



**Perinatal and
Maternal Mortality
Review Committee**

*He matenga ohorere, he wairua uiui,
wairua mutunga-kore*

First Report to the Minister of Health

June 2005 to June 2007

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O eternal spirit – the grief of a sudden, untimely death
but we will not stop our pursuit and endeavours to seek answers

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Disclaimer

The Perinatal and Maternal Mortality Review Committee prepared this report.
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Chairperson's Introduction



It is nearly two years since the Minister of Health established the Perinatal and Maternal Mortality Review Committee (PMMRC). This committee was established because of concerns that perinatal and maternal mortality was currently not audited in New Zealand and

that there were areas where mortality could possibly be reduced. A survey of key stakeholders in the maternity sector showed overwhelming consensus that a national perinatal and maternal mortality review was required.

We first met in August 2005. Our initial efforts were focused on establishing a system for reporting all perinatal deaths, using a Rapid Reporting Form based on the Perinatal Society of Australia and New Zealand (PSANZ) guidelines. A pilot of paper-based report forms was conducted in early 2006, and from 1 July 2006, we have collected information about nearly all perinatal deaths via a web-based system. This is an impressive achievement that has only been fulfilled because of the work of local co-ordinators appointed by each of the District Health Boards (DHBs). We are very grateful for their co-operation in reporting. As a result of their efforts, all DHBs are now taking part in the web-based submission of information on each perinatal death, an achievement in itself.

Communication has been the key to ensuring co-operation and collaboration in reporting perinatal deaths. With this in mind, we have held three local co-ordinators' workshops. It is encouraging that every DHB is actively participating in perinatal mortality review.

As a result of this collaboration, local review committees are supported to hold local meetings where perinatal deaths are reviewed with the aim of improving maternity care.

In October 2006, we appointed a national co-ordinator, Vicki Masson. Vicki is a midwife with a special interest in high-risk pregnancies. She is responsible for following up on all the missing perinatal and maternal deaths' information and ensuring that the data is complete. She is also providing support to all the local co-ordinators and acts as a first point of contact for many lead maternity carers.

In the last year, the PMMRC has established a Maternal Mortality Review Working Group, chaired by Dr Claire McClintock, which reports to the PMMRC. At the time of writing, this group had held two meetings and is piloting the use of maternal death reporting forms. Using the local co-ordinators network to report maternal deaths is an important part of this process. Members of the group also attended the annual workshop of the National Advisory Committee, in Australia which enabled us to consider our own process.

In the legislation establishing the PMMRC, we were also asked to review morbidity. The problems with definitions and identifying cases make this a challenging task. Our approach has been to consider serious morbidity for newborn infants, and we have held a workshop to consider auditing cases of neonatal encephalopathy (NE). It is our intention to establish a neonatal encephalopathy working group which will also report to the PMMRC.

Thank you to everyone who has assisted the work of the PMMRC in its establishment phase. The PMMRC feels greatly supported by all who are working to improve maternity care and the health of newborn infants in New Zealand.

We look forward to working with you in the future and to this, the publication of our first report.

A handwritten signature in black ink, appearing to read 'C. Farquhar'.

Professor Cynthia Farquhar, Chairperson
July 2007

Recommendations

The PMMRC recommends that the Minister of Health:

1. notes that the PMMRC has established a national perinatal database and DHB system of perinatal mortality data collection
2. notes the importance of accurate, robust and timely clinical data on all pregnancies and establishes a national perinatal database so that perinatal mortality rates can be calculated and comparisons can be made between babies who die and those who survive the perinatal period
3. requires DHBs to ensure that all providers of maternity services provide support to parents, families and whānau who have experienced perinatal or maternal loss, including providing access to information, counselling and clinical follow-up
4. requires the Ministry to develop and improve the provision of perinatal pathology services for accessibility, training and appropriateness and to ensure quality and equitable services are available across the country
5. approves the establishment of a neonatal encephalopathy working group as included in the PMMRC 2007/08 work plan
6. notes that there are significant challenges to auditing and reviewing perinatal mortality and morbidity given the current, limited information systems available
7. requires health professionals to recommend a post-mortem examination following a maternal death when a coronial investigation is not undertaken.

1 Setting up the Perinatal and Maternal Mortality Review Committee

In 2003, the Ministry of Health (the Ministry) undertook a consultation phase and sought the views of stakeholders regarding the establishment of the PMMRC. Ninety-seven percent of respondents supported the establishment of a national mortality review system for perinatal and maternal deaths in Aotearoa/New Zealand. Nominations for committee membership were sought in 2004.

The Minister of Health (the Minister) appointed 10 members to the PMMRC in June 2005. There was a great deal of interest shown in being part of the PMMRC. The final 10 appointments were chosen because they collectively had knowledge of:

- quality improvement and risk management, in particular, quality assurance in the health sector
- data and information gathering systems and analysis
- clinical epidemiology
- DHB service provision and management
- clinical practice in neonatal paediatrics, perinatal pathology, obstetrics and midwifery
- Māori health
- Pacific peoples' health
- consumer participation and representation.

The PMMRC met for the first time on 5 August 2005. The functions of the committee were outlined in the terms of reference as:

- to review and report to the Minister (or other specified committees) on perinatal and maternal deaths with a view to reducing the numbers of perinatal and maternal deaths and to encouraging continuous quality improvement through the promotion of quality assurance programmes
- to advise on any other matters related to perinatal and maternal mortality that the Minister should specify in any further notice to the committee

- to develop strategic plans and methodologies that are designed to reduce morbidity and mortality and that are relevant to the committee's functions.

The committee is bound by the relevant sections in the New Zealand Public Health and Disability Act 2000 (NZPHD Act) and by the committee's terms of reference. The committee is directly responsible to the Minister and is expected to give advice and report directly to the Minister independent of any government departments, professional bodies, etc.

The committee is supported and advised on process matters by a secretariat based in the Ministry.

1.1 Key objectives for the Perinatal and Maternal Mortality Review Committee

The PMMRC primarily aims to reduce the number of preventable perinatal and maternal deaths.

The focus of committee efforts, thus far, has been to establish a comprehensive system for collecting data about perinatal deaths to:

- improve knowledge and understanding about the causes of perinatal death
- accurately capture information that might have relevance in understanding the reasons for perinatal death
- enable the identification of predictors and/or mediators of pregnancy and birth outcomes
- assist the research, development and implementation of effective preventative, diagnostic and remedial therapies or treatments
- avoid duplication but ensure compatibility with other relevant data sets, especially information that is collected by:

- the New Zealand Health Information Service (NZHIS), for example, the National Minimum Data Set (NMDS) and the Maternal and Newborn Information System (MNIS)
- Births, Deaths and Marriages (BDM)
- various college or specialist data sets, for example, data sets of the Perinatal Society of Australia and New Zealand (PSANZ), the New Zealand College of Midwives (NZCOM) and the Midwifery and Maternity Provider Organisation (MMPO)
- other mortality committees, for example, the Child and Youth Mortality Review Committee (CYMRC).

To be able to make national and international comparison is a priority.

Over the last year, the PMMRC has completed:

- the pilot and introduction of a perinatal mortality data collection form
- the establishment and training of local co-ordinators in every region
- the appointment of a national co-ordinator
- the implementation of electronic data collection systems
- the refinement of the process for guaranteeing data quality assurance.

More recently, the committee has turned its attention towards establishing a system for gathering information about maternal deaths (see chapter 10: Maternal Mortality).

2 Establishing a Perinatal Mortality Reporting System

At the first PMMRC meeting, it was decided to consider international models for perinatal mortality review. Both Australia and England have a system of reporting perinatal deaths, although in Australia only some states are involved. After discussion, it was decided that the PMMRC would need to develop its own data collection sheets, incorporating what was thought to be the best of the international models. Fortunately, PSANZ had recently considered this issue and had developed very comprehensive forms, which it agreed could be used as a template. The form needed to address the fact that Aotearoa/New Zealand has different models of care from Australia and the United Kingdom. In early 2006, paper versions of the data collection form were piloted, and after further iterations, a web-based form was established, which has proved a successful system for data collection.

A perinatal death is defined as the death of any fetus or baby over 20 weeks gestation (or over 400 grams if gestation is not known) and before 28 days of life. The data collection form, usually completed by the lead maternity carer (LMC), is known as the Rapid Reporting Form. The flow of information in this data collection process is shown in Figure 1.

