

**CHILD AND YOUTH MORTALITY REVIEW COMMITTEE**

*Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi*

Sixth Report on the Activities of the Child and Youth Mortality Review Committee

1 January 2010 to 30 June 2011

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| **Disclaimer**  The Child and Youth Mortality Review Committee prepared this report.  This report does not necessarily represent the views or policy decisions of the Health Quality & Safety Commission. |

# Foreword

I am pleased to introduce the *Sixth Report on the Activities of the Child and Youth Mortality Review Committee*, which is the CYMRC’s first report to the Health Quality & Safety Commission.

In the past year, the CYMRC has examined the deaths of small children in driveway run overs, the impact of alcohol on the deaths of children and young people in New Zealand, accidental suffocation and strangulation of infants, accidental poisoning in youth and palliative care for children and young people. Two topic reports have been published and others are being developed. The CYMRC has also engaged widely with other sectors, consulting, advising and actively working to create change.

The CYMRC has challenged the Commission to change and improve. It made the following three recommendations in this Sixth Report.

It is recommended the Commission:

* develop an internal system to maintain and support safety and quality from a child and youth perspective
* encourage District Health Boards (DHBs) to develop better policies to promote the prevention of Sudden Unexpected Death in Infancy (SUDI)
* provide central leadership to the CYMRC network of local child and youth mortality review groups in the DHBs.

The Commission’s Board has welcomed these recommendations, and supports their implementation.

Furthermore, the CYMRC has suggested that its DHB-based network of local mortality review groups be used across the Commission:

* as a link between the Commission, DHBs and local communities
* to assist in the facilitation of information distribution
* to support local quality improvement initiatives.

The Commission’s Board welcomes the opportunity to work with the CYMRC network in this way. It will enable the use of existing resource in new ways across the Commission, maximising effectiveness without additional cost.

In the area of SUDI, the CYMRC has also begun developing information for DHBs around best practice. It is working on this with the Perinatal and Maternal Mortality Review Committee and the Commission Board.

Congratulations to the CYMRC – and in particular to the CYMRC Chair, Dr Nick Baker – for its recent work. A great deal has been achieved. The Commission’s Board looks forward to supporting the CYMRC as it continues to influence and lead system improvement and change.

Professor Alan Merry ONZM

Chair

*Health Quality & Safety Commission*

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# Introduction

The Child and Youth Mortality Review Committee (CYMRC) transferred to the Health Quality & Safety Commission (the Commission) on 23 April 2011. Members of the CYMRC are now appointed by, and accountable to, the Commission. The CYMRC aims to identify, address and potentially decrease the number of infant, child and youth deaths in New Zealand.

The CYMRC is required to:

* 1. review and report to the Commission on deaths that are within the Committee’s scope, with a view to reducing these manner of deaths and to support the continuous quality improvement through the promotion of ongoing quality assurance programmes
  2. advise on any other matter related to mortality that the Commission specifies in writing
  3. develop strategic plans and methodologies that are designed to reduce morbidity and mortality and are relevant to the Committee’s functions.

# The CYMRC system

Since its inception in 2001, the CYMRC has developed a sophisticated system to support its data collection, analysis, and reporting functions (Figure 1). Following every death of an individual aged between 28 days and 24 years, semi-automated data collection from multiple sources occurs. Death notifications are stored in the secure CYMRC database and initiate a lengthy process of mortality review and reporting. The database is managed by the New Zealand Mortality Review Data Group (MRDG) at the University of Otago.

**Figure 1: The CYMRC System**



The CYMRC maintains a network of 21 DHB-based, multi-sectoral Local Child and Youth Mortality Review Groups (LCYMRGs) throughout New Zealand. These LCYMRGs review deaths that occur within their districts using information collected from local agents and the CYMRC database. LCYMRGs input findings and recommendations from the death reviews into the CYMRC’s national database. LCYMRGs also use the influence of their members to improve local systems in order to prevent similar deaths in the future. In reviewing cases, the LCYMRGs seek opportunities to improve:

1. the overall quality of care and services, within each region and nationwide
2. community responses following a death (eg, the manner by which memorial services are conducted or support services offered to family, friends, and whānau)
3. systems of care and communication, that might occur within DHBs and across all sectors of society.

The CYMRC maintains an overview of this network, and uses the findings from the mortality review and data collection process to produce three types of reports: summaries of national data, reports on specific categories of death, and DHB reports.

## Summaries of national data

Traditionally, the CYMRC annual report has been accompanied by an overview of all child and youth deaths in New Zealand, generally in 5-year time periods. This year, the CYMRC has transitioned to an online reporting system for this data. This means that up to date data will always be available online, but will no longer be tied to a CYMRC annual reporting cycle. Presently, data for the 2006-2010 time period is available at <https://secure-www.otago.ac.nz/nzmrdg/reports.html>. The committee is working to have a data from the previous year available before the end of the next year.

## Reports on specific categories of death (also known as special topic reports)

With its *Fifth Report to the Minister of Health* (2009), the CYMRC began to publish detailed reports on specific categories of death. The CYMRC intends to report on two topics per year (a health topic and an injury topic) along with one report on a specific population group.

Instead of releasing a single report each year, the CYMRC has decided to stagger the release dates of these special topic reports, which will allow the release to be well-prepared and timed for greatest effect. From 1 January 2010 to the present, the CYMRC has sought to develop better systems for these labour-intensive reports. The CYMRC has learned that working with a well-engaged stakeholder group is vital, not only for the quality of data analysis, but also for the development and implementation of the recommendations.

Table 1 provides a summary of the in-depth, special topic reports that the CYMRC has recently published or is currently preparing for publication. Sometimes the topics selected are driven by community priorities or current events (eg, alcohol). Other times, topics are selected because researchers have approached the CYMRC with a specific interest.

**Table 1: CYMRC Special Topic Reports 2009 to 2012**

|  |  |  |
| --- | --- | --- |
| **Topic** | **Publication Date** | **Progress** |
| Sudden Unexpected Infant Death | Dec 2009 | See below for summary of action |
| Drowning Under Five Years | Dec 2009 | See Appendix 2 |
| Youth Risk Taking | Dec 2009 | See Appendix 2 |
| Suicide | Dec 2009 | See Appendix 2 |
| Systems | Dec 2009 | See Appendix 2 |
| Slow Speed Run Over | Aug 2011 | See below for summary of action |
| Alcohol | Sept 2011 | See below for summary of action |
| Suffocation/strangulation | April 2012 | With panel of special editors |
| Poisoning | May 2012 | Draft out for stakeholder input |
| Off Road Vehicles | Sept 2012 | In process |
| Anticipated Mortality  *(CYMRC data shared with researcher)* | 2012 | Publication in peer reviewed journal pending |
| Māori Report | 2012 | Early phases of data analysis |
| Chronic CNS Diseases | 2012 | Early phases of data analysis |
| Vaccine Preventable Diseases | 2012 | Early phases of data analysis |
| Asthma |  | On Hold |
| Impact of neglect on mortality (‘Children known to CYF’) |  | Scoping |

## DHB Reports

While the LCYMRGs submit large quantities of information to the CYMRC, there has often been some concern that the CYMRC has not provided aggregate information back to these groups often enough to help inform their local work.

As a result, the MRDG recently developed a DHB-reporting template that will allow the CYMRC to provide regular reports to each DHB. The first batch of these reports was provided to the DHBs in June 2011. There were some challenges associated with this because local data contains small numbers that are potentially identifiable so advisory information on the management of small numbers to preserve case confidentiality was provided to the LCYMRGs along with the reports.

At this point in time, these reports have not been made widely available (due to the concerns over identifiable data). Over the next six months this flow of information will be monitored, and it may prove possible subsequently to publish these local reports on the CYMRC website. In the meantime, the LCYMRGs can use this information to inform local communities.

# The local child and youth mortality review network

The CYMRC maintains a network of 21 local child and youth mortality review groups (LCYMRGs) in New Zealand. There is one in every DHB, with Southern DHB maintaining two. The funding for this CYMRC LCYMRG network comes from a Cabinet Appropriation.

