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Maternal mortality: data linkage methodology

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



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*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 65

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ISBN 978-1-74249-631-3

Suggested citation

Australian Institute of Health and Welfare 2014. Maternal mortality: data linkage methodology—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 65. Canberra: AIHW.

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Published by the Australian Institute of Health and Welfare

Contents

Acknowledgments..... iv

Abbreviations..... v

1 Background.....1

2 Methods.....4

3 Analysis13

4 Confidentiality and data protection.....14

5 Conclusion15

References16

List of tables.....17

List of figures.....18

Related publications19

Acknowledgments

The main authors of this report were Professor Elizabeth Sullivan (formerly of) and Dr Michelle Bonello of the Australian Institute of Health and Welfare (AIHW) National Perinatal Epidemiology and Statistics Unit (NPESU). Colleagues at the AIHW assisted in preparing this report.

The AIHW acknowledges the time, effort and expertise contributed by members of the National Maternity Data Development Project Advisory Group.

This report was funded by the Department of Health as a component of the National Maternity Data Development Project.

Abbreviations

AIHW	Australian Institute of Health and Welfare
BMI	body mass index
DLU	Data Linkage Unit
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10 th Revision
NACMM	National Advisory Committee on Maternal Mortality
NCIS	National Coronial Information System
NDI	National Death Index
NICU	Neonatal Intensive Care Unit
NMDDP	National Maternity Data Development Project
NPDC	National Perinatal Data Collection
NPESU	National Perinatal Epidemiology and Statistics Unit
PSANZ	Perinatal Society of Australia and New Zealand
PSID	Project Specific Identifications
SCN	Special Care Nursery
SLA	Statistical Local Area
S/T	states and territories
STMMCs	State and Territory Maternal Mortality Committees
UK	United Kingdom
WHO	World Health Organization

1 Background

The Maternal Mortality Project is a project component that comes under the umbrella of the National Maternal Data Development Project (NMDDP). The Australian Institute of Health and Welfare (AIHW) was contracted by the Department of Health to undertake the NMDDP. The work is being done with the National Perinatal Epidemiology and Statistics Unit (NPESU), a collaborating unit of the AIHW.

The Maternal Mortality Project consists of two separate but related components. One component, the Maternal Death Report, aims to develop a nationally consistent and confidential maternal death enquiry system and develop a national report on maternal mortality. The proposed report will include both descriptive statistics and a qualitative learning outcome approach where vignettes of cases and expert opinion may be included to facilitate better learning. The second component, Data Linkage, aims to provide an enhanced process for ascertainment of maternal deaths and late maternal deaths (later than 6 weeks but less than 1 year after finish of pregnancy) in Australia. This paper details the methodology for the data linkage component.

Between 2000 and 2002, one in every 8,975 women in Australia died within 6 weeks of giving birth or terminating pregnancy. Among Indigenous women who gave birth, there was one maternal death per 2,177 women – a rate 4 times as high as for non-Indigenous women (Sullivan & King 2006; King et al. 2004).

Internationally, maternal mortality is one measure used to compare maternal health outcomes between countries and is a crude indicator of society's health care services. As such, there is national and international scrutiny of maternal mortality reports and a duty to ensure that the information is correct and complete. More importantly, the lessons learnt from detailed examination of these deaths can inform policy and improve practice in antenatal and obstetric care.

Definition of maternal deaths

A maternal death in Australia is defined as occurring anytime during pregnancy and up to 42 days post-partum and classified as:

- **direct deaths** resulting from obstetric complications of the pregnancy state
- **indirect deaths** resulting from previous existing disease, or disease that developed during pregnancy and which were not due to direct obstetric causes, but which may have been aggravated by the physiological effects of pregnancy
- **incidental deaths** occurring in pregnancy or the puerperium, where the pregnancy is unlikely to have contributed significantly to the death (King et al. 2004).

In the 10th revision of the International Classification of Diseases (ICD-10), the definition of a maternal death was broadened to include *late maternal deaths*, defined as the death of a woman from direct or indirect causes more than 42 days, but less than 1 year after the end of pregnancy (WHO 1993).

