An Overview of Statutory and Administrative Datasets:
Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

Bree Heffernan    Sonya Sheridan    Jane Freemantle
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This image represents 'connections' and their relevance to health and wellbeing. Our connections with mother earth and the natural world keep us well and our connections with one another through family and community heal us and keep us whole.

Shawana Andrews
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Acknowledgments

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List of Abbreviations

ABS  Australian Bureau of Statistics
ACCHO  Aboriginal Community Controlled Health Organisation
ACIR  Australian Childhood Immunisation Register
ADIS  Alcohol and Other Drug Information System
AHLO  Aboriginal Hospital Liaison Officer
AHLOC  Aboriginal Hospital Liaison Officer Collection
AIHW  Australian Institute of Health and Welfare
ATR  Australian Twin Registry
BEACH  Bettering the Evaluation and Care of Health
CCOPMM  Consultative Council on Obstetric and Paediatric Mortality and Morbidity
DEECD  Department of Education and Early Childhood Development
DHS  Department of Human Services
DoJ  Department of Justice
HREC  Human Research Ethics Committee
NATSIHS  National Aboriginal and Torres Strait Islander Health Survey
NCIS  National Coroners Information System
NHDD  National Health Data Dictionary
PDC  Perinatal Data Collection
RBDM  Registry of Births, Deaths and Marriages
VACCHO  Victorian Aboriginal Community Controlled Health Organisation
VAED  Victorian Admitted Episodes Dataset
VBDR  Victorian Birth Defects Register
VCAMS  Victorian Child and Adolescent Monitoring System
VCR  Victorian Cancer Registry
VEMD  Victorian Emergency Minimum Dataset
VPDCU  Victorian Perinatal Data Collection Unit
VRB  Victorian Registry of Births
VRD  Victorian Registry of Deaths
This report examines the collection of data describing the health of Victorian infants, children and young people with particular reference to the collection of Indigenous status. The report summarises the available data, the reported accuracy and completeness of Indigenous status, the processes for requesting access and ethical clearance to use data for research purposes, and contact details for data custodians. It also includes a discussion on the barriers to obtaining accurate data on Indigenous status.

The 16 datasets contained in this report (Appendix 9, Datasets A–P) include birth and death registers and data collections, hospital inpatient and emergency department datasets, and infectious disease, dental, and cancer registers. These datasets collect information describing Aboriginal and Torres Strait Islander infants, children and young people, and most also collect information describing adults. There are a number of national and statewide surveys and datasets that collect health information on the Victorian Aboriginal population that do not have a central repository nor permit access to data for research purposes; these collections and surveys have been excluded.

Of the 16 datasets examined, 14 are managed by Victorian state government departments or clinical councils, one by a Victorian university, and another by a Victorian non-profit organisation. Of the 14 Victorian government datasets, three fall under the auspice of the Department of Justice (DoJ), eight under the Department of Human Services (DHS) and three the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM). See Appendix 3 for an overview of datasets collecting health data on Victorian Aboriginal (and non-Aboriginal) children, infants and young people.

For the purpose of analysis, a number of collections have been split into more than one to account for differences in data items collected for different episodes of care, or different data requirements on forms feeding into the one dataset. The 16 collections are therefore split into 20 for analysis.

Of the 20 datasets surveyed in March 2009, seven indicated that they collect the Indigenous status of the mother (35 per cent), 16 the Indigenous status of the child/client (80 per cent), and three the Indigenous status of the father (15 per cent). Two datasets surveyed did not collect the Indigenous status of the child/client or either parent: the National Coroners Information System (NCIS) and the Australian Twin Registry (ATR). Only one custodian reported that they collect Indigenous status for all three: the Aboriginal Hospital Liaison Officer (Births) Collection (AHLOC).

Many of the data custodians surveyed indicated that they were not confident in the accuracy with which Indigenous status was recorded in their dataset. Some commented...
that they were unable to respond on behalf of collecting agencies, and others commented that the degree of confidence varied according to the agency collecting and submitting the information to the database. Only one respondent reported that they were ‘very confident’ of the accuracy of the information recorded, and three reported that they were ‘confident’. Responses are summarised in Appendix 5.

This report highlights inconsistencies in the accuracy of identifying Victoria’s Aboriginal infants, children and young people in statutory and administrative datasets. Australian state and territory authorities, often in partnership with the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS), continue to develop programs to improve the completeness with which Indigenous status is recorded. Work continues to be undertaken by the Victorian Registry of Births, Deaths and Marriages (RBDM) to improve the accuracy and completeness of Indigenous identification in vital statistics, while DHS has initiated activities to improve identification in Victorian administrative datasets. Some of these strategies are outlined in Appendix 7.

This report is accurate as at March 2009. The information it contains will rapidly date as new strategies are implemented to address, and potentially improve, deficiencies in the completeness and accuracy of Indigenous identification.

This report will be reviewed in two years’ time with a view to updating the availability and robustness of data describing the health of Victorian Aboriginal and Torres Strait Islander (and non-Aboriginal) infants, children and young people.
Project Aims

The aim of this report is to provide a better understanding of how accurately and completely administrative and statutory datasets collect data on infant, child, and young peoples’ health, with a specific reference to the recording of Indigenous status.

This report is the first output from the Victorian Aboriginal Child Mortality Study (1988–2008), currently being undertaken by researchers at the Onemda VicHealth Koori Health Unit, the University of Melbourne, in conjunction with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), and funded by the Australian Research Council. This five-year study will link data from a number of statutory and administrative datasets to produce a complete birth and mortality profile for Aboriginal (and non-Aboriginal) infants, children and young people in Victoria born between 1988 and 2008. The aim of the overall study is to better identify Victorian Aboriginal births, as well as infant, child and youth deaths, to identify the patterns and trends in mortality and the existing disparities in outcomes between Aboriginal and non-Aboriginal populations, and to identify the context and circumstances of these deaths.

An understanding of the integrity of the data and the processes for acquiring access to these data was an essential first step in this process.

In addition, an understanding of the availability and quality of data describing Aboriginal and Torres Strait Islander health in Victoria is crucial to accurately reporting population health status. Indigenous status data will have an important role to play in establishing a baseline from which to measure the effectiveness of initiatives currently underway to improve Indigenous identification in health datasets. The accurate recording of Indigenous status will be fundamental in measuring whether ‘the gap’ in Aboriginal and non-Aboriginal health in Victoria is indeed closing.

This report is the first comprehensive resource developed for researchers, data custodians and government agencies outlining the availability and robustness of data describing the health of Victorian Aboriginal (and non-Aboriginal) infants, children, and young people.
Background

Reliable health data on Aboriginal and Torres Strait Islander people in Victoria are needed to inform policy development and program delivery, and to evaluate the effectiveness of policies and interventions aimed at improving services and population health status. Accurate service data also assist in monitoring changes in population wellbeing and accounting for government expenditure.\(^1\)

The issue of under-identification of Indigenous status in health datasets is not a new concern, but a longstanding issue referenced in countless AIHW, ABS and government and peer reviewed journal publications. Prior to 1976, no Australian jurisdiction separately identified Aboriginal and Torres Strait Islander people in vital statistics or hospital-based collections. In 1984, the Australian Government initiated moves to identify all Aboriginal and Torres Strait Islander Australians in birth and death data collections.\(^2\) By the end of 1999, all major vital statistics and hospital-based collections included the Indigenous status of people who were born, died or admitted to hospital in every Australian state and territory, although the collection of these data were not necessarily mandatory.

### Table 1: Identification of Indigenous status in health and mortality administrative and statutory collections: Year of commencement by jurisdiction

<table>
<thead>
<tr>
<th>Type of collection</th>
<th>Year of commencement of identifying Indigenous status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NSW</td>
</tr>
</tbody>
</table>

Source: ABS Vital Statistics.

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Today, the recording of Indigenous status in health datasets is widely reported to be inconsistent, particularly in the south-eastern Australian jurisdictions of Victoria, South Australia, New South Wales, the Australian Capital Territory, and Tasmania. Owing to this inconsistency, in 2005, the AIHW made a decision to exclude Victorian hospital statistics from national reports on Aboriginal health. This decision was later reversed as a result of an audit conducted in 2007, which concluded that the level of identification of Aboriginal and Torres Strait Islander patients in Victoria had improved to the point where data from 2004–05 could be included in national analyses.\(^5\)

The ABS reports that the identification of Indigenous status in deaths registered in south-eastern jurisdictions is not sufficiently complete, nor the number of identified Indigenous deaths large enough, to produce reliable coverage or life expectancy estimates.\(^4\) As a result, the life expectancy ‘gap’ cannot currently be calculated for these jurisdictions individually.

There are a number of factors widely believed to contribute to the misclassification and under-reporting of Indigenous status in health datasets. These include: inconsistent application of the agreed national standard for asking the question of Aboriginal or Torres Strait Islander origin, inadequate staff training in the task of data collection, lack of staff awareness as to the importance of collecting accurate information, staff concerns about negative reactions to the Indigenous status question from Aboriginal and non-Aboriginal respondents, and a belief that Aboriginal patients feel disinclined to acknowledge their Aboriginality when the question is asked in an inappropriate way.\(^5\)

At this point, it is worth noting the ‘Commonwealth Definition’ of an Aboriginal or Torres Strait Islander person as per the High Court judgement in the case of Commonwealth v Tasmania (1983) 46 ALR 625:

> An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives.\(^6\)

Thus there are three components to the Commonwealth definition:

1. descent,
2. self-identification, and
3. acceptance by the community.\(^7\)

In practice, in most general purpose statistical and administrative collections it is not feasible to determine whether a person is accepted by his or her community as an Indigenous person. Therefore, the standard question of Indigenous status relates to descent and self-identification only.\(^8\) In addition, there is no requirement to provide ‘proof’ of descent.

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3. AIHW 2005, Improving the Quality of Indigenous Identification in Hospital Separations Data, Health Services Series no. 25, AIHW Cat. No. HSE 101, AIHW, Canberra.
5. ibid.
6. ibid.
Each client should be given the opportunity to identify his/her Aboriginal and/or Torres Strait Islander origin by answering the question in the format prescribed by the ABS.

Format of the standard question:

‘Are you of Aboriginal or Torres Strait Islander origin?’  

Different articulations of the question can be used where a friend or relative is answering on behalf of the client.

[Is the person] [Is (name)] of Aboriginal or Torres Strait Islander origin?

It is not possible to determine a person’s Aboriginal or Torres Strait Islander origin or identity based on his or her physical features, name, or any existing knowledge of his or her cultural origins. Although a person’s Aboriginal and/or Torres Strait Islander origin will not change over time, their willingness to identify might change depending on the context or circumstances in which they are being asked.

Therefore, the ABS has prescribed that:

to achieve an acceptable quality of Indigenous Status data, it is imperative that interviewers endeavour to apply the standard question module to all respondents and to record every response regardless of the person’s appearance, name, country of birth or other perceptions about the person’s background.  

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2 ibid.
3 ibid.
Methodology

At the commencement of this study, researchers identified administrative and statutory datasets that collect information on infant, child and young peoples’ health in Victoria.

A questionnaire was developed for data custodians requesting information on the scope, accuracy and completeness, storage and accessibility, and reporting of data, with a primary focus on the identification of Indigenous status.

The questionnaire was trialled with several custodians and amended before wider distribution. Custodians were contacted either by telephone or email (or both) and invited to participate in the study by completing the questionnaire (see Appendix 1). An overview of the purpose of the project was also provided in a letter accompanying the questionnaire (see Appendix 2).

In some instances, arrangements were made with data custodians to discuss and complete the questionnaire in person. Custodians were asked to provide web links or attachments for inclusion in this discussion paper, principally outlining data access and ethics protocols.

Responses were collated and sent back to data custodians for validation, requesting any amendments and/or endorsement. If amendments were requested, these were attended to and the questionnaire was resent to the custodian for final endorsement. Results from completed questionnaires were entered into a database and analysed for inclusion in this discussion paper. Completed questionnaires and attachments are included in Appendix 9.

Inclusions and exclusions

Inclusions

Only datasets that include information on Victorian Aboriginal infant, child and youth health, have a central repository, and provide access for research purposes have been included in this report. Appendix 3 provides an overview of datasets collecting information on Aboriginal child health in Victoria and their custodians.

Although this study is primarily concerned with the collection of data in Victoria, a number of national collections were considered with respect to the information they collect on Victorian Aboriginal (and non-Aboriginal) children. These datasets include the NCIS, the ATR and the Australian Childhood Immunisation Register (ACIR). The first two datasets are included in this report, the latter is not.

Exclusions

The ACIR is a national register that includes Victorian Aboriginal children. The collection is administered by Medicare Australia and includes details of vaccinations given to children under seven years of age who live in Australia. A representative from the ACIR was
invited to participate in this study but declined. Further information can be accessed from the Medicare website: <www.medicareaustralia.gov.au>.

The Registry of Births, Deaths and Marriages in each jurisdiction provides birth, mortality and perinatal mortality data to the ABS Health and Vital Statistics Unit. The ABS coordinates requests for access to data for statistical purposes however, data remain the property of jurisdictional registries, and approval is required from registries for access to unit record level data through the ABS. Given this is a secondary access point to Victorian data managed by the Victorian Registry—a dataset already featured in this study—the ABS collection is not included in this report.

Patient information collected through General Practice is neither submitted to a central repository nor used for research purposes. It has therefore been excluded from this report. An Indigenous identifier is included in General Practice patient records, and the Royal Australian College of General Practitioners has published guidelines for the appropriate ascertainment of Aboriginal and Torres Islander identity.12

Similarly, patient data collected in Aboriginal Community Controlled Health Organisations (ACCHOs) have been excluded. Identifiable patient level data are neither submitted to a central database nor available for access by researchers at a statewide level. However, there may be instances where researchers have been granted access to patient level data in an ACCHO through negotiation with the individual community. An Indigenous identifier exists in ACCHO patient information recall systems.

An Indigenous identifier was added to the Medicare Australia national database in November 2002. This was to enable greater understanding of access to Medicare Services and Pharmaceutical Benefits by Aboriginal and Torres Strait Islander people, and the more accurate measurement of the effectiveness of current and future initiatives. As Aboriginal and/or Torres Strait Islander identification is completely voluntary, the coverage of the Voluntary Indigenous Identifier is incomplete and this information is therefore generally not available to researchers. A more complete description of the database has therefore not been included in this report.

In Victoria, pathology request forms completed by general practitioners, specialists, and hospital clinicians do not include an Indigenous identifier. Pathology services are provided across Victoria by a number of laboratories, each using their own pathology forms. An Indigenous identifier is included on pathology request forms in a number of other Australian jurisdictions, but Indigenous status is not currently routinely collected in Victoria.

Survey data

There are a number of national and jurisdictional surveys collecting health information from the Aboriginal people of Victoria. As a general rule, survey data have been excluded from this report as data are

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12 The Royal Australian College of General Practitioners (RACGP) 2006, ‘The Identification of Aboriginal and Torres Strait Islander People’, Fact Sheet, RACGP, Melbourne.
collected from a sample population and as such are non population-based.

The Australian Census of Population and Housing (the Census) is conducted by ABS every five years and is the ‘biggest statistical collection in Australia’. The Census collects information on the population and housing characteristics of people living in Australia on Census night. On the Census form a question asks whether each person is of Aboriginal and/or Torres Strait Islander origin. Completion of the Census form by every Australian household is compulsory.

Access to published Census data is provided free of charge online via the ABS website. Data may be searched according to a topic of interest and/or geographic location. There are a number of defined topics disaggregated by Indigenous status; these include education and training, housing, labour, language and culture, and population size and distribution. Where data are not available online, the ABS can provide customised data for a fee through its consultancy service. The Census is primarily a survey of population and housing characteristics; health information is chiefly collected through the ABS series of health surveys.

‘The National Aboriginal and Torres Strait Islander Health Survey (NATSISHS) is the largest health survey of Aboriginal and Torres Strait Islander Australians conducted by ABS’ in remote and non-remote areas throughout Australia. ‘In 2004–05, the sample size was 10,439 persons (or about one in 45 of the total Indigenous population)’. The survey, conducted by ABS, is ‘designed to collect a range of information about health related issues including health status and actions and socioeconomic circumstances’. Results are published in aggregate and separately for each jurisdiction. The next NATSIHS is due for release in late 2009.

The Victorian Population Health Survey is an annual survey of the health of the Victorian population conducted by DHS. The survey forms part of the department’s health ‘surveillance program’, used to inform ‘decisions about public health priorities’. In the 2007 report, a small proportion of residents in the randomly selected sample of 7500 households identified themselves as being of Aboriginal or Torres Strait Islander origin (0.9 per cent). Results are not reported separately by Indigenous status.

The Department of Education and Early Childhood Development (DEECD) works with other parts of government to systematically monitor the safety, health, development, learning and wellbeing of Victorian children and young people, from birth to adulthood. This includes building the Victorian Child and Adolescent Monitoring System (VCAMS) to bring together and make available information on agreed outcomes for children, young...

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13 ABS, 2006 Census: Information about Aboriginal and Torres Strait Islanders: <http://www.abs.gov.au/websitedbs/d3310114.nsf/51c9a3d2d6eddf0ca26ebc0118404d525f0ba6df454ea2571e9e007d6e710OpenDocument>


people and their families. Some data are sourced from programs and operations across Victorian Government, but other information needs to be separately sought through new population surveys. Although data are not yet available on some important areas, VCAMS surveys continue to address many of the data gaps on child outcomes and an increasing amount of VCAMS data is being made available to state and local government. Data from VCAMS are disaggregated by Indigenous status where possible.\(^\text{17}\)

Information about general practice activity is available from the Bettering the Evaluation and Care of Health (BEACH) survey. BEACH is a collaboration between the AIHW and the University of Sydney. The survey began in 1998 and collects information about the consultation, the patient, the patient’s presenting problems, and the management of each problem. The survey questionnaire includes an Indigenous identifier (Aboriginal Yes/No, or Torres Strait Islander Yes/No). However, it is unknown to what extent General Practitioners conducting the survey ask the question of their patients and consistently record the answer. A detailed summary of the BEACH survey can be found in the General Practice Activity in Australia series.\(^\text{18}\)

In summary, 16 statutory and administrative datasets collecting information on the health of Victorian Aboriginal (and non-Aboriginal) infants, children and young people have been included in this report. These datasets are population-based, have a central repository and protocols for access to data for research purposes. Datasets that do not fulfil these criteria have been excluded.


Discussion

This report has a particular focus on the collection, recording, submission and reporting of Indigenous status in statutory and administrative datasets describing the health of Victoria’s infants, children and young people.

Datasets that identify the Aboriginal and Torres Strait Islander origin of Victoria’s children include birth and death registers, hospital inpatient and emergency department collections and infections disease, dental, and cancer registers.

Data custodians participating in this study were asked to identify the data variables included in their dataset from a pre-defined list as outlined in table 2 (data collected when the child is the ‘client’).

Table 2: Pre-defined answers to the question ‘What type of data are captured in this database?’

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child/client:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
<td>Indigenous status</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Demographic information</td>
<td>Demographic information</td>
</tr>
<tr>
<td>Pregnancy information</td>
<td>Birth information</td>
<td>Employment status</td>
</tr>
<tr>
<td>Delivery information</td>
<td>Delivery information</td>
<td></td>
</tr>
<tr>
<td>Death information</td>
<td>Death information</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Responses to this question are summarised in Appendix 4.

Three collections appear more than once in Appendix 4, Figure 1 and Table 3 to account for differences in data collected for different types of episodes of care, or different requirements on forms feeding into the one dataset.

- In the Victorian Admitted Episodes Dataset (VAED), the Indigenous status of the mother and baby is recorded in separate patient records when the admission to hospital relates to a birth. Indigenous status of the mother is not collected for any subsequent child hospitalisation.

- There are three parts to the Aboriginal Hospital Liaison Officer Collection (AHLOC): births, hospitalisations and deaths. The AHLOC includes an Indigenous identifier for the mother and father in the event of a birth, an identifier for the mother and baby, but not the father for a child’s admission to hospital for any reason other than birth, and, by inclusion, identification of Indigenous status in the event of a death.

- In Victoria, notification of a death is provided to the RBDM on three hard copy, or online forms: the Death Registration Statement, Medical Certificate of Cause of Perinatal Death (fetal or perinatal death of a child aged <28 days), and/or the Medical Certificate of Cause of Death (of a person aged 28 days or older). Indigenous status of the father is collected for a fetal or perinatal death only, but is not collected on the other two forms. Indigenous status is recorded for a deceased child on two of three forms: the Death Registration Statement and the Medical Certificate of Cause of Death. The Perinatal Certificate of Cause of Death collects information on the Indigenous status of the father and mother, but not the child.

Figure 1: Proportion of data collections surveyed collecting the Indigenous status of the child/client and his or her mother and father, March 2009

Note: proportions calculated from 20 datasets (16 collections)
Responses to questionnaires from 20 datasets (16 collections) indicate the following with regard to the collection of Indigenous status:

Information collected on the mother, child and father when the child is the client:

- seven from 20 datasets (35 per cent) collect the Indigenous status of the mother
- 16 from 20 datasets (80 per cent) collect the Indigenous status of the baby/child/client (65 per cent prior to 1 January 2009)
- three from 20 datasets (15 per cent) collect the Indigenous status of the father.

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Indigenous status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mother</td>
<td>Child/client</td>
<td>Father</td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection (births)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection (hospitalisations and deaths)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Child Dentistry Register</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Consultative Council on Obstetric and Paediatric Mortality and Morbidity</td>
<td>Yes</td>
<td>Yes (from Jan 2009)</td>
<td>No</td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Operational Data Store (Mental Health Client Management Interface)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Perinatal Data Collection</td>
<td>Yes</td>
<td>Yes (from Jan 2009)</td>
<td>No</td>
</tr>
<tr>
<td>Primary Health Data Collection</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset (childhood admission)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset (birth episode, separate mother and baby patient records)</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Birth Defects Register</td>
<td>Yes</td>
<td>Yes (from Jan 2009)</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Cancer Registry</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Emergency Minimum Dataset</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Registry of Births</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Registry of Deaths (Death registration statement)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Registry of Deaths (Medical certificate of cause of death)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Victorian Registry of Deaths (Perinatal certificate of cause of death)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Proportion – Yes (from 20 collections)</td>
<td>35%</td>
<td>80%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Table 3: Summary of responses regarding the collection of Indigenous status by dataset, March 2009
The Indigenous identifier

The Indigenous identification of an infant or child is ascertained in a number of different ways. In some collections, the Indigenous status of the child is provided by the accompanying parent or guardian in response to the question asked by administrative personnel. In other collections, the identification of the child is derived from the identification of one or both parents, sometimes on a registration form either completed by a parent or by administrative staff.

In later years, a child when answering for him or herself might not identify as a parent identified him or her in the early years. In datasets where a patient record can be created at birth (e.g. the VAED), this question should be re-asked at each subsequent episode of care to account for a person's changing propensity to identify his or her Aboriginal and/or Torres Strait Islander identity, but also to correct information that may have been incorrectly recorded at birth or at a previous episode of care.

If the Indigenous status of the mother and father is collected independently in a dataset, the status of the baby or child can be derived from a positive identification of either parent. Similarly, if the Indigenous status of the mother and baby are recorded for a birth episode, the Indigenous status of the father might, in some circumstances, be determined if the baby is identified as Indigenous and the mother is identified as non-Indigenous, assuming that the baby is taking his or her father's Indigenous identity. However, estimating the Indigenous status of an adolescent or adult based on that of his or her mother or father is much less reliable given the adolescent may choose not to self identify as an Indigenous person after childhood.

Historically, Indigenous status has been assigned to a baby based on the Indigenous identification of his or her mother. Prior to 1 January 2009, the Victorian Perinatal Data Collection (VPDC), the Victorian Birth Defects Register (VBDR), and CCOPMM only recorded the Indigenous status of the mother and not that of the baby. Changes came into effect on 1 January 2009 to include the Indigenous status of the baby on the Birth Report Form for the first time. This form (completed by midwives and submitted to the VPDCU, DHS) is a data source for all three datasets. This addition aims to identify those babies born to non-Aboriginal mothers and Aboriginal fathers. Birth registration data published by ABS in 2007 (sourced from birth registration data submitted to ABS by the RBDM in each jurisdiction) suggests that in all of the Aboriginal and Torres Strait Islander births in 2006, 13 per cent were born to parents that both identified as Indigenous, 44.8 per cent to mothers that identified as Indigenous only, and 41.3 per cent to fathers that identified as Indigenous only. Therefore, based on 2006 data, an estimated 40 per cent of Aboriginal and Torres Strait Islander babies born in Victoria would not have been registered as Aboriginal in the VPDC, VBDR and CCOPMM in the years prior to 2009.

The ATR and the NCIS are the only two datasets surveyed that do not currently collect the Indigenous status of the child or either parent. The national ATR includes a field titled ‘ethnicity’ (a free text field) and does not have a separate field to collect Indigenous status. The ATR has indicated that an Indigenous identifier will be added to the collection at the next review in late 2009.

The NCIS relies on data collected by police officers attending the scene of a death. There are a number of collection tools used by police in different Australian states and territories to notify a death to a coroner; some include an Indigenous identifier and others do not. The NCIS Unit has been involved in a project (also involving the Commonwealth Department of Health and Ageing and other stakeholders) to facilitate the design and implementation of a standard police form for reporting a death to a coroner across Australia. An Indigenous identifier is included on this national form. While this form has not yet been implemented in Victoria, the form is being used in Tasmania, Queensland, ACT, NT, and will soon be used in NSW. Victoria is currently working on ways to implement the form within its jurisdiction.

The results of this study reveal there is very little information collected on the father in the datasets surveyed. The Indigenous status of the father is collected in three of the 20 datasets (16 collections surveyed), or 15 per cent. These include the AHLO collection, the Victorian Registry of Births, and the Victorian Registry of Deaths (for fetal or perinatal deaths only). Basic demographic information is collected in three of 20 datasets (15 per cent), and employment status is recorded in two of 20 (10 per cent). As mentioned earlier, if the Indigenous status of the mother and child are both collected and the mother is registered as non-Indigenous and the baby as Indigenous, the father’s Indigenous status may be derived. However, in the instance where the mother and baby are both recorded as Indigenous, there is no way of determining the father’s Indigenous status on this information alone.

Published counts of Aboriginal births in Victoria tend to vary between individual datasets as demonstrated in Table 4. One causal factor could be the inconsistent classification of ‘Aboriginal births’ between datasets (those born to Aboriginal mothers versus those born to Aboriginal mothers and/or fathers). Other potential barriers to the accurate recording of Indigenous status are explored in greater detail later in this paper.

Table 4: Aboriginal and Torres Strait Islander births by dataset and year, Victoria, 1999–2006/07

<table>
<thead>
<tr>
<th>Source</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003/04</th>
<th>2004/05</th>
<th>2005/06</th>
<th>2006/07</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHLO – Total Aboriginal births</td>
<td>353</td>
<td>303</td>
<td>363</td>
<td>299</td>
<td>310</td>
<td>397</td>
<td>449</td>
<td>550</td>
</tr>
<tr>
<td>PDCU – Births to Aboriginal mothers</td>
<td>452</td>
<td>377</td>
<td>421</td>
<td>416</td>
<td>362</td>
<td>435</td>
<td>538</td>
<td>569</td>
</tr>
<tr>
<td>RBDM – Total Aboriginal births</td>
<td>521</td>
<td>452</td>
<td>522</td>
<td>601</td>
<td>722</td>
<td>719</td>
<td>802</td>
<td>782</td>
</tr>
<tr>
<td>VAED – Births to Aboriginal mothers</td>
<td>363</td>
<td>333</td>
<td>379</td>
<td>411</td>
<td>n/a</td>
<td>433</td>
<td>502</td>
<td>589</td>
</tr>
</tbody>
</table>

Many of the respondents in this study indicated they had little confidence in the accuracy with which Indigenous status was recorded in their dataset. Some indicated that they were unable to comment on behalf of collecting agencies, and others indicated that their degree of confidence varied according to the agency collecting and submitting the information. Only one respondent reported that he/she was ‘very confident’ of accuracy, and three reported that they were ‘confident’. Responses are summarised in Appendix 5.

The estimated under-identification and misclassification of Indigenous status in health statistics is widely speculated to be due to a combination of two factors: a failure to ask and record a client’s Indigenous status, and/or a failure to self-identify Indigenous origin when asked.20

The AIHW proposes a number of reasons why a service provider may feel uncomfortable asking a client if he/she is of Aboriginal or Torres Strait Islander origin and reasons why a client may feel uncomfortable self-identifying:

- service providers may not wish to appear to be discriminating against Indigenous people;
- the question may seem silly when the answer may appear to be obvious (especially for Aboriginal and Torres Strait Islander service providers who may have been assisting the client for some period of time);
- a service provider may feel that the information is intrusive (or that a client/patient may be offended by the question);
- a service provider may feel that they could not explain to a client/patient why the question needs to be asked if the client/patient wanted to know;
- a service provider may feel that the question is irrelevant—assuming that they don’t have any clients who are Indigenous (or alternatively don’t have any clients who are not Aboriginal or Torres Strait Islander);
- Indigenous people may not feel confident that the information will be kept confidential by the service provider; and
- Indigenous people may feel that they are being “monitored” or singled out for special attention.21

Data custodians participating in this study were asked to identify barriers to obtaining information about a person’s Indigenous status from the pre-defined list outlined in Table 5.

Respondents were able to select more than one barrier from this list, and six respondents elected to do so. The three responses selected most often were:

- Indigenous person may not feel comfortable declaring their status;
- Administrative staff fear a negative response to the question being asked; and
- Administrative or medical staff may feel that the question is irrelevant.

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21 ibid.
A number of custodians felt unable to comment on behalf of agencies collecting and submitting the data, while others provided additional suggestions for the perceived barriers. Personnel from agencies collecting the data from clients may be able to answer this question with greater confidence given they are directly involved in the collection of data, while custodians are removed from this process.

Data custodians were also asked to select the data improvement strategies they employ from the pre-defined list in Table 6.

Respondents were able to select more than one strategy from the list, and all but two chose to do so (from 16 datasets). The three responses selected most often (in order) were:
- Staff education,
- Mandatory data fields, and
- Benchmarking with other jurisdictions.

Table 5: Pre-defined answers to the question ‘What are the barriers to obtaining information about a person’s Indigenous status?’

