

# **New Zealand Child and Youth Mortality Review Committee**

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## **National data overview**

NZ MORTALITY REVIEW DATA GROUP

2010

# Methodology

## Overview

The Child & Youth Mortality Review process includes national data collection, review of individual deaths in the DHB region where the person resided and a national review of collated information. Precise processes have evolved over the past seven years. Many people and organisations are involved in providing information, reviewing deaths, collating information, analysing and reviewing collated data. The various stages that have contributed to the formation of this report include:

1. National organisations and some individuals provide information directly to the Mortality Review Data Group.
2. The information held centrally is available for use at local review meetings via appointed DHB co-ordinators.
3. After each death is reviewed, these DHB coordinators add further information to the national database.
4. The Mortality Review Data Group collate and analyse information held in the national collection for the CYMRC.
5. The CYMRC reviews the collated case information as well as locally identified issues and recommendations. This provides a detailed overview of regional and national trends, which can be used to inform prevention strategies and support recommendations at both a local and national level.
6. Subject experts use collated case information to prepare sections of the report and the CYMRC advisors review recommendations.
7. Finally the CYMRC considers all available information and feedback in order to make recommendations to the Minister of Health, health professionals and members of the public in the Committee's annual report.

## Data collection

The Mortality Review Data Group collect, securely store and link case information about all child and youth deaths from 1 January 2002 for the CYMRC. Information comes from a variety of sources, including:

1. Births, Deaths and Marriages (Department of Internal Affairs)
2. Ministry of Health
3. Child, Youth and Family (Ministry of Social Development)
4. Water Safety New Zealand
5. Coroners
6. Coronial Services (Ministry of Justice)
7. Ministry of Transport
8. Local child and youth mortality review groups
9. Families of the deceased.

Information is provided in varying formats as well as being sent at times and time intervals that suit the data source. A weekly extract from Birth, Deaths and Marriages is the primary source of notification of relevant deaths. Organisations such as Water Safety New Zealand and the Ministries of Health and Transport routinely provide selected information on all relevant deaths. The CYMRC continues to consider other suitable data sources in addition to these and to liaise with other organisations.

Some source providers have changed data format or have only recently started providing information. For example Child, Youth and Family provide information for cases which they have had contact with from June 2006 onwards. (The age range considered has gradually expanded from infant and preschool to include all deaths in 2009). The majority of coroners have provided information on coronial cases from January 2003. The Mortality Review Data Group enters and codes all information from the disparate and often conflicting data sources, in order to help facilitate local review as well as national reporting.

Figure M.1: Flow of case information from sources to the Mortality Review Database