## CYMRC’s lead coordinator and the maintenance of the network

In 2008, the CYMRC contracted with the Whanganui DHB to employ a full-time lead coordinator whose primary focus during 2008, 2009 and 2010 was the establishment of a LCYMRG in every DHB. All DHBs received initial funding for the LCYMRGs via contract variations to the Crown Funding Agreement.[[1]](#footnote-1)

Once the network was established, the focus transitioned from establishment to on-going support, quality improvement, and monitoring. In November 2010, the lead coordinator position became a part-time role that was contracted directly to the Ministry of Health. New contract variations were developed between the Ministry of Health and the DHBs that placed greater emphasis on quality improvements and outcomes. When the CYMRC transferred to the Commission on 23 April 2011, the contract variations were terminated and contracts were established between the DHBs and the Commission to maintain the LCYMRGs.

Over the next few months additional changes to the system are planned, with specific moves to make the network more self-supporting by using the expertise that is already within the network to: orientate new members, share expertise related to specific types of review, improve list-server communication and develop a self-managing system for the regular networking teleconferences.

While there are these moves to make the system more self-supporting, there is still a need for oversight. At this point, it is not clear who will maintain oversight of this network. One possibility would be a role within the Commission that has oversight across the Commission’s entire Quality Network with regard to children and young people.

## Composition of each LCYMRG

Each local child and youth mortality review group is led by a chair and a local coordinator.

As the chairs and coordinators are becoming more knowledgeable in regards to mortality review, the CYMRC is finding that many coordinators are developing areas of special expertise. This knowledge and experience is proving a valuable resource to what is now a national network of LCYMRGs.

Moreover, collaborative approaches are being developed to make the best use of this emerging national network. For example, the Whanganui and MidCentral LCYMRGs have a shared coordinator. The three Auckland area LCYMRGs work closely together and do some reviews collaboratively. The Hutt Valley and Capital & Coast LCYMRGs have divided reviews across both DHBs, with the child deaths reviews led by Capital & Coast and adolescent death reviews led by Hutt Valley.

The LCYMRGs are comprised of strong, multi-sectoral teams that are addressing community issues and concerns. The CYMRC is grateful for the involvement of local agents and their supporting organisations.[[2]](#footnote-2) Local groups typically have strong support from Police, Child Youth and Family, DHB quality teams, ambulance, Ministry of Education, Well Child providers, local iwi and other nominated agents. Local agents from these organisations attend the meetings at the expense of their own organisations; the CYMRC does not pay them for their participation. Agents bring information to help inform the local mortality reviews and use what is learnt during review to implement quality improvement in their own, and other, organisations. Some examples of local level successes include:

* improved vaccine coverage for children and young people with chronic conditions
* signs warning of hazards on beaches, rural roads and motorways
* identification of risks facing some groups of rural workers
* development of SUDI prevention coalitions, training systems and resources
* improved support for families after the death of a child
* training for youth workers around risk-taking behaviours
* provision of more appropriate space for families to grieve with the deceased
* increased momentum around child injury prevention
* information provision to support local suicide prevention coordinators.

## Training workshops

With a large disseminated network with over 400 agents, there is an increasing body of work needed to maintain consistency and quality across the network. To develop consistent best practice and to encourage collaborative development between each review group, the lead coordinator organises local coordinators’ and chairs’ training and development workshops.

In 2010, there were two rounds of regional meetings. These took place in geographical clusters. The six South Island local coordinators gathered for meetings in Christchurch. Three North Island meetings were held; one in Palmerston North, one in Rotorua and one in Auckland. The regional meetings are valuable because the smaller numbers make training and inter-regional dialogue more effective. No regional meetings have been planned for 2011 because the national workshop, which is scheduled for 3-4 November in Wellington, is set for two days rather than just one.

The national workshop is now a yearly event. The 2010 national meeting was held on 9 June in Wellington. All the coordinators and the majority of chairs from DHBs around the country gathered to discuss ways to continue to strengthen and improve the local mortality review processes, with a particular focus on local actions and outcomes.

## Development of a new mortality review logic framework

Another element of quality improvement across the CYMRC network involves helping the LCYMRGs to identify opportunities for improvement, develop evidence-based strategies for local change, and record the outcomes of their efforts. To facilitate this process, a logic framework has recently been developed (Figure 2). It is anticipated this will go live with local groups shortly and the timing will enable any glitches to be ironed out before further training at the November workshop.

**Figure 2: Mortality Review Logic Framework**

**Death**

**After Death Events**



Means



Context



Understanding of Causal Pathway



Issue



Recommendations



Local Action



**Outcome**



**Advisors**



**CYMRC**



**Data group**



**Report**

**Pre**

**-**

**Death Events and Circumstances**



National Action



Context Statement



Results

The logic framework is designed to use the power of the CYMRC data system to facilitate systems improvement by converting long complex stories into elements that can be used to facilitate change. The framework supports local groups in the development of evidence-based recommendations and then tracks the process of systems improvement that follows towards measurable outcome changes.

In a mortality review meeting, the LCYMRG discusses and seeks to understand the timelines and causal pathways leading up to the death. Review groups then consider the points at which the causal pathways preceding death could have been blocked or interrupted. These are then described using a context and issue statement. The context statement aims to describe the context in which the death occurred. The issue statement then describes the systems issue which needs to be addressed. Here is an example:

*Context: in the context of a 12 year old child who suffered from a chronic condition but died of influenza, the protection provided by an influenza vaccination was not present*

*Issue: therefore, it is noted that the systems designed to support influenza vaccine coverage for children with chronic conditions are poorly developed.*

The LCYMRG then identifies recommendation(s) which aim to address the identified issue and decides what actions are needed to rectify the problem. The LCYMRGs identify who from their group can carry out the action.

*Recommendation: those most vulnerable to influenza need to be identified and systems need to be developed to promote and facilitate their vaccination.*

*Action: the community paediatrician from the LCYMRG will discuss this issue (in a non-identifiable way) at the vaccination steering group and work with paediatric staff and PHOs in the region to develop better systems.*

The LCYMRG can also record the result of any action taken. As this can also be shared, it provides a record of initiatives that other groups can pick up and also supports national processes.

*Result: selected families and GPs receive written communication that highlights the need for vaccination; a new electronic field to promote flu vaccination after discharge was developed; a system to fund vaccination for household contacts of vulnerable infants under 6 months old was also developed. Over 400 letters have since been sent out to GPs and families annually; feedback suggested that parents strongly supported the action and appreciated the letters. In addition, local GP recall systems now automatically recall children with chronic conditions.*

Space also exists in the CYMRC database for LCYMRGs to document any measurable outcomes and changes that might be indicators of the success or failure of the actions. In the example above, positive outcomes might include documenting an increase in vaccine coverage in children and young people with chronic conditions or a reduction in influenza cases or hospital bed days in this vulnerable group.

As the framework maintains confidentiality with identifiable elements excluded, it can be shared with advisors and stakeholders to support CYMRC reporting and systems change at a national level. Therefore, the combination of context statement, issue statement and recommendation needs to give a reader, who has not seen the full details of the case, a clear indication of the causal pathway which the LCYMRG seeks to block or interrupt.

The CYMRC hopes that the development of this logic framework will help the LCYMRGs to translate their findings into positive action and provide a way to share the benefit gained at a local level from death review more widely.

## Links to DHB quality teams

Much of the CYMRC work relates to quality improvement within the health sector, with a specific focus on child and youth health. A stocktake was undertaken to find out how the CYMRC’s LCYMRGs link to the quality teams in the DHBs. Three types of links were noted:

* the CYMRC local coordinator can be a member of the quality team, often also engaged in other quality activities
* the CYMRC local coordinator can work alongside the quality team in the DHB, with regular meetings and communication
* quality team members (eg, risk managers or quality improvement coordinators) can be agents of LCYMRGs.

Different DHBs appear to have different arrangements, but it is apparent that these linkages can, in most cases, be strengthened. The CYMRC would like to see the development of quality hubs in the DHBs that might eventually link to the Commission.

## Maintaining the LCYMRG network

The LCYMRG network would ideally be part of the aforementioned quality team. Presently, there is a need for it to connect more closely with the quality teams in the DHBs and to the Commission’s wider quality networks. The CYMRC’s LCYMRGs link into the secondary care services of every DHB as well as to primary care and mental health, as well as Police, Child Youth and Family, Well Child Services, local government, Ministry of Education, and many other sectors. The expertise, wide linkages and influence of these groups means they have considerable potential beyond the specific needs of child and youth mortality review and local systems change.

