



Australian Government

**Australian Institute of
Health and Welfare**

Towards better Indigenous health data



Australian Government

**Australian Institute of
Health and Welfare**

*Authoritative information and statistics
to promote better health and wellbeing*

Towards better Indigenous health data

Australian Institute of Health and Welfare
Canberra

Cat. no. IHW 93

The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is authoritative information and statistics to promote better health and wellbeing.

© Australian Institute of Health and Welfare 2013



This product, excluding the AIHW logo, Commonwealth Coat of Arms and any material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC-BY 3.0) licence. Excluded material owned by third parties may include, for example, design and layout, images obtained under licence from third parties and signatures. We have made all reasonable efforts to identify and label material owned by third parties.

You may distribute, remix and build upon this work. However, you must attribute the AIHW as the copyright holder of the work in compliance with our attribution policy available at <www.aihw.gov.au/copyright/>. The full terms and conditions of this licence are available at <<http://creativecommons.org/licenses/by/3.0/au/>>.

Enquiries relating to copyright should be addressed to the Head of the Communications, Media and Marketing Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

ISBN 978-1-74249-434-0

Suggested citation

Australian Institute of Health and Welfare 2013. Towards better Indigenous health data. Cat. no. IHW 93. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair

Dr Andrew Refshauge

Director

David Kalisch

Any enquiries about or comments on this publication should be directed to:

Communications, Media and Marketing Unit

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Tel: (02) 6244 1032

Email: info@aihw.gov.au

Published by the Australian Institute of Health and Welfare

Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

- Acknowledgments..... v
- Abbreviations..... vi
- Summary viii
- 1 Background.....1**
 - 1.1 Why Indigenous status is important1
 - 1.2 *National best practice guidelines for collecting Indigenous status in health data sets*.....2
 - 1.3 COAG Closing the Gap commitments.....3
- 2 The Guidelines support and evaluation project6**
 - 2.1 Description and methodology.....6
 - 2.2 AIHW support for Guidelines implementation11
 - 2.3 Other AIHW data improvement projects15
- 3 Information on sectors and data sets17**
 - 3.1 Hospital sector.....18
 - 3.2 Alcohol and other drug treatment services sector24
 - 3.3 Mental health services sector.....27
 - 3.4 Cross-sector data sets32
 - 3.5 Summary of Indigenous data quality40
 - 3.6 Discussion42
- 4 Jurisdiction-based data improvement activities.....43**
 - 4.1 New South Wales.....43
 - 4.2 Victoria47
 - 4.3 Queensland50
 - 4.4 Western Australia52
 - 4.5 South Australia.....53
 - 4.6 Tasmania56
 - 4.7 Australian Capital Territory56
 - 4.8 Northern Territory58
 - 4.9 Discussion59
- 5 General practice sector62**
 - 5.1 Context and recent developments62
 - 5.2 Improving identification in general practice.....64
 - 5.3 Improving identification in e-health systems65

5.4 Discussion	67
6 Conclusions and next steps	68
6.1 Summary of current state of play	68
6.2 Areas for further work	69
Appendix A: National Indigenous Reform Agreement, Schedule F.....	71
References.....	74
List of tables	77
List of figures	78

Acknowledgments

This report was written by Helen Kehoe, Helen Johnstone, Meke Kamps and Ronda Ramsay from the Social and Indigenous Group at the Australian Institute of Health and Welfare, with assistance from Mieke Van Doeland and Kathleen Jackson. Fadwa Al-Yaman managed the project and the writing of the report.

Thanks are extended to staff of state and territory governments who provided substantial input to Chapter 4, and to staff of the Office for Aboriginal and Torres Strait Islander Health who provided valuable comments on the drafts.

Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
AODTS NMDS	Alcohol and Other Drug Treatment Services National Minimum Data Set
COAG	Council of Australian Governments
DoHA	Department of Health and Ageing
MBS	Medicare Benefits Schedule
NAGATSIHID	National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data
NATSIHON	National Aboriginal and Torres Strait Islander Health Officials' Network (renamed NATSIHSC in 2012)
NATSIHSC	National Aboriginal and Torres Strait Islander Health Standing Committee (previously NATSIHON)
NEHTA	National E-Health Transition Authority
NIDISC	National Indigenous Data Improvement Support Centre
NIRA	National Indigenous Reform Agreement
NIRA PIMG	National Indigenous Reform Agreement Performance Information Management Group
NMDS	National Minimum Data Set
NPESU	National Perinatal Epidemiology and Statistics Unit
OATSIH	Office for Aboriginal and Torres Strait Islander Health
OBIP	Overarching Bilateral Indigenous Plan
OSR	OATSIH Services Reporting
PBS	Pharmaceutical Benefits Scheme
PCEHR	Personally Controlled Electronic Health Record
RACGP	Royal Australian College of General Practitioners

Symbols

–	rounded to zero
%	per cent
n.a.	not available
..	not applicable
n.p.	not published

Summary

This report describes Phase 1 of a support and evaluation project for the AIHW *National best practice guidelines for collecting Indigenous status in health data sets* (the Guidelines). The project, conducted between July 2011 and December 2012, helped to implement the Guidelines in selected areas, to document implementation activities, to collect baseline information, and to identify barriers to and facilitators for implementation.

The processes for, and status of, Guidelines implementation varied across data sets and health sectors in scope for this project.

- In the hospitals sector (which supplies data for the National Hospital Morbidity Database and National Perinatal Data Collection), Indigenous status data are generally of high quality and additional support for Guidelines implementation is not currently required.
- The drug treatment services sector (which supplies data for the Alcohol and Other Drugs Treatment Services National Minimum Data Set) includes a mix of government and non-government service providers. Some jurisdictions have distributed the Guidelines and undertaken activities in the sector to improve data, but there is scope for more work on implementation in the sector.
- The mental health services sector (which supplies data for the National Residential and Community Care databases) has undergone reforms with implications for data collection. Future support for Guidelines implementation will be considered as these changes are embedded.
- The National Diabetes Register has limited coverage of diabetes in the Aboriginal and Torres Strait Islander population, and Guidelines implementation is therefore not a priority at this stage.
- Cancer registries require upstream work in the general practice sector and pathology messaging to improve identification; the project will provide support in these sectors where possible.
- The general practice sector is notable as identification is needed for service delivery as well as for data improvements. Targeted support to the general practice sector was provided in Phase 1 of the project and will continue in the next phases of the project.

Further implementation of the Guidelines could be facilitated by:

- recognising non-jurisdiction stakeholders as essential partners in Guidelines implementation, as the capacity of jurisdictions to implement the Guidelines varies across health sectors
- supporting jurisdiction implementation processes; for example, by strengthening reporting mechanisms through more detailed description of Guidelines implementation activities to better monitor progress and by identifying areas in need of greater support
- providing targeted support in selected areas to assist in the systematic implementation of the Guidelines
- fostering national coordination in the general practice sector.

1 Background

1.1 Why Indigenous status is important

The collection of the Indigenous status of patients/clients by health-care providers is important for improving Aboriginal and Torres Strait Islander health. While identification has greatly improved in some health sectors, other sectors have potential for further improvement. Under-identification of Indigenous status has serious implications for Aboriginal and Torres Strait Islander health in two ways.

- Firstly, it prevents delivery of targeted services to Aboriginal and Torres Strait Islander people. If clinicians do not know which of their patients/clients are Indigenous, they are unable to offer them health interventions that are specific to Aboriginal and Torres Strait Islander people.
- Secondly, incomplete and unreliable data on Indigenous health impede effective responses to the higher burden of disease and death among Aboriginal and Torres Strait Islander people, and make accurate assessment of progress in ‘closing the gap’ difficult.

Establishing Indigenous status in the health sector

In the health sector, identifying Indigenous status entails asking all patients/clients the question listed in Box 1.1. below, and recording the response. This question has been endorsed as the nationally consistent way to establish Indigenous status to meet the agreed national data definition of Indigenous status.

Box 1.1: National standard Indigenous status question

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

The standard response options:

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander

For clients of both Aboriginal and Torres Strait Islander origin, both ‘Yes’ boxes should be ticked.

The response to this question is the only requirement for determining Indigenous status and for providing access to health interventions and services that are specific to Aboriginal and Torres Strait Islander people – no further evidence or checking is needed.

The quality of health data compiled at both jurisdictional and national levels wholly depends on the involvement of front-line staff. Nurses, doctors, medical receptionists, ward clerks and many other service providers are the human interface between the health system and patients/clients. It is at this interface that the national standard Indigenous status question must be asked and responses recorded. The primary role for the majority of service providers is clinical patient care, however, with data collection generally a secondary consideration. Processes to implement the Guidelines are likely to be most effective where the clinical responsibilities of service providers are recognised and supported.

Everyone has an Indigenous status: non-Indigenous people should have their status recorded as 'non-Indigenous'. While all patients/clients should be asked the national standard Indigenous status question, responding to this question is not compulsory. Service providers who ask the question should explain the reasons for it: that is, to improve data at a population level and to enable access to Indigenous-specific services at the individual level.

1.2 National best practice guidelines for collecting Indigenous status in health data sets

The *National best practice guidelines for collecting Indigenous status in health data sets* (the Guidelines) were developed by the Australian Institute of Health and Welfare (AIHW) to provide consistent advice on the collection of Indigenous status in health data sets, and to recommend strategies for implementing best practice and improving data quality.

The Guidelines support the application of the National Health Data Standard on Indigenous status data by providing advice on how to:

- ask the national standard Indigenous status question
- record and code responses
- ensure the Indigenous status item is completed and properly coded for all patient records.

The Guidelines recommend best practice in various situations (such as births, deaths, and patient incapacity). They also provide advice to front-line staff on implementation issues such as responding to frequently asked questions.

The Guidelines were informed by a review of research into Aboriginal and Torres Strait Islander under-identification. They were developed in consultation with stakeholders, service providers, health authorities and data custodians, and considered key data sets important to Aboriginal and Torres Strait Islander health. The process outlined the serious implications of under-reporting of Indigenous data for Aboriginal and Torres Strait Islander people, as well as for the work of researchers, health service staff, policy makers and health service planners.

Although not formally endorsed by the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) until 2009, the Guidelines were being developed before this date. They were therefore incorporated into the National Indigenous Reform Agreement (NIRA) data quality improvement projects approved by the Council of Australian Governments (COAG) in 2008.

Release of the Guidelines and ongoing support from the NIDISC

The Guidelines, released by the AIHW in 2010, were published on the AIHW website, are available in printed format and were widely distributed to state and territory health departments, stakeholder organisations, and individuals involved in their development.

The AIHW established the National Indigenous Data Improvement Support Centre (NIDISC) as a point of contact for persons seeking advice and support in implementing the Guidelines. The NIDISC provides advice, hard copies of materials, and referrals to other agencies as appropriate (see Chapter 2).

1.3 COAG Closing the Gap commitments

COAG Closing the Gap commitments aim to overcome key health disparities between Indigenous and non-Indigenous Australians (Box 1.2).

Box 1.2: COAG Closing the Gap commitments

In 2008, COAG agreed to six ambitious targets to address the disadvantage faced by Indigenous Australians in life expectancy, child mortality, education and employment. They are to:

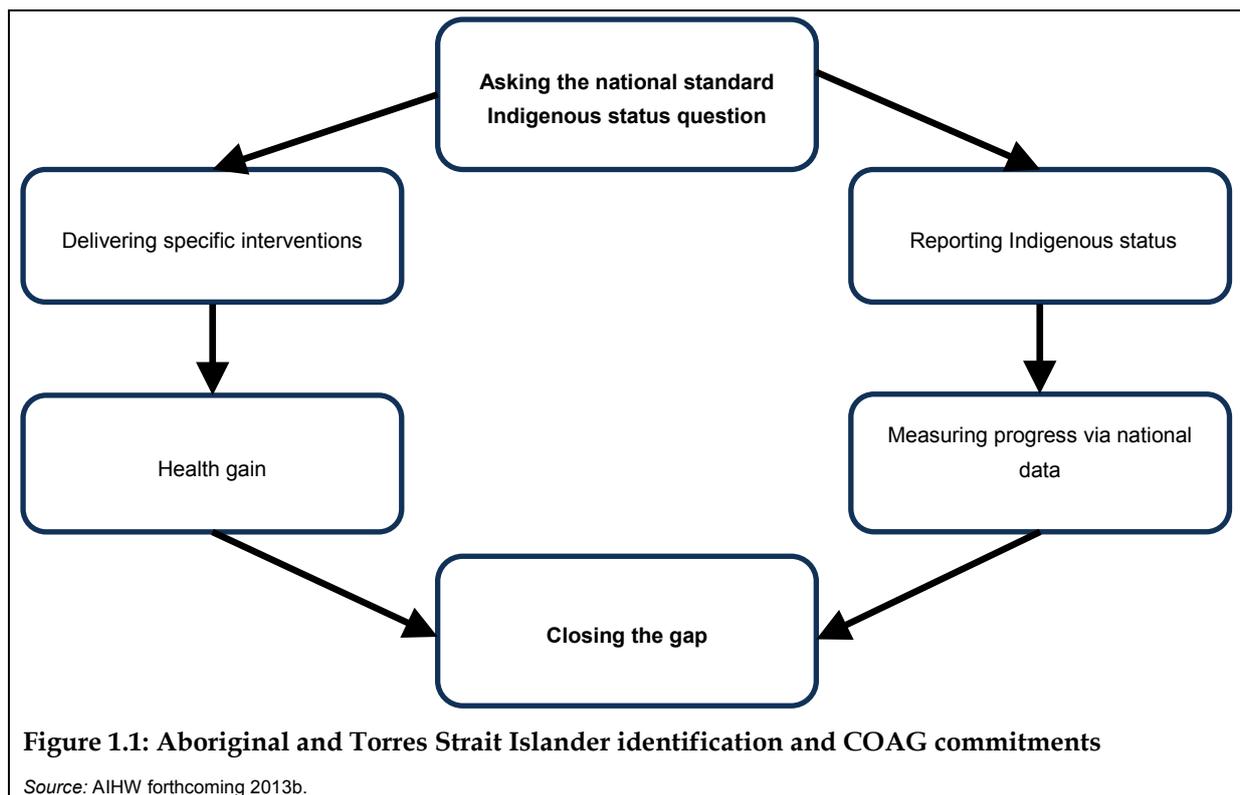
- close the gap in life expectancy within a generation (by 2031)
- halve the gap in mortality rates for Indigenous children under five by 2018
- ensure access to early childhood education for all Indigenous four year olds in remote communities by 2013
- halve the gap in reading, writing and numeracy achievements for children by 2018
- halve the gap for Indigenous students in Year 12 (or equivalent) attainment rates by 2020
- halve the gap in employment outcomes between Indigenous and other Australians by 2018.

The targets are set out in the National Indigenous Reform Agreement which commits the Commonwealth, States and Territories to unprecedented levels of investment to close the gap in Indigenous disadvantage.

Source: COAG 2011.

An important element of achieving the commitments is the delivery of targeted health interventions. A range of health initiatives specific to Aboriginal and Torres Strait Islander people were developed by governments to overcome the health disparities between Indigenous and non-Indigenous Australians. If health providers do not have processes in place to seek Indigenous status, they are unable to offer these services to Aboriginal and Torres Strait Islander people.

Another fundamental aspect of achieving the COAG commitments is the capacity to measure health gaps between Indigenous and non-Indigenous people, and to monitor progress in closing those gaps. Deficiencies in identifying Indigenous status in data sets impede the capacity to accurately report progress on COAG commitments (Figure 1.1).



NIRA data improvement activities

Recognising the importance of Aboriginal and Torres Strait Islander data, the NIRA included a range of activities to improve data quality. Schedule F of the NIRA detailed these data improvement activities at the national and jurisdictional levels (Appendix A). At the national level, the agencies with responsibility for these activities were the AIHW, the Australian Bureau of Statistics (ABS) and the Department of Health and Ageing (DoHA).

As well as this Guidelines evaluation project, AIHW data improvement projects include:

- analysing the level of Indigenous identification in key health data sets
- developing best practice guidelines for Indigenous data linkage
- developing the AIHW Enhanced Indigenous Mortality Data Linkage Project
- enhancing perinatal information to collect data in relation to substance use during pregnancy, to child and maternal health and to the Indigenous status of the baby
- developing a business case for implementing a nationally consistent pathology data collection, including Indigenous status to improve information about a range of health conditions
- developing National Key Performance Indicators (in collaboration with the DoHA).

The status of these projects is outlined in Section 2.3.

National level commitments were matched by a range of undertakings at the jurisdiction level (Box 1.3). These included adopting the national standard Indigenous status question, improving procedures for collecting Indigenous status information and awareness-raising initiatives.

Box 1.3: Jurisdiction commitments in Schedule F of the NIRA

- All jurisdictions will adopt the standard ABS Indigenous status question and recording categories on data collection forms and information systems for key data sets
- All jurisdictions will improve procedures for collecting Indigenous status information in health and education data by training staff in key data collection positions about how and why to ask the Indigenous status question and to raise awareness about its importance. (This included a commitment to implement the Guidelines in the education and health sectors.)
- All jurisdictions will develop and implement initiatives to raise the Indigenous community's awareness about the importance of identifying as Indigenous when accessing services and to therefore raise the propensity for identification.

Source: COAG 2011.

Implementing and evaluating the Guidelines

Jurisdictions are committed to implementing the Guidelines in the health sector by December 2012. The AIHW and the ABS were given responsibility for periodic evaluations of how the Guidelines had been implemented in the jurisdictions across the various health and education data collections.

The evaluation of the Guidelines was divided according to agency roles. The AIHW evaluated the implementation of the Guidelines in the health sector, and the ABS in the education sector, as well as for births, deaths and marriages data sets.

2 The Guidelines support and evaluation project

The Guidelines support and evaluation project was developed by the AIHW in response to its NIRA commitments to evaluate the implementation of the Guidelines in the health sector. Development of the support aspect of the project recognised that while some health sectors and some data sets had good-quality Indigenous data and well-developed processes for data collection, other sectors required more support to implement the Guidelines and to improve identification processes.

2.1 Description and methodology

Scope of the project: sectors and data sets

The data sets in scope for the AIHW support and evaluation project are the National Hospital Morbidity Database, National Perinatal Data Collection, National Community Mental Health Care Database, National Residential Mental Health Care Database, Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS NMDS), the Australian Cancer Database and the National Diabetes Register. The general practice sector was also in scope due to its role in data collection and service delivery.

General practitioners are the gatekeepers for a range of health interventions specific to Aboriginal and Torres Strait Islander people, for which effective identification processes are essential. In terms of data collection, general practitioners initiate many of the pathology requests that provide cancer notifications; send information to the National Notifiable Diseases Surveillance System; and, via death certificates, provide data to the National Mortality Database.

The project's approach was based on sectors rather than data sets. Data sets are constructed in central statistical agencies and largely depend on information gathered at the service level in health sectors such as hospitals, alcohol treatment services or general practices. Improvements in data collection processes made in one health sector will lead to improvements in all data sets to which that health sector contributes. For example, hospitals generate data for the National Hospital Morbidity Database, the National Perinatal Data Collection and others. Efforts to improve data collection processes in hospitals will therefore impact on several data collections.

While some health settings, like hospitals, generate data for multiple national data sets, other health settings, like alcohol and other drug treatment services, generate data for a single data set. Taking the converse approach, some national data sets draw input from only one health sector, while others draw input from multiple health settings. For example, the National Diabetes Register draws input from hospitals, paediatricians and diabetes educators.

While there are common issues across sectors and data sets, each has different levels of identification coverage, is at different stages of implementation, and faces different challenges in improving further. In addition, some data sets are underpinned by NMDSs (where the collection of Indigenous status is mandated), while others are not (Box 2.1).