<table>
<thead>
<tr>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form not completed</td>
</tr>
<tr>
<td>Indigenous person may not feel comfortable declaring their status</td>
</tr>
<tr>
<td>Language barrier</td>
</tr>
<tr>
<td>Service provider may not wish to appear to be discriminating</td>
</tr>
<tr>
<td>Administrative or medical staff may feel that the question is irrelevant</td>
</tr>
<tr>
<td>Administrative staff not comfortable asking the question</td>
</tr>
<tr>
<td>Administrative staff do not understand why the question is being asked</td>
</tr>
<tr>
<td>Administrative staff fear a negative response to question being asked</td>
</tr>
<tr>
<td>Response not provided</td>
</tr>
<tr>
<td>Unable to Comment</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Table 6: Pre-defined answers to the question ‘How do you ensure data quality?’

<table>
<thead>
<tr>
<th>Answer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandatory data fields</td>
<td></td>
</tr>
<tr>
<td>Benchmarking with other jurisdictions</td>
<td></td>
</tr>
<tr>
<td>Timely submission of data</td>
<td></td>
</tr>
<tr>
<td>Audits to ensure accuracy and consistency</td>
<td></td>
</tr>
<tr>
<td>Staff education</td>
<td></td>
</tr>
<tr>
<td>Warning and error alerts</td>
<td></td>
</tr>
<tr>
<td>Timely entry of data</td>
<td></td>
</tr>
<tr>
<td>Administrative staff follows up with client when forms incomplete</td>
<td></td>
</tr>
</tbody>
</table>
Custodians were not asked to outline the content covered in existing protocols for staff education with respect to the accurate recording of Indigenous status. Therefore, it is unknown to what degree staff education is currently being utilised to address the barriers nominated by custodians.

Perhaps the coverage and accuracy of data identifying Aboriginal and Torres Strait Islander status may improve through educating personnel as to:

- the importance of asking the ‘standard question’ of every client irrespective of their appearance;
- explaining the purpose of collecting the information and who uses the data; and
- why clients may be apprehensive to identify their Aboriginal and/or Torres Strait Islander origin.

In the responses provided by custodians (summarised in Appendix 7), there was no mention of strategies to educate Aboriginal and Torres Strait Islander people of the importance of declaring their Indigenous origin. If a reluctance to identify is a leading barrier to accurate data collection, then perhaps a strategy to overcome this impediment could be considered by data custodians, either individually or collectively. However, it is worth noting that responses to this question have been provided solely by data custodians and it is therefore possible that strategies to improve the collection of Indigenous status, including educating the Aboriginal community to self-identify, are being developed in other areas of government, or by individual service providers of which data custodians are not aware.

Finally, data custodians were asked to outline the guidelines for access to their data and the protocols for obtaining ethical clearances for research involving these data. Most custodians reported that application for access to data should be made in writing to the data custodian. Some reported they had a specific access agreement, and all reported that access to potentially identifiable information required an application to a properly constituted Human Research Ethics Committee (HREC). In some instances, approval from any HREC would be sufficient (such as the researcher’s university HREC), in other instances, application must be made to the custodian’s HREC. Specific instructions provided by custodians are included in completed questionnaires in Appendix 9. A summary of responses to this question is also provided in Appendix 8.
Conclusion

In the early stages of planning the Victorian Aboriginal Child Mortality Study, researchers recognised there was little existing information that identified and described datasets recording the health of Aboriginal infants, children and young people in Victoria.

Researchers decided to review existing datasets in conjunction with data custodians, to identify the data items collected in these datasets, the accuracy and completeness of the recording of Indigenous status, and the protocols for accessing data from custodians for research purposes.

The resulting resource has proven invaluable in the preparatory stages of the study, and should also prove extremely useful to other researchers and government policy makers working in the field of Aboriginal health, particularly child health.

Measuring progress in achieving the goal of ‘closing the gap’ is a priority of the Commonwealth Government’s ongoing Indigenous reform agenda. Accurate recording of Indigenous status is crucial to the Federal and State Governments’ evaluation of initiatives being developed and implemented, and in measuring progress towards achieving this goal.

Information provided by data custodians in this study confirms an inconsistent and incomplete recording of Indigenous status in many of the datasets surveyed. Importantly, custodians identified a number of strategies currently being employed to improve coverage and accuracy. Authors of this report would like to acknowledge the continuing activities of government and funded-agencies individually and collectively to strengthen the accuracy of these data.

This report is accurate as at March 2009, and the content will be reviewed in two years. As such, this report will provide an important baseline from which the effectiveness of current initiatives and activities aimed at improving the recording of Indigenous status may be evaluated.

This discussion paper would not have been possible without the valued contribution of data custodians. Authors are very grateful for the time and expertise custodians have generously provided in order that the information contained in this document may be accurate, informative and complete.
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Appendices

Appendix 1: Questionnaire template

The purpose of this questionnaire is to review and describe Victorian statutory and administrative databases that capture information describing child mortality and morbidity, with a particular focus on the (accurate) collection of the Indigenous status.

DATABASE
Q.1 What is the name of the data collection? ____________________________

CUSTODIAN
Q.2 Who is or are the custodian/s of the data? ____________________________

Please provide contact details of the custodian.
Name:___________________________
Position/job title:___________________________
Phone:___________________________
E-Mail Address:___________________________

Are you happy to be included in our acknowledgements?
☐ Yes ☐ No

DATA COLLECTION
Q.3 What type of data are captured in this database? (Multiple boxes may be ticked).

<table>
<thead>
<tr>
<th>Mother</th>
<th>Child</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Indigenous status</td>
<td>□ Indigenous status</td>
<td>□ Indigenous status</td>
</tr>
<tr>
<td>□ Demographic information</td>
<td>□ Demographic information</td>
<td>□ Demographic</td>
</tr>
<tr>
<td>□ Smoking status</td>
<td>□ Birth information</td>
<td>□ Employment Status</td>
</tr>
<tr>
<td>□ Pregnancy information</td>
<td>□ Death information</td>
<td></td>
</tr>
<tr>
<td>□ Delivery information</td>
<td>□ Delivery information</td>
<td></td>
</tr>
<tr>
<td>□ Death information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Employment Status</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q3a. **Does the database include identifying information?**

Mother
- [ ] Name
- [ ] Maiden Name
- [ ] Address at baby's birth
- [ ] Other

Child
- [ ] Name
- [ ] DOB
- [ ] Address at birth
- [ ] Other

Father
- [ ] Name
- [ ] Other

*If other, please state:*
- Mother: ____________________________________________________
- Child: _____________________________________________________
- Father: ____________________________________________________

Q.4  **Can we obtain a copy of all the available variables attached as an appendix?**

- [ ] Yes  
- [ ] No

*If not, please provide reason:______________________________________

Is there any cost involved in accessing the data?

- [ ] Yes  
- [ ] No

*If yes, please provide an approximate cost:_________________________

Q.5  **How are the primary data collected? (Multiple boxes may be ticked)**

- [ ] Form is completed by the client.
- [ ] Form is completed by person/s accompanying the client (for example, a spouse or parent).
- [ ] Form is completed by the Indigenous Liaison Officer.
- [ ] Form is completed by administration staff.
- [ ] Administrative staff enters information directly into the database from interview.
- [ ] Other (for example, Liaison Officer)

*Please Specify:____________________________________________________

Q.6  **When are the data collected? (Multiple boxes may be ticked)**

- [ ] Before the episode of care/event (for example, at pre-admission).
- [ ] During the episode of care/event (for example, at admission).
- [ ] After the episode of care/event.

Q.7  **How do the custodians obtain the data that are included in the database? (Multiple boxes may be ticked)**

- [ ] Surveys
- [ ] Data is obtained from external entities and is downloaded via a web interface.
- [ ] Data is obtained from external entities in paper format (for example, a notification of birth form).
- [ ] Data is obtained directly from the person acting on behalf of the client (for example, parent, relative, funeral director or staff member of a service/institution, etc.)

*If so, who are the external entities?__________________________________

---

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
### STORAGE AND ACCESSIBILITY

**Q.8** In what format do the custodians store the data?
- □ Electronic
- □ Electronic and paper base
- □ Paper based
- □ Microfiche
- □ Microfilm
- □ Other ________________________

**Q.9** Where do the custodians store the data?
- □ On premises
- □ Off premises

**Q.10** Is the data easily accessible? (For example, research purposes).
- □ Yes
- □ No

*If not, why? ________________________

### REPORTING

**Q.11** How often are the data received by the data repository/custodians?
- □ Within 12–24 hours
- □ Quarterly
- □ Other (please specify) ________________________
- □ Weekly
- □ Bi-annually
- □ Monthly
- □ Continuous submission

**Q.12** Is reporting of these data to the custodian a statutory requirement?
- □ Yes
- □ No
- □ Don’t know

*If yes, under which Act? (For example, Health Records Act 2001): ________________________

**Q.13** Is reporting of these data an administrative requirement? (For example, DHS Funding Policy Guidelines, WEIS)
- □ Yes
- □ No

*Comments: ________________________

**Q.14** Do you submit your data to a national or state database?
- □ Yes
- □ No

*If yes, please name the database: ________________________

### INDIGENOUS STATUS

**Q.15** Is an Indigenous identifier used?
- □ Yes
- □ No

**Q.16** Is it mandatory for vendors to populate the indigenous identifier field?
- □ Yes
- □ No

*If yes, when did it become mandatory? (Please provide year in which the identifier became mandatory) ________________________
Q.17 When is the Indigenous status entered?
☐ At the time of collection ☐ When the data is submitted to the custodian

Q.18 Are questions asked to determine the Indigenous status of a client/patient?
☐ Yes ☐ No

Q.19 If yes, what possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin?’
☐ Aboriginal but not Torres Strait Islander origin
☐ Torres Strait Islander but not Aboriginal origin
☐ Both Aboriginal and Torres Strait Islander origin
☐ Neither Aboriginal nor Torres Strait Islander origin
☐ Not stated/inadequately described
☐ Other (please specify)

Q.20 Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
☐ Yes ☐ No ☐ Don’t know

Q.21 What are the barriers to obtaining information about a person’s Indigenous status? (Multiple boxes may be ticked).
☐ Form not completed
☐ Indigenous patient may not feel comfortable declaring their status.
☐ Language barrier
☐ Service provider may not wish to appear to be discriminating.
☐ Administrative or medical staff may feel that the question is irrelevant.
☐ Administrative staff not comfortable asking the question.
☐ Administrative staff do not understand why the question is being asked.
☐ Administrative staff fear a negative response to question being asked.
☐ Other (please specify)

Q.22 Does your information system allow for the Indigenous status to be left blank at the time of collection?
☐ Yes ☐ No

Q.23 How confident are you that the Indigenous status is accurate?
☐ Very confident ☐ Confident ☐ Not confident ☐ Unsure

From what year would you be confident of accurate data collection? (Please specify year) __________ Year
DATA ACCESS

Q.24 How does one obtain access to these data?

Q.25 What ethics clearances are required to access your data?

Q.26 Do you have an access agreement outlining the conditions of access to your data base?

☐ Yes ☐ No

If yes, can you attach a condition of access agreement as an appendix?

☐ Yes ☐ No

Q.27 If no, what are the conditions of access to your database? (For example, storage, use, disposal, etc.)

Q.28 Are your data used for research purposes?

☐ Yes ☐ No

DATA STANDARDS

Q.29 Do you comply with data standards? (For example, Health Data Standards and System Unit)

☐ Yes ☐ No

Q.30 If yes, which data standards?

Q.31 Who enforces the standards?

Q.32 Does your organisation utilise a data dictionary?

☐ Yes ☐ No

If yes, who developed your data dictionary and did you base your definitions on an existing data dictionary? (For example, The National Health Data Dictionary)
DATA QUALITY

Q.33 How do you ensure data quality?

☐ Mandatory data fields
☐ Timely submission of data
☐ Staff education
☐ Timely entry of data
☐ Other (Please specify) ____________________________

☐ Benchmarking with other jurisdictions
☐ Audits to ensure accuracy and consistency
☐ Warning and error alerts
☐ Administrative staff follows up with client/guardian when forms are incomplete

Thank you for taking the time to complete this questionnaire.
Appendix 2
Preamble to questionnaire: A

Dear Sir,

We would be delighted if you would participate in a statewide assessment of Victorian statutory and administrative databases that capture data relating to infants, children and young adults with a particular emphasis on accurate identification of the Indigenous population.

There are a number of data sets in Victoria that describe the health and wellbeing of infants, children and young people. These databases vary in the data they collect, the ages included in the database, the period of data collection, the integrity of the data and accessibility and governance. In particular, the databases vary considerably in the inclusion, accuracy and completeness of data describing the Indigenous status of those included in the datasets.

The enclosed questionnaire will seek information that identifies the type, description and robustness of the variables that are included in the data sets. In particular, we will seek information that will allow us to establish the completeness and accuracy of Indigenous identification in these data sets with the aim of producing a monograph that describes the availability, accessibility and integrity of data for those working in the area of paediatric research.

The information that we collect will be collated and used for the purpose as stated above. You will receive a copy of the completed report.

We acknowledge that your time is extremely valuable and wish to take this opportunity to thank you for taking the time to complete the attached questionnaire.

If you have any further queries, do not hesitate to contact Sonya Sheridan on 03 8344 9336 or via email smsheridan@students.latrobe.edu.au or myself on 03 8344 9164 or via e-mail j.freemantle@unimelb.edu.au

Kind Regards

Associate Professor Jane Freemantle
Appendix 2
Preamble to questionnaire: B

Dear Sir,

We would be delighted if you would participate in a statewide assessment of Victorian statutory and administrative databases that capture data relating to infants, children and young adults with a particular emphasis on accurate identification of the Indigenous population.

There are a number of data sets in Victoria that describe the health and wellbeing of infants, children and young people. These databases vary in the data they collect, the ages included in the database, the period of data collection, the integrity of the data and accessibility and governance. In particular, the databases vary considerably in the inclusion, accuracy and completeness of data describing the Indigenous status of those included in the datasets.

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The information that we collect will be collated and used for the purpose as stated above. You will receive a copy of the completed report.

We acknowledge that your time is extremely valuable and wish to take this opportunity to thank you for taking the time to complete the attached questionnaire.

If you have any further queries, do not hesitate to contact Bree Heffernan on 03 8344 9336 or via email breeh@unimelb.edu.au or myself on 03 8344 9164 or via e-mail j.freemantle@unimelb.edu.au

Kind Regards

C. Jane Freemantle

Associate Professor Jane Freemantle

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Datasets collecting health and mortality data on Victorian Aboriginal (and non-Aboriginal) infants, children and young people

### Appendix 3:

Datasets collecting health and mortality data on Victorian Aboriginal (and non-Aboriginal) infants, children, and young people

**Victorian State Government**
- Department of Justice (DoJ)
- Department of Human Services (DHS)
- Consultative Council on Obstetric & Paediatric Mortality and Morbidity, Health Act 1988 (VIC)
- Department of Education & Early Childhood Development (DEECD)
- Medicare Australia
- Australian Bureau of Statistics (ABS)
- Australian Institute of Health and Welfare
- Cancer Council Victoria
- The University of Melbourne

**Commonwealth Government**
- Victorian Registry of Births
- Victorian Registry of Deaths
- Victorian Institute of Forensic Medicine
- National Coroners Information System
- Australian Childhood Immunisation Register
- *Victorian Child and Maternity Services*
- *Bettering the Evaluation and Care of Health Survey (BEACH)*

**Other**
- *Population and Housing Census*
- *National Aboriginal and Torres Strait Islander Health Survey*

- Victorin Perinatal Data Collection
- Consultative Council on Paediatric & Obstetric Mortality & Morbidity
- Victorian Birth Defects Register
- Victorian Cancer Registry
- Australian Twin Registry
- Australian Institute of Health and Welfare
- *Victorian Population Health Survey*
- Department of Human Services (DHS)
- Consultative Council on Obstetric & Paediatric Mortality and Morbidity
- Victorian Admitted Episodes Dataset
- Victorian Emergency Minimum Dataset
- Aboriginal Hospital Liaison Officer Collection

- Alcohol & Other Drug Information System
- Operational Data Store: Mental Health Client Management Interface
- Child Dentistry Register
- Primary Health Dataset
- Notification of Infectious Diseases
- *Victorian Population Health Survey*
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
Responses to the question ‘What data are captured in this database?’ by dataset

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Mother</th>
<th>Baby</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous Demographic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Smoking</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Delivery</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Death</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Employment</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Indigenous</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Demographic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Smoking</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Employment</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Indigenous</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Demographic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Smoking</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Employment</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection (births)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection (hospitalisations &amp; deaths)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Consultative Council on Obstetric &amp; Paediatric Mortality &amp; Morbidity</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Dental Health Program</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Country of birth only</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Operational Data Store (Mental Health Client Management Interface)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Primary Health Data Collection v4.01</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset (birth episode)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Appendix 4: Responses to the question ‘What data are captured in this database?’ by dataset
### Responses to the question ‘What data are captured in this database?’ by dataset (cont.)

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Data Captured (pre-defined list)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Victorian Admitted Episodes</td>
</tr>
<tr>
<td></td>
<td>Victorian Birth Defects Register</td>
</tr>
<tr>
<td></td>
<td>Victorian Cancer Registry</td>
</tr>
<tr>
<td></td>
<td>Victorian Emergency Minimum</td>
</tr>
<tr>
<td></td>
<td>Minimum Dataset</td>
</tr>
<tr>
<td></td>
<td>Victorian Perinatal Data</td>
</tr>
<tr>
<td></td>
<td>Collection</td>
</tr>
<tr>
<td></td>
<td>Victorian Registry of Births</td>
</tr>
<tr>
<td></td>
<td>Victorian Registry of Deaths</td>
</tr>
<tr>
<td></td>
<td>(Death registration statement)</td>
</tr>
<tr>
<td></td>
<td>Victorian Registry of Deaths</td>
</tr>
<tr>
<td></td>
<td>(Medical certificate of cause of</td>
</tr>
<tr>
<td></td>
<td>death)</td>
</tr>
<tr>
<td></td>
<td>Victorian Registry of Deaths</td>
</tr>
<tr>
<td></td>
<td>(Perinatal certificate of cause of death)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 5:

**Responses to the question 'How confident are you that the Indigenous status is accurate?' by dataset**

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Confidence</th>
<th>Other/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection</td>
<td>Not confident</td>
<td>Very confident from 1988. There is a high degree of confidence in the accuracy of Indigenous identification in data submitted by AHLOs. Confidence in the level of coverage varies depending on the submitting hospital, the location and size of the hospital and the AHLOs period/s of leave.</td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>Not confident</td>
<td>Confident from 2001.</td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>Confident</td>
<td>Participants can supply as much or as little information regarding ethnicity and medical conditions as they feel comfortable. Confident from 1980.</td>
</tr>
<tr>
<td>Birth Defects Register</td>
<td>Confident</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Consultative Council on Obstetric &amp; Paediatric Mortality &amp; Morbidity</td>
<td>Confident</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Dental Health Program</td>
<td>Not confident</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>Confident</td>
<td>Not confident.</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>Confident</td>
<td>Some jurisdictions are considered to be quite accurate whilst others require attention. This is mainly due to a lack of the indigenous question on the police report of death in certain jurisdictions.</td>
</tr>
<tr>
<td>Operational Data Store (Mental Health Client Management Interface)</td>
<td>Confident</td>
<td>Not confident.</td>
</tr>
<tr>
<td>Perinatal Data Collection</td>
<td>Confident</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Primary Health Data Collection v4.01</td>
<td>Not confident</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset</td>
<td>Confident</td>
<td>Confidence varies depending on the collecting hospital. The coverage of Indigenous status tends to vary according to the size of the local Aboriginal population and the geographic location.</td>
</tr>
<tr>
<td>Victorian Cancer Registry</td>
<td>Confident</td>
<td>Unsure. for cancers frequently treated outside the hospital setting (e.g. Melanoma), there is little information submitted. For cancers treated in hospital, VCR data is as complete as that of the treating hospital.</td>
</tr>
<tr>
<td>Victorian Emergency Minimum Dataset</td>
<td>Confident</td>
<td>Confidence varies depending on the collecting hospital. The coverage of Indigenous status tends to vary according to the size of the local Aboriginal population and the geographic location.</td>
</tr>
<tr>
<td>Victorian Registry of Births</td>
<td>Confident</td>
<td>Information is provided by the child's parent/s and is presumed to be accurate. Further information is sought if there is a reason to query the data.</td>
</tr>
<tr>
<td>Victorian Registry of Deaths</td>
<td>Confident</td>
<td>Information is usually provided by the deceased's next of kin and as such is presumed to be accurate.</td>
</tr>
</tbody>
</table>
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
### Responses to the question “What are the barriers to obtaining information about a person’s Indigenous status?” by dataset

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Barriers (pre-defined list)</th>
<th>Other/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection</td>
<td>✅  ✅  ✅  ✅  ✅  ✅</td>
<td>AHLOs in part rely on the information collected by admission staff. Some Aboriginal patients who do not want to see the AHLO may not identify themselves as Indigenous for that reason.</td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>✅</td>
<td></td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>✅</td>
<td>Twins or guardian do not wish to identify as being of Aboriginal or Torres Strait Islander descent.</td>
</tr>
<tr>
<td>Consultative Council on Obstetric and Paediatric Mortality and Morbidity</td>
<td>✅</td>
<td>The VPDCU believes there to be under-reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.</td>
</tr>
<tr>
<td>Dental Health Program</td>
<td>✅</td>
<td></td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>✅  ✅</td>
<td>Additional barriers unknown.</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>✅  ✅</td>
<td>The main identifying source of this information is deceased and it is not always possible to obtain information from a reliable source. Police may not feel comfortable asking the question of a grieving family.</td>
</tr>
<tr>
<td>Operational Data Store</td>
<td>✅  ✅  ✅  ✅  ✅  ✅</td>
<td></td>
</tr>
</tbody>
</table>
## Responses to the question ‘What are the barriers to obtaining information about a person’s Indigenous status?’ by dataset (cont.)

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Barriers (pre-defined list)</th>
<th>Other/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Health Data Collection</td>
<td>Form not completed, Indigenous person may not feel comfortable declaring their status, Language barrier, Service provider may not wish to appear to be discriminating</td>
<td>The custodian’s work area cannot respond on the behalf of agencies.</td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset</td>
<td>✓</td>
<td>Time pressures on administrative staff.</td>
</tr>
<tr>
<td>Victorian Birth Defects Register</td>
<td>✓</td>
<td>The Victorian Perinatal Data Collection Unit (VPDCU) believes there to be under-reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.</td>
</tr>
<tr>
<td>Victorian Cancer Registry</td>
<td>✓</td>
<td>Data submitted to VCR may be incomplete or inaccurate depending on the source.</td>
</tr>
<tr>
<td>Victorian Emergency Minimum Dataset</td>
<td>✓</td>
<td>Time pressures on administrative staff.</td>
</tr>
<tr>
<td>Victorian Perinatal Data Collection</td>
<td>✓</td>
<td>The VPDCU believes there to be under-reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.</td>
</tr>
<tr>
<td>Victorian Registry of Births</td>
<td>✓</td>
<td>The Birth Registration Statement requires self-identification by the parent/s as to their Indigenous status.</td>
</tr>
<tr>
<td>Victorian Registry of Deaths</td>
<td>✓</td>
<td>Information regarding a person’s Indigenous status is obtained from the medical practitioner, who may not be in a position to know, and from the informant (via the funeral director). If the informant is not a relative of the deceased, they may not know the deceased’s Indigenous status.</td>
</tr>
</tbody>
</table>
### Appendix 7: Responses to the question 'How do you ensure data quality?' by dataset

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Methods (pre-defined list)</th>
<th>Other/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>･</td>
<td>Verification with online applicants to ensure that data are accuracy and consent is legitimate.</td>
</tr>
<tr>
<td>Child Dentistry Register</td>
<td>✓</td>
<td>Reminder alerts.</td>
</tr>
<tr>
<td>Consultative Council on Obstetric &amp; Paediatric Mortality &amp; Morbidity</td>
<td>✓</td>
<td>User manuals.</td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>✓</td>
<td>Quality Reports provided back to coders in feedback loop and requirement to amend incorrect coding. Support phone/email for coding questions, coder tips newsletter and coding manual.</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Operational Data Store (Mental Health Client Management Interface)</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Primary Health Data Collection</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Victorian Admitted Episodes Dataset</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Victorian Birth Defects Register</td>
<td>✓</td>
<td>User manuals.</td>
</tr>
<tr>
<td>Victorian Cancer Registry</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Victorian Emergency Minimum Dataset</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Victorian Perinatal Data Collection</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Victorian Registry of Births</td>
<td>✓</td>
<td>Data quality is ensured by cross checking records and making further inquiries where necessary.</td>
</tr>
<tr>
<td>Victorian Registry of Deaths</td>
<td>✓</td>
<td>Data quality is ensured by cross checking records and making further inquiries where necessary.</td>
</tr>
</tbody>
</table>
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
### Guidelines for access and ethical clearances, by dataset

<table>
<thead>
<tr>
<th>Dataset</th>
<th>How does one gain access to these data?</th>
<th>What ethics clearances are required to access your data?</th>
<th>Access agreement available?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Hospital Liaison Officer Collection</td>
<td>By request from the data custodian.</td>
<td>Raw data will be released if ethics approval is obtained through a properly constituted Ethics Committee process.</td>
<td>No</td>
</tr>
<tr>
<td>Alcohol and Other Drug Information System</td>
<td>By application to the Mental Health and Drugs Division, Department of Human Services.</td>
<td>Ethics clearance is required only if data are requested that could lead to potential identification of a client. Aggregated, de-identified data can be provided without ethics clearance.</td>
<td>No</td>
</tr>
<tr>
<td>Australian Twin Registry</td>
<td>By contacting the ATR and following the application procedure as per the Application Approval Flowchart.</td>
<td>Approval from your organisation's Human Ethics Research Committee (HREC) must be provided, however, all requests must be approved by the ATR.</td>
<td>Yes</td>
</tr>
<tr>
<td>Child Dentistry Register</td>
<td>From DHS according to DHS guidelines, this data is limited and would not be appropriate for population studies or making generalisations.</td>
<td>That depends on what it would be used for.</td>
<td>Normal DHS processes</td>
</tr>
<tr>
<td>Consultative Council on Obstetric and Paediatric Mortality and Morbidity</td>
<td>All requests for unpublished information must be put in writing to CCOPMM.</td>
<td>Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted HREC must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.</td>
<td>Yes</td>
</tr>
<tr>
<td>Health (Infectious Diseases) Regulations, 2001</td>
<td>For non-published data there is a data request procedure. See attached Data Request Form.</td>
<td>If data are requested for research purposes then an ethics clearance is required.</td>
<td>Yes</td>
</tr>
<tr>
<td>National Coroners Information System</td>
<td>De-identified data in aggregate can be requested from the data custodian and released subject to approval by the relevant Coroner's Office. Applications for direct access to the data must also be approved by an ethics committee and there is soon to be an Indigenous Reference Group.</td>
<td>The applicant must first go through his/her institution's ethics committee before completing the Department of Justice Application Form. All applications submitted to the NOS are reviewed by the NCIS Research Committee before being forwarded to the Department of Justice HREC. All applications are required to be approved by the Victorian Department of Justice HREC. If applying to access NSW identifying data, or WA data, additional ethics committee approval may need to be obtained.</td>
<td>Yes</td>
</tr>
<tr>
<td>Operational Data Store (Mental Health Client Management Interface)</td>
<td>By application to the Manager, Information, Analysis and Reporting Unit, Mental Health and Drugs Division, DHS.</td>
<td>Ethics approval is required for access to any identifiable data.</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary Health Data Collection</td>
<td>With a written request including a business/research case for the use of the data.</td>
<td>Depending on the level of information required, ethics clearance may be required. Advice would be provided on receipt of a request.</td>
<td>Standard DHS data access agreements are used.</td>
</tr>
</tbody>
</table>
### Guidelines for access and ethical clearances, by dataset (cont.)

<table>
<thead>
<tr>
<th>Dataset</th>
<th>How does one gain access to these data?</th>
<th>What ethics clearances are required to access your data?</th>
<th>Access agreement available?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victorian Admitted Episodes Dataset</td>
<td>By written request to the data custodian providing full details of the use to which data would be put, together with a list of all data items required. Authorisation is not automatic.</td>
<td>Formal approval is required from a fully constituted HREC for all research proposals.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Birth Defects Register</td>
<td>All requests for unpublished information must be put in writing to CCOPMM.</td>
<td>Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted HREC must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Cancer Registry</td>
<td>Access to VOR data can be obtained via the data custodian.</td>
<td>The custodian will release aggregated data upon request. Requests for identified data about cancer patients must be approved by the HREC.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Emergency Minimum Dataset</td>
<td>By written request to the data custodian providing full details of the use to which data would be put, together with a list of all data items required. Authorisation is not automatic.</td>
<td>Formal approval is required from a fully constituted HREC for all research proposals.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Perinatal Data Collection</td>
<td>All requests for unpublished information must be put in writing to CCOPMM.</td>
<td>Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted HREC must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Registry of Births</td>
<td>Access to these data can be obtained via the data custodian. The RBDM maintains an Access Policy as required under the Births, Deaths and Marriages Registration Act and applicants are required to meet the conditions outlined therein.</td>
<td>Approval from the applicant’s HREC must be provided, however, all requests for access by medical researchers to restricted records must also be approved by the Registrar.</td>
<td>Yes</td>
</tr>
<tr>
<td>Victorian Registry of Deaths</td>
<td>Access to these data can be obtained via the data custodian. The RBDM maintains an Access Policy as required under the Births, Deaths and Marriages Registration Act and applicants are required to meet the conditions outlined therein.</td>
<td>Approval from the applicant’s HREC must be provided, however, all requests for access by medical researchers to restricted records must also be approved by the Registrar.</td>
<td>Yes</td>
</tr>
</tbody>
</table>
## Appendix 9: Summary

This appendix contains 16 datasets: each with a questionnaire completed by the data custodian and related attachments and weblinks.

