

# Appendix A: Aboriginal and Torres Strait Islander identification in national health data collections

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

Australian Institute of Health and Welfare 2010. National best practice guidelines for collecting Indigenous status in health data sets. Cat. no. IHW 29. Canberra: AIHW.

This appendix elaborates current thinking about the level of identification of Aboriginal and Torres Strait Islander people in national health and health-related data collections. The discussion starts with an examination of the challenges in deriving population estimates for the Aboriginal and Torres Strait Islander population, and the approaches taken by the Australian Bureau of Statistics (ABS) in addressing these challenges. This is followed by an examination of the latest available data from a range of health and health-related data collections and the available evidence on the coverage of Aboriginal or Torres Strait Islander identification.

The analyses presented focus on national and jurisdictional-level trends. There are, however, issues more specific to particular regions. For example, in more remote areas of the Northern Territory, where a larger proportion of the population is Aboriginal, the quality of the data may be better, as staff may be more willing to ask the Indigenous status question and clients may be more willing to declare their Indigenous status.

Several studies have found that the collection of Indigenous status is poorer in metropolitan regions where Aboriginal and Torres Strait Islander people make up a much smaller proportion of the overall population, and better in areas with higher proportions of Aboriginal and Torres Strait Islander people (AHMAC & ATSIHWIU 1999, AIHW 2005; Young 2001).

## Population estimates

Estimates of the size and characteristics of the Aboriginal and Torres Strait Islander population are derived from the Australian Census conducted every 5 years by the ABS. Through the Census, the standard Indigenous status question is asked of all persons in Australia.

There are two main issues to be addressed in using data from the Census: non-response to the Indigenous status question and the net under-count. In some cases, Census returns do not include a response to the Indigenous status question. In the 2006 Census, for example, there was a non-response rate of 1.7% for this question.

The second issue is that the census form is not completed for all persons in Australia at the time of the Census. While every effort is made to ensure full coverage of people and dwellings in Australia in each census, inevitably small numbers of people will have been

missed, while others will have been counted more than once. In Australia, more people are missed from the Census than are counted more than once. The net effect of over-count and under-count is called *net under-count*.

To measure net under-count of the Australian population, the ABS conducts a post enumeration survey (PES) shortly after the Census. The PES is a sample survey that provides an independent check of census coverage. Based on the PES, the ABS estimates that the net under-count for Aboriginal and Torres Strait Islander people was 11.5% in the 2006 Census, compared with 2.7% for the rest of the population (ABS 2007a).

The estimated resident population for Australia and for individual states and territories, by age, sex and Aboriginal and Torres Strait Islander status, are compiled using the Census, PES and other demographic information. The ABS estimate of the resident Aboriginal and Torres Strait Islander population at 30 June 2006 was 517,000 (ABS 2008a). This represents an increase of 12% between the 2001 and 2006 censuses, while the census count for the total population increased by 6% over the same period (ABS 2008b).

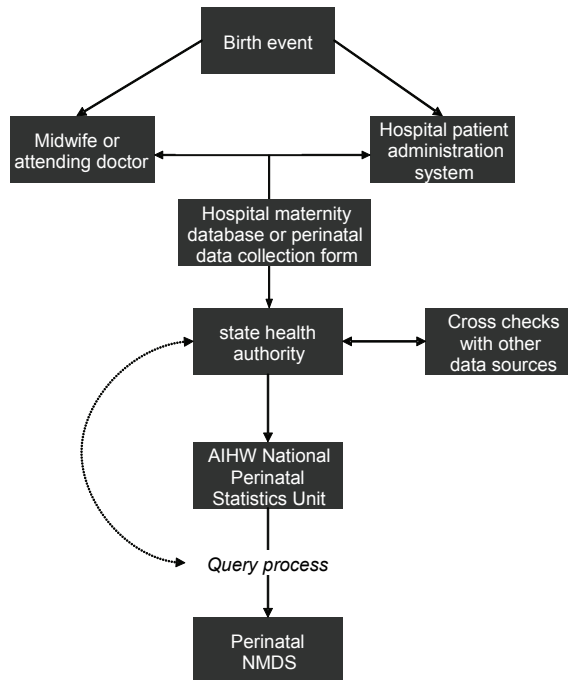
The ABS also prepared experimental estimates and projections of the Aboriginal and Torres Strait Islander population. These provide estimates for the intercensal years and projections for around eight years following the latest Census. Separate methods have been adopted for developing the Aboriginal and Torres Strait Islander estimates and projections, as significant intercensal volatility in Aboriginal and Torres Strait Islander census counts and the quality of the data on births, deaths and migration do not support the standard approach to population estimation.