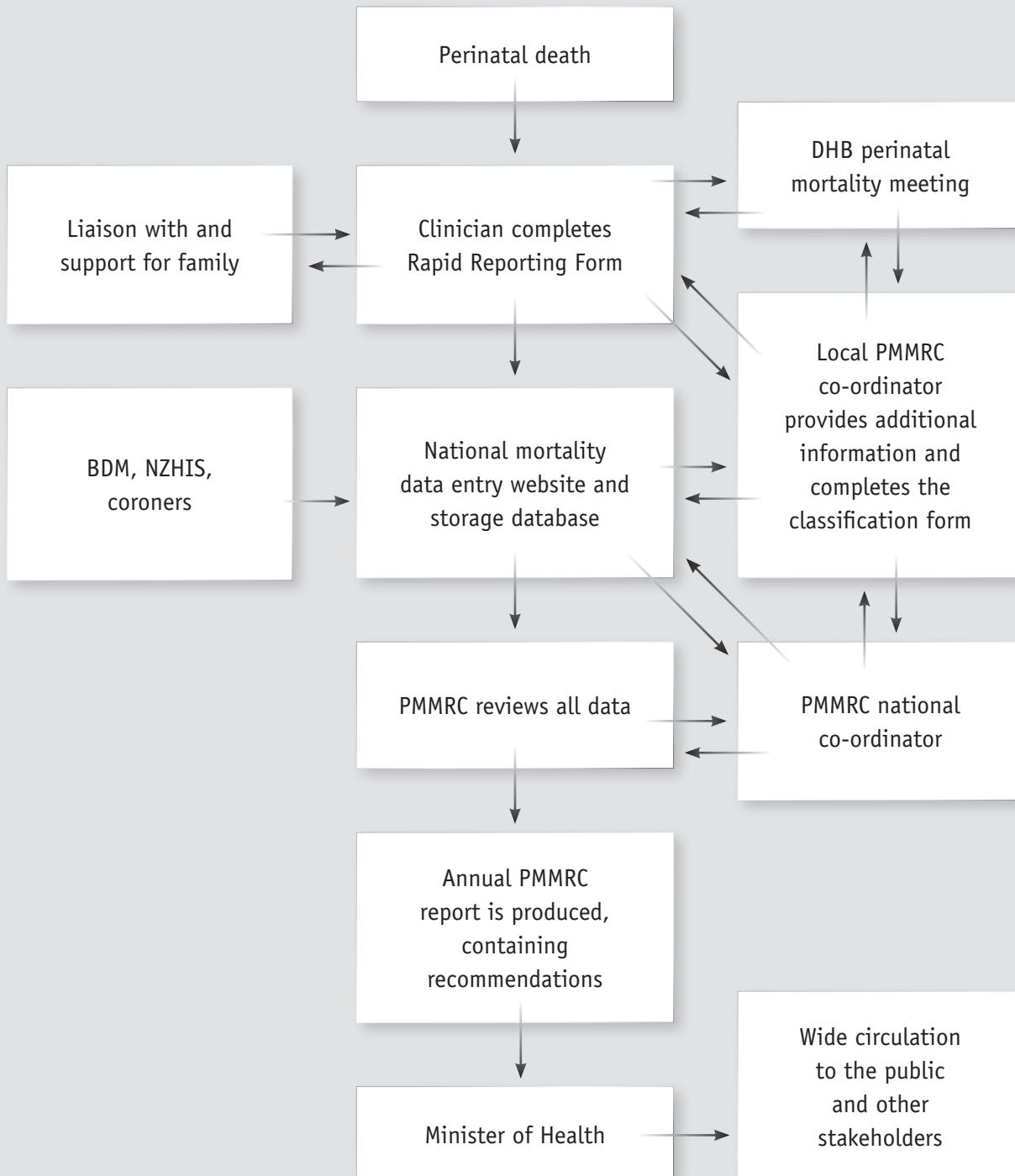
All perinatal deaths are reported regardless of whether or not they were terminations of pregnancy. The Rapid Reporting Form is completed either online or in its paper form, and this is submitted to the Mortality Database at the University of Otago, where the information is then checked by the national co-ordinator, Vicki Masson. The national co-ordinator then informs local co-ordinators about the perinatal deaths within their DHB.

The purpose of the local perinatal review meeting is to review any deaths and to consider any health systems' failures with a view to improving quality. These activities are usually registered as Protected Quality Assurance Activities under the Health Practitioners Competence Assurance Act 2003 (HPCA Act).

Following the local perinatal review meeting, each perinatal death is classified using the PMMRC Classification Form. The completed forms along with any additional information, for example, a post-mortem report, histology or missing data is submitted by the local co-ordinator, and the national co-ordinator enters it onto the Mortality Database.

The data is held by the Mortality Database at the University of Otago and will be compiled into an annual report that is analysed each year. The annual reports are sent to the Minister with recommendations.

Figure 1. Flow of information in the PMMRC's perinatal data collection process



3 Perinatal and Maternal Mortality: Issues for Māori

Tēnā koutou i runga i ngā āhuatanga o te wā. Kei te tangi te ngākau mo ngā tini aituā kei te rohe katoa. Tēnā koutou i raro i ngā manaakitanga o te wāhi ngaro, ki te kore rātou, kua kore hoki mātou. Ka waiho ake rātou te hunga wairua ki a rātou. Ki a tātou o te ao kikokiko nei, tēnā koutou, tēnā koutou, tēnā koutou katoa.

Māori representation on the PMMRC commenced with analysis of the available data (NZHIS Maternal and Newborn Information 2000–2003). The analysis identified several themes.

- Perinatal mortality rates appeared to be on the increase from 2000 to 2003 for all ethnic groups in New Zealand but were higher in New Zealand Māori (26%) than in New Zealanders of European descent (8%).
- Approximately 70% of perinatal deaths were stillbirths, but the rate of stillbirths increased in all groups except New Zealanders of European descent, and Māori rates increased by 24% from 2000 to 2003.

A number of risk factors have been associated with perinatal mortality, including biological, social, economic, cultural, environmental and behavioural factors, but medical causes and quality of care must also be considered. The need for multivariate lifespan models that explore relationships and interactions between such risk factors has been well described (Tew 1986, 1998; New Zealand Health Information Service 2003; Misra et al 2003; Craig et al 2003; Johnson & Daviss 2005).

Perinatal specialists have identified the need for post-mortem examination to explain the unspecified deaths, which are seen to be a category of ‘uninvestigated’ rather than ‘unexplained deaths’ (Craig et al 2003). In 1999,

less than 40% of the deaths in this category underwent post-mortem examination (see chapter 5: Perinatal Post-mortem Examinations). There is a marked socioeconomic gradient in the unspecified deaths, which may be due to lower rates of post-mortem examination among women from more deprived populations, including Māori.

3.1 Mātauranga Māori considerations, challenges and priorities

The main objective of the PMMRC is to gather knowledge that can reduce preventable perinatal and maternal mortality. This objective is commended, but it is recognised that the manner in which knowledge is pursued within the medico-scientific model may concern many Māori. In particular, the development and increasing use of highly invasive techniques and technologies could impinge and intrude on Māori whakapapa, the system lacks a Māori ethics framework and ethical review and approval systems need to be improved.

Likely outcomes of the perinatal data collection system will include more accurate information about the biological/physiological causes of perinatal death, specifically ‘unexplained’ fetal deaths, for which Māori carry the greatest burden; expansion of the perinatal data set; opportunities to explore relationships between demographic, bio-physiological and systemic variables, for example, maternal age, education, ethnicity, obstetric history, place of delivery, medical history, obstetric conditions, obstetric care, use of medications, quality, timing, amount and place of care; a reduction in the number of perinatal deaths as a result of the development and implementation of new screening/preventative/intervention techniques, for example, early identification of risk factors, timely interventions and/or termination of unlikely successes; and new opportunities for co-operation, collaboration and partnership in perinatal platforms for teaching, research and technology development in the national and international arena.

Against this background, a number of mātauranga Māori considerations, challenges and priorities have been identified (Palmer 2005, 2006a, 2006b), and the following questions need consideration.

- Will post-mortem examination of the infant, to identify physiological cause of 'unspecified' or 'uninvestigated' deaths, simply confirm what is already known about the causes of perinatal mortality?
- Will those who currently carry the burden of perinatal mortality, benefit most from investment in medical or socioeconomic interventions, for example, will they obtain better housing, food, living conditions?
- Will PMMRC processes contribute to the marginalisation of Māori identity and normalisation of a medicalised approach to birth, life and death that is underpinned by a know-how, ideology, avoidance of death at all costs and the medicalisation of core cultural experiences essential to the formation of identity?
- Kawa and tikanga of birth and death should be driven by whānau values, beliefs and practices, including the transmission of knowledge from one generation to another and active participation in birth and death rites. Such knowledge is a taonga tukuiho; it must be nurtured and protected. Will the process of mortality review interfere with this knowledge transmission practice?
- Many people value and respect the few midwives, tapuhi and tohunga who have the courage and strength to support birthing whānau in the home and community, thus facilitating the transmission of indigenous birth and death rites. How is this practice protected within the process of the PMMRC mortality review?
- Human beings are not immortal; some of us are not meant to dwell in the physical realm of human beings; death provides opportunities for regeneration, renewal and growth; grief, death and the loss of loved ones are fundamental human experiences that provide important lessons about life, emotions, values and how to deal with life events, stress and relationships; some who are saved through medical interventions may be left with lifelong disabilities. What are the implications of perinatal mortality review within this context? Who decides which deaths are preventable? At what stages will the medical model intervene? Will whānau have the right to refuse intervention?

- Engagement with the medical model is a choice; whānau must have the skills, knowledge, information and support to make an informed choice. Whānau have the right to manage miscarriage and/or the loss of a pregnancy without interference from the medical model. They have the right to say no to the medicalisation of their birth, life and death experiences. Will whānau have the right to opt out of the perinatal review process, including any post-mortem examination and the collection of any mortality data? Will whānau have the right to refuse obstetric screening and intervention techniques? How will professionals support and empower whānau to make their own decisions?

To address mātauranga Māori concerns, the following recommendations were submitted to the PMMRC.

- Pamphlets, information sheets and support processes are needed to explain PMMRC objectives/process, mātauranga Māori perspectives/positions and post-mortem examination techniques and procedures, including the benefits/risks for Māori of tissue sampling/storage, having photos taken, retaining the placenta, procedures for return and disposal, possible enforcement scenarios.
- There must be mechanisms and processes in place that enable Māori to retain ownership, authority, control and kaitiakitanga (guardianship) over PMMRC processes and outcomes such as the collection, use or development of Māori data, tissue samples, genetic material, or knowledge.
- Data collection techniques are needed to enable analysis of sociocultural, environmental and other variables of interest to Māori, for example, the role of cultural identity, marginalisation, deprivation, waiora and whānau ora as mediators of the perinatal event.

3.2 The PMMRC response to mātauranga Māori recommendations

Māori committee members from the two mortality committees (PMMRC and CYMRC) and the National Health Epidemiology and Quality Assurance Advisory Committee (EpiQual) were funded to meet on 27 September 2006 to discuss the following issues:

- the role of Māori committee members on mortality committees
- effective utilisation of mortality data in Māori communities
- development of a kaitiaki role around the mortality review process and outcomes.