<table>
<thead>
<tr>
<th>Dataset A</th>
<th>Aboriginal Hospital Liaison Officer Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Information on Koori Mothers and Babies (notification form)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dataset B</th>
<th>Alcohol and Other Drug Information System</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dataset C</th>
<th>Australian Twin Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fees Incurred for Use of Facility</td>
</tr>
<tr>
<td></td>
<td>Application Approval Flowchart</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.twins.org.au">www.twins.org.au</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dataset D</th>
<th>Consultative Council on Obstetric and Paediatric Mortality and Morbidity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Birth Report Form A (from 2009)</td>
</tr>
<tr>
<td></td>
<td>Clinical Councils Unit: Data release policy 1.0</td>
</tr>
<tr>
<td></td>
<td>Application for the release of data from CCOPMM</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dataset E</th>
<th>Dental Health Program</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dataset F</th>
<th>Health (Infectious Diseases) Regulations, 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Standard Notification of Infectious Disease form</td>
</tr>
<tr>
<td></td>
<td>Communicable Diseases Data Request Form</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dataset G</th>
<th>National Coroners Information System</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Existing Police Notification Form</td>
</tr>
<tr>
<td></td>
<td>Proposed Police Notification Form</td>
</tr>
<tr>
<td></td>
<td>NCIS Information Sheet 2009</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.ncis.org.au">www.ncis.org.au</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dataset H</th>
<th>Operational Data Store (Mental Health Client Management Interface)</th>
</tr>
</thead>
</table>
### Dataset I
**Primary Health Dataset**

### Dataset J
**Victorian Admitted Episodes Dataset**

### Dataset K
**Victorian Birth Defects Register**
- Birth Defects Notification Form
- Birth Report Form A (from 2009)
- Application for the release of data from CCOPMM
- Clinical Councils Unit: Data release policy 1.0

### Dataset L
**Victorian Cancer Registry**
- Victorian Cancer Registry Notification Form (Cancer Act 1958)
  www.cancervic.org.au

### Dataset M
**Victorian Emergency Minimum Dataset**

### Dataset N
**Victorian Perinatal Data Collection**
- Birth Report Form A (from 2009)
- Clinical Councils Unit: Data release policy 1.0
- Application for the release of data from CCOPMM

### Dataset O
**Victorian Registry of Births**
- Variables included in the Victorian Birth Registry
- BDM Research Access Policy

### Dataset P
**Victorian Registry of Deaths**
- Death Registration Statement (excerpt)
- Medical Certificate of Cause of Perinatal Death (excerpt)
- Medical Certificate of Cause of Death of a person aged 28 days or older (excerpt)
- BDM Research Access Policy

*Note: Forms and policies common to the VPDC, VBDR & CCOPMM are repeated.*
Appendix 9: Datasets

Dataset A: Aboriginal Hospital Liaison Officer Collection

CUSTODIAN
Custodian: Koori Human Services Unit, Department of Human Services
Name: Mary Sullivan
Position/job title: Senior Project Officer
Phone: 03 9096 7240
Email Address: mary.sullivan@dhs.vic.gov.au

SUMMARY
The Koori Human Services Unit (KHSU) collects information on births, deaths and hospitalisations. A monthly Aboriginal Hospital Liaison Officer (AHLO) report is provided to the KHSU. A form is completed for every Aboriginal admission (collected up to and including 2006/07) and information on births is provided on a separate form. Information regarding Aboriginal deaths is provided to the KHSU on a voluntary basis on a third form.

Data collected in the Aboriginal Hospital Liaison Officer Collection (AHLOC) is primarily used to validate the collection of the Indigenous identifier in other datasets such as the Victorian Admitted Episodes Dataset.

DATA COLLECTION
What data are captured in this database?

i) Births:
Information collected in the event of a birth:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Demographic information</td>
</tr>
<tr>
<td>Pregnancy information</td>
<td>Birth information</td>
</tr>
<tr>
<td>Delivery information</td>
<td>Delivery information</td>
</tr>
</tbody>
</table>

See attached for a copy of the Information on Koori Mothers and Babies AHLO collection form.
ii) **Deaths**

Information collected when the deceased is a child:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death information</td>
<td></td>
</tr>
</tbody>
</table>

iii) **Hospitalisations (collected until 2006/07):**

Information collected for a hospitalised child:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
</tbody>
</table>

**Does the database include identifying information?**

- Yes, identifying information regarding Aboriginal deaths is provided to KHSU voluntarily and can include the name and age of the deceased and location of death.
- Identifying information is not collected for births or hospitalisations.

**How are the primary data collected?**

- Forms are completed by AHLOs from information collected during patient interview and from hospital patient records.

**When are the data collected?**

- Data are collected by AHLOs before, during and after an episode of care.

**How do the custodians obtain the data that are included in the database?**

- Data are submitted to the data custodian by AHLOs located in Victorian public hospitals either electronically or in paper based format.

**Who are the external entities?**

- AHLOs, hospital administration, and midwifery staff.

**STORAGE AND ACCESSIBILITY**

**In what format do the custodians store the data?**

- Electronically in a Microsoft Access database and in paper form.

**Where do the custodians store the data?**

- Data are stored on the premises at the Department of Human Services, 50 Lonsdale Street, Melbourne, Victoria, 3000.

**Are the data easily accessible?**

- Yes.
Is there a cost involved in accessing the data?
• No.

REPORTING

How often are the data received by the data repository/custodians?
• Data are reported by AHLOs to the data custodian on a monthly basis.

Is reporting of these data to the custodian a statutory requirement?
• No, however, collection of data is governed by the Health Records Act (2001).

Is reporting of these data an administrative requirement?
• No, reporting of these data is not included in the Department of Human Services Funding and Policy Guidelines. However, reporting of these data is included in AHLO position descriptions. Data on Aboriginal deaths are provided as a courtesy, not under obligation.

Do you submit your data to a national or state database?
• No, however, Aboriginal death data are reported to the Australian Bureau of Statistics for verification purposes.

INDIGENOUS STATUS

Is an Indigenous identifier used?
• Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
• Yes, Indigenous status is mandatory on the online mother and baby form.

When did it become mandatory for vendors to populate the Indigenous identifier field?
• 1988.

When is the Indigenous status entered?
• At the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?
• Yes.

What possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin’?
• Yes / no.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
• Yes.
What are the barriers to obtaining information about a person's Indigenous status?

- Aboriginal patients may not feel comfortable declaring their status to administrative staff.
- Administrative or medical staff may feel that the question is irrelevant.
- Administrative staff may not feel comfortable asking the question.
- Administrative staff do not understand why the question is being asked.
- Administrative staff fear a negative response to question being asked.

AHLOs in part rely on the information collected by admission, pre-admission and Emergency Department administrative staff. They may also identify Aboriginal patients by sight in the hospital or by name off an admission list. Some Aboriginal patients who do not want to see the AHLO may not identify themselves as Indigenous for that reason.

Does your information system allow for the Indigenous status to be left blank at the time of collection?

- Yes, when information is collected by the AHLO manually on a hard copy form.

How confident are you that the Indigenous status is accurate?

- Very confident. There is a high degree of confidence in the accuracy of Indigenous identification in data submitted by AHLOs. Confidence in the level of coverage varies depending on the submitting hospital, the location and size of the hospital and the AHLOs period/s of leave.

From what year would you be confident of accurate data collection?


ACCESS TO DATA

How does one obtain access to these data?

- By request from the data custodian.

What ethics clearances are required to access your data?

- The custodian will release aggregated data on approval of the source and purpose of the request.
- Raw data will be released if ethics approval is obtained through a properly constituted Ethics Committee process.

Do you have an access agreement outlining the conditions of access to your data base?

- No.

If no, what are the conditions of access to your database?

- Data must be held in a separate stand alone database.
- Data can only be utilised on site at the Department of Human Services.
- Data must be disposed of after use.
- Data must not be reported without prior authority of the Custodian.
Are your data used for research purposes?
• Yes.

DATA STANDARDS

Do you comply with data standards?
• No.

Does your organisation utilise a data dictionary?
• Yes, based on the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
• Mandatory data fields on eforms.
• External entities submit data in a timely manner.
• Staff education.
• Audits to ensure accuracy and consistency.
INFORMATION ON KOORI MOTHERS AND BABIES

A) MOTHER (Koori mothers only)
This section must be completed for all Aboriginal and Torres Strait Islander mothers.

Month (actual month of birth) 
Year 

1) AHLO Hospital

2) Is mother recorded as Koori by Hospital
   □ Yes □ No

3) Age(mother)

4) Admission date

5) Did mother receive antenatal care
   □ Yes □ No □ Few

6) Does mother have any obstetric complications/medical conditions?
   If yes, please select from options:(Allows for multi selection)
   - Premature rupture of membranes
   - Pre-eclampsia
   - Diabetes
   - Cardiac disease
   - Chronic Renal Disease
   - Hypertension
   - Other
   If other is selected, please state other conditions:

7) Type of Birth
   □ Spontaneous cephalic
   □ Elective Caesarean
   □ Emergency Caesarean
   □ Vaginal Breech
   □ Other
   If 'other' is selected, please specify.

8) Date of discharge (Mother)

9) Discharge status (Mother)
   □ Home □ Transfer
   If transfer, please state place of transfer
   Reason for transfer

10) Has mother/liaison officer contacted the MCHN?
   □ Yes □ No □ Unknown

11) Is this mother’s first born?
   □ Yes □ No

Previous Pregnancies: (Excluding this pregnancy)
12) How many other births/children has mother had?
Please complete a separate form for each baby of multiple birth

**B.BABY (All Babies with a Koori mother and/or father)**

13) Hospital of Birth (actual place of delivery)

Actual place of birth, please state if:  □ Intended (planned)  □ Emergency

14) Gestation (weeks) □ <32     □ 32-36     □ 37-40     □ =41

15) Date of birth

16) Is mother Koori?  □ Yes     □ No

17) Is father Koori?  □ Yes     □ No     □ Unknown

18) Did the hospital record the baby as Koori?  □ Yes     □ No     □ Unknown

19) Plurality  □ Single     □ Twins     □ Other

If 'other' is selected, specify other plurality

20) Sex  □ Male     □ Female     □ Indeterminate

21) Birthweight (grams)

22) Condition  □ Liveborn     □ Stillborn     □ Neonatal death

If stillborn, write mother's initials

23) Does the baby have any birth defect or neonatal morbidity or illness  □ Yes     □ No

If yes, please state birth defect/neonatal morbidity

Birth defect

Neonatal Morbidity

24) Discharge Date

25) Discharge status (baby)  □ Home     □ Transfer     □ Other

If transfer, please state place of transfer
Appendix 9

Dataset B: Alcohol and Other Drug Information System

CUSTODIAN

Custodian: Mental Health and Drugs Division, Department of Human Services
Name: Rob Knight
Position/job title: Senior Information Analyst
Phone: 03 9096 0000
Email Address: Rob.knight@dhs.vic.gov.au

SUMMARY

The Alcohol and Drug Information System (ADIS) is a collection of all Victorian government funded drug treatment services data. This includes:

- client socio-demographic and geographic data
- drug treatment data
- drink drive data
- brokerage data
- Primary Health Service data
- secondary consultation data.

Data are submitted to DHS via a range of data collection systems used to monitor agency performance. Together with other information, this collection is used extensively to inform service planning and policy development.

DATA COLLECTION

What data are captured in this database?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Birth information</td>
<td></td>
</tr>
</tbody>
</table>

Note: Indigenous status, demographic or birth information is captured for the client only. No information is captured regarding other members of the family unit. Information is based on courses of treatment and not the client per se.
Does the database include identifying information?
- No, the data extracts provided to DHS from the collection systems do not include identifying information.

How are the primary data collected?
- Quarterly extracts from the agency AoD treatment system is performed and forwarded to DHS.

When are the data collected?
- Before and during an episode of care.

How do the custodians obtain the data that are included in the database?
- Data are obtained from external entities via Emzil.

Who are the external entities?
- Agencies providing treatment to clients who have a drug problem, or are looking to stop or reduce their alcohol or drug use.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- Data are stored electronically.

Where do the custodians store the data?
- On the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000.

Are the data easily accessible?
- Yes.

Is there a cost involved in accessing the data?
- No.

REPORTING

How often are the data received by the data repository/custodians?
- Data are received quarterly.

Is reporting of these data to the custodian a statutory requirement?
- No.

Is reporting of these data an administrative requirement?
- Yes, to ensure that AoD treatment agencies are meeting State and Commonwealth AoD treatment targets.

Do you submit your data to a national or state database?
- Yes, to the Alcohol and Other Drug Treatment System National Minimum Dataset (AODTS–NMDS).
INDIGENOUS STATUS

Is an Indigenous identifier used?
• Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
• Yes.

When did it become mandatory for vendors to populate the Indigenous identifier field?
• Not known.

When is the Indigenous status entered?
• At the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?
• Yes.

What possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin?’
• Aboriginal but not Torres Strait Islander origin.
• Torres Straight Islander but not Aboriginal origin.
• Both Aboriginal and Torres Strait Islander origin.
• Neither Aboriginal nor Torres Strait Islander origin.
• Not stated/inadequately described.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
• Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
• Indigenous patient may not feel comfortable declaring their status.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
• No.

How confident are you that the Indigenous status is accurate?
• Confident.

From what year would you be confident of accurate data collection?
• 2001.
ACCESS TO DATA

How does one obtain access to these data?
- By application to the Mental Health and Drugs Division, Department of Human Services.

What ethics clearances are required to access your data?
- Ethics clearance is required only if data are requested that could lead to potential identification of a client. Aggregated, de-identified data can be provided without ethics clearance.

Do you have an access agreement outlining the conditions of access to your data base?
- No.

If no, what are the conditions of access to your database?
- Information provided is the property of DHS.
- Reproduction of any part, or all of the data provided, is not permitted without appropriate authorisation.

Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards?
- Yes, National Health Data Standards where applicable.

Who enforces the standards?
- Self-enforced.

Does your organisation utilise a data dictionary?
- Yes, based on the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
- Mandatory data fields
- Staff education
- Audits to ensure accuracy and consistency
- Warning and error alerts.
SUMMARY

The Australian Twin Registry (ATR) is a not-for-profit organisation which facilitates and supports medical and scientific studies that involve the participation of twins and that use the special characteristics of twins to enable questions of health and wellbeing relevant to Australians to be answered in ways that they otherwise could not.

In order to facilitate these studies, the ATR maintains a national register of twin pairs who are willing to consider participating in health related research. Twins are able to help researchers study the impact of genetic and environmental factors on health and the treatment and prevention of disease in a special way.

The ATR is funded by the federal government through the National Health and Medical Research Council in order to put researchers in touch with twins who might be willing to take part in particular projects. More than 31,000 pairs of twins have joined the Registry, making it the largest volunteer registry of its kind in the world.

DATA COLLECTION

What data are captured in this database?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic info</td>
<td>Demographic info</td>
<td>Demographic info</td>
</tr>
<tr>
<td>Birth info</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity (from 2005)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Does the database include identifying information?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name</td>
<td>Name</td>
</tr>
<tr>
<td>Spouse or partner’s name</td>
<td>Address, phone number, email, mobile number</td>
<td>Date of birth</td>
</tr>
</tbody>
</table>

How are the primary data collected?
- A registration form is completed by the parent when the twins are under the age of 18 years.
- A registration form is completed by both twins when they are over the age of 18 years. Both twins must consent to join the register.

When are the data collected?
- After the birth of the twins.

How do the custodians obtain the data that are included in the database?
- Data are obtained from the guardian or the twins in a paper based twin registration form.
- A twin registration form is completed over the internet. A staff member from the ATR follows up with the twins or guardian to confirm details.

Who are the external entities?
- The guardian of the twins or the twins themselves when over the age of 18 years.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- Electronic. Forms submitted in hard copy are scanned for backup once entered into the database.

Where do the custodians store the data?
- Data are stored on premises at the Australian Twin Registry, Centre for MEGA Epidemiology, School Population Health, The University of Melbourne, Lvl 1, 723 Swanston St, Melbourne 3010.

Are the data easily accessible?
- Yes.

Is there a cost involved in accessing the data?

REPORTING

How often are the data received by the data repository/custodians?
- Reporting is not mandatory. This is a voluntary register.
Is reporting of these data to the custodian a statutory requirement?
• No.

Is reporting of these data an administrative requirement?
• No.

Do you submit your data to a national or state database?
• No, the ATR is the national database.

INDIGENOUS STATUS

Is an Indigenous identifier used?
• No, however, ethnicity has been included as a voluntary field since 2005.

Is it mandatory for vendors to populate the Indigenous identifier field?
• No.

When did it become mandatory for vendors to populate the Indigenous identifier field?
• Not applicable.

When is the Indigenous status entered?
• If the Aboriginality of the twins is reported, the status is entered into the database within approximately seven to fourteen days of receiving the information.

Are questions asked to determine the Indigenous status of a client/patient?
• No.

What possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin?’
• Not applicable.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
• Not applicable.

What are the barriers to obtaining information about a person’s Indigenous status?
• The twins or guardian do not wish to identify as being of Aboriginal or Torres Strait Islander descent.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
• Not applicable.

How confident are you that the Indigenous status is accurate?
• Confident. The participants can supply as much or as little information regarding ethnicity and medical conditions as they feel comfortable.
From what year would you be confident of accurate data collection?
- 1980.

**ACCESS TO DATA**

How does one obtain access to these data?
- By contacting the ATR and following the application procedure as per the Application Approval flowchart, see attached or: <http://www.twins.org.au/files/ATR_App_Process_Flowchart.pdf>
- Applications require an expression of interest form in the first instance and an ATR Full Application Form following initial approval. See: How to approach the ATR about a study: <http://www.twins.org.au/index.php?page=58>
- All requests to use the ATR are carefully reviewed. Approved projects must satisfy ethical guidelines and be of significant value to the area of proposed research.

What ethics clearances are required to access your data?
- Approval from your organisation’s Human Ethics Research Committee must be provided, however, all requests must be approved by the ATR.

Do you have an access agreement outlining the conditions of access to your data base?

Are your data used for research purposes?
- Yes.

**DATA STANDARDS**

Do you comply with data standards?
- No.

Does your organisation utilise a data dictionary?
- No.

**DATA QUALITY**

How do you ensure data quality?
- Staff education.
- Timely entry of data.
- Audits to ensure accuracy and consistency.
- Administrative staff follow-up with the twins or guardian when forms are incomplete.
- Verification with online applicants to ensure that data are accuracy and consent is legitimate.
### Application Approval Procedure

**Please Note:** This is a sequential procedure - parties cannot move forward until previous item finished.

#### Preliminary Discussion

Researchers are encouraged to consider early discussion with ATR Management, Director, Deputy Director, Coordinator, Project Support. This process can be very useful to explore possible twin models, available cohorts, existing data. The ATR can also provide details regarding sample availability, assistance in drafting approach documentation, discussion regarding possible limitations and advice regarding methodology. Communication can occur via telephone, teleconference, face to face meeting or email.

![Diagram of Application Approval Procedure](image)

<table>
<thead>
<tr>
<th>Expression of Interest (EoI) submitted to ATR</th>
<th>ATR determines availability of resources and suitability of study in use registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATR provides 'In Principle' Approval</td>
<td>ATR provides letter outlining reasons &amp; options for resubmission</td>
</tr>
</tbody>
</table>

#### Exploration of Fund

The ATR encourages collaboration regarding development of study methodology, approach documentation, questionnaires etc.

The ATR can also provide a letter to attach to Grant Application, provide assistance in developing sections of Grant Applications and provide assistance in drafting ethics submissions.

<table>
<thead>
<tr>
<th>Researcher prepares and submits funding application to NHMRC or other funding body</th>
<th>ATR collaborates with researcher to complete Full ATR Application in Confidence (incl. copy of Grant Application if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>If Applicable: Researcher forwards copies of Grant Application Review comments to ATR</td>
</tr>
<tr>
<td></td>
<td>If Applicable: Researcher receives notification of funding</td>
</tr>
</tbody>
</table>

#### Full Application Review

<table>
<thead>
<tr>
<th>Reviewers document outstanding issues.</th>
<th>ATR forwards correspondence to researchers outlining outstanding issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATR collaborates with ATR to solve issues identified in Review Process</td>
<td>ATR collaborates with Researchers to finalise Approach Materials and Logistics</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interactive process</th>
<th>Funding Successful</th>
<th>Funding Not Successful</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>ATR provides approval of Full Application pending Ethics Approval</th>
<th>ATR provides letter outlining reasons &amp; options for resubmission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved</td>
<td>Not Approved</td>
</tr>
</tbody>
</table>

#### Ethics Approval

<table>
<thead>
<tr>
<th>Researcher submits Ethics Application to own Institutional Ethics Committee</th>
<th>ATR collaborates with Researchers to complete Ethics Submission to Uni of Melb HREC</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATR collaborates with Researchers to solve issues identified in Ethics Application Process</td>
<td>Notification of Ethics Committee(s) approval</td>
</tr>
</tbody>
</table>

**An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People**

The Australian Twin Registry is supported by an Enabling Grant from the National Health & Medical Research Council, and administered by The University of Melbourne.
Australian Twin Registry Policy
Fees Incurred for Use of Facility

Version 1.05
Publication Date: 27 January 2009

Purpose
The Australian Twin Registry (ATR) charges researchers for the cost of mailing out and follow up of potential study participants.

Set Up and Administration Fees
A one-off set up fee of $165 - $275 is charged, the amount depending on the logistics and complexity of the study. This covers set up of the study on the ATR database and general administration required to begin recruitment.

Mail Out Costs
Administration fees are charged as 3 hours per 100 approaches at $38.50 per hour. This charge covers labour required to select potential participants, create database mailout files, print, photocopy, collate, fold and insert approach documentation and sort ready for bulk mailing. Mailout materials and postage are charged on a cost recovery basis. Approach packages are tailored to meet the specific requirements of the researcher.

Reply Paid
Researchers are charged the cost of Reply Paid postage per mail response returned. This charge averages $25 - $75 per 100 letters sent depending on the response rate.

Response Processing
This task includes opening and sorting mail related to the study, logging the ATR member’s response, entering any special requirements defined by the member (i.e. specific times to contact, interest in participation in specific phases of the study) and filing ready for end of week reporting. This is charged at the administration rate of $38.50 per hour. Time taken to complete this activity per study is logged for invoicing purposes.

Follow Up Letters
Follow up letters are charged as above, and costs for this largely depend on the initial total response rate and the researchers own timeframes and requirements.

Follow Up Phone Calls
This service is optional for researchers and use depends on the researchers own timeframes and requirements.

Phone follow up costs are calculated at $53.35 per hour as a rolled up rate for labour, line and call costs. The number of hours required will depend on how soon researchers wish phone follow up to occur (before or after a follow up letter etc) and whether the study is eligible for verbal consent to be taken (this can require more time to ensure that the participant understands the study and has the opportunity to ask questions, but tends to increase response rates and therefore reduce overall mailout costs). Time taken to complete this activity per study is logged for invoicing purposes.

Reporting
This activity covers end of week quality checks, generation of response rate reports and uploading participant files to researchers. This task usually takes half an hour to an hour per week per study depending on the complexity and scale of the study and is charged at the administration rate of $38.50 per hour. Time taken to complete this activity per study is logged for invoicing purposes.

Australian Twin Registry
Level 1 / 723 Swanston Street
Carlton Victoria
Australia 3053

Telephone: +61 3 9347 2983
Freecall: 1800 037 021 Australia-wide
Facsimile: +61 3 9349 5815
Email: dph-twins@unimelb.edu.au
Web: www.twins.org.au

Patrons
Sir James Balderson AC
Mr Robert Balderson CMG MC
Mr Stephen Waugh
Mr Mark Waugh

The Australian Twin Registry is supported by an Enabling Grant from the National Health and Medical Research Council administered by The University of Melbourne.

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Tracing and Resending
Costs for tracing and re-mailing of any Return To Sender letters are borne by the ATR.

Method
Researchers are invoiced and provided with a detailed report indicating all charges. Time taken in Response Processing and Telephone Follow Up activities per study per day are logged in the ATR database for invoicing purposes. Invoicing periods usually span 6 months and are undertaken in May and November to coincide with end of financial and calendar years. Research teams are able to negotiate changes to invoice timing and frequency depending on their needs.

Sample Initial Mailout Costs

<table>
<thead>
<tr>
<th>Activity</th>
<th>Item</th>
<th>Price per item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>3 hours admin per 100 approaches</td>
<td>$38.50 per hour</td>
</tr>
<tr>
<td></td>
<td>1 x colour page ATR cover letter</td>
<td>$0.33 per page</td>
</tr>
<tr>
<td></td>
<td>2 x colour pages researcher letter/info sheet</td>
<td>$0.33 per page</td>
</tr>
<tr>
<td></td>
<td>1 x Reply Paid Envelope</td>
<td>$0.06 per envelope</td>
</tr>
<tr>
<td></td>
<td>1 x window faced envelope</td>
<td>$0.06 per envelope</td>
</tr>
<tr>
<td></td>
<td>1 x postage</td>
<td>$0.55 per postage</td>
</tr>
<tr>
<td></td>
<td>TOTAL cost per individual per Approach Package</td>
<td>$1.74 per approach package</td>
</tr>
<tr>
<td>Reply Paid</td>
<td>Cost for postage per Reply Paid envelope received</td>
<td>$0.55</td>
</tr>
<tr>
<td>Response Processing</td>
<td>Actual time taken is logged for invoicing purposes.</td>
<td>$38.50 per hour</td>
</tr>
<tr>
<td>Follow Up</td>
<td>Letters – admin and materials charged as above. Actual time taken is logged for invoicing purposes.</td>
<td>$38.50 per hour</td>
</tr>
<tr>
<td></td>
<td>Phone follow up - average 10 individuals contacted per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$53.35 per hour</td>
</tr>
<tr>
<td>Reporting</td>
<td>Approx 0.5 – 1 hour per week per study. Actual time taken is logged for invoicing purposes.</td>
<td>$38.50 per hour</td>
</tr>
</tbody>
</table>

Sample Total Costs per Study

Case 1:  
- Simple coordination plan
- Juniors (1 approach package per family)
- 30 families to be enrolled
- 100 families mailed based on assumption of 30% “Yes” response rate (conservative estimate)
- Phone follow up required and study eligible for verbal response to be taken via phone

<table>
<thead>
<tr>
<th>Activity</th>
<th>Item and price</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>Set up</td>
<td>$165.50</td>
</tr>
<tr>
<td></td>
<td>Admin @ $38.50 per hour x 3 hours per 100 letters</td>
<td></td>
</tr>
<tr>
<td>Standard Approach</td>
<td>1 approach package per family x 100 families @ $1.74 per approach package (see example above)</td>
<td>$174.00</td>
</tr>
<tr>
<td>Package</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reply Paid</td>
<td>Assume a 30% Reply Paid after first approach = 30 families (Both “Yes” and “No” responses received) @ $0.55 per envelope</td>
<td>$16.50</td>
</tr>
<tr>
<td>Response Processing</td>
<td>Assume 70% (70 families) require follow up phone-call Approx 10 families followed up per hour, verbal response taken 10 families per hour = approx 7 hours required @ $53.35 per hour Actual time taken is logged for invoicing purposes.</td>
<td>$373.45</td>
</tr>
<tr>
<td>Follow up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reporting</td>
<td>Approx 0.5 hours report processing @ $38.50 per hour Actual time taken is logged for invoicing purposes.</td>
<td>$19.25</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>$882.95</td>
</tr>
</tbody>
</table>
Case 2:
- Simple coordination plan
- Adults (2 approach packages per pair)
- 300 pairs to be enrolled
- 1000 pairs mailed based on assumption of 30% Double - Yes response rate
- 2000 approach packages mailed over the course of 10 weeks (200 letters per week)
- Phone follow up required and study eligible for verbal response to be taken via phone

<table>
<thead>
<tr>
<th>Activity</th>
<th>Item and price</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>Set up</td>
<td>$165</td>
</tr>
<tr>
<td></td>
<td>2 approach packages per pair x 1000 pairs = 2000 approach packages. Admin @ $38.50 x 3 hours per 100 approach packages</td>
<td>$2310</td>
</tr>
<tr>
<td>Standard Approach Package</td>
<td>2000 approach packages @ $1.74 per approach package (see example above)</td>
<td>$3480</td>
</tr>
<tr>
<td>Reply Paid</td>
<td>Assume a 30% Reply Paid after first approach = 600 individual responses (Both &quot;Yes&quot; and &quot;No&quot; responses received) @ $0.55 per envelope received</td>
<td>$330</td>
</tr>
<tr>
<td>Response Processing</td>
<td>600 responses - approx 1 hour per 60 responses = approx 10 hours @ $38.50 per hour Actual time taken is logged for invoicing purposes.</td>
<td>$385</td>
</tr>
<tr>
<td>Follow up</td>
<td>Assume 70% (1400 individuals) require follow up phone-call Approx 10 individuals followed up per hour, verbal response taken = approx 140 hours required @ $53.35 per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$7469</td>
</tr>
<tr>
<td>Reporting</td>
<td>Approx 0.5 hours - 1 hour report processing per week over 10 weeks @ $38.50 per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$385</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>$9,635.05</strong></td>
</tr>
</tbody>
</table>

Case 3:
- Complex coordination plan
- Adults (2 approach packages per pair)
- 300 pairs to be enrolled
- 1000 pairs mailed based on assumption of 30% Double - Yes response rate
- 2000 approach packages mailed over the course of 10 weeks (200 letters per week)
- Phone follow up required and study eligible for verbal response to be taken via phone
- Screening questionnaire included
- Screening questionnaire processing required (assume this doubles response processing time and increases telephone follow up time required)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Item and price</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>Set up</td>
<td>$275</td>
</tr>
<tr>
<td></td>
<td>2 approach packages per pair x 1000 pairs = 2000 approach packages. Admin @ $38.50 x 3 hours per 100 approach packages</td>
<td>$2310</td>
</tr>
<tr>
<td>Standard Approach Package</td>
<td>Standard package plus Additional screening questionnaire - 2 b&amp;w pages @$0.08 per page Additional information sheet - 2 b&amp;w pages @$0.08 per page Total $2.06 per approach package</td>
<td>$4120</td>
</tr>
<tr>
<td>Reply Paid</td>
<td>Assume a 30% Reply Paid after first approach = 600 individual responses (Both &quot;Yes&quot; and &quot;No&quot; responses received) @ $0.55 per envelope received</td>
<td>$330</td>
</tr>
<tr>
<td>Response Processing</td>
<td>Approx 1 hour response processing per 30 responses (including additional screening questionnaire processing) = approx 20 hours @ $38.50 per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$770</td>
</tr>
<tr>
<td>Follow up</td>
<td>Assume 70% (1400 individuals) require follow up phone-call Average of 8 individuals followed up per hour (includes time to take a verbal response and administer screening questionnaire verbally if participating) = approx 175 hours required @ $53.35 per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$9336.25</td>
</tr>
<tr>
<td>Reporting</td>
<td>Approx 0.5 hours - 1 hour report processing per week over 10 weeks @ $38.50 per hour. Actual time taken is logged for invoicing purposes.</td>
<td>$385</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>$17,526.25</strong></td>
</tr>
</tbody>
</table>
Appendix 9

Dataset D: Consultative Council on Obstetric and Paediatric Mortality and Morbidity

CUSTODIAN

Custodian: Consultative Council on Obstetric and Paediatric Mortality and Morbidity.

