

Appendix D: Report on the flow of Indigenous status information in six health data sets

This appendix should be read together with the main report: National best practice guidelines for collecting Indigenous status in health data sets

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This appendix briefly explores the data pathway in each of six health data sets where the flow of data on Indigenous status has been examined, and the factors that could affect the quality of these data at each step along the pathway.

The information flow in most of the health data collections under consideration consists of three key stages:

- point of service, where information on Indigenous status is collected from the individual using the service and recorded – identification as Indigenous is voluntary (stage 1)
- compilation of data in state and territory registers or data collections (stage 2)
- compilation in national data collections (stage 3).

The exceptions are:

- birth registrations where the first stage (birth) is captured in the midwives data collection (perinatal) and only the second and third stages are recorded
- Bettering the Evaluation and Care of Health (BEACH) data where the second stage is bypassed because BEACH is a survey not an administrative data collection
- Medicare registration data where the first and second stages are bypassed.

Table D1 illustrates the information flow for each collection.

Table D1: Flow of information for health data collections

Data collection	1. Point of service	2. State/territory data custodian	3. National data custodian
National Perinatal Data Collection	<i>Perinatal collection forms</i> Completed by the attending midwife or other attending medical practitioner Demographic information may be obtained from hospital admission/pre-admission forms completed by hospital admission and other staff	State and territory health authorities (perinatal data collections)	National Perinatal Statistics Unit—collaborating unit of the Australian Institute of Health and Welfare (AIHW)
Birth registrations	n.a. (self-completed form)	State and territory registrars of births, deaths and marriages	Australian Bureau of Statistics (ABS)
Bettering the Evaluation and Care of Health (BEACH) survey	<i>BEACH survey form</i> Completed by general practitioners	n.a.	General Practice Statistics and Classification Centre—collaborating unit of the AIHW
Medicare Australia/Pharmaceutical Benefits Scheme	n.a. (self-completed form)	n.a.	Health Insurance Commission
National Hospital Morbidity Database	<i>Various (including admission, episode of care, discharge)</i> Completed by hospital admissions and other staff	State and territory health authorities	AIHW
National Mortality Database	<i>Death registration application form</i> Completed by funeral director or other person responsible for the disposal of the body—personal details are usually provided by the family or next of kin <i>Cause of death certificate form</i> Completed by the medical practitioner certifying the death For deaths reported to a coroner, the autopsy certificate form is completed by the coroner (note: not all coroner-referred deaths will have an autopsy form)	State and territory registrars of births, deaths and marriages	ABS

n.a. Not applicable.

Perinatal data

Point of service

The collection of data for perinatal collections (including Indigenous status) is usually the responsibility of the midwife or another attending medical practitioner – that is, the person providing the health service to the individual being asked the question. A midwife usually obtains Indigenous status information from the mother (along with other demographic information such as birthdate, marital status and country of birth) either at the antenatal clinic before delivery or, in some hospitals, when the mother comes to the maternity ward for the baby's birth. On occasions, mothers may present to hospital unexpectedly and midwives will try to find out details, such as the mother's Indigenous status, at some point after delivery.

In some hospitals, patient demographic information such as Indigenous status is obtained from the hospital database (for example, via the pre-admission or admission form), in which case the information is usually collected by admission staff. In such hospitals, midwives will only collect Indigenous status information if it is not already recorded in the hospital database. Any further information is collected by midwives after delivery.

If Indigenous status is obtained from the hospital database, it is often not checked or validated by midwives and so is subject to the same data quality issues as the hospital data collection. If Indigenous status is missing on the mother's record, there is generally little follow-up by midwives to obtain this information after delivery. In a small number of hospitals, information that is recorded by midwives is then sent to the admission office so that the mother can be admitted to hospital. If Indigenous status has not been recorded by maternity staff, admissions staff may contact the midwives to try to obtain this information, but it is not always successful. In some cases, admission staff may check that the information recorded by the midwife is correct by re-asking the question.

In most hospitals, only the mother's Indigenous status is asked and recorded, rather than that of the baby or the father, and thus the mother's Indigenous status is used to determine the baby's Indigenous status. In some hospitals, however, Indigenous status of the baby may also be asked and recorded. In other hospitals, both the mother's and father's Indigenous status is asked and/or recorded and is used to determine the Indigenous status of the baby (in such cases, if either the mother or father is Aboriginal or Torres Strait Islander, then the baby is correspondingly recorded as Aboriginal or Torres Strait Islander). On rare occasions, the mother may inform staff that the father is Aboriginal or Torres Strait Islander, or in some instances, staff may know that father's Indigenous status through local knowledge of the family. In such instances, the baby may be recorded as Aboriginal or Torres Strait Islander in the system.

Information obtained is usually entered into the hospital maternity database or equivalent, and/or recorded on perinatal collection forms that are sent to the state/territory health authorities. The hospital maternity database is often separate to the hospital inpatient database. The information that is recorded in the hospital maternity database, and the categories used for some of the items such as Indigenous status, may differ to those contained on the perinatal collection forms.

Each jurisdiction uses its own unique collection form (see page 25 for the form used in New South Wales). Generally, the same type of information is collected on perinatal collection forms from jurisdiction to jurisdiction, but some variations exist. Table D2 lists the items most or all jurisdictions include on their perinatal information forms.

Table D2: Data items collected by most jurisdictions on perinatal forms

Type of information	Data items
Mother's demographics	Date of birth, country of birth, Indigenous status, marital status
Previous pregnancies	Number to term, type, date of completion of last pregnancy, outcome, method of delivery of last birth, number of caesareans
Present pregnancy	Date of last menstrual period, prenatal diagnosis, antenatal care, medical conditions, obstetric complications, procedures and operations
Labour and delivery	Onset of labour, type of labour/birth, reason/method for inducing labour, length of labour, pain relief/anaesthetics, presentation at birth, complications during labour, type/method of delivery, perineal status
Baby's details	Date of birth, sex, plurality, birth weight, estimated gestational age, Apgar score, resuscitation, congenital anomalies, neonatal morbidity
Postnatal care	Admitted to neonatal intensive care or special care nursery
Discharge status of mother and baby	Discharged, transferred or died/stillbirth

While all forms include a question on the mother's Indigenous status (or from which Indigenous status can be derived), the format varies between jurisdictions and in its level of compliance with the standard question (Box D1). New South Wales, Victoria, Queensland, Tasmania and the Australian Capital Territory conform to varying degrees with the standard question, by including options for the mother to identify as Aboriginal, Torres Strait Islander, both Aboriginal and Torres Strait Islander or neither. Only Queensland and Tasmania, however, include tick boxes for each of the categories; other listed jurisdictions require the midwife to tick both the Aboriginal and Torres Strait Islander boxes if the person identifies as both.

