



Child and Youth Mortality Review Committee

Te Rōpū Arotake Auau Mate
o te Hunga Tamariki, Taiohi

**Second Report to the Minister of Health
1 July 2003 to 31 December 2004**

Disclaimer

The Child and Youth Mortality Review prepared this report.

This report does not necessarily represent the views or policy decisions of the Ministry of Health.

Citation: Child and Youth Mortality Review Committee, Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi. 2005. *Second Report to the Minister of Health, 1 July 2003 to 31 December 2004*. Wellington: Child and Youth Mortality Review Committee.

Published in June 2005 by the
Child and Youth Mortality Review Committee
PO Box 5013, Wellington, New Zealand

ISBN 0-478-28369-5 (Book)
ISBN 0-478-28370-9 (Internet)
HP 4107

This document is available on the Committee's website at:
<http://www.newhealth.govt.nz/cymrc>



Chair's Introduction

It is my pleasure to introduce the second annual report from the Child and Youth Mortality Review Committee (CYMRC) to the Minister of Health. This report focuses on the committee's activities from 1 July 2003 to 31 December 2004.

The CYMRC's first annual report¹ outlined the committee's activities over its first 18 months: setting up systems for mortality review, coordinating collection data from government agencies, developing the central mortality database and building good relationships with other review processes.

The CYMRC can now report on the analysis of the data collected using our own systems. As a consequence, I believe the CYMRC can now make useful recommendations.

Our system's full development requires the national data collection system to be checked, reviewed and supplemented by the activities of local agents of the CYMRC. This local review, editing and addition to the national database is essential, as the quality of health-related information available on deaths of children and young people via routine judicial and administrative processes is extremely variable and frequently does not identify in a consistent manner the systems and societal issues that need to change to decrease the number of child and youth deaths in this country.

Not only is local involvement necessary to improve quality of information, it is also critically important in changing how things work. Change must occur at many levels and local ownership of the process is essential. It is, therefore, critically important that the role of the local agents of the national committee is recognised and supported.

The CYMRC supports the policy direction taken in the Coroners Bill, currently undergoing public consultation. The CYMRC believes that having fewer full-time coroners and a chief coroner will better enable a closer working relationship between the coronial system and mortality review systems. We look forward to working closely with the reconfigured coronial system.

The challenge facing both the mortality review systems and the coronial system is how to collect high quality, consistent health and social information about the deaths of children and young people. Accurate information will allow both systems to make effective and evidence-based recommendations to the Government and other agencies. A systematic collection of coronial information will be an important part of this, but even more important will be deciding on how and by whom health and social information will be collected.

The CYMRC-sponsored, Cross Departmental Research Pool (CDRP) funded project titled 'Environmentally sensitive deaths in New Zealand children and youth' will go some way towards defining health and social information collection roles. This project will begin in 2005 and will be managed by the Ministry of Health.

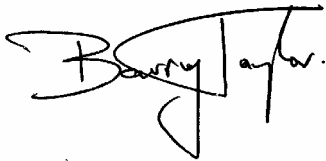
I would like to take this opportunity to express my thanks to the former members of the CYMRC, whose appointment terms expired last year. I personally appreciated their support and insights during the CYMRC's crucial development phase.

I would also like to welcome the new members to the CYMRC. Their skills and experience will help to increase the momentum for mortality review.

¹ Available at <http://www.newhealth.govt.nz/cymrc/Publications.htm>.

The government and non-government agencies that supply data, expertise and advice also deserve the CYMRC's thanks. Their help in fostering support for mortality review has been very much appreciated.

I hope the following report is useful to the Minister of Health and to all the many contributing agencies and individuals, who I gratefully thank for their support.

A handwritten signature in black ink that reads "Barry Taylor". The signature is written in a cursive style with a large, sweeping initial 'B' and a distinct 'T'.

Professor Barry Taylor

Chair
Child and Youth Mortality Review Committee

Contents

Chair's Introduction	iii
1 Highlights of CYMRC Activities	1
1.1 Meetings	1
1.2 Science Subgroup	1
1.3 Advisors to CYMRC	1
1.4 Annual report	2
1.5 Website	2
1.6 Information brochure for families and whanau	2
1.7 Local review processes	2
1.8 Training for local reviews	3
1.9 Research projects	3
1.10 Data analysis	3
1.11 Changes to CYMRC membership	4
2 Challenges for the Mortality Review Process	5
2.1 Quality of information	5
2.2 Attributing cause of death	7
2.3 Confidentiality	8
2.4 Legal issues	8
2.5 Place of families and whanau in review processes	9
2.6 Resourcing the mortality review	10
3 Projects Commissioned by the CYMRC	11
3.1 Water deaths in children and youth 1980–2002	11
3.2 Review of deaths from infection in hospital, 2002–03	13
3.3 Evaluation of pilot local mortality review sites	14
4 Cross-departmental Research Pool Bid: Environmentally-sensitive Deaths in New Zealand Children and Youth: What are the Modifiable Factors?	18
5 Strategic Objectives for 2005/06	19
6 Recommendations	20
6.1 Recommendations for functioning of national review process	20
6.2 Recommendations on functioning of local review process	20
6.3 Recommendations for decreasing child and youth mortality in New Zealand	20
Appendices	
Appendix A: Child and Youth Mortality Statistics	25
Appendix B: Criteria for Accessing Mortality Data and Application Form	46

List of Tables

Table 1:	Summary of data supplied by government agencies	5
Table 2:	CYMRC's strategic objectives and goals	19
Table A1:	Causes of death for post-neonates (28 days–12 months) in 2002, 2003	28
Table A2:	Causes of death for 1–4-year-olds, 2002 and 2003	30
Table A3:	Causes of death for 5–9-year-olds, 2002 and 2003	32
Table A4:	Causes of death for 10–14-year-olds, 2002 and 2003	34
Table A5:	Causes of death for 15–19-year-olds, 2002 and 2003	36
Table A6:	Causes of death for 20–24 year olds in 2002 and 2003	38
Table A7:	Main category and intent of death by age group, 2002 and 2003 combined	39
Table A8:	The 10 major causes of death by ethnicity, 2002 and 2003 combined	40
Table A9:	The 10 major causes of death by gender, 2002 and 2003 combined	41
Table A10:	Sudden unexpected death in infancy (SUDI) risk factors (from police reports and local review), 89 deaths 2002 and 2003 combined	42
Table A11:	Sudden unexpected death in infancy, ethnicity by gender	43
Table A12:	Sudden unexpected death in infancy (SUDI) ethnicity by age group, 2002 and 2003	43
Table A13:	Deaths from self-harm by age and gender , 2002 and 2003	44
Table A14:	Means of death from self-harm, 2002 and 2003	44
Table A15:	Self-harm deaths by ethnicity and age group, 2002 and 2003	45

List of Figures

Figure 1:	Drowning rates per 100,000 age-specific population in children and young people aged under 25, 1980–2002	12
Figure 2:	OECD infant mortality (deaths per 1000 live births), 2002	21
Figure A1:	Infant, neonatal and post-neonatal mortality rate (per 1000 live births), 1979–2003	27
Figure A2:	Post-neonatal categories of death (224 deaths), 2002 and 2003	27
Figure A3:	Mortality rate (per 100,000 population) for 1–4-year-olds, 1979–2003	29
Figure A4:	Categories of death for 1–4-year-olds (150 deaths), 2002 and 2003	29
Figure A5:	Mortality rate (per 100,000 population) for 5–9-year-olds, 1979–2003	31
Figure A6:	Categories of death of 5–9-year-olds (86 deaths), 2002 and 2003	31
Figure A7:	Mortality rate (per 100,000 population) for 10–14-year-olds, 1979–2003	33
Figure A8:	Categories of death of 10–14-year-olds (110 deaths), 2002 and 2003	33
Figure A9:	Mortality rates (per 100,000 population) for 15–19-year-olds, 1979–2003	35
Figure A10:	Categories of death of 15–19-year-olds (387 deaths), 2002 and 2003	35
Figure A11:	Mortality rate (per 100,000 population) for 20–24-year-olds, 1979–2003	37
Figure A12:	Categories of death for 20–24-year-olds (392 deaths), 2002 and 2003	37

1 Highlights of CYMRC Activities

This section overviews the activities undertaken by the CYMRC from 1 July 2003 to 31 December 2004.

1.1 Meetings

The CYMRC met five times in Wellington during this time. The meetings were each held over two days. The meeting format includes report backs and discussion on CYMRC projects, an opportunity to comment on mortality data, and a meeting with advisors from government ministries. Three two-hour updating teleconferences were held between most two-day meetings. Meetings in Wellington were held on:

- 24 and 25 July 2003
- 13 and 14 November 2003
- 27 and 28 February 2004
- 10 and 11 June 2004
- 10 and 11 November 2004 (informal meeting).

1.2 Science Subgroup

The CYMRC convened the Science Subgroup. Its purpose is to provide governance and oversight of the Child and Youth Mortality Data Group (the Data Group). The Science Subgroup will assess applications from researchers for access to the database.

The CYMRC encourages researchers to access the database for research projects. The Data Group can be contacted at mortality.group@stonebow.otago.ac.nz.

The criteria for accessing mortality data and the application form are in Appendix B.

1.3 Advisors to CYMRC

The CYMRC has forged links with several government agencies that also have a policy or an operational focus on the health and wellbeing of children and young people.

The government agencies and their advisors are as follows:

Child, Youth and Family	Kate Ridley
Ministry of Education	Cathye Haddock
Ministry of Health (Mental Health Directorate)	Basia Arnold
Ministry of Pacific Island Affairs	Abba Fidow
Ministry of Youth Development	Sue van Daatselaar
Office of the Children's Commissioner	Mavis Duncanson (Dr)
Office of the Police Commissioner	Steve Christian (Superintendent)
Te Puni Kokiri	Maraea Bellamy

The advisors are invited to meet with the CYMRC on the second day of each CYMRC meeting.

The relationship between the CYMRC and the coroners is crucial to the functioning of review processes. The Coroners' Council has nominated a representative who attends CYMRC meetings as an advisor and liaison point between the two groups. Dr Murray Jamieson, the Coroner at Auckland, undertook this role until November 2003. His contribution was invaluable to the early development of mortality review processes. David Dowthwaite, the Rotorua Coroner is the current Coroners' Council representative.

1.4 Annual report

Mortality review committees established under sections 11 and 18 of the New Zealand Public Health and Disability Act 2000 must report at least annually to the Minister of Health. The CYMRC's first annual report was widely distributed in February 2004.

1.5 Website

The CYMRC website (www.newhealth.govt.nz/cymrc) is supported by the Ministry of Health. The CYMRC uses it to provide the wider community with more information about mortality review.

The first report is available from <http://www.newhealth.govt.nz/cymrc/Publications.htm>.

1.6 Information brochure for families and whanau

The CYMRC is committed to giving the community good information about mortality review processes. The CYMRC developed a brochure for families and whanau bereaved by the death of a child or young person. The brochure overviews the CYMRC and mortality review processes and suggests sources of information and support for bereaved families, as well as how families may contribute.

The brochure has been distributed free to members of the Funeral Directors Association of New Zealand Inc., general practitioners, and hospital and community paediatric services.

The CYMRC is particularly grateful to the funeral directors who agreed to distribute the brochure and extends its sincere thanks for this support.

See the brochure at <http://www.newhealth.govt.nz/cymrc/Documents/mortality.pdf>. Copies are also available by emailing cymrc@moh.govt.nz.

1.7 Local review processes

The CYMRC has spent considerable time and effort to develop viable mortality review processes and the means for analysing the causes of death leading to evidence-based recommendations for action.

Having members of the CYMRC involved with, the then, two pilot local mortality review groups has facilitated the process of establishing local review processes. Methods for undertaking local review have been explored, and a formal evaluation of pilot local mortality review processes has been commissioned. See Section 4.3 for a summary of the evaluation.

1.8 Training for local reviews

The CYMRC sponsored a training workshop in May 2004 for District Health Board (DHB) staff involved in mortality review processes. Sixteen people from 13 DHBs attended the workshop in Wellington.

The participants received training in the use of the central database and the review processes. Participants gave good feedback on the workshop.

The CYMRC anticipates holding another training workshop before the end of June 2005.

1.9 Research projects

The CYMRC commissioned two research projects and one evaluation.

- Water Deaths in Children and Youth 1980–2002 (see section 4.1)
- Review of Deaths from Infection in Hospital 2002–03 (see section 4.2)
- Evaluation of Pilot Local Mortality Review Sites (an independent evaluation undertaken by Dr Alison Stewart of the Otago Polytechnic School of Nursing and Midwifery, see section 4.3).

1.10 Data analysis

The database overseen by the CYMRC has had data added to it from 1 January 2002. The CYMRC has examined the mortality trends of child and young people on the basis of this data.

Core data is collected centrally from some government sources. 'Community' sourced information is also entered into the database when local review processes are under way. The comprehensive data collection allows analysis of trends and the circumstances around deaths.

The analysis of the data is reported following age bands:

- post-neonatal (28 days to 1 year)
- 1–4 years
- 5–9 years
- 10–14 years
- 15–19 years
- 20–24 years.

Data analysis, when combined with individual case review at the local level, is essential for understanding the underlying factors and providing a basis for recommendations

A detailed description of the data trends and recommendations based on this analysis are in Appendix A.

1.11 Changes to CYMRC membership

Appointments to statutory committees are an output of the Ministry of Health, not the CYMRC.

Since the CYMRC was first appointed in 2001, the following people have been members of the Committee:

- Amster Reedy
- Barry Taylor (Professor) (Chair)
- Beth Wood
- Carol Everard
- David Tipene-Leach (Dr)
- Ian Hassall (Dr)
- Jane Zuccollo (Dr)
- Pat Tuohy (Dr) (nominee of the Director-General of Health)
- Patrick Kelly (Dr)
- Peter Watson (Dr)
- Shannon Pakura (nominee of the Chief Executive of Child, Youth and Family)
- Teuila Percival (Dr).

The Minister of Health appointed the second CYMRC in December 2004. The appointments of the committee members are for a period until December 2006 or December 2007.

The current CYMRC is composed of the following people:

- Reappointments
 - Amster Reedy
 - Barry Taylor (Professor) (Chair)
 - David Tipene-Leach (Dr)
 - Ian Hassall (Dr)
 - Pat Tuohy (Dr) (nominee of the Director-General of Health)
- New appointments
 - Christopher Morris
 - Joanne Baxter (Dr)
 - Marie Connolly (nominee of the Chief Executive of Child, Youth and Family Service)
 - Russell Franklin (Dr)
 - Tracie Mafile'o.

For more information about the CYMRC and its membership, see its website (www.newhealth.govt.nz/cymrc).

