



**Perinatal and
Maternal Mortality
Review Committee**

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

Perinatal and Maternal Mortality in New Zealand 2006

**Second Report to the Minister of Health
July 2007 to June 2008**

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The grief of a sudden, untimely death will never be forgotten*

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Chair's Introduction



It is three years since the Minister of Health established the Perinatal and Maternal Mortality Review Committee (PMMRC). The aim of the committee is to identify areas in maternity and newborn care where improvements could be made. With this aim in mind, the PMMRC database was set up to review all perinatal and maternal deaths in New Zealand in order to reduce perinatal and maternal deaths through audit and feedback.

The purpose of this report is to provide an accurate estimate of the absolute numbers and rates of perinatal and maternal deaths in New Zealand, to describe the risk factors for perinatal deaths, and to attempt to identify where the attention of maternity and neonatal services might be focused to prevent perinatal and maternal deaths. This year we are pleased to be able to report the first output of our data collection system. This system is based on the collaborative efforts of Lead Maternity Carers, local co-ordinators and clinicians of the District Health Boards supported by a National Co-ordinator. A national database has been created by the Mortality Review Data Group of the University of Otago from which we are reporting perinatal mortality data for the latter half of 2006 and a full year of maternal mortality data.

The data we have collected suggest that our rates of perinatal mortality are similar to those of the Australian states of Victoria and Western Australia and the United Kingdom.

We are also reporting for the first time the maternal deaths that have been identified by the Maternal Mortality Review Working Group chaired by Dr Claire McLintock of the University of Auckland. This working group reports to the PMMRC. Although the rate of maternal deaths is higher than that reported in previous years, the difference is likely to be explained by increased reporting via local co-ordinators. The number of deaths overall is too low to support statistical comparisons.

Communication continues to be central to ensuring co-operation and collaboration in reporting perinatal mortality. We have held annual training workshops in 2006, 2007 and 2008 with local co-ordinators. The local co-ordinators in turn, have been active in reviewing perinatal deaths within their own District Health Board. These meetings aim to look for improvements in local services. I am pleased to report that all District Health Boards are now holding regular local mortality review meetings, which has only happened since the establishment of the PMMRC.

In the legislation establishing the PMMRC, we were also asked to review morbidity. For this purpose, in 2007 a Neonatal Encephalopathy Working Group was established, chaired by Dr Malcolm Battin of the University of Auckland and reporting to the PMMRC. This group is working to develop a process for identification of cases and data collection. In addition, the committee held a workshop on perinatal pathology services in New Zealand, particularly focusing on workforce issues in the future. The report from that workshop is presented in Appendix 4.

Thank you to everyone who has supported the work of the committee 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.



Professor Cynthia Farquhar

Chair

Perinatal and Maternal Mortality Review Committee

Executive Summary and Recommendations

Terms of reference and mortality definitions

- The Perinatal and Maternal Mortality Review Committee (PMMRC) is responsible for reviewing maternal deaths and all deaths of infants born after 20 weeks gestation up to and including 28 days of life or weighing at least 400 g if gestation is unknown.
- A maternal death is the 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.
- The maternal mortality ratio was calculated per 100,000 maternities. Maternities were defined as all live births and fetal deaths at 20 weeks or beyond or weighing 400 g or more if gestation unknown.
- Perinatal mortality rate is fetal death and early neonatal death per 1000 total babies born at 20 weeks or beyond or weighing at least 400g if gestation is unknown.

Key points

- Approximately one in 100 babies died between 20 weeks gestation and the first 28 days of life during the period 1 July and 31 December 2006. Perinatal mortality rates in New Zealand are comparable with the rates reported in Australia and the United Kingdom.
- Perinatal and maternal mortality data previously published by the New Zealand Health Information Service appear to have underestimated mortality rates.
- The PMMRC reporting system has led to the ascertainment of more cases than previously reported.
- One-third of perinatal deaths were associated with fetal abnormalities. The next most common cause of perinatal death was preterm birth. It should be noted that for one in five stillbirths no cause is found.
- Pacific and Māori women and women under the age of 20 years were found to have higher rates of perinatal mortality.

Recommendations relating to perinatal mortality

The Minister of Health notes that the PMMRC will undertake the following actions with a view to reducing perinatal deaths.

- Undertake detailed analysis of stillbirths among Pacific women and of neonatal deaths among Māori infants in its next annual report.
- Undertake detailed analysis of perinatal mortality among mothers under the age of 20 years in its next annual report.

The Minister of Health requests the Ministry of Health to undertake the following actions with a view to reducing perinatal deaths.

- Promote the Ministry of Health's pregnancy guidelines to Lead Maternity Carers for:
 - diabetes screening
 - smoking cessation
 - family violence screening.
- Inform Lead Maternity Carers that bleeding during pregnancy, regardless of the apparent cause, is a possible risk factor for perinatal death. Therefore women with bleeding during pregnancy should be closely monitored for fetal growth restriction and preterm labour.
- Request Lead Maternity Carers to measure height and weight at the first antenatal visit and to use a customised growth chart to record fundal height to improve the recognition of infants who are small for gestational age.
- Request that all families who experience a fetal or neonatal death be offered a post mortem examination for their infant, especially if a clear cause of death has not been established. Ideally the post mortem examination should be provided by a perinatal pathologist.

- Develop and improve the provision of perinatal pathology services with regards to accessibility, training and appropriateness and to ensure quality and equitable services are available across the country.
- Assign all babies, regardless of whether stillborn or live-born, a National Health Index number at the time of birth.
- Develop national guidelines for District Health Boards (DHBs) to provide better support to parents, families and whānau around a perinatal death. The Ministry of Health develops support and information resources for the community.

The Minister of Health requests the Information Directorate (formerly New Zealand Health Information Service) to undertake the following action with a view to reducing perinatal deaths.

- Provide timely and robust denominator data on births in New Zealand.

Recommendations relating to maternal mortality

It is recommended that the following actions be undertaken with a view to reducing maternal deaths.

- The Minister of Health continues to support national reporting of maternal deaths. Each death has the potential to highlight where improvements in clinical care and social services are needed and where more resources are required.
- The Minister of Health requests each DHB to carry out a review of all maternal deaths under the auspices of the DHB perinatal and maternal mortality review groups.
- The Minister of Health notes complete case ascertainment is essential to ensure maternal mortality statistics are accurate.
- All maternal deaths should be referred to a coroner (a legal requirement that has been in place since 1 July 2007).
- The New Zealand medical death certificate should be modified to include a tick box to indicate if a woman has been pregnant within one year of the death.
- The Minister of Health requests the Ministry of Health to identify women at risk due to poor maternal mental health, and notes that improved access to maternal mental health services is required across all DHBs. Women at risk must have a clear management plan and in particular a crisis management plan.
- The Minister of Health notes that the PMMRC has hosted a national conference on maternal mental health in 2008 to raise awareness of the risks of maternal mental health problems and to determine methods of improving access to care.
- The Minister of Health encourages improved communication between primary and secondary services. A variety of means might be used such as woman-held maternity notes, integrated notes systems and electronic transfer of information.
- The Minister of Health recommends that all staff involved in care of pregnant women should undertake regular training in management of obstetric emergencies.
- The Minister of Health recommends that each acute obstetric unit develops a massive transfusion protocol to respond to major obstetric haemorrhage. One possibility would be to develop this protocol as a national process to support local processes.

Recommendations relating to support for parents, families and whānau

The Minister of Health notes that the PMMRC will undertake the following action with a view to supporting parents, families and whānau who have experienced a perinatal or maternal death.

- Investigate how DHBs might be better supported or guided to provide support to parents, families and whānau and how support and information can be resourced in our communities.

1 Perinatal Mortality (1 July – 31 December 2006)

1.1 Introduction

In New Zealand, maternity care is funded by the Ministry of Health through 21 District Health Boards (DHBs). The clinical care is provided by Lead Maternity Carers, who receive funding from the Ministry of Health. These clinicians may be self-employed midwives, general practitioners, private obstetricians or hospital based midwives and obstetricians. These services are free to the patients except in the case of a private obstetrician, who has the right to charge for their services.

Lead Maternity Carers are required to obtain access agreements with any maternity facility where they intend to provide care. They are also required to provide back-up arrangements.

Women have the right to choose who they engage as their Lead Maternity Carer. However, there are guidelines about appropriate care that have been agreed between the professional colleges and the Ministry of Health (Ministry of Health 2000).

1.2 Methodology

1.2.1 Data sources and quality

After the establishment of the Perinatal and Maternal Mortality Review Committee (PMMRC), and following consultation with and agreement from various stakeholders, it was agreed that reviewing all perinatal deaths would require the collection of detailed clinical information on each perinatal death with the assistance of the Lead Maternity Carer and the District Health Boards (DHBs).

An expanded description of the data collection methods is available from the first PMMRC report (PMMRC 2007).

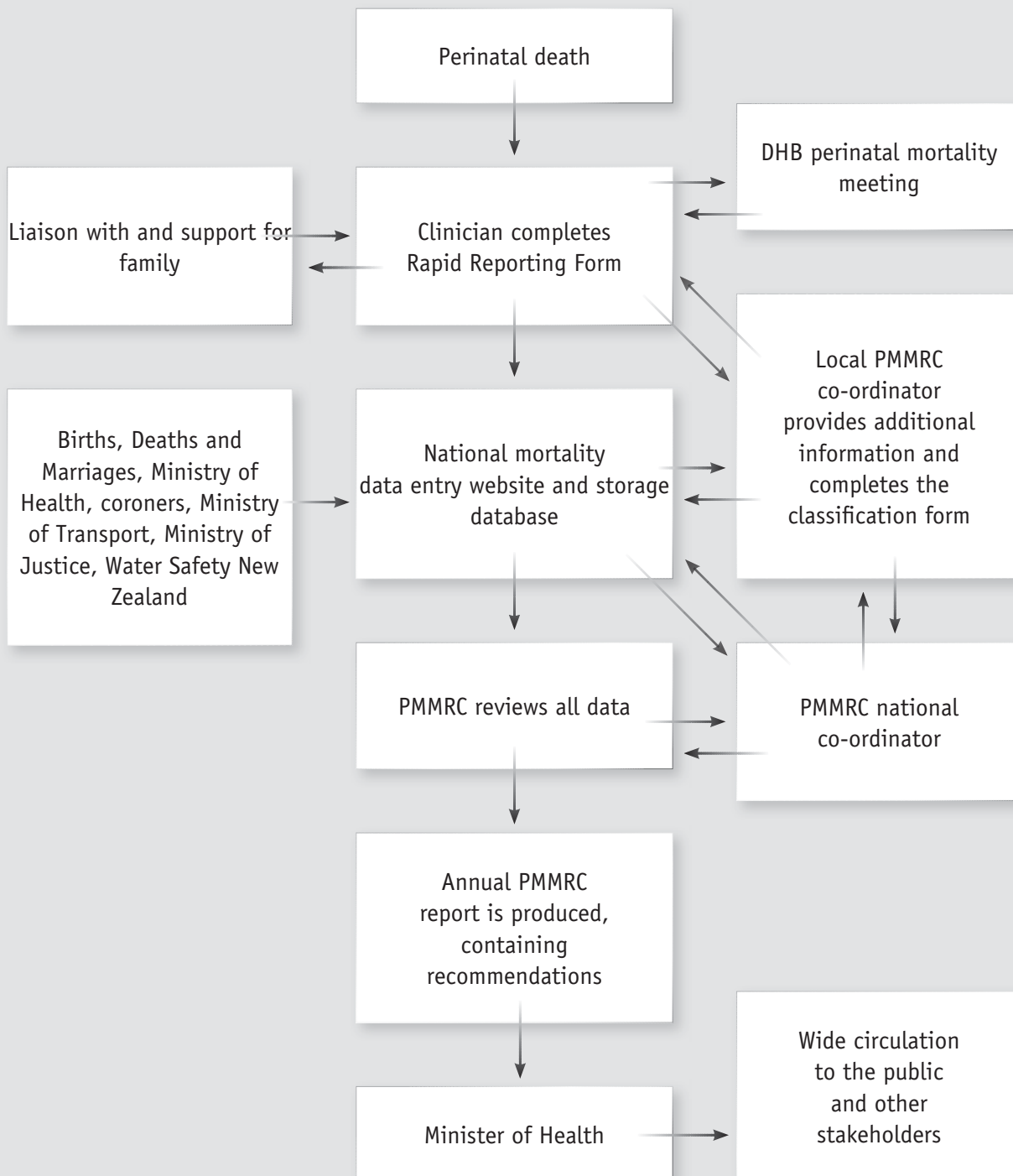
The PMMRC approached all DHBs in New Zealand requesting that they help to establish a network of local PMMRC co-ordinators. Each DHB was asked to submit the name of an individual who would have the role of co-ordinating the PMMRC review of perinatal deaths within their DHB. This role included identifying perinatal deaths and co-ordinating the collection of the required data in either paper- or web-based form. These data were submitted to the central data collection held by the Mortality Review Data Group at the University of Otago in order to create a national data set. The co-ordinators were also asked to be responsible for initiating local clinical review of each case, including assigning classification codes, and for ensuring that appropriate follow-up with the parents was undertaken in a timely manner.

After local review the local co-ordinator completes the PMMRC Classification Form. The classification system that has been adopted is the Perinatal Society of Australia and New Zealand (PSANZ) system of classification (PSANZ 2005). This system includes both perinatal and neonatal classifications, which are listed in Appendix 1 of this report. Attached to the classification form are the post mortem and histology reports. Figure 1.1 describes the PMMRC process.

The national data set of all perinatal deaths identified by the PMMRC is held by the University of Otago. The data set is a compilation of data submitted by the local co-ordinators via the PMMRC website, death notifications and some additional data from Births, Deaths and Marriages. The PMMRC website, established by the University of Otago at the request of the PMMRC, enables web-based data to be submitted by completing rapid reporting forms. These forms include a form for information on the mother – that is, her past medical and obstetric history, and details of the birth and outcomes – and a form for baby details. Before the website was established, the rapid reporting forms were pilot tested for 100 perinatal deaths.

When a perinatal death occurs, the Lead Maternity Carer is required to complete the rapid reporting forms within 48 hours. Classification of cause of death forms are completed by the local co-ordinator. Both of these information sources are entered either by web-based entry or in paper form. A user guide describes the definitions used and the data elements (PMMRC 2006).

Figure 1.1: Flow of information in the PMMRC's perinatal data collection process



Perinatal deaths that occur outside the hospital setting are most often identified via the Births, Deaths and Marriages register. The local co-ordinator then arranges with the Lead Maternity Carer involved for the completion of the rapid reporting forms and classification forms.

A National Co-ordinator of the PMMRC was appointed in October 2006. This position was established to ensure timely completion of all rapid reporting forms and classification forms, and to provide support and education to the local co-ordinators.

This report includes perinatal mortality data for six months (from 1 July 2006 to 31 December 2006). This report can be considered the pilot phase for the first full year of data which will be reported for 2007 in 2009.

1.2.2 PMMRC data validation

There are at least two sources of notification for every death. Deaths that occur in hospital are usually first notified through the rapid reporting forms. The Mortality Review Data Group monitors and follows up on missing stillbirth and death registrations. Out-of-hospital deaths are usually first notified either by the coroner or by the Births, Deaths and Marriages register. In these cases the local co-ordinator arranges for the Lead Maternity Carer involved to complete the rapid reporting forms.

Data are regularly cleaned to eliminate duplicate records, follow up missing mother or baby forms, clarify DHB of residence where this is inconsistent with the residential address, and rectify other inconsistencies identified by the Mortality Review Data Group.

All 'cause of perinatal death' classifications were reviewed by the National Co-ordinator. Complicated cases were checked with Associate Professor L McCowan (PMMRC member with expertise in classifications) with advice from the PMMRC as required.

The National Co-ordinator audited all data supplied on a random selection of 10 percent of perinatal deaths. The clinical records were requested from the relevant DHBs. The auditor made the classifications, which were then compared with the original classification. In 10 percent of cases the classification was different. The remainder of the entered data fields were accurate in cases where data were entered but available data had not been entered in some records.

1.2.3 Denominator data

The denominator data, referring to all births in New Zealand between 1 July 2006 and 31 December 2006, and used to calculate mortality rates, were provided by the New Zealand Health Information Service (NZHIS). These data arise from the National Minimum Dataset which includes data on all in-hospital events. Of note, homebirths are not included in the denominator data.

Currently within the NZHIS data on maternity and newborns, there is no link between mothers and babies.¹ Further, data on fetal deaths do not reach the National Minimum Dataset as these babies are not admitted to hospital and so are not coded. Data relating to births are also supplied by Births, Deaths and Marriages to Statistics New Zealand but some births and deaths are not registered or are registered later than the year in which they occurred. The Births, Deaths and Marriages register does not receive National Health Index (NHI) numbers (New Zealand's unique individual health identifier) so its registrations are not easily matched with NZHIS maternity data.

¹ From 1 July 2008 DHBs are required to submit the mother's NHI number with the record for the baby to the National Minimum Dataset. This information will not be included in the records for babies born in private facilities, however, due to a system limitation (usually these records account for between 5 and 10 percent of all in-hospital births).

1.2.4 Data analysis

The perinatal deaths presented in this report occurred between 1 July 2006 and 31 December 2006 (that is, this period deals with date of death not date of death registration). The data were extracted from the PMMRC database on 1 February 2008. A small number of deaths notified after this date are included in the mortality rates but not in the remainder of the analyses in this report.

The frequencies and discrete statistics were computed from the PMMRC database by the Mortality Review Data Group. Percentages have been rounded to one decimal place when the denominator is all births, and whole numbers when the denominator is deaths only. In some cases, due to rounding, the percentages do not add to exactly 100 percent.

Ninety-five percent confidence intervals for mortality rates have been computed using the Exact method. The confidence interval represents the degree of uncertainty around the point estimate of the rate for this six-month period. This uncertainty arises from the absolute number of deaths and from the number of births from which the deaths arose. If the number of births is large then the confidence interval (that is, the level of uncertainty) is generally small, while if the number of births is small the confidence interval is large. The confidence interval represents the limits within which the 'true' rate is most likely to lie. This calculation is necessary when numbers are small because the point estimate of the rate calculated from the data given may by chance have taken a wide range of values. The confidence interval describes this range.

It is possible to compare rates by looking at the confidence intervals. If the confidence intervals for two rates do not overlap it is likely the rates are different. If the confidence intervals do overlap, they may or may not be different.

In Figure 1.6, which demonstrates perinatal mortality by residence, the confidence intervals for perinatal mortality by DHB of residence have been plotted along with the national perinatal mortality rate. If the confidence interval for the DHB of residence rate does not include the national rate, then it is likely that this rate differs from the national average rate.

Where cases have missing data, these cases have been included in the data tables or discussed in the text. Percentages in the tables generally include missing data, though the text sometimes describes findings among women with complete data only. Where missing data exceeds 30 percent of all possible data points, the data have generally not been presented.

1.2.5 Definitions

Ethnicity

Ethnicity data on deaths were collected in two ways: first from information supplied to the Registrar of Births, Deaths and Marriages by parents, and second on the rapid reporting forms completed by the Lead Maternity Carer. In both instances, ethnicity recorded is as identified by the mother/parents. Multiple ethnicities can be identified for both mother and baby. The PMMRC has followed the guidelines from the Ministry of Health (2004, p 10) to prioritise ethnicity. The tables in this report categorise ethnicity into the following groups: Māori, Pacific, Indian, Other Asian, Other, New Zealand European. One prioritised ethnicity is presented when ethnicity data are given.

Ethnicity denominator data are reported for mothers and babies and these data are from the respective NZHIS data sets. Baby ethnicity is used for the primary analyses in this report. Maternal ethnicity data are provided in the appendices.

Mortality rates

The following definitions were used by the PMMRC.

Fetal death is the death of a baby born at 20 weeks or beyond (≥ 20 weeks) or weighing at least 400 g if gestation is unknown. Fetal death includes stillbirth and termination of pregnancy.

Fetal death rate is calculated per 1000 babies born alive or born dead at 20 weeks or beyond or weighing at least 400 g if gestation is unknown.

Neonatal death is the death of any baby showing signs of life at 20 weeks or beyond or weighing at least 400 g if gestation is unknown. Early neonatal death occurs within the first seven days of life (including deaths on the seventh day). Late neonatal death occurs between the 8th day and the 28th day including deaths on the 28th day. Neonatal death rate is calculated per 1000 babies born alive at 20 weeks or beyond or weighing at least 400g if gestation is unknown.

Perinatal mortality rate is calculated as fetal deaths and early neonatal deaths per 1000 total babies born alive or born dead at 20 weeks or beyond or weighing at least 400 g if gestation is unknown.

In some places this report refers to a United Kingdom definition of perinatal mortality, from the Confidential Enquiry into Maternal and Child Health (CEMACH). This definition excludes fetal deaths between 20 and 24 weeks (Pearson 2008).

Perinatal-related mortality rate is calculated as fetal deaths and early and late neonatal deaths per 1000 total babies born alive or born dead at 20 weeks or beyond or weighing at least 400 g if gestation is unknown.

Lethal and terminated fetal abnormalities are all fetal deaths with PSANZ-PDC classification of congenital abnormality and neonatal deaths with PSANZ-NDC classification of congenital abnormality.

Intrapartum stillbirth rate is calculated as death of non-anomalous babies of at least 24 weeks gestation who entered labour alive but then died during labour per 10,000 non-anomalous births of at least 24 weeks gestation.

Customised birthweight centiles adjust newborn size for the maternal variables of weight, height, ethnicity and parity as well as for infant sex and gestation at birth. Centile calculators are available online from the Gestation Network (<http://www.gestation.net>). For fetal deaths the gestation at the time of estimated death (not birth) is used to calculate the birthweight centile.

