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# **National perinatal mortality data reporting project: issues paper, October 2012**

**Foundations for enhanced maternity data collection  
and reporting in Australia: National Maternity Data  
Development Project Stage 1**





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Health and Welfare**

*Authoritative information and statistics  
to promote better health and wellbeing*

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**National Maternity Data Development Project: Stage 1**

Australian Institute of Health and Welfare  
Canberra

Cat. no. PER 66

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# Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ANZSA	Australian and New Zealand Stillbirth Alliance
CCOPMM	Consultative Council on Obstetric and Paediatric Mortality and Morbidity
ICD	International Classification of Diseases
MCCPD	Medical Certificate of Cause of Perinatal Death
NHDD	National Health Data Dictionary
NHMRC	National Health and Medical Research Council
NMDDP	National Maternity Data Development Project
NMDS	National Minimum Data Set
NMSP	National Maternity Services Plan
NPDC	National Perinatal Data Collection
NPESU	National Perinatal Epidemiology and Statistics Unit
NSW	New South Wales
NT	Northern Territory
NZ	New Zealand
OECD	Organisation for Economic Co-operation and Development
PMMRC	Perinatal and Maternal Mortality Review Committee
PSANZ	Perinatal Society of Australia and New Zealand
Qld	Queensland
RBDM	Register of Births, Deaths and Marriages
ROGS	Report on Government Services
SA	South Australia
Tas	Tasmania
UK	United Kingdom
Vic	Victoria
WA	Western Australia
WHO	World Health Organization





# 1 Introduction

This paper outlines issues and considers the options for collecting and reporting standardised national perinatal mortality data. This investigation was a project component of the National Maternity Data Development Project (NMDDP) Stage 1.

There were 2,609 perinatal deaths reported in Australia in 2010. This equates to 1 in every 115 births (ABS 2012). There currently is no nationally standardised data collection that allows comprehensive reporting of perinatal mortality in relation to maternity services.

Standardised data have agreed definitions and are supported by nationally consistent data collection and reporting practices. Standard data are designed so that data supplied from each state and territory to a national collection is uniform for the whole population (AIHW 2007). These principles are incorporated into data development principles and practices used to create National Minimum Data Sets (NMDSs).

## 1.1 Definition of perinatal mortality in Australia

Perinatal mortality is a measure that encompasses fetal deaths (stillbirths) and neonatal deaths that occur in the perinatal period. The scope of the perinatal period in Australia is defined in the National Health Data Dictionary (NHDD) (AIHW 2012). It is longer than the period specified in the World Health Organization (WHO) definition, but is consistent with WHO definitions of stillbirth and neonatal death (see Box 1).

### **Box 1: NHDD definitions relevant to the measurement of perinatal mortality**

**The perinatal period:** commences at 20 completed weeks (140 days) of gestation and ends 28 completed days after birth. This definition of perinatal period differs from that recommended by the World Health Organization (WHO). In the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (WHO 1992) the perinatal period is defined as commencing 'at 22 completed weeks (154 days) of gestation (the time when birthweight is normally 500 grams) and ends seven completed days after birth' [Item 327314].

**Stillbirth:** a fetal death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight [Item 327266].

**Neonatal death:** the death of a live birth which occurs during the first 28 days of life [Item 327250].

**Live birth:** the complete expulsion or extraction from the mother of a baby, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of the voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached.

*Source:* National Health Data Dictionary (AIHW 2012).

A standard computational method for calculating perinatal mortality rate (see Box 2) uses the annual number of 3 defined vital events: stillbirths, neonatal deaths and live births. The resulting proportion is by convention expressed per 1,000 total births.

**Box 2: Calculation of perinatal mortality rate**

$$\text{Perinatal mortality rate} = \frac{\text{Number of stillbirths} + \text{number of neonatal deaths}}{\text{Number of live births} + \text{number of stillbirths}} \times 1000$$

## 1.2 Policy relevance of perinatal mortality

Perinatal mortality rates are one of the key performance indicators for safety and quality of hospital maternity services in the Productivity Commission's annual publication *Report on Government Services* (ROGS). The report focuses on services that: make an important contribution to the health of the community; reflect government priorities; represent significant components of government recurrent expenditure; and have common objectives across jurisdictions (SCRGSP 2012).

ROGS indicators align with indicators in other national agreements. Perinatal mortality is one of the measures used in the National Indigenous Reform Agreement to monitor progress in reducing the level of disadvantage experienced by Indigenous Australians (NIRA 2012).

In addition, the authors of the National Maternity Services Plan have recognised perinatal mortality surveillance as necessary for monitoring the safety and quality of maternity care (AHMC 2011). To be of best value as a marker of the quality of maternity care, perinatal mortality data need to be able to be reported against the health services and interventions provided to women for their care during pregnancy and at birth.

To be of best value as a comparative index in public health, perinatal mortality data should be able to be adjusted for social and demographic characteristics of pregnant women; and when used to compare health services, further adjustment for case complexity is highly desirable. To achieve this, comprehensive information about each perinatal death must be able to be integrated or linked with the pregnancy and birth information available in the National Perinatal Data Collection.

## 1.3 Project objective

The objective of this project is to consider the options for collecting and reporting standardised perinatal mortality data that are integrated with national perinatal and maternity information.

## 2 Current status of perinatal mortality reporting

### 2.1 National reports of perinatal mortality

The official source of mortality data in Australia is the Australian Bureau of Statistics (ABS). From 2007 to 2009, perinatal mortality was reported in a separate series, *Perinatal deaths, Australia* (ABS 2011). Up to 2006, and from 2010 onwards, perinatal mortality information has been included as a section in *Causes of Death, Australia* (ABS 2012).

The source of ABS perinatal information is stillbirth and death registration data provided by the Registrars of Births Deaths and Marriages in each of the 8 states and territories. These data include registered cause of death coded to the International Classification of Diseases, 10<sup>th</sup> revision (ICD-10). These data are in turn coded and compiled into aggregate statistics.