Maternal death ascertainment

Australian maternal death reporting has up to now relied on collation of information about maternal deaths from State and Territory Maternal Mortality Committees (STMMCs). Maternal deaths are notified to Committees by clinicians, in particular midwives and by

hospitals and health departments. They are also reported through coronial and post-mortem investigations. Requirements for mandatory reporting of maternal deaths vary by states and territories. Maternal deaths are further ascertained from perinatal and hospital morbidity collections and death certificate data derived from the Registrars of Births, Deaths and Marriages (RBDMs). These data provide minimal information on all-cause mortality, and include maternal age, state/territory and year of death.

There has been little research to validate the reporting of maternal deaths in Australia. A survey of obstetricians undertaken in Queensland hospitals revealed under-reporting of 34% of maternal deaths for the period 1994–1997 (King & Flenady 1999). Similarly, a pilot linkage study in NSW, which is described in detail below, found under-reporting of 20% of maternal deaths (Cliffe et al. 2008).

There is no nationally agreed standard method for reporting and reviewing maternal deaths, or identifying which indirect deaths should be further investigated. All deaths are classified using ICD–10 definitions (WHO 1993). An extract of maternal death data is provided by each STMMC to AIHW. Previously, this data was compiled into a national data collection and a triennial report prepared with expert input from the AIHW National Advisory Committee on Maternal Mortality (NACMM), which reviewed all deaths to ensure national consistency with classification. This process was reviewed as part of the NMDDP.

Maternal and late maternal death data issues

With advances in medical technology keeping patients alive for longer periods, women who once may have died during pregnancy or within 6 weeks of birth are dying later. These cases are being missed by current surveillance systems. Late maternal deaths are not monitored and/or are missed by individual jurisdictions because there is no efficient process to identify late maternal deaths and no agreement on national reporting. Nor is there agreement on the value of investigating late deaths. For the period 1997–2002, only 13 late maternal deaths were reported nationally, reflecting that these deaths were out of scope for many jurisdictional review processes. Ascertainment of these late deaths may be further complicated if women, between giving birth and dying, have changed their place of residence from one jurisdiction to another. No national study of late maternal deaths in Australia has been conducted to date.

This study focuses on maternal deaths in pregnancy and within a year of birth. Maternal deaths from pregnancies that end before 20 weeks gestation are not captured by jurisdictional perinatal collections. However, selected causes of maternal deaths from pregnancies that end before 20 weeks gestation are captured in the AIHW National Death Index (NDI) database, for example ectopic pregnancy and septic abortion, which will be included in this study. These pregnancies, if known, will be flagged on the death certificate or reported with autopsy results to the National Coroner's Information System (NCIS), which feeds into the NDI.

Data linkage provides an enhanced process for maternal death ascertainment. It has the advantage of being population based, uses routinely available data and has the potential to be a sustainable surveillance tool for maternal deaths. For more information about data linkage, see <<http://www.aihw.gov.au/access/201204/feature/data-linkage.cfm>>.

Pilot study: the New South Wales linkage project

In 2005–2006, a linkage study was undertaken to assess the accuracy of maternal death ascertainment in New South Wales to determine the burden of late maternal deaths in NSW and to pilot the method for a national study on maternal deaths. An extract of the NSW

Midwives Data Collection was linked to the AIHW NDI for the period 1994–2002. The linkage identified 173 maternal deaths: 97 maternal and 76 late maternal deaths (Cliffe et al. 2008). The linkage identified 19 new maternal deaths (occurring <42 days after a birth) that were not known to the jurisdiction, representing a 20% increase in ascertainment for the study period. The 76 late maternal deaths included 3 direct and 73 indirect maternal deaths. Only 6 (7.9%) of the late maternal deaths were known to the jurisdiction's Maternal Mortality Committee. The most common causes of late maternal death were suicide (23), cardiac disorders (16) and accidents and violence (16). Furthermore, late maternal deaths were as prevalent as maternal deaths in pregnancy and the puerperium. If this applies across all jurisdictions, the true maternal mortality rates in Australia are currently grossly under-reported.