Name: Anne-Maree Szauer

Position/job title: Manager, Clinical Councils Unit

Phone: 03 9096 2759

Email Address: anne-maree.szauer@dhs.vic.gov.au


SUMMARY

The Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM) was established in 1962 under the Health Act 1958 (the Act) and is the advisory body to the Minister for Health on maternal, perinatal and paediatric deaths.

The CCOPMM collects data on Victorian deaths and includes all perinatal deaths (stillbirths and neonates) from 20 weeks gestation or 400gr birth weight; all infant and child deaths up to, but not including the eighteenth birthday; and all maternal deaths.

Case files are created from death certificates received from the Registry of Births, Deaths and Marriages. Information is then sought from many sources including hospital patient records, individual doctors, pathology departments, Coronial Services, and the Newborn Emergency Transport Service.

Data are collected by the CCOPMM with the purpose of:

- collecting, studying, researching and interpreting information on and in relation to births in Victoria
- identifying and monitoring trends in respect of perinatal health including congenital abnormalities
- providing information to the Secretary on the requirements for the planning of neonatal care units
- providing information to the medical profession for the research into the epidemiology of perinatal mortality and disorders including congenital abnormalities
- establishing and maintaining a register of congenital abnormalities.

Data are also used to identify clinical features of each death and to assess preventability.

Information provided to the CCOPMM is privileged from access by any third party, including the courts. However, CCOPMM may, if it determines that it is in the public interest to do so, provide information to bodies specified in section 162FB of the Act.
DATA COLLECTION

What data are captured in this database?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status (from January 2009)</td>
<td>Demographic information</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Demographic information</td>
<td>Demographic information</td>
</tr>
<tr>
<td>Pregnancy information</td>
<td>Birth information</td>
<td>Death information</td>
</tr>
</tbody>
</table>

Does the database include identifying information?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name (in some instances)</td>
<td>Name</td>
</tr>
<tr>
<td>Maiden name</td>
<td>Date of birth</td>
<td>Gender</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address at birth</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How are the primary data collected?

- Primary data are collected from multiple sources; the majority from hospital case records, individual doctors, pathology departments, Coronal Services, and the Newborn Emergency Transport Service. Death certificates are received from the Registry of Births, Deaths and Marriages.

When are the data collected?

- After the event of a death.

How do the custodians obtain the data that are included in the database?

- Data are provided to the CCOPMM by the aforementioned entities and directly from the person acting on behalf of the deceased.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Data are stored in electronic and paper based formats.

Where do the custodians store the data?

- Current data are stored on the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000.
- Archived data are stored at the State Archives.

Are the data easily accessible?

- No, stringent processes have been put in place to safeguard the security and confidentiality of any data released by CCOPMM. Refer to the Data release policy attached.

Is there a cost involved in accessing the data?

- No.
REPORTING

How often are the data received by the data repository/custodians?

- Data are continuously submitted to CCOPMM as events occur.

Is reporting of these data to the custodian a statutory requirement?

- Reporting regarding anything required for CCOPMM to meet its functions can be requested by CCOPMM under 162FA of the Act.

Is reporting of these data an administrative requirement?

- No.

Do you submit your data to a national or state database?

- Yes, data are provided to the National Perinatal Statistics Unit and to the International Clearinghouse for Birth Defects Monitoring Systems.

INDIGENOUS STATUS

Is an Indigenous identifier used?

- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?

- It is not mandatory for vendors to populate the Indigenous identifier field for CCOPMM.

When is the Indigenous status entered?

- Vendors enter the Indigenous status of the mother at the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?

- Yes, vendors that supply data to the CCOPMM are required to determine Indigenous status on the Birth Report Form A (attached); this information is not required from other suppliers of death information.

- Midwives and hospital personnel are required to determine the Indigenous status of the mother, and effective 1 January 2009, the Indigenous status of the baby in the Perinatal Data Collection.

- Funeral Directors and Medical Practitioners are required to determine the Indigenous status of a deceased person for records submitted to the Register of Births, Deaths and Marriages.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?

- Aboriginal
- TSI
- No.
Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?

- Yes.

What are the barriers to obtaining information about a person's Indigenous status?

- The VPDCU believes there to be an under reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.

Does your information system allow for the Indigenous status to be left blank at the time of collection?

- Pre- 1 Jan 2009, the Indigenous status of the mother was a mandatory field. Post-2009 the Indigenous status of the baby is also a mandatory field. If we are able to access a Victorian birth form for a child then we will have either the mother's Indigenous status or both the mother and baby's if it is born after Jan 2009.

How confident are you that the Indigenous status is accurate?

- Unsure.

ACCESS TO DATA

How does one obtain access to these data?

- Processes relating to the access of data for research purposes were reviewed in November 2008.
- All requests for unpublished information must be put in writing to CCOPMM (if not for the purpose of formalised research. See request form attached or via web link: <http://www.health.vic.gov.au/perinatal/forms>.
- A copy of the request will be forwarded to the CCOPMM representative for approval. The CCOPMM encourages the release of data to health professionals for statistical and research purposes; however, the CCOPMM must comply with the Act and any information that identifies any patient, cannot be provided to any individual external to CCOPMM for the purpose of research without the written consent of:
  a. written permission has been given by the mother concerned; and
  b. if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and
  c. if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.

What ethics clearances are required to access your data?

- Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted Human Research Ethics Committee must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.
Do you have an access agreement outlining the conditions of access to your data base?
• Yes, see attached: Data release policy.

Are your data used for research purposes?
• Yes.

DATA STANDARDS

Do you comply with data standards?
• Yes, the majority of data items comply with the National Perinatal Minimum Data Set, which is collected by all States and Territories and sent to the National Perinatal Statistics Unit for the production of the annual report on Australia’s mothers and babies. The Department of Human Services has also developed a common client dataset.

Who enforces the standards?
• Data standards are enforced by the National Perinatal Statistics Unit and the Department of Human Services Data Standards and Systems.

Does your organisation utilise a data dictionary?
• Yes, DHS developed a Common Client Data Dictionary with reference to the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
• Mandatory data fields
• Staff education
• Audits to ensure accuracy and consistency
• Administrative staff follow up with external entities when forms are incomplete or there are discrepancies
• User manuals.
**BIRTH REPORT FORM A (from 2009)**

### MOTHER
- **Mother UR number:**
- **Admission date:**
- **Suburb:**
- **Public/Private Patient:**
  - [ ] Public
  - [ ] Private
- **Country of Birth:**
  - [ ] Mother
  - [ ] Father
- **Postcode:**

### Hospital
- **Intended Place of Birth:**
- **Actual Place of Birth:**
  - Hospital (specify):
  - Birth Centre: [ ] Home
  - Other (specify):

### Indigenous Status
- [ ] Mother: (circle one or more)
  - [ ] Aboriginal
  - [ ] Non-Aboriginal
- [ ] Father: (circle one or more)
  - [ ] Aboriginal
  - [ ] Non-Aboriginal

### Marital Status
- [ ] Married
- [ ] Widowed
- [ ] Divorced
- [ ] Separated
- [ ] De facto
- [ ] Unknown

### Birth Date
- [ ] Mother:
- [ ] Father:
- [ ] Full gestation:

### Height
- [ ] cm

### Weight
- [ ] kg

### Labour, Birth & Postnatal
- **Onset labour:**
  - Date:
  - Time:
- **Rupture of membranes:**
  - Date:
  - Time:
- **Labour:**
  - Spontaneous:
  - Augmented:
  - Induced:
  - Medical:
  - Surgical:
  - Labour induced or augmented:
  - [ ] circle one or more
- **Prostaglandins:**
  - [ ] Other

### Baby UR:
- Complete a separate form if full for each baby of a multiple birth.
- **Birthdate:**
- **Estimated gestation at birth:**
  - (week(s):
- **Sex:**
  - Male:
  - Female:
  - Indeterminate:
- **Plurality:**
  - Single:
  - Twins:
  - (this record refers to:
  - (during labour):
  - (labour):
- **Birthweight:**
  - (grams):
- **Apgar:**
  - 1 minute:
  - 5 minutes:
  - 10 minutes:
- **Time to established respiration:**
  - (minutes):
- **Resuscitation - mechanical:**
  - None:
  - ETT with air:
  - Suction:
  - ETT with O2:
  - O2 therapy:
  - CPR with air:
  - IPPR with air:
  - IPPR with O2:
  - Cardiac massage:
  - Other (specify):
- **Resuscitation - drugs (specify):**

### Congenital Anomalies:
- [ ] CVS / CNS / MS / GI / UG / Resp / Skin / Other
  - [ ] Circle & Specify:

### Paediatrician:
- [ ] Neonatal morbidity:
  - [ ] Specify:

### A/N Care provider:
- [ ] Obstetrician:
  - Midwife:
  - GP:
  - Other:
- [ ] Procedures and operations:
  - [ ] Ultrasound:
    - 10 - 14 weeks (specify no.):
    - 15 - 26 weeks (specify no.):
    - > 27 weeks (specify no.):
    - IM Steroids (2 doses):
    - ART (specify):
    - Other (specify):

### A/N Care Provider:
- [ ] Obstetrician:
  - Midwife:
  - GP:
  - Other:

### Procedures and Operations:
- [ ] Ultrasound:
  - 10 - 14 weeks (specify):
  - 15 - 26 weeks (specify):
  - > 27 weeks (specify):
  - IM Steroids (2 doses):
  - ART (specify):
  - Other (specify):

### Complications/Events of labour and birth:
- [ ] Antibiotics:
  - Shoulder:
  - Water:

### Lead Intrapartum care provider:
- [ ] Obstetrician:
  - Midwife:
  - GP:
  - Other:

### Prophylactic oxytocin 3rd stage:
- [ ] Manual removal of placenta:
  - [ ] (specify):

### Perineal status:
- [ ] Laceration:
  - [ ] Repaired:

### Blood loss (mls):
- [ ] Transfusion:
  - [ ] Postpartum complications:
  - [ ] Specified:

### Admitted to HDU/ICU (Mother):
- [ ] Date:

### An Overview of Statutory and Administrative Datasets:
- Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
DATA RELEASE POLICY & GUIDELINES

<table>
<thead>
<tr>
<th>Date of policy: 28 November 2008</th>
<th>Version: 1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy review date: November 2009</td>
<td>Approved by: Manager, Clinical Councils</td>
</tr>
</tbody>
</table>

Overview

The purpose of this document is to outline current policy and procedures regarding access to the data sets developed and maintained by the Clinical Councils Unit (CCU), in the Statewide Quality Branch of the Department of Human Services (DHS). These data sets currently include:

- the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM), incorporating:
  - the Victorian Perinatal Data Collection (VPDC), and
  - the Victorian Birth Defects Register (VBDR)
- the Victorian Surgical Consultative Council (VSCC), incorporating:
  - the Surgical Outcomes Information Initiative (SOII), and
- the Victorian Consultative Council on Anaesthetic Mortality and Morbidity’s (VCCAMM) Reporting Management System.

It is anticipated that this document will be reviewed on an annual basis in response to changes in legislation and in data management policy and procedures.

Background

The collections held by CCOPMM, VSCC and VCCAMM within the CCU are clinical data collections based on identified individual level data provided to the Department of Human Services by hospitals and individual medical practitioners. Data are provided to the CCOPMM by all public and private hospitals (including private day procedure centres) as is required by the Health Act 1958 (the Act), while data are provided to the other collections by selected public and private hospitals on a voluntary basis.

The purpose of these data collections is to conduct study and research into mortality and morbidity in selected populations, to support health service planning and develop government policy with the aim of preventing avoidable deaths and promoting healthy outcomes in these populations. The data collections also support Victoria’s reporting obligations under the National Health Information Agreement (NHIA) and the Australian Health Care Agreement (AHCA).

Policy statement

All three consultative councils are restricted by the Health Act 1958 from releasing identified or re-identifiable data to persons not specified in the Act. In the case of VCCAMM and VSCC this is only permissible with consent of the person whose information is to be released and the Minister.

In the case of CCOPMM the release of identifiable information to any persons not listed in S162FB of the Act is only permissible for the purpose of medical research with the consent of the mother, the health service where the child was born and if possible the medical practitioner or midwife present at the birth. Non-identifiable information may be released by VSCC and VCCAMM under S24A (3) of the Act. However non-identifiable information can only be released by CCOPMM through the Secretary of the department under S162F (1) (d).
Guidelines:
Responsibility for the use and disclosure of data sets held in the CCU resides with each of the consultative councils. The release of data is managed by each consultative council’s secretariat.

Release of identifiable data for research purposes (CCOPMM)
Requests for identifiable data including proposals to link data using identifying information are to be submitted to CCOPMM for consideration.

Identifiable information will only be released in accordance with section 6 (2) the Health (Consultative Council on Obstetric and Paediatric Mortality and Morbidity) Regulations 2002, which provides for the release of identifying information to a member of the medical profession for the purposes of undertaking medical research, if:

(a) written permission has been given by the mother concerned; and
(b) if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and
(c) if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.

Where the above conditions cannot be met, a research proposal requesting identifiable information can only proceed if CCOPMM elect to undertake the research themselves. In such circumstances, the proposed research must align to the functions and work plan of CCOPMM, satisfy a public interest test and accord with both the requirements of the Victorian Human Rights Charter and the Health Privacy Principles contained in the Health Records Act 2001.

If a proposal is endorsed by CCOPMM, internal resources will be utilised to conduct research if possible. If internal resources are not available, an external research body may be co-opted to undertake the proposed research. In this circumstance, contractual arrangements must be entered into between CCOPMM and the research agency, clearly articulating use and storage of data and reporting requirements.

Requests for non-identifiable data (CCOPMM)
Applications for the release of de-identified aggregate data are to be made to the Secretary (or delegate) of the Department of Human Services. Requests are then referred to the Manager, Clinical Councils Unit for consideration.

Applications will be assessed against the mandatory criteria that the data requested is de-identified and statistical in nature, and that release of the data satisfies a public interest assessment. CCOPMM’s assessment of the public interest will be undertaken on a case by case basis to ensure consideration of all relevant circumstances. Each application will be assessed against current operational and legal considerations, including the requirements of the Human Rights Charter and the Health Privacy Principles contained in the Health Records Act 2001.

Any linkage of individual level data from CCOPMM with other individual level data sets requires the approval of both the purpose of and the methodology to be used for the linkage by either the Council or the Secretary of the Department of Human Services.

Enquiries about the information in this document should be directed to the Manager, Clinical Councils Unit, 9096 2759.
Application for the release of data from CCOPMM for the purpose of research.

**REQUEST DETAILS**

<table>
<thead>
<tr>
<th>Requestor:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lead investigator (if different from requestor):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Qualifications of lead investigator:</th>
</tr>
</thead>
<tbody>
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<table>
<thead>
<tr>
<th>Organisation:</th>
</tr>
</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Phone:</th>
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<table>
<thead>
<tr>
<th>Email:</th>
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<table>
<thead>
<tr>
<th>Postal address:</th>
</tr>
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<tbody>
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<table>
<thead>
<tr>
<th>Date:</th>
</tr>
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<td></td>
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<table>
<thead>
<tr>
<th>Outline of project design in lay language:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Public interest factors**

(Please state why the release of this data will have a public interest benefit)

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
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<td></td>
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</tbody>
</table>

**Data variables requested:**

(Please describe variables of interest and why each is required)

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
### An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

#### Consultative Council on Obstetric and Paediatric Mortality and Morbidity

<table>
<thead>
<tr>
<th>Provide a statement outlining how the project achieves HPP1.1 &amp; 2.2 as described in the Health Records Act 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide a statement outlining how the project is compliant with Human Rights Charter. A copy of the charter can be viewed at or downloaded from <a href="http://www.humanrightscommission.vic.gov.au">www.humanrightscommission.vic.gov.au</a></td>
</tr>
<tr>
<td>Provide any additional information that is relevant to the consideration of this application.</td>
</tr>
</tbody>
</table>
Appendix 9

Dataset E: Dental Health Program Data Collection

CUSTODIAN

Custodian: Department of Human Services
Name: Catherine James
Position/job title: Manager, Primary Health Programs, Primary Care Branch, Rural & Regional Health and Aged Care Services Division
Phone: 03 9096 8762
Email Address: catherine.james@dhs.vic.gov.au

SUMMARY

The Department of Human Services (DHS) funds the provision of dental services to children. These services are provided by community health services and the Royal Dental Hospital of Melbourne. As part of the Dental Health Program demographic, oral health status and treatment data are collected and provided to the department.

DATA COLLECTION

What data are captured in this database?
- Client information in line with the RRHACS Common Client Data set.
- Oral health status in the form of dmft/DMFT.
- Treatment data by Dental Item Schedule.

When the client is a child:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>Child:</td>
<td>Father:</td>
</tr>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
</tbody>
</table>

Does the database include identifying information?

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>Child:</td>
<td>Father:</td>
</tr>
<tr>
<td>Nil</td>
<td>Name</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Date of birth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Indigenous status</td>
<td></td>
</tr>
</tbody>
</table>
How are the primary data collected?
- Demographic information is completed by the client or parent on a hard copy form and manually entered by administrative staff.
- The Decayed, Missing Filled (DMF) Score is derived from the electronic dental chart recorded in the Patient Management System by clinical staff.

When are the data collected?
- Demographic information is collected from the client before the episode of care. The DMF Score is calculated during the examination process at the commencement of a course of care.

How do the custodians obtain the data that are included in the database?
- Data are entered into the Patient Management System where each agency has a separate database stored centrally at a data centre. The data are sourced or extracted from the agency databases directly from the data centre.

Who are the external entities?
- Community health services and Dental Health Services Victoria

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- Data are stored electronically in SQL databases.

Where do the custodians store the data?
- Data are stored at the central data centre located at Tally Ho, 4 Wesley Crt. East Burwood.

Are the data easily accessible?
- Yes.

Is there a cost involved in accessing the data?
- No.

REPORTING

How often are the data received by the data repository/custodians?
- Monthly, quarterly and on an annual basis.

Is reporting of these data to the custodian a statutory requirement?
- No.

Is reporting of these data to the custodian an administrative requirement?
- Yes.

Do you submit your data to a national or state database?
- Yes.
INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes, but not well reported.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- Since the collection commenced in 1991.

When is the Indigenous status entered?
- At the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Aboriginal but not Torres Strait Islander origin.
- Torres Straight Islander but not Aboriginal origin.
- Both Aboriginal and Torres Strait Islander origin.
- Neither Aboriginal nor Torres Strait Islander origin.
- Not stated/inadequately described.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
- Yes.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
- No, however, it defaults to non-Indigenous.

How confident are you that the Indigenous status is accurate?
- Not confident.

ACCESS TO DATA

How does one obtain access to these data?
- From DHS according to DHS guidelines, this data is limited and would not be appropriate for population studies or making generalisations.

What ethics clearances are required to access your data?
- That depends on what it would be used for.
Do you have an access agreement outlining the conditions of access to your data base?
• Normal DHS processes.

Are your data used for research purposes?
• Not to my knowledge.

DATA STANDARDS

Do you comply with data standards?
• No, a specific set of data standards are not complied with.

Does your organisation utilise a data dictionary?
• No.

DATA QUALITY

How do you ensure data quality?
• Mandatory data fields.
• Real time entry of data into PMI.
• Staff education.
• Reminder alerts.
Appendix 9

Dataset F: Health (Infectious Diseases) Regulations, 2001

CUSTODIAN

Custodian: Communicable Disease Prevention and Control Unit, Department of Human Services

Name: Dr Rosemary Lester

Position/job title: Assistant Director, Communicable Disease Prevention and Control Unit, Public Health Branch

Phone: 1300 651 160

Email Address: infectious.diseases@dhs.vic.gov.au


SUMMARY

Surveillance for communicable diseases occurs under the authority of the Health (Infectious Diseases) Regulations 2001. These Regulations require medical practitioners and pathology laboratories to notify the Department when they diagnose certain communicable diseases. In Victoria, the Department of Human Services conducts surveillance on infectious diseases to pinpoint outbreaks and to prevent the spread of infection. Notifications of infectious diseases from medical practitioners and laboratories are the fundamental component of the surveillance. The Health (Infectious Diseases) Regulations aim to:

- Provide for the notification of certain infectious diseases
- Protect public health by preventing, or containing, outbreaks of infectious diseases.

DATA COLLECTION

What data are captured in this database?

Information collected when the patient is a child:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Demographic information</td>
<td>Birth information*</td>
</tr>
<tr>
<td>Death information*</td>
<td>Delivery information*</td>
<td></td>
</tr>
</tbody>
</table>

* Information collected where relevant for notifiable condition.

**Does the database include identifying information?**

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of birth</td>
<td>Name</td>
<td>Country of birth</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Infectious disease information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How are the primary data collected?**

- Form is completed by person/s accompanying the client.
- Form is completed by Administrative Staff.
- Primary data sources are Medical Practitioners and laboratories. Some data may be collected directly from the patient.

**When are the data collected?**

- Data are collected during and after an episode of care/event.

**How do the custodians obtain the data that are included in the database?**

- Data are obtained directly from the person acting on behalf of the client or from external entities.

**Who are the external entities?**

- Medical Practitioners, laboratories and local government.

**STORAGE AND ACCESSIBILITY**

**In what format do the custodians store the data?**

- Electronic and paper based.

**Where do the custodians store the data?**

- On the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000 and archived off premises.

**Are the data easily accessible?**

- Yes.

**Is there a cost involved in accessing the data?**

- No.
REPORTING

How often are the data received by the data repository/custodians?
- Data are received by the data custodian within 12–24 hours.

Is reporting of these data to the custodian a statutory requirement?
- Yes, under the Health (Infectious Diseases) Regulations 2001.

Is reporting of these data an administrative requirement?
- No.

Do you submit your data to a national or state database?
- Yes, de-identified data are submitted to the National Notifiable Disease Surveillance Scheme.

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- 1990.

When is the Indigenous status entered?
- At the time of collection, or sometimes by staff in the Communicable Diseases Unit if the case is followed-up.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes, the medical practitioner asks the question of Indigenous status. If cases are followed up by a public health practitioner in the Communicable Diseases Unit, then cases are usually asked this question as well.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both Aboriginal and Torres Strait Islander.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
- Unknown.
What are the barriers to obtaining information about a person's Indigenous status?

- Form not completed
- Service provider may not with to appear discriminating
- Additional barriers unknown.

Does your information system allow for the Indigenous status to be left blank at the time of collection?

- Yes.

How confident are you that the Indigenous status is accurate?

- Not confident.

ACCESS TO DATA

How does one obtain access to these data?

- Some data are publicly available through the DHS website or in published reports. For non-published data there is a data request procedure. See attached: Communicable Diseases Data Request Form.

What ethics clearances are required to access your data?

- If data are requested for research purposes then an ethics clearance is required.

Do you have an access agreement outlining the conditions of access to your data base?

- Yes, see attached: Communicable Diseases Data Request Form.

Are your data used for research purposes?

- Yes.

DATA STANDARDS

Do you comply with data standards?

- Yes, the National Health Data Standards.

Does your organisation utilise a data dictionary?

- Yes, the DHS Minimum Client Dataset based on the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?

- Mandatory data fields
- Benchmarking with other jurisdictions
- Staff education
- Timely entry of data
- Administrative staff will sometimes follow up with client/guardians when forms are incomplete.

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
### 1. Sexually Transmitted Infections

<table>
<thead>
<tr>
<th>Infection</th>
<th>First two letters only:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chlamydia trachomatis</td>
<td>Family name</td>
</tr>
<tr>
<td>Gonorrhea</td>
<td>First name</td>
</tr>
<tr>
<td>Syphilis</td>
<td>Postcode of residence</td>
</tr>
</tbody>
</table>

### 2. Other Infectious Diseases

<table>
<thead>
<tr>
<th>Disease</th>
<th>You must also complete sections 3 and 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anthrax</td>
<td></td>
</tr>
<tr>
<td>Brucellosis</td>
<td></td>
</tr>
<tr>
<td>Campylobacteriosis</td>
<td></td>
</tr>
<tr>
<td>Cholera</td>
<td></td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease</td>
<td></td>
</tr>
<tr>
<td>Classical CJD</td>
<td></td>
</tr>
<tr>
<td>Variant CJD</td>
<td></td>
</tr>
</tbody>
</table>

### 3. Details for ALL Notifiable Diseases

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth (or Age)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
</tr>
<tr>
<td>Patient alive?</td>
<td>Alive</td>
</tr>
<tr>
<td>Clinical comments</td>
<td>Include risk factors, mode of transmission (if any) et al.</td>
</tr>
</tbody>
</table>

### 4. Notifier Details

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of notifying doctor, laboratory or hospital</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>City/Suburb/Town</td>
<td></td>
</tr>
<tr>
<td>Postcode</td>
<td></td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Signature</td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td></td>
</tr>
</tbody>
</table>

---

Diseases marked with the symbol require immediate notification by telephoning 1300 651160. Further instructions are provided on the back of this form. Please print clearly and tick boxes where applicable.
Notifying Cases of Infectious Diseases in Victoria

Your Requirement to Notify

Infectious diseases still occur frequently throughout the world, so constant vigilance is required to prevent the reappearance of diseases thought to have been conquered. Changes in lifestyle have also led to the emergence of new threats to public health from infection. Health authorities depend on both medical practitioners and laboratories for information on the incidence of infectious diseases. Notification is vital in efforts to prevent or control the spread of infection. Notifiable Infectious Diseases are included in Schedule 3 of the Health (Infectious Diseases) Regulations 2001 and are divided into four groups on the basis of the method of notification and the information required. With the exception of HIV/AIDS, these groups are all included on this form (see reverse side).

When to Notify

A medical practitioner who becomes aware that a person the practitioner is attending shows evidence of, has died with, or is a carrier of a notifiable disease must notify as follows:

**Group A**
Diseases require immediate notification to the Department of Human Services by telephone or fax upon initial diagnosis (presumptive or confirmed), followed by written notification within five days. These diseases are bolded on the form and are marked with the \( \text{\symbol{126}} \) symbol.

**Group B**
Diseases require written notification to the Department of Human Services upon initial diagnosis (presumptive or confirmed) within five days.

**Group C**
Diseases include the sexually transmitted infections and require written notification to the Department of Human Services upon initial diagnosis (presumptive or confirmed) within five days. To preclude identification of the patient, only the first two letters of the family and given name of the patient are required.

**Group D**
Diseases include HIV (Human Immunodeficiency-virus) and AIDS (Acquired Immunodeficiency Syndrome) and written notification is required within five days of initial diagnosis. A separate form is used for this purpose due to the need to have national uniformity in collection of data. Copies of this form are forwarded to the diagnosing medical practitioner with the laboratory confirmation of HIV infection.

The Department provides pre-printed Reply Paid envelopes (no stamps required) and STD toll free telephone and facsimile numbers to make notifying as simple as possible. Copies of the form, information on diseases and outbreaks, media releases, disease surveillance data, privacy information and other publications are all available at the Department of Human Services Internet site [www.health.vic.gov.au/ideas](http://www.health.vic.gov.au/ideas). A secure online notification form is also available at this website under the link 'Notifying cases > What to notify.'

Privacy Legislation

Commonwealth and State Privacy Legislation does not negate the responsibility to notify the specified diseases nor to provide the information requested on this form. Doctors have a responsibility to inform their patients that their information is being provided to the Department of Human Services. The Department is committed to protecting the confidentiality of the information it receives and is bound by strict policies. Further information about privacy and notifiable diseases is available from the Department's Communicable Disease Prevention and Control Unit.

Further Information

All notifications and related inquiries should be directed to:

**Communicable Disease Prevention and Control Unit**
Victorian Government Department of Human Services
Reply Paid 65937, Melbourne VIC 8060
(No postage stamp required)

Telephone 1300 651160 (After hours service available) or Facsimile 1300 651170
(1300 numbers are charged at the cost of a local call)

Please PRINT clearly and retain a copy of the notification for your records.

Thank you.

September 2008
## Data Request Form

**Date of request**

**Name of requesting person**

**Agency name**

**Address**

**Email**

DHS employee?  □Yes  □No

**Data requested**

**Format in which data is required**

Is identifying information required?  □Yes  □No  
If yes, specify why and whether consent has been obtained and whether the relevant privacy guidelines have been consulted.

**Reason for request**

□Research project  □Departmental report  □Student project  □Other, specify—

If for research purposes, has this been approved by the DHS Ethics Committee?  □Yes  □No  
If yes, state approval date and attach a copy of letter

If no to above, will the project be submitted to the DHS ethics committee?  □Yes  □No

To whom and how will this information be disclosed/disseminated?

**Date data required**

Action taken  □Released  □Not released  □Other, specify—

**Actioning officer**

Release approved by  Program Manager, EQuIP  
Manager, Communicable Diseases Section

---

Complete forms should be filed with the Program Manager, EQuIP, Communicable Diseases Section

**IMPORTANT:** The data are released for the purposes stated in the application only.
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
Appendix 9

Dataset G: National Coroners Information System

CUSTODIAN

Custodian: Victorian Institute of Forensic Medicine
Name: Jessica Pearse
Position/job title: Manager, National Coroners Information System
Phone: 03 9684 4414
Email Address: jessicap@vifm.org
Web: www.ncis.org.au

SUMMARY

The National Coroners Information System (NCIS) is a world first national database of coronial information, which contains data from the coronial files of all Australian states and territories (except Queensland) dating back to 1 July 2000. Queensland data commences from 1 January 2001. The NCIS assists Coroners, government agencies and researchers around Australia to obtain timely and efficient access to coronial data, which can then be used to inform death and injury prevention activities.

The NCIS includes full text reports such as coronial findings, toxicology reports, police narrative, autopsy reports, as well as coded information such as demographic details about the deceased, cause of death, mechanism and objects involved in death.

One of its primary functions 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.

Approved research and government agencies also utilise the NCIS to obtain valuable information concerning the circumstances of reported fatalities, to assist in the development of community health and safety strategies.