The experimental estimates and projections are used extensively in estimating a range of health indicators, and in some cases estimating the extent of under-identification in health data collections.

## **The Perinatal National Minimum Data Set (NMDS)**

The Perinatal NMDS includes data on all births that have occurred in Australia in hospitals, birth centres and the community. All births of at least 20 weeks gestation or 400 grams birth weight are in scope, including both live and stillborn births. Figure A1 describes the processes that are involved with the creation of the Perinatal NMDS. State and territory health authorities provide the data to the Australian Institute of Health and Welfare (AIHW) National Perinatal Statistics Unit for national collation, on an annual basis.

Data collections are managed by each state and territory. Data are collected by the attending midwife or other medical practitioner and recorded on perinatal collection forms, either in paper or electronic format. Each state and territory has its own unique collection form on which information about the mother, her baby and details of the pregnancy, labour and delivery are recorded.



**Figure A1: Processes associated with the creation of Perinatal National Minimum Data Set (NMDS)**

The Perinatal NMDS is used to identify how many Aboriginal and Torres Strait Islander mothers use perinatal care and whether they identify their children as Aboriginal or Torres Strait Islander. While the national collection includes data on the Aboriginal or Torres Strait Islander status of the mother, a major limitation is that it does not provide data on the Aboriginal or Torres Strait Islander status of babies, although some jurisdictions collect this information.

An evaluation of the Perinatal NMDS data from 2000 showed that all jurisdictions adhered to the *National health data dictionary* (NHDD) definition of Indigenous status and all but one (Tasmania) provided data in accordance with the NHDD data domains (Laws & Sullivan 2004).

The proportion of confinements to Aboriginal and Torres Strait Islander mothers has remained around 4% and the proportion of ‘not stated/inadequately described’ responses to the Indigenous status question has been very low – below 0.1% over the past few years (Stage 1 project report – see *Introduction* in the main report for stages in guideline development).

A study was undertaken by the AIHW in 2007 which assessed the quality of Indigenous status information in perinatal data in each state and territory. This involved a survey that was sent to midwifery managers across Australia to determine how many hospitals in each jurisdiction obtain from admission records the Indigenous status information of mothers giving birth, and how many collect this information independently. The assessment also involved analysis of the variability in the number and proportion of mothers recorded as Aboriginal or Torres Strait Islander in the perinatal data collection, over time and across jurisdictions, for the period 1991–2004. The outcomes of this assessment showed that Indigenous status data from New South Wales, Victoria, Queensland, Western Australia,

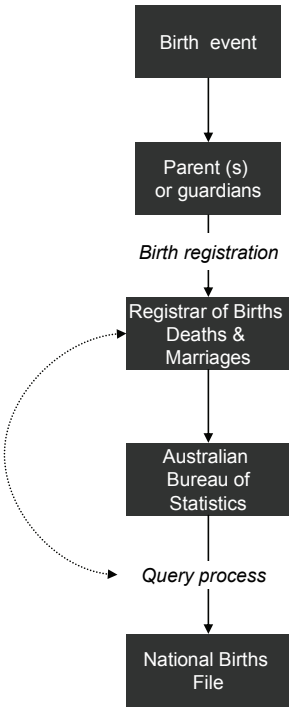
South Australia and the Northern Territory were suitable for trends analysis. Perinatal data from Tasmania, although improving, were deemed to be of insufficient quality. Although the most recent data from the Australian Capital Territory were of publishable quality, the data were not yet of sufficient stability to support trends analysis (AIHW: Leeds et al. 2007).

## Birth registration data

Registration of births is the responsibility of state and territory registrars of births, deaths and marriages and is based on the data provided on an information form completed by the parents of the child. Figure A2 describes the processes that are involved with the creation of the national births data.