Aims of the data linkage project

This project aims to undertake linkage of national perinatal and death datasets to determine the incidence of maternal and late maternal deaths in Australia. The overall aim of this study is to test the proposition that maternal deaths are under-ascertained in Australia. The focus is the limitations of current reporting mechanisms and the absence of routine reporting of late maternal deaths. The aims of the study are:

- Extend data linkage of perinatal data and mortality data as a method of ascertaining maternal deaths, including late maternal deaths, to the whole of Australia, building upon the findings of the NSW pilot linkage study.
- Determine the incidence and causes of maternal deaths, including late maternal deaths, in women whose pregnancies have reached 20 weeks gestation.
- Determine the incidence and causes of maternal deaths where a pregnancy has ended at less than 20 weeks gestation, as identified by specific ICD-10, Chapter XV Obstetric codes (for example, ectopic pregnancy).
- Assess the validity of current ascertainment of maternal and late maternal deaths in Australia.

2 Methods

The data collections that will be linked for this study are as follows.

State and territory perinatal data collections: Midwives or perinatal data collections are state-and-territory-based epidemiological collections of information about pregnancy and childbirth. Data are collected for each birth and include information about both the mothers and the babies. Each Australian state and territory is responsible for collecting data relating to births in their jurisdiction. The collected data are held by a data custodian within the relevant health department. The scope of the perinatal collections is all live births and stillbirths in Australia, irrespective of site, where the pregnancy was of at least 20 weeks gestation or at least 400 grams birthweight. We recognise that some women will have more than 1 birth during the study period.

The AIHW National Death Index (NDI): The NDI is a database housed at the AIHW; it contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. Information held in the NDI is designed to facilitate the conduct of epidemiological studies. The NDI provides codes for the underlying cause of death and all other causes of death. This information is derived by linking the NDI registration numbers with the National Mortality Database. The estimated mortality study population is approximately 40,000 women of reproductive age (defined here as 15–49) who died during the period 1 January 1998 to 31 December 2010 (or the most recent data available). For more information about the NDI and the National Mortality Database, see <<http://www.aihw.gov.au/deaths/aihw-deaths-data/>>.

National Coronial Information System (NCIS): The NCIS is a national data storage system for Australian coronial cases containing information about every death reported to an Australian coroner since July 2000 (January 2001 for Queensland). Cause of death data from the NCIS is provided to the NDI and can be released with clearance from the NCIS data custodian. The NCIS has been approved for inclusion in this study, with the purpose of updating the NDI.

State and Territory Maternal Mortality Committees (STMMC): These committees investigate maternal deaths. Data are collected for each maternal death and include information about the death and the pregnancy. Each Australian state and territory is responsible for collecting data on maternal deaths and notifying the local STMMC or equivalent. The STMMC conducts a review of the death and assigns a cause and classification of maternal death where possible. Availability of named or unnamed data for linkage with the NDI varies by STMMC. Therefore data may not be available from all jurisdictions, particularly for earlier years. However all available data for the study period of 1998–2010 will be requested. This data will be used to investigate if STMMC Cause of death is the same as the NDI Cause of death. Information on the classification of death will enable evaluation of current STMMC strategies for data collection and ascertainment of maternal deaths.

Study design

This study will be retrospective, using collected population data from Australia. Data linkage methodology will be used to identify deaths of women aged 15–49 years occurring within 1 year of a birth. These deaths will be classified as maternal or non-maternal. Maternal deaths will be defined as maternal deaths and late maternal deaths that occurred during a pregnancy, or within one year of giving birth/termination of a pregnancy, as

evidenced by linkage with a birth record and death record for the same individual. Additionally, deaths due to early pregnancy loss where there is no perinatal or STMMC record (unlinked death records) but an obstetric-related cause of death will be included in some of the analyses and computation of maternal mortality.

Modification to methodology during project

Two supplementary variables: Whether the baby was delivered, and Classification of maternal death, were requested from the STMMCs to be able to properly interpret data on pregnancy status at the time of a woman's death. These were used to assist with determining whether the death could be a maternal or late maternal death. The NPDC collects data on births (live or stillbirth but not undelivered) therefore if the baby was undelivered before the woman's death, there would be no NPDC record. These variables were used in the analysis to determine whether a linked perinatal record for the death was expected.