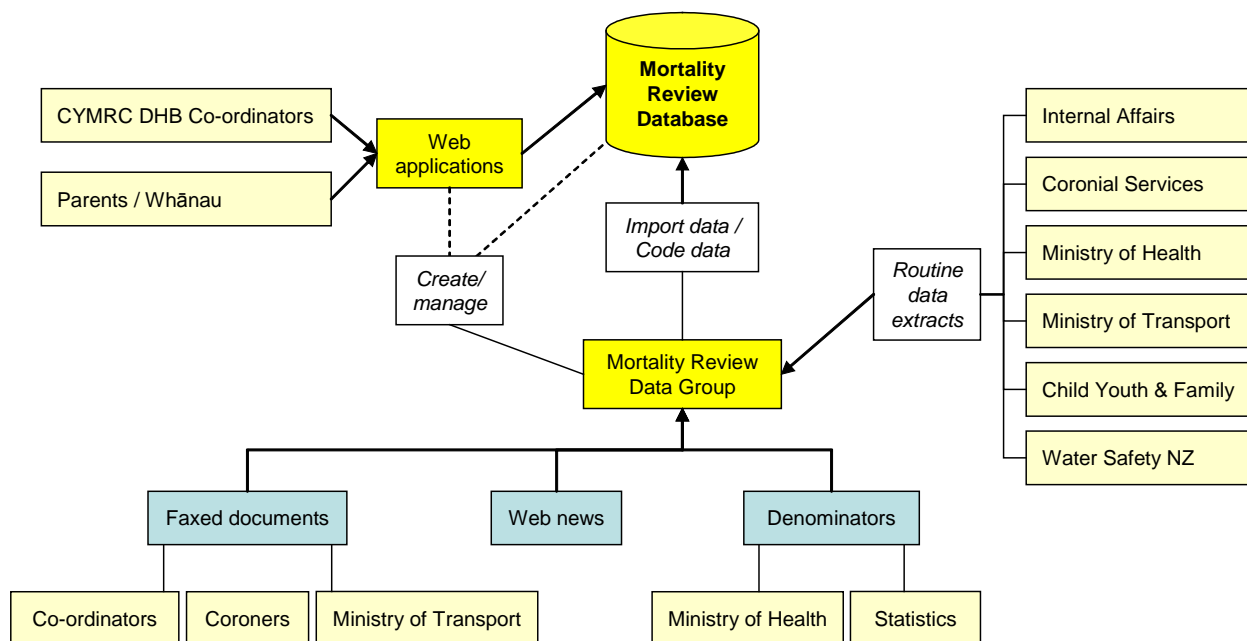


Figure M.1 illustrates these sources of information and some of the processing. The Mortality Review Data Group maintains two websites which allow individuals to directly contribute information. A link on the public website ([www.cymrc.health.govt.nz](http://www.cymrc.health.govt.nz)) allows families to provide feedback on health systems. The DHB co-ordinator adds further details both before and after local review, via a private website. As well as data extracts - directly entered data and coded data - the information system also includes documents faxed by coroners (pre-2010), electronic format coronial case information (post-2010), copies of news reports and denominators (provided by Statistics New Zealand and the Ministry of Health).

The Mortality Review Data Group identifies the NHI of the person for which each item of information is received. They import data into the Mortality Review Database and link information received from the various sources that relates to the same case. To facilitate both the local review and collation processes, the data is coded across a range of variables. These include age group, ethnicity, underlying cause of death, DHB of usual residence, place of death, and region that should review the death. Data is regularly cleaned to eliminate duplicate records, follow up missing person details, clarify DHB of residence (where this is inconsistent with the residential address), and rectify other identified inconsistencies.

When interpreting the CYMRC data it must be remembered that it is derived from a database that is continually being updated. The strength of this approach is that the data pool for each death can continue to grow as more data comes in; all information is retained and available for local mortality review. For the purposes of generating data for ministerial reports, often data sources are prioritised with respect to their importance in coding specific fields, even where this data may change from year to year as new data sources become available. For example, the

initial source of a death may be a news item. If new information received relating to the death changes, the classification of the cause of death, then the subsequent report, may state the death as owing to a different cause than in previous sources. This means that consecutive annual reports may have slightly different numbers in any one category, but the most recent reports should be the most accurate.

## **The local review process**

The CYMRC review process relies on information from the DHB of residence of the deceased child or youth. The co-ordinators of the local child and youth mortality review groups collect information from local organisations involved in the life and death of the individual. New information gathered as part of the local review process is entered into the Mortality Review Database.

Each local child and youth mortality review group (LCYMRG), has appointed a chair and a co-ordinator. When the death of a child or youth aged between 28 days and 24 years occurs within a co-ordinator's region, the co-ordinator will access the secure database to gather initial information on the deceased. The co-ordinator will then initiate information requests to the various members of the local child and youth mortality review group who each act as a representative of their particular organisation.

As official agents of the CYMRC, the local child and youth mortality review group members can access their organisation's records to identify and collect any information that may be relevant to the review process. The members bring this information to the review meeting and provide relevant details, as needed, for the review. Each review is facilitated by the local chair, whose task it is to bring together all the relevant factors relating to a death. These may be recorded against a timeline, or charted using a white board, computer and data projector, or recorded on paper.

