Australian Government
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Enhancing maternity data collection and reporting in Australia

National Maternity Data Development Project Stage 3 and 4

Working paper

AIHW

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Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1000
Email: info@aihw.gov.au

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Abbreviations

ACN	Australian College of Midwives
ACSQHC	Australian Commission on Safety and Quality in Health Care
AGPN	Australian General Practice Network
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
ANZNN	Australian and New Zealand Neonatal Network
AODTS-NMDS	Alcohol and other Drug treatment Services NMDS
ARBD	alcohol related birth defects
ARND	alcohol related neuro-development disorders
ASSIST	Alcohol, Smoking and Substance Involvement Screening Test
BMI	Body Mass Index
CADUMS	Canadian Alcohol and Drug Use Monitoring Survey
CanFASDRN	Canada Fetal Alcohol Spectrum Disorder Research Network
CALD	culturally and linguistically diverse
CAR-BC	Centre for Addiction Research - British Columbia
CDRG	Clinical and Data Reference Group
CCOPMM	Consultative Council on Obstetric and Paediatric Mortality and Morbidity
COAG	Council of Australian Governments
DSS	Data Set Specification
DV	Domestic Violence
eNMDR	Electronic National Maternal Death Reporting tool
EPDS	Edinburgh Postnatal Depression Scale
FAEE	fatty acid ethyl esters
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
HARK	Humiliation, Afraid, Rape, Kick Screening Tool
HFL	Healthy for Life
HITS	Hurt, Insult, Threaten, Scream Screening Tool

ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
LSIC	Longitudinal study of Indigenous Children
MaCCS	Maternity Care Classification System
MCRI	Murdoch Children's Research Institute
METeOR	Metadata Online Registry
MIM	Maternity Information Matrix
MoC	Model of Care
MoC DSS	Maternity Model of Care Data Set Specification
MSIJC	Maternity Services Inter Jurisdictional Committee
NAS	neonatal abstinence syndrome
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NBEDS	National Best Endeavours Data Set
NDSHS	National Drug Strategy Household Survey
NHIPPC	National Health Information and Performance Principal Committee
NHISSC	National Health Information Standards and Statistics Committee
NHS	National Health Survey
NIRA	National Indigenous Reform Agreement
NMDDP	National Maternity Data Development Project
NMDR	National Maternal Death Reporting
NMDS	National Minimum Data Set
NMMDC	National Maternal Mortality Data Collection
NMMAC	National Maternal Mortality Advisory Committee
NMPM AG	National Maternal and Perinatal Mortality Advisory Group
NMSP	National Maternity Services Plan
NNS	National Nutritional Survey
NPDC	National Perinatal Data Collection
NPDDC	National Perinatal Data Development Committee
NPDI	National Perinatal Depression Initiative
NPESU	National Perinatal Epidemiology and Statistics Unit

OATSIH	Office of Aboriginal and Torres Strait Islander Health
PDC	Perinatal data collection
PIP	Pregnancy Information Program
PSANZ	Perinatal Society of Australia and New Zealand
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SBIRT	Screening, brief intervention and referral to treatment
SCoH	Standing Council on Health
SURP-P	Substance Use Risk Profile-Pregnancy
SDVWP	Screening for Domestic Violence Working Party
UNSW	University of New South Wales
VAED	Victorian admitted episode dataset
VPDC	Victorian Perinatal Data Collection
VMR	Victorian Maternity Record
WHO	World Health Organization

Summary

The National Maternity Data Development Project (NMDDP) was established in response to recommendations of the National Maternity Services Plan (NMSP) around improved maternity data collection and reporting.

The primary aim of the NMDDP is the development of nationally consistent maternal and perinatal data collection. This report outlines the progress, led by the AIHW that was made during stages 3 and 4 of the data development project.

Stage 1 of the NMDDP conducted between May 2011 and June 2013 consisted of identifying and prioritising data gaps and inconsistencies in the existing National Perinatal Data Collection (NPDC) and developing a plan to deal with these; developing a nomenclature for defining models of maternity care and the Maternity Care Classification System (MaCCS); achieving progress towards national agreement on standardised reporting of maternal mortality; progressing the national maternal mortality report for 2006–10 and piloting a data linkage study to achieve better ascertainment of maternal deaths; and progressing the standardised national data collection and reporting for perinatal deaths.

The second stage focussed on continuing the development of priority data items and of the MaCCS, extending maternal mortality reporting work, developing methods to better capture and report on national perinatal mortality, and providing greater access to maternal and perinatal data through web tools. Stage 2 was conducted between July 2013 and June 2015.

Stages 3 and 4 conducted from July 2015 to June 2017 included the following achievements:

- the development of nationally consistent maternal and perinatal mortality data collection in Australia with standardised data specifications, annual reporting and data base development
- further progress on developing the data items and type of data to be collected for the psychosocial maternal risk factors (alcohol use during pregnancy, mental health, domestic violence and illicit drug use) that are important contributors to outcomes for mothers and babies
- pilot testing and then the release of an updated data portal module for the maternity models of care (MaCCS) data collection
- an update to the Maternity Information Matrix (MIM) to include the most recent information on data collections and data items relevant to perinatal and maternal health.

1 Introduction

The National Perinatal Data Collection (NPDC) collates nationally consistent data about mothers and their births from states and territories. The information includes mandatory and voluntary data items on details of antenatal care, care during labour and the delivery and care after birth. This data is used to support different reports produced by the AIHW, but there are still data gaps that remain. The NMDDP is working towards filling the data gaps in the national collection by progressing ongoing collections and further developing data items. This report outlines progress made under Stages 3 and 4 of the NMDDP.

1.1 The National Perinatal Data Collection

National reporting on pregnancy and childbirth for mothers, and the characteristics of, and outcomes for their babies is currently based on the NPDC, held at the Australian Institute of Health and Welfare (AIHW). The NPDC is specified by the Perinatal National Minimum Data Set (NMDS), which at June 2016 contained 31 mandatory data items supplied by each jurisdiction (see Appendix A), as well as numerous voluntary data items supplied to varying degrees by some jurisdictions.

The NPDC includes data on all live births and stillbirths of at least 400 grams birthweight, or at least 20 weeks gestation. Collection of perinatal data occurs in each state and territory and is undertaken by midwives. The data are obtained from clinical and administrative records and information systems, including records of antenatal care, the care provided during labour and the delivery, and care provided after birth, as well as self-reported information from the mothers themselves. Various maternity information systems are used in hospitals across Australia and, while their primary purpose is clinical management, they are also feeder systems for the perinatal data collection.

The collection form (either paper or computerised) is usually completed at, or shortly after, the birth episode and may be reviewed and updated before the mother's discharge. The collection is not designed to record information after discharge, even if the mother, or her baby, is re-admitted to the same hospital within the puerperium.

1.2 National Maternity Data Development Project

The National Maternity Data Development Project (NMDDP) was established in response to the National Maternity Services Plan's (NMSPs) recommendations around improved data collection and reporting. The primary aim of the NMDDP is to ensure Action 4.1.5 of the National Maternity Services Plan (NMSP) is carried out, namely: *The Australian Government funds the development of nationally consistent maternal and perinatal data collection.*

Stage 1 of the NMDDP was conducted between May 2011 and June 2013 involved:

- identifying and prioritising mechanisms to fill data gaps and remove inconsistencies in the existing National Perinatal Data Collection (NPDC)
- developing a nomenclature for defining and categorising models of maternity care (MaCCS)
- working towards national agreement on standardised reporting of maternal mortality and produce a national maternal mortality report for 2006–10, and piloting a data linkage study to increase ascertainment of late maternal deaths
- developing standardised national data collection and reporting for perinatal deaths.

See *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* at <https://www.aihw.gov.au/reports/mothers-babies/foundations-for-enhanced-maternity-data-collection> for a full report on Stage 1.

Stage 2 of the NMDDP was conducted between July 2013 and June 2015. The second stage focussed on continuing the development of priority data items and of the Maternity Care Classification System (MaCCS), extending maternal mortality reporting work, developing methods to better capture and report on national perinatal mortality, and providing greater access to maternal and perinatal data through web tools. A report on the outcomes of Stage 2 of the NMDDP was released in February 2016 and can be found at <https://www.aihw.gov.au/reports/mothers-babies/enhancing-maternity-data-collection-reporting>.

Related to this, as part of the National Indigenous Reform Agreement (NIRA), the Council of Australian Governments (COAG) agreed to the enhancement of perinatal data to capture additional information in relation to antenatal care and alcohol use during pregnancy. COAG provided funding to the Australian Institute of Health and Welfare (AIHW) to facilitate the development of data items for inclusion in the Perinatal National Minimum Data Set through Schedule F of the NIRA.

This report outlines the work undertaken in stage 3 (July 2015 to June 2016) and stage 4 (July 2016 to June 2017) of the NMDDP. The main focus of this work was to continue the development of nationally consistent maternal and perinatal data collection in Australia through:

- establishing ongoing national data collections and reporting for maternal mortality and perinatal mortality (Chapter 2)
- progressing data development work on priority psychosocial data items (Chapter 3)
- continuing the development of maternity models of care (MaCCS) including the release of another data portal module, and further updates to the Maternity Information Matrix (MIM) (Chapter 4).

1.3 Project governance and consultation

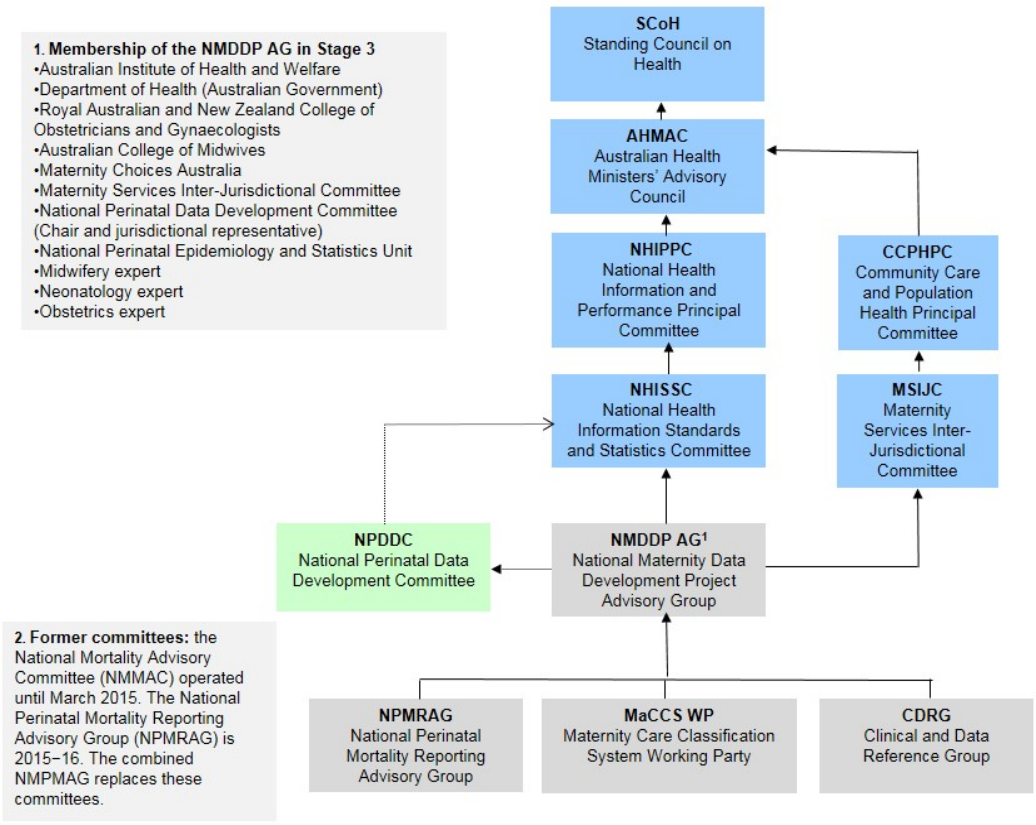
The NMDDP is guided by a project advisory group (NMDDP AG). The advisory group consists of key experts in the fields of obstetrics, midwifery, research, statistics, consumer advocacy and health policy. A list of members of the group is provided at Attachment B.

Subgroups were also established under the auspices of the NMDDP AG to provide advice on content specific topics. They are:

- the National Maternal and Perinatal Mortality Advisory Group (NMPM AG), which assists with work on maternal and perinatal mortality
- the MaCCS Working Party for advice on developing a data collection tool which allows for classification of maternity models of care available in Australia
- the Clinical and Data Reference Group (CDRG), which guides the data development work for clinical data items.

Each of these groups act in an advisory capacity to the AIHW. A list of members of these groups is provided in Appendix B, and the relationships between the groups as well as higher-level reporting pathways are illustrated in Figure 1.1.

In addition to the advisory group, the National Perinatal Data Development Committee (NPDDC) provides advice to the AIHW on the National Perinatal Data Collection (NPDC), including the National Minimum Data Set. The NPDDC consists of jurisdictional perinatal data collection managers who consider and approve changes to the NPDC which are then submitted to the National Health Information Standards and Statistics Committee (NHISSC). The NHISSC makes recommendations to the National Health Information Performance and Principal Committee (NHIPPC) which reports to the Australian Health Ministers' Advisory Council (AHMAC) and to all Health Ministers via the Standing Council on Health (SCoH).



Notes

1. The grey boxes represent NMDDP AG and direct reporting committees. Green box represents indirect reporting; blue boxes are for higher level AHMAC committees.
2. A review of the Australian Health Ministers' Advisory Council (AHMAC) reporting structure is currently underway, consequently the above figure depicting the governance structure may change accordingly.

Figure 1.1: Governance structure for Stage 3 and 4 of the National Maternity Data Development Project

2 Maternal and perinatal mortality data collections and reporting

The AIHW established the National Maternity Data Development Project (NMDDP) in response to recommendations in the Australian Government's 2008 Maternity Services Review and the subsequent 2010–2015 National Maternity Services Plan (National Maternity Services Plan 2010). The Department of Health commissioned the AIHW to implement several recommendations around improved maternity data collection and reporting, including Action 2.1, detailed in the National Maternity Services Plan, which requires 'collection of nationally consistent maternal and perinatal mortality and morbidity data and mechanisms to improve outcomes for mothers and babies'. The Plan indicates that success would be indicated by 'national maternal and perinatal mortality and morbidity reports are produced'.

During Stage 1 of the NMDDP (2011–13), options were investigated for standardised national reporting of perinatal mortality using data from the NPDC and other data sets containing information about perinatal deaths. There was universal support from stakeholders for a regular national perinatal mortality report. Stakeholders also recommended that a data set specification (DSS) or national minimum data set (NMDS) of national data standards for perinatal mortality be developed. The Stage 1 work has been reported in detail in *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* available at <https://www.aihw.gov.au/reports/mothers-babies/foundations-for-enhanced-maternity-data-collection>.

During Stage 2 (2013–15), an investigation was conducted into how to overcome the gaps and the key issues described in Stage 1 of the NMDDP. Preliminary findings have been reported in *Enhancing maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 2* available at <https://www.aihw.gov.au/reports/mothers-babies/enhancing-maternity-data-collection-reporting>.

The first national perinatal mortality report, *Perinatal Deaths in Australia 1993–2012* was published in October 2016, available at <https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-1993-2012>. Two comprehensive reports on maternal mortality have also been published as part of the NMDDP, *Maternal deaths in Australia 2006–2010* and *Maternal deaths in Australia 2008–2012*, available at <https://www.aihw.gov.au/reports/mothers-babies/enhancing-maternity-data-collection-reporting>.

The Plan and the NMDDP, in Stages 3 and 4 (2015–17), has provided a degree of security regarding future continuing data collection and reporting regarding national maternal and perinatal mortality. To further advance this work, AIHW instituted a project, *Developing ongoing national maternal and perinatal mortality data collections and reporting mechanisms within AIHW.* This project refined and consolidated national maternal and perinatal data collection and reporting in Australia with the aim of establishing ongoing monitoring and surveillance of maternal and perinatal outcomes. The project's progress is the subject of this report.

2.1 Background

The World Health Organization estimates that more than 300,000 women die, world-wide, from preventable causes in relation to pregnancy and child birth (WHO 2015a). Audit of maternal deaths is thought to be one of the oldest forms of healthcare quality review undertaken. There are around 30 maternal deaths per annum in Australia. The maternal mortality ratio for 2008–2012 was 7.1 per 100,000 women who gave birth (AIHW: Humphrey et al. 2015a).

National maternal mortality reporting in Australia has been undertaken since 1964. At times it has been restricted by funding issues, leading to intermittent timelines, variable reporting cycles, inconsistent report structures, considerable lag between data collection and reporting, and overall uncertainty regarding future reporting. These reports have studied deaths defined as 'the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes' (WHO 2011). In recent years study of 'late maternal deaths' (deaths after 42 days and within 365 days of the end of pregnancy) have also been undertaken by a number of state and territory maternal mortality review committees. Late deaths related to maternal psychosocial issues have been seen as particularly important.

The World Health Organization has published estimates that, in 2009, there were 2.6 million stillbirths globally and among the 133 million babies born alive each year, 2.8 million die in the first week of life. The majority of these deaths occur in developing countries (WHO 2015b). A perinatal death is the stillbirth of a baby of 20 or more completed weeks of gestation or of 400 grams or more birthweight; or the neonatal death of a live born baby within 28 days of birth. In Australia there are just under 3,000 perinatal deaths per annum. The most recent national rate reported, for 2013, was 10 per 1,000 women giving birth in Australia (AIHW 2015b).

Perinatal deaths have not been reported as comprehensively as maternal deaths in Australia. They are currently included in the *Australia's Mothers and Babies* series of reports and a separate report regarding stillbirths in Australia was published in 2014 (AIHW: Hilder et al. 2014a).

Overall, maternal and perinatal mortality collection has been an ad hoc research based process and it is timely to move to a sustainable co-operative ongoing process with transparent governance structures.

2.2 Project progress

Establishment of ongoing national maternal and perinatal mortality data collections required revision of the maternal and perinatal mortality data acquisition and reporting mechanisms to improve the access to information from jurisdictions and other users, whilst minimising any unnecessary burden on jurisdictional health data sources.

A stakeholder workshop was held on 16 October 2015, convened to develop a forward plan in establishing sustainable national maternal and perinatal mortality data collections and associated review and reporting of these important sentinel events in maternity care.

A pre-workshop discussion paper and jurisdictional questionnaire provided background to workshop participants and have been previously included in an unpublished report to the Department of Health, *Developing ongoing national maternal and perinatal data collections and reporting mechanisms within AIHW: Stakeholder workshop report*, 16 October 2015.

Stakeholder workshop

The purpose of the workshop was to obtain informed key stakeholder advice and support regarding the most appropriate methodology for development of a sustainable and effective program for regular maternal mortality and perinatal mortality review and reporting. The principal stakeholders were deemed to be members of jurisdictional maternal and perinatal mortality review committees and perinatal data managers from all states and territories.

The objectives of the consultation process were to build national consensus regarding ongoing monitoring and surveillance of maternal and perinatal outcomes and develop a clear governance process to oversee this work. The AIHW wishes to move towards establishing ongoing sustainable national maternal and perinatal mortality data collections and reporting to provide for surveillance of maternal and perinatal outcomes.

There was clear support for a single National Maternal and Perinatal Mortality Advisory Group (NMPM AG), reporting to the National Maternity Data Development Project Advisory Group (NMDDP AG), to coordinate ongoing monitoring and surveillance of maternal and perinatal mortality.

Maternal mortality

Triennial national maternal mortality reports commenced in Australia in the 1964 to 1966 triennium and continued until the 2003 to 2005 triennium. Subsequent overlapping quinquennial Maternal Deaths in Australia reports for the years 2006–2010 (AIHW: Johnson et al. 2014b) and 2008–2012 (AIHW: Humphrey et al. 2015a) were published under the auspices of AIHW as part of the NMDDP (AIHW 2014c) funded by the Department of Health. All reports considered maternal deaths within the WHO definition (that is, during pregnancy or within 42 days of the end of pregnancy).

There was clear advice from NMPM AG to the AIHW that data should be collected on an annual basis, under agreements between the AIHW and jurisdictional health authorities, to populate an AIHW-based national maternal mortality database. After validation processes are completed these data should be available to the jurisdictions if requested. This process should not be set up as a research project, but as an important national health database.

The frequency of reporting was reviewed, with the most favoured option being annual reporting of the most relevant trended rate and cause of death information via the AIHW website and a triennial formal AIHW report. Reporting should include an increased emphasis on contributory factors, should continue to refer to best practice points and their evidence base, and the continuing inclusions of anonymised case vignettes was firmly requested. An overall increase in clinical emphasis was an important theme running through the discussion. It was agreed that a standardised set of data specifications and a prospective timetable for data transfer from jurisdictions to AIHW are needed to maximise the ability of the jurisdictional data custodians to meet such requests in an effective and timely fashion.

Perinatal mortality

The workshop agreed that reporting of all perinatal deaths (stillbirths and neonatal deaths) together in a separate publication would enable better focus on safety and quality improvement issues than when they are reported as part of *Australia's Mothers and Babies* reports.

Increased emphasis on clinical issues and quality of care and safety outcomes along with examination of contributory factors were deemed important, along with inclusion of de-identified example case reviews and links to evidence-based guidelines where available.

Annual data collection and trend reporting was preferred and the method of data collection reviewed. Development of data specifications and integration of perinatal mortality data items into current AIHW–Jurisdictional data transfers was seen as critical to assisting jurisdictions to meet provision of these data items.

The preferred use of the Perinatal Society of Australia and New Zealand (PSANZ) classifications of cause of perinatal death was agreed. The primary value of the PSANZ classifications is that they are based on a full clinical review of the cause of death after all available investigations were concluded. A potential for 'theming' reports around some known significant contributory factors (such as maternal obesity and diabetes) was seen in a very positive light. Statistical analysis of major outcome issues to minimise the effects of confounders was encouraged. A concentration on late gestational perinatal deaths, which are the most likely to be potentially avoidable, was discussed as having the greatest potential for health-outcome gain in terms of seeking to reduce the burden of perinatal death in our community.

Post-workshop action plan

The workshop garnered broad support for harmonising and streamlining processes, standardising data, and sharing key learnings with the aim of preventing avoidable maternal and perinatal deaths.