There was late incorporation of the WHO *Application of the ICD-10 to deaths during pregnancy, childbirth and the puerperium: ICD-MM* (WHO 2012), which is used to classify maternal deaths. This document was released after the methodology for this project was developed. It provides a standardised, internationally acceptable and relevant means of classifying maternal deaths when clinical review of deaths is not available.

Data linkage

Data used for this study will include all births in the perinatal data collections for the 12 calendar years 1998–2009; all deaths of women in the 13 calendar years 1998–2010 from the NDI (and NCIS); and all maternal deaths reported to STMMCs (where data are available) over 1998–2010. The most recent available data will be requested from both the state and territory perinatal data collections and the NDI. Ascertainment of jurisdictional STMMC maternal deaths (excluding late maternal deaths) will be compared with data linkage ascertainment to evaluate processes and determine the rate of under-ascertainment.

The process of data linkage is outlined below and is summarised in Figure 2.1. The variables used for the linkage are listed in Table 2.1. The linkage follows the standard protocol for data linkage of datasets within the dedicated integrating authority Data Linkage Unit (DLU) at AIHW. The standard data linkage algorithm compares all permutations of names to enable identification of people where transposition of first, other or surnames may have occurred. The method for data linkage is as follows:

1. The states and territories (S/T) will attach S/T Project Specific Identifications (PSID) to all perinatal data and these will be unique to each record. The identifiable variables from the data set will be sent to the AIHW DLU (Table 2.1, Column A) to link the data to the NDI-NCIS.
2. The de-identifiable perinatal variables will be sent to NPESU (Table 2.1, Column B) with the S/T PSID attached.
3. For linked data, AIHW DLU will derive the interval between a woman giving birth and her death by calculating the number of days between the date of birth of the baby, and the date of death of the mother from the perinatal data. Linked records with a birth to death interval of less than 365 days will be retained as linked records in the final linked data. Linked records with a birth to death interval of 365 days or more will be disassociated. There may be more than one set of linked records for a mother (a mother who died but had a multiple birth or two pregnancies in the year leading up to her death). Where this occurs, the AIHW DLU will retain a single matched record in the final linked data with the shortest birth-to-death interval.

4. The STMMCs will attach a STMMC PSID to maternal mortality data and these will be unique to each record. The identifiable variables from the data will be sent to AIHW DLU (Table 2.1, Column C) to link the data to the NDI-NCIS.
5. The de-identifiable STMMC data will be sent to NPESU (Table 2.1, Column D) with the STMMC PSID attached. It is possible that some data may not be available from jurisdictions, particularly for the earlier years. All available data for the study period will be requested. This data will also enable the ascertainment of reviewed maternal deaths to be compared to maternal deaths ascertained by data linkage.
6. Perinatal and STMMC data will not be retained by AIHW DLU for more than 6 months after the linkage has been completed.
7. The AIHW DLU will send NPESU data for all deaths of women of reproductive age (15–49) with the variables listed in Table 2.1 (Column E). Included in this data set will be data with the S/T, AIHW and STMMC PSIDs attached to the maternal death data and the generated variables.
8. NPESU will then link the perinatal data received from the S/T perinatal data (Table 2.1, Column B) and the STMMC (Table 2.1, Column D) to the NDI data received from AIHW (Table 2.1, Column E) using the unique PSIDs. The resulting data for analysis will be a de-identified data set containing all births and all deaths of women of reproductive age. Women who had a birth and died within 1 year will have linked records. The data will also include information of maternal death review status.

Data requested

The data items that will be requested from state and territory perinatal collections, the STMMCs and the NDI-NCIS are listed in five groups, to show where de-identifiable and identifiable variables will be sent (Table 2.1).

