

	<p><b>CHILD AND YOUTH MORTALITY REVIEW COMMITTEE</b></p> <p>Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi</p> <p><b>Meeting Minutes</b>  <b>Thursday 13 and Friday 14 November 2008</b>  <b>9.00 am to 5.00 pm</b></p>
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<b>In Attendance:</b>	Nick Baker (NB), Russell Franklin (RF), Chris Morris (CM), Eru George (EG), Anganette Hall (AH), Barry Taylor (BT), Liz Craig (LC), Marie Connolly (MC)
<b>Apologies:</b>	Riana Manual (RM)
<b>Guests:</b>	Glenys Needs (GN)
<b>Secretariat:</b>	Shelley Hanifan (SH), Gillian Grew (GG), Jacob White (JW), Terry Sarten (TS), Trina Tautau (TT)

<b>Agenda Items:</b>	<b>Summary of Discussions and Decisions</b>
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<b>CYMRC Meeting – Thursday 13 November 2008</b>	
<b>Opening</b>	Meeting opened up with karakia.
<b>Previous minutes</b>	<p>11 &amp; 12 September 2008</p> <ul style="list-style-type: none"> <li>- The minutes were discussed, TT apologised for the inaccuracies. The following action points were carried over:</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>GN – to clarify with Māori SIDS that they have what they want.</b></li> <li>- <b>Coroner’s meeting – SH &amp; GN to meet with Karen Vaughan of Coroner’s Office</b></li> <li>- <b>JW – to set up meeting for NB, SH, BT &amp; GG with chief coroner, coroner’s office, before end of year.</b></li> <li>- <b>SH – to follow up with Canterbury DHB Lawyer and DHB Lawyers group about training and liaison opportunities.</b></li> <li>- <b>GG – to follow up with MOH Child Health over recommendation four of fourth report building into child health review and invite appropriate person to next SUDI Working Group meeting.</b></li> <li>- <b>JW – to invite Craig Wright (PHI) to next SUDI working group to discuss prevalence of smoking in pregnant women.</b></li> <li>- <b>GG – to investigate MOH member for CYMRC.</b></li> <li>- <b>NB/JW – to write a letter to Gabrielle McDonald who</b></li> </ul>

	<p>did a report three years ago on drowning in the first year of life, letting her know we would like her to update us on the past three years.</p> <ul style="list-style-type: none"> <li>- JW – to invite Gabrielle McDonald to present her findings at the February meeting.</li> <li>- BT – to contact Joanne Baxter to find out if she is interested in updating/reviewing the Māori report.</li> <li>- JW – to follow up with Bill Harrison (Police) re National P47a forms for the collection of SUDI death scene investigation (to be forwarded to Datagroup)</li> <li>- JW – for future agenda’s numbers should be added for each item and linked to papers in meeting booklet.</li> </ul>
<p><b>Correspondence inwards</b></p>	<p>Pat Tuohy regarding Consumer Affairs and bath seats</p> <ul style="list-style-type: none"> <li>- Australian standards – requirement that bath seats have a permanent warning label</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- BT – to ask Gabrielle to find out latest information around bath drownings and include in the drowning review for 5<sup>th</sup> annual report</li> <li>- SH – build ongoing relationship with Ministry of Consumer Affairs, a work - partnership with Safekids and appropriate others.</li> </ul> <p>Pat Tuohy – Palliative Care for non-residents</p> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- NB/JW – write a letter to Pat Tuohy thanking him for the letter and asking him to ensure that all DHBs are aware of this issue.</li> </ul> <p>Steve Chadwick – Fourth Annual Report. No reply necessary</p>
<p><b>SUDI Working Group</b></p>	<ul style="list-style-type: none"> <li>- Positive response of invitees for working group. David Tipene Leach has declined, advising that Māori SIDS representative would be able to represent him.</li> <li>- What are the interventions to support safe sleeping that would be appropriate? – e.g Cot rental/gift scheme.</li> <li>- Do we need more Māori providers in the Working Group?</li> <li>- Need basic information from Well Child providers about current sleeping practices links to recommendation 4 of 4<sup>th</sup> report.</li> <li>- Need to know more about who is providing Well Child services for low dep. families and Māori in particular.</li> <li>- Problems with delays in information release following last workshop were discussed.</li> </ul>