The remaining jurisdictions use varying category formats. In the Northern Territory, no category exists for Torres Strait Islander – a mother can identify as Aboriginal or non-Aboriginal. In Western Australia, Indigenous status is within questions on ethnic origin, where the mother can identify as an Aboriginal and/or Torres Strait Islander. In South Australia it is within questions on race, and includes categories for Aboriginal, Torres Strait Islander and both. Only the Northern Territory form includes an option for recording 'not stated' on the form.

None of the state/territory perinatal collection forms include a question on the Indigenous status of the baby or father, although on occasions this information may be written on the forms by midwives if it is known to them.

Other forms may be used within the hospital that collect information on the father's Indigenous status as well as the mother's; however, these are generally not used to inform what is recorded on the state/territory perinatal collection form. For example, in South Australia, a supplementary pregnancy record is given to women at their first antenatal visit after confirmation of her pregnancy. This is provided by the women's general practitioner (GP), obstetrician or midwife. Both the mother and partner have the opportunity to complete Indigenous status information on the pregnancy record but information on the partner's Indigenous status is often not completed. The Indigenous status of the father is sometimes added manually to the pregnancy record by staff. The question that is asked on the

pregnancy record is: 'ethnicity/cultural background'. No options are given. In New South Wales, a booking form is used in some hospitals for mothers due to give birth; the form includes a question on the father's ethnicity, but it is also an open-ended question. Some area health services in NSW are beginning to include a question on the partner's Indigenous status on perinatal forms.

Box D1: State and territory perinatal collection forms – format of question on Indigenous status

NSW midwives data collection form (NSW Midwives Data Collection)

Indigenous status:

- Aboriginal
- Torres Strait Islander
- Aboriginal and Torres Strait Islander
- None of the above

Perinatal morbidity statistics form (Victorian Perinatal Data Collection)

Aboriginal (mother):

- No
- Aboriginal
- Torres Strait Islander

Perinatal data collection form (MR63D) (Queensland Perinatal Data Collection)

Indigenous status:

- Aboriginal
- Torres Strait Islander
- Aboriginal and Torres Strait Islander
- Neither Aboriginal nor Torres Strait Islander

Notification of case attended form (Western Australian Midwives Notification System)

Ethnic origin:

- Caucasian
- Aboriginal/TSI

Supplementary birth record (South Australian Perinatal Statistics Collection)

Race:

- Caucasian
- Aboriginal
- Asian
- Torres Strait Islander (TSI)
- Aboriginal and TSI
- Other

(continued)

Box 1 (continued): State and territory perinatal collection forms – format of question on Indigenous status

Perinatal data collection form (Tasmanian Perinatal Data Collection)

Indigenous status:

- Neither Aboriginal nor Torres Strait Islander
- Aboriginal
- Torres Strait Islander
- Both Aboriginal and Torres Strait Islander

Northern Territory midwives collection

Aboriginality:

- Aboriginal
- Non-Aboriginal
- Not stated

ACT midwives data collection form (ACT Maternal Perinatal Data Collection)

Indigenous status:

- Not Indigenous
- Australian Aboriginal
- Torres Strait Islander

Source: State and territory midwife collection forms.

State/territory perinatal collections

Perinatal data are submitted to state and territory health authorities in paper format and/or electronically. Depending on the jurisdiction, forms are submitted for each birth on a weekly or monthly basis, or within a specified time period after the birth of the baby (for example, 28 or 35 days). In the Northern Territory, perinatal data are extracted from the Northern Territory Hospital Information System every six weeks.

In most states and territories, data are collected on mother's demographics, previous pregnancies, current pregnancy, labour, birth and postnatal details, baby's details, postnatal care and discharge status of mother and baby.

Health authorities are responsible for collating data in their respective perinatal databases:

- New South Wales (NSW) Midwives Data Collection
- Victorian Perinatal Data Collection
- Queensland Perinatal Data Collection
- Western Australian Midwives Notification System
- South Australian Perinatal Statistics Collection
- Tasmanian Perinatal Data Collection

- Australian Capital Territory (ACT) Maternal Perinatal Data Collection
- Northern Territory Midwives Collection.

Depending on the format of the Indigenous identifier in the database, some mapping work may be required to transfer the data recorded on the collection form to the database (this occurs in South Australia and Victoria).

Before compilation, some health authorities may use a range of 'data check procedures' to fill in missing data, clarify inconsistent data and check validity. Preliminary information suggests that different jurisdictions use a varying combination of these:

- follow-up with hospital admissions, medical records staff and/or attending midwives (for missing data and for discrepancies or queries regarding Indigenous status data)
- cross-checking with hospital-based administrative data collections or other administrative collections (such as Births, Deaths and Marriages) (for missing data, inconsistent data and some general quality-control data checking)
- validating cross-tabulations (for example, Indigenous status against country of birth)
- cross-checking with previous records for the mother in the perinatal database, if the mother has had a previous birth
- comparing against previous years' numbers to evaluate changes in reporting and potential errors.

Some jurisdictions (namely Victoria, South Australia and Queensland) have undertaken specific evaluation projects in the past that have looked at Indigenous status validation.

Defaults are generally not used for missing data; some jurisdictions have indicated they include a 'not stated/non-response' category in their database for Indigenous status.

National perinatal data

National perinatal data are compiled in the National Perinatal Data Collection, which comprises data items as specified in the Perinatal National Minimum Data Set (NMDS), plus additional items collected by the states and territories. The Perinatal NMDS is a specification for data collected on all live births and all stillbirths of at least 20 weeks gestation and/or at least 400 grams birth weight, in hospitals, birth centres and the community in Australia. The Perinatal NMDS was established in 1997 and currently consists of 17 data items (Table D3).

Table D3: Data items collected in the Perinatal National Minimum Data Set (NMDS)

Type of information	Data items
Birth	Birth order, birth status, birth weight (total grams), Apgar score (at 5 minutes)
Birth event	Birth plurality, delivery method, labour onset type, setting (actual), state or territory of birth
Episode of admitted patient care	Separation date
Establishment	Organisation identifier (Australian)
Female (pregnant)	Estimated gestational age (total weeks)
Person	Country of birth, date of birth, Indigenous status, person identifier (within establishment/agency), sex

Perinatal data for each year ending 31 December are sent annually, in electronic format, by health authorities in the various jurisdictions to the National Perinatal Statistics Unit (NPSU), a collaborating centre of the Australian Institute of Health and Welfare (AIHW). The NPSU is

responsible for cleaning, validating and compiling national data. Data are published annually in the *Australia's mothers and babies* report series, usually around two years after the year of data collection. For example, the 2003 data were published in *Australia's mothers and babies 2003* (Laws & Sullivan 2005) in December 2005.