Perinatal deaths data are also published annually by the Australian Institute of Health and Welfare (AIHW) in the *Australia's mothers and babies* series of reports – the most recent issue of which was for 2011 (Li et al. 2013). This report is based on data collected at the time of birth by state and territory health authorities, which is subsequently collated to form the National Perinatal Data Collection (NPDC). The report presents national information on pregnancy and childbirth for all births in Australia. This includes information provided by states and territories from multidisciplinary perinatal review and assignment of the Perinatal Society for Australia and New Zealand (PSANZ) Perinatal Death Classification and/or the PSANZ Neonatal Death Classification.

For 2009, ABS reported 9.0 (ABS 2010) and AIHW reported 9.8 (Li et al. 2013) perinatal deaths per 1,000 total births in Australia. Different collecting and reporting methods can result in differences in the numbers of perinatal deaths reported in any given year (see Appendix A). Aggregation of data over a longer period can minimise these variations in total perinatal deaths reported – but even so, separate examinations of stillbirths and neonatal deaths reported over 2004–2009 suggest that over this period the ABS under-reported stillbirths by a factor of 15%, while 8% of neonatal deaths were not available to AIHW for reporting. These differences were more marked within some individual jurisdictions (see Appendix A).

### 2.2 Jurisdictional reporting

All states and territories publish or have published information about perinatal deaths occurring in their jurisdiction or related to their residents. Perinatal mortality may be included with reports that focus on mortality, with or without maternal mortality included, or may comprise a chapter in the jurisdiction's birth report, as shown in Table 2.1.

Data used to report perinatal mortality in state and territory reports are in all cases but one derived from reviews of perinatal deaths within each jurisdiction. The exception is the Northern Territory (NT), where deaths registration data (from the NT Registrar of Births, Deaths and Marriages) are used.

**Table 2.1: Perinatal mortality reports in Australian jurisdictions**

Jurisdiction	Perinatal mortality reporting
NSW	The Ministry (previously Department) of Health has published its thirteenth annual <i>Mothers and babies</i> report, which includes a chapter on perinatal deaths.
Vic	The Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM) publishes an annual report of perinatal deaths that have been reviewed by the Council.
Qld	Queensland Health has published <i>Maternal and perinatal mortality and morbidity in Queensland</i> (2011), which includes a chapter on perinatal deaths occurring in Queensland for the period 2000–2009. This is the second report of the Queensland Maternal and Perinatal Quality Council since it reconvened in mid-2009 after a 3-year period of inactivity during which its purpose and functions were reviewed.
WA	The Western Australian Department of Health publishes a triennial report on perinatal and infant mortality. The most recent report, <i>The 13<sup>th</sup> report of the Perinatal and Infant Mortality Committee of Western Australia for deaths in the triennium 2005–07</i> , provides a comprehensive and detailed description of the deaths within its scope.
SA	<i>Maternal, perinatal and infant mortality in South Australia 2009</i> is the 24th annual report of its kind, and, as its title suggests, includes a chapter on perinatal deaths. Statistics presented in the report for perinatal (and post-neonatal) deaths relate only to babies born in South Australia.
Tas	The Department of Health and Human Services publishes a <i>Council of Obstetric and Paediatric Mortality and Morbidity annual report</i> , which includes a chapter on perinatal deaths.
ACT	ACT Health has published 2 reports, <i>Perinatal mortality in the ACT 2001–2005</i> and <i>Perinatal mortality in the ACT 2006–2010</i> . The reports aggregate data in 5-year periods because perinatal mortality rates can fluctuate from year to year due to the small population size in the ACT.
NT	The NT Child Deaths Review and Prevention Committee has published its second annual report, <i>NT Child Deaths Review and Prevention Committee 2012–13</i> . The report is based on data obtained from the Registrar of Births, Deaths and Marriages.

## 2.3 Perinatal mortality reporting elsewhere

### International perinatal mortality reporting

National perinatal mortality reporting occurs in many countries, including New Zealand, Canada, the United States, Scotland and the United Kingdom.

Relevant perinatal mortality reports from each of these countries were reviewed to obtain comparative information on scope and methods of data collection and reporting. One advantage was that these nations have relatively comparable populations to Australia's in terms of access to medical care. The reports were also used to inform development of a preliminary outline for an Australian perinatal mortality report.

The review also showed some variability in definitions of stillbirth and neonatal death among countries. For example, in New Zealand, perinatal mortality is defined as a fetal death or stillbirth of at least 20 weeks gestation or 400 grams birthweight (same as Australia), and a neonatal death as occurring at less than 7 completed days (Australia less than 28 completed days). Some countries in Europe align with the New Zealand definitions (for example, parts of northern and eastern Europe) while others such as Ireland and United Kingdom use the same definitions as Australia.

It can be seen that across a selection of nations, a fetal death or stillbirth can be defined, variously, as occurring after 20, 22, 24 and 28 weeks gestation, and between 350 and 1,000 grams birthweight, if birthweight is considered in the definition.

It is therefore imperative that specific definitions are considered before comparisons are made between Australian perinatal mortality data and those of other nations.

## **National perinatal reporting in New Zealand**

New Zealand has developed and implemented comprehensive data collection and reporting processes to investigate and report perinatal mortality. Implementation of perinatal mortality surveillance followed extensive consultation and research to determine the requirements of stakeholders and the capacity of existing systems to develop the reporting processes.

A national perinatal death dataset is compiled using data from a number of sources including local “coordinators”, deaths notifications and the Register of Births, Deaths and Marriages. A website run by the University of Otago was commissioned by the Perinatal and Maternal Mortality Review Committee (PMMRC) which enables web-based data entry of perinatal deaths.

In the event of a perinatal death, lead maternity carers complete rapid reporting forms within 48 hours. Review of the questions on these forms occurs annually to ensure robust data collection. Following local review, a coordinator completes the PMMRC classification form.

New Zealand uses the PSANZ classification system for reporting perinatal deaths. The PSANZ classification system includes both perinatal and neonatal classifications. Critical to the success of the New Zealand mortality reporting processes, for both maternal and perinatal deaths, has been the legislation put in place to support data supply and review with legal privilege status protecting the proceedings and significant penalties in place if requests for information are not adhered to.

There are significant administrative, governance and legislative differences between New Zealand and Australia which need to be taken into consideration when assessing possible adoption of these processes to the Australian setting. New Zealand has one health department and twenty District Health Boards nationally and approximately 62,000 births annually. In comparison, Australia has approximately 300,000 births annually in eight jurisdictions, each with its own governance and legislative arrangements.