The main actions from the workshop were to:

- establish ongoing national maternal and perinatal mortality data collections. This will include a revision of the current maternal and perinatal mortality data acquisition and reporting mechanisms to minimise any unnecessary burden on jurisdictions and to improve the accessibility of information to jurisdictions and other users
- establish the NMPM AG as a sub-committee of the existing NMDDP AG (see Figure 1.1). The NMPM AG is to work on the development of reporting templates and exploring ways to incorporate standardised reporting of clinical information including contributing factors as well as providing advice on other work relating to the national maternal and perinatal mortality data collections and reporting.

Initial steps to be undertaken by the AIHW were defined as:

- developing a project plan
- seeking nominations to establish the NMPM AG in preparation for its first meeting in February/March 2016 (see Appendix B)
- starting negotiations with state and territory health authorities regarding data provision agreements, including timelines for future data requests
- briefing the NMDDP AG at its December meeting regarding the outcomes of this workshop
- writing the report of the workshop.

Advisory group review of workshop outcomes

A report from the 16 October 2015 stakeholder workshop was tabled at a meeting of the NMDDP AG) on 4 December 2015. It noted that the main outcome of the workshop was to develop an ongoing annual collection of maternal and perinatal data with standardised data sets and definitions. It endorsed the development of a National Maternal and Perinatal Mortality Advisory Group (NMPM AG) that would report back to the NMDDP AG.

The terms of reference were discussed and the following membership was agreed:

- State or territory jurisdictional nominations
- Chairs of state and territory maternal and perinatal mortality review committees
- professional organisational representatives, including the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the Australian College of Midwives (ACN), the Australian and New Zealand Neonatal Network (ANZNN), the Perinatal Society of Australia and New Zealand (PSANZ) and the Royal College of Pathologists of Australasia (RCPA)
- a consumer representative
- the National Perinatal Data Development Committee (NPDDC)
- the AIHW Collaborating Centre National Perinatal Epidemiology and Statistics Unit (NPESU)
- a New Zealand representative
- the Australian Institute of Health and Welfare (AIHW).

First NMPM AG meeting

The National Maternal and Perinatal Mortality Advisory Group (NMPM AG) met for the first time in a face-to-face meeting on 1 March 2016.

Membership

The initial twenty-four members of NMPM AG (Appendix B) were recruited by invitations being issued to state and territory health departments, state, territory and New Zealand maternal and perinatal mortality review committees, relevant specialist medical and midwifery professional organisations, and a prominent consumer group. The resultant membership group includes nine obstetricians, three neonatal paediatricians, three midwives, one pathologist, five jurisdictional health bureaucrats and one consumer representative, along with the Head of the AIHW Indigenous and Children's Group and the Director of the AIHW collaborating unit NPESU.

Terms of Reference

The draft Terms of Reference, previously endorsed by NMDDP AG, were reviewed by the meeting. Additional clauses were added to ensure that NMPM AG had strong input into the reporting process, would be able to provide future advice regarding reporting of severe maternal and perinatal morbidity, and had the ability to consider possible future mechanisms for providing feedback to state and territory health departments and to state and territory maternal and perinatal mortality review committees. The revised Terms of Reference (Appendix C) are to be forwarded to NMDDP AG for review at their next meeting.

A draft project work plan was accepted.

Maternal mortality data collection

The confusing existence of two different forms both called the National Maternal Death Reporting form (NMDR) was reviewed. The 'short NMDR' had been developed by NPESU as a vehicle for states and territories to provide a data set to national maternal mortality data set for the purposes of developing a database for the *Maternal Deaths in Australia 2006–2010* and *Maternal Deaths in Australia 2008–2012* reports (AIHW: Johnson et al. 2014b; AIHW: Humphrey et al. 2015a). The 'long NMDR' was developed by the previous National Maternal Mortality Advisory Committee (NMMAC) for use by state and territory maternal

mortality review committees to seek information from clinicians who cared for a woman who died.

The ‘short NMDR’ form, with suggested modifications, was agreed to be an appropriate model on which to base an electronic reporting structure for states and territories to provide data to an AIHW-managed National Maternal Mortality Data Collection (NMMDC). The electronic reporting structure, based on the modified structure and the resulting DSSs, is then to be used as the basis for an AIHW in-house development of the electronic reporting methodology (Electronic National Maternal Death Reporting program; eNMDR).

As the ‘long NMDR’ form is now only used by one state (the Queensland Maternal and Perinatal Quality Council, QMPQC) NMPM AG agreed that it was not a matter for ongoing national management.

The contributing factor assessment methodology used in Victoria by the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM) and the contributory and potentially avoidable factors methodology used by New Zealand Perinatal and Maternal Mortality Review Committee (PMMRC) (Farquhar et al. 2011) were considered in a discussion about the most appropriate way to report the presence or absence of avoidable factors which may have contributed to a maternal death. The NMPM AG decided to adopt the CCOPMM structure of reporting contributing factor assessment (see Table 2.1).

Table 2.1: Classification of significance of contributing factors

Contributing factor
No suboptimal care factors identified
Sub-optimal factor(s) identified but unlikely to have contributed to outcome (insignificant)
Sub-optimal factor(s) identified might have contributed to outcome (possible)
Sub-optimal factor(s) identified likely to have contributed to outcome (significant)
Contributing factor assessment not undertaken

Source: Consultative Council on Obstetrics and Paediatric Mortality and Morbidity.

Perinatal mortality data collection

The NMPM AG reviewed the current methodology of data capture for the report regarding perinatal deaths between 1993 and 2012 being currently written by NPESU. Data for this report have been developed from the National Perinatal Data Collection (NPDC) plus a number of extra data elements specific to perinatal death that were requested from the state and territory health departments (‘supplementary’ perinatal mortality data) that may be linked to the relevant NPDC records.

Work being undertaken between the Mater Research Institute and CCOPMM to examine the feasibility of an electronic data entry system for perinatal mortality data was noted, as was the possibility of development of an AIHW electronic data entry program for perinatal mortality data. The meeting agreed to review the Mater-CCOPMM project in the future, but there were concerns regarding the availability of state and territory health department personnel who would enter data into either of these electronic systems.

The group agreed that, at this point in time, the most appropriate methodology would be to continue with a suitably revised supplementary data set for perinatal deaths being provided by state and territory health departments for 2013 and 2014 cases which can be linked to the relevant NPDC records held by the AIHW. Provision of data in this manner is covered under current agreements between state and territory health departments and the AIHW. By 2015 it

is planned that the revised supplementary data set will be included in the routine NPDC collection.

To facilitate the proposed theming of future reports around maternal body mass index (BMI), diabetes and hypertension the need to add specific data requests regarding these matters was reviewed. METeOR items regarding these issues were noted as being added to the Perinatal Data Set Specifications for 2015–2016 and would begin implementation from 1 July 2014. Not all states may be able to supply them immediately.

Reporting of maternal and perinatal mortality

The meeting agreed with the conclusion of the October 2015 workshop that national maternal mortality reporting should revert to triennial formal reporting, with summary trend data being reported annually via the AIHW website. To assist with trend data analysis, all efforts should be made to obtain a copy of the 2006–2012 maternal death data obtained from the state and territory health departments by the NPESU for preparation of the *Maternal Deaths in Australia 2006–2010* and *Maternal Deaths in Australia 2008–2012* reports (AIHW: Johnson et al. 2014b; AIHW: Humphrey et al. 2015a).

The meeting concluded that national perinatal mortality reporting should occur more frequently as the numbers are larger. Biennial formal reporting of perinatal deaths was agreed as well as summary trend perinatal mortality data being reported annually via the AIHW website.

Associated project activity

Data set specifications and collection

National maternal mortality data

Revised national maternal mortality DSSs have been developed for the future National Maternal Mortality Data Collection based upon the NMPM AG review of the data set collected for the 2006–2010 and 2008–2012 maternal deaths in Australia reports (Appendix D). Changes made include reference to a national agreed level of hospital care available (Clinical service capability), improved reference to care models involved, strengthening of data collection relating to domestic violence, more appropriate reference to reporting to the coroner and autopsy performance, and new items relating to assessment by the state/territory maternal mortality review committee of the presence or absence of contributing factors in the death. The NMPM AG recognises that some of these new and revised data items may take some time to fully implement on a state/territory basis and, after communicating the changes to the relevant health departments and committees, will be carefully reviewing the quality of these data items.

This revised DSS, with the endorsement of the May 2016 NMPM AG meeting, has been used to request data from the state and territory health departments for a Maternal Deaths in Australia 2012–2014 report and for annual reporting of maternal death trends via the AIHW website. This data request will be facilitated by the use of the electronic national maternal death data reporting facility (eNMDR). The AIHW Information Division is undertaking this development work in-house.

National perinatal mortality data

The supplementary perinatal mortality data set specifications have been revised, after the NMPM AG review. Changes made include better definition of the type of perinatal death and rationalisation of the autopsy and investigation data fields. Inclusion of several METeOR items relating to maternal diabetes and hypertension, plus height and weight to allow BMI calculation was considered. These METeOR items have been added to the NPDC, with implementation by states and territories beginning with July 2014 case data, and their provision is likely to be incremental. Items relating to the assessment by the state/territory perinatal mortality review committee of the presence or absence of contributing factors in the death are under ongoing consideration by the NMPM AG. As with the revised and new maternal death data items, the NMPM AG recognises that some of these new and revised data items may take some time to fully implement on a state/territory basis and, after communicating the changes to the relevant health departments and committees, will be carefully reviewing the quality of these data items.

This revised supplementary perinatal mortality DSS has been used to request data from the state and territory health departments for a Perinatal Deaths in Australia 2013–2014 report and for annual reporting of perinatal death trends via the AIHW website (Appendix E). In the longer term, the AIHW will seek to add these items to the ongoing NPDC data collection process.

Data development for new data set specifications

The AIHW will progress formal data development for both DSSs, including developing national health data (METeOR) standards for items in the DSS where these do not already exist and seeking endorsement of the new DSSs by the NHIPPC and incorporating them in the National Health Information Agreement.

Report options and structure

Draft *Maternal Deaths in Australia 2012–2014 and Perinatal Deaths in Australia 2013–2014* report structures, including all table and figure shells, were reviewed at the May 2016 meeting of the NMPM AG and the table shells were refined. The table shell changes are reflected in the data set specifications mentioned above. Data requests to state and territory health departments will commence after the NMPM AG has endorsed these draft report structures and after consultation with AIHW statisticians.

It is anticipated that 2006–2014 maternal mortality data will become fully available and form the basis of an ongoing National Maternal Mortality Data Collection (NMMDC), allowing for more widespread trend analysis than is currently possible, both for inclusion in a formal maternal deaths in Australia 2012–2014 report, and for annual website reporting.

The addition of 2013–2014 perinatal mortality data to the existing National Perinatal Mortality Data Collection (NPMDC) will facilitate development of a formal perinatal deaths in Australia 2013–2014 report, and for annual website reporting.

Ethics approval

Application was made to the AIHW Ethics Committee seeking approval for establishing a new AIHW-based National Maternal Mortality Data Collection (NMMDC). The application noted that this would be a new collection for the AIHW, as the National Perinatal Epidemiology and Statistics Unit (NPESU) in contract to the AIHW, have collated previous maternal death databases. Those databases were established as research projects under a complex set of jurisdictional and AIHW Human Research Ethics Committee (HREC)

approvals and were used for the purposes of producing one off publications in the AIHW *Maternal Deaths in Australia* series dating back to 1997.

The purpose of the 2016 AIHW Ethics Committee application was to establish a new collection that will be ongoing and will form part of the AIHW's suite of standard data collections in a similar manner, for example; to which the NPDC operates. The application noted that the NMMDC will contribute to protection and promotion for the health of pregnant women through national surveillance and monitoring of the cause(s) of death of women in association with pregnancy; providing national information that can be used to assess the quality and safety of maternity services; and providing national information that can be used to assess equity of access to and utilisation of maternity services. Establishing a national and ongoing collection will serve to maximise ascertainment, validity and quality of maternal death reporting in Australia. The AIHW Ethics Committee approved this application on 1 March 2016.

Application was also made to the AIHW Ethics Committee for the National Perinatal Mortality Data Collection (NPMDC). The application was framed somewhat differently to the NMMDC application in that this collection has already commenced for the years 1993 to 2012 through the addition of supplementary data fields to the existing and already ethically approved NPDC. The NPDC already contains some information on baby deaths and the mothers of those babies. Supplementary perinatal mortality data from jurisdictional review committees will be collected and joined with these NPDC data. Together these data items will form the NPMDC. The application sought to ensure that the supplementary data items, which are not collected through standard perinatal data collection processes as is the case with the NPDC, are covered under ethics. The AIHW Ethics Committee approved this application on 17 May 2016.

Maternity Services Inter-Jurisdictional Committee (MSIJC) consultation

The NMPM AG expressed the firm view that quality and safety in the care of mothers and their babies should be increasingly highlighted in future reporting of maternal and perinatal deaths. The inclusion of good practice points in the *Maternal Deaths in Australia 2006–2010* and *Maternal Deaths in Australia 2008–2012* reports (AIHW: Johnson et al. 2014b; AIHW: Humphrey et al. 2015a) was commended as a means of ensuring that clinicians are keeping up awareness of best practice. There was agreement with the AIHW position that such good practice points should be based upon strong evidence and established guidelines from reputable sources.

Clinical recommendations were noted in New Zealand and United Kingdom maternal and perinatal mortality reports, and the possible future inclusion of formal recommendations in Australian maternal and perinatal mortality reports was canvassed. The NMPM AG supported the inclusion of recommendations where appropriate in future reports. The AIHW, while supportive in principle, noted at this time that such recommendations are not standard practice for its reports.

Support was also sought and gained in principle from the Maternity Services Inter-jurisdictional Committee (MSIJC) for the inclusion of recommendations in future national maternal and perinatal mortality reports. The MSIJC, a cross jurisdictional maternal health policy committee convened by the AHMAC, suggested that such recommendations should be consistent with the work of the Australian Commission on Safety and Quality in Health Care (ACSQHC) and that the AIHW and the NMPM AG should approach any recommendations in a strategic fashion that allowed for relevant organisations to follow-up their implementation.

The MSIJC members also supported the outlined objectives of developing a program of regular maternal and perinatal death data collection and report production as an appropriate implementation of the Maternity Services Plan. The increased concentration on quality and safety in maternal and newborn care was welcomed. Good practice points, included in the 2006–2010 and 2008–2012 Maternal Deaths in Australia reports, were seen in a positive light.

Second NMPM AG meeting

The NMPM AG met by teleconference on 11 May 2016. The primary purposes of this meeting were to agree to the revised Terms of Reference, review outstanding questions regarding the maternal and perinatal mortality data items to be requested for the NMMDC and NPMDC, and to review draft maternal and perinatal mortality report outlines. These aims were successfully achieved and the resulting finalised lists of maternal and perinatal mortality data items are found at appendices E and F, respectively. The group agreed to seek a suitable Fellow of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) as an additional member.

2.3 Planned future steps

The work reported above has set the foundation for the sustainable development of ongoing maternal and perinatal mortality data collections by the AIHW, with regular reporting both by formal reports and by brief web-based trend reports.

Maternal mortality data collection

It was proposed that data be requested 18 months after the end of the calendar year, commencing with 2013 and 2014 data requests in July 2016. The AIHW built and tested the Electronic National Maternal Death Reporting tool (eNMDR) for the input of maternal mortality data into the National Maternal Mortality Data Collection (NMMDC) by the states and territories. This interface contains some basic validation checks, skips, pick lists, free text fields where appropriate and the ability to upload reports. Data submitters in each jurisdiction that want to use the tool are able to log in and send data securely. Data are exportable in electronic and printable formats.

Maternal mortality reporting

Formal national maternal deaths reports will be produced every three years. Summary and trend information will also be reported on the AIHW website. The small numbers of maternal deaths each year may limit what can be placed on the web annually, due to statistical and privacy concerns—this will be explored once data are available.

Topics for web reports may include:

- maternal mortality (direct and indirect deaths) ratios, trends
- age-standardised maternal mortality rates, trends
- age distribution of maternal deaths of mothers giving birth
- age specific maternal mortality rates
- cause of maternal deaths
- Indigenous maternal mortality ratios.

Perinatal mortality data collection

The supplementary data items for 2013 and 2014 perinatal deaths were requested from state and territory health departments in the next financial year, between July and September of 2016. The NPDC data for 2013 has already been provided and the 2014 data supply is under way.

As most data items for reporting on perinatal mortality are sourced from the NPDC, the supplementary perinatal mortality data items will be added to the subsequent annual NPDC data requests that occur in March of each year (Appendix E).

State and territory perinatal data collection managers have indicated that, by the time they supply data to the AIHW (first submission usually around May), most perinatal deaths would be finalised for two years prior; that is, 2014 perinatal deaths data would be available by May 2016. A small number of deaths may have to be provided in a later submission.

Perinatal mortality reporting

A formal national perinatal deaths report will be produced every two years and summary information will be reported on the AIHW website annually.

Topics for web reports could include:

- stillbirth, neonatal and perinatal mortality rates (trend)
- perinatal mortality by maternal age and year
- perinatal mortality by plurality and year
- perinatal mortality by gestational age and year
- cause of perinatal deaths
- perinatal mortality rate by PSANZ NDC
- neonatal mortality rate by PSANZ NDC
- perinatal mortality by PSANZ code and Indigenous status.

Timelines (estimates) for data requests and reporting

The planned timeline for requesting maternal and perinatal mortality data from state/territory and the reporting of the data is outlined in Table 2.2.

Table 2.2: Planned timelines for data requests and report production and release

	Annual data requests	Web summaries	Full report public release
Maternal mortality	July 2016	March/April of following year[a][b]	August of following year[a] (every 3rd year)
Perinatal mortality 2013–2014	September 2016	March/April of following year[a]	September of following year[a] (every 2nd year)[a]
Perinatal mortality future years	March 2017 onwards[c]	November/December same year[d]	April of following year (every 2nd year)[d]

(a) For example, if 2014 data were requested in 2016, the web summary would be published in March/April 2017 and the full report published in August/September 2017.then triennially for maternal mortality and biennially for perinatal mortality.

(b) Note that small numbers of maternal deaths each year may limit what can be placed on the web annually—this will be explored once data are available.

(c) From 2017, for 2015 data will be added to the NPDC data request and requested annually thereafter.

(d) For example, 2015 data would be requested in March 2017, the web summary would be published in November/December 2017 and the full report published in April 2018.

2.4 Conclusion

This chapter summarises progress towards developing a sustainable methodology for ongoing AIHW-based national maternal and perinatal death data collections and associated review and reporting of these important sentinel events in maternity care, as part of the National Maternity Data Development Project.

A stakeholder workshop was convened in October 2015, to develop a forward plan in establishing a sustainable national maternal and perinatal mortality data collection and reporting plan. The primary agreed outcome from this workshop was that it was timely to move from an ad hoc research based process to a sustainable co-operative ongoing process with transparent governance structures. Increased emphasis on quality of care and safety of outcomes in reporting was a strong theme in the discussions. A National Maternal and Perinatal Mortality Advisory Group (NMPM AG) to oversight this work was recommended.

The National Maternity Data Development Project Advisory Group (NMDDP AG), when endorsing the 'Developing ongoing national maternal and perinatal mortality data collections and reporting mechanisms within the AIHW' project (the project) at its meeting of 4 December 2015, indicated that the NMPM AG required clear and transparent Terms of Reference and that continuing NMDDP AG oversight of the processes is important.

An action plan was developed and endorsed by the first NMPM AG meeting, held on 1 March 2016, with the following underlying major principles:

- Both maternal death and perinatal death data should be collected on an annual basis, under an AIHW-jurisdictions set of agreements, to populate ongoing AIHW-based national maternal and perinatal mortality databases. After validation processes are completed these data should be available to the jurisdictions.
- Standardised data specifications for both maternal death and perinatal death data items are to be developed, along with a prospective timetable for required data transfer from jurisdictions to the AIHW. The format by which jurisdictions report data to the AIHW should be revised for relevance, compliance with the data set specifications, and user friendliness.
- The frequency of reporting should include annual reporting of the most relevant trend rate and causation information relating to maternal and perinatal death via the AIHW website, triennial formal reporting of maternal deaths allowing triennial trend reporting to be re-established and biennial formal reporting of perinatal deaths.
- An overall increase in clinical emphasis is an important principle for future reports. Reporting should include an increased emphasis on contributory factors, should continue to refer to best practice points and their evidence base, and should continue to include anonymised maternal death case vignettes.
- The use of the Perinatal Society of Australia and New Zealand classifications of cause of perinatal death (PSANZ-PDC and PSANZ-NDC) is preferred over the ICD-10 classification. The ICD-10 classification is, also, to be reported for international comparability.

The satisfactory progress with this action plan was reviewed at the 11 May 2016 meeting of the NMPM AG. Outstanding questions regarding data items to be collected were resolved and draft outlines of maternal and perinatal mortality reports were reviewed. The draft plan for 2016–17 was agreed, with data collection and database development undertaken in the second half of 2016 and in 2017. Publications are planned for late 2017 and early 2018.

3 Psychosocial data development

Maternal risk factors such as alcohol use, mental health, domestic violence and illicit drug use are important contributors for health outcomes for mothers and babies. Alcohol use by pregnant women is considered one of the most important modifiable risk factors affecting fetal growth and development during pregnancy and the wellbeing of the child both in the short term and long term (AIHW 2010). Mental health morbidity associated with the perinatal period is now recognised as a major public health issue. Pregnant women who use drugs are at risk from a range of social, health and physical risks and their babies are at risk from being born with addictions to premature birth and low birthweights. Women experiencing domestic violence are at greater risk of complications during pregnancy, such as inadequate weight gain, infection, miscarriage, antepartum haemorrhage and low birthweight.

Stage 1 of the NMDDP identified these maternal risks as a key information gap and determined after extensive consultation that alcohol use, mental health, domestic violence and illicit drug use were priority data items for development and national standardisation.

3.1 Alcohol use during pregnancy

Alcohol is a known teratogen, and widely accepted as the most common preventable cause of intellectual impairment in particular and congenital anomaly in general (AIHW 2011a). Fetal exposure to alcohol has been strongly associated with developmental anomalies predominantly affecting the brain. The risks of birth defects during pregnancy are increased with high, frequent alcohol use during the first trimester (Coyne et al. 2008). Variation in the timing, dose and frequency of alcohol use by the mother, and individual susceptibility of the fetus, contribute to the range and severity of the physical abnormalities and functional impairments that may arise. The associated intellectual and emotional impairments are life-long and can be profound. The visible anomalies are much more subtle and in many cases there is no external physical evidence of damage. The umbrella term for these abnormalities is fetal alcohol spectrum disorder or FASD (Burns et al. 2009).