Box 2.1: National data requirements

The National Health Information Agreement of 2011 underpins the development, collection and sharing of health information in Australia, including the development, endorsement and maintenance of national data standards. Signatories to the agreement are state and territory government health authorities; the AIHW; the Australian Commission on Safety and Quality in Health Care; and the Australian Government, represented by the ABS, the DoHA, the Department of Veterans Affairs and the Department of Human Services.

Details of the agreement are available at the following AIHW website:
<<http://meteor.aihw.gov.au/content/index.phtml/itemId/182135>>.

The agreement aims to improve the health of all Australians through providing nationally consistent high-quality health information. This work includes developing standard data definitions and data elements for use in all Australian health data collections, to ensure information is collected consistently and is comparable across various settings and locations (AIHW 2012f).

The standards for a particular data collection are collated into a data set specification, which is a formal description of the data items for collection and their associated metadata. Where the data collection is mandated – for example by agreement between all jurisdictions under the National Healthcare Agreement – it is called a National Minimum Data Set (NMDS). An NMDS, therefore, is a minimum set of data elements agreed for mandatory collection and reporting at a national level. All NMDSs in scope for this project include a requirement for Indigenous status to be collected and recorded.

Data definitions, information about relevant data dictionaries, information on NMDSs and data set specifications are stored in METeOR, Australia's repository for national metadata standards for the health, community services and housing assistance sectors. The Indigenous status data element (under person attributes) is available at the following AIHW website: <meteor.aihw.gov.au/content/index.phtml/itemId/291036>.

Methodology

The work program for the project comprises three separate phases to be conducted over 3 financial years from 2011–12 to 2013–14 (Table 2.1):

- Phase 1: Implementation review and collection of baseline information
- Phase 2: Ongoing monitoring and targeted support
- Phase 3: Assessment of overall implementation progress.

Table 2.1: Overview of the support and evaluation project

Stage	Key activities	Timing	Ongoing
Phase 1: Implementation review and collection of baseline information	(a) Ensure processes at the national level support implementation of the Guidelines (chapters 2 and 5) (b) Develop baseline information on the attributes and data quality of relevant health sectors and data sets. Identify barriers to and facilitators for Guidelines implementation (chapters 3 and 5) (c) Outline data improvement activities undertaken by jurisdictions (Chapter 4) (d) Provide targeted assistance to support implementation in selected sectors and data sets (Chapter 5)	July 2011– June 2012	Guidelines implementation support via NIDISC (Chapter 2)
<i>Report on Phase 1 (this report)</i>			
Phase 2: Ongoing monitoring and targeted support	(a) Continue to monitor implementation of the Guidelines, data quality, and identify barriers to and facilitators for implementation (b) Provide targeted assistance to support implementation in selected sectors and data sets	July 2012– June 2013	
Phase 3: Assessment of overall implementation progress	(a) Continue targeted assistance as informed by previous phases (b) Analyse overall implementation	July 2013– June 2014	
<i>Report on Phases 2 and 3 (final report)</i>			

Outline of Phase 1

This report outlines the findings from the four components of Phase 1 of the project. It also includes information on activities undertaken by the NIDISC, which continues to provide support for the Guidelines across all phases of the project, as requested by users.

(a) National level support for implementation

The AIHW undertook national level processes to support Guidelines implementation (Chapter 2). These included ongoing support provided through the NIDISC, as well as work to promote the implementation of the Guidelines through national committees and data working groups.

In addition, the AIHW worked to ensure that e-health initiatives prioritised the collection, recording and transmission of Indigenous status information. The range of e-health initiatives currently being implemented presents an opportunity to drive standardisation of Indigenous status functionality in software used by health service providers. This work is reported in Chapter 5 on the general practice sector.

(b) Baseline information and identification of barriers and facilitators

The project compiled baseline information on data set attributes and data quality for the relevant sectors and data sets in scope (chapters 3 and 5). Information on data set attributes included source and type of data, level of control by jurisdictions, and policy relevance of the data set.

Assessment of data quality

The quality of Indigenous status data across key health data sets can be undermined by a range of issues including misclassification, structural limitations and high proportions of ‘unknown’ Indigenous status.

This project used three measures to assess Indigenous data quality across relevant data sets:

- an assessment of relevant **structural limitations** – including the scope and coverage of data collections that impact on the usefulness of the data sets in providing policy-relevant information about the Aboriginal and Torres Strait Islander population
- the **proportion of records with ‘not stated’ Indigenous status** responses – which provides only a broad indication of data quality, as ‘not stated’ records can be caused by either:
 - service providers not asking the national standard Indigenous status question and ticking the ‘not stated’ box. This practice does not comply with the Guidelines and should be eliminated
 - patients choosing not to disclose their Indigenous status
- **assessments specific to data sets** – undertaken both nationally and by jurisdictions or data custodians of individual data sets, though the basis of and criteria for these assessments of data quality are not standard and may vary across jurisdictions and data sets.

(c) Activities to improve jurisdiction data

Activities undertaken to improve jurisdiction data since the NIRA was signed in 2008 were compiled from:

- existing jurisdiction reports to the National Indigenous Reform Agreement Performance Information Management Group (NIRA PIMG)
- jurisdiction responses to a more specific template developed by the project
- input provided by jurisdiction representatives on the National Aboriginal and Torres Strait Islander Health Standing Committee (NATSIHSC).

The information on data improvement activities is reported at the jurisdiction level in Chapter 4.

(d) Provision of targeted assistance to support implementation

The project provided targeted assistance to support Guidelines implementation. After initial analysis of the current status of identification processes in different sectors and data sets, the general practice sector was identified as key for Phase 1 of the project. The activities undertaken in the general practice sector are reported in Chapter 5.

Challenges for Guidelines implementation

The COAG’s recognition in the NIRA that Indigenous data collection should conform to standard processes – and that the Guidelines provided this standard – constituted considerable progress in this field. The agreement of all jurisdictions to implement the Guidelines across health sectors was also important. However, full implementation of the Guidelines faces a number of challenges.

Some difficulties are common to all guidelines which seek to change behaviours. There are a large number of clinical and other guidelines targeting health professionals; however, the gap between recommended and actual practice can be considerable (Turner et al. 2008). Even in hierarchical organisations, compliance with guideline material can be difficult to mandate. Implementation of guidelines dealing with non-clinical issues, such as these Guidelines, presents an even greater challenge compared with those dealing with core clinical practice.

The complexity of the health system and the number of stakeholders involved contributes to implementation difficulties (Table 2.2). Greater recognition of these barriers, integration of the Guidelines into supporting systems, partnerships with sector-specific health provider stakeholder groups and better understanding of the factors that influence the health service providers who collect this information would all assist further implementation.

Other challenges in implementing the Guidelines stem from the complexities inherent in the COAG processes that required this reform. The COAG commitments to Closing the Gap for Aboriginal and Torres Strait Islander people have been articulated through a number of linked processes. The overarching agreement, the NIRA, is supported by a range of more specific National Partnership Agreements – including National Partnership Agreements regarding Closing the Gap in Indigenous Health Outcomes, Indigenous Economic Participation, and Indigenous Early Childhood Development – and signatory governments are engaged in progressing actions relevant to each of these areas. Implementation of the Guidelines is a small supporting project stipulated by one deliverable in one of eight schedules to the NIRA.

Guidelines implementation is also interlinked with associated data quality improvement efforts at both national and jurisdiction levels. This makes delineation of implementation work specific to the Guidelines complex. For example, other jurisdictional NIRA undertakings, such as initiatives to raise the awareness of Aboriginal and Torres Strait Islander people about the importance of identifying as Indigenous, will affect how Aboriginal and Torres Strait Islander people may respond when asked the national standard Indigenous status question.

Table 2.2: Health sectors and data sets in project scope (shaded), and responsibilities for implementation of the Guidelines

Sectors	Data sets	Who can ensure Guidelines implementation?
Hospitals	National Hospital Morbidity Database National Perinatal Data Collection	Jurisdictions (public hospitals)
Mental health service providers	National Community Mental Health Care Database National Residential Mental Health Care Database	Jurisdictions and service providers
Alcohol and other drug treatment service providers	AODTS NMDS	Jurisdictions and service providers
General practice sector	Australian Cancer Database PAP smear registers Communicable and notifiable disease registers National Mortality Database	General practice stakeholder groups such as the DoHA, the Australian Medicare Local Alliance, the Royal Australian College of General Practitioners (RACGP), and the Australian College of Rural and Remote Medicine
Various—including hospitals, general practitioners, pathology labs	Australian Cancer Database	Jurisdictions (public hospitals) General practitioners and their stakeholder groups, pathologists and laboratory stakeholders
Various—including hospitals, paediatricians, diabetes educators	National Diabetes Register	Jurisdictions (public hospitals) Paediatricians, general practitioners and diabetes educators, professional and representational groups

2.2 AIHW support for Guidelines implementation

The AIHW provides support for implementation of the Guidelines at the national level. This is provided through the NIDISC, as well as through national committees and data working groups.

National Indigenous Data Improvement Support Centre

Since the release of the Guidelines in April 2010, the AIHW has provided ongoing support for implementation through the NIDISC. The NIDISC provides data custodians, service providers and other stakeholders with copies of the Guidelines, information, and training resources. It addresses queries and provides advice, and refers stakeholders to other agencies as appropriate.

Resources provided include hard copies of the Guidelines and a related brochure and poster. As well as soft copies of the Guidelines, electronic resources include:

- staff training tips covering the basic competencies staff need to correctly collect the Indigenous status of patients/clients, as recommended in the Guidelines
- a staff training tool for use in gauging staff knowledge of best practice for collecting Indigenous status
- a patient fact sheet explaining the collection of Indigenous status to patients.

Dissemination of NIDISC resources

Since April 2010, the NIDISC has responded to more than 250 requests for resources from organisations and individuals and distributed over 2,000 copies of the Guidelines.

More than one-quarter of requests for resources came from the general practice sector via Divisions of General Practice (now Medicare Locals), with hospitals generating the second highest number of these requests. Queensland, New South Wales and Victoria initiated 80% of resource requests, whereas no Northern Territory organisations contacted the NIDISC (Table 2.3).

Apart from requests for copies of the Guidelines themselves, demand was also strong for posters (over 6,000 distributed) and brochures (more than 34,000 distributed). Organisations in Queensland, Victoria and New South Wales ordered over 80% of the posters, 90% of the brochures and 80% of the total number of Guidelines distributed (Table 2.4).

Table 2.3: Number of requests for NIDISC resources by organisation type, April 2010–December 2012

Requesting organisation	National bodies	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	
										No.	%
Divisions of general practice/General practitioner networks/Primary health-care networks/Medicare Locals	1	21	19	26	1	2	2	0	0	72	28.2
Hospitals	..	13	15	13	0	3	0	1	0	45	17.6
Local general practice clinics	..	9	4	17	4	0	3	0	0	37	14.5
Government departments	6	8	4	5	1	1	4	5	0	34	13.3
Area health services/local health services/community health services	..	7	10	7	2	1	0	0	0	27	10.6
Aboriginal Community Controlled Health Sector	0	4	3	0	0	0	0	0	0	7	2.7
Medical colleges	6	6	2.4
Universities/TAFEs/teaching institutions/students	..	2	2	2	0	0	0	0	0	6	2.4
Private persons	..	1	1	1	0	0	2	0	0	5	2.0
National E-Health Transition Authority (NEHTA)/ Medical Software Industry Association	3	3	1.2
Aged care/Community mental health/Alcohol and other drug treatment services	..	1	1	1	0	0	0	0	0	3	1.2
Other health associations/agencies	2	3	2	0	1	2	0	0	0	10	3.9
Total	18	69	61	72	9	9	11	6	0	255	100

Note: Sum percentages may not total 100% due to rounding.

Table 2.4: NIDISC resources distributed, April 2010–December 2012

	Posters		Brochures		Guidelines	
	No.	Per cent	No.	Per cent	No.	Per cent
New South Wales	1,473	23.5	10,332	29.8	723	30.2
Victoria	1,673	26.6	8,080	23.3	543	22.7
Queensland	2,396	38.2	12,790	36.8	647	27.0
Western Australia	54	0.9	200	0.6	67	2.8
South Australia	125	2.0	325	0.9	69	2.9
Tasmania	170	2.7	1,160	3.3	110	4.6
Northern Territory	0	0.0	0	0.0	0	0.0
Australian Capital Territory	145	2.3	800	2.3	58	2.4
Other	243	3.9	1,023	2.9	177	7.4
Total	6,279	100.0	34,710	100.0	2,394	100.0

Notes:

1. Sum percentages may not total 100% due to rounding.
2. 'Other' is defined as the AIHW distributing resources at conferences, and resources distributed to persons or locations unknown.

In addition to distributing resources, the NIDISC page was posted on the AIHW website. However, numbers of views of this page were low and traffic was variable. Page views increased from 229 in 2010 to over 2,100 in 2011, before decreasing to 1,522 in 2012.

Liaison with national committees and data groups

National committees

The project has two primary reporting routes—firstly, to COAG as the initiator of this NIRA-generated work and, secondly, to the Australian Health Ministers’ Advisory Council (AHMAC) in relation to ongoing Aboriginal and Torres Strait Islander health data issues.

Liaison with COAG takes place via the NIRA PIMG, which was established in 2009 with representation from all jurisdictions as well as from relevant Australian Government agencies. The NIRA PIMG’s role is to promote consistency in Aboriginal and Torres Strait Islander data collection and ensure that there is a coordinated approach to required data development work both within NIRA and across other relevant National Partnership Agreements. The NIRA PIMG is a subcommittee of the Working Group on Indigenous Reform. To achieve COAG Closing the Gap targets, this Working Group drives the Aboriginal and Torres Strait Islander reform agenda through engagement on both mainstream COAG agreements and those specific to Aboriginal and Torres Strait Islander people. Reports on the project are provided to NIRA PIMG regularly.

Liaison with AHMAC takes place via NAGATSIHID, which provides broad strategic advice to AHMAC and its National Health Information and Performance Principal Committee. Project progress reports are provided at each NAGATSIHID meeting, with specific papers submitted where appropriate.

An additional consultation forum was provided by the then National Aboriginal and Torres Strait Islander Health Officials’ Network (NATSIHON) (renamed the National Aboriginal and Torres Strait Islander Health Standing Committee, NATSIHSC, in 2012) which comprises senior Aboriginal and Torres Strait Islander health officials from all jurisdictions and from the Australian Government. As well as providing regular updates, the AIHW facilitated a workshop with NATSIHON members on the project and sought input from jurisdictions on progress with implementation of the Guidelines.

Liaison with national committees is summarised at Table 2.5.

Table 2.5: Liaison with relevant national committees

Committee	Communication
NIRA PIMG	Regular project updates provided as part of AIHW data quality reporting (quarterly) Report by jurisdictions on NIRA Schedule F requirements (annually)
NAGATSIHID	Regular project updates provided as part of AIHW data quality reporting (twice yearly) Joint paper to meeting (September 2011) AIHW paper on changes to work plan and issues in e-health (March 2012)
NATSIHSC	Regular project updates provided as part of AIHW data quality reporting (annually) A discussion facilitated by the AIHW to share ideas and knowledge of completed work, and provide avenues for continued work in jurisdictions (May 2012)
Joint NAGATSIHID and NATSIHSC	Report by jurisdictions against NIRA Schedule F data improvement activities (annually) AIHW update on progress of the project, especially recent work with the NEHTA, and the outcomes of the general practice workshop held in December 2011 (March 2012)

Data working groups

Data working groups were important communication points for the project. Liaison with these bodies sought to provide advice on the project, and raise awareness about the Guidelines and the implementation timeline required by the NIRA. Data working groups were also approached for their input regarding the implementation status and activities conducted in individual data sets (Table 2.6).

Table 2.6: Liaison with data custodians

Data set	Data working group	Communication
Alcohol and Other Drug Treatment Services National Minimum Data Set	AODTS NMDS Working Group	December 2011: written advice regarding work plan and the Guidelines provided. Requested information on work completed on implementing the Guidelines. April 2012: written advice on progress of the project provided. Requested continued commitment to implementing the Guidelines.
National Perinatal Data Collection	National Perinatal Data Development Committee	March 2012: written advice on progress of the project provided.
National Hospital Morbidity Database		Liaison with AIHW data custodians as needed. Written advice not required due to conduct of hospital audit.
Community Mental Health Care Database and Residential Mental Health Care Database	National Mental Health Working Group	Liaison with AIHW data custodians as needed. Written advice to working group not required due to full work schedule as part of reform agenda.
Australian Cancer Database	Cancer Monitoring Advisory Group	Liaison with AIHW data custodians as needed.
National Diabetes Register	National Diabetes Data Working Group	Liaison with AIHW data custodians as needed.
Communicable and notifiable disease registers	Communicable Diseases Network of Australia Secretariat	Briefing provided to the Health Protection and Surveillance Branch, DoHA, April 2012.

Additional support

The project promoted national consistency in Indigenous status identification across the settings and agencies involved in this work. The project sought to build cross-references between the Guidelines and relevant national standards such as the National Health Data Standards, which set national standards for the collection of data.

The project also worked to ensure e-health initiatives prioritise the collection, recording and transmission of Indigenous status information. E-health initiatives not only are important in themselves, but also present an opportunity to drive standardisation of Indigenous status functionality in software used by health service providers. Information on work undertaken regarding e-health is included in Chapter 5.

A number of Australian Government departments and agencies produce materials referring to Aboriginal and Torres Strait Islander identification, and the project promoted inter-agency consistency of guidance to health providers in implementing the Guidelines.

2.3 Other AIHW data improvement projects

The Guidelines support and evaluation project is closely related to other NIRA Schedule F data quality improvement projects. The status of those projects for which the AIHW has either had shared or sole responsibility is outlined below. Jurisdictions' activities under Schedule F are outlined in Chapter 4.

Analysis of level of Indigenous identification in key data sets

During 2011–12, the AIHW, in collaboration with jurisdictions, undertook an assessment of levels of under-identification in selected public hospitals in all states and territories. Under-identification was assessed through an audit comparing the results of face-to-face interviews with patients with the information recorded in the administrative record (AIHW 2013). This project is ongoing and future work on assessing the level of under-identification using different methods may include mental health, alcohol and other drugs treatment services, and cancer data sets. The aim is to improve the accuracy of Indigenous health information and statistics and to support their use in monitoring progress towards meeting COAG-agreed targets for improving the health status of Aboriginal and Torres Strait Islander people.

Development of National best practice guidelines for data linkage

This was conducted by AIHW and the ABS. It developed consistent principles and practices to inform the linking of data to improve the completeness and consistency of Indigenous status information in key data sets. Best practice guidelines for data linkage were published in 2012 (AIHW & ABS 2012).

Development of the AIHW Enhanced Indigenous Mortality Data Linkage Project

The main purpose of this project is to create a time series of linked mortality data that contains enhanced Indigenous identification. The project will develop a permanent enhanced mortality database that will be used to provide better estimates of Indigenous mortality and life expectancy for research purposes.

The project involves linking death registrations based on notifications in the National Death Index with other data sources that contain information on Indigenous deaths. These data sources are the National Hospital Morbidity Database, the Residential Aged Care Data Collection, and the National Perinatal Data Collection.

Development of enhanced Perinatal NMDS

From 2012, the Indigenous status of the baby – in addition to the Indigenous status of the mother – was collected in all jurisdictions. This enables perinatal reports to include the Indigenous status of all babies, not only those born to Aboriginal and Torres Strait Islander mothers. In addition, data items to measure smoking during pregnancy and antenatal care have been developed and are currently being collected. Additional work on collecting consistent national information on alcohol use during pregnancy is underway.