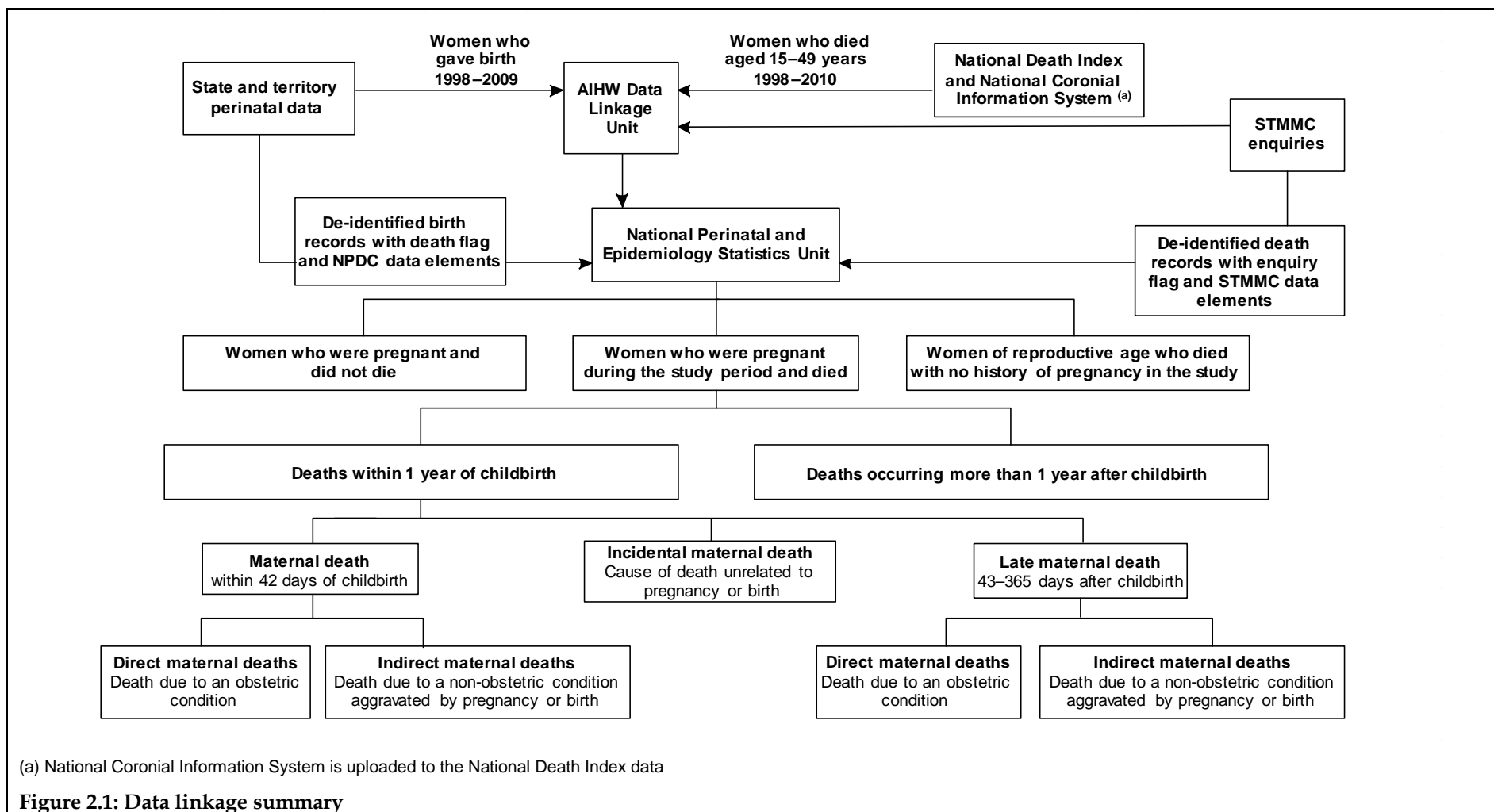


Table 2.1: Variable list

State and territory perinatal data		STMMC data		AIHW DLU — NDI–NCIS data
A. Linkage fields (sent to AIHW DLU)	B. Analysis fields (sent to NPESU)	C. Linkage fields (sent to AIHW DLU)	D. Analysis fields (sent to NPESU)	E. Analysis fields (sent to NPESU)
S/T project-specific ID	S/T project-specific ID	STMMC project-specific ID	STMMC project-specific ID	S/T, STMMC & AIHW project-specific ID
Postcode/Statistical Local Area (SLA) of residence	Postcode/SLA or socioeconomic index for areas (SEIFA)/remoteness classification		Committee cause of death	Postcode/SLA of usual residence
State	Country of birth	State	Committee classification of death (direct, indirect, incidental)	State/territory of death registration
Indigenous status (mother)	Indigenous status (mother)		Indigenous status (mother)	Race (Indigenous status: mother)
			Pregnancy status at time of death	Number of days post termination of pregnancy or birth at maternal death (generated variable)
Mother's last name	Gestational age at birth	Mother's last name	Maternal/late maternal death	Place of death
Mother's first name	Year of delivery	Mother's first name		Day of death
Mother's given names		Mother's given names		Professional type of the person who certified the death
Mother's date of birth	Mother's age of giving birth	Mother's date of birth		Mother's age at death (in years)
Mother's date of death (if known)	Antenatal length of stay (in days, not dates)	Mother's date of death (if known)		Year of delivery
	Postnatal length of stay (in days, not dates)			Year of death
Mother's date of separation				Mother's age at giving birth