FASD encompasses Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), alcohol related neuro-development disorders (ARND) and alcohol related birth defects (ARBD). These conditions and abnormalities form a continuum of effect arising from fetal alcohol exposure, which has shown to affect normal fetal development and functioning of the brain and brain tissue. FAS and pFAS are distinguished by distinctive abnormalities within facial features and/or growth retardation or central nervous system neuro-development abnormality of the brain and central nervous system. Symptoms associated with ARND and ARBD are less obvious and are most likely to manifest as behavioural or cognitive abnormalities with no physical abnormalities present. There is some evidence to suggest that the different developmental symptoms associated with FASD correspond to alcohol consumption in different stages of pregnancy (Coyne et al. 2008). Alcohol use during the first trimester is associated with the onset of FAS while alcohol use in later pregnancy is associated with cognitive and behavioural problems (Coyne et al. 2008).

Diagnosis of FASD, in the absence of facial abnormalities, is problematic without the presence of documented maternal alcohol consumption during pregnancy, as the symptoms associated with ARND and ARBD can readily be attributed to other causes (Stratton et al. 1996).

Recent international literature highlights the difficulties associated with determining the prevalence of FASD because of the limited capacity to make a FASD diagnosis in the absence of evidence of maternal drinking (AIHW 2011a). Additionally this is compounded by the fact that alcohol consumption during pregnancy does not necessarily result in FASD.

Currently in Australia, the Perinatal National Minimal Data Set (NMDS) contained in the Metadata Online Registry (METeOR) does not include data item(s) on alcohol use in pregnancy, nor is there national consensus on how alcohol use in pregnancy should be collected or reported. As a result, there is currently no ongoing national data collection of FASD and the prevalence of these conditions in Australia is unknown and unable to be accurately ascertained. Given the seriousness of FASD, and the limited information available to health professionals concerning its epidemiology, the establishment of a national data set should be given high priority. The national data set should be designed to: capture trends in maternal drinking, risk factors for potential harm caused by FASD, the identification of at risk populations and to assist in the diagnosis of FASD. What remains to be decided is what information needs to be collected in order to establish a national data set and which method of collection is best suited to this purpose.

What information needs to be captured?

While there is conclusive evidence on the relationship between alcohol consumption during pregnancy and developmental anomalies in the unborn fetus, there is no linear relationship between quantity of alcohol consumed and FASD. Children exposed to high levels of alcohol in utero are not all affected in same way and may express no symptoms at all (Burns et al. 2009). Additionally, there is a lack of evidence suggesting a causal link exists between low to moderate levels of alcohol consumption during pregnancy and the emergence of FASD in exposed children (O'Leary et al. 2006). Alcohol consumption in pregnancy is considered a risk factor for adverse perinatal outcomes and Fetal Alcohol Spectrum Disorders (FASD) which is estimated to be prevalent in as many as 2% to 5% of children in Australia (May et al. 2014).

Currently, there is some dispute surrounding the potential harms associated with low levels of alcohol consumption on the unborn child during pregnancy and as such, a safe level of alcohol consumption has yet to be determined. It remains unclear in the literature whether the effects of alcohol on the fetus are associated with dose or are threshold dependant—meaning that currently no safe level of alcohol use has been found for pregnant mothers (NHMRC 2009; O'Leary et al. 2006).

Factors found to influence the expression of FASD include the variation in the timing, dose and frequency of alcohol use by the mother and individual susceptibility of the fetus contributes to the range and severity of the physical abnormalities and functional impairments that may arise. As noted above, alcohol consumption at different stages during pregnancy may result in different FASD symptoms (Coyne et al. 2008). Capturing information regarding the timing of alcohol use during pregnancy should therefore be considered for inclusion in any data collection. It is recommended by the National Perinatal Epidemiology and Statistics Unit (NPESU) that alcohol use during pregnancy should be collected twice during pregnancy, before and after 20 weeks gestation.

There is no diagnostic test available that can identify children adversely affected by alcohol exposure prior to birth (AIHW 2010).

The lack of certainty in the literature regarding alcohol consumption during pregnancy has allowed differing interpretations and conclusions and thus different policy guidelines regarding alcohol consumption during pregnancy both nationally and internationally.

Even so, the majority of health policy guidelines regarding alcohol consumption during pregnancy recommend either abstinence from alcohol (Canada, United States) or not consuming alcohol as the safest option (Australia) (O'Leary et al. 2006).

Recent evidence suggests that, despite the national guidelines recommending the safest option for women who are pregnant or planning a pregnancy is not to drink (NHMRC 2009), the persistence and prevalence of alcohol consumption during pregnancy is still high. Up to 40% of women acknowledge that they drank alcohol and at least 10% that they had binged. Whilst this proportion does reduce in the second trimester, likely due to women finding out they are pregnant, up to 7% of women are still identifying as drinking after this point (O'Keeffe et al 2015). Additionally, a recent study undertaken in a remote Australian location indicated that 55% of pregnant women were drinking and the prevalence of FAS was 120 per 1,000 children, suggesting that this rate was one of the highest rates per capita in the world (Fitzpatrick et al. 2015).

Understanding the prevalence and extent of drug affected pregnancies is crucial, as screening, brief intervention, and referral to treatment have been found to significantly reduce alcohol or substance use and improve pregnancy outcomes for mothers and babies (Chang et al. 2006; Farr et al. 2014; Pong et al. 2010).

In Australia, no national standardised data exists to be able to monitor trends, develop and evaluate interventions and improve perinatal outcomes on modifiable risk factors, such as alcohol use in pregnancy.

Current methods to measure alcohol intake during pregnancy

There are five possible approaches that could be used to measure the prevalence of alcohol consumption during pregnancy: self-report; passive surveillance; neonatal/maternal hair analysis; testing meconium for alcohol use; and record linkage.

Self-report

To date, the only way of measuring alcohol use during pregnancy in Australia has been self-report. This method is currently used in three jurisdictions: Australian Capital Territory; Northern Territory; and Tasmania. In these three jurisdictions, alcohol use in pregnancy is routinely captured in the midwives data collections, however, each use different methods as there is no standardised collection method.

Standardised self-reporting measures are currently the only viable and available measure for capturing information regarding alcohol consumption in the first trimester due to the absence of an effective biomarker during this period (Bearer et al. 2005). Evidence suggests that alcohol consumption in the second and third trimesters is indicative of alcohol consumption during the first trimester (AIHW 2011a).

It is recognised that self-reported data does not offer a reliable or accurate tool for capturing information about alcohol consumption during pregnancy as information is likely to be retrospective and affected by recall bias (AIHW 2010). In addition, self-reporting of alcohol consumption can be unreliable because of the inaccuracy of recall, particularly for heavy drinkers, where there may be severe cognitive impairment (AIHW 2011b). Other possible reasons for inaccuracy of self-report data may include not being asked about drinking patterns by health-care providers, respondents wanting to provide socially acceptable answers, and simply not knowing how to measure standard drinks and therefore reporting incorrect drinking patterns or behaviour. For example, a woman reporting that she consumes one drink per week may not be the same as reporting one standard drink per week. It has been shown that pregnant women are likely to under-report the amount of alcohol they

consume when reporting concurrently in comparison to retrospectively (AIHW 2011c). While under-reporting poses a potential threat to the quality of self-reported data in relation to alcohol use in pregnancy, methods have been devised in an attempt to improve data quality with some success. For example, indirect self-reporting methods that ask pregnant women how many drinks they can consume before passing out have been successful in flagging high alcohol consumption during pregnancy (Bearer et al. 2005). It also may be possible to determine a statistical correction factor that could be utilised to counter the effects of under-reporting at the population level.

Subjective screening instruments do exist in Australia, particularly to capture information regarding high levels of alcohol consumption during pregnancy (AIHW 2011c). Some of the most common screening tools used by health professionals to determine excessive drinking include: T-ACE (Tolerance, Annoyed, Cut Down, Eye Opener), TWEAK (Tolerance, Worry, Eye Opener, Amnesia, Cut Down), and AUDIT (Alcohol Use Disorders Identification Test). Unlike other screening tools, AUDIT does include questions relating to frequency, quantity and binge drinking, however AUDIT has not been developed or extended to screen for alcohol use during pregnancy.

It should be noted that the use of standardised (the same question is asked in the same way for each respondent) self-report indicators is not restricted to measuring alcohol consumption and is commonly used to monitor other health risk behaviours such as smoking with a high degree of success (Patrick et al. 1994).

Similar to the issues surrounding measuring alcohol usage amongst pregnant women, maternal self-reports probably under-estimate the prevalence of smoking in pregnancy (Swamy et al. 2011). However, some studies comparing self-reported data with biochemical test results have shown that self-report measures are as effective as biochemical tests (Swamy et al. 2011).

Passive surveillance

Passive surveillance refers to the collection of information from established routinely collected data sources. The data may be obtained from a single source or multiple sources. While being efficient and relatively cheap compared with the costs associated with establishing an entirely new data source, information from routine data sources may be incomplete and are not necessarily standardised. Data from multiple independently collected routine data sources can overcome these drawbacks by providing external validation and the ability to supplement data missing from different sources.

The application of capture-recapture processing (a method of comparative analysis of data from various independent sources that adjusts for missing cases), can produce better estimates of prevalence than those from any of the individual data sources (AIHW 2011b).

Collections which may have the capacity to include ICD-10-AM coded FASD diagnosis (once developed) are the admitted hospital patient collections—including the National Hospital Morbidity Database (NHMD), emergency data collections and the congenital anomaly data collections. A further potential data collection that could be considered is the disability services data collections or the alcohol and other drugs treatment services (ADOTS) as women admitted for alcohol rehabilitation are the most likely to have children with FASD (AIHW 2011d).

Objective measures

Neonatal/maternal hair analysis

It is suggested that objective methods utilised for diagnostic purposes must be evidence based, sensitive and specific, and account for other exposures during pregnancy (AIHW 2011b).

There are two possible objective methods which could optimise the collection of accurate information regarding alcohol consumption during pregnancy, each involving the analysis of hair taken either from the neonate or the mother.

Mother's hair or neonate hair can be used as an effective biomarker with which to determine alcohol use through the analysis of fatty acid ethyl esters (FAEE), an ethanol metabolite, that has been shown to be an effective indicator of high levels of alcohol use and alcoholism during pregnancy (De Giovanni et al. 2007).

Neonatal hair begins to grow in the last 3–4 months of pregnancy, thus the testing of neonatal hair can provide a useful biomarker of excessive alcohol exposure in the last trimester (AIHW 2011b). Neonatal hair analysis cannot capture alcohol exposure in the first trimester; however, it does provide an easy and effective means of determining high levels of alcohol exposure in the third trimester (AIHW 2011b), which, as noted earlier, is usually indicative of excessive alcohol use in the first trimester. In addition to the detection of alcohol use, neonatal hair analysis can also provide an objective measure of detecting other drug use such as cocaine (Klein et al. 2002).

As stated above, the main limitation to the use of neonatal hair as a measure of alcohol consumption is that it can only provide information about alcohol exposure in the last trimester. Testing mother's hair, in contrast, may enable analysis of alcohol consumption throughout pregnancy. Nevertheless, there could be other confounders such as the use of hair dye and the effect this would have on maternal hair analysis (AIHW 2011b).

One study that used FAEE as an indicator of alcohol consumption in parents at risk (parents determined to have a history of excessive alcohol use) of having children with FASD, found that maternal FAEE hair analysis is a potentially powerful tool with which to detect excessive alcohol use in the perinatal period (Kulaga et al. 2009; Kulaga et al. 2010).

Building upon these findings, a more recent study of maternal/paternal hair analysis was expanded to examine the possibility that FASD may be compounded by polydrug exposure (Kulaga et al. 2010). Using hair analysis, this study found that mothers testing positive for heavy alcohol use were also found to have a threefold increased risk of testing positive for cocaine. Using alcohol and other drugs during pregnancy may increase fetal risk of FASD (Kulaga et al. 2010). Limitations to this method are that it is still in early stages of development, the potential for privacy/consent issues and the feasibility of testing hair at the population level.

Testing meconium for alcohol use

Meconium is comprised of materials ingested during gestation, including amniotic fluid, mucus, bile, epithelial cells, and water (Shor et al. 2010). Testing meconium for FAEE is another objective measure which could identify mothers who consumed excessive amounts of alcohol (more than four standard drinks on one occasion) in the second and third trimesters (Chudley 2008).

A positive FAEE meconium test is not a definitive diagnosis of FASD, but does identify neonates who were prenatally exposed to alcohol and are at a higher risk of this disorder

(Zelner et al. 2010). The most significant benefit of this test would be the early identification of at-risk children who need monitoring and follow-up and the ease and accuracy of collection (Shor et al. 2010).

For example, a meconium test is proposed as an effective evidence-based objective measure however it cannot necessarily guarantee that other factors during pregnancy, such as smoking, do not affect the diagnosis (Burd et al. 2010). Similarly, meconium tests can detect heavy or binge drinking in the second and third trimesters, but cannot detect alcohol consumption in the first trimester (prior to 13 weeks) nor can it determine occasional or moderate drinking (Bearer et al. 2005).

The limitations associated with using meconium for alcohol use are the same as those listed above under Neonatal/maternal hair analysis.

Record linkage of available data sources

Record linkage involves bringing together records derived from different sources, but relating to the same individual (D'Arcy et al. 1999). Linked data records are important because they provide a powerful tool for health-care research, in particular longitudinal studies (Young et al. 2001). Linkage of health records has been used to support public health and surveillance (D'Arcy et al. 1999). Current legislation in Australia stipulates that individual consent is required (AIHW 2011a).

The Australian Longitudinal Study on Women's Health (ALSWH) was the first study in Australia to link data on such a large scale within the current legislation that requires consent from each individual (Young et al. 2001). There was some bias in the study, for example less younger women agreed to consent than older women. This was explained by three main possible reasons—that younger women move more often and may not have received the postal request, are often more concerned about privacy issues than older women, and are less trusting of government departments and the security of data (Young et al. 2001).

A United Kingdom study on mother's consent to linkage of survey data with her child's birth records in a multi-ethnic national cohort study found that most (92%) mothers of the 19,000 babies born between 2000 and 2001 consented to linkage of the data (Tate et al. 2006). What this study also found was that certain groups were less likely to consent, including mothers from ethnic minority groups, mothers with higher education backgrounds, and mothers in their 20s and 30s.

As outlined by Young (2001), there is an alternative approach to data linkage that does not require individual consent (AIHW 2011b). This involves a linkage agency obtaining survey and administrative files (that contain identifiers), linking the files without consent and then removing all identifiers. The main advantage of this mode of data linkage is the possibility of large numbers of cases being linked without the time consuming task of seeking individual consent. It may not, however, benefit longitudinal studies.

Linked administrative data in maternal and child health has also been successfully performed in Australia as early as 1994 (Stanley et al. 1994). More recent studies have linked data from the NSW Inpatient Statistics Collection to the NSW Midwives Data Collection over a five year period to examine the obstetric and neonatal outcomes for women with an alcohol-related hospital admission or illicit drug use during pregnancy compared with the general obstetric population (Burns & Mattick 2007; Burns et al. 2006).

These studies indicated that linked population-level administrative data may provide an effective means for evaluating outcomes associated with alcohol use in pregnancy (Burns & Mattick 2007; Burns et al. 2006) or other important outcomes in maternal and

neonatal health. Linked population data has also been used in the neonatal setting to determine prevalence of neonatal abstinence syndrome (Burns et al. 2006).

The AIHW paper *Collection and data sources in Australia relevant to Fetal Alcohol Spectrum Disorders* states that opportunities for data linkage in the context of alcohol consumption, pregnancy and FASD are limited as none of the current collections are in a position to associate the manifest symptoms of FASD with fetal alcohol exposure (AIHW 2010). The above paper does identify one potential source for data linkage namely, the Australian Paediatric Surveillance Unit (APSU) Fetal Alcohol Syndrome study; however, this study is limited to FAS diagnosis after birth and does not capture information relevant to the epidemiology of FASD conditions, such as ARND and ARBD, as these conditions are not associated with physical defects and, as such, may go undiagnosed in the absence of documented alcohol consumption during pregnancy.

International data collections and methods

Policies and guidelines in other English-speaking countries derive mostly from reviews of the current literature available on alcohol use in pregnancy and are similar in scope to Australia (O'Leary et al. 2006). Internationally there are currently no established data collections specifically designed to capture maternal alcohol use during pregnancy. Most developed nations use more generalist data collections pertaining to definitions and levels of alcohol consumption.

The World Health Organization (WHO) define hazardous drinking (excluding pregnant women), as more than 60 grams of alcohol in one session (equal to six and above standard drinks in Australia) (WHO 2000). The WHO suggests that when measuring individual alcohol consumption patterns a 'graduated quantity frequency' method is preferred. This method requires that questions about the quantity and frequency of alcohol consumption be asked to help determine short-term and long-term health consequences. This information can be collected in (but not confined to) the following ways:

- in a clinical setting with questions asked by a primary healthcare professional
- as a self-completed questionnaire in a clinical setting
- as part of a health survey
- as part of a computer aided telephone interview.

The WHO notes that the most effective method to achieve high response rates regarding personal alcohol consumption derive from questionnaires that ensure participant confidentiality (WHO 2000). Regarding data collection methods for alcohol consumption, the WHO recommend the use of surveys as data derived from surveys approximate who the drinker is and allow for comparisons between relevant sub populations, which is essential to the development of targeted intervention strategies aimed at reducing alcohol-related harm (WHO 2000).

Canada

The Canadian Alcohol and Drug Use Monitoring Survey (CADUMS) is an ongoing general population survey of alcohol and illicit drug use among Canadians aged 15 and older, sponsored by Health Canada. It was developed in collaboration with the Centre for Addictions and Mental Health (CAMH), the Centre for Addiction Research—British Columbia (CAR-BC), Alberta Health Services (formerly, Alberta Alcohol and Drug Abuse Commission), Manitoba Health, the Centre québecois de lutte aux dépendances (CQLD), and the Canadian Centre on Substance Abuse (CCSA). Designed to provide annual national and

provincial estimates of alcohol and drug-related behaviors and outcomes, CADUMS was launched in April 2008.

Annually, the targeted number of CADUMS interviews to be conducted by telephone is 1,008 per province, randomly selected to produce a national survey of 10,080 interviews annually. Due to methodological issues, the territories are not included in the survey. The response rate for the 2010 CADUMS was 44.4%, which was consistent with the response rate for the 2009 CADUMS (44.7%). Table 3.1 outlines the definitions associated with alcohol consumption that was used by the CADUMS.

Table 3.1: Definitions of alcohol consumption as utilised by the CADUMS

Terms	Definitions
Prevalence	the proportion of a group or population reporting the indicated behaviour or outcome, usually expressed as a percentage
Past-year use	reported use in the 12 months preceding the interview
Age of initiation	the age at which a person first used alcohol or a drug
Abstainer	a person who has never used alcohol in their life
Former drinker	a person who has used alcohol in their life, but not in the past year
Harm	Alcohol and Drug related harms include harms in any of the following 8 areas: physical health; friendships and social life; financial position; home life or marriage; work, studies or employment opportunities; legal problems; difficulty learning; and housing problems
Light infrequent drinker	a person who drinks less than once per week on average in a year, and usually consumes less than 5 drinks on each drinking occasion
Light frequent drinker	a person who drinks once or more per week on average in a year, and usually consumes less than 5 drinks on each drinking occasion
Heavy infrequent drinker	a person who drinks less frequently than once per week, and usually consumes five or more drinks on each drinking occasion
Heavy frequent drinker	a person who drinks one or more times per week on average in a year, and usually consumes five or more drinks on each drinking occasion

Source: Canadian Alcohol and Drug Use Monitoring Survey.

Canada has been active in developing capacity for assessing and responding to FASD through the development of national guidelines for the diagnosis of FASD.

A pivotal feature of the guidelines is the use of a multidisciplinary team that includes physicians, psychologists, speech pathologists, occupational therapists and social workers. Assessment of the capacity of the emerging multidisciplinary clinics in 2005 and 2006 indicated an increased need for diagnostic capacity and confirmed continuing demands for FASD assessment (AIHW 2011b). A screening toolkit for FASD was developed to identify individuals who require formal diagnosis. The toolkit includes five tools to assess people at different life stages, including meconium testing (organic materials such as amniotic fluid, mucus, bile, epithelial cells, and water ingested during gestation) for newborns (AIHW 2011b).

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASDRN) is active in promoting research to improve consistency in diagnosis, appropriate and effective interventions and prevention programs that are sensitive to culture and gender, respectively (Salmon & Clarren 2011).

United Kingdom

The United Kingdom employs the following definitions of alcohol consumption within its data collections:

- Adult men should not regularly drink more than 3–4 units (one unit of alcohol is equivalent to one standard drink (10 grams) in Australia) of alcohol a day.
- Adult women should not regularly drink more than 2–3 units a day.

The United Kingdom's National health statistics report *Statistics on Alcohol: England, 2010* brings together data from a number of health surveys conducted in the United Kingdom such as the General lifestyle survey and the Omnibus survey. Both surveys include questions regarding personal alcohol use (NHS 2010).

A number of sources collect information on the number of units drunk in an average week and the amount drunk on the heaviest drinking day in the last week. Neither of these indicators precisely measure consumption against the above definitions.

Hazardous drinking is defined as a pattern of drinking which brings about the risk of physical or psychological harm. Harmful drinking, a subset of hazardous drinking, is defined as a pattern of drinking which is likely to cause physical or psychological harm.

Substance dependence is defined by the International Classification of Diseases and related health problems (ICD-10) as a cluster of behavioural, cognitive and physiological phenomena that can develop after repeated substance use.

United States of America

In 2005, the United States Surgeon General advised that no level of alcohol consumption by pregnant women during any point in their pregnancy could be considered safe due to the risk of fetal alcohol syndrome (United States Department of Human Services 2005).

The Centers for Disease Control and Prevention (CDC) Alcohol Team defines a standard drink as containing 14.0 grams of alcohol and uses the following definitions to determine alcohol misuse:

a) Alcohol misuse:

- for women, more than one drink per day on average
- for men, more than two drinks per day on average

b) Binge drinking:

- for women, four or more drinks during a single occasion
- for men, five or more drinks during a single occasion.

