere classified (R00-R99)	12	10
19	Injury, poisoning and certain other consequences of external causes (S00-T98)	35	25
20	External causes of morbidity and mortality U50-Y98	2	0
21	Factors influencing health status and contact with health services (Z00-Z99)	0	0
<b>TOTAL</b>		<b>128</b>	<b>94</b>

\*28days-17years

**2006 SUDI deaths: SUDI Category by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Australia Total
<b>Explained</b>										
Acute illness (not recognised as life threatening)								2		
Pre-existing condition (not previously recognised by health profession)								1		
Accident (unintentional trauma)								5		
Intentional Trauma								1		
Poisoning								0		
<b>Unexplained</b>										
SIDS (R95)								19		
Unascertained (R96)								2		
<b>TOTAL</b>								<b>30</b>		

**2006 Total Deaths: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC*	WA	Australia Total
<b>EXTERNAL</b>										
<b>Transport fatalities (V01-V99)</b>								29		
<b>Accidental drownings (W65-W74)</b>								8		
<b>Suicide</b>										
known intent (X60-X84)								12		
suspected from codes (Y10-Y34)								0		
<b>Fatal assault (X85-Y09)</b>								4		
<b>Fire (X00-X09)</b>								3		
<b>MORBID</b>										
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								20		
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								29		
<b>Infections</b>										
A00-B99								5		
G00-G09								3		
J00-J22								2		
<b>Neoplasms</b>										
Malignant neoplasms (C00-C96)								25		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)										

**2006 Deaths, < 1 year old: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC*		WA	Australia Total
								M	F		
<b>EXTERNAL</b>											
Transport fatalities (V01-V99)								0	0		
Accidental drownings (W65-W74)								0	1		
<b>Suicide</b>											
known intent (X60-X84)								0	0		
suspected from codes (Y10-Y34)								0	0		
Fatal assault (X85-Y09)								1	0		
Fire (X00-X09)								0	1		
<b>TOTAL EXTERNAL</b>								<b>1</b>	<b>2</b>		
<b>MORBID</b>											
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								11	8		
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								13	9		
<b>Infections</b>											
A00-B99								1	1		
G00-G09								1	1		
J00-J22								2	0		
<b>Neoplasms</b>											
Malignant neoplasms (C00-C96)								0	1		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	0		
<b>TOTAL MORBID</b>								<b>28</b>	<b>20</b>		

\*0-1year for external causes; 28days-1year for morbid conditions

**2006 Deaths, 1-4 year old: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC		WA	Australia Total
								M	F		
<b>EXTERNAL</b>											
<b>Transport fatalities (V01-V99)</b>								1	1		
<b>Accidental drownings (W65-W74)</b>								2	1		
<b>Suicide</b>											
known intent (X60-X84)								0	0		
suspected from codes (Y10-Y34)								0	0		
<b>Fatal assault (X85-Y09)</b>								0	1		
<b>Fire (X00-X09)</b>								1	0		
<b>TOTAL EXTERNAL</b>								<b>4</b>	<b>3</b>		
<b>MORBID</b>											
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								0	0		
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								1	3		
<b>Infections</b>											
A00-B99								1	1		
G00-G09								0	0		
J00-J22								0	1		
<b>Neoplasms</b>											
Malignant neoplasms (C00-C96)								3	2		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	0		
<b>TOTAL MORBID</b>								<b>5</b>	<b>7</b>		

**2006 Deaths, 5-9 year old: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC		WA	Australia Total
								M	F		
<b>EXTERNAL</b>											
Transport fatalities (V01-V99)								1	1		
Accidental drownings (W65-W74)								2	2		
<b>Suicide</b>											
known intent (X60-X84)								0	0		
suspected from codes (Y10-Y34)								0	0		
Fatal assault (X85-Y09)								1	0		
Fire (X00-X09)								0	0		
<b>TOTAL EXTERNAL</b>								<b>4</b>	<b>3</b>		
<b>MORBID</b>											
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								1	0		
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								0	1		
<b>Infections</b>											
A00-B99								1	0		
G00-G09											
J00-J22											
<b>Neoplasms</b>											
Malignant neoplasms (C00-C96)								3	3		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	0		
<b>TOTAL MORBID</b>								<b>5</b>	<b>4</b>		

**2006 Deaths, 10-14 year old: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Australia Total
<b>EXTERNAL</b>								<b>M</b>	<b>F</b>	
<b>Transport fatalities (V01-V99)</b>								4	1	
<b>Accidental drownings (W65-W74)</b>								0	0	
<b>Suicide</b>										
known intent (X60-X84)								3	1	
suspected from codes (Y10-Y34)								0	0	
<b>Fatal assault (X85-Y09)</b>								0	0	
<b>Fire (X00-X09)</b>								1	0	
<b>TOTAL EXTERNAL</b>								<b>8</b>	<b>2</b>	
<b>MORBID</b>										
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								0	0	
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								2	0	
<b>Infections</b>										
A00-B99								0	0	
G00-G09										
J00-J22										
<b>Neoplasms</b>										
Malignant neoplasms (C00-C96)								4	1	
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	0	
<b>TOTAL MORBID</b>								<b>6</b>	<b>1</b>	

**2006 Deaths, 15-17 year old: Category of Death by State**

	NZ	ACT	NSW	NT	QLD	SA	TAS	VIC		WA	Australia Total
								M	F		
<b>EXTERNAL</b>											
<b>Transport fatalities (V01-V99)</b>								9	11		
<b>Accidental drownings (W65-W74)</b>								0	0		
<b>Suicide</b>											
known intent (X60-X84)								7	1		
suspected from codes (Y10-Y34)								0	0		
<b>Fatal assault (X85-Y09)</b>								1	0		
<b>Fire (X00-X09)</b>								0	0		
<b>TOTAL EXTERNAL</b>								<b>17</b>	<b>12</b>		
<b>MORBID</b>											
<b>Certain conditions arising in the perinatal period (P00-P99)</b>								0	0		
<b>Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)</b>								0	0		
<b>Infections</b>											
A00-B99								0	0		
G00-G09											
J00-J22											
<b>Neoplasms</b>											
Malignant neoplasms (C00-C96)								4	4		
In situ, benign and neoplasms of uncertain or unknown behaviour (D00-D48)								0	0		
<b>TOTAL MORBID</b>								<b>4</b>	<b>4</b>		