The PMMRC, along with the CYMRC and the Quality Improvement Committee (QIC, previously EpiQual), accepted most of the group's recommendations and agreed that the Māori committee members would:

- contribute to the analysis, interpretation and general application of data
- identify priorities for Māori and explore new or emerging issues that may have relevance for Māori
- ensure progress on the issues and priorities that are identified for Māori.

In addition, the PMMRC has produced a pamphlet explaining the general purpose of this committee and has approved the distribution of a pānui that aims to explain the procedures, objectives and people likely to be involved in perinatal post-mortem examination for whānau, families and kaitiaki who have experienced a perinatal death.

During 2007, mātauranga Māori contributions to the PMMRC will primarily involve:

- engagement in the analysis and interpretation of the perinatal mortality data that has been collected for Māori over the last year
- continuing the identification of Māori-specific issues, particularly clarifying the kaitiaki function and the role that Māori committee members may have on each of the mortality committees
- identifying ways in which the data set can be broadened to enable analysis of sociocultural, environmental and other variables of interest to Māori.

More than two years after the inaugural meeting, the mana of the PMMRC was conceptualised in the following whakatauaiki:

*He matenga ohorere,
he wairua uiui, wairua mutunga-kore.*

In this proverb, given by Amster Reedy of Ngāti Porou, the untimely death of a loved one is mourned amidst the need to continue our search for the right answers.

*Heoi anō, kāore he take o ēnei kōrero ki te
kore te reo kei roto i te māngai o te iwi.*

4 Classification of Perinatal Deaths

The PMMRC uses the PSANZ system to classify all perinatal deaths (see Appendix F). The PSANZ classification system and guide, which were first developed in 2003, were produced as a result of the collaborative efforts of members of a multidisciplinary special interest group of PSANZ, including representatives from New Zealand. This classification system, which is now used throughout Australia and New Zealand enables a uniform classification of all perinatal deaths by obstetric antecedent cause, using the PSANZ Perinatal Death Classification (PSANZ-PDC). In addition, for neonatal deaths, conditions in the neonatal period that lead to the death are classified separately, using the PSANZ Neonatal Death Classification (PSANZ-NDC).

The purpose of the PSANZ-PDC is to identify the most important obstetric factor(s) that led to the chain of events that resulted in the death.

The purpose of the PSANZ-NDC is to identify, in addition to the PSANZ-PDC, the most important factor(s) in the neonatal period that caused the death.

5 Perinatal Post-mortem Examinations

Perinatal pathology is a subspecialty of anatomic pathology and is based on post-mortem examinations. Currently in Aotearoa/New Zealand there is one full-time perinatal pathologist who is based in Wellington and is employed by both Capital & Coast and Auckland DHBs.

There is a paediatric pathologist in Auckland whose main work is paediatric surgical pathology and the provision of a perinatal post-mortem examination service for North Shore Hospital, Waitemata DHB. If this pathologist is not available, then the Wellington-based pathologist provides cover. The South Island has two pathologists with training in perinatal pathology. One is in Dunedin and has training in perinatal and paediatric pathology but is employed in anatomic pathology. The other is a perinatal and paediatric pathologist employed in routine anatomic pathology in Christchurch.

The perinatal post-mortem examination remains the 'gold standard' for investigating a stillborn or infant death – and indeed for a death of any age. It is currently the procedure that, when performed by a pathologist with expertise in the field, yields the most information and thus allows more accurate diagnosis and classification of the cause of death. The entire post-mortem examination, which includes the operative procedure, microscopy, literature search around the case and report writing, takes on average six hours, with some complex cases taking far longer.

The perinatal post-mortem examination is invasive in a similar way to a large surgical operation. There is a body of literature devoted to discussing the role of Magnetic Resonance Imaging (MRI) as a replacement for the post-mortem examination, but this system has been identified as having limitations – not least the lack of availability of the service in smaller centres and out of office hours in centres that have the facility. MRI can provide useful and diagnostic information, particularly when the parents have refused post-mortem examination. However, currently it is best regarded as a useful tool to complement rather than replace the post-mortem examination.

The perinatal post-mortem examination rate in New Zealand is well below 75% (the percentage recommended by the 1988 and 2001 joint working party reports of the College of Obstetrics and Gynaecology and the Royal College of Pathology, London). There is great variability in rates of post-mortem examinations between centres for a variety of reasons. The main reasons are cultural beliefs of both the family and staff, the attitude of the staff caring for the mother and possible travel arrangements for the deceased baby. There is difficulty in getting post-mortem examinations in remoter parts of the country without direct air services to the site of the post-mortem examination. The rate of examination is higher in Wellington possibly because the parents can meet the pathologist before the post-mortem examination and discuss the procedure.

The PMMRC has recommended that all DHBs seek to have those perinatal deaths where the parents have consented to post-mortem examination examined by a pathologist with training in perinatal pathology. Following this recommendation, the Wellington-based pathologist has received a number of enquiries concerning the likelihood of providing a post-mortem examination service in centres outside Wellington. Many of these centres are small, and the main issues will be funding for the service and the complex travel arrangements that are required to reach the destination. However, there is enthusiasm for the creation of a specialist service in the field of perinatal loss.

Currently, one pathologist performs most post-mortem examinations on babies in Wellington. In 2006, the Wellington pathologist undertook 180 post-mortem examinations (that were not subject to coroners' investigation) of babies over 20 weeks gestation from a variety of DHBs.

The babies from Auckland, Counties Manukau, Waikato and Nelson Marlborough DHBs are flown to Wellington on routine flights. The process is completed in one day. For those centres that do not have frequent flights, the infant may stay overnight to return the following morning.

There is now a protocol for transporting babies by plane to the perinatal pathologist in Wellington. This protocol has been informed by the collective experiences of those who regularly send babies from their areas. The babies travel in the hold of the aeroplane and are delivered and collected at both airports by a designated funeral director. When the post-mortem examination is completed, the baby is returned to the family or their funeral director. There has been no decline in consent for post-mortem examination since babies have been flown to Wellington, and this is likely to be in part because of the confidence of the obstetric and neonatal staff that useful information will be gained as a result of a post-mortem examination. More importantly, the babies are returned to the family within the shortest possible period of time, and all care is taken to keep their bodies in the best possible condition.

In the case of Hawke's Bay, MidCentral and Whanganui DHBs, which are closer to Wellington, the infants are driven to Wellington by hospital staff or by members of the family.

The perinatal pathology service in Wellington is performed by one pathologist who is on call seven days a week. This is the only way to ensure that those parents who consent to post-mortem examination of their baby do not retract their consent because they have to wait for two days over the weekend before the event can proceed. The pathologist does not have a registrar, and there is no contingency plan for continuity of the service or reasonable rostering. Auckland is the only DHB with specifically designated paediatric and perinatal pathologists.

It is a significant decision for bereaved parents to consent to a post-mortem examination in the period immediately after the death of their baby. The fact that so many parents do consent probably reflects the belief that useful information will be gained from such an examination.

In 2007/2008, we hope to hold a workshop on the provision of perinatal post-mortem services across New Zealand with the aim of improving access to these services.

Recommendation

The PMMRC recommends that the Minister requires the Ministry to develop and improve the provision of perinatal pathology services, for accessibility training and appropriateness, to ensure that high-quality and equitable services are available across the country.

6 Supporting Parents and Families

The latest statistics for perinatal deaths indicate that 596 babies between 20 weeks gestation and 28 days following birth died in Aotearoa/New Zealand in 2000 and 2001 (New Zealand Health Information Service 2003). From that figure, we can surmise that hundreds of families were grieving and in need of some support and, very likely, some information and resources. Unfortunately, we do not have any state-funded support structures in Aotearoa/New Zealand for perinatal death support, so many of those families will have looked either to community-based baby loss support organisations, Internet-based support or support from other agencies in their community, such as churches or family. Many of the 21 DHBs report that they do not have a formalised pregnancy loss service, and although a number provide counselling through their social work departments, the typical period of contact for bereaved parents and families is up to two months following the baby's death (based on preliminary results of the 2006/07 PMMRC survey of New Zealand DHBs' pregnancy loss services).

Currently, there are a small number of community-based, not-for-profit organisations that work to support bereaved families grieving the death of their baby. They are Sands (Stillbirth and Newborn Death Support), which has 24 groups or contact people around the country; Miscarriage Support, of which there are a small number of groups; Twin Loss, an Internet-based support organisation; Trauma And Birth Stress (TABS), an Auckland-based organisation that provides support to women with post-traumatic stress disorder (PTSD) resulting from childbirth; and the Christchurch Multiple Birth Club bereavement support. There are other agencies whose work may overlap with perinatal death support, such as Project Rachel (post-abortion support through the Catholic church) and PATHS (Post Abortion Trauma Healing Service), Parent to Parent and the Māori SIDS, Pacific SIDS and two other SIDS support organisations (Auckland and Wellington).

Baby loss support organisations are generally made up of men and women who have experienced the death of a baby and wish to support others going through a similar experience. They are funded through philanthropic grants, government funding such as the Community Organisation Grants Scheme (COGS) and donations from businesses and individuals. The time spent offering a variety of support services is predominantly voluntary and, as such, many groups go through periods of inactivity due to member burn-out. Thus bereaved families cannot rely on there being a committed organisation in their community, due to the stresses of busy lives combined with running a community organisation that focuses on supporting people in grief. This is unfortunate but a reality for many families in Aotearoa/New Zealand.

