The development of the National Maternity Information Matrix
Contents

• Background – NPESU and the National Maternity Data Development Project

• What is maternity data, who collects it and why

• The Maternity Information Matrix v1 – historical

• The Maternity Information Matrix v2 – the process, issues, challenges and final result

• Where to next?
The NPESU – our mission

"To improve the health and well-being of Australian mothers and babies, we will supply health statistics and epidemiological information to enable well informed community discussion and decision making about reproductive and perinatal health. We will also provide leadership and excellence in reproductive and perinatal health research and teaching.”
The NPESU

• Part of the Perinatal and Reproductive Epidemiology Research Unit (PRERU) at UNSW Medicine, School of Women’s and Children’s Health

• The National Perinatal Epidemiology and Statistics Unit (NPESU) was first established in 1979

• A collaborating unit of the Australian Institute of Health and Welfare (AIHW)

• Staff include researchers, epidemiologists and postgraduate students in public health, perinatal and reproductive health and epidemiology

• The NPESU publishes national reports on reproductive and perinatal health which cover pregnancy outcomes, maternal and perinatal morbidity and mortality, assisted reproduction and congenital anomalies
National Maternity Data Development Project (NMDDP)

• Funding NMDDP: Department of Health and Ageing (DoHA)

• Australian Institute of Health and Welfare (AIHW) and National Perinatal Epidemiology and Statistics Unit (NPESU) collaborative program of work

• NPESU lead – Maternity Information Matrix
What is maternity data?

- Information that is collected about pregnancy, labour, birth, the health of mothers up to 42 days after the birth, and babies up to 28 days after birth.

- For some types of information, the period of data collection is extended.

- Data about rare events such as deaths and severe maternal and neonatal morbidity, are also included in specialist data collections.
Who collects maternity data?

- Hospitals – midwives, doctors, other clinicians, administration
- State/territory health departments – hospital morbidity systems, perinatal data collection, perinatal and maternal deaths, congenital abnormalities
- Vital registries (and ABS) – births, deaths, stillbirths
- Specialist information collections (administered by PRERU/NPESU/AIHW) – ANZNN, ACAMS, Perinatal NMDS, AMOSS, NHMD
- Coroners
Data Sources

What is maternity data used for?

- Track progress against national and international indicators
- Routine reporting
- Service planning
- Performance monitoring
- Quality and safety reviews (including to classify deaths and sentinel events)
- Epidemiological studies and other research
- Reporting of Aboriginal and Torres Strait Islander health statistics
The Maternity Information Matrix v1

• Commenced in 2010 - data collection forms, guidelines for data collection and/or data dictionaries were obtained from managers of each data collection

• An electronic inventory (in Microsoft Excel) organised by topic, to correspond with each stage in the maternity pathway with data items grouped into subject areas and subtopics

• For each data item the matrix also provides comparative information on the scope, definitions, availability and reporting

• A data collection overview for each collection modelled on the ABS Data Quality Statement (DQS) summarised information about each data collection’s institutional environment, relevance and scope, timeliness, accuracy, accessibility, and interpretability
The Maternity Information Matrix v2

- Web version of MIMv1 was developed

- Updated in August 2011 based on data collection practices as at 1 July 2011 with some structural changes and completed January 2012

- Used as the baseline for analysis of information needs and gaps as part of scoping information needs and gaps in national data in the NMDDP

- Benefit of HIM viewpoint
What I was faced with…

• 45 collections from vastly different sources: ABS, Coroners, Births Deaths and Marriages, Departments of Health, AIHW, NPESU

• Different data standards and varying degrees of documentation

But – I had my HIM knowledge about good data practices and standards!

• Different collection methods – paper and electronic

• Different versions

• Custodians all over the country

• Relying on goodwill for information from busy people
Process

- Contact all data custodians or representatives
- Copies of data collection forms if applicable
- Compare to MIMv1 data
- Search for latest online information
- Review data dictionaries/guides for use
- Update master spreadsheet
- Write data collection overviews
- Review and approval by data custodians
- Upload by web developers to online database – MIMv2
### Collection Method