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| The CYMRC recommends that the Commission should:   1. consider how CYMRC’s national network of Local Child and Youth Mortality Review Groups can be developed and used for quality improvement of child and youth health services across New Zealand, supporting aspects of the Commission’s work beyond mortality review. |

# CYMRC’s partners

## CYMRC advisory group

Before the CYMRC makes recommendations in its reports, it seeks advisor input. The CYMRC Advisory Group is made up of experts in child and youth from government, non-government and private organisations throughout New Zealand. The advisors maintain a vested interest in the work of the CYMRC and will seek to implement many of its recommendations. As a result, they are seen as key stakeholders. At minimum, advisors are invited to meet with the CYMRC at least once a year, but additional communication might take place via email and teleconference.

The relationship between the CYMRC and the Advisory Group is mutually beneficial. The CYMRC reports and recommendations are more robust when the CYMRC has worked with key stakeholders throughout the entire process of data collection, analysis and reporting. The advisors are able to help the CYMRC understand how widespread certain issues might be and suggest ways of changing systems. At the same time, the Advisory Group has the opportunity to influence the development of the CYMRC work programme, join a network of like-minded colleagues who are engaged in similar work, and take findings back to their respective organisations. The Advisory Group adds value to the CYMRC process by providing expert guidance, advice, and support. The CYMRC is able to make high-quality, well-informed, evidence-based recommendations due to the involvement of its Advisory Group.

During 2010 and 2011, the following advisors provided guidance and support to the CYMRC:

|  |  |
| --- | --- |
| ACC | Anne Rose |
| ACC | John Wren |
| Change for Our Children | Stephanie Cowan |
| Ministry of Consumer Affairs | Lou Parker |
| Ministry of Consumer Affairs | Martin Rushton |
| Ministry of Education |  |
| Ralph Lane |  |
| Ministry of Health | Chris Laurenson |
|  |  |
| Ministry of Youth Development | Susan Wauchop |
| New Zealand Police | Bill Harrison |
| New Zealand Police | Belinda Himiona |
| New Zealand Police | John Lyall |
| New Zealand Police | Inspector Tracy Patterson |
| New Zealand Police | Mark Stables |
| Office of the Chief Social Worker | Emma Craigie |
| Office of the Children’s Commissioner | Marlane Welsh-Sauni |
| Office of the Children’s Commissioner | Nic Johnstone |
| Royal New Zealand Plunket Society | Erin Beatson |
| Royal New Zealand Plunket Society | Sue Campbell |
| Safekids New Zealand | Moses Alatini |
| Safekids New Zealand | Anne Weaver |
| Whakawhetu, formerly Māori SIDS | Kodi Hapi |

## Coronial Relations

The relationship between the CYMRC and New Zealand Coronial Services is very important. While the CYMRC retrieves data from many sources, the coronial services data provides a considerable amount of information about the context and circumstances of the death. At the national level, the CYMRC has co-opted to the committee Judge Neil MacLean, Chief Coroner, and Rhea Lewthwaite, Researcher, Coronial Services. This co-option to the CYMRC has helped to improve relations between the CYMRC and Coronial Services. In addition, each LCYMRG has strived to build a strong relationship with the local coroners of the region. The diagrams below (Figure 3 and Figure 4) highlight improvements in information flow that have been implemented over the last 18 months.

Through work with the National Coronial Services Unit, the Chief Coroner and the Ministry of Health’s Information Team, information flow from the Coronial Service to the Ministry of Health has been improved. Previously there were substantial challenges because the Coronial System had multiple links to the health system resulting in inefficient communication and, at times, confusion (Figure 3).

**Figure 3: Previous flow of CYMRC data**



With the development of the National Coronial Information System, it has been possible to develop, for a large part, a one-to-one relationship with the coronial system, which provides information to the Ministry of Health’s Information Team that can then be passed on to the various mortality committees as needed (Figure 4). This information flow has begun recently and the LCYMRGs are being provided with detailed information from the national database to inform local review.

Local groups are also encouraged to develop good relationships with Coroners and it is felt that this can be a positive two-way relationship. Coronial systems can provide additional information to inform local review and local review is able to support the implementation of recommendations made by Coroners.

**Figure 4: Current flow of CYMRC data**



## The Mortality Review Committees’ Māori Caucus

The Māori Caucus is made up of Māori members from each of the mortality review committees (MRCs), but also includes expertise from certain areas, as required. It is an unofficial advisory committee to the national MRCs, and its members collectively seek to:

* provide support and mentorship for Māori MRC members
* identify opportunities for collaboration and improving MRC outcomes for Māori
* assist in recruiting and appointing Māori MRC members
* improve the quality of MRC data collection and analysis of findings for Māori
* contribute to the development of MRC resources, information, and processes for Māori.

Since its establishment in 2006, the Caucus has met eight times and has discussed a range of issues related to mortality review in New Zealand. Some of the issues of particular relevance for the Caucus during 2010 and 2011 were post mortems and tissue retention, ethnicity classification, smoking cessation, and strategies to prevent Sudden Unexpected Death in Infancy (SUDI). A new policy of ethnicity classification proposed by the CYMRC’s scientific sub-committee has been supported by the Caucus.

The CYMRC is especially concerned that the rate for a number of mortality causes is significantly higher for Māori children and young people. The CYMRC is keen to produce a more detailed report on Māori child and youth mortality; the Caucus will provide guidance on how this should be done to get the most benefit. A preliminary analysis of the data for a new report of Māori child and youth mortality was discussed at the July 2011 CYMRC meeting.

# Causes of death relevant to the CYMRC

## Preventing sudden unexpected death in infancy

Sudden unexpected death in infancy (SUDI) is a cause of death relevant to both the CYMRC and the Perinatal and Maternal Mortality Review Committee (PMMRC). The committees have agreements to share information and work together on the topic.

About 60 infants die each year from sudden unexpected death. Chapter 1 of the CYMRC’s *Fifth Report to the Minister of Health* (2009) highlighted how attention to sleeping environments could save approximately forty of these lives. Despite a vast body of knowledge about what needs to happen, a substantial gap remains between this knowledge and what actually happens for infants in many households and some hospitals.

Since many of these deaths are preventable, the CYMRC continues to actively promote its SUDI-prevention recommendations (which can be found in Appendix 2 of this report). A review of case histories reveals that known risk factors continue to contribute to many of the deaths so substantial opportunities exist to reduce the death toll through population health work and targeted interventions.

In 2009, a SUDI Working Group – made up of members of CYMRC, PMMRC, key experts from the primary health sector, and representatives of non-government organisations – was organised to enable a better understanding of the challenges around developing shared messages and strategies for reducing SUDI. A smaller sub-group met early in 2010 and has been working with the Ministry of Health to progress the recommendations in the CYMRC’s *Fifth Report*, especially those that relate to the Ministry of Health developing a single work stream to address SUDI prevention.

In the first half of 2011, the CYMRC worked with the Ministry of Health to review the majority of Māori health plans for DHBs in New Zealand and was very surprised that SUDI prevention featured in few. The Ministry of Health requested that the six DHBs with the highest rates of SUDI develop a SUDI action plan and has set SUDI prevention targets. The CYMRC has provided detailed reports for these six DHBs highlighting the extent of the problem in their community. It is hoped that the setting of targets by the Ministry of Health will elevate the importance of prevention.

Following the Christchurch earthquake, the CYMRC also worked with the Ministry of Health to develop a media release highlighting the risks to infants in make-shift sleeping arrangements. Subsequently, the CYMRC has supported Change for Our Children’s successful campaign to release of over 700 Pepi-pods in Christchurch to provide safe sleep environments for infants that may have suffered family upheaval because of the earthquake.[[3]](#footnote-3)

Over the last 18 months, a pilot programme between the Ministry of Health and the National Coronial Services Unit was conducted in the three Auckland DHBs and Northland that seeks to provide support to families that have suffered a SUDI, while also collecting additional data on these cases. This programme has provided vastly improved death scene assessment and data collection to support prevention. It has also highlighted an enormous gap for families after the death of their infant. In fact, many times the health-trained death scene assessor (also known as the SUDI referral advisor), who was employed by this pilot project, walked alongside families through the events following the death, including handing their baby over for a post-mortem, discussing post-mortem reports and liaising with police and coroners. The SUDI advisor also linked services and provided a large amount of training to local health professionals, based on the learnings in these DHBs. The future of this programme is not clear. The CYMRC believes DHBs should collect as much information as possible after the death of an infant to support local prevention and should also consider sudden infant death as a community sentinel event. The CYMRC also believes that the death of an infant in the community should trigger support for families in the same way as the death of an infant in hospital does. The lack of such a service is currently a gap in most DHBs in New Zealand.