New Zealand Deprivation score (NZDep 2001) is an index of socioeconomic deprivation based on variables from the Census of Population and Dwellings 2001. The score is assigned according to place of residence and presented as a decile (or quintile in some cases). Increasing deciles of deprivation, from least deprived at decile 1 to most deprived at decile 10, are associated with higher mortality and rates of many diseases (Salmond and Crampton 2002a, 2002b).

Lead Maternity Carer is defined in the Maternity Services Notice 2007 and means a person who:

- (a) is –
 - (i) is a general practitioner with a diploma in obstetrics (or equivalent, as determined by the New Zealand College of General Practitioners); or
 - (ii) is a midwife; or
 - (iii) an obstetrician; and
- (b) is either –
 - (i) a maternity provider in his or her own right; or
 - (ii) an employee or contractor of a maternity provider; and
- (c) has been selected by the woman to provide her lead maternity care.

Data not reported

Many of the data points collected in the rapid reporting forms for each death have not been reported here. In many cases they are not reported because the principal reason for collection was review of cause of death classification. In other cases they are not reported because numbers were insufficient or because data collection was incomplete. When missing data were greater than 30 percent of all possible data points, the data were usually not reported. If the questions were not clear, the PMMRC has made efforts for them to be clarified.

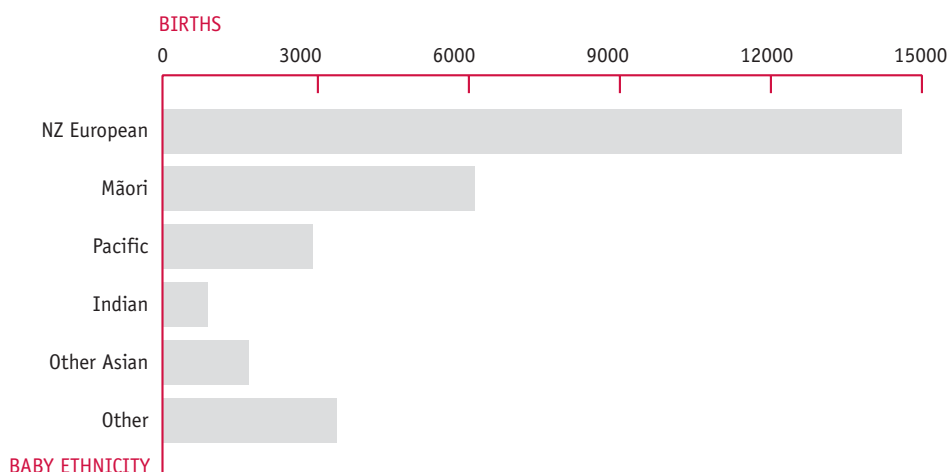
1.3 Births in New Zealand 1 July – 31 December 2006

It is recognised that the NZHIS National Minimum Dataset does not include all births during this period – specifically, it excludes stillbirths and home births. However, it represents the most comprehensive data collection available in New Zealand at this time. Although data on home births are added to the in-hospital National Minimum Dataset, this expanded data set was not available for analysis at the time this report was prepared. The following data are presented with this limitation in view.

In the National Minimum Dataset, 29,967 babies were recorded for the period 1 July to 31 December 2006. The distribution of the ethnicities of those babies is shown in Figure 1.2.

The National Minimum Dataset recorded 29,415 mothers as giving birth in the six months from 1 July to 31 December 2006.

Figure 1.2: Distribution of baby ethnicities among births in New Zealand, 1 July – 31 December 2006



Note: For frequency data and proportions, see Table 1.6.

Figure 1.3 shows distribution of all births by socioeconomic deprivation decile, where decile 1 represents the least deprived and 10 the most deprived in socioeconomic terms.

Figure 1.3: Distribution of socioeconomic deprivation deciles among births in New Zealand, 1 July – 31 December 2006

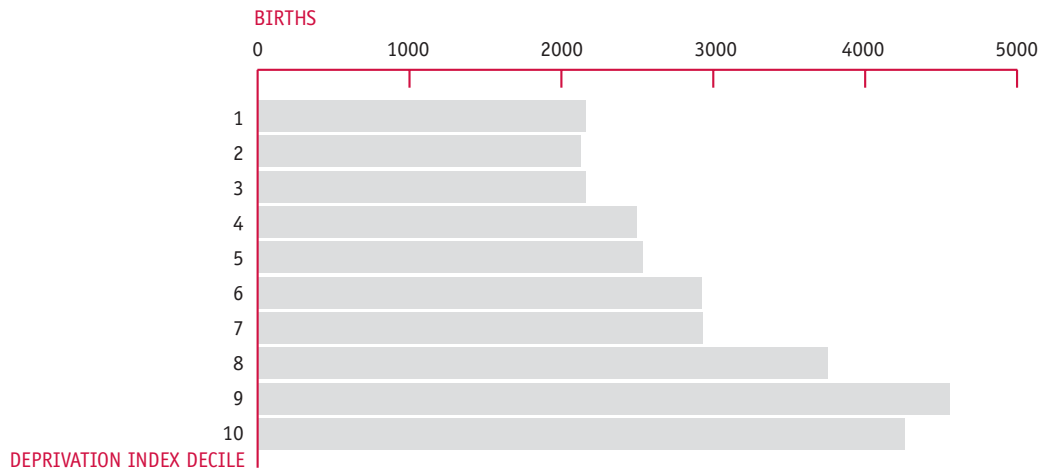
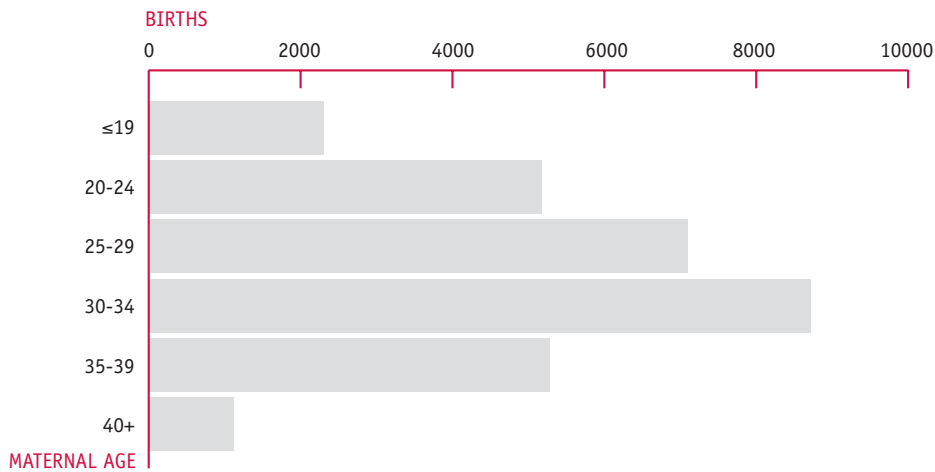


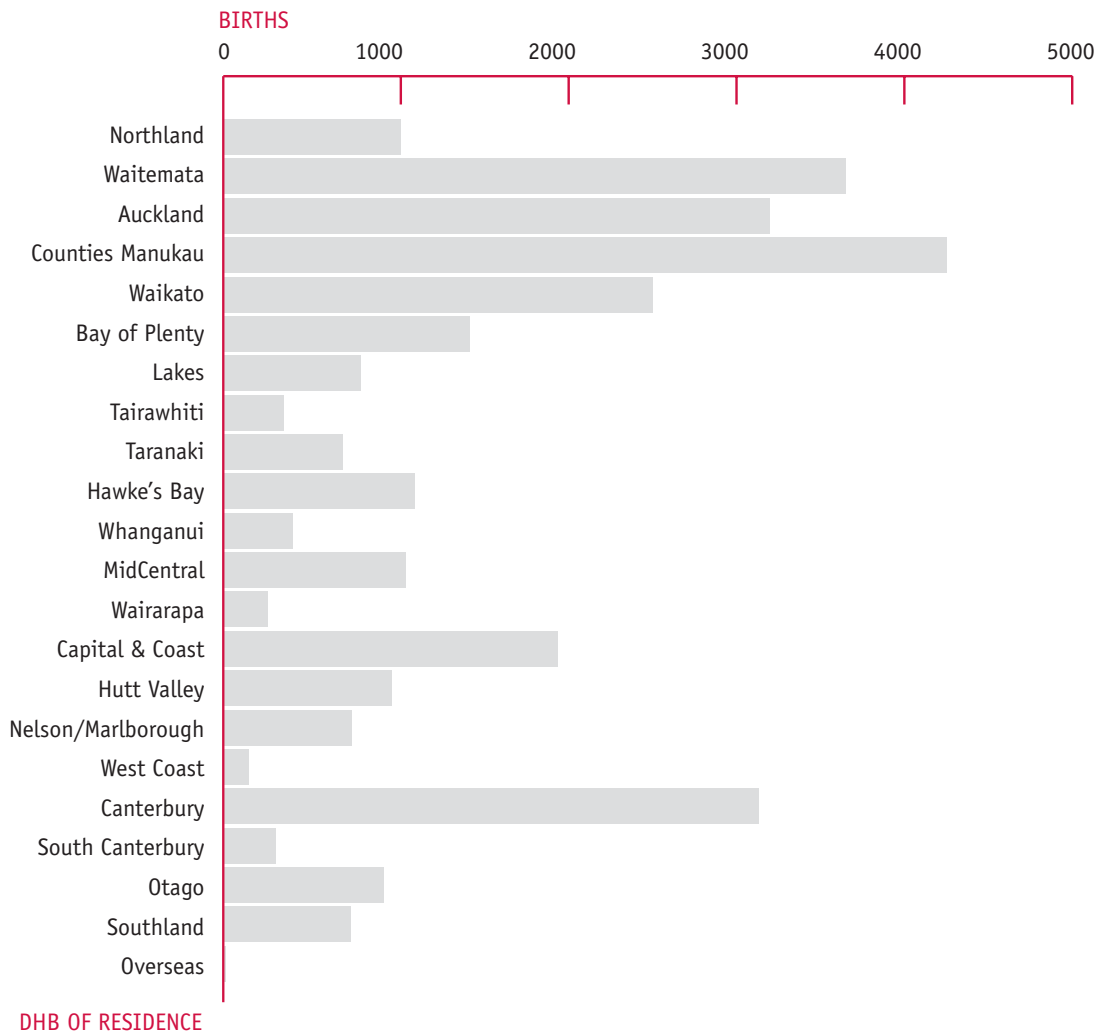
Figure 1.4 presents the distribution of ages among mothers in the second six months of 2006, while the way that mothers are distributed by DHB of residence is shown in Figure 1.5. Comprehensive data on the demographic characteristics of women giving birth in New Zealand are provided in NZHIS reports on maternity data from 2004 and 2005 (NZHIS 2007b, 2008).

Figure 1.4: Distribution of maternal age among births in New Zealand, 1 July – 31 December 2006



Note: For frequency data and proportions, see Table 1.9.

Figure 1.5: Distribution of DHB of residence among births in New Zealand, 1 July – 31 December 2006



Note: For frequency data and proportions, see Table A.B1 (Appendix B).

1.4 Perinatal and perinatal-related mortality

1.4.1 Perinatal deaths and rates

Table 1.1 summarises the number of perinatal and perinatal-related deaths and the associated mortality rates in New Zealand for the second six months of 2006. The perinatal mortality rate was 11.6 per 1000 births. This rate is compared below with others reported for New Zealand and internationally.

Table 1.1: Perinatal and perinatal-related mortality rates in New Zealand, 1 July – 31 December 2006

| | n | Rate (using NZ definition) | Rate (using UK definition) ⁷ |
|---|--------|----------------------------------|---|
| Number of births (NZHIS) | 29,967 | | |
| Number of fetal deaths (terminations and stillbirths) ¹ | 267 | 8.9 ² | |
| Number of early neonatal deaths <7 days ¹ | 81 | | |
| Number of late neonatal deaths 8-28 days ¹ | 17 | | |
| Total neonatal deaths <28 days | 98 | 3.3 ³ | |
| Perinatal deaths | 348 | 11.6 ⁴ | 7.8 |
| Perinatal-related deaths | 365 | 12.2 ⁵ | 8.3 |
| Perinatal deaths (excluding lethal and terminated fetal abnormalities) ⁶ | 237 | 7.9 ⁶ | 6.1 |
| Perinatal-related deaths (excluding lethal and terminated fetal abnormalities) ⁶ | 249 | 8.3 | 6.5 |

Notes:

- 1 There were 9 additional deaths (3 stillbirths and 6 neonatal deaths) reported after the analysis was complete which have been included in this table and in calculation of rates but which have not been included in the remainder of this report.
- 2 Fetal death rate per 1000 babies born (includes terminations and stillbirths).
- 3 Neonatal death rate per 1000 live-born babies.
- 4 Fetal deaths and early neonatal deaths per 1000 babies born.
- 5 Fetal deaths and early and late neonatal deaths per 1000 babies born.
- 6 Lethal and terminated fetal abnormalities are all fetal deaths with PSANZ-PDC of congenital abnormality and neonatal deaths with PSANZ-NDC of congenital abnormality.
- 7 Rates were calculated using UK (CEMACH) definition for perinatal mortality which is babies stillborn after 24 weeks gestation and deaths of live-born babies per 1000 live births and stillbirths (Pearson 2008).

Comparison with earlier New Zealand rates

The New Zealand perinatal mortality rate reported above (11.6 per 1000 births) is consistent with the New Zealand rate of 11.2/1000 reported for 2004 (NZHIS 2007a) but higher than the 9.8/1000 provisionally reported for 2005 (NZHIS 2008).

The higher rate reported here compared with the NZHIS provisional report for 2005 is probably not indicative of deterioration in perinatal health. It is more likely to result from an increased ascertainment of perinatal deaths using the recently introduced PMMRC methodology, which involves a network of local co-ordinators appointed by DHBs and widely supported by clinicians.

Because a new methodology for ascertainment of deaths has been instituted, time trend data for New Zealand are not presented in this report.

International comparisons

The New Zealand perinatal mortality rate (11.6/1000) is comparable with the 2005 rates of 12.7/1000 reported for the Australian state of Victoria and 10.1/1000 for Western Australia; both of these reports used the same definition as that used in New Zealand (CCOPMM 2007, Gee et al.2006).

The Confidential Enquiry into Maternal and Child Health reported a rate of 7.9/1000 for neonatal deaths and fetal deaths at or beyond 24 weeks for England, Wales and Northern Ireland in 2006 (Pearson 2008). This rate is comparable with the rate of 7.8/1000 calculated for New Zealand using the same criteria.

Fetal deaths

As indicated in Table 1.1, approximately three-quarters of all perinatal-related deaths in New Zealand were fetal deaths. Of the fetal deaths, one-third were terminations and two-thirds stillbirths.

The New Zealand fetal death rate of 8.9/1000 is higher than the rate of 7.4/1000 in 2005 from Western Australia and comparable with the 9.0/1000 in 2005 in Victoria.

Stillbirths

As shown in Table 1.2, one-quarter of stillbirths were babies born before 24 weeks, and about 30 percent were term babies (≥ 37 weeks).

Table 1.2: Gestation at birth and timing of death among stillbirths in New Zealand, 1 July – 31 December 2006

| | Stillbirths N = 186 | |
|-----------------------------|------------------------|----|
| | n | % |
| Gestation at birth | | |
| 20–23 weeks | 49 | 26 |
| 24–27 weeks | 26 | 14 |
| 28–31 weeks | 21 | 11 |
| 32–36 weeks | 32 | 17 |
| 37–40 weeks | 44 | 24 |
| 41+ weeks | 14 | 8 |
| Time of death | | |
| Antepartum | 129 | 70 |
| Intrapartum – first stage | 19 | 10 |
| Intrapartum – second stage | 8 | 4 |
| Intrapartum – unknown stage | 6 | 3 |
| Unknown | 24 | 13 |

Thirty-three (18 percent) of the stillbirths are known to have occurred during labour. Sixteen of these deaths were at 20 to 23 weeks, four from 24 to 31 weeks, one from 32 to 36 weeks, nine between 37 and 40 weeks, and three at over 40 weeks.

The intrapartum stillbirth rate (excluding perinatal mortalities < 24 weeks and lethal fetal abnormalities) was 5.4/10,000 (16/29,796). These deaths are likely to be the subject of more in-depth investigation in later reports.

Terminations

Table 1.3 shows that obstetric antecedent (PSANZ-PDC) cause of death was reported as congenital abnormality in 87 percent of terminations. The remainder were assigned as for specific perinatal conditions or maternal conditions, such as severe pre-eclampsia or fetal growth restriction.

Table 1.3: Obstetric antecedent classification and gestation at termination of pregnancy in New Zealand, 1 July – 31 December 2006

| | Termination of pregnancy N = 78 | |
|-----------------------------------|------------------------------------|----|
| | n | % |
| Obstetric antecedent cause | | |
| Congenital abnormality | 68 | 87 |
| Maternal condition | 3 | 4 |
| Specific perinatal conditions | 5 | 6 |
| Fetal growth restriction | 2 | 3 |
| Gestation at birth | | |
| 20–23 weeks | 67 | 86 |
| 24–27 weeks | 10 | 13 |
| 28–31 weeks | 1 | 1 |

Neonatal deaths

Around 80 percent of neonatal deaths in the first month of life occurred in the first week (Table 1.4). Of deaths of babies born alive after 24 weeks, 50 percent died within the first 24 hours.

The neonatal mortality rate of 3.3/1000 live births is consistent with the 2005 rates of 2.7/1000 in Western Australia, 3.7/1000 in Victoria and 3.5/1000 in South Australia (Gee et al.2006, CCOPMM 2007, MPIMSA 2007).

Table 1.4: Clinical details of neonatal deaths in New Zealand, 1 July – 31 December 2006

| | Total neonatal deaths N = 92 | | Neonatal deaths < 24 weeks N = 29 | | Neonatal deaths ≥ 24 weeks N = 63 | |
|---------------------------|---------------------------------|----|---|----|---|----|
| | n | % | n | % | n | % |
| Gestation at birth | | | | | | |
| 20–23 weeks | 29 | 32 | | | | |
| 24–27 weeks | 14 | 15 | | | | |
| 28–31 weeks | 7 | 8 | | | | |
| 32–36 weeks | 11 | 12 | | | | |
| 37–40 weeks | 26 | 28 | | | | |
| 41+ weeks | 5 | 5 | | | | |
| Age at death | | | | | | |
| ≤ 1 day | 57 | 62 | 27 | 93 | 30 | 48 |
| 2–7 days | 17 | 18 | 1 | 3 | 16 | 25 |
| 8–14 days | 6 | 7 | | | 6 | 10 |
| 15–21 days | 6 | 7 | | | 6 | 10 |
| 22–28 days | 5 | 5 | | | 5 | 8 |
| Unknown | 1 | 1 | 1 | 3 | | |
| Place of death | | | | | | |
| Home | 9 | 10 | | | 9 | 14 |
| Hospital | 80 | 87 | 28 | 97 | 52 | 83 |
| Other | 1 | 1 | | | 1 | 2 |
| Unknown | 2 | 2 | 1 | 3 | 1 | 2 |
| Apgar 5 minutes | | | | | | |
| 0–3 | 56 | 61 | 28 | 97 | 28 | 44 |
| 4–5 | 8 | 9 | | | 8 | 13 |
| 6–7 | 8 | 9 | | | 8 | 13 |
| ≥ 8 | 19 | 21 | | | 19 | 30 |
| Unknown | 1 | 1 | 1 | 3 | | |

Of the 52 babies who died in hospital from 24 weeks, 34 (65 percent) died in a neonatal unit, five in the delivery unit, two in a postnatal ward and two in an operating theatre. Five died in unspecified hospital locations. The majority of deaths of neonates under 24 weeks occurred in a delivery unit.

Of the nine babies who died at home, eight were born in hospital and the place of birth of the ninth is unknown.

Sixty-one percent of all neonatal deaths, and 44 percent of neonatal deaths of over 24 weeks gestation, were in very poor condition at birth demonstrated by an Apgar score of less than 4 at five minutes. Only 30 percent of neonatal deaths over 24 weeks had an Apgar score of 8 or greater at 5 minutes.

An attempt at resuscitation was made in 45 cases (49 percent). Of these 45, five were unable to be resuscitated, and one of these babies was under 24 weeks.

Forty infants (43 percent) were not resuscitated. Twenty-six of these babies were born at less than 24 weeks and eight died due to congenital abnormality.

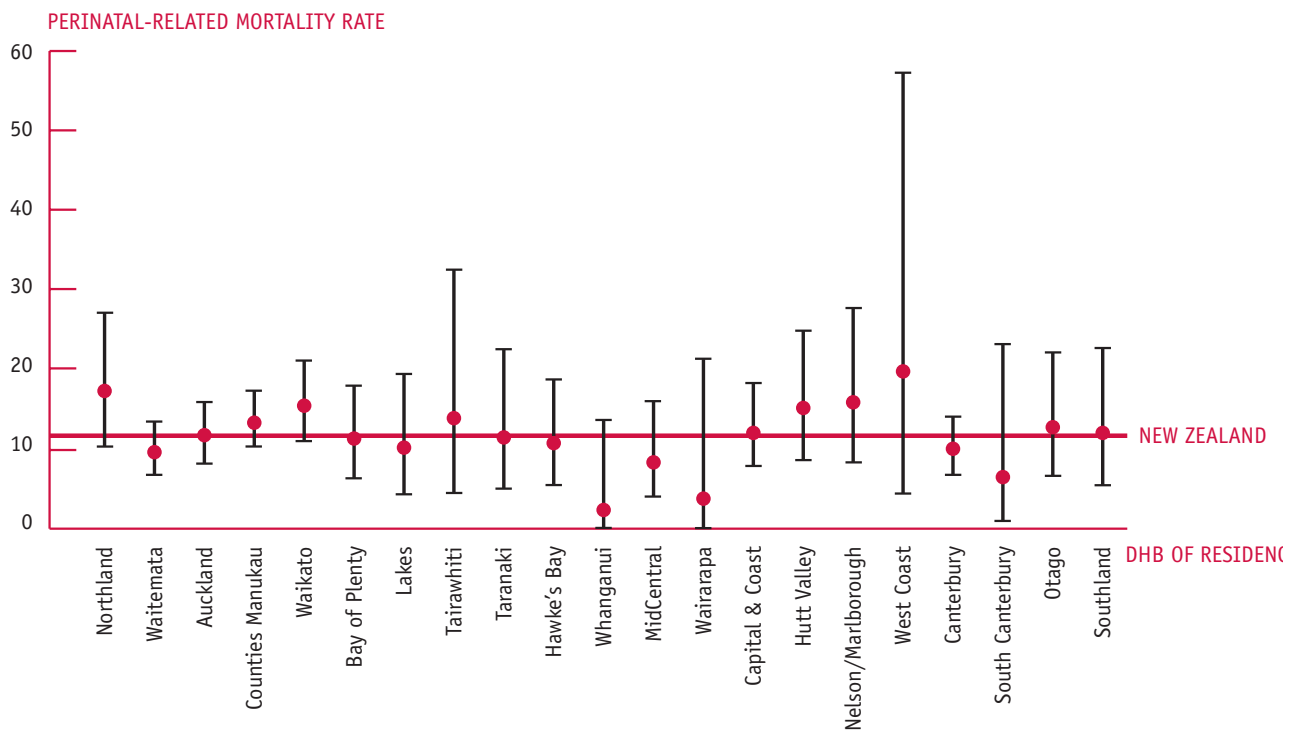
The resuscitation status of seven babies was unknown.