Review of pathology processes

The AIHW has completed a business case considering the inclusion of Indigenous status on pathology request forms as a way to improve Indigenous identification in national cancer, communicable disease and cervical screening registers. The publication of the business case in 2013 will complete this project; however, efforts to improve Indigenous identification in pathology-generated data will continue (AIHW forthcoming 2013a).

National Key Performance Indicators

This data quality project involves developing National Key Performance Indicators for all Indigenous primary health-care services that receive funding from Australian, state or territory governments. A set of indicators, which were developed in consultation with key stakeholders and approved by AHMAC, will be rolled out progressively during 2012–2014. From December 2012, the collection will be expanded to include all Aboriginal and Torres Strait Islander primary health-care services funded by the Office for Aboriginal and Torres Strait Islander Health (OATSIH), comprising about 200 services. It is expected that, from mid-2014, data collection will be further expanded to include Indigenous-specific primary health-care services funded by states and territories as well as those funded by OATSIH.

3 Information on sectors and data sets

This chapter provides information on the data set attributes and Indigenous status data quality for each of the health sectors and data sets in scope for the project. Key features of the data sets relevant to that health sector are described through a description of the data set, including its scope, purpose and coverage; the flow of data from health settings to data collections; and the extent to which Aboriginal and Torres Strait Islander status is included.

The following criteria were used to assess Aboriginal and Torres Strait Islander data quality in each data set:

- structural limitations
- the proportion of ‘not stated’ responses
- existing assessments of data quality in specific data sets. As described in Chapter 2, the basis of and criteria for many of these assessments are not known and may vary across jurisdictions and data sets.

The Guidelines project used a sector-based approach, as these sectors are the interfaces where services are delivered and data are collected (Table 3.1). Guidelines implementation work in any particular sector should improve Indigenous status in all data sets to which that sector contributes. Where the data sets in scope for the project were contained within a sector, data improvement activities and reporting were relatively straightforward.

Other data sets in scope, namely the Australian Cancer Database and the National Diabetes Register, gather information across a number of sectors including those not specifically in scope for the project. For example, cancer data are collected from pathology laboratories and oncologists as well as from general practitioners. This makes efforts to improve data in these data sets more difficult to undertake and to report.

The general practice sector does not currently have an overarching data set, but the sector contributes data to a number of different data sets. Improved identification in this sector is vital for improving Aboriginal and Torres Strait Islander data in those data sets, as well as for improving the uptake of health interventions specific to Aboriginal and Torres Strait Islander people. The general practice sector is covered separately in Chapter 5.

Table 3.1: Sectors and data sets in scope

Sector	Data sets in scope completely contained within the sector	Other data sets in scope deriving data from the sector
Hospital sector	National Hospital Morbidity Database National Perinatal Data Collection	Australian Cancer Database National Diabetes Register
Mental health sector	National Community Mental Health Care Database National Residential Mental Health Care Database	
Alcohol and other drugs	AODTS NMDS	
General practice sector		Australian Cancer Database National Diabetes Register

Jurisdictions are responsible for implementing the Guidelines in the health sector; however, the influence that jurisdictions have over the uptake of the Guidelines varies across sectors and data sets (Table 2.2). This ranges from high levels of influence in public hospitals, which jurisdictions administer, to low levels of influence in private general practice where jurisdictions have little capacity to mandate change.

3.1 Hospital sector

Of 5.3 million public hospital separations in 2010–11, 305,910 (5.8%) were hospitalisations for Aboriginal and Torres Strait Islander patients. Indigenous Australians are hospitalised at about 2.8 times the rate of non-Indigenous Australians (AIHW 2012b). Higher hospitalisation rates to some extent reflect lack of access to primary health care for Aboriginal and Torres Strait Islander people, as indicated by their higher levels of avoidable admissions (ABS & AIHW 2008).

Improved preventative measures and primary health-care service provision are the focus for much of the recent Australian Government Closing the Gap funding allocations. However, improved tertiary level care has the potential to make considerable contributions to improved health outcomes for Aboriginal and Torres Strait Islander people (NHFA & AHHA 2010). Improving treatment disparities and achieving better health outcomes for Aboriginal and Torres Strait Islander people in hospital are necessary factors in reducing the gap in life expectancies between Indigenous and non-Indigenous people.

Given the level of control that jurisdictions have in the public hospital sector, their capacity to implement Guidelines-compliant processes in this sector is likely to be high. In private hospitals, however, governance arrangements are mixed as many private hospitals are owned by corporate hospital chains with boards of directors operating on a commercial basis, while smaller hospitals may have variable decision-making processes (Duckett & Willcox 2011:219–20).

Compared with non-Indigenous Australians, Aboriginal and Torres Strait Islander people are more likely to use the services of public hospitals than private hospitals. Treatment in private hospitals, which involves up-front payments or out-of-pocket expenses, may be less accessible to many Aboriginal and Torres Strait Islander people who are unable to meet such requirements. In addition, Aboriginal and Torres Strait Islander people have lower rates of private health insurance coverage than non-Indigenous people. About 15–20% of Indigenous Australians have private health insurance cover and this also impacts on their relative access to private hospitals (AIHW 2010c:8).

Accreditation processes may offer scope to increase compliance with the Guidelines in both private and public hospital settings. The majority of public and private hospitals are accredited, either through the Australian Council on Healthcare Standards or other accreditation processes (Duckett & Willcox 2011:215). However, the National Safety and Quality Health Service Standards, against which hospitals are accredited, do not specifically address Indigenous identification.

Of the national data sets in scope for this project, two are collected within the hospitals sector, namely the National Hospital Morbidity Database and the National Perinatal Data Collection. Both are underpinned by NMDSs: the Admitted Patient Care NMDS and the Perinatal NMDS. These two data sets are detailed below.

National Hospital Morbidity Database

The National Hospital Morbidity Database compiles episode-level records from admitted patient morbidity data collection systems in Australian hospitals. It is a comprehensive data set that has records for all episodes of admitted patient care from essentially all public and private hospitals in Australia. The data supplied are based on the NMDS for Admitted Patient Care and include demographic, administrative and length-of-stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.

The purpose of the National Hospital Morbidity Database is to collect information about care provided to admitted patients in Australian hospitals. Its scope is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, freestanding day hospital facilities, and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, correction authorities and in Australia’s off-shore territories are not in scope, but some are included. The hospital separations data do not include episodes of non-admitted patient care provided in outpatient clinics or emergency departments. Patients in these settings may be admitted subsequently, with the care provided to them as admitted patients being included in the National Hospital Morbidity Database.

Data flow

Admitted patient data are collected at admission, during the course of the patient’s stay and at separation. Indigenous status is usually recorded at admission. Hospitals forward admitted patient data to state and territory health authorities, who in turn provide data to the AIHW (Figure 3.1).

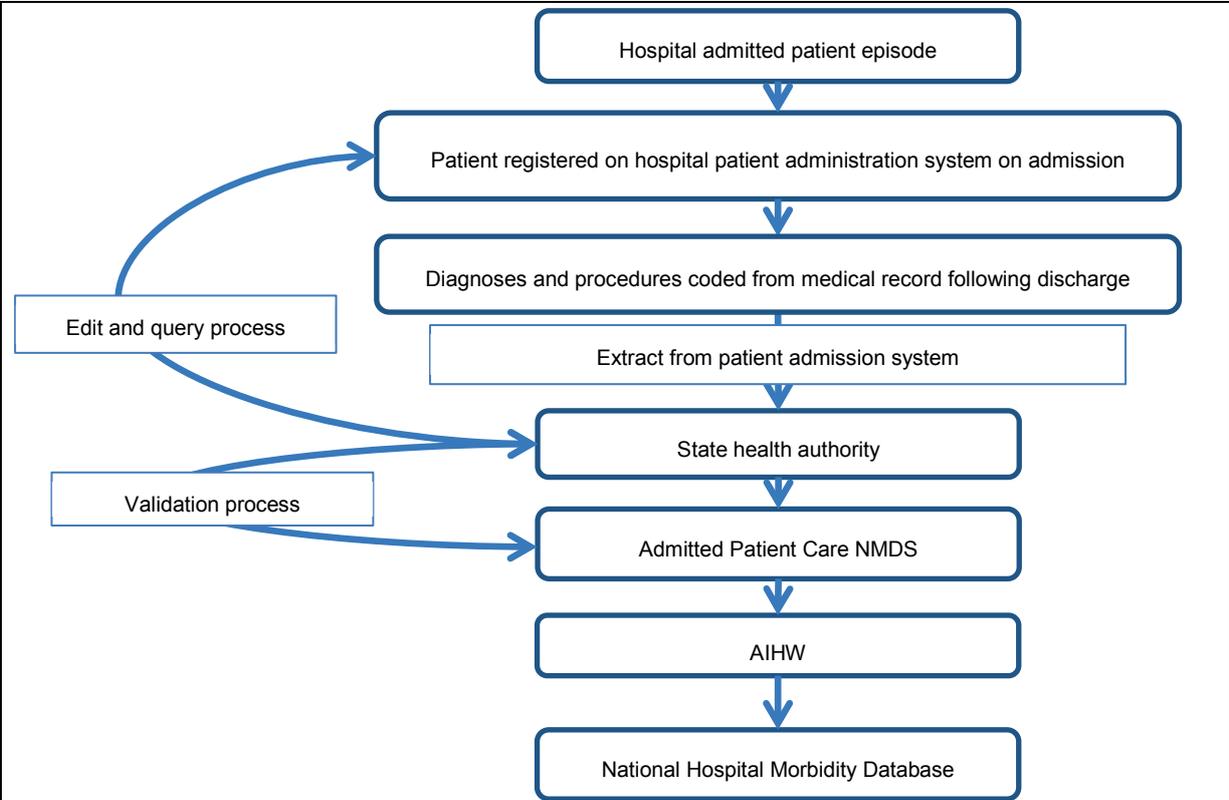


Figure 3.1: Data flow to National Hospital Morbidity Database

Indigenous data quality issues

The National Hospital Morbidity Database contains episode-level records from admitted patient morbidity data collection systems in Australian hospitals. As required by the NMDS, the data collected include information on Indigenous status.

Structural limitations

Indigenous Australians have much higher hospitalisation rates than non-Indigenous Australians; despite this, 4% of Aboriginal and Torres Strait Islander people in non-remote areas reported problems with accessing hospital-based health care – with the corresponding proportion rising to 15% in remote areas (AHMAC 2012). Reported barriers to access included insufficient services in the area, lack of transport, and cost. Financial barriers are likely to be more pronounced in private hospitals due to up-front costs and lower rates of private health insurance.

The extent to which Aboriginal and Torres Strait Islander people experience access barriers to hospital-based care will impact upon the coverage of hospital-generated data.

Proportion of 'not stated'

The percentage of 'not stated' responses in public hospital separations data is low, ranging between 0.7% in Victoria to 4.6% in South Australia (Table 3.2). It should be noted that Western Australia does not record the category of 'not stated' in hospital records; instead 'not stated' responses are reported as non-Indigenous.

Table 3.2: Number of hospital separations, by Indigenous status, 2010–11

Indigenous status	NSW	Vic	Qld	WA ^(a)	SA	Tas	ACT	NT	Aust
Indigenous	62,385	16,416	78,263	50,135	20,826	2,837	2,128	72,920	305,910
Non-Indigenous	1,507,520	1,468,985	872,535	498,137	351,331	94,652	90,172	31,513	4,914,845
'Not stated'	12,899	10,640	13,551	n.a.	17,997	1,844	1,445	1	58,377
Total separations	1,582,804	1,496,041	964,349	548,272	390,154	99,333	93,745	104,434	5,279,132
Percentage 'not stated'	0.8	0.7	1.4	n.a.	4.6	1.9	1.5	—	1.1

(a) Western Australian systems do not record 'not stated' responses.

Note: Data for public hospitals only.

Source: AIHW 2012b.

Assessment specific to data set

2007–08 audit

During 2007 and 2008, the AIHW, in collaboration with jurisdictions, assessed the level of Indigenous under-identification in hospital data in all states and territories (AIHW 2010c).

The assessment focused on public hospitals and advised that private hospital data not be separately reported. The report included several recommendations for improving the quality of Indigenous status data in the private hospital sector.

For New South Wales, Victoria, Queensland, Western Australia, South Australia, Tasmania and the Northern Territory, the audit of Indigenous identification in hospital separations data was undertaken by interviewing a sample of admitted patients in hospital about their Indigenous status (considered the 'gold standard' means of correctly ascertaining Indigenous status), and comparing patient responses with the Indigenous status information recorded

on the hospital admission records. For the Australian Capital Territory, a linkage project was used to assess Indigenous identification.

Results indicated that public hospitals in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory had adequate Indigenous identification (80% or higher overall levels of Indigenous identification) in their hospital separations data. For Tasmania and the Australian Capital Territory, the levels of Indigenous identification were not considered acceptable for analysis purposes.

It was therefore recommended that reporting of Indigenous hospital separations data be limited to information from New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory, individually or in aggregate.

2011–12 audit

During 2011–12, the AIHW, in collaboration with jurisdictions, assessed the level of under-identification in selected public hospitals in all states and territories.

Under-identification was assessed through an audit comparing the results of face-to-face interviews with patients with the information recorded in the administrative record (AIHW 2013).

The audit determined both completeness and correction factors:

- completeness refers to the number of correctly identified individuals within the sample in both the interview and the hospital record
- correction factors are calculated to adjust Indigenous data where Indigenous status is incomplete, inaccurate or not stated.

This means where completeness is high, the correction factor is close to 1.00, as little adjustment is needed. Where completeness is low, the correction factor increases as more adjustment is needed.

Nationally, about 88% of Indigenous Australians were identified correctly in public hospital admissions data and a national correction factor of 1.09 was calculated (Table 3.3). All states and territories were found to have some level of under-identification of Aboriginal and Torres Strait Islander patients in their public hospital statistics, with levels of completeness between 58% in the Australian Capital Territory and 98% in the Northern Territory. Correction factors calculated for jurisdictions were between 1.00 for the Northern Territory to 1.69 for the Australian Capital Territory.

Table 3.3: Completeness and correction factors at jurisdiction level

Jurisdiction	Total sample (no.)	Completeness (%)	Correction factor
New South Wales	5,109	80	1.20
Victoria	4,307	78	1.23
Queensland	3,516	87	1.08
Western Australia	1,482	96	1.01
South Australia	1,243	91	1.10
Tasmania	1,772	64	1.37
Australian Capital Territory	1,857	58	1.69
Northern Territory	813	98	1.00
Australia	20,099	88	1.09

Source: AIHW 2013.

The correction factors are applied as a statistical correction to all national analyses of Indigenous admitted patient care (for data from 2010–11 onwards) to adjust total hospital separations data (public hospitals and public and private hospitals combined) at:

- the national level
- the national level by remoteness
- the state and territory level
- remoteness levels within jurisdictions.

National Perinatal Data Collection

The National Perinatal Data Collection is the national repository of pregnancy and childbirth data. The data are based on births reported to the perinatal data collection in each state and territory, as mandated through the Perinatal NMDS.

The scope of the NMDS includes all births in all Australian hospitals, birth centres and the community of at least 20 weeks gestation or 400 grams birthweight (including both live and stillborn births). State and territory health authorities provide the data to the AIHW National Perinatal Epidemiology and Statistics Unit (NPESU) for national collation on an annual basis.

Jurisdictional capacity to ensure Guidelines-compliant processes within public hospitals is relatively high. Furthermore, as most births take place in hospitals, the quality of Indigenous information provided to the National Perinatal Data Collection is likely to reflect these processes.

Data flow

Perinatal data are collected at the time of the birth and are either recorded on the National Perinatal Data Collection form or directly in the hospital maternity database. Hospitals forward perinatal data to state and territory health authorities, who in turn provide data to the NPESU (Figure 3.2).

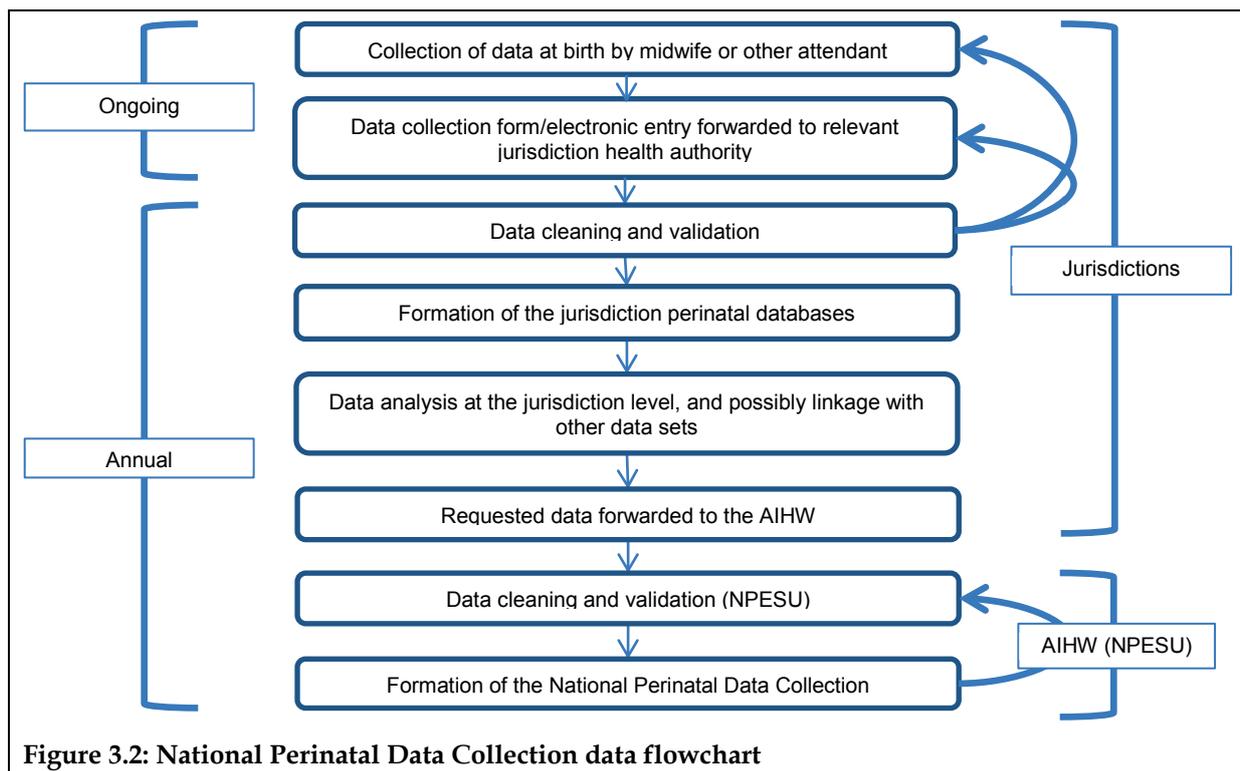


Figure 3.2: National Perinatal Data Collection data flowchart

Indigenous data quality issues

As required by the NMDS, all states and territories have a data item to record Indigenous status of the mother on their perinatal form, although there are some differences among the jurisdictions.

Since 2005, all jurisdictions have provided information on Indigenous status of the mother in accordance with the NMDS. No national information has been collected about the father's Indigenous status. Before 2012, Victoria was the only state to collect information about the baby's Indigenous status (AIHW 2011a).

From 2012, Indigenous status of the baby has been collected in all jurisdictions. This enables perinatal reports to include the Indigenous status of all babies (Li et al. 2011). When these data become available, they can, where appropriate, be used in conjunction with existing data on the Indigenous status of the mother to:

- update information about babies of Aboriginal and Torres Strait Islander mothers
- generate new information about all babies identified as Aboriginal and/or Torres Strait Islander.