<table>
<thead>
<tr>
<th>Data Item</th>
<th>FEMMAT (NSC)</th>
<th>NDDC</th>
<th>QLD</th>
<th>NT</th>
<th>WA</th>
<th>SA</th>
<th>VICT</th>
<th>ACT</th>
<th>TAS</th>
<th>ANZIN</th>
<th>INDD</th>
<th>ANMOS</th>
<th>ACMAS</th>
<th>RHMD</th>
<th>NCS</th>
<th>NSW</th>
<th>WA</th>
<th>SA</th>
<th>VICT</th>
<th>ABS</th>
<th>NSW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Demographics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alias (also known as)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other given names</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s maiden name</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s date of birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indigenous status of mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity of mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area of usual residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Period of pregnancy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area of residence during the</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>first 10 weeks of pregnancy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statistical Local Area of usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone number</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s unit record number</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AT in which a birth took place</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital code</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of marriage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place of marriage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of marriage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous children of the mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal occupation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collection Method</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maternity Information Matrix</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing data</td>
<td>Existing data</td>
<td>Existing data</td>
<td>Existing data</td>
<td>Existing data</td>
<td>Data definitions/description as per MERRH, SIT guidelines, SIT report, NHMD</td>
<td>Data characteristics: scope, timeliness</td>
<td>Most recent published data</td>
</tr>
<tr>
<td>Data Item Framework</td>
<td>Data Item</td>
<td>Data Item</td>
<td>Collections in which the Item Appears</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>----------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Maternal demographics</td>
<td>Mother's name</td>
<td>Mother's name</td>
<td>SIT Perinatal Data Collections (NT, electronic only), SIT Births Registration Collections, NSW, SA, Vic, WA, Births of Stillborn or Perinatal Deaths Register, SIT Deaths and Perinatal Deaths Registration Collections, NCH</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Definitions:

SIT Perinatal Data Collections (NT): The full first name should be recorded. Do not use abbreviated forms of the name or Nick names. The legal surname should be recorded. If an alias or assumed name is used, this should be indicated in brackets following the legal name. WA: The first middle surname of the mother, a hospital code may be used. QLD: The surname, second name and first name of the mother. SA: The surname and then the mother's given names. WA: The legal surname should always be given. If an alias or assumed name is used, this should be indicated in brackets in the same position following the legal surname. No Anglicized versions of forenames are to be given, e.g., Usha Mary. TAS: The mother's first name and last name, and any middle names.

Scope: SIT Perinatal Data Collections excl. NT (paper and online): data are collected for all births, both live and stillborn, of 20 weeks gestation or above/birthweight. SIT Births Registration Collections: all births that are live and have not been previously registered. The delivery of a stillbirth irrespective of the duration of pregnancy, after being born, breech or shows any evidence of life such as a heartbeat. SIT Deaths Registration Collections: all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence is overseas. Deaths of Australian residents that occurred outside Australia are collected by SIT Registrars but not included in ABS deaths statistics. Notifications in both Collecting States in NSW, Vic, SA and the Northern Territory (data Collections in all states). Data are collected for live births and fetal deaths + 20 weeks gestation or > 400g birthweight with one or more congenital anomalies. For the four SITs, with Births Deaths Registrar, notifications include TOP due to congenital anomalies. The period of detection varies between SITs, ranging from 1 year (NSW) to 16 years (Vic). Notifiable conditions vary between SITs. NCH. What constitutes a reportable death varies by jurisdiction. Notifications are usually made by a police officer or a medical practitioner, however any person may notify the coroner if they believe that a reportable death has occurred. SIT Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and in Australia.

Data are not published.

<table>
<thead>
<tr>
<th>Maternal demographics</th>
<th>Mother's name</th>
<th>Alias (also known as)</th>
<th>WA, NT, SA, ACT Deaths Registration Collections</th>
<th>No definition specified</th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Scope: WA, NT, SA, ACT: Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas. Data availability - Data are not available. Timeframe: As of.

Data are not published.

<table>
<thead>
<tr>
<th>Maternal demographics</th>
<th>Mother's name</th>
<th>Other given names</th>
<th>NT, ACT Deaths Registration Collections</th>
<th>Description</th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Scope: NT, ACT: Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and deaths of Australian residents that occurred outside Australia. Data availability: Data are not available. Timeframe: As of.