1.4.2 Demography of perinatal mortalities

Place of residence

Figure 1.6 demonstrates rates of perinatal-related mortality (fetal death and early and late neonatal deaths) with 95 percent confidence limits by DHB of residence. The solid line represents the national rate of perinatal-related mortality of 12.2/1000 for this six-month period. The large confidence intervals for the Tairāwhiti and West Coast rates reflect the small numbers of births at these hospitals.

Figure 1.6: Perinatal-related mortality rates by DHB of residence with 95 percent confidence limits compared with national perinatal-related mortality in New Zealand, 1 July – 31 December 2006

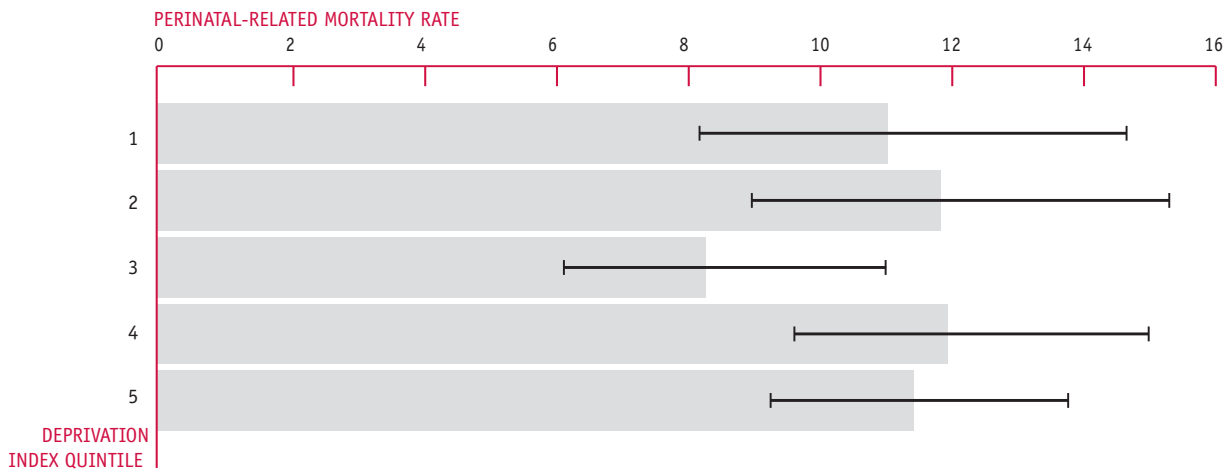


The 95 percent confidence intervals for all DHBs span the line representing the national perinatal-related mortality rate. They indicate that no DHB has a rate significantly different from the rate for the country as a whole.

Social disadvantage

Figure 1.7 shows perinatal-related mortality rate by socioeconomic deprivation quintile, with quintile 1 representing the least deprived and 5 the most deprived.

Figure 1.7: Perinatal-related mortality by socioeconomic deprivation index quintile (with 95 percent confidence limits) in New Zealand, 1 July – 31 December 2006



No clear association is seen here between socioeconomic deprivation index and perinatal-related mortality. *Fetal and Infant Deaths Report 2003 & 2004* (NZHIS 2007a) showed no clear association between deprivation quintile and perinatal mortality rates in quintiles 2 to 4 but a clear difference across 1997–2004 between quintiles 1 and 5. The lack of statistical difference in the current data may reflect the relatively small number of deaths during this six-month interval.

Gender, ethnicity, gestation and birthweight

As Table 1.5 shows, 41 percent of all fetal and neonatal deaths within the first month of life occurred among babies born before 24 weeks gestation. A quarter occurred at term. Thirty-one percent of deaths occurred in babies weighing less than 500 g at birth. Fifty-five percent occurred in babies weighing less than 1000 g, and 71 percent in babies weighing less than 2500g.

Table 1.5: Gender, ethnicity and birthweight among perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| | Fetal deaths | | | | | | | |
|---------------------------|------------------------|----|------------------------|----|---------------------------|----|--|----|
| | Terminations N = 78 | | Stillbirths N = 186 | | Neonatal deaths N = 92 | | Perinatal-related deaths N = 356 | |
| | n | % | n | % | n | % | n | % |
| Gender | | | | | | | | |
| Male | 39 | 50 | 91 | 49 | 50 | 54 | 180 | 51 |
| Female | 39 | 50 | 86 | 46 | 42 | 46 | 167 | 47 |
| Unknown | | | 9 | 5 | | | 9 | 3 |
| Ethnicity (baby) | | | | | | | | |
| New Zealand European | 43 | 55 | 77 | 41 | 34 | 37 | 154 | 43 |
| Māori | 15 | 19 | 42 | 23 | 37 | 40 | 94 | 26 |
| Pacific | 6 | 8 | 35 | 19 | 10 | 11 | 51 | 14 |
| Indian | 3 | 4 | 8 | 4 | 3 | 3 | 14 | 4 |
| Other Asian | 7 | 9 | 11 | 6 | 2 | 2 | 20 | 6 |
| Other (including unknown) | 4 | 5 | 13 | 7 | 6 | 7 | 23 | 7 |
| Gestation at birth | | | | | | | | |
| 20–23 weeks | 67 | 86 | 49 | 26 | 29 | 32 | 145 | 41 |
| 24–27 weeks | 10 | 13 | 26 | 14 | 14 | 15 | 50 | 14 |
| 28–31 weeks | 1 | 1 | 21 | 11 | 7 | 8 | 28 | 8 |
| 32–36 weeks | | | 32 | 17 | 11 | 12 | 44 | 12 |
| 37–40 weeks | | | 44 | 24 | 26 | 28 | 70 | 20 |
| 41+ weeks | | | 14 | 8 | 5 | 5 | 19 | 5 |
| Birthweight | | | | | | | | |
| < 500 g | 53 | 68 | 40 | 22 | 16 | 17 | 109 | 31 |
| 500–999 g | 20 | 26 | 45 | 24 | 20 | 22 | 85 | 24 |
| 1000–1499 g | 2 | 3 | 12 | 6 | 10 | 11 | 24 | 7 |
| 1500–1999 g | 1 | 1 | 6 | 3 | 2 | 2 | 9 | 3 |
| 2000–2499 g | | | 19 | 10 | 6 | 7 | 25 | 7 |
| 2500–2999 g | | | 19 | 10 | 5 | 5 | 24 | 7 |
| 3000–3499 g | | | 17 | 9 | 11 | 12 | 28 | 8 |
| 3500–3999 g | | | 16 | 9 | 11 | 12 | 27 | 8 |
| 4000–4499 g | | | 3 | 2 | 5 | 5 | 8 | 2 |
| ≥ 4500 g | | | 1 | 1 | 2 | 2 | 3 | 1 |
| Unknown | 2 | 3 | 8 | 4 | 4 | 4 | 14 | 4 |

Note: Baby's ethnicity has been prioritised as outlined in Ministry of Health (2004). Baby's ethnicity data have been taken from the Births, Deaths and Marriages registration of the baby's birth where available and, where they were not available from this source, from the rapid response forms (n = 61). No source of ethnicity data was available for three babies.

Table 1.6 shows there is no apparent differential in death rates by gender during this limited data collection period.

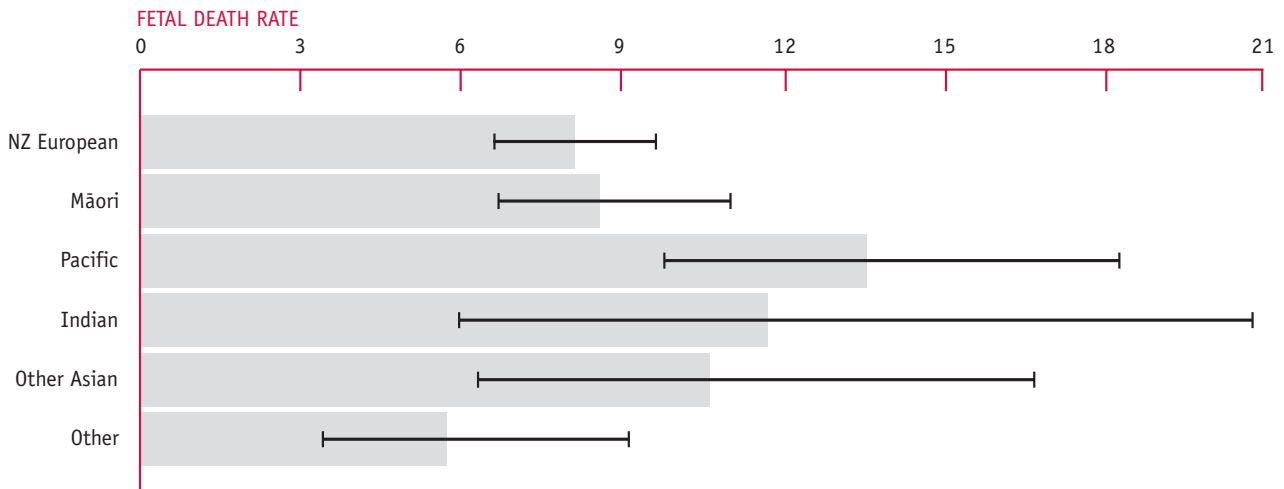
Table 1.6: Termination, stillbirth, neonatal and perinatal-related mortality by gender and ethnicity of babies in New Zealand, 1 July – 31 December 2006

| | Total births | | Fetal deaths | | | | Neonatal deaths | | Perinatal-related deaths | |
|---------------------------|--------------|------|--------------|------|-------------|------|-----------------|------|--------------------------|------|
| | | | Terminations | | Stillbirths | | | | | |
| | n | % | n | rate | n | rate | n | rate | n | rate |
| Total | 29,967 | 100 | 78 | 2.6 | 186 | 6.2 | 92 | 3.1 | 356 | 11.9 |
| Gender | | | | | | | | | | |
| Male | 15,417 | 51.4 | 39 | 2.5 | 91 | 5.9 | 50 | 3.2 | 180 | 11.7 |
| Female | 14,549 | 48.6 | 39 | 2.7 | 86 | 5.9 | 42 | 2.9 | 167 | 11.5 |
| Unknown | 1 | | | | 9 | | | | 9 | |
| Ethnicity (baby) | | | | | | | | | | |
| New Zealand European | 14,744 | 49.2 | 43 | 2.9 | 77 | 5.2 | 34 | 2.3 | 154 | 10.4 |
| Māori | 6,623 | 22.1 | 15 | 2.3 | 42 | 6.3 | 37 | 5.9 | 94 | 14.2 |
| Pacific | 3,017 | 10.1 | 6 | 2.0 | 35 | 11.6 | 10 | 3.3 | 51 | 16.9 |
| Indian | 937 | 3.1 | 3 | 3.2 | 8 | 8.5 | 3 | 3.2 | 14 | 14.9 |
| Other Asian | 1,689 | 5.6 | 7 | 4.1 | 11 | 6.5 | 2 | 1.2 | 20 | 11.8 |
| Other (including unknown) | 2,957 | 9.9 | 4 | 1.4 | 13 | 4.4 | 6 | 2.0 | 23 | 7.8 |

Note: Baby's ethnicity has been prioritised as outlined in Ministry of Health (2004). Baby's ethnicity data have been taken from the Births, Deaths and Marriages registration of the baby's birth where available and, where they were not available from this source, from the rapid response forms (n = 61). No source of ethnicity data was available for three babies.

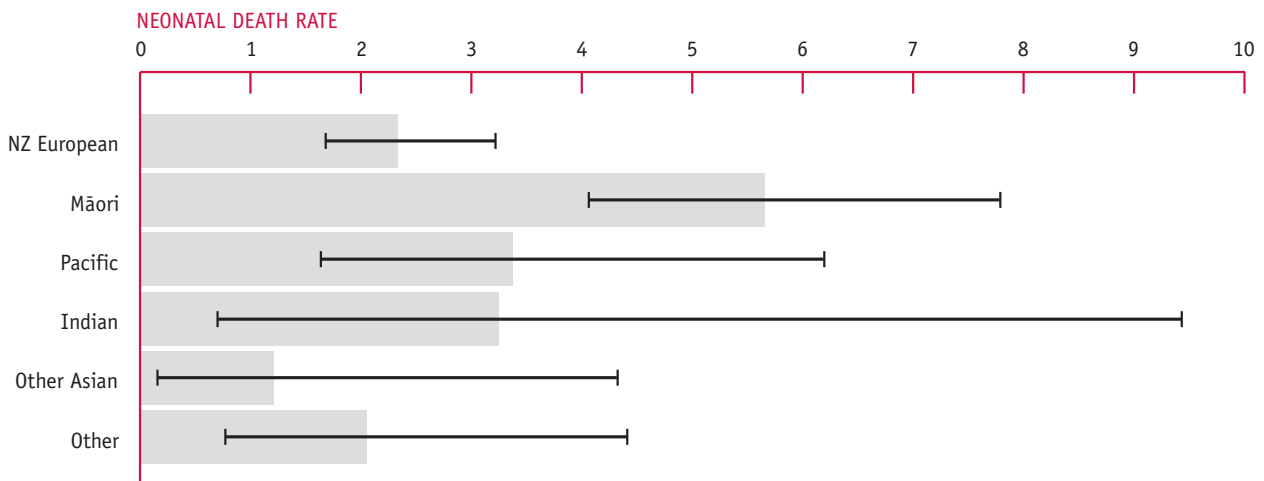
Table 1.6 also shows ethnicity-specific mortality rates where the numerator and denominator are baby ethnicity. This analysis demonstrates higher perinatal mortality among babies identified as Māori ($p = 0.02$) due to increased neonatal deaths and as Pacific peoples ($p = 0.002$) due to increased rates of stillbirths compared with New Zealand European babies. A similar trend may exist for Indian babies but the numbers involved are insufficient to explore the relationship.

Figure 1.8: Baby ethnicity-specific fetal death rates (with 95 percent confidence limits) in New Zealand, 1 July – 31 December 2006



Figures 1.8 and 1.9 show ethnicity-specific death rates in relation to the ethnicity of the baby. Death rates using mothers' ethnicity are presented in Appendix B (Table A.B2).

Figure 1.9: Baby ethnicity-specific neonatal death rates (with 95 percent confidence limits) in New Zealand, 1 July – 31 December 2006



Pacific babies are at increased risk of death during pregnancy and Māori babies are at increased risk in the neonatal period compared with New Zealand European babies. These differences will be explored in later reports in which a broader time span (and hence larger numbers) will enable more detailed analysis.

Recommendation

The Minister of Health notes that the PMMRC will undertake detailed analysis of stillbirths among Pacific women and neonatal deaths among Māori infants in its next annual report.

Table 1.7 presents estimated rates for termination, stillbirth, neonatal and perinatal-related death broken down by gestation and birthweight. The denominator data are unreliable for babies under 32 weeks and weighing less than 1500 g at birth. For this reason, the denominator column, which is first in Table 1.7, has not been populated for these early gestations. As described in Section 1.2, the lack of reliability is a result of the way in which birth and fetal death data in New Zealand are collected. Therefore reliable mortality rates cannot be calculated for these groups.

Further, due to the small numbers of deaths in this six month period, the estimations of death rate by gestation and birthweight are imprecise.

Table 1.7: Termination, stillbirth, neonatal and perinatal-related mortality by gestation and birthweight in New Zealand, 1 July – 31 December 2006

| | Total births | | Fetal deaths | | | | Neonatal deaths | | Perinatal-related deaths | |
|---------------------------|--------------|------|--------------|------|-------------|------|-----------------|------|--------------------------|------|
| | | | Terminations | | Stillbirths | | | | | |
| | n | % | n | rate | n | rate | n | rate | n | rate |
| Total | 29,967 | | 78 | 2.6 | 186 | 6.2 | 92 | 3.1 | 356 | 11.9 |
| Gestation at birth | | | | | | | | | | |
| 20–23 weeks | * | | 67 | * | 49 | * | 29 | * | 145 | * |
| 24–27 weeks | * | | 10 | * | 26 | * | 14 | * | 50 | * |
| 28–31 weeks | * | | 1 | * | 21 | * | 7 | * | 28 | * |
| 32–36 weeks | 1,780 | 5.9 | | | 32 | 18.0 | 11 | 6.3 | 44 | 24.7 |
| 37–40 weeks | 21,914 | 73.1 | | | 44 | 2.0 | 26 | 1.2 | 70 | 3.2 |
| 41+ weeks | 5,533 | 18.5 | | | 14 | 2.5 | 5 | 0.9 | 19 | 3.4 |
| Unknown | 387 | 1.3 | | | | | | | | |
| Birthweight | | | | | | | | | | |
| < 500 g | * | | 53 | * | 40 | * | 16 | * | 109 | * |
| 500–999 g | * | | 20 | * | 45 | * | 20 | * | 85 | * |
| 1000–1499 g | * | | 2 | * | 12 | * | 10 | * | 24 | * |
| 1500–1999 g | 353 | 1.2 | 1 | 2.8 | 6 | 17.0 | 2 | 5.8 | 9 | 25.5 |
| 2000–2499 g | 1,065 | 3.6 | | | 19 | 17.8 | 6 | 5.7 | 25 | 23.5 |
| 2500–2999 g | 4,089 | 13.6 | | | 19 | 4.6 | 5 | 1.2 | 24 | 5.9 |
| 3000–3499 g | 9,928 | 33.1 | | | 17 | 1.7 | 11 | 1.1 | 28 | 2.8 |
| 3500–3999 g | 9,784 | 32.6 | | | 16 | 1.6 | 11 | 1.1 | 27 | 2.8 |
| 4000–4499 g | 3,654 | 12.2 | | | 3 | 0.8 | 5 | 1.4 | 8 | 2.2 |
| ≥ 4500 g | 774 | 2.6 | | | 1 | 1.3 | 2 | 2.6 | 3 | 3.9 |
| Unknown | 2 | | 2 | | 8 | | 4 | | 14 | |

Note: * No data provided as denominator unreliable.

Multiple births

As Table 1.8 shows, there were 841 infants born in multiple pregnancies, making up 3 percent of all births over the second six months of 2006. The perinatal mortality rate is almost three times higher for multiple births compared with singleton births. The higher rate is consistent with published data.

In nine twin pregnancies, both babies died in the perinatal period.

Of the 27 twin perinatal mortalities, 16 were monochorionic diamniotic twins, who are at risk of twin-to-twin transfusion syndrome. Among these 16 infants, the cause of death was specific perinatal conditions (twin-to-twin transfusion syndrome) in 10 and spontaneous preterm birth in six.

Table 1.8: Multiple birth and perinatal-related mortality in New Zealand, 1 July – 31 December 2006

| Type of birth | Births | | Fetal deaths | | | | | | Neonatal deaths | | | Perinatal-related deaths | | |
|--------------------------|------------|------|--------------|------|------|-------------|------|------|-----------------|------|------|--------------------------|------|------|
| | N = 29,967 | | Terminations | | | Stillbirths | | | N = 91 | | | N = 355 | | |
| | n | % | n | % | rate | n | % | rate | n | % | rate | n | % | rate |
| Singleton | 29,126 | 97.2 | 76 | 97.4 | 2.6 | 172 | 92.5 | 5.9 | 80 | 87.0 | 2.9 | 328 | 92.1 | 11.3 |
| Multiple | 841 | 2.8 | 2 | 2.6 | 2.4 | 14 | 7.5 | 16.6 | 11 | 12.0 | 13.3 | 27 | 7.6 | 32.1 |
| Dichorionic diamniotic | | | | | | 2 | 14 | | 3 | 27 | | 5 | 19 | |
| Monochorionic diamniotic | | | 2 | 100 | | 7 | 50 | | 7 | 64 | | 16 | 59 | |
| Monoamniotic | | | | | | 1 | 7 | | 1 | 9 | | 2 | 7 | |
| Unknown | | | | | | 4 | 29 | | | | | 4 | 15 | |

Note: There is one unknown plurality.