DATA COLLECTION

What data are captured in this database?
In the instance of a deceased infant or child:

<table>
<thead>
<tr>
<th>Mother</th>
<th>Child</th>
<th>Father*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death information</td>
<td></td>
</tr>
</tbody>
</table>

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

Note: There may be some additional information about the mother and/or father provided in text reports such as police narrative, coronial findings, and autopsy and toxicology reports.

See attached: Existing Police Notification Form.

Does the database include identifying information?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Name</td>
<td>Nil</td>
</tr>
<tr>
<td>Date of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential address</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other identifying information may be available within full text reports attached to the system such as names of mothers or father or other persons involved in the incident.

How are the primary data collected?

- Primary information is collected from a range of different sources as part of the coroners investigation into death and is stored within the hard copy coroners file. This includes information from police, medical and scientific experts, witnesses and other specialist reports or analysis.
- All data are entered into the NCIS as per the information available from the coronial file held within the investigating Coroner’s Court.
- Additional codes (occupation codes, ICD–10 and ASGC) are provided directly to NCIS from external agencies (Australian Safety and Compensation Council and Australian Bureau of Statistics).

When are the data collected?

- Data are collected after an episode of death and throughout the coronial investigation. The timelines for data entry on the NCIS are dependent on the jurisdiction in which the death occurred. For the majority of jurisdictions initial data are entered onto a local case management system about the basics surrounding the death (which is then uploaded to the NCIS overnight) with further information populated as the case progresses.

How do the custodians obtain the data that are included in the database?

- Data are collected from uploads from local Coroners Court systems, or are entered directly into the NCIS via the internet.

Who are the external entities?

- External entities include the police, forensic toxicologists, forensic pathologists and coroners.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Electronic format. The NCIS is built on an Informix SQL platform.
Where do the custodians store the data?

- Although the NCIS is an internet based database the main server is based on the premises at the Victorian Institute of Forensic Medicine, 57–83 Kavanagh Street, Southbank, 3006. Back-ups are conducted nightly and copies are stored off site.

Are the data easily accessible?

- Access is limited to those with a bona fide interest or investment in the data contained within the database. Death investigators (coroners, forensic medical/scientific staff, police assisting the coroner) are given access upon approval by the State Coroner in that jurisdiction. Third Party users (such as researchers, government departments or non-profit groups) are required to submit formal applications which must be approved by the Victorian Department of Justice Ethics Committee before being granted access. Note: media or private organisations are unable to obtain direct access to the system.

- There are several levels of access. Not everyone requires and/or receives access to identifying data, or every jurisdiction. Once permission has been granted the NCIS can be accessed via the internet.

Is there a cost involved in accessing the data?

- Yes, there may be a fee payable. All fees are levied on a cost recovery basis and will depend on the product or service selected.

REPORTING

How often are the data received by the data repository/custodians?

- Entry into the local system begins upon notification of the death to the Coroner’s Office and will continue until the case has been fully investigated and closed by the Coroner.

- Data is uploaded nightly from the local court systems in most of the eight Australian jurisdictions.

Is reporting of these data to the custodian a statutory requirement?

- No.

Is reporting of these data an administrative requirement?

- Yes, there is a licence agreement with each Australian State and Territory permitting the transfer of coronial information in accordance with Privacy Legislation for storage and dissemination via the NCIS.

Do you submit your data to a national or state database?

- No, the NCIS is the national database.

INDIGENOUS STATUS

Is an Indigenous identifier used?

- Yes, an Indigenous identifier is included in the National database; however, information on Indigenous status is often not available for Victorian cases because it is not currently included on the Police Notification Form currently used in Victoria. See attached: Police Report of

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Death for the Coroner notification form. An Indigenous identifier is included on the new Police Notification Form yet to be implemented in Victoria. See attached: Proposed Police Notification Form.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes, it is mandatory for NCIS data entry staff to populate this field; however, this information may not always have been collected during the Coronial process.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- An Indigenous identifier was included in the national database at the commencement of the NCIS in 2000.

When is the Indigenous status entered?
- Indigenous status is usually entered at the time of initial data entry, which includes basic demographics surrounding the deceased.

Are questions asked to determine the Indigenous status of a client/patient?
- Each jurisdiction has a Police Notification Form to report a death to the coroner, and in the majority of jurisdictions, a question about the Indigenous status of the deceased is included on this form. However, it is unknown as to whether this question is asked routinely by police of next of kin, or any other methods of determination used. An Indigenous identifier is not currently included on the Police Report of Death for the Coroner form in Victoria, yet Indigenous status may be determined in full-text reports.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Aboriginal but not Torres Strait Islander origin
- Torres Straight Islander but not Aboriginal origin
- Both Aboriginal and Torres Strait Islander origin
- Neither Aboriginal nor Torres Strait Islander origin
- Unlikely to be known.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
- Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
- The main identifying source of this information is deceased and is it not always possible to obtain the information from a reliable source.
- Police, administrative or medical staff may feel that the question is irrelevant.
- Police may not feel comfortable asking the question of a grieving family.
- Police may fear a negative response to the question being asked.
Does your information system allow for the Indigenous status to be left blank at the time of collection?

- No, the database requires an entry; however, if no information is available the status is recorded as “unlikely to be known”.

How confident are you that the Indigenous status is accurate?

- Not confident. Some jurisdictions are considered to be quite accurate whilst others require attention. This is mainly due to a lack of the Indigenous question on the police report of death in certain jurisdictions.

ACCESS TO DATA

How does one obtain access to these data?

- De-identified data in aggregate can be requested from the data custodian and released subject to approval by the relevant Coroner’s Office. Information provided to the applicant can range from basic statistical data to the provision of detailed reports, which include additional analysis and commentary. Applications for direct access to the data must also be approved by an ethics committee and there is soon to be an Indigenous Reference Group, which will advise the Department of Justice Ethics Committee on any issues concerning research applications which deal primarily with a review of Indigenous deaths.


What ethics clearances are required to access your data?

- The applicant must first go through his/her institution’s ethics committee before completing the Department of Justice Application Form.
- All applications submitted to the NCIS are reviewed by the NCIS Research Committee before being forwarded to the Department of Justice Ethics Committee.
- All applications are required to be approved by the Victorian Department of Justice Research Ethics Committee.


- If applying to access NSW identifying data, or WA data, additional ethics committee approval may need to be obtained.

Do you have an access agreement outlining the conditions of access to your data base?


Are your data used for research purposes?

- Yes.
DATA STANDARDS

Do you comply with data standards?

- Yes, ISO9001 quality management standards, ASGC (Australian Standard Geographical Classification) Codes, ICECI (International Classification for External Cause Injury) codes and access protocols in line with State Privacy Legislation.

Who enforces the standards?

- The VIFM is regularly accredited and the NCIS is assessed at this time for ISO9001 compliance along with other departments of the VIFM.

- Data standards are not enforced; however, the Australian Bureau of Statistics encourages the use of the Australian Standard Geographical Classification Codes (ASGC) to improve the comparability and usefulness of statistics, and the NCIS also displays ICD–10 codes (from ABS). The majority of the codesets are based on either those stipulated in the National Health Data Dictionary (NHDD) sponsored by the Australian Institute of Health and Welfare or the International Classification for External Cause Injury (ICECI) sponsored by the World Health Organisation.

Does your organisation utilise a data dictionary?

- Yes. The NCIS Data Dictionary was introduced when the collection was first developed. There are several data fields that were developed by a coding committee and users; these are usually case specific for the investigation and conclusion of a coronial case.

DATA QUALITY

How do you ensure data quality?

- Mandatory data fields and validation
- External entities submit data in a timely manner
- Coder education and training
- Quality Assurance Program to audit all closed cases in an attempt to ensure accuracy and consistency
- Quality Reports provided back to coders in feedback loop and requirement to amend incorrect coding
- Support phone/email for coding questions, coder tips newsletter and coding manual.
### Section 1 – DECEASED’S DETAILS

#### 1.1 Deceased’s Demographics

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>a) Family Name:</td>
<td>b) Given Name(s):</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>c) Aliases (if known):</td>
<td>d) Sex: Male Female Unknown</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>e) Date of Death (between):</td>
<td>f) Date of Birth:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td>h) Marital Status:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never Married</td>
<td>Married</td>
<td>Widowed</td>
<td></td>
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<tr>
<td></td>
<td>Divorced</td>
<td>Separated</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>i) Usual Address:</td>
<td>I) State:</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>j) Suburb/Town:</td>
<td>m) Country:</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>k) Postcode:</td>
<td>n) Residency:</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>o) Country of Birth:</td>
<td>p) Usual Occupation:</td>
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<tr>
<td>q) Employment Status:</td>
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<tr>
<td>r) Was deceased from non-English speaking background?</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Unknown</td>
<td>No</td>
<td>Yes (specify)</td>
<td></td>
</tr>
</tbody>
</table>

(NB. This question is worded to be consistent with Australian Bureau of Statistics requirements.)

| s) Was the deceased of Aboriginal or Torres Strait Islander origin? |   |
|   | No | Yes, Aboriginal origin | Yes, Torres Strait Islander Origin |
| t) Were there other deaths associated with this incident? |   |
|   | Unknown | No | Yes (specify how many) |

#### 1.2 Medical Information

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>a) Did an ambulance attend the scene?</td>
<td>Yes</td>
<td>No</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>b) Was the deceased treated by ambulance officers?</td>
<td>Yes</td>
<td>No</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>c(i) Were drugs administered by medic / paramedic prior to death?</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>No</td>
<td></td>
<td></td>
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<tr>
<td>c(ii) If yes, specify:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Date Last Visited Doctor:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Known Medical History:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>No known history</td>
<td>Yes (specify)</td>
<td></td>
</tr>
<tr>
<td>f) Was deceased known to be on medication?</td>
<td>Yes (specify)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>g) Was deceased suspected of having an infectious disease at time of death?</td>
<td>Yes (specify)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

#### 1.3 History

<p>| | | | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>a) Did the deceased have a known history of any of the following?</td>
<td></td>
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<tr>
<td>(Source of information may include medical record, police record, other official record, family/friends).</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Criminal Record</td>
<td>Intellectual Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time in Custody</td>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time in a Mental Health Institution</td>
<td>Psychiatric Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Release from an institution within the last week</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Type:</td>
<td></td>
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</tbody>
</table>

### Section 2 – LOCATION OF DEATH (tick one box only)

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>Recreation Area</td>
<td>School / Other Institution / Public Administration Area</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sports or Athletics Area</td>
<td>Correctional Facility (eg prison, youth training centre)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Farm (not incl farm house)</td>
<td>Residential Facility (eg retirement village)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital or other Health Service</td>
<td>Street or Highway</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mine or Quarry</td>
<td>Trade or Service Area</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Industrial or Construction Area</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Section 3 – ACTIVITY AT TIME OF DEATH (tick one box only)

- Sports and Active Recreation
- Engaged in Formal Education (Student)
- Resting / Sleeping / Eating / Personal Activity
- Other (specify)
- Leisure Activity
- Domestic Duties
- Volunteer Work
- Unknown
- Nursed / Cared For

Section 4 – CAUSE OF DEATH DETAILS

- a) Apparent Case Type: 
  - Suspected Suicide
  - Homicide
  - Accident
  - Natural
  - Unknown

- b) Apparent Cause of Death:
- c) Incident Circumstances: (tick ONE or MORE boxes & ensure you also complete additional section specified)
  - Natural
  - Work Related Death (section 8)
  - Unexpected Infant / Child Death (section 16)
  - Hospital Death
  - Death Involving a Weapon / Firearm (section 9)
  - Death Involving an Anaesthetic
  - Fire / Burn Related Death (section 10)
  - Hanging Death
  - Transport Related Death (section 12)
  - Homicide
  - Suspected Suicide (section 13)
  - Unknown
  - Drug/Alcohol/Poison Related Death (section 14)
  - Other (eg. electrocution, fall, sporting) (specify)

Section 5 – INCIDENT DETAILS

5.1 Incident

- a) Police Event / Reference No.: 
- b) Incident Date (dd/mm/yyyy):
- c) Approximate Incident Time (24hr format):
- d) Location Address:
- e) Suburb/Town:
- f) State:
- g) Postcode:

5.2 Found Dead / Dying

- a) Date (dd/mm/yyyy):
- b) Approximate Time (24hr format):
- c) Location Address:
- d) Suburb/Town:
- e) State:
- f) Postcode:
- g) Found By:
- h) Phone Number:
- i) Of Address:
- j) Postcode:

5.3 Last Seen Alive

- a) Date (dd/mm/yyyy):
- b) Approximate Time (24hr format):
- c) Location Address:
- d) Suburb/Town:
- e) State:
- f) Postcode:
- g) Last Seen By:
- h) Phone Number:
- i) Of Address:
- j) Postcode:

5.4 Next of Kin Details

- a) Senior Next of Kin:
- b) Relationship:
- c) Phone Number:
- d) Address:
- e) Postcode:

Shaded area = information not contained on the NCIS

NCIS Minimum Data Set – Version 4, June 2001 page 2 of 9

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People.
Section 6 – SUMMARY OF INCIDENT

a) Have or will charges be laid in relation to the death:
   - Unknown
   - Yes (specify)
   - No

b) Summary of Circumstances:

Section 7 – REPORTING INFORMATION

7.1 Death Reported to Police By

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>b) Date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Time (24hr):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Address:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Postcode:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Phone Number:</td>
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</tr>
</tbody>
</table>

7.2 Reporting Police Member

<p>| | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>b) Rank and Number:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Station:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Ph No.:</td>
<td>e) Fax:</td>
<td>f) Signature:</td>
</tr>
</tbody>
</table>

7.3 Investigating Police Member

<p>| | | |</p>
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</tr>
</thead>
<tbody>
<tr>
<td>b) Rank and Number:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Station:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Ph No.:</td>
<td>e) Fax:</td>
<td>f) Signature:</td>
</tr>
</tbody>
</table>
Section 8 – WORK-RELATED DEATH (at work, travelling to / from work or travelling as part of work)
a) Did death occur while:
☐ working (incl. travelling for work) ☐ travelling to / from work (commuting) ☐ not known if working or commuting
b) Occupation at time of death (if different from usual occupation):
c) Industry:

Section 9 – CONSUMER PRODUCT-RELATED DEATH
a) Were any products or substances significantly involved in contributing to the death?
☐ Yes ☐ No ☐ Unknown
b) If yes, describe product(s) or substance(s) : (Include make and model of product(s) if known)
Product 1:
Product 2:
Product 3:
c) How was the product or substance involved in contributing to the death?
Product 1: ☐ Defect or Malfunction ☐ Misuse ☐ Design Fault ☐ Unknown
☐ Other Problem, specify:
Product 2: ☐ Defect or Malfunction ☐ Misuse ☐ Design Fault ☐ Unknown
☐ Other Problem, specify:
Product 3: ☐ Defect or Malfunction ☐ Misuse ☐ Design Fault ☐ Unknown
☐ Other Problem, specify:

Section 10 – DEATH INVOLVING A WEAPON / FIREARM
a) Type of weapon: ☐ Firearm (complete 10.1) ☐ Other weapon (specify):
b) Who inflicted fatal wound?
☐ Deceased ☐ Other person ☐ Unknown

10.1 Firearm
a) Type of firearm (eg. make, model, type, action, calibre, category)
b)(i) Was the firearm registered?
☐ Yes ☐ No ☐ Unknown
b)(ii) If yes, to whom?
☐ Deceased ☐ User (if not deceased) ☐ Other ☐ Unknown
c) Was the user licensed to use that category of firearm?
☐ Yes ☐ No ☐ Unknown

Section 11 – FIRE / BURN RELATED DEATH
a) Setting of Incident
☐ Private Building ☐ Public Building ☐ Outdoor Area ☐ Other (specify):
If building:
b)(i) Were smoke alarms present?
☐ Unknown ☐ No ☐ Yes
b)(ii) If yes, were they activated?
☐ Unknown ☐ No ☐ Yes
c)(i) Was a sprinkler system present?
☐ Unknown ☐ No ☐ Yes
c)(ii) If yes, was it activated?
☐ Unknown ☐ No ☐ Yes
d)(i) Were there barriers to escape?
☐ Unknown ☐ No ☐ Yes
d)(ii) If yes, specify:
☐ Locked exits ☐ Barred windows ☐ Other (specify):
Section 12 – TRANSPORT-RELATED DEATH
Does not include water-vessel. Describe road/rail and weather conditions in summary of incident.

a) Types of vehicles involved in incident: (tick all relevant boxes)
- Motor Vehicle
- Motor Cycle
- Tram / light rail
- Train
- Aircraft
- Bicycle
- Other, specify:

b) No. of vehicles involved: 

(c) Role of the deceased at time of incident?
- Driver / Rider or Pilot
- Passenger
- Pedestrian
- Cyclist
- Other (specify)

e) Is drug/alcohol involvement suspected?
- No
- Yes
- Unknown

f) Vehicle / Aircraft Descriptions:

- Vehicle
- Make/Model/Description
- Year
- Speed Category

Deceased’s Vehicle: 

Vehicle 2: 

Vehicle 3: 

Vehicle 4: 

- Was the deceased wearing a seat belt?
- N/A
- Unknown
- No
- Yes

h) Were airbags installed and activated?
- N/A
- Unknown
- No
- Yes
- Specify below

i) Airbags Installed
- Driver
- Front passenger
- Right side
- Left side
- Other (specify)

j) Are cycle rider, was helmet being worn?
- Unknown
- No
- Yes

Section 13 – SUSPECTED SUICIDE

a) What evidence is there to indicate that the deceased intended suicide? (tick the relevant box(es))
- Statement to Family/Friends
- Statement to Health Professional
- Other (specify):

b) Has the deceased previously attempted suicide?
- No
- Yes
- Unknown

b(i) If yes, approx number of times:

b(ii) Has the deceased previously been hospitalised for self harm?
- No
- Yes
- Unknown

b(iii) If yes, approx number of times:

- Relationship Breakdown
- Sexual Abuse
- Financial Problems
- Loss of a Loved One
- Illness
- Prospect of Criminal Sanction
- Alcohol / Drug Dependency
- Unknown
- Other (specify)

e) Was deceased being treated / seen by any of the following professionals? (tick relevant box(es))
- General Practitioner
- Psychiatrist
- Psychologist
- Case Manager

f) Was the death accompanied by the murder / suicide of other person(s)?
- No
- Yes

f(i) If yes, what was the relationship between the deceased and the person(s)?

Shaded area = information not contained on the NCIS

NCIS Minimum Data Set – Version 4, June 2001 page 5 of 9
Section 14 – SUSPECTED DRUG / ALCOHOL / POISON RELATED DEATH

a)(i) Was there evidence of drug / alcohol / substance use? □ Yes □ No

a)(ii) If yes, tick the relevant box(es):
- □ Alcohol or empty containers
- □ Prescription or over-the-counter drugs
- □ Illicit / prohibited drugs
- □ Poisons or gases (including carbon monoxide)
- □ Injecting or other drug paraphernalia (eg. needle, syringe, tourniquet, bong, straw)
- □ Statement by deceased prior to death or by witness
- □ Items related to volatile substance abuse (eg. petrol, paint, glue)

b)(i) Was there evidence of drug administration on the body of the deceased? □ Unknown □ No □ Yes

b)(ii) If yes, what? (eg injection marks, powder on nose)

14.1 Suspected Drug / Substance Abuse

a) Apparent substance(s) used (if known):
- □ Date of last use:
- □ Time of last use:
- □ Administered By: □ Unknown □ Self □ Other
- □ Location of last use:
- □ Symptoms of drug use:
- □ When symptoms first appeared:
- □ Route of administration (tick one or more)

14.2 History

a) Did the deceased have a history of any of the following? (tick the relevant boxes)
Source of information may include medical records, police records, other official records, family/friends
- □ Abuse of alcohol □ Abuse of other drugs
- □ Abused of prescription of over-the-counter drugs □ Source: □ heroin or other opiates
- □ Abuse of volatile substances (eg. petrol, glue, paint) □ Source: □ amphetamines
- □ Exposure to poisons or gases: □ Type: □ cocaine
- □ Drug treatment program(s): □ Source: □ marijuana

14.3 Prescription Medication

a)(i) Was the deceased recently prescribed any medication? □ Unknown □ No □ Yes

a)(ii) If yes, date:
- □ Prescribing doctor:
- □ Phone:
- □ Address:
- □ Suburb:
- □ Postcode:

b) List the drug(s) and quantities prescribed and amount remaining:

Shaded area = information not contained on the NCIS
NCIS Minimum Data Set – Version 4, June 2001 page 6 of 9
### Section 15 - DROWNING / WATER-RELATED DEATH

#### 15.1 Type of Aquatic Environment

<table>
<thead>
<tr>
<th></th>
<th>b) Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Place</td>
<td>Public</td>
</tr>
<tr>
<td>-</td>
<td>Bath tub</td>
</tr>
<tr>
<td>-</td>
<td>Dam</td>
</tr>
<tr>
<td>-</td>
<td>Ocean</td>
</tr>
<tr>
<td>-</td>
<td>Swimming Pool (above ground)</td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
</tr>
</tbody>
</table>

#### 15.2 Activity at Time of Death (tick the relevant box(es))

- Fishing (including spear fishing)
- Skin Diving / Snorkelling
- Attempting a Rescue
- Diving (eg. Scuba / SSBA / Platform)
- Swimming, Paddling or Wading
- Walking / Playing Near Water
- Incident Involving a Water Vessel
- Board Riding (eg. Surfing, Body Boarding)
- Water-skiing
- Bathing
- Unknown, no witness
- Other (specify)

#### 15.2.2 Did the activity involve any of the following? (tick the relevant box(es))

- Fell / Wandered / Jumped into water
- Injury / accident
- Swept away by water (eg. off rocks, by rip)
- Hypothermia

#### 15.3 Deceased’s Swimming Ability

- Strong
- Competent
- Weak
- Non-Swimmer
- Unknown

#### 15.4 Death Involving a Water Vessel

**a)** Did the death involve a water vessel?  
- Yes
- No (go to 15.5)

**b)** Type of Vessel:  
- Commercial
- Recreational
- Unknown

**c)** Number of people on board the vessel?  
- Yes
- No
- Unknown

**d)** Were life jackets / personal flotation devices available on the vessel?  
- Yes
- No
- Unknown

**d)** If yes, was a life jacket / personal flotation device worn by the deceased?  
- Yes
- No
- Unknown

#### 15.5 Supervision

**a)** Was the deceased under supervision?  
- Unknown
- No (go to c)
- Yes (go to b)

**b)** If yes, by whom?  
- b(i) Describe the extent and level of the supervision:

**c)** Was the area being patrolled by life guards at the time?  
- N/A
- Unknown
- No
- Yes
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

15.6 Conditions at Time of the Incident

a) What were the prevailing environmental conditions where the death occurred?

i) Weather:  
- Unknown
- Clear
- Hazy
- Cloudy
- Rain
- Flood
- Fog

ii) Wind:  
- Unknown
- None
- Light
- Strong
- Gale

iii) Tide:  
- Unknown
- In
- Out

iv) Waves:  
- Unknown
- < 1 metre
- 1 – 2 metres
- > 2 metres

15.7 Rescue & Resuscitation

a) Was any attempt made to rescue the deceased?

- Unknown
- No
- Yes (by whom)

b) What equipment was used to assist in this rescue?

c) Was any attempt made to resuscitate the deceased?

- Unknown
- No
- Yes (by whom)

d) Was the person trained in resuscitation?

- Unknown
- Yes
- No

15.8 Signage

a) Were there warning signs in the area where the death occurred?

- N/A
- No
- Yes (specify)

15.9 Marine Animals

a) Was the death caused by a water animal? (e.g. shark, crocodile, box jelly fish)

- N/A
- Unknown
- No
- Yes (specify)

15.10 Swimming Pools / Spas / Dam / Pond

a)(i) Was the pool/spa/dam/pond fenced?  
- No (go to a(ii))
- Yes (specify and go to a(iii))

a)(ii) If no, were there any other barriers between the pool/spa/dam/pond and other structures? (e.g. door and window locks)

- Unknown
- No
- Yes (specify)

a)(iii) If yes, which diagram best represents fence installation? (S = Structure eg. house)

- 1
- 2
- 3
- 4
- 5
- 6
- 7 (other)

b) If “other”, describe fence or other barrier separating pool/spa/dam/pond from structure.

c) Describe type of fence (e.g. height, material, horizontal bars)

d) Using the diagram, indicate the position of gate in reference to the pool/spa/dam/pond.

- Top
- Bottom
- Left
- Right

e) Was the fence or gate defective?

- Unknown
- No
- Yes (describe defect)

f) Was gate self-latching?

- Unknown
- No
- Yes

g) Was gate open or closed at the time of the incident?

- Unknown
- Open
- Closed

Shaded area = information not contained on the NCIS
NCIS Minimum Data Set- Version 4, June 2001 page 8of 9
### Section 16 – UNEXPECTED INFANT / CHILD DEATH

#### 16.1 Scene

<table>
<thead>
<tr>
<th>a) Where was the infant found?</th>
<th>Parent’s Bedroom</th>
<th>Other (specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant’s Bedroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Was the infant sleeping alone?</td>
<td>Yes</td>
<td>No (go to bi)</td>
</tr>
<tr>
<td>b(i) If No, with whom?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position of infant when found</td>
<td>On Back</td>
<td>On Stomach</td>
</tr>
<tr>
<td>Head to right side</td>
<td>Head to left side</td>
<td>Head face down</td>
</tr>
<tr>
<td>d) Were any items covering the infant’s head/face?</td>
<td>Unknown</td>
<td>No</td>
</tr>
<tr>
<td>e) Were there signs of mechanical causes of strangulation or suffocation?</td>
<td>Unknown</td>
<td>No</td>
</tr>
</tbody>
</table>

#### 16.2 Medical Information

<table>
<thead>
<tr>
<th>a) Was the infant born prematurely?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>b) Did the infant have any of the following in the 2 weeks prior to death?</td>
<td>Fever</td>
<td>Recent injury or other illness</td>
<td></td>
</tr>
<tr>
<td>Cold</td>
<td>Wheezing</td>
<td>Diarrhoea</td>
<td></td>
</tr>
<tr>
<td>Sniffles</td>
<td>Vomiting</td>
<td>Recent Inoculation</td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Was the child known to have any of the following?</td>
<td>Abnormal Development</td>
<td>Recent Exposure to Contagious Disease</td>
<td>Medical Equipment in Use</td>
</tr>
<tr>
<td>Known Allergies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d(i) Has there been any other child die in the immediate family?</td>
<td>Unknown</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>d(ii) If yes, what was the cause of death?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 16.3 Other Information

<table>
<thead>
<tr>
<th>a) Were there any signs of habitual smoking in the household?</th>
<th>Unknown</th>
<th>No</th>
<th>Yes (describe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>b) Was there any evidence of alcohol or drug use around the infant?</td>
<td>Unknown</td>
<td>No</td>
<td>Yes (describe)</td>
</tr>
<tr>
<td>c) Is there any history of family violence?</td>
<td>Unknown</td>
<td>No</td>
<td>Yes (describe)</td>
</tr>
</tbody>
</table>

---

Shaded area = information not contained on the NCIS

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An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
INFORMATION SHEET FOR
GOVERNMENT DEPARTMENTS AND AGENCIES AND
DEATH/INJURY SURVEILLANCE OR RESEARCH AGENCIES

GENERAL INFORMATION
As of 1 January 2001, government and research agencies are able to gain access to coronial data from the National Coroners Information System (NCIS) rather than directly from Australian State and Territory Coroners' Offices. All requests for access to coronial information for research purposes must be referred to the NCIS (a section of the Victorian Institute of Forensic Medicine (VIFM)) as a request for access to the NCIS database.

What is the NCIS?
The NCIS is a centralised coronial database that was originally developed by the Monash University National Centre for Coronial Information (MUNCCI), and is now managed by the VIFM. It contains case detail information from the coronial files of all participating States and Territories. A detailed list of available data items is contained on the next page.

Access to the NCIS is available to authorised users via the Internet. You must use an Internet Explorer browser, Version 5.0 or greater. You cannot access the NCIS until your application has been approved and you have been issued with a user name and password.

The benefit of the NCIS is that it makes coronial data available in a more timely and accessible way. It also relieves the burden on participating coronial offices of managing access to coronial files.

Who May Apply?
Applications are open to individuals or organisations with a role or interest in public health and safety (eg research and public sector agencies). If you have a personal interest in a particular coronial case (for example, you are a relative or friend of a deceased person) you should contact the Office of the State or Chief Coroner in which the case was reported. If you are a solicitor acting in a current coronial matter you should also contact the Office of the relevant State or Chief Coroner.

Is There an Access Fee?
Yes, there may be a fee payable by your organisation. All fees are levied on a cost recovery basis and will depend on the product or service selected. For further information about what fees may apply, please refer to the NCIS website, or contact the NCIS on nci@vifm.org.

What is the Quality of the Data?
The data contained in the NCIS is provided by participating coronial offices. The quality of the data is therefore the same as that contained in coronial files. The NCIS has in place a rigorous quality assurance program which seeks to identify and rectify any data coding issues.

What Browser Do I Need?
Internet Explorer 5.0 or greater.

---

1 The process in this Information Sheet does NOT apply to family members or friends of a deceased, a solicitor representing a party in an inquest or to private organisations.
What Data Is Available?

The NCIS contains variables (both text and coded) and key text reports. Variables include:

- Name*, Date of birth*, Date of notification of death
- Age, Sex, Place of usual residence*
- Period of residence in Australia, Country of birth
- Employment status, Usual occupation
- If a work-related incident: Occupation at the time, Industry
- Marital status
- Indigenous identification
- Time/location of incident, Activity at time of incident
- Intent (both suspected at time death reported and final)
- Mechanism of injury (primary, secondary and tertiary)
- Object or substance involved (primary, secondary and tertiary)
- Cause of death (primary, secondary and tertiary)
- Where the death is related to a motor vehicle accident: Vehicle type, Driver/passenger, Context

Additional coded fields provided by the Australian Bureau of Statistics (ABS):
- ICD-10 Cause of Death codes (primary and underlying codes)
- ASGC Residential location codes

Key text reports include:
- Police narrative of circumstances*, Autopsy report*, Toxicology report* and Finding*.

The items marked with an asterisk (*) are identifying data items which are only available to Level 1 users (see below).

Data for all participating jurisdictions dates back to 1 July 2000, except for Queensland, for which data is only available from 1 January 2001 onwards. If you require access to data for cases reported prior to these time periods, please contact the NCIS to discuss what information may be made available.

What Levels of Access Are There?