The United States Department of Health and Human Services (DHHS) report *Women in Substance Abuse Treatment: Results from the Alcohol and Drug Services Study (ADSS)* details the percentages of substance abuse treatment clients having a child/children at admission by gender as well as treatment facilities that provide women-only facilities, childcare services, prenatal care services, special programs for women and special programs for pregnant women (Brady & Ashley 2005).

The study consisted of a mail questionnaire collected by telephone interview with facility directors at non-correctional alcohol and drug treatment facilities representing 12,387 facilities nationwide (Brady & Ashley 2005). In 2004 the Substance Abuse and Mental Health Services Administration estimated that four per cent of females admitted for treatment were known to be pregnant when admitted (Brady & Ashley 2005). The collection of this data

could potentially facilitate the identification of children at risk of prenatal exposure to alcohol and therefore facilitating early identification and clinical intervention of FASD.

Data collected in Australia

In Australia, all jurisdictions have indicated that they currently use prompts within the maternity record to remind clinicians to ask about alcohol use in pregnancy. Two jurisdictions are known to use the validated screening tool AUDIT-C within their hand-held records; however it is unlikely that this is used universally across the jurisdiction. Table 3.2 provides details of what jurisdictions collect data on alcohol use in pregnancy.

Table 3.2: Alcohol use data collected and recorded by jurisdictions

	Alcohol use screening/data		Perinatal data collection	
Jurisdiction	**Maternity record**	**Data collection form**	**Screening completed**	**AUDIT-C score collected**
NSW	✓	X	X	X
Vic[(a)]	✓	X	X	X
Qld[(b)]	✓	✓[(c)]	✓[(c)]	X
WA[(b)]	✓	X	X	X
SA	✓	X	X	X
Tas	✓	✓	X	X
ACT	✓	✓	X	X
NT	✓	✓	X	X

(a) Questions: How many standard drinks per week before pregnancy; how many standard drinks per week currently?

(b) Uses AUDIT-C in HHR however, it is unlikely that this is used universally across the jurisdiction.

(c) Screening indicator collected only.

(d) At the state and territory level, data regarding alcohol use in pregnancy is currently collected in three jurisdictions: Tasmania; the Australian Capital Territory; and the Northern Territory. Methods of data collection in these jurisdictions varies, these differences are outlined below.

Source: State and territory (unpublished).

Three jurisdictions currently collect data related to alcohol consumption for the Perinatal National Perinatal Data Collection (NPDC) however the information is not collected in a standard manner and therefore unable to be used for any national reporting. See Table 3.3 for a summary table of the data collected in the NPDC.

Tasmania

Tasmania collects information on whether the woman has consumed alcohol in her current pregnancy as a ‘Yes’ or ‘No’ response. If a ‘yes’ response is recorded, then the quantity (dose) of alcohol consumed is recorded as either less than, or more than one standard drink per day. However, this method does not record frequency of alcohol consumption.

Australian Capital Territory

The Australian Capital Territory (ACT) collects data on whether the woman has consumed alcohol during her current pregnancy and, if she has, information on the number of standard drinks per week (dose and frequency).

Northern Territory

The Northern Territory (NT) has three different methods used to collect information for the midwives perinatal data collection. These include an electronic database used by the public hospitals, an online version used by remote centres with internet access and a paper copy used in private health care and for women who were not admitted to hospital. The NT collects data about alcohol consumption at the first antenatal visit and again at 36 weeks gestation. There is a blank field next to this item on the paper version and the information may be noted in a variety of ways including the number of standard drinks per day or per week, although there are no prompts given. The online and electronic databases capture alcohol consumption at the first visit and also at 36 weeks only as a 'Yes, No or Unknown' response (timing).

Table 3.3: Summary of perinatal data collection about alcohol use in pregnancy

State/Territory	Data about alcohol use included	Amount of alcohol consumed (options available on the form)
Tasmania	Consumed alcohol Y/N	<1 standard drink/day >1 standard drink/day (tick boxes)
Northern Territory	Alcohol: 1st visit and 36 weeks visit, with a blank field next to each gestation or 'Yes/No/Unknown' response	No prompt given to indicate what information should be collected.
Australian Capital Territory	Alcohol consumption during pregnancy: 'Yes/No'.	The number of standard drinks per week.

Source: State and territory (unpublished).

The NT and the ACT do not provide any guidelines for data collection and the Tasmanian guidelines do not provide any further information about collecting data on alcohol consumption other than the above information.

The NT is the only jurisdiction to capture information regarding timing of alcohol consumption (first antenatal visit and at 36 weeks), while Tasmania and the ACT capture information regarding dose in terms of standard drinks consumed (daily/weekly, respectively).

Currently no jurisdiction captures information regarding if or when a pregnant woman ceases drinking alcohol once she is aware she is pregnant.

National collections

National Key Performance Indicators (nKPI) for primary health care

The AIHW collects data for an indicator measuring risk of harm from alcohol consumption amongst regular clients attending Indigenous-specific primary health-care organisations as part of the nKPI data collection. To develop the indicator, the AIHW commissioned Professor Kate Conigrave (Senior staff Specialist and Professor Addiction Medicine Royal Prince Alfred Hospital and Sydney Medical School) to consider the most appropriate screening tool for collecting information on risk from alcohol among Aboriginal and Torres Strait Islander people in primary healthcare settings. Professor Conigrave concluded that AUDIT-C is the most appropriate tool available for use for Indigenous Australians.

National Drug Strategy Household Survey

The National Drug Strategy Household Survey (NDSHS) collects information on tobacco, alcohol and other drug use, attitudes and beliefs and is conducted every three years. The NDSHS is managed by the AIHW on behalf of the Department of Health. The 2013 NDSHS includes questions based on the AUDIT-C for alcohol use in pregnancy. The data captured in the NDSHS also aims to identify behaviour changes in alcohol use as a result of pregnancy (AIHW 2014d).

Other potential data sources

Young et al (2007), in an international review of data available through child welfare systems, identified two potential data sources that might be utilised to monitor families that are registered in both child welfare services and substance abuse treatment services, as a method to identify children at risk of maltreatment. These data sources offer a cross-system data opportunity for identifying children at potential risk.

The study suggests that three categories of effected children can be identified: children in child welfare services whose parents are identified as having a substance disorder; children of parents who enter substance abuse treatment and who may be a risk of harm or neglect; and children who have been prenatally exposed to alcohol or drugs (Young et al. 2007). Child welfare services use the child as the unit of analysis and substance abuse treatment centres use the individual as the unit of analysis and cross-system data analysis may enable identification of children and pregnant women at high risk.

An Australian prospective surveillance study reported that 67.4% of children diagnosed with FAS were also involved with Department of Community Services, including child protection (Elliot et al. 2008). Further development of this data source could provide valuable information such as identifying: females of childbearing age at risk; children at risk; future children at risk; children who may have characteristics of FASD and assessment of such; an estimation of the prevalence of pregnant women and FASD in this population; and a means of intervention and prevention (AIHW 2011a).

Other data sources that collect information on alcohol use during pregnancy include:

- state and territory perinatal data collections (mentioned above)
- Alcohol and other Drug treatment Services NMDS (AODTS-NMDS)
- the National Drug Strategy Household Survey (NDSHS) (mentioned above)
- the National Aboriginal and Torres Strait Islander Social Survey (NATSISS)
- National Health Survey (NHS)
- National Nutritional Survey (NNS)
- Footprint in time: The Longitudinal study of Indigenous Children (LSIC)
- the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)
- Healthy for Life (HFL).

The paper Collections and data sources in Australia with data relevant to fetal alcohol spectrum disorders (AIHW 2011d) identified several limitations with these data collections, most importantly none are able to associate fetal alcohol exposure with FASD as no data source was designed with this purpose in mind (AIHW 2011d). Further limitations of the data sources noted in the paper include: data is usually de-identified from the onset of collection; accessibility and participant response bias; and most lack questions regarding dose,

frequency and timing of alcohol use (AIHW 2011d). Of the data collections mentioned in Collections and data sources in Australia with data relevant to Fetal Alcohol Spectrum Disorders (AIHW 2011d); the Healthy for Life (HFL) data collection is a potential existing data source, which could be modified by including additional questions to collect data on alcohol use in pregnancy.

HFL is a program funded by the Office of Aboriginal and Torres Strait Islander Health (OATSIH). The data are submitted from primary health-care services participating in the HFL program and are focused on child and maternal health and chronic disease. Currently the HFL data collection consists of 11 clinical quantitative indicators and 11 qualitative indicators. The quantitative indicators cover maternal and child health including antenatal care, risk factors during pregnancy, birthweight, child health checks and immunisation.

Indicators on chronic diseases cover adult health checks, chronic disease management plans, glycated haemoglobin (HbA1c) levels and blood pressure. Data are provided in an aggregate format on regular clients for each of these indicators either annually or six-monthly. However, HFL is targeted at a specific population (mothers of Indigenous babies) and as such is not designed to capture data from the general population. HFL does include questions concerning timing of alcohol usage: before 13 weeks of pregnancy (first trimester) and 28 weeks (third trimester); in addition to questions relating to dose and frequency. HFL also provides a definition of high and low alcohol consumption.

The benefit of the HFL model is that alcohol consumption in both the first and third trimesters is measured making it suitable for collecting data that could be useful for FAS and FASD, however, the limitation of HFL is that definitions and questions regarding high and low alcohol usage are based on weekly rather than daily consumption patterns. Therefore the data may not be sensitive enough to capture levels of risky drinking that may cause FAS and FASD.

Current position

The information provided above has sought to provide some discussion on a potential best method for capturing data relevant to alcohol use during pregnancy. We have examined current methods, policies and practices that can be employed to measure alcohol consumption during pregnancy.

Once captured, data concerning alcohol use in pregnancy is intended to be used to determine the use of alcohol in pregnancy including trends in female drinking, potential FASD harm, assist with diagnosis of FASD, and identifying at-risk populations who may drink. It should be noted that this data item(s) will not assist in creating a FASD data collection, however it could be used to monitor the outcomes of FASD health promotion/prevention programs.

Currently, there is no single national source of information about FASD from which its epidemiology and prevalence can be determined, nor is there a national data source in which information regarding alcohol use in pregnancy is recorded.

Neither is there sufficient evidence to suggest that medical professionals routinely ask and record questions about alcohol use during pregnancy and determining the presence of alcohol within pregnancy is problematic. There is no single means of measuring alcohol use that is not hindered by methodological limitations. While, it has been shown that biomarkers, while effective in being able to determine the presence of alcohol, are unable to be used to determine more specific information about dose, and frequency of alcohol use, information which is crucial to the epidemiology of FAS and FASD. A further limitation of biomarkers is that they can’t detect alcohol use in the first trimester. This is the period of development

closely associated with the onset of FAS. The failings of biomarkers to account for patterns of alcohol use in term dose and frequency, coupled with their inability to detect alcohol use in the first trimester, do not make them viable options for measuring alcohol use in pregnancy in relation to the epidemiology and onset of FAS and FASD.

A clinical self-report tool for use by general practitioners would provide a suitable method for determining alcohol consumption during pregnancy because it would not be hindered by retrospective reporting. This tool could be effectively administered in a non-threatening patient-professional relationship, which may assist to overcome response bias and develop pregnant women's understanding of alcohol unit measurement.

Research suggests that self-report methods are currently the only viable methods available that have the capacity to measure alcohol consumption during pregnancy in relation to dose, timing, frequency and ability to determine alcohol use in the first trimester. Similar to the use of biomarkers, there are methodological limitations associated with data collections derived from self-report such as response and recall bias which can result in the under-reporting of alcohol consumption. Further limitations with self-reporting alcohol consumption includes a lack of standardised questions about alcohol use during pregnancy and standardised national guidelines as to what information should be collected, however, these limitations may be accounted for through the implementation of concurrent rather than retrospective reporting and the creation of a series of standardised questions that account for dose, and frequency of alcohol use at the national level.

Based on the information currently available it is recommended that the collection of alcohol use in pregnancy would be best captured through: a self-report questionnaire or survey that captures information pertaining to dose and frequency of alcohol consumption and that midwives are likely to be the best positioned to administer the questions.

Evidence and support for the use of AUDIT-C tool

A wide range of evidence suggests that the AUDIT-C is widely implemented and utilised in clinical practice and is a reliable and validated screening tool.

The report *Alcohol in pregnancy: what questions should we be asking?* (Muggli et al. 2010*),* recommends that self-administered questionnaires to measure alcohol use by prenatal women should include relevant information on alcohol consumption. This information coupled with graphic representations of locally produced alcoholic drinks can assist participants to determine the number of standard drinks they are likely to have consumed (Muggli et al. 2010). A second recommendation is that data about alcohol consumption should be generated through questions relating to drinking habits and time of exposure. The report also recommends that all pregnant women be screened for alcohol intake via a valid clinical instrument and educational material regarding the dangers of alcohol use in pregnancy distributed. The report promotes the *Alcohol and pregnancy lifestyles kit* as the best available educational tool.

The *Alcohol and Pregnancy Lifestyles Kit* is recommended by the Monograph of the IGC on Drugs as the method best suited for the capture and collection of information pertaining to alcohol use in pregnancy. The *Alcohol and Pregnancy Lifestyles Kit* includes an evidence-based guide for health-care professionals about screening pregnant women for alcohol use, a three-question validated screening instrument (AUDIT-C) designed to capture alcohol use in terms of frequency and dose, and provides a detailed intervention strategy to assist pregnant women to cease or reduce their alcohol usage. Additionally, it has an established distribution network through the Australian General Practice Network (AGPN) (Muggli et al. 2010).

The *Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016* identifies national priorities to *Improve data collections to understand the extent of FASD in Australia* including that women are routinely screened regarding their alcohol consumption, using nationally standardised questions. Additionally, they have set a performance indicator that 20% of all pregnant women will be screened on their alcohol consumption using the AUDIT-C (FARE 2013).

In 2014, the Foundation for Alcohol Research and Education (FARE) launched a resource targeted at health professionals, *Women Want to Know,* which provides advice; guidance and training on talking to women about their alcohol use when pregnant (see <http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk>). This project was funded by the Department of Health and developed in collaboration with the Royal Australian College of General Practitioners, Royal Australian and New Zealand College of Obstetricians and Gynaecologists, the Australian College of Midwives, the Australian Medical Association, Australian Medicare Locals Alliance and Maternity Choices Australia. The advice provided to health professionals specifically recommends the use of the AUDIT-C as an assessment tool see, <http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk-audit-c>.

In 2013, in working towards developing a diagnosis tool for FASD in Australia, an expert panel recommended that standard assessment of prenatal alcohol exposure using the AUDIT-C should be administered in combination with a clinical interview and case note review in order to obtain additional information about consumption patterns and timing (Watkins, Elliott, Wilkins et al. 2013).

An Australian study which sought to identify perceptions about screening for FASD amongst health professionals agreed that any assessment of prenatal exposure should identify and record the number of standard drinks consumed on a typical drinking occasion, the frequency of drinking, the frequency of excessive drinking and the timing of alcohol intake during pregnancy. The majority of participants (71%) believed that this should be assessed with a formal tool, with 89% of participants preferring AUDIT-C (Watkins, Elliott, Halliday et al. 2013).

In May 2016, the Australian FASD Diagnostic Tool and Referral Guide was publicly released. The Tool is available on the Telethon Kids Institute website at: <http://alcoholpregnancy.telethonkids.org.au/Australian-FASD-Diagnostic-Instrument>. A number of resources are attached to the tool and are available for health professionals, including the AUDIT-C screening tool, which is recommend for use with pregnant women.

The three questions utilised by the AUDIT-C are:

1. How often do you have a drink containing alcohol?
2. How many standard drinks containing alcohol do you have on a typical day?
3. How often do you have six or more drinks on one occasion?

The proposed data items related to dose and frequency that are based on question 1 and 2 of the AUDIT-C are shown in Table 3.4.

Table 3.4: Proposed data items for AUDIT-C

Question	Values	Meaning
1. How often do you have a drink containing alcohol? (Frequency)	1	Never
	2	Monthly or less
	3	2–4 times a month
	4	2–3 times a week
	5	4 or more times a week
	9	Not stated/inadequately described
2. How many standard drinks containing alcohol do you have on a typical day? (Dose)	1	1 or 2
	2	3 or 4
	3	5 or 6
	4	7 to 9
	5	10 or more
	9	Consumption not reported

Data development

Since 2010, the AIHW in partnership with the NPDDC has been progressing work to develop a nationally agreed, uniform method for measuring and recording alcohol use in pregnancy. This has involved:

- 2010—discussion of data collection options including: self-report, passive surveillance, maternal hair analysis, meconium testing and data linkage
- 2012—workshop with key stakeholders at UNSW including clinical, academic and state and territory department of health representatives
- 2012–13—ongoing multilateral consultations with state and territory stakeholders
- 2013—a review of current collection measures and a detailed review and assessment of collection instruments and possible mechanisms for collection.

Additionally, in 2014, the first stage of the NMDDP identified collection of information on alcohol in pregnancy as a medium term priority data item.

At this stage, the NPDDC has agreed that a national set of standard data items that capture alcohol use in relation to dose and frequency needs to be developed. However, as yet, the NPDDC has been unable to determine the best method or instrument (tool) to collect this information and has indicated that external advice needs to be sought. Some issues raised by the NPDDC in relation to an appropriate collection tool were:

- ‘collection of a standard drink’ and the inability to conceptualise a ‘standard drink’ within an antenatal setting
- use of consistent (visual) tool for alcohol screening
- value of the new alcohol related data and its ability to provide useful clinical information that enables improved outcomes for mothers and babies
- value of self-reported data.

Focus groups on use of AUDIT-C

In order to examine some of the issues that raised by the NPDDC, in June 2015, the AIHW commissioned the Murdoch Children’s Research Institute to explore the views of maternity clinicians on asking pregnant women about their alcohol use and the feasibility of using the AUDIT-C for this purpose; and to explore the views of pregnant women on being asked

about alcohol use as part of their maternity care and having this information reported at a national level.

Outcome of study

Mainstream settings

Midwives in mainstream settings reported that they always ask pregnant women about their alcohol use as part of a relaxed conversation, however, pregnant women reported having little recollection of being asked about their alcohol use and when it was recalled, they noted the question was closed in nature and that an assumption was made by the midwife that they weren't drinking.

Clinical knowledge on the harms of alcohol use in pregnancy was low amongst midwife participants in mainstream settings, possibly due to a low level of training, clinical support or options for referral. All agreed that this needed to be improved. Pregnant women reported that they were aware that high levels of alcohol consumption were harmful but were uncertain regarding lower levels of alcohol consumption, particularly social drinking. Women reported that if more information was available, they would be able to make an 'informed decision' regarding their drinking.

Overall responses to the AUDIT-C in the mainstream setting were positive with all agreeing that it was important to collect this data to inform clinical care. A visual guide would also be helpful. It was generally agreed that the AUDIT-C could be incorporated into their clinical practice provided implementation was done with appropriate training and support.

Indigenous settings

Overall, the level of awareness of the harms of alcohol use in pregnancy was very high amongst maternity clinicians in Indigenous settings and for this reason pregnant women were asked about their drinking at almost every appointment. The importance of building a relationship was highlighted as key to being able to broach these sensitive discussions.

Midwives and pregnant women stressed the importance of a women's environment and its influence on her decision to drink, particularly in regard to building the relationship and being able to reinforce messages on reducing or cutting out alcohol consumption, if possible.

Pregnant women were very aware that alcohol use was 'harmful' however, they were less sure on the actual effects on the baby. Despite this, and in contrast to the discussions around informed choice and social drinking with non-Indigenous pregnant women, Indigenous pregnant women had strong opinions that not drinking at all was the only option. Both groups raised the possibility of a public education campaign that targets the dangers of drinking in pregnancy.

Maternity clinicians noted that they already asked very similar questions to the AUDIT-C, and tailored the questions to be culturally appropriate. Indigenous women reiterated that it was important to collect information on alcohol use at most antenatal appointments and were happy to have this reported at a national level.

Key findings of the study

Generally the focus groups found that midwives and pregnant women believe that asking questions about alcohol use in pregnancy is important and necessary. The AUDIT-C was found to be a useful tool to collect this information and provided a mechanism for midwives to open a conversation with pregnant women about alcohol use under the proviso of data collection. The study provided support to continue development of a standardised method of

data collection regarding alcohol use in pregnancy to be incorporated into the National Perinatal Minimum Dataset based on the AUDIT-C.

1. Awareness levels of alcohol related harm in pregnancy within Indigenous settings among both midwifes and pregnant women were significantly higher than mainstream settings.
2. Questions regarding a woman's alcohol use in pregnancy should be part of a discussion with the midwife and should be asked without judgment or assumptions.
3. The reasons for collecting this information should be explained.
4. The importance of building a relaxed and comfortable relationship between the maternity clinician and women builds trust and allows women to answer more honestly and raise any of her concerns.
5. The AUDIT-C is a useful tool to assess alcohol in pregnancy but the question may need to be adapted to suit the context.
6. Training and clinical support needs to be provided to midwives who felt there was a lack of this type of support.
7. A public awareness campaign on the harms from alcohol in pregnancy was warranted due to the lack of knowledge of alcohol related harms within the community and in clinical care.

Consultation

NMDDAG meeting of 4 December 2015

Members were asked to note that the AIHW has engaged the Murdoch Children's Research Institute (MCRI) to conduct focus groups with midwives and pregnant women to measure their attitudes to asking questions about alcohol consumption and the AUDIT-C screening tool. Members were also advised that following the outcomes of this testing, it was highly likely that the AIHW would be seeking a jurisdiction to undertake pilot testing of the AUDIT-C as a screening tool.

Members were advised that the AIHW has received feedback from jurisdiction data custodians that issues such as the additional burden on midwives, the quality of self-reported data and issues of directing clinical practice are the current barriers for implementing a mandated data collection tool. The focus groups are seeking to further explore and inform these issues raised by jurisdictional data custodians.

Members' comments included:

- Is further pilot testing of the AUDIT-C necessary as the MCRI have already completed research on AUDIT-C and found it is the best way to guide clinicians on the next steps and it is also relatively quick.
- The resource 'What women want to know' was developed to assist midwives on how to ask the questions, and deal with answers.
- Queensland advised that they are already asking screening questions.
- Tasmania noted they do collect some alcohol information but will need to check on how that is done.
- Some members were concerned about the time to complete the AUDIT-C, and also the added stress on midwives when there are no referral services. Members were advised that the 'no' answers would not increase the burden, and the lack of resources and services needs to be dealt with so the most appropriate questions can be asked.