It would increase the utility of an Australian report to include a section that provides comparative perinatal mortality rates to other published international reports.

## **2.4 Issues for reporting perinatal mortality**

### **Ascertainment of neonatal deaths**

Data sources used in the ascertainment of perinatal deaths vary between jurisdictions. Information from the consultation with perinatal data custodians (or representatives) revealed that significant resources are expended in ascertaining deaths that occur within the scope of the relevant legislation.

In all jurisdictions, neonatal deaths are reported to the jurisdictional RBDM by the attending medical practitioners who also notify relevant perinatal data custodians. If cases are referred to the coroner, the coroner notifies the RBDM.

Data sources, used in the ascertainment of perinatal mortality clinical review and reporting vary in each jurisdiction. These data sources are presented in Table 2.2.

**Table 2.2: Data sources used for ascertainment of neonatal deaths**

State or territory	Data sources
NSW	Jurisdictional RBDM and Coroner The NSW Perinatal Data Collection (formerly known as the Midwives Data Collection) NSW Register of Congenital Conditions NSW Admitted Patient Data Collection
Vic	Jurisdictional RBDM and Coroner Victorian Perinatal Data Collection Victorian Birth Defects Register Confidential Medical Report on Perinatal Death (completed by clinicians)
Qld	Jurisdictional RBDM and Coroner Perinatal Data Collection Unit, Health Statistics Centre
WA	Jurisdictional RBDM and Coroner Stillbirths and infant deaths are notified directly to the Executive Director of Public Health by attending medical practitioners as a requirement of the <i>Health Act 1911, State of Western Australia</i> . Midwives report all births (and stillbirths) to the Department of Health via the Midwives Database. This database is cross-referenced with RBDM to ensure completeness of records
SA	Jurisdictional RBDM and Coroner
Tas	Jurisdictional RBDM and Coroner Electronic Perinatal Database ( <i>ObstetrixTas</i> )
ACT	Jurisdictional RBDM and Coroner The major source of data is information contained in ACT Confidential Report on Perinatal Death Forms, which include placental pathology and autopsy details. Data are cross-referenced with information from the ACT Maternal Perinatal Data Collection, the ACT Admitted Patient Care Data Collection and ABS deaths data for the ACT
NT	Jurisdictional RBDM and Coroner The main source of data on child deaths is the RBDM, which also has a database of stillbirths. Data are also obtained from national bodies such as ABS and AIHW, as well as the NCIS, which provides data on child deaths.

There is no standard process for notification and review when a perinatal death occurs in a different jurisdiction to where the baby was born, resulting in variable reviewing and reporting practices in each jurisdiction. Some jurisdictions have processes in place for cross-referencing with the RBDM, such as Victoria, Queensland and Western Australia or with other jurisdictional data collections, such as the Australian Capital Territory, to improve ascertainment. These cross border flow cases are often not reported to the health authority in which they were born on and thus may not be included in any reports or statistical analysis.

## Cross-border flows

Neonatal deaths that occur outside the jurisdiction of birth are an issue for jurisdictional ascertainment and reporting. Each jurisdiction has legislation that defines the scope for

perinatal death reporting. For example, in the Northern Territory, the death of a child who is usually resident in the Territory, regardless of where the death occurred, would be reported. In Queensland, reviews are only undertaken on perinatal deaths of babies born in the state. For example, if a baby were born in New South Wales and died in Queensland there would be no review of a perinatal death in Queensland. In South Australia, reviews are undertaken on all perinatal deaths that occur in the state.

Jurisdictional definitions of what constitutes a reviewable death vary and may result in some neonatal deaths being systematically excluded from review. Neonates may be transported interstate for specialist medical treatment or because an interstate facility happens to be the closest tertiary hospital for treatment. This usually occurs when there is serious risk to the health of the baby and some die whilst receiving treatment interstate. Currently there are no formal arrangements in place to notify the birth jurisdiction of these deaths.

In Victoria there is special provision for information to flow to between Albury (NSW) /Wodonga (Victoria). Since the closure of Albury hospital births and perinatal deaths of NSW resident babies born in Wodonga are registered in NSW. Victoria does seek information from other states however what is received can be quite limited. There are protocols in place for information leaving Victoria and it usually comes in as a data request and needs approval by CCOPMM. Under the regulation, Victoria can share unidentified data and can share identified data with AIHW.

Babies born in South Australia that die interstate are included in the statistical analysis where information is available. Deaths of babies in South Australia who were born interstate are not included in state based analyses or reporting.

The New South Wales Perinatal Data Collection receives notification of women whose usual place of residence is outside of NSW and who give birth in NSW. However, it does not receive notifications of births outside NSW to women usually resident in NSW.

In the Australian Capital Territory, perinatal deaths for both ACT and non-ACT residents are monitored and reviewed. In the ACT, during the period 2001–2005, 15.6% of births were to mothers who were not usual residents of the ACT. The ACT report is based on perinatal deaths for babies of ACT residents where the birth occurred in the ACT. Residents from other jurisdictions are excluded from the ACT report as are ACT residents who gave birth outside the ACT to enable a population based analysis. However the latter number is reported to be small.

In the Northern Territory, about 3% of the total child deaths in the most recent report were sourced from interstate registries. However, the NT reported that it was difficult to get detailed information about these interstate child deaths due to privacy issues which then makes coding of these deaths problematic. The NT report recognises that there may be marginal under-reporting in the report despite their efforts to source the data.

Tasmania and Queensland have no processes in place to ascertain cross border deaths.

The issue of information sharing about child deaths outside their usual jurisdiction is on the agenda of the Australian and New Zealand Child Death Review and Prevention Group (CCYPCGQ 2009), which is a national, cross-jurisdictional group that has representatives of child death review teams in all Australian jurisdictions and New Zealand.

## Classification of cause of death

The International Classification of Diseases (ICD) is part of the WHO Family of International Classifications and is used internationally for mortality classification. The ICD code applied to registered cause of death by ABS is reported nationally in Australia (ABS, 2012) and used for comparisons between countries. ICD codes can also be applied to cause of death determinations following multidisciplinary review. In Victoria, the CCOPMM assigns the ICD code to cause of neonatal deaths but not to cause of stillbirth. This reflects the limitations recognised in ICD classification, particularly for stillbirths, due to the range and detail of codes available.