Continued

Table 2.1 (continued): Variable list

State and territory perinatal data		STMMC data		AIHW DLU — NDI–NCIS data
A. Linkage fields (sent to AIHW DLU)	B. Analysis fields (sent to NPESU)	C. Linkage fields (sent to AIHW DLU)	D. Analysis fields (sent to NPESU)	E. Analysis fields (sent to NPESU)
Date of birth for each baby born	Mode of birth			NDI data
	Onset of labour			Cause of maternal death (ICD-10)
	State where woman gave birth			All other cause(s) of death (if multiple) (ICD-10)
	Type of induction			State
	Type of augmentation			NCIS data
	Plurality			Coroner flag y/n
	Place of giving birth			Coronial cause of death
	Hospital status public/private			Autopsy flag y/n
	Number of births per year for birthing hospital			STMMC data
	Hospital code (hospital size for SA) (All private hospitals coded as 1 in WA)			Death reviewed by STMMC flag y/n (generated variable)
	Mother's separation status (includes death or transfer to other hospital)			
	Maternal medical condition 1 (essential hypertension)			
	Maternal medical condition 2 (diabetes mellitus)			
	Obstetric complication 1 (pregnancy induced hypertension)			
	Obstetric complication 2 (gestational diabetes)			
	Ante-partum haemorrhage			
	Placenta praevia			

Continued

Table 2.1 (continued): Variable list

State and territory perinatal data		STMMC data		AIHW DLU — NDI–NCIS data
A. Linkage fields (sent to AIHW DLU)	B. Analysis fields (sent to NPESU)	C. Linkage fields (sent to AIHW DLU)	D. Analysis fields (sent to NPESU)	E. Analysis fields (sent to NPESU)
	Placental abruption			
	Pre-labour rupture of membranes			
	Postpartum haemorrhage			
	Previous caesarean section			
	Mode of delivery for the last pregnancy			
	Previous singleton, higher order multiple births			
	Number of previous pregnancies			
	Outcome of previous pregnancies (live birth, still birth, neonatal death and perinatal death numbers)			
	Number of previous caesarean sections			
	Method of birth last delivery			
	Presentation at birth			
	Method/type of birth			
	No labour			
	Retained placenta			
	Maternal weight and height			
	Perineal/genital laceration/tear			
	Maternal BMI			
	Assisted reproductive technology			
	Number of antenatal visits			

Continued

Table 2.1 (continued): Variable list

State and territory perinatal data		STMMC data		AIHW DLU — NDI–NCIS data
A. Linkage fields (sent to AIHW DLU)	B. Analysis fields (sent to NPESU)	C. Linkage fields (sent to AIHW DLU)	D. Analysis fields (sent to NPESU)	E. Analysis fields (sent to NPESU)
	Gestation at first antenatal visit			
	Smoking status			
	Baby			
	Baby's birth status (live or fetal death)			
	Baby's separation status			
	Birth order			
	Baby outcome			
	Baby's sex			
	Length of stay NICU/SCN			
	Resuscitation of baby			
	5 minute APGAR score of baby			
	Baby's gestation			
	Baby's birthweight			
	Fetal distress in labour			
	Baby's mode of separation			
	PSANZ cause of perinatal death			
	Year of birth for each baby born			

Classifying maternal deaths

The primary data generated by linkage for this project is a set of information about *Deaths among all women who were pregnant or gave birth in the years 1998–2009* and died in the years 1998–2010. By associating 'Date of birth' and 'Date of death', a secondary data set of *Late maternal deaths 1998–2010* will be generated; that is, deaths within a year of giving birth.