Members agreed to continue developing 'Alcohol use in pregnancy' as a data item and to progress these items to the NPDDC.

NMDDAG meeting of 3 May 2016

Following informal bilateral discussions with jurisdictions on their ability or willingness to implement psychosocial data items, an option to present data items based on 'screening during antenatal care' as part of a staged approach to data development was proposed for consideration by the NPDDC. Additionally, as data items related to dose and frequency had been unable to progress and the outcome of the MCRI focus group study was still pending. It was agreed that this was currently the best approach.

The NPDDC met on 3 May 2016 to consider inclusion to the NMDS (or into the NPDC as a voluntary item at a minimum) of a data item that indicates if alcohol screening was undertaken during antenatal care (Appendix F). It is intended that this item would ensure that all women are screened for their alcohol use and would ensure intervention and treatment where necessary.

The AIHW gave an update on work that the AIHW has been undertaking in relation to data development. In particular, that the AIHW has engaged the Murdoch Children's Institute to undertake work to explore the feasibility of collecting this data consistently and efficiently with midwives and pregnant women and to explore the specific issues raised by jurisdictions in relation to the use of the AUDIT-C and asking questions about alcohol. Members noted the papers.

NPDDC members were also asked to consider/discuss the inclusion to the NPDC of a data item that indicates if alcohol screening was undertaken during antenatal care.

Members noted the following:

- Queensland for the last 12 months collects similar items and indications are that approximately 80% of mothers are screened (slightly better in public than private). The screening covers four items: alcohol use, substance use, mental health and domestic violence. For public hospitals this comes primarily from the hand-held records, for private most likely self-reported at the booking in visit. The results of the screening are not collected by the Perinatal data collection (PDC).
- There were concerns raised about screening items being out of the scope of the collection as they are regarding the level of care delivered rather than the health of the women.
- The data item as is does not ask women about their alcohol use. The AIHW noted that this is still flagged for future development.
- Mandating a particular level of detail for a data item may actually hamper data collection.
- The collection of this data is more likely to tell us more about the healthy mothers rather than those more at risk and does not provide details of change of behavior. Additionally, a lot of perinatal data is collected at the birth of the baby; it is hard to know how this item will assist in identifying mothers at risk.
- Currently, Antenatal guidelines recommend a discussion, not screening; for example, the AUDIT-C.
- Jurisdictions emphasised that there are different and complex processes for being able to implement these data items. Jurisdictions will need to consult with their own networks on whether these data should be collected.

The NPDDC considered inclusion of the NPDC psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development. This approach was not deemed suitable for a number of reasons and it was suggested that all data items that would be included in the NPDC should be considered in their entirety.

Overall, NPDDC members agreed that they would need to develop a consultation process within their jurisdiction and asked the AIHW to produce a document which would assist in facilitating this process. The AIHW developed and circulated this paper with feedback from jurisdictions forming the basis of data development as part of Stage 4 of the NMDDP.

Inter-jurisdictional consultation process

The NPDDC at the 3 May 2016 meeting, considered the inclusion to the NPDC, psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development.

Jurisdictions were asked, to consult within their own networks on the collection of data items related to alcohol consumption in pregnancy, in particular, questions related to dose and frequency which are based on the validated screening tool for alcohol use, the AUDIT-C which is designed to ensure intervention and treatment where necessary. A majority of jurisdictions, who responded, supported the collection of data items relating to alcohol consumption in pregnancy, with a couple of these jurisdictions already collecting basic screening indicator data for these items.

NPDDC: meeting of 16 December 2016

The NPDDC considered the inclusion of the above draft data items to the perinatal data collection following the jurisdictional consultation.

The AIHW introduced the agenda paper and in particular highlighted the results of the Murdoch Children's Research Institute (MCRI) study.

The AIHW noted that the results of the jurisdictional consultation were included in the paper. Jurisdictions provided verbal updates on their consultations.

The Northern Territory noted that after consulting with their drug and alcohol areas, they are not supportive of collecting these data items as they believe the AUDIT-C to be a clinical tool only and not a data collection tool. They currently collect alcohol use before 20 weeks and after 20 weeks (y/n), asked at any time throughout the antenatal period. The Northern Territory will continue to collect this flag only.

Western Australia consulted its reference group in August 2016 and they agreed to start collecting these data from July 2017. Western Australia noted that the question needs to be reworded so that it asks the question in the third person.

New South Wales agreed to forward the consultation papers on to further stakeholders within that state.

Victoria will formally notify the AIHW of its intentions but will be planning to implement the collection of these data item in July 2017 for commencement on 1 January 2018.

Currently, the Queensland hand-held record has questions related to alcohol which are identical to AUDIT-C. These results are not reported to the PDC. Queensland still questions if the NPDC the most appropriate collection to get this information.

South Australia is due to review their hand-held record data items in 2017 and alcohol collection will be on the agenda. They will collect at the 1st visit <20 weeks, and then in the 2nd half of pregnancy matching to birth defects data with the intention of commencing in 2019.

The Australian Capital Territory currently collects alcohol related data on the hand-held record at two points <20 and >20 weeks. They are using a tool and will find out which tool.

Tasmania indicated that they have been reporting these data for a year (public and private). Tasmania also indicated that any changes to PDC items can be implemented within their systems readily. Overall, Tasmania is supportive of these items moving to the Perinatal National Best Endeavours Data Set (NBEDS).

Apart from the Northern Territory, there was majority support from the NPDDC to progress these data items to the NBEDS by developing a business case, noting that consultation will need to continue with jurisdictions and implementation would not be able to occur until 2018–19 collection.

3.2 Screening for mental health

Perinatal mental health screening is not currently reported nationally and not being able to report on perinatal mental health screening has been identified as a key gap and national guidelines for screening for perinatal depression and research and data collection have been included as key elements in the National Perinatal Depression Initiative (NPDI).

A summary of mental health data captured at the jurisdictional level can be found in attachment G.

The National Maternity Data Development Project (NMDDP) stage 3 includes perinatal mental health screening data development as a medium to long term priority item. Mental health morbidity associated with the perinatal period is now recognised as a major public health issue. The AIHW's work on the NMDDP has been in response to recommendations of the National Maternity Services Plan (NMSP) to enhance perinatal data collections and reporting. The NMDDP's main focus is to action 4.1.5 of the NMSP. Data development work on perinatal mental health screening commenced in the first 2 stages of the NMDDP, stage 3 has continued to progress data development work on mental health screening.

Details of the NMDDP priority information is available in the report *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* (AIHW 2014e). Priority data items were progressed through different consultation processes including visits to jurisdictions and mapping against existing data collections to establish an expected time frame for data development items (AIHW 2014e).

Data development

The AIHW previously has engaged the National Perinatal Epidemiology and Statistics Unit (NPESU) to complete the consultation with stakeholders phase for mental health screening. The consultations evaluated the impact of psychosocial screening and what data should be collected; the consultations also formed the basis for items to be discussed in a national workshop.

In October 2013, a discussion paper was developed to assist workshop participants to focus on the development of standardised data elements relating to perinatal mental health for national implementation. The paper listed different issues for consideration and 11 possible data items for discussion. The paper was sent to all workshop participants before the meeting to ensure enough time for all data items to be considered. When considering the data items the participants were asked to assess each potential item against a benefit criterion. The workshop was convened on 9 October 2013 to discuss the polled data items. The workshop participants were split into 3 groups to assess each of the potential data items

against the benefit criterion. The participants decided on 3 preferred draft data items that would need further redrafting (see Table 3.5).

Workshop attendees' comments:

- The workshop attendees all agreed on the 3 draft data items.
- Concerns were raised about there not being an agreed tool for screening and that all data items needed to be drafted in a broad way to allow for the use of different tools.
- Attendees also decided recording the screening scores would not be beneficial due to the different gestations and ensuring that was accurately recorded, it has been flagged for a possibly future inclusion.

Attendees of the workshop were asked to register their interest in being a part of the working group to re-draft the draft data items proposed during the workshop.

The working group met for the first time on 20 November 2013 to review the draft data items from the October 2013 workshop. The data items were further refined and after some discussions the group agreed to the proposed 3 data items to go for further consultation. At the completion of the Working group, three draft data items were agreed on (see Table 3.5).

Table 3.5: Draft data items for mental health

	Data item	Values
1	Antenatal depression/anxiety screening conducted	Yes; Not offered; Declined; Unknown or not stated
2	Additional follow-up indicated due to the identification of perinatal mental health risk factors	Yes; No; Not applicable; Unknown or not stated
3	Presence or history of mental health condition NB: Guide for use would specify that this is by self-report or documented evidence	Yes; No; Unknown or not stated

Current situation

The three data items have been proposed to collect data on:

- depression/anxiety screening in the antenatal period
- psychosocial referral in the antenatal period
- presence or history of a mental health condition.

These data items will produce relevant national level data for comparison across and within jurisdictions. The scope has been somewhat refined from earlier drafts of the data items to allow a set of questions that will still cover a broad area of screening, additional referral and also presence and history of mental health.

The mental health screening data items have been drafted in METeOR (Attachment F). The draft data items include a nationally agreed and consistent name, definition and guidelines for their collection. This will allow data to be consistently reported on both within and across jurisdictions.

Definition

Included within the draft data items is the following definition of screening.

> **Screening:** process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.
>
> *Source:* UK National Screening Committee, 2013.

It is proposed that this is included as a glossary item attached to each data element within the NPDC. This definition was proposed and agreed by the Perinatal Mental Health workshop participants.

Timing

Participants at the workshop discussed the data capture and how to record the information if screening was to occur more than once during a pregnancy. It was noted that only the most recent results would be recorded in the data collection.

Tool

The data items do not recommend a specific tool, however they do propose that a validated tool is recommended. The Edinburgh Postnatal Depression Scale (EPDS) is cited as an example of a reliable validated tool, but does not limit jurisdictions to just EPDS as it is not a diagnostic tool.

The scores from the validated tool will not be recorded in the data collection, only whether the screening occurred or not. The scores from the tool will be used to inform the midwives of potential at risk patients and if a referral is required. If screening does not occur, a flexible approach for potential at risk patients is also suitable to identify whether an additional follow-up is required.

The following information provides a brief overview (detailed information in Attachment G) of jurisdictions mental health data collections, including a summary table (see Table 3.6) of the data collected and recorded by each jurisdiction. It provides details of what information is recorded in the maternity or hand-held record, the data collection form and any other information that is included in the perinatal data collections.

The mental health screening is generally being completed during the antenatal booking visit and subsequent screening is available and encouraged in some jurisdictions.

Table 3.6: Perinatal mental health data collected and recorded by jurisdictions

Jurisdiction	Maternity record	Perinatal data collection		
		Data collection form	EPDS screening completed	EPDS score collected
NSW	✓	X	X	X
Vic	X	X	X	X
Qld	✓	✓	✓	✓
WA	✓	X	X	X
SA	✓	X	X	X
Tas	X	X	X	X
ACT	✓	✓	X	✓
NT	X	X	X	X

Source: State and territory (unpublished).

Consultation

NMDDP AG: meeting of 4 December 2015

The NMDDP AG met on 4 December 2015 to discuss the next steps for mental health screening data development including agreeing on the draft national data standards in METeOR and the definition of screening.

Members were asked to also consider the screening definition proposed, agree the scope and timing of screening, agree to the use of the EPDS as an example of a validated tool.

Members agreed to the above items as presented and agreed that only the initial screening results of mental health should be recorded in the data collection instead of the most recent results. As the national guidelines request all women be asked as early as possible.

The 3 data items were considered by the NMDDP AG members and agreed that these draft data items could now progress to the the NPDDC for agreement.

It was noted that there may be concerns around all jurisdictions implementing the 3 questions both in practice and on the Perinatal Data Collection forms, yet these were items for the NPDDC to consider.

NPDDC: meeting of 3 May 2016

Following informal bilateral discussions with jurisdictions on their ability or willingness to implement psychosocial data items, an option to present data items based on ‘screening during antenatal care’ as part of a staged approach to data development was proposed for consideration by the NPDDC. Consequently, at the 3 May 2016 NPDDC meeting, the AIHW sought NPDDC agreement on collecting if mental health screening was conducted in the antenatal period as a voluntary item in the NPDC.

The NPDDC were asked to consider three options for collecting data related to mental health screening:

1. antenatal depression/anxiety screening indicator
2. antenatal depression/anxiety screening indicator, and EPDS score
3. antenatal depression/anxiety screening indicator, perinatal mental health additional follow-up indicator, and presence or history of mental health condition indicator.

Option 1: Antenatal depression/anxiety screening indicator

This option would use the screening question 'Was antenatal depression/anxiety screening conducted?' with the allowable values of 'yes/not offered/declined/unknown/not stated'. Details of the draft meteor item are available at Attachment F.

There are several benefits of starting by just collecting if screening occurred:

- The main benefit of collecting data on mental health screening is whether screening is occurring is the most important outcome for both the mother and baby.
- Jurisdictional burden is reduced to implementing one question.
- The screening data for analysis would be available much sooner and once the data is able to be analysed, if it is of a high quality, there would be a case to further progress related data items such as option 1 and 2.

This data item does not mandate a specific screening tool for collection; however it does recommend that a validated tool is used.

It is noted that five jurisdictions already collect this data on the hand-held record with another two jurisdictions also including this data on their PDC forms.

The AIHW is to seek agreement to this option as the minimum position and to have this placed on the NHISSC workplan at the upcoming May meeting.

This option would not require pilot testing and the AIHW would be seeking implementation as soon as possible pending agreement by NHISSC/NHIPPC.

Option 2: Antenatal depression/anxiety screening indicator, and EPDS score

This option seeks to build upon Option 1 by including the collection of the EDS score.

This option would use the screening question 'Was antenatal depression/anxiety screening conducted?' with the allowable values of 'yes/not offered/declined/unknown/not stated' and would seek to capture the EPDS score as a numerical value in the DSS.

This option would involve mandating the EPDS as the validated mental health screening tool that would be used by all jurisdictions and maternity services. Currently, the *Clinical Practice Guidelines Antenatal care—Module 1* recommends the use of the EPDS at least once during the pregnancy (AHMAC 2012) and as noted the majority of jurisdictions are already using and recording the EPDS for pregnant women. It is anticipated that this will help to facilitate implementation of these data items in jurisdictions and allow for nationally consistent comparable data.

It is noted that five jurisdictions are already utilising the EPDS screening as part of the hand-held record with another two jurisdictions reporting the EPDS score on their PDC forms.

It is not anticipated that this option would require pilot testing given that a majority of jurisdictions are already collecting this data.

Option 3: Antenatal depression/anxiety screening indicator, perinatal mental health additional follow-up indicator, and presence or history of mental health condition indicator

This option also builds upon Option 1 and seeks to include information on additional follow-up and presence or history of mental health. The three data items have been proposed, consulted and agreed on by the NMDDP AG to collect data on:

- depression/anxiety screening in the antenatal period
- psychosocial follow-up in the antenatal period
- presence or history of a mental health condition.

These items will produce relevant national level data for comparison across and within jurisdictions. The scope has been somewhat refined from earlier drafts of the data items to allow a set of questions that will still cover a broad area of screening, additional follow-up and also presence and history of mental health.

Currently, the draft data items include a nationally agreed and consistent name, definition and guidelines for their collection. This will allow data to be consistently reported both within and across jurisdictions. These data items related to depression/anxiety screening in the antenatal period, psychosocial follow-up in the antenatal period and presence or history of a mental health condition do not recommend a specific tool, however they do propose that a validated tool such as the EPDS is recommended.

Using this option, scores from the validated tool will not be recorded in the data collection but will be used to inform the midwives of potential at risk patients and if additional follow-up is required.

It is anticipated that this option would require pilot testing.

Outcome of meeting

The AIHW sought NPDDC agreement to consider inclusion to the NPDC a data item that indicates if antenatal depression/anxiety screening was undertaken during antenatal care. This data item would ensure that all women are screened for their mental health and would ensure intervention and treatment where necessary.

The AIHW also sought NPDDC input into the feasibility of collecting data related to antenatal mental health, in particular the EPDS score (Option 2) or an indicator related to follow-up and presence or history of mental health conditions (Option 3).

Members noted the following:

- The EPDS score had not been recommended by the Working Party (WP) as this would tie the data to a particular tool, noting that the EPDS is recommended by the currently clinical guidelines.
- The WP had recommended that the data item should not include just screening on its own but rather the three data items:
  - antenatal depression/anxiety screening indicator
  - psychosocial follow-up in the antenatal period
  - a presence or history of a mental health condition and that these items together provided the best outcome together.
- Jurisdictions requested that a consultation paper (based on the meeting papers) be developed to allow them to circulate to their own networks (clinicians, hospitals, and so forth) to seek feedback and input to the way forward.

- Members noted that the options, as presented in the paper, were confusing and this needed to be dealt with in the consultation paper. It was agreed to include discussion of why the EPDS was not the best option to include, but to progress follow-up, presence and history indicators.
- The Guide for use for the data item Female-presence or history of mental health condition indicator—Code 1 'current pregnancy' needs to be reviewed.

The NPDDC considered inclusion to the NPDC psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development. This approach was not deemed suitable for a number of reasons and it was suggested that all data items that would be included in the NPDC should be considered in their entirety.

Overall, NPDDC members agreed that they would need to develop a consultation process within their jurisdiction and asked the AIHW to produce a document which would assist in facilitating this process. The AIHW has developed this paper and circulated to jurisdictions. Feedback formed the basis of progressing this data development.

Inter-jurisdictional consultation process

The NPDDC at the 3 May 2016 meeting, considered the inclusion to the NPDC, psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development.

Jurisdictions were asked, to consult within their own networks on the collection of data items related to antenatal depression/anxiety screening; follow-up required; presence or history of mental illness. There was consensus among jurisdictions, who responded that collecting data on perinatal mental health was important; however, one jurisdiction did not support, at this time, the presence or history of mental health illness.

NPDDC: meeting of 16 December 2016

The NPDDC considered the inclusion of the above draft data items to the perinatal data collection following the jurisdictional consultation.

Jurisdictions overwhelmingly noted that they were still unclear why these data are wanted and what they will be used for. Each noted that their own guidelines clearly note that this kind of screening is recommended and they work under the assumption that this is occurring.

Jurisdictions noted that they found considerable issues with the presence/history indicator. It was suggested that this data may already be collected as part of the pre-existing medical conditions (including previous). The AIHW agreed to review the list of pre-existing conditions to see if there is an opportunity for some mappable data.

Overall, the NPDDC agreed that these data items are important, but do not agree to the proposed indicators as they are.

Further development on this indicator will cease as no jurisdiction was supportive of collecting these data.

3.3 Screening for Domestic Violence

Women experiencing domestic violence (DV) are at greater risk of complications during pregnancy, such as inadequate weight gain, infection, miscarriage, haemorrhage and low birthweight. Such women are slower to make contact with health services for antenatal care than women who are not exposed to violence, and their babies are more likely to have a problem diagnosed after birth.

Action item 2.3.3 of the National Maternity Services Plan seeks to develop and expand appropriate maternity care for women who may be vulnerable due to medical, socioeconomic and other risk factors. Additionally, the NMDDP identified domestic violence as a high priority item for data development during Stage 1. As part of Stage 2 of the NMDDP, the AIHW has continued to progress items related to the development of DV data item.

Data development

In October 2013, a workshop was held at the AIHW to discuss the development of a domestic violence data item. As a result, the NMDDP AG agreed to form a Screening for Domestic Violence Working Party (SDVWP) and to examine issues associated with data development.

The first SDVWP meeting was held in March 2014. The NMDDP AG was updated on outcomes of the meeting in April 2014 and was advised that the inclusion of any domestic violence data in the NPDC would involve a complex long-term project. The NMDDP AG agreed exploratory work should continue, particularly in relation to the development of a national set of recommended questions for DV screening in the perinatal context.

The SDVWP met again in September 2014 and discussed the rationale for collecting domestic violence data in the NPDC, questions for national use and potential collection methods. The rationale for collection and two potential screening tools (HITS and HARK) were discussed at the NMDDP AG in October 2014. The NMDDP AG noted the rationale proposed by the WP and agreed that the HARK tool was the preferred validated screening tool.

The agreed rationale formed the basis for the *Screening for domestic violence during pregnancy: options for future reporting in the National Perinatal Data Collection* discussion paper (<https://www.aihw.gov.au/reports/mothers-babies/screening-for-domestic-violence-during-pregnancy>) which was developed in consultation with the SDVWP. This report published on 18 August 2015 discusses barriers to and opportunities for the collection of data on screening for domestic violence during pregnancy. It proposes options for data collection through the NPDC, which includes data about every woman who gives birth in Australia.

Current situation

The report made a number of recommendations which the AIHW sought to build upon as part of the Stage 3 data development for domestic violence including the need to obtain consensus on:

1. a definition of a definition of domestic violence
2. a preferred option for data collection
3. a potential NPDC data item.

These data items were presented to the NMDDP AG at the 4 December 2015 meeting for discussion and consideration.

Consultation

NMDDP AG: meeting of 4 December 2015

The NMDDP AG met on 4 December 2015 to discuss the recommendations of the *Screening for domestic violence during pregnancy: options for future reporting in the National Perinatal Data Collection* discussion paper.

1. Definition of domestic violence

The NMDDP AG was asked to consider the definition of domestic violence.

Previously, the SDVWP had agreed a broad definition of DV was required in order to allow flexibility in screening in addition to capturing different kinds of violence. The SDVWP agreed that the definition as provided in the National Plan to Reduce Violence against Women and their Children (COAG 2011:2) was the most appropriate:

> *Domestic violence refers to acts of violence that occur between people who have, or have had, an intimate relationship. The central element is a pattern of behaviour aimed at controlling a partner through fear; for example, by using behaviour which is violent or by threatening any act that might cause harm or suffering. Domestic violence can include physical, sexual, emotional or psychological abuse.*

The considerations of the SDVWP in reaching this consensus are outlined on page 14 of the report. Broadly, the SDVWP agreed that the elements of the definition that were important were that it:

- is limited to domestic violence to partner or ex-partner abuse as this is consistent with the national plan; most screening tools used in pregnancy; and with research indicating that partners or ex-partners are the most likely perpetrators of violence
- should include threats of violence because threats can increase cortisol levels which can have a negative impact on health outcomes for mother and baby.