The Perinatal Society of Australia and New Zealand (PSANZ) classification system has been developed by clinicians and provides more clinically relevant information and descriptions of the perinatal death. The PSANZ classification system can identify preventable factors associated with perinatal death using a systematic application of clinically relevant categories. PSANZ cause of death is used by perinatal review committees in all Australian states and territories.

Both PSANZ and ICD coding provide valuable information for perinatal death review, data collection and comparison, particularly for international comparison. The feasibility of dual reporting, using PSANZ and ICD, would have to be further explored but would increase the utility of the report.

## 2.5 Sources of perinatal mortality data

### Vital registration data

Birth and death registration is mandatory in each jurisdiction. At least 2 forms of notification of a death are required to fully register a perinatal death: the Medical Certificate of Cause of Perinatal Death (MCCPD); and a statement from either the funeral director in the case of a neonatal death, or from the parents in the case of a stillbirth. Partial registration is carried out if some, but not all information is received.

The statutory instruments and registration practices related to registration of births and perinatal deaths vary between jurisdictions. A different definition of 'birth' applies in South Australia, where terminations of pregnancy after 20 weeks are explicitly excluded and cannot be registered as a birth. Also in South Australia, unlike the other jurisdictions, the definition of 'live birth' incorporates a recent High Court decision to include reflex activity as a sign of life (see Box 1 in Chapter 1 for more information on the standard definition applied in all other jurisdictions).

Other variations and similarities include the following:

- In Queensland, in certain circumstances, alternative informants may provide the statement comprising the second part of notification needed to fully register a perinatal death.
- All states and territories (except for Western Australia) register stillbirths only as births.
- In Western Australia a stillbirth is registered as both a birth and a death.
- Neonatal deaths in all states and territories are registered as deaths.



## **Fact of death file**

The RBDMs in each jurisdiction contribute data from notifications about each death to a central file that was formerly maintained by the Tasmanian RBDM, but is now collated by AIHW. This file was instituted to enable information to be shared between RBDMs about deaths in all jurisdictions and assist with the process of flagging birth register records of persons who have died. The file is also used to provide information about deaths for the National Death Index.

## **Registered cause of death**

In all states and territories a perinatal death must be certified by either a doctor using the MCCPD or by a coroner. In 2010, 96.7% of perinatal deaths were certified by a doctor, with the remaining 3.3% certified by a coroner (ABS 2012).

In line with WHO's suggested process for registration of perinatal deaths, the MCCPD forms used in all states and territories separately list maternal causes and fetal or infant causes of death. In jurisdictions that do not specify the main fetal and main maternal cause, the first listed condition on the certificate is used. The MCCPD is usually completed soon after death and does not take into consideration later findings from post mortem pathology or autopsy results. A further limitation of the information on MCCPDs is that they may be filled out by junior medical staff. Concern exists among the medical profession that certification is no longer included in the undergraduate medical curriculum.

Vital registration data from each jurisdiction are sent to the ABS for inclusion in national perinatal data collections. Coronial investigations can delay completion of a registration, and introduce a lag into the reporting of these deaths by the ABS.

## **National Data Management Framework**

In 2007 the ABS completed a review of governance arrangements surrounding production and distribution of unit record deaths data. The review determined that legislation did not support distribution of unit record data outside the ABS, and ABS subsequently ceased production of the ABS *Cause of death* and ABS *Cause of perinatal death* unit record files.

As a remedy, RBDMs, led by Queensland and with assistance from the ABS, have started the National Data Management Framework project to develop their own capacity for compiling and distributing cause of death unit record files.

The legislative and system capabilities of each jurisdiction have been reviewed, and testing is underway of a process for producing national unit record data files from registration data that incorporates registered cause of death coded to ICD by the ABS.

An evaluation of progress is expected to be made available to stakeholders when the project concludes. The resulting cause-of-death files will include information about neonatal deaths, but not stillbirths. However, the National Data Management Framework is expected to establish principles that can be extended to compilation of other data from RBDM such as the perinatal mortality unit record file.

## **State and territory perinatal data collections and the National Perinatal Data Collection**

Perinatal mortality data are collected by states and territories as part of their perinatal data collections (also called midwives data collections). After every birth, midwives or other staff collect perinatal data from clinical records, administrative records and other information systems – this applies to all babies born in hospitals, birth centres and the community. Information recorded includes sociodemographic, risk factor and pregnancy details for the mother, and records of antenatal care, care provided during labour and delivery, and postnatal care. Each state and territory has its own form and/or electronic system for collecting these data, which are then forwarded to the relevant state and territory health department for their respective perinatal data collections and eventual publication in jurisdictional reports.

A standardised extract of electronic data from each state and territory collection is requested annually by AIHW for the NPDC. Records received from states and territories are anonymous, that is they do not include any names or addresses – but they do include a unique set of identification numbers so that the source record from which the data originated can be identified at source. Data supplied to the AIHW include items in the Perinatal National Minimum Data Set (NMDS), which are mandated under national agreements, and additional data items provided voluntarily by the states and territories (Li 2011).

Stillbirths are reported as part of the mandatory items. Neonatal deaths, age at neonatal death, cause(s) of death and autopsy status are voluntarily supplied by most (but not all) jurisdictions. Information in the NPDC about neonatal deaths is known to be incomplete as there may be no knowledge of deaths that occur outside the birth hospital.

## **State and territory multidisciplinary perinatal death reviews**

Each jurisdiction either has or is instituting a process for multidisciplinary review of perinatal deaths. These committees review clinical information regarding all deaths, including the results of post mortem investigations, and assign a classification of cause of death. Stakeholders have overwhelmingly supported continuation of multidisciplinary review of perinatal deaths to assign cause of death.

Committees to review perinatal deaths are currently convened by health authorities in all jurisdictions except New South Wales and the Northern Territory. At the time of writing, restructuring of the NSW Ministry of Health was in progress, and in the Northern Territory regulations for recently enacted legislation to establish such a committee were yet to be finalised.