Advice regarding classification of maternal and late maternal death was sought from the National Maternal Mortality Advisory Committee. The Committee agreed to the recommendation to use the WHO *Application of the ICD-10 to deaths during pregnancy, childbirth and the puerperium: ICD-MM* (WHO 2012). It is a feasible approach for the classification of routinely collected death data using an internationally accepted method when clinical death review data are not available.

3 Analysis

This study will evaluate the contribution of pregnancy as a risk factor for all-cause mortality and specific causes of death in women at different reproductive ages. Maternal deaths will be categorised using the ICD-10. All causes of death of women who died within 42 days of a birth or with a pregnancy-related condition will be classified as 'direct', 'indirect' or 'incidental' based on information available as to the cause of death. Incidental deaths are maternal deaths where the pregnancy is unlikely to have contributed significantly to the death, such as being a passenger in a motor vehicle accident. The number and type of incidental deaths will be reported but not included in the pregnancy-related mortality analysis. The classification of deaths will be based on *Contributory cause of death* rather than *Underlying cause of death* as recorded on the death certificate in some cases. All causes of death of women who die after 42 days and within 1 year of a birth or with a pregnancy related condition, will be reviewed and classified as a late maternal death, and as either a 'direct' or 'indirect' death based on information available as to the cause of death.

To assist in analysis of national pregnancy-related mortality, a descriptive analysis of maternal deaths will be undertaken in line with the processes outlined above. Accordingly, deaths will be considered in 2 groups:

- deaths occurring during pregnancy and within 42 days of pregnancy ending
- deaths between 43 and 365 days of pregnancy ending, where the death is considered to have been directly or indirectly due to pregnancy or childbirth (late maternal deaths).

Comparisons of the causes of death and the characteristics of women and their pregnancies will be carried out. Characteristics of each group will be determined using descriptive statistics, and chi-squared analysis will be used to determine whether any associations between causes of death and group characteristics are statistically significant. The level of under-reporting of maternal deaths following childbirth will be estimated, and updated estimates of maternal mortality will be produced.

The analysis will be undertaken noting the constraints of small numbers.

4 Confidentiality and data protection

All staff involved in the study recognise the prime importance of maintaining confidentiality and respecting the privacy of the individuals to whom the data relate.

Ethical approval from the states and territories for this study and permission from each of the source data custodians will be obtained before any data are received for the study.

Data linkage procedures will ensure that the agencies linking the person-identifiable data do not have access to any other demographic or clinical information about the women or their babies. Similarly, staff preparing the study data and researchers using it will not have access to information about the identity of the women whose delivery and death information is being used.

The process of data linkage will adhere to the AIHW Data Linkage Protocol, which protects the privacy and confidentiality of individuals whose information is contained in the data sets, during both the linking of data sets and subsequent analysis.

5 Conclusion

What will this study add to current knowledge?

We consider data linkage to be an efficient approach to investigating maternal death ascertainment. This study will provide more complete information on maternal deaths and be the first national study of late maternal deaths in Australia. The study will allow Australia to develop information bases similar to those of countries such as the United Kingdom and Canada, where processes are already under way to identify and investigate late maternal deaths as a public health priority.

The results will contribute to a culture of awareness of late maternal deaths, so that they will no longer be seen as one-off events unrelated to pregnancy. The increased investigation of these deaths aims to support other safety and quality initiatives in routine obstetric and midwifery care and settings.

Rare events can become lost in summary statistics, and the higher frequency of undesirable outcomes in disadvantaged groups can be overlooked. This linkage study will provide the most comprehensive information on maternal and late maternal deaths in Australia to date. It will accurately determine the number of maternal and late maternal deaths in Australia over a recent 13-year period (subject to data availability), describe the causes and characteristics of those deaths, and provide a baseline for monitoring deaths in the future.

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List of tables

Table 2.1: Variable list.....8

List of figures

Figure 2.1: Data linkage summary7

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 report presents a data linkage methodology to ascertain the number of maternal and late maternal deaths in Australia. 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*.