In the first half of 2012, the CYMRC will be reporting on a subset of SUDI cases where the baby suffered suffocation while asleep. The CYMRC is very grateful to the PMMRC for sharing information about cases of babies under 28 days of age for this report. This report will describe the circumstances of suffocation and provide further momentum to support safe sleep. Early data from this report was presented at the Paediatric Society of New Zealand Conference in 2010.

In some quarters, outrage around the concept that some infants die while sleeping in a family bed, because of suffocation, has made it difficult to discuss the risks that are associated with co-sleeping. The CYMRC hopes that providing details about how infants suffocate within family beds and in cots will lead to an appropriate response by the community. This is a vital but difficult issue, and the CYMRC is continuing to work with Whakawhetu (previously known as Māori SIDS), Change for Our Children and Taha (Well Pacific Mother and Infant Service) as they are key providers of sudden infant death prevention services. The CYMRC also supports the development of multidisciplinary local SUDI prevention alliance groups in each DHB.

The graphic below was developed for a presentation given by the CYMRC Chair at the Asia Pacific Coroners Conference in 2010 (Figure 5). It highlights how a large proportion of deaths (probably more than forty) can be prevented if infants sleep in the safe manner described in the CYMRC’s *Fifth Report*.

**Figure 5: Interaction between cause of death, vulnerability and environmental factors in sudden unexpected death in infancy**



***Note: each figure 10 represents ten infants who die with the balance of contributing factor diagrammatically indicated above.***

***SUDI=Sudden Unexpected Death in Infancy, SIDS=Sudden Infant Death Syndrome***

Another factor that contributes to SUDI is maternal smoking. The CYMRC is pleased to see that smoking cessation efforts are gaining increased importance within DHBs, particularly in relation to the Minister of Health’s smoking targets. If SUDI prevention is to gain even more momentum, it is important that support for smoking cessation *in pregnancy* be increased because the benefits derived from smoking cessation in pregnancy are significant.

The CYMRC would like to see greater uptake of its SUDI-prevention recommendations. As an example, in its *Fifth Report*, the CYMRC recommended that every DHB implement a safe sleep policy. Some DHBs are clearly performing this work, but others are not and some of the “safe sleep policies” developed are not safe. The CYMRC notes that a locally driven participative approach is important to drive change; however, such an approach needs central leadership to ensure quality and consistency across the country. A central leadership team that shares innovative practices can also reduce duplication of effort.

The CYMRC notes that its recommendation calling for greater central cohesion of SUDI messages and its recommendation that every DHB implement a safe sleep policy (see R1.1 and R1.4 in Appendix 2) should be taken together to fashion an approach that allows for local participation but with strong direction from a central entity that is able to conduct quality audits across the DHBs.  The CYMRC believes this would be an area of care suitable for support from the Commission working with maternity, neonatal and paediatric services. Such SUDI-prevention recommendations could now be given new momentum and impetus with support from the Commission.

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| The CYMRC recommends that the Commission should:   1. support DHBs in developing quality improvement systems that promote evidence-based safe sleeping practices for infants, which are modelled in every DHB and supported by clear policy and audit systems. A network across DHBs should provide clear national guidance, reduce duplication and minimise variation, while also supporting local participation in training and development of safe sleep practices. |

## Low speed vehicle fatalities

An in-depth report on low speed vehicle fatalities (also known as slow speed run over) was released in August 2011. This work was developed over 18 months by the CYMRC and we believe the path followed for this report is one that should be copied in the future.

The committee engaged with key prevention partners to develop recommendations, including Safekids New Zealand, the AA Driver Education Foundation, Housing New Zealand, the New Zealand Police Serious Crash Unit, the New Zealand Transport Authority (NZTA) and injury prevention researchers.

Preventing slow speed run over is a key prevention objective of Safekids New Zealand; they launched a national campaign to prevent slow speed run over in 2011 and held a series of workshops in every DHB during 2011. These workshops were informed by information collected by the CYMRC and joint media work occurred between Safekids New Zealand, injury prevention researchers, Housing New Zealand and the CYMRC.

The Chair of the CYMRC presented data related to slow speed run over at the national Kids Trauma Conference in May 2011. Such early networking is very important; a considerable amount of work already occurred to implement the recommendations in this detailed report before the full report was made public.

## The involvement of alcohol consumption in the deaths of children and young people in New Zealand

In September 2011, the CYMRC released a special report on the involvement of alcohol consumption in the deaths of children and young people in New Zealand during the years 2005 to 2007. Specifically, this reports examined deaths caused by motor vehicle accidents in 2007 and deaths caused by drowning, assault, suffocation, poisoning and falls from 2005 to 2007.

Preliminary analysis of this report was submitted to the Law Commission in 2009 and has since been read by a number of stakeholders from Police, Ministry of Transport, Ministry of Justice, and Ministry of Health. As a result, many of the legislative recommendations in this report were addressed in the Land Transport (Road Safety and Other Matters) Amendment Act 2011 and were included in the deliberations related to the Alcohol Reform Bill. We believe this is an important report outlining the severity of alcohol-related harm, and will continue to inform public debate.

In a number of communities, work has occurred related to the prevention of alcohol-related harm. This work has grown out of local group initiatives and is especially linked with youth risk-taking behaviour.

## Systems improvement throughout the health care sector

The Systems Chapter of the CYMRC’s *Fifth Report* highlighted that children and young people have health care needs that are different to those of adults and require specific provisions in the design of systems. In that report the CYMRC wrote:

*The current restructuring of the health system provides an opportunity to better support a holistic approach to Child and Youth, to increase collaboration and coordination and reduce service gaps by providing oversight from a single section or division within the Ministry of Health or National Health Board.*

And

*All DHBs need a team approach and leadership to create and support a holistic approach to child and youth health. The CYMRC recommends a portfolio manager for children and youth or similar in every DHB.*

The CYMRC has not seen an uptake of these recommendations but still feels that they are very important. They are especially poignant with regard to addressing the needs of vulnerable children. The Commission has an opportunity to create structures that appreciates the unique needs of children and young people, particularly in relation to health services.

|  |
| --- |
| The CYMRC recommends that the Commission should:   1. develop a system to maintain and support child and youth services from a quality perspective. For instance, at minimum, one person within the Commission should be responsible for the oversight of all child and youth health services from a quality perspective. The Commission would then be able to support a similar approach at the DHB level, resulting in a strengthened quality network for child and youth that promotes opportunities to share innovation across DHBs. |

# Summary of CYMRC recommendations to the Health Quality & Safety Commission

The CYMRC makes the following recommendations to the Commission.

1. Consider how CYMRC’s national network of Local Child and Youth Mortality Review Groups can be developed and used for quality improvement of child and youth health services across New Zealand, supporting aspects of the Commission’s work beyond mortality review.
2. Support DHBs in developing quality improvement systems that promote evidence-based safe sleeping practices for infants, which are modelled in every DHB and supported by clear policy and audit systems. A network across DHBs should provide clear national guidance, reduce duplication and minimise variation, while also supporting local participation in training and development of safe sleep practices.
3. Develop a system to maintain and support child and youth services from a quality perspective. For instance, at minimum, one person within the Commission should be responsible for the oversight of all child and youth health services from a quality perspective. The Commission would then be able to support a similar approach at the DHB level, resulting in a strengthened quality network for child and youth that promotes opportunities to share innovation across DHBs.