One of the aforementioned groups, Sands, secured funding to employ a full-time, national project co-ordinator in 2006. Having a dedicated worker to support the voluntary members and to address many issues facing bereaved families is invaluable to both bereaved families and baby-loss organisation alike. The group was also able to use the funding to: maintain a website, generate resources, instigate and implement national training of Sands members, represent Aotearoa/New Zealand at overseas conferences, develop national guidelines for issues about perinatal death, establish national communication between Sands groups and other baby loss organisations and provide a central point of contact for bereaved parents, families and whānau through which they could identify what information would be helpful and what local community organisation might support them. The funding was available for one year only, and total costs for the initiatives introduced by the group for that year, including the salary, totalled to \$83,230.00. As a result of the development of the Sands national project co-ordinator position, it has become apparent that there is a need in our community for a central point of contact for support and information relate to perinatal deaths.

As a result of contact with bereaved parents, families and whānau, the Sands national project co-ordinator identified a number of issues, including the following points.

- There is a lack of information about the different forms of perinatal death (such as deaths up to 20 weeks, termination due to medical abnormality, specific medical conditions, third-trimester deaths).
- Affordable and appropriate counselling needs to be made available to families who are experiencing grief at the loss of a baby.
- Bereaved parents, families and whānau experience feelings of isolation (they are unsure who to contact, how to locate an organisation that would offer support, what is available in their community).
- There is no one available to answer specific questions (medical questions, issues around maternity leave, parental tax credits, birth certificates, funeral matters).
- There is a lack of resources specific to the situation in Aotearoa/New Zealand (most available pamphlets, books and booklets are American).
- Resources that are produced by Aotearoa/New Zealand baby-loss organisations are generally published in English only due to a lack of funding (with the exception of Miscarriage Support Auckland, which has pamphlets available in Māori, Samoan, Chinese and English).
- Our experience shows that untreated and unrecognised grief easily leads to depression, which becomes a mental health issue (this is especially pertinent to the PMMRC's brief in regard to maternal deaths).

From the discussion above, it is clear that parents, families and whānau who have experienced a perinatal death may experience inconsistent and irregular support or indeed no support at all. It is also noted that many Aotearoa/New Zealand families will benefit from the compassion and foresight of decision-makers who have identified the need for funded support programmes that will result in healthy outcomes for bereaved families following a suicide. We need to consider the requirements of bereaved families following a perinatal death to the same degree.

Recommendation

The PMMRC recommends that the Minister requires DHBs to ensure that all providers of maternity services provide support to parents, families and whānau who have experienced perinatal or maternal loss, including providing access to information, counselling and clinical follow-up.

7 Local Co-ordinators, Agents and Workshops

A key requirement of the PMMRC is to provide regular and relevant reports to the Minister. The committee requires comprehensive and timely information. To achieve this objective, local co-ordinators were appointed, which led to the appointment of a national co-ordinator. The co-ordinators provide advice and support to local clinicians, who are responsible for completing comprehensive Rapid Reporting Forms for a central database. The national co-ordinator collates regional data and prepares relevant reports for the PMMRC. The model of regional support for frontline clinical staff to provide information closely mirrors the successful model of regional co-ordination established by the CYMRC.

7.1 Establishment of local co-ordinators

The process taken to develop the local co-ordinator role is set out below.

In September 2005 a letter was sent to all DHB Chief Executive Officers outlining the role and responsibilities of the PMMRC. The letter also included a request that DHBs support the development of local co-ordinators.

The committee members continued to develop, define and refine the perinatal Rapid Reporting Form. The form has been designed to profile environmental, personal and health factors for both the mother and the deceased infant.

By March 2006, 19 of the 21 DHBs had received expressions of interest from clinical staff to act as local co-ordinators. A follow-up letter was sent to those DHBs that had not yet nominated representatives.

The first local co-ordinator workshop was held in May 2006. This was a very productive meeting, and a number of issues associated with the development of the Rapid Reporting Form and ways of working were resolved, or agreed to be trialled. Another outcome of the day was the development of a flow chart that has proved helpful in profiling the pathway for reporting perinatal deaths. A subsequent workshop was held in October 2006.

In June 2006, a letter was sent to all LMCs providing further details on the roles of local co-ordinators (including contact details) and the functions of the PMMRC. The letter invited all LMCs to be responsible for reporting perinatal and maternal deaths (for patients in their care) and provided information on how to make contact with the PMMRC chairperson.

7.2 Establishment of National Co-ordinator role

Once the local co-ordinators had been established, the need to collate and disseminate timely and relevant information on perinatal and/or maternal deaths became a priority for the PMMRC. In October 2006, a national co-ordinator was appointed. Since this appointment, two further workshops for PMMRC members and co-ordinators have been held. Subsequent workshops have built on the successes of previous sessions.

8 Neonatal Encephalopathy

Although the main function of the PMMRC is to document the causes of perinatal and maternal deaths in Aotearoa/New Zealand, another function is to develop strategic plans and methodologies that are designed to reduce morbidity. The first area of focus related to morbidity that the committee will investigate is that of neonatal encephalopathy (NE) because the long-term outcomes of NE result in developmental delay and/or cerebral palsy.

The impetus to address this area initially came from concern about the clinical problem of

hypoxic ischaemic encephalopathy (HIE) in the newborn. HIE is one cause of NE and is the clinical manifestation of an asphyxial episode severe enough to result in clinical symptoms of organ dysfunction. HIE is a symptom not a final diagnosis.

Asphyxia in the perinatal period usually includes a combination of diminished blood flow (causing ischaemia) and decreased oxygen supply (causing hypoxia) to vital organs. There are many causes of asphyxia, occurring pre-partum, intra-partum or post-partum. When all organs of the body can be affected. Most symptoms arise from effects on the brain, liver, heart and kidneys. The liver, heart and kidneys will usually recover, but serious asphyxia can result in permanent brain damage. The resultant clinical syndrome is termed HIE and is graded as mild (Grade 1), moderate (Grade 2) or severe (Grade 3). Grades 2 and 3 HIE are a significant cause of both illness and death for full-term infants cared for in level 3 neonatal units in Aotearoa/New Zealand, but no national data is available to judge how significant a problem HIE is in relation to the general population.

A workshop was held with the Accident Compensation Corporation as part of the February 22nd PMMRC committee meeting to further explore whether we could document the rates and causes of NE in Aotearoa/New Zealand. Dr Malcolm Battin, from The University of Auckland School of Medicine, a neonatal paediatrician with a research interest in this topic, provided an overview of the current medical literature. Data presented indicated that current data collection is insufficient to accurately determine the prevalence of NE. This means that alternative methods of data collection need to be found. Much of the literature already available discusses the broader topic of NE, which includes causes of encephalopathy other than those related to hypoxic ischaemic events. It was felt appropriate that if the PMMRC was going to try and document the prevalence of this type of brain damage in infants in Aotearoa/New Zealand, it should use a broader, more inclusive approach and encompass all types of NE in the data collection to ensure that no potentially preventable types of encephalopathy are excluded.

Current improvements to the national perinatal data collection are not likely to be sufficient to capture data on those infants with NE who survive the neonatal period. The PMMRC will be looking at the best way to collect information on NE so that rates can be measured over time for the whole population. Then an assessment can be made as to what proportion of perinatal asphyxia leading to NE might be preventable and whether other types of NE might be preventable in some situations. Pending the Minister's approval, the PMMRC hopes to establish a NE working group in 2007/08.

Recommendation

The PMMRC recommends that the Minister approves the establishment of a NE working group as included in the PMMRC 2007/08 work plan.

9 Privacy and Legal Issues

The core task of the PMMRC is to collect data on maternal and perinatal mortality in order to identify patterns of disease that can be prevented. The data set must be as complete as possible to provide all available evidence so that the PMMRC can identify any systematic or professional issues and focus clearly on preventing future deaths. There is a powerful moral and ethical imperative for clinicians to provide complete mortality data so that the PMMRC can identify strategies to help avoid the future deaths of mothers and babies.

The NZPHD Act identifies fines if people fail to provide the PMMRC with information about perinatal and maternal mortality.

The PMMRC data collection system meets the Guidelines for Observational Studies (2006) compiled by the National Ethics Advisory Committee (National Ethics Advisory Committee 2006).

The PMMRC supports quality assurance activities surrounding maternal and perinatal deaths by helping to collect full data on each death.

In the 1980s and 1990s, accurate data collection became difficult to achieve as practitioners became subject to manslaughter prosecutions. A subsequent change in the Crimes Act and the protected status of quality assurance activities under the HPCA Act has encouraged the re-emergence of accurate data collection with the co-operation of practitioners.

However, a recent manslaughter case (Channel 9 2007) has highlighted concerns that practitioners in the maternity and perinatal area have about the confidentiality of quality assurance activities and reports being subject to criminal investigations. Without the full, frank and open co-operation of practitioners, the PMMRC will have difficulty providing accurate data about perinatal and maternal deaths.

9.1 The purpose of the data collection

Families are entitled to know exactly why the PMMRC is collecting data. Information is available to them via a pamphlet.

Broadly the purpose of data collection for the PMMRC is outlined in the NZPHD Act (Part 2 s18(1)(a) and (b)), which describes the PMMRC's function to review and report to the Minister with a view to reducing the numbers of death and to continuous quality improvement.

9.2 Sources of the PMMRC data

The PMMRC information pamphlet and website outline the sources of the PMMRC data.

The death of a baby or mother is likely to be a difficult time for family members, and so where possible, information is usually obtained from 'indirect' sources, not directly from the family. The data is collected from reliable sources such as health professionals and national databases. Family members are not excluded from providing or checking data, and the family medical history can be an important component of determining cause of death.

The PMMRC believes that it is essential that family members or others do not find the data collection process for the PMMRC intrusive. Although the legislation gives agents of the PMMRC the authority to collect data, families must not feel coerced into supplying information.

9.3 Accuracy, storage, security and retention

All agents of the PMMRC are aware of the need to keep PMMRC data confidential; that is why agents have to sign a confidentiality statement before they are appointed as agents and every three years thereafter.

Agents who do not adhere to the confidentiality requirements are liable to a fine up to \$10,000.