2 Challenges for the Mortality Review Process

2.1 Quality of information

Section 2(1) of Schedule 5 of the New Zealand Public Health and Disability Act 2000 (the Act) provides:

2 Chairperson may require person to give information –

- (1) If a mortality review committee gives its chairperson, or an agent the committee appoints for the purpose, authority in writing to do so, the chairperson or agent may, by notice in writing to any person, require the person to give the committee information in the person’s possession, or under the person’s control, and relevant to the performance by the committee of any of its functions.

This provision has enabled the CYMRC to request data on deceased children and young people. Government and non-government agencies have been supplying requested information in a timely manner. Table 1 shows the sources and type of information supplied by various government agencies.

Table 1: Summary of data supplied by government agencies

Source of information	Type of information	Frequency of supply
Births, Deaths and Marriages (BDM)	Information is sourced from birth and death registrations. Birth and death registrations are supplied as matches for people aged under seven (about 50 percent of eligible cases are matched). Funeral directors usually make death notifications. They submit the death certificate as determined by the attending doctor. Data includes: <ul style="list-style-type: none"> • registered birth names (and aliases) • date and place of birth • mother’s and father’s names • date of death • place of death • cause of death as given by the doctor. 	Weekly
New Zealand Health Information Service (NZHIS)	The NZHIS is a business unit within the Ministry of Health. The NZHIS searches its databases, covering: <ul style="list-style-type: none"> • the National Minimum Data Set (secondary care admission information) • the National Health Index • maternity and newborn data • medical warnings • mortality • the cancer registry • mental health. 	Monthly

Source of information	Type of information	Frequency of supply
Land Transport New Zealand (LTNZ)	LTNZ was the Land Transport Safety Authority. LTNZ provides data on the deaths of all children and young people on public roads (but not farms, private roads or driveways). Data supplied is from on-scene investigations the Police and LTNZ undertake at the time of a road death. Data includes: <ul style="list-style-type: none"> • suspected use of alcohol • seatbelt usage • the time of the day • the type of road • the causes • the weather • road conditions • the other vehicles involved. 	Monthly
Water Safety New Zealand (WSNZ)	WSNZ is a non-governmental organisation. WSNZ provides data and background information for all water related deaths.	Monthly
Ministry of Justice	The Coroners Court determines when, where and how a death occurred. Court data includes: <ul style="list-style-type: none"> • the verdict • summary of cause or circumstances. 	Monthly
Individual coroners	More than 60 coroners are nationally distributed across New Zealand. Coroners have been asked to provide any information, including: <ul style="list-style-type: none"> • initial police reports • the pathologist's interim and final reports • the coroner's findings. 	Faxed to Data Group when available.

Most coroners are supplying information to the CYMRC in a timely manner. The CYMRC anticipates full reporting from the coroners will result from the proposed legislative changes to the coronial system.

Considerable work needs to be done to clarify what health-related information is collected for the coronial process. The CYMRC considers the following questions need to be answered:

- When is the information collected?
- Who collects the information?
- Where is the information stored?

In the meantime the CYMRC will continue to liaise with coroners to obtain a complete and adequate information set of the life and circumstances of children and young people who die.

2.2 Attributing cause of death

The timeliness of data collection is a crucial aspect of data quality assurance. Timely data flows enable accuracy to be checked while facts are still fresh in people's minds.

Figures and data produced in this report (Appendix A) are based on coding the cause of death to a single underlying cause (ICD-10).² In many cases, the attribution is based on three documents: the death certificate, the police report from the death scene and the pathologist's preliminary report. To ensure consistency, the CYMRC has decided to code the death to the 'main underlying' cause of death and to use ICD-10 classifications.

Deciding the main underlying cause of death can be difficult, especially when the child dies with multiple underlying causes.

The CYMRC has decided to attribute the deaths to a most relevant underlying cause, as its focus is where the most effective prevention could occur. In reality, multiple underlying causes often exist, so the CYMRC is considering how best to address this in future reports. For this report only one major underlying cause has been attributed to each case, usually the most distal (earliest probable) cause.

The following three examples (based on real examples) illustrate how cause of death is been attributed. These examples may help interpretation of the figures and tables in Appendix A.

- *Example 1:* A child suffered from severe perinatal asphyxia in the newborn period, leaving her profoundly disabled and she had recurrent chest infections due to difficulty in swallowing. At eight years of age she is found dead one morning and the post-mortem reveals pneumonia. This death would be attributed to 'certain conditions originating in the perinatal period'. This particular underlying cause of death can thus be present for a death at any age and usually requires the underlying picture to be severe developmental or medical consequence of perinatal asphyxia or extreme prematurity. In this case 'infection' would not be considered the 'main underlying cause'.
- *Example 2:* A 13-year-old known to have cystic fibrosis dies from respiratory failure during a severe chest infection. This death would be coded as a respiratory death rather than a death from infectious or parasitic disease.
- *Example 3:* A child with complex congenital heart disease dies two days after major surgery. This death would be coded to 'congenital malformations, deformations and chromosomal abnormalities' rather than to a 'disease of the circulatory system'.

When a death is coded as 'injury, poisoning and certain other consequences of external causes', an intent classification is also used, these being unintentional or intentional self-harm, assault, event of undetermined intent, health systems failure and injury occurring during law enforcement activities and/or acts of war.

Intent is often not obvious. When no decision can be made easily, the case is coded as "undetermined intent". The balance of probabilities based on all evidence available is used. When a local group of agents has considered the case in depth, their decision would be taken. When the case has not been reviewed in depth, the Data Group would look at all available evidence, and make a decision.

² Using the International Classification of Diseases version 10.

2.3 Confidentiality

Critical to the long-term future of child and young people mortality review is the confidence placed in the process by the public and individual practitioners.

Also critical to the success of child and youth mortality review is the knowledge that information requested by the CYMRC – directly or through its agents – is kept confidential. The Act acknowledges this by requiring strict confidentiality and containing provisions for fines and penalties for any breaches of the Act. All agents and members of the Data Group sign a confidentiality agreement (outlined in the first annual report).

The CYMRC has developed a confidentiality policy, which includes the following principles:

- written material containing personal details is kept to a minimum
- minutes or notes from local reviews are limited to action points, not personal details
- the central mortality database is protected by name and password
- data entry or download uses the Secure Sockets Layer (SSL) protocol with 128-bit encryption (ie, the same security protocol used for on-line banking and other sensitive web-based transactions)
- a private and secure website is used for some data transfer.

2.4 Legal issues

Some DHBS have expressed concerns about the control over the mortality review process, control over the information produced, confidentiality of information produced, and any potential liability of those involved in the process. This has resulted in the restating of the Act's intention and of the powers of an agent appointed by the chair of the CYMRC below.

- The CYMRC cannot delegate its legislative functions of reviewing and reporting about the deaths of children and youth to another "committee". The CYMRC can appoint 'agents' for the purposes of collecting information. Agents can meet together and share information about cases. The Act allows the CYMRC to appoint individuals as agents.
- The CYMRC may appoint an unlimited number of agents. These agents may be appointed for specific purposes that can include review of the deaths so the review's conclusions can be passed to the CYMRC and data entered into the central database.
- Agents cannot simultaneously interview (or case conference) with a group of people involved in a death when some of that group do not already have access to the information that will be discussed. When a case conference has been held (under some other auspice) before meeting with the group of agents committee, a simultaneous discussion with the group of agents is legitimate.
- Agents may request information from other people or groups. Any person or group from whom information is requested may refer the request to the Office of the Ombudsmen (www.ombudsmen.govt.nz) if they believe the request is unjustified. The Ombudsmen may give advice about the nature of the request or rule whether the request is or is not justified.

Two issues remain unclear and of concern to the CYMRC. The Act does not allow full case conference reviews. In this context a case conference is multi-disciplinary meeting of multiple agencies sharing information about a specific case (or similar cases).

Auckland and Waitemata DHBs worked with the CYMRC to develop mortality review processes in 2003–04. In selected cases, the case conference model of in-depth review yielded valuable insights for case workers as well as useful conclusions for the CYMRC. However, after concerns of the legitimacy of such reviews were voiced, the case conference reviews were discontinued. Despite the perceived difficulties with case conferences, the CYMRC believes case conferences would lead to better quality data, better interagency coordination, and an ability to make recommendations for the prevention of deaths in relation to local and national systems and practices. The current process is limited to the collection of information serially from individual informants rather than in an information-sharing group context.

It is also unclear how a group of agents can make local recommendations for changes in policies or practices.

The CYMRC recommends further policy work be undertaken to:

- suggest to government that the legislation be modified to allow case conference reviews
- clarify how local review processes can lead to local changes in policies and practices.

2.5 Place of families and whanau in review processes

Bereaved families and whanau suffer enormous pain and grief. Experience shows many families feel a strong need to try to prevent other families going through the same trauma. Parents have indicated they would like to be involved in any process that would help achieve this aim. The whole mortality review process is directed towards this aim, so parents and families and the mortality review process should be aligned where possible.

The CYMRC has developed principles to enable two levels of parental involvement in the mortality review process.

The first is that the public needs to know about mortality review processes. To this end, the CYMRC has developed a brochure describing the process. The brochure was trialled with bereaved parents, who generously participated in the brochure's creation and whose feedback was incorporated into the final brochure.

The pamphlet was distributed by members of the Funeral Directors Association of New Zealand and is also available from general practitioners and paediatric departments.

Secondly, parents will be given the opportunity to provide information directly to the Data Group via a web-enabled feedback form. Thus, both the CYMRC and its agents will be able to view parents' comments. These comments will help inform the CYMRC's recommendations to the Minister of Health. Like other information supplied to the CYMRC, comments made by parents will be confidential.

The CYMRC has been clear in their information to families that the CYMRC cannot advise or action 'complaints' about the care of a child or young person. The CYMRC is developing information for parents.

The mortality review process may help other families by helping to change the system. It is important for families to realise that no direct individual feedback on the CYMRC's conclusions will be possible because of the Act's confidentiality requirements.

2.6 Resourcing the mortality review

The resources made available for mortality review have supported the developmental stages of a robust process and a base of learning that will be applied to further mortality review processes (the perinatal and maternal mortality reviews). It has allowed the development of a unique web-based database for the rapid collection of mortality information about children and young people.

A priority for the CYMRC is working with DHBs to address the resourcing of local child and youth mortality review processes. The Provider Quality Specification of the Operation Policy Framework, states:

- A.6.A** Each DHB is expected to implement quality processes dedicated to reducing mortality and morbidity generally. The Child and Youth Mortality Review Committee are developing review processes specifically for child and youth deaths (28 days to 24 years). These processes may provide a good base for undertaking systematic child and youth mortality review.

Potentially there are both costs and benefits to the DHB from being involved with the mortality review processes.

An interdependent relationship exists between the CYMRC and DHBs. To develop this relationship the CYMRC allows local agents to access the centralised database and makes available documented processes, quality control information and peer support to local review processes. Contributing information to the national system in turn provides users of the system some surety that the work will contribute to a national picture, and will assist with the development of recommendations to the Minister of Health.

DHBs will face some costs associated with mortality review processes. A coordinator for the local process will be required. Their functions would include liaising with local agencies involved with the child to obtain additional information for the database, convening meetings of the agents, entering comments from agents into the database. The CYMRC estimates a 0.1–0.2 full-time equivalent local coordinator for every 1000 births. The local coordinator would also need secure office space, computer equipment, travel and training.

Uncounted is the time commitment from individual local agents, whose contribution comes at personal and institutional costs. The CYMRC feels this is a core quality assurance activity that will be highly valuable to the individual and their employer. Involvement in multi-agency collaboration and activity is a requirement on most government agencies (and professional bodies). Mortality review is an example of such an activity. The colleges and professional associations of practitioners require involvement in quality improvement activities and it is expected as a part of normal professional life.

3 Projects Commissioned by the CYMRC

3.1 Water deaths in children and youth 1980–2002

Water Safety New Zealand is a non-governmental organisation that ensures the community's water education safety needs are met.

Water Safety New Zealand had more than 20 years of data (DrownBase™) that had not been analysed in any detail. During 2003–04, Dr Gabrielle McDonald analysed the data as part of her professional training and development at the University of Otago. The CYMRC is grateful to Water Safety New Zealand for allowing it to use their data.

The project examined the epidemiology of drowning in people aged 0–24 in New Zealand to identify appropriate interventions that might reduce child and youth death from drowning.

The project reviewed the detailed reports collated by Water Safety New Zealand of child and youth drownings from 1980–2002. The full report is available from the websites of the CYMRC (www.newhealth.govt.nz/cymrc) and Water Safety New Zealand (www.watersafety.org.nz).

Key facts from the research project

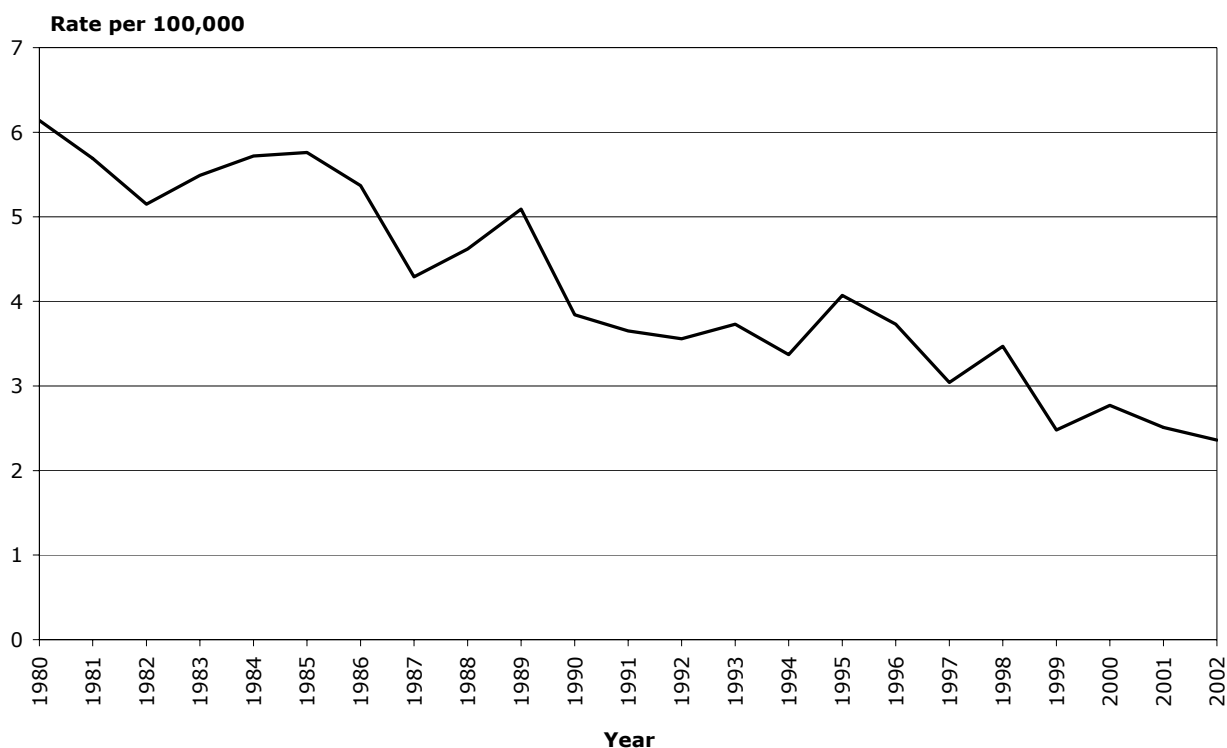
The research project determined that:

- 1334 children and young people drowned over the 23-year study period
- 76 percent of children and young people who drowned were male
- the highest rate of drowning was in the group aged 1–4 (6.9 per 100,000 population)³
- the second highest rate of drowning was in the group aged 15–24 (5.9 per 100,000 population)
- accidental immersions were the most common activity before drowning (in 37 percent of cases) followed by swimming (18 percent) and motor vehicle accidents (14 percent)
- 67 percent of infant and toddler drownings occurred in the bathtub
- drowning in home swimming pools was the main cause of drowning in the group aged 1–4 (42 percent)
- the number of toddler deaths in home pools reduced, coinciding with legislation requiring domestic pools to be fenced
- 15–19-year-olds drowned predominantly as a result of motor vehicle accidents and in natural bodies of water (lakes, rivers and the sea)
- 28 percent of 15–19-year-old drownings involved alcohol.