# Appendix 1: CYMRC membership, meetings, and sub-groups

## CYMRC membership

**Current members**

|  |  |  |
| --- | --- | --- |
| Dr Nick Baker (Chair) | Community Paediatrician | Nelson Marlborough DHB |
| Mr Eruini George | Pou Herenga | Lakes DHB |
| Dr Anganette Hall | Adolescent Medicine Specialist & Paediatrician | Hutt Valley DHB |
| Mrs Sue Matthews | Clinical Nurse Leader | Kaitiaki Nursing Services and an elected member of Western Bay of Plenty District Council |
| Professor Edwin Mitchell | Child Health Research | University of Auckland |
| Mr Paul Nixon or  Mrs Emma Craigie | Chief Social Worker  Principal Advisor | in the Office of the Chief Social Worker (nominees of the Chief Executive of the Ministry of Social Development) |
| Mrs Anthea Simcock | CEO | Child Matters |
| Dr Sharon Wong | Paediatrician and  Clinical Senior Lecturer, Department of Paediatrics, Child and Youth Health | Waitemata DHB  University of Auckland |
| Vacant |  | (nominee from the Ministry of Health) |

**Co-opted members**

|  |  |  |
| --- | --- | --- |
| Dr Stuart Dalziel | Paediatric Emergency Medicine Specialist | co-opted for his research expertise |
| Dr Rebecca Hayman | Paediatric Emergency Medicine Fellow | co-opted for her research expertise |
| Ms Rhea Lewthwaite | Researcher, Coronial Services | co-opted to facilitate data sharing between CYMRC and Coronial Services |
| Judge Neil MacLean | Chief Coroner | co-opted to facilitate relationships between CYMRC and Coronial Services |

**Former members (who served on the CYMRC for part of the time period covered in this report)**

|  |  |
| --- | --- |
| Mrs Mary (Mere) Tiki Balzer | resigned February 2011 |
| Dr Marie Connolly, nominee of the Chief Executive of the Ministry of Social Development | resigned July 2010 |
| Dr Elizabeth Craig | term expired 2010 |
| Dr Russell Franklin | term expired 2010 |
| Dr Constance Lehman, nominee of the Director-General of Health | resigned in 2011 |
| Mrs Riana Manuel | term expired 2010 |
| Professor Barry Taylor | term expired 2010 |

For more information about the CYMRC and its current membership, see the CYMRC’s section on the Commission’s website [www.hqsc.govt.nz](http://www.hqsc.govt.nz)

## CYMRC meetings

The CYMRC met five times in Wellington during 2010, and twice in Wellington and once by teleconference during the first half of 2011. The meetings were held on:

* 11 February 2010
* 6 and 7 May 2010
* 5 and 6 August 2010
* 20 and 21 September 2010
* 4 November 2010
* 24 February 2011 (via teleconference)
* 8 April 2011
* 3 June 2011.

## Executive group

In 2010, the CYMRC established an Executive Group to serve as its operational arm. The purpose of the Executive Group is to implement the directives of the CYMRC by managing operational details. It was necessary to form this group for two main reasons: first, now that the CYMRC has successfully established 21 LCYMRGs throughout New Zealand, a considerable amount of energy must be devoted to their maintenance. Second, the growing amount of information held in the database has allowed the CYMRC to engage in more complex data analysis, but this requires more research expertise. The CYMRC Executive Group manages this operational work, thus ensuring that the CYMRC is able to focus on governance, particularly in regards to the development of recommendations and strategies to reduce deaths.

The Executive Group is made up of the Chair of the CYMRC, the Director of the Mortality Review Data Group, the Manager of the Mortality Review Data Group, the CYMRC Lead Coordinator, and the Senior Policy Analyst supporting the CYMRC from the Commission.

The Executive Group has initially been meeting fortnightly via videoconference.

As a result of the Executive Group, it has proved possible to have fewer two-day meetings of CYMRC in 2011 and it is anticipated that this trend will continue.

## 

## Scientific sub-committee

A CYMRC scientific sub-committee has been in operation for a number of years. The purpose of the sub-committee is to:

* advise the CYMRC on priorities for research into potentially preventable causes of child and youth deaths in New Zealand
* develop processes that promote and authorise the access, use and publication of scientific works that include CYMRC data
* maintain an overview of research and check that data is being reviewed and appropriately reported.

The scientific sub-committee held seven teleconferences during 2010 and the first half of 2011. One of the primary concerns for the sub-committee was the quality of CYMRC reporting. During 2010, the CYMRC contracted epidemiologist Dr Liz Craig to develop a reporting protocol handbook to streamline the CYMRC’s reporting process, develop more consistency in reporting, and reduce errata.

# Appendix 2: CYMRC Previous Recommendations, with an update on progress

## CYMRC First Annual Report Recommendations, 2002–2003

This report covered the initial set-up year of the committee, and in the recommendations the Minister of Health was asked to note a number of key issues the committee was working on or was concerned about. These issues were as follows:

| **Recommendation** | **Chair’s 2011 update on progress** |
| --- | --- |
| R1.1 CYMRC’s intention to collect, in a central database, complete and accurate data on every child and youth that dies in New Zealand, to provide a solid evidential base for developing preventive strategies. | The database continues to be housed by the New Zealand Mortality Review Data Group at the University of Otago. It is now used by coordinators from every DHB in the country. Work on continuous quality improvement is continuing as outlined above. |
| R1.2 The varying nature and extent of data at the coronial level, which limits the ability to undertake robust, in-depth mortality reviews. The CYMRC supported the establishment of a coronial information system. | Information is now being received from the National Coronial Database. An excellent working relationship exists with the Chief Coroner. Local Child and Youth Mortality Review Groups are working with local Coroners to develop relationships which can be mutually beneficial, particularly improving information flow. |
| R1.3 The need for a working group drawing members from the Ministry of Justice, Department for Courts, Police, Coroners’ Council, ACC, Ministry of Health and CYMRC to develop protocols that authorise the collection of standardised and consistent data for different types of child and youth deaths. | The Working Group was never established. The work of Local Child and Youth Mortality Review Groups has brought about the improvement of some types of data collection and consistency. Ongoing work is needed. |
| R1.4 The initiation of a project (for which CYMRC obtained a funding grant) to evaluate the role of a health-trained investigator to collect information for both the coroner and the mortality review process. This would involve a case-control study for SUDI and a case study of youth suicides. | The role of health-trained investigator to collect information following sudden infant deaths was established. Very positive responses were received from families, communities, Police, Coronial Services and Local Child and Youth Mortality Review Groups. When the initial pilot concluded, an interim rollover pilot was secured but it is not clear what will happen in the future. |
| R1.5 The CYMRC requested senior advisors for the committee from the Police Commissioner’s office, Commissioner for Children, Ministry of Education, and District Health Boards. | The role of the Advisors is continuing to develop with regular involvement with the CYMRC as well as advising on report writing and “reality checking” recommendations from Local Child and Youth Mortality Review Groups and the CYMRC. |
| R1.6 The fact that the establishing of local mortality review groups relies on the support and resourcing from District Health Boards. The necessary costs may be a significant barrier to implementation for local mortality review groups across the country. | All DHBs are now engaged with the Child and Youth Mortality Review Process with their own Local Child and Youth Mortality Review Groups. The Lead Coordinator for each group is funded by a contract with the Co |

## CYMRC Second Annual Report Recommendations, 2003–2004

In the second report, recommendations were made on the functioning of the review process and on measures for decreasing child and youth mortality in New Zealand.