Structural limitations

Issues of access to hospitals noted in relation to the National Hospital Morbidity Database are likely to have less relevance in regard to perinatal data, as the National Perinatal Data Collection includes data on all births in Australian hospitals, birth centres and the community.

Proportion of 'not stated'

The percentage of 'not stated' responses in perinatal data ranges from 0.04% in Queensland to 1.5% in Victoria (Table 3.4). 'Not stated' percentages were not reported for Western Australia, South Australia and Tasmania.

Table 3.4: Women^(a) who gave birth, Indigenous status, states and territories, 2009

	NSW	Vic	Qld	WA ^(b)	SA	Tas	ACT ^(c)	NT	Aust
Indigenous	2,904	838	3,332	1,738	607	284	107	1,474	11,284
Non-Indigenous	91,958	70,328	57,665	29,022	18,994	5,996	5,601	2,369	281,933
'Not stated'	176	1,079	24	n.a.	n.a.	n.a.	28	16	1,323
Total number of women	95,038	72,245	61,021	30,760	19,601	6,280	5,736	3,859	294,540
Percentage 'not stated'	0.2	1.5	—	n.a.	n.a.	n.a.	0.5	0.4	0.4

(a) Indigenous status of the baby has been collected from 2012 onwards.

(b) Western Australian systems do not record 'not stated' responses.

(c) A total of 15.9% of women who gave birth in the Australian Capital Territory were not residents of the Territory. Care must be taken when interpreting percentages. For example, 24.3% of Aboriginal or Torres Strait Islander women who gave birth in the Australian Capital Territory in 2009 were not residents of the Territory.

Note: Provisional data were provided by Victoria for this table.

Source: AIHW 2011a.

Assessment specific to data set

In 2007, the AIHW, in collaboration with the NPESU, released a report on Indigenous mothers and their babies which included an assessment of the quality of Indigenous status data (Leeds et al. 2007). This study investigated how many hospitals in each jurisdiction obtained Indigenous status information of women giving birth from admission records and how many collected this information independently. The report recommended that midwives ask all mothers their Indigenous status.

Even if Indigenous status has already been recorded, such as when the data are taken from the hospital database or admission form, this information should be verified with the mother directly.

Results of the assessment of the quality of Indigenous status in perinatal data in each state and territory over the period 1991–2004 showed that:

- data from New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory were suitable for trends analysis from 1991 onwards
- data from the Australian Capital Territory and Tasmania were not considered sufficiently stable to be included in trends analysis, mainly because of the small population size and some issues with data quality over the reporting period (Leeds et al. 2007).

3.2 Alcohol and other drug treatment services sector

The alcohol and other drug treatment services sector generates information for the AODTS NMDS. Services making up this sector are primarily funded by governments and can be delivered either directly by government services or by non-government organisations funded through service delivery agreements. The capacity of jurisdictions to ensure Guidelines-compliant processes is likely to be higher in agencies under the direct control of jurisdictions than in contracted non-government organisations. In most jurisdictions, there were more non-government than government agencies providing alcohol and other drug treatment services. The exceptions were New South Wales and South Australia, where, in both cases, more than 70% of services in scope were government agencies.

There are a range of treatment services available for Aboriginal and Torres Strait Islander people who require interventions for alcohol and drug use. As well as the mainstream services outlined above, there are 48 services specific to Aboriginal and Torres Strait Islander people that focus on substance misuse issues. In addition, the network of around 150 Aboriginal Community Controlled Health Services (ACCHSs) provides holistic care as well as targeted programs for substance misuse issues. Both services that are specific to Aboriginal and Torres Strait Islander people and the ACCHS sector are funded by the Australian Government via DoHA and as such are outside the scope of the AODTS NMDS. Instead, data are collected annually from these services in the OATSIH Services Reporting (OSR).

Alcohol and other drug treatment services sector NMDS

The AODTS NMDS is a nationally agreed set of data items collected by service providers funded by state and territory governments, in both the government and non-government sectors. State and territory health authorities collate these data and the AIHW compiles them into a national data set.

The AODTS NMDS provides demographic information, including Indigenous status, about clients who use treatment services; data about the drugs that concern clients; and information about the treatments clients receive. Some administrative information about treatment agencies is also collected. The AODTS NMDS has been implemented to help monitor and evaluate key objectives of the National Drug Strategy 2010–15 and to plan, manage and improve the quality of alcohol and other drug treatment services.

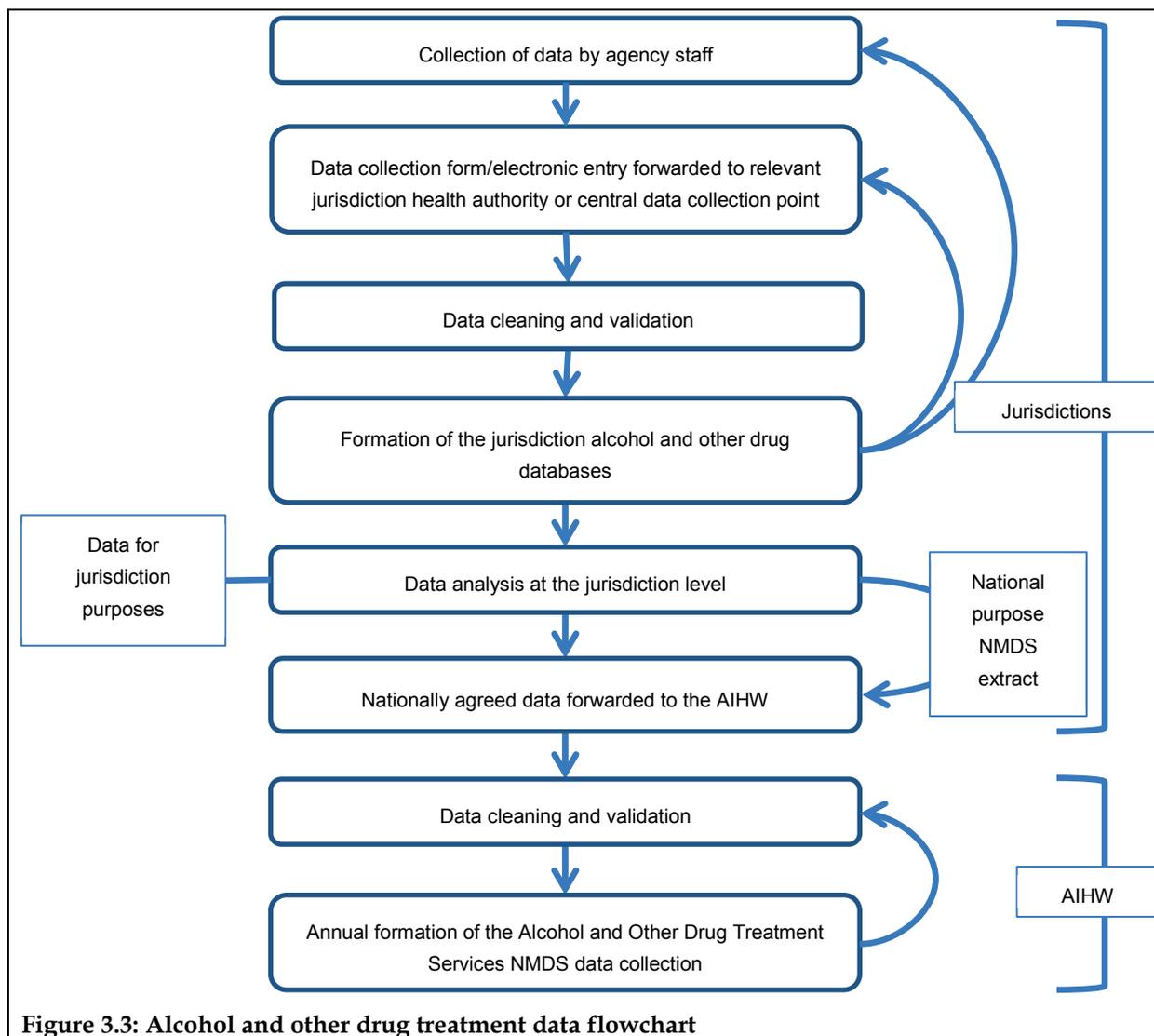
In 2009–10, 670 alcohol and other drug treatment agencies provided data to the AODTS NMDS (AIHW 2012g). In the same period, 145,631 closed treatment episodes were recorded, of which 139,614 (96%) were for clients seeking treatment for their own substance use. Of all episodes recorded, 18,300 were Indigenous (13%). The Northern Territory had the greatest proportion of episodes where people sought assistance in relation to another person's drug use (11%).

The number of closed treatment episodes collected in the AODTS NMDS does not equate to the total number of people in Australia receiving treatment for alcohol and other drug use. The current collection method does not identify when a client receives multiple treatment episodes in the same or different agencies, either concurrently or consecutively. Jurisdictions are working towards implementing a collection method to allow for the counting of clients, not just episodes.

Data flow

Alcohol and other drug treatment agencies funded by state and territory governments collect the agreed data items and forward this information to the appropriate health authority. Agencies are responsible for ensuring the required information is accurately recorded, that their clients are generally aware of the purpose for which the information is being collected and that their data collection and storage methods comply with existing privacy principles.

For most states and territories, the data provided for the national collection are a subset of a more detailed jurisdictional data set used for planning at that level. Figure 3.3 demonstrates the processes involved in constructing the national data.



Indigenous data quality issues

The AODTS NMDS has a mandatory field to complete for Indigenous status, and all services are required to collect this information. Therefore, the NMDS can provide data on people who access mainstream substance misuse services in scope and who have identified as being of Aboriginal and or Torres Strait Islander origin.

Structural limitations of data set

The AODTS NMDS provides only part of the picture in relation to substance misuse services relevant to Indigenous Australians. It does not include services specific to Aboriginal and Torres Strait Islander people, whether provided by stand-alone substance misuse services or as part of holistic care in the ACCHS sector. These services generally provide data on the substance misuse services they provide through OATSIH-managed processes, which were established before the AODTS NMDS was developed. The AODTS NMDS and OSR data should therefore be seen as complementary data sources in building a complete picture of substance misuse services for Aboriginal and Torres Strait Islander people.

Proportion of 'not stated'

In 2009–10, Indigenous status was not stated for 6% of alcohol and other drug treatment episodes nationally (Table 3.5). This reflects a similar proportion to that observed in 2008–09.

Table 3.5: Alcohol and other drug treatment closed episodes, Indigenous status, states and territories, 2009–10

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Indigenous	3,929	3,118	3,470	3,754	1,108	150	343	2,428	18,300
Non-Indigenous	30,372	44,204	17,866	13,284	7,616	1,179	2,884	1,324	118,729
'Not stated'	901	4,811	1,754	149	368	215	358	46	8,602
Total number of encounters	35,202	52,133	23,090	17,187	9,092	1,544	3,585	3,798	145,631
Percentage 'not stated'	2.6	9.2	7.6	0.9	4.0	12.2	10.0	1.2	5.9

Source: AIHW analysis of the AODTS NMDS.

Assessment specific to data set

No formal assessment on the quality of Aboriginal and Torres Strait Islander data has been undertaken for this data set.

3.3 Mental health services sector

Mental health-related services are provided in Australia in a variety of ways – from hospitalisation and other residential care, through hospital-based outpatient services and community mental health-care services to consultations with both specialists and general practitioners. The Australian Government supports mental health-related services by subsidising certain consultations and other medical and allied health services through the Medicare Benefits Schedule (MBS), and prescribed medications via the Pharmaceutical Benefits Scheme (PBS).

As well as funding ACCHSs, the Australian Government also provides some funding for services delivered by states and territories. State and territory governments fund and deliver services and assist with broader needs, such as hospital services, accommodation support and community-based care services.

Mental illness is frequently treated in community- and hospital-based ambulatory care settings. Collectively, these services are referred to as the community mental health-care sector. Mental health care may also be provided through residential services. These services provide specialised mental health care, on an overnight basis, in a domestic-like environment. Residential mental health services may include rehabilitation, treatment or extended care.

Of the national data sets in scope for this project, two are collected within the mental health sector, namely the National Community Mental Health Care Database and the National Residential Mental Health Care Database. Both are underpinned by NMDSs that include a requirement for the reporting of Indigenous status. The mental health sector has recently undergone significant reforms impacting on data collection, and additional investment in the sector has focused attention on data development and reporting. As these processes are embedded, the second phase of the project may provide opportunities to consider Indigenous status quality issues.

In addition to mainstream community and residential services, there are also mental health-care services specifically targeted to the needs of the Aboriginal and Torres Strait Islander population that are funded directly by the Australian Government. For example, the network of around 150 ACCHSs provides holistic care for mental as well as physical health issues. Many ACCHSs include specific social and emotional wellbeing services and programs, such as through services provided by Bringing Them Home counsellors. Separate Link Up services also provide counselling and support to Aboriginal and Torres Strait Islander people of the Stolen Generations. These mental health services are reported as part of OSR and are not part of the National Community Mental Health Care Database.

National Community Mental Health Care Database

The National Community Mental Health Care Database, commenced in 2000–01, contains data on all ambulatory mental health service contacts provided by community mental health-care services operated by state and territory governments and as specified by the Community Mental Health Care NMDS. Services funded directly by the Australian Government, such as Aboriginal and Torres Strait Islander specific services, are not in scope for this collection and instead report through the OSR data collection.

There were 160 specialised mental health service organisations providing community mental health-care services that reported to the National Community Mental Health Care Database in 2009–10.

A mental health service contact for the purposes of this collection is defined as the provision of a clinically significant service by a specialised mental health service provider for patients/clients (other than those admitted to psychiatric hospitals or designated psychiatric units in acute care hospitals and those resident in 24-hour staffed specialised residential mental health services), where the nature of the service would normally warrant a dated entry in the clinical record of the patient/client in question.

Any one patient can have one or more service contacts over the relevant reporting period. Service contacts are not restricted to face-to-face communication but can include telephone, video link or other forms of direct communication. Service contacts can also be either with the patient or with a third party, such as a carer or family member, or other professional or mental health worker or other service provider(s).

There are variations across jurisdictions in the scope and definition of a service contact. For example, New South Wales, Queensland, South Australia and Tasmania may include written correspondence as service contacts while others do not.

Data flow

Mental health staff collect demographic data from mental health patients/clients at the start of the first service contact, and Indigenous status is usually recorded at this time. Mental health service providers forward patient data to state and territory health authorities, who in turn provide data to the AIHW (Figure 3.4).

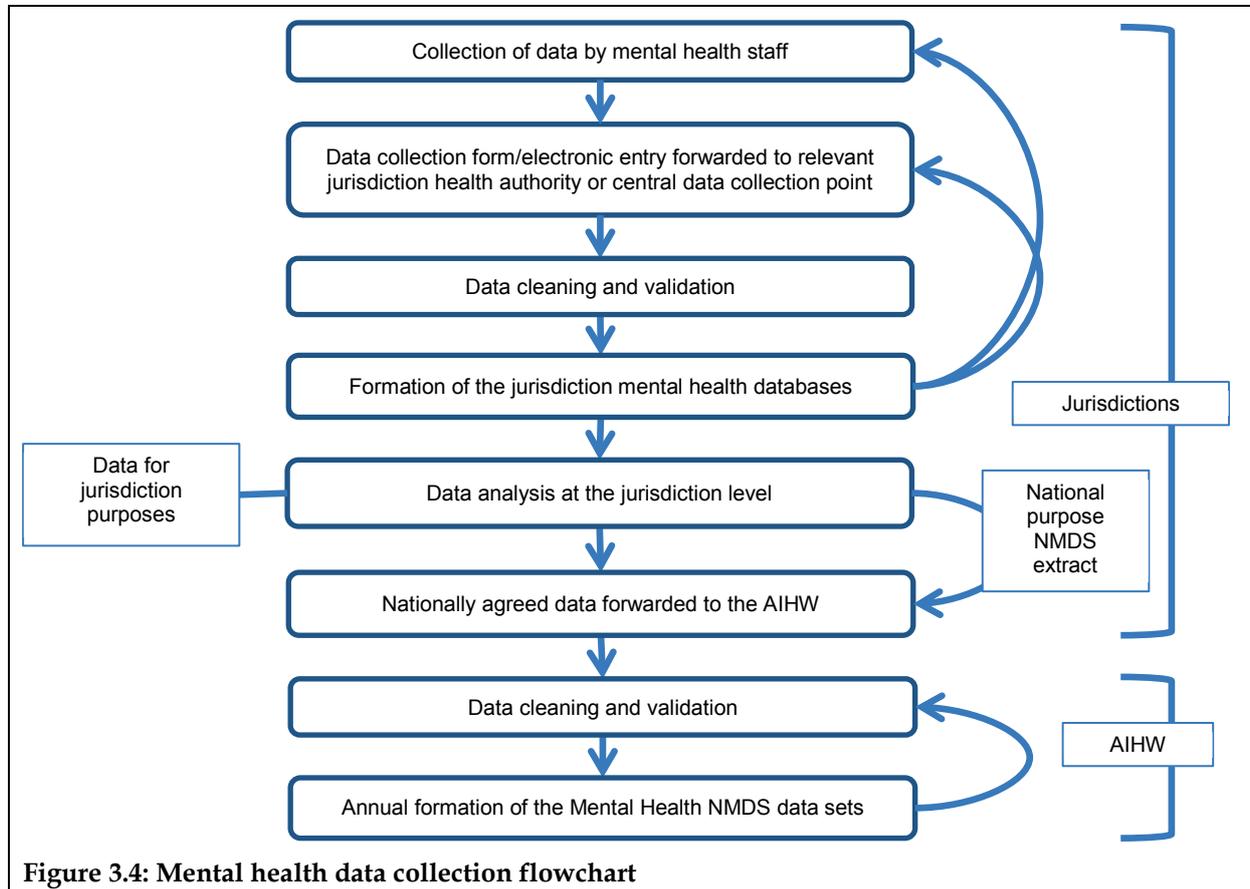


Figure 3.4: Mental health data collection flowchart

Indigenous data quality issues

The National Community Mental Health Care Database requires the collection of Indigenous status of patients/clients, as per the NMDS requirements.

The overall number of community mental health-care service contacts recorded by the National Community Mental Health Care Database indicates the importance of community based care (Table 3.6). Aboriginal and Torres Strait Islander people access community mental health care at higher rates than non-Indigenous Australians.

Structural limitations of data set

The National Community Mental Health Care Database provides only part of the picture in relation to use of mental health services for Aboriginal and Torres Strait Islander people. This is because the ACCHS sector and other services specific to Aboriginal and Torres Strait Islander people are not included in this collection; they are instead reported via the OSR collection (AIHW 2012a). The OSR data and the National Community Mental Health Care Database should therefore be considered as complementary data sources.

Proportion of 'not stated'

The percentage of records with 'not stated' Indigenous status varied across states, ranging from 0.2% in Queensland to 19.1% in New South Wales in 2009–10 (Table 3.6). Overall for Australia, 'not stated' records accounted for 8.8% of all community mental health-care service contacts. Two jurisdictions (New South Wales and South Australia) had more than 10% of contacts with 'not stated' Indigenous status, indicating scope for additional improvements in data collection.