Although these statistics make grim reading, Figure 1 shows a steady reduction in the annual number of water-related deaths over the 23-year period.

³ Rate per 100,000 population means if there were 100,000 1–4-years-olds, 6.9 would drown in a year.

Figure 1: Drowning rates per 100,000 age-specific population in children and young people aged under 25, 1980–2002



The CYMRC recommends, as a result of the Water Deaths in Children and Youth 1980–2002 project:

- All children under the age of three should be constantly supervised in the bath by an adult.
- Children under the age of five should not be left to supervise younger children in the bath.
- All home pools need to be fenced in compliance with the Fencing of Swimming Pools Act 1987.
- Gates to swimming pools must never be propped open.
- Adults need to constantly supervise toddlers when they are near any body of water.
- Adolescents, particularly males, need to know about and practice water safety.
- Children and young people having adequate swimming ability is vital.
- Alcohol use when people are engaged in water-based recreation should be discouraged. People should pay attention to weather conditions, safety equipment and their skill level before engaging in water-based recreation.
- The appropriate use of buoyancy aids is essential.

The CYMRC have reviewed the *Drowning Prevention Strategy: Towards a water safe New Zealand 2005–2015: Draft consultation document*,⁴ and support its proposals.

⁴ Minister of ACC. 2004. *Drowning Prevention Strategy: Towards a water safe New Zealand 2005–2015: Draft consultation document*. Wellington: Accident Compensation Corporation. URL: <http://www.nzips.govt.nz/documents/drowning-strategy-draft-consultation-document.pdf> (accessed 21 February 2005).

3.2 Review of deaths from infection in hospital, 2002–03

Throughout New Zealand systems of variable quality are in place to review the deaths of children and young people in hospital.

A national survey undertaken by the CYMRC in 2002–03 of hospital mortality review processes indicates that at least 40 percent of child and youth deaths, as inpatients, were not reviewed. One reason for this low rate is large paediatric caseloads making timely paediatrician attendance at such reviews difficult to arrange.

The CYMRC believes a minimal process should be in place for all inpatient deaths. The Review of Deaths from Infection in Hospital 2002–03 project was the first effort to develop a rapid reporting form (RRF) to be filled in by the senior medical and nursing clinician involved in any hospital death.

Over the summer of 2003 a medical student, Ailar Ansarian, was awarded a University of Otago summer research scholarship to work on this project. The work is summarised below. The RRFs development continues. The CYMRC plans that from January 2005 RRFs will be sent to each DHB coronial liaison paediatrician, who will identify the main medical and nursing clinician involved in a death and ask them to fill in an RRF. The RRF will be returned to the Data Group for entry into the mortality database. These reports will inform local mortality review and the CYMRC.

The decision was made to test the RRF for the group that died of infectious deaths in hospital during 2002 and 2003.

Key points from the trial

The research determined that:

- there were 79 deaths from infectious disease nationally over this period
- 95 of 158 RRFs were returned (a response rate of 61%). Of these 48 were from medical personnel and 49 from nursing. There was at least one response for 67 cases (85% of cases)
- 36 percent (35 out of 97) of the respondents identified 55 instances where system issues affected the care of the child or young person in 18 cases
- of those who identified system failure issues:
 - 35 percent identified system failures at the prevention level
 - 41 percent identified system failures at the pre-hospital level
 - 41 percent identified system failures at the hospital level
 - 32 percent identified system failures that occurred after the death.

(Note that the respondents could identify systems problems at more than one level, so the overall percentage is greater than 100 percent.)

The amount of time invested in completing an RRF varied, with 78 percent of respondents taking less than 15 minutes to complete it.

More than half (53) of the respondents clearly stated the RRF would provide more useful information about system failures if it were filled out closer to the time the death occurred.

The response rate of 61 percent is encouraging, especially as many of the deaths would have occurred up to two years earlier. Most comments were positive and constructive. Thus, clinicians who have a child or young person die in their care recognise and accept the need for a reflective analysis of preventable system failures that may have occurred. The majority of respondents (55 percent) believed the best time to complete the RRF was within one month of the death.

The CYMRC has agreed to the final modified RRFs being sent to clinicians within one month of a death being registered with the CYMRC. The Data Group manages this process.

3.3 Evaluation of pilot local mortality review sites

In mid-2002, the CYMRC wrote to DHBs asking them to volunteer to pilot local mortality review processes. Auckland and Waitemata DHBs (working jointly) and Tairāwhiti DHB were willing to pilot the processes.

Otago DHB volunteered to participate but did not develop a functioning committee until mid-2004.

In mid-2004, the CYMRC commissioned Dr Alison Stewart⁵ to independently evaluate the local mortality review. Following is the executive summary of the report. The full report is available from the Secretariat (cymrc.govt.nz).

Lessons learned from two child and youth local mortality review committees during the pilot period 2003–04

Executive summary

1 Introduction

This report summarises the key findings of an inquiry process to:

- document the progress of two pilot local mortality review committees (LMRCs)
- identify lessons from the pilot sites which can inform the Child Youth Mortality Review Committee (CYMRC) decisions for future local mortality review groups.

2 Background

The ministerially appointed national CYMRC was established in 2001 under the provisions of the New Zealand Public Health and Disability Act (2000) with responsibilities to report on and review deaths of children and youth aged 4 weeks to 24 years. During 2002-3, the CYMRC established a national Mortality Database to supply information, obtained from routine data sources such as birth and death certificates, to LMRCs. In 2003 two pilot site LMRCs were established with the purpose of developing local child and youth mortality review processes before extending the methodology nationwide. In 2004 a further five LMRCs began to establish. The findings in this report refer to the pilot period January 2003 to September 2004.

⁵ Dr Stewart is Director of Post-graduate Programmes at the School of Nursing at the Otago Polytechnic, Dunedin.

3 Method

The inquiry process was informed by an established constructivist approach for evaluation. Sources of information included existing documents from LMRCs and comments from stakeholders who had been involved with the CYMRC and/or LMRC activities. Forty stakeholders offered comment in meetings (34) telephone interview (4) or writing (2). Participation included over 70% of current LMRC members and 15 of 16 specifically identified stakeholders from local and central agencies (eg, education, Coroner's Council, Child Youth and Family, Ministry of Health).

4 Context of pilot LMRCs

Tairawhiti District Child Youth Mortality Review Committee (TDCYMRC) has responsibility for deaths in the Tairawhiti District Health Board area, which totalled 13 during 2003. The committee has 14 members, meets bimonthly for two hours and has focused on gathering information and beginning review processes. The co-ordinator role is funded four hours per week by the DHB.

Auckland and Waitemata Child Youth Mortality Review Committee (AWCYMRC) has responsibility for deaths in both the Auckland and Waitemata District Health Board (DHB) areas. There was in excess of 100 deaths in 2003. The committee has 8–14 members meeting monthly for four hours. The full-time co-ordinator role is funded by the two DHBs. Work has included trialling a range of review approaches.

5 Establishment and functioning of LMRCs

Both pilot sites spent time **forming** the committee. This included developing a shared vision for mortality review, consulting with Maori and local communities, scoping sources of available information and determining the way in which review could be undertaken.

Once the LMRC was functional, attention was focused on **gathering information** to enter for the Mortality Database and for use at review meetings. This involved the coordinator and committee members approaching service providers (such as police, health professionals, school counsellors) to obtain records and observations from personnel involved with families. A number of quality issues were identified including: access to information; missing records; inadequate or illegible documentation; and the need for adequate death scene investigation. The place of family/whanau in mortality review was of concern for the LMRCs and CYMRC. It was not resolved during the pilot period. A pamphlet informing bereaved families about the work of the CYMRC is being disseminated nationally during January 2005.

As part of developing **review processes**, Sentinel Event Review methodology was trialled. The purpose was to maintain a focus on system issues preceding the death in order to identify any appropriate changes that could prevent future deaths. Experience from the AWCYMRC indicated that there was insufficient resourcing to fully implement the methodology, therefore an adaptation was used for subsequent reviews. This enabled the CYMRC to identify four levels of review:

- Level 1: Summary – for all deaths using information from routine datasets
- Level 2a: Paper – for all deaths using level 1 information supplemented by written records
- Level 2b: In-depth – for selected deaths using additional information sourced from workers involved with the child/youth
- Level 3: Participant – for selected deaths with the workers involved with the child/youth attending the LMRC review meeting.

Pilot work included: identifying frameworks to organise information; determining the sequence of information presentation; and the type of review tools utilised. The AWCYMRC refined the process of participant review to have senior representatives from agencies attending meetings with, where appropriate, the worker involved with the family. This strategy provided support to the worker and offered senior expertise to assist with identification of system failures. Comments from some review participants emphasise their commitment to the educative function of this process and illustrate that changes were subsequently implemented in practice.

Resource implications for local mortality review were identified by stakeholders and included:

- time taken to source information and to undertake review
- the importance of an infrastructure to enable LMRCs develop consistent information gathering and review processes.

Evidence from the pilot sites indicates that the CYMRC review methodology is feasible since pilot sites became functional and reviews identified:

- local trends
- unique cases of concern
- missing information
- themes and profiles emerging cross cases
- conclusions and recommendations from in-depth review of selected cases.

6 Lessons that might be learned and associated recommendations

Throughout the pilot period, a range of lessons have been learned and integrated into the developing review processes. In addition, there are current changes which have implications for the future methodology. These include: the forthcoming revised Coroners' Act; the forthcoming development of roles which will assist information gathering (such as DHB Coronial Liaison Paediatricians and health trained investigator); a recent legal opinion on the provisions of mortality review under the NZPHDA which has re-named LMRCs as *local mortality review groups* (LMRGs) and precludes the use of participant review where several workers simultaneously engage in round-table discussion with LMRG members. Based on findings from this inquiry and the changing context a number of comments and recommendations have been made in the following areas.

- 1) Moving from the development phase of the pilot period to articulate the nationwide methodology with documented expectations of processes and practices for information gathering and review.
- 2) Restoring confidence in the continuation of local mortality review following the uncertainty during 2004 regarding the management of confidentiality for participant review under the provisions of the NZPHDA.
- 3) Clarifying the role and responsibilities of LMRGs with regard to: functional relationship with the CYMRC; communication and reporting structure; and degree of autonomy for context-specific practices including authority to disseminate recommendations and implement local changes.
- 4) Negotiating an annual work programme between the CYMRC and each LMRG which takes into account nationwide goals, local mortality issues and available resources.
- 5) Continuing discussion between the LMRGs and the CYMRC regarding the place of families/whanau in mortality review. It is suggested that the effectiveness of the distribution of the information pamphlet for bereaved families is assessed at the end of 2005.

- 6) Continuing the CYMRC activities to assist LMRGs access information from local agencies. This should include disseminating information materials about mortality review to service providers and further consolidating memoranda of understanding with central agencies to share information.
- 7) Scoping the feasibility and effectiveness of using standard report forms as part of LMRG information gathering processes.
- 8) Continuing and developing the education programme for LMRGs which was started in 2003.
- 9) Continuing to refine the process of LMRG information gathering and data entry to the Mortality Database in order to ensure alignment with future strategies for national reporting and review.
- 10) Developing a strategy to evaluate the outcomes of the CYMRC and LMRG activity.
- 11) Ensuring that there is sufficient secretariat/project manager support for the work of **both** the CYMRC and the LMRGs. The latter includes: establishing new LMRGs; maintenance of functioning LMRGs; and, in the short-term, articulating the details of the methodology for use nationwide.

4 Cross-departmental Research Pool Bid: Environmentally-sensitive Deaths in New Zealand Children and Youth: What are the Modifiable Factors?

The Cross-Departmental Research Pool (CDRP) supports and funds policy-related research in government departments.

The CDRP's objectives are to:⁶

- fund high quality cross-departmental research that will support the Government's policies
- facilitate new relationships and capabilities within and between departments so departments take greater responsibility for investing in long-term high quality research
- develop a portfolio of research activity divided between smaller, short-term projects to facilitate new relationships and capabilities, and multi-year large scale projects to provide key building blocks for the Government's decision making.

The CYMRC was instrumental in preparing an application to the CDRP in 2002 into Environmentally Sensitive Deaths in New Zealand Children and Youth: What Are the Modifiable Factors? The project brought together the Ministry of Health, Ministry of Youth Affairs (now the Ministry of Youth Development) and ACC. The Department of Courts, the Coroners' Council, Te Puni Kokiri, Child, Youth and Family Service, the Office of the Police Commissioner, and the Ministry of Education supported the project. The Ministry of Social Development and Ministry of Justice expressed a policy interest in the project.

The proposed project will place health trained investigators into the coronial investigation team for two specific types of death: sudden unexpected deaths (about 80 each year) and youth suicide deaths (about 90 each year). The information collected will go directly to coroners and will inform the CYMRC. These investigators will also help families to access any health or support services they need. For sudden unexpected deaths they will also ask the same (or similar) questions of four control families to establish the level of risk associated with specific environmental and social exposures that might then inform direct intervention at the population level.

Public Health Intelligence in the Ministry of Health's Public Health Directorate will manage the project. A project manager will be appointed early in 2005.

⁶ See Ministry of Research, Science and Technology. No date. Cross Department Research Pool. www.morst.govt.nz/?CHANNEL=CROSS+DEPARTMENTAL+RESEARCH+POOL&PAGE=Cross+Department+Research+Pool (accessed 17 February 2005).