| **Recommendations for the functioning of the national review process** | **Chair’s 2011 update on progress** |
| --- | --- |
| R2.1 A formal service level agreement should be signed between the CYMRC chair and the Ministry of Health about the parties’ mutual obligations. | After a period with frequent changes of staff, the Ministry of Health finally consolidated a strong team to support the Mortality Review Committees. This is led by a Manager of the Mortality Review Committees. The transition to the Commission provides further opportunities to promote system quality. |
| R2.2 The value of an interactive Internet-based child and youth mortality database should be recognised and receive secure funding in the medium term. | The interactive web-based database is working well to support local groups. Continuous quality improvement of this database needs to be achieved. As increasing amounts of data are available for analysis, systems for analysis need to be developed. |
| R2.3 Data collection and sharing protocols between the coroners, police and CYMRC should be specifically mentioned and allowed for in the Coroners Bill. | Mostly, there is excellent sharing of information between the Police, Coronial Services and the Child and Youth Mortality Review Committee. The police service has very strongly supported the process of local review. The new linkage of coronial data via the Ministry of Health’s Information Team in 2011 has further improved this system. |
| R2.4 Further policy work should be carried out, with a view to legislative change, to enable case conferences with a range of professionals and agencies to inform mortality review. | The New Zealand Public Health and Disability Act 2000 does not currently allow for this. If the Act is to be reviewed in the future, the Child and Youth Mortality Review Committee will consider making an appropriate submission. |
| R2.5 Local mortality review should be recognised as providing detailed and high-quality information that can be accessed to inform prevention strategies. | With local mortality review groups in every District Health Boards, their value is becoming more widely known. Various reports this year have highlighted the local actions that these groups have achieved. The new DHB reports in 2011 will further help. |
| R2.6 Multi-agency local review processes should be recognised as promoting networking, local system change and increasing social capital. | Very positive feedback has been received, particularly from the new District Health Boards that have recently come on board, with regard to improved networking ability, which helps to gain mutual understanding, initiate change, and make linkages that previously were not occurring. |
| R2.7 A project team should be funded with members from DHBs and the CYMRC to develop written protocols for local mortality review processes and for reporting at the local level to participating agencies. | The handbook to support local child and youth mortality review processes needs to be redrafted and brought up to date along with a data dictionary. |
| R2.8 DHBs should note the requirement for child and youth mortality review as part of the Provider Quality Specifications (in the Operation Policy Framework). | An increasing number of District Health Boards are recognising the importance Child and Youth Mortality Review as a core quality improvement activity. The process seems to “sell itself” with increasing support. |
| R2.9 All advisors and health care providers should actively promote safe sleeping practices.  All services that offer care to infants and mothers should provide safe sleeping environments for infants. | Unsafe sleeping practices continue to contribute to a substantial proportion of sudden infant deaths in New Zealand. (See the discussion in this report about proposed new directions.) |
| R2.10 Further work should be undertaken to make sure the ‘safe environment’ message effectively reaches high-risk families, and that providers of care maintain their knowledge and advice on safe sleeping environments. | Unsafe sleeping practices continue to contribute to a substantial proportion of sudden infant deaths in New Zealand. (See the discussion in this report about proposed new directions.) |
| R2.11 Earlier use should be made of the inter-agency case management for complex high-risk families with young infants or babies. | This is a continuing concern. More DHBs now have high need antenatal care pathways. |
| R2.12 A protocol for sensitive death scene investigation should be collaboratively developed at a national level by police, coronial and health services (including pathologists), and Māori. | The health-trained investigator role is supporting clear protocols in the four District Health Boards where this role is available. With the future of this project being uncertain, the needs of families after a death need to be addressed. |
| R2.13 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 own homes. This information should also be in the Well Child booklet. | Information is now in the Well Child book, is part of routine Well Child care, is highlighted in picture resources, and Plunket and Water Safety NZ have run a specific campaign. Chapter 2 of the Fifth Report has been widely used to highlight and address the problem. |
| R2.14 Adult services (especially mental health services) should 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 by the health service. | It is a continuing observation that children may, at times, be invisible to the services that care for their parents. Some DHBs have developed DNA care pathways, but further work is needed. Services for Children of Parents with Mental Illness (COPMI) have been developed but are not universal.  This issue is also one that may be looked at, in part, by the Family Violence Death Review Committee. |
| R2.15 Adequate housing and a safe environment are 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. | The current work on slow speed run over has been valuable to flag some home safety issues and investment is occurring from Housing New Zealand. |
| R2.16 The CYMRC should share information with the Ministry of Consumer Affairs about the safety of bath seats and swimming rings for babies and infants, as in the previous 2 years at least two deaths were related to the unsupervised use of these products. | They remain available for sale within New Zealand and carry a warning label. |

## CYMRC Third Annual Report Recommendations, 2004–2005

The recommendations in the third report were as follows:

| **Recommendation** | **Chair’s 2011 update on progress** |
| --- | --- |
| R3.1 The Ministry of Health should evaluate its current SUDI prevention messages and consider ways for effective health promotion strategies about baby-safe environments, particularly those relating to safe sleeping practices and smoking during pregnancy. These strategies need to be effective in Māori and Pacific communities. | See the related narrative in the body of this report. |
| R3.2 The Minister of Health should note the ongoing high rate of mortality among Māori children and youth, and the level of disparity between Māori and non-Māori. | Plans are under way for a specific Māori report to be produced. |
| R3.3 The Minister of Health should note the CYMRC’s concern that in some cases there is poor continuity of care in the post-neonatal age group. | The proposed DHB quality indicator around enrolment of babies with General Practice by four weeks of age is gaining some traction in DHBs. |
| R3.4 The Minister of Health should note that the CYMRC has written jointly with SAFEKIDS to the Minister of Consumer Affairs asking her to consider the banning of baby bath seats in New Zealand. | Such seats are still for sale. |
| R3.5 The Minister should note the emergence of suicide in the 10–14 years age group and that the CYMRC will write to other relevant groups, including the All Ages Suicide Prevention Strategy Group, about this issue. | The trend for 10 – 14 year old youth is hard to establish with small number variation. Continuing reduction in youth suicide appears to be occurring. (See the CYMRC data online and the Ministry of Health’s Suicide Fact Sheets.) |
| R3.6 NZHIS should discuss with the Department of Internal Affairs ways to transfer information more quickly from Births, Deaths and Marriages to NZHIS, and thus through to health organisations that use NHI numbers. | Local groups continue to be surprised that key information systems and people are not aware that a child or young person has died. This, in part, has driven the recommendation in this report around the After the Death of a Child Care Pathway. |
| R3.7 The Land Transport Safety Authority (LTSA) and the Government should consider the findings of recent research into vehicular-related deaths among children and young people in New Zealand and undertake any measures that may minimise the risk of such deaths. | The CYMRC was very pleased to see the Land Transport Safety Authority looking at the Safer Journeys project. Recommendations related to this issue are documented in Chapter 3 of the *Fifth Report* and have, or are becoming, part of legislative change. |
| R3.8 The Minister of Health should note the need for consistent and adequate support for families after the death of their child. This does not appear to be the case at present, and the CYMRC will be having further discussions with Victim Support, coroners and the police before making clear recommendations on this issue. The Minister should also note that the Cross Departmental Research Pool (CDRP), developed by the CYMRC and sponsored by the Ministry of Health, may have some impact on this issue. | It is hoped with the work of the Local Child and Youth Mortality Review Groups in every District Health Board that after the death of a child care pathways can be more clearly established, resulting in better support for families. |

## CYMRC Fourth Annual Report Recommendations, 2002–2006

The recommendations in the fourth report were as follows:

| **Recommendation** | **Chair’s 2011 update on progress** |
| --- | --- |
| R4.1 All lead maternity carers (LMCs) and providers of Well Child services focus on clarifying with parents what is known about safe sleeping environments for infants. | See the related narrative in the body of this report. |
| R4.2 Culturally appropriate and safe places for sleeping babies need developing and promoting. | Research is occurring in this area. A major challenge is ensuring that new sleeping arrangements do not come with unexpected hazards. |
| R4.3 Smoking in pregnancy needs to be a key focus of the Ministry of Health’s smoking cessation programme. | It is very pleasing to see the Ministry of Health is continuing to emphasise the importance of smoking cessation in pregnancy. The CYMRC feels that this work could be more closely linked to prevention of sudden infant death. |
| R4.4 National monitoring of known risks should be considered as part of the Well Child contract to measure the effectiveness of prevention work. | The Review of the Well Child Service Framework is still ongoing. We are not aware of any contractual changes that have led Well Child providers to specifically report how successful their interventions have been. It would be useful if Well Child providers document the proportion of infants that are sleeping on their backs in a safe place and whether smoking cessation services have been successful. |
| R4.5 (As we have previously recommended) there needs to be improved communication between providers, including confirmation that referrals have been received. | The QIC project on outpatient referrals and e-referral work, which might now sit under the Commission, should improve this situation. The special needs of children and young people do, however, need to be born in mind. |
| R4.6 All District Health Boards develop or review their policy and practice on the transition of care to adult services for children and youth with complex health (including mental health) needs. | CYMRC planned work on chronic conditions is likely to highlight new directions around transitions. |
| R4.7 Government (particularly the Ministries of Education, Justice, Social Development and Health) and those working with children and youth, as a priority, actively identify and address barriers to inter-agency communication and working together. | Work across agencies remains a significant challenge. The further rollout of the Strengthening Families initiative and the High and Complex Needs Strategy are seen as very positive, but further work is needed to ensure children with the highest needs navigate their way between various government departments without falling through the cracks. |
| R4.8 The current work to develop and establish a child health information system accessible to all those in New Zealand providing health services to a child be given a high priority. | A Child Health Information System remains a significant challenge. Parts of the system are in place with the development of the National Immunisation Register, Newborn Hearing Screening Database, Oral Health Service databases, B4School Database and others. The challenge is linking this information in the best interests of the child. It remains tragic that after death, we can link data and note how services could be improved. Such linking should occur prior to death. The new work on Health and Education Assessments of Children in Care is seen as an excellent example of improved access to co-ordinated support. |
| R4.9 Consideration be given to a co-ordinated process for follow-up of families after SUDI deaths as part of the current review of Well Child services. | It is hoped that the process advocated by the Child and Youth Mortality Review Committee, with the development of Local After the Death of a Child Care pathways, will lead to local solutions to better support families following SUDI deaths. |
| R4.10 Suggests to the relevant Minister that that there is a need for leadership on these matters from the Accident Compensation Corporation (ACC) and Occupational Safety and Health, Department of Labour (OSH), and in particular from the recently appointed Director of Injury Prevention at ACC. | There continues to be a paucity of information around the cost of child and youth injury in New Zealand and, for some classes of injury, different organisations review the scene making understanding the full picture more difficult. |
| R4.11 Encourage all DHBs to institute the recommendations of the Youth Health Action Plan (Ministry of Health. 2002. *Youth Health: A guide to action*. Wellington: Ministry of Health). Available under publications on www.moh.govt.nz. | It is very pleasing to see the rollout of some additional youth health services, particularly Health Support for Young People in the most deprived schools and alternative education. Youth health, however, remains a significant concern, as highlighted in Chapters 3, 4 and 5 of the *Fifth Report*. Implementing the Youth Health Action Plan remains a valuable way forwards. |
| R4.12 Requests the Ministry of Health to undertake further work related to alcohol, with a focus on effective methods of altering our current youth ‘alcohol bingeing’ culture. | The CYMRC published a report on alcohol-related harm in September 2011. |
| R4.13 Requests the Ministry of Health to develop further incentives for District Health Boards to support the evolving of local and national processes for mortality review. | The CYMRC is delighted that all District Health Boards are now involved in the Local Child and Youth Mortality Review process and that a Lead Coordinator can work across all 21 District Health Boards. As described in the narrative of this report, the focus is now shifting towards local action and quality. |