Table 3.6: Community mental-health-care service contacts, by Indigenous status and state and territory, 2009–10

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
	Number								
Indigenous	209,543	32,202	78,074	40,120	28,533	19,610	7,804	15,008	430,894
Non-Indigenous	1,604,984	1,681,351	803,254	617,936	446,762	178,757	226,842	23,514	5,583,400
'Not stated'	427,507	22,457	2,130	22,078	68,053	14,232	22,851	462	579,770
Total	2,242,034	1,736,010	883,458	680,134	543,348	212,599	257,497	38,984	6,594,064
Percentage 'not stated'	19.1	1.3	0.2	3.2	12.5	6.7	8.9	1.2	8.8
	Number per 1,000 population^(a)								
Indigenous	1,459.1	971.2	530.2	554.4	941.3	1,211.1	1,767.0	217.4	841.8
Non-Indigenous	231.7	309.4	190.6	284.5	288.8	380.4	649.0	141.6	262.0
Total	317.6	317.7	202.4	303.8	344.8	435.2	728.4	163.6	302.5

(a) Rates were directly age standardised using the Australian 2001 standard population.

Source: AIHW analysis of National Community Mental Health Care Database.

Assessment specific to data set

Data from the National Community Mental Health Care Database on Indigenous status should be interpreted with caution as the data quality and completeness of Indigenous identification vary across jurisdictions.

Some states and territories provided their own assessments of the quality of Indigenous data for 2009–10 (AIHW 2012e).

- New South Wales, Tasmania and the Australian Capital Territory considered the quality of the Indigenous status data to be acceptable.
- Victoria reported the quality of Indigenous status data was acceptable, but noted there were areas for improvement in the collection of Indigenous status based on the Guidelines.
- Queensland reported the quality of Indigenous data was acceptable at the broad level; that is, in distinguishing Indigenous Australians and other Australians. However, Queensland believed there were quality issues regarding the coding of more specific details (that is, Aboriginal, Torres Strait Islander, or both Aboriginal and Torres Strait Islander).

National Residential Mental Health Care Database

The National Residential Mental Health Care Database contains data on episodes of residential care provided by government-funded residential mental health services as specified by the Residential Mental Health Care NMDS. Data collated include information relating to each episode of residential care provided by the relevant mental health services.

A total of 38 specialised mental health organisations reported to the National Residential Mental Health Care Database in 2009–10.

The scope for this collection is all episodes of residential care for residents in government-funded residential mental health services that employ mental health trained staff onsite 24 hours per day, except those residential care services in receipt of funding under the *Aged Care Act 1997* (Cwlth) and subject to Australian Government reporting requirements. The inclusion of services that are government funded but not government operated – and services not staffed for 24 hours a day – is optional, with 11 such organisations included in the 2009–10 collection.

Data flow

See data flow section from Community mental health services (Figure 3.4).

Indigenous data quality issues

The collection of Aboriginal and Torres Strait Islander status data is required by the Residential Mental Health Care NMDS.

The number of episodes of care for Indigenous clients recorded by the National Residential Mental Health Care Database was low in most jurisdictions, as care is more often delivered via non-acute hospital and home-based accommodation support services than via residential services in scope for this database (Table 3.7). Victoria and Tasmania report higher numbers of episodes of care as both rely on residential services to a greater extent than other jurisdictions.

Four of the five jurisdictions with reported or published numbers of residential episodes per 10,000 indicated the rate is higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people. This may reflect variations in completeness of Aboriginal and Torres Strait Islander identification among residents or different patterns of service use by Indigenous and non-Indigenous people.

Structural limitations of data set

There are no specific structural limitations to the data set. Rates of Indigenous clients, however, vary considerably across jurisdictions, possibly reflecting differences in the availability of services, and variations in access for Indigenous people. For example, Queensland, where about 30% of Aboriginal and or Torres Strait Islander people live, does not report any government-operated residential mental health services.

Proportion of 'not stated'

In 2009–10, the level of 'not stated' Indigenous status in the National Residential Mental Health Care Database varied across jurisdictions. In the jurisdictions for which data was available, the percentage of mental health care episodes where Indigenous status was shown as 'not stated' ranged from nil in New South Wales and the Northern Territory to about 14% in Tasmania.

Table 3.7: Residential mental health-care episodes, by Indigenous status and state and territory, 2009–10

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Number								
Indigenous	18	27	..	n.p.	19	16	n.p.	33
Non-Indigenous	196	2,200	..	215	190	780	55	49
'Not stated'	0	13	..	n.p.	10	133	n.p.	0
Total	214	2,240	..	223	219	929	57	82
Percentage 'not stated'	0.0	0.6	..	n.a.	4.6	14.3	n.a.	0.0
Number per 10,000 population^(a)								
Indigenous	1.2	9.8	..	n.p.	6.4	11.6	n.p.	4.4
Non-Indigenous	0.3	4.0	..	n.p.	1.3	15.2	n.p.	2.8
Total	0.3	4.1	..	n.p.	1.4	17.7	n.p.	3.4

(a) Rates were directly age standardised using the Australian 2001 standard population.

Note: Queensland does not report any government-operated residential mental health services.

Source: AIHW analysis of National Residential Mental Health Care Database.

Assessment specific to data set

Data from the National Residential Mental Health Care Database on Indigenous status should be interpreted with caution due to the varying quality and completeness across jurisdictions. Although the basis of and criteria for these assessments are not known and may vary across jurisdictions, some states and territories provided the following information on the quality of Indigenous data for 2009–10.

- Western Australia, South Australia, the Northern Territory and the Australian Capital Territory considered the quality of the Indigenous status data to be acceptable.
- Victoria and New South Wales reported the quality of Indigenous status data was acceptable. However, Victoria noted there were areas for improvement in the collection of Indigenous status based on the Guidelines (AIHW 2010b).
- Tasmania reported the quality of Indigenous status data collected required improvement and was being addressed by implementing a new mental health information system.

3.4 Cross-sector data sets

This project defined cross-sector data sets as those that draw data from multiple sources. This section describes:

- the Australian Cancer Database, which is drawn from data provided to the state and territory cancer registries by general practitioners, hospitals and radiation oncology services
- the National Diabetes Register, which is drawn from data provided by diabetes educators, medical practitioners and others.

Australian Cancer Database

Cancer registries in states and territories are the repositories for details of all cancers diagnosed in Australia. The Australian Cancer Database was established in 1986 as the national repository of cancer incidence and mortality statistics. It includes data about the number of diagnoses of cancer by its primary origin. It contains all new cases of cancer in Australia since 1 January 1982, excluding basal cell carcinoma and squamous cell carcinoma of the skin. The database holds information on more than 1.8 million Australian cancer cases diagnosed from 1982.

Pathology reports are the principal source of notifications of cancer diagnoses in all jurisdictions (AIHW forthcoming 2013a) and diagnosis through a pathological examination is considered to be the 'gold standard'. In most states and territories, legislation requires the person in charge of a pathology service to forward a copy of the pathology report to the cancer registry (usually within the range of 7 days and 3 months).

Data flow

Although the Australian Cancer Database is not underpinned by an NMDS, all Australian states and territories have legislation requiring mandatory reporting of new cases of cancer to jurisdictional cancer registries, which supply the data annually to the AIHW. The state and territory cancer registries obtain their information from a variety of sources (Figure 3.5). While these notification sources vary from state to state, notifications are generally received from pathology laboratories; radiation oncology units; hospitals; and Registrars of Births, Deaths and Marriages. Some states and territories also receive information from nursing homes.

Data collected by cancer registries include identifying and demographic information, brief medical details on the cancer, pathology results and cause of death.

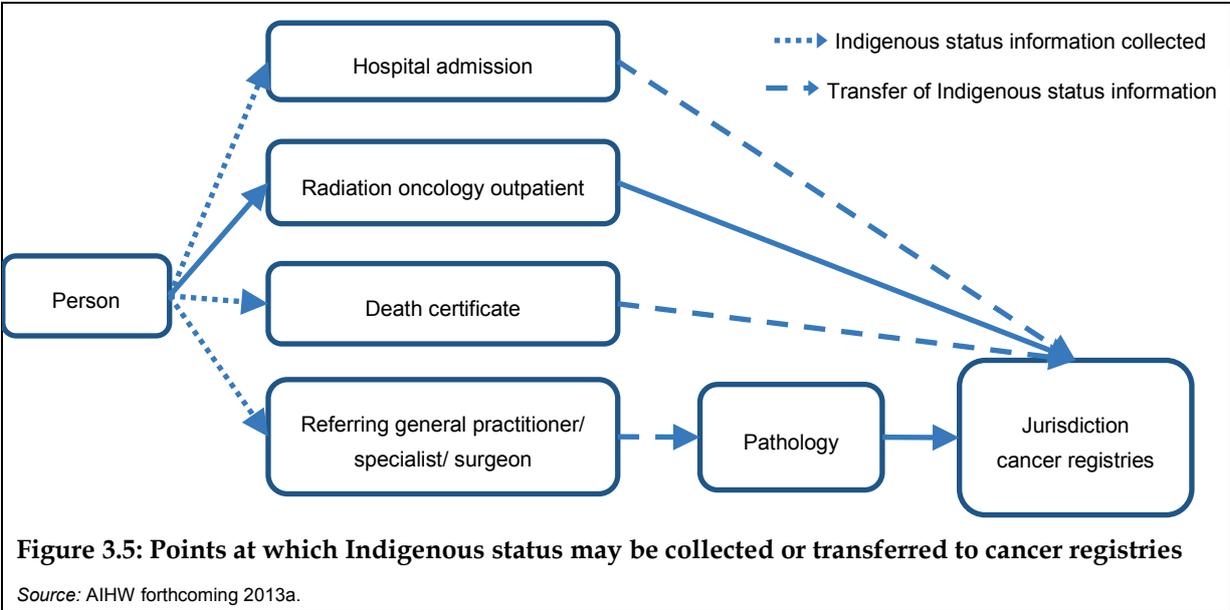


Figure 3.5: Points at which Indigenous status may be collected or transferred to cancer registries

Source: AIHW forthcoming 2013a.

Indigenous data quality issues

Although the Australian Cancer Database includes a field for Indigenous status that accords with the national standard, the collection of Aboriginal and Torres Strait Islander status in cancer data is not consistent across jurisdictions or routes of notification (pathology processes, death certificates and hospital data). Questions and response options used to identify Indigenous status may vary or may not be asked at all, and adherence to national standards is not guaranteed. The extent to which legislative changes would be needed in order to mandate the collection of Indigenous status by pathology processes and hospitals varies across jurisdictions (Table 3.8).

Table 3.8: Summary of information regarding Indigenous status in jurisdictional cancer registries

Jurisdiction	Per cent of notifications that source information from pathology	Completion rate 2006 ^(a)	Indigenous status in national standard format?	Are legislative changes required to mandate the collection of Indigenous status by pathology?	Are legislative changes required to mandate the collection of Indigenous status by hospitals?
New South Wales	86	n.a.	yes	yes	no
Victoria	n.a.	76.6	no	yes	no
Queensland	80	83.1	yes	yes	no
Western Australia	n.a.	98.4	no ^(b)	no	no
South Australia	n.a.	83.2	yes	yes	no
Tasmania	94	39.4	yes	yes	no
Australian Capital Territory	n.a.	n.a.	yes	yes	yes
Northern Territory	95	97.0	yes	no	no

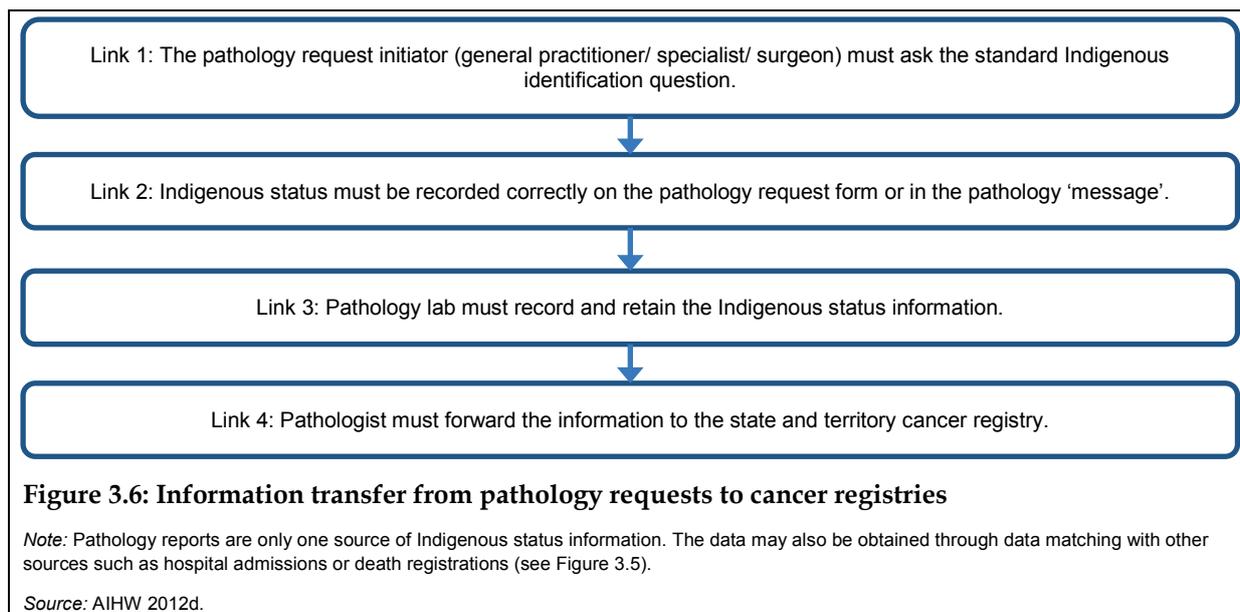
(a) Completion rate is the proportion of records that have Indigenous status information recorded.

(b) New Western Australian data is in the standard format; however, non-standard format is retained for preservation of historical data.

Source: AIHW forthcoming 2013a.

In relation to pathology requests, pathology services do not deal directly with the patient, and thus are unable to seek demographic information such as Indigenous status from the patient. The referring doctor may ask for the patient's Indigenous status during consultation but this information is rarely recorded as most pathology request forms do not include space for Indigenous status. Even when Indigenous status is recorded on pathology request forms, this information may not be transferred to the pathology report and then to the registries (Figure 3.6).

Where there is no Indigenous status information on the pathology report, data matching with subsequent reports, such as hospital admissions or death registrations, is undertaken to establish the Indigenous status of a person with cancer. Data matching is undertaken for most patients, as only a small number of cancer cases (for example, melanoma) rely on the pathology report alone for patient demographic information. In some cases where Indigenous status is missing on other sources, the information may be obtained through direct follow-up with the hospital or treating doctor.



Structural limitations of data set

An NMDS is not currently in place for cancer registries. Development of an NMDS may support improved Indigenous data collection and this is currently being considered.

Proportion of 'not stated'

When a report, usually a pathology report, is received with no Indigenous status information, the Indigenous status field on the record is entered either as 'missing, not stated/inadequately described' or 'non-Indigenous'. When a second record is received – usually from a hospital, radiation oncology department or from Births, Deaths and Marriages – this record will be matched to the information from the pathology report so that the indicated Indigenous status can overwrite the missing information. This process is understood to occur for all records where an additional source of information is received. However, Indigenous status information may not always be completed on the secondary source, resulting in missing Indigenous status information persisting in some records.

The percentage of 'not stated' Indigenous status in recorded incidences of cancers between 2003 and 2007 in the four jurisdictions reporting such information (Queensland, Western Australia, South Australia and the Northern Territory) was 11% (Table 3.9). The level of missing data was particularly high for prostate cancer and melanoma of the skin. This may be because these cancers are more likely to be treated outside the hospital setting where levels of Aboriginal and Torres Strait Islander identification are generally lower than within the hospital system (AIHW 2010a).

Table 3.9: Cancer incidence and mortality, by Indigenous status, selected states, 2003–07

Indigenous status	Incidence^(a)	Mortality^(b)
Indigenous	2,291	1,813
Non-Indigenous	168,554	134,303
'Not stated'	22,053	1,179
Total number	192,898	137,295
Percentage of 'not stated'	11.4	0.9

(a) Includes data from Queensland, Western Australia, South Australia and the Northern Territory.

(b) Includes data from New South Wales, Queensland, Western Australia, South Australia and the Northern Territory.

Source: AIHW 2012c.

The percentage of records with 'not stated' Indigenous status for cancer mortality was much lower than that for cancer incidence. Between 2003 and 2007 in the five jurisdictions reporting this information (New South Wales, Queensland, Western Australia, South Australia and the Northern Territory), the percentage of records in the 'not stated' category was 0.9% (Table 3.9).

Assessment specific to data set

All state and territory cancer registries receive Indigenous status information, but the quality of this information provided to the Australian Cancer Database varies considerably across jurisdictions. In some jurisdictions, data quality is considered insufficient for analysis by the state authorities providing the data and by the AIHW. Data quality is considered to be acceptable in four jurisdictions (Queensland, Western Australia, South Australia and the Northern Territory). As noted earlier, the basis of and criteria for most assessments of data quality in specific data sets are not known and may vary across jurisdictions and data sets. An assessment of the accuracy of Indigenous status data in the Northern Territory Cancer Registry found it was likely that Indigenous incidence rates were under-estimated by about 18% (Condon et al. 2004). An assessment of Indigenous data quality in all state and territory cancer registries suggested that actual cancer incidence in the Aboriginal and Torres Strait Islander population was under-estimated by 15-25% (Zhang et al. 2011).

National Diabetes Register

The National Diabetes Register, which commenced in 1999, is an incident-case register intended to record the number of new cases of insulin-treated diabetes in Australia. The register includes Australians with insulin-treated diabetes who:

- are diagnosed via the Australasian Paediatric Endocrine Group (comprising children aged under 15 at the time of diagnosis) or
- are registered with the National Diabetes Services Scheme.

The National Diabetes Services Scheme is an initiative of the Australian Government, administered by the non-government organisation Diabetes Australia. It delivers diabetes-related products at subsidised prices and provides information and support services to people with diabetes. People with both insulin-treated and non-insulin treated diabetes can access products through the scheme.

Availability of access points for the scheme is higher in non-remote areas and co-payments from users are required. In remote areas, Aboriginal Health Services provide an alternative source of some diabetes-related products. As these are not mediated by the National Diabetes Services Scheme, they are not in scope for collection of data in the National Diabetes Register.

Data provided to the register are not mandated by an NMDS. Arrangements between the Australian Government and Diabetes Australia support data requests, including Indigenous status, from contributing data sources. The Australasian Paediatric Endocrine Group also provides Indigenous data through its reporting processes. The National Diabetes Register itself does not have capacity to influence the collection and transmission of Indigenous status information. Likewise, jurisdictions do not generally have influence over the health providers who collect information that is used to create the National Diabetes Register.

Data flow

There are two data sources used to create and validate the National Diabetes Register: the Australasian Paediatric Endocrine Group and the National Diabetes Services Scheme (Figure 3.7).