Procedures for perinatal death reviews vary between jurisdictions, reflecting differences in population size, legislative arrangements and possibly the level of resources available for these activities. In small centres and non-metropolitan areas there may be limited availability of specialists, particularly neonatologists, geneticists and dedicated perinatal pathologists.

Some form of legal privilege is used in all jurisdictions that currently undertake perinatal deaths reviews. The quality of information provided about cause of perinatal death may be improved in a limited number of cases if the deliberations of the review panel can be open and there is no possibility that these could be released under freedom of information laws or subject to subpoena in cases under litigation.

The need for quality control and standardisation of the review process has been raised by some stakeholders, who have suggested an oversight national committee, or a group of review committee chairpersons, to harmonise procedures and standardise data from perinatal mortality review committees. The use of a minimum data set for perinatal mortality review, such as used by the Perinatal Society of Australia and New Zealand (PSANZ) and Australian and New Zealand Stillbirth Alliance (ANZSA) would be of value to this process.

In most jurisdictions deaths known to have resulted from termination of pregnancy are not reviewed, but in these cases the cause of death is already established. Legitimate concerns have been raised about the timing of termination of pregnancy for fetal abnormalities as these can skew the extremely preterm (less than 24 weeks' gestational age) section of the distribution of perinatal deaths.

Legal privilege may be useful when assigning termination of pregnancy status to perinatal deaths in those jurisdictions where termination of pregnancy is still illegal.

## **Other potential data sources**

A three year research project being led by researchers at the Mater Medical Research Institute in Queensland and funded by the National Health and Medical Research Council (NHMRC) is piloting the use of web-based reporting to collect the data for all stillbirths from hospitals in Australia. The tool uses the National Perinatal Death Clinical Audit Tool developed by PSANZ and ANZSA that is used in New Zealand for collecting information in hospitals about each perinatal death (see the ANZSA website for more information about the tool <<http://www.stillbirthalliance.org.au>>).

The project has the support of health departments for state-wide participation in Queensland, Victoria, the Australian Capital Territory and the Northern Territory. South Australia and Western Australia are in the process of obtaining ethics approval for state-wide data collection, and in New South Wales and Tasmania, individual hospitals have been enlisted. The purpose of this data collection system is to provide the critical data needed for hospital or regional reviews of perinatal deaths in conjunction with the results of post-mortem investigations. The research is focused on stillbirth data, but the option exists to use the system for collecting standardised data about neonatal deaths for local audit or submission to state/territory health authorities. The data collection includes fields for the PSANZ Perinatal Death Classification and the PSANZ Neonatal Death Classification with both coded and text fields to incorporate the outcome of multidisciplinary review of the circumstances of the death.

These data were not designed as a data collection for national reporting of perinatal mortality. Many of the data items do not appear in national perinatal data and of those that do, not all align with data items in the Perinatal NMDS or other NHDD data items. This limits the use of this collection as a basis for national perinatal mortality reporting as there would either be no denominator data available or numerator-denominator disconnect for the non-standard items. This standardised web-based based data collection system could, however, have value as the basis for validation and quality control of cause of perinatal death at a jurisdictional or national level, if it is taken up by all state and territory health departments.

## **Electronic clinical system for assigning cause of death**

Over the past two years New South Wales Health has been developing an electronic clinical system to assist clinicians in applying the PSANZ cause-of-death

classification. The system consists of a computerised decision tree, which uses a series of cascading questions that leads clinicians through the decision process and records their responses in tick boxes. The back end of the system determines which branches are followed, resulting in assignment of a final PSANZ cause-of-death category. The aim is to support clinicians involved with patient care and with access to a full medical record to assign and categorise cause of death more accurately than is possible using the current PSANZ 2-page data collection form.

## 3 Options for national perinatal mortality reporting

### 3.1 Options for standardised national integrated perinatal mortality data

The number of data items about each perinatal death needed for national reporting purposes is relatively small. Key among these is information about place of death, timing of death in relation to labour, age in hours and days at neonatal death, and cause of death. However, to be of use as an indicator that can contribute to monitoring the quality of maternity services, perinatal mortality data need to be integrated with data about the health care provided during pregnancy and childbirth.

There are two basic options for developing an integrated perinatal mortality data collection nationally:

- Develop a new separate perinatal mortality NMDS and data collection
  - This option recognises specific health institution sources, processes and timeframes for obtaining information about perinatal deaths  
Arrangements would be needed to link perinatal deaths data from this separate collection with births data collected through the current NPDC.
- Extend the existing Perinatal NMDS, as used in the NPDC, to include standardised perinatal mortality data items
  - This option uses existing infrastructure, facilitates coherent reporting and avoids duplication of effort by increasing the usefulness of an established data collection to monitor pregnancy and birth outcomes. Delayed supply of these items could be agreed so that the timeliness of the main collection is not compromised.

Irrespective of whether perinatal mortality data are collected as a new NMDS or as part of the existing Perinatal NMDS, there will need to be strategies in place for:

- ensuring complete ascertainment of perinatal deaths, particularly for neonates who move between jurisdictions after birth
- ensuring consistent processes for determination of cause of death
- integrating perinatal deaths data with births data (see 'Strategies for integrating perinatal deaths data with births data' later in this section).

#### Ascertainment

Under-ascertainment of neonatal deaths in the NPDC can be overcome by using data from jurisdictional perinatal mortality review committees as the primary source of perinatal deaths data. Health authorities already have arrangements for cross-checking their perinatal deaths data against deaths registration data. This has the advantage of being able to use information from RBDM, who are independently informed about these deaths, to promote complete ascertainment.

## **Strategies to deal with cross border flows**

As outlined in Chapter 2, babies who die in a different state or territory to the one in which they were born pose particular challenges for data collection. Formalisation of the process for sharing data between jurisdictions about babies who move between jurisdictions, particularly those who die, would be useful.

Irrespective of whether the review takes place where the baby was born or where the baby died, information about each death should be provided by the reviewing committee to: the health authority in the state/territory of usual residence, the health authority in the state/territory in which the baby was born, and the health authority in the state/territory in which the death occurred.

## **Multidisciplinary review**

Multidisciplinary review of all perinatal deaths provides best information about the cause(s) of perinatal death, but to date there is no standard process involved. Most states and territories review all the deaths that occur within their boundaries. But, as noted earlier, in Queensland perinatal mortality reviews have been restricted to babies whose birth and death both occurred in that state.