All jurisdictions require parents to register the birth of a child within 60 days of the birth, and for both parents to complete their details and sign the registration form. The birth registration form in each state and territory collects information on the Indigenous status of the mother and of the father, but not the child.

Agreed standard birth data items are forwarded monthly by registrars to the ABS where they are compiled as aggregated statistics in the ABS births publication.



**Figure A2: Processes associated with the creation of national births data**

In 2008, 5% of birth registrations were identified as Aboriginal or Torres Strait Islander – that is, either the mother or the father or both mother and father identified as Aboriginal or Torres Strait Islander – an increase from 4.2% of birth registrations in 1998 (ABS 2009). The proportion of birth registrations where neither parent indicated their Indigenous status ranged between 0.5% and 0.7% of all births registered in Australia between 1998 and 2005.

Of the births recorded as Aboriginal and Torres Strait Islander in 2008, around one-third (32%) were to parents who both identified as being Aboriginal or Torres Strait Islander, 41% were to mothers who identified as Aboriginal or Torres Strait Islander (but the father was non-Indigenous, not acknowledged or did not have Aboriginal or Torres Strait Islander status recorded) and 27% were to fathers who identified as Aboriginal or Torres Strait Islander (but the mother was non-Indigenous, or did not have Aboriginal or Torres Strait Islander status recorded) (ABS 2009). Even where one parent is acknowledged as Aboriginal or Torres Strait Islander, the Indigenous status of the other parent may not be recorded. Around 35% of Aboriginal and Torres Strait Islander births in 2005 did not have the Indigenous status of one parent recorded, which is estimated to be around 1.5% of all births. The implied coverage of Indigenous status in birth registrations can be estimated by taking the ratio of the number of registered Aboriginal and Torres Strait Islander births and comparing it with the number of projected Aboriginal and Torres Strait Islander births for a given year or period. The projected births are derived from the experimental Indigenous population estimates and projections discussed previously. The implied coverage of Aboriginal and Torres Strait Islander births for the period 2002–2006 was 95.5% (ABS 2007b). In this period, the lowest coverage was in the Australian Capital Territory (82.8%) and the highest in the Northern Territory (107.2%). For the states, coverage ranged from 89.3% in New South Wales to 99.2% in South Australia (Table A1).

**Table A1: Aboriginal and Torres Strait Islander births, implied coverage, 2002–2006**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust <sup>(a)</sup>
Number of births registered as Aboriginal and/or Torres Strait Islander	16,781	3,626	17,301	8,560	3,361	1,992	449	7,728	59,808
Projected number of Aboriginal and Torres Strait Islander births	18,799	3,738	17,597	9,007	3,388	2,329	542	7,207	62,631
Implied coverage of Aboriginal and Torres Strait Islander births	89.3	97.0	98.3	95.0	99.2	85.5	82.8	107.2	95.5

(a) Includes other territories.

Source: ABS 2007b.

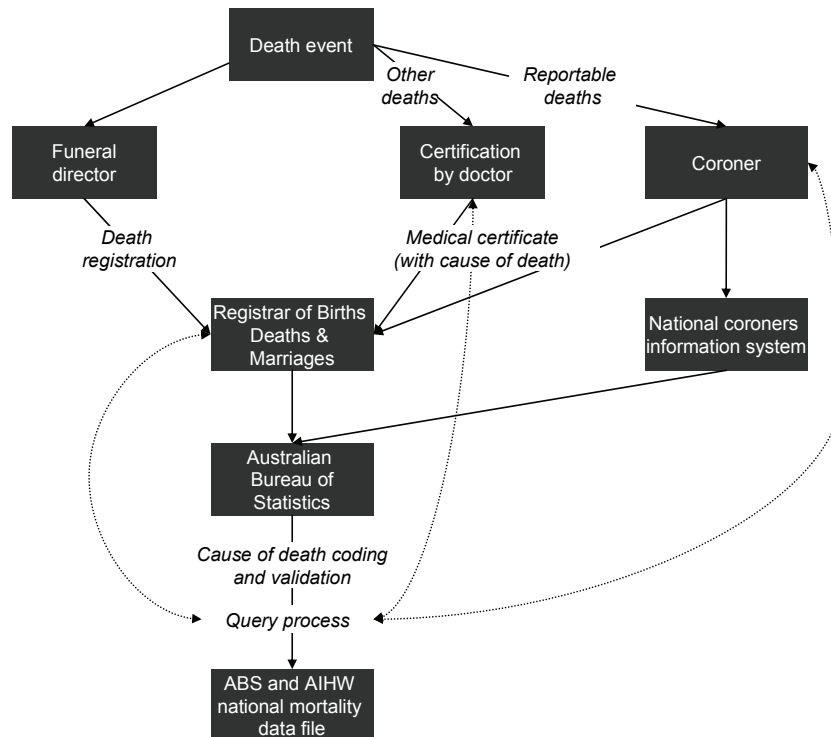
## Comparison of the Perinatal NMDS and birth registrations