2. Options for data collection

The NMDDP AG was asked to consider three options for collecting data related to screening for domestic violence.

Three options for screening for domestic violence and the related data collection within the NPDC were outlined within the discussion paper. The preferred option of the SDVWP was Option 2: a short validated DV screening tool to ensure that jurisdictions collect the same validated information for national collation and comparison. The options considered by the NMPDDP AG are outlined below:

Option 1: Develop a minimum set of standard questions based on questions that are currently used across jurisdictions

Screening is undertaken in the majority of jurisdictions; however, the tools and measures differ across the country. A review of the types of questions asked across jurisdictions provided the following most common questions:

- Within the last year, have you (ever) been hit, slapped or hurt in other ways by your partner or ex-partner? OR (In the last year,) has (your partner) or someone in your family or household ever pushed, hit, kicked, punched or otherwise hurt you?
- Are you (ever) afraid of your partner or ex-partner (or someone in your family)?

- (In the last year) has (your partner) or someone in your family or household ever (often) put you down, humiliated you or tried to control what you can or cannot do?
- (In the last year), has your partner or ex-partner (ever hurt) or threatened to hurt you (in any way)?
- Would you like help with any of this now?

This option would entail developing a minimum set of questions based on these questions. This option would require additional work to determine the validity of these questions and if they were fit for purpose.

Option 2: Seek to implement a nationally consistent approach by mandating a recommended validated DV screening tool

This option was the preferred option of the SDVWP to allow for consistent national reporting (see page 48). Two validated tools were identified by the SDVWP: the HARK (Humiliation, Afraid, Rape, Kick) and the HITS (Hurt, Insult, Threaten, Scream) screening tools (examples of the tools are provided at page 70 of the report). The SDVWP did not make a recommendation on which was the preferred screening tool of either the HITS or HARK screening tools.

The NMDDP have previously considered the HITS and HARK tools at the October 2014 meeting and agreed that the HARK tool was the preferred validated tool due to its simplicity. See Table 3.7 for the questions contained in the HARK screening tool.

Table 3.7: Questions contained in the HARK screening tools

Screening Tool	Questions, response categories, scoring procedures and notes
The Humiliation, Afraid, Rape, Kick (HARK) Screening Tool	(1) 'Within the last year, have you been humiliated or emotionally abused in other ways by your partner or your ex-partner?' (2) 'Within the last year, have you been afraid of your partner or ex-partner?' (3) 'Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?' (4) 'Within the last year, have you been kicked, hit, slapped or otherwise physically hurt by your partner or ex-partner?' Response categories: Yes or No for each question Scoring procedure: Each yes answer scores 1 point so a patient may score 0, 1, 2, 3 or 4. Each score has a different meaning that is, different likelihood ratio and post-test odds). Answering yes to 3 or 4 questions produces a specificity of 100% meaning DV is present. While answering yes to one or two of the questions is less specific, the optimal HARK cut-off score was deemed to be greater than or equal to 1 (Sohal et al. 2007). This cut-off maximises the true positives whilst minimising the false positives.

Source: Sohal et al. 2007.

The HARK tool also limits data collection to the previous 12 months which would be ideal for NPDC reporting.

Option 3: Implement a flexible screening approach that is consistent with the National Antenatal Care Guidelines that enables different screening depending on the person

The National Antenatal Care Guidelines currently recommend that midwives tailor their questions to women about domestic violence depending on the woman and the circumstances. The guidelines recommend the use of direct, indirect or an assessment based on the midwives relationship with the women. This option was not favoured by the SDVWP due to issues with data quality, invalidated questions and ambiguous answers.

3. Potential NPDC data item

The NMDDP AG was asked to consider data item indicators related to screening for domestic violence (see Table 3.8). The results of the above screening methods would not be reported to the NPDC, the outcomes of the screening are the suggested data items. The following indicators are proposed:

- a screening indicator to indicate whether screening was conducted
- a disclosure indicator to indicate whether DV was disclosed
- an item to capture whether additional follow-up was indicated if DV is disclosed.

Table 3.8: Possible National Perinatal Data Collection data items

Data item	Values
Whether screening for DV was conducted	Yes, Not offered, Declined, Unknown or not stated
Whether DV was disclosed	Yes, No, Not applicable, Unknown or not stated
Whether additional follow-up was indicated due to disclosure of DV	Yes, No, Not applicable, Unknown or not stated

Members noted the progress of the domestic violence screening data development to date. The three options for data collection were considered:

1. developing a minimum set of standard questions based on questions that are currently in use across jurisdictions

2. seeking to implement a nationally consistent approach by mandating a recommended validated DV screening tool
3. implementing a flexible screening approach that is consistent with the national Antenatal Care Guidelines that enables different screening depending on the person.

The NMDDP AG noted that the preferred option of the SDVWP was option 2 and agreed. However, they opted not to mandate a tool for screening as there is no evidence to suggest certain tools are better than others. It was decided to request that a validated tool be used and noted that the HARK tool is such an example. As a result, the draft data items were updated accordingly (see Attachment F).

The NMDDP AG agreed that the draft data items are valuable, reliable and feasible to collect and could progress to the NPDDC for consideration.

NPDDC meeting of 3 May 2016

At the 3 May 2016 NPDDC meeting, the AIHW sought NPDDC agreement on collecting as a voluntary item in the NPDC, if DV screening was conducted in the antenatal period. Following informal bilateral discussions with jurisdictions on their ability or willingness to implement psychosocial data items, an option to present data items based on 'screening during antenatal care' as part of a staged approach to data development was proposed for consideration by the NPDDC.

It is anticipated that the burden on jurisdictions is reduced by having to implement 1 question in relation to domestic violence. Additionally, screening all pregnant women for domestic violence can allow for greater identification of at risk women and appropriate referral.

This option will provide an indicator of whether a female has received DV screening, as represented by a code with the allowable values of 'yes/not offered/declined/unknown/not stated'. Details of the draft METeOR item are available at Attachment F. This data item does not mandate a specific screening tool for collection; however it does recommend that a validated tool is used. This option would not require pilot testing.

In addition to a domestic violence screening indicator, the NPDDC are asked to discuss and consider the feasibility of collecting the following additional indicators:

- a disclosure indicator to indicate whether DV was disclosed
- an item to capture whether additional follow-up was indicated if DV is disclosed.

These data items were agreed by the NMDDP AG in December 2016.

Members were asked to note work to date by the AIHW on progressing data items in regard to collecting data about domestic violence screening in pregnancy. Members were asked to consider the inclusion of a screening indicator in the NPDC and how to progress any future data development.

The NPDDC considered inclusion to the NPDC psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development. This approach was not deemed suitable for a number of reasons and it was suggested that all data items that would be included in the NPDC should be considered in their entirety.

Overall, NPDDC members agreed that they would need to develop a consultation process within their jurisdiction and asked the AIHW to produce a document which would assist in facilitating this process. The AIHW developed and circulated this paper that formed the basis of progressing this data development as part of Stage 4 of the NMDDP.

Inter-jurisdictional consultation process

The NPDDC at the 3 May 2016 meeting considered the inclusion to the NPDC, psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development. This approach was not deemed suitable for a number of reasons and it was suggested that all data items that would be included in the NPDC should be considered in their entirety.

Jurisdictions were asked, to consult within their own networks on the collection of data items related to domestic violence, namely a screening indicator, disclosure indicator and a follow-up due to disclosure indicator. Most of the jurisdictions, who responded, noted that it would be valuable to have national comparable data for domestic violence; however, there was concern raised that a significant amount of effort would be needed to collect this data. Furthermore, a jurisdiction questioned whether the NPDC would be the appropriate avenue to collect this level of information.

NPDDC meeting of 16 December 2016

The NPDDC considered the inclusion of the above draft data items to the perinatal data collection following the jurisdictional consultation.

Jurisdictions noted they have issues with the indicators; in particular, they are worried that confidentiality issues may put women at additional risk due to the identified data at the state level. Additionally, Victoria noted that due to their Royal Commission into DV, they would prefer to wait for the outcomes of that in case of policy implementations.

It was agreed that due to confidentiality sensitivities and legislative issues currently underway in some jurisdictions that this data development should be revisited at a later stage.

3.4 Illicit substance use during pregnancy

Action item 2.3.3 of the NMSP recommends that Australian Governments develop and expand appropriate maternity care for women who may be vulnerable due to medical, socioeconomic and other risk factors including illicit substance use.

In 2011, the NMDDP provided advice on enhancement of the Perinatal Data Collection (PDC). Illicit substance use was identified as a topic of potential national importance; however, due to the difficulties associated with implementing this data item, it was identified as a long term goal for national standardisation and/or data development due to the increased risk of maternal and fetal morbidity. Details of the NMDDP priority information is available in the report *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* (AIHW 2014e).

The AIHW has sought to clarify the context and feasibility of collecting this data.

Data development

Why is it important to examine illicit and prescription drug use in the perinatal period?

There is currently no comprehensive approach to national data collection on drug use in pregnancy. Without routine and consistent national collection, Australia is unable to monitor the extent of illicit drug use in pregnancy, its associations with pregnancy events and outcomes for mothers and babies, and service provision for responding. This is a serious barrier to informing and developing policy and program responses.

While recognising that the benefits of illicit drug use screening for women and their babies are not always clear or simple to evaluate, collecting screening and disclosure data via the NPDC may help to better understand women's pregnancy and health outcomes.

Why collect data in the National Perinatal Data Collection?

The NPDC is an annual census of mothers which collects data on approximately 300,000 births per year. It is the main source of national reporting on pregnancy and childbirth for mothers, and the characteristics and outcomes of their babies.

The NPDC provides a unique opportunity to collect data from all mothers, some examples include:

(a) Currently, no routine national data collection for illicit drug use in pregnancy exists and no other data source (for example, the NDSHS) can provide such comprehensive coverage of the population and the subject matter area.

(b) Population level data is needed to drive policies, programs, service planning and delivery.

(c) While aggregated de-identified data would be used for routine reporting, the NPDC also provides opportunities for data linkage to explore individual women's outcomes (using other variables within the NPDC) as well as children's longer term outcomes if linkage to childhood data sets later becomes possible

(d) It could provide data on the sustainability of screening programs.

However, there are a range of data quality issues that exist and before any reliable national data could be collected pilot studies need to determine the best type of data to collect as well as how to collect such data.

How will the data be used?

The primary uses for NPDC data on substance use in pregnancy include:

(a) annual reporting to identify substance use rates and patterns in pregnancy

(b) analysis to examine correlations between substance use and other clinical characteristics or perinatal risk factors. For example, low birthweight, premature labour and birth, miscarriage, haemorrhage (which are already included in the NPDC) as well as maternal mental health, inadequate weight gain and models of care (which are not currently part of the NPDC but are being considered for inclusion)

(c) disaggregations to examine different geographic levels and sub-populations to identify high risk groups (survey data is unlikely to provide adequate sample sizes for generating reliable data for Aboriginal and Torres Strait Islander people or other specific sub - populations)

The rationale for collecting data in the NPDC will need to be agreed to by the NMDDP Advisory Group. Currently there is no other data collection that provides the coverage of all mothers and births in Australia.

However, there are many issues that still need to be considered before any data item(s) could be proposed for collection in the NPDC.

Current situation

Policy initiatives related to illicit substance use in pregnancy

National Maternity Services Plan

The National Maternity Services Plan (2010–2015) provided a five year vision for maternity care in Australia in order to maintain the high standard of safety and quality in maternity care already provided in Australia, in addition to improving access to services and choice of models of care. The plan identified, in particular, women who may be at risk due to factors such as drug use.

Action 2.3 of the National Maternity Services Plan was to develop and expand appropriate maternity care for women who may be vulnerable due to medical, socioeconomic and other risk factors.

> Specific groups of Australians with particular cultural and clinical needs may experience poorer maternity outcomes than the general population. These groups include (but are not limited to) culturally and linguistically diverse (CALD) women; women with pre-existing medical conditions; adolescent mothers; older mothers; obese women; women using cigarettes, alcohol and illicit substances; women experiencing mental illness; and women in prisons. Each of these groups has specific maternity care needs.
>
> *Source:* available at <http://www.health.gov.au/internet/publications/publishing.nsf/Content/pacd-maternityservicesplan-toc~pacd-maternityservicesplan-chapter8>.

The plan focused on identifying and expanding appropriate and successful maternity care for women at risk.

National Antenatal Care Guidelines

The National Maternity Services Plan also mandated the development of the National Evidence based Antenatal Care Guidelines as a priority. The guidelines were designed to provide high-quality, evidence based antenatal care to pregnant women. Two modules of the Clinical Practice Guidelines—Antenatal Care were produced. Module 1 covers the first trimester of pregnancy and provides details of care for special needs groups such as women and Module 2 which deals with trimester 2 and 3. The guidelines note that lifestyle factors such as the use of illicit drugs have been shown to increase risk for pregnancy and birth complications.

National Perinatal Depression Initiative

The National Perinatal Depression Initiative (NPDI) was developed in 2008 with the aim to improve the detection and treatment for expectant and new mothers experiencing depression. Key elements of the initiative include:

- routine and universal screening
- follow-up support and care for women assessed as being at risk of or experiencing perinatal depression
- workforce training and development
- research and data collection
- national guidelines for screening perinatal depression
- community awareness.

The Perinatal Mental Health National Action Plan, developed as part of the National Perinatal Depression Initiative notes that co-morbidity of mental health issues and drug and alcohol issues result in less than optimal health for mothers and babies. The Perinatal Mental Health National Action Plan has also recommended that 'psychosocial assessment can be readily integrated into existing routine practices that focus on social wellbeing; for example, routine (and in some settings, mandatory) questions for domestic violence, and drug and alcohol use' (Beyond Blue 2011).

The National Drug Strategy

The National Drug Strategy provides a framework for the Australian Government, and states and territories to reduce alcohol, tobacco and drug-related harms for individuals and the community. The national policy has been in force since 1985. The 2010–15 iteration is the sixth update of the strategy. The strategy is built upon a nationally agreed harm minimisation approach and provides three pillars of effective reduction: demand reduction; supply reduction and harm reduction. The strategy clearly outlines an objective to reduce the harm of drug use to families (Ministerial Council on Drug Strategy 2011). An updated National Drug Strategy 2016–2025 is currently being developed—see <www.nationaldrugstrategy.gov.au>. This work provides support to a number of policy initiatives regarding maternal health and drug use.

Available data

A number of data collections hold information about the prevalence of drug use in Australia, however, it is important to note that none of the data below is specific to all pregnant women.

National Drug Strategy Household Survey

The National Drug Strategy Household Survey (NDSHS) collects information on alcohol, tobacco and illicit drug use amongst the general population of Australia. Approximately 24,000 people across Australia are surveyed on their substance use in addition to their attitudes and opinions on substance use. It also allows for comparisons across geographical locations and population groups.

Alcohol and other drug treatment services in Australia—National Minimum Data Set

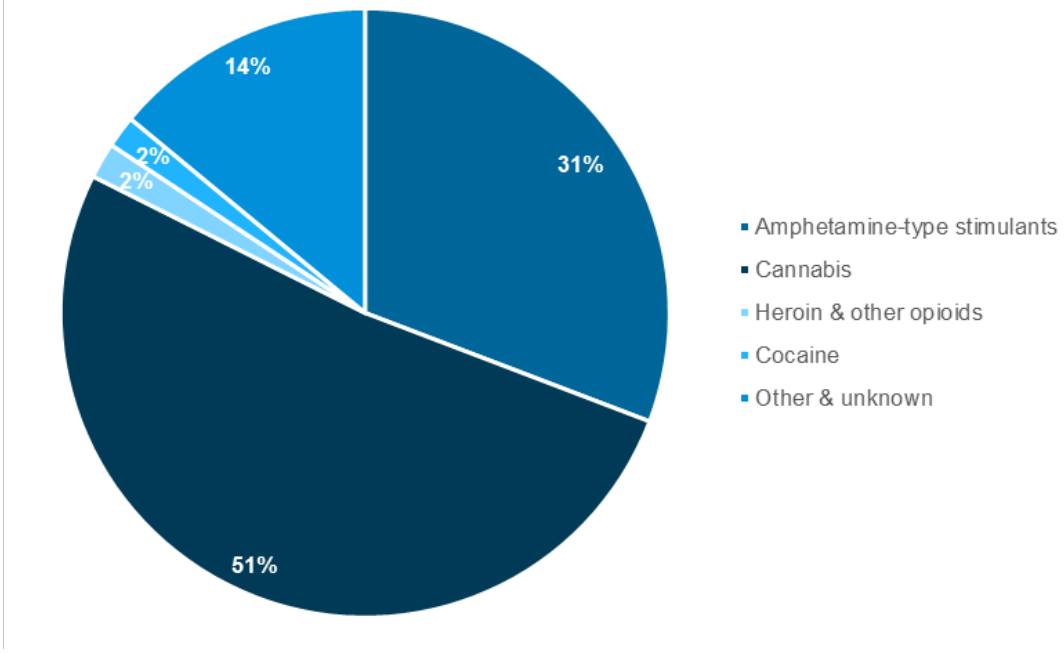
The Alcohol and other drug treatment services national minimum data set includes information on clients and treatment episodes for publicly funded treatment agencies. The services that are reported on relate to people who are seeking help or treatment for their own drug use or people seeking assistance for another's drug use.

It does not include information on additional agencies that provide: services primarily concerned with health promotion or accommodation; private agencies that do not receive public funding; and needle and syringe programs.

Illicit Drug Data Report (IDDR)

The Australian Criminal Intelligence Commission produces the Illicit Drug Data Report annually. The report provides a statistical picture of the illicit drug market in Australia. The information within the report is collated from Australian state and territory police agencies, the Australian Federal Police, Australian Customs and Border Protection Service and forensic laboratories. Recent data indicates that the number of seizures, the amount of drugs seized and drug arrests were at record numbers in 2015–16. Drug seizures totalled 115,421 up from 2014–15 (105,862). Drugs seized amounted to 21.0 tonnes down from 23.5 tonnes in 2014–15, and national illicit drug arrests were 154,538 up from 133,926 in 2014–15

(Australian Crime Commission 2017). Figure 3.1 provides an overview of the proportion of drugs by type that accounted for drug arrests in 2015–16.



Source: Australian Criminal Intelligence Commission 2017.

Figure 3.1: National illicit drug arrests, 2015–16, (%)

Data gaps

Whilst there is information related to drug use, criminality and treatment facilities, there is currently no information available to provide a population based measure of the national prevalence of substance use in pregnancy.

Generally, there is a paucity of data available on the prevalence of drug use by pregnant women in Australia. Current studies are generally small in nature and are not able to be extrapolated to the general public. As the majority are also survey based and specific, there is limited data on the prevalence of different types of drugs used by pregnant women and birth outcomes for the babies of these women.

A substance use data item in the NPDC will assist with population monitoring, policy and program development and research on substance use in pregnancy. In addition, the development of this type of data is aimed at improving the health outcomes for mothers and babies.

Proposed scope of data collection

Stage 1 of the NMDDP conducted an extensive consultation process to identify the priority items for data development. Substance use was identified by the NMDDP AG as a maternal and perinatal risk factor that was essential for data development.

The consultations identified a range of information regarding substance use in pregnancy that should be collected including:

- prescribed and over-the-counter medications
- information about a pregnant woman's prior interaction with drug and alcohol services

- data on consumption prior to conception and prior to confirmation of pregnancy
- the types of drugs and administration methods
- frequency of usage and quality of substances
- types of treatment accessed and received
- availability of treatment services
- strategies for managing chronic pain.

Currently this scope is very wide and these issues would need to be considered by a workshop/working party as to what was most appropriate and/or possible.

Data quality issues

Unless a substance use data item was to become part of the nationally mandated NMDS, the quality of data is expected to be poor. Without a nationally standardised data item, the ability to collect data from all services (including private) and compare this data at a national level is impossible. Any ability to report national level prevalence is likewise hampered.

It is noted that the reliability of self-reported data is questioned and this is an issue that the NPDDC/workshop will need to consider.

Challenges to collection

Based on the work undertaken to collect alcohol use in pregnancy, it is anticipated that there will be some challenges to collecting this data, namely:

- collecting this data bears an additional burden on midwives and clinicians
- sensitivity and possible legal issues
- availability of referral pathways
- suitability of perinatal data collection as the vehicle
- issues of self-reporting
- national agreement on how to collect this data
- whether the data will be useful once collected
- the data (if any) is already collected by jurisdictions
- whether there is an appetite/identified need for this data on a national level.

Why should we collect data on substance use?

Pregnant women who use drugs are at risk from a unique range of social, health and physical risks. Risks can include poor health and nutrition, homelessness, anxiety and depression, and increased risk of sexually transmitted disease (Miles et al. 2014). Lifestyle issues associated with drug use may also increase the likelihood of participating in high risk activities such as prostitution, theft and violence to support drug use. These activities may have further risk consequences such as these women becoming victims of violence (ACOG 2012).

Babies born to mothers who use drugs are at risk, in addition to the risks stated above, are also at additional risk from neonatal abstinence syndrome (NAS) such as hyperirritability; gastrointestinal dysfunction; respiratory distress; autonomic signs and convulsions; premature birth, and low birthweight. Longer term risk indicates poor neurodevelopmental outcomes such as behaviour and learning difficulties to these babies (Abdel-Latif et al. 2013; Burns et al. 2006).

Understanding the prevalence and extent of drug affected pregnancies is crucial, as studies have demonstrated that screening, brief intervention, and referral to treatment (SBIRT) have significant effects on reducing the drug use of pregnant women and improving outcomes for babies (ACOG 2012). Ensuring that adequate referral services are available and accessible is also a necessary consideration for governments and service providers.

Prevalence of drug use in Australia

It is estimated that around 1 in 7 Australians have used an illicit drug in the past 12 months. In total it is estimated that 8 million (42%) Australians aged over 14 have used a drug in their lifetime and 2.9 (15%) million have used a drug in the past twelve months. The figure for overall drug use has remained relatively unchanged for the past 10 years; however the types of drugs being used has significantly changed. For example, pharmaceutical misuse has risen from 4.2% to 4.7% in 2013 and the use of drugs such as ecstasy and heroin has declined (AIHW 2014d).

People aged 20–29 were the most likely to have used a drug within the past twelve months (27% of that age group) (AIHW 2014d).