5 Strategic Objectives for 2005/06

The CYMRC has agreed its strategic objectives, and developed goals for 2005/06 (see Table 2).

The work programme that will underpin these strategic objectives is in development.

Table 2: CYMRC's strategic objectives and goals

Strategic objectives	Goals for 2005/06
Quality processes	Develop processes for mortality review at a local level. Improve the quality and analysis of the database, including the establishment of parents reporting to database. Refine and identify multiple cause attribution for cases. Enhance data links from other national databases. Develop a methodology for making evidence-based recommendations to reduce child and youth mortality.
Prevention and research	Identify priorities to reduce Maori child and youth mortality. Provide in-depth analysis of high priority areas. Oversee the Cross-Department Research Pool project.
Communication and partnership	Enhance an effective working relationship with other review processes, especially the coronial and death investigation process. Promote the broad ownership of the mortality review process.

6 Recommendations

6.1 Recommendations for functioning of national review process

The CYMRC recommends:

1. a formal service level agreement is signed between the CYMRC chair and the Ministry of Health about the parties' mutual obligations
2. the value of an interactive internet-based Child and Youth Mortality Database is recognised and receives secure funding in the medium term
3. data collection and sharing protocols between the coroners, police and CYMRC are **specifically** mentioned and allowed in the Coroners Bill
4. Further policy work is carried out, with a view to a legislative change, to enable case conferences with a range of professionals and agencies to inform mortality review.

6.2 Recommendations on functioning of local review process

The CYMRC recommends:

5. the recommendations from the Evaluation of the Pilot Local Mortality Review Sites are noted
6. local mortality review be recognised as providing detailed and high quality information that can be accessed to inform the recommendations for prevention
7. that multi-agency local review processes be recognised as promoting networking, local system change and increasing social capital
8. a project team is funded with members from DHBs and the CYMRC to develop written protocols for:
 - local mortality review processes
 - reporting at the local level to participating agencies
9. DHBs note the requirement for child and youth mortality review as part of the Provider Quality Specifications (Quality requirements for clinical effectiveness in the Operation Policy Framework, section A.6.A).

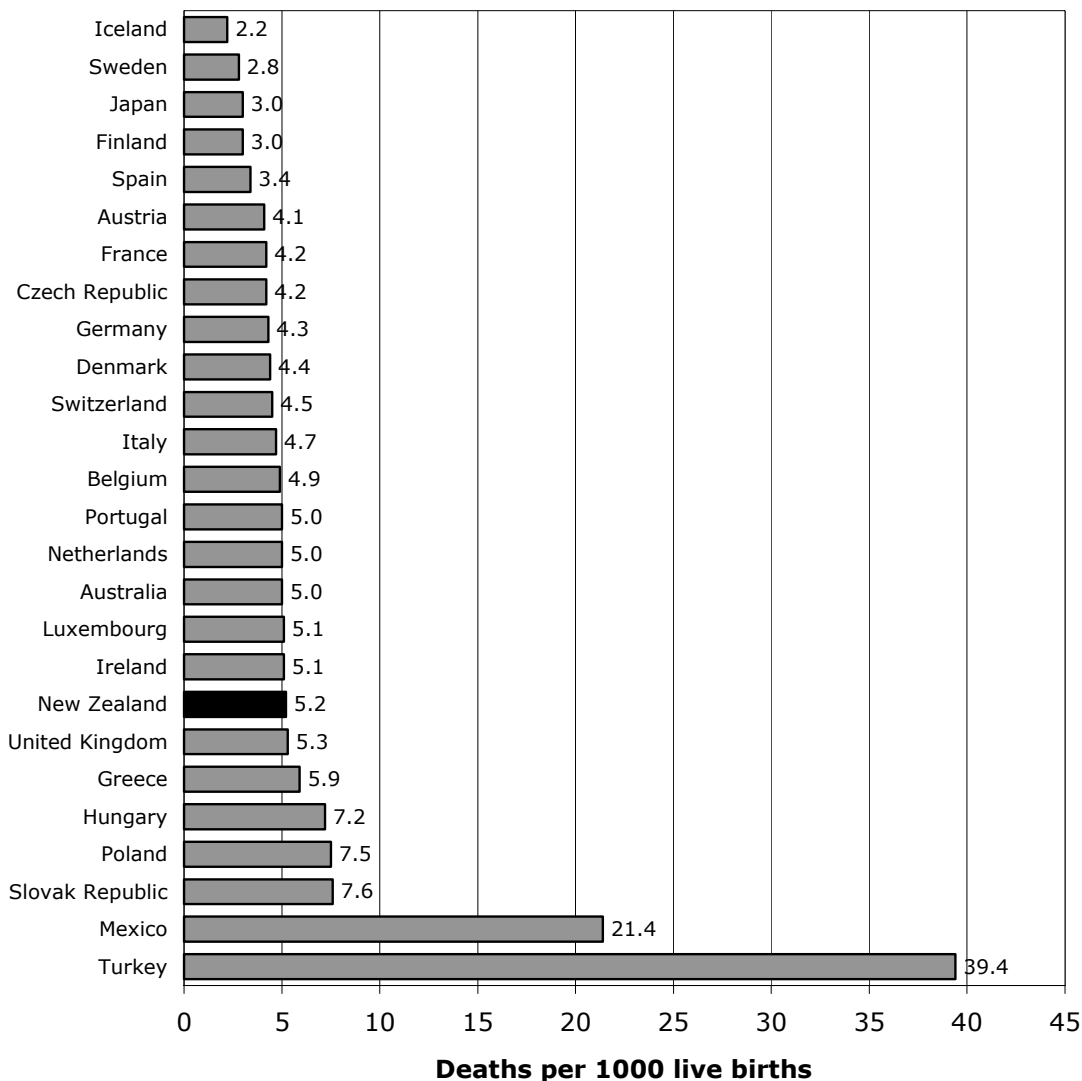
6.3 Recommendations for decreasing child and youth mortality in New Zealand

Overall, child and youth mortality in New Zealand continues to decline. Current rates are in Appendix A.

The CYMRC's first annual report noted specific concerns in the areas of youth suicide and sudden unexpected deaths in infancy. The solution for these problems requires involvement of all parts of our community. Reductions in mortality rates are possible. This is highlighted by the fact that most Organisation for Economic Co-operation and Development (OECD) countries now have lower rates of child and youth mortality. Of the 26 OECD countries that have reported on infant mortality for 2002, New Zealand is ranked nineteenth (see Figure 2).

The CYMRC's recommendations are by age group.

Figure 2: OECD infant mortality (deaths per 1000 live births), 2002



Note: Canada, Korea and the United States of America have not yet reported 2002 data.

Source: Organisation for Economic Co-operation and Development. No date. *Infant mortality, deaths per 1000 live births*. URL: <http://www.oecd.org/dataoecd/13/40/31963124.xls> (accessed 31 January 2005).

Post-neonatal (28 days to 1 year)

Infant mortality continues to decrease with New Zealand’s total mortality rate comparable with those in Australia and the United Kingdom (see Figure 2). For the last 10 years, improvements have mainly been in a continuing decline in post-neonatal mortality. Within this group aged 28 days to 1 year, combining Sudden Unexpected Death of Infants (SUDI) undetermined and ‘awaiting coroners findings’ gives 41 to 48 deaths per year, a rate of 0.76 to 0.93 per 1000 live births. This is still considerably higher than in many other countries.

It is generally thought that with careful implementation a prevention campaign that targets safe sleep practices (ie, babies sleeping on their back, the avoidance of maternal smoking, no bedsharing when the mother is a smoker, and avoiding covering the baby’s the face) that SUDI rates of 0.1 to 0.2 per 1000 live births are achievable. Therefore, in New Zealand, potential exists for a further 40 post-neonatal deaths each year to be prevented.

Case reviews at the local level have identified several important issues in promoting and ensuring a safe sleeping environment for babies. In some cases there has been a lack of active promotion of these well-known recommendations for safe sleeping in babies. The CYMRC has also found cases where support for, and the knowledge of, these safe practices are not present in the community. This most often occurs when the infant is being cared for in unusual situations, such as being looked after by someone new (eg, foster care or women's refuge) or into a new environment (eg, on holiday).

In these often stressful situations, attention to and the provision of a safe environment for babies is essential.

The CYMRC recommends:

10. all advisors and health care providers actively promote safe sleeping practices
11. all services that offer care to infants and mothers provide safe sleeping environments for infants
12. further work is undertaken to make sure the 'safe environment' message effectively reaches high-risk families and providers of care maintain their knowledge and advise on safe sleeping environments
13. *Earlier* use is made of the interagency case management (eg, Strengthening Families) for complex high-risk families with young infants or babies
14. a protocol for sensitive death scene investigation is collaboratively developed at a national level by police, coronial and health services (including pathologists) and Maori. The CYMRC continues to maintain an interest in its development.

Early childhood (1–4 years)

In the 1–4 years age group a continued slow decline in overall mortality rate exists. The death rates are much lower than for children aged under 1 year. While medical illness or congenital abnormality contributes the largest cause of death, unintentional injuries remain a cause of 36 percent of the deaths in this group.

Within this group three important preventable causes of death stand out: deaths in motor vehicle accidents, drowning and fire. In-depth reviews continue to suggest a variable quality investigation of the health circumstances around some deaths in this age group.

Children in motor vehicle accidents will be the subject of a research project in 2005/06. Initial analysis of Land Transport Safety Authority data about children was undertaken over the 2004/05 summer and will be reported on in the next annual report.

Drowning deaths of young children was the subject of a substantial research project. The results of the project are in section 4.1. The full report is on the websites of the CYMRC (www.newhealth.govt.nz/cymrc) and Water Safety New Zealand (www.watersafety.org.nz). Based on this research project, the CYMRC recommends:

15. leaving children less than three years of age alone in a bath presents a significant drowning risk. Therefore, parents must be given information to help them understand and manage the risk in their homes
16. this information should be in the Well Child booklet (formerly the 'Plunket book').

As a result of the in-depth review of children in this age group the CYMRC recommends:

17. adult services (especially mental health services) actively consider the safety of the children in the family of an adult mental health service consumer. In particular, parents not turning up for appointments may signal an increased risk for children in that environment. A parent or caregiver not turning up for a mental health appointment should trigger a prompt follow up (eg, a phone call or home visit) by the health service
18. adequate housing and a safe environment is not provided to many children who die of unintentional injuries. The CYMRC recommends continued effort by government agencies and others to improve housing quality, especially where children are living
19. the CYMRC shares information with the Ministry of Consumer Affairs about the safety of bath seats and swimming rings for babies and infants, as in the last two years at least two deaths were related to the unsupervised use of these products.

Mid-childhood (5–9 years)

A slow decline in the death rate for the group aged 5–9 continues, with relatively little change in the last seven years. Deaths on public roads and drownings are important issues. Death from cancer causes a quarter of these deaths.

No in-depth case reviews were done in this age group.

Late childhood (10–14 years)

While injuries from motor vehicle accidents and childhood cancer dominate the causes of death in the group aged 10–14, the CYMRC notes with concern the suicide and assault related deaths in this group. The means of suicide in this group is almost always hanging. The lethality and easy access to this means of suicide suggest it is important to develop a culture that does not suggest this as an acceptable option. The dramatisation of suicide by hanging in recent films is of concern.

No in-depth case reviews were done in this age group.

Adolescence (15–19 years)

The death rate in the group aged 15–19 has decreased over the last six years. Only 25 percent of the deaths were directly related to a medical cause. Most deaths were influenced more by social and environmental factors. The main cause of death category is unintentional injury, mainly motor vehicle accidents on public roads. The decrease in the rate over recent years is mainly due to decreases in this category of death. The other main category of death is intentional self-harm (25 percent of deaths), mainly by suffocation.

Not enough in-depth reviews of these deaths have been done to make any more than initial comments. In many of the deaths an important role appears to be played by alcohol and other drug abuse. Victims' early background suggests to the CYMRC that an ongoing major focus on child abuse prevention is important. The CYMRC endorses the work being done by Child, Youth and Family and the Ministry of Social Development called 'Sustainable responses to demand,' which focuses on young people's transitions to stability.⁷ Transition periods appear to be the high-risk time for suicide. Initial case reviews suggest that vulnerable children and youth should receive ongoing support when leaving a service or an educational institution, or at times of high family stress.

⁷ Sustainable Responses to Demand – from an internal Child, Youth and Family project document. (CYF, Wellington, 2004).

The CYMRC will develop a picture of practices in the community that may contribute to death from motor vehicle accidents as a focus of the 2005/06 work programme.

Youth (20–24 years)

There has been a decrease in deaths in this age group over the last 20 years, mainly as a result of fewer motor vehicle accidents.

Despite this, most deaths have preventable elements. The most important are unintentional injuries, with motor vehicle accidents the main cause (25 percent of all deaths in this age group). The second largest cause, accounting for 26 percent of deaths, is suicide, with the main method being suffocation. For this age group, poisoning (by carbon monoxide) is a more prominent cause of death than in the group aged 15–19. Note that in a large group of deaths (especially vehicular deaths) intent is unclear.

The CYMRC has insufficient insights from in-depth reviews to make any clear recommendations. However, further recognition of the cultural determinants of depression, suicide and mental illness, and the need for culturally appropriate health services have been identified as important for preventing deaths in this age group.

Appendix A: Child and Youth Mortality Statistics

Introduction

The Child and Youth Mortality Review Committee (CYMRC) has reviewed available child and youth mortality figures and historical trends in New Zealand. The sources of data were:

- the New Zealand Health Information Service (NZHIS) for historic mortality rate data
- Statistics New Zealand for live births and mean resident population estimates for 2002 and 2003
- the CYMRC database for mortality data.

Information collected and kept by the NZHIS has been available in public reports since the 1930s. Usually official information on these matters is reported on average three years after the completion of each year. For this report, we are using the data from 1979 until 2000, which is the latest information available as of March 2005. It is important to note that NZHIS official death statistics are based on year of registration of death, not on date of death.

The CYMRC database collects data on deaths from 1 January 2002. Data comes from a variety of sources including:

- Births, Deaths and Marriages (BDM)
- NZHIS
- Land Transport Safety Authority (now Land Transport New Zealand)
- Water Safety New Zealand
- individual coroners
- the Coroners Court
- local CYMRC agents.

Further data sources are being investigated.

Data from the various sources is linked using the National Health Index (NHI). Linking data received is not always straightforward, because:

- each individual does not necessarily have a unique NHI
- some individuals are registered with different names and/or addresses to those recorded with the NHI or by the police
- of the delay in BDM registration of some deaths.