The Perinatal NMDS includes a data element 'Indigenous status' defined as 'a measure of whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin'. The domain values are in accordance with the equivalent data domains in the *National health data dictionary* (NHDD) standard (and hence the Australian Bureau of Statistics (ABS) standard for Indigenous status).

States and territories are required to provide Indigenous status data in NHDD format, which are derived from Indigenous status fields in their respective databases. (It is understood that most or all jurisdictions do not undertake any mapping work to complete this requirement.) An evaluation of the Perinatal NMDS data from 2000 ascertained that all jurisdictions adhered to the NHDD definition of Indigenous status and all but one provided data in accordance with the NHDD data domains (Laws & Sullivan 2004). Tasmania provided, and continues to provide, Indigenous status data as 1 'Indigenous' and 9 'other', the latter of which cannot be differentiated between non-Indigenous and unknown/not stated. Tasmanian Indigenous status data are therefore not published in the national perinatal report series. It should also be noted that for 2003 onwards, Western Australia provided Indigenous status data as 'Indigenous' and 'non-Indigenous' whereas in previous years they provided data according to the NHDD categories (Laws & Sullivan 2005). These data were derived from the Western Australian perinatal form, while in the past, Indigenous status data was extracted from the Western Australian hospital morbidity system which does not have a 'not stated' option.

Perinatal data are checked and validated on an annual basis when calendar year data are provided by the states and territories. Indigenous status data are validated by comparing the number and proportion of Indigenous records against the previous year's data, to see if there has been an unusual increase or decrease in the number of mothers or babies recorded as Indigenous in any jurisdiction, and by comparing Indigenous status against country of birth. The latter is not considered particularly useful as some Aboriginal and Torres Strait Islander women correctly report being born overseas in places such as Papua New Guinea, Samoa and other nearby islands. Other edits may be undertaken throughout the year if discrepancies are found.

Queries on invalid codes or inconsistencies in the data are sent to the perinatal data manager in each state and territory to check and follow up. If minor changes are required, these are provided in writing and the changes are made by the NPSU. If major changes are required, an updated data extract is sent to the NPSU by the relevant jurisdictions.

There is generally no follow-up at the national level to obtain missing Indigenous status data, as there are few women recorded with a 'not stated' Indigenous status in the perinatal data collection.

Birth registration

State/territory birth data collections

For birth data, there is no point of service. Parents are required to complete a birth registration form for every newborn child and submit it to the state/territory registrar of births, deaths and marriages within 60 days of the birth (see page 26-27 for the form used in Queensland). This form is different for each jurisdiction; however, all states and territories collect information on the Indigenous status of both parents using the standard ABS question. The details and signature of both the mother and father is requested; however, in practice, these are not always obtained from both parents. If the signature of the father cannot be obtained, the registrar will omit the father's details and the mother must submit a statutory declaration stating that she does not know who the father is.

In all jurisdictions except the Northern Territory, a child will be classified as Indigenous if one or both parents identify as being Indigenous. In the Northern Territory, the parent fills out the information on Indigenous status, including that of the child. While this information is forwarded to the ABS, the default setting used for all states and territories, including the Northern Territory, is that the child is recorded as Indigenous if either the mother or father is recorded as Indigenous, regardless of what is recorded as the child's Indigenous status on the birth registration form.

The information collected on birth registration forms is shown in Table D4.

Table D4: Data items collected on birth registration forms

Type of information	Data items
Child's details	Surname, given name(s)
Birth details	Date of birth, sex, location of birth, child's weight at birth, order of birth (if multiple birth), whether child was born alive, gestation period for stillborns, name and address of doctor or midwife attending birth
Mother's details	Surname, maiden name, given name(s), date of birth, place of birth, age at birth of child, Aboriginal and/or Torres Strait Islander origin, residential address during majority of pregnancy, usual occupation
Father's details	Surname, given name(s), date of birth, place of birth, age at birth of child, Aboriginal and/or Torres Strait Islander origin, usual residence, usual occupation
Marriage details	Date and place of marriage – if applicable
Previous children of this relationship	First names, age, date of birth, sex
Other child of the mother but not of this relationship	First names, age, date of birth, sex (in some jurisdictions only)

Note that some of the information collected on birth registration forms can vary between jurisdictions. For example, the usual residence and usual occupation questions are asked differently across jurisdictions; some states and territories may also omit the usual occupation question altogether.

The birth registration form is submitted in paper format to the state/territory registrar of births, deaths and marriages, where the information is entered into the state/territory databases.

National births data

Standard birth data items are forwarded monthly by registrars of births, deaths and marriages to the ABS where they are compiled as aggregated statistics. The ABS is currently confirming with registrars a new list of standard birth data items to be supplied for births data for 2007 onwards. The ABS has asked registrars to collect all items; however, this will not occur in the short to medium term.

The data items which were collected in the national collection in 2004 are shown in Table D5.

Table D5: Data items collected in the national births data collection

Type of information	Data items
Registration details	Registration year, registration month, state/territory of registration
Child's details	Sex of child, Indigenous status of child, year/month/day of birth of child, state or territory of usual residence, statistical division of usual residence, statistical subdivision of usual residence, statistical local area of usual residence
Mother's details	Mother's age, Indigenous status of mother, country of birth of mother
Father's details	Father's age, Indigenous status of father, country of birth of father, father's occupation
Marriage details	Nuptiality, duration of marriage, year of marriage, month of marriage, country of marriage
Previous children of this relationship	Plurality, previous children of the current relationship

Annual births data are published in the ABS *Births* report series towards the end of the following year. For example, 2005 birth registration data were published in *Births, Australia, 2005* (ABS 2006a) in October 2006. The data are presented per calendar year as year of registration.

The usual interval between a birth and its registration, particularly if the birth occurred towards the end of the calendar year, may mean registration is delayed until the following year. An examination of births registered by year of occurrence compared with births registered by year of registration, found that the proportion of births being registered in the year they occurred has fallen from 90% in 1992 to 89% in 2005 (ABS 2006a). There is great variation between states and territories (from a delay of 3.3 months in Queensland to 1.1 months in the Northern Territory). When comparing Indigenous and non-Indigenous births, a higher proportion of Indigenous births are registered late (that is, not in the year they occur) than all births (22% compared to 11%).