<b>Public Health Medicine Registrar</b>	<ul style="list-style-type: none"> <li>- NB – has developed a draft job description, which involves SUDI review and reports and reviewing the Committees data collection.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>NB – to get job description approved by Training Programme and work towards the appointment of a PH Registrar.</b></li> </ul>
<b>Scientific Group Feedback</b>	<ul style="list-style-type: none"> <li>- There is ongoing negotiation with Datagroup – the contract is not yet signed off. Important that the Committee or Scientific Group have a role in developing the new contract.</li> <li>- LC – declared potential conflict of interest as she will be working at Otago University next year.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>SH – to organise a meeting with all Mortality Review Committee Chairs and the Scientific Group in January regarding the contract. If anyone in the Committee wants to be a part of the discussion, let SH know.</b></li> <li>- <b>Agreement that after the above meeting the issues are brought back to CYMRC meeting for agreement.</b></li> <li>- <b>NB – ask Riana to lead the Scientific Group in any matters that relate to the contract with the University of Otago.</b></li> <li>- <b>GG – find out Amanda DeSouza’s availability.</b></li> <li>- <b>JW – find out if we can co-opt Amanda DeSouza as a member of the Committee and to advise on data issues across committees.</b></li> <li>- Ongoing issues with database access for researchers. Initially thought we could partition the data and de-identify data easily. This is not feasible from an IT perspective in the short term.</li> <li>- Anyone wanting access will need to apply for ethics approval.</li> <li>- New legislation coming in for identity services raises issues with allowing access to data. SH gaining a health legal opinion to who owns the data.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>Interim Data Policy – Research access with ethics approval is required for access to de-identified data only</b></li> <li>- <b>Where the Committee seeks information to further the goals of the Committee on a topic, the Committee may give direct access to someone with</b></li> </ul>

	<p><b>agent status and decide on a case-by-case basis how to disseminate information. The Committee will own the intellectual property.</b></p> <ul style="list-style-type: none"> <li>- <b>Response to external queries – will provide de-identified data only.</b></li> <li>- <b>SH/JW - a formal data policy needs to be drafted and approved by the Minister.</b></li> </ul>
<p><b>Relationship – MSD/CYFS</b></p>	<ul style="list-style-type: none"> <li>- Letter to Marie Connolly, MSD, highlighting the following issues: review of children known to MSD; access to CYFS information, CYFS representatives working with local CYMR groups need written guidance; relationship with the Office of the Commissioner for Children; definition of “known to Child Youth and Family”, and; Advisor/s from broader elements of MSD</li> <li>- MC – 1: MSD would review deaths of all children in the care of the CE. CYMRC could use the MSD review during the local review process.</li> <li>- Concern from local groups that CYF local representatives are not always taking information to the meetings.</li> <li>- Need to have written guidance for CYF representatives on local groups.</li> <li>- CYF advisor role: Agreed that we will keep Kelly Anderson as the advisor for the Committee.</li> <li>- Not clear if representatives from other areas of MSD are needed, keep under review.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>TS – to draft a generic protocol for representatives on local groups around role and responsibilities for hand book, and to work with Kelly Anderson to formulate specific protocol for CYF representatives.</b></li> <li>- <b>MC – currently CYMRC receives information from CYFS up to 17 years old. Find out if that can be expanded to 24 years.</b></li> </ul>
<p><b>Relationship – Office of the Commissioner for Children</b></p>	<ul style="list-style-type: none"> <li>- Relationship with the Office of the Commissioner: Agreed that the Committee has a strong relationship with the Children’s Commissioner.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>NB – to talk to the Commissioner for Children regarding their relationship with the Committee.</b></li> </ul>
<p><b>Working with Advisors</b></p>	<ul style="list-style-type: none"> <li>- Looked at the policy for working with advisors.</li> <li>- Local Groups will be given further guidance about the</li> </ul>

	<p>format for draft recommendations, a context statement plus recommendation/s. The Datagroup provides local draft recommendations to the Lead Coordinator eight weeks prior to CYMRC meetings. The Lead Coordinator to process the recommendations, clumping similar ones and removing any identifiable elements then, pass them through the Chair and then send out to advisors six weeks prior to the meeting. The Committee will also be given copies of recommendations at this time.</p> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>GN – provide local recommendations to TS eight weeks prior to each meeting the Advisors attend.</b></li> <li>- <b>JW – send out list of advisors to the Committee seeking suggestions as to who should be added to the list.</b></li> <li>- <b>JW – put together a list of key stakeholders so that relationships can be built.</b></li> </ul>
<b>Chairs &amp; Coordinators Workshop</b>	<ul style="list-style-type: none"> <li>- All current DHB local groups were well represented. Yet-to-be-established DHBs were also represented.</li> <li>- Discussed how Auckland area DHBs could work together, and how the small DHBs would engage in the process.</li> <li>- Started developing a consistent approach across the country, realising that every local area would have different needs.</li> <li>- Shared ideas of key participants to local groups.</li> <li>- The local groups are managing to review all deaths. The larger DHBs have established sub-groups to review certain deaths.</li> <li>- Recommendations and issues were discussed and how these could be better written.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>TS – to develop a template for local annual reporting to CPHAC and CYMRC.</b></li> <li>- <b>Secretariat – to explore possibilities within the work plan for the option to provide mentors from existing DHB coordinators to support new ones.</b></li> <li>- <b>TS/JW – plan a further training workshop for the first half of 2009.</b></li> </ul>
<b>Fifth annual report</b>	<p><b>Issues discussed:</b></p> <ul style="list-style-type: none"> <li>- Goal – finalise Report by December 2008 and final version to the Minister by March 2009.</li> <li>- Report is 2003-2007.</li> <li>- GN to pull out SUDI related recommendations.</li> <li>- Drowning graph – need to change the clarity/add colour.</li> </ul>