Based on the information obtained, the Child and Youth Mortality Data Group (the Data Group) codes NHI, age group, ethnicity, District Health Board (DHB) and the underlying cause of death for all deaths. For deaths from external causes, the intent is also coded. As discussed in section 2.2 (page 7), the Data Group has coded deaths to a single underlying cause when often multiple underlying causes exist. The Data Group has used the single underlying cause most likely to be considered preventable – usually the most distal cause. In the following tables the 'Subject to Coroner's Finding' category refers to deaths for which no coroners' findings have yet been received and no other information regarding the cause of death has been received from other sources. Year of death refers to calendar year of actual death, not of death registration.

It is important to note that we have in this report included all deaths in New Zealand within the age-groups specified (including visitors to New Zealand). Between 1.2% and 3% of deaths are in children or youth who have an overseas "home" address. In calculating rates, the rates quoted include those with an overseas home address whilst denominator in the rates calculation do not include anyone who has not been resident in New Zealand greater than six months. Thus our rate calculations will be slight over-estimates of the real rate. We plan to separate out these deaths in future annual reports and calculate rates only on New Zealand resident deaths.

Readers need to be aware that CYMRC data have limitations because the data are derived from a database that is being continually updated. The Data Group believes very few deaths will be notified to it more than one year after the death and the rates will be comparable with finalised NZHIS figures. However, this will need to be tested once the NZHIS releases its official statistics for 2002.

For this second report, CYMRC data is analysed for 1 January 2002 to 31 December 2003. This data is reported as of 28 January 2005. Because of small numbers in some groups the two years have been combined for the percentages of the categories of death in each age group.

This year the Data Group has presented age-specific ethnicity rates only for the two major focus areas: sudden unexpected deaths of infants (SUDI) and suicide. The Data Group also presents ethnicity data for the 10 most common causes of death. The CYMRC will report age-specific rates by ethnicity next year with a further in-depth analysis of Maori child and youth mortality in New Zealand.

Infant mortality (deaths in first year of life)

Infant mortality is the number of deaths of infants aged 52 weeks or less. The infant mortality rate (expressed as the number of deaths per 1000 live births) is frequently used to compare the standard of services in different countries.

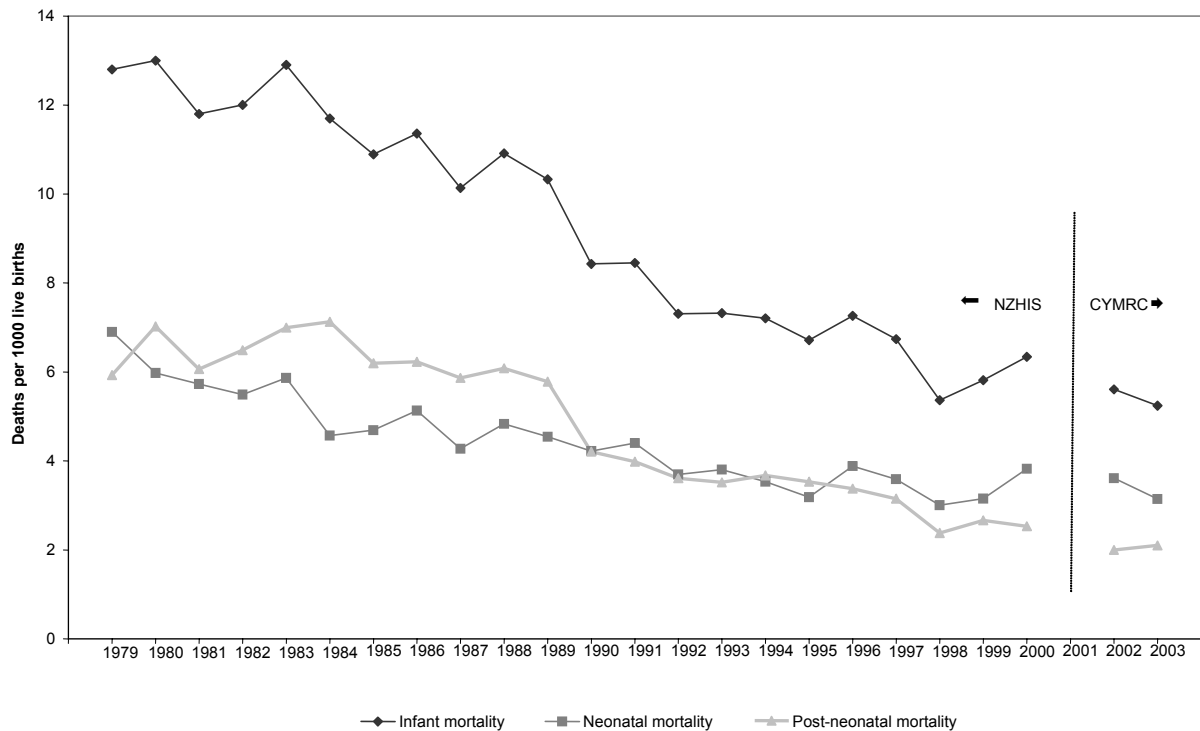
The infant mortality figure is the total of the two following groups.

- Neonatal mortality: The deaths in the first 28 days of life (four weeks), being a reasonable overall measure of maternal health, midwifery, obstetric and neonatal intensive care services.
- Post-neonatal mortality: Deaths from 29–365 days of life. A measure of preventative work done with mothers and families before and after birth, and including the psychosocial environment they live in.

For the sake of completeness, the Data Group has included deaths in the first month of life in the infant mortality trend graph, even though it is not in the CYMRC's brief to review those deaths.

Trends for all three rates are shown next, with the first, infant mortality, showing for the total population, that is, how New Zealand has done over time in Figure A1.

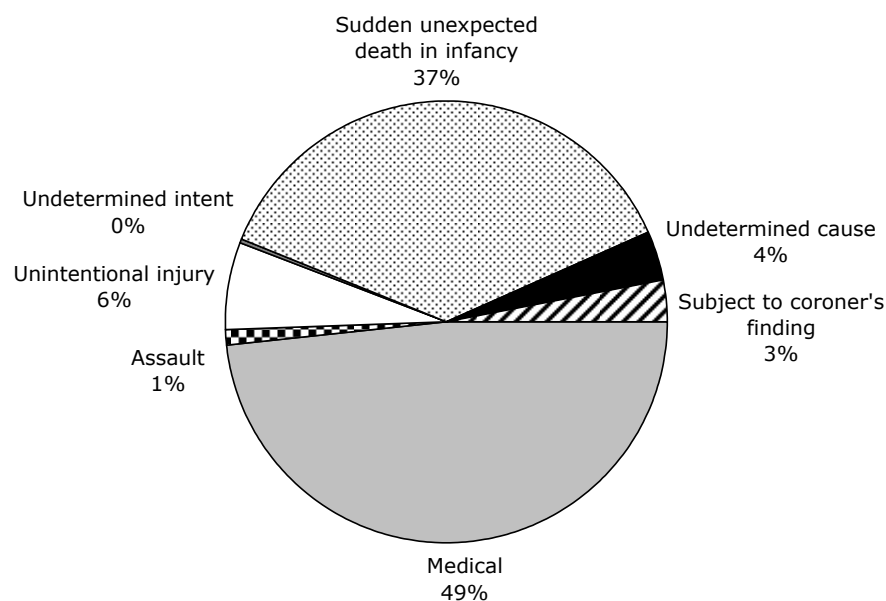
Figure A1: Infant, neonatal and post-neonatal mortality rate (per 1000 live births), 1979–2003



Post-neonatal mortality (28 days to 1 year)

The majority of post-neonatal deaths occur outside hospital. The largest group is medical (48 percent), with congenital malformations being the largest contributor to this group. Sudden unexpected death in infancy (SUDI) is the second highest cause (37 percent). (See Figures A1 and A2 and Table A1.)

Figure A2: Post-neonatal categories of death (224 deaths), 2002 and 2003



SUDI deaths are looked at in more detail on page 41.

Table A1: Causes of death for post-neonates (28 days–12 months) in 2002, 2003

Category	Cause	Deaths				Rate (per 1000 live births)	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease	12	11	23	10	0.22	0.20
	Neoplasms		1	1	0	0.00	0.02
	Endocrine, nutritional and metabolic diseases	1	1	2	1	0.02	0.02
	Diseases of nervous system	8	9	17	8	0.15	0.16
	Diseases of circulatory system	4	3	7	3	0.07	0.05
	Diseases of respiratory system		2	2	1	0.00	0.04
	Diseases of digestive system		2	2	1	0.00	0.04
	Certain conditions originating in the perinatal period	12	8	20	9	0.22	0.14
	Congenital malformations, deformations and chromosomal abnormalities	18	16	34	15	0.33	0.29
	Total medical	55	53	108	48	1.02	0.94
Unintentional injury	Drowning/submersion	1	1	2	1	0.02	0.02
	Vehicular	3		3	1	0.06	0.00
	Suffocation	5	4	9	4	0.09	0.07
		Total unintentional injury	9	5	14	6	0.17
Assault	Struck by, against	2		2	1	0.04	0.00
	Suffocation	1		1	0	0.02	0.00
		Total assault	3		3	1	0.06
Undetermined intent	Suffocation		1	1	0	0.00	0.02
		Total undetermined intent		1	1	0	0.00
Sudden unexpected death in infancy*	Total sudden unexpected death in infancy	33	50	83	37	0.61	0.89
Undetermined cause	Total undetermined cause	5	3	8	4	0.09	0.05
Coroner	Total subject to coroner's finding	3	4	7	3	0.06	0.07
Grand total		108	116	224	100	2.00	2.07

* Further details on SUDI deaths are on page 41.

Child mortality (1–14 years)

The following figures and tables are shown for three age bands: 1–4 years (Figures A3 and A4 and Table A2), 5–9 years (Figures A5 and A6 and Table A3) and 10–14 years (Figures A7 and A8 and Table A4). The mortality rates are calculated as the number of deaths per 100,000 estimated mean resident population of the respective age group.

The majority of these deaths are due to medical causes. Over one third of deaths are due to unintentional injury, with motor vehicle accidents being the major contributor. 5–9-year-olds have the lowest mortality rate.

1-4 years

Figure A3: Age specific mortality rate for children 1-4 years, 1979-2003

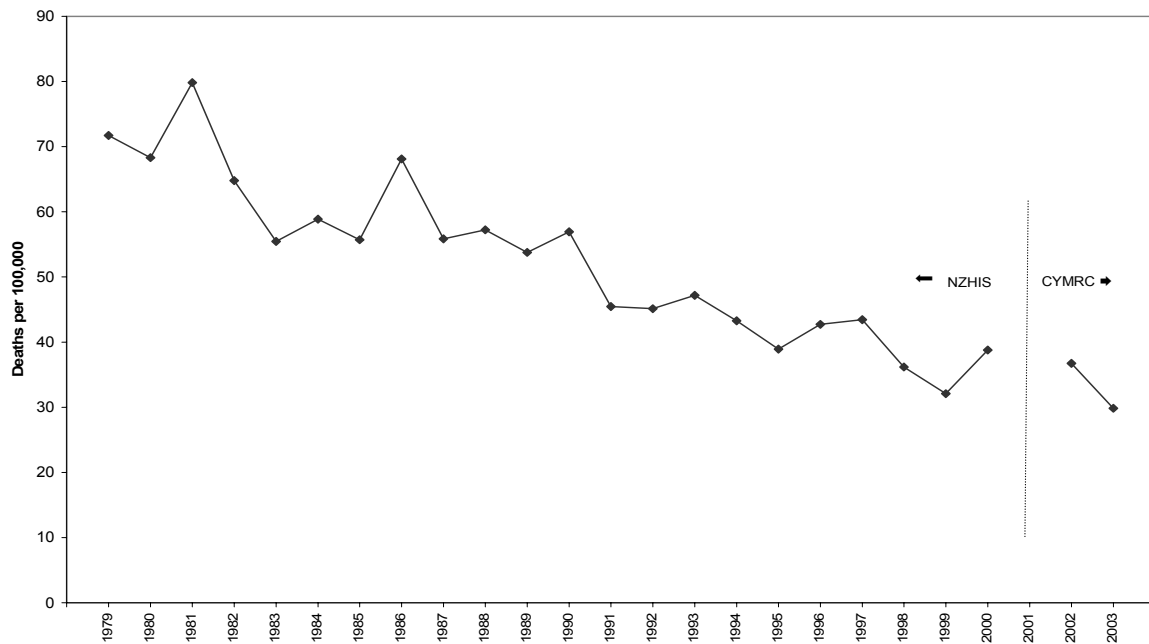


Figure A4: Categories of death for 1-4-year-olds (150 deaths), 2002 and 2003

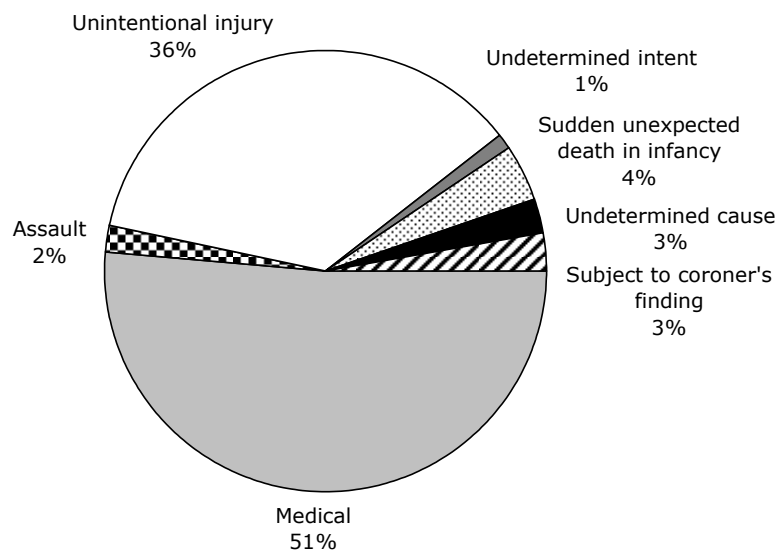


Table A2: Causes of death for 1–4-year-olds, 2002 and 2003

Category	Cause	Deaths				Age specific rate per 100,000	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease	10	6	16	11	4.43	2.67
	Neoplasms	7	7	14	9	3.10	3.12
	Diseases of the blood and blood-forming organs and disorders of immune system	1		1	1	0.44	0.00
	Endocrine, nutritional and metabolic diseases	7	4	11	7	3.10	1.78
	Diseases of nervous system	4	4	8	5	1.77	1.78
	Diseases of circulatory system		1	1	1	0.00	0.45
	Diseases of respiratory system	2	1	3	2	0.89	0.45
	Diseases of digestive system	1	1	2	1	0.44	0.45
	Diseases of genitourinary system			0	0	0.00	0.00
	Certain conditions originating in the perinatal period	5	5	10	7	2.21	2.23
	Congenital malformations, deformations and chromosomal abnormalities	3	8	11	7	1.33	3.56
		Total medical	40	37	77	51	17.72
Unintentional injury	Drowning/submersion	11	7	18	12	4.87	3.12
	Fire/burn/heat/smoke	8	1	9	6	3.54	0.45
	Vehicular	9	11	20	13	3.99	4.90
	Poisoning	1		1	1	0.44	0.00
	Struck by, against	1		1	1	0.44	0.00
	Suffocation	2	3	5	3	0.89	1.34
	Total unintentional injury	32	22	54	36	14.17	9.80
Assault	Struck by, against	2	1	3	2	0.89	0.45
	Total assault	2	1	3	2	0.89	0.45
Undetermined intent	Drowning/submersion	1	1	2	1	0.44	0.45
	Total undetermined intent	1	1	2	1	0.44	0.45
Sudden unexpected death in infancy (SUDI)	Total sudden unexpected death in infancy	2	4	6	4	0.89	1.78
Undetermined cause	Total undetermined cause	3	1	4	3	1.33	0.45
Subject to coroner's finding	Total subject to coroner's finding	3	1	4	3	1.33	0.45
Grand total		83	67	150	100	36.76	29.84