Indigenous status is generally validated as part of the overall process of data editing; however, there are specific edits and reports which look specifically at Indigenous status. Data checks on Indigenous status for individual records are performed on a monthly basis as files are received. Further checks are undertaken at an aggregate level on quarterly and annual bases. Examples of checks undertaken include comparing the number and proportion of Indigenous records against the previous year's data and comparing Indigenous status against country of birth. In the past, a person's Indigenous status was changed if they were born overseas, however recently this practice has been changed to bring births data more in line with the Census and ABS standard practice. These figures are now examined at an aggregate level and if the number of overseas-born Indigenous persons born exceeds set tolerances then it is investigated further.

When a potential error or issue is identified regarding Indigenous status information, the ABS will usually contact the registrars of births, deaths and marriages in each state and

territory. They are asked to verify if their systems reflect what the ABS has recorded in their system and whether they know of any event or issue that may have caused the quality of the data to be in question.

There is no national authoritative data source to undertake data linkage or comparison with births data; however, certain sources such as the Victorian Koori Register may be used for comparisons on an ad hoc basis. No follow-up action is currently undertaken to obtain missing Indigenous status information in the national birth data collection.

Data quality and validation processes are currently being reviewed with a view to implement any changes for 2007 data. The ABS is also working with registrars to assist in improving data entry and coding practices in each jurisdiction.

Bettering the Evaluation and Care of Health (BEACH) survey of general practice

Point of service

Each year, a random sample of approximately 1,000 general practitioners (GPs) records details of 100 doctor-patient encounters of all types. It is a rolling sample, recruited approximately three weeks ahead. Approximately 20 GPs participate each week, 50 weeks a year. The information on each GP-patient encounter is recorded on paper-based forms (see page 28), including the Indigenous status of the patient. The response categories are in the following format:

- Aboriginal: yes/no
- Torres Strait Islander: yes/no.

GPs are required to ask the standard ABS question for Indigenous status; however, it is not known how often or consistently this is used. The reliability of the results of the BEACH survey has been tested in a substudy of about 9,000 patients encountered during the survey. The substudy found that when the question on Indigenous status is asked of the patient within the context of a series of questions about origin and cultural background, 2.2% will identify as Aboriginal and/or Torres Strait Islander, which is twice the rate routinely recorded in BEACH. However, this difference was not statistically significant.

Each participating GP also completes a GP characteristics form.

BEACH data collection

The participating GPs submit the encounter forms and GP characteristics form to the Australian General Practice Statistics and Classification Centre (AGPSCC) of the University of Sydney (a collaborating unit of the AIHW) where they are compiled in the BEACH database. The AGPSCC follows up non-returns by regular telephone calls for up to three months after the set recording time.

The information collected on the encounter and GP characteristics forms and included in the BEACH data set is shown in Table D6. The name of the patient is not collected.

Table D6: Data items collected in the Bettering the Evaluation and Care of Health (BEACH) survey

Type of information	Data items
Encounter details	Date of consultation, type of consultation (direct, indirect), Medicare/Veterans' Affairs item number (where applicable) and other payment source
Patient details	Date of birth, sex, postcode of residence, Australian Government concession card holder, holder of a Repatriation health card (from the Australian Department of Veterans' Affairs), non-English-speaking background (NESB), Aboriginal person (self-identification) and Torres Strait Islander (self-identification), up to three patient reasons for encounter (RFEs)
Details of problems managed at encounter	At least one and up to four problems, new or continuing problem
Management of each problem	
Medications	Medications prescribed, supplied by the GP and medications advised for over-the-counter purchase including: brand name, form (where required), strength, regimen, status (if new or continuing medication for this problem for this patient) and number of repeats
Treatments	Other treatments provided for each problem including counselling, advice and education, and procedures undertaken
Referrals	New referrals to medical specialists, allied health professionals and hospital
Investigations	Pathology tests, imaging and other investigations ordered at the encounter
General practitioner (GP) characteristics	Age, sex, years in general practice, number of GP sessions worked per week, number of GPs working in the practice, postcode of major practice address, country of graduation, postgraduate general practice training and Royal Australian College of General Practitioners fellowship (FRACGP) status, after hours care arrangements, use of computers in the practice, whether the practice is accredited, whether it is a teaching practice, work undertaken in other clinical settings, hours worked in direct patient care and hours on call per week

BEACH data are published annually in the *General practice activity in Australia* report series. For example, data from April 2004 to March 2005 were reported in *General practice activity in Australia 2004–05* (AIHW 2005a) in December 2005.

Indigenous status data are stored in the database as two variables:

- Aboriginal
- Torres Strait Islander.

Each of these can have values of yes (1), no (2) or missing. This enables output of Indigenous status according to the standard categories:

- Aboriginal
- Torres Strait Islander
- Aboriginal and Torres Strait Islander
- non-Indigenous
- not stated.

Using this system, rather than the ABS standard question on Indigenous status, means that the following additional combinations can be generated:

- Aboriginal but missing Torres Strait Islander status
- Torres Strait Islander but missing Aboriginal status
- not Aboriginal but missing Torres Strait Islander status
- not Torres Strait Islander but missing Aboriginal status.

Neither of the two data items is mandatory in the database.

A quality assurance program to ensure reliability of data entry includes ongoing development of computer-aided error checks ('locks') at the data entry stage and a physical check of samples of data entered versus those on the original recording form. Further logical data checks are conducted using software processes on a regular basis.

Validation of Indigenous status data is not undertaken on a regular basis; however, substudies are carried out every couple of years which aim to validate the data. Comparisons are undertaken on an annual basis, comparing the number and proportion of Indigenous status records for the current year against the previous year's data.

As the name of the patient is not collected on the survey form, missing Indigenous status information cannot be followed up.

Medicare Australia/Pharmaceutical Benefits Scheme

Point of service

To obtain a Medicare card, either the person applying for the card or parents of a newborn baby are required to complete a Medicare enrolment application form (see pages 29-31) possibly with the help of hospital staff. People over the age of 15 years can apply for a separate Medicare card by completing a copy/transfer application form (see pages 32-33). In November 2002, the ABS standard question on Indigenous status was included on both these forms; it is voluntary to complete. The question was added so that access to mainstream Medicare services and the Pharmaceutical Benefits Scheme (PBS) by Indigenous Australians could be assessed more accurately.

The forms are lodged at a Medicare Australia office or by mail and therefore there may be no opportunity for Medicare staff to ask the question on Indigenous status; instead, completion of the question is the responsibility of the person completing the form. On occasion, a person may register for Medicare by phone, in which case they will be asked the question on Indigenous status by staff. Information collected on the Medicare enrolment forms is shown in Table D7.

Table D7: Data items collected on the Medicare enrolment form and copy/transfer application form

Type of information	Data items
Name	Title, family name, first name, second name, previous name
Contact details	Mailing address, residential address, home telephone, work telephone
Medicare card details	Whether will be listed on Medicare card, previous Medicare card number
Other details	Date of birth, sex, reason for entry to Australia (if born outside Australia), entry date (if born outside Australia), departure date (if born outside Australia), Indigenous status

Note: These details are collected for each person to be listed on the Medicare card.