There are two levels of access that may be approved:

**Level 1** includes all variables and reports, including the items listed above with an asterisk (*).

**Level 2** provides all data items except those items above with an asterisk (*).

If you intend to seek Level 1 access your application will need to clearly specify why these data items are relevant and important to your stated purpose. Similarly, if you are seeking access to indigenous origin identification, you will also need to specify why this data item is relevant and important to your stated purpose.

**THE APPLICATION PROCESS**

All Third Party applications for access to NCIS data must be considered by the Victorian Department of Justice Research Ethics Committee (‘the Ethics Committee’).
Applications are usually approved for periods of up to three (3) years.

Whether you are seeking Level 1 or Level 2 access, all applications for access to NCIS data must be submitted to the NCIS on the required application forms. If you are seeking Level 1 access for Western Australian data you must also follow the special procedure set out on the next page.

The current version of the Ethics Committee’s Application Form is May 2008, with Appendix A also required to be completed in order to supplement the Application. There are strict time lines for the submission of applications. The submission dates are listed on the next page.

You are required to lodge your application via email. The application process will generally take between 8 to 12 weeks.

All applications will first be considered by the NCIS Research Committee (NRC) which will form an opinion on the adequacy of each application. The NRC meets on an as needs basis. If there are any problems or issues with your application at this stage, you will be contacted by the NCIS as soon as practicable to discuss either amending the application or other appropriate action.

All applications that are approved by the NRC will then be forwarded to the Ethics Committee, which meets at the end of each month. The applicant will be advised of the Ethics Committee’s decision within five working days of the Committee meeting.

If your application is approved by the Ethics Committee, your organisation will be required to enter into a written NCIS Access Agreement with the Victorian Institute of Forensic Medicine (VIFM). A template of the Access Agreement is available on our web site. Once the Access Agreement is executed by both the applicant organisation and the VIFM, and the relevant fee has been paid, user names and passwords will then be issued to each approved Authorised User.

In making an application for access to NCIS data, please note the following:

• If the applicant is from an institution which has its own ethics committee, the project must be referred to and approved by that committee before the application is submitted to the NCIS Access Liaison Officer for consideration. If the project is not submitted to the host institution’s ethics committee, the reasons for this must be clearly outlined in the Application.

• It is a term of the Access Agreement that the applicant agrees to be bound by the terms of the NCIS Privacy Protocols and any conditions specified by the Ethics Committee.

• The applicant will be required to submit progress reports and /or an annual report on the conduct of the project to the NCIS/VIFM by the dates specified in the Access Agreement.

• The applicant will be responsible for ensuring that there are appropriate security arrangements in place in their organisation and that there are appropriate procedures in place for the disposal of NCIS data where required in accordance with the provisions of the Access Agreement and the NCIS Privacy Protocols.

APPLICATIONS FOR LEVEL 1 ACCESS TO WESTERN AUSTRALIAN DATA

Western Australia requires that applications for Level 1 access to Western Australian data must also be approved by the Western Australian Coronial Ethics Committee (WA CEC). Once your application has been considered by the Department of Justice Research Ethics Committee, the NCIS Access Liaison Officer will manage the process of applying to the WA CEC on your behalf.
WHEN CAN APPLICATIONS BE MADE?
Application forms are available by following the links to Research Ethics on the Victorian Department of Justice web site http://www.justice.vic.gov.au. Applications should be submitted via email to ncisapplications@vifm.org in accordance with the due dates specified below.

PROPOSED SUBMISSION TIMELINES 2009

<table>
<thead>
<tr>
<th>Department of Justice Research Ethics Committee</th>
<th>Western Australian Coronial Ethics Committee</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closing Date</td>
<td>Meeting Date</td>
</tr>
<tr>
<td>15 January 2009</td>
<td>27 January 2009</td>
</tr>
<tr>
<td>12 February 2009</td>
<td>24 February 2009</td>
</tr>
<tr>
<td>19 March 2009</td>
<td>31 March 2009</td>
</tr>
<tr>
<td>16 April 2009</td>
<td>28 April 2009</td>
</tr>
<tr>
<td>14 May 2009</td>
<td>26 May 2009</td>
</tr>
<tr>
<td>18 June 2009</td>
<td>30 June 2009</td>
</tr>
<tr>
<td>16 July 2009</td>
<td>28 July 2009</td>
</tr>
<tr>
<td>13 August 2009</td>
<td>25 August 2009</td>
</tr>
<tr>
<td>17 September 2009</td>
<td>29 September 2009</td>
</tr>
<tr>
<td>15 October 2009</td>
<td>27 October 2009</td>
</tr>
<tr>
<td>12 November 2009</td>
<td>24 November 2009</td>
</tr>
</tbody>
</table>

FURTHER INFORMATION
If you would like any further information please visit the NCIS web site at www.ncis.org.au. Queries may also be directed to ncisapplications@vifm.org, or telephone (03) 9684 - 4323.
Appendix 9

Dataset H: Operational Data Store (Mental Health Client Management Interface)

CUSTODIAN

Custodian: Information, Analysis and Reporting (IAR) Unit, Mental Health and Drugs Division, Department of Human Services

Name: Tracey Burgess

Position/job title: Manager, IAR Unit

Phone: 03 9096 6112

Email Address: tracey.burgess@dhs.vic.gov.au


SUMMARY

The Operational Data Store (ODS) is the central data repository for the Victorian public hospital Mental Health Client Management Interface (CMI).

When the clinical decision is made to commence a period of care for a consumer in a Mental Health hospital facility, it is recorded through the opening of a case on the site’s CMI. Data are then accessible to the Data Custodian via the state-wide centralised ODS, however, not all data recorded in the CMI are accessible in the ODS.

These applications were designed to enable capture, management and access to a state-wide centralised information system required by mental health practitioners, the Office of the Chief Psychiatrist (OCP), the Mental Health Review Board (MHRB) and Department of Human Services.

This questionnaire relates to the centralised ODS database for which the IAR Unit is Data Custodian.

DATA COLLECTION

What data are captured in this database?

When the child is the client:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Birth information</td>
<td></td>
</tr>
</tbody>
</table>

Note: There is capacity to record information on the client’s mother and father in the hospitals CMI, however, this information is not accessible via the centralised ODS, and therefore, not available to researchers.
Does the database include identifying information?

Mother:  
- Name: Nil
- Date of birth
- Address

Child:  
- Name
- Date of birth

Father:  
- Name
- Date of birth
- Address

How are the primary data collected?
- Administrative staff enter information directly into the database from interview with the person acting on behalf of the client.

When are the data collected?
- Before, during and after an episode of care.

How do the custodians obtain the data that are included in the database?
- Data are accessible to the Custodian on the ODS as soon as they are entered onto the CMI by hospital administrators.

Who are the external entities?
- Administrators in public hospital based mental health services.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- Data are stored electronically.

Where do the custodians store the data?
- On and off the premises, the Department of Human Services, 50 Lonsdale Street, Melbourne, 3000.

Are the data easily accessible?
- Yes, a selection of CMI data are accessible to researchers via the ODS Custodian.

Is there a cost involved in accessing the data?
- No.

REPORTING

How often are the data received by the data repository/custodians?
- Data are accessible within 12–24 hours.

Is reporting of these data to the custodian a statutory requirement?
- Yes, the Mental Health Act (1986).

Is reporting of these data an administrative requirement?
- Yes, under the Victoria Public Hospitals and Mental Health Services: Policy and Funding Guidelines 2008–09.

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Do you submit your data to a national or state database?
- Yes, the Australian Institute of Welfare National Minimum Dataset.

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes.

When did it become mandatory for vendors to populate the Indigenous identifier field?

When is the Indigenous status entered?
- At the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Aboriginal but not Torres Strait Islander origin.
- Torres Straight Islander but not Aboriginal origin.
- Both Aboriginal and Torres Strait Islander origin.
- Neither Aboriginal nor Torres Strait Islander origin.
- Question unable to be asked.
- Patient refused to answer.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
- Not known.

What are the barriers to obtaining information about a person’s Indigenous status?
- Indigenous patient may not feel comfortable declaring their status.
- Service Provider may not wish to appear to be discriminating.
- Administrative staff not comfortable asking the question.
- Administrative staff fear a negative response to the question being asked.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
- No.
How confident are you that the Indigenous status is accurate?
- Not confident.

ACCESS TO DATA

How does one obtain access to these data?
- By application to the Manager, Information, Analysis and Reporting Unit, Mental Health and Drugs Division, Department of Human Services.

What ethics clearances are required to access your data?
- Ethics approval is required for access to any identifiable data.

Do you have an access agreement outlining the conditions of access to your data base?
- The Conditions of Release of Client Level Data Sets from the Victorian Redevelopment of Acute and Psychiatric Information Directions (RAPID) is currently under review. Version 2 of this document is due for release in late 2009. Please contact the data custodian for more information.

Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards?
- Yes, National Health Data Standards.

Who enforces the standards?
- Information Management Strategy Unit, Department of Human Services.

Does your organisation utilise a data dictionary?
- Yes, based on the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
- Mandatory data fields
- Timely submission of data
- Staff education
- Timely entry of data
- Audits to ensure accuracy and consistency
- Warning and error alerts.
Appendix 9

Dataset I: Primary Health Data Collection v4.01

CUSTODIAN

Custodian: Primary Health Branch, Rural and Regional Health and Aged Care Division, Department of Human Services

Name: Janet Laverick

Position/job title: Director, Primary Health Branch

Phone: 03 9096 0000

E- Mail Address: janet.laverick@dhs.vic.gov.au

SUMMARY

The Primary Health Data Collection is reported to by agencies funded to provide community based allied health and nursing services. Client demographics and service provision measures are reported on a quarterly basis.

DATA COLLECTION

What data are captured in this database?

When the patient is a child:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(date of birth, suburb, postcode and LGA)</td>
<td></td>
</tr>
</tbody>
</table>

Does the database include identifying information?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Date of birth</td>
<td>Nil</td>
</tr>
</tbody>
</table>

How are the primary data collected?

- Primary data are collected by clinicians/administrative staff and entered directly into the agency’s client management system. Data are then submitted electronically to DHS as per reporting requirements. On receipt at DHS data are loaded to a central data repository.

When are the data collected?

- Data are collected during and after each occasion of service/event.
How do the custodians obtain the data that are included in the database?

- Data are reported quarterly and transmitted electronically.

Who are the external entities?

- Agencies funded by the Victorian Government to provide community health services in Victoria.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Data are stored electronically.

Where do the custodians store the data?

- Data are stored on the premises at 50 Lonsdale St, Melbourne 3000.

Are the data easily accessible?

- Data are relatively easy to access.

Is there a cost involved in accessing the data?

- No.

REPORTING

How often are the data received by the data repository/custodians?

- Data are received quarterly.

Is reporting of these data to the custodian a statutory requirement?

- No, reporting is not a statutory requirement.

Is reporting of these data an administrative requirement?

- Yes, reporting is a requirement of service agreements with funding from the department.

Do you submit your data to a national or state database?

- Yes, an aggregate subset of the data is reported to the Commonwealth in the AIMS database. This includes quarterly counts of occasions of service by the service type (physiotherapy, podiatry, etc) that were provided by hospitals funded to provide community services, particularly in rural areas.

INDIGENOUS STATUS

Is an Indigenous identifier used?

- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?

- Yes, Indigenous status is specified as a mandatory field for vendors to populate but there is a high rate of ‘not stated’.
When did it become mandatory for vendors to populate the Indigenous identifier field?
• 2001.

When is the Indigenous status entered?
• Good practice would have Indigenous status entered at the time of collection but the department cannot guarantee this is always the practice.

Are questions asked to determine the Indigenous status of a client/patient?
• It is departmental policy that this is the case, but it cannot be guaranteed that this policy is implemented in all reporting agencies.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
• Aboriginal but not Torres Strait Islander origin.
• Torres Straight Islander but not Aboriginal origin.
• Both Aboriginal and Torres Strait Islander origin.
• Neither Aboriginal nor Torres Strait Islander origin.
• Not stated.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
• Unknown.

What are the barriers to obtaining information about a person’s Indigenous status?
• The custodian’s work area cannot respond on the behalf of agencies.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
• There are seven client management systems reporting to this collection. Specifications for the collection require this element to be mandatory however the custodian’s work area cannot confirm what each system allows.

How confident are you that the Indigenous status is accurate?
• Not confident.

ACCESS TO DATA

How does one obtain access to these data?
• With a written request including a business/research case for the use of the data.

What ethics clearances are required to access your data?
• Depending on the level of information required, ethics clearance may be required. Advice would be provided on receipt of a request.
Do you have an access agreement outlining the conditions of access to your database?
• Standard DHS data access agreements are used.

Are your data used for research purposes?
• Infrequently.

DATA STANDARDS

Do you comply with data standards?
• Yes, DHS standards such as the Common Client Data Dictionary are complied with currently and further development of the collection is aligned with data standardisation work across DHS.

Does your organisation utilise a data dictionary?
• Yes, the DHS Common Client Data Dictionary managed by the DHS Information Management Strategy Unit.

DATA QUALITY

How do you ensure data quality?
• Mandatory data fields
• External entities submit data in a timely manner
• Staff education
• Timely entry of data
• Audits to ensure accuracy and consistency
• Warning and error alerts.
Appendix 9

Dataset J: Victorian Admitted Episodes Dataset

CUSTODIAN

Custodian: Health Information Section, Funding Health & Information Policy Branch, Metropolitan Health & Aged Care Services, Victorian Department of Human Services

Name: Dr. Neil Powers

Position/job title: Senior Information Policy Advisor

Phone: 03 9096 0000

E- Mail Address: Neil.Powers@dhs.vic.gov.au


SUMMARY

The Department of Human Services (DHS) maintains morbidity data on all admitted patient episodes of care in Victoria in order to fund public hospitals equitably under the casemix system and to support health service planning, policy formulation and epidemiological research.

These are consistent with the State’s reporting obligations under the National Health Information Agreement and the Australian Health Care Agreement, and section 9 of the Victorian Health Act 1958 (General Amendment 1988) which requires the Secretary of the Department to establish a comprehensive information system on the:

- causes, effects and nature of illness among Victorians
- determinants of good health and ill health
- utilisation of health services in Victoria.

To meet these objectives, all public and private acute hospitals, including acute facilities in rehabilitation and extended care institutions and day procedure centres, are required to report the relevant minimum data set of admitted patient activity.

These (de-identified) demographic, administrative and clinical data are then compiled into the Victorian Admitted Episode Dataset (VAED). Victorian hospitals must transmit data to the VAED via the PRS/2 system, an interface between a hospital’s in-house patient management system and the VAED.

DATA COLLECTION

What data are captured in this database?

a) In the event of a birth of a child:
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td>Smoking status</td>
<td>Birth information</td>
<td></td>
</tr>
<tr>
<td>Delivery information</td>
<td>Death information</td>
<td></td>
</tr>
<tr>
<td>Death information</td>
<td>Delivery information</td>
<td></td>
</tr>
</tbody>
</table>

Note: Data on a mother and child are recorded in separate patient records. Information on the father is not collected at the time of birth. Data are not collected for the mother or father if a child is admitted to hospital for an episode other than birth.

b) In the event of an infant, child or youth admission (not birth related):

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td>Demographic information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Does the database include identifying information?
The VAED contains potentially identifying data items such as date of birth and Medicare number. However, it does not include the full given or surname or address. A combination of some or all of the following data items could identify a patient.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td>Age</td>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td>Date of birth</td>
<td></td>
</tr>
<tr>
<td>Medicare number and the first three letters of the given name on the card</td>
<td>Medicare number and the first three letters of the given name on the card</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Patient locality; suburb and postcode</td>
<td>Patient locality; suburb and postcode</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td>Country of birth</td>
<td></td>
</tr>
</tbody>
</table>

Note: Data on a mother and child are recorded in separate patient records in the event of a birth. Data are not collected on the mother if a child is admitted for an episode other than birth.

How are the primary data collected?
- Hospital personnel, predominantly pre-admission and admission staff and ward clerks enter patient demographic information directly into the Patient Record System.

When are the data collected?
- Data are collected before, during and after an episode of care.

How do the custodians obtain the data that are included in the database?
- Hospitals submit data to DHS electronically on a monthly basis.
Who are the external entities?
- Victorian public and private hospitals.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- Electronically.

Where do the custodians store the data?
- On the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000.

Are the data easily accessible?
- No, data are kept at unit record level and privacy legislative provisions are rigorous.

Is there a cost involved in accessing the data?
- Yes, there is a cost for some users including universities, students and other members of the public.

REPORTING

How often are the data received by the data repository/custodians?
- Data are transmitted to the custodian on a monthly basis.

Is reporting of these data to the custodian a statutory requirement?
- Yes, DHS requires all acute hospitals registered under the Health Services Act 1988 to report relevant admitted patient activity to the VAED using data formats and transmission protocols specified by the Department.

- Private hospitals are required to submit data as specified in the Health Services (Private Hospitals and Day Procedure Centres) Regulations 2002.

- Data must be consistent with the State’s reporting obligations under the National Health Information Agreement, the Australian Health Care Agreement, and section 9 of the Victorian Health Act 1958.

- In addition, the Health Records Act 2001 regulates the collection and handling of health data to protect the privacy of individuals’ health information.

Is reporting of these data an administrative requirement?
- Yes, under the Victoria–public hospitals and mental health services: Policy and funding guidelines 2008–09.

Do you submit your data to a national or state database?
INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes, it is mandatory for hospitals to populate the Indigenous identifier.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- The Indigenous identifier was introduced in 1993, and has been mandatory since then.

When is the Indigenous status entered?
- At the time of patient registration.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes, hospital staff are required to ask clients of their Indigenous origin.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Aboriginal but not Torres Strait Islander origin.
- Torres Straight Islander but not Aboriginal origin.
- Both Aboriginal and Torres Strait Islander origin.
- Neither Aboriginal nor Torres Strait Islander origin.
- Question unable to be asked.
- Patient refused to answer.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
- Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
- Aboriginal patients may not feel comfortable declaring their status to administrative staff.
- Administrative or medical staff may feel that the question is irrelevant.
- Administrative staff may not feel comfortable asking the question.
- Administrative staff do not understand why the question is being asked.
- Administrative staff fear a negative response to question being asked.
- Time pressures on Administrative staff.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
- Unsure of the setup at individual hospitals, however, the field cannot be left blank in the consolidated system.
How confident are you that the Indigenous status is accurate?
- Confidence varies depending on the collecting hospital. The coverage of Indigenous status tends to vary according to the size of the local Aboriginal population and the geographic location. Accuracy tends to be better in rural hospitals where the Aboriginal population is larger, and in hospitals with Aboriginal Hospital Liaison Officers.

From what year would you be confident of accurate data collection?
- Accuracy is improving with strategies to educate registration staff and encourage self identification.

ACCESS TO DATA

How does one obtain access to these data?
- By written request to the data custodian providing full details of the use to which data would be put, together with a list of all data items required. Authorisation is not automatic.

What ethics clearances are required to access your data?

Do you have an access agreement outlining the conditions of access to your data base?

Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards?
- Yes, standards are established and maintained by the data custodian's work area, Health Information, Funding, Health & Information Policy Branch, DHS.

Does your organisation utilise a data dictionary?
- Yes, the data dictionary was developed by DHS with appropriate reference to other sources such as National Health Data Dictionary, ABS etc.

DATA QUALITY

How do you ensure data quality?
- Mandatory data fields
- External entities submit data in a timely manner
- Staff education
- Audits to ensure accuracy and consistency
- Warning and error alerts.
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
Appendix 9

Dataset K: Victorian Birth Defects Register

CUSTODIAN

Custodian: Consultative Council on Obstetrics and Perinatal Mortality and Morbidity (CCOPMM).

Name: Anne-Maree Szauer

Position/job title: Manager, Clinical Councils Unit, DHS

Phone: 03 9096 2759

Email Address: anne-maree.szauer@dhs.vic.gov.au


SUMMARY

The Victorian Birth Defects Register (VBDR) collects information on all birth defects for livebirths, stillbirths and terminations of pregnancy occurring since January 1, 1982. The maintenance of this register is an ongoing function of the CCOPMM.

A birth defect is an abnormality in body structure or chemistry which was present at birth, although it may not have been noticed at birth. Birth defects may be first recognised long after birth. The VBDR holds information on diagnoses made in a child up to 15 years of age.

The VBDR:

- determines how often birth defects are occurring in Victoria and identify changing health service needs (prevalence and survival data);
- gives statistical information to organisations responsible for planning and providing health care facilities for those with birth defects, or who provide information to those concerned about having a baby with a birth defect;
- provides information for epidemiological research to increase knowledge of aetiology and preventability of birth defects;
- assesses effectiveness of primary prevention and screening for birth defects;
- investigates reports of community and health provider concerns related to perceived clusters or changes in frequency of birth defects; and
- provides data to the National Perinatal Statistics Unit and to the International Clearinghouse for Birth Defects Monitoring Systems.

Since 1992 the VBDR has been updated from hospital inpatient listings from the Royal Children’s Hospital (RCH) detailing all children born since 1982 who have subsequently been admitted to the RCH with a birth defect. We have also obtained listings of all children born since 1982 who have visited the RCH Cardiology Unit and Genetic Health Services Victoria Metabolic Clinic, either as an
inpatient or outpatient. This procedure has also been adopted for Monash Medical Centre where the inpatient listings date back to 1992.

**DATA COLLECTION**

**What data are captured in this database?**

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Indigenous status (from Jan 09)</td>
<td>Nil</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td>Pregnancy information</td>
<td>Birth information</td>
<td></td>
</tr>
<tr>
<td>Delivery information</td>
<td>Delivery information</td>
<td></td>
</tr>
<tr>
<td>Death information</td>
<td>Death information</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Does the database include identifying information?**

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name</td>
<td>Nil</td>
</tr>
<tr>
<td>Address</td>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How are the primary data collected?**

- The VBDR places much reliance on the notification of birth defects from midwives completing the Perinatal *Birth Report Form A*; approximately 50 per cent of birth defects are notified this way.
- The other 50 per cent are notified by a variety of sources: hospital inpatient and outpatient listings, maternal and child health nurses, cytogenic laboratories, death certificates and autopsy reports, and private paediatricians who complete a Birth Defects Notification Form.

**When are the data collected?**

- Data are collected before, during and after an episode of care. Some information may be collected at the time of birth and other information may be collected long after birth when the defect is first recognised.

**How do the custodians obtain the data that are included in the database?**

- Birth data are submitted routinely by midwives completing the Perinatal *Birth Report Form A*.
- Additional information is provided on request by maternal and child health nurses, cytogenic laboratories, the Coroner and private paediatricians. Listings are also provided by the Royal Children’s Hospital, Monash Medical Centre and Genetic Health Services Victoria.

**Who are the external entities?**

- External entities include midwives, maternal and child health nurses, cytogenic laboratories, the Coroner and private paediatricians.
STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- In electronic and paper base formats.

Where do the custodians store the data?
- Current data is stored on the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000. Archived data are stored at the State Archives.

Are the data easily accessible?
- Yes, electronic data are easily accessible. An approval process must be adhered to in accordance with CCOPMM guidelines prior to any access being granted.

Is there a cost involved in accessing the data?
- No.

REPORTING

How often are the data received by the data repository/custodians?
- Data are submitted by midwives continuously and data from other sources are received on request.

Is reporting of these data to the custodian a statutory requirement?
- Reporting regarding anything required for CCOPMM to meet its functions can be requested by CCOPMM under 162FA of the Act. In the case of birth defects, this information has been requested of the Royal Children’s Hospital and Monash Medical Centre. Information received on the birth form is a statutory requirement, however not all birth defects are identified at the time of birth; therefore other sources of notification are used.

Is reporting of these data an administrative requirement?
- No.

Do you submit your data to a national or state database?
- Yes, data are submitted to the National Perinatal Statistics Unit and the International Clearinghouse for Birth Defects Monitoring Systems

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.
Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes, it is mandatory for midwives to populate the Indigenous identifier when completing the perinatal data collection.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- For midwives: 1982 (perinatal data collection).

When is the Indigenous status entered?
- At the time of collection.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes.

What possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin?’
- Aboriginal
- TSI
- No.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
- Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
- The VPDCU believes there to be an under reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.

How confident are you that the Indigenous status is accurate?
- Unsure.

ACCESS TO DATA

How does one obtain access to these data?
- Processes relating to the access of data for research purposes were reviewed in November 2008.

- All requests for unpublished information must be put in writing to CCOPMM (if not for the purpose of formalised research). See request form attached or via web link: <http://www.health.vic.gov.au/perinatal/forms>

- A copy of the request will be forwarded to the CCOPMM representative for approval. The CCOPMM encourages the release of data to health professionals for statistical and research purposes; however, the CCOPMM must comply with the Act and any information that identifies any patient, cannot be provided to any individual external to CCOPMM for the purpose of research without the written consent of:
  - written permission has been given by the mother concerned; and
b. if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and  
c. if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.


What ethics clearances are required to access your data?
• Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted Human Research Ethics Committee must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.

Do you have an access agreement outlining the conditions of access to your data base?
• Yes, see attached: Data release policy.

Are your data used for research purposes?
• Yes.

DATA STANDARDS

Do you comply with data standards?
• Yes, the majority of data items comply with the National Perinatal Minimum Data Set, which is collected by all States and Territories and sent to the National Perinatal Statistics Unit for the production of the annual report on Australia’s mothers and babies. The Department of Human Services has also developed a common client dataset.

Who enforces the standards?
• Data standards are enforced by the National Perinatal Statistics Unit and the Department of Human Services Data Standards and Systems.

Does your organisation utilise a data dictionary?
• Yes, DHS developed a Common Client Data Dictionary with reference to the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
• Mandatory data fields  
• Staff education  
• Audits to ensure accuracy and consistency  
• Administrative staff follow up with external entities when forms are incomplete or there are discrepancies  
• User manuals.
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
<table>
<thead>
<tr>
<th>Mother’s Full Name:</th>
<th>Sex:</th>
<th>Male □</th>
<th>Female □</th>
<th>Unknown □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s Surname at delivery of this child:</td>
<td>Plurality:</td>
<td>Single □</td>
<td>Twins □</td>
<td>Other □</td>
</tr>
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<td>Birthdate (Mother):</td>
<td>Condition:</td>
<td>Livebirth □</td>
<td>Stillbirth □</td>
<td>Termination &lt;20 weeks □</td>
</tr>
<tr>
<td>Child’s Surname:</td>
<td>If multiple birth:</td>
<td>Order:</td>
<td>First □</td>
<td>Second □</td>
</tr>
<tr>
<td>Given Names:</td>
<td>Address:</td>
<td>Suburb: □</td>
<td>Postcode: □</td>
<td></td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>Hospital of Birth:</td>
<td>State of birth, if not Victoria:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Movies died,</td>
<td>Yes □</td>
<td>No □</td>
<td>Date of death</td>
<td></td>
</tr>
<tr>
<td>Was a birth defect diagnosed prenatally?</td>
<td>Relevant medical or family history?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes □</td>
<td>No □</td>
<td>Method(s) of prenatal testing?</td>
<td>Please circle methods used</td>
<td></td>
</tr>
<tr>
<td>Ultrasound □</td>
<td>Maternal serum screening □</td>
<td>Gestation(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amniocentesis □</td>
<td>Other □</td>
<td>CVS □</td>
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<tr>
<td>CVS □</td>
<td>Please specify?</td>
<td></td>
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<tr>
<td>Describe in detail all birth defects/malformations present. Give name of syndrome if known.</td>
<td></td>
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</tr>
<tr>
<td>Karyotype:</td>
<td>Balanced: □</td>
<td>Unbalanced: □</td>
<td></td>
<td></td>
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<tr>
<td>Position (if bilateral circle both right and left)</td>
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<tr>
<td>Right</td>
<td>Left</td>
<td>Description:</td>
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</tr>
</tbody>
</table>

Notifier’s Details:
Name of Notifier: □ Signature: □ Date: □
Address: □ Position Title: □
Suburb: □ Postcode: □ Phone: □

This copy to be retained by notifier
DATA RELEASE POLICY & GUIDELINES

<table>
<thead>
<tr>
<th>Date of policy: 28 November 2008</th>
<th>Version: 1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy review date: November 2009</td>
<td>Approved by: Manager, Clinical Councils</td>
</tr>
</tbody>
</table>

Overview

The purpose of this document is to outline current policy and procedures regarding access to the data sets developed and maintained by the Clinical Councils Unit (CCU), in the Statewide Quality Branch of the Department of Human Services (DHS). These data sets currently include:

- the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM), incorporating:
  - the Victorian Perinatal Data Collection (VPDC), and
  - the Victorian Birth Defects Register (VBDR)
- the Victorian Surgical Consultative Council (VSCC), incorporating:
  - the Surgical Outcomes Information Initiative (SOII), and
- the Victorian Consultative Council on Anaesthetic Mortality and Morbidity’s (VCCAMM) Reporting Management System.

It is anticipated that this document will be reviewed on an annual basis in response to changes in legislation and in data management policy and procedures.

Background

The collections held by CCOPMM, VSCC and VCCAMM within the CCU are clinical data collections based on identified individual level data provided to the Department of Human Services by hospitals and individual medical practitioners. Data are provided to the CCOPMM by all public and private hospitals (including private day procedure centres) as is required by the Health Act 1958 (the Act), while data are provided to the other collections by selected public and private hospitals on a voluntary basis.

The purpose of these data collections is to conduct study and research into mortality and morbidity in selected populations, to support health service planning and develop government policy with the aim of preventing avoidable deaths and promoting healthy outcomes in these populations. The data collections also support Victoria’s reporting obligations under the National Health Information Agreement (NHIA) and the Australian Health Care Agreement (AHCA).

Policy statement

All three consultative councils are restricted by the Health Act 1958 from releasing identified or re-identifiable data to persons not specified in the Act. In the case of VCCAMM and VSCC this is only permissible with consent of the person whose information is to be released and the Minister.

In the case of CCOPMM the release of identifiable information to any persons not listed in S162FB of the Act is only permissible for the purpose of medical research with the consent of the mother, the health service where the child was born and if possible the medical practitioner or midwife present at the birth. Non-identifiable information may be released by VSCC and VCCAMM under S24A (3) of the Act. However non-identifiable information can only be released by CCOPMM through the Secretary of the department under S162F (1) (d).
Guidelines:
Responsibility for the use and disclosure of data sets held in the CCU resides with each of the consultative councils. The release of data is managed by each consultative council’s secretariat.

*Release of identifiable data for research purposes (CCOPMM)*

Requests for identifiable data including proposals to link data using identifying information are to be submitted to CCOPMM for consideration.