Maternal age

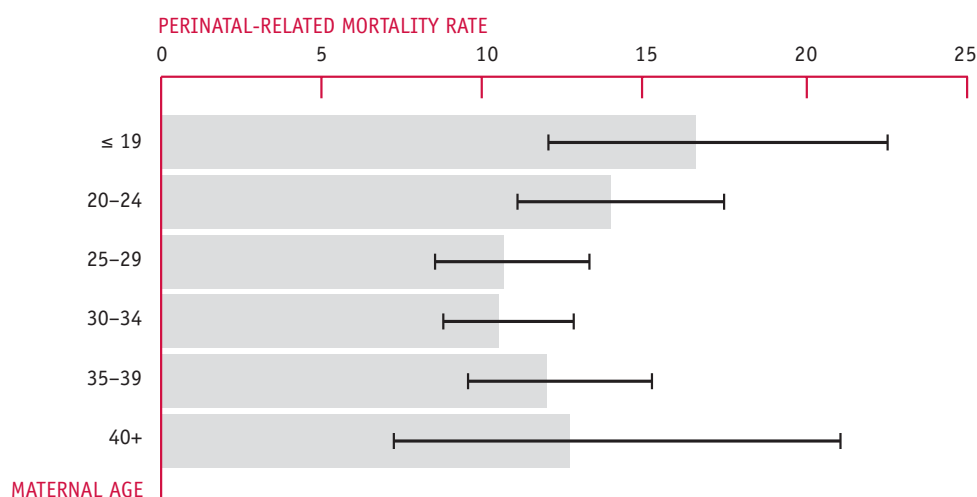
An association between maternal age and perinatal mortality has been documented previously. The report on maternity for 2004 demonstrates that perinatal mortality rate is increased among both younger (under 20 years old) and older women (40 years and over) compared with women aged 20–39 years (NZHIS 2007b). This 'U-shaped' association between maternal age and perinatal mortality is also reported in the CEMACH report on perinatal mortalities in 2006 (Pearson 2008).

Table 1.9 and Figure 1.10 present data to explore the relationship between maternal age and perinatal related mortality for the second six months of 2006. The only statistically significant association in this regard from these data was excess perinatal related mortality among mothers under 20 years old compared with mothers aged 25–34 years.

Table 1.9: Maternal age and perinatal-related mortality in New Zealand, 1 July – 31 December 2006

| Maternal age (years) | Births | | Fetal deaths | | | | | | Neonatal deaths | | | Perinatal related deaths | | |
|----------------------|---------------|--------------|--------------|--------------|------------|-------------|--------------|------------|-----------------|--------------|------------|--------------------------|--------------|-------------|
| | | | Terminations | | | Stillbirths | | | n | % | NND rate | n | % | rate |
| | n | % | n | % | TOP rate | n | % | SB rate | | | | | | |
| ≤ 19 | 2,296 | 7.7 | 3 | 3.8 | 1.3 | 18 | 9.7 | 7.8 | 17 | 18.5 | 7.5 | 38 | 10.7 | 16.6 |
| 20–24 | 5,172 | 17.3 | 12 | 15.4 | 2.3 | 42 | 22.6 | 8.1 | 18 | 19.6 | 3.5 | 72 | 20.2 | 13.9 |
| 25–29 | 7,085 | 23.6 | 22 | 28.2 | 3.1 | 33 | 17.7 | 4.7 | 20 | 21.7 | 2.8 | 75 | 21.1 | 10.6 |
| 30–34 | 8,709 | 29.1 | 24 | 30.8 | 2.8 | 49 | 26.3 | 5.6 | 18 | 19.6 | 2.1 | 91 | 25.6 | 10.4 |
| 35–39 | 5,277 | 17.6 | 14 | 17.9 | 2.7 | 37 | 19.9 | 7.0 | 12 | 13.0 | 2.3 | 63 | 17.7 | 11.9 |
| 40+ | 1,107 | 3.7 | 3 | 3.8 | 2.7 | 6 | 3.2 | 5.4 | 5 | 5.4 | 4.6 | 14 | 3.9 | 12.6 |
| Unknown | 321 | 1.1 | 0 | 0.0 | 0.0 | 1 | 0.5 | 3.1 | 2 | 2.2 | 6.3 | 3 | 0.8 | 9.3 |
| Total | 29,967 | 100.0 | 78 | 100.0 | 2.6 | 186 | 100.0 | 6.2 | 92 | 100.0 | 3.1 | 356 | 100.0 | 11.9 |

Figure 1.10: Perinatal-related mortality rate by maternal age (with 95 percent confidence limits) in New Zealand, 1 July – 31 December 2006



Eleven percent of perinatal-related deaths occurred among teen mothers, which is out of proportion to the 8 percent of mothers in this age group. More in-depth analysis is required in future reports to determine why these excess deaths occurred and whether maternity services might reduce this excess in future.

Recommendation

The Minister of Health notes that PMMRC will undertake detailed analysis of perinatal mortality among mothers under the age of 20 years in its next annual report.

Maternal smoking

Unfortunately, smoking data were not available for 20 percent of mothers who experienced a perinatal-related mortality. However, among the 283 mothers with known smoking status, the rate of smoking was 26 percent (Table 1.10). More specifically, 16 percent of mothers having a termination and 29 percent of mothers experiencing a stillbirth or neonatal death were smokers.

No national denominator data are available for smoking in pregnancy. However a rate of 6.5 percent at the end of pregnancy was reported by National Women's in 2006 (National Women's 2006).

Smoking cessation support should be offered to all pregnant smokers (Ministry of Health 2007b).

Recommendation

The Minister of Health requests the Ministry of Health to promote its pregnancy guidelines to Lead Maternity Carers for smoking cessation.

Table 1.10: Maternal smoking and perinatal-related mortality in New Zealand, 1 July – 31 December 2006

| Currently smoking | Fetal deaths | | | | | | Perinatal related deaths | |
|-------------------|--------------|----|-------------|----|-----------------|----|--------------------------|----|
| | Terminations | | Stillbirths | | Neonatal deaths | | N = 356 | |
| | N = 78 | | N = 186 | | N = 92 | | | |
| | n | % | n | % | n | % | n | % |
| Yes | 10 | 13 | 41 | 22 | 22 | 24 | 73 | 21 |
| No | 53 | 68 | 110 | 59 | 47 | 51 | 210 | 59 |
| Unknown | 15 | 19 | 35 | 19 | 23 | 25 | 73 | 21 |

1.4.3 Causes of perinatal mortality

Obstetric antecedent classification (PSANZ-PDC)

The obstetric antecedent classification is applied to fetal and neonatal deaths (see Appendix A for further detail on this classification system). Neonatal deaths are also assigned a neonatal code to provide information on the factors in the neonatal period that were associated with the death. Table 1.11 presents the range of primary obstetric antecedent causes of perinatal-related deaths. Figure 1.11 provides a visual comparison of fetal and neonatal deaths in terms of their obstetric antecedent cause.

Table 1.11 indicates that the most common primary cause of perinatal-related death, for both fetal and neonatal deaths, was congenital abnormality. This cause of death accounted for 90 fetal deaths, 23 neonatal deaths and 32 percent of all the perinatal-related deaths.

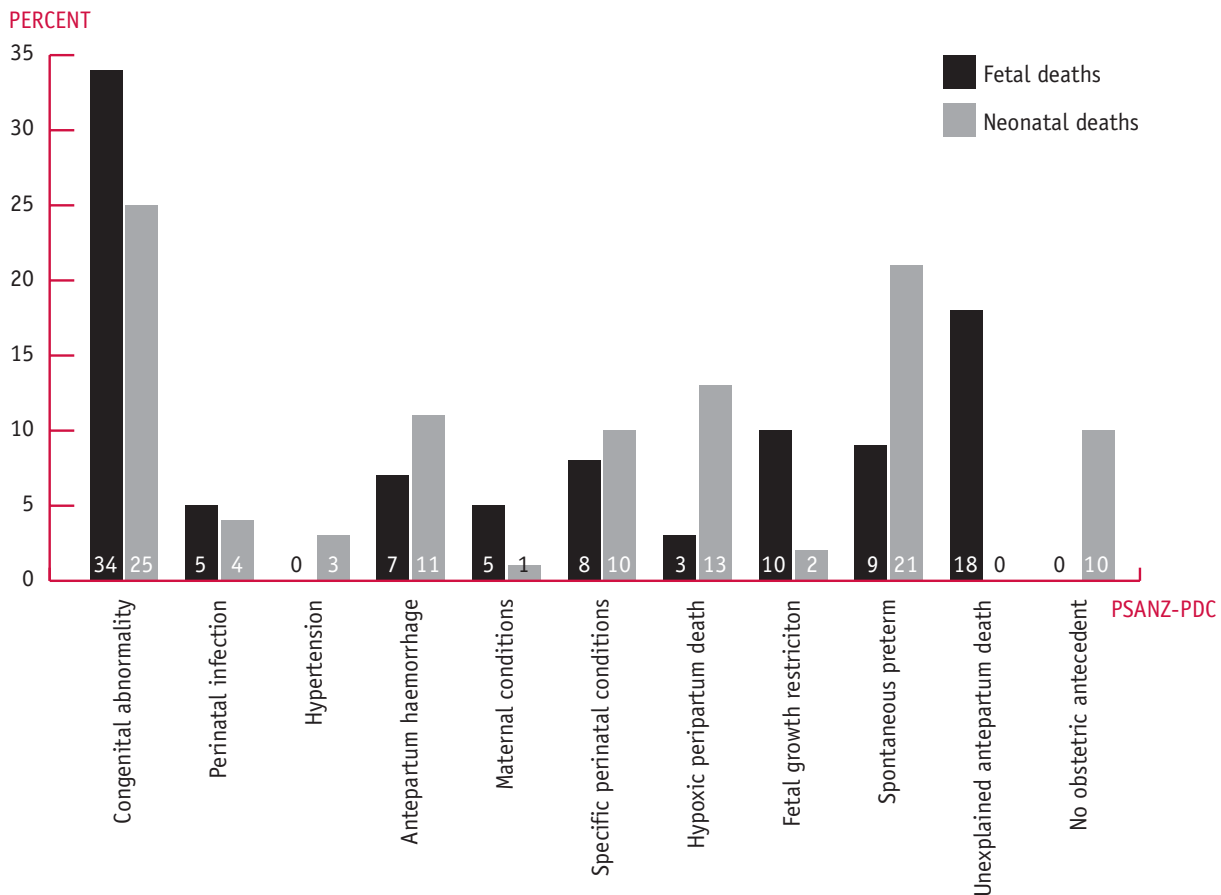
Fetal and Infant Deaths 2003 & 2004 (NZHIS 2007a) reported that congenital malformations, deformations and chromosomal abnormalities accounted for 28 percent of fetal deaths and 22 percent of infant deaths in New Zealand which is slightly lower than the 34 percent and 25 percent respectively reported here. This difference may be explained by this report's use of the PSANZ classification system, assigned by clinicians after an in-depth review of the cause of death and reported here, rather than the ICD-10 code that the hospital clinical coders applied and that formed the basis for the report in 2003 and 2004.

In the Victorian report of 2005, which used the PSANZ classification system, 17 percent of stillbirths (including terminations) and 34 percent of neonatal deaths were classified as congenital abnormality, for which the rate was 22 percent overall. The lower rate of congenital abnormality in Victoria as cause of death among fetal deaths is probably due to a higher rate of termination for maternal psychosocial reasons (CCOPMM 2007).

Table 1.11: Primary obstetric antecedent classification (PSANZ-PDC) among perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| Classification | Fetal deaths N = 264 | | Neonatal deaths N = 92 | | Perinatal related deaths N = 356 | |
|-------------------------------|-------------------------|----|---------------------------|----|-------------------------------------|----|
| | n | % | n | % | n | % |
| Congenital abnormality | 90 | 34 | 23 | 25 | 113 | 32 |
| Perinatal infection | 13 | 5 | 4 | 4 | 17 | 5 |
| Hypertension | 1 | 0 | 3 | 3 | 4 | 1 |
| Antepartum haemorrhage | 18 | 7 | 10 | 11 | 29 | 8 |
| Maternal conditions | 13 | 5 | 1 | 1 | 14 | 4 |
| Specific perinatal conditions | 20 | 8 | 9 | 10 | 30 | 8 |
| Hypoxic peripartum death | 9 | 3 | 12 | 13 | 21 | 6 |
| Fetal growth restriction | 27 | 10 | 2 | 2 | 29 | 8 |
| Spontaneous preterm | 25 | 9 | 19 | 21 | 44 | 12 |
| Unexplained antepartum death | 48 | 18 | | | 48 | 14 |
| No obstetric antecedent | | | 9 | 10 | 9 | 3 |

Figure 1.11: Relative distribution of fetal and neonatal deaths by obstetric antecedent classification (PSANZ-PDC) in New Zealand, 1 July – 31 December 2006



The second most commonly reported classification for fetal death was the category of unexplained (18 percent), which was also the second most common classification overall. There may be a genuine difficulty in determining cause of perinatal-related death, perhaps partly reflecting the low overall rate of post mortem in this report: only 33 percent of the 48 unexplained stillbirths had a post mortem.

The second most common cause of neonatal death was spontaneous preterm birth, consistent with other reports.

Ten percent of fetal deaths were classified as due to fetal growth restriction.

In a minority of cases, more than one PDC classification code was assigned. An additional code is assigned when more than one factor is thought to have contributed to the death. Around a quarter of babies were assigned an associated code and, as Table 1.12 indicates, the distribution of these associated codes was similar to the distribution of primary codes. Congenital abnormality was assigned as a primary or associated code in 32 percent of perinatal-related deaths.

Table 1.12: Primary and associated obstetric antecedent classifications (PSANZ-PDC) among perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| Classification | Primary perinatal classification | | Associated PDC classification 1 | | Associated PDC classification 2 | | Assigned PDC classifications | |
|-------------------------------|----------------------------------|------------|---------------------------------|-----------|---------------------------------|----------|------------------------------|----|
| | N = 356 | | N = 356 | | N = 356 | | N = 356 | |
| | n | % | n | % | n | % | n ¹ | % |
| Congenital abnormality | 113 | 32 | 1 | 0 | | | 114 | 32 |
| Perinatal infection | 17 | 5 | 5 | 1 | 1 | | 23 | 6 |
| Hypertension | 4 | 1 | 3 | 1 | 1 | | 8 | 2 |
| Antepartum haemorrhage | 28 | 8 | 12 | 3 | 2 | 1 | 42 | 12 |
| Maternal conditions | 14 | 4 | 12 | 3 | 4 | 1 | 30 | 8 |
| Specific perinatal conditions | 29 | 8 | 5 | 1 | 1 | | 35 | 10 |
| Hypoxic peripartum death | 21 | 6 | 4 | 1 | 2 | 1 | 27 | 8 |
| Fetal growth restriction | 29 | 8 | 22 | 6 | 3 | 1 | 54 | 15 |
| Spontaneous preterm | 44 | 12 | 21 | 6 | | | 65 | 18 |
| Unexplained antepartum death | 48 | 13 | 6 | | | | 49 | 14 |
| No obstetric antecedent | 9 | 3 | | | | | 9 | 3 |
| Total | 356 | 100 | 86 | 24 | 14 | 4 | | |

Note:

1 The percentages in this column add to more than 100 as some deaths are associated with more than one classification.

Of the 64 spontaneous preterm births, 16 had confirmed chorioamnionitis. However, in 43 perinatal-related deaths, chorioamnionitis could not be conclusively excluded.

Neonatal death classification (PSANZ-NDC)

At least one neonatal code is applied to all neonatal deaths. As with PDC codes, deaths can be coded with more than one NDC code. Table 1.13 numerates all assigned codes for neonatal deaths. Ten percent were assigned a second code.

The most commonly coded cause of neonatal death was extreme prematurity (babies born prior to viability), which was assigned to 30 infants (33 percent). Extreme prematurity was assigned as the primary code in 30 percent of neonatal deaths. The second most common code was congenital abnormality which was assigned to 23 babies (25 percent).

Seventeen percent of babies were given a neurological classification as a cause of death, which is comparable with the Victorian report (CCOPMM. 2007).

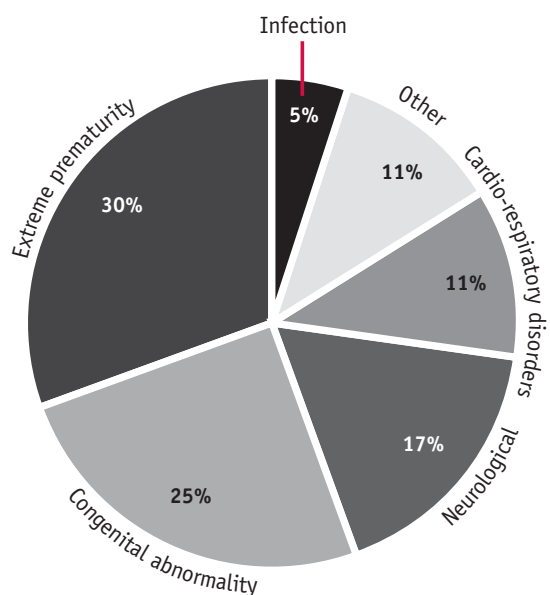
Table 1.13: Neonatal death classification (NDC) and use of associated NDC codes among neonatal deaths in New Zealand, 1 July – 31 December 2006

| Classification | Primary neonatal death classification | | Associated NDC classification 1 | | Associated NDC classification 2 | |
|------------------------------|---------------------------------------|------------|---------------------------------|-----------|---------------------------------|----------------|
| | N = 92 | | N = 92 | | N = 92 | |
| | n | % | n | % | n | % ¹ |
| Congenital abnormality | 23 | 25 | | | 23 | 25 |
| Extreme prematurity | 28 | 30 | 2 | 2 | 30 | 33 |
| Cardio-respiratory disorders | 10 | 11 | 5 | 5 | 15 | 16 |
| Infection | 5 | 5 | | | 5 | 5 |
| Neurological | 16 | 17 | | | 16 | 17 |
| Gastrointestinal | | | | | | |
| Other | 10 | 11 | 2 | 2 | 12 | 13 |
| Total | 92 | 100 | 9 | 10 | | |

Note:

1 The percentages in this column add to more than 100 as some deaths are associated with more than one classification.

Figure 1.12: Primary neonatal death classification (PSANZ-NDC) in New Zealand, 1 July – 31 December 2006



As noted in Table 1.14, neonatal deaths are assigned an obstetric antecedent cause of death and a neonatal cause. This table demonstrates how these codes may be assigned for individual babies. For instance, of the four babies assigned an antecedent cause of perinatal infection, three babies were classified as dying of extreme prematurity.

Table 1.14: Association between obstetric antecedent classification of death (PDC) and neonatal death classification (NDC) among all neonatal deaths in New Zealand, 1 July – 31 December 2006

| Perinatal death classification | Total | Neonatal death classification | | | | | | |
|--------------------------------|-----------|-------------------------------|---------------------|-----------------------------|-----------|--------------|------------------|-----------|
| | | Congenital abnormality | Extreme prematurity | Cardio-respiratory disorder | Infection | Neurological | Gastrointestinal | Other |
| Congenital abnormality | 23 | 23 | | | | | | |
| Perinatal infection | 4 | | 3 | | 1 | | | |
| Hypertension | 3 | | 1 | 2 | | | | |
| Antepartum haemorrhage | 10 | | 5 | 1 | 1 | 3 | | |
| Maternal conditions | 1 | | | | | 1 | | |
| Specific perinatal conditions | 9 | | 5 | 2 | | 1 | | 1 |
| Hypoxic peripartum death | 12 | | | 1 | | 10 | | 1 |
| Fetal growth restriction | 2 | | | | 1 | 1 | | |
| Spontaneous preterm | 19 | | 14 | 3 | 2 | | | |
| No obstetric antecedent | 9 | | | 1 | | | | 8 |
| Total | 92 | 23 | 28 | 10 | 5 | 16 | 0 | 10 |

Based on the PDC, or obstetric antecedent cause, the most common primary cause of neonatal death was congenital abnormality followed by spontaneous preterm birth and then hypoxic peripartum death. According to the neonatal classification of cause of death (NDC), however, the most common cause was extreme prematurity.

Obstetric antecedent cause of death by gestational age

Table 1.15 (along with Tables 1.16 and 1.17 that follow) provides an overview of the distribution of causes of death among fetal and neonatal deaths by gestation. However, given that the number of cases in total is small, and in each gestation group is smaller still, few conclusions can be drawn.

Forty percent of preterm fetal deaths were due to congenital abnormality. Fetal death from congenital abnormality was unusual at term. Termination for fetal abnormality is responsible for many of these preterm fetal deaths.

Of the 58 fetal deaths of term babies, 25 (43 percent) were unexplained. The next most common cause of death at term was hypoxic peripartum death.

Table 1.15: Primary obstetric antecedent classification (PDC) of fetal death by gestational age in New Zealand, 1 July – 31 December 2006

| Classification | Total | Gestational age | | | | | | | | | | | |
|-------------------------------|------------|-----------------|-----------|-------------|-----------|-------------|----------|-------------|-----------|-------------|-----------|-----------|----------|
| | | 20–23 weeks | | 24–27 weeks | | 28–31 weeks | | 32–36 weeks | | 37–40 weeks | | 41+ weeks | |
| | | n | % | n | % | n | % | n | % | n | % | n | % |
| Congenital abnormality | 90 | 61 | 68 | 11 | 12 | 8 | 9 | 3 | 3 | 7 | 8 | | |
| Perinatal infection | 13 | 3 | 23 | 4 | 31 | | | 1 | 8 | 4 | 31 | 1 | 8 |
| Hypertension | 1 | | | | | | | | | 1 | 100 | | |
| Antepartum haemorrhage | 18 | 8 | 44 | 3 | 17 | 1 | 6 | 2 | 11 | 4 | 22 | | |
| Maternal conditions | 13 | 6 | 46 | 2 | 15 | 1 | 8 | 2 | 15 | 2 | 15 | | |
| Specific perinatal conditions | 20 | 11 | 55 | 3 | 15 | 2 | 10 | 3 | 15 | 1 | 5 | | |
| Hypoxic peripartum death | 9 | | | | | | | | | 6 | 67 | 3 | 33 |
| Fetal growth restriction | 27 | 2 | 7 | 6 | 22 | 5 | 19 | 10 | 37 | 1 | 4 | 3 | 11 |
| Spontaneous preterm | 25 | 20 | 80 | 2 | 8 | 2 | 8 | 1 | 4 | | | | |
| Unexplained antepartum death | 48 | 5 | 10 | 5 | 10 | 2 | 4 | 11 | 23 | 18 | 38 | 7 | 15 |
| Total | 264 | 116 | 44 | 36 | 14 | 21 | 8 | 33 | 13 | 44 | 17 | 14 | 5 |

As Table 1.16 indicates, spontaneous preterm birth was the predominant antecedent to neonatal death among preterm infants. In almost all term neonatal deaths, on the other hand, hypoxic peripartum death or congenital abnormality was assigned as the antecedent cause of death, when one was assigned.