As the Indigenous status question is voluntary to complete on Medicare registration forms, there is no follow-up by staff to obtain missing Indigenous status information. Customers who have previously identified as Aboriginal and/or Torres Strait Islander on a registration form are also able to contact Medicare and have this removed from their record.

An Indigenous identifier is not currently included on the Medicare claim form.

Medicare database

Information from the forms is entered directly into the Medicare database. When patients make a Medicare claim, details of the claim are also entered into the database.

There is no regular publication of Medicare data.

Because the Indigenous identifier was only introduced relatively recently, the coverage of Indigenous Australians in this database is not complete. Aboriginal and Torres Strait Islander Australians who had identified as Indigenous in this database as at 1 July 2005 numbered 80,658.

Indigenous status is not checked or validated in any way.

National Hospital Morbidity Database

Point of service

There are multiple points of service in hospitals; for example, reception at emergency departments, inpatient services and mental health services. For admitted patients, hospital admission staff are, in most instances, the point of service for hospital morbidity data. Ward clerks may also collect patient demographic information. In rural areas, nurses, doctors, 24-hour clerical staff, allied health staff and community health staff may be the point-of-service staff in hospitals. Females admitted to hospital to give birth will be captured in the National Hospital Morbidity Database, the perinatal and the birth registration data collections.

Patient demographic information is occasionally obtained from GP referral forms sent to the hospital.

Indigenous status is usually asked verbally by staff via a patient registration form and the details then entered electronically; however, in some hospitals, patients are asked to complete a form. For pre-admissions, Indigenous status is usually collected via a form that the patient completes and sends to the hospital, and the information is entered electronically at the time of admission.

Indigenous status is supposed to be asked along with general demographic questions (often after country of birth and followed by questions on cultural background and language), usually on admission or soon thereafter. However, the details may not be re-collected if a patient has previously been admitted to the hospital or has been transferred from another area of the hospital (such as the emergency department) and the information was already collected there. Indigenous status is often not checked or validated by staff after admission to hospital. Some public hospitals employ Aboriginal liaison officers (ALOs) whose responsibilities may include assisting accurate recording of Indigenous status (for example,

checking and updating information on Indigenous patients). ALOs are employed in many public hospitals in Victoria, Queensland, the Australian Capital Territory and Northern Territory at selected locations (AIHW 2005b). They are more commonly employed in hospitals in regions with a high proportion of Indigenous people. Private hospitals, however, do not currently employ ALOs.

The standard question and categories are used when patients present to hospital at all or most public hospitals in most jurisdictions (see AIHW 2005b).

All public hospitals in the Northern Territory, Tasmania and Queensland record Indigenous status according to the NHDD definition and categories in their inpatient admission systems.

Victoria does not include a 'not stated/unreported' category in their data system – the categories used to record Indigenous status are: 'Aboriginal', 'Torres Strait Islander', 'Aboriginal and Torres Strait Islander', 'not Aboriginal or Torres Strait Islander', 'question not able to be asked' and 'declined to answer'.

In New South Wales, two main systems operate in hospitals across the state, both of which have categories for 'declined to respond' and 'unknown'. One system also has a category for 'not stated' as well as the other standard categories. Some hospitals and area health services in New South Wales have systems that use the NHDD codes for Indigenous status.

In Western Australia, two systems also operate, one for regional hospitals and one for metropolitan hospitals (and Bunbury). In regional hospitals, there is no 'not stated' or 'unknown' category and thus non-Indigenous and unknown records get coded to 'other'. In metropolitan hospitals, systems include 'other' and 'unknown' categories, however a patient is not able to be discharged with an 'unknown' code and thus this will be changed to a valid code ('other') on discharge.

In South Australia and the Australian Capital Territory, the categories used to record Indigenous status in patient admission systems vary between hospitals. They may be based on the standard categories or a variation (for example, related to race or with a 'not stated' category).

The standard question does not appear to be universally applied in private hospitals, although it is used when patients present to hospital at most private hospitals in Western Australia and South Australia, and some private hospitals in Victoria (AIHW 2005b). Victoria and the Australian Capital Territory also report recording Indigenous status according to the NHDD standard in their patient administration systems in private hospitals. Some systems in South Australian and Tasmanian private hospitals also use the NHDD standard.

In most jurisdictions, Indigenous status is a mandatory field which has to be completed before progressing to the next question. In most public hospital systems there is no default option; however, in some hospitals the system default may be set to non-Indigenous.

Some public hospitals have procedures for follow-up of unreported data – it is usually the responsibility of the ward clerks to obtain any missing information before the patient is discharged; however, such procedures are generally not strictly adhered to. Generally, no follow-up is undertaken in private hospitals to retrieve missing Indigenous status information.

In hospitals in most states and territories, there is no official regular mandatory training of staff on the collection and recording of Indigenous status data. In some states and territories, initial training/orientation sessions are provided to new staff, which may include information on the importance of collecting Indigenous status data. Ongoing training and updates tend to be fairly minimal in most jurisdictions. In South Australia, hospital inpatient

collection training is conducted every two years and contains an Indigenous component. In Victoria and Western Australia, one-off information sessions are sometimes offered to staff which provide information on why and how information about Indigenous identification should be asked and what happens to the data collected by hospitals. In New South Wales, training for clinical and admission staff on Indigenous identification was run in 2004 and all staff were expected to attend; however, this training has not been run since. Some hospitals offer cultural awareness programs to ground staff and support staff, including programs that cover a broad understanding of Aboriginal culture and beliefs and/or courses on collecting patient information which focus on Indigenous patients.

State/territory hospital collections

Each health authority collects hospital morbidity data for specified state-based hospital morbidity collections and for transfer to the national collection. Data that are recorded in hospital patient admission systems are forwarded electronically to health authorities on a monthly basis.

In South Australia, the Australian Capital Territory and Tasmania (private), hospitals are required to map their codes for Indigenous status according to the standard categories before sending the data to their the state/territory health authority.

In Victoria and Western Australia, there is no 'not stated/unreported' category in the state-based hospital morbidity data collections. Therefore in Victoria, records recorded as 'declined to answer' or 'question not able to be asked' get coded as non-Indigenous by the Department of Human Services before sending the data to the AIHW.

In Western Australia, hospital records with an 'unknown' code or empty field will be mapped to non-Indigenous by the Western Australian Department of Health before sending the data to the AIHW.