The formal agreement (contract) that the Ministry undertakes with the Mortality Database Group outlines the requirements for the database group to manage the data safely.

The Māori committee members of both the PMMRC and CYMRC along with those of the QIC meet as a group at least annually and are available to consider issues about access to and security of the data in relation to Māori.

9.3.1 Accuracy

Accuracy of information is important for the work of the PMMRC, and families who are involved in a death may also want assurance that every effort is being made to ensure that the PMMRC data is accurate. The Mortality Database Group's contract outlines the requirements for the group to make every effort to ensure data is accurate.

The data collection system used by the Mortality Database Group means that there is cross-checking of data coming in from various sources.

9.3.2 Transferring NHI numbers

National Health Index (NHI) numbers are viewed as identifiable data and therefore are treated with utmost care. NHI numbers are not emailed. Lists of NHI numbers are transferred using the QuickPlace (see 9.3.8 below), on discs via registered courier post or via secure faxes.

Individual NHI numbers are sometimes communicated via telephone – fixed landlines – not cordless or mobile phones as these are not secure forms of communication.

9.3.3 Security of data entry

The mortality database is web-enabled. This means that information is available to users who have authorised access to the database via an Internet connection. Whilst the transmission of data via the web is not normally secure, systems have been established to protect the mortality database. The database uses secure socket layer (SSL) connections for the transmission of data. This involves encrypting the information that is to be transmitted between the web server and the web client so that it will be unreadable to anyone intercepting it at any point between. It also allows the user to be certain that they are connected to the correct web server. SSL is widely used for online financial transactions by banks and companies around the world.

9.3.4 Security measures taken by co-ordinators

All files are kept in a locked filing cabinet in the office to which only the co-ordinator has access.

The computer used by the co-ordinator is accessed via a complex password.

Information about individuals in the database is accessed only via the web wherever possible and is not downloaded to the co-ordinator's computer system.

The automatic back-up system for the co-ordinator's computer is kept secure by the organisation's official information technology processes.

The co-ordinator, whenever possible, contacts people directly to discuss access to relevant information.

Any documents that need to be destroyed are destroyed by approved document security services.

9.3.5 Security measures taken by the Mortality Database Group

Faxes containing personal information are received by a confidential direct-access fax attached to a computer. Confidential faxes can be received 24 hours a day throughout the year. Access to these faxes is only possible by those who have password-protected access to the computer. As all faxes are received electronically, no paper records are kept.

Employees of the Database Group have authorised individual password access to the database.

Downloads of data from government or non-government organisations to the database are received either by email, by using SSL from a secure server or by floppy disc sent by recorded courier delivery.

All paper records are kept in a locked filing cabinet.

9.3.6 Security measures to be taken by researchers

Researchers who formerly apply, meet the criteria and have received approval, will be provided with non-identifiable data using secure transmission processes.

9.3.7 Passwords

Everyone involved with mortality review is encouraged to have a unique password that involves a combination of upper and lower-case letters, numbers and symbols.

9.3.8 QuickPlace

A password protected website has been established that is supported by the Ministry. This is called QuickPlace. QuickPlace provides secure access to information and is restricted to agents of the Committee.

9.4 Use and disclosure of data

The PMMRC data does not have to be released under the Official Information Act 1982.

The PMMRC data cannot be obtained by the Police (unless they are investigating a crime punishable by imprisonment for a term of two years or more) or the Health and Disability Commissioner.

The PMMRC reports to the Minister (which are released publicly) do not identify individuals who have died.

9.5 Access and correction of data

The issue of family members accessing and correcting the PMMRC data is complex. Where possible, it is hoped that any concerns held by family members will be allayed by the PMMRC information pamphlet and by the PMMRC reputation for accuracy (see 9.3.1 above).

9.6 Using the PMMRC knowledge locally

Agents of the PMMRC usually also have roles as health care professionals and employees. When acting as agents, they act only within the strict parameters of the legislation.

Agents can never use identifiable information that they have obtained in their role as a PMMRC agent. However, they can use the general knowledge gained from their role as an agent in their other roles, as long as individuals or specific events are not identified.

Agents focus on identifying systems issues (rather than individual culpability) that need to be reviewed and fixed.

9.7 Respect

All agents aim to maintain high levels of respect for the deceased and the family.

10 Maternal Mortality

The PMMRC terms of reference require the committee to review 'direct' maternal deaths. A Maternal Mortality Review Working Group has been set up to develop a process for the national collection of data relating to maternal deaths. The aim is to review these deaths and to identify preventable causes of maternal mortality.

The working group is led by Claire McIntock (obstetric physician) and includes three members of the PMMRC, Cynthia Farquhar, Mollie Wilson and Jacqueline Anderson. Other working group members are Alistair Haslam (obstetrician and gynaecologist), Jeanette McFarlane (pathologist), Alison Eddy (midwife), John Walker (anaesthetist), Cathy Hapgood (psychiatrist) and supported by Vicki Masson (PMMRC national co-ordinator). The working group held its first meeting on 6 October 2006.

A previous Maternal Mortality Review Committee ceased to function in 1995. So the only reports have been by NZHIS which has reported on numbers of maternal deaths since 2000 (and 1988–1999 can be accessed) but there is no clinical analysis with these figures. The working group must identify 'direct' pregnancy-related deaths but also reviews the 'indirect' deaths, in particular, but not necessarily confined to, those related to surgery, psychiatric illness and family violence.

Several international definitions of maternal death have been reviewed, and a decision has been made to adopt the following World Health Organization (WHO) definition from the International Classification of Diseases, 10th Edition.

Maternal death: death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.

In addition, the following (not in the WHO definition) were added to the scope of the Maternal Mortality Review Working Group.

Direct maternal deaths: those resulting from conditions or complications or their management that are unique to pregnancy, occurring during the antenatal, intra-partum or post-partum period.

Indirect maternal deaths: those resulting from previously existing disease or disease that develops during pregnancy and is aggravated by physiologic effects of pregnancy, for example, epilepsy, diabetes, cardiac disease and death from suicide.

This definition excludes maternal deaths occurring between 42 days and one year of birth. There have been some indications that suicide deaths occur in this late phase and the working group may look at this.

Following review of a number of international data collection formats, the group has developed a data collection tool relevant to Aotearoa/New Zealand. Guidelines to assist clinicians in completing data collection are also being developed. Data collection commenced in 2006.

In order for the working group to be able to identify any maternal deaths that occur nationally, discussions with NZHIS and BDM is required to assess the practicality of notification of such a death being included on a death certificate.

There is also concern that not all deaths that may be classified as maternal deaths within the definitions adopted by the working group would be notified to the coroner or that those women necessarily undergo a post-mortem examination.

The Maternal Mortality Review Working Group notes that as of 1 July 2007 all maternal deaths should be reported to the coroner.

Recommendation

The PMMRC recommends that the Minister requires health professionals to recommend a post-mortem examination following a maternal death when a coronial investigation is not undertaken.

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Abbreviations

BDM	Births, Deaths and Marriages (Department of Internal Affairs)
COGS	Community Organisation Grants Scheme
CYMRC	Child and Youth Mortality Review Committee
DHB	District Health Board
EpiQual	National Health Epidemiology and Quality Assurance Advisory Committee (now known as the Quality Improvement Committee)
HIE	Hypoxic ischaemic encephalopathy (see also NE)
HPCA Act	Health Practitioners Competence Assurance Act 2003
LMC	Lead maternity carer
MMPO	Midwifery and Maternity Provider Organisation
MNIS	Maternal and Newborn Information System
MRI	Magnetic Resonance Imaging
NE	Neonatal encephalopathy (see also HIE)
NHI	National Health Index
NMDS	National Minimum Data Set
NZCOM	New Zealand College of Midwives
NZPHD Act	New Zealand Public Health and Disability Act 2000
NZHIS	New Zealand Health Information Service
PMMRC	Perinatal and Maternal Mortality Review Committee
PSANZ	Perinatal Society of Australia and New Zealand
PSANZ-PDC	PSANZ Perinatal Death Classification
PSANZ-NDC	PSANZ Neonatal Death Classification
PTSD	Post-traumatic stress disorder
QIC	Quality Improvement Committee
SSL	Secure socket layer

Glossary

Agent

Under Schedule 5 of the NZPHD Act, the chairperson of, or an agent appointed by a mortality review committee, has the power to require information relevant to the committee's functions. Any person of whom such information is required must take all reasonable steps to comply. The kinds of information that an agent may require include information that is normally protected by obligations of confidentiality including (but not limited to) patient records, clinical information and information related to either of these two categories; answers to specific questions which that person can answer, and information that became known solely as a result of a protected quality assurance activity.

Asphyxial episode

A situation where there is a severely deficient supply of oxygen to the body.

District Health Board (DHB)

The organisation responsible for providing, or funding the provision of, health and disability services in its district. There are 21 DHBs in Aotearoa/New Zealand, and they have existed since 1 January 2001 when the NZPHD Act came into force.

Epidemiology

The study of the distribution and determinants of a disease, or other health-related events, in populations.

Histology

The study of tissues of the body to help diagnose illness or cause of death.

Hypoxic Ischaemic Encephalopathy (HIE)

Hypoxic Ischaemic Encephalopathy (HIE) results when there is a lack of blood flow causing damage to the organs including the brain. If the lack of blood flow occurs around childbirth this can cause NE.

Level 3 neonatal unit

A level 3 unit provides neonatal intensive care and high dependency care. This means that it has the facility to care for extremely premature infants from 24 weeks gestation and sick babies requiring ventilation, intravenous feeding and other types of intensive care monitoring and treatment.

Maternal death

The definition of maternal death used by PMMRC is: Death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy.

This includes deaths resulting from conditions or complications or their management that are unique to pregnancy, occurring during the antenatal, intra-partum or post-partum period. Also included are deaths resulting from previously existing disease or disease that develops during pregnancy and is aggravated by physiologic effects of pregnancy, for example, epilepsy, diabetes, cardiac disease and death from suicide.

