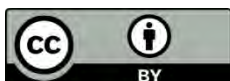


# Queensland perinatal and infant mortality taskforce report

April 2015

## **Queensland perinatal and infant mortality taskforce report**

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# Contents

Acknowledgement .....	1
Summary .....	1
Context .....	2
Rationale for the taskforce .....	2
Terms of reference .....	3
Membership .....	3
Previous work in relation to examining the causes and circumstances of Queensland's perinatal mortality rate .....	4
Background .....	5
Defining perinatal and infant mortality .....	6
(a) Perinatal mortality .....	6
(b) Infant mortality .....	7
International comparisons .....	7
Policy context .....	7
Analysis and key findings .....	8
Current practice initiatives .....	8
Comparisons of perinatal mortality rates between jurisdictions .....	10
Comparison of perinatal death rates between data sources .....	11
Examination and identification of common trends, causes and the circumstances of perinatal and infant deaths in Queensland .....	14
Infant mortality .....	19
Modifiable and non-modifiable factors influencing perinatal mortality .....	23
Future actions .....	26
Data collection and reporting .....	26
Enhance the roles of Queensland Maternal and Perinatal Quality Council and the Queensland Paediatric Quality Council .....	26
Clinical and systemic review of perinatal and infant deaths .....	27
Support for low volume rural maternity facilities .....	27
Enhancing clinical practice and strategies to address risk factors .....	27
Appendices .....	29
Abbreviations .....	30
References .....	31

## Acknowledgement

The Queensland Perinatal Taskforce (taskforce) acknowledges the sensitive nature of discussing perinatal and infant deaths and that this is an issue that touches the lives of many families. While it is easy to talk about statistics in a dispassionate manner the reality is that what is meant to be a happy event occasionally ends in tragedy that affects the lives of many people in a deeply personal way. The taskforce would like to express its sincere condolences to the mothers and families who have experienced a stillbirth or an infant death. It would also like to acknowledge the efforts of health practitioners who work to ensure a birth is a safe and happy event and who have supported those who have lived through a perinatal or infant death. These tragic events not only affect families, but also health staff.

## Summary

In August 2014, the Department of Health was asked to establish a taskforce to prepare a report for the former Queensland Minister for Health by 31 March 2015. The purpose of the taskforce was to examine the causes and circumstances of Queensland's high perinatal mortality rate and suggest appropriate policy and practice responses. The request to establish the taskforce was in response to a number of reports which showed that Queensland had a higher perinatal and infant mortality rate than most other Australian states and territories over a number of years.

- Fetal death (stillbirth) is defined as the death of a fetus which did not at any time after delivery breathe or show any other evidence of life, such as a heartbeat.
- Fetal deaths by definition include only infants weighing at least 400 grams or of a gestational age of at least 20 weeks.
- Neonatal death is the death of a live born infant within 28 days of birth.
- A perinatal death is a fetal or neonatal death.
- Infant mortality is defined as the death of a live born child less than one year of age.

Perinatal and infant mortality is influenced by a range of factors, such as individual risk factors present in the mother and fetus/infant, access to maternity services and quality of care provided. Socio-demographic factors may contribute to outcomes through increased risk behaviours, such as smoking and alcohol consumption, and factors, such as nutrition. There are a number of risk factors for perinatal mortality that are of particular risk in Indigenous populations. Sometimes perinatal and infant deaths are not able to be explained and many unfortunately cannot be prevented.

Maternal and infant health plays a crucial role in future health and wellbeing. Perinatal and infant death rates are an important indicator of the safety and quality of maternity services.

Different data sources make comparisons between jurisdictions difficult, however the taskforce is of the view that Queensland does not have a higher perinatal mortality rate compared with the Australian rate. This is due to Queensland having a higher neonatal mortality rate and a lower stillbirth rate, the sum of which gives a perinatal mortality rate comparable with the rest of Australia.

Based on the average of Australian and Queensland rates between 2007–2011, if Queensland had the same rates as Australia, Queensland would have 41 less neonatal deaths per year and 48 more stillbirths per year. In total, if Queensland had the same perinatal mortality rates as Australia for the past five years it would have seven more perinatal deaths per year on average.

The taskforce has concluded that the majority of perinatal deaths are unavoidable, as the causes of these deaths are due to lethal congenital anomalies, or deaths of babies born at or before the threshold of viability. It is not clear why Queensland has a higher neonatal mortality rate than Australia, however the taskforce believes that action should be taken to reduce any avoidable deaths.

In relation to post-neonatal infant mortality, the data shows an increased number of deaths in Queensland compared with other jurisdictions. For 2008–2010, the Queensland post-neonatal mortality rate was 1.5 per 1,000 live births and the rate for Australia was 1.2 per 1,000 live births. This equates to Queensland having an average extra 19 post-neonatal deaths per year compared with if Queensland had the same post-neonatal mortality rate as Australia.<sup>1</sup>

The rate of these deaths is low in both Australia and Queensland, relative to the rates of neonatal deaths and stillbirths. The low rate means the difference between Queensland and other jurisdictions is uncertain, however the taskforce believes the additional number of post neonatal infant deaths is enough to warrant further action.

The taskforce has made a range of findings and suggestions for future actions that cover a range of areas:

- improving data collection and reporting
- enhancing the role of the Queensland Maternal and Perinatal Quality Council (QMPQC) and the Queensland Paediatric Quality Council (QPQC)
- improving clinical and systemic review of perinatal and infant deaths
- supporting low volume maternity facilities
- enhancing clinical practice and strategies to address risk factors.

These future actions are designed to ensure there is a more accurate and comparable data set, a better understanding of the causes of death and associated trends, and a more effective system to respond to and address any emerging trends. The ultimate goal is to prevent, where possible, stillbirths or avoidable infant deaths.

## Context

### Rationale for the taskforce

In August 2014, the Department of Health was asked to establish a Queensland Perinatal Taskforce (taskforce) to prepare a report for the former Queensland Minister for Health by 31 March 2015. The purpose of the taskforce was to examine the causes

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<sup>1</sup> Based on 2008–10 data. More recent data is not yet available to allow comparison for a more recent period.

and circumstances of Queensland's high perinatal mortality rate and suggest appropriate policy and practice responses. The request to establish the taskforce was in response to a number of reports which showed that Queensland had a higher perinatal and infant mortality rate than most other Australian states and territories over a number of years.

Specifically, in July 2014, the National Health Performance Authority (NHPA) released a report titled *Healthy Communities: Maternal and Child Health 2009–2012*. The report showed that Queensland's infant and young child mortality rate was higher than all other jurisdictions, except the Northern Territory. The report also compared the mortality rates within seven peer groups of the 61 Medicare Local regions within Australia. These peer groups were established by the NHPA as it considered that these peer groups comprised of Medicare Local regions with similar socio-economic and demographic characteristics. The report found that Queensland's Medicare Local regions had either the highest or close to the highest mortality rate against their peers during the reporting period, noting that 70 per cent of the infant and young child deaths occurred before 28 days of life.

In addition to the NHPA report, Queensland's performance as reported in the annual *Report on Government Services (RoGS)* indicates Queensland had a higher perinatal and infant mortality rate over many years when compared with other jurisdictions, and often second only to the Northern Territory.

While the taskforce was initially formed to examine the apparent higher rate of perinatal mortality in Queensland, the membership of the taskforce considered that it should extend the scope to include infants up to one year of age. An expanded scope was considered appropriate due to concerns that Queensland also had a high post neonatal mortality rate (28–364 days of age) in comparison to other jurisdictions, and that there was an interrelationship between the neonatal period (0–27 days of age) and post neonatal periods.

## Terms of reference

The taskforce approved its *Terms of reference* establishing its purpose and processes. Importantly, the purpose of the taskforce was to:

- identify the impact of potential differences in recording practices of perinatal deaths in Queensland and other jurisdictions
- examine and identify common causes and the circumstances of perinatal and infant deaths in Queensland
- recommend solutions to reduce the rate of perinatal and infant mortality in Queensland
- provide recommendations regarding future policy and practice development for maternal, perinatal and infant health and care in Queensland.

## Membership

The taskforce's membership was based on knowledge and expertise in the areas of obstetrics, neonatal care, paediatrics, statistics and policy. Importantly, it included experts from interstate to act as critical friends in the taskforce's deliberations.

The membership was as follows:

Chair:

- Dr Jeannette Young, Chief Health Officer, Queensland

Members:

- Associate Professor Rebecca Kimble, Chair, Statewide Maternity and Neonatal Clinical Network
- Professor David Ellwood, Co-Chair, Perinatal Mortality Sub-Committee, QMPQC
- Dr Adrienne Gordon, Neonatologist, Royal Prince Alfred Hospital, Sydney
- Professor Michael Peek, Associate Dean and Head of School, Nepean Clinical School, University of Sydney
- Professor Cindy Shannon, Pro Vice-Chancellor (Indigenous Education), University of Queensland
- Mr Steve Armitage, Principal Commissioner, Queensland Family and Child Commission
- Dr Julie McEniery, Chair, Queensland Child and Youth Clinical Network and Chair, QPQC
- Dr David Cartwright, Director of Neonatology, Royal Brisbane and Women's Hospital
- Dr Frances Hughes, Chief Nursing and Midwifery Officer, Queensland Health

Ex-officio members:

- Ms Marianna Serghi, Executive Advisor, Aboriginal and Torres Strait Islander Health, Queensland Department of Health
- Ms Sue Cornes, Executive Director, Health Statistics Branch, Queensland Department of Health
- Ms Bronwyn Nardi, Senior Director, Policy and Clinician Engagement, Queensland Department of Health
- Mr Graham Kraak, Director, Strategic Policy, Queensland Department of Health

## **Previous work in relation to examining the causes and circumstances of Queensland's perinatal mortality rate**

The taskforce acknowledges the work of dedicated clinicians over many years in relation to perinatal and infant care in Queensland, and their efforts to improve outcomes for Queensland's children. Indeed, much of the work of the taskforce was made easier because of the previous work done by various quality councils and working groups.