In New South Wales, data that are recorded in the hospital systems get passed on to the relevant Area Health Service Health Information Exchange System and then onto the New South Wales Department of Health, which undertakes mapping to align all codes for Indigenous status with the NHDD categories before sending the data to AIHW. Records recorded as 'declined to respond' and 'unknown' will usually get mapped to 'not stated'.

In Queensland and Tasmanian public hospitals and the Northern Territory, hospital systems use the standard codes for Indigenous status and thus there is no need for any mapping to be done by the health authorities. For private hospitals in Queensland, Queensland Health maps the codes to the standard categories before sending the data to the AIHW.

Some auditing of Indigenous status data is undertaken by the health authorities in Victoria, Western Australia and Queensland and the area health services (AHSs) in New South Wales. In Victoria, hospital records are checked for any apparent errors (such as a substantial increase in the number of Indigenous patients recorded in a particular hospital). Any potential errors are followed up with the hospital admission staff, and/or an ALO (if employed in the hospital).

Western Australia carries out frequent edits of the data they receive from hospitals, and will follow up any apparent discrepancies with the hospital if required (for example, if the patient is coded as Indigenous and was born overseas, or the Indigenous status of the patient is different in the midwives collection compared to the hospital morbidity collection).

In Queensland, hospital records are cross-checked for errors by comparing the place of birth with Indigenous status. If a patient was born overseas and is recorded as Indigenous, then the system will send an error message. This will then be followed-up with the hospital, if possible, and may result in the Indigenous status being changed on the system.

In New South Wales, the Department of Health and AHS undertake some auditing of Indigenous status data. The department runs regular edit checks in all admitted patient, emergency department and mental health services data by comparing Indigenous status with country of birth and language spoken. Some AHSs also undertake error checks against country of birth and language. Any potential errors are usually followed up with the hospital and changed if necessary. In some AHSs, the medical record sections in hospitals receive automatic error checks on 'unknown' records. In some cases, this occurs daily which allows follow-up with the patient; however, in some AHSs it only occurs weekly and often the patient has been discharged. Sometimes, the code is changed to 'neither Aboriginal or Torres Strait Islander' without being checked.

Most states and territories have admitted patient data collection manuals regarding the collection of information in hospitals, which include information on the data item for Indigenous status. The manuals stipulate what question should be asked to determine a patient's Indigenous status ('Are you of Aboriginal or Torres Strait Islander origin?') and what categories should be used to record this information. The data collection manuals for some states and territories also specify that the question should be asked of all persons admitted to hospital, and that the next of kin or carer should be asked if the patient is unable to provide the information. Victoria and New South Wales are the only states which have policies/guidelines specific to the collection of Indigenous status in hospitals and/or health services.

In Victoria, a document produced by the Department of Human Services, Koori Human Services Unit on the principles of recording Aboriginal status is available (updated version available in 2007). An information sheet is also available for all staff involved in hospital admissions. It contains information on why it is important for Indigenous status to be collected, what question should be asked, how it should be recorded and who uses the data. It also contains some answers to commonly asked questions about collecting data on Aboriginality, such as how to record the Indigenous status of children and babies, what to do if a patient asks why the question is being asked or changes their mind about whether they are Indigenous, and why the question must be asked of people who do not look Aboriginal.

In New South Wales (NSW), better practice guidelines to improve the level of Aboriginal and Torres Strait Islander identification in the NSW public health system were produced by NSW Department of Health in 2000. These guidelines contain information on why it is important to know Aboriginal and Torres Strait Islander origin information, what question should be asked, why this question needs to be asked, why the question has been difficult to ask, who is responsible for collecting Aboriginality information, organisational issues, cultural issues and staff training. A document on the principles for recording Aboriginal and Torres Strait Islander origin information of patients was also produced by the NSW Department of Health in 2000. It includes principles regarding consistent and comprehensive data (such as ensuring that the standard question is asked of all patients), right to service, right to refuse, change of status, explanation about why the information is collected, sensitivity, quality assurance, privacy and training.

National Hospital Morbidity Database (NHMD)

The NHMD is a collection of confidentialised summary records from admitted patient morbidity data collection systems in Australian hospitals, including public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities. Each record refers to an episode of admitted patient care or 'separation', which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay which starts or ends with a change in type of care. The data in the NHMD is based on the National Minimum Data Set for Admitted Patient Care (Table D8).

Table D8: Data items in the National Minimum Data Set for Admitted Patient Care

Type of information	Data items
Demographic information	Area of usual residence; country of birth; date of birth; Indigenous status; sex
Medical information	Additional diagnosis; diagnosis; diagnosis-related group; infant weight, neonate, stillborn; major diagnostic category; mental health legal status; principal diagnosis; procedure
Details of the hospital stay	Admission date; care type; funding source for hospital patient; hospital insurance status; intended length of hospital stay; inter-hospital contracted patient; mode of admission; mode of separation; number of days of hospital-in-the-home care; number of leave periods; number of qualified days for newborns; separation date; source of referral to public psychiatric hospital; total leave days; total psychiatric care days; urgency of admission; acute care episode for admitted patients; admission; admitted patient; episode of admitted patient care; hospital boarder; hospital-in-the-home care; same day patient
Other details	Activity when injured; admitted patient election status; external cause; Medicare eligibility status; person identifier; place of occurrence of external cause of injury; live birth; neonate; newborn qualification status; patient

The AIHW is the data custodian for the NHMD and receives data from health authorities on an annual basis in January. Data are published in the *Australian hospital statistics* series in May each year. For example, data for the 2004–05 financial year were sent to the AIHW in January 2006 and were published in *Australian hospital statistics 2004–05* in May 2006 (AIHW 2006). Data on hospitalisations of Indigenous Australians are published in accordance with the recommendations and guidelines provided in the AIHW 2005 report *Improving the quality of Indigenous identification in hospital separations data* (AIHW 2005).

Indigenous status is recorded according to the NHDD definition and categories, and the AIHW validate Indigenous status data by comparing against country of birth, eligibility for Medicare and percentage of Indigenous separations in the previous year's data. Any potential errors are followed up with the state and territory health authorities, who are supplied Indigenous status frequencies, comparisons to previous year's data and a list of records thought to be inconsistent. Data providers are asked to indicate if the data are considered correct, or can be resupplied. The entire data set is expected to be resupplied on correction; however, unless the health authority believes there has been a data transmission or extraction problem, they will usually not follow it up with the relevant hospital or resupply the data.

All validation queries are sent out soon after the hospital data have been supplied to the AIHW, and state/territory health authorities are given one month to make any corrections and resupply the data. Not all queries are sent to the jurisdictions, only those which are more than likely to be incorrect. It is rare to get improved data sent back; however, a small number of records are occasionally updated to correct either country of birth or Indigenous status

where a mismatch is obvious (for example, for newborns). Since jurisdictions have used variable definitions of Indigenous status from year to year, the AIHW has recommended caution when comparing Indigenous status data between jurisdictions, over time and between hospital sectors.