Mortality Database Group

A group comprising the Otago University staff who run the mortality database in accordance with the formal agreement between the Ministry and the University of Otago.

National Health Index (NHI) number

A unique identifier that is assigned to every person who uses health and disability support services in Aotearoa/New Zealand. A person's NHI number is stored on the NHI along with that person's demographic details. The NHI and associated NHI numbers are used to help with planning, co-ordinating and providing health and disability support services across Aotearoa/New Zealand.

Neonatal

Relates to the first 28 days of life.

Neonatal encephalopathy (NE)

Brain damage due to reduction of blood flow and/or oxygen in the perinatal period. If the baby survives it is likely to suffer brain damage leading to developmental delay and/or cerebral palsy.

Neonatal paediatrics

A branch of medicine that deals with the medical care of babies up to four weeks after birth.

Obstetrics

The surgical specialty dealing with the care of a woman and her offspring during pregnancy, childbirth and the period shortly after birth.

Perinatal death

The definition used by PMMRC is death of any fetus or baby over 20 weeks gestation (or over 400 grams if gestation is not known) and before 28 days of life.

Perinatal pathology

The study of the body (usually a post-mortem examination) after a perinatal death to determine cause of death.

Protected quality assurance activity

An activity undertaken to improve the practices and competence of health practitioners by assessing the health services provided by such practitioners. It is a useful tool in helping to avoid adverse health outcomes by improving practice or quality of care. The Minister can declare a quality assurance activity protected under the HPCA Act if satisfied that it is in the public interest to keep the quality assurance activity confidential.

Sudden unexpected death in infancy

A broad category used to encompass Sudden Infant Death Syndrome or 'cot death' (SIDS); infants found in adult beds where no direct evidence of overlying exists and other similar deaths where a thorough post-mortem and death scene investigation are needed to determine cause of death. Unexpected means that the cause was not recognised before the death (CYMRC 2006).

Appendix A: The PMMRC Membership and Meetings 2006/07

Membership

Professor Cynthia Farquhar
Jacqueline Anderson
Vicki Culling
Dr Dawn Elder
Deborah Harris
Associate Professor Lesley McCowan
Dr Stephanie Palmer
Mollie Wilson
Dr Jane Zuccollo
Dr Ted Hughes

For more information about the PMMRC and its membership, see its website:
<http://www.pmmrc.health.govt.nz>

Meetings

The PMMRC met nine times in Wellington from June 2005 to June 2007. Meetings were held on:

5 August 2005
11 November 2005
20 March 2006
20 June 2006
24 July 2006
29 August 2006
31 October 2006
22 February 2007
9 May 2007

Appendix B: Terms of Reference

1. Scope of the Committee

- 1.1 The Perinatal and Maternal Mortality Review Committee (the Committee) is a ministerial committee appointed under sections 11 and 18 of the New Zealand Public Health and Disability Act 2000 (the Act). The committee is appointed by, and accountable to, the Minister of Health (the Minister).
- 1.2 The functions of the Perinatal and Maternal Mortality Review Committee are:
- to review and report to the Minister (or other specified committees) on perinatal and maternal deaths, with a view to reducing the numbers of perinatal and maternal deaths, and to continuous quality improvement through the promotion of quality assurance programmes; and
 - to advise on any other matters related to perinatal and maternal mortality that the Minister specifies in any further notice to the committee
 - to develop strategic plans and methodologies that are designed to reduce morbidity and mortality and that are relevant to the Committee's functions.

Definition

For the purposes of the Terms of Reference of the Perinatal and Maternal Mortality Review Committee:

- Perinatal is defined as the age range from 20 weeks completed gestation (400 grams birthweight) to 28 completed days after birth.
- Maternal deaths are defined as deaths directly related to pregnancy or childbirth.

2. Composition of the Committee

- 2.1 The Committee will have a maximum of 10 members appointed by the Minister.
- Desired skills and knowledge of the collective committee membership
- 2.2 Collectively the Committee will have:
- knowledge of quality improvement and risk management, in particular quality assurance in the health sector
 - knowledge of data and information gathering systems and analysis
 - knowledge and experience of clinical epidemiology
 - knowledge of DHB service provision and management
 - clinical experience in neonatal paediatrics, perinatal pathology, obstetrics and midwifery
 - knowledge of Māori health
 - knowledge of Pacific peoples health
 - knowledge of consumer participation and representation.

Nomination process

- 2.3 The nomination process will comply with the requirements of the State Services Commission.

3. Terms and Conditions of Appointment

- 3.1 The Minister of Health appoints members of the Perinatal and Maternal Mortality Review Committee for a term of office of up to three years. The terms of office of members of the Perinatal and Maternal Mortality Review Committee will be staggered to ensure continuity of membership. Members may be reappointed from time to time. No member may hold office for more than six consecutive years.
- 3.2 Any member of the Perinatal and Maternal Mortality Review Committee may at any time resign as a member by advising the Minister of Health in writing.
- 3.3 Any member of the Perinatal and Maternal Mortality Review Committee may at any time be removed from office by the Minister of Health for inability to perform the functions of office, bankruptcy, neglect of duty or misconduct, proved to the satisfaction of the Minister.

3.4 The Minister may from time to time alter or reconstitute the Perinatal and Maternal Mortality Review Committee, or discharge any member of the Perinatal and Maternal Mortality Review Committee or appoint new members to the Perinatal and Maternal Mortality Review Committee for the purpose of decreasing or increasing the membership or filling any vacancies.

4. Chairperson

4.1 The Minister will appoint a member of the Perinatal and Maternal Mortality Review Committee to be its Chairperson. The Chairperson will preside at every meeting of the Perinatal and Maternal Mortality Review Committee at which they are present.

4.2 The Committee may from time to time appoint a member as Deputy Chairperson.

4.3 The Chairperson of Perinatal and Maternal Mortality Review Committee is likely to be appointed as a member of the National Health Epidemiology and Quality Assurance Advisory Committee (EpiQual). The Chair, therefore, should be aware that an approximate six days of meetings in Wellington would be required as part of that commitment.

5. Duties and Responsibilities of a Member

5.1 This section sets out the Minister of Health's expectations regarding the duties and responsibilities of a person appointed as a member of the Perinatal and Maternal Mortality Review Committee.

5.2 As an independent statutory body, the Perinatal and Maternal Mortality Review Committee has an obligation to conduct its activities in an open and ethical manner. The Perinatal and Maternal Mortality Review Committee has a duty to operate in an effective manner within the parameters of its functions as set out in its Terms of Reference.

5.4 The Perinatal and Maternal Mortality Review Committee members should have a commitment to work for the greater good of the committee.

5.5 There is an expectation that members will make every effort to attend all the Perinatal and Maternal Mortality Review Committee meetings and devote sufficient time to become familiar with the affairs of the committee and the wider environment within which it operates.

5.6 Members have a duty to act responsibly with regard to the effective and efficient administration of the Perinatal and Maternal Mortality Review Committee and the use of committee funds.

6. Conflicts of Interest

6.1 Members must perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will help protect the Perinatal and Maternal Mortality Review Committee and its members and will ensure it retains public confidence.

6.2 Members attend meetings and undertake committee activities as independent persons responsible to the committee as a whole. Members are not appointed as representatives of professional organisations and groups. The Perinatal and Maternal Mortality Review Committee should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.

6.3 When members believe they have a conflict of interest on a subject that will prevent them from reaching an impartial decision or undertaking an activity consistent with the committee's functions, they must declare that conflict of interest and withdraw themselves from the discussion and/or activity.

7. Confidentiality

The maintenance of confidentiality is crucial to the functioning of mortality review committees. Members must note the statutory requirement of s.18 (7) of the Act that prohibits disclosure of information contrary to Schedule 5 of the Act. Disclosure of such information is an offence and is liable, on summary conviction, to a fine not exceeding \$10,000.

8. Fees and Allowances

Members are entitled to be paid fees for attendance at meetings of both the Committee and its subcommittees. The level of fees is set in accordance with the State Services Commission's framework for fees for statutory bodies.

The Chairperson will receive \$450.00 per day (plus half a day's preparation fee for each meeting). In addition, there is an allowance of two extra days per month to cover additional work undertaken.

The attendance fee for members is set at \$320 per day (plus half a day's preparation fee for each meeting).

9. Meetings of the Committee

- 9.1 Meetings will be held in Wellington. Actual and reasonable expenses for activities required by the Committee of its members (for example, travel, accommodation, literature searches) will be met from the Committee's budget provided prior approval is received.
- 9.2 At any meeting, a quorum shall consist of seven members. A quorum must include either the Chairperson or Deputy Chairperson.
- 9.3 Every question before any meeting shall generally be determined by consensus decision-making. Where a consensus cannot be reached, a majority vote will apply. Where a decision cannot be reached through consensus and a majority vote is made, the Chairperson shall have the casting vote.

10. Performance Measures

10.1 The Perinatal and Maternal Mortality Review Committee will be effectively meeting its tasks when it provides relevant and timely advice to the Minister of Health based on research, analysis and consultation with appropriate groups and organisations.

The Perinatal and Maternal Mortality Review Committee must:

- agree in advance to a work programme with the Minister of Health
- achieve its agreed work programme
- stay within its allocated budget.

10.2 The Committee will agree a work programme in advance with the Minister that fulfils its functions and can be achieved within a sufficient, allocated budget.

10.3 In carrying out its functions, the Committee must ensure that:

- appropriate consultation has occurred when developing a methodology and subsequently disseminating findings
- any recommendations are developed in the context of available evidence
- any advice and recommendations comply with the laws of New Zealand
- its recommendations are published and widely available.

11. Treaty of Waitangi

The Committee is expected to undertake its tasks in a manner consistent with the principles of the Treaty of Waitangi.