Queensland has two quality councils, the Queensland Maternal and Perinatal Quality Council (QMPQC) and the Queensland Paediatric Quality Council (QPQC), which advise and recommend actions to the Minister for Health and Minister for Ambulance Services regarding maternal, perinatal and paediatric health. The quality councils were established in 2001 and held in abeyance from 2006 until 2010. While the quality

councils have now been re-established their profile and visibility is much reduced and consequently they have limited capacity to make recommendations and monitor their implementation.

The QMPQC provides advice and makes recommendations to the Minister for Health and Minister for Ambulance Services, and the Director-General of Queensland Health on matters relating to statewide and facility specific morbidity and mortality. The QMPQC has a number of sub-committees, including the Perinatal Mortality Sub-Committee that reviews and classifies perinatal deaths using the Perinatal Society of Australia and New Zealand (PSANZ) classification system as a means of identifying preventable factors associated with perinatal death. The sub-committee also provides education and support to hospitals in perinatal mortality audit, and makes recommendations and good practice points through the council's biennial report to the Minister for Health and Minister for Ambulance Services.

The QPQC has been established to:

- collect and analyse clinical information regarding paediatric mortality and morbidity in Queensland to identify statewide and facility-specific trends
- make recommendations to the Minister for Health and Minister for Ambulance Services on standards and quality indicators of paediatric clinical care to enable health providers in Queensland to improve safety and quality
- assist with the adoption of such standards in both public and private sectors.

Prior to the formation of the taskforce, a Perinatal Mortality Working Group was formed in September 2013 to examine the causes of the apparent higher incidence of perinatal mortality in Queensland, and to identify action to address these causes. The working group identified a number of areas where improvements can be made to reduce the perinatal mortality rate, including reinforcing public health messages for expectant mothers. The taskforce has considered the suggestions made by this group in forming its recommendations.

## Background

In Australia in 2012, there were a total of 312,153 births of which 63,709 were in Queensland. Of the Queensland births, 459 were fetal deaths (stillbirths) and 182 were neonatal deaths making a total of 641 perinatal deaths. This equates to approximately 10 perinatal deaths per 1,000 births.<sup>2</sup>

Perinatal and infant mortality is influenced by a range of factors, such as individual risk factors present in the mother and fetus/infant, access to maternity services and quality of care provided. Socio-demographic factors may contribute to outcomes through increased risk behaviours, such as smoking and alcohol consumption, and factors, such as nutrition. Sometimes perinatal and infant deaths are cannot be explained and many, unfortunately, cannot be prevented.

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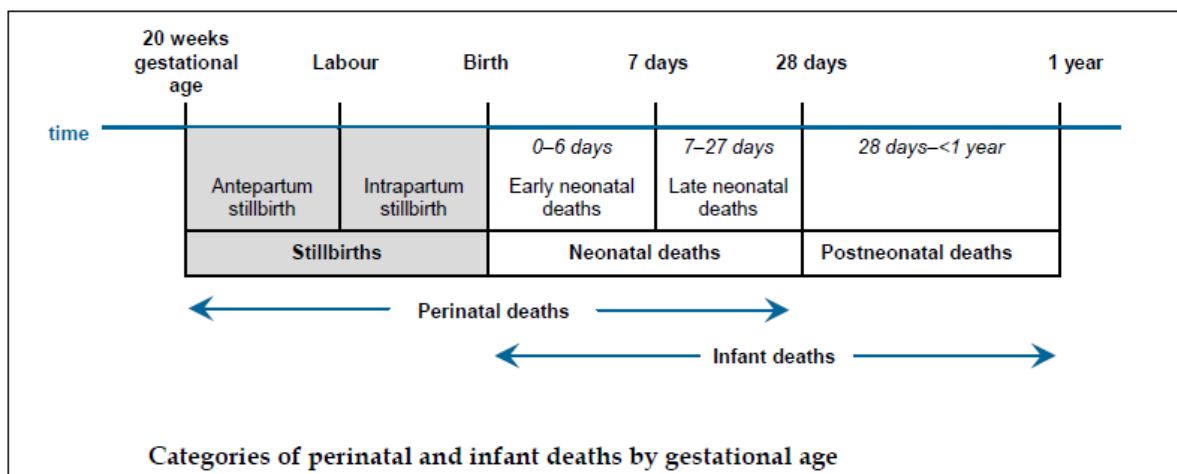
<sup>2</sup> AIHW (2013) Australia's mothers and babies 2012, [www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129550054](http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129550054) (accessed 12 March 2015)



## Defining perinatal and infant mortality

It is important there is a clear understanding of the different terms that are used both in the report and in other reports. Figure 1 below provides the categorisation of deaths based on gestational or infant age.

**Figure 1** Timeline for perinatal and infant deaths<sup>3</sup>



It should be noted that while the figure depicts a hard line between a stillbirth and neonatal death, the differentiation between these two categories is defined as whether or not a baby had at least one heartbeat or took one breath immediately after birth. In practice, this may not always be readily observable and so there may be some fluidity between the numbers of stillbirths and neonatal deaths.

### (a) Perinatal mortality

Each jurisdiction has its own legislative definitions of perinatal mortality, live birth, stillbirth and neonatal death, and data collection practices. The RoGS defines a perinatal death as a fetal death or neonatal death. A fetal death (stillbirth) is the death of a fetus which did not at any time after delivery breathe or show any other evidence of life, such as a heartbeat. Fetal deaths by definition include only infants weighing at least 400 grams or of a gestational age of at least 20 weeks. A neonatal death is the death of a live born infant within 28 days of birth.<sup>4</sup> In Queensland, the *Public Health Act 2005* defines a baby not born alive (i.e. a stillbirth) as one who has shown no sign of respiration or heartbeat, or other sign of life, after completely leaving the child's mother, and who has been gestated for 20 weeks or more, or weighs 400 grams or more.<sup>5</sup>

<sup>3</sup> AIHW (2013) Australia's mothers and babies 2011, [www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545698](http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545698) (accessed 11 December 2014)

<sup>4</sup> Report on Government Services 2015, [www.pc.gov.au/research/recurring/report-on-government-services/2015/health/public-hospitals/rogs-2015-volume-e-chapter11.pdf](http://www.pc.gov.au/research/recurring/report-on-government-services/2015/health/public-hospitals/rogs-2015-volume-e-chapter11.pdf) (accessed 23 April 2015)

<sup>5</sup> Public Health Act 2005 <https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PubHealA05.pdf> (accessed 23 April 2015)

## (b) Infant mortality

Infant mortality is defined as the death of a live born child less than one year of age.

## International comparisons

Making meaningful comparisons between Australia's perinatal mortality rate and other countries is very difficult as different weights, gestational ages and time after birth limits apply to perinatal deaths. The World Health Organization (WHO) recommends reporting stillbirths weighing 500 grams or born at or after 22 weeks gestation and defines neonatal deaths among live born babies up to seven days after birth. However, WHO restricts the criteria for international comparisons to birthweight of 1000 grams, gestational age of 28 weeks (if birthweight is unavailable) and deaths in the first seven days after birth. The definition applied has an impact on the reported rates, especially when lower gestational ages and lower birthweight are included. This is important because perinatal mortality generally increases with decreasing birthweight, decreasing gestational age and multiple births. Therefore, caution is needed when comparing published reports of Australia's perinatal rate with published figures for other countries.

## Policy context

The *National Maternity Services Plan*<sup>6</sup> (NMSP) provides a strategic national framework to guide policy and program development over five years from 2010. It aims to improve, coordinate and ensure greater access to maternity services in Australia. Priorities for the NMSP encompass four areas: access, service delivery, workforce and infrastructure. It identifies a range of actions that may have an impact on perinatal and infant mortality, including increase access to high quality maternity care, such as:

- expanding models of care
- ensuring Australian maternity services provide high-quality evidence-based maternity care
- ensuring all maternity care is provided within a safety and quality system.

Queensland is implementing the NMSP through a range of initiatives, including ensuring that pregnant women have timely access to appropriate antenatal services as close to home as possible, reintroduction of birthing services in some rural areas and the expansion of postnatal support services (including the mums and bubs visits following birth). In addition, evolving service models and Hospital and Health Service maternity development intentions are captured twice a year as part of the *Maternity Service Overview Report*.

The NMSP recognises the need for consistent, comprehensive national data collection, monitoring and review of maternal and perinatal mortality and morbidity. The *National Maternity Data Development Project* was established to improve maternity data

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<sup>6</sup> National Maternity Services Plan (2010),

[http://www.health.gov.au/internet/main/publishing.nsf/Content/8AF951CE492C799FCA257BF0001C1A4E/\\$File/maternityplan.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8AF951CE492C799FCA257BF0001C1A4E/$File/maternityplan.pdf) (accessed 16 February 2015)

collection and outcome reporting. This project is also focusing on improving consistency of perinatal mortality data through the *Perinatal Mortality Report Project*.