5–9 years

Figure A5: Age specific mortality rate for children 5–9 years, 1979–2003

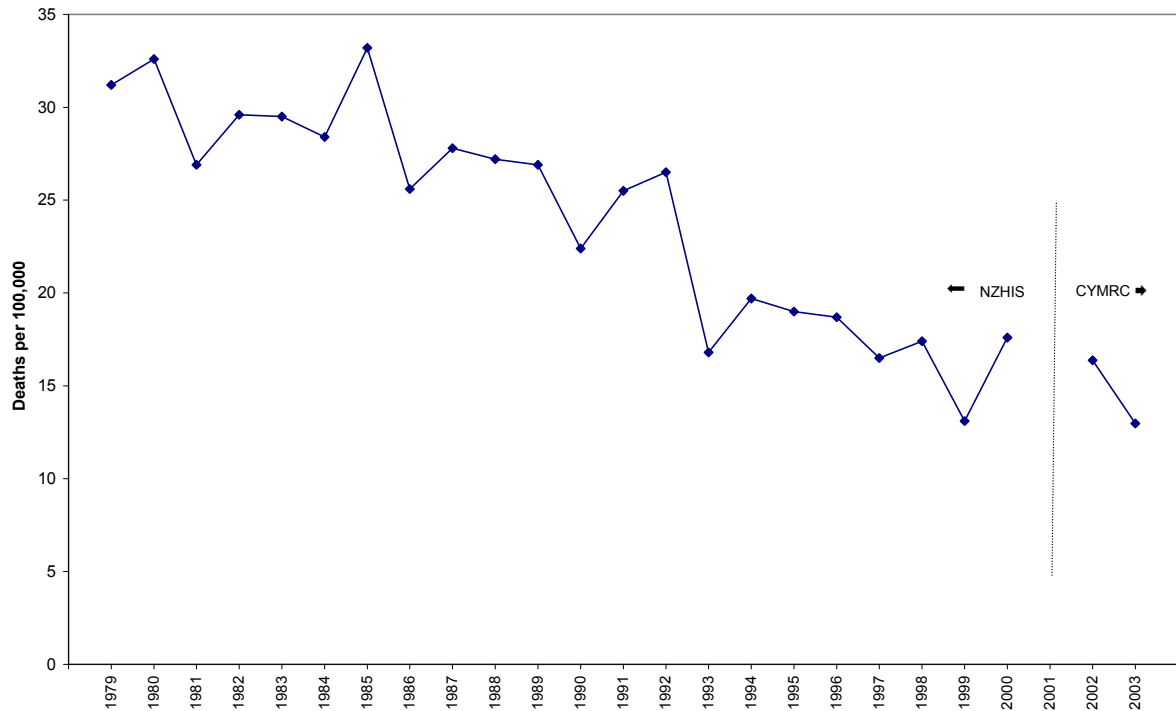


Figure A6: Categories of death of 5–9-year-olds (86 deaths), 2002 and 2003

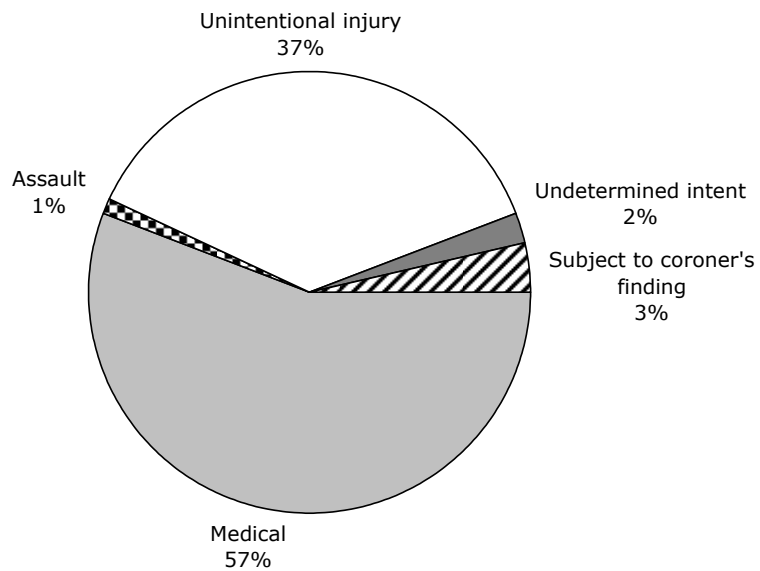


Table A3: Causes of death for 5–9-year-olds, 2002 and 2003

Category	Cause	Deaths				Age specific rate per 100,000	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease	5	3	8	9	1.71	1.02
	Neoplasms	12	6	18	21	4.09	2.05
	Endocrine, nutritional and metabolic diseases		1	1	1	0.00	0.34
	Diseases of nervous system	1	1	2	2	0.34	0.34
	Diseases of circulatory system	2	3	5	6	0.68	1.02
	Diseases of respiratory system	2	1	3	3	0.68	0.34
	Diseases of digestive system	2		2	2	0.68	0.00
	Diseases of genitourinary system		1	1	1	0.00	0.34
	Certain conditions originating in the perinatal period	2	1	3	3	0.68	0.34
	Congenital malformations, deformations and chromosomal abnormalities	4	1	5	6	1.36	0.34
	Total medical	30	18	48	56	10.23	6.15
Unintentional injury	Drowning/submersion	4	2	6	7	1.36	0.68
	Fire/burn/heat/smoke		3	3	3	0.00	1.02
	Vehicular	12	9	21	24	4.09	3.07
	Struck by, against		1	1	1	0.00	0.34
	Suffocation		1	1	1	0.00	0.34
	Total unintentional injury	16	16	32	37	5.46	5.46
Assault	Struck by, against		1	1	1	0.00	0.34
	Total assault		1	1	1	0.00	0.34
Undetermined intent	Drowning/submersion		1	1	1	0.00	0.34
	Vehicular	1		1	1	0.34	0.00
	Total undetermined intent	1	1	2	2	0.34	0.34
Coroner	Total subject to coroner's finding	1	2	3	3	0.34	0.68
Grand total		48	38	86	100	16.37	12.98

10–14 years

Figure A7: Age specific mortality rate for children 10–14 years, 1979–2003

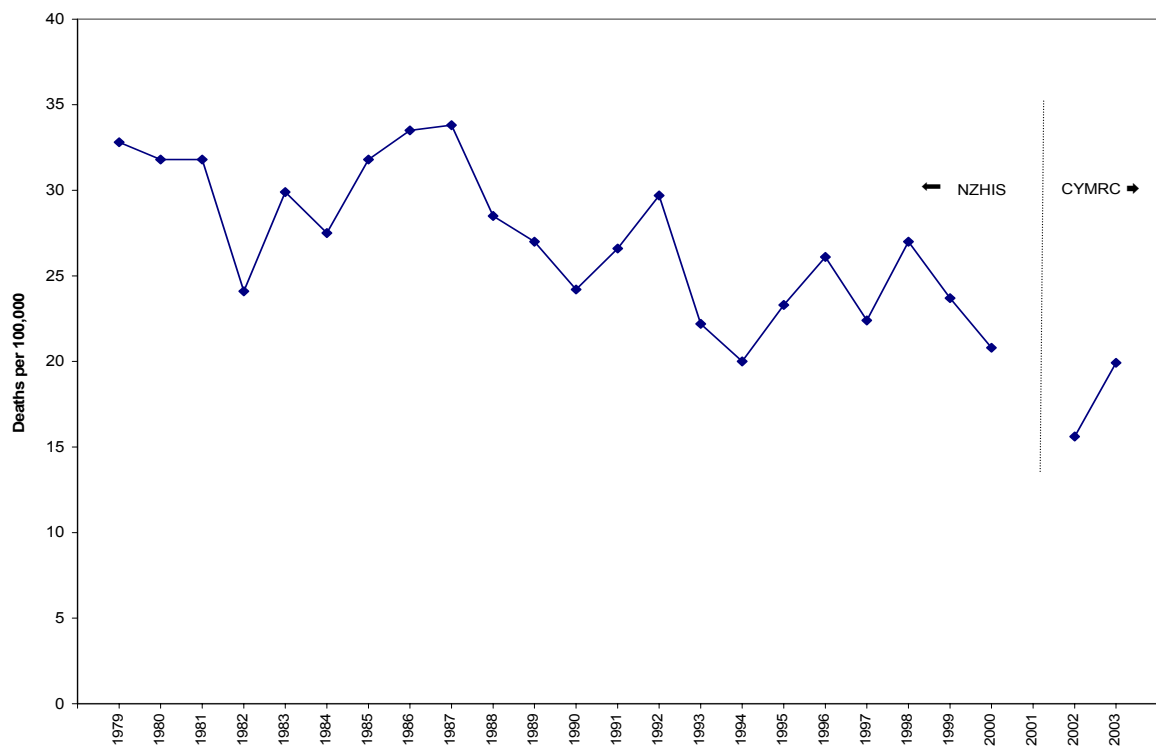


Figure A8: Categories of death of 10–14-year-olds (110 deaths), 2002 and 2003

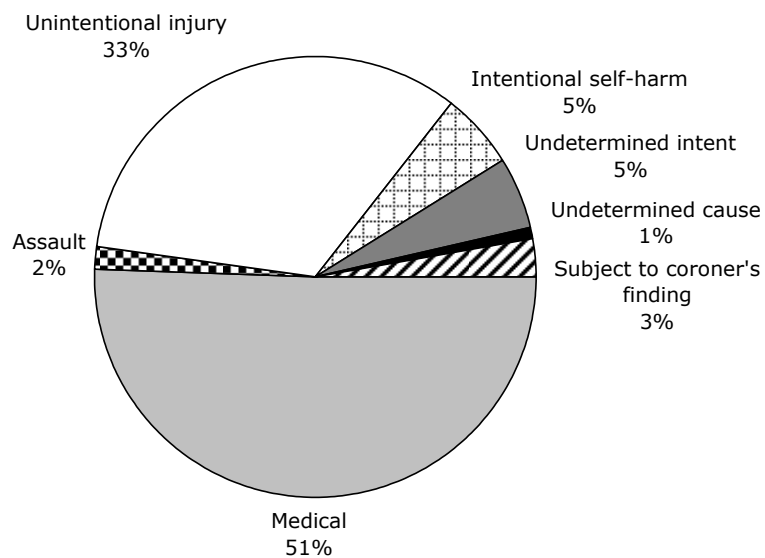


Table A4: Causes of death for 10–14-year-olds, 2002 and 2003

Category	Cause	Deaths				Age specific rate per 100,000	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease		3	3	3	0.00	0.96
	Neoplasms	9	9	18	16	2.93	2.89
	Endocrine, nutritional and metabolic diseases	2	1	3	3	0.65	0.32
	Diseases of nervous system	2	6	8	7	0.65	1.93
	Diseases of circulatory system	3	1	4	4	0.98	0.32
	Diseases of respiratory system	1	2	3	3	0.33	0.64
	Diseases of genitourinary system		1	1	1	0.00	0.32
	Certain conditions originating in the perinatal period	2	5	7	6	0.65	1.61
	Congenital malformations, deformations and chromosomal abnormalities	4	5	9	8	1.30	1.61
	Total medical		23	33	56	51	7.48
Unintentional injury	Drowning/submersion	2	3	5	5	0.65	0.96
	Fall	2	1	3	3	0.65	0.32
	Fire/burn/heat/smoke		1	1	1	0.00	0.32
	Vehicular	13	11	24	22	4.55	3.53
	Poisoning	1	1	2	2	0.33	0.32
	Suffocation		1	1	1	0.00	0.32
	Total unintentional injury		18	18	36	33	6.18
Suicide	Suffocation	2	4	6	5	0.65	1.29
	Total suicide	2	4	6	5	0.65	1.29
Assault	Struck by, against	2		2	2	0.65	0.00
	Total assault	2		2	2	0.65	0.00
Undetermined intent	Drowning/submersion		1	1	1	0.00	0.32
	Vehicular	3	1	4	3	0.65	0.32
	Struck by, against		1	1	1	0.00	0.32
	Total undetermined intent	3	3	6	5	0.65	0.96
Undetermined cause	Total undetermined cause		1	1	1	0.00	0.32
Coroner	Total subject to coroner's finding		3	3	3	0.00	0.96
Grand total		48	62	110	100	15.61	19.92

Youth mortality (15–24 years)

The following figures for youth mortality are shown in two age bands: 15–19 years (Figures A9 and A10 and Table A5) and 20–24 years (Figures A11 and A12 and Table A6). The mortality rate is calculated as the number of deaths per 100,000 estimated mean resident population of the respective age group.

In 2002, 20–24-year-olds had the highest mortality rate, but in 2003, 15–19-year-olds had the highest mortality rate. The major causes of death in these age groups are motor vehicle accidents and suicide. Medical causes drop to being just under 25 percent of all deaths.