## CYMRC Fifth Annual Report Recommendations, 2002–2008

The recommendations in the fifth report were as follows:

| **Recommendation** | **Chair’s 2011 update on progress** |
| --- | --- |
| R1.1 That the Ministry of Health consolidate within the Child, Youth, and Maternity Policy work-stream all its efforts to prevent SUDI. This would provide greater central cohesion and more support for providers to maximise their impact, while also respecting the need for a plurality of approaches. | There is continuing concern that the Ministry of Health has not consolidated all work-streams into a single entity. This has been complicated by the ongoing restructuring of the Ministry of Health. It is hoped that the new SUDI prevention targets will be supported by consolidated work-streams within the Ministry of Health. |
| R1.2 That action on smoking cessation, before, during, and after pregnancy, be elevated to a level consistent with its status as a major health concern, especially for Māori and be more clearly linked to prevention of SUDI. DHBs should be required to report the smoking/smokefree pregnancy status of their populations as a requirement of funding agreements | It is pleasing that smoking cessation has been chosen as the Minister’s target for District Health Boards. This has galvanised considerable work in this area. Further work is needed to ensure that this consistency extends into the area of smoking cessation in pregnancy, especially around supporting young Māori women in not starting to smoke, and then into smoking cessation in pregnancy with a view to reducing the toll of sudden infant death. |
| R1.3 Research into SUDI needs to be targeted to fill knowledge gaps, particularly with regard to safe sleeping environments for Māori babies. There is evidence about unsafe sleeping practices, but there is a paucity of evidence about what represents safe sleeping practices and innovations, as well as what practically works to bridge the gap between what is known about safe sleep and what is done to keep infants safe. | Following correspondence to the Health Research Council, research funding has been awarded to look at the safety of sleeping environments, such as the wahakura, and it is hoped that this research, once available, will allow clear evidence-based advice to be given to families. |
| R1.4 That every DHB implement a safe infant sleeping policy:  a. for modelling safe sleeping practices in neonatal and postnatal facilities  b.to ensure safe sleeping arrangements are in place for all babies at every sleep before discharge home  c. to advise on safe strategies for night feeds and settling infants. | As highlighted in the accompanying narrative in this report, these safe sleep policies are in development in a number of DHBs but consistency and quality across DHBs needs to be enhanced and all DHBs are not yet developing such policies. |
| R1.5 That DHBs monitor and report on:   1. the continuity of care in early infancy between Lead Maternity Carers, hospital services, Well Child providers and general practitioners 2. the proportion of infants who have a named general practitioner recorded in the National Immunisation Register by four weeks of age (which is one potential performance indicator). | Challenges still exist in ensuring that every baby is supported by a Well Child provider and that there is smooth continuity of care between Lead Maternity Carers and Well Child Services and General Practice.  The development of the ‘enrolled with a GP’ marker by four weeks of age has been discussed at a national epidemiology workshop and some DHBs have included work towards this indicator in their district annual plans. |
| R2.1 The current pool fencing legislation has worked well to reduce child drowning. Any changes in legislation regarding pool fencing should ensure that the risk of drowning is further reduced through increased child safety provisions. | When this recommendation was written, the CYMRC was concerned that some moves were afoot to remove bureaucracy from local government that could have impaired the strength of the existing legislation. The CYMRC is no longer aware that such action is occurring. |
| R2.2 Local authorities should consider where systems to support ongoing compliance with the legislation on pool fencing and overall pool safety can be improved. | An increasing number of local authorities are developing systems to support ongoing compliance with the legislation on pool fencing. |
| R2.3 Information on the burden of disease from traumatic brain injury arising from non-fatal submersion should be collected to support the prioritisation of intervention(s). | There are some challenges with linking burden of disease data from ACC with cause of injury to target prevention. It is hoped that the CYMRC involvement with the New Zealand Injury Prevention Strategy stakeholder group may begin to address these issues. |
| R2.4 Those with a medical condition that predisposes them to unconsciousness (such as epilepsy) should be advised to shower rather than take baths. | Such advice is contained in literature from the Epilepsy Association but the CYMRC is not aware of how extensively it is practiced by health professionals. |
| R2.5 When new caregivers are taught to bathe their babies, a simple safety strategy should be taught: ‘if you leave the bathroom, take your baby/child with you’. | A specific campaign has been run by the Water Safety NZ Council, in conjunction with Plunket, around the dangers of babies in baths and some new graphic resources have been developed supporting parents in taking babies with them from the bathroom should they have to answer the telephone. |
| R3.1 The allowable breath alcohol level for young and/or novice drivers should be lowered to zero. | In 2011, the BAC was lowered to zero for young drivers. Issues around novice drivers are still being addressed. |
| R3.2 Develop strategies to improve the safety of the environment. Such strategies might include the following:   1. change regulations regarding access to alcohol 2. change the Ministry of Transport regulations for licensing young drivers, introducing a system with more steps that better acknowledge the time taken to acquire the necessary skills 3. encourage initiatives to reduce driver distraction and fatigue, such as the November 2009 ban on hand held cell phones 4. review enforcement to ensure strategies used achieve increased safety. | Alcohol reform legislation has been before Parliament.  The Ministry of Transport graduated licensing scheme is being strengthened.  Concerns exist around driver distractions, fatigue and enforcement of Restricted Driving Licences.  New television adverts have appeared with regard to teen driving and parental responsibility. |
| R3.3 Recognise injury as one of the most important health threats for young people and include it in the health policy agenda, including specific elements related to risk taking. | The CYMRC is very pleased to see that the Peter Gluckman report on adolescent morbidity (May 2011) has picked up on a number of these issues and we look forward to the government’s response |
| R3.4 Improve the collection and linkage of data about serious injury to allow better surveillance, analysis and reporting of the huge burden that injury imposes. | Further work in this area is required. Hopefully, engagement with the New Zealand Injury Prevention Strategy Stakeholder Group will facilitate such action. |
| R3.5 Youth health promotion, life skill programmes and injury prevention should include strategies to build risk competence and resilience that involve both young people and their parents. | The CYMRC is awaiting the government’s response to the Peter Gluckman report on adolescent morbidity from May 2011. |
| R3.6 Care pathways should be developed to support universal opportune psychosocial screening of young people which is linked to effective interventions to reduce risk if positive screening occurs. | National training around the HEADSS assessment is occurring in all the PHOs. Further work is needed around formulating plans related to prevention based on opportune psychosocial assessment and development of support pathways. |
| R3.7 Health professionals should provide opportune psychosocial screening (as in the HEADSS assessment) to all young people seen in health services. This includes screening for risky motor vehicle behaviours, especially in conjunction with alcohol use. | See above. |
| R3.8 Health professionals need to support parents and acknowledge the importance they play in the wellbeing of teenagers in their care. This includes educating parents on the hazards associated with learning to drive and using motor vehicles. | The new TV advertising campaign from the LTSA is specifically targeted to address this issue. |
| R3.9 Health professionals need to help others to understand the development of young people and work with communities to create opportunities that build risk competence and resilience, especially for young men. | The CYMRC is awaiting the government’s response to the Peter Gluckman report on adolescent morbidity from May 2011. |
| R4.1 The CYMRC supports, as a high priority, specific preventative work in every DHB, with central leadership, to achieve the seven goals of the *New Zealand Suicide Prevention Strategy*. | A number of DHBs have Suicide Prevention Coordinators. It is not clear what is happening in DHBs where such coordinators are not in place. The CYMRC has recently been engaged in a response to a suicide cluster where it was clear that coordinated work at a DHB level was difficult to achieve. |
| R4.2 The youth-focused actions suggested from *In Our Hands* should be remembered and youth specific elements should continue to be formulated within the current suicide prevention initiatives.   * Health services geared towards, and accessible to, young people (eg, youth one-stop shops and school health clinics). * Endorsement of youth health standards, similar to those promoted by the Society of Youth Health Professionals Aotearoa New Zealand (SYHPANZ). * Greater intersectoral collaboration, working across primary and secondary care, school services and mental health services, including drug and alcohol. * Support research about the nature, correlates and causes of suicidal behaviours, and research into resiliency. | The Peter Gluckman report on adolescent morbidity from May 2011 addresses these issues and recommends further work to support youth health and wellbeing. |