Table 1.16: Primary obstetric antecedent classification (PDC) of neonatal deaths by gestational age in New Zealand, 1 July – 31 December 2006

| Classification | Total | Gestational age | | | | | | | | | | | |
|-------------------------------|-----------|-----------------|-----------|-------------|-----------|-------------|----------|-------------|-----------|-------------|-----------|-----------|----------|
| | | 20–23 weeks | | 24–27 weeks | | 28–31 weeks | | 32–36 weeks | | 37–40 weeks | | 41+ weeks | |
| | | n | % | n | % | n | % | n | % | n | % | n | % |
| Congenital abnormality | 23 | 1 | 4 | 2 | 9 | 4 | 17 | 8 | 35 | 7 | 30 | 1 | 4 |
| Perinatal infection | 4 | 4 | 100 | | | | | | | | | | |
| Hypertension | 3 | 1 | 33 | 2 | 67 | | | | | | | | |
| Antepartum haemorrhage | 10 | 6 | 60 | 2 | 20 | 1 | 10 | 1 | 10 | | | | |
| Maternal conditions | 1 | | | | | | | 1 | 100 | | | | |
| Specific perinatal conditions | 9 | 5 | 56 | 1 | 11 | 1 | 11 | 1 | 11 | 1 | 11 | | |
| Hypoxic peripartum death | 12 | | | | | | | | | 10 | 83 | 2 | 17 |
| Fetal growth restriction | 2 | | | 1 | 50 | | | | | 1 | 50 | | |
| Spontaneous preterm | 19 | 12 | 63 | 6 | 32 | 1 | 5 | | | | | | |
| No Obstetric Antecedent | 9 | | | | | | | | | 7 | 78 | 2 | 22 |
| Total | 92 | 29 | 32 | 14 | 15 | 7 | 8 | 11 | 12 | 26 | 28 | 5 | 5 |

Table 1.17: Primary neonatal classification (NDC) of neonatal deaths by gestational age in New Zealand, 1 July – 31 December 2006

| Classification | Total | Gestational age | | | | | | | | | | | |
|------------------------------|-----------|-----------------|-----------|-------------|-----------|-------------|----------|-------------|-----------|-------------|-----------|-----------|----------|
| | | 20–23 weeks | | 24–27 weeks | | 28–31 weeks | | 32–36 weeks | | 37–40 weeks | | 41+ weeks | |
| | | n | % | n | % | n | % | n | % | n | % | n | % |
| Congenital abnormality | 23 | 1 | 4 | 2 | 9 | 4 | 17 | 8 | 35 | 7 | 30 | 1 | 4 |
| Extreme prematurity | 28 | 26 | 93 | 2 | 7 | | | | | | | | |
| Cardio-respiratory disorders | 10 | | | 6 | 60 | 1 | 10 | 1 | 10 | 1 | 10 | 1 | 10 |
| Infection | 5 | 2 | 40 | 3 | 60 | | | | | | | | |
| Neurological | 16 | | | 1 | 6 | 2 | 13 | 2 | 13 | 9 | 50 | 2 | 13 |
| Gastrointestinal | | | | | | | | | | | | | |
| Other | 10 | | | | | | | | | 9 | 90 | 1 | 10 |
| Total | 92 | 29 | 32 | 14 | 15 | 7 | 8 | 11 | 12 | 26 | 28 | 5 | 5 |

Sixty-three percent of neonatal deaths reported as due to neurological causes were born at term (Table 1.17). All of these were hypoxic ischaemic encephalopathy/perinatal asphyxia.

1.4.4 Maternity care

Antenatal caregiver

Table 1.18 shows how many mothers who experienced a perinatal-related death were booked with an antenatal caregiver at the time of the death. Sixteen babies (4 percent) were born to mothers who were not booked with a Lead Maternity Carer prior to the perinatal-related death. The booking status of a further 34 mothers was unknown.

Table 1.18: Booking status of mothers of perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| Was the mother booked with a Lead Maternity Carer? | Fetal deaths | | | | | | | |
|--|--------------|----|-------------|----|-----------------|----|--------------------------|----|
| | Terminations | | Stillbirths | | Neonatal deaths | | Perinatal-related deaths | |
| | N = 78 | | N = 186 | | N = 92 | | N = 356 | |
| | n | % | n | % | n | % | n | % |
| Yes | 67 | 86 | 158 | 85 | 81 | 88 | 306 | 86 |
| No | 4 | 5 | 7 | 4 | 5 | 5 | 16 | 4 |
| Missing | 7 | 9 | 21 | 11 | 6 | 7 | 34 | 10 |

Tables 1.19 and 1.20 provide data on provision of care for women whose babies died. They identify the type of Lead Maternity Carer at booking and again at time of birth.

Table 1.19: Type of Lead Maternity Carer at booking and at birth by type of perinatal-related death in New Zealand, 1 July – 31 December 2006

| Lead Maternity Carer (LMC) | Fetal deaths | | | | | | | | | | | | Perinatal-related deaths | | | |
|--|------------------------|----|-------|----|------------------------|----|-------|----|---------------------------|----|-------|----|-------------------------------------|----|-------|----|
| | Terminations N = 78 | | | | Stillbirths N = 186 | | | | Neonatal deaths N = 92 | | | | Perinatal-related deaths N = 356 | | | |
| | Booking | | Birth | | Booking | | Birth | | Booking | | Birth | | Booking | | Birth | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Self-employed midwife | 45 | 58 | 13 | 17 | 95 | 51 | 67 | 36 | 54 | 59 | 27 | 29 | 194 | 54 | 107 | 30 |
| Hospital clinic/ midwife/ Obstetrician | 14 | 18 | 47 | 60 | 49 | 26 | 73 | 39 | 22 | 24 | 47 | 51 | 85 | 24 | 167 | 47 |
| General practitioner | 1 | 1 | 1 | 1 | 3 | 2 | 1 | 1 | | | 0 | 0 | 4 | 1 | 2 | 1 |
| Private obstetrician | 4 | 5 | 2 | 3 | 9 | 5 | 7 | 4 | 1 | 1 | 3 | 3 | 14 | 4 | 12 | 3 |
| Unbooked | 4 | 5 | 4 | 5 | 7 | 4 | 7 | 4 | 5 | 5 | 5 | 5 | 16 | 4 | 16 | 4 |
| Not stated if booked | 7 | 9 | 7 | 9 | 21 | 11 | 21 | 11 | 6 | 7 | 6 | 7 | 34 | 10 | 34 | 10 |
| Booked but LMC not stated | 3 | 4 | 4 | 5 | 2 | 1 | 10 | 5 | 4 | 4 | 4 | 4 | 9 | 3 | 18 | 5 |

Between 1 July 2006 and 31 December 2006 approximately 29,000 mothers registered with an LMC. Midwives (both self-employed and hospital-based) made up 88% of these registrations, obstetricians 8%, general practitioners just over 3%; and for a small number of women, the LMC occupation was not recorded.

Table 1.20: Type of Lead Maternity Carer at booking and at birth in New Zealand, 1 July – 31 December 2006

| Lead Maternity Carer at booking | Lead Maternity Carer (LMC) at birth | | | | | | | | | | |
|--|-------------------------------------|----------------------------------|----|---|----|-------------------------------|----|--------------------------------|----|--|----|
| | Total N = 306 | Self-employed midwife N = 107 | | Hospital clinic/ midwife/ obstetrician N = 167 | | General practitioner N = 2 | | Private obstetrician N = 12 | | Booked but LMC not stated at birth N = 18 | |
| | | n | % | n | % | n | % | n | % | n | % |
| Self-employed midwife | 194 | 105 | 54 | 76 | 39 | | | 4 | 2 | 9 | 5 |
| Hospital clinic/ midwife/obstetrician | 85 | 1 | 1 | 80 | 94 | | | | | 4 | 5 |
| General practitioner | 4 | 1 | 25 | 1 | 25 | 2 | 50 | | | | |
| Private obstetrician | 14 | | | 6 | 43 | | | 8 | 57 | | |
| Booked but LMC not stated at booking | 9 | | | 4 | 44 | | | | | 5 | 56 |

Note: This table excludes unbooked mothers.

It is apparent that some women changed their Lead Maternity Carer from booking to birth, and that these transfers of care resulted in fewer women under the care of independent midwives and more under hospital care by birth. This change probably reflects recognition of risk and appropriate use of hospital services.

Antenatal visits

For 38 percent of women, no data are available on the gestation at their first visit to their Lead Maternity Carer.

Of mothers whose babies were stillborn or died in the neonatal period and for whom data were provided, 53 percent are known to have had their first antenatal visit before 13 weeks gestation and 83 percent are known to have been for their first antenatal visit prior to 20 weeks.

The most recent report from CEMACH recommended that all pregnant women book with an antenatal caregiver before 12 weeks (Pearson 2008).

Screening for diabetes

Table 1.21 presents the numbers screened for diabetes among those women who experienced a perinatal-related death at or beyond 28 weeks gestation.

Table 1.21: Screening for diabetes among booked women where perinatal-related death occurred at or beyond 28 weeks gestation in New Zealand, 1 July – 31 December 2006

| Screened for diabetes | N = 140 | |
|-----------------------|---------|----|
| | n | % |
| Yes | 73 | 52 |
| No | 34 | 24 |
| Unknown | 33 | 24 |

Note: This table excludes 10 women with pre-existing diabetes for whom screening was unnecessary.

Of the 73 women screened who gave birth at or beyond 28 weeks, 2 (3 percent) were found to have gestational diabetes.

The Ministry of Health recommends that screening for diabetes is undertaken between 24 and 28 weeks gestation (Ministry of Health 2007a). The low rate of screening among mothers who experience perinatal-related death may be a reflection of the amount of antenatal care available to these mothers. It may also reflect a failure by caregivers to follow the Ministry of Health recommendations.

Family violence screening

At least 42 percent of mothers whose babies died in the perinatal period were not screened for family violence. A further 18 percent may have been unscreened as no data on their screening status were available.

Of the six women who were identified through screening as exposed to family violence, only two were known to have been referred to the relevant support agencies.

Although these figures are disappointing, there are no national data on screening or referral rates with which to compare them. National recommendations for family violence interventions were published in 2002 (Ministry of Health 2002).

Recommendation

The Minister of Health requests the Ministry of Health to promote its pregnancy guidelines to Lead Maternity Carers for diabetes screening and family violence screening.

1.4.5 Clinical characteristics of pregnancy

Vaginal bleeding

Bleeding in pregnancy was common among women whose babies died perinatally. As Table 1.22 indicates, it is reported to have occurred in at least 23 percent of these pregnancies. Among women who had bleeding, it occurred before 20 weeks in at least half and beyond 20 weeks in at least three-quarters of cases.

Table 1.22: Vaginal bleeding during pregnancy among perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| Vaginal bleeding | Fetal deaths | | | | | | Perinatal-related death | |
|------------------|--------------|----|-------------|----|-----------------|----|-------------------------|----|
| | Terminations | | Stillbirths | | Neonatal deaths | | death | |
| | N = 78 | | N = 186 | | N = 92 | | N = 356 | |
| | n | % | n | % | n | % | n | % |
| Yes | 5 | 6 | 43 | 23 | 33 | 36 | 81 | 23 |
| No | 57 | 73 | 107 | 58 | 43 | 47 | 207 | 58 |
| Unknown | 16 | 21 | 36 | 19 | 16 | 17 | 68 | 19 |

The most commonly reported cause of bleeding at or beyond 20 weeks was abruption, which was reported in 18 women.

Recommendation

The Minister of Health requests the Ministry of Health to inform Lead Maternity Carers that PMMRC has indicated that bleeding during pregnancy, regardless of the apparent cause, is a risk factor for perinatal-related death. Therefore women with bleeding during pregnancy should be closely monitored for fetal growth restriction and preterm labour.

Antenatal corticosteroids

Antenatal corticosteroids are given to women at risk of preterm birth before 34 weeks to accelerate the maturation of the baby's alveoli and improve lung function after birth. A complete course of steroids is two doses, 24 hours apart.

Corticosteroids were given to 14 mothers among the 21 neonatal deaths (67 percent) delivered between 24 and 32 weeks. A further eight infants born at less than 24 weeks were given antenatal steroids. These babies might have been given antenatal steroids because gestation was unknown or because active management was planned for a baby of 23 weeks.

Antenatal identification of small for gestational age infants

Table 1.23 shows that growth restriction (defined as birthweight less than the 10th customised centile) was present in 94 of 186 stillbirths (51 percent) and 37 of 92 neonatal deaths (40 percent). These rates are consistent with previous publications, which have shown high rates of small for gestational age measured by customised centile in fetal deaths as well as in neonatal deaths (McCowan et al 2007; Battin et al 2007).

Of small for gestational age stillbirths and neonatal deaths, growth restriction was suspected antenatally in only a quarter of cases.

Strategies that increase antenatal detection of the small, vulnerable baby should be recommended. Customised antenatal growth charts (which graph fundal height according to gestation) have been found to double antenatal detection of small for gestational age babies before birth and are recommended by the Royal College of Obstetricians and Gynaecologists for use in routine clinical practice. The centile calculator software can be downloaded free from the Gestation Network (www.gestation.net) and it incorporates data from New Zealand births.

In all but 2 of the 35 cases where growth restriction was suspected antenatally (95 percent), an ultrasound scan was performed.

Recommendation

The Minister of Health requests the Ministry of Health to request Lead Maternity Carers to measure height and weight at the first antenatal visit and to use a customised growth chart to record fundal height to improve recognition of infants who are small for gestational age.

Table 1.23: Antenatal diagnosis of small for gestational age (SGA) among stillbirths and neonatal deaths in New Zealand, 1 July – 31 December 2006

| Type of death | Total | Suspected growth restriction | | | | | | | | | |
|---------------------|-------|------------------------------|----|---------------------------|----|-------------------------------|---|---------------------------|---|---------|----|
| | | No | | Yes and confirmed by scan | | Yes but normal growth on scan | | Yes but no scan performed | | Unknown | |
| | | n | % | n | % | n | % | n | % | n | % |
| SGA stillbirths | 94 | 44 | 47 | 21 | 22 | 2 | 2 | 1 | 1 | 26 | 28 |
| SGA neonatal deaths | 37 | 16 | 43 | 9 | 24 | 1 | 3 | 1 | 3 | 10 | 27 |

Note: SGA is defined as less than the 10th customised centile.

Place of birth and antenatal transfer

Table 1.24 analyses perinatal mortality in terms of any differences between intended and actual place of birth. Actual place of birth differed from intended place of birth for 62 babies (17 percent) (17 terminations, 28 stillbirths and 17 neonatal deaths). Timing of transfer was unknown in 9 cases (15 percent). Where the timing of the transfer was known, it occurred prior to labour in three-quarters of the cases.

Perinatal-related death of babies born at home

Of the 11 deaths of babies born at home, only four were planned home births. An accurate count of homebirths is required to make a conclusive statement about mortality risk in this group. Of the unplanned home births, four intended to birth at a level 2 or 3 hospital, and three were unbooked.

Table 1.24: Place of birth and antenatal transfer among perinatal-related deaths in New Zealand, 1 July – 31 December 2006

| | Fetal deaths | | | | | | Perinatal-related deaths | |
|--------------------------------|--------------|----|-------------|----|-----------------|----|--------------------------|----|
| | Terminations | | Stillbirths | | Neonatal deaths | | N = 356 | |
| | N = 78 | | N = 186 | | N = 92 | | | |
| | n | % | n | % | n | % | n | % |
| Intended place of birth | | | | | | | | |
| Home | 1 | 1 | 4 | 2 | 4 | 4 | 9 | 3 |
| Birthing unit | 2 | 3 | 12 | 6 | 5 | 5 | 19 | 5 |
| Hospital level 1 | 1 | 1 | 10 | 5 | 2 | 2 | 13 | 4 |
| Hospital level 2 | 18 | 23 | 55 | 30 | 35 | 38 | 108 | 30 |
| Hospital level 3 | 43 | 55 | 72 | 39 | 32 | 35 | 147 | 41 |
| Unknown | 13 | 17 | 33 | 18 | 14 | 15 | 60 | 17 |
| Actual place of birth | | | | | | | | |
| Home | | | 7 | 4 | 4 | 4 | 11 | 3 |
| Birthing unit | | | 1 | 1 | 1 | 1 | 2 | 1 |
| Hospital level 1 | | | 4 | 2 | 2 | 2 | 6 | 2 |
| Hospital level 2 | 9 | 12 | 69 | 37 | 33 | 36 | 111 | 31 |
| Hospital level 3 | 69 | 88 | 101 | 54 | 50 | 54 | 220 | 62 |
| Unknown | | | 4 | 2 | 2 | 2 | 6 | 2 |

Maternal outcome

Table 1.25: Maternal outcome associated with perinatal-related death in New Zealand, 1 July – 31 December 2006

| Maternal outcome | Fetal deaths | | | | | | Perinatal-related deaths | |
|----------------------------------|--------------|----|-------------|----|-----------------|----|--------------------------|----|
| | Terminations | | Stillbirths | | Neonatal deaths | | deaths | |
| | N = 78 | | N = 186 | | N = 92 | | N = 356 | |
| | n | % | n | % | n | % | n | % |
| Alive without serious morbidity | 77 | 99 | 181 | 97 | 91 | 99 | 348 | 98 |
| Alive but with serious morbidity | 1 | 1 | 2 | 1 | 1 | 1 | 4 | 1 |
| Death | | | 3 | 2 | | | 3 | 1 |

Four women with a perinatal-related death themselves experienced serious morbidity following delivery, as reported in Table 1.25. Their outcomes included spontaneous cerebrovascular haemorrhage, placenta percreta (followed by hysterectomy) and pulmonary embolism.

There were three maternal deaths resulting in associated perinatal-related mortality. These are reported in more detail in Section 2.

1.5 Investigation of perinatal-related death

Table 1.26 reports on the level of completeness of investigations that were undertaken. An optimal investigation was known to have been completed in only 36 percent of perinatal related deaths.

Recommendation

The Minister of Health requests the Ministry of Health to request that all families who experience a fetal or neonatal death be offered a post mortem examination for their infant, especially if a clear cause of death has not been established. Ideally the post mortem examination should be provided by a perinatal pathologist.

Table 1.26: Completeness of perinatal investigations following perinatal-related death in New Zealand, 1 July – 31 December 2006

| Level of completeness of investigation | Fetal deaths | | | | Neonatal deaths | | Perinatal-related deaths | |
|--|--------------|----|-------------|----|-----------------|----|--------------------------|----|
| | Terminations | | Stillbirths | | N = 92 | | N = 356 | |
| | N = 78 | | N = 186 | | n | % | n | % |
| Optimum investigation ¹ | 32 | 41 | 65 | 35 | 32 | 35 | 129 | 36 |
| Partial investigations only ² | 11 | 14 | 41 | 22 | 18 | 20 | 70 | 20 |
| No investigations ³ | 20 | 26 | 29 | 16 | 27 | 29 | 76 | 21 |
| Unknown | 15 | 19 | 51 | 27 | 15 | 16 | 81 | 23 |

Notes:

¹ Optimal investigation or post mortem was defined as karyotype or full post mortem completed.

² No post mortem; investigations may include placental pathology, MRI, ultrasound scan, X-ray.

³ No post mortem or placental pathology, MRI, ultrasound scan or X-ray was undertaken.

2 Maternal Mortality (1 January – 31 December 2006)

2.1 Introduction

The Terms of Reference of the Perinatal and Maternal Mortality Review Committee (PMMRC) require the committee to review 'direct' maternal deaths. In addition, in discussion with the Ministry of Health, it has decided to review the 'indirect' deaths, in particular, but not necessarily confined to, those related to surgery, psychiatric illness and family violence. A Maternal Mortality Review Working Group (MMRWG) has been established to develop a process for the national collection of data relating to maternal deaths. The MMRWG reports to the PMMRC. The aim of the MMRWG is to review maternal deaths and to identify preventable causes of maternal mortality with the expectation that this will lead to improvements in care by shared learning about these relatively rare occurrences.

The MMRWG is chaired by Claire McLintock (obstetric physician) and includes three members of the PMMRC: Cindy Farquhar (PMMRC Chair), Mollie Wilson and Jacqueline Anderson. Other working group members are Alastair Haslam (obstetrician and gynaecologist), Jeanette McFarlane (pathologist), Alison Eddy (midwife), John Walker (anaesthetist) and Cathy Hapgood (psychiatrist). The MMRWG is supported by Vicki Masson (PMMRC National Co-ordinator). It held its first meeting on 6 October 2006, and held three further meetings in 2007.

A predecessor of the working group, the Maternal Mortality Review Committee, ceased to function in 1995. Since 2000 the New Zealand Health Information Service (NZHIS, now Information Directorate within the Ministry of Health) has reported on the number of maternal deaths but these figures have not been analysed; nor has any in-depth review of cases been reported. The total number of deaths reported by the NZHIS since 1993 are presented in Table 2.1.