15–19 years

Figure A9: Age specific mortality rate for youth 15–19 years, 1979–2003

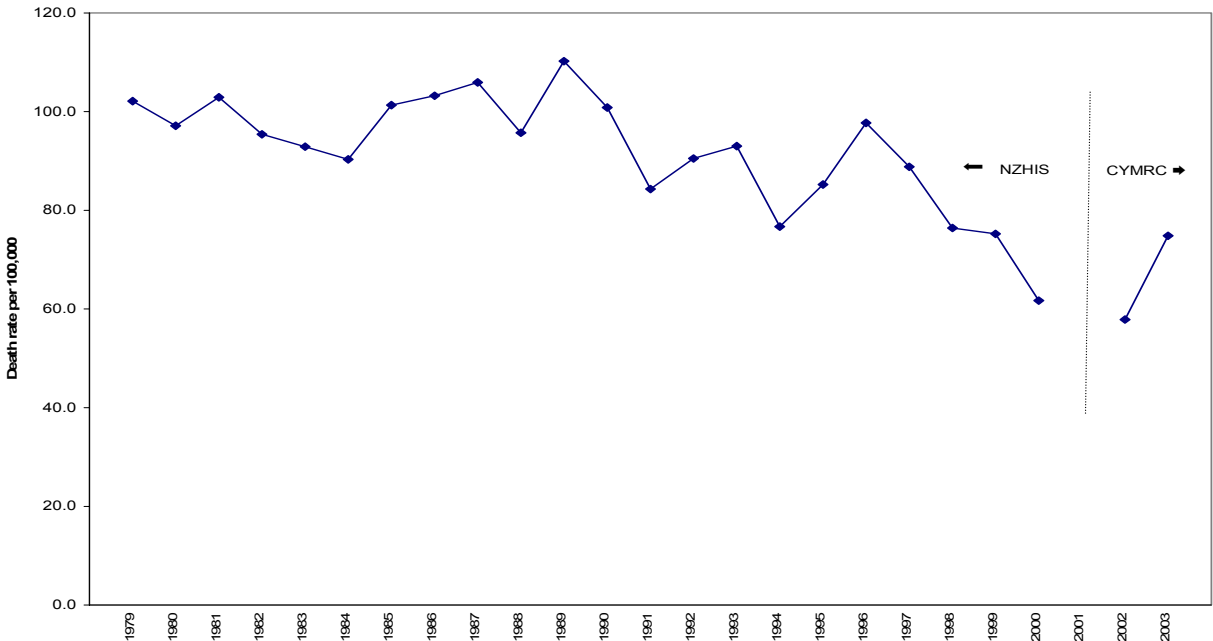


Figure A10: Categories of death of 15–19-year-olds (387 deaths), 2002 and 2003

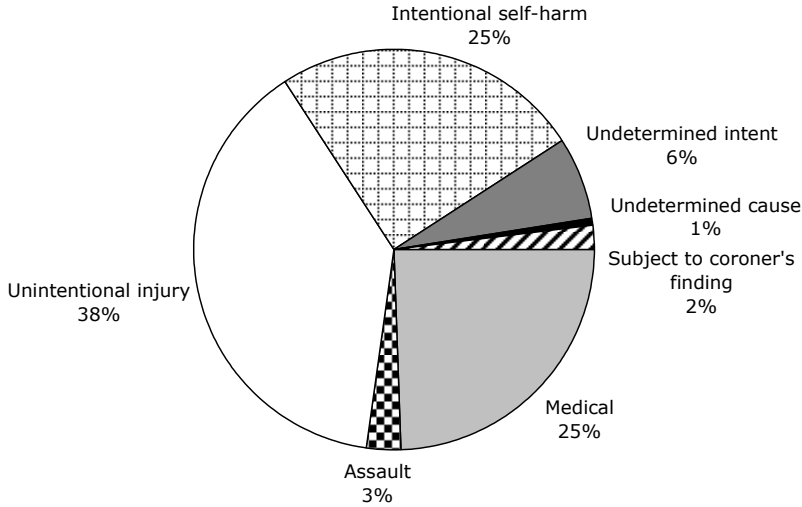


Table A5: Causes of death for 15–19-year-olds, 2002 and 2003

Category	Cause	Deaths				Age specific rate per 100,000	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease	8	7	15	4	2.79	2.37
	Neoplasms	7	17	24	6	2.44	5.76
	Diseases of nervous system	8	5	13	3	2.79	1.69
	Diseases of circulatory system	9	13	22	5	3.14	4.06
	Diseases of respiratory system	5	5	10	3	1.74	1.69
	Diseases of digestive system		2	2	1	0.00	0.68
	Diseases of musculoskeletal system and connective tissue		2	2	1	0.00	0.68
	Diseases of genitourinary system		3	3	1	0.00	1.02
	Certain conditions originating in the perinatal period	3	1	4	1	1.05	0.34
		Total medical	40	55	95	25	13.94
Unintentional injury	Adverse effect of drug or medicament	1		1	0	0.35	0.00
	Drowning/submersion	4	4	8	2	1.39	1.35
	Fall	2		2	1	0.70	0.00
	Fire/burn/heat/smoke	4		4	1	1.39	0.00
	Machinery	1		1	0	0.35	0.00
	Vehicular	51	63	114	30	18.12	21.33
	Poisoning	3	9	12	3	1.05	3.05
	Struck by, against		2	2	1	0.00	0.68
	Suffocation	3	3	6	2	1.05	1.02
	Total unintentional injury	69	81	150	39	24.39	27.43
Suicide	Drowning/submersion		1	1	0	0.00	0.34
	Fall	1	3	4	1	0.35	1.02
	Firearm	4	2	6	2	1.39	0.68
	Vehicular	1	1	2	1	0.35	0.34
	Poisoning	4	5	9	2	1.39	1.69
	Suffocation	31	44	75	19	10.80	14.90
		Total suicide	41	56	97	25	14.29
Assault	Cut/pierce	1	1	2	1	0.35	0.34
	Vehicular		1	1	0	0.00	0.34
	Struck by, against	4	3	7	2	1.39	1.02
		Total assault	5	5	10	3	1.74
Undetermined intent	Poisoning	1		1	0	0.35	0.00
	Cut/pierce		1	1	0	0.00	0.34
	Fall	1	1	2	1	0.35	0.34
	Vehicular	5	16	21	6	2.09	5.42
		Total undetermined intent	7	18	25	6	2.79
Undetermined cause	Total undetermined cause	2		2	1	0.70	0.00
Coroner	Total subject to coroner's finding	2	6	8	2	0.70	2.03
Grand total		166	221	387	100	58.54	74.50

20–24 years

Figure A11: Age specific mortality rate for youth 20–24 years, 1979–2003

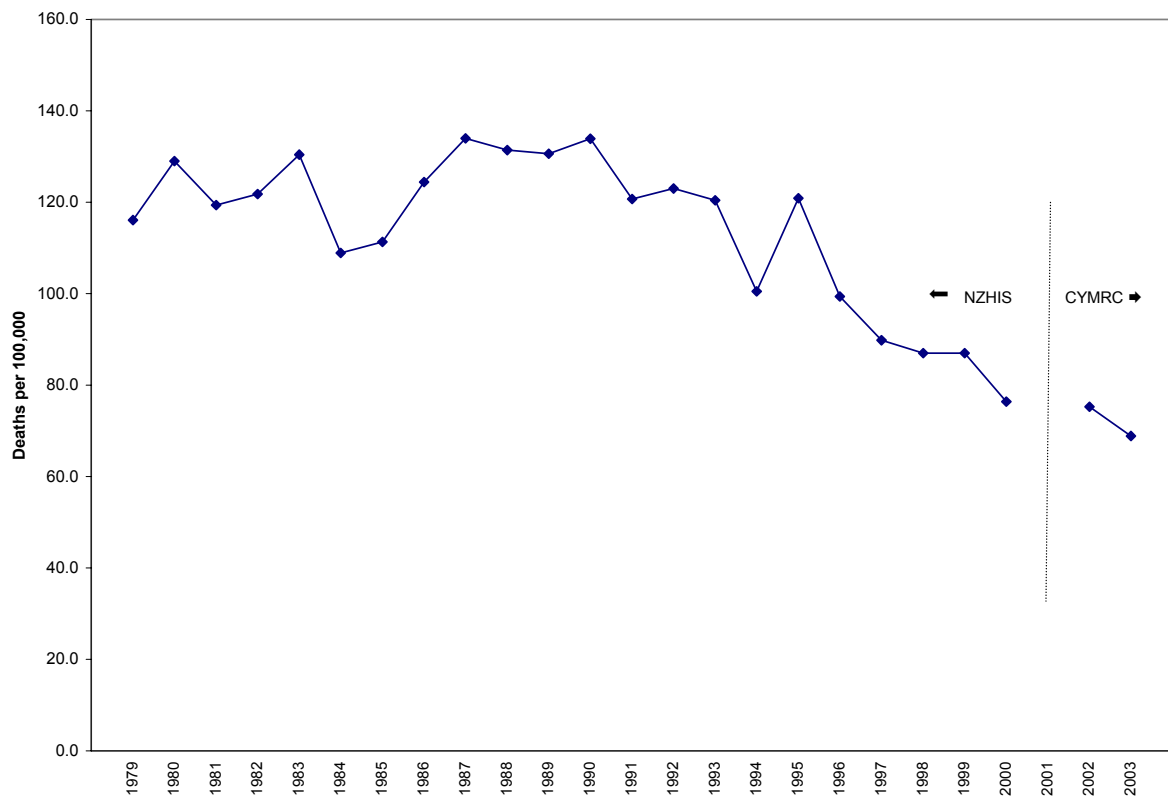


Figure A12: Categories of death for 20–24-year-olds (392 deaths), 2002 and 2003

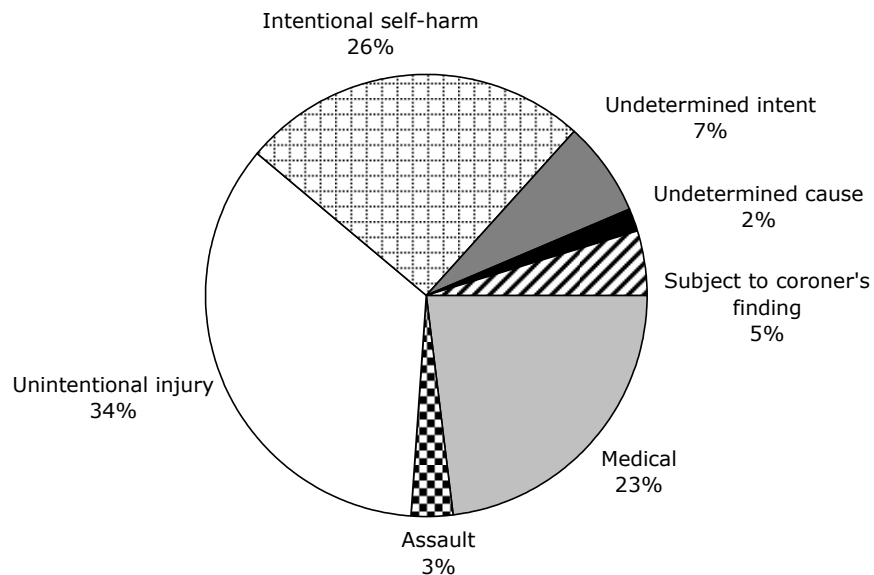


Table A6: Causes of death for 20–24 year olds in 2002 and 2003

Category	Cause	Deaths				Age specific rate per 100,000	
		2002	2003	Total	%	2002	2003
Medical	Infectious and parasitic disease	2	5	7	2	0.75	1.79
	Neoplasms	16	16	32	8	6.02	5.74
	Diseases of the blood, blood-forming organs and disorders of immune system	1		1	0	0.38	0.00
	Endocrine, nutritional and metabolic diseases	1		1	0	0.38	0.00
	Diseases of nervous system	6	8	14	4	2.26	2.87
	Diseases of circulatory system	7	10	17	4	2.63	3.59
	Diseases of respiratory system	9	2	11	3	3.39	0.72
	Certain conditions originating in the perinatal period	2	3	5	1	0.75	1.08
	Congenital malformations, deformations and chromosomal abnormalities	2		2	1	0.75	0.00
	Total medical		46	44	90	23	17.31
Unintentional injury	Drowning/submersion	8	7	15	4	3.01	2.51
	Fall	2	1	3	1	0.75	0.36
	Fire/burn/heat/smoke	2	1	3	1	0.75	0.36
	Firearm		1	1	0	0.00	0.36
	Vehicular	49	49	98	25	18.44	17.58
	Natural/environmental/animal	2		2	1	0.75	0.00
	Poisoning	4	7	11	3	1.51	2.51
	Struck by, against	3	1	4	1	1.13	0.36
	Suffocation		1	1	0	0.00	0.36
Total unintentional injury		70	68	138	34	26.35	24.39
Suicide	Cut/pierce	1	1	2	1	0.38	0.36
	Drowning/submersion	2		2	1	0.75	0.00
	Fall	2	3	5	1	0.75	1.08
	Fire/burn/heat/smoke	1		1	0	0.38	0.00
	Firearm	2	1	3	1	0.75	0.36
	Vehicular	2	2	4	1	0.75	0.72
	Poisoning	14	12	26	7	5.27	4.30
	Suffocation	29	27	56	14	10.91	9.68
	Electrocution		1	1	0	0.00	0.36
Total suicide		53	47	100	26	19.94	16.86
Assault	Cut/pierce	3	6	9	2	1.13	2.15
	Firearm	1		1	0	0.38	0.00
	Struck by, against		1	1	0	0.00	0.36
	Suffocation		1	1	0	0.00	0.36
Total assault		4	8	12	3	1.51	2.87
Undetermined intent	Drowning/submersion		2	2	1	0.00	0.72
	Fall	2		2	0	0.38	0.00
	Vehicular	6	14	20	5	2.26	5.02
	Natural/environmental/animal	1		1	0	0.38	0.00
	Poisoning	1	1	2	1	0.38	0.36
Total undetermined intent		10	17	27	7	3.39	6.10
Undetermined cause	Total undetermined cause	6		6	2	2.26	0.00
Coroner	Total subject to coroner's finding	11	8	19	5	4.14	2.87
Grand total		200	192	392	100	74.52	68.87

All age groups (4 weeks to 24 years)

To summarise cause of death for the entire age range of the CYMRC for the two years, three tables follow (Tables A7, A8 and A9).

Table A7 shows category and intent by age group. Table A8 shows major causes by ethnicity (using the ethnicity codes in the database as at 28 January 2005). Table A9 shows the major causes by gender.

Of the causes of death, unintentional injury and SUDI were selected for further investigation.