Perinatal and infant mortality rates are one of the key performance indicators for hospital maternity services in the annual RoGS, which focuses on services that make an important contribution to health of the community, reflect government priorities, represent significant components of government recurrent expenditure and have common objectives across jurisdictions. Queensland's perinatal and infant death rates in the RoGS shows that Queensland has had a higher perinatal and infant mortality rate over many years when compared with other jurisdictions, and often second only to the Northern Territory.

Perinatal and infant mortality rates are higher for Aboriginal and Torres Strait Islander babies. In the 2015 RoGS, the perinatal death rate for Queensland Indigenous children was 11.1 compared with 9.8 for non-Indigenous children. The infant mortality rate for Queensland Aboriginal and Torres Strait Islander children was 6.9 compared with 4.5 for non-Indigenous children. Closing the gap in child health outcomes between Indigenous and non-Indigenous Australians is a priority area of action, endorsed in 2008 by the Council of Australian Governments (COAG). As part of the COAG agenda, the Commonwealth, states and territories agreed to the target of halving the gap in mortality rates for Indigenous children under five by 2018.

## Analysis and key findings

### Current practice initiatives

Queensland Health undertakes a range of activities to address risk factors and intervene to prevent perinatal and infant death whenever possible, including, but not limited to:

- Ongoing risk assessment and management during the antenatal, intra-partum and post-partum period.
- Continuity of maternity care models to provide seamless and integrated care, and the identification and management of risks.
- *Perinatal and Infant Death Review*—the QMPQC review all perinatal deaths and classifies deaths using the Perinatal Society of Australia and New Zealand (PSANZ) classification system. The purpose of classifying deaths according to the PSANZ classification system is to identify preventable factors associated with perinatal death, through the systematic application of clinically relevant categories to large populations. In the near future, the QPQC will undertake a similar process of reviewing all infant deaths in Queensland. The review's purpose will identify trends, causes and identify preventable factors
- The Health Statistics Branch conducts regular analysis of perinatal, admitted patient and death registration data, and prepares reports in conjunction with the QMPQC to identify and highlight any issues of concern.

- The Patient Safety Unit monitors critical incidents across the state on a daily basis, tracking any potential trends in patient safety issues and identifying opportunities for improvement in patient care.
- The Children's Early Warning Tool (CEWT) is a clinical observation chart for use in general medical and surgical paediatric settings, and has been designed in accordance with human factors principles:
  - CEWT includes the capacity to record respiratory rate, level of respiratory distress, oxygen flow rate, oxygen saturations, temperature, heart rate, blood pressure, and capillary refill, level of consciousness and pain level graphically over time.
  - CEWT includes thresholds for each physiological parameter that indicate abnormality and specifies the physiological abnormalities that trigger escalation in care, including the actions required when care is escalated.
  - CEWT is used around the state in all paediatric settings and assist clinicians in recognising and responding to clinical deterioration.
- The Queensland Maternity Early Warning Tool (Q-MEWT) is a clinical observation chart for use in antenatal and post-natal clinical settings, and has been designed in accordance with human factors principles:
  - Q-MEWT includes the capacity to record maternal respiratory rate, oxygen saturations, oxygen flow rate, systolic blood pressure, diastolic blood pressure, heart rate, and temperature, level of consciousness and blood loss pain level graphically over time. The antenatal version of Q-MEWT also has the capacity to record fetal heart rate.
  - Q-MEWT includes thresholds for each physiological parameter that indicate abnormality and specifies the physiological abnormalities that trigger escalation in care, including the actions required when care is escalated.
  - Q-MEWT is used around the state in all maternity settings except the Townsville Hospital and assists clinicians in recognising and responding to clinical deterioration.
- Ryan's Rule is a patient, family and carer escalation process. Ryan's Rule provides a standardised statewide process for patients or relatives to seek an independent clinical review. Ryan's Rule provides an additional safety net for patients and their families in obtaining assistance.
- The enhanced Maternal and Child Health Service (the *Mums and Bubs* initiative) aims to enhance maternal and infant health and wellbeing by providing two home visits in the first month of a baby's life. These visits can be followed up with consultations at community centres at key developmental stages, namely, two, four, six to eight and 12 months of age. Home visits are provided by a midwife or a child health nurse and give parents an opportunity to discuss a range of early parenting and child development issues in the comfort of their own homes. These visits include an assessment of the growth and development of the child and the health of the mother following birth. It is also an opportunity to provide accurate information and advice on subjects, such as immunisation, sleep, safe environments to prevent injuries, the importance of reading to young children, breastfeeding and nutrition, and anticipatory guidance for child growth and development.

- Cross checking of birth and death data—in Queensland a rigorous process is undertaken by the Health Statistics Branch to cross check all birth and death data to ensure Queensland data is as complete as possible.
- Hospital and Health Services (HHSs) are encouraged to access the *Improving Perinatal Review and Outcomes Via Education (IMPROVE)* program. IMPROVE provides education to healthcare professionals on how to use the PSANZ *Perinatal Mortality Guidelines* to ensure mothers and families receive the best care in the hospital setting. IMPROVE covers appropriate practices around principles of bereavement care, communicating with parents about autopsy, clinical examination, placental and post-mortem examination, investigation, classification, and audit of stillbirth.

While there are numerous strategies, programs and initiatives that aim to improve the health and wellbeing of children and families, more work is required to align services and focus them on efforts to reduce perinatal and infant mortality.

Finding 1: Queensland provides excellent maternity care, however improvement in maternity services should be continuous.

Finding 2: Work is required to better align services and focus them on efforts to reduce perinatal and infant mortality.

## Comparisons of perinatal mortality rates between jurisdictions

Each jurisdiction has its own legislative definitions of perinatal mortality, live birth, stillbirth and neonatal death, and data collection practices. This leads to differences in the way in which data is recorded and reported to the Australian Bureau of Statistics (ABS) or the Australian Institute of Health and Welfare (AIHW).

In addition to differences in definition, there are also two different sources of perinatal mortality data in Australia. The official source of mortality data in Australia is the ABS. The source of ABS perinatal information is stillbirth and death registration data provided by the Registrar of Births, Deaths and Marriages in each state and territory. Mortality rates reported in RoGS are sourced from ABS data.

Perinatal deaths are also reported annually in the *Australia's Mothers and Babies Report* series produced by the AIHW and the National Perinatal Epidemiology and Statistics Unit (NPESU). This report is based on data collected at the time of birth by each state and territory health authorities that is collected to form the National Perinatal Data Collection (NPDC).

There is currently no nationally standardised data collection that allows for consistent reporting of perinatal mortality across jurisdictions. The taskforce considers this to be a significant issue and makes it impossible to accurately compare perinatal mortality rates across Australia. The *National Maternity Data Development Project* is addressing this issue through the *Perinatal Mortality Report Project* and is aiming to publish a

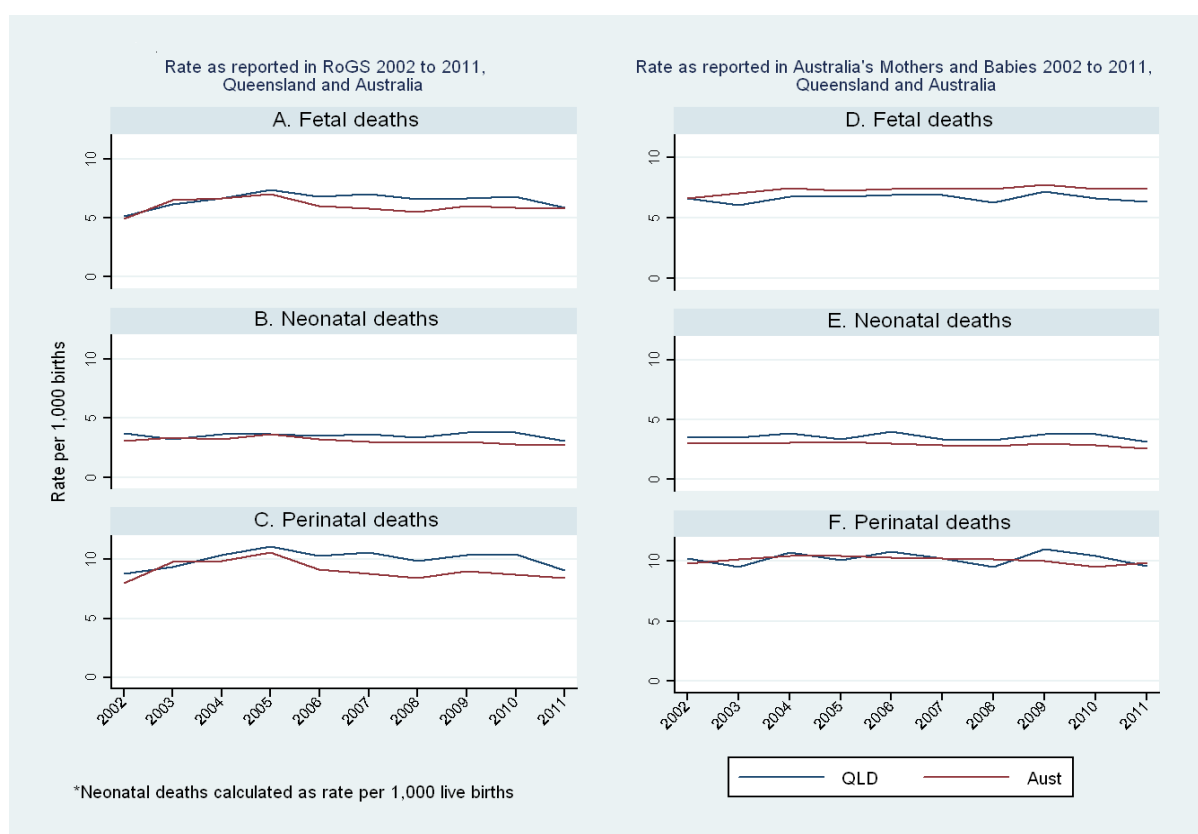
report, 'Perinatal Deaths in Australia 1993–2012' in mid-2015, however much work will be required to address this issue in practice.