Table 2.1 : Annual maternal mortality ratio in New Zealand, 1993–2006 (NZHIS data)

| | 1993 | 1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 |
|---------------------------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| No. of Maternal Deaths | 10 | 4 | 2 | 4 | 3 | 4 | 4 | 5 | 3 | 8 | 4 | 4 | 5 | 6 |
| Total no. maternities | 59232 | 57771 | 58121 | 57696 | 58024 | 55694 | 57481 | 57974 | 56186 | 54411 | 56527 | 58578 | 58245 | 59721 |
| Maternal mortality ratio ¹ | 16.9 | 6.9 | 3.4 | 6.9 | 5.2 | 7.2 | 7.0 | 8.6 | 5.3 | 14.7 | 7.1 | 6.8 | 8.6 | 10.0 |

1 MMR is maternal deaths per 100,000 maternities

1993 was the last year that the Maternal Mortality Review Committee of the MOH reported maternal deaths and in 1995 this committee was disbanded amidst concerns regarding a lack of legal protection for those clinicians involved in the care of the women who died. The disbandment of this review process may explain the decrease in numbers of maternal deaths reported from 1994 until 2006 when the new PMMRC committee was formed. This data was provided by NZHIS.

Definitions

Several international definitions of maternal death were considered. The World Health Organization (WHO) definition from the International Classification of Diseases (10th edition) is as follows:

Maternal related 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.

It was decided to adopt the following definition used in the Confidential Enquiry into Maternal and Child Health (CEMACH) of the United Kingdom to describe the maternal deaths.

- **Direct maternal deaths:** those resulting from obstetric complications of the pregnant state (pregnancy, labour or puerperium), from interventions, omissions, incorrect treatment, or from a chain of events resulting from the above.
- **Indirect maternal deaths:** those resulting from previous existing disease or disease that developed during pregnancy and was not due to direct obstetric causes, but which was aggravated by the physiologic effects of pregnancy.
- **Coincidental:** deaths from unrelated causes which happen to occur in pregnancy or the puerperium.

This definition excludes maternal deaths occurring between 42 days and one year of the birth. It is known that some maternal deaths occur in this late period; the working group may in time consider those deaths although the identification of these deaths may be difficult.

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

2.2 Methodology

From the beginning of 2006, PMMRC local co-ordinators were requested to notify all maternal deaths to the National Co-ordinator of the PMMRC. Deaths were also brought to the working group's attention by the coroner or when reported in the media. Following notification of a maternal death, the National Co-ordinator issued maternal death reporting forms to the local co-ordinator concerned. That local co-ordinator was then responsible for gathering the relevant clinical information from clinical staff involved with the woman's care.

Each completed reporting form, along with relevant clinical information, was reviewed by a designated member of the MMRWG, who presented a summary of the case and findings to the working group. Each case was then discussed in detail by all MMRWG members and a summary of the case findings and recommendations was sent to the Minister of Health.

The maternal mortality ratio was calculated per 100,000 maternities. Maternities were defined as all live births and fetal deaths at 20 weeks or beyond, or weighing 400 g or more if gestation was unknown.

The cause of each death was classified using the CEMACH classification system (Lewis 2007).

For each death, potentially avoidable features were noted. It was considered that there were no avoidable features if no aspects of care were identified that would have changed the clinical outcome. If potentially avoidable features were considered present, then these were classified as either:

- major features where there were aspects of care that would have been likely to affect the outcome if they had been appropriately recognised and acted on
- minor features where there were aspects of care that were less than ideal but considered unlikely to have affected the outcome.

Potentially avoidable features considered included systems level issues (eg, funding, management, organisation, staffing levels), clinical factors (eg, competency, training, judgement), environmental factors (eg, inadequate facilities, distance) and issues relating to the woman and her family (eg, unbooked pregnancies, language barriers, social isolation).

2.3 Findings

Fourteen maternal deaths were reported in 2006 (see Table 2.2). Six of these deaths were direct maternal deaths: three due to amniotic fluid embolism, one due to postpartum haemorrhage and two as a result of maternal sepsis. One coincidental death was not included in this report.

In 2006 there were 59,643 maternities, comprising 59,193 live births (Statistics New Zealand) and an estimated 450 fetal deaths. The total maternal mortality ratio (ie, including both direct and indirect maternal deaths) was 23.5 per 100,000 maternities (95 percent confidence interval 12.8, 39.4). The direct ratio of maternal deaths was 10.1 per 100,000 maternities (95 percent confidence interval 3.7, 21.9) and the indirect ratio (which includes one unclassifiable death) was 13.4 per 100,000 maternities (95 percent confidence interval 5.8, 26.4). The wide confidence intervals indicate that the precision of the ratio estimates is poor.

Tables 2.3–2.5 provide other details on the circumstances of the maternal deaths – specifically, the timing of death, the place of birth and the place of death.

Table 2.2: Causes of maternal death in New Zealand, 2006

| Cause of death | Number of deaths |
|---------------------------------|------------------|
| Direct maternal deaths | |
| Amniotic fluid embolism | 3 |
| Postpartum haemorrhage | 1 |
| Sepsis | 2 |
| Indirect maternal deaths | |
| Suicide | 4 |
| Intracranial haemorrhage | 1 |
| Pre-existing medical condition | 2 |
| Unclassifiable | 1 |

Table 2.3: Time of maternal death in New Zealand, 2006

| Time of death | Number of deaths |
|---------------------------|------------------|
| Antenatal | |
| 20–30 weeks gestation | 5 |
| 30–40 weeks gestation | 0 |
| Postnatal | |
| 24 hours after delivery | 4 |
| 1–14 days after delivery | 2 |
| 15–42 days after delivery | 3 |

Table 2.4: Place of birth associated with maternal death in New Zealand, 2006

| Place of birth | Number of deaths |
|----------------|------------------|
| Not delivered | 5 |
| Hospital | 8 |
| Community | 1 |

Table 2.5: Place of maternal death in New Zealand, 2006

| Place of death | Number of deaths |
|----------------|------------------|
| Community | 7 |
| Hospital | 7 |

Coronial referral and investigation

Of the 14 maternal deaths, 12 were discussed with the coroner and 11 were investigated. Since 1 July 2007 it has been a legal requirement to report all maternal deaths to the coroner.

Avoidable features

The following major potentially avoidable features were noted in three cases.

- Communication between clinicians of different District Health Boards (DHBs) was incomplete or ineffective, especially at the time of transfer of care, which delayed the notification of a woman with identified risk factors.
- Multiple clinical records for the same patient within the same DHB were not integrated. As a result, clinicians (in both primary and secondary care) lacked access to all the available information.
- Uncertain lines of clinical responsibility led to difficulty identifying the person with overall responsibility for care and task completion.
- The response to massive obstetric haemorrhage was inadequate, with delayed commencement of transfusion of blood and blood products.

2.4 Discussion

This is the first report of maternal deaths in New Zealand since the establishment of the PMMRC. Data provided by the NZHIS include half the number of maternal deaths reported by the PMMRC for 2006 (see Table 2.1). The data for the years 1993–2006 are likely to be an underestimate as they are derived from death certificate documentation.

The reported United Kingdom maternal mortality rate for 2003–2005 was 13.9 deaths per 100,000 maternities (Lewis 2007). The author of that CEMACH report points out that if it relied on data from death certificates alone, the UK maternal death rate would be only 7 per 100,000.

In Australia for the years 2003–2005, the maternal mortality ratio, based on direct and indirect deaths, was 8.4 deaths per 100,000 women who gave birth (Sullivan et al 2007). It appears from the commentary in the Australian report that this rate should be compared with the lower rates from New Zealand and the United Kingdom death certificate data due to inadequate ascertainment processes in Australia.

It would be premature to draw conclusions from one year of data. In future, it is planned to report maternal mortality in each annual report of the PMMRC. In addition, every three years a larger report will be prepared with cumulative data (as is the practice in the UK and Australia) which will allow for more detailed statistical analysis.

Recommendations

The Maternal Mortality Review Working Group of the PMMRC recommends that the following actions be undertaken with a view to reducing maternal deaths.

1. The Minister of Health continues to support national reporting of maternal deaths. Each death has the potential to highlight where improvements in clinical care and social services are needed and where more resources are required.
2. The Minister of Health requests each DHB carry out a review on all maternal deaths under the auspices of the DHB perinatal and maternal mortality review groups.
3. The Minister of Health notes complete case ascertainment is essential to ensure maternal mortality statistics are accurate.
4. All maternal deaths should be referred to a coroner (a legal requirement that has been in place since 1 July 2007).
5. The New Zealand medical death certificate should be modified to include a tick box to indicate if a woman has been pregnant within one year of the death.
6. The Minister of Health requests the Ministry of Health to identify women at risk due to poor maternal mental health, and improved access to maternal mental health services is required across all DHBs. Women at risk must have a clear management plan and in particular a crisis management plan.
7. The Minister of Health encourages improved communication between primary and secondary services. A variety of means should be used such as woman-held maternity notes, integrated notes systems and electronic transfer of information.
8. The Minister of Health notes that the PMMRC will have hosted national conference on maternal mental health in 2008 to raise awareness of the risks of maternal mental health problems and determine methods to improve access to care.
9. The Minister of Health recommends that all staff involved in care of pregnant women should undertake regular training in management of obstetric emergencies.
10. The Ministry of Health recommends that each acute obstetric unit develops a massive transfusion protocol to respond to major obstetric haemorrhage. One possibility would be to develop this protocol as a national process to support local processes.

3 Roles and Responsibilities of National Co-ordinator

In October 2006, a National Co-ordinator of the Perinatal and Maternal Mortality Review Committee (PMMRC) was appointed. The primary role of the PMMRC National Co-ordinator is to support Lead Maternity Carers, clinicians and District Health Board (DHB) local co-ordinators in the completion of data collection following either perinatal or maternal death. She is also available to answer queries from families and the public regarding perinatal and maternal mortality.

While the National Co-ordinator is located at the University of Auckland she also visits different DHBs to assist with their local PMMRC processes. This assistance includes supporting DHBs with establishing and improving perinatal mortality review meetings. To date 8 of the 21 DHBs have been visited and the feedback has been very positive.

The National Co-ordinator has presented information on the PMMRC and its role at conferences and workshops both nationally and internationally as well as at DHB grief study days. Annual workshop have been held to help train and support DHB local co-ordinators, with a focus on classification of the cause of death.

By noting any issues or suggestions for improvement of data collection, the National Co-ordinator assists with the development and enhancement of the PMMRC information system. The National Co-ordinator answers queries relating to access, usability, data or information that arise with use of the information system and ensures data accuracy and integrity. An audit of perinatal-related mortality information was undertaken for 2006 perinatal-related mortality and is in progress for perinatal-related mortality in 2007.

The National Co-ordinator works closely with the PMMRC Chair Professor Cindy Farquhar and the committee, reporting on issues related to data quality and providing feedback on any concerns that have been raised or new clinical issues. The National Co-ordinator also produces data reports from the database before each PMMRC meeting. Close working relationships exist with the secretariat at the Ministry of Health, the Mortality Review Data Group and the Office of the Chief Coroner.

The National Co-ordinator has assisted with the planning and preparation of this report, and provided supporting explanations for the analysis of the data it contains.

4 Issues for Parents, Families and Whānau

Commendable progress has been made in collecting data and moving closer to knowing exactly how many babies have died and the circumstances in which they have died. Unfortunately, however, there has not been an equivalent level of progress in supporting parents, families and whānau following the death of a baby or babies.

In its first report to the Minister of Health, the PMMRC noted a number of issues for bereaved parents, families and whānau (PMMRC 2007). Those issues included a lack of information about perinatal-related mortality; the need for affordable counselling; feelings of isolation; the absence of anyone to answer specific questions; a lack of resources, especially those particular to the situation for the New Zealand population; and the publication of almost all available resources in the English language only.

Following the identification of these issues, the 2007 report made the recommendation that the Minister require that DHBs ensure all providers of maternity services provide support to parents, families and whānau who have experienced perinatal or maternal loss. That support would include providing access to information, counselling and clinical follow-up.

In its endeavour to assess the scope of support throughout the country, the PMMRC carried out a brief survey of DHBs in March 2007. The survey enquired about the levels of support each DHB provides to parents, families and whānau following a pregnancy, baby or infant loss. Following some encouragement, it gained a 100 percent response rate.

The resulting data are not presented here as particularly robust or scientifically vigorous. Indeed, since this survey was carried out, a small number of DHBs have implemented changes and used the survey as the impetus to provide better support to parents, families and whānau. Therefore, it does not provide a to-the-minute snapshot of support services in New Zealand. Rather, the 'results' are presented here as an illustration of the paucity and inconsistency of support across the country. It is suggested they are read descriptively rather than quantitatively.

The information from the survey is summed up as follows.

- Ten of the 21 DHBs reported that they had a 'pregnancy loss service'.
- Teams in the pregnancy loss services were made up of social workers, ministers, chaplains, cultural advisors, genetic counsellors, maternal mental health staff, and doctors.
- One DHB reported having specialised pregnancy loss counsellors.
- One DHB reported having a specialised service caring for all deaths in its hospital.
- Where the DHB had no pregnancy loss service, it was asked whether parents, families and whānau were referred for counselling. In response, 14 DHBs noted that 'counselling' was provided by obstetricians, midwives, social workers, gynaecologists, cultural advisors, chaplains, Sands, Women's Health Service, and paediatricians. (Counselling is presented in quotation marks above because the majority of the roles listed are not specialised counsellors.)
- Six of the 21 DHBs noted that they maintained contact with the parents and/or families and whānau for less than two months; while three of the 21 maintained contact for a year.
- Twenty DHBs provided written material to parents, families and whānau (one did not respond to the question): 18 provided Sands information and 10 provided their own DHB information.
- Only seven DHBs felt there was a need for more written information. (These DHBs identified the following as among the topics that need to be covered: grief, post mortem, future pregnancies, burial choices, taking baby home, long-term grief, lists of books available.)
- When asked to rate their own service, six DHBs stated they thought that they provided a very good service, ten that their service was adequate and two that their service was minimal. Three DHBs did not answer this question.
- Three DHBs noted that they had an evaluation mechanism for their pregnancy loss service – via the general complaints system, through a generic DHB feedback form and through the New Zealand College of Midwives systems.

The survey concluded by asking respondents for their comments. One theme that was predominant in the comments was the desire for a centralised, national direction or guidance on perinatal-related death support and information. For example, it was suggested that:

- a 'national direction of what a Pregnancy Loss Service looks like would be helpful'
- 'national approaches in terms of resource allocation would also be helpful'
- a 'central repository of written material [would be] hugely helpful'
- 'national guidelines on pregnancy loss' were needed.

Another area identified as needing attention was the increasing number of parents who are faced with an unexpected fetal diagnosis and are then expected to make a decision about continuing or terminating the pregnancy. There is very little information for parents, especially locally produced information, that supports families and whānau in making this incredibly hard decision.

Finally, respondents highlighted the need for continuous and 'seamless' care for parents, families and whānau as they leave the hospital and go back to their communities.

It is evident that the need still exists for some co-ordinated support for parents, families and whānau who experience the death of a baby. The brief survey undertaken by the PMMRC illustrates the inconsistency and variation of support throughout the country and the immediate need for some guidance for DHBs in order that they feel informed and guided in their development of support services and resources.

Recommendation

The Minister of Health charges the PMMRC with investigating how DHBs might be better supported or guided to provide support to parents, families and whānau with a perinatal or maternal death and how support and information can be resourced in our communities.

Appendix A: Classifications of the Perinatal Society of Australia and New Zealand

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 <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

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
-

Appendix B: Additional Tables

Table A.B1: Perinatal-related mortality and DHB of maternal domicile in New Zealand, 1 July – 31 December 2006

| DHB of maternal domicile | Total births N = 29,967 | | Fetal deaths | | | | | | Neonatal deaths | | | Perinatal-related deaths | | |
|--------------------------|----------------------------|------|------------------------|------|------|------------------------|------|------|-----------------|------|------|--------------------------|------|------|
| | | | Terminations N = 78 | | | Stillbirths N = 186 | | | N = 92 | | | N = 356 | | |
| | n | % | n | % | rate | n | % | rate | n | % | rate | n | % | rate |
| Northland | 1,043 | 3.5 | | | | 12 | 6.5 | 11.5 | 6 | 6.5 | 5.8 | 18 | 5.1 | 17.3 |
| Waitemata | 3,668 | 12.2 | 8 | 10.3 | 2.2 | 20 | 10.8 | 5.5 | 7 | 7.6 | 1.9 | 35 | 9.8 | 9.5 |
| Auckland | 3,221 | 10.7 | 12 | 15.4 | 3.7 | 19 | 10.2 | 5.9 | 6 | 6.5 | 1.9 | 37 | 10.4 | 11.5 |
| Counties Manukau | 4,261 | 14.2 | 7 | 9.0 | 1.6 | 41 | 22.0 | 9.6 | 9 | 9.8 | 2.1 | 57 | 16.0 | 13.4 |
| Waikato | 2,532 | 8.4 | 11 | 14.1 | 4.3 | 17 | 9.1 | 6.7 | 11 | 12.0 | 4.4 | 39 | 11.0 | 15.4 |
| Bay of Plenty | 1,453 | 4.8 | 5 | 6.4 | 3.4 | 5 | 2.7 | 3.4 | 6 | 6.5 | 4.2 | 16 | 4.5 | 11.0 |
| Lakes | 811 | 2.7 | | | | 8 | 4.3 | 9.9 | | | | 8 | 2.2 | 9.9 |
| Tairāwhiti | 356 | 1.2 | | | | 3 | 1.6 | 8.4 | 2 | 2.2 | 5.7 | 5 | 1.4 | 14.0 |
| Taranaki | 701 | 2.3 | 2 | 2.6 | 2.9 | 5 | 2.7 | 7.1 | 1 | 1.1 | 1.4 | 8 | 2.2 | 11.4 |
| Hawke's Bay | 1,126 | 3.8 | 3 | 3.8 | 2.7 | 3 | 1.6 | 2.7 | 6 | 6.5 | 5.4 | 12 | 3.4 | 10.7 |
| Whanganui | 412 | 1.4 | | | | 1 | 0.5 | 2.4 | | | | 1 | 0.3 | 2.4 |
| MidCentral | 1,074 | 3.6 | | | | 6 | 3.2 | 5.6 | 3 | 3.3 | 2.8 | 9 | 2.5 | 8.4 |
| Wairarapa | 261 | 0.9 | | | | 1 | 0.5 | 3.8 | | | | 1 | 0.3 | 3.8 |
| Capital & Coast | 1,968 | 6.6 | 7 | 9.0 | 3.6 | 11 | 5.9 | 5.6 | 6 | 6.5 | 3.1 | 24 | 6.7 | 12.2 |
| Hutt Valley | 993 | 3.3 | 6 | 7.7 | 6.0 | 6 | 3.2 | 6.0 | 3 | 3.3 | 3.1 | 15 | 4.2 | 15.1 |
| Nelson Marlborough | 756 | 2.5 | 3 | 3.8 | 4.0 | 4 | 2.2 | 5.3 | 5 | 5.4 | 6.7 | 12 | 3.4 | 15.9 |
| West Coast | 151 | 0.5 | 1 | 1.3 | 6.6 | 1 | 0.5 | 6.6 | 1 | 1.1 | 6.7 | 3 | 0.8 | 19.9 |
| Canterbury | 3,155 | 10.5 | 9 | 11.5 | 2.9 | 14 | 7.5 | 4.4 | 8 | 8.7 | 2.6 | 31 | 8.7 | 9.8 |
| South Canterbury | 311 | 1.0 | 1 | 1.3 | 3.2 | | | | 1 | 1.1 | 3.2 | 2 | 0.6 | 6.4 |
| Otago | 948 | 3.2 | 2 | 2.6 | 2.1 | 3 | 1.6 | 3.2 | 7 | 7.6 | 7.4 | 12 | 3.4 | 12.7 |
| Southland | 749 | 2.5 | | | | 6 | 3.2 | 8.0 | 3 | 3.3 | 4.0 | 9 | 2.5 | 12.0 |
| Overseas | 15 | 0.1 | | | | | | | 1 | 1.1 | * | 1 | 0.3 | * |
| Unknown | 2 | 0.0 | 1 | 1.3 | * | | | | | | | 1 | 0.3 | * |

Note: * No rate provided as denominator unreliable.

The perinatal mortality rate among babies of mothers who identify themselves as Pacific peoples (Table A.B2) is significantly higher than among babies of mothers identifying as New Zealand European ($p = 0.02$). No significant increase in ethnic-specific mortality rate is seen among babies of mothers identifying as Māori although this association was seen in the baby ethnic-specific rates. The striking difference among babies of Pacific mothers relates to a higher rate of fetal death (termination and stillbirth combined).

Babies born to mothers identifying as Māori have a higher rate of neonatal death than babies born to mothers identifying as New Zealand European ($p = 0.001$) or as Other Asian ($p = 0.02$).

In *Fetal and Infant Deaths 2003 & 2004* (NZHIS 2007a) and *Statistical Information on Hospital-based Maternity Events 2005* (NZHIS 2008), babies of Pacific mothers were also found to have the highest perinatal mortality rate.

Table A.B2: Perinatal-related mortality by maternal ethnicity in New Zealand, 1 July – 31 December 2006

| Maternal ethnicity | Births (NZHIS) | | Fetal deaths | | | | | | Neonatal deaths | | | Perinatal-related deaths | | |
|--------------------------|----------------|--------------|--------------|--------------|-------------|------------|--------------|-------------|-----------------|--------------|------------|--------------------------|--------------|-------------|
| | | | Terminations | | Stillbirths | | | | | | | | | |
| | n | % | n | % | TOP rate | n | % | SB rate | n | % | NND rate | n | % | rate |
| New Zealand European | 14,407 | 49.0 | 43 | 55.1 | 3.0 | 79 | 42.5 | 5.5 | 38 | 41.3 | 2.7 | 160 | 44.9 | 11.1 |
| Māori | 6,095 | 20.7 | 9 | 11.5 | 1.5 | 41 | 22.0 | 6.7 | 33 | 35.9 | 5.5 | 83 | 23.3 | 13.6 |
| Pacific | 2,938 | 10.0 | 4 | 5.1 | 1.4 | 33 | 17.7 | 11.2 | 11 | 12.0 | 3.8 | 48 | 13.5 | 16.3 |
| Indian | 886 | 3.0 | 3 | 3.8 | 3.4 | 7 | 3.8 | 7.9 | 3 | 3.3 | 3.4 | 13 | 3.7 | 14.7 |
| Other Asian | 1,687 | 5.7 | 8 | 10.3 | 4.7 | 11 | 5.9 | 6.5 | 2 | 2.2 | 1.2 | 21 | 5.9 | 12.4 |
| Other (includes unknown) | 3,402 | 11.6 | 11 | 14.1 | 3.2 | 15 | 8.1 | 4.4 | 5 | 5.4 | 1.5 | 31 | 8.7 | 9.1 |
| Total | 29,415 | 100.0 | 78 | 100.0 | 2.7 | 186 | 100.0 | 6.3 | 92 | 100.0 | 3.2 | 356 | 100.0 | 12.1 |

Notes:

- 1 This table contains one entry per mother rather than one entry per baby as in all other tables in this report. Therefore the denominator for perinatal mortality rate is a slight underestimate of all babies born. As there is no direct link between maternal data in the national maternity dataset and baby data, some mother–baby pairs do not match.
- 2 Maternal ethnicity is mother’s ethnicity from NZHIS for denominator and mother’s ethnicity from PMMRC collection for mothers experiencing perinatal loss.