Data are not published.

| Maternal demographics | Father's name | | WA Perinatal Data Collection | Data are collected for all births, both live and stillborn, of 20 weeks gestation or above/birthweight. SIT Deaths Registration Collections: all deaths that are live and have not been previously registered. The delivery of a stillbirth irrespective of the duration of pregnancy, after being born, breech or shows any evidence of life such as a heartbeat. SIT Deaths Registration Collections: all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence is overseas. Deaths of Australian residents that occurred outside Australia are collected by SIT Registrars but not included in ABS deaths statistics. Notifications in both Collecting States in NSW, Vic, SA and the Northern Territory (data Collections in all states). Data are collected for live births and fetal deaths + 20 weeks gestation or > 400g birthweight with one or more congenital anomalies. For the four SITs, with Births Deaths Registrar, notifications include TOP due to congenital anomalies. The period of detection varies between SITs, ranging from 1 year (NSW) to 16 years (Vic). Notifiable conditions vary between SITs. NCH. What constitutes a reportable death varies by jurisdiction. Notifications are usually made by a police officer or a medical practitioner, however any person may notify the coroner if they believe that a reportable death has occurred. SIT Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and in Australia.

Data are not published.

<table>
<thead>
<tr>
<th>Maternal demographics</th>
<th>Father's name</th>
<th></th>
<th>NT, ACT Deaths Registration Collections</th>
<th>Description</th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Scope: NT, ACT: Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and deaths of Australian residents that occurred outside Australia. Data availability: Data are not available. Timeframe: As of.

Data are not published.

| Maternal demographics | Father's name | | WA Perinatal Data Collection | Data are collected for all births, both live and stillborn, of 20 weeks gestation or above/birthweight. SIT Deaths Registration Collections: all deaths that are live and have not been previously registered. The delivery of a stillbirth irrespective of the duration of pregnancy, after being born, breech or shows any evidence of life such as a heartbeat. SIT Deaths Registration Collections: all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence is overseas. Deaths of Australian residents that occurred outside Australia are collected by SIT Registrars but not included in ABS deaths statistics. Notifications in both Collecting States in NSW, Vic, SA and the Northern Territory (data Collections in all states). Data are collected for live births and fetal deaths + 20 weeks gestation or > 400g birthweight with one or more congenital anomalies. For the four SITs, with Births Deaths Registrar, notifications include TOP due to congenital anomalies. The period of detection varies between SITs, ranging from 1 year (NSW) to 16 years (Vic). Notifiable conditions vary between SITs. NCH. What constitutes a reportable death varies by jurisdiction. Notifications are usually made by a police officer or a medical practitioner, however any person may notify the coroner if they believe that a reportable death has occurred. SIT Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and in Australia.

Data are not published.

| Maternal demographics | Mother's name | | SIT Births Registration Collections, NSW, SA, Vic, WA, Births of Stillborn or Perinatal Deaths Register, SIT Deaths and Perinatal Deaths Registration Collections, NCH | | | |

Definitions:

SIT Perinatal Data Collections (NT): The full first name should be recorded. Do not use abbreviated forms of the name or Nick names. The legal surname should be recorded. If an alias or assumed name is used, this should be indicated in brackets following the legal name. WA: The first middle surname of the mother, a hospital code may be used. QLD: The surname, second name and first name of the mother. SA: The surname and then the mother's given names. WA: The legal surname should always be given. If an alias or assumed name is used, this should be indicated in brackets in the same position following the legal surname. No Anglicized versions of forenames are to be given, e.g., Usha Mary. TAS: The mother's first name and last name, and any middle names.

Scope: SIT Perinatal Data Collections excl. NT (paper and online): data are collected for all births, both live and stillborn, of 20 weeks gestation or above/birthweight. SIT Births Registration Collections: all births that are live and have not been previously registered. The delivery of a stillbirth irrespective of the duration of pregnancy, after being born, breech or shows any evidence of life such as a heartbeat. SIT Deaths Registration Collections: all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence is overseas. Deaths of Australian residents that occurred outside Australia are collected by SIT Registrars but not included in ABS deaths statistics. Notifications in both Collecting States in NSW, Vic, SA and the Northern Territory (data Collections in all states). Data are collected for live births and fetal deaths + 20 weeks gestation or > 400g birthweight with one or more congenital anomalies. For the four SITs, with Births Deaths Registrar, notifications include TOP due to congenital anomalies. The period of detection varies between SITs, ranging from 1 year (NSW) to 16 years (Vic). Notifiable conditions vary between SITs. NCH. What constitutes a reportable death varies by jurisdiction. Notifications are usually made by a police officer or a medical practitioner, however any person may notify the coroner if they believe that a reportable death has occurred. SIT Deaths Registration Collections: all deaths that occurred and were registered in these SITs, including deaths of persons whose place of usual residence is overseas and in Australia.