**Finding 3:** Due to different legislative definitions, data sources and recording practices it is difficult to compare Queensland's perinatal mortality rate to that of other Australian jurisdictions.

## Comparison of perinatal death rates between data sources

In both RoGS and the *Australia's Mothers and Babies report* series, an excess in the rate of neonatal mortality in Queensland relative to Australia has been observed over the last decade (refer to Figure 2 below, plots B and E). In RoGS only, an excess in stillbirths and perinatal mortality rates has been observed in Queensland over this period (refer to Figure 2 below, plots A and C).

**Figure 2 Neonatal, fetal (stillbirth) and perinatal mortality rate, as reported in RoGS and the AIHW Australia's Mothers and Babies reports, 2002 to 2011, Queensland and Australia**



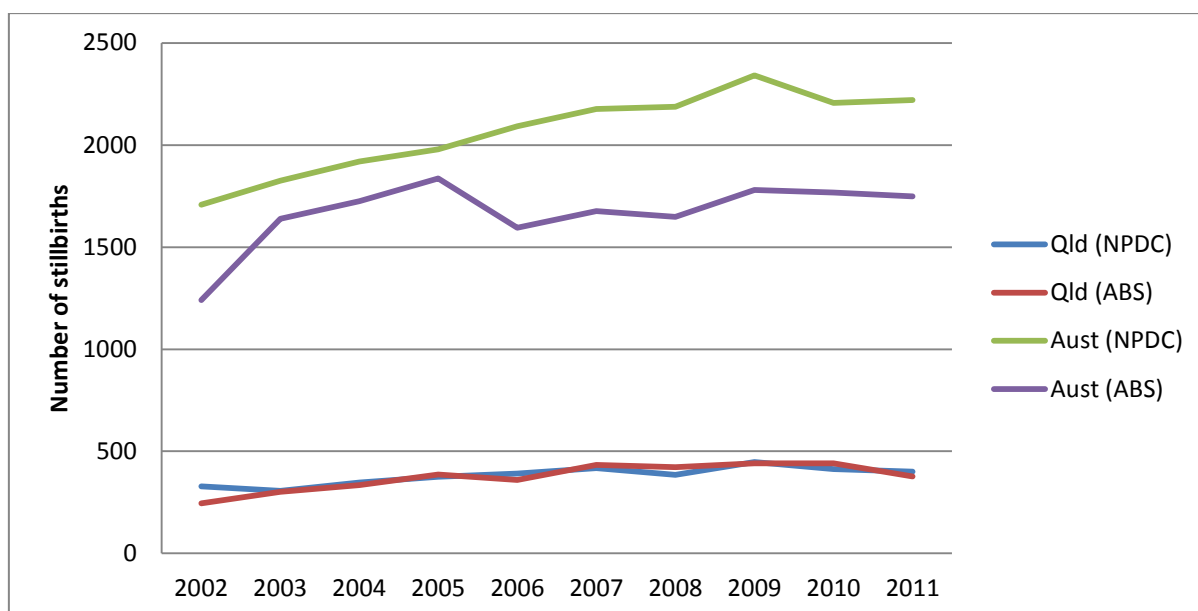
It is important to note the data used to calculate these indicators in the two reports come from two different sources.

- In the RoGS, stillbirths and neonatal mortality are based on birth and death registration data as reported by the ABS.
- In the AIHW *Australia's Mothers and Babies* reports, stillbirths and neonatal mortality are based on NPDC.

Comparison of numbers of stillbirths for Queensland and Australia from the two data sources over the last decade shows that for all of Australia a large number of stillbirths have consistently been missed in data submitted to the ABS compared with those reported to the AIHW for the NPDC. The number submitted to the ABS and AIHW for Queensland is very similar (refer to Figure 3). This reflects the rigorous cross checking of birth and death data undertaken by Queensland Health to ensure all data submitted is accurate.

Based on the average of Australian and Queensland rates for the past five years as per the AIHW, if Queensland had the same rates as Australia, Queensland would have 41 less neonatal deaths per year and 48 more stillbirths per year. In total, if Queensland had the same mortality rates as Australia for the past five years it would have seven more perinatal deaths per year on average.

**Figure 3** Count of stillbirths in Australia’s Mothers and Babies reports (NPDC) and RoGS (based on ABS data), 2002 to 2011, Queensland and Australia.



Source: National Perinatal Data Collection; ABS Perinatal deaths, Australia, Cat. No. 3304.0, Canberra (unpublished).

Variation in legislation and practices for registration of stillbirths across jurisdictions is likely to be the cause of the lower rate of stillbirths in the ABS data compared to those captured in the NPDC.

- In all jurisdictions, registration of stillbirths requires notification by a doctor and by one or both parents. While within most jurisdictions there is capacity to partially register a stillbirth, only fully registered stillbirths are reported to the ABS for inclusion in calculation of national statistics.<sup>7</sup> It has been noted that in Queensland alternative informants may provide the second part of a notification to fully register a perinatal death.<sup>8</sup>

<sup>7</sup> AIHW, 2014, AIHW, Hilder et al, 2014

<sup>8</sup> AIHW, 2014

- The higher capture rates in Queensland may also be because in Queensland stillbirths are registered as a birth and a death, whereas in the majority of jurisdictions (apart from Western Australia) they are only registered as a birth.
- Further, at least in South Australia, terminations of pregnancy are explicitly excluded from vital statistics reporting (that is, birth and death registrations), but are included in the data reported to the NPDC. Some removal of terminations also occurs in Victoria where terminations of pregnancy for psychosocial reasons (which in 2010 was 191 of 743 stillbirths) are not included in vital statistics reported to the ABS.

This suggests that Queensland does not have a higher perinatal mortality rate than other jurisdictions. That is, while the neonatal mortality rate in Queensland is higher than in Australia, the stillbirth rate is actually lower, if the more complete data is used to make the comparison (refer to Figure 2, plots D and F).

Possible reasons for the higher rate of neonatal deaths and lower rate of stillbirths in Queensland include:

- The difference may be related to variation in classification of deaths. The timing of neonatal deaths by jurisdiction was examined to investigate whether classification of babies who take one or two breaths at birth may be occurring differently across jurisdictions. Data was extracted from death registration data for the period for which national data was available (2002–2006). Appendix A shows the cumulative proportion of neonatal deaths by jurisdiction by time. This figure suggests that it is not a simple misclassification issue since classification of deaths during the first few minutes or even hours is similar in Queensland to other jurisdictions.
- The difference may reflect a variation in environment or practice, resulting in a greater proportion of the babies who do not survive the perinatal period being born alive in Queensland than in other jurisdictions.
  - Some of the variation in proportion may be related to coding of termination of pregnancy. In some jurisdictions, all terminations are automatically classified as a stillbirth while in Queensland terminations of pregnancy where the baby is born alive are classified as a neonatal death. If births that occurred in Queensland that were coded as a live birth and had termination of pregnancy listed as the main cause of death (20 out of 99 births with the main cause of death coded as termination of pregnancy) were counted as a stillbirth, the stillbirth rate in Queensland in 2011 would increase from 6.4 to 6.8 per 1,000 births and the neonatal mortality rate would decrease from 3.2 to 2.9 per 1,000 live births. As this only includes deaths where the main cause of death was able to be coded as termination of pregnancy and there are numerous deaths that are likely to be terminations of pregnancy, but that do not explicitly state that it is a termination (e.g. inductions prior to 24 weeks gestation) so are not coded as such, it is likely that the decrease in Queensland's neonatal mortality rate if all terminations were reclassified as stillbirths would be even greater.
  - It is also possible that the difficulty in accessing a late termination in Queensland may result in a number of babies with lethal congenital anomalies being born alive, but subsequently dying and being counted as a neonatal death. Causes of death for infant deaths in Queensland and Australia are shown in Appendix B. Possibly the higher rate for congenital anomalies that commonly result in a termination of pregnancy, such as chromosomal abnormalities, in Queensland is supportive of this hypothesis.



Based on available data, it is not clear why Queensland has a higher neonatal mortality rate than Australia, though it does appear the excess in neonatal deaths is largely balanced out by a lower rate of stillbirths (refer to Figure 2, Plots D, E and F).

Finding 4: Queensland does not have a higher overall perinatal mortality rate than other Australian jurisdictions, but does have a higher neonatal mortality rate.

Finding 5: The majority of perinatal deaths are unavoidable, for example, deaths due to lethal congenital anomalies, or deaths of babies born at the threshold of viability.

Finding 6: It is not clear why Queensland has a higher neonatal mortality rate than Australia, however action should be taken to reduce any avoidable deaths.

Finding 7: Queensland's recording of terminations of pregnancy by clinicians on death certificates and in hospital records is often not adequate to allow clear identification of perinatal deaths that are the result of termination of pregnancy. There are no national standards relating to:

- recording of terminations of pregnancy
- the degree of certainty required to allow them to be coded as such
- the practices associated with assignment of terminations of pregnancy as a stillbirth or live birth.