The number of Aboriginal and Torres Strait Islander births recorded through the Perinatal NMDS and birth registrations can be compared. When comparing the number of live births to Aboriginal and Torres Strait Islander mothers in both collections in 2006, there are around 15% more births to Aboriginal and Torres Strait Islander mothers recorded in the Perinatal NMDS than in birth registrations (ABS 2007b; AIHW 2007). This is a significant increase from 2004 when there were around 3% more births to Aboriginal and Torres Strait Islander mothers in the Perinatal NMDS. Differences between the Perinatal NMDS and birth registrations data may in part be due to low coverage of registrations of Aboriginal and Torres Strait Islander births. Failure to collect Indigenous status may also affect the Perinatal NMDS. As a result, interpretations of Aboriginal and Torres Strait Islander births data from either source can be unreliable in the absence of a rigorous qualitative analysis of the data.

The identification of children born to Aboriginal and Torres Strait Islander mothers is important in mapping demographic trends, particularly in relation to epidemiological data.

## Mortality data

All deaths occurring in Australia are registered with the registrars of births, deaths and marriages in each state and territory. Figure A3 describes the processes that are involved with the development of the National Mortality Database from the death registrations.



**Figure A3: Processes associated with the creation of ABS and AIHW National Mortality Database**

Two forms are submitted to the registrar, with Indigenous status required for each:

- a death registration form, which is usually completed by the funeral director or other person responsible for the disposal of the body
- a medical certificate (cause of death) form, which is completed by the medical practitioner certifying the death or, in some cases, by a coroner.

The registrars of births, deaths and marriages forward data on the characteristics of the deceased and their cause of death to the ABS for coding. Following coding, the data are made available to the AIHW, which maintains the National Mortality Database. The database consists of de-identified unit record level data and comprises most of the information recorded on death registration forms and medical (cause of death) certificates, including Indigenous status. Indigenous status information from the two sources are kept in the database, although these may not be consistent for an individual.

While it is considered likely that most deaths of Aboriginal and Torres Strait Islander people are registered, a proportion of these deceased are not reported as Aboriginal or Torres Strait Islander by the family, health worker or funeral director during the death registration process. That is, while data is provided to the ABS for the Indigenous status question for 99% of all deaths, there are concerns regarding the accuracy of the data. The Indigenous status question is not always directly asked of relatives and friends of the deceased by the funeral

director. Detailed breakdowns of Aboriginal and Torres Strait Islander deaths are therefore only provided only for five jurisdictions – New South Wales, Queensland, South Australia, Western Australia and the Northern Territory.

## **Bettering the Evaluation and Care of Health (BEACH) survey**

The BEACH survey began in 1998 and collects data on general practice activity in Australia. The survey is run almost continuously and involves a random sample of 1,000 general practitioners (GPs) across Australia who record details of around 100 consecutive doctor-patient encounters. Approximately 20 GPs participate each week, 50 weeks a year. Through the survey, the GP records information on their patients' Indigenous status, using a 'yes' or 'no' tick box to indicate whether the patient is an Aboriginal and/or Torres Strait Islander person (AIHW: Britt et al. 2008).

The participating GPs submit the survey forms to the Australian General Practice Statistics and Classification Centre of the University of Sydney where they are compiled in the BEACH database and sent to the AIHW. BEACH data are published annually by the AIHW in the *General practice activity in Australia* report series.