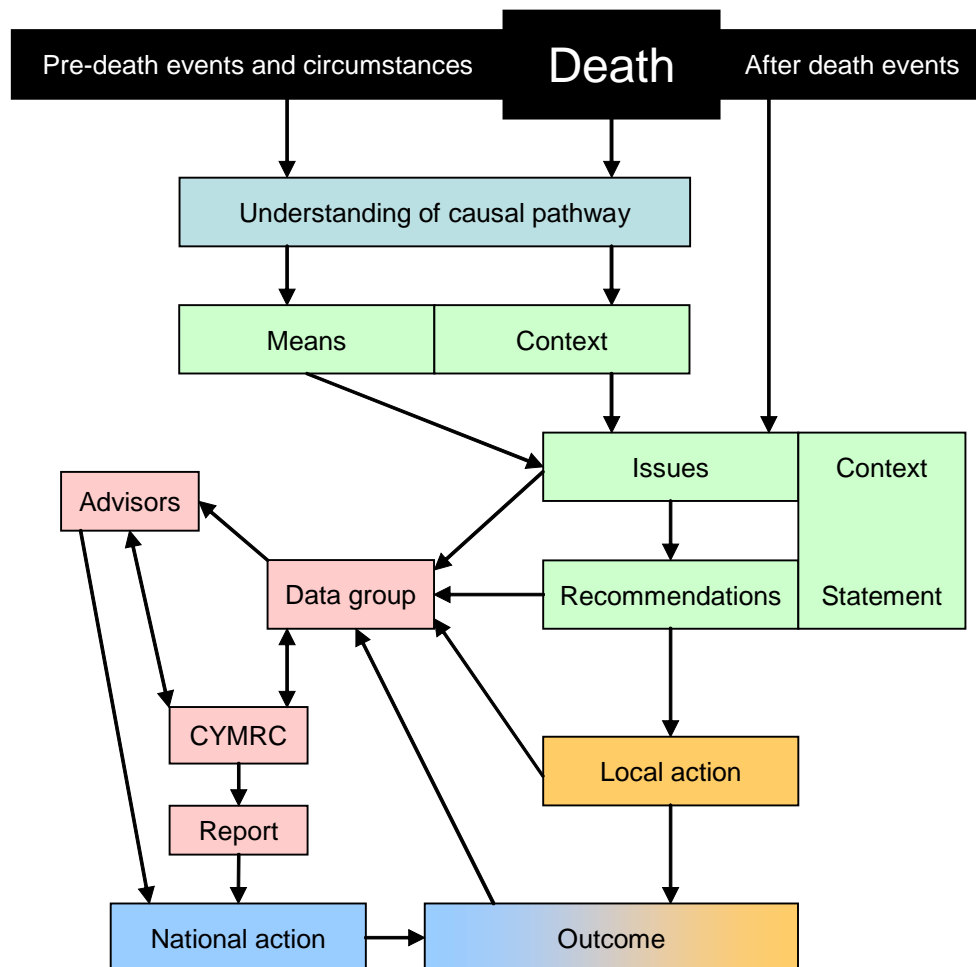
Information shared in the context of the review meeting must remain confidential to the process. Issues identified in the meeting that require urgent action from participating agencies, such as aspects of illegal activity or the safety of others, must be dealt with outside the review process using the normal inter-agency protocols and procedures. This ensures that participants do not compromise the no blame focus of the review process or the confidentiality agreement signed as a condition of agent status. The process is exempt from Official Information Act requirements, but complaints about procedures can be reported to and investigated by the Ombudsman.

A review group might meet several times before all the information has been gathered on a case. Once all the information has been gathered, the group may choose to highlight issues or make specific recommendations. Local recommendations may be delegated to specific group members if the agency they represent is needed to facilitate a response. It is important that the issues and recommendations be presented in a way that does not assign blame but rather focuses on changes that could prevent future deaths.

Once a local death review is completed, the co-ordinator will enter all the relevant data into the secure national database. In this way, issues, recommendations and follow-up actions are forwarded to the CYMRC.

The local child and youth mortality review group process allows high levels of detail about the context of death to be obtained. The process itself supports learning from cases to be acted upon locally. Although only a small proportion of deaths prior to 2009 have been reviewed, the increased coverage of the local child and youth mortality review groups will allow for many more system improvements. A challenging process is to distil this detailed contextual information into recommendations that can work nationally.