This means it is likely that reporting of terminations of pregnancy in Queensland is not consistent with other jurisdictions which may have an impact on the relative proportion of stillbirths and neonatal deaths in Queensland relative to other jurisdictions. Further, the timing of terminations will have an impact on where and how they are recorded (that is whether they are recorded as a birth and a death in official records) and there are no data available to allow an evaluation of this issue.

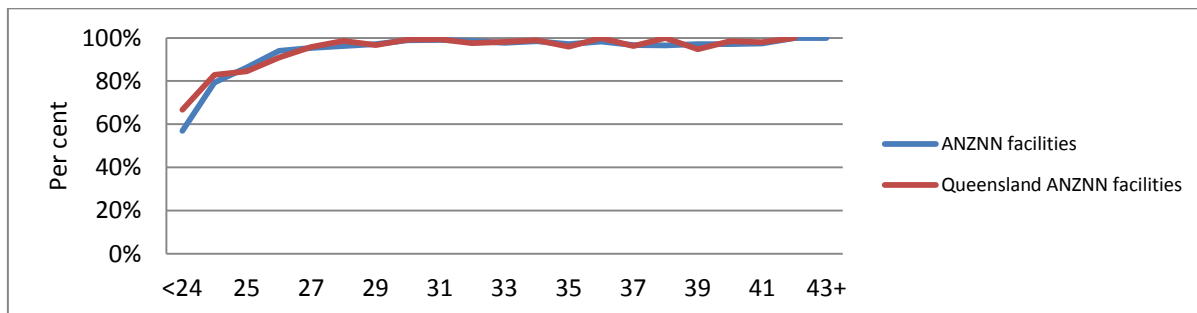
## **Examination and identification of common trends, causes and the circumstances of perinatal and infant deaths in Queensland**

The neonatal mortality rate in Queensland was compared within several sub-populations to further explore factors related to the higher neonatal mortality rate in Queensland.

Neonatal mortality rates for babies admitted to neonatal intensive care units (NICU) and special care nurseries (SCN) in Queensland were compared with those included in an audit conducted by the Australian and New Zealand Neonatal Network, reported in

the Australian and New Zealand Neonatal Network (ANZNN) report.<sup>9</sup> The proportion of babies surviving to 28 days, by gestational age, was compared (refer to Figures 4 and 5). These results show the neonatal mortality rate is very similar in Queensland and ANZNN hospitals for babies who are treated in a level two or three facility.

**Figure 4** Proportion surviving to 28 days in level three registrants by gestational age at birth, 2012, Queensland facilities included in ANZNN and all facilities included in ANZNN audit (including Queensland)

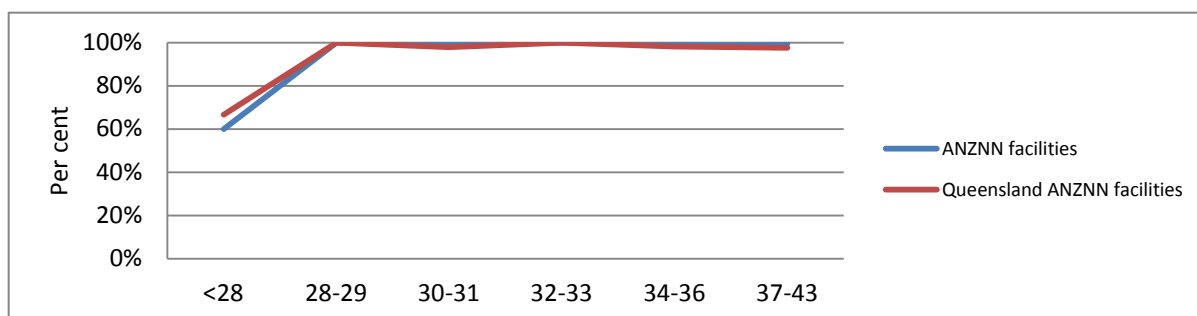


Source: ANZNN data for Queensland received 19 January 2015, Table 30: Report of the ANZNN, Chow, S.S.W. 2014. Report of the ANZNN 2012. Sydney: ANZNN.

**Notes:**

- Only babies who were born in 2012 and registered to an ANZNN member NICU (level three) in Queensland are included.
- Only babies who met ANZNN criteria were registered. Numbers are therefore not reflective of all births or admissions to NICU/special care.
- Admission to a member NICU/special care unit does not imply ANZNN registration to that unit, even if the baby met ANZNN criteria (that is, if transferred from another interstate member unit).

**Figure 5** Proportion surviving to 28 days in level two registrants by gestational age at birth, 2012, Queensland facilities included in ANZNN and all facilities included in ANZNN audit (including Queensland)



Source: ANZNN data for Queensland received 19 January 2015, Table 38: Report of the ANZNN (accessed 8 October 2014 via [www.npesu.unsw.edu.au/data-collection/australian-new-zealand-neonatal-network-anznn](http://www.npesu.unsw.edu.au/data-collection/australian-new-zealand-neonatal-network-anznn))

**Notes:**

- Only babies who were born in 2012 and registered to an ANZNN member NICU (level two) are included.

<sup>9</sup> Chow, S.S.W. 2014. Report of the ANZNN 2012. Sydney: ANZNN.

- *Only babies who met ANZNN criteria were registered. Numbers are therefore not reflective of all births or admissions to NICU/special care.*
- *Admission to a member NICU/special care unit does not imply ANZNN registration to that unit, even if the baby met ANZNN criteria (e.g. If transferred from another interstate member unit).*
- *Not all special care units in Queensland are ANZNN members.*

Births to Indigenous women have been shown to be associated with higher rates of neonatal mortality than births to non-Indigenous women.<sup>10</sup> However, the small number of births to Indigenous women relative to non-Indigenous women in Queensland and Australia means the high rates of neonatal mortality in Queensland women cannot be solely explained by the higher rates of Indigenous neonatal mortality.<sup>11</sup>

Access to care at the required level for births within Queensland is largely controlled through providing antenatal care and screening and transferring high-risk women to facilities with a level of care appropriate to their level of risk. However, not all risk can be identified prior to the birth event, particularly for babies born unexpectedly at a very early gestation. Further analyses were conducted to explore the impact of facility volume on neonatal mortality rates with adjustment for selected risk factors. A ratio of observed neonatal mortality rate to that expected if differences in gestation, maternal smoking and severe congenital anomalies were removed was calculated for three types of facility: specialist obstetric services with maternal-fetal medicine and NICU, specialist obstetric services with a SCN and all births occurring outside of these facilities (facilities with neither a NICU nor SCN and babies born outside of hospital). Coded terminations of pregnancy were removed so that facilities where a larger number of terminations were performed were not unfairly disadvantaged. These analyses found that smaller facilities were associated with a higher risk of neonatal mortality (refer to Table 1).

Improving access to the combined first trimester screening which includes a nuchal translucency scan at 12 weeks may assist families and reduce the neonatal death rate by providing women and families with information with which to make decisions about whether to continue a pregnancy when severe chromosomal abnormalities have been detected. Issues related to equity of access for women living in rural and remote areas, Indigenous women, and low socio-economic circumstances would need to be addressed so that all women have access to this screening in accordance with their risk status.<sup>12</sup>

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<sup>10</sup> Utz et al., 2014

<sup>11</sup> ABS 3303.0 Causes of Death, Australia, 2012, released 25 March 2014

<sup>12</sup> StatBite 44, Antenatal Screening in Queensland 1 July 2007 to 30 June 2010: Maternal characteristics [www.health.qld.gov.au/hstu/pdf/statbite/statbite44.pdf](http://www.health.qld.gov.au/hstu/pdf/statbite/statbite44.pdf) (accessed 1 April 2015)

**Table 1 Standardised mortality ratios adjusted for gestation, maternal smoking and severe congenital anomalies (excluding coded terminations of pregnancy\*), Queensland 2011**

Facility type	Standardised mortality ratio (observed/expected)**	Lower 95% confidence limit	Upper 95% confidence limit
Specialist obstetric services with maternal-fetal medicine and NICU	0.82	0.66	0.97
Specialist obstetric services with a SCN	1.28	1.07	1.50
All other births	1.63	1.05	2.20

Source: Queensland Perinatal Data Collection. \*Records where the baby's main cause of death was recorded as P96.4 'Termination of pregnancy, affecting foetus and newborn' were excluded. \*\*Ratios less than one indicate lower observed mortality rate than expected; ratios greater than one indicate higher observed mortality rate than expected.

Within Queensland, higher rates of neonatal mortality occur in several HHSs, as shown in Appendix C. A multivariate analysis of factors related to variation in risk showed that several modifiable factors, including maternal smoking, lower than recommended levels of antenatal care, and maternal overweight and obesity are related to higher rates of neonatal mortality and its precursor, pre-term births. Perinatal mortality, post-neonatal mortality, length of gestation, birth weight and risk factors found in multivariate modelling to be associated with an increased risk of adverse outcomes are presented by HHS of usual residence for Queensland. Comparable figures for Australia are also provided (refer to Appendix C). This data shows there is variation in outcomes and risk factors within Queensland that may be reduced through improved access to antenatal care and reduction in risk factors, such as smoking during pregnancy.