Use of regional or hospital committees for multidisciplinary review could result in the emergence of further variations in processes because of possible variations in the composition/staffing of the committees. This may be particularly so in non-metropolitan areas, where specialist opinion from perinatal pathologists, geneticists or neonatologists may not be available due to lack of such staff in these areas.

## **Legal protections**

Legal privilege and information sharing have been identified as fundamental to the process of high quality, comprehensive perinatal mortality reviews and assignment of best 'evidence-based' cause of perinatal death. This may be especially relevant in jurisdictions where termination of pregnancy is still illegal.

Review of jurisdictional legislation that provides legal privilege to perinatal review committee proceedings, and privacy issues around release of identified or de-identified data, was beyond the scope of this project.

## **Classifying cause of death**

Registered cause of death by ICD code, despite its limitations, is an international standard used and reported in many other countries – many of which do not have the facility to enquire further into perinatal mortality.

For perinatal deaths, better information about cause of death can be obtained from reviewing health records and the results of clinical investigations carried out after death. Since 2005, Australian clinicians have supported the use of PSANZ classifications for reporting perinatal deaths.

Ideally, perinatal mortality data should incorporate cause of death data using ICD as well as PSANZ classification systems.

## **Strategies for integrating perinatal deaths data with births data**

Inclusion of a unique identifier for each perinatal death record that is also used in all other perinatal and maternity data collections is critical for ensuring accurate integration of perinatal mortality data with births data. This could be an extension of the existing system whereby jurisdictional health departments apply de-identified serial numbers to perinatal data records for supply to the NPDC.

Additional protocols may need to be developed to help with communications about individual perinatal deaths within and between jurisdictions, and for linking perinatal deaths data with the correct record in the perinatal birth data collection. The strategies employed will need to be tailored to ensure compliance with privacy and data protection legislation operating in each jurisdiction.

## **Reconciliation of ABS and health department (perinatal) data**

Building capacity for national reconciliation of vital registration and perinatal data will be needed to avoid differential reporting of perinatal mortality in domestic and international arenas.

## **3.2 Options for national perinatal mortality report content and structure**

Stakeholder consultation about the content and structure of a future national perinatal mortality report was undertaken for this project. Opinions of key stakeholders were sought on ways to increase the usefulness of a report, and potentially provide learning outcomes or practice points. Appendix B provides further information on the consultation process.

Perinatal mortality reports or chapters published by each jurisdiction were reviewed by the authors for content and structure suitable for the Australian setting. International reports from New Zealand, Canada, the United States, Scotland and the United Kingdom were also reviewed.

Examples of the international reports were sent to all stakeholders consulted (except the Registrars of Births, Deaths and Marriages) for their views on the content and structure of international perinatal mortality reporting.

The main issues arising from the consultation that would inform the content and structure of a new future national perinatal mortality report are summarised below.

### **Consensus for integrated routine national reporting of perinatal mortality**

There was universal support for national perinatal mortality data that are integrated with national maternity information.

There was national consensus for routine national reporting for perinatal mortality.

### **Use of cause-specific mortality versus all-cause mortality**

The outcome of the consultation was that both cause-specific and all-cause mortality should be included in the report. This reflected the need to identify potentially preventable versus

inevitable deaths. Different strategies for prevention and risk reduction apply to the different causes of perinatal death. For example very different strategies will apply for extreme preterm birth compared to unexplained term stillbirths.

## **Process for reconciliation of vital statistics and health data**

Health authorities already have arrangements for cross-checking their perinatal death data against vital registration data held by RDBMs. Opportunities exist at this cross-checking stage to add a common record identifier for each perinatal death to both sets of data. This will allow later linkage and reconciliation when producing national data using deaths registration and health authority sources.

## **Specific disaggregations**

Varied themes and approaches emerged from the consultation for the types of disaggregations that could be included in the report. State and territory breakdown was mentioned often. The less populous states and/or territories, however, would have such low numbers that only aggregated data could be published for them, and therefore such comparisons would have limitations.

Other suggested disaggregations include: Indigenous status; maternal age; body mass index; smoking; the ABS's Socio-Economic Indexes for Areas (SEIFA); remoteness area; maternal education; country of birth; and in-hospital versus out-of-hospital birth (possibly further broken down into planned home birth, spontaneous birth, and free birthing).

Disaggregations would have to be carefully analysed to ensure the data presented are valid and confounding effects are considered, for example, the analysis of hospital birth versus out of hospital birth.

## **Format (case studies/scenarios, data cubes)**

Stakeholders were asked for their views on including case studies in the report if privacy and ethical issues could be overcome. There was consensus that including case studies would facilitate learning and markedly increase the usefulness of the report.

Views were mixed on presenting information in the form of online data cubes. Some stakeholders supported the idea while others thought that information obtainable through data cubes should be included in the report itself.

## **3.3 Proposed perinatal mortality report outline**

The consultation and review processes described in Section 3.2 and Appendix B informed the development of a proposed perinatal mortality report outline. The outline is presented in Table 3.1.