Data are not published.
Definitions vs Descriptions

• Some data collections had a data dictionary, some had a guide for use, some had *nothing*!

• The metadata pages included definitions – especially important when an item appeared in more than one collection (same name, many different interpretations)

• When is a definition not a definition but a description?

• Further revisions necessary
Data Item vs Data Value

- Some data collections had both paper and electronic forms
- Many forms had ‘tick boxes’ rather than yes/no
- MIM v1 had included many items that were really data values
- Example:
  - Data item: Obstetric complications (antenatal)
  - Data values included tick boxes for: APH, GDM, PIH…

- But, some forms had these values as discrete data items under a heading of ‘Obstetric Complications’ with a yes/no for presence or absence, therefore data item, not data value and if absent then ‘no’ must be selected rather than a tick for those that were present

- Most precise way to identify data item from data value was by looking at the metadata if available (often not!)

- Revision of all items required
Data Collection Overviews vs Data Quality Statements

- ABS use Data Quality Statements (DQS) to present information about the quality of a statistical collection or product using the Data Quality Framework.

- DQS can only be completed by data custodian responsible for a collection, not a third party, alternative solution was using Data Collection Overviews with similar categories.
The Result – MIMv2


Live demonstration
## MIM Index

### Jump to collection:
- Perinatal
- Congenital Anomalies
- Other National
- Deaths
- Perinatal Mortality Review Committees
- Perinatal Deaths

### Jump to area:
- Parental demographics
  - Maternal characteristics
    - Risk factors
    - Antenatal
      - Health services - Antenatal care
        - Maternal Morbidity - low-risk:
          - Maternal Morbidity - pre-eclampsia
    - Labour and birth
      - Maternal health services - intrapartum care
      - Labour and birth
        - Complications of labour
    - Postnatal
      - Health services - postpartum care
        - Interventions - postpartum
  - Neonatal
    - Baby demographics
    - Baby characteristics
    - Neonatal morbidity
    - Neonatal mortality
    - Neonatal feeding
  - Mortality
    - Maternal mortality
    - Perinatal mortality

### Data Items

<table>
<thead>
<tr>
<th>Parental demographics</th>
<th>Perinatal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s demographic data</td>
<td></td>
</tr>
<tr>
<td>Mother’s name</td>
<td></td>
</tr>
<tr>
<td>Mother’s maiden name</td>
<td></td>
</tr>
<tr>
<td>Mother’s date of birth</td>
<td></td>
</tr>
<tr>
<td>Mother’s Indigenous status</td>
<td></td>
</tr>
<tr>
<td>Mother’s country of birth</td>
<td></td>
</tr>
<tr>
<td>Mother’s race</td>
<td></td>
</tr>
<tr>
<td>Mother’s residence</td>
<td></td>
</tr>
<tr>
<td>Neonatal mortality</td>
<td></td>
</tr>
<tr>
<td>Neonatal feeding</td>
<td></td>
</tr>
<tr>
<td>Maternal mortality</td>
<td></td>
</tr>
<tr>
<td>Perinatal mortality</td>
<td></td>
</tr>
</tbody>
</table>

### Data Sources:
- MIMIS
- NEDHC
- NSW
- VIC
- QLD
- WA
- SA
- TAS
- ACT
- NT
- ACAN

---

**The Result - Index**

---

**UNSW**

**AUSTRALIA**
# The Result - Metadata

## Details

<table>
<thead>
<tr>
<th>DATA ITEM</th>
<th>Obstetric complications</th>
</tr>
</thead>
</table>

### Data Item Category

- Maternal Morbidity - gestational

### Collections Containing the Item

- National Perinatal Data Collection (NPDC)
- VIC Perinatal Data Collection (VIC PDC)
- QLD Perinatal Data Collection (QLD PDC)
- WA Perinatal Data Collection (WA PDC)
- SA Perinatal Data Collection (SA PDC)
- TAS Perinatal Data Collection (TAS PDC)
- NT Perinatal Data Collection (NT PDC)
- Australasian Maternity Outcomes Surveillance System (AMOSS)
- NSW Maternal and Perinatal Committee (NSW PMC)
- ACT Perinatal Mortality Committee (ACT PMC)

## Existing Meta Data

### Data Definitions

**Definition:**

AMOSS: Complications or conditions that arose during pregnancy that are directly attributable to the pregnancy and may have significantly affected care during the current pregnancy and/or pregnancy outcome.