Prevalence of Australians seeking treatment for drug problems

The number of Australians seeking treatment for drug related problems is increasing. Across Australia, there are 795 publically funded AOD treatment agencies which provided treatment to 118,741 clients in 2013–14, an increase of 8% from 110, 427 since 2012. The majority of treatment episodes were for those seeking treatment for their own drug use (112,573) and approximately 7,174 clients were seeking treatment for another's drug use. Geographically, the agencies providing treatment are primarily located in *Major cities* (57%) and *Inner Regional* Areas (23%), with 7% located in *Remote* or *Very remote* areas. Approximately 14% of clients were Aboriginal and Torres Strait Islander and clients aged between 20 and 39 represented 56% of clients receiving treatment for their own drug use.

Nationally, the main drug of concern for people was alcohol and accounted for 40% of all treatment episodes. Other significant drugs of concern are: cannabis (24%), amphetamines (17%) and heroin (7%). Since 2009–10 the proportion of episodes for amphetamines has increased significantly from 7% to 17%. Ecstasy was the principle drug in 1% of episodes, benzodiazepines make up 2% of treatments and licit opioids (prescription drugs such as morphine, buprenorphine, methadone, oxycodone, fentanyl and pethidine or over-the-counter opioids such as codeine) make up 4% of episodes (AIHW 2016).

Prevalence of pregnant women using drugs

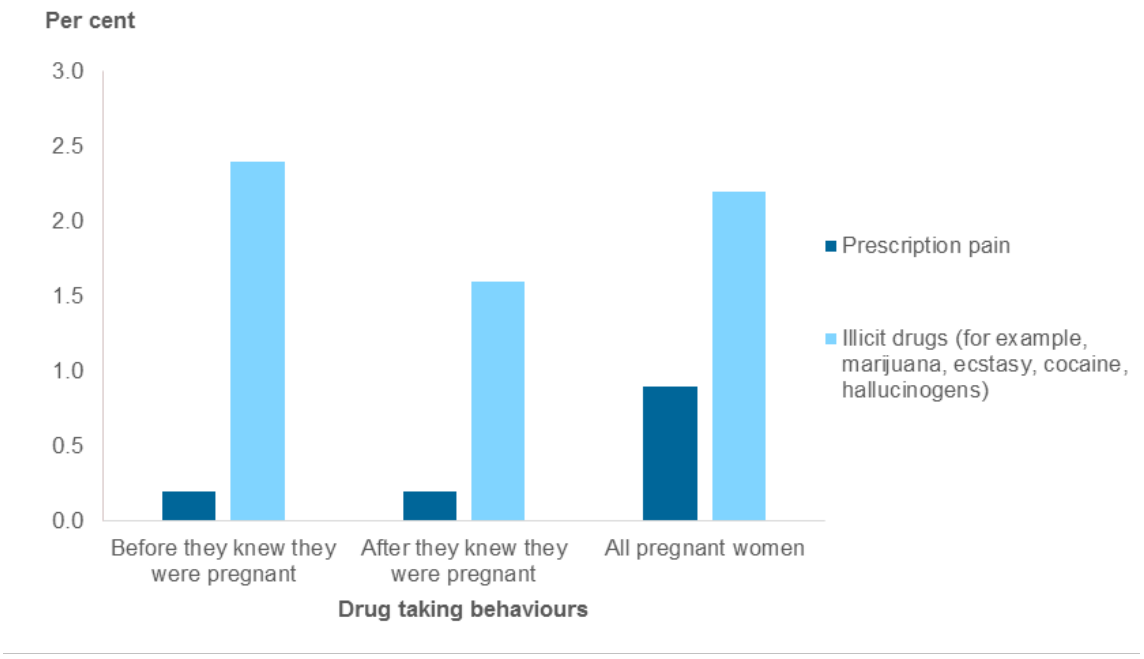
The number of pregnant women who use illicit and/or prescription drugs is not well known and limited population based data currently exists.

Overall drug use by Australian women indicates that 38.1% of women have used drugs in their lifetime, 12.0% in the last 12 months and 6.3% in the last month. Of those who had indicated drug use within the past 12 months, over one-third (37.4%) were aged between 14–49 (AIHW 2014d).

Data from the Australian Longitudinal Study on Women's Health has indicated that drug use by young women (22–27 years) is high with 58% of young women having used an illicit drug at some time in their life. Cannabis was the most used drug (57%) followed by amphetamines (16%), ecstasy (15%) and LSD (14%) (Turner et al. 2003).

Some data relating to the substance use and behaviours of pregnant women are included in the NDSHS. In 2013, 2.4% of pregnant women have indicated that they used an illicit drug

before they knew they were pregnant. This reduced to 1.6% after they were pregnant. Regardless of if they knew they were pregnant or not, 2.2% indicated they had used an illicit drug such as marijuana and 0.99% had misused prescription analgesics (Figure 3.2) (AIHW 2014d).



* Base is pregnant women who were unaware they were pregnant.

Source: National Drug Household Survey 2013: Online table 8.12.

Figure 3.2: Drug taking behaviour before and after knowledge of pregnancy, pregnant women aged 14–49, 2013 (%)

A large scale study undertaken at the Mater Mothers' Hospital in Brisbane over the period 2000–2006, interviewed approximately 25,000 pregnant women as part of their booking in visit. Midwives were trained on how to ask about their substance use and the questions were asked face to face and then entered into the electronic maternity record. Questions were asked about a range of illicit drugs including past and regular/current use. Women who identified current use offered intervention and were referred to the hospital's specialist alcohol and drug service. The results of the study indicated that over 3% of pregnant women were currently using drugs, predominately cannabis. Drug use by pregnant women is shown in Table 3.9.

Table 3.9: Self-reported drug use, Mater Mother's Hospital (public), Brisbane 2000–2006

	Cannabis (%)	Amphetamines (%)	Ecstasy (%)	Heroin (%)
Lifetime use	26.2	8.8%	5.6	2.6
Regular use[(a)]	9.5	3.4	0.9	1.7
Current use[(b)]	2.6	0.4	0.0	0.3

(a) Regular use was asked at the booking in visit and refers to regular and current use.

(b) Current use was measured during the second trimester and assumed that use had continued in the first trimester.

Source: Hayatbakhsh et al. 2011.

It is also anticipated that self-reported data is likely to be underestimated due to women's feelings of guilt and fear of judicial repercussions (Kassada et al. 2013). However, data on the validity of self-reported data suggests that it is highly reliable for research (Barnea et al. 1987).

International prevalence of drug use by pregnant women

International evidence appears to support the hypothesis that prevalence figures are under quoted in Australia. The most recent annual National Survey on Drug Use and Health in the United States found that one in twenty pregnant women had used illegal substances, with the majority of use being related to marijuana (4.1%), followed by prescription drugs (1.3%). The results of this survey are based on the self-reported responses of 65,000 participants (Center for Behavioural Health Statistics and Quality 2015).

A 2006 United States study found that 5.2% of mothers had used methamphetamine during their pregnancy, 6% had used marijuana and 1.3% prenatally. Less than 1% of the sample used heroin, benzodiazepines or hallucinogens. The data in the study was self-reported and consisted of 1,632 mothers over multiple sites. It should be noted that this study was conducted in an area where abuse of methamphetamine is a notable concern. This study also found that single, poorly educated women were more likely to be illicit drug users, and was concordant with research that indicates high-risk groups of pregnant women are likely to be the most effective targets of intervention (Arria et al. 2006).

A Brazilian study looked at the prevalence of drug abuse amongst 394 pregnant women across 25 primary health-care services, over a six month period. Of the 394 pregnant women interviewed as part of the study, 72 women (18%) indicated that they had used drugs during the pregnancy. The most commonly used drugs were cigarettes followed by alcohol. Overall, the proportion of pregnant women who indicated that they had been using illicit drugs was 1.5%, of this proportion 0.5% indicated that they were using alcohol, cocaine (crack) and marijuana frequently. The study noted it was possible that the pregnant women within this study were likely to under-report their drug use due to feelings of guilt (Kassada et al. 2013).

Self-reported survey data is always thought to have limitations related to under-reporting, for example, another study screened urine for substance use conducted over a four month period at the time of birth. Of the 462 who were screened, 19% tested positive to 1 or more substances (Azadi & Dildy 2008).

Known harms caused by substance use

Drug use whilst pregnant has been associated with a range of negative outcomes for babies including intrauterine growth restriction, restricted fetal growth, abruptio placentae, fetal death, pre-term labour, intrauterine passage of meconium, lower birthweight, neonatal abstinence syndrome, and neurocognitive delays and impairment (ACOG Committee on Health Care for Underserved Women and American Society of Addiction Medicine 2012; Azadi & Dildy 2008; Burns et al. 2006; Chang et al. 2008; David et al. 2014; El-Mohandes et al. 2003).

Additionally, recreational drug use has been associated with fetal malformations such as gastrochisis, facial cleft, renal anomaly or cardiac defect. A study found that 18% of babies born with a diagnosis of gastrochisis tested positive for maternal recreational drug use when maternal hair was tested for first trimester drug use. Likewise the study also found that babies born with brain defects were twice as likely to have a mother who used illegal drugs in pregnancy than babies with normal brains. Of the 517 women who participated in the study, one in six revealed that they had used recreational drugs—predominantly cannabis and

cocaine—around conception or during pregnancy, which was also confirmed by maternal hair testing (David et al. 2014).

It is estimated that 80% of women use at least one prescription or over-the counter drug whilst pregnant and nearly 40% of pregnant women report a chronic health condition which requires medication. Women, whilst pregnant may also take other drugs such as vitamins or minerals all of which have very little known about any potential teratogenic effects (Kennedy 2011). For example, over-the-counter drugs are not without risks as a number of studies have demonstrated congenital heart defects associated with first trimester use of codeine (ACOG Committee on Health Care for Underserved Women an American Society of Addiction Medicine 2012).

Additionally, illicit drug use after birth is also associated with an increased risk of child neglect, exposure to violence, behavioural problems and strongly correlated with teenage substance use (Farr et al. 2014).

Being pregnant can provide women with a unique opportunity to stop or reduce their drug use, in addition to allowing health professionals to provide effective intervention and positive behaviour changes (Chang et al. 2008). Inadequate prenatal care and drug use are associated risk factors for perinatal morbidity and mortality (El-Mohandes et al. 2003). When accessing care, women who are pregnant and use drugs are often perceived as being selfish and deviant, with little regard for their baby not only by the general public but often by the health professional who work with them. Midwives are encouraged to engage with all women with respect and promote safe and effective care. To this end, continuity of care models try to establish a relationship of trust between the midwife and woman in order to achieve improved outcomes for mother and baby such as lower surgical birth and improved breastfeeding. However, if negativity from her midwife is experienced the woman is likely to have limited trust in her midwife thus affecting the quality of care (Miles et al. 2014).

Table 3.10 provides a summary of suspected effects described in humans after exposure to illicit drugs during pregnancy.

Table 3.10: Suspected effects described in humans after exposure to illicit drugs during pregnancy

Illicit Drug	Effects on Mother/Pregnancy	Potential Structural Effects	Neurobehavioral Effects
Cannabis	Shorter gestation Lower birthweight	None specific	Impaired executive function
Opioids	Preterm delivery PPROM Meconium-stained amniotic fluid IUGR Chorioamnionitis Fetal death	Congenital heart defects Neural tube defect	Neonatal abstinence syndrome Aggressiveness Impulsiveness Increased temper Poorer self-confidence Impaired memory Impaired perception
Cocaine	Preterm delivery Placental abruption Uterine rupture Fetal death IUGR	Necrotizing enterocolitis Disagreement regarding structural defects	Impaired language development Attention deficits in males Inhibition deficits in males
Amphetamines	Maternal psychiatric diagnosis	Oral clefts Smaller head circumference Shorter length Disagreement regarding other structural defects	Increased emotional reactivity Depression Anxiety ADHD Externalizing behavior Aggressiveness
Hallucinogens	No data	PCP: Microcephaly Abnormal facies Intracranial abnormalities Respiratory anomalies Cardiovascular defects Urinary tract anomalies Musculoskeletal abnormalities	PCP: Attachment disorder
		LSD: Limb defects Ocular abnormalities	LSD: No data
		MDMA: Congenital heart disease Musculoskeletal abnormalities	MDMA: Impaired motor abilities at 4 mo
		Peyote: No data	Peyote: No data
Inhalants	Maternal electrolyte abnormalities Maternal arrhythmias Maternal RTA IUGR Preterm labor	Microcephaly Craniofacial abnormalities similar to those seen in fetal alcohol syndrome	Developmental delay Growth impairment Attention deficits Language deficits Cerebellar dysfunction

ADHD: attention-deficit/hyperactivity disorder; IUGR: intrauterine growth restriction; LSD: lysergic acid diethylamide; MDMA: 3, 4-methylenedioxymethamphetamine (ecstasy); PCP: phencyclidine; PPROM: preterm premature rupture of membranes; RTA: renal tubular acidosis.

Source: Holbrook & Rayburn 2014.

Characteristics of pregnant women using drugs

Overall, evidence suggests that women who use illicit drugs are likely to be socially disadvantaged; more likely to live in poverty; have lower educational attainment; are unemployed and have limited access to childcare and transport (Adams 2008). Risk factors for substance use are experience of childhood physical or sexual abuse, partner abuse, family discord and having had a diagnosis of depression (Denton et al. 2014; Turner et al. 2003.

An Australian study used record linkage to examine illicit drug use in pregnancy based on drug-related hospital admissions with obstetric and perinatal outcomes over a five-year period. Mothers who were identified as drug users were likely to be younger mothers, had higher parity, were Indigenous, and were heavy smokers (Burns et al. 2006). Likewise a strong relationship between smoking and drug use has also been demonstrated by Hutchins and DiPietro (1997).

Additionally, the comorbidity of drug use and mental health is well established, with general acceptance that substance abuse increases amongst those with mental health problems and higher rates of mental health problems will be found amongst those who abuse substances (Adams 2008). A strong correlation has also been found between mental illness and drug use, with the use of prescription drugs for mental health conditions likely and addition to poly-drug use (Scully et al. 2004).

Women who are drug users are more likely to be more advanced in their pregnancies when attending antenatal care for the first time than non-drug users. Drug users were on average attending antenatal care for the first time at 20 weeks compared with 12 weeks for non-drug users. Additionally, drug using mothers were five times more likely than non-drug users to arrive at the hospital for delivery without having received any antenatal care (Abdel-Latif et al. 2013; Burns et al. 2006). Additionally, women who are drug users are less likely to access postnatal care and immunisation programs for infants, although the literature on the long term effects of parental drug use on infant and child development are limited (Bartu et al. 2006).

Illicit Substance use and screening

What is illicit substance use?

The Ministerial Council on Drug Strategy has agreed that ‘illicit use of a drug’ or ‘illicit substance use’ can refer to illegal drugs; the misuse of medications or other psychoactive substances that are used in a harmful way.

- Illegal drugs are those that are prohibited from manufacture, sale, possession or distribution; for example, heroin, cocaine, cannabis, ecstasy or amphetamine-type stimulants.
- The misuse of medications may refer to prescription or over-the-counter medications that are used in ways that are not intended. This may include opioid-based pain relief medications, opioid substitution therapies, benzodiazepines, over-the-counter codeine and steroids.
- Psychoactive substances may refer to legal or illegal substances that may be used in a potentially harmful way; for example, kava, synthetic cannabis or other synthetic drugs and inhalants such as glue (AIHW 2014d; MCDS 2011).

The above description will be recommended for use in the NPDC to provide consistency across data sets.

What is screening?

Screening and intervention during pregnancy is associated with reducing risky behaviours by pregnant women (Chang et al. 2006). Screening, brief intervention and referral to treatment (referred to as SBIRT) has been found to be an effective method to reduce substance use in pregnant women (Farr et al. 2014). Additionally, when pregnant women are able to access rehabilitation programs, behaviours such as drug seeking and chaotic lifestyle practices have been found to be reduced and pregnancy outcomes for mothers and babies are improved (Pong et al. 2010).

Screening has also been found to improve neonatal outcomes for assisted ventilation, preterm delivery and low birthweight. An evaluation of an obstetrician clinic-based prenatal substance abuse treatment program on perinatal outcomes found that maternal and newborn outcomes were significantly improved when substance abuse treatment programs were integrated with antenatal visits. Screening of all pregnant women was a fundamental component of the program, with education also provided to all women screened. Where risk was identified intervention and referral was offered (Goler et al. 2008).

The following definition has been agreed by a Screening in Domestic Violence Working Party (formed under the NMDDP AG) in the context of domestic violence screening. It is intended to be a generic glossary item within the NPDC and would apply equally to illicit substance screening.

The wording of the proposed glossary item is:

> **Screening:** process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.
>
> *Source:* UK National Screening Committee. 2013.

The AIHW would not be seeking to divert from this definition.

In 2014, the World Health Organization (WHO) released Guidelines for the identification and management of substance use and substance use disorders in pregnancy. The guidelines were developed to assist professionals to help women who are pregnant or who have recently had a child, who use drugs or alcohol to achieve healthy outcomes for themselves and their child. At the time of development there were no global guidelines that provided evidence based recommendations for the identification and management of substance use in pregnancy. The guidelines focused on six areas:

1. Screening and brief intervention
2. Psychosocial interventions
3. Detoxification
4. Dependence management
5. Infant feeding
6. Management of infant withdrawal.

The guidelines recommend that all pregnant women should be asked about their use of alcohol and other substances as early as possible and at every antenatal visit using a validated screening tool.

It was determined that asking at every visit was a key component of identification as some women are only likely to disclose this information after building a trusting relationship with

their care provider. Whilst the guidelines note that there is a low quality of evidence to support the evidence of effect, however, it was determined that the potential benefits by psychosocial screening outweighed any harms. The burden of implementation was also considered to be minimal.

Screening tools

The WHO *Guidelines for the identification and management of substance use and substance use disorders in pregnancy* further recommend that where alcohol or drug use is identified, brief interventions should be offered (WHO 2014). The following validated screening tools have been recommended for use by the WHO. A summary of the recommended screening tools is also provided at Table 3.11.

ASSIST

The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) is an 8 item questionnaire developed by the WHO. It is designed to detect psychoactive substance use in a primary health care setting. The information collected is on substances used over the lifetime; substance use in the past three months; problems related to substance use; risk of current or future harm; dependence level and injecting drug use. The substances included are: tobacco, alcohol, cannabis, cocaine, amphetamine type stimulants, sedatives, hallucinogens, inhalants, opioids and other drugs. The ASSIST was designed to build upon the AUDIT (Alcohol use, also developed by the WHO which screens for alcohol use). It has a sensitivity of 67% for alcohol and 100% for cannabis. The specificity for alcohol is 36% and for cannabis 20%.

4Ps Plus

The 4P's Plus screen for substance use in pregnancy is based on five questions that have demonstrated through previous research to be strongly correlated with substance abuse (see Box 1). Two questions in particular regarding smoking and alcohol use in the previous month have been found to have strong predictive validity of drug use. The 4Ps Plus screening test (Box 1) is designed to identify women who use lower levels of drugs and alcohol and as such may not be identified by other screening methods that use a threshold measure. It is designed to quickly identify those patients that may need intervention and follow-up. It also has the added benefit of identifying substance use that occurred before the woman may have known she was pregnant.(Chasnoff et al. 2007).

Box 1: The 4P's Plus screen for substance use in pregnancy

Parents	Did either of your parents ever have a problem with alcohol or drugs?
Partner	Does your partner have a problem with alcohol or drugs?
Past	Have you ever drunk beer, wine or liquor?
Pregnancy	In the month before you knew you were pregnant, how many cigarettes did you smoke?
	In the month before you knew you were pregnant, how many beers/wine/liquor did you drink?

The 4P's Plus screening tool has shown very good validity with a sensitivity of 87% and specificity of 76%. It should be noted however, that the 4P's Plus is not freely available as it is licenced (Chasnoff et al. 2007).

PIP (Pregnancy information program)

The Pregnancy Information Program (PIP) is a computerised questionnaire containing 67 items (over 200 questions) over 9 topic areas (see Figure 3.3). It collects information on: mother demographics including social and financial supports and living situation; health and birth history; eating choices; smoking; alcohol—current use, past use, history of problems including family members; drugs and medicine including over-the-counter and illicit drugs and lifetime use; sexual health; psychosocial support and stress, anxiety; domestic violence.

Source: Pregnancy Information Program.

Figure 3.3: Screenshot of the Pregnancy Information Program

Substance Use Risk Profile—Pregnancy

The Substance Use Risk Profile-Pregnancy (SURP-P) scale consists of 3 questions (Box 2). The SURP-P scale has been shown to be a simple and effective way to screen for alcohol and illicit substance use with pregnant women and reports to be highly predictive of substance use with a high sensitivity (91%) and an adequate specificity (67%).

Box 2: Substance Use Risk Profile-Pregnancy Scale (SURP-P)

Have you ever smoked marijuana?

In the month before you knew you were pregnant, how many beers, how much wine, or how much liquor did you drink?

Have you ever felt that you needed to cut down on your drug or alcohol use?

Subjects who answer no to all questions are deemed to be low risk, those who answered yes to 1 question were deemed to be at moderate risk, and those who answered yes to 2–3 questions were deemed to be at high risk of having a positive screen result for alcohol or illicit drug use.

Table 3.11 provides a summary of the screening tools that have been recommended by the World Health Organization.

Table 3.11: Summary of screening tools recommended by the World Health Organization

Screening tool	Substances screened	Number of items	Other considerations	Sensitivity	Specificity
ASSIST (Alcohol, smoking and substance involvement screening test v3)	Tobacco, alcohol and substances	^8	Not validated for pregnant women Questions 1–7 ask about 10 classes of substances	Alcohol: 67% Cannabis: 100%	Alcohol: 36% Cannabis: 20%
4P's Plus	Alcohol and general substance use	4	Inpatient and outpatient	87%	76%
HSQ (Hospital screening questionnaire)	Tobacco, alcohol and substances	18–40	Inpatient: Postpartum	-	-
PIP (Pregnancy information program)	Tobacco, alcohol and substances	200	Antenatal clinic and Ob/Gyn Offices	-	-
SURP-P (Substance use risk profile—pregnancy)	Alcohol and substances	3	Antenatal clinic	Low risk: 80%–100% High risk: 48%–100%	Low risk: 61%–63% High risk: 84%–86%

Source: World Health Organization 2014.

Timing of screening

It would be recommended that universal and routine screening assessment be offered *at least once* in the antenatal period at the earliest opportunity (for example, booking-in visit), with a preferred review and repeat assessment in the third trimester.