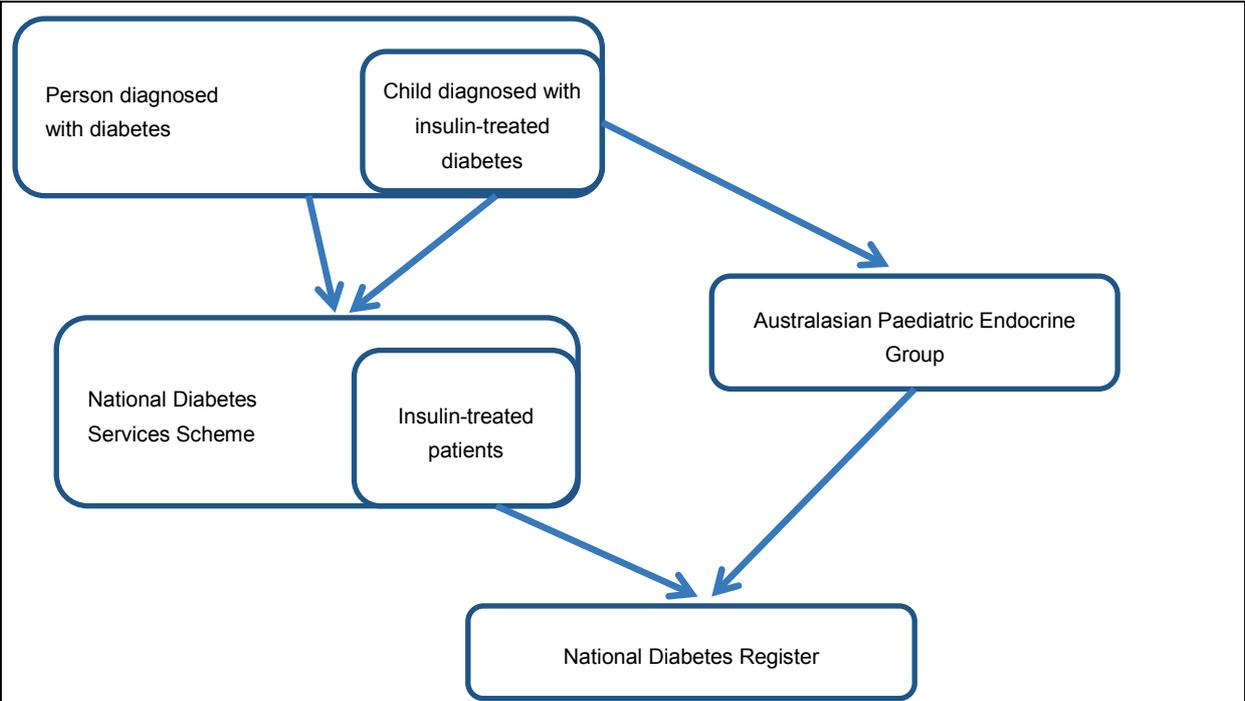


Figure 3.7: National Diabetes Register patient data flowchart

Note: There are disproportionate barriers to Aboriginal and Torres Strait Islander people accessing the National Diabetes Services Scheme because they are more likely to have non-insulin dependent diabetes.

Australasian Paediatric Endocrine Group

Details of individuals diagnosed are sent to Australasian Paediatric Endocrine Group data collections at the jurisdiction level, and then forwarded to the National Diabetes Register. These data are generated by medical professionals who diagnose diabetes in children.

National Diabetes Services Scheme

All people with diabetes requiring insulin treatment who are registered for the National Diabetes Services Scheme are included in the National Diabetes Register. As people with non-insulin treated diabetes can also access products from National Diabetes Services Scheme, the register includes only a subset of people accessing the scheme.

Indigenous status is collected via the National Diabetes Services Scheme registration form, which must be completed to access the scheme's services. The registration form, which includes the national standard Indigenous status question, requires a certification of diabetes diagnosis from a medical practitioner or certified diabetes educator. Individual form data, including Indigenous status where available, are transferred to the National Diabetes Services Scheme data base, which holds all registrant and sales data. This collection forms the basis of data provided to the AIHW, which creates the National Diabetes Register.

Indigenous data quality issues

Although the National Diabetes Register is not underpinned by an NMDS, it records Aboriginal and Torres Strait Islander status where provided by the National Diabetes Services Scheme and Australasian Paediatric Endocrine Group.

Structural limitations of data set

The National Diabetes Register has a number of structural limitations regarding the capture of diabetes within the Aboriginal and Torres Strait Islander population (Table 3.10). The register includes only people whose diabetes requires insulin treatment, and the majority of the diabetes burden in the Aboriginal and Torres Strait Islander population is not insulin-treated (AHMAC 2011). There are indications that Aboriginal and Torres Strait Islander people are less likely to be prescribed insulin than non-Indigenous people, even when clinical findings of poor glycaemic control indicate this is needed (McDermott et al. 2004).

Other limitations, such as the register's poor coverage of people in remote areas (especially Aboriginal and Torres Strait Islander people), and the consequent need to consider the inclusion of data from sources other than the National Diabetes Services Scheme and the Australasian Paediatric Endocrine Group, have previously been recognised (AIHW 2001:21). Overall, these limitations have a disproportionate impact on Aboriginal and Torres Strait Islander people. In its current form, the National Diabetes Register provides limited coverage of diabetes among the Aboriginal and Torres Strait Islander population. Efforts to improve the quality of Indigenous data are unlikely to have a substantive impact on reporting given these limitations.

Future data sources, such as enhancements to the ABS National Health Surveys and the implementation of National Key Performance Indicators for reporting which include a number of diabetes-relevant indicators, may offer improved data on diabetes in the Aboriginal and Torres Strait Islander population.

Table 3.10: Limitations of the National Diabetes Register in relation to Aboriginal and Torres Strait Islander people

Attribute	Implications for Aboriginal and Torres Strait Islander people
People with undiagnosed diabetes are not included in the National Diabetes Register.	Indications are that undiagnosed diabetes is higher in Aboriginal and Torres Strait Islander populations. Localised studies undertaken to investigate prevalence in Aboriginal and Torres Strait Islander communities have found diabetes rates of between 2–10 times that of the non-Indigenous Australian rate (AHMAC 2011).
People with diabetes not requiring insulin are not included in the National Diabetes Register.	Aboriginal and Torres Strait Islander people are 3.4 times as likely as non-Aboriginal and Torres Strait Islander people to have diabetes not treated with insulin (AHMAC 2011).
People with diabetes requiring insulin but who do not access products via the National Diabetes Services Scheme are not included in the National Diabetes Register.	Aboriginal and Torres Strait Islander people have less access to the National Diabetes Services Scheme than non-Indigenous people because: <ul style="list-style-type: none"> • National Diabetes Services Scheme outlets are concentrated in urban areas: a higher percentage of Aboriginal and Torres Strait Islander people live in regional and remote areas with reduced access to National Diabetes Services Scheme outlets. • Remote area Aboriginal Health Services participating in the section 100 scheme provide no-cost access to PBS items: not only medications (insulin) but also non-medication items (such as urine- and blood-test strips). This lessens the need for access to National Diabetes Services Scheme supply in these areas. Although all clients of remote area health services (not just Aboriginal and Torres Strait Islander people) can access these services, Aboriginal and Torres Strait Islander people are the primary recipients, and a higher percentage of Aboriginal and Torres Strait Islander people live in remote areas compared with non-Indigenous people. • The National Diabetes Services Scheme requires a co-payment from the patient. Any service that requires an up-front co-payment presents a financial barrier for low-income people: Aboriginal and Torres Strait Islander people are over-represented in low-income brackets.

Proportion of 'not stated'

Before 2005, National Diabetes Services Scheme processes recorded registrants as non-Indigenous if the response to the national standard Indigenous status question was not completed on the registration form. In early 2005, the National Diabetes Services Scheme database was amended to add 'inadequate/not stated' as an extra value to the Indigenous status variable and this was made the default in accordance with requirements of the National Health Data Dictionary (AIHW 2012f). According to *Insulin-treated diabetes in Australia 2000–2007* (AIHW 2011b), the proportion of records for 2005–07 with a 'not stated' Indigenous status in the National Diabetes Register was 8.7% (Table 3.11).

Table 3.11: National Diabetes Register registrants, Indigenous status, by states and territories^(a), 2005–07

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust ^(b)
Indigenous	401	51	727	229	79	26	11	124	1,648
Non-Indigenous	19,828	11,056	10,431	3,600	3,573	988	648	185	50,316
'Not stated'	1,000	2,708	423	235	228	262	83	10	4,954
Total number of new registrants	21,229	13,815	11,581	4,064	3,880	1,276	742	319	56,918
Percentage of 'not stated'	4.7	19.6	3.7	5.8	5.9	20.5	11.2	3.1	8.7

(a) State/territory of current residence.

(b) Totals include records where state or territory of current residence was unknown.

Source: AIHW 2011b.

Assessment specific to data set

Assessments of Indigenous data quality in the National Diabetes Register have not been undertaken. However, given the low coverage of Aboriginal and Torres Strait Islander people with diabetes in the register, such assessments are unlikely to have a substantive impact on reporting.

3.5 Summary of Indigenous data quality

The quality of the Indigenous data in some data sets is high, reflecting previous investments over the last decade. This was particularly the case for the two data collections in the hospitals sector – the National Hospital Morbidity Database and the National Perinatal Data Collection. In other data collections, as well as in some jurisdictions, there were a number of indicators that suggested data quality could be improved.

Structural limitations

The structural limitations of data sets are summarised in Table 3.12. As noted above, the National Diabetes Register has limited coverage of Aboriginal and Torres Strait Islanders with diabetes, and both the AODTS NMDS and the Community Mental Health Care NMDS have some scope limitations.

Table 3.12: Structural limitations of data sets summary

Data set	Structural limitations affecting data and policy relevance
National Hospital Morbidity Database	Nil
National Perinatal Data Collection	Nil
AODTS NMDS	Some scope limitations
Community Mental Health Care NMDS	Some scope limitations
Residential Mental Health Care NMDS	Nil
Australian Cancer Database	Nil (though no NMDS in place)
National Diabetes Register	Limited coverage

Proportion of ‘not stated’

The number of records where Indigenous status is recorded as ‘not stated’ is another broad indicator of data quality: ideally, this should be low. Available data on levels of ‘not stated’ records across the data sets indicate Indigenous data quality is highest in hospital separations and perinatal data sets, and lowest in community mental health-care services and the National Diabetes Register (Table 3.13). While ‘not stated’ responses are not recorded in hospitals in Western Australia (being recorded as ‘not Indigenous’ instead), levels of correct Indigenous identification are high in Western Australia (Table 3.13). The proportion of ‘not stated’ responses varies across jurisdictions, with Tasmania having relatively high proportions of this category across a number of data sets.

Table 3.13: Percentage of 'not stated' Indigenous status by data set

Data set	Year	NSW	Vic	Qld ^(a)	WA	SA	Tas	ACT	NT
National Hospital Morbidity database ^(b)	2010–11	◆	◆	◆	◆ ^(c)	◆	◆	◆	◆
National Perinatal Data Collection	2009	◆	◆	◆	n.a.	n.a.	n.a.	◆	◆
Alcohol and other drug treatment services NMDS	2009–10	◆	◇	◇	◆	◆	◇	◇	◆
National community mental health care database	2009–10	◇	◆	◆	◆	◇	◇	◇	◆
Residential mental health care database	2009–10	◆	◆	n.a.	n.p.	◆	◇	n.p.	◆
Cancer registries ^(d)	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
National Diabetes Register	2005–07	◆	◇	◆	◇	◇	◇	◇	◆

(a) Queensland does not report any government-operated residential mental health services.

(b) Hospital separations data for 'not stated' Indigenous status are for public hospitals only.

(c) Western Australian hospitals do not record 'not stated' responses.

(d) Cancer data are published at an aggregate level based on data from New South Wales (mortality rates only), Queensland, Western Australia, South Australia and the Northern Territory. Data are not available at jurisdiction level.

Note: The percentage of 'not stated' records is represented by the following symbols: 0–5% "◆", 5–10% "◇", more than 10% "◇".

Source: See tables 3.2, 3.4, 3.5, 3.6, 3.7, 3.8 and 3.11.

Assessments specific to data sets

Assessments of data quality of specific data sets are also an indicator of data quality, though the methodology used for these varies considerably from independent audits for hospital admissions to self-report from jurisdictions. Indigenous data quality was assessed as being poorest in the National Community Mental Health Care Database and the cancer registries. In relation to jurisdictions, available assessments suggest data quality was lowest in the Australian Capital Territory and Tasmania (Table 3.14).

Table 3.14: Assessments of Indigenous data quality specific to data sets

Data set	Assessed by	Applicable year	Data assessed to be of sufficient quality							
			NSW	Vic	Qld	WA	SA	Tas	ACT	NT
National Hospital Morbidity Database	AIHW	2011–12	yes	yes	yes	yes	yes	yes	yes	yes
National Perinatal Data Collection	NPESU	1991–2004	yes	yes	yes	yes	yes	no	no	yes
AODTS NMDS	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)
National Community Mental Health Care Database	States/ territories	2009–10	yes	yes	yes	n.a.	n.a.	yes	yes	(a)
National Residential Mental Health Care Database	States/ territories	2009–10	yes	yes	n.a.	yes	yes	no	yes	yes
Cancer registries	State/ territory registries	unknown	no	no	yes	yes	yes	no	no	yes
National Diabetes Register	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)	(a)

Note: 'Yes' denotes Indigenous data were assessed to be of sufficient quality to be reported; 'No' denotes the data were assessed to be not of sufficient quality to be reported. The methodology used for these assessments is unknown, and might differ across data collections. If an Indigenous data quality assessment has not been undertaken or has not been provided by the jurisdiction, it is marked as '(a)'

3.6 Discussion

The quality of Indigenous data and the extent to which the Guidelines have been implemented varied considerably across sectors and data sets, in part reflecting differences in the extent of historical, as well as more recent, data improvement activities.

Under Schedule F of the NIRA, state and territory governments have agreed to implement the Guidelines throughout the health system. In health sectors where service providers are not directly under the control of state and territory governments, however, jurisdictions have limited capacity to ensure implementation. Hence, alternative strategies to support implementation need to be considered.

In the public hospital sector, jurisdiction lines of control are relatively strong and there has been considerable investment in improving Indigenous data over the last decade. Reflecting this, Aboriginal and Torres Strait Islanders were correctly identified in over 88% of public hospital admissions. It should be noted that episodes of non-admitted patient care – for example, care provided in outpatient clinics and emergency departments – are not included in these data. The quality of Indigenous data collected in these settings is not known. Considerable improvements have been made to the National Perinatal Data Collection, including the capture of information on all Indigenous babies not just those born to Indigenous mothers.

The alcohol and other drug treatment services sector comprises a mix of both government and non-government services, with correspondingly varying levels of jurisdictional capacity to ensure that processes comply with the Guidelines. Some jurisdictions have undertaken training to improve data collection within the alcohol and other drug treatment services sector, but there is scope for more strategic implementation in this sector.

Mental health services reporting is aligned with residential and community-based service provision. There were small numbers of mental health contacts in the residential sector recorded where clients identified as Indigenous; however, data from community mental health-care services indicate comparatively high rates of service provision to Indigenous people. Recent additional investment in the sector has focused attention on data development and reporting. As these processes are embedded, the second phase of the project may provide opportunities to support Indigenous status quality.

Indigenous status recorded in cancer registries can come from a number of different sources including pathology reports, or through data matching with sources such as hospital admissions and death registrations. The inclusion of Indigenous status in pathology reports depends on good practice throughout the information supply chain, but most links in the chain are not subject to jurisdictional control. Ensuring pathology request forms include Indigenous status, and that the health providers who initiate pathology requests complete this field, is essential to this process. The work done by the project regarding e-pathology processes and in the general practice sector, as described in Chapter 5, contributes to addressing these issues.

In its current form, the National Diabetes Register provides limited coverage of diabetes in the Aboriginal and Torres Strait Islander population.

In relation to jurisdictions, the analyses indicated Indigenous data quality is poorest in the jurisdictions with smaller Indigenous populations.

4 Jurisdiction-based data improvement activities

By signing the NIRA in 2008, jurisdictions committed to a range of data quality improvement projects, including implementing the Guidelines throughout the health sector by December 2012.

The NIRA was to be progressed through cooperative work between all signatories to realise its objectives and commitments, including through developing Overarching Bilateral Indigenous Plans (OBIPs). Schedule F required all jurisdictions to develop a schedule to their OBIP to clearly articulate the concrete, objectively verifiable activities that jurisdictions would undertake against the Schedule F data quality projects in the period up to 30 June 2013. These primarily focus on the three Schedule F projects (referred to as actions 4, 5 and 6) for which jurisdictions are responsible. They comprise:

- adopting the national standard Indigenous status question and recording categories on data collection forms and information systems for key data sets (Action 4)
- improving procedures for collecting Indigenous status information in health and education data by training staff in key data collection positions about how and why to ask the national standard Indigenous status question and by raising awareness about its importance. This project included implementation by all jurisdictions of the Guidelines in the health sector, to be completed by December 2012 (Action 5)
- developing and implementing initiatives to raise Aboriginal and Torres Strait Islander people's awareness of the importance of identifying as Indigenous when accessing services, and to therefore raise the propensity for identification (Action 6).

These projects are closely related and all impact on implementing the Guidelines. Therefore, rather than focusing narrowly on Guidelines implementation as described in Action 5, this chapter includes information about all three projects. It summarises activities undertaken by jurisdictions since the NIRA was agreed in 2008, both at an overarching level and at the level of specific data sets. In doing so, this chapter provides an overview of the current status of jurisdictional progress towards their Schedule F data quality improvement projects. National level work undertaken during the project is detailed in Chapter 2.

4.1 New South Wales

The New South Wales OBIP was signed in February 2011. It contained a commitment to implement specific measures under the Agreed Data Quality Improvements (Schedule F of NIRA) and to set these out in a schedule attached to the OBIP within 6 months of its being agreed. The schedule, which was finalised in May 2011, sets out the action plan of Aboriginal Affairs New South Wales to address Schedule F requirements.

Schedule F overarching data quality improvement projects

Action 4 status

The New South Wales Schedule stipulated Action 4 would be addressed by an audit of New South Wales Government information systems. The audit was to survey government data management systems, determine current operational capacity to support best practice in

Indigenous self-identification, and ensure the consistent use and application of the national standard Indigenous status question. This process was intended to identify and address issues such as business rules where some online questions automatically defaulted to a 'no' response when a response to the question had not been recorded.

Other projects reported by New South Wales relevant to Action 4 requirements included the following.

- New South Wales Health revised processes in all data collection forms and information systems for key data sets to comply with the national standard Indigenous status question and recording categories.
- The revised Policy Directive Aboriginal and Torres Strait Islander Origin – Recording of Information of Patients and Clients was released in July 2012 and will be reviewed in 2017. The policy directive outlined the requirements for collecting and recording accurate information on the Aboriginal and Torres Strait Islander status of all clients of public health services in New South Wales, including all hospital and perinatal services. The policy directive is available at www.health.nsw.gov.au/policies/pd/2012/PD2012_042.html.
- The New South Wales Attorney-General and Justice Department advised that the Registry for Births, Deaths and Marriages had adopted the national standard Indigenous status question and recording categories on birth and death registration forms.

Action 5 status

The New South Wales Schedule stipulated Action 5 would be addressed by researching best practice and auditing agencies to check congruence between current practice and best practice through four phases, as described below.

Phase I: Communicate project.

1. To establish a list of agencies accessed by Aboriginal and Torres Strait Islander clients where the issue of identification is relevant, and to establish a consultation strategy for each agency and department.
2. Determine if a working group is necessary for consultation purposes.

Phase II: Research knowledge, attitudes and practices of front-line staff concerning Indigenous self-identification.

1. Create an evidence base of documented knowledge, attitudes and practices of government front-line staff concerning the Indigenous identification process undertaken with clients.
 - a. Review existing literature to identify the experiences of front-line staff when asking the national standard Indigenous status question across health, education and other key government agencies.
 - b. Review existing literature to identify the issues related to identification by Aboriginal and Torres Strait Islander clients accessing health, education and other key government agencies.
 - c. Provide gap analysis between Indigenous issues identified in literature and understanding of these issues by front-line staff in health, education and other key government agencies. Determine the gap between Indigenous issues from current research and whether the current Guidelines addresses these issues.

2. Determine if the existing literature, which is largely from health agencies, provides the government with sufficient insight into practices within all key New South Wales Government agencies.
 - a. Survey and analyse the current research and information available to the government about best practices guidelines and current practices in all government agencies and whether this information provides the government with sufficient information about all government agency activity in relation to training front-line staff.
 - b. If the existing literature does not provide sufficient insight into all agency activity, undertake research of front-line staff knowledge, attitudes and practices.