Appendix C:

Perinatal and Pathology Service Provision in New Zealand

**A report by the Perinatal and Maternal Mortality
Review Committee**

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Foreword

Accurate documentation of the reasons for fetal and neonatal deaths allows any changes in cause of perinatal death over time to be analysed and preventability to be assessed. Until recently the cause of death listed on the death certificate has been the cause used by the New Zealand Health Information Service to document and monitor perinatal deaths annually in this country. This practice is concerning given that the certified cause of death can be discordant with the cause of death as determined by case review, in around 50 percent of neonatal deaths (Hunt and Barr 2000).

The Perinatal and Maternal Mortality Review Committee (PMMRC) has been charged with the job of reviewing perinatal deaths in New Zealand. Data collection has commenced and the second annual PMMRC report to be produced in 2008 will include analysis of the first available data, which have been collected from the last six months of 2006. Although a range of clinical data are being collected, in many cases the information most likely to elucidate the main cause of death of any infant is that obtained from the post mortem examination. Without a high consent rate for, and ready availability of perinatal post mortem examinations, the information available to the PMMRC to assign a cause for each perinatal death reviewed will be significantly compromised. Most importantly, as many parents want to know 'the reason why' their baby or child died, a diagnosis based on well-informed analysis is required.

This report has been produced by the PMMRC to discuss provision of perinatal pathology services in New Zealand. Both perinatal and paediatric pathology are sub-specialities of anatomic pathology. Like many services in New Zealand orientated to infants and children rather than adults, access to these services is variable and resources are limited and stretched. This report highlights these issues and makes a number of recommendations to:

- facilitate improved services in the current environment
- ensure that a planned approach is taken to sustain and improve this important clinical service.

The main focus of this report is perinatal pathology services and the recommendations in particular are focused on these services. Paediatric pathology services will also be discussed as they are closely related to perinatal pathology services.

Dawn Elder

Executive Summary

1. Families and whānau in all areas of the country and of all ethnicities should have an equal opportunity to receive a considered and complete investigation after a perinatal death, including appropriate support and follow-up.
2. Post mortem remains the gold standard for clarifying cause of death for the majority of fetal, perinatal, neonatal and infant deaths and provides important information for parents concerning future pregnancies.
3. All families and whānau who experience a fetal or neonatal death should be offered a post mortem examination as part of the investigation of that death. Ideally this service should be provided by a perinatal pathologist.
4. As post mortem examination may not be an acceptable investigation for all families and whānau, guidelines for the investigation of perinatal death must offer alternatives to post mortem. The guidelines must be clear about when these alternatives are likely to provide sufficient information to explain the cause of death and when the information that will be gained will be limited and possibly not contribute to the explanation at all.
5. Perinatal pathology in New Zealand should be a sustainable service, accessible seven days a week. The service should incorporate a national clinical network and build on the strengths of the current model.
6. Because there is a worldwide shortage of perinatal and paediatric pathologists, the best solution to the current shortage in New Zealand is to offer training locally.
7. A training post should be set up in New Zealand for a junior consultant to undertake advanced training in perinatal and paediatric pathology.

The Importance of Perinatal and Paediatric Pathology

Introduction

In 1997–1998 a national review of paediatric specialty services was undertaken and the findings published in *Through the Eyes of a Child* (HFA 1998). This report lists nine principles that should underlie the provision of health services for children and young people. These principles are that services must be:

- child and family focused
- as close to home as possible within the bounds of quality and safety
- provided to achieve equity of outcome
- based on international best practice, research and education
- monitored and evaluated regularly
- integrated with other health services
- culturally safe
- fiscally responsible.

Pathology and laboratory services were addressed in this report. It recommended that paediatric and perinatal autopsies (post mortems) and surgical pathology should be performed by pathologists with appropriate specialist training. A further recommendation was that two or three specialist trained paediatric/perinatal pathologists should be appointed over the next three years.

Utility of perinatal and paediatric pathology

Post mortem remains the gold standard for clarifying cause of death for all age groups but particularly in the perinatal and paediatric age range. The post mortem can confirm clinical diagnoses made before death and contribute new information about the cause of death and associated factors. The information it provides may be important for two reasons.

1. It may significantly change the advice given to families about recurrence risks for a future pregnancy.
2. The clinical knowledge gained from the post mortem can influence how clinicians caring for a woman and her infant manage another similar case.

Local studies have confirmed the utility of expert perinatal autopsy in the New Zealand population. For example, in a review of 56 neonatal deaths over a two-year period 73 percent of those deaths had a post mortem and of those, new clinical information was found in 59 percent (Sanders et al 1999). In addition, in a review of autopsy reports for 29 very preterm infants dying at less than 28 days of age, new findings were made in 79.3 percent of them and significantly changed the diagnosis in 27.6 percent (Elder and Zuccollo 2005).

Overseas studies confirm the utility of post mortem in auditing antenatal diagnosis of fetal anomaly (Amini et al 2006; Sun et al 1999; Scott 2002; Dickinson et al 2007). Although more sophisticated ultrasound techniques aid visualisation and therefore facilitate more accurate diagnoses, continual monitoring of antenatal diagnoses is important especially when they are the basis of decisions to terminate pregnancy (Isaksen et al 2000). Post mortem can refine the estimate of the risk of recurrence of fetal anomaly in 27 percent of cases (Boyd 2004).

Post mortem is critical after fatal perinatal asphyxia. Information obtained from a post mortem may change final diagnoses; for example, it could indicate that the asphyxial insult occurred prior to labour (Becher et al 2004; Elder et al 2005). This potential for providing key information has important implications if concerns are being aired about the clinical practice of those who cared for the mother in labour. This information comes from histological examination of the brain and will not be available from magnetic resonance imaging (MRI) examination.

Placental examination is a critical aspect of a perinatal pathologist's workload. Placental abnormalities can be associated with adverse neurological outcome in preterm and growth restricted infants (Redline et al 2000; Viscardi and Sun 2001). Recognised indications for placental examination are pregnancies with one or more of the following features (RCOG and RCP 2001):

- multiple pregnancy
- small for gestational age infant (below the third centile for age and sex)
- neonatal hypoxic ischaemic encephalopathy
- early neonatal sepsis
- preterm labour less than 34 weeks
- congenital malformations
- macroscopic placental abnormalities
- recurrent antepartum haemorrhage
- clinical chorioamnionitis
- established maternal diabetes
- severe pre-eclampsia.

In a busy obstetric service the need for this examination provides a significant workload for pathology services.

Alternatives to full post mortem examination

There has been concern about decreasing consent rates for post mortem because of controversy over organ retention in the United Kingdom, Australia and New Zealand (Khong and Tanner 2006; Adappa et al 2007). If parents are reluctant to consent to a full post mortem examination, it may be useful to limit a post mortem to taking samples for histology from what is clinically thought to be the most affected organ(s). A limited autopsy will, however, obtain only limited information. The procedure becomes a biopsy after death and significant information may be lost if the organs being assessed cannot be examined fully and tissue samples for microscopy cannot be taken from all organs.

MRI has been considered as a second best alternative to post mortem. MRI can provide good correlation for central nervous system abnormalities but is poor at detecting cardiovascular anomalies. Problems arise with both access to MRI and access to expertise in reporting necropsy MRI (Griffiths et al 2005; Brookes 2006). Histology is not available unless targeted image-guided biopsy is also included in the examination. Computed tomography (CT) scanning of the head has a poor correlation with post mortem findings in infants who have died because of perinatal asphyxia; and routine X-ray is of limited use except in specific cases (Flodmark et al 1980; Olsen et al 2003).

If parental consent is not obtained for post mortem and the fetus or infant is dysmorphic or has evidence of other congenital anomalies, it can be helpful for an expert in dysmorphology to make a clinical examination. Those with expertise in this area are perinatal pathologists or geneticists with expertise in fetal anomalies. Clinical photos should be taken and the infant should be weighed and measured. For some genetic and chromosomal abnormalities a clear diagnosis can be made from blood or other fluid samples taken for genetic testing before or after birth. In such cases post mortem will not always be required to accurately define the cause of death.

The Current Situation of Perinatal and Paediatric Pathology Services

Pathology workforce in New Zealand and overseas

In New Zealand, a perinatal pathology service has developed in an opportunistic, piecemeal fashion and is dependent on the interests and availability of suitably trained pathologists around the country. There has been no specific funding allocated to this service nor has there been formalised specialist training in perinatal pathology in New Zealand. Although the most current workforce analysis published by the New Zealand Committee of Pathologists reports on a number of pathology sub-specialties, it does not mention paediatric and perinatal pathology (New Zealand Committee of Pathologists 2007).

The workload involves performing and reporting post mortems, supervising placental histology reporting, and attending multidisciplinary meetings. Perinatal mortality or education meetings are important forums in which obstetricians and paediatricians discuss cases with the pathologist. These meetings are held in referring institutions on a regular (eg, monthly) basis.

In New Zealand the population ratio is 1 pathologist per 20,000 people (or, in terms of a full-time equivalent (FTE), 1 FTE per 27,877 people). In contrast, in Australia (where there is a severe workforce crisis) the ratio is 1 per 15,925. New Zealand would need another 59 pathologists to reach even Australian levels (New Zealand Committee of Pathologists 2007).

In the United Kingdom there are significant shortages in paediatric and perinatal pathology (Squier and Ironside 2006). In a British study involving 60 consultants from level II and III neonatal units, 40 percent reported they did not routinely offer a post mortem examination and the most common reason for not offering it was lack of availability of a perinatal pathologist (Rose et al 2006).

Auckland

The perinatal workload is shared between an FTE position in Auckland and a 0.6 FTE position (0.4 FTE for the Auckland District Health Board (DHB) and 0.2 FTE for the National Forensic Pathology Service) delivered from Wellington.

The Auckland role includes coverage at Auckland City and Middlemore Hospitals. Specific responsibilities involve:

- the examination of the pregnancy product losses less than 20 weeks gestation
- paediatric surgical pathology including renal biopsies (this load is shared with a general pathologist)
- perinatal pathology at North Shore and Waitakere Hospitals
- attendance at Auckland City Hospital's Maternal Fetal Medicine meeting
- participation in the anatomic pathology 'on call' roster in Auckland.

At North Shore and Middlemore Hospitals, placentas are examined by a general anatomic pathologist unless specifically referred on to a perinatal pathologist.

When undertaking responsibilities for Auckland, the Wellington pathologist's responsibilities include:

- examination of pregnancy losses 20 weeks gestation and over
- post mortem examination of all neonatal and some childhood deaths
- forensic responsibilities in regard to specific deaths
- travel to Auckland two to three times a month for mortality meetings; if appropriate, post mortems may be carried out during this time
- attendance at Paediatric Intensive Care Unit and cardiac mortality meetings
- attendance at the monthly Auckland City and Middlemore Hospital's perinatal mortality meetings.

The Wellington specialist pathologist makes herself available seven days a week to facilitate a prompt service (see Appendix 3 for views of parents). Her responsibilities specific to Wellington are outlined below.

Clearly the above schedule of responsibilities involves considerable travel for the expert Wellington perinatal/paediatric pathologist. Although service responsibilities have been well organised, such a schedule relies on the commitment and positive relationship of a very small group of individuals. In addition there is a need to transport deceased infants from Auckland City and Middlemore Hospitals to Wellington for post mortem.

Wellington

The Wellington-based perinatal/paediatric pathologist is responsible for service locally and also takes referral from other DHBs. These responsibilities include:

- responsibility for the fetal and perinatal workload at Wellington and Hutt hospitals
- supervision of 'sign-out' of all placental histology reports
- provision of DHB perinatal pathology services for MidCentral, Waikato, Rotorua, Tauranga, Gisborne, Whanganui, Masterton, Taranaki, Hawke's Bay, and Nelson Marlborough DHBs when requested
- attendance at mortality meetings at Hutt Valley, MidCentral and Hawke's Bay DHBs at intervals of three to four months
- monthly PowerPoint presentations of cases for Waikato meetings
- attendance at other DHBs as required/on demand.

These services are provided seven days a week.

In addition, time is contracted to the National Forensic Pathology Service as noted above in relation to Auckland. This workload involves attendance at coroner's inquests and court proceedings over a wide area of the North Island.

Christchurch

At Christchurch Hospital until recently, a general trained anatomic pathologist, with an interest in perinatal and paediatric pathology provided the perinatal pathology service. More recently a perinatal and anatomic pathologist joined the service. However, this specialist pathologist is predominantly involved in the adult surgical pathology service and participates in the anatomic pathology roster at Christchurch Hospital. Canterbury DHB also provides services to Timaru, Ashburton and the West Coast.

Dunedin

Until early 2007 a specialist perinatal pathologist provided a service in conjunction with providing clinical time to adult surgical pathology services at Otago DHB. Since early 2007, when the DHB laboratory service was restructured, the specialist perinatal/paediatric pathologist has provided a perinatal/paediatric service under a separate contract from the private laboratory provider. In addition to this service, this specialist pathologist provides extra work for forensic cases and does occasional locums in adult surgical and autopsy pathology around South Island laboratories. Cases in Oamaru and Central Otago also receive expert services by this specialist. However, most Southland DHB cases are performed by a general anatomic pathologist at that site.

It needs to be noted that as a result of the restructuring of Otago DHB laboratory services, perinatal services were almost lost. It would appear that without the strong case presented by key clinical stakeholders, this important element of laboratory services would have been lost.

Perinatal workload

Preliminary information from PMMRC data collection suggests that there may be up to 700 perinatal deaths per year. If 75 percent of these deceased infants were referred for post mortem, this would represent a workload of 525 cases per year. Each post mortem is at least eight hours of work. Therefore two full-time equivalent perinatal pathologists would be required just to do this number of post mortems without any time allocated to mortality meetings, teaching or research, or review of placental histology. This volume excludes referral for post mortem of infants dying after 28 days of age and referral for examination of fetuses dying before 20 weeks gestation.

When assessing perinatal workload, placental examination also needs to be taken into account. Larger tertiary centres will assess up to 400 to 500 placentas a year.

Based on this conservative estimate, the current workload is unsustainable. There is no visible acknowledgement from DHBs of the need for succession planning in this key sub-specialty service.

Issues for Perinatal and Paediatric Pathology Services

Issues related to recruitment

Due to the worldwide shortage of perinatal and paediatric pathologists, any response to the problem in New Zealand will need to include:

- provision of local training in perinatal and paediatric pathology
- strategies to attract suitably qualified pathologists from overseas.

Trainees in pathology who are advanced in New Zealand are the likely source of our future perinatal pathology workforce. However, if recruitment is to be successful, a sustainable position with appropriate supports will need to be offered. For a career in perinatal pathology to be considered by these trainees, there is a need for:

- the colleges to clearly identify the sub-specialties of paediatric and perinatal pathology and to offer opportunities for training and accreditation in these specialties
- remuneration at consultant level to be competitive with remuneration rates for anatomic pathologists working in private or in a combined public-private environment
- a nationwide perinatal/paediatric pathology service with a national 'on call' service in place so that no single pathologist is the only person providing a seven-day service.

Can the work be done by anatomic pathology specialists?

There are many reasons why paediatric and in particular perinatal pathology requires expertise and experience different from that appropriate for general adult anatomic pathology. These reasons include the following.

- The range of diseases being assessed, especially those that are genetic, congenital and metabolic in aetiology, is different.
- Many of the malignancies that present in childhood are different from those seen in adult medicine.
- An understanding of normal developmental changes and perturbations of embryology is required.
- Preparation of the necessary samples, such as those taken when investigating possible inborn errors of metabolism, can require special care.
- Different surgical techniques are used in autopsy on fetuses, infants and young children. These can be critical as parents frequently want to have the body of their infant or child at home after the post mortem.

- Paediatric and perinatal pathology services are essential to support secondary, tertiary paediatric, neonatal and obstetric care. These services care for patients in an age group where the effect of any pathological process on the developing child can differ from the effect of the same process on the mature adult.
- There are separate textbooks, journals, meetings, courses, exams and quality assurance processes, also indicating that the issues are different.

Post mortem examinations performed by specialist perinatal pathologists in regional centres are more likely than those completed in non-regional centres to conform to minimum standards (92–100 percent compared with 28–69 percent) and to yield additional information (Cartlidge et al 1995; Vujanic et al 1998). Expertise in placental histological examination is also important as general surgical pathologists may fail to recognise the clinical relevance of placental lesions (Hargitai et al 2004). The Clothier report (Clothier et al 1994) recommended specialist paediatric pathology in all cases of unexpected or clinically unaccountable death in children.

In many areas of New Zealand, histological reporting on paediatric pathology specimens is included in the general pathology services workload. This arrangement works well in many areas. There are also areas in New Zealand where in the past anatomic pathologists have performed post mortems locally because there was no alternative specialist service. These practitioners are now referring these cases on for specialist attention. These referrals have significantly increased the workload of the specialist perinatal pathology service.

What is the current efficiency and effectiveness of the service?

The current service is under considerable strain. Although a high-quality service is being provided, mainly by a single experienced practitioner, for the majority of the age-related population in New Zealand, there is no 'on call' sustainable service for perinatal pathology. The seven-day service is dependent on the goodwill of this one practitioner and it is not sustainable.

The target gold standard post mortem rate is 75 percent for perinatal deaths. This rate is near to being achieved in Wellington but not in other centres. Since there has been a regular perinatal pathology service in Auckland provided by Capital & Coast DHB, pathologist post mortem rates have increased significantly. Further increases in referrals indicate a more robust approach to the investigation of perinatal death but this change has also increased pressure on an already over-stretched system.

To be effective a perinatal pathology service must be embedded in the core services for which it provides clinical information, such as the obstetric, paediatric and genetic services of the referring organisation. Some families and whānau may find it helpful to meet the perinatal pathologist prior to consenting to the procedure (see Appendix 3). These interactions are not possible when the perinatal service is based away from a tertiary centre. Over 50 percent of deceased infants who are currently transported to Capital & Coast DHB for post mortem come from a centre with tertiary obstetric and neonatal services that should expect to be supported by a local perinatal pathology service.

The current schedule is absolutely dependent on the commitment, expertise and goodwill of a very small number of individuals and is exceedingly vulnerable. There is an urgent need to provide a national approach to the planning of perinatal pathology services for New Zealand. Such an approach should incorporate the successes of the current process and provide for an expanded service aligned to the clinical demands of the relevant population.

One demonstration of the effects of the current tensions is that the overload of a fragmented (national) system results in delays in final reports for post mortem examinations. It is distressing for parents when they return for follow-up after the death of an infant and the final post mortem results are not available.

In addition, as post mortem reports take priority, signing out of placental histology reports on live-born infants may be delayed. Sometimes knowledge of the placental histology may have implications for the care of a live-born infant with significant postnatal problems, but this information may not be available in a timely manner. From a risk management perspective such delays are unacceptable and avoidable.

Issues related to training

The website and manual of the Royal College of Pathologists of Australasia do not recognise perinatal pathology as a sub-specialty in any obvious way. On the website, seven career pamphlets are advertised, covering microbiology, genetics, anatomical, haematology, immunopathology, chemical and forensic but not perinatal or paediatric pathology (<http://www.rcpamannual.edu.au>).

This matter is currently under discussion within the college, specifically within the Paediatric Pathology Group of Australia and New Zealand. These discussions will involve addressing training and accreditation of post-fellowship trainees wishing to pursue a career in paediatric and perinatal pathology.

Recommendations for Provision of Perinatal and Paediatric Pathology Services

Changes that can be made immediately and be effective immediately

Recruitment

- Create a senior registrar / junior consultant training post in Capital & Coast DHB from 2009 to assist and support the onerous workload cover and 'on call' support in Wellington.
- Re-advertise a full-time Auckland perinatal pathology position.

Retention

- Arrange locum support to enable accrued annual leave to be taken by the perinatal pathologist.

Effectiveness

- Develop national guidelines for referral to ensure the information that the pathologist requires for post mortem is relevant and appropriate.

Efficiency

- Ensure appropriate administrative support is available to enable reports to be released in a timely manner.

Changes that can be made immediately but will take three to four years to show an effect

Recruitment

- Set up a senior registrar / junior consultant training post based initially at Capital & Coast DHB with the support of the Royal College of Pathologists of Australasia. This post should involve a two-year training programme that comprises six months based in Wellington (focusing on perinatal pathology), six months in Auckland (focusing on perinatal and paediatric surgical pathology) and one year of overseas experience.
- Ensure the Royal College of Pathologists of Australasia recognises perinatal and paediatric pathology as a sub-specialty area and that workforce coverage is monitored through a national plan.

Retention

- Ensure remuneration is competitive with other pathology sub-specialities.
- Ensure an appropriate national roster system is in place so that no single perinatal pathologist is always on call.
- Ensure training is appropriate and clinical support services are in place.