	<ul style="list-style-type: none"> <li>- Drowning pie graph – can we add numbers.</li> <li>- Table 1 – location of drownings – add percentage column.</li> <li>- GN – pull drowning related recommendations to see drowning section can be built on.</li> <li>- Add “policy implications”?</li> <li>- Need sex ratio for drownings.</li> <li>- GN to update drowning data and make sure it’s consistent with Water Safety data.</li> <li>- Report should reference the Committee’s previous report on drowning.</li> <li>- Add policy implications and community messages to SUDI section.</li> <li>- NZ data is different from other data Fig 3 S 10 – interpret with caution.</li> <li>- JW – update re suicide pilots from Maria Cotter.</li> <li>- Māori Report – Guest Ed – Nicki Cooper, Suicide?</li> <li>- Barry – final editing – looking at more recent data.</li> <li>- Suicide – ethnicity &amp; gender by rate.</li> <li>- NB – request Simon Denny to do guest ed.</li> <li>- MOT information re issues on licensing young drivers.</li> <li>- Issues around asthma care – transition to adult services?</li> <li>- Post mortem access issues.</li> <li>- N = ? on figs ? ethnic dist rates, by age – on rates figs as may be confusing.</li> <li>- F 21 – insert all age groups mortality rates and - pr 100,000.</li> <li>- GN – Datagroup report to get circulated with papers prior to meetings.</li> <li>- 2.7 T 10 should say – 4 wks to 4 yrs.</li> <li>- Simon D will need access to Table 10.</li> <li>- Graph T 10.</li> <li>- GN – consider putting DHB comparison for SUDI.</li> </ul>
<b>CYMRC Meeting – Friday 14 November 2008</b> <b>Note: No quorum – discussion only.</b>	
<b>In Attendance:</b>	Nick Baker (NB), Russell Franklin (RF), Chris Morris (CM), Eru George (EG), Anganette Hall (AH), Barry Taylor (BT), Liz Craig (LC),
<b>Apologies:</b>	Riana Manual, Marie Connolly
<b>Guests:</b>	Glenys Needs (GN)
<b>Secretariat:</b>	Shelley Hanifan (SH), Gillian Grew (GG), Jacob White (JW), Terry Sarten (TS), Trina Tautau (TT)
<b>Data Request – Te Pou contract</b>	<p>Meeting with: Sunny Collins – Psychiatrist, Barry Taylor - Suicide Prevention Coordinator, Hutt Valley DHB,</p> <p>Barry Taylor – CYMRC, Glenys Needs – Database Group are listed as co-investigators</p> <p>The group is involved in the Te Pou contract have responded to</p>

	<p>an RFP for suicide research that involves defining trends in suicide means, defining trends for individual in means of suicide chosen, defining what attributes access to means. MOH believe finding out trends in suicide means can enable prevention. The group's proposal has been accepted and they have access to two other databases but would like access to the CYMRC data also.</p> <p>Discussion was had and the issue around the ownership of data and policy for access by researchers.</p> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>SH – to let the researchers know that CYMRC's processes need to be sorted out before we can give research the access to data.</b></li> <li>- <b>We could look at getting funding in future to carry out our own research (item for next agenda).</b></li> <li>- <b>NB – will draft a hypothetical letter to go to Health Legal regarding research access.</b></li> <li>- <b>In future there needs to be criteria to assess the content of applications for research.</b></li> </ul>
<p><b>Management of stress levels for those dealing with death reviews</b></p>	<ul style="list-style-type: none"> <li>- Coordinators are talking about the stress levels of group members and how members can be supported.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>TS – to look at harm minimisation processes. Guidelines could be provided in the handbook.</b></li> </ul>
<p><b>Progress on recommendations – response from MOH</b></p>	<ul style="list-style-type: none"> <li>- MOH's response goes through all the recommendations within CYMRC's fourth report and responds by advising the current MOH work in these areas.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>NB – to write a letter to Pat Tuohy regarding recommendation four clarifying the recommendation and explaining why the response is inappropriate.</b></li> <li>- <b>JW – to formerly invite ACC to provide an advisor to the Committee.</b></li> <li>- <b>SH – look into research issues with Health Legal.</b></li> </ul>
<p><b>Response from MOH Advisor</b></p>	<ul style="list-style-type: none"> <li>- Ministry Advisor sent through a response to the local recommendations.</li> </ul> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li>- <b>JW – to look at Min of Education guidelines around traumatic incidence response to feed into the next meeting.</b></li> </ul>
<p><b>Further discussions:</b></p>	<ul style="list-style-type: none"> <li>- Consider the recommendations and responses from Maria in conjunction with findings from Prof. Barry Taylor (CYMRC) cluster research.</li> <li>- Consider a recommendation about information being given about privacy and confusion by providers, in the context of suicide, abuse, etc. Terry to pick up.</li> <li>- The above builds on Recommendation 7 in CYMRC's</li> </ul>

	previous report.
<b>Meeting concluded at 5.00pm</b>	
<b>Next Meeting:</b>	Thursday 12 and Friday 13 February 2009