Figure M.2: Local review group conceptualisation of causal pathway from death event



As seen in Figure M.2, for every death there is a *context* in which it occurs and a *means* of death. The context of a death describes the cluster of personal and environmental factors (eg, risk factors or circumstances) that together contribute to, or fail to prevent, a death. The means of death describes the final event or disease state that led to a death. The same context may lead to death by a variety of means (eg, unsupervised toddlers or youth risk-taking).

A *causal pathway* is determined by understanding how the context and means of death came together with lethal consequences. Along the causal pathway it is possible to identify points where something could have happened differently. These are referred to as 'issues'. Issues can also arise with regard to actions that occurred after a death.

When the issues are considered at the local or national level, it is often possible to identify ways to interrupt causal pathways or improve after-death actions. Such consideration leads to the generation of *recommendations*, which are expressed in two parts: a context statement and a proposed action. Placing the recommendation into context allows it to be shared with others in a depersonalised way for wider consideration.

Recommendations can result in local action as members of the LCYMRG take the learning from the review back to their work and alter practices. Recommendations are collected on the database for thematic analysis to influence work of the committee and their advisors, thus helping in the understanding of the quantitative data in the database and leading to recommendations in the Annual Report. It is planned that the database will maintain a record of what actions occur as a result of this work and, where possible, what the final outcome is at a community level.

## Analysis and coding

### Mortality data

The data for this report was extracted from the Mortality Review Database on 1 October 2010. The child and youth deaths presented in this report all occurred between 1 January 2004 and 31 December 2009. In all Tables, the *year of death* refers to the calendar year of the actual death (not the year of death registration).

### Cause of death

In response to requests for more detailed ICD-10 coding, the Ministry of Health extract was altered in 2008 to include their mortality coding. Cause of death was assigned using the Main Underlying Cause of Death data from the National Mortality Collection, Ministry of Health. This is coded in ICD-10-AM. Where there was no ICD-10-AM code assigned, the cause of death was determined by the information gained through the process of local

review of the case. In addition, for deaths in infants less than one year of age, 'SUDI' was assigned as the cause of death where any of the following ICD-10-AM codes were listed as the main underlying cause of death in the Mortality Collection: R95 (sudden infant death syndrome), R96 (other sudden death, cause unknown), R98 (unattended death), R99 (other ill-defined and unspecified causes of mortality), W75 (accidental suffocation and strangulation in bed) and W78 (inhalation of gastric contents). If the case was greater than one year of age these deaths were classified as Sudden Unexpected Death (SUD).

## Ethnicity

Ethnicity data is available from Births, Deaths and Marriages, Ministry of Health, local sources and from coronial records. The Mortality Review Data Group prioritises both data sources and specific ethnicities. Further details are available from the Mortality Review Data Group. The Tables in this report prioritise ethnicities in the following order: Māori, Pacific, Asian and Other (including New Zealand European). Ethnicity comparisons shown in the current report are between Māori and non-Māori.

## Statistics

The frequencies and discrete statistics were computed from the database by the Mortality Review Data Group. Percentages have been displayed with one decimal place. In some cases, due to rounding, the percentages do not sum exactly to 100%.

Where presented, 95% confidence intervals for rates have been calculated using the Fay's and Feuer's Method [1] according to CDC's National Vital Statistics Report [2]. These confidence intervals should be used when comparing two rates and, when there is no overlap, this indicates that there is a statistically significant difference.

The denominator for mortality rate calculations is taken from the estimated resident population (for 30 June in the year of death), as published by Statistics New Zealand. This is based on a projection on the count, including: all residents in the most recent census and residents who were temporarily overseas at the time of the most recent census, with an adjustment up for residents who may have been missed by the census or an adjustment down for anyone who may have been counted twice. Rates are per 100,000 age specific population for most age groups, except for those <1 year where rates are shown per 1000 live births.

The deaths of non-New Zealand residents are excluded from the main sections of the report because the denominator in rate calculations (estimated resident population from Statistics New Zealand) excludes visitors from overseas.



1. Fay, M., and Feuer, E., Confidence intervals for directly standardized rates: a method based on the gamma distribution. 1997, *Statistics in Medicine* 16: 791-801.
2. Centers for Disease Control and Prevention, National Vital Statistics Report. Volume 57, Number 14, pp. 128 - 134.