Neonatal mortality rates by gestational age, birthweight and plurality in Queensland and Australia were compared (refer to Tables 2 to 4). The data suggests neonatal mortality rates in Queensland are similar to the Australian rate for very low gestational ages (20–27 weeks), but higher for all other categories, including at term. This pattern provides support for the assertion that very early births are not merely being differently classified in Queensland as neonatal deaths rather than as stillbirths. In addition, it suggests management of births occurring at very early gestation is similar in Queensland to other jurisdictions. The data also shows that Queensland has a much lower stillbirth rate than Australia for babies born at low gestational age and birth weight. The results by plurality (refer to Table 4) also show a lower stillbirth rate and a higher neonatal mortality rate in Queensland than in the rest of Australia for both singletons and twins. These results suggest an underlying practice or process that is consistent across gestation, birthweight and plurality that is resulting in a higher neonatal mortality rate and a lower stillbirth rate.

**Table 2 Stillbirth, neonatal and perinatal mortality rates per 1,000 births (b) by gestational age, 2011, Queensland and Australia**

	Gestational age (weeks)				
	20–27	28–31	32–36	37–41	42 and over
<b>Queensland</b>					
Stillbirths	424.1	81.3	12.4	1.3	0.0
Neonatal deaths (a)	390.5	28.8	5.8	0.7	0.0
Perinatal deaths (a)	649.0	107.8	18.1	1.9	0.0
<b>Australia</b>					
Stillbirths	505.7	81.2	13.3	1.4	1.4
Neonatal deaths (a)	392.7	27.2	3.5	0.4	0.0
Perinatal deaths (a)	699.8	106.1	16.8	1.8	1.9

(a) Except in Western Australian and Queensland, these may exclude neonatal deaths within 28 days of birth for babies transferred to another hospital or readmitted to hospital and those dying at home.

(b) Stillbirth and perinatal death rates were calculated using all births (live births and stillbirths). Neonatal death rates were calculated using all live births.

Source: Queensland Perinatal Data Collection, National Perinatal Data Collection

**Table 3 Stillbirth, neonatal and perinatal mortality rates per 1,000 births (b) by birth weight, 2011, Queensland and Australia**

	Birth weight (g)				
	Less than 1,500	1,500–2,499	2,500–2,999	3,000–3,999	4,000 and over
<b>Queensland</b>					
Stillbirths	290.6	12.0	2.9	1.0	0.9
Neonatal deaths (a)	198.3	7.3	2.1	0.5	0.1
Perinatal deaths (a)	431.2	19.2	5.0	1.5	1.0
<b>Australia</b>					
Stillbirths	334.6	13.3	3.4	1.1	1.0
Neonatal deaths (a)	186.0	5.1	1.0	0.3	0.3
Perinatal deaths (a)	458.4	18.4	4.3	1.4	1.2

(a) Except in Western Australia and Queensland, these may exclude neonatal deaths within 28 days of birth for babies transferred to another hospital or readmitted to hospital and those dying at home.

(b) Stillbirth and perinatal death rates were calculated using all births (live births and stillbirths). Neonatal death rates were calculated using all live births.

Source: Queensland Perinatal Data Collection, National Perinatal Data Collection

**Table 4 Stillbirth, neonatal and perinatal mortality rates per 1,000 births (b) by plurality, 2011, Queensland and Australia**

	Plurality		
	Singletons	Twins	Higher-order multiples
<b>Queensland</b>			
Stillbirths	6.1	15.5	74.1
Neonatal deaths (a)	2.8	16.3	0.0
Perinatal deaths (a)	8.8	31.5	74.1
<b>Australia</b>			
Stillbirths	6.9	20.6	70.2
Neonatal deaths (a)	2.2	14.6	23.6
Perinatal deaths (a)	9.1	34.8	92.1

(a) Except in Western Australia and Queensland, these may exclude neonatal deaths within 28 days of birth for babies transferred to another hospital or readmitted to hospital and those dying at home.

(b) Stillbirth and perinatal death rates were calculated using all births (live births and stillbirths). Neonatal death rates were calculated using all live births.

Source: Queensland Perinatal Data Collection, National Perinatal Data Collection

**Finding 8:** There is lower perinatal mortality associated with facilities with direct access to specialist services. Smaller facilities were associated with a higher risk of neonatal mortality. Access to specialist services is important for high-risk births. Babies with a high risk of mortality are more likely to survive if they are born at facilities with direct access to specialist services.

**Finding 9:** Modifiable factors, including maternal smoking, lower than recommended levels of antenatal care, and maternal overweight and obesity are related to higher rates of neonatal mortality.

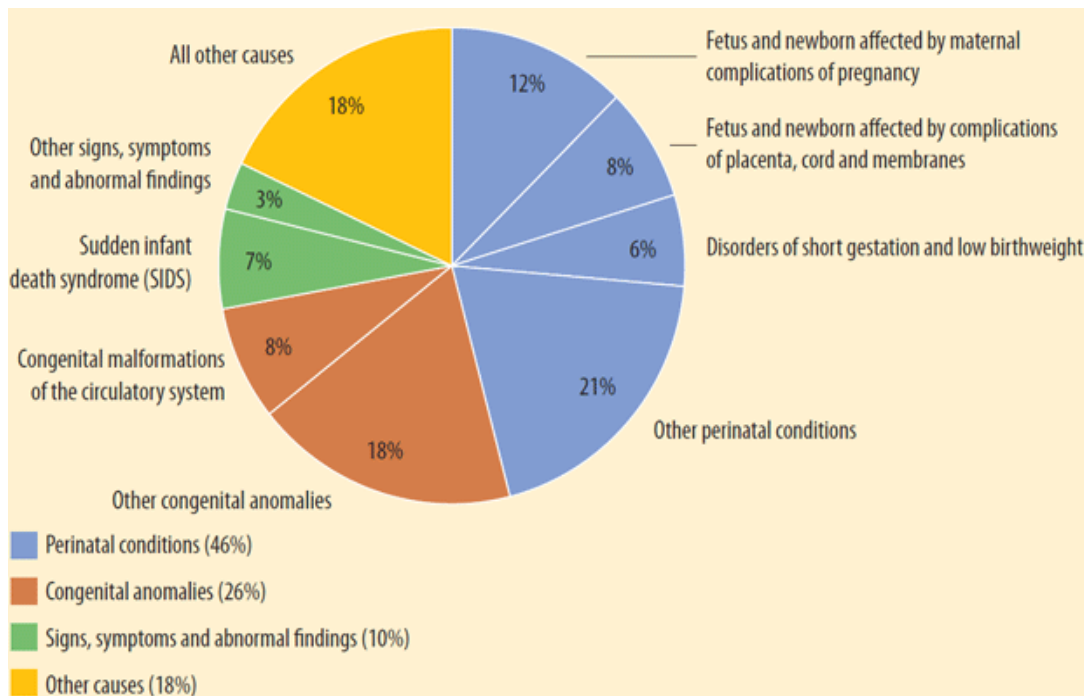
**Finding 10:** Improving access to the combined first trimester screening may assist families and reduce the neonatal death rate by providing women and families with information with which to make decisions about whether to continue a pregnancy when severe chromosomal abnormalities have been detected.

## Infant mortality

In 2010, there were 1229 deaths in Australia of infants aged less than one year, which is almost three-quarters (71 per cent) of all deaths among children aged 0–14 years. More than two-thirds (69 per cent) of infant deaths (deaths before the age of one) were in the neonatal period (first 28 days), of which almost half (48 per cent) were on the day of birth.

The three leading causes of infant death are perinatal conditions (such as maternal complications during pregnancy), congenital anomalies and other symptoms, signs and abnormal findings (which include Sudden Infant Death Syndrome)—refer to Figure 6.

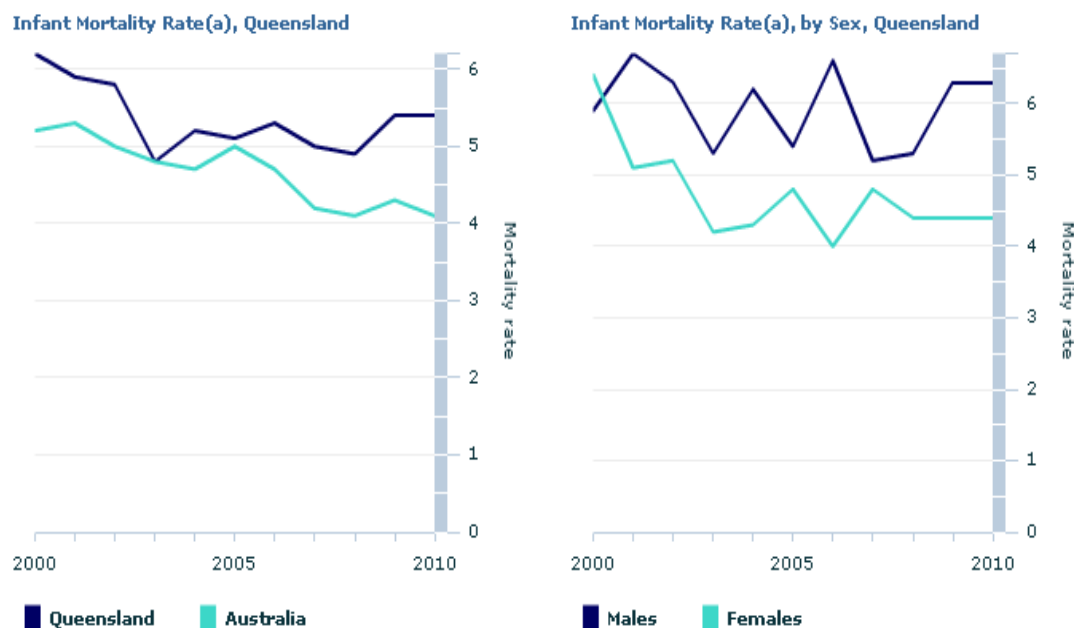
**Figure 6** Leading causes of infant mortality 2008–2010<sup>13</sup>



In 2010 in Queensland, infant mortality rates were 5.4 per 1,000 compared to the Australian rate of 4.1 per 1,000 (refer to Figure 7). There is a gender difference in infant mortality in Queensland (refer to Figure 7). The rate for males was 6.3 infant deaths per 1,000 live births in 2010 while the rate for females was 4.4. While the small numbers result in a large amount of annual fluctuation in rates, it appears that the rate for males has remained constant since 2000 while the rate for females appears to have declined.