Phase III: Conduct an audit of New South Wales Government agencies by comparing current practice with best practice as determined by research and related literature.

Request agencies to provide information on current practice (including staff training material, frequency of staff training etc.) related to asking and explaining the national standard Indigenous status question.

This was to involve a survey of current training packages used for front-line staff including the use of generic 'cultural competency' training modules.

Phase IV: Develop report with recommendations for core curriculum to train front-line staff in Indigenous identification.

Combine research from Phase I and II to develop recommendations around core curriculum content.

Include recommendations about ongoing oversight of staff training and maintenance of best practice.

New South Wales reported the best practice project had been completed. The review of evidence concerning best practice for determining and recording the Indigenous status of New South Wales Government service agency clients had been undertaken. This review was largely informed by the Guidelines, but also considered literature beyond health to consider data collection informing all measures in the NIRA.

Between February 2011 and February 2012, Aboriginal Affairs New South Wales reviewed current practice within relevant agencies with reference to the available evidence for best practice. The New South Wales agencies involved included the Ministry of Health; the Department of Education and Communities; and the Registry of Births, Deaths and Marriages. The project included:

- a review of information resources and training packages used to train staff in key data collection positions
- a list of recommendations to support staff competencies
- the development of a checklist detailing 17 components of best practice against which government agencies could review their work.

Other projects reported by New South Wales Health relevant to Action 5 requirements included the following.

- *Respecting the difference: an Aboriginal cultural training framework for NSW health* (NSW Health 2011) – a mandatory cultural training framework for all staff working in health, which included information on collecting Indigenous status information. This training applied to all staff employed within the New South Wales health system including all local health districts, specialist health networks and the Ministry of Health.

- *Improved reporting of Aboriginal and Torres Strait Islander peoples on population datasets using record linkage* (NSW Health 2012), described the improvements in reporting achieved by using methods of record linkage, and explored the impact of any changes in reporting due to record linkage on a selection of indicators of health status and health service use.

In addition, New South Wales Health participated in the AIHW's 2011–12 AIHW Admitted Patients Data Quality Survey to assess the completeness of identification in the Admitted Patients Data Collection (AIHW 2013).

Action 6 status

The New South Wales Schedule stipulated Action 6 would be addressed by a project to increase the Indigenous community's propensity to identify, which would:

- document and understand the barriers to self-identification in Indigenous communities, work directly with communities to raise awareness about the importance of Indigenous identification in meeting the Closing the Gap targets for Indigenous Australians
- work with government agencies to broker solutions to overcome barriers to self-identification
- provide ongoing monitoring and evaluation of progress over time.

Two Senior Project Officers have been employed – one in Newcastle and the other in Dubbo – to undertake this project.

Other projects undertaken by New South Wales Health relevant to Action 6 requirements included the following.

- In response to community concerns, the New South Wales Ministerial Taskforce on Aboriginal Affairs considered, during 2012, a number of issues related to recognising cultural identity. The New South Wales Government will work with Aboriginal community organisations to determine what role government should take in this sphere. The final report will be informed by taskforce deliberations.
- Local Health Districts were supported in undertaking locally designed and implemented initiatives to raise awareness about the importance of identifying. The Office of Aboriginal Affairs contacted Local Health Districts directly and examples have been provided.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Efforts at the jurisdiction level to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated.

New South Wales Health advised it began the New South Wales Hospitals Identification Project in 2012.

This project aims to improve the cultural competency of services provided to Aboriginal and Torres Strait Islander people in New South Wales hospitals by:

- developing a framework based on continuing quality improvement processes
- implementing the framework

- assessing the effectiveness of the framework in improving cultural competency by tracking improvements in Aboriginal and Torres Strait Islander identification in routinely collected data sets.

Starting times for the project are randomly allocated to each participating hospital according to the design methodology of the evaluation (that is, multiple baseline, interrupted time series). While this project will be completed in mid-2014, data improvements will be ongoing. A report on outcomes will be provided when the project is completed. Data providing evidence of improved identification will be available via Health Statistics New South Wales on the New South Wales Health website.

National Perinatal Data Collection

New South Wales now collects the Indigenous status of the baby, as well as that of the mother.

Alcohol and other drug treatment services sector

New South Wales reported staff in the alcohol and other drug treatment services sector have been trained to ask the national standard Indigenous status question. The Guidelines have been distributed to assist in supporting the collection and coding of this question. Training regarding the collection of information via non-government organisations is provided by New South Wales Health Services when deploying the collection database. New South Wales Health examines data collected and follows up data quality issues (including Indigenous status) with Local Health Districts on an ongoing basis.

Mental health services sector

Training has been provided to staff in mental health services on how to ask the national standard Indigenous status question. The Guidelines have been distributed and discussions about Indigenous status have begun with the Mental Health Information Development Program, New South Wales government agencies responsible for aged services, and Disability and Home Care Managers at Local Health Districts. The New South Wales Ministry of Health examines data collected and follows up data quality issues. The Guidelines were discussed and distributed at the state-wide Mental Health Information Management Forum in September 2012.

4.2 Victoria

The Victorian OBIP, signed in November 2010, contained a schedule addressing data quality improvements. The OBIP Data Reform Group was formed following the May 2011 meeting of the OBIP Steering Committee and first met in September 2011. The Data Reform Group developed a forward work plan which was agreed in April 2012. The current focus of the group is creating a repository of metadata relating to government administered data sets with Indigenous-status identifiers. The aim of the project is improve the discovery of data and associated metadata for data sets containing Indigenous status identifiers.

Schedule F overarching data quality improvement projects

Victoria advised it has adopted the national standard Indigenous status question in all appropriate health data sets, comprising:

- hospital-based data sets (Victorian Admitted Episodes Data Set, Victorian Emergency Minimum Data Set and Elective Surgery Information System)

- Home and Community Care Minimum Data Set
- Victorian Perinatal Data Collection
- Victorian Population Health Survey
- Alcohol and Drug Information System
- Victorian Integrated Non-Admitted Health Data Set
- Notification of Infectious Diseases Data Collection.

The additional responses 'patient refused to answer' and 'question not able to be asked' may be recorded in some data sets. In these situations, such responses are included in the code 'not stated'. Where the provision of services would be compromised by collecting client details, Indigenous status is not collected. For example, alcohol and drug outreach services and needle exchanges do not request client data, as clients use these services only if personal information is not collected.

Victoria reported that other activities relevant to Action 4 requirements comprised the following.

- Improvements were made to the Home and Community Care National Minimum Data Set through the Strengthening Home and Community Care in Aboriginal communities Project. This project improved data on the Indigenous status of Home and Community Care clients. This entailed an analysis of Aboriginal Home and Community Care clients, begun in 2011, which mapped client demographics, service use and access to services.
- General Practice Victoria and the RACGP have encouraged member Divisions of General Practice (now Medicare Locals) to improve identification of Aboriginal and Torres Strait Islander patients/clients and to promote the use of Medicare-rebated Aboriginal and Torres Strait Islander health checks.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Efforts at the jurisdiction level to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated. Victoria advised the Improving Care for Aboriginal and Torres Strait Islander Patients Program emphasised the need for accurate recording of Indigenous status and encouraged staff training. Hospitals send data to the Victorian Admitted Episodes Data Set, the Victorian Emergency Minimum Data Set and the Elective Surgery Information System. While the program is focused on admitted patients, training of hospital staff through this program improves the quality of data in all hospital-based data sets. Training for collecting Aboriginal and Torres Strait Islander status is targeted at staff who collect patient data, in particular admissions clerks, ward clerks and midwives.

National Perinatal Data Collection

Victoria began collecting the Indigenous status of the baby in January 2009. Data from 2009 and 2010 are being analysed for the level of compliance and accuracy, and data quality analysis is continuing.

Mental health services sector

The Developmental Review of the Improving Care of Aboriginal and Torres Strait Islander Patients and the Koori Mental Health Liaison Officer programs in 2011 recommended increased cultural awareness training. Cultural awareness training for senior executives in the Victorian Department of Health, Mental Health and Drugs Division and in some Area Mental Health services has commenced. Training does not yet include Guidelines-relevant material but senior staff have been advised that they are accountable for accurate identification.

Australian Cancer Database

Victoria advised that a pilot project on collecting Indigenous status on pathology forms had been conducted in two phases.

- The first phase targeted 300 nurse Pap test providers who use the Victorian Cytology Service. The national standard Indigenous status question was included on the existing pathology request form and nurse Pap test providers were asked to collect this information between September and December 2008. Rather than issuing a completely new request form, a stamp with the national standard Indigenous status question and answers was added to the form. The form did not need to be approved by Medicare.
A training workshop was offered to nurse Pap test providers using Victorian Cytology Services. Key Aboriginal women in the community explained the importance of collecting this information and about 40 nurses attended. Analysis of the Pap tests taken by nurses during this period revealed that 5,753 Pap tests were conducted by 289 nurse Pap test providers, and of these 48% had Indigenous status recorded. About 33% of nurses did not record Indigenous identification, 13% always recorded Indigenous identification and 54% recorded this information some of the time. Of the nurses who attended the workshop and were surveyed, 93% went on to record Indigenous identification all of the time.
- The second phase, begun in 2011, aimed to increase the proportion of nurse Pap test providers collecting Indigenous status information and involved:
 - working more closely with the Aboriginal and Torres Strait Islander health sector and developing a communication strategy for this
 - inviting general practitioners onto the working group to engage the general practice sector
 - investigating medical software to determine its capacity to collect Indigenous status information.

Currently all Pap Screen nurses report to the Victorian Cytology Service, and forms include Indigenous status.

Next steps in implementation include:

- considering the feasibility of including Indigenous status on general practitioner reports
- amending the *Cancer Act 1958* (Vic.) to resolve legislative barriers to data collection
- implementing systems and processes for the Victorian Cervical Cytology Registry to receive and record the Indigenous status of women who participate in Victoria's Cervical Cancer Screening program
- extending education programs on asking women their Indigenous status from nurse Pap test providers to general practitioners and other health professionals

- conducting a data linkage project to establish a baseline on participation of Aboriginal and Torres Strait Islander women in cervical screening.

In 2012, work was undertaken to include Indigenous status in cervical screening data through including Indigenous status on pathology forms. This work was based on a pilot study which showed this change was effectively adopted by cervical screening nurses.

4.3 Queensland

The Queensland OBIP was signed in February 2011. It contained commitments to:

- establish a Data Quality Improvements Working Group by June 2011
- develop a Queensland Bilateral Action Plan for Improving Data Quality by July 2011
- establish a monitoring and reporting framework to enable the OBIP Board of Management to monitor progress of data quality improvements against agreed timelines.

The Queensland Data Quality Improvements Working Group has been established and supports the overall OBIP Board of Management. This Board, which was assigned responsibility for coordinating and reporting on the collective progress and data quality improvements across each COAG National Agreement and National Partnership, has met twice. The Bilateral Action Plan for Improving Data Quality has been developed and includes a monitoring and reporting framework to enable the overall OBIP management group to monitor progress of data quality improvements against agreed timelines. The Action Plan specifically refers to implementing the Guidelines in the health sector.

Schedule F overarching data quality improvement projects

Queensland Health advised a project was undertaken from 2009 to 2011 to ensure patient data collection forms in health service districts included the national standard Indigenous status question as set out in the Guidelines. The project included state-wide systems improvement, and the development of educational and promotional material and cultural resources.

Local projects were undertaken in all 17 health service districts throughout Queensland to understand and overcome local barriers to accurate identification. The training has been incorporated into the Aboriginal and Torres Strait Islander Cultural Practice Program and has been provided to administrative and front-line staff.

In February 2012, the Deputy Director General Performance and Accountability Division approved the following two policy documents:

- Queensland Health Policy: Collection of Indigenous Status in Health Data Sets
- Implementation Standards for Collection of Indigenous Status in Health Data Sets.

These documents are available on the Queensland Health website.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Efforts at the jurisdiction level to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction

level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated. Queensland Health advised the progress of improving the collection of Indigenous status in public hospitals is being monitored. Two key performance indicators have been developed and are included in performance reporting for Health District Managers. These indicators are:

- the estimated level of completion of Indigenous status in Queensland acute public hospitals, compiled annually in order to monitor progress in improving Indigenous status recording in public hospitals
- the number and proportion of admitted patient records with Indigenous status marked as 'not stated'.

The indicators will be updated annually.

In addition, Queensland Health elected to add the key performance indicator of 'not stated' to its Decision Support System. Hospital chief executive officers and executives within Queensland Health use the Decision Support System to assist in monitoring and quality control of key performance indicators. The 'not stated' indicator is displayed on the Decision Support System, at state and district levels, and preliminary data are available for the current month, as it is refreshed daily. 'Not stated' is monitored frequently by districts; therefore, reporting this key performance indicator on the Decision Support System ensures the most up-to-date data are available to decision makers.

National Perinatal Data Collection

Queensland advised the Indigenous status of both mother and baby have been added to the patient's record. A specific poster and brochure on identifying as Indigenous were developed for birthing areas and distributed to services throughout Queensland. As a consequence of these improvements, Queensland's data quality, timeliness and breadth of information collected were found to be of a high standard (Donnolley & Li 2012). Queensland was one of only two jurisdictions that achieved full compliance with all required data elements.

Alcohol and other drug treatment services

The Queensland community-based alcohol and other drug treatment services use a computer-based system to record their clients, and Indigenous status is a mandatory field. Categories for response codes are consistent with the Guidelines.

Mental health sector services

Queensland advised a Consumer Demographic Information form used in the mental health sector (which allowed for Indigenous status to be selected) was provided to clients to complete. The Systems and Collections team send validations to the mental health information managers each month to follow up, to assist with data integrity.

Australian Cancer Database

Queensland advised there have been no new strategies to improve Indigenous status data for the Queensland Cervical Screening Program and Pap Smear Registry as there is no national mechanism for collection of Aboriginal and Torres Strait Islander status on pathology forms. The Queensland Cervical Screening Program and Pap Smear Registry are unable to require pathology laboratories to record Indigenous status.

4.4 Western Australia

The Western Australian OBIP was signed in September 2012, and Schedule I to the OBIP sets out the data quality improvement processes to be undertaken in that jurisdiction. These include:

- establishing the Data Quality Improvement Working Group to the OBIP Governance Committee
- developing the Western Australian Action Plan for Improving Data Quality
- establishing a monitoring and reporting framework to enable the OBIP Governance Committee to monitor progress of data quality improvements against agreed timelines.

Since the recent finalisation of the OBIP, Western Australia has proceeded to establish agreed mechanisms to progress Schedule F of the NIRA.

Schedule F overarching data quality improvement projects

Western Australia advised it is implementing the Guidelines in health and education data sets. This implementation will be supported by the collaborative project 'Getting our Story Right'. This project will develop best practice guidelines for deriving Indigenous status when dealing with linked data where identification may be inconsistent across multiple linked data sets. During 2012, the ABS, the Department of Health Western Australia and the Telethon Institute for Child Health Research worked to develop different methods for deriving Indigenous status from multiple data sources. The study used the resources of the Western Australian Data Linkage System to assess Indigenous identification as recorded across more than 10 data sources and over more than 40 years. Various methods of deriving Indigenous status were explored and the impact of these methods was examined against a selection of health and educational outcomes such as mortality rates, hospitalisation rates, and reading and writing scores.

Improvements specific to data collections

National Perinatal Data Collection

In relation to the Midwives Data Collection System, Western Australia reported:

- a new data item has been added to the collection requesting Indigenous status of the infant/s, adopting standard data items provided by the NMDS (began January 2012)
- the current data item in the collection requesting 'ethnic origin' of the mother has been amended so Indigenous status can be reported according to the NMDS definitions (to be implemented in January 2013)
- a collaborative project to develop best practice has been undertaken.

Western Australia reported in response to the requirement for recording of Indigenous status of the baby that, from 1 January 2013, it has adopted the national standard Indigenous status question and recording categories on data collection forms and information systems for the Midwives Notification System.

Staff in key data collection positions associated with the Midwives Notification System will be provided with training about how and why to ask the national standard Indigenous status question. The training will raise awareness about the importance of the new question as part of this implementation process.

Alcohol and other drug treatment services

Western Australia reported Aboriginal and Torres Strait Islander identification is included on Episode Registration forms. The database in use, SIMS, automatically generates a list of records which do not include required NMDS data. Services using the SIMS database are encouraged to check error reports regularly and correct any records listed.

Training is provided to services using the SIMS database. Training includes discussion about the purpose and importance of the NMDS, how to collect data when working with clients, and how to enter the items into the SIMS database. The Guidelines have not been used as part of this training.

Australian Cancer Database

Western Australia advised the Western Australian Cervical Cancer Prevention Program and the Department of Health Western Australia worked to include Indigenous status on pathology forms so that this information could be collected in the state's cervical screening register. Initial stages aimed to have all public hospital laboratories in the state collecting and recording Indigenous status information. In 2008, of the nine laboratories contributing data, four public hospital laboratories (PathWest) in Western Australia modified their systems to enable the collection of Indigenous status.

In late 2008, PathWest introduced the national standard Indigenous status question on some of its pathology request forms. This was partly as a result of work undertaken by the Western Australian Cervical Cancer Prevention Program. The change was also prompted by a formal request by the Communicable Disease Centre to include Indigenous status as part of the daily notification of positive results by electronic download from the PathWest laboratory information system to the Communicable Disease Centre database.

Since 2009, the Western Australian Cervical Cancer Prevention Program has worked with PathWest to modify the question format and the recording categories (that is, separate categories for Aboriginal and/or Torres Strait Islander origin) so they align with the national standard. Work is proceeding to ensure the national standard Indigenous status question is used consistently on all forms. Once this has been achieved with public hospital laboratories, it will be presented to private laboratories for incorporation.

The Western Australian Cancer Registry also contributed to developing the Pathology Business Case. Data items have been included in exports from pathology laboratories to the registry. This will enable the transfer of Indigenous data to the registry when request forms are modified to allow the information to be entered when the initiators of the requests complete this information.

4.5 South Australia

The South Australian OBIP, signed in January 2010, included a schedule addressing agreed data quality improvement areas.

Schedule F overarching data quality improvement projects

South Australia advised its OBIP is aligned to the South Australian Implementation Plans for:

- the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes
- the National Partnership Agreement on Indigenous Early Childhood Development.

An OBIP Working Group monitors and oversees matters of priority and progress relating to the OBIP and the COAG Building Blocks. Furthermore, the recommendations contained in the South Australia Health *Aboriginal Health Care Plan (2010–16)* have been incorporated into the South Australian OBIP.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Efforts at the jurisdiction level to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated. South Australia advised the national standard Indigenous status question and recording categories have been adopted in systems and forms related to admitted patients data.

South Australia reported that the ABS has been funded through South Australia Health's COAG investment to support Indigenous data improvements. The project, undertaken in 2010, developed a training package informed by the Guidelines for staff who manage data and/or perform data entry about:

- the importance of collecting Indigenous identifier information
- the correct way of asking the national standard Indigenous status question and recording the response
- strategies for dealing with special circumstances, such as seeking the Indigenous status of children and patients/clients who are unconscious.

The training targeted front-line staff working across hospital sites in metropolitan Adelaide and regional communities, as well as various mainstream primary care services throughout South Australia.

The first state-wide training program was concluded in late 2011. Over 430 front-line staff attended training sessions held in 40 locations spread through the state, including hospital staff from emergency departments, outpatient clinics, inpatient wards and admission offices; and administrative staff from primary health-care services (for example community health and community mental health centres). The second state-wide training program began in late 2012.