| R4.3 The impact of modern communications technologies on adolescent suicide should be acknowledged and better understood.   * The Ministry of Health review of its guideline *Suicide and the Media* should include advice around modern technologies. * Health research funding bodies should consider funding research to identify if and how modern technologies contribute to suicidal predisposition, precipitation and completion. | Work from assessment of a suicide cluster with a particular interest in mock means of communication has been submitted for publication. Further work is needed in this area. It will be an ideal topic for Suicide Prevention Coordinators at DHBs to pick up. |
| R4.4 The Ministries of Health and Education should jointly review the role of school counsellors. This review should consider: whether the role is educational guidance counsellors or health/social services counsellors; staffing levels; training requirements; professional development; and how they might be better supported by the health sector. School counsellors should:   * have appropriate skills * be registered with a professional association * be integrated into the whole of the school * have regular supervision from someone with appropriate skills * have a supportive relationship with mental health workers. | The CYMRC is not aware of any progress in this area. |
| R4.5 Appropriate procedures and use of Ministry of Education post traumatic incident support by schools should be included within the elements of school performance reviewed by the Education Review Office. | The CYMRC has written to ERO recommending this action and local groups are raising this issue following traumatic incidents. |
| R4.6 The Ministry of Health should monitor and respond to performance of primary health organisations (PHOs) with regard to coverage of service and capitation for care in young people. | PHO performance monitoring programmes do not have a strong emphasis on child or youth health. |
| R4.7 Each DHB should have in place:   * a suicide prevention action plan to implement the *New Zealand Suicide Prevention Strategy 2006–2016*, with a focus on youth * a mechanism for identifying community-based health crises, including those relating to mental health and suicidality, which links to a multidisciplinary response with clearly assigned responsibilities * a mechanism for supporting families bereaved by suicide * a system that uses what is learnt from cases of suicide to modify local systems of care, prevention and support * an assigned role for specific staff to maintain a strong supportive relationship between youth mental health services and school counsellors * a system whereby referrals from school counsellors receive timely care * a system that ensures all mental health concerns are taken seriously * PHOs need to make efforts to improve coverage of care for young people and use strategies such as youth one-stop shops and school based clinics to enable increased coverage. | We believe this work is progressing in areas where there are Suicide Prevention Coordinators. In areas where such people are not in place, work has been less obvious. |
| R5.1 The Government needs to continue to promote intersectoral communication, planning and review. This needs to be in each department’s outputs, and funded. | Some exciting initiatives are occurring, most noticeably the new Gateway Assessment where children or young people receive health and education assessments as they attain status with Child Youth and Family. The Strengthening Families initiative continues to have positive achievements as well. |
| R5.2 The current restructuring of the health system provides an opportunity to better support a holistic approach to Child and Youth, to increase collaboration and coordination and reduce service gaps by providing oversight from a single section or division within the Ministry of Health or National Health Board. | At this time it appears that cohesion for child and youth health care has, if anything, become less apparent in the Ministry of Health and no single section of the National Health Board has a focus on Child and Youth Health. Exciting developments are, however, occurring with the development of the CYMRC’s National Child and Youth Network and some Regional Child and Youth Networks. The Commission needs to consider if there are any ways it can support this important recommendation. |
| R5.3 Coordination is needed between sectors to develop effective responses that address the types of deaths that cross boundaries between government agencies. Driveway deaths, farm transport deaths and recreational off road are examples where leadership and cooperation are required to reduce the number of deaths and injuries. | It is hoped that the release of the low speed run-over chapter will more clearly highlight this gap. Further work is needed with regard to off-road deaths, although Occupational Health and Safety has recently enhanced focus with regards to farm deaths. The New Zealand Injury Prevention Strategy stakeholder group also supports this recommendation. |
| R5.4 The health sector has a duty to use appropriate risk assessment tools and, where risk is identified, interventions should occur. | New needs assessment tools are being developed with regard to sudden infant death jointly between Plunket, College of Midwives and the Werry Foundation. The implementation of the 2011 Gluckman Report may further this issue for youth. |
| R5.5 All DHBs need a team approach and leadership to create and support a holistic approach to child and youth health. The CYMRC recommends a portfolio manager for children and youth, or similar, in every DHB. | A number of DHBs have made excellent progress in this area with appointment of portfolio managers for Child and Youth and strong networks within District Health Boards. This issue was discussed at a national Child and Youth Epidemiology Workshop in May 2011. The Commission might consider if there are any ways it can support this important recommendation in regards to the expectations of DHBs. |
| R5.6 All DHBs should have a system to plan and implement transition of young people from paediatric to adult services. | Transitions for young people from Paediatric Services to Adult Services remain a challenge. Further work this year for the release of a chapter on chronic neurological condition may further address and clarify these issues. |
| R5.7 Additional services should be developed that recognise and meet the needs of young people (defined as those aged 12–24 years), and improve access for those living in rural areas. | CYMRC is not aware of any work in this area. |
| R5.8 All DHBs should develop a pathway outlining local care after the death of a child or young person, including planning for access to appropriate post mortem examinations where indicated. | Some local groups are developing After The Death of a Child Care Pathways but progress overall has been slow. Recent discussions with the Chief Coroner may facilitate improved access to post-mortem reports. |
| R5.9 All DHBs should ensure systems provide access to sustainable paediatric pathology services in every district. | The CYMRC is very pleased that Paediatric Pathology is to become one of the National Services. Submissions on the service specification for this service have gone to the National Health Board from CYMRC. |
| R5.10 Professionals must recognise that the transition between care providers can be a vulnerable time for children and adolescents. | This remains a difficult issue. The development of electronic medical records may help at this time. Little progress has been made. |
| R5.11 Professionals should consider how systems ensure continuous care after referral or discharge and for those that do not attend appointments. | A number of DHBs have developed policies with regard to clinical follow-up of patients who do not attend appointments. This is a potential area of leadership from the Commission with regard to single point of entry and methods of managing outpatient services. |
| R5.12 Professionals should engage in ongoing training across all the sectors working with children and young people, particularly health, to ensure the legislated pathways for sharing information about risk are understood and managed collaboratively. | Misunderstanding of the Privacy Act, and when it facilitates appropriate information sharing, continues to be a concern. Further training in this area is needed. |
| R5.13 Professionals have a responsibility to recognise when interpreters are needed and to make sure they are available and provided. | In many parts of the country access to interpreters is improving with the use of services such as Language Line. It remains a concern that health professionals do not always recognise when an interpreter may be needed. This could be a further issue for consideration by the Commission. |

1. The Crown Funding Agreement is the agreement between the Ministry of Health, acting on behalf of the Crown, and the DHBs, in which the Crown agrees to provide money in return for service provision as specified in the agreement. [↑](#footnote-ref-1)
2. Mortality review committee agents are defined in the New Zealand Public Health and Disability Act 2000: “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” (Schedule 5, section 2.1). Each LCYMRG appoints agents to help collect data, conduct local reviews, develop recommendations, and implement quality improvement measures. Overall, there are more than 400 CYMRC agents in New Zealand. [↑](#footnote-ref-2)
3. See www.changeforourchildren.co.nz/safe\_start\_programme/pepi-pod. [↑](#footnote-ref-3)