Table A7: Main category and intent of death by age group, 2002 and 2003 combined

Category and intent	4-52 weeks	1-4 years	5-9 years	10-14 years	15-19 years	20-24 years	Total	%
Medical	108	77	48	56	95	90	474	35
Unintentional injury	14	54	32	36	150	138	424	31
Intentional self-harm				6	97	100	203	15
Sudden unexpected death in infancy	83	6					89	7
Undetermined intent	1	2	2	6	25	27	63	5
Subject to coroner	7	4	3	3	8	19	44	3
Assault	3	3	1	2	10	12	31	2
Undetermined cause	8	4		1	2	6	21	2
Total	224	150	86	110	387	392	1349	100

Table A8: The 10 major causes of death by ethnicity, 2002 and 2003 combined

Cause	Intent	Pakeha	Maori	Pacific Island	Asian	Other	Total
Vehicular	Accidental	142	82	23	25	9	281
	Self-harm	4	1			1	6
	Assault		1				1
	Undetermined	31	9	1		4	45
	Vehicular total	177	93	24	25	14	333
Suffocation	Accidental	9	9	3	2		23
	Self-harm	59	55	11	2	10	137
	Assault	1			1		2
	Undetermined		1				1
	Suffocation total	69	65	14	5	10	163
Neoplasms		59	27	6	7	8	107
Sudden unexplained death in infancy		25	57	6		1	89
Infectious and parasitic disease		28	26	12	2	4	72
Poisoning	Accidental	13	11	2			26
	Self-harm	27	5	2	1		35
	Undetermined	1	2				3
	Poisoning total	41	18	4	1		64
Diseases of nervous system		40	11	5	4	3	63
Drowning	Accidental	26	20	2	5	1	54
	Self-harm		1		2		3
	Undetermined	3	2	1			6
	Drowning total	29	23	3	7	1	63
Congenital abnormalities		27	10	9	6	7	59
Diseases of circulatory system		25	17	10	1	4	57

Table A9: The 10 major causes of death by gender, 2002 and 2003 combined

Cause	Intent	Female	Male	Total
Vehicular	Accidental	85	196	281
	Self-harm	1	5	6
	Assault	1		1
	Undetermined	8	37	45
	Vehicular total	95	238	333
Suffocation	Accidental	10	13	23
	Self-harm	40	97	137
	Assault	2		2
	Undetermined		1	1
	Suffocation total	52	111	163
Neoplasms		41	66	107
Sudden unexpected death in infancy		34	55	89
Infectious and parasitic disease		41	31	72
Poisoning	Accidental	6	20	26
	Self-harm	16	19	35
	Undetermined	2	1	3
	Poisoning total	24	40	64
	Diseases of nervous system		26	37
Drowning	Accidental	16	38	54
	Self-harm	2	1	3
	Undetermined	1	5	6
	Drowning total	19	44	63
	Congenital abnormalities		27	32
Diseases of circulatory system		20	37	57

Sudden unexplained death in infancy

SUDI is a broad category used to encompass Sudden Infant Death Syndrome (SIDS) and other similar deaths that do not fall into the definition of SIDS, which requires a 'thorough post-mortem and death scene examination'. When an adequate post-mortem or death scene examination has not occurred, some coroners are now using the term 'undetermined' or 'unascertained' for the cause of death. It also includes the group of infants found dead in adult beds where no direct evidence of overlying exists (a group for which some coroners are now using the term 'accidental asphyxia'). An excellent review and the current status of the definition of SIDS is in *Sudden Unexpected Deaths in Infancy: The New South Wales experience*.⁸

⁸ New South Wales Commission for Children and Young People (Patricia Malins, Sharon Burke, Karen Freeman, Dr Ruth Lawrence, Christine Blatch, Penelope Irvine and Dr Melissa Sankey). 2005. *Sudden Unexpected Deaths in Infancy: The New South Wales experience*. A report written for the New South Wales Child Death Review Team. Sydney: New South Wales Commission for Children and Young People, New South Wales Child Death Review Team. The full report can be requested from www.kids.nsw.gov.au.

Thus, the term SUDI includes cases where the infant's death was sudden and unexpected (the cause of death was not recognised before the death). The category is limited to infants found dead after they were placed to sleep. This definition excludes infants who die unexpectedly in misadventures due to external injury (such as transport incidents) and accidental drowning and is identical to the definition used in the New South Wales report.

New Zealand has a proud record of identifying, through research, important risk factors for SUDI and SIDS deaths. Public health intervention (beginning in 1990/91) has been successful in lowering previously high rates of death. Other countries have instituted the same measures and have seen a similar decline in death rates.

The main risk factors identified have been a prone sleep position, maternal smoking and infant bed-sharing with a sleeping adult where the mother smoked during pregnancy. Breastfeeding has a protective effect, as does sharing a bedroom. The CYMRC believes collecting information about these well-known risk factors is a reasonable expectation in any investigation of a SUDI death. The information available from current systems relates to the 89 SUDI deaths in 2002 and 2003 (Table A10).

Table A10: Sudden unexpected death in infancy (SUDI) risk factors (from police reports and local review), 89 deaths 2002 and 2003 combined

Risk factor	Yes	No	Not recorded	Total
Placed prone	7	27	55	89
Found prone	16	15	58	89
Smokers in family	18	2	69	89
Maternal smoker	0	2	87	89
Bedshare with adult	16	32	41	89

The results show that current systems are not collecting this information consistently, as in only 38 percent of SUDI cases was information on whether the infant was placed prone available.

Despite this, the CYMRC can report some babies are still being placed prone, with 8 percent of SUDI infants being placed prone and 18 percent being found prone.

Maternal smoking status in these deaths is particularly poorly recorded.

Perhaps most concerning of all is the ethnicity data (Tables A11 and A12). Over the two-year period, 57 of the 89 babies who died of SUDI were classified as Maori (64 percent). Thus for Maori the SUDI death rate is 1.3–2.2 deaths for every 1000 Maori live births, while the non-Maori rate is four times lower. This large differential has been put down to the combination of high rates of maternal smoking among Maori women who also sleep in bed with their infants – a cultural norm for Maori. Further research is needed into ways that mothers who smoke are able to safely sleep with their babies, and to find other specific risk factors amendable to preventive action. In the meantime, all organisations and people providing health care to Maori families need to actively advise on safe sleeping environments for babies.

Table A11: Sudden unexpected death in infancy, ethnicity by gender

Ethnicity	Female			Male			Total
	4–52 weeks	1–4 years	Total	4–52 weeks	1–4 years	Total	
Maori	21		21	33	3	36	57
Pacific Island	4	1	5	1		1	6
Other	7	1	8	17	1	18	26
Grand total	32	2	34	51	4	55	89

Table A12: Sudden unexpected death in infancy (SUDI) ethnicity by age group, 2002 and 2003

Ethnicity	4–52 weeks					1–4 years			Total
	2002	Per 1000 live births	2003	Per 1000 live births	Total	2002	2003	Total	
Maori	20	1.34	34	2.17	54	1	2	3	57
Pacific Island	3	0.52	2	0.33	5		1	1	6
Other	10	0.30	14	0.41	24	1	1	2	26
Total	33	0.61	50	0.89	83	2	4	6	89

Suicide

Serious self-harm continues to be a major issue for New Zealand adolescents and youth. It appears that female rates are rising while male rates are dropping with no real change in total youth rates from figures for 2001 released by the NZHIS in April 2004 (see <http://www.nzhis.govt.nz/stats/youthsuicidefacts.pdf>). (See Tables A13, A14 and A15.)

Readers need to be aware the coding of death to self-harm in the Data Group's figures combines information from multiple sources and the decision on the death being likely to be a self-harm death is based on consideration of this information. It is possible the group's decisions may favour allocation of death to suicide compared with the final NZHIS figures. Initial comparison of our 2002 figures with the official NZHIS numbers for the same year suggest almost identical numbers of deaths from deliberate self-harm in the 15 to 24 year age group.

A significant group of injury deaths exists where the intent was unclear or no coronial decision on intent has been made. For 2003, this consisted of 55 deaths of people aged 10–24 years. In the future, careful and consistent investigation these deaths may lead to better classification as to intention.

For females the 15 to 24 year age group rate appears to have risen from 5.8 and 8.7 per 100,000 in 2000 and 2001 to 10.7 and 12.8 per 100,000 for the years 2002 and 2003. For males, the equivalent rates were 29.9 and 31.1 for 2000 and 2001 while dropping to 23.2 and 22.9 deaths per 100,000 in 2002 and 2003. It appears likely that the increase in female youth suicide death rate relates to the increasing use of hanging as a method of suicide.

Most deaths occur by hanging in males (71 percent) and females (61 percent), with an increased proportion of deaths by poisoning (mainly carbon monoxide poisoning) in the 20–24 age group and females.

As in previous years, Maori rates are higher than for non-Maori, with 35 percent of female suicide deaths being classified as Maori and 32 percent of male deaths classified as Maori.

Table A13: Deaths from self-harm by age and gender , 2002 and 2003

Gender	Age group	Deaths			Age specific rate per 100,000	
		2002	2003	Total	2002	2003
Female	10–14 years		1	1		0.66
	15–19 years	16	19	35	11.42	13.19
	20–24 years	13	17	30	9.86	12.39
	Total female	29	37	66	6.87	8.55
Male	10–14 years	2	3	5	1.30	1.88
	15–19 years	25	37	62	17.02	24.47
	20–24 years	40	30	70	29.88	21.18
	Total male	67	70	137	15.29	15.46
Both	10–14 years	2	4	6	0.65	1.29
	15–19 years	41	56	97	14.29	18.96
	20–24 years	53	47	100	19.94	16.86
	Grand total	96	107	203	11.16	12.09

Table A14: Means of death from self-harm, 2002 and 2003

Means of self-harm deaths	Female			Male			Total
	2002	2003	Total	2002	2003	Total	
Suffocation	19	21	40	43	54	97	137
Poisoning	6	10	16	12	7	19	35
Fall	1	3	4	2	3	5	9
Firearm	1	1	2	5	2	7	9
Vehicular		1	1	3	2	5	6
Drowning/submersion	1	1	2	1		1	3
Cut/pierce				1	1	2	2
Fire/burn/heat/smoke	1		1				1
Electrocution					1	1	1
Grand total	29	37	66	67	70	137	203

Table A15: Self-harm deaths by ethnicity and age group, 2002 and 2003

Ethnicity	10–14 years			15–19 years			20–24 years			Total
	2002	2003	Total	2002	2003	Total	2002	2003	Total	
Female only										
Maori		1	1	6	9	15	4	3	7	23
Pacific Island					1	1	2	1	3	4
Asian							1	1	2	2
Other				10	9	19	6	12	18	37
Female total		1	1	16	19	35	13	17	30	66
Male only										
Maori	1	3	4	9	9	18	12	10	22	44
Pacific Island				1	3	4	4	1	5	9
Asian				2		2	1	1	2	4
Other	1		1	13	25	38	23	18	41	80
Male total	2	3	5	25	37	62	40	30	70	137
Combined										
Maori	1	4	5	15	18	33	16	13	29	67
Pacific Island				1	4	5	6	2	8	13
Asian				2		2	2	2	4	6
Other	1		1	23	32	57	29	30	59	117
Grand total	2	4	6	41	54	97	53	47	100	203

Appendix B: Criteria for Accessing Mortality Data and Application Form

This section gives the outline of the 'Application for Access Form', and is provided for information. An electronic version can be obtained from the Secretariat (cymrc@moh.govt.nz).

CYMRC – Criteria for accessing mortality data

Purpose

This document is the policy document that identifies the conduct of the any research that is undertaken using data collected by the CYMRC. This includes identification of roles and responsibilities of investigators, the safe-keeping of the data, use of the data and issues concerning publication and authorship.

Background

The New Zealand Child and Youth Mortality Committee was established under the New Zealand Health and Disability Act (2000). The committee reports directly to the Minister of Health and is supported by the Ministry of Health. The CYMRC terms of reference include: to review and report to the Minister (of Health) on deaths of people aged between four weeks and 24 years, with a view to reducing the numbers of deaths of this group.

The CYMRC has employed a Data Group to set up and maintain a web-based database of all child and youth deaths (age range 28 days to 24 years inclusive) in New Zealand as of 1 January 2002. The Data Group is currently located within the Department of Women's and Children's Health, University of Otago. The CYMRC has also established a Scientific Sub-Committee whose role is to advise the CYMRC on priorities for research, monitor use of and access to the data, and determine dissemination of research findings.

Applications

Applications for access to the data held by the Data Group are considered by the Scientific Sub-Committee (SSC). This document gives guidance on the processes by which access to the data may be obtained.

Researchers who are interested in applying for access to the data held by the New Zealand Child and Youth Mortality Review Committee must first contact the CYMRC Data Group to register their interest (contact mortality.group@stonebow.otago.ac.nz). A formal application will then need to be made on the CYMRC data access application form.

The SSC will give fair and impartial consideration to all applications, with, where appropriate, the advice of independent referees. The SSC may also make inquiries to help avoid duplication or possible conflict with the work of other researchers in the same field.

The SSC reserve the right to request additional information to support the application.

Investigators are asked to take into account when planning their study that the process from first discussion to acceptance may take several months. The CYMRC must receive applications which are ready for submission one month prior to the SSC meeting, to allow time to circulate documents for review. The SSC will typically meet four times a year and information on meeting dates is available from the CYMRC.

Eligibility

Any research project that involves analysis of data on the deaths of children and youth (ages 28 days–24 years inclusive) may be eligible to gain access to data held by the CYMRC.

The CYMRC must be certain that studies conducted using the CYMRC data are well designed and worthwhile. In order to ascertain this, the SSC will take into consideration the scientific interest and public health importance of the proposed study, its methodology and the likelihood of beneficial outcomes.

The CYMRC is unable to provide any data that will allow for the identification of deceased children or youth.

Formal requirements

The proposed study must obtain ethical approval through your local ethics committee, and if relevant notifying them that this will be a multi-centre study.

Data will be provided only for the time period agreed to between the researchers and the SSC. Any request for an extension of the timeframe must be requested at least three months prior to the completion of the study period.

Adequate funding or organisational arrangements must have been obtained for the completion of the research.

Security of data

Once permission is granted data will be provided by the Data Group to the study's principal investigator in a password protected MS Access database file. Data is required to be stored by investigators in a password-protected computer.

The data set is not to be copied or forwarded to any other individuals (other than co-investigators) or organisation other than those identified as investigators on the application form.

At the end of the agreed timeframe for which the data has been provided all copies of the data must be destroyed and acknowledgment of this sent to the CYMRC.

Reports and articles

Investigators are asked to declare that they will acknowledge the assistance of the CYMRC in any manuscripts submitted for publication. However, the CYMRC does not exercise any control whatsoever over where research workers publish their results, nor does it require being included in authorship. The CYMRC requires a copy of published articles and abstracts presented at meetings and information about any other relevant presentations, publications or media interviews. Summary information of reports and articles will be included in the annual report the CYMRC makes to the Minister of Health.

Application for data access

Research title

Investigators

Indicate principal investigator by asterisk.

Host institution

Statement of research questions

Proposed starting date

Proposed duration of study

Background information

Please include:

- past relevant research (is this project contributing new knowledge?)
- rationale for proposed research (why is this project important?)
- anticipated outcomes of research (how will the results change policy and/or practice?)
- proposed dissemination of results
- any other relevant information.

Research methods

Describe the proposed data analysis.

Ethical approval

- Ethics approval obtained (please attach a copy of the letter of approval)
- Ethics approval to be sought

(You will need to notify you local ethics committee if this is a multi-centre study.)

References

Extra information

Please provide the following information:

- CVs of the named investigators
- Details of funding arrangements
- Sign-off from your host institution
- Other

Please ensure that four (4) copies of this application are attached.

Signed Date.....
(Principal Investigator)

Signed Date.....
(Investigator 2)

Signed Date.....
(Investigator 3)

Signed Date.....
(Investigator 4)