**Table 3.1: Perinatal mortality in Australia, report outline**

Report structure	Content
<b>1. Executive summary</b>	
<b>2. Introduction</b>	Outline of key issues in perinatal mortality, statement of the purpose and objectives of the report
<b>3. Methodology</b>	
<i>Data sources</i>	Description of the processes used within each jurisdiction for: ascertainment of perinatal deaths; multidisciplinary review of perinatal deaths data; classification of multidisciplinary-reviewed cause of death; integration of perinatal review data with data used for the Perinatal NMDS; and collation of state and territory information to form a national collection
<i>Validation and reconciliation</i>	Description of the process within each state and territory for cross-checking of RBDM and health authority collections of perinatal deaths data
<i>Data analysis</i>	Perinatal mortality and cause-specific perinatal mortality rates and relative rates will be used to describe the absolute and relative frequency of perinatal deaths and its components. In view of the relative rarity of these events, variability bands (using Poisson methods) will be applied to comparative statistics
<b>4. Definitions</b>	
<i>Neonatal death; Stillbirth; Perinatal death; Live birth</i>	Definitions in the NHDD, and as applied to the data for perinatal death
<i>Cause of death classifications</i>	Descriptions referencing the ICD and PSANZ systems for classifying cause of death
<b>5. Perinatal mortality results</b>	
<i>Figures and high level tables in the body of the report supported by an appendix or a supplementary volume of detailed tabulations of data, and figures showing descriptive statistics (rates) for the Australian population, including national and state and territory values</i>	
<i>a. Causes of perinatal deaths in Australia</i>	Conditions and categories of cause of death for stillbirth, neonatal and perinatal deaths, with cause-specific perinatal mortality rates and proportion (percentage) of all deaths, to show the relative frequency and contribution of each condition to overall perinatal mortality
<i>b. Risk factor and contributory factor monitoring</i>	Tabulations of all-cause (total perinatal), stillbirth, neonatal and agreed preventable-cause-specific mortality rates among populations defined by their geographical, sociodemographic, obstetric and service utilisation distributions
<i>c. Perinatal deaths in Australia, how do we compare?</i>	Comparison of Australian perinatal mortality rates with countries that have comparable published data. This would involve the production of 3 tables for stillbirths, neonatal and perinatal mortality using the most recent Organisation for Economic Co-operation and Development (OECD) data. For some countries other statistical comparisons (using published data) can be made provided that the statistics used take into account any differences in definitions of births and perinatal deaths. Agreement can be sought with New Zealand to produce a series of more extensive comparison tables reflecting the close relationship between Australia and New Zealand in maternity workforces and training.
<b>6. Discussion and conclusions</b>	
<b>7. References</b>	

# Appendix A: Stillbirths and neonatal deaths reported nationally

Data published by the ABS uses births and deaths registered in the reference year; the AIHW reports deaths among babies born in the reference year.

Changes in requirements for welfare benefits and efforts to improve completeness of birth and death registrations in recent years by RBDM have increased the numbers of registrations. Late registrations are provided to ABS and reported with other vital events registered in that year. This can lead to year-on-year differences, particularly for numbers of vital events reported for some jurisdictions. Aggregating numbers of stillbirths and neonatal deaths over time overcomes these differences.

Comparison of the number of stillbirths and neonatal deaths reported by ABS and AIHW in the 6 years from 2004 to 2009 by state and territory (Table A.1) suggests that over this period ABS under-reported stillbirths by a factor of 16%, while information on 8% of neonatal deaths were not available to AIHW. These differences were more marked within most individual jurisdictions.

**Table A.1: Stillbirths and neonatal deaths in ABS perinatal deaths collection and the AIHW National Perinatal Data Collection (NPDC), Australia 2004–2009**

	State or territory of usual residence								Australia
	NSW	Vic <sup>(a)</sup>	Qld	WA	SA	Tas	ACT	NT	
<b>Stillbirths</b>	<i>Numbers</i>								
NPDC	3,828	2,682	2,502	1,340	816	285	210	217	11,880
ABS	2,946	2,160	2,378	1,129	563	285	171	196	10,261
<b>Neonatal deaths</b>									
NPDC	1,488	1,117	1,220	391	291	84	89	109	4,789
ABS	1,772	1,039	1,243	382	268	94	101	111	5,212
<b>Difference</b>	<i>Percentage difference<sup>(b)</sup></i>								
Stillbirths	-29.9	-24.2	-5.2	-18.7	-44.9	0.0	-22.8	-10.7	-15.8
Neonatal deaths	16.0	-7.5	1.9	-2.4	-8.6	10.6	11.9	1.8	8.1

(a) Information about area of usual residence and neonatal death was not provided to the NPDC by Victoria in 2009. NPDC and ABS data from Victoria in 2009 were therefore not included in this table.

(b) Difference is the number of deaths reported in the ABS perinatal deaths collection minus the number of deaths reported in the NPDC relative to the number reported from the ABS perinatal deaths collection expressed as a percentage.

Sources: *Australia's mothers and babies* (2004, 2005, 2006, 2007, 2008, 2009, published by AIHW), NPDC (unpublished data), *ABS Perinatal deaths* (2004, 2005, 2006, 2007, 2008, 2009) (ABS cat. no. 3304.0),

## Appendix B: Consultation

The consultation process for this paper involved meetings with key stakeholders Australia-wide and in New Zealand. Stakeholders consulted included state and territory perinatal data collection data custodians, chairpersons of perinatal mortality review committees, and representatives of the Registrars of Births, Deaths and Marriages as well as relevant professional colleges and organisations, and a consumer representative.

A list of all stakeholders consulted is in Table B1 below.

The consultations were recorded and scribed into a summary document. The consultation summary was sent back to stakeholders for verification. This provided an opportunity for follow-up of further information and for review by the consultee's group/board if necessary. It was explicitly stated that the responses were to be presented on behalf of the agency/organisation being consulted, and not the individual. This provision lengthened the consultation period but enabled a verified and agreed representation of the agency/organisation's views, which was important.

The second part of the consultation involved a detailed discussion around the content, structure and format of a proposed Australian perinatal mortality report. Usefulness and national and international comparability were the key aspects discussed.

### Consultation list

Table B.1 Consultation list

Jurisdiction	Organisation	Name	Position	Date of consultation
<b>Registrars and delegates of Births Deaths and Marriages</b>				
NSW	New South Wales Registry of Births, Deaths and Marriages	Sharon Swinbourne	Assistant Registrar, Registration Services	20 July 2012
Qld	Queensland Registry of Births, Deaths and Marriages	Jo Phillips	Principal Business Project Consultant, Revitalisation Program	20 July 2012
		Jo Moore	Principal Project Officer	
Vic	Victorian Registry of Births, Deaths and Marriages	Erin Keleher	Registrar and Director	17 August 2012
WA	Western Australian Registry of Births, Deaths and Marriages	Rohan Quinn	Manager, Registration Services and Policy	7 August 2012
		Michael Cousins	Team Supervisor	
SA	South Australian Registry of Births, Deaths and Marriages	Helen Paues	Deputy Registrar	16 August 2012
Tas	Tasmanian Registry of Births, Deaths and Marriages, Department of Justice	Ann Owen	Manager, Births, Deaths and Marriages	16 August 2012
		Jacqueline Hine		