Most states/territories will not inform the AIHW of any data error checks they have undertaken themselves. They may inform the AIHW if there is a problem with data from a particular establishment and it has been followed up and cannot be corrected. The AIHW will inform the state/territory data custodians of any data checks and edits that will be carried out on the provided data. Following data resupply, the AIHW will provide data custodians with new frequencies to validate the corrected data.

The AIHW also runs state-wide queries on the proportion of records with a 'not stated' Indigenous status reported. State/territory health authorities are asked to contact all public hospitals that have more than 10%, and all private hospitals that have more than 15% of all records reported with a 'not stated' Indigenous status, to see whether this proportion can be reduced and whether there is a reason why the proportion of 'not stated' records is high. On most occasions, what has been recorded by the hospital remains unchanged.

State and territory data providers are also asked to provide advice on the likely quality of Indigenous status data on an annual basis.

National Mortality Database

Point of service

Information on the Indigenous status of the deceased person is obtained from the following sources:

- the medical practitioner certifying the death completes the cause of death certificate (medical certificate) form, or if it is a reportable death under a particular jurisdiction's Coroners Act, the coroner completes the autopsy certificate form
- the funeral director or other person responsible for the disposal of the body completes the death registration form, based on information provided by the family or next of kin or other responsible person who knew the deceased. However, in cases where there is no family – for example, in cases of unidentified remains – the form may be filled out by a doctor or police officer. This form must be signed by the next of kin or other responsible person. Forms in all jurisdictions ask for the relationship of the informant to the deceased but do not state that it has to be signed by the next of kin.

(See pages 34-39 for the Queensland version of death registration, cause of death certificate and autopsy certificate forms.)

For perinatal deaths, the Indigenous status of the deceased is also asked on the perinatal supplement (to cause of death certificate) form which is completed by the medical practitioner. However, for stillbirths, Indigenous status is collected using the same rules as apply to birth registrations. It may be obtained from hospital admission/pre-admission forms, or from the hospital database.

All of the above forms use the ABS standard question on Indigenous status.

The cause of death certificate (and perinatal supplement, if applicable) must be submitted to the state/territory registrar of births, deaths and marriages within 48 hours of the death occurring, and the death registration form must be submitted within 7 or 14 days of burial or cremation, depending on the jurisdiction.

A diagram on the key steps in recording a death is described in Figure D1 below.

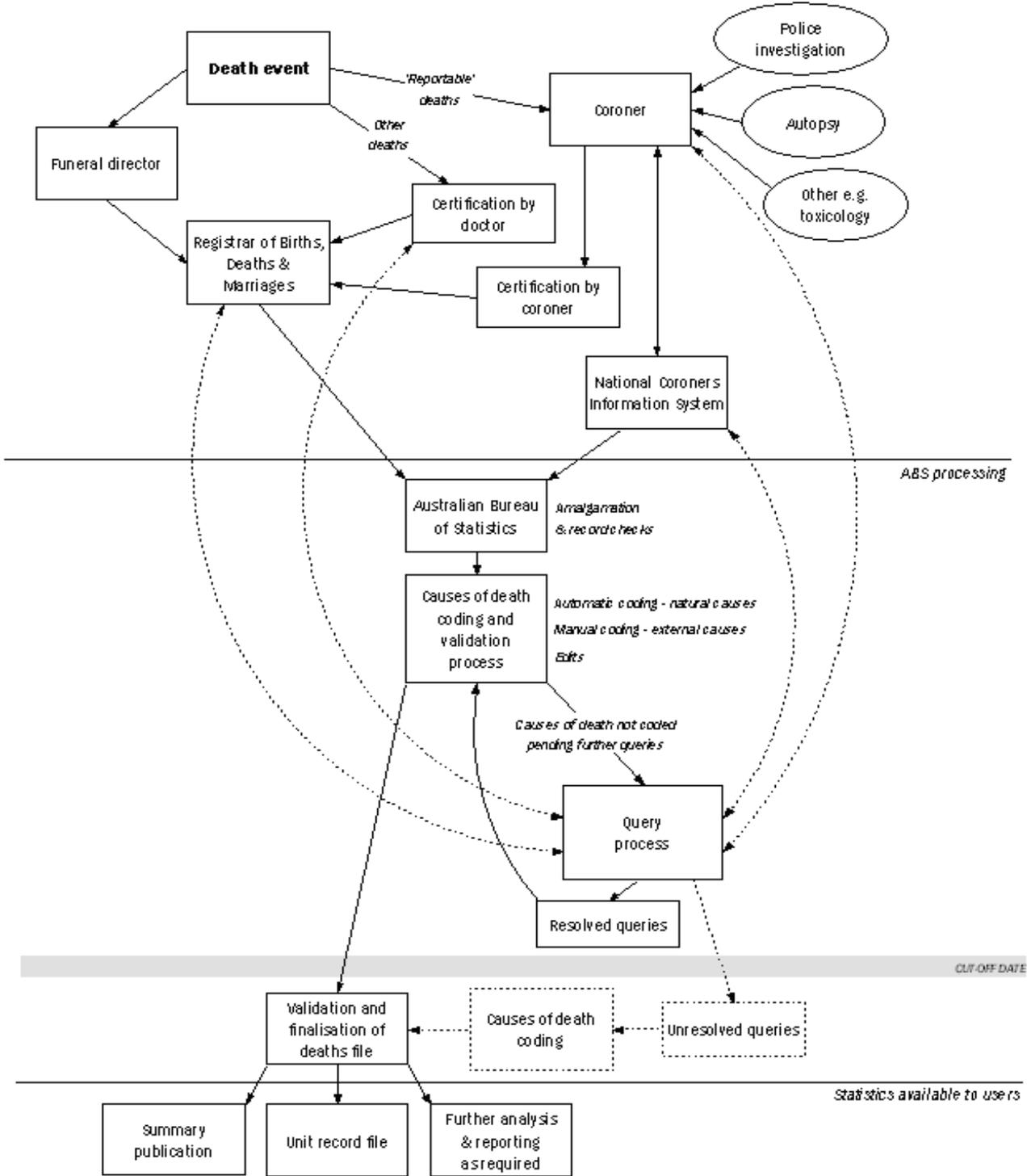


Figure D1: Death records process – deaths registered in a specific calendar year

State/territory mortality data collections

Information on the databases and methods used by jurisdictions to clarify inconsistent data and check the validity of data have not been obtained, as this information will be obtained as part of the major review of Indigenous identification in mortality data which the ABS is currently undertaking. Information based on case studies and discussions with the state/territory registrars of births, deaths and marriages is provided below.