**Description:**

- QLD PDC: Complications occurring during the period immediately preceding delivery (not including the intrapartum period) that are directly attributable to the pregnancy and may have significantly affected care during the current pregnancy and/or pregnancy outcome.
- NSW PMC: Other conditions in the pregnancy (list of items include twin to twin transfusion, fetomaternal haemorrhage, uterine abnormality, birth trauma, haemolytic disease, idiopathic hydrops, drug dependence/abuse, other.
- ACT PMC: Obstetric complications including: APA/Placenta praevia, APA/other, Abruptio placenta, pregnancy induced hypertension, prelabour ROM, ROM less than 24 hours, ROM greater than 24 hours, gestational diabetes, threatened abortion, threatened preterm labour, fetal distress, IUGR, Oligohydramnios, polyhydramnios, twin twin transfusion syndrome (TTTS), fetal anomaly, cervical incompetence, other.

### Additional Information

No additional information

### Related items

No related items
The Result - DCOs

Data Collection Overview

<table>
<thead>
<tr>
<th>DATA COLLECTION OVERVIEW</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Coroners Information System (NCIS)</td>
</tr>
</tbody>
</table>

Data Sources

Data are collated from state and territory Coroners' Offices for all reportable deaths.

Institutional Environment

The NCIS is an initiative of the Australasian Coroners Society, and is maintained by the Victorian Institute of Forensic Medicine (VIFM). The NCIS is a national, internet-based data storage and retrieval system for Australian coronial cases. All deaths reported to an Australian coroner since July 2000 (January 2001 in Queensland) have been entered into the NCIS. The NCIS is funded by a range of Commonwealth and State/Territory agencies.

The primary role of the NCIS is to assist coroners in their role as death investigators, by providing them with the ability to review previous coronial cases that may be similar in nature to current investigations, enhancing their ability to identify and address systematic hazards within the community. Usually a police officer or a medical practitioner will notify the Coroner of any death that may be a 'reportable' death. It is open however, to any person to notify the Coroner if they believe that a reportable death has occurred.

Data entry is performed at each of the coroners' offices into local case management systems by coronial clerks. Data from these case management systems is uploaded to the NCIS on a regular basis (in most cases nightly). Full text documents are either attached to the local case management systems by the coroner's courts, or transferred directly to the NCIS from the originating organisation (e.g., Post-mortem reports from the Forensic Science Centre). The Coroners clerks use the information contained within the coronal file as the basis for their data entry. All information transferred to the NCIS is performed in accordance with State and Federal Privacy legislation.

Each of the states and territories has a licensed agreement with the Victorian Institute of Forensic Medicine that permits the transfer of coronial information for storage and dissemination via the NCIS. Each state and territory also has its own Act, which governs the powers and duties of the Coroner.

NCIS is continually working to obtain as many documents in electronic format as possible. Country reports are sometimes only available in a paper form, and some laboratory systems may not yet be able to transfer their reports electronically. Discussion underway with the Office of the Australian Safety and Compensation Council (previously the National Occupational Health and Safety Commission) for the provision of a number of additional coded fields relating to work-related fatalities. Additional data fields arising from other projects involving the national police form and drugs module may also be added to the NCIS data set in the future.

Relevance and Scope

What constitutes a 'reportable death' varies by jurisdiction. Although the following list is not exhaustive, in general, a death must be reported to a Coroner in the following instances:

- where the person died unexpectedly and the cause of death is unknown,
- where the person died in a violent or unnatural manner,
- where the person died during or as a result of an anaesthetic,
Where to next?

- MIM needs to be updated regularly as data collections are dynamic
- Suggested improvements for v3:
  eg split definitions and descriptions, data values vs data items, custodians provide DQS
- Inclusion of other relevant data collections:
  eg maternal mortality data, workforce data
- Dependant on recurrent funding
Thank you

Questions?

n.donnolley@unsw.edu.au

References