In 2004–05, an estimated 2.0% of GP-patient encounters related to patients identified as Aboriginal and/or Torres Strait Islander, which represents an increase from 2001–02 and 2002–03. However, for a further 11.7% of GP-patient encounters, Indigenous status was 'not stated'. This level of under-reporting is higher than for most other national data sets.

The reliability of the results of the BEACH survey has been tested in a sub-study of about 9,000 patients encountered during the survey in 2003. The sub-study 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 self-report as Aboriginal and/or Torres Strait Islander, which is twice the rate routinely recorded in BEACH. However, this difference was not statistically significant (AIHW: Britt et al. 2003).

## **Medicare registration (Voluntary Indigenous Identifier)**

Since November 2002, the standard Indigenous status question has been included on forms for persons registering with Medicare Australia or requesting a new Medicare card. The question is asked in relation to the cardholder and any other family member named on the card. Responding to the question is voluntary and there is an explanation of the reasons for the question and the use of the data included on the form. This is referred to as the Voluntary Indigenous Identifier.

Indigenous status can be updated if a person needs to change or update their registration details such as address, and this can be done either over the phone or online. In addition, registered Medicare users are able to complete a voluntary Indigenous identification form at any time. However, the question will not be asked specifically by staff after a person has registered for the first time. The Voluntary Indigenous Identifier is only used internally by Medicare Australia and is not accessible outside of Medicare. It therefore has no relation to service delivery.

Because the Voluntary Indigenous Identifier was only introduced recently, the coverage of Aboriginal and Torres Strait Islander Australians in this database is not complete. There were 140,971 people who had identified as Aboriginal and/or Torres Strait Islander in this database at 2 October 2006; around 28% of the estimated Aboriginal and Torres Strait Islander population. However, there had been a rapid expansion in the number of enrollees who identified as Aboriginal and/or Torres Strait Islander, from 47,200 people in August 2004 (Stage 1 project report).

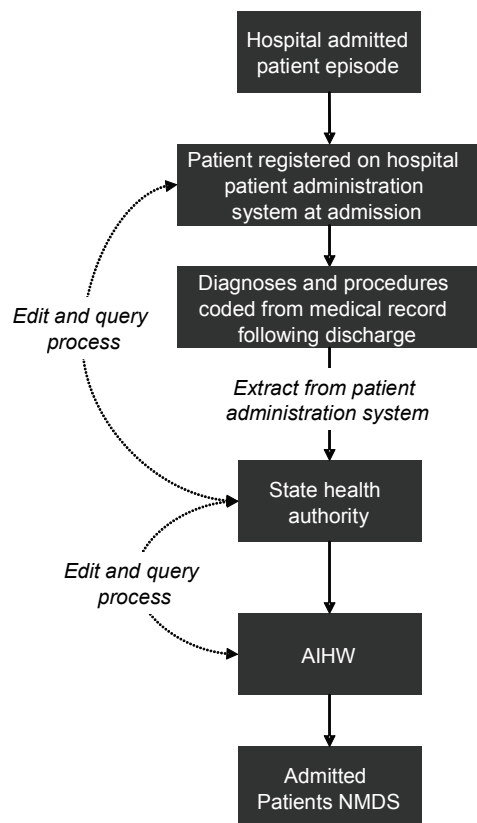
Estimated coverage is higher for younger people, with an estimated 50.5% of Aboriginal and Torres Strait Islander children aged 0–4 years registered on the Medicare database in October 2006. In contrast, only an estimated 19.2% of those aged 50 years and over were registered (Stage 1 project report).

To date, the database has not been analysed to estimate the numbers of people who have identified themselves as non-Indigenous, and those who have either not responded to the question or have not been presented with an opportunity to respond to the question.

## **Hospital morbidity data**

Hospital morbidity data relate to episodes of admitted patient care (counted at separation of the patient from the service) in public and private hospitals (including psychiatric hospitals and day procedure centres). Data are collected at admission, during the course of the patient's stay and at discharge. Indigenous status is usually recorded at admission. Hospitals forward data to state and territory health authorities, who in turn provide data to the AIHW. Figure A4 describes the processes that are involved with the creation of the national hospital morbidity data.