12. Reporting Requirements

12.1 The Perinatal and Maternal Mortality Review Committee is required to keep minutes of all committee meetings that outline the issues discussed and include a clear record of any decisions or recommendations made.

12.2 The Perinatal and Maternal Mortality Review Committee is required to prepare an annual report to the Minister of Health setting out its activities and comparing its performance to its agreed work programme and summarising any advice that it has given to the Minister of Health. The Perinatal and Maternal Mortality Review Committee's report is to include the rationale for its advice and any relevant evidence and/or documentation. This report will be tabled by the Minister of Health in the House of Representatives pursuant to section 18(3) of the Act.

13. Servicing the Committee

13.1 The Ministry of Health will provide an administrative, policy and analytic Secretariat to the Committee. The Ministry will employ the Secretariat.

13.2 The Ministry of Health will employ staff to service the Perinatal and Maternal Mortality Review Committee out of the Committee's allocated budget.

14. Working Arrangements

14.1 The Perinatal and Maternal Mortality Review Committee must, during its first year of operation, address establishment issues necessary to develop strategic plans and methodologies. This includes:

- determining the availability, reliability and validity of existing data collection processes
- determining what, if any, additional data could reasonably be collected, from whom, and for what purposes in order that the Perinatal and Maternal Mortality Review Committee can undertake its functions

- developing an interface with existing inquiry systems
- establishing functional relationships with Child and Youth Mortality Review Committee (CYMRC) and the National Health Epidemiology and Quality Assurance Advisory Committee (EpiQual)
- ensuring that appropriate consultation has occurred, where required
- establishing processes to ensure security of personal information as referred to in clause 3 of schedule 5 of the Act
- providing the Minister of Health with advance notice of any media statements or reports to be published

14.2 Depending on activities in the work programme, where appropriate the Committee must make reasonable effort to consult with:

- other mortality review committees as established, especially the CYMRC
- relevant government bodies
- relevant professional and consumer organisations
- relevant stakeholders with expertise in mortality review.

14.3 The timing and frequency of meetings will be determined by the tasks the Committee is obliged to fulfil and as part of its work programme to be agreed with the Minister.

Appendix C: Local Co-ordinators and other Agents of the PMMRC

DHB District	Name	Employer and Work Role	Expiry
All	Vicki Masson	National Co-ordinator PMMRC The University of Auckland	29/10/09
All	Jennifer Martin	Senior Research Analyst Ministry of Social Development	12/11/09
All	Glenys Needs	Manager Mortality Database Group	18/05/10
All	Claire McClinock	Obstetric Physician The University of Auckland/Auckland DHB	06/03/10
All	Cathy Hapgood	Psychiatrist Waitemata DHB	23/07/10
All	Alison Eddy	Midwifery Advisor College of Midwives	23/07/10
All	John Walker	Specialist Anaesthetist Waitemata DHB	24/07/10
All	Jeanette McFarlane	Pathologist Auckland DHB	06/08/10
Northland	Ian Page	Obstetrician/Gynaecologist Northland DHB	29/10/09
Waitemata	Sue Belgrave	Obstetrician Waitemata DHB	29/10/09
Waitemata	Eleanor Gates	Quality Midwife Waitemata DHB	23/07/10
Auckland	Lesley McCowan	Obstetrician The University of Auckland/Auckland DHB	29/10/09
Counties Manukau	Nerida Titchiner	Obstetrician/Gynaecologist Counties Manukau DHB	29/10/09
Counties Manukau	Graham Parry	Obstetrician Counties Manukau DHB	06/03/10
Waikato	Alastair Haslam	Clinical Director Women's Health Obstetrician/Gynaecologist Waikato DHB	29/10/09
Waikato	Sarah Waymouth	Obstetrician/Gynaecologist Waikato DHB	29/10/09
Waikato	Phil Weston	Paediatrician Waikato DHB	17/05/10
Bay of Plenty	Margret Norris	Midwifery Advisor/Clinical Leader Bay of Plenty DHB	29/10/09
Lakes	Lorraine Anderson	Midwife Lakes DHB	29/10/09
Lakes	Tivanti Pilapitiya	Clinical Nurse Educator SCBU/Midwife Lakes DHB	29/10/09
Tairāwhiti	Sandra Walsh	Midwife Educator Tairāwhiti DHB	06/02/10

Taranaki	Miriam Oliver	Clinical Midwife Leader Taranaki DHB	29/10/09
Hawke's Bay	Lynda Croft	Obstetrician/Gynaecologist Specialist Hawke's Bay DHB	29/10/09
Whanganui	Lucy Pettit	Midwife/Clinical Midwifery Educator Whanganui DHB	29/10/09
Whanganui	Robyn McDougal	Midwife Whanganui DHB	29/10/09
MidCentral	Leona Dann	Charge Midwife MidCentral DHB	06/02/10
MidCentral	Kenneth Clark	Obstetrician/Gynaecologist MidCentral DHB	06/02/10
Wairarapa	Nasser Shehata	Obstetrician Wairarapa DHB	29/10/09
Wairarapa	Donna Purvis	Team Leader Midwifery Wairarapa DHB	29/10/09
Capital & Coast Health	Dawn Elder	Paediatrician University of Otago/Capital & Coast DHB	29/10/09
Capital & Coast Health	Rose Elder	Obstetrician Capital & Coast DHB	25/06/10
Hutt Valley	Joanne McMullan	Midwife Hutt Valley DHB	29/10/09
Hutt Valley	Charlotte Smith	Midwife Hutt Valley DHB	29/10/09
Nelson Marlborough	Kevin Hill	Specialist Obstetrician Nelson Marlborough DHB	26/02/10
Nelson Marlborough	Lois McTaggart	Clinical Midwife Leader Nelson Marlborough DHB	29/10/09
West Coast	Jude Bruce	Midwifery Co-ordinator/LMC Midwife West Coast DHB	18/02/10
West Coast	Mary McGrane	Midwife West Coast DHB	06/08/10
Canterbury	Glynn Russell	Neonatal Paediatrician Canterbury DHB	29/10/09
Canterbury	Dianne Leishman	Midwife Canterbury DHB	29/10/09
South Canterbury	John Weir	Obstetrician/Gynaecologist South Canterbury DHB	29/10/09
South Canterbury	Dianne Keeman	Clinical Leader Maternity Services (Midwife) South Canterbury DHB	15/03/10
Otago	Susan Fleming	Clinical Director Consultant Obstetrician/Gynaecologist Otago DHB	15/04/10
Otago	Helen Flockton	Charge Midwife Manager Otago DHB	15/04/10
Southland	Jennifer Humphries	Associate Director of Nursing & Midwifery Southland DHB	29/10/09

Appendix D: Forms to Appoint Agents of the PMMRC

This notice appoints the undersigned person as an agent of the PMMRC for the specific purposes listed below.

Scope of Agents of the PMMRC

The role of Agent of the PMMRC is limited to mortality review activities, as prescribed by the PMMRC, that are:

- within the area of the District Health Board identified below, and
- in relation to perinatal (from 20 weeks gestation or a birthweight over 400 grams if gestation unknown to 28 days after birth) and maternal deaths that are related to pregnancy or childbirth, and
- acting as an Agent of the PMMRC who can require any person, by notice in writing, to give the PMMRC any information in the person's possession, or under the person's control, and relevant to the performance by the PMMRC of any of its functions pursuant to Clause 2, Schedule 5 of the New Zealand Public Health and Disability Act 2000.

Name of Agent of the PMMRC	
District Health Board District	
Employer	
Work Role (usual occupation, for example, midwife, paediatrician, police officer)	
Contact Phone Number	
Email Address	
Work Address	

This appointment is valid for a period of three years from the date below; or until the PMMRC revokes the appointment in writing; or until any of the details given above change, for example, the person leaves their current employment.

Offence Statement

It is an offence under section 18 of the New Zealand Public Health and Disability Act 2000 to disclose information contrary to Schedule 5, and punishable by a fine of up to \$10,000 and disciplinary proceedings if a member of a registered occupational profession.

With the authority of the Perinatal and Maternal Mortality Review Committee:

Signed: _____ Date: _____

Professor Cynthia Farquhar

Chair, PMMRC

CONFIDENTIALITY AGREEMENT

The PMMRC reviews and reports to the Minister of Health, on perinatal and maternal deaths with a view to reducing the numbers of deaths.

Local perinatal and maternal mortality review groups made up of Agents of the PMMRC, review and report to the PMMRC on the deaths of local babies and mothers and make recommendations at a local level.

Under the New Zealand Public Health and Disability Act 2000 (the Act) the Chairperson or an Agent of the PMMRC may, by notice in writing, require a person to give the PMMRC information in that person's possession or under that person's control. The meaning of 'information' is defined in clause 3 of Schedule 5 to the Act.

Schedule 5 also places statutory limits on the disclosure of information by the PMMRC. The PMMRC (and its Agents) cannot disclose that information unless for the purposes of the Committee carrying out its functions or with a Ministerial authority in accordance with the Act.

Section 18 of the Act provides that a person who discloses information contrary to Schedule 5 is:

- liable on summary conviction to a maximum fine of \$10,000; and
- if a member of a registered occupational profession liable to disciplinary proceedings of that profession.

I

(Agent's name in capital letters) agree and undertake that:

- I will not disclose any Information to any person other than in accordance with the provisions of the New Zealand Public Health and Disability Act 2000, or unless otherwise authorised in accordance with law or as required by law;
- I will use my best endeavours to prevent the unauthorised disclosure of Information and to keep all documents containing Information secure.

For the purposes of this agreement 'Information' means:

Personal information (as defined in the Privacy Act 1993) about an identifiable individual and including information relating to a death that is maintained by the Registrar-General pursuant to the Births, Deaths, and Marriages Registration Act 1995, or any former Act; and

Information that has become known to you only because of the Committee's functions being carried out, whether or not the carrying out of those functions is completed.