<sup>13</sup>AiHW, [www.aihw.gov.au/child-health/health/](http://www.aihw.gov.au/child-health/health/)

**Figure 7 Infant mortality<sup>14</sup>**



Two-thirds of infant deaths occur in the neonatal period (0–27 days). Available data from the ABS suggests there is an excess in post-neonatal deaths in Queensland relative to Australia. From 2008–2010, the rate of post-neonatal deaths was 1.5 per 1,000 live births while in Australia it was 1.2 per 1,000 live births. This equates to Queensland having an average extra 19 post-neonatal deaths per year compared with if Queensland had the same post-neonatal mortality rate as Australia.<sup>15</sup> A separate analysis of post-neonatal deaths to determine the basis for the excess would be beneficial, however this is limited by a lack of available information:

- In reports published by the ABS, cause of death by jurisdiction is provided only in very broad categories and only for infants (ages 0–1 years) as a whole (refer to Appendix B). It is not possible to remove the neonatal portion of deaths as the ABS only publish total perinatal deaths by jurisdiction by cause (that is, inclusive of stillbirths).
- The Health Statistics Branch within the Queensland Department of Health has access to older cause of death data for all of Australia (2002–2006) so some analysis is possible at a more granular level. However, the age of this data may mean that any issues identified may not be current. Further, changes in coding practices by the ABS may contribute further to the data not being reflective of current issues. Access is currently being negotiated to national *cause of death* data up to 2012, but it is not yet clear when these data will be made available.

<sup>14</sup> ABS, [www.abs.gov.au/ausstats/abs@.nsf/Lookup/by+Subject/1367.0~2012~Main+Features~Infant+Mortality~4.17#](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by+Subject/1367.0~2012~Main+Features~Infant+Mortality~4.17#)

<sup>15</sup> Based on 2008–10 data. More recent data is not yet available to allow comparison for a more recent period.



Based on analysis of available data (2002–2006), a number of causes of death within the categories that were identified in Appendix B, resulted in more deaths in Queensland than nationally—showed a higher rate in Queensland than in Australia. Table 5 shows the number of extra deaths that occurred in Queensland over the four-year period (2002–2006) compared with if Queensland had the same mortality rate for these causes of death as Australia. The per cent excess is also shown for each individual cause of death and for the broader category. Conditions included in Table 5 are those where there were at least five extra deaths in Queensland over the four-year period (2002–2006) than would have occurred if Queensland had the national rate for these conditions. As discussed above, this is only intended as a broad indication of possible areas that may be candidates for further investigation. The lack of available data for the more recent period means it is possible that these causes of death are no longer contributing to Queensland’s excess. It should be noted that this data is subject to issues with variation in coding of causes of death. For example, the higher rate of Sudden Infant Death Syndrome in Queensland (refer to Table 5 and Figure 8) may be due to variation in the detail being provided to the ABS for infant deaths occurring in Queensland that means they are coded to this more generic cause of death rather than being coded to more specific causes.

**Table 5 Comparison of frequency of causes of infant death for those causes with the greatest discrepancies, Queensland and Australia, 2002–2006.**

ICD-10-AM	Period*	Excess cases in Queensland**	relative magnitude of difference (Qld vs Aust)***
<b>Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery (P00-P04)</b>			
<i>P008 - Fetus and newborn affected by other maternal conditions</i>	N	13	20% higher
<i>P010 - Fetus and newborn affected by incompetent cervix</i>	N	6	19% higher
<i>P011 - Fetus and newborn affected by premature rupture of membranes</i>	N	12	27% higher
<i>P012 - Fetus and newborn affected by oligohydramnios</i>	N	11	2.7 times higher
<i>P013 - Fetus and newborn affected by polyhydramnios</i>	N	6	2.4 times higher
<i>P018 - Fetus and newborn affected by other maternal complications of pregnancy</i>	N	13	2.0 times higher
<i>P021 - Fetus and newborn affected by other forms of placental separation and haemorrhage</i>	N	14	25% higher
<i>P023 - Fetus and newborn affected by placental transfusion syndromes</i>	N	-6	33% lower
<i>P038 - Fetus and newborn affected by other specified complications of labour and delivery</i>	N	-5	83% lower
<b>Disorders related to length of gestation and fetal growth (P05-P08)</b>			
<i>P070 - Extremely low birth weight</i>	N	9	42% higher
<i>P072 - Extreme immaturity</i>	N	-11	27% lower
<i>P073 - Other preterm infants</i>	N	5	32% higher
<b>Respiratory and cardiovascular disorders specific to the perinatal period (P20-P29)</b>			
<i>P279 - Unspecified chronic respiratory disease originating in the perinatal period</i>	N, PN	5	78% higher
<b>Ill-defined and unknown causes of mortality (R95-R99)</b>			
<i>R95 - Sudden infant death syndrome</i>	N, PN	17	20% higher
<i>R98 - Unattended death</i>	N, PN	-7	46% lower
<i>R99 - Other ill-defined and unspecified causes of mortality</i>	PN	7	17% higher
<b>Congenital malformations of the circulatory system (Q20-Q28)</b>			
<i>Q234 - Hypoplastic left heart syndrome</i>	N, PN	5	24% higher
<b>Chromosomal abnormalities, not elsewhere classified (Q90-Q99)</b>			
<i>Q909 - Down syndrome, unspecified</i>	N, PN	-5	35% lower

Source: Queensland Cause of Death Unit Record File (Accessed 10 December 2014), Birth, Australia, 2013 (accessed 10 December 2014), ABS.

\*N=Conditions affecting the neonatal period, PN=Conditions affecting the post-neonatal period.

\*\*The total number of extra or reduced cases in Queensland between 2002–2006 if Queensland had the same rate of death as Australia for that cause of death.

\*\*\*The relative excess or reduction in mortality rate for Queensland compared with Australia for this period.

NB. Because a different period was available for analysis by specific causes, the excess for broader categories does not apply to those shown in the table in Appendix B.

**Figure 8** Trend of deaths where the underlying cause was recorded as Sudden Infant Death Syndrome, Queensland and Australia, 2003–2012p



Source: Causes of Death, Australia 2012 (Accessed 10 December 2014); Birth, Australia 2013 (Accessed 10 December 2014), ABS. pData for 2011 and 2012 are preliminary and subject to change.

**Finding 11:** Two-thirds of infant deaths occur in the neonatal period (0–27 days).

**Finding 12:** Limitations in the recording of cause of death by medical practitioners on death certificates prevents a clear understanding of the reasons for any excess of infant deaths in Queensland. The delay in availability of national cause of death data to Queensland Health means that at this stage it is not possible to conduct an analysis of the causes of death where Queensland has a higher rate than other jurisdictions.

**Finding 13:** While the rate of post-neonatal deaths is low in both Australia and Queensland relative to the rates of neonatal deaths and stillbirths the data shows an increased number of deaths in Queensland. The reasons for this require further investigation and action.

## Modifiable and non-modifiable factors influencing perinatal mortality

Recently, an internal working group undertook a multivariate statistical analysis to assess known risk factors of adverse perinatal outcomes (stillbirths, neonatal deaths and prematurity) in order to identify those risk factors that:

- best account for the disparity in perinatal death outcomes between the Indigenous and non-Indigenous populations
- contribute most strongly to adverse perinatal outcomes.

The statistical analysis found that significant risk factors for neonatal mortality (deaths among live born infants within the first 28 days of life) in decreasing order of

importance are prematurity (being born prior to 37 weeks of gestation), inadequate antenatal care, maternal obesity, intrauterine growth restriction and antepartum haemorrhage.

Significant risk factors for stillbirths in decreasing order of importance are intrauterine growth restriction, inadequate antenatal care, maternal overweight and obesity, antepartum haemorrhage, young maternal age, and pre-existing diabetes. Stillbirths are more likely to occur prior to 37 weeks gestation.

The order of importance of risk factors for prematurity differs by the Indigenous status of the mother. The strongest predictors of preterm birth for Indigenous women are smoking during pregnancy and inadequate antenatal visits. For non-Indigenous births, the strongest predictors were antepartum haemorrhage, having no previous births, pre-eclampsia, and having had a previous caesarean section. Inadequate antenatal care and smoking during pregnancy were significant, but accounted for a smaller proportion of preterm births.

Other significant predictors that account for a very small proportion of preterm births in the total population are lower socioeconomic status, not being married or in a de facto relationship, older maternal age, maternal underweight, pre-existing diabetes, pre-existing hypertension, chronic kidney disease, having had a previous stillbirth, gestational diabetes, and gestational hypertension. Being born to an Indigenous mother remains a small (accounting for a maximum of 1.5 percent of preterm births), but significant predictor of prematurity even after adjusting for all other risk factors. This may be because other risk factors for prematurity, that are not available in the QPDC, such as poor nutrition and alcohol and illicit drug use, are higher in the Indigenous population.