**Figure A4: Processes associated with the creation of the Admitted Patients National Minimum Data Set (NMDS) – the national hospital mortality data collection**

In the period 2007–08, there were 276,000 hospital separations (episodes of care for admitted patients) for Aboriginal and Torres Strait Islander patients, around 3.5% of all separations. The proportion of separations of Aboriginal and Torres Strait Islander persons was higher in public hospitals (5.4% or 256,425 separations) compared with private hospitals (0.6% or 20,015 separations). Of all Aboriginal and Torres Strait Islander separations, nearly 93% occurred in public hospitals (AIHW 2009).

The proportion of Aboriginal and Torres Strait Islander separations in public hospitals increased over the 11-year period 1996–97 to 2007–08, from 3.7% to 5.4%. In private hospitals, it stayed around 0.2% to 0.3% until 2003–04, when there was a modest increase to 0.5%.

‘Not stated’ responses to the Indigenous status question were around 1% in public hospital and 4% in private hospitals in 2007–08, which is a reduction from 1998–99 when 2% of responses in public hospitals and 8% of responses in private hospitals had a ‘not stated’ Indigenous status (AIHW 2009).

Under-identification of Aboriginal and Torres Strait Islander patients has been documented through a range of studies (AIHW 2005). In studies based on patient interviews, the proportions of Aboriginal and Torres Strait Islander patients found to have been correctly identified in hospital records were:

- 93% overall for the five Northern Territory public hospitals in 1997

- 85% overall for 11 public hospitals in five jurisdictions in 1998
- 86% overall for 26 public hospitals in Western Australia in 2000
- 74% overall for two metropolitan public hospitals in Queensland in 2000.

In addition:

- A study of linked multiple patient episodes for Aboriginal and Torres Strait Islander people in New South Wales in 1997–98 found that Indigenous status had been incorrectly specified for 12% of episodes.
- An estimate of separations for Aboriginal and Torres Strait Islander people in Victoria in 2001–02, based on information from Aboriginal and Torres Strait Islander hospital liaison officers and population-based adjustment to hospital counts, suggested a net 22% under-count for the state.

Since these studies have been conducted, there have been increasing numbers of hospital separations reported for Aboriginal and Torres Strait Islander patients in all states and territories, suggesting that there have been improvements. A study has recently been completed by the AIHW that compared what was recorded on hospital records with information collected at patient interviews (AIHW forthcoming). This study has provided more current estimates of the level of under-identification in hospital data by both state/territory and remoteness area.

Table A3 presents the proportions of Aboriginal and Torres Strait Islander patients correctly identified in hospital records by state and territory, and Table A4 presents the proportions of Aboriginal and Torres Strait Islander patients correctly identified in hospital records by remoteness category.

**Table A2: Estimates of completeness (Aboriginal and Torres Strait Islander identification level) from the AIHW hospital survey, by state/territory, 2007 (per cent)**

NSW	Vic	Qld	WA	SA	Tas <sup>(a)</sup>	ACT <sup>(b)</sup>	NT	Aust
88	84	86	97	87	48	58	96	89

(a) Estimate for Tasmania was based on survey results from *Inner regional* and *Outer regional* hospitals only.

(b) Estimate for the Australian Capital Territory was based on a linkage project of hospital record data and data from Winnunga Nimmityjah Aboriginal Medical Service.

Source: AIHW (forthcoming).

**Table A3: Estimates of completeness (Aboriginal and Torres Strait Islander identification level) from the AIHW hospital survey, by remoteness area, 2007 (per cent)**

Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia
80	87	94	97	89

Source: AIHW (forthcoming).

In 2005, it was recommended that when using Indigenous status information from the hospital morbidity data for analytical purposes, only data for Queensland, Western Australia, South Australia and the Northern Territory should be used, either at the individual state/territory level or in aggregate (AIHW 2005). In addition, it was recommended that analyses based on data from these jurisdictions should be accompanied by caveats about limitations imposed by jurisdictional differences in data quality and about the data not necessarily being representative of the jurisdictions excluded (AIHW 2005).

Since the completion of the AIHW study involving hospital audits in 2007 discussed above, it is recommended that data from New South Wales and Victoria as well as Queensland, Western Australia, South Australia and the Northern Territory be used in the analysis of hospital data for Aboriginal and Torres Strait Islander Australians from 2004-05 onwards.