*(continued)*

**Table B.1 (continued): Consultation list**

<b>Jurisdiction</b>	<b>Organisation</b>	<b>Name</b>	<b>Position</b>	<b>Date of consultation</b>
ACT	ACT Registry of Births, Deaths and Marriages, Office of Regulatory Services	Josh Rynehart	Deputy Registrar-General	13 August 2012
		Amanda Anastasi	Deputy Registrar	
NT	Northern Territory Registry of Births, Deaths and Marriages	Wendy Endenburg	Senior Deputy Registrar-General	16 August 2012
		Kelli Fleay	Office Manager	
<b>Chairs and delegates of Perinatal Mortality Committees and Perinatal Data Custodians</b>				
NSW	NSW Ministerial Committee for Maternal and Perinatal Mortality Review	Marie Paule Austin	Chair and Director, Perinatal and Women's Mental Health Unit, University of New South Wales and St John of God Health Care	30 August 2012
		Paul Craven	Neonatologist and Staff Specialist, Neonatal Intensive Care Unit, John Hunter Children's Hospital	
	NSW Perinatal Data Custodian	Lee Taylor	Associate Director, Epidemiology and Biostatistics, Centre for Epidemiology and Evidence, NSW Ministry of Health	
Vic	Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity	Jeremy Oats	Chair, Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity	7 August 2012
	Victorian Perinatal Data Custodian	Kate Gibson	Team Leader, Research and Audit, Clinical Councils Unit, Victorian Department of Health	
Qld	Queensland Maternal and Perinatal Quality Committee (QMPQC)	Vicki Flenady	Chair of QMPQC Perinatal Mortality Subcommittee	27 August 2012
	Queensland Perinatal Data Custodian	Joanne Bunney	Perinatal Database Manager	
WA	Committee for Perinatal Mortality Review	Vivien Gee	Maternal and Child Health Unit, Data Collection and Analysis, Department of Health, Western Australia	8 August 2012
SA	SA Committee Maternal and Perinatal Review	Jodie Dodd	Chair, Committee Maternal and Perinatal Review; Maternal Fetal Medicine Specialist; NHMRC Practitioner Fellow, Discipline of Obstetrics & Gynaecology, Women's and Children's Hospital Adelaide	10 August 2012
		Prof. Gus Dekker	Professor in Obstetrics and Gynaecology, University of Adelaide	
	SA Perinatal Data Custodian	Wendy Scheil	Perinatal Data Custodian	

*(continued)*

**Table B.1 (continued): Consultation list**

<b>Jurisdiction</b>	<b>Organisation</b>	<b>Name</b>	<b>Position</b>	<b>Date of consultation</b>
Tas	Chair of Perinatal Mortality and Morbidity Subcommittee of Tasmanian Consultative Council on Perinatal Mortality	Amanda Dennis	Perinatal Death Review Committees	30 July 2012
ACT	ACT Perinatal Mortality Committee	Alison Kent	Chair, ACT Perinatal Mortality Committee; A/Prof ANU Medical School; Senior Staff Specialist, Department of Neonatology, Canberra Hospital	31 July 2012
	Population Health Informatics, Epidemiology Branch, ACT Health	Ros Sexton	Information Manager	
		Wayne Anderson	Data Manager	
		Louise Freebairn	Acting Manager, Epidemiology Branch, ACT Health; Member ACT Perinatal Mortality Committee	
	Calvary Hospital	Dr Sim Hom Tam	Chair, Calvary Perinatal Mortality Committee; Obstetrician, Calvary Hospital	
		Chris Falez	Manager, Maternity Services, Calvary Hospital	
		Cathy Kernan		
		Elizabeth Bishop		
NT	Northern Territory Perinatal Mortality Committee	Karen Dempsey	Chair Perinatal Mortality Committee, Health Gains Planning Unit, Epidemiology Branch	3 August 2012
		Steven Guthridge	Director, Health Gains Planning Unit, Epidemiology Branch	
	NT Perinatal Data Custodian	Lee O'Neil	Data Custodian	
<b>Colleges, stakeholders and delegates</b>				
National	Australian Bureau of Statistics, Perinatal Statistics Group	James Eynstone-Hinkins	A/g Director, Social and Demographic Statistics	20 July 2012
		Paul Hoffman	Assistant Director, Health Team, Health and Vital Statistics Unit	
National	Sands Australia: Miscarriage, Stillbirth and Newborn Death Support	Christine Simmons	President	20 July 2012
		Wendy Bushby	Representative member	
National & NZ	Australia and New Zealand Neonatal Network	Adrienne Gordon	Representative member	24 August 2012
National	Australian College of Midwives	Della Forster	Delegated representative, Professor of Midwifery and Maternity Services Research, La Trobe University and Royal Women's Hospital	13th August 2012

*(continued)*

**Table B.1 (continued): Consultation list**

<b>Jurisdiction</b>	<b>Organisation</b>	<b>Name</b>	<b>Position</b>	<b>Date of consultation</b>
National	Royal College of Pathologists Australia	Adrian Charles	Delegated representative; Associate Professor, Schools of Pathology and Laboratory Medicine, Women and Infants Health, Paediatrics, University of Western Australia	8 August 2012
NZ	New Zealand Perinatal and Maternal Mortality Review Committee	Cindy Farquhar Vicki Masson	President General Manager	1 August 2012
Aust & NZ	Royal Australian and New Zealand College of Obstetricians and Gynaecologists	Michael Permezel	Vice President, Education and Training	16 August 2012
Aust & NZ	Perinatal Society of Australia and New Zealand	Vicki Flenady*	President	27 August 2012
	Australia and New Zealand Stillbirth Alliance	Adrian Charles	Chair	
	ACT Maternal Perinatal Information Network	David Elwood	Representative member	

\* Ms Flenady was also consulted in her role as Chair of the Perinatal Mortality Subcommittee of the Queensland Maternal and Perinatal Quality Committee (QMPQC).

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## Related publications

Australian Institute of Health and Welfare 2014. Foundations for enhanced maternity data collection and reporting in Australia: National maternity data development project Stage 1. Cat. no. PER 60. Canberra: AIHW.



This paper presents findings on the issues that need to be considered in order to produce a national perinatal mortality report that is relevant to maternity services. It is one of several components of the National Maternity Data Development Project and is a companion report to the publication *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1*.