I have read the statutory provisions of the New Zealand Public Health and Disability Act 2000 attached to this agreement.

I have read and understood the above confidentiality statement and agree to be bound by its terms.

Signed: _____ Date: _____

Proposed Agent of the PMMRC

Appendix E: Contact Details

Website

The PMMRC website (<http://www.pmmrc.health.govt.nz>) is supported by the Ministry. The PMMRC uses the website to provide the wider community with more information about mortality review and related issues.

Mortality review committees established under sections 11 and 18 of the NZPHD Act must report at least annually to the Minister. The PMMRC annual report is available from <http://www.pmmrc.health.govt.nz> under Resources: Publications.

Information brochure for families and whānau

The information brochure for families and whānau is available on the PMMRC website (<http://www.pmmrc.health.govt.nz>) under Resources: Publications or by emailing pmmrc@moh.govt.nz

Contact details

The PMMRC can be contacted at:

Perinatal and Maternal Mortality

Review Committee

c/o Ministry of Health

PO Box 5013

Wellington

Email: pmmrc@moh.govt.nz

Appendix F: PSANZ Classifications

www.psanz.org.au

PSANZ Perinatal Death Classification (PSANZ-PDC)

1 Congenital abnormality (including terminations for congenital abnormalities)

- 1.1 Central nervous system
- 1.2 Cardiovascular system
- 1.3 Urinary system
- 1.4 Gastrointestinal system
- 1.5 Chromosomal
- 1.6 Metabolic
- 1.7 Multiple/non chromosomal syndromes
- 1.8 Other congenital abnormality
 - 1.81 Musculoskeletal
 - 1.82 Respiratory
 - 1.83 Diaphragmatic hernia
 - 1.84 Haematological
 - 1.85 Tumours
 - 1.88 Other specified congenital abnormality
- 1.9 Unspecified congenital abnormality

2 Perinatal infection

- 2.1 Bacterial
 - 2.11 Group B Streptococcus
 - 2.12 E coli
 - 2.13 Listeria monocytogenes
 - 2.14 Spirochaetal, for example, Syphilis
 - 2.18 Other bacterial
 - 2.19 Unspecified bacterial
- 2.2 Viral
 - 2.21 Cytomegalovirus
 - 2.22 Parvovirus
 - 2.23 Herpes simplex virus
 - 2.24 Rubella virus
 - 2.28 Other viral
 - 2.29 Unspecified viral
- 2.3 Protozoal, for example, Toxoplasma
- 2.5 Fungal
- 2.8 Other specified organism
- 2.9 Other unspecified organism

3 Hypertension

- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, for example, renal disease
- 3.3 Chronic hypertension: unspecified
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
 - 3.51 With laboratory evidence of thrombophilia

- 3.6 Pre-eclampsia superimposed on chronic hypertension
 - 3.61 With laboratory evidence of thrombophilia
- 3.9 Unspecified hypertension
- 4 Antepartum haemorrhage (APH)**
 - 4.1 Placental abruption
 - 4.11 With laboratory evidence of thrombophilia
 - 4.2 Placenta praevia
 - 4.3 Vasa praevia
 - 4.8 Other APH
 - 4.9 APH of undetermined origin
- 5 Maternal conditions**
 - 5.1 Termination of pregnancy for maternal psychosocial indications
 - 5.2 Diabetes/Gestational diabetes
 - 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
 - 5.4 Maternal sepsis
 - 5.5 Lupus obstetric syndrome
 - 5.6 Obstetric cholestasis
 - 5.8 Other specified maternal conditions
- 6 Specific perinatal conditions**
 - 6.1 Twin-twin transfusion
 - 6.2 Fetomaternal haemorrhage
 - 6.3 Antepartum cord complications (for example, cord haemorrhage; true knot with evidence of occlusion)
 - 6.4 Uterine abnormalities, for example, bicornuate uterus, cervical incompetence
 - 6.5 Birth trauma (typically infants of >24 weeks gestation or >600 grams birthweight)
 - 6.6 Alloimmune disease
 - 6.61 Rhesus
 - 6.62 ABO
 - 6.63 Kell
 - 6.64 Alloimmune thrombocytopenia
 - 6.68 Other
 - 6.69 Unspecified
 - 6.7 Idiopathic hydrops
 - 6.8 Other specific perinatal conditions (includes iatrogenic conditions such as rupture of membranes after amniocentesis, termination of pregnancy for suspected but unconfirmed congenital abnormality).
- 7 Hypoxic peripartum death (typically infants of >24 weeks gestation or >600 grams birthweight)**
 - 7.1 With intra-partum complications
 - 7.11 Uterine rupture
 - 7.12 Cord prolapse
 - 7.13 Shoulder dystocia
 - 7.18 Other
 - 7.2 Evidence of non-reassuring fetal status in a normally grown infant (for example, abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intra-partum complications)
- 7.3 No intra-partum complications and no evidence of non-reassuring fetal status
- 7.9 Unspecified hypoxic peripartum death
- 8 Fetal Growth Restriction (FGR)**
 - 8.1 With evidence of reduced vascular perfusion on Doppler studies and/or placental histopathology (for example, significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
 - 8.2 With chronic villitis
 - 8.3 No placental pathology
 - 8.4 No examination of placenta
 - 8.8 Other specified placental pathology
 - 8.9 Unspecified or not known whether placenta examined
- 9 Spontaneous preterm (< 37 weeks gestation)**
 - 9.1 Spontaneous preterm with intact membranes, or membrane rupture \geq 24 hours before delivery
 - 9.11 With chorioamnionitis on placental histopathology
 - 9.12 Without chorioamnionitis on placental histopathology
 - 9.13 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.17 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.19 Unspecified or not known whether placenta examined
 - 9.2 Spontaneous preterm with membrane rupture <24 hours before delivery
 - 9.21 With chorioamnionitis on placental histopathology
 - 9.22 Without chorioamnionitis on placental histopathology
 - 9.23 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.27 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.29 Unspecified or not known whether placenta examined
 - 9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery
 - 9.31 With chorioamnionitis on placental histopathology
 - 9.32 Without chorioamnionitis on placental histopathology
 - 9.33 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.37 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.39 Unspecified or not known whether placenta examined

10 Unexplained antepartum death

- 10.1 With evidence of reduced vascular perfusion on Doppler studies and/or placental histopathology (for example, significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- 10.2 With chronic villitis
- 10.3 No placental pathology
- 10.7 No examination of placenta
- 10.8 Other specified placental pathology
- 10.9 Unspecified or not known whether placenta examined

11 No obstetric antecedent

- 11.1 Sudden Infant Death Syndrome (SIDS)
 - 11.11 SIDS Category IA: Classic features of SIDS present and completely documented
 - 11.12 SIDS Category IB: Classic features of SIDS present but incompletely documented
 - 11.13 SIDS Category II: Infant deaths that meet Category I except for one or more features
- 11.2 Postnatally acquired infection
- 11.3 Accidental asphyxiation
- 11.4 Other accident, poisoning or violence (postnatal)
- 11.8 Other specified
- 11.9 Unknown/Undetermined
 - 11.91 Unclassified Sudden Infant Death
 - 11.92 Other Unknown/Undetermined

PSANZ Neonatal Death Classification (PSANZ-NDC)

1. Congenital abnormality (including terminations for congenital abnormalities)

- 1.1 Central nervous system
- 1.2 Cardiovascular system
- 1.3 Urinary system
- 1.4 Gastrointestinal system
- 1.5 Chromosomal
- 1.6 Metabolic
- 1.7 Multiple/Non-chromosomal syndromes
- 1.8 Other congenital abnormality
 - 1.81 Musculoskeletal
 - 1.82 Respiratory
 - 1.83 Diaphragmatic hernia
 - 1.84 Haematological
 - 1.85 Tumours
 - 1.88 Other specified congenital abnormality
- 1.9 Unspecified congenital abnormality

2. Extreme prematurity (typically infants of ≤ 24 weeks gestation or ≤ 600 grams birthweight)

- 2.1 Not resuscitated
- 2.2 Unsuccessful resuscitation
- 2.9 Unspecified or not known whether resuscitation attempted

3. Cardio-respiratory disorders

- 3.1 Hyaline membrane disease/Respiratory distress syndrome (RDS)
- 3.2 Meconium aspiration syndrome
- 3.3 Primary persistent pulmonary hypertension
- 3.4 Pulmonary hypoplasia
- 3.5 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
- 3.8 Other

4. Infection

- 4.1 Bacterial
 - 4.11 Congenital bacterial
 - 4.12 Acquired bacterial
- 4.2 Viral
 - 4.21 Congenital viral
 - 4.22 Acquired viral
- 4.3 Protozoal, for example, Toxoplasma
- 4.4 Spirochaetal, for example, Syphilis
- 4.5 Fungal
- 4.8 Other
- 4.9 Unspecified organism

5. Neurological

- 5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia (typically infants of >24 weeks gestation or >600 grams birthweight)
- 5.2 Intracranial haemorrhage
- 5.8 Other

6. Gastrointestinal

- 6.1 Necrotising enterocolitis
- 6.8 Other

7 Other

- 7.1 Sudden Infant Death Syndrome (SIDS)
 - 7.11 SIDS Category IA: Classic features of SIDS present and completely documented.
 - 7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.
 - 7.13 SIDS Category II: Infant deaths that meet Category I except for one or more features
- 7.2 Multisystem failure – only if unknown primary cause or trigger event
- 7.3 Trauma
- 7.8 Other specified
- 7.9 Unknown/Undetermined
 - 7.91 Unclassified Sudden Infant Death
 - 7.92 Other Unknown/Undetermined

*Heoi anō, kāore he take
o ēnei kōrero ki te kore
te reo kei roto i
te māngai o te iwi.*