Effectiveness

- With all DHBs undertake a full assessment of workload, identify the FTEs required and develop a long-term succession planning process that includes predictors based on an increased referral rate for perinatal post mortem and placental histology assessment.
- Reconfigure organisation of the service to be a nationwide service using the framework of a national clinical network.

Efficiency

- Align perinatal death support services so that clinicians using perinatal pathology services are competent in issues of consent for post mortem and in providing feedback regarding post mortem results to families.

Outcomes sought

- Fully supported perinatal and paediatric pathology services should be available in Wellington.
- Fully supported paediatric and perinatal pathology services should be available in Auckland.
- Fully supported perinatal pathology services for the South Island could be centralised to a single location.

Appendix 1: The Scope of Perinatal and Paediatric Pathology

In its multidisciplinary review of fetal, perinatal and paediatric pathology services in the United Kingdom, the Royal College of Paediatrics and Child Health (RCPCH) states that 'pathology and histopathology services for children should be provided in the long term only by paediatric pathologists and those with relevant specialist expertise' (RCPCH 2002, p 7). Services should be concentrated at specialist sites, paediatric pathology should not be subsumed into other pathology services, and action to preserve and develop services requires government and professional colleges to recognise the critical importance of the service.

The Tertiary Services Review published by the New Zealand Paediatric Society in 1998 emphasises that health care for children should be provided by professionals trained in looking after children. The society concurs that it would be 'illogical' not to carry this principle into paediatric services after death (PSNZ 1998).

Paediatric pathology

'The scope of paediatric pathology is defined by the age of the patients and not by the disease or organ affected' (RCPCH 2002, p 8). Paediatric pathology includes clinical services, teaching, research, audit, and the setting of standards and protocols (RCPCH 2002). It involves autopsy, forensic medicine and surgical specimen histology. A post mortem examination may include gross anatomical and histopathological examination, histopathology and molecular biology, photos, X-rays and MRI.

All these functions require paediatric pathology to be embedded in expert radiology, cytogenetics and other laboratory services.

Perinatal pathology

The knowledge and skill set required to practise in perinatal pathology differ from those required for paediatric pathology alone. The perinatal pathologist must have expertise in dysmorphology and be familiar with embryology and the changes occurring in the developing fetus. As many stillborn fetuses die some time before delivery, perinatal pathologists must be able to distinguish abnormalities due to post mortem change from true physical findings.

The scope of perinatal pathology includes examination of fetal deaths taking place at or after 20 weeks gestation and neonatal deaths up to 28 days of life. It includes examination of fetuses of less than 20 weeks gestation. Termination of pregnancy is another important reason for post mortem as part of clinical audit of antenatal diagnosis. Perinatal pathology also includes examination of the placenta, after either live birth or fetal death.

Appendix 2: Perinatal Pathology Workshop

In October 2007 a workshop was held in Wellington to discuss issues around the provision of perinatal pathology services in New Zealand. All pathologists practising perinatal pathology in New Zealand were present. Specifically the aim was to set an action plan detailing how to increase, sustain and support perinatal pathology services in New Zealand. This plan and the attendees at this workshop are listed at the end of this appendix.

The chair set the scene with a discussion of the role of perinatal pathology and the current workload issues in perinatal pathology in New Zealand. Dr Jeannette McFarlane then tabled a letter summarising some of the current workload issues in New Zealand. She emphasised that on the retirement of Dr Zucollo it is unlikely that anybody would be available to take on Dr Zucollo's current workload without some serious workforce planning. If no one took on the workload, it would mean cutting services in Auckland, Wellington and, because of Dr Zucollo's role nationally, in most of the North Island secondary perinatal centres. Such cuts would create a big gap in provision of perinatal and paediatric forensic pathology services locally, regionally and nationally. Dr McFarlane emphasised the importance of providing training in perinatal pathology locally to solve this impending workforce crisis, given the past experience of difficulty in filling perinatal and paediatric pathology positions in Auckland.

The other pathologists present also talked individually about the services provided in their area. In the South Island providing perinatal pathology services is currently not sustainable unless they are involved in anatomic pathology.

Dr Nick Baker, representing the Paediatric Society of New Zealand, gave a presentation on a Framework for Sustainable Nationwide Services for Children and Young People in New Zealand. The aim is to apply this framework to a number of tertiary specialities that serve the infant and paediatric population of New Zealand. The model requires a cross-DHB approach to the provision of services and thus centralised national planning. Examples of services where this approach has been or is to be applied are paediatric oncology services and paediatric rheumatology services. Perinatal pathology services are an ideal fit for this sort of model. The national forensic services model has been suggested as a guide to planning a national perinatal service.

Vicki Culling, a PMMRC member, presented information on the transportation of deceased fetuses and infants referred for post mortem at another DHB. Some effort has already gone into developing protocols for air travel for deceased infants, including the development of a carrycot with an inbuilt cooling device. Despite concerns about the need for travel of infants for post mortem, this practice appears not to have deterred families from consenting for the procedure as perinatal post mortem rates at Auckland and Middlemore Hospitals have increased since a service has been provided in Wellington. The most likely reason for this increase is the perceived value of the clinical information provided by the specialist pathologist at the monthly perinatal mortality meetings when post mortem results have been presented.

There was some discussion about DHB planning and funding processes. It is clear that perinatal pathology services fall under the radar of the majority of DHBs in the country. Visibility of the service is a significant issue. Funding for perinatal pathology positions could be based on a combined model with input from DHBs and forensic services, as well as from universities in view of their teaching and research function.

The rest of the workshop focused on discussion about ways of resolving these issues. A combined approach is required with support from individual DHBs, District Health Boards New Zealand, the professional colleges, the Ministry of Health and the Clinical Training Agency. These agencies also need to be reliably informed about the nature of problem. This report highlights the issue and proposes solutions. The Clinical Training Agency has indicated that support can be provided for a training position if the need is documented.

Action plan

The following plan was tabled to progress the issues discussed. It was determined that:

1. a report of the meeting and the issues of concern be presented
2. discussions be held with the Royal College of Pathologists of Australasia about training
3. the matter be raised with the Council of Medical Colleges

4. an exercise be undertaken to job-size perinatal and paediatric pathology workload as accurately as possible
5. more detail be developed around a plan for a national network of perinatal services
6. a parental viewpoint be presented and considered.

Progress as at June 2008 aligned to the above points.

1. This report represents a completion of task 1.
2. Discussions are in progress within the college on training.
3. Feedback has not yet been received from the Council of Medical Colleges.
4. Some work has been done on job-sizing but more detail is required.
5. There is 'work in progress' with the Ministry of Health to progress the planning of national clinical networks.
6. A parental viewpoint has been sought and is profiled in Appendix 3.

Workshop attendees

Dawn Elder (Chair of Workshop), Paediatrician, Capital & Coast DHB; Committee Member, PMMRC

Vicki Culling, National Coordinator, Sands; Committee Member, PMMRC

Nick Baker, Community Paediatrician, Nelson Marlborough DHB; President of Paediatric Society; Committee Member, Child and Youth Mortality Review Committee

Jane Zuccollo, Perinatal Pathologist based in Capital & Coast; also employed by Auckland DHB and National Forensic Pathology Service

Mollie Wilson, Hawke's Bay DHB; Committee Member, PMMRC

Jeannette McFarlane, Paediatric and Perinatal Pathologist, LabPlus, Auckland

Jerzy Stanek, Pathologist, Canterbury DHB

Andrew Campbell-Stokes, Technical Advisory Services (TAS)

Janice Donaldson, Senior Portfolio Manager, SIG, DHBZ

Noelyn Hung, Pathologist, Dunedin

John Marwick, Ministry of Health (for part of the meeting)

Gillian Bohm, Principal Advisor, Quality Improvement and Audit, Ministry of Health; PMMRC Secretariat

Faith Roberts, Senior Policy Analyst (committees), Quality and Safety, Ministry of Health; PMMRC Secretariat

Apologies

Cindy Farquhar, Chairperson, PMMRC, Postgraduate Professor of Obstetrics and Gynaecology, University of Auckland, Auckland

Judge Neil MacLean, Chief Coroner

Lesley McCowan, Associate Professor Obstetrics & Gynaecology; Committee Member, PMMRC

Simon Stables, Head of National Forensic Pathology Service

Martin Sage, Regional Forensic Pathologist, Christchurch

Deborah Harris, Nurse Practitioner, Waikato Neonatal Unit; Deputy Chair, PMMRC

Appendix 3: The Family Perspective

The death of a child, infant, newborn or fetus is a major life event for any family unit and in particular for the parents of the child. At the time of the death, it can be difficult for parents to fully comprehend the processes necessary to enable a full understanding of the reason or reasons why their child died. At a six-week follow-up review, emotions relating to the death will be less raw and the parents will have many questions to ask.

It is important that the perinatal services provided for the family at the time of the infant or fetal death are expert and inclusive so that enough information will be available to answer those questions. To provide this level of service, those providing services must have a full understanding of the investigations that it is appropriate to request and of how to guide the family through the consent process.

Māori and Pacific families

For families of any ethnicity, giving consent for a post mortem examination for their deceased infant is a very significant decision. The issue is particularly significant for Māori and Pacific families.

From a review of 10 years of neonatal deaths at Wellington Hospital, it was found that consent rates by ethnicity were 71 percent for Caucasian and other groups, 50 percent for Māori and 35 percent for Pacific families. Māori families were more likely to consent to a post mortem examination when their infant was nearer term than when very preterm (Wong et al 2008). These results suggest that Māori families may be more willing to consent to post mortem examination when cause of death is less clear and less expected.

In a review of causes of late fetal death over the period 1980–1999, post mortem rates fell by 23 percent (from 53 percent to 41 percent) (Craig et al 2004). Māori and Pacific babies and those in more socioeconomically deprived areas, as defined by the New Zealand Deprivation Index, were significantly less likely to undergo post mortem. For these families, these findings represent an inadequate investigation of the fetal death.

An important issue for Māori is access to their deceased infant. Consent is therefore much more likely if the post mortem can be done in a timely manner. Timeliness means provision of perinatal pathology services seven days a week, throughout the working day and sometimes into early evening.

A viewpoint from bereaved families

Sands (Stillbirth and Newborn Death Support) New Zealand is a voluntary, parent-run, non-profit organisation set up to support parents and families who have experienced the death of a baby. Most members/supporters are also bereaved parents. Sands New Zealand has provided the following commentary from bereaved parents about their experiences of perinatal pathology services in New Zealand².

Recognition of the need for a trained, specialist perinatal pathologist in New Zealand is certainly not restricted to health professionals and policy makers. Parents, families and whānau who experience the death of a baby are the 'consumers' or 'clients' of such a service and from our collective experiences we want to support the call for funding for a specialised perinatal pathology training position in New Zealand.

As bereaved parents of babies who have died at various gestations and ages and under various circumstances, the Sands community is regularly faced with the minimisation of our babies' lives and the lesser expectations of services concerned with perinatal mortality. We welcome this opportunity to add our voices to the call for specialist perinatal pathology services and acknowledge the significance and importance of speaking on behalf of future parents and families who will experience the death of a baby and look for answers as many of us have done.

It is important to acknowledge the context within which these decisions are being considered. We are aware that historically there have been negative professional perceptions of the value of perinatal pathology and we are also aware of the workforce crisis facing pathology in New Zealand and the calls for immediate action in the training

² Comments have been used with permission of the parents.

and retention of all specialist pathologists throughout the country. Having acknowledged those issues, we remain committed to supporting the funding of a specialist perinatal pathologist, based on our own varied experiences and further that call to include the need for thorough training and information on perinatal pathology for all medical [maternity] staff.

Families in the Sands community have faced a variety of experiences in regards to pathology; indeed, many of us have had firsthand experience of not receiving specialist perinatal pathology care:

... the main thing that was really hard was when our baby was returned to us she had major damage from the autopsy on her forehead and also the Funeral Director advised us not to undress her as she apparently had a lot of areas behind her head and back that had also been damaged ...

...when he left us to have the post mortem he was dressed in a gown and nappy, showing no skin tears or damage. When he was returned to us there was skin damage on his forehead and more on his chin, he didn't have a nappy on and his gown was stained with seeping fluid. It was devastating to see him like that; I wanted to know what they had done with him, how the damage happened, who didn't think to put a nappy back on him. To the professionals it seemed as if he was just another dead baby, to us he was our son who deserved more respect ...

These babies were not seen by a specialist perinatal pathologist. The babies' parents have been left with unwelcome memories and potential regrets due to the way their babies were treated. Admittedly, a baby's death is exceptionally tragic and circumstances can be trying but there are no valid reasons why their families should be treated any differently than other groups who experience death. Our babies deserve care and respect as do our bereaved parents and families.

Many parents faced with the death of their baby are also faced with their first immediate experience of death. Unsurprisingly, they have preconceptions about the post mortem which can be allayed by specialist provision of services and thorough information being presented:

... to be honest I didn't have any idea what a post mortem really meant, I mistakenly thought it was some very unnatural act that they wanted to do on my son ... I believe that if the process was explained more I might have given it more consideration ... [this parent chose not to have a post mortem performed]

... we felt that the autopsy was really important when our baby died although initially struggled with the thought of what they would do to our baby ...

... I can't really remember a lot about making the decision to have it done or anyone explaining much to us about it at all. I think we just kept asking why it happened and it was suggested that we do it to get some answers ...

... however a post mortem was offered, and being under the influence of heaps of morphine and in shock, I agreed at the time ... I wished someone had discussed with us why a post mortem was to be done as our baby's condition has already been diagnosed ...

... we were asked if we would like a post mortem by our midwife. We didn't hesitate to say yes as we really wanted to know why or how he had died. However, we had no idea what the pathologist would do, who they were, where they do it, who actually handled our baby, except that he'd be away for about 6 hours. It was a very long wait ...

Parents and families want to make decisions based on all possible information; this includes the decision to have a post mortem undertaken on their baby. Health professionals still feel the need to 'protect' us and shield us from further pain. We appreciate the sentiments behind this notion but recommend transparency and the provision of as much information as possible. If we choose to have a post mortem done on our baby, we want to know that the best possible person is doing it and that the results will be the best possible. We want information '... explained carefully, not glossed over or the judgement made that we were idiots or might be upset ...'

Parents are faced with incredibly hard decisions at a tragic and often traumatic time. It is unacceptable to have inconsistent and arbitrary care of our deceased babies – and cruel that some parents consider themselves ‘lucky’ to have had only minimal care. Misinformation and inconsistency still prevail throughout our hospitals:

... yes I regret having a post mortem with Noah. This is only because of the way we were treated on the day Noah was born. I had 15 minutes with my son, was told I could not bath him, dress him, take clay imprints of his hands and feet etc ...

... we went to our 8 week follow-up appointment to be seen by a complete stranger, as the registrar we had seen at the diagnosis of death was on leave, only to be told there weren't any results available yet when we asked about the post mortem. The registrar contacted the pathologist's office and we were then asked if we were sure we had a post mortem completed on our baby as they couldn't find any record of our baby. They did eventually find the records after searching under my name, not my baby's name (he was not registered and didn't have his own NHI number), however the reports were not completed. We left shattered and heart-broken, none the wiser as to what was going on. We were rung a few days later which just happened to be Christmas Eve and told the post mortem showed 'No Cause of Death Identified', and the results would be sent out in the mail. What a wonderful Christmas Present this was to be. To this day 6½ years later I still have not a medical person sit down with me and explain the results or its technical jargon, and yes I lodged a formal complaint about the appalling service we received ...

When a bereaved family has had their baby taken care of by a perinatal pathologist, the difference is clear:

... the post mortem proved that it shouldn't happen again, so this eased my mind. Also, the care and respect with which they treated both us and our daughter made me feel that we had made the right decision. Our daughter died in 2004, but just recently, after emailing [the pathology] department, I have received the very precious photos that were taken before her post mortem. These photos mean I have three new, very precious memories, of my daughter.

... The specialist perinatal pathologist took wonderful care of Noah. When he came home I undressed him and looked at him and could see the care that was taken with him. I will forever be grateful to the perinatal pathologist for this. I called the perinatal pathologist shortly after Noah was born and said that the hospital had only given me one photo of Noah and did she have any I could have. The perinatal pathologist had a long conversation with me answering all my questions about Noah and Hope. After asking about and describing Hope to her, she told me that Hope would have had [condition] also. That is a question that I always believed we would never know the answer to. The perinatal pathologist then forwarded on to me two photos of Noah which I treasure. I also emailed the perinatal pathologist several months later asking her more questions about [condition] and she emailed me a long and detailed letter back. The perinatal pathologist truly cares about these babies and their families. As I said, I will be eternally grateful to her. Yes I regret having the pm done ... but I am so grateful it was the perinatal pathologist who performed it as I have heard many stories about babies coming back in states where you can see that no care was taken. I don't know what I would have done if this had happened to Noah ...

We are lucky to have a family-centred, skilled, expert perinatal pathologist in New Zealand and we should seize the opportunity to have other pathologists trained under her. Through such expertise, we can ensure that expert skills in clinical and psychosocial practice are continued in New Zealand.

Some parents will always choose to have a post mortem for the sake of their future children, and for this reason alone we need expert skills and experience in order to establish any possible answers for the deaths of our babies and ensuring the best outcome for our future children:

... the best news was that it was nothing genetic that she died from which was a huge relief as she was our first baby and we wanted to get as much information as possible to help us when we decided to have another baby ...

... I now have two girls and wonder whether my very naive decision not to have a post mortem will somehow have an effect on them if they go on to have children ...

... I used to wish we hadn't had it done for the fact that it gave us no definite results, but have come to realise that by having it done it ruled out any genetic disorders or other problems that may occur so therefore in a roundabout way we did get some answers – just not the ones we wanted ...

... I needed to know if what had happened with C was going to happen with any other child I would conceive. The post mortem proved that it shouldn't happen again, so this eased my mind ...

As a community of parents and families who have experienced one of life's hardest challenges, we are aware of the potential for good practice and the positive effect it would have on those families who are yet to go through the tragedy of perinatal death:

... if there was a specialist perinatal pathologist in all of our major hospitals available to sit down with families prior to the post mortem so you could meet them, have explained if you wish what they were going to do, that they would be doing the procedure themselves, and return your baby to you with a brief initial finding to be followed up at a later meeting at the conclusion of all results, [it] would be fantastic. This would help eliminate some of the added grief, anger and stress at an already traumatic time of families' lives ...

Sands cannot speak for all bereaved parents and families of babies that have died in New Zealand. However, we do see, or have contact with, a great number of bereaved families throughout the country and therefore speak with 'authority' on the topic. We are hopeful that the addition of parents' and families' voices to the report will help to secure the necessary funding for specialist perinatal pathologist positions in New Zealand.

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Appendix D: Local Co-ordinators of the PMMRC

| DHB | Local Co-ordinator | Work Role |
|----------------------------|----------------------|---|
| Northland | Yvonne Morgan | Clinical Charge Midwife |
| | Chris Cullen | Quality/Risk Facilitator |
| Waitemata | Dr Sue Belgrave | Clinical Director of Obstetrics |
| | Eleanor Gates | Quality Midwife |
| Auckland | Dr Emma Parry | Obstetrician |
| | Dr Lesley McCowan | Associate Professor |
| Counties Manukau | Dr Graham Parry | Consultant Obstetrician |
| | Dr Nerida Titchiner. | Consultant Obstetrician |
| | Dr Sarah Wadsworth | Consultant Obstetrician |
| Waikato | Dr Alastair Haslam | Clinical Unit Leader Obstetrics and Gynaecology |
| | Dr Sarah Waymouth | Obstetrician and Gynaecologist |
| | Dr Phil Weston | Paediatrician |
| | Tracey Crow | Midwife |
| Bay of Plenty | Margret Norris | Midwife Leader |
| Lakes | Tivanti Pilapitaya | CNE SCBU, Midwife |
| | Lorraine Anderson | Midwife |
| Tairāwhiti | Sandra Walsh | Midwifery Educator |
| | Estelle Mulligan | Midwife, Gisborne Hospital |
| Taranaki | Amanda Hinks | Clinical Midwife Leader |
| Hawke's Bay | Dr Lynda Croft | Obstetrician and Gynaecologist |
| Whanganui | Lucy Pettit | Midwife |
| | Robyn McDougal | Midwife |
| MidCentral | Billie Clayton | Midwife Educator |
| | Dr Ken Clarke | Consultant Obstetrician |
| Wairarapa | Donna Purvis | Team Leader Midwifery |
| Capital & Coast | Dr Dawn Elder | Senior Lecturer, Dept of Paediatrics |
| | Dr Rose Elder | Obstetrician |
| Hutt Valley | Joanne McMullan | Midwife |
| | Charlotte Smith | Midwife, Hutt Hospital |
| Nelson Marlborough | Dr Kevin Hill | Consultant Obstetrician/Gynaecologist |
| | Lois McTaggart | Clinical Midwife Leader |

| DHB | Local Co-ordinator | Work Role |
|------------------------------|--------------------|--|
| West Coast | Jude Bruce | Midwife |
| | Mary McGrane | Midwife |
| Canterbury | Dianne Leishman | Midwife |
| | Sonya Matthews | Midwife, Christchurch Women's Hospital |
| South Canterbury | Dr John Weir | Consultant Obstetrics and Gynaecology |
| | Dianne Keeman | Clinical Leader Maternity Services (Midwife) |
| Otago | Dr Susan Fleming | Medical Clinical Director Women's Health |
| | Helen Flockton | Charge Midwife |
| Southland | Jenny Humphries | Associate Director of Nursing and Midwifery, Maternal & Child |
| National Co-ordinator | Vicki Masson | v.masson@auckland.ac.nz Ph 09 373 7599 ext 84440 027 372 4833 Fax 09 303 5969 |

List of Abbreviations

| | |
|-----------|---|
| DHB | District Health Board |
| LMC | Lead Maternity Carer |
| MMRWG | Maternal Mortality Review Working Group |
| MRI | Magnetic resonance imaging |
| NHI | National Health Index |
| NZDep | New Zealand Deprivation Score |
| 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 |

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