Identifiable information will only be released in accordance with section 6 (2) the *Health (Consultative Council on Obstetric and Paediatric Mortality and Morbidity) Regulations 2002*, which provides for the release of identifying information to a member of the medical profession for the purposes of undertaking medical research, if:

(a) written permission has been given by the mother concerned; and
(b) if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and
(c) if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.

Where the above conditions cannot be met, a research proposal requesting identifiable information can only proceed if CCOPMM elect to undertake the research themselves. In such circumstances, the proposed research must align to the functions and work plan of CCOPMM, satisfy a public interest test and accord with both the requirements of the Victorian Human Rights Charter and the Health Privacy Principles contained in the *Health Records Act 2001*.

If a proposal is endorsed by CCOPMM, internal resources will be utilised to conduct research if possible. If internal resources are not available, an external research body may be co-opted to undertake the proposed research. In this circumstance, contractual arrangements must be entered into between CCOPMM and the research agency, clearly articulating use and storage of data and reporting requirements.

*Requests for non-identifiable data (CCOPMM)*

Applications for the release of de-identified aggregate data are to be made to the Secretary (or delegate) of the Department of Human Services. Requests are then referred to the Manager, Clinical Councils Unit for consideration.

Applications will be assessed against the mandatory criteria that the data requested is de-identified and statistical in nature, and that release of the data satisfies a public interest assessment. CCOPMM’s assessment of the public interest will be undertaken on a case by case basis to ensure consideration of all relevant circumstances. Each application will be assessed against current operational and legal considerations, including the requirements of the Human Rights Charter and the Health Privacy Principles contained in the *Health Records Act 2001*.

Any linkage of individual level data from CCOPMM with other individual level data sets requires the approval of both the purpose of and the methodology to be used for the linkage by either the Council or the Secretary of the Department of Human Services.

Enquiries about the information in this document should be directed to the Manager, Clinical Councils Unit, 9096 2759.
Application for the release of data from CCOPMM for the purpose of research.

<table>
<thead>
<tr>
<th>REQUEST DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requestor:</td>
</tr>
<tr>
<td>Lead investigator (if different from requestor):</td>
</tr>
<tr>
<td>Qualifications of lead investigator:</td>
</tr>
<tr>
<td>Organisation:</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
<tr>
<td>Email:</td>
</tr>
<tr>
<td>Postal address:</td>
</tr>
<tr>
<td>Date:</td>
</tr>
<tr>
<td>Outline of project design in lay language:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Public interest factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Please state why the release of this data will have a public interest benefit)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data variables requested:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Please describe variables of interest and why each is required)</td>
</tr>
</tbody>
</table>
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
Appendix 9

Dataset L: Victorian Cancer Registry

CUSTODIAN

Custodian: Cancer Council Victoria
Name: Professor Graham Giles
Position/job title: Director, Cancer Epidemiology Centre
Phone: 03 9635 5000
E- Mail Address: cec@cancervic.org.au
Web: http://www.cancervic.org.au

SUMMARY

The Victorian Cancer Registry (VCR) collects incidence and mortality statistics on all invasive cancers except basal cell and squamous cell carcinomas of the skin.

The collection is required by law (Cancer Act 1981) so that Victoria has up-to-date and accurate figures, useful for improving cancer prevention, control and treatment.

VCR has collected data from major Melbourne hospitals since 1939 but has collected population based data only since 1982. All information is confidential and held under tight security.

VCR publishes CanStats; a digest of facts and figures produced by the Cancer Epidemiology Centre. Several issues are published each year including the annual report of latest available cancer incidence and mortality statistics from VCR.


DATA COLLECTION

What data are captured in this database?

In the event the client is a child:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous Status</td>
<td>Nil</td>
</tr>
</tbody>
</table>

- Demographic information
- Death information
- Information about cancer diagnosis

See attached: Victorian Cancer Registry Notification Form (Cancer Act 1958).
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People

Note: the majority of notifications are no longer received on paper forms but are now received electronically via the Victorian Cancer Registry Internet portal (VCRIP) as either e-forms or electronic file downloads.

Does the database include identifying information?

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Name</td>
<td>Nil</td>
</tr>
</tbody>
</table>

| Date of birth | Usual residential address (at diagnosis) | Medicare number |

How are the primary data collected?

- Data are extracted from hospital medical records by e-form, electronic file or manual form.
  Data are also collected from pathology reports, which can be either electronically downloaded by VCR or obtained in hardcopy.

When are the data collected?

- After the episode of care or event.

How do the custodians obtain the data that are included in the database?

- Data are obtained from external entities and downloaded via a web interface or in paper format.
- Data are obtained directly from the person acting on behalf of the patient.
- Data are usually obtained from databases and medical records at institutions attended by the client.

Who are the external entities?

- Hospitals, pathology labs, radiation therapy centres, prescribed screening registers and the Registry of Births, Deaths and Marriages.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Electronic and paper based formats.

Where do the custodians store the data?

- Data are stored on the premises at the Cancer Council Victoria, 1 Rathdowne Street, Carlton, Victoria, 3053.
- Deceased records are archived off site (Public Record Office Victoria) after they have been scanned as optical images for desktop retrieval.

Are the data easily accessible?

- Yes, data are easily accessible subject to approval by the Data Release Committee/HREC as per data access guidelines.
Is there a cost involved in accessing the data?
- Access to data and analysis is usually provided without charge. Complex and time-consuming requests may be charged on a cost-recovery basis.

REPORTING

How often are the data received by the data repository/custodians?
- Weekly, monthly and quarterly. The frequency of data received varies between notifying institutions.

Is reporting of these data to the custodian a statutory requirement?
- Yes, reporting of these data is a statutory requirement under the Cancer Act (1981).

Is reporting of these data an administrative requirement?
- No.

Do you submit your data to a national or state database?
- Yes, data are submitted annually to the National Cancer Database, at the National Cancer Statistics Clearing House (NCSCH) at the Australian Institute of Health and Welfare.

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes, it is mandatory for Victorian hospitals to collect Indigenous Status who then notify VCR. Notifications from pathology labs do not include an Indigenous identifier.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- It has been mandatory for all Victorian public hospitals to collect Indigenous status since 1993 and this data element has been on the VCR Reporting Schedule since the Cancer Act amendments of 1981.

When is the Indigenous status entered?
- Indigenous status is recorded at the time of collection by external entities.

Are questions asked to determine the Indigenous status of a client/patient?
- It is mandatory for hospitals to ask the client if they are of Indigenous origin, however, VCR does not collect this information directly from the client.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Questions are not asked by VCR to determine the Indigenous status of a patient/client. The Victorian Cancer Registry is reliant on Victorian private and public hospitals asking the question. Answers are recorded as per the national standard.
Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?

- Not applicable.

What are the barriers to obtaining information about a person’s Indigenous status?

- Data submitted to VCR may be incomplete or inaccurate depending on the source of the notification.

Does your information system allow for the Indigenous status to be left blank at the time of collection?

- Yes.

How confident are you that the Indigenous status is accurate?

- Unsure, for cancers frequently treated outside the hospital setting (e.g., Melanoma), there is little information submitted. For cancers treated in hospital, VCR data is as complete as that of the treating hospital.

From what year would you be confident of accurate data collection?

- Year 2000. There has been a definite increase in reporting since the late 1990’s.

- It has been mandatory for all Victorian public hospitals to collect Indigenous status since 1993.

ACCESS TO DATA

How does one obtain access to these data?

- Access to VCR data can be obtained via the data custodian.

What ethics clearances are required to access your data?

- The custodian will release aggregated data upon request.

- Requests for identified data about cancer patients must be approved by the Human Research Ethics Committee (HREC).

Do you have an access agreement outlining the conditions of access to your data base?


Are your data used for research purposes?

- Yes.

DATA STANDARDS

Do you comply with data standards?

- Yes, where available, the National Health Data Dictionary.

Who enforces the standards?
Data passes through rigorous quality assurance processes using rules and edits from the International Agency for Research on Cancer in addition to internal procedures.

**Does your organisation utilise a data dictionary?**
- Yes, National Health Data Dictionary.

**DATA QUALITY**

**How do you ensure data quality?**
- Mandatory data fields
- Timely submission of data
- Staff education
- Timely entry of data
- Benchmarking with other jurisdictions
- Audits to ensure accuracy and consistency
- Warning and error alerts
- Administrative staff follow-up with client/guardian when forms are incomplete.
### VICTORIAN CANCER REGISTRY NOTIFICATION FORM (Cancer Act 1958)

Instructions corresponding to each numbered section are printed on the reverse side of this form.

<table>
<thead>
<tr>
<th>1</th>
<th>NAME OF FACILITY</th>
<th>NOTIFIER NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Please affix patient I.D. label or complete all boxes</td>
<td></td>
</tr>
<tr>
<td>2.1</td>
<td>Unit Record No.</td>
<td></td>
</tr>
<tr>
<td>2.2</td>
<td>Medicare No.</td>
<td></td>
</tr>
<tr>
<td>2.3</td>
<td>Surname</td>
<td></td>
</tr>
<tr>
<td>2.4</td>
<td>First name</td>
<td></td>
</tr>
<tr>
<td>2.5</td>
<td>Second name</td>
<td></td>
</tr>
<tr>
<td>2.6</td>
<td>Sex</td>
<td>Male</td>
</tr>
<tr>
<td>2.7</td>
<td>Date of birth</td>
<td></td>
</tr>
<tr>
<td>2.8</td>
<td>Usual residential address</td>
<td></td>
</tr>
<tr>
<td>2.9</td>
<td>Postcode</td>
<td>LGA</td>
</tr>
<tr>
<td>3</td>
<td>Maiden name (if applicable)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Country of birth (specify State if born in Australia)</td>
<td></td>
</tr>
<tr>
<td>4.1</td>
<td>Indigenous status</td>
<td>Not stated</td>
</tr>
<tr>
<td>5</td>
<td>Date of FIRST consultation/admission to YOUR FACILITY for THIS CANCER</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Was this cancer diagnosed PRIOR to consultation/admission to your facility?</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>Date of FIRST diagnosis of THIS CANCER</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>The PRIMARY site is</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Metastatic site(s)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Histological type in words</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Tumour Laterality (paired organs only)</td>
<td>Right</td>
</tr>
<tr>
<td>12</td>
<td>Circle ALL investigations relevant to the diagnosis of THIS CANCER?</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Treating doctor’s name and address</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Local doctor’s name and address</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>DEATH DETAILS</td>
<td>Date of death</td>
</tr>
<tr>
<td>16</td>
<td>Name</td>
<td>Signature</td>
</tr>
</tbody>
</table>

---

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
Appendix 9

**Dataset M:** Victorian Emergency Minimum Dataset

**CUSTODIAN**

**Custodian:** Health Information Section, Funding Health & Information Policy Branch, Metropolitan Health & Aged Care Services, Victorian Department of Human Services

**Name:** Dr Neil Powers

**Position/job title:** Senior Information Policy Advisor

**Phone:** 03 9096 0000

**Email Address:** Neil.Powers@dhs.vic.gov.au

**Web:** www.health.vic.gov.au/hdss/vemd/

**SUMMARY**

The Victorian Emergency Minimum Dataset (VEMD) contains de-identified demographic, administrative and clinical data detailing presentations at Victorian public hospitals that receive the non-admitted emergency services grant, and other hospitals as designated by DHS.

Submission to the VEMD commenced in October 1995 as an initiative of the Department of Human Services in collaboration with the Victorian Emergency Department’s Association, the Australasian College for Emergency Medicine Victoria Faculty, the Emergency Nurse’s Association, and Monash University Accident Research Centre (MUARC).

In order to maintain and protect patient privacy, only the minimum data required for effective monitoring and analysis purposes are collected. Hospital must transmit data to the VEMD according to the Victoria-public hospitals and mental health services, Policy and Funding Guidelines, General Conditions of Funding for the current year.

**DATA COLLECTION**

**What data are captured in this database?**

In the event of a child presenting at an Emergency Department:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>Demographic information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Clinical information</td>
<td></td>
</tr>
</tbody>
</table>

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Note: If a mother, father and/or child present at an Emergency Department, the VEMD only includes data on those who were treated or triaged. In the unlikely event of a birth in an Emergency Department, the mother and baby would usually be admitted and recorded in the VAED.


Does the database include identifying information?

The VEMD contains potentially identifying data items such as date of birth and Medicare number. However, it does not include the full given or surname or address. A combination of some or all of the following data items could identify a patient.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td>Age</td>
<td>Date of birth</td>
<td>Gender</td>
</tr>
<tr>
<td>Medicare number and the first three letters of the given name on the card</td>
<td>Patient locality; suburb and postcode</td>
<td>Country of birth</td>
</tr>
</tbody>
</table>

How are the primary data collected?

- Hospital personnel, predominantly Emergency Department Admission staff collect patient demographic information and enter it directly into the Patient Record System.

When are the data collected?

- Information is collected before, during and after an episode of care.

How do the custodians obtain the data that are included in the database?

- Hospitals submit data to DHS electronically on a monthly basis.

Who are the external entities?

- Victorian public and private hospitals.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Electronically.

Where do the custodians store the data?

- On the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000.

Is the data easily accessible?

- No, data are kept at unit record level and privacy legislative provisions are rigorous.
Is there a cost involved in accessing the data?
• Yes, there is a cost for some users including universities, students and other members of the public.

REPORTING

How often are the data received by the data repository/custodians?
• Data are transmitted to the custodian on a monthly basis.

Is reporting of these data to the custodian a statutory requirement?
• Public hospitals with Emergency Departments report to the VEMD, private hospitals do not.
• Data must be consistent with the State's reporting obligations under the National Health Information Agreement, the Australian Health Care Agreement, and section 9 of the Victorian Health Act 1958.
• In addition, the Health Records Act 2001 regulates the collection and handling of health data to protect the privacy of individuals’ health information.

Is reporting of these data an administrative requirement?
• Yes, under the Victoria–public hospitals and mental health services: Policy and funding guidelines 2008–09.

Do you submit your data to a national or state database?

INDIGENOUS STATUS

Is an Indigenous identifier used?
• Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
• Yes, it is mandatory for hospitals to populate the Indigenous identifier.

When did it become mandatory for vendors to populate the Indigenous identifier field?
• The Indigenous identifier was introduced in 1993, and has been mandatory since then.

When is the Indigenous status entered?
• At the time of patient registration.

Are questions asked to determine the Indigenous status of a client/patient?
• Yes, hospital staff are required to ask clients of their Indigenous origin.

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?

- Aboriginal but not Torres Strait Islander origin.
- Torres Straight Islander but not Aboriginal origin.
- Both Aboriginal and Torres Strait Islander origin.
- Neither Aboriginal nor Torres Strait Islander origin.
- Question unable to be asked.
- Patient refused to answer.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?

- Yes.

What are the barriers to obtaining information about a person’s Indigenous status?

- Aboriginal patients may not feel comfortable declaring their status to administrative staff.
- Administrative or medical staff may feel that the question is irrelevant.
- Administrative staff may not feel comfortable asking the question.
- Administrative staff do not understand why the question is being asked.
- Administrative staff fear a negative response to question being asked.
- Time pressures on Administrative staff.

Does your information system allow for the Indigenous status to be left blank at the time of collection?

- Unsure of the setup at individual hospitals, however, the field cannot be left blank in the consolidated system.

How confident are you that the Indigenous status is accurate?

- Confidence varies depending on the collecting hospital. The coverage of Indigenous status tends to vary according to the size of the local Aboriginal population and the geographic location. Accuracy tends to be better in rural hospitals where the Aboriginal population is larger, and in hospitals with Aboriginal Hospital Liaison Officers.

From what year would you be confident of accurate data collection?

- Accuracy is improving with strategies to educate registration staff and encourage self identification.

ACCESS TO DATA

How does one obtain access to these data?

- By written request to the data custodian providing full details of the use to which data would be put, together with a list of all data items required. Authorisation is not automatic.
What ethics clearances are required to access your data?

Do you have an access agreement outlining the conditions of access to your data base?

Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards?
- Yes, standards are established and maintained by the Data Custodian’s work area.

Who enforces the standards?
- Health Information Section, Funding, Health & Information Policy Branch, DHS.

Does your organisation utilise a data dictionary?
- Yes, the data dictionary was developed by DHS with appropriate reference to other sources such as National Health Data Dictionary, ABS etc.

DATA QUALITY

How do you ensure data quality?
- Mandatory data fields
- External entities submit data in a timely manner
- Staff education
- Audits to ensure accuracy and consistency
- Warning and error alerts.
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
Appendix 9

**Dataset N: Victorian Perinatal Data Collection**

**CUSTODIAN**

**Custodian:** Consultative Council on Obstetrics and Perinatal Mortality and Morbidity.

**Name:** Anne-Maree Szauer

**Position/job title:** Manager, Clinical Councils Unit

**Phone:** 03 9096 2759

**E-Mail Address:** anne-maree.szauer@dhs.vic.gov.au

**Web:** www.health.vic.gov.au/perinatal/

**SUMMARY**

The Victorian Perinatal Data Collection Unit (VPDCU) was established in 1982, by an amendment to the Health Act 1958 (the Act) under the auspices of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM).

The VPDCU was established to provide CCOPMM with the ability to collect and analyse data to enable it to undertake its functions under the Act.

The data collected via a Birth Report Form A contains information on obstetric conditions, procedures and outcomes, neonatal morbidity and birth defects relating to every birth in Victoria of at least 20 weeks gestation, or if gestation is unknown at least 400gr birth weight.

The majority of data items, of which there are over 100, comply with the National Perinatal Minimum Data Set, which is collected by all States and Territories (all other states have a similar Unit to VPDCU) and are sent to the National Perinatal Statistics Unit for the production of the annual report on Australia’s mothers and babies.

The VPDCU is responsible to the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM) the advisory body to the Minister of Health on maternal, perinatal and paediatric deaths.

**DATA COLLECTION**

**What data are captured in this database?**

In the event of a birth of a child:
An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People

Mother:   Child:   Father:
Indigenous status  Indigenous status (from 1 January 2009)*  Nil
Demographic information  Demographic information
Pregnancy information  Birth information
Delivery information  Delivery information
Smoking status (from 1 January 2009)*  Death information

Note: changes to the collection effective 1 January 2009 include the addition of questions regarding smoking and the Indigenous status of the baby.


Does the database include identifying information for Mother, Father or Child?

Mother:   Child:   Father:
Name  Date of birth  Nil
Address

How are the primary data collected?
- The primary data are predominantly collected by midwives and entered into a Birth Report Form A which is then forwarded to the VPDCU.

When are the data collected?
- Before, during and after an episode of care. Some information may be collected during antenatal visits and other, after the birth of the baby.

How do the custodians obtain the data that are included in the database?
- A form is printed from the VPDCU webpage. Once completed, it is mailed to DHS for administrative staff to enter into the database.
- To assist with the timely acquisition of data, health services will be able to submit data electronically during 2009. Testing of the electronic process will commence early in 2009. This is with the view to a wider rollout in the future.

Who are the external entities?
- Midwives, nursing staff and medical practitioners.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?
- In electronic and paper base formats.

Where do the custodians store the data?
- Current data are stored on the premises at the Department of Human Services, 50 Lonsdale St, Melbourne 3000. Archived data is stored at the State Archives.
Are the data easily accessible?
- Yes, electronic data are easily accessible. An approval process must be adhered to in accordance with CCOPMM guidelines prior to any access being granted. In some instances, paper archives may need to be retrieved from archives. Refer to the data the Clinical Councils Unit data release policy.

Is there a cost involved in accessing the data?
- No.

REPORTING

How often are the data received by the data repository/custodians?
- Data is continuously submitted to the VPDCU.

Is reporting of these data to the custodian a statutory requirement?
- Yes, under the Health Act 1958.

Is reporting of these data an administrative requirement?
- No.

Do you submit your data to a national or state database?
- Yes, data are submitted to the National Perinatal Statistics Unit.

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes.

When did it become mandatory for vendors to populate the Indigenous identifier field?
- 1982.

When is the Indigenous status entered?
- The Indigenous status is entered at the time data is collected.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes.

What possible answers are there to the question “Are you of Aboriginal or Torres Strait Islander origin”?
- Aboriginal
- TSI
- No.
Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Straight Islander descent?
• Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
• The VPDCU believes there to be an under reporting of Indigenous status, however, cannot confirm specific barriers to obtaining identification as this issue has not been specifically surveyed or researched.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
• No.

How confident are you that the Indigenous status is accurate?
• Unsure.

ACCESS TO DATA

How does one obtain access to these data?
• Processes relating to the access of data for research purposes were reviewed in November 2008.
• All requests for unpublished information must be put in writing to CCOPMM, if not for the purpose of formalised research. See Application for the release of data from CCOPMM attached or via web link: <http://www.health.vic.gov.au/perinatal/forms>.
• A copy of the request will be forwarded to the CCOPMM representative for approval. The CCOPMM encourages the release of data to health professionals for statistical and research purposes; however, the CCOPMM must comply with the Act and any information that identifies any patient, cannot be provided to any individual external to CCOPMM for the purpose of research without the written consent of:
  a. written permission has been given by the mother concerned; and
  b. if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and
  c. if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.

What ethics clearances are required to access your data?
• Any formal research proposal involving perinatal data provision must conform to the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans 1999. Before the project can begin, a properly constituted Human Research Ethics Committee must have given approval. The application must be provided on the appropriate forms and tabled at a meeting of CCOPMM for consideration.

Do you have an access agreement outlining the conditions of access to your data base?
• Yes, see attached: Data release policy.
Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards?
- Yes, the majority of data items comply with the National Perinatal Minimum Data Set, which is collected by all States and Territories and sent to the National Perinatal Statistics Unit for the production of the annual report on Australia’s mothers and babies. The Department of Human Services has also developed a common client dataset, which the perinatal data collection is compliant with.

Who enforces the standards?
- Data standards are enforced by the National Perinatal Statistics Unit and the Department of Human Services Data Standards and Systems.

Does your organisation utilise a data dictionary?
- Yes, DHS developed a Common Client Data Dictionary with reference to the National Health Data Dictionary.

DATA QUALITY

How do you ensure data quality?
- Mandatory data fields
- Staff education
- Audits to ensure accuracy and consistency
- Administrative staff follow up with external entities when forms are incomplete or there are discrepancies
- User manuals.
BIRTH REPORT FORM A (from 2009)

MOTHER
Mother UR number: ____________________
Admission date: ___________ Day ___________ Month ___________ Year
Suburb: ____________________
Public/Private Patient: Public
Country of Birth: (Mother) ____________________
Indigenous Status (Mother): (circle one or more) ____________________
Aboriginal T Sis No T No
Marital Status (Mother): Married
Single T Widowed T Divorced T Separated T Unknown T
Divorced Date: ___________ Day ___________ Month ___________ Year
Marital Status (Father): Married
Single T Widowed T Divorced T Separated T Unknown T
Divorced Date: ___________ Day ___________ Month ___________ Year
Birthdate (Mother): ___________ Day ___________ Month ___________ Year
Weight: ____________________ Kg
Height: ____________________ cm

REPRODUCTIVE HISTORY
G: ___________ P: ___________
Total number: (including this pregnancy) ___________
Live birth: ___________ died: ___________
Abortion: ___________ Ectopic: ___________
Ectopic: ___________
Date of completion of last pregnancy: (month/day) ___________
Outcome of last pregnancy: Live birth
- Abortion: ___________ - spontaneous: ___________
- induced: ___________
- died: ___________
- induced: ___________
- died: ___________
- Ectopic: ___________
- Unknown: ___________
Was last birth a caesarean section?: Yes T No T
Total no. of previous caesarean sections: ___________
Plan for VBAC: (if prev CS) ___________

THIS PREGNANCY
Agreed due date: ___________
Estimated gest. age at 1st A/N visit: ___________
Maternal medical conditions:
- Existing medical conditions: ___________
- Pre-existing: ___________
- Hypertension: ___________
- Renal (specify): ___________
- Psychosocial (specify): ___________
- Other (specify): ___________
Obstetric complications:
- Gestational diabetes: ___________
- Pre-eclampsia: ___________
- GBS+: ___________
- Placenta praevia: ___________
- - without haemorrhage: ___________
- Placental abruption: ___________
- Other (specify): ___________
A/N care provider:
- Obstetrician: Midwife: GP: None: ___________
- Procedures and operations: ___________
- Ultrasonography 10 - 14 weeks (specify no.): ___________
- Ultrasonography 15 - 26 weeks (specify no.): ___________
- Ultrasonography 27 weeks (specify no.): ___________
- Cervical suture: ___________
- IM Steroids (2 doses): ___________
- ART (specify): ___________
- Other (specify): ___________
Occasional data: ___________

Labour, Birth & Postnatal
Onset labour: ____________________ Date ____________________ Time ___________
Rupture of membranes: ____________________ Date ____________________ Time ___________
Labour:
- Spontaneous: ___________
- Augmented: ___________
- Induced: ___________
- Medical: ___________
- Surgical: ___________
If labour induced or augmented: (circle one or more) ____________________
- Oxytocin: ___________
- ARM: ___________
- Prostaglandins: ___________
- Other (specify): ___________

Specify indication for induction:
- Fetal monitoring in labour: (circle one or more) ___________
- Intermittent Ausc: ___________
- Internal CTG: ___________
- Admission CTG: ___________
- Fetal blood sampling: ___________
- Intermittent CTG: ___________
- None: ___________
- Cont. external CTG: ___________
Method of birth:
- Unassisted vaginal delivery: ___________
- Forceps: ___________
- Vacuum: ___________
- Planned C/S: ___________
- - No labour: ___________
- Labours: ___________
- Unplanned C/S: ___________
- - No labour: ___________
- Labours: ___________

Indications for operative birth:
- Analgesia for labour: ___________
- Anesthesia for operative delivery: ___________

Complications/events of labour and birth:
- Antibiotics: ___________
- Shoulder dystocia: ___________
- Water birth: ___________

Lead intrapartum care provider:
- Obstetrician: Midwife: GP: None: ___________

DISCHARGE
Date of discharge from place of birth: ___________
Mother date: ___________ Day ___________ Month ___________ Year
Baby date: ___________
Discharge status: Mother: Baby: ___________
- Discharged: ___________
- Died: ___________
- Transferred to (specify): ___________
Admitted to HDU/ICU: (Mother) ___________
Admitted to HDU/ICU: (Baby) ___________

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria's Aboriginal Infants, Children and Young People
DATA RELEASE POLICY & GUIDELINES

<table>
<thead>
<tr>
<th>Date of policy: 28 November 2008</th>
<th>Version: 1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy review date: November 2009</td>
<td>Approved by: Manager, Clinical Councils</td>
</tr>
</tbody>
</table>

Overview

The purpose of this document is to outline current policy and procedures regarding access to the data sets developed and maintained by the Clinical Councils Unit (CCU), in the Statewide Quality Branch of the Department of Human Services (DHS). These data sets currently include:

- the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM), incorporating:
  - the Victorian Perinatal Data Collection (VPDC), and
  - the Victorian Birth Defects Register (VBDR)
- the Victorian Surgical Consultative Council (VSCC), incorporating:
  - the Surgical Outcomes Information Initiative (SOII), and
- the Victorian Consultative Council on Anaesthetic Mortality and Morbidity’s (VCCAMM) Reporting Management System.

It is anticipated that this document will be reviewed on an annual basis in response to changes in legislation and in data management policy and procedures.

Background

The collections held by CCOPMM, VSCC and VCCAMM within the CCU are clinical data collections based on identified individual level data provided to the Department of Human Services by hospitals and individual medical practitioners. Data are provided to the CCOPMM by all public and private hospitals (including private day procedure centres) as is required by the Health Act 1958 (the Act), while data are provided to the other collections by selected public and private hospitals on a voluntary basis.

The purpose of these data collections is to conduct study and research into mortality and morbidity in selected populations, to support health service planning and develop government policy with the aim of preventing avoidable deaths and promoting healthy outcomes in these populations. The data collections also support Victoria’s reporting obligations under the National Health Information Agreement (NHIA) and the Australian Health Care Agreement (AHCA).

Policy statement

All three consultative councils are restricted by the Health Act 1958 from releasing identified or re-identifiable data to persons not specified in the Act. In the case of VCCAMM and VSCC this is only permissible with consent of the person whose information is to be released and the Minister.

In the case of CCOPMM the release of identifiable information to any persons not listed in S162FB of the Act is only permissible for the purpose of medical research with the consent of the mother, the health service where the child was born and if possible the medical practitioner or midwife present at the birth. Non-identifiable information may be released by VSCC and VCCAMM under S24A (3) of the Act. However non-identifiable information can only be released by CCOPMM through the Secretary of the department under S162F (1) (d).
Guidelines:
Responsibility for the use and disclosure of data sets held in the CCU resides with each of the consultative councils. The release of data is managed by each consultative council’s secretariat.

Release of identifiable data for research purposes (CCOPMM)
Requests for identifiable data including proposals to link data using identifying information are to be submitted to CCOPMM for consideration.

Identifiable information will only be released in accordance with section 6 (2) the Health (Consultative Council on Obstetric and Paediatric Mortality and Morbidity) Regulations 2002, which provides for the release of identifying information to a member of the medical profession for the purposes of undertaking medical research, if:

(a) written permission has been given by the mother concerned; and
(b) if possible, written permission has been given by the either the medical practitioner or midwife who attended the birth; and
(c) if the birth occurred in a hospital, written permission has been given by the proprietor of the hospital.

Where the above conditions cannot be met, a research proposal requesting identifiable information can only proceed if CCOPMM elect to undertake the research themselves. In such circumstances, the proposed research must align to the functions and work plan of CCOPMM, satisfy a public interest test and accord with both the requirements of the Victorian Human Rights Charter and the Health Privacy Principles contained in the Health Records Act 2001.

If a proposal is endorsed by CCOPMM, internal resources will be utilised to conduct research if possible. If internal resources are not available, an external research body may be co-opted to undertake the proposed research. In this circumstance, contractual arrangements must be entered into between CCOPMM and the research agency, clearly articulating use and storage of data and reporting requirements.

Requests for non-identifiable data (CCOPMM)
Applications for the release of de-identified aggregate data are to be made to the Secretary (or delegate) of the Department of Human Services. Requests are then referred to the Manager, Clinical Councils Unit for consideration.