Current situation for screening and reporting

This section reviews what practices are currently being used within each jurisdiction to screen for substance use within pregnancy and any data collected or reported upon (see Appendix H for request for information).

Whilst each jurisdiction makes recommendations that women be routinely asked about their substance use during the booking in visit and as part of the hand-held record, the majority do not collect data regarding specific drug use or follow-up information.

Table 3.12 provides a summary of what information is currently collected by jurisdictions. Many jurisdictions provided advice that this type of data presents legal considerations given that jurisdictional-level data is identified and clinicians may be obliged under mandatory reporting legislation.

Queensland includes data in their Perinatal Data Collection if screening was conducted (yes/no). It does not include the results of screening or other information on drug use. The majority of other jurisdictions HHR contain a prompt for conducting screening. They do not collect information on the results of screening.

Table 3.12: Perinatal illicit substance data collected and recorded by jurisdictions

Jurisdiction	Maternity record	Data collection form	Perinatal Data Collection
NSW	X	X	X
Vic	✓	X	X
Qld[(a)]	✓	✓	✓
WA	X	X	X
SA	✓	X	X
Tas	✓	X	X
ACT	✓	X	X
NT	X	X	X

(a) Queensland collects information on if substance use screening was conducted only.

Source: State and territories (unpublished).

Jurisdictions were contacted and asked a number of questions about screening practices for substance use including data collection and reporting. A copy of the questionnaire that was provided to jurisdictions can be found at Attachment H. A summary of each jurisdiction's responses are provided below.

New South Wales

In New South Wales (NSW), the NSW Health *Clinical Guidelines for the Management of Substance Use during Pregnancy, Birth and the Postnatal Period* recommend that all pregnant women are asked about their current and previous drug use at the booking-in visit. The guidelines recommend that all drugs are screened for including prescription medication, over-the-counter medications, alcohol and tobacco, caffeine and other illicit substances. (NSW Health 2014).

Screening methods are likely to vary between hospitals and maternity services and may also differ between private or public. Likewise any prompts to conduct screening either on data collection forms or in clinical systems will vary between various locations.

Currently, the retention of any data captured by screening is also unknown as it is not mandatory to collect this data. At the state level, no aggregate data is collated or reported in New South Wales, and as the NSW PDC is a personally identified data set, it is preferential not to collect information on illegal activity on the PDC.

Mandatory reporting for pregnant women who are using substances may be required in New South Wales. The NSW Mandatory Reporter Guide provides guidelines for reporting risks to the unborn child or newborn (NSW Government 2016).

Victoria

In Victoria, universal perinatal mental health, including two questions related to alcohol and drug use, have been introduced in all Victorian maternity settings through the National Perinatal Depression Initiative (NPDI). It is however, unknown if all Victorian maternity settings have implemented the screening process and as a result it is anticipated that routine screening for substance use is likely to be variable across the state.

The two recommended questions in the perinatal mental health screening are:

- Do you currently use alcohol or drugs?
- Do you think either you or your partner has a problem with drugs or alcohol?

Victoria, when screening does not differentiate between illicit or prescription drugs as both are known to impact the developing fetus and often prescription drugs are overlooked as being harmful. The information once collected is included in the woman's medical record and is not collected as part of the Victorian Perinatal Data Collection (VPDC).

The Victorian Department of Health and Human Services has also developed the Victorian Maternity Record (VMR) see <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/mothers-and-babies/maternity-newborn-services/vic-maternity-record>. The VMR is a standard, hand-held pregnancy record that has been adopted across public health services in Victoria. Pregnant women are encouraged to bring the record to all GP and hospital antenatal appointments. The purpose of the VMR is to:

- encourage consistency of information
- enhance communication between service providers
- promote women's involvement in decisions around their care.

Public maternity services should tell all pregnant women about the VMR and offer/encourage them to use this resource, however it is not mandatory. Alcohol and substance use is assessed and recorded on the VMR by the health practitioner (GP, midwife, and so forth). If used, the doctor or midwife will fill in the VMR form at each visit and the form is carried by the woman.

As a part of the maternity history section of the VMR, women are asked:

- history of drug use (free text)
- if they are receiving treatment (Yes/No)
- if yes, what the treatment is and where are they having it (free text).

This information is **not** collected in the VPDC.

The timing and frequency of screening for drug use is variable across providers with regards to the antenatal and/or postnatal periods. All pregnant women should be provided with the VMR at their first visit after confirmation of pregnancy. Questions specifically related to drug use are asked by the doctor or midwife at, or soon after the initial visit.

It is anticipated that more frequent assessments should be made if concerns exist such as women who present:

- after 20 weeks pregnancy
- with homelessness
- with altered mental state.

If screening differences exist between public and private care in Victoria, they are unknown as the collection of this data is not mandatory. Currently Victoria does not collect data on reasons why screening is not completed and/or referral information.

The recording of individual responses to screening questions is variable across maternity services in Victoria. Each setting would use their own form of records (that is, electronic, paper based, and so forth). Furthermore, in the Victorian admitted episode dataset (VAED), some information regarding drug use is noted as part of the episode record. This information would usually be collected during the maternal birth episode—the specifications are as follows:

- referral to Alcohol and drug treatment service, arranged before discharge at the separation

- Alcohol and Drug Program noted as the primary care type (although in most/all cases) the care type would be based on the pregnancy, not drug dependency.

In Victoria, aggregated data is not available electronically as the Victorian Perinatal Data Collection does not have a specific data element for collecting information on screening for illicit drug use in pregnancy. Health services occasionally submit ICD-10 codes relating to illicit drug use in other data items such as 'maternal medical conditions' however this is not consistent and is not mandatory. Victoria does not report on any illicit substance use in their maternity or perinatal reporting.

Currently, there are no specific jurisdictional legislation requirements that would prevent aggregate data on illicit drug use being provided to the Australian Government. Additionally there are no specific jurisdictional guidelines that govern reporting of illicit drug use in pregnancy to the police, Department of Health, Human Services, or other services.

Queensland

From 1 July 2015, the following data item has been included in the Queensland Perinatal Data Collection as a mandatory reporting item (see Table 3.13). All public and private sector Queensland facilities routinely screen all pregnant women who have had a planned antenatal visit. Where antenatal care has not occurred the response will be no.

Table 3.13: Queensland data item for illicit substance use screening

Data item	Data type	Value	Notes
Antenatal Screening performed for Illicit Drug Use	1 num	Indicates whether antenatal screening was performed for Illicit Drug Use 1 = No 2 = Yes 9 = not stated/unknown	Must be equal to 1, 2, or 9 Must be equal to 1 if antenatal care flag = 1 Must not be null

Source: Queensland 2016.

In public facilities, a full screening assessment is conducted at the first visit followed by routine screen at every visit. In private facilities a full assessment is done at the pre-admission appointment. The screening is conducted by face-to-face questioning.

Queensland does not collect reasons why screening did not occur.

Prompting for screening may occur via a number of different methods including the patient hand-held record, paper data collection form, and a prompt from the electronic data collection system. The responses to screening are sent to the PDC as a single answer response 'Yes/No/Unknown'.

It is unknown if there would be any legal constraints on providing this data to the Australian Government and advice would need to be sought. Some legal considerations regarding mandatory reporting will need to be made also as currently, hospital and Health Services report concerns to the Department of Child Safety if the mother's drug use may affect the baby.

Western Australia

In Western Australia, this information is collected as part of usual clinical care and is not reported to the Department of Health data collections. It is recorded in various clinical documents like medical records and computer systems available to clinicians such as GP practices, maternity hospitals, and so forth.

Western Australia was unable to provide details on the extent that data is available electronically.

Western Australia was unable to provide details on whether this data will be able to be provided to the Australian Government.

South Australia

In South Australia (SA), pregnant women are asked about illicit drug use at the booking visit. The South Australian Pregnancy Record has a question on illicit drug use to prompt the question being asked at the booking visit, however, the woman may offer this information at any antenatal visit. Midwives will follow-up at antenatal visits if an issue has been identified in previous visits, and refer accordingly. Some women may not be screened as not all private obstetricians use the South Australian (hand-held) Pregnancy Record, which prompts regarding illicit drug use. The reasons for not screening are not recorded.

Other screening measures such as blood/hair/tissue analysis is not undertaken routinely on pregnant women in South Australia.

Electronic collection of data is likely to vary across the State and currently there is no data that would be collected, collated or reported on a jurisdictional level.

Only un-named information is provided to the Australian Government, however, there is likely to be under-reporting to the South Australian State Collection, due to concerns regarding the collection form being identified. It can also be a problem if the pregnant woman is under the age of consent. The health professional may feel obligated to make a report to Families SA—and this may in fact prevent midwives asking the question.

It is suggested that not identifying the patient would be a better way to collect the data, for example; as they used to collect the ‘fit kits’ for the aids harm minimisation program some years ago.

Tasmania

In Tasmania, all women are routinely screened for illicit drug use at the booking in visit. Women who have identified as using drugs (historically or currently) are asked at each visit.

Responses to screening questions are collected via direct face-to-face questioning.

Screening processes between public and private services are likely to be similar.

Tasmania does not collect any reasons why screening is not conducted as screening is a mandatory field in their electronic system.

The data is stored electronically and is available at an aggregate level for regular reporting. For example, at the largest public hospital, the women who use illicit drugs are seen in a specific antenatal clinic that base the delivery of specialist care on issues identified and documented in the electronic system.

No reporting of this data occurs at the jurisdictional level. It is currently unknown if this data would be able to be reported to the NPDC. Some mandatory reporting issues may exist for the collection of this data.

Australian Capital Territory

In the Australian Capital Territory (ACT), all pregnant women are routinely screened for illicit drug use at the booking in visit. Women are likely to be screened by their general practitioner when the pregnancy is confirmed and again at the booking in visit (14–16 weeks). Screening will continue if applicable or the midwife is concerned.

Responses to screening questions are collected via direct face-to-face questioning.

- There would be no significant differences in illicit drug screening between public and private care in the ACT, but women who are identified as high risk (indicating current use of illicit substances) are generally referred to the public system (as the private ward is a Level 2 Hospital and not equipped to handle such cases). The public offer model of care Pregnancy enhancement programme (PEP), 1 midwife offering continuity of antenatal care within a multidisciplinary model VS individual private care.
- The reasons for why screening is not completed and/or referral information is not collected at the jurisdictional level. The ACT Maternal Perinatal Data Collection includes a field asking 'Substance use during pregnancy?' and use of illicit substances is reported in this field as a yes/no/not stated. Prompts to collect this information are contained in the electronic system, paper forms and the hand-held record.
- Responses to the screening will then be recorded into the BirthPac system which is specific to the antenatal context. The Birth Outcomes System (BOS) is used to collect and manage public system Perinatal data. While collected in the system, these data are not currently available in aggregated form, however, the system infrastructure and processes would require significant change to allow such data to be collected and reported. No reporting of this data occurs at the jurisdictional level and there are no known issues as to why this data could not be reported to the NPDC. Some mandatory reporting issues may exist for collection of this data as hospitals are mandated to report to care-and-protection services of any mother identified as a current user of illicit substances. Pre-birth alert will also be conducted and, if applicable, a care and protection notification.

Northern Territory

The Northern Territory (NT) recommends that midwives or health professionals discuss women's drug use as part of the booking in visit. The Medical History section of the Hand-held Pregnancy Record form and if indicated this information is recorded in the free text within this form.

Antenatal care providers are trained to inquire again about illicit drug usage after the first visit if there is a known history or if there is an indication that the client is using illicit drugs. In most cases a formal screening tool is not used.

There are no restrictions to reporting this data to the Australian Government provided that it was approved with the National Perinatal Data Collection. Some mandatory reporting issues need to be considered as part of the NT Information Act and the Department of Health Privacy Policy.

Consultation

NMDDP AG meeting of 3 December 2015

Members were provided with an outline of an information paper that is being developed by the AIHW to help inform the development of an illicit substance use data item in the NPDC. The information paper would be used to help inform a workshop that would seek to explore these issues further.

Members agreed that a workshop should be convened, but had questions on the scope of the collection and the legal ramifications of such a collection. The AIHW advised that these issues would be covered in the information paper and will seek to explore drugs that are likely to cause harm to a baby rather than just focus on illicit drugs.

All members of the Advisory Group will be invited to participate in the workshop and members are asked to provide any other nominations out of session.

NPDDC meeting of 3 May 2016

Members were asked to note work to date by the AIHW on progressing data items in regard to collecting data about illicit substance use in pregnancy. Members were asked to consider the inclusion of a screening indicator in the NPDC and how to progress any future data development.

Members discussed the following issues:

- that any data items proposed to be collected (screening plus any additional items) should be considered together rather than splitting them out, however, it was noted that due to the sensitivity and potential legal issues associated with this data item that it could be more conducive to negotiate an agreement to just collect screening
- the ACT noted that they currently collect 'substance use documented' and this has led to confusion in the definition and question
- NSW also noted difficulties with the definition and the scope of any data collected
- Northern Territory noted that the wording within the indicator was not clear and should be simplified
- Queensland noted that they are currently collecting screening only with a response rate of 94% of public, 42% of private hospitals are reporting yes to screening, unknowns are currently 1% public and 6% private. The PDC is identified but any reporting is de-identified, noting that only screening occurred information is collected. Any other data, such as drug use is coded within the medical record
- South Australia notes that clinicians are likely to request a legal view on providing this data.

The NPDDC considered inclusion to the NPDC psychosocial data items related to 'screening during antenatal care' as part of a staged approach to data development. This approach was not deemed suitable for a number of reasons and it was suggested that all data items that would be included in the NPDC should be considered in their entirety.

Overall, NPDDC members agreed that they would need to develop a consultation process within their jurisdiction and asked the AIHW to produce a document which would assist in facilitating this process The AIHW has developed this paper and circulated to jurisdictions. Feedback formed the basis of progressing data development.

Inter-jurisdictional consultation process

Jurisdictions were asked, to consult within their own networks on the collection of data items related to substance use in pregnancy.

As a result of the meeting, the AIHW produced an explanatory document to assist jurisdictions with facilitating a consultation process within their respective networks on the data development of relevant psychosocial data. Of the jurisdictions who responded, there was some concerns about the unresolved issues surrounding collecting substance use in pregnancy and the need for a national workshop to explore these concerns prior to agreement of data items to be collected. Substance use in pregnancy data development workshop.

A workshop regarding substance use in pregnancy data development was held in Canberra on 15 December 2016. The workshop was attended by data custodians, researchers, policymakers and clinicians. The discussion at the workshop focussed on six domains:

1. Scope and definitions
2. Data item options
3. Screening tools/collection
4. Implementation
5. Data recording and reporting
6. Alternatives.

Generally, it was noted that there are considerable issues with collecting this data, primarily around legal considerations including privacy and identification. It was agreed that the PDC at state level had too many legal considerations including those that could not be anticipated into the future if the legislation should be amended. It was agreed that this outcome presented an unacceptable unintended risk to the woman.

Additionally, what type of data to be collected was problematic, if data was aggregated into a y/n indicator, it would not provide any detail of what drugs presented harms and therefore would not contribute to outcomes for mothers or babies. Likewise if the data is disaggregated into drug types—it would also have little value because of the small numbers.

A number of alternative data sources/collections were suggested which the AIHW will investigate. A workshop report can be found in Appendix I.

NPDDC meeting of 16 December 2016

The NPDDC considered the inclusion of the above draft data items to the perinatal data collection following the jurisdictional consultation and the substance use data development workshop. The NPDDC agreed with the outcomes of the workshop and agreed that further development on this indicator will cease as no jurisdiction was supportive of collecting these data.

4 Improvements to maternity data

There were two major developments in the national maternity data, the development of the Maternity Care Classification System (MaCCS) data collection and an update to the Maternity Information Matrix (MIM).

4.1 Maternity Care Classification System data collection

The Maternity Care Classification System (MaCCS) was developed as one of the components of the NMDDP. The concept and content of the MaCCS were developed in Stage 1 and 2 of the NMDDP, including the development of the Maternity Model of Care Data Set Specification (MoC DSS). The current stage of the project has been the development of an electronic web-based data collection tool—the MaCCS DCT—that has been developed collaboratively between the AIHW and the NPESU based on specifications developed in Stage 2. The MaCCS DCT will populate a national data collection based on the MoC DSS and will be hosted and maintained by the AIHW.

The MoC DSS is separate from the perinatal NMDS and will allow collection of data about what maternity models of care women received. The new DSS contains 18 new data elements and metadata including a new object class, new properties and new glossary items. The DSS will allow nationally consistent data to be available for analysis across and within jurisdictions.

Currently, there are no data options to allow the MaCCS information to be collected as part of the National Perinatal Data Collection (NPDC). The AIHW would like the NPDDC to consider adding 2 new data elements to the Perinatal DSS to record the model of care received. The 2 new items would be around the *Principal model of care* and *Model of care prior to birth*, these items are derived from the MoC DSS and would allow the models of care to be attached to the mother's record and reported on accordingly.

The MaCCS DCT is an online survey based tool that allows for data about the maternity models of care offered by maternity services to be input accordingly. It provides more detailed information about maternity models of care, with finer distinctions between categories. It retains the advantage of being able to group similar models into a major model category.

The development of the MaCCS DCT has included product testing, both internal alpha testing and external beta testing via a national pilot. The national MaCCS DCT pilot was held in maternity services around Australia between 29 February and 15 April 2016. The aim of the pilot testing was to identify any technical faults in the code that might have been missed during alpha testing, to ensure that the product was acceptable to users and that the MaCCS DCT was fit for purpose. Exposing the MaCCS DCT to a live environment with entry of real models of care also aimed to identify any business rules that might conflict with established models.

During the pilot, 100 models of care were entered into the MaCCS DCT by 31 participants on behalf of 35 maternity services. The models of care entered during the pilot were classified to all of the Major Model Categories with the exception of 'Private midwifery care'. A total of 15 notifications of 'errors' were received from eight participants, however after reviewing each of the notifications, only 7 were found to be genuine errors in the program. These have since been dealt with by the developers. The smaller than expected number of errors identified

during the pilot reflects the success of the development process and collaborative relationship between the AIHW developers and the NPESU Project Manager. Changes made to the MaCCS DCT post the pilot relating to how users register for access to the software could not be piloted.

Participants in the pilot testing were also asked to complete a feedback survey on their experience of using the MaCCS DCT via an electronic survey. Fourteen participants completed the survey (45% response rate) and overall reported the MaCCS DCT very easy to use and the built-in guidance helpful. All except one participant took longer than 4 minutes to enter a single model of care (50% took 4–6 minutes and 29% took 7–10 minutes). Based on the average number of models of care provided by an individual maternity service (4–5 models, range 1–13) it is estimated that it would take an average of less than 30 minutes once per year to classify all of their models of care using the MaCCS DCT (range 4–130 minutes).

The development and piloting of the MaCCS DCT has been a unique project for the AIHW and the NPESU and has demonstrated a high level of success through collaboration and partnering of different skill sets and teams. The results of the highly successful pilot indicate that the MaCCS DCT will function appropriately according to the specifications, is acceptable to users and will improve the accuracy of classifying models of maternity care.

The MaCCS DCT went live in August 2016 and is available at <https://maccs.aihw.gov.au/login>. User registration is required. In order for collection of data to commence the AIHW sought formal nominations of a staff member from each facility that provides planned maternity services and is involved in reporting maternity data. This involved writing to jurisdictions and seeking these nominations.

Progress of data supply

The MaCCS DCT will assist maternity services to provide their models of care data to the collection on an annual basis. Once data collection has commenced and a period of six months of collection has passed, an evaluation of the quality of these data will be undertaken with a view to integrate these data into the National Perinatal Data Collection. Formal consultation is expected to begin with jurisdictional perinatal data custodians on how best to develop these data items so that the woman's model of care can appear in her Perinatal Data Collection record. All jurisdictions will be able to access information on the models of care in their state or territory.

As at 23 January 2017, six jurisdictions had supplied data consisting of 235 models of care. Table 4.1 provides details of the models of care reported by jurisdiction.

Table 4.1: Models of care supplied by jurisdiction and participating hospitals

Jurisdiction	Hospitals	Models of care		
		Submitted	Saved	Deleted
New South Wales	22	37	53	4
Victoria	5	9	12	0
Queensland	17	54	13	3
South Australia	3	2	1	0
Western Australia	1*	0	1	0
Northern Territory	7*	22	19	5
Australia	**47***	**124**	**99**	**12**

* Including State-wide reported.

Source: State and territories (unpublished).

4.2 Maternity Information Matrix

The MIM is a metadata collection providing a summary of data items in Australian national and jurisdictional data collections relevant to maternal and perinatal health. It allows for comparisons across 45 data collections including perinatal collections, births and deaths, congenital anomalies and other specialist collections. It includes nearly 500 data items and metadata for each item including definitions and descriptions.

The MIM was updated as part of Stage 3 of the NMDDP and reflects data collection practices as at July 2016. The MIM is available at <http://maternitymatrix.aihw.gov.au/Pages/About-the-MIM.aspx>.

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Related publications

The report, *Enhancing maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 3 and 4*, is part of a stage series. This and the earlier edition relating to Stage 1 and Stage 2 can be downloaded for free from the AIHW website <https://www.aihw.gov.au/reports/mothers-babies/foundations-for-enhanced-maternity-data-collection> and <https://www.aihw.gov.au/reports/mothers-babies/enhancing-maternity-data-collection-and-reporting>. The website also includes information on ordering printed copies.

The following AIHW publications relating to maternal and perinatal health might also be of interest:

- AIHW 2016. Peripartum hysterectomy in Australia: a working paper using the National Hospital Morbidity Database 2003–04 to 2013–14. Cat. no. PER 85. Canberra: AIHW.
- AIHW 2015. Screening for domestic violence during pregnancy: options for future reporting in the National Perinatal Data Collection. Cat. no. PER 71. Canberra: AIHW.
- AIHW: Bonello MR, Hilder L & Sullivan EA 2014. Fetal alcohol spectrum disorders: strategies to address information gaps. Cat. no. PER 67. Canberra: AIHW.

This working paper presents findings of Stage 3 and 4 of the National Maternity Data Development Project, which was established in response to the National Maternity Services Plan. Stage 3 and 4 has seen substantial progress in: data development for psychosocial data items; the development of ongoing maternal and perinatal mortality data collections reporting; and the development of a data portal for the maternity models of care data collection.

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