In all states and territories, forms are submitted to the state/territory registrars of births, deaths and marriages in paper format; however, South Australia is about to start pilot testing electronic submission of the death registration statement by funeral directors.

In Queensland, there are some details on the death registration and cause of death forms that are not entered into the registry database. Some examples of such details are date and place of death of deceased spouse (if applicable), the name of the witness to the signing of the form, the duration of the illness and the presence of a pacemaker or radioactive device. In South Australia, details of the 'main tasks' in the occupational questions are not entered into the database.

Indigenous status is a mandatory field in all state/territory databases.

In most states and territories (New South Wales, Queensland, Tasmania, the Australian Capital Territory and Northern Territory), both the death registration and cause of death (medical certificate) forms are used to obtain Indigenous status information.

In Queensland and the Australian Capital Territory, if there is a discrepancy in the information on Indigenous status on the different forms, the information on the death registration form is accepted rather than the cause of death form, as the former contains information which has been obtained from the next of kin and is therefore likely to be more accurate. In Queensland, if Indigenous status is missing on the death registration form, the information on the cause of death form is used, while in the Australian Capital Territory it is recorded as 'unknown'. Where Indigenous status is missing on both forms, then it is recorded as missing.

In the Northern Territory, if the deceased is recorded as Indigenous on either source, then they are recorded as Indigenous in the database.

In Tasmania, if the information on the two forms does not match, then the doctor is contacted to confirm details. If the information still does not accord, then the death certificate (death registration form) is considered more accurate.

In New South Wales, if the two forms do not accord then the funeral director is asked to follow it up with the family, and in some cases the doctor is consulted. Where the person has been recorded as Indigenous on the death registration form and not on the medical (death) certificate, then they are recorded as Indigenous in the database.

In Victoria, South Australia and Western Australia, information on the medical certificate and death registration statement forms is recorded in separate databases and thus there is no cross-checking between the two if information on the two forms does not accord. The death registration statement form is regarded as the better source for death registration; however, both are sent to the ABS. In South Australia, a report of cases with conflicting Indigenous status is sent monthly to the ABS.

It is important to note that from January 2007, most jurisdictions have supplied the Indigenous identifier on the death registration form and the cause of death form. The ABS is currently checking with registrars regarding the quality and cleansing processes applied to

each of these data items. The ABS has asked for both of these forms so that Indigenous status can be coded consistently across jurisdictions. Negotiations are ongoing with the jurisdictions that do not currently supply this data item.

In most states and territories, if Indigenous status is missing on both forms, then there is no follow-up or validation to obtain this information. In the Northern Territory, however, it is possible to link deaths data with the births database to ascertain Indigenous status. There is generally no follow-up with the doctor or funeral director if data are missing or any further validation of Indigenous status.

ABS and AIHW National Mortality Database

The state/territory registrars of births, deaths and marriages send death registration data to the ABS monthly in electronic format. In Queensland, original forms are not sent to the ABS, except for perinatal deaths, for which the ABS is sent a photocopy of the cause of death and perinatal supplement forms.

The ABS receives the coroner's information directly from the coroner and the National Coronial Information System.

Once the mortality data have been coded and cleaned, an electronic copy is sent to the AIHW. The data items included in the AIHW National Mortality Database are shown in Table D9.

Table D9: Data items in the Australian Institute of Health and Welfare (AIHW) National Mortality Database

Type of information	Data items
Demographic information	Sex, age at death, age group, usual residence (5-digit), usual residence (9-digit), occupation, country of birth, duration of residence in Australia, marital status, age at first marriage, date of first marriage, place of first marriage, number of issue (number of children), date of birth, Indigenous status, RRMA residence
Details of death	Year of registration, state of registration, registration district, month of registration, registration number, certification, hospital, place of death, date of death, post mortem, drowning flag, cancer flag, maternal death flag, tuberculosis flag, leukaemia flag, AIDS flag, asthma flag, analgesic nephropathy flag, asbestosis flag, drug flag, remoteness (5 fields) place of occurrence, activity code, firearms flag, underlying cause of death (numeric ICD-7, ICD-8, ICD-9), underlying cause of death (alpha-numeric ICD-10), additional causes of death

Note: RRMA = Rural, Remote and Metropolitan Areas (classification); ICD = International Statistical Classification of Diseases and Related Health Problems.

It is important to note that not all of these data items are available for every year.

Mortality data are published annually by the ABS at the end of the following calendar year. For example, 2005 mortality data were published in *Deaths, Australia, 2005* in November 2006 (ABS 2006b).

The data received by the ABS are subjected to standard quality and editing measures. Indigenous status is generally validated as part of the overall process of data editing; however, there are specific edits and reports which look at Indigenous status. Data checks on Indigenous status for individual records are performed on a monthly basis as files are received. Further checks are undertaken at an aggregate level on quarterly and annual bases. Examples of checks undertaken include comparing the number and proportion of Indigenous records against the previous year's data and comparing Indigenous status against country of birth. In the past, a person's Indigenous status was changed if they were

born overseas; however, this practice has recently been changed to bring deaths data more in line with the Census and ABS standard practice.

When a potential error or issue is identified regarding Indigenous status information, the ABS will usually contact the registrars of births, deaths and marriages in each state and territory. They are asked to verify if their systems reflect what the ABS has recorded in their system and whether they know of any event or issue that may have caused the quality of the data to be in question.

Data validation practices are currently being reviewed with a view to implement any changes for 2007 data. The ABS is also working with state/territory registrars to assist in improving data entry and coding practices in each jurisdiction.

There is no national authoritative data source to undertake data linkage or comparison with deaths data; however, certain sources such as the Victorian Koori Register may be used for comparisons on an ad hoc basis.

Before 2007, no follow-up was undertaken by the ABS to obtain missing Indigenous status information in the death registration collection. From January 2007 onwards, five out of the eight states and territories (Western Australia, South Australia, Tasmania, the Australian Capital Territory and Northern Territory) have agreed to provide the ABS with the medical cause of death certificate as well as the death registration form, so that missing information can be obtained from a secondary source. If a person is identified as Indigenous on either form then they will be recorded as Indigenous. Negotiations are continuing with New South Wales, Queensland and Victoria, which are not currently able to provide Indigenous status from the medical (death) certificate.

Other information

The ABS is currently undertaking a number of projects investigating ways of resolving inconsistent Indigenous status data. These include:

- working with registrars to develop higher-quality, more consistent coding practices
- developing business rules for resolution of conflicts.

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