Applications will be assessed against the mandatory criteria that the data requested is de-identified and statistical in nature, and that release of the data satisfies a public interest assessment. CCOPMM’s assessment of the public interest will be undertaken on a case by case basis to ensure consideration of all relevant circumstances. Each application will be assessed against current operational and legal considerations, including the requirements of the Human Rights Charter and the Health Privacy Principles contained in the Health Records Act 2001.

Any linkage of individual level data from CCOPMM with other individual level data sets requires the approval of both the purpose of and the methodology to be used for the linkage by either the Council or the Secretary of the Department of Human Services.

Enquiries about the information in this document should be directed to the Manager, Clinical Councils Unit, 9096 2759.
Application for the release of data from CCOPMM for the purpose of research.

<table>
<thead>
<tr>
<th>REQUEST DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requestor:</td>
</tr>
<tr>
<td>Lead investigator (if different from requestor):</td>
</tr>
<tr>
<td>Qualifications of lead investigator:</td>
</tr>
<tr>
<td>Organisation:</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
<tr>
<td>Email:</td>
</tr>
<tr>
<td>Postal address:</td>
</tr>
<tr>
<td>Date:</td>
</tr>
<tr>
<td>Outline of project design in lay language:</td>
</tr>
</tbody>
</table>

**Public interest factors**  
(Please state why the release of this data will have a public interest benefit)

**Data variables requested:**  
(Please describe variables of interest and why each is required)
<table>
<thead>
<tr>
<th>Provide a statement outlining how the project achieves HPP1.1 &amp; 2.2 as described in the Health Records Act 2001</th>
</tr>
</thead>
</table>

| Provide a statement outlining how the project is compliant with Human Rights Charter. A copy of the charter can be viewed at or downloaded from www.humanrightscommission.vic.gov.au |

| Provide any additional information that is relevant to the consideration of this application. |
Appendix 9

Dataset O: Victorian Registry of Births: Victorian Registry of Births, Deaths & Marriages

CUSTODIAN

Custodian: The Registrar
Name: Helen Trihas
Position/job title: Registrar
Phone: 9613 5903
Email Address: Helen.trihas@justice.vic.gov.au
Web: <http://online.justice.vic.gov.au/servlet/bdm_home>

SUMMARY

The Victorian Registry of Births, Deaths and Marriages (RBDM) was established in July 1853 and holds registers for recording the life events of people in Victoria.

Key functions of the RBDM include recording all births, deaths, marriages and changes of name in Victoria, collecting and disseminating statistical data for government and other organisations, providing certificates for births, deaths and marriages in Victoria and facilitating the legal process for people born or residing in Victoria to change their name.

The law requires that notification of birth be given within 48 hours by the doctor midwife or other person attending the mother at the birth; and that a birth be registered by the parents within 60 days of the birth. However the Registry accepts registrations made at a later stage.

To register a child’s birth, parents must jointly complete a Birth Registration Statement (BRS) and send it to the Victorian Registry of Births, Deaths and Marriages. When a child is born in a maternity hospital or by a midwife, a BRS is given to the new parent/s and, in the case of a multiple birth; a separate BRS must be completed for each child.

DATA COLLECTION

What type of data are captured in this database?
Pertaining to the birth record:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Demographic information</td>
<td>Indigenous status</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Birth information</td>
<td>Demographic information</td>
</tr>
<tr>
<td>Employment information</td>
<td>Death Information</td>
<td>Employment information</td>
</tr>
</tbody>
</table>

See attached: Variables included in the Victorian Birth Registry.
Does your database include identifying information pertaining to Mother, Father or Child?

- Yes.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name</td>
<td>Name</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Date of birth</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Residential address</td>
<td>Place of birth</td>
<td>Residential address</td>
</tr>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
<td></td>
</tr>
<tr>
<td>Contact details</td>
<td>Contact details</td>
<td></td>
</tr>
</tbody>
</table>

How are the primary data collected?

- When a child is born in Victoria, a BRS is given to the new parents at the maternity hospital or by the midwife. In the case of a multiple birth, a separate BRS must be completed for each child. A child’s birth must be registered within 60 days of the child’s birth however the Registry accepts late registrations. The responsibility rests with the parent or parents of the child to submit the BRS to the RBDM.

- The RBDM also receives notification of the birth from the hospital where the birth took place or from the doctor or midwife attending the birth. These notifications are matched with the BRS’s received from parents.

When are the data collected?

- After the birth of a child.

How do the custodians obtain the data that are included in the database?

- It is the joint responsibility of the Mother and Father of the child to complete the BRS within the designated time frame. However, the RBDM will accept late registration or a registration from one parent when it is not practicable to obtain signatures from both parents.

Who are the external entities?

- The Mother and Father of the child, hospital, midwife or doctor.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Electronic and paper based formats.

Where do the custodians store the data?

- Data are stored on the premises at the Victorian Registry of Births, Deaths and Marriages. The hardcopy records are moved offsite after the processing period to secondary storage approved by the Public Records Office. The RBDM also maintains back-up tapes of the information on the Birth Register.

Are the data easily accessible?

- Data are easily accessible to Registry officers who are responsible for ensuring that births are properly registered. The RBDM maintains an access policy that dictates the terms on which individuals may apply for information on the registers.
Is there a cost involved in accessing the data?
- Yes, statutory fees apply for obtaining certificates or information held on the registers.

REPORTING

How often are the data received by the data repository/custodians?
- A birth notification is received from the hospital where the birth took place or from a midwife within 48 hours of the birth. A BRS is usually received from the parents of a child within 60 days of the child being born.

Is reporting of these data to the custodian a statutory requirement?
- Yes, reporting of these data is a statutory requirement under the Births, Deaths and Marriages Registration Act 1996.

Is reporting of these data an administrative requirement?
- No. It is a legislative requirement.

Do you submit your data to a national or state database?
- Yes, non-identifying data is submitted to the Australian Bureau of Statistics on a monthly basis.

INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes, the RBDM is reliant on a parent declaring themselves to be of Aboriginal or Torres Strait Island origin.

When is the Indigenous status entered?
- The Indigenous status is entered when data are submitted to the RBDM.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes, the BRS includes a question regarding the Indigenous status of each parent and medical and midwifery staff may ask the question of parents if providing assistance filling out the BRS.

What possible answers are there to the question ‘Are you of Aboriginal or Torres Strait Islander origin?’
- Aboriginal origin
- Torres Strait Island origin
- Both
- No.
Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
• Yes.

What are the barriers to obtaining information about a person's Indigenous status?
• The BRS requires self-identification by the parent/s as to their Indigenous status.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
• Yes, parents are able to leave the field blank on the hard copy form at the time of completion. However, the Registry makes further inquiries where this question is unanswered.

How confident are you that the Indigenous status is accurate?
• Information is provided by the child's parent/s and is presumed to be accurate. Further information is sought if there is a reason to query the data.

From what year would you be confident of accurate data collection?
• Information regarding Indigenous status was not collected prior to 1986.

ACCESS TO DATA

How does one obtain access to these data?
• Access to these data can be obtained via the data custodian. The RBDM maintains an Access Policy as required under the Births, Deaths and Marriages Registration Act and applicants are required to meet the conditions outlined therein.

What ethics clearances are required to access your data?
• Approval from the applicant's Human Ethics Research Committee must be provided, however, all requests for access by medical researchers to restricted records must also be approved by the Registrar. The full set of conditions to be met by medical researchers and historians are set out in the attached BDM Access Policy.

Do you have an access agreement outlining the conditions of access to your data base?
• Yes, see attached: BDM Access Policy.

Are your data used for research purposes?
• Yes.

DATA STANDARDS

Do you comply with data standards? If yes, which data standards?
• The RBDM has a duty to maintain records of life events which is conferred by the Births, Deaths and Marriages Registration Act. As such, the standards are dictated by the Act and RBDM policies and procedures support and enforce this.
Does your organisation utilise a data dictionary?

- No.

DATA QUALITY

How do you ensure data quality?

- Data quality is ensured by cross checking records and making further inquiries where necessary regarding a particular record.
Variables included in the Victorian Birth Registry

Child
- Surname
- Given Name
- Date of Birth
- Sex
- Birth Weight
- Length at Birth
- Head Circumference
- Eye Colour
- Time of Birth
- Birth Place eg Hospital, Home, Ambulance
- Single or Multiple Birth
- Live Born
- Still Born
- Details of Doctor or Midwife

Mother
- Surname
- Maiden Name
- Given Name
- Occupation at time of birth
- Date of Birth
- Place of Birth
- Year arrived in Australia if applicable
- Aboriginal or Torres Straight Islander
- Contact Details
- E-mail Address

Father
- Surname
- Maiden Name
- Given Name
- Occupation at time of birth
- Date of Birth
- Place of Birth
- Year arrived in Australia if applicable
- Aboriginal or Torres Straight Islander
- Contact Details
- E-mail Address
Medical Researchers

Medical research organisations may seek access to BDM’s restricted records to, for example:
- Track the mortality rate of patients who have participated in a medical trial
- Link causes of death to known illness
- Establish the hereditary nature of diseases

Medical Research organisations may also approach BDM for access to information for the purpose of data-cleansing only. In such instances, Access Policy provisions on data-cleansing apply.

Medical researchers may request one of two things:
1. Data matching by BDM – researcher supplies BDM with information (eg. a patient list) and BDM then matches this data against the records held in the register
2. Provision of data from the registers – BDM supplies records (fields of data supplied may vary) to enable the researcher to undertake their own data matching.

Generally only the following information from the registers will be released to medical researchers:
- Death information: surname, given name, street address, suburb and postcode of the deceased’s usual residence, sex, date of birth, place of death, age of the deceased, date of death and possible causes of death
- Birth records: date of birth, place of birth

Other information, including information about parents and children of deceased may be released where a medical researcher can show this is crucial to the research.

1.1.1 Conditions of Access

All requests for access by medical researchers for medical research to restricted records must be approved by the Registrar.

Medical researchers must:
- Provide a letter specifying the reason for seeking access to restricted records on the institutions letterhead (where applicable) and must include:
  - Faculty/departmental approval indicating any intended publication of information;
  - Outline the reasons why the research is in the public interest; and
  - Provide a copy of the registered person’s written consent allowing the researcher to access their information;
    - If the researcher is unable to provide the registered person’s written consent, they must explain why they are unable to obtain their consent;

AND

- Provide approval from their organisation’s Human Research Ethics Committee; and
- Provide a written undertaking that the information will remain secure after its release by BDM.

In determining whether access is granted consideration should be given to factors including:
- The nature of the researcher’s interest
- The public interest served by releasing the information to the researcher
- The sensitivity and quantity of the information
- The use to be made of the information
- Other relevant factors including:
  - Protection of registered persons’ privacy
  - Whether the researcher will be honest and ethical in their research and dissemination of results
  - That privacy protection takes precedence over the research’s expected benefits
  - That the research is justified in terms of its potential contribution to knowledge
NB: Medical researchers may be required to enter into a Memorandum of Understanding outlining the terms and conditions of access to BDM information.

### 1.1.2 Information which may be released and format
To be assessed on a case by case basis.

<table>
<thead>
<tr>
<th></th>
<th>Standard certificates</th>
<th>Non-POI certificates</th>
<th>Uncertified copies of certificates</th>
<th>Index on website</th>
<th>Abbreviated Death Certificate</th>
<th>Data</th>
<th>Letters of verification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Death</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Marriage</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>CON</td>
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<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Deed Poll</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Recognised details</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Appendix 9

Dataset P: Victorian Registry of Deaths: Victorian Registry of Births, Deaths & Marriages

CUSTODIAN

Custodian: The Registrar
Name: Helen Trihas
Position/job title: Registrar
Phone: 9613 5903
Email Address: Helen.trihas@justice.vic.gov.au
Web: https://online.justice.vic.gov.au/bdm/home

SUMMARY

The Victorian Registry of Births, Deaths and Marriages (RBDM) was established in July 1853 and holds registers for recording the life events of people in Victoria.

Key functions of the RBDM include recording all births and deaths in Victoria, collecting and disseminating statistical data for government and other organisations, providing certificates for births, deaths and marriages in Victoria and facilitating the legal process for people born or residing in Victoria to change their name.

The funeral director or other person who arranges for the disposal of the deceased’s body must collect all the information required for the registration of a death and submit it to the RBDM on a Death Registration Statement within 7 days of the disposal.

Additionally, the Medical Practitioner who signed the death certificate must submit either a Medical Certificate of Cause of Perinatal Death (for a deceased person aged less than 28 days), or a Medical Certificate of Cause of Death (for a deceased person aged 28 days or over) within 48 hours of death. Where a death is referred to the Coroner for investigation he/she will issue a report and authorise disposal of the body.

Information from both the Death Registration Statement received from the funeral director and the Medical Certificate Cause of Death (or Coroner’s report where applicable) are used to populate the death record.

DATA COLLECTION

What type of data are captured in this database?

If the deceased is a child:

An Overview of Statutory and Administrative Datasets: Describing the Health of Victoria’s Aboriginal Infants, Children and Young People
i) **Death Registration Statement** completed by a Funeral Director.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment information</td>
<td>Indigenous status</td>
<td>Employment information</td>
</tr>
<tr>
<td>Demographic information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death Information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ii) **Medical Certificate of Cause of Death** (used where the deceased is aged 28 days or over) completed by a Medical Practitioner.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Deceased:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Indigenous status</td>
<td>Nil</td>
</tr>
<tr>
<td>Demographic information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

iii) **Medical Certificate of Cause of Perinatal Death** completed by a Medical Practitioner.

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td>Demographic information</td>
<td>Indigenous status</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Birth information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death information</td>
<td></td>
</tr>
</tbody>
</table>

See attached extracts from the Death Registration Statement, Medical Certificate of Cause of Perinatal Death, and Medical Certificate of Cause of Death forms.

**Does your database include identifying information pertaining to Mother, Father or Child?**

- Yes, the three sources of data above together include the following identifiable information:

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Child:</th>
<th>Father:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name</td>
<td>Name</td>
</tr>
<tr>
<td>Indigenous status</td>
<td>Indigenous status</td>
<td>Indigenous status</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Date of birth</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
<td>Residential address</td>
</tr>
</tbody>
</table>

*Note: Identifying information is also collected on the deceased sibling/s, spouse/s and children, and the informant.*

**How are the primary data collected?**

- The funeral director or other person arranging the disposal of the deceased’s body collects all the information required for the Death Registration Statement from the informant (usually a family member of the deceased) and submits it to the RBDM within 7 days of the disposal.

- Additionally, the Medical Practitioner who signed the death certificate must submit either a Medical Certificate of Cause of Perinatal Death (for a deceased person aged less than 28 days), or a Medical Certificate of Cause of Death (for a deceased person aged 28 days or over) within 48 hours of death. Where a death is referred to the Coroner for investigation he/she issues a report and authorises disposal of the body.

**When are the data collected?**

- After death; information is received within 7 days of the disposal of the body from the funeral director and within 48 hours of death from the doctor.
How do the custodians obtain the data that are included in the database?

- Data included in the database are obtained from the Death Registration Statement, Medical Certificate of Cause of Perinatal Death, and/or the Medical Certificate of Cause of Death (of a person 28 days or over) submitted either in hard copy or online.

Who are the external entities?

- Funeral Directors, Medical Practitioners or other person’s arranging disposal of the deceased’s body.

STORAGE AND ACCESSIBILITY

In what format do the custodians store the data?

- Electronic and paper based.

Where do the custodians store the data?

- Data are stored on the premises at the Victorian Registry of Births, Deaths and Marriages. The hardcopy records are moved offsite after the processing period to secondary storage approved by the Public Records Office. The RBDM also maintains back-up tapes of the information on the Death Register.

Are the data easily accessible?

- Data are easily accessible to Registry officers who are responsible for ensuring that the death registration is completed. The RBDM maintains an access policy that dictates the terms on which individuals may apply for information on the registers.

Is there a cost involved in accessing the data?

- Yes, statutory fees apply for obtaining certificates or information held on the registers.

REPORTING

How often are the data received by the data repository/custodians?

- Data are received within seven days of disposal of the body from the funeral director and within 48 hours of death from the medical practitioner.

Is reporting of these data to the custodian a statutory requirement?

- Yes, reporting of these data is a statutory requirement under the Births, Deaths and Marriages Registration Act 1996.

Is reporting of these data an administrative requirement?

- No. It is a legislative requirement.

Do you submit your data to a national or state database?

- Yes, data are submitted to the Australian Bureau of Statistics on a monthly basis.
INDIGENOUS STATUS

Is an Indigenous identifier used?
- Yes.

Is it mandatory for vendors to populate the Indigenous identifier field?
- Yes. An option to make a response of ‘unknown’ will shortly be removed from the online death registration statement.

When is the Indigenous status entered?
- The Indigenous status is entered in to the data collection when data is submitted to the Registry of Births Deaths and Marriages.

Are questions asked to determine the Indigenous status of a client/patient?
- Yes, the Medical Certificate of Causes of Death, the Death Registration Statement and the Medical Certificate of cause of Perinatal Death include a question regarding Indigenous status. Funeral Directors and Medical Practitioners are required to ask this question of next of kin when completing the forms. Where these questions are not completed the Registry makes further inquiries to obtain the information.

What possible answers are there to the question ‘Was the deceased of Aboriginal or Torres Strait Islander origin?’
- Aboriginal
- Torres Strait Island
- Both
- No.

Are administrative and medical staff aware that the patient can be of both Aboriginal and Torres Strait Islander descent?
- Yes.

What are the barriers to obtaining information about a person’s Indigenous status?
- Information regarding a person’s Indigenous status is obtained from the medical practitioner, who may not be in a position to know and from the informant (via the funeral director). If the informant is not a relative of the deceased, they may not know the deceased’s Indigenous status.

Does your information system allow for the Indigenous status to be left blank at the time of collection?
- The person providing information regarding the deceased may not answer this question however the Registry makes further inquiries if the documentation is left blank on this question.

How confident are you that the Indigenous status is accurate?
- Information is usually provided by the deceased’s next of kin and as such is presumed to be accurate.
From what year would you be confident of accurate data collection?
- Information regarding the Indigenous status of a deceased has been collected since 1986.

ACCESS TO DATA

How does one obtain access to these data?
- Access to these data can be obtained via the data custodian. The RBDM maintains an Access Policy as required under the Births, Deaths and Marriages Registration Act and applicants are required to meet the conditions outlined therein.

What ethics clearances are required to access your data?
- Approval from the applicant’s Human Ethics Research Committee must be provided, however, all requests for access by medical researchers to restricted records must also be approved by the Registrar.

Do you have an access agreement outlining the conditions of access to your data base?
- Yes, see attached: BDM Access Policy.

Are your data used for research purposes?
- Yes.

DATA STANDARDS

Do you comply with data standards? If yes, which data standards?
- The RBDM has a duty to maintain registers under the Births, Deaths and Marriages Registration Act. As such, the standards are dictated by the Act and RBDM policies and procedures support and enforce this.

Does your organisation utilise a data dictionary?
- No.

DATA QUALITY

How do you ensure data quality?
- Data quality is ensured by cross checking records and making further inquiries where necessary.

Note: Extracts from RBDM forms are attached. These forms are provided in part.
PART ONE – DEATH REGISTRATION

Step 1 - Deceased's Details

1. Surname (family name)
   ______________________________

2. Given name(s)
   ______________________________

3. Date of death
   D D M M Y Y Y Y

4. Date of birth
   D D M M Y Y Y Y

5. Sex of deceased
   ☐ Male ☐ Female

6. Age at death
   ____________________________
   Years OR ____________ Months

7. Place of death
   a) Name of place/institution
   ______________________________

   b) Street no. and name
   ______________________________

   c) Suburb/Town
   ______________________________

   d) State ☐ ☐ e) Postcode ☐ ☐

8. Was the deceased born in Australia?
   ☐ Yes - Please specify place of birth

   Suburb/Town
   ______________________________

   State ☐ ☐

   ☐ No - Please specify the place of birth

   Suburb/Town
   ______________________________

   State ☐ ☐

9. For how long did the deceased live in Australia?
   ☐ Since birth OR ____________ Years ____________ Months

10. Deceased's residential address
    a) Name of place/institution
    ______________________________

    b) Street no. and name
    ______________________________

    c) Suburb/Town
    ______________________________

    d) State ☐ ☐ e) Postcode ☐ ☐

11. What was the usual occupation of the deceased before death?
   Note. Usual occupation may include accountant, doctor, home duties, or teacher.

   ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

12. Was the deceased retired?
   ☐ Yes ☐ No

13. Was the deceased a pensioner?
   ☐ Yes ☐ No

14. Was the deceased of Aboriginal or Torres Strait Island origin?
   ☐ Yes - Please specify origin
   ☐ Aboriginal ☐ Torres Strait Islander ☐ Both

15. What was the marital status of the deceased at time of death?
   ☐ Married ☐ Widowed ☐ Never married ☐ Divorced ☐ Unknown

   If previously married, please list all marriages of the deceased (starting with the most recent)

   Note. If more than three marriages, attach a separate sheet with the required details.

   a) Surname of spouse (family name at time of marriage):
   ______________________________

   b) Given name(s)
   ______________________________

   c) Place of marriage - Suburb/Town:
   ______________________________

   d) State: ____________________________

   Deceased's age at time of marriage ____________ years

   e) Country (if outside Australia):
   _______________________________________

   f) If transported overseas, specify region:
   _______________________________________

   Suburb/Town
   ______________________________

   State ☐ ☐

   g) If not disposing of them within 30 days of or sent overseas, provide details:
   ______________________________

   h) Return to the informant:
   ______________________________

   i) Method of communication
   ______________________________

   j) Informant's name
   ______________________________

   k) Relationship to deceased
   ______________________________

   l) Address
   ______________________________

   m) Provide legible handwriting
   ______________________________

   n) Date
   ______________________________

   o) Signature
   ______________________________

   p) Officer number
   ______________________________

   q) Reg. details
   ______________________________

   r) Error code
   ______________________________

   s) Date of registration
   ______________________________

   t) Date of printing
   ______________________________

   u) Date of death
   ______________________________

   v) Date of birth
   ______________________________

   w) Date of marriage
   ______________________________

   x) Date of death
   ______________________________

   y) Date of birth
   ______________________________

   z) Date of marriage
   ______________________________

   A defi nition of a domestic relationship is in the Reg. details

   This form is the property of the Registrar of Births, Deaths and Marriages. Do not use for any other purpose.
### PART TWO – Deceased Child’s Details

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Surname (family name) If known</td>
<td></td>
</tr>
<tr>
<td>7. Given name(s) If known</td>
<td></td>
</tr>
<tr>
<td>8. Date of birth/still-birth</td>
<td></td>
</tr>
<tr>
<td>10. Sex of deceased</td>
<td>Male/ Female/ Indeterminate</td>
</tr>
<tr>
<td>11. Weight at birth/still-birth</td>
<td>Grams</td>
</tr>
<tr>
<td>12. Gestation period</td>
<td>Weeks (best estimate)</td>
</tr>
<tr>
<td>13. Place of birth/still-birth</td>
<td></td>
</tr>
<tr>
<td>14. Was the child one of multiple births?</td>
<td>Yes/ No</td>
</tr>
<tr>
<td>15. Other - Please specify</td>
<td></td>
</tr>
</tbody>
</table>

### PART THREE – Mother’s Details

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Surname (family name)</td>
<td></td>
</tr>
<tr>
<td>16. Given name(s)</td>
<td></td>
</tr>
<tr>
<td>17. Date of birth</td>
<td></td>
</tr>
<tr>
<td>18. Residential address</td>
<td></td>
</tr>
<tr>
<td>19. Daytime telephone number</td>
<td></td>
</tr>
</tbody>
</table>

### PART FIVE – Supporting Information

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18.1 Date of examination</td>
<td></td>
</tr>
<tr>
<td>18.2 Hospital name (or other location)</td>
<td></td>
</tr>
<tr>
<td>18.3 Suburb/ Town</td>
<td></td>
</tr>
<tr>
<td>18.4 State</td>
<td></td>
</tr>
<tr>
<td>18.5 Postcode</td>
<td></td>
</tr>
<tr>
<td>18.6 Email address</td>
<td></td>
</tr>
<tr>
<td>18.7 Daytime telephone number</td>
<td></td>
</tr>
<tr>
<td>18.8 Business name</td>
<td></td>
</tr>
<tr>
<td>18.9 The particulars and cause(s) of death recorded in this certificate are true to the best of my knowledge and belief.</td>
<td></td>
</tr>
<tr>
<td>18.10 Medical practitioner’s signature</td>
<td></td>
</tr>
</tbody>
</table>

### PART SIX – Medical Practitioner’s Details

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>19.1 Date of birth</td>
<td></td>
</tr>
<tr>
<td>19.2 Hospital name (or other location)</td>
<td></td>
</tr>
<tr>
<td>19.3 Suburb/ Town</td>
<td></td>
</tr>
<tr>
<td>19.4 State</td>
<td></td>
</tr>
<tr>
<td>19.5 Postcode</td>
<td></td>
</tr>
<tr>
<td>19.6 Email address</td>
<td></td>
</tr>
<tr>
<td>19.7 Daytime telephone number</td>
<td></td>
</tr>
<tr>
<td>19.8 Business name</td>
<td></td>
</tr>
<tr>
<td>19.9 The particulars and cause(s) of death recorded in this certificate are true to the best of my knowledge and belief.</td>
<td></td>
</tr>
<tr>
<td>19.10 Medical practitioner’s signature</td>
<td></td>
</tr>
</tbody>
</table>

---

**Note.**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**Definitions of a still-birth, and reportable and reviewable deaths are included overleaf under ‘Statutory Requirements’.”**

---

**PART FOUR – Cause of Death**

- Please specify cause of death.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**PART SIX – Medical Practitioner’s Details**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**Note.**

- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**PART SIX – Medical Practitioner’s Details**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**Note.**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**PART SIX – Medical Practitioner’s Details**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**Note.**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**PART SIX – Medical Practitioner’s Details**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**Note.**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.

---

**PART SIX – Medical Practitioner’s Details**

- Please circle.
- Please specify date of examination.
- Please specify origin.
- Please specify name.
PART TWO – Deceased’s Details

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Surname (family name)</td>
<td></td>
</tr>
<tr>
<td>6. Given name(s)</td>
<td></td>
</tr>
<tr>
<td>7. Date of death</td>
<td></td>
</tr>
<tr>
<td>8. Date of birth</td>
<td></td>
</tr>
<tr>
<td>9. Sex of deceased</td>
<td>Male □ Female □</td>
</tr>
<tr>
<td>10. How did you confirm the deceased’s identity?</td>
<td>Personal knowledge □ Medical records □ Deceased’s relative □</td>
</tr>
<tr>
<td></td>
<td>Deceased’s relative surname (family name)</td>
</tr>
<tr>
<td></td>
<td>Deceased’s relative given name</td>
</tr>
<tr>
<td></td>
<td>Relationship to the deceased (e.g. husband, sister or uncle)</td>
</tr>
<tr>
<td>11. Where did the death occur?</td>
<td>Hospital □ Nursing home □ Place of residence □ Other - Please specify</td>
</tr>
<tr>
<td></td>
<td>other location (e.g. roadside)</td>
</tr>
<tr>
<td>12. Place of death</td>
<td>a) Name of place/institution (if applicable)</td>
</tr>
<tr>
<td></td>
<td>b) Street no. and name</td>
</tr>
<tr>
<td></td>
<td>c) Suburb/Town</td>
</tr>
<tr>
<td></td>
<td>d) State □ e) Postcode</td>
</tr>
<tr>
<td>13. Was the deceased of Aboriginal or Torres Strait Island origin?</td>
<td>Yes - Please specify origin</td>
</tr>
<tr>
<td></td>
<td>Aboriginal □ Torres Strait Islander □ Both □</td>
</tr>
<tr>
<td></td>
<td>No □</td>
</tr>
<tr>
<td>14. Was a post mortem examination held?</td>
<td>Yes □ No □ Yet to be held</td>
</tr>
</tbody>
</table>
Medical Researchers

Medical research organisations may seek access to BDM’s restricted records to, for example:
- Track the mortality rate of patients who have participated in a medical trial
- Link causes of death to known illness
- Establish the hereditary nature of diseases

Medical Research organisations may also approach BDM for access to information for the purpose of data-cleansing only. In such instances, Access Policy provisions on data-cleansing apply.

Medical researchers may request one of two things:
1. Data matching by BDM – researcher supplies BDM with information (eg. a patient list) and BDM then matches this data against the records held in the register
2. Provision of data from the registers – BDM supplies records (fields of data supplied may vary) to enable the researcher to undertake their own data matching.

Generally only the following information from the registers will be released to medical researchers:
- Death information: surname, given name, street address, suburb and postcode of the deceased’s usual residence, sex, date of birth, place of death, age of the deceased, date of death and possible causes of death
- Birth records: date of birth, place of birth

Other information, including information about parents and children of deceased may be released where a medical researcher can show this is crucial to the research.

1.1.1 Conditions of Access

All requests for access by medical researchers for medical research to restricted records must be approved by the Registrar.

Medical researchers must:
- Provide a letter specifying the reason for seeking access to restricted records on the institutions letterhead (where applicable) and must include:
  - Faculty/departmental approval indicating any intended publication of information;
  - Outline the reasons why the research is in the public interest; and
  - Provide a copy of the registered person’s written consent allowing the researcher to access their information;
    - If the researcher is unable to provide the registered person’s written consent, they must explain why they are unable to obtain their consent;

AND

- Provide approval from their organisation’s Human Research Ethics Committee; and
- Provide a written undertaking that the information will remain secure after its release by BDM.

In determining whether access is granted consideration should be given to factors including:
- The nature of the researcher’s interest
- The public interest served by releasing the information to the researcher
- The sensitivity and quantity of the information
- The use to be made of the information
- Other relevant factors including:
  - Protection of registered persons’ privacy
  - Whether the researcher will be honest and ethical in their research and dissemination of results
  - That privacy protection takes precedence over the research’s expected benefits
  - That the research is justified in terms of its potential contribution to knowledge
NB: Medical researchers may be required to enter into a Memorandum of Understanding outlining the terms and conditions of access to BDM information.

1.1.2 Information which may be released and format
To be assessed on a case by case basis.

<table>
<thead>
<tr>
<th></th>
<th>Standard certificates</th>
<th>Non-POI certificates</th>
<th>Uncertified copies of certificates</th>
<th>Index on website</th>
<th>Abbreviated Death Certificate</th>
<th>Data</th>
<th>Letters of verification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Death</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Marriage</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>CON</td>
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<td>No</td>
<td>No</td>
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<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Deed Poll</td>
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<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Recognised details</td>
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<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>