The results of the statistical analysis suggest that:

- The higher perinatal mortality rate among babies born to Indigenous mothers is associated with higher rates of risk factors among the Indigenous population, such as prematurity, pre-existing diabetes, inadequate antenatal care, smoking during pregnancy, and not being in a married or de facto relationship (which could be an indicator for poor social support).
- Reduction of risk factors in Indigenous women and in women with poorer socioeconomic status and social support is required.
- Key strategies to reduce risk factors, including smoking and poor nutrition during pregnancy include increased targeting of risk groups and promotion of and improved access to existing antenatal care programs.
- Maternal overweight and obesity are risk factors for perinatal mortality over and above preterm birth.

The risk factors contributing to the higher perinatal mortality rate among babies born to Indigenous mothers are modifiable. Given the higher rates of teenage births, culturally appropriate sexual and reproductive health education programs for young Indigenous women, and Indigenous antenatal services are required. As described previously there is also a variation in outcomes and risk factors by HHS (refer to Appendix C). HHSs should tailor their response to the risk and socio-demographic profile of their community and actively work to reduce the perinatal and infant mortality rates in their communities.

Overall risk factors that warrant further action are:

- prematurity
- low birthweight
- maternal smoking
- maternal body mass index
- presence of one or more congenital anomaly
- socio-economic disadvantage as measured by Socio-economic Indexes for Areas (SEIFA)
- remoteness of the primary residence of the mothers as measured by the Accessibility/Remoteness Index of Australia (ARIA+)
- attending less than the recommended number of antenatal visits.

Queensland also has a high rate of unidentified causes of death. As a result, it is hard to definitively determine any modifiable or non-modifiable factors which may have affected these births and deaths. Many practitioners recommend that in order to alter this more post-mortems must be performed, however this may be difficult as many parents do not wish to have an autopsy performed. Less than one-third of babies dying in the perinatal period have an autopsy (28.7 per cent in 2002–2013). The autopsy rate for stillborn babies has remained relatively constant over the last several years, but has dropped from 37.4 per cent in 2009 to 31.1 per cent in 2013, the rate of neonatal death autopsy has declined in that period from 27.6 per cent to 17.5 per cent.<sup>16</sup> Programs, such as the IMPROVE initiative can help to facilitate an increase in autopsy rates by providing resources and support for staff to enhance communication with families regarding autopsy.

Finding 14: There are a number of risk factors for perinatal mortality that are of particular risk in Indigenous populations, such as prematurity, pre-existing diabetes, inadequate antenatal care, smoking during pregnancy, and not being in a married or de facto relationship. A reduction of these risk factors is required.

Finding 15: There are a range of modifiable risk factors that will contribute to a reduction in the Indigenous perinatal and infant mortality rate in Queensland. This may be addressed through the provision of reproductive health and education programs for young women and timely, culturally appropriate Indigenous antenatal care.

Finding 16: The high rate of unidentified cause of death impacts on the ability to develop appropriate responses to address modifiable risk factors.

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<sup>16</sup> Analysis of the Queensland Perinatal Data Collection by the Queensland Maternal and Perinatal Quality Council

## Future actions

Based on the analysis of the issues relating to perinatal and infant mortality in Queensland, the taskforce recommends the following future actions be considered.

### Data collection and reporting

There is a lack of consistency in practice and legislation regarding reporting of stillbirths and a lack of consistent classification within data at a state and national level on key issues, such as terminations of pregnancy. The *National Maternity Data Development Project* through its *Perinatal Mortality Report Project* is addressing this issue, and Queensland should actively participate in this process and advocate for changes in the systems and processes that would result in more accurate and useful perinatal mortality information.

- 1a. Consideration should be given to strengthening mechanisms to identify cause of death, including increasing autopsy rates, training and guidelines for medical practitioners in completing cause of death details on death certificates, given that a significant number of deaths are 'unexplained'.
- 1b. Queensland should advocate that RoGS use national perinatal data as the source for comparison of perinatal deaths or include caveats regarding the impact of variation in submission of stillbirth data to the ABS by jurisdiction.

Rationale: to improve consistency and quality of data collection and reporting.

### Enhance the roles of Queensland Maternal and Perinatal Quality Council and the Queensland Paediatric Quality Council

Consideration should be given to enhancing the roles of the QMPQC and the QPQC and fostering partnership between the quality councils and other stakeholders.

- 2b. Consideration should be given to resourcing the QMPQC and QPQC through a project officer position to facilitate partnership between the quality councils, Patient Safety Unit and Health Statistics Branch, case analysis and review and further detailed data analysis.
- 2c. Consideration should be given to establishing mechanisms to ensure that quality council report recommendations are considered and implemented as appropriate with progress on implementation reported to the Minister for Health and Minister for Ambulance Services as a way of driving ongoing improvement.
- 2d. Opportunities for partnership between the QMPQC, QPQC, statewide clinical networks, Patient Safety Unit, the Nursing and Midwifery Office Queensland, and Queensland Family and Child Commission should be pursued.

Rationale: enhance the capacity of the health system to identify trends and responses to perinatal and infant mortality.

## Clinical and systemic review of perinatal and infant deaths

- 3a Consideration should be given to establishing governance systems in HHSs, including key performance indicators, to monitor the causes and circumstances of perinatal and infant deaths within their communities, inform service improvement, and reduce avoidable perinatal and infant deaths.
- 3b Information should be made available to the QMPQC and QPQC to support their statewide role.

Rationale: enhance the capacity to HHSs to monitor its own performance and make necessary improvements.

## Support for low volume rural maternity facilities

There appears to be a link between low volume facilities and perinatal deaths.

- 4a The process for establishing new maternity services should ensure that services, facilities, partnerships, referral pathways and supports are in place so that high quality care can be provided.
- 4b Enhance the ability to identify risk and improve referral pathways.
- 4c Enhance opportunities for ongoing staff education, training and clinical review in low volume maternity facilities.
- 4d Enhance capacity of high volume facilities to support low volume rural maternity facilities.

Rationale: better support for rural and remote maternity services to care for women and their families.

## Enhancing clinical practice and strategies to address risk factors

Strategies to address specific risk factors need to be targeted at both the individual (clinical) level and population level to address individual factors as well as the social determinants of health. Strategies should be considered from a whole-of-life perspective rather than focusing only on the period of pregnancy.

- 5a All programs, initiatives and practices that provide services to young women, women of child bearing age and/or contemplating becoming pregnant, and children should actively look for opportunities to strengthen their alignment and focus efforts on reducing perinatal and infant deaths. This includes sharing information and working with private birthing facilities and general practitioners.
- 5b HHSs should ensure they are providing care in line with the *National Evidence-Based Antenatal Care Guidelines*.
- 5c Access to combined first trimester screening should be enhanced so women and families have adequate and timely information to make decisions about whether to continue a pregnancy when severe chromosomal abnormalities have been detected. Equity of access issues for women living in rural and remote areas, and

low socio-economic circumstances should also be addressed so all women have access to this screening in accordance with their risk status.

- 5d HHSs should ensure problematic scan results are reviewed and followed up immediately.
- 5e Smoking:
  - Target public health messages towards women who are of child bearing age and/or contemplating becoming pregnant.
  - For Indigenous women and families, support awareness of and dissemination of culturally appropriate public health messages and materials, such as the Institute for Urban Indigenous Health’s Deadly Choices campaign.
  - Provide specific interventions with women during the antenatal period, tailored to the stage of pregnancy.
- 5f Obesity:
  - Target public health messages towards women who are of child bearing age and/or contemplating becoming pregnant.
  - Provide specific interventions with women during the antenatal period, tailored to the stage of pregnancy.
- 5g Indigenous
  - Provide culturally appropriate women’s health, including reproductive health and education programs for young women, and maternity services that will encourage Aboriginal and Torres Strait Islander women to access timely healthcare.
- 5h HHSs should provide enhanced services for women with higher risk pregnancies that incorporate interventions based on known risk factors for perinatal and infant death.
- 5i Tailor services to encourage women with socioeconomic vulnerabilities who are harder to reach/difficult to engage to access antenatal care services earlier and at the recommended number of visits.
- 5j HHSs should ensure safe sleeping messages are embedded into clinical practice.

Rationale: reducing known modifiable risk factors will help to minimise the perinatal and infant death rates.

## Appendices

### Appendix A:

- Cumulative percentage of timing of death for neonatal deaths, by state of usual residence, 2002–2006

### Appendix B:

- Underlying causes of death for infant deaths 2012, Queensland and Australia

### Appendix C:

- Rate of Perinatal Mortality and Selected Perinatal Risk Factors, 2010–12p., and post-neonatal Death, 2008–10p., by Hospital and Health Service of usual residence, compared with Queensland



## Abbreviations

AIHW	Australian Institute of Health and Welfare
NPESU	National Perinatal Epidemiology and Statistics Unit
ARIA+	Accessibility/Remoteness Index of Australia
COAG	Council of Australian Governments
HHS	Hospital and Health Service
IMPROVE	Improving Perinatal Review and Outcomes Via Education
NICU	Neonatal Intensive Care Unit
NMOQ	Nursing and Midwifery Office of Queensland
NMSP	National Maternity Services Plan
NPDC	National Perinatal Data Collection
PSANZ	Perinatal Society of Australia and New Zealand
QMPQC	Queensland Maternal and Perinatal Quality Council
QPDC	Queensland Perinatal Data Collection
QPIMT	Queensland Perinatal and Infant Mortality Taskforce
QPQC	Queensland Paediatric Quality Council
RoGS	Report on Government Services
SCN	Special Care Nursery
SEIFA	Socio-economic Indexes for Areas

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