Having identified the need for improvements in the way the health sector describes and measures primary health-care activities, South Australia established an Out-of-Hospital Services Minimum Data Set. This data set includes the National Data Dictionary definition of Indigenous status, representing the agreed core elements collected for describing out-of-hospital care services in South Australia. This data set is collated in a central repository which comprises data from community health, community mental health, public dental services, drug and alcohol services, child and family services, district nursing services and palliative care. The new repository enables data to be produced on the use of these services by Aboriginal and Torres Strait Islander people.

A case mix payment system is in operation which applies a 30% loading to Aboriginal and Torres Strait Islander hospital separations. This provides an incentive for improved Aboriginal and Torres Strait Islander identification.

National Perinatal Data Collection

South Australia reported the national standard Indigenous status question and recording categories had been adopted in systems and forms related to perinatal data. In addition, Indigenous status information in the National Perinatal Data Collection was cross-checked with hospital morbidity data and data from the South Australian Registry of Births, Deaths and Marriages.

Alcohol and other drug treatment services

South Australia advised the national standard Indigenous status question and recording categories have been adopted in systems and forms related to data collection for alcohol and other drug treatment services. Drug and Alcohol Services South Australia is a state-wide health service, which is responsible for addressing alcohol, tobacco, pharmaceutical and illicit drug issues across the state. South Australia has developed a training package and provided training sessions informed by the Guidelines. The second round of these training sessions started in the second half of 2012 and targeted front-line staff working in Drug and Alcohol Services South Australia.

Mental health sector services

The national standard Indigenous status question and recording categories have been adopted in systems and forms related to the two mental health data collections. The training package discussed above also targeted front-line staff working in community mental health services. South Australia had only one residential facility at the time the first round of training was undertaken. The mental health sector was targeted in the second round of training.

Australian Cancer Database

South Australia advised that South Australia Health and SA Pathology had completed the first part of a project entitled 'Aboriginal Identification Requirements in Pathology Systems'. SA Pathology is the sole provider of pathology in the public hospital sector and a major provider to the private general practitioner and specialist market. The initial emphasis was to add Aboriginal and Torres Strait Islander status information requirements to pathology forms. This involved extensive consultation with SA Pathology providers and other jurisdictional providers. This enabled information sharing and the identification of lessons learnt from other jurisdictions that had implemented similar projects. This resulted in information requirements for Aboriginal and Torres Strait Islander status being added to pathology forms as well as to metropolitan-based hospital systems. While pathology forms have been addressed, the emphasis now is to enable collection of the Indigenous Identifier into an IT solution, as this is a considerable gap that needs attention. The redevelopment of SA Pathology's Laboratory Information System, which aims to be completed by June 2014, is a key IT solution that will integrate Aboriginal and Torres Strait Islander status information, and enable the use of collected data.

Further project work is being undertaken to review the downstream impacts on affected registries, which include input and advice from the ACCHSs, general practice clinics, Medicare Locals and Well Women's Cervical Screening programs. South Australia Health is determining how best to ensure systems provide consistent and continuous transfer of Aboriginal and Torres Strait Islander status data across South Australia Health. Additional systems training will be required to support staff in collecting information.

A full report on the outcomes of the project 'Aboriginal Identification Requirements in Pathology Systems' will become available in 2014. This will take into account the further project work on registries and the time required to redevelop SA Pathology's Laboratory Information System.

The second round of Indigenous identifier training sessions started in the second half of 2012 and specifically targeted staff working in SA Pathology.

4.6 Tasmania

The Tasmanian OBIP was finalised in March 2011. It included agreements to:

- develop a joint Action Plan for prioritising and improving data quality, and setting out the details of data improvements, activities and timelines
- establish a Data Quality Improvement Subcommittee, responsible for driving, monitoring and reporting to the OBIP Governance Committee on improvements to the performance indicator data required to measure and monitor Closing the Gap progress in Tasmania.

Schedule F overarching data quality improvement projects

Tasmania advised that the Data Quality Improvement Subcommittee has been established and implementation of the Guidelines is progressing under these arrangements. This work is part of the draft Joint Action Plan.

Tasmania reported that its Department of Health and Human Services undertook a major review of Aboriginal data collection practices in 2003–04. In 2005, the department mandated use of the national standard Indigenous status question and recording categories and implemented improvements. This included funding an Aboriginal Liaison Officer in each hospital network and providing awareness training (including the asking of the national standard Indigenous status question). This training targeted departmental staff involved in service provision and data collection.

The department will review these measures and the extent of compliance. The Guidelines will be used as a checklist for this work.

4.7 Australian Capital Territory

The Australian Capital Territory OBIP was signed in March 2012. It included an agreement to implement specific measures under the Agreed Data Quality Improvements (Schedule F of NIRA) and to set these out in a schedule attached to the OBIP within 6 months of its being agreed.

The Australian Capital Territory advised this schedule is currently under development and, when finalised, will also take account of data quality improvements underway since 2009.

Schedule F overarching data quality improvement projects

The Australian Capital Territory advised the national standard Indigenous status question is used in Australian Capital Territory Health Directorate data collection and information systems. This directorate is responsible for delivering health care and health-related services

in the Australian Capital Territory through public hospitals as well as community health, mental health and population health programs.

The Identification Information and Awareness project undertaken by the Australian Capital Territory included a community awareness component. AIHW posters and brochures providing information on the importance of and reasons for identifying as being of Aboriginal and/or Torres Strait Islander origin were placed at key entry points to directorate services. Information was also provided at main entry points to Calvary Hospital and in major clinical areas.

The Australian Capital Territory Medicare Local Closing the Gap program works with general practitioners and their patients to improve Aboriginal and Torres Strait Islander identification in data collections. Improving data in primary health care will contribute to a more comprehensive picture of Aboriginal and Torres Strait Islander access to health services and outcomes in the Australian Capital Territory.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Jurisdiction-level efforts to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated. The Australian Capital Territory Health Directorate participated in the AIHW's Aboriginal and Torres Strait Islander identification in hospitals data audit. The Australian Capital Territory correction factor will be used in reporting on the NIRA, the National Healthcare Agreement, and will be applied as an adjustment factor to published hospital separations data at the jurisdiction level.

National Perinatal Data Collection

The Australian Capital Territory advised the Identification Information and Awareness Project commenced with maternity units at the Canberra Hospital and Calvary Health Care Australian Capital Territory. Following endorsement by the Executive Council in October 2011, it was being implemented across all areas of the directorate.

In December 2011, the Deputy Director-General, Canberra Hospital and Health Services issued a communiqué to all relevant clerical staff, managers and executive directors on asking the national standard Indigenous status question, alerting them to available training. Aboriginal and Torres Strait Islander identification has also been added to the agenda of the Administration and Clerical Excellence Committee. The Aboriginal and Torres Strait Islander Health Unit was available to assist with in-services on asking the national standard Indigenous status question.

Australian Cancer Database

The Australian Capital Territory advised its directorate has added an Aboriginal and Torres Strait Islander identifier as a mandatory field on Australian Capital Territory pathology forms. Improving identification on pathology forms has flow-on effects in improving identification in other data sets – for example, the Australian Capital Territory Cancer Registry, Communicable Disease Register and hospital data.

4.8 Northern Territory

The Northern Territory OBIP was signed in 2010. It included an agreement to populate a schedule with specific activities to improve data quality in the Northern Territory, to be finalised as soon as possible during 2010. The Northern Territory advised this schedule has not been finalised to date. However, the actions in relation to Indigenous data are essentially complete, with the proviso that initiatives regarding community awareness of the national standard Indigenous status question and staff training are ongoing. The ABS has offered to assist with this training.

Schedule F overarching data quality improvement projects

The Northern Territory has implemented the national standard Indigenous status question, including in CareSys and Primary Care Information System, the medical information systems collecting and managing health data in the territory. Indigenous identification procedures used in recording categories on data collection forms and information systems for key data sets in the Northern Territory conform with national standard approaches. Indigenous status is also collected through the My eHealth Record (the rebranded Shared Electronic Health Record), which also assists with evaluating the effectiveness of the service.

Improvements specific to data collections

Admitted patient care data

Jurisdictions contribute information for collection at the national level; for example, through the National Hospital Morbidity Database. Jurisdiction level efforts to improve Indigenous data quality in their admitted patient care data may impact only at jurisdiction level or may also affect contributions from which national collections, such as the National Hospital Morbidity Database, are generated. The Northern Territory advised the procedures used in asking the national standard Indigenous status question conform to the ABS approach. Demographic details of clients are held within central data sets and are used by most departmental data sets. The Northern Territory has developed a Hospital Registration Number, with which clients can be tracked across the territory, from hospitals to community health services. Northern Territory public hospital pathology reports have a Hospital Registration Number which can be linked to demographic variables including Indigenous status.

The recording of Indigenous status in Northern Territory public hospitals has been recognised as being of high quality (Foley et al. 2012). At each visit to any Northern Territory hospital, the patient/guardian is asked whether or not they identified themselves or their child as Aboriginal or Torres Strait Islander or both Aboriginal and Torres Strait Islander. The information is then entered into the Client Master Index module in the Hospital Information System (known as the CareSys system). The hospital attendance/visits and patient demographic details for each attendance are extracted by the Data Warehouse for reporting purposes.

The Northern Territory has conducted data quality surveys of demographic information in client record data on three occasions. All three survey reports have been published and are available in both hard copy and on the Northern Territory Health website. These surveys involved validation of client records by face-to-face interviews with hospital admitted patients. The quality of Indigenous status data in each of the three surveys was 94% (1997), 97% (2008) and 98% (2011). For example, the audit undertaken in 2011 by the Health

Department found 'the high level of accuracy recorded in previous Northern Territory surveys had been maintained. The level of accuracy for each data item in 2011 was sex (99%), Indigenous status (98%), country of birth (97%), district of residence (91%), year of birth (89%) and date of birth (83%)' (Foley et al. 2012).

National Perinatal Data Collection

For newborn babies, the mother's Indigenous status is asked directly of the mother. The mother's Indigenous status is then entered into the Client Master Index module in the Hospital Information System. The newborn Indigenous status will then default with the mother's Indigenous status in the Maternity module in the Hospital Information System. Northern Territory provides data to the National Perinatal Data Collection on an annual basis, including Indigenous status of the baby and smoking during pregnancy.

Australian Cancer Database

The Northern Territory noted pathology request forms include a field for Indigenous status but this is rarely completed. As noted above, the Hospital Registration Number developed by the Northern Territory enables all clients to be tracked throughout the territory, from hospitals to community health services. Northern Territory public hospital pathology reports use the Hospital Registration Number and this can be linked to Indigenous status against the patient data in the source system. The Northern Territory also advised the new *Cancer (Registration) Act 2009* extended existing requirements for cancer notifications from pathology results and death certificates to include diagnosis during hospital admission. There are also new powers to oblige medical practitioners to complete missing information on notifications. Indigenous status is validated against the Department of Health electronic client information system.

4.9 Discussion

As required by the NIRA, all jurisdictions have developed OBIPs which commit to data improvement activities, and all are engaged in various data improvement activities relevant to Guidelines implementation (Table 4.1). Gaining a cohesive national picture of the status of Guidelines implementation, however, has proved challenging for a number of reasons.

- Firstly, Indigenous data quality improvement efforts predate the NIRA and the requirements of Schedule F. Existing strategies and programs may not readily fit within new reporting mechanisms, despite their relevance and importance.
- Secondly, connections between commitments included in the NIRA Schedule F and concrete project delivery are sometimes difficult to trace. For example, while all OBIPs recognise the importance of data quality improvements, only the Tasmanian agreement includes specific reference to the NIRA requirement to implement the Guidelines by December 2012. Some other jurisdictions have specific data quality schedules or plans, while some have moved forward on data quality work through different means.
- Thirdly, while responsibilities for COAG processes and national level agreements are generally situated within central agencies, responsibilities for health data improvements rest with health agencies, Indigenous-specific agencies or both.
- Finally, while some jurisdictional activities align directly with particular data quality improvement projects under Schedule F of the NIRA, others are less specific and are relevant to more than one project. This partly reflects intrinsic interrelationships between actions 4, 5 and 6, but also means that overall progress reporting is complicated.

A closer alignment of on-the-ground data quality improvement projects with the high-level commitment to Guidelines implementation may address these issues. Such strengthened alignments would assist in developing a more robust national picture of the progress of Guidelines implementation and in identifying sectors and data sets in need of additional support.

It is, however, clear that a range of activities have occurred in all jurisdictions, ranging from training of front-line staff and review of existing policies, to aligning data collection processes with the Guidelines. Given the challenges of ensuring and maintaining Guidelines-compliant processes, there is scope for further improvements through more systematised and holistic approaches. For example, additional gains may be supported by providing periodic refresher courses (as well as introductory training), ensuring software (as well as paper forms) is Guidelines-compliant, and moving towards accreditation processes that prioritise collection of Indigenous status. Greater coordination, including information sharing, between responsible agencies across jurisdictions may enhance these implementation processes.

Table 4.1: Summary of OBIP status and implementation, all jurisdictions

Jurisdiction	OBIP signed	OBIP data quality commitments	Status of OBIP data quality commitments
New South Wales	February 2011	Develop Schedule of Agreed Data Quality Improvements	Completed
Victoria	November 2010	Establish Data Quality Improvements Subcommittee	Completed
Queensland	February 2011	Establish Data Quality Improvements Working Group by June 2011	Completed
		Develop Queensland Bilateral Action Plan for Improving Data Quality by July 2011	Completed
		Establish a monitoring and reporting framework to enable the OBIP Board of Management to monitor progress of data quality improvements against agreed timelines	Completed
Western Australia	September 2012	Establish Data Quality Improvement Working Group to OBIP Governance Committee	Begun October 2012
		Develop Western Australian Action Plan for Improving Data Quality	Begun October 2012
		Establish monitoring and reporting framework to enable the OBIP Governance Committee to monitor progress of data quality improvements against agreed timelines	Begun October 2012
South Australia	January 2010	OBIP Working Group in train	Underway
Tasmania	March 2011	Develop joint Action Plan for prioritising and improving data quality, setting out the details of data improvements, activities and timelines	Underway
		Establish a Data Quality Improvement Subcommittee	Completed
Australian Capital Territory	March 2012	Implement specific measures under the Agreed Data Quality Improvements (Schedule F of NIRA); set these out in a schedule attached to the OBIP within 6 months of its being agreed	Schedule under development
Northern Territory	2010	Populate a schedule with specific activities to improve data quality in the Northern Territory as soon as possible during 2010	Schedule under development

5 General practice sector

The general practice sector plays a key role in primary health care for Aboriginal and Torres Strait Islander people. Improving the collection of Indigenous status of all general practice patients is needed to improve both the uptake of health interventions specific to Aboriginal and Torres Strait Islander people mediated by general practice and the health data to which general practitioners contribute.

The National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes sets out the responsibilities of both the Australian Government and state and territory governments in delivering the COAG Closing the Gap commitment in health. The Australian Government's contribution to this National Partnership Agreement – the Indigenous Chronic Disease Package – included measures focused on the general practice sector and their patients/clients. Some measures expanded the range of health interventions specific to Aboriginal and Torres Strait Islander people mediated by general practice, while others strengthened support for change management at the practice level.

Specific assessments of general practice identification processes have not been undertaken since the Indigenous Chronic Disease Package measures and other relevant reforms were introduced. While implementation of some reforms is encouraging, previous studies and current indications suggest that identification processes could be further improved.

The general practice sector was identified as a key sector for support in Phase 1 of this project due to the importance of Indigenous identification for both service delivery and data collection. Given the focus on this sector, a detailed report of the work undertaken has been published separately (AIHW forthcoming 2013b).

5.1 Context and recent developments

While various national level policy levers can be used to influence the general practice sector, it is not controlled by government. Hence, changes such as adopting the Guidelines cannot be centrally mandated. Most general practitioners work in private rooms under corporate or individual ownership. The general practice sector also has a diverse range of stakeholders, both government and non-government, who play a role in improved Indigenous identification. These factors mean that general practice is a challenging sector in which to improve Indigenous identification. The involvement of sector-specific stakeholders, such as professional bodies and colleges, is needed to undertake change management processes.

Identification in the general practice sector is especially important for service delivery as well as for data collection purposes. The sector provides access to the greatest range of health interventions specific to Aboriginal and Torres Strait Islander people.

Health interventions specific to Aboriginal and Torres Strait Islander people mediated by general practitioners

There is a range of health interventions available specifically for Aboriginal and Torres Strait Islander people which are designed to address the higher morbidity and mortality levels in this population. The majority of these interventions are mediated by general practitioners; general practitioners may either provide them directly or refer patients/clients to other providers (Box 5.1).

Box 5.1: Main health interventions specific to Aboriginal and Torres Strait Islander people mediated by general practitioners

- MBS-related health checks for all ages (MBS item 715)
- Follow-up services after a health check: provided by a practice nurse or a registered Aboriginal Health Worker (MBS item 10987) or by allied health professionals (MBS items 81300–81360)
- Different recommended immunisation schedules for Aboriginal and Torres Strait Islander adults and for Aboriginal and Torres Strait Islander children in some areas
- Listings on the PBS for Aboriginal and Torres Strait Islander people only
- Cheaper medicines through the PBS co-payment measure
- Support via Aboriginal and Torres Strait Islander-specific Care Coordinators

Note: measures not mediated by general practitioners (e.g. community based healthy lifestyle workers and tobacco action workers) are not included here.

There is scope to increase the coverage of many health interventions specific Aboriginal and Torres Strait Islander people mediated by general practitioners (AIHW forthcoming 2013b). While there are no recent studies specifically on identification practices, previous studies identified that lack of routine identification processes that were Guidelines-compliant was a major impediment to optimal uptake of the interventions (Kehoe & Lovett 2008; Norris et al. 2004; Riley et al. 2004). While specific investigations have not been repeated since implementation of recent reforms, broad data on general practice activity indicate little change in the proportion of patient encounters recorded as Aboriginal and or Torres Strait Islander. This proportion was 1.2 in 2002–03 and 1.6 in 2011–12 but the variation between the beginning and end of this period was not statistically significant (Britt et al. 2012).

General practice input to data collections

General practitioners contribute to a number of data collections:

- **Cancer and Pap smear registries** – Pathology request forms, many of which are completed by general practitioners, are an important source of data for both cancer and Pap smear registries. In many instances, Indigenous status is not recorded on these forms; and even when the form includes an Indigenous status item, this field is often not completed by the requesting clinician.
- **Notifiable communicable disease register** – While data sources for this register vary across jurisdictions, the general practice sector, via pathology requests, plays a pivotal role in improving Indigenous status coverage.
- **Mortality data sets** – Medical practitioners, including general practitioners, complete Medical Certificates of Cause of Death and these are a major contributor to national deaths data.

Improvements in Indigenous identification in the general practice sector are needed in order to improve quality and completeness of Aboriginal and Torres Strait Islander data in all these collections. Data generation will be enhanced by embedding Indigenous data collection processes in the clinical or financial core business of practice management and health services to patients.

Related supporting measures

A number of measures have been introduced either through the Indigenous Chronic Disease Package or by the RACGP to improve processes to collect Indigenous status of all patients/clients in general practice. A new Practice Incentive Program (the Indigenous Health Incentive) and new workforces to support improved access to care in Medicare Locals were both initiated under the Indigenous Chronic Disease Package. The RACGP also:

- strengthened general practice accreditation requirements for routine identification processes
- issued a supporting statement to help general practice meet those requirements
- developed online cultural awareness training for general practice staff with Australian Government funding.

5.2 Improving identification in general practice

Available data, which predate recent reforms, indicate that only a minority of mainstream general practices have routine identification processes for all patients (Kehoe 2007; Kehoe & Lovett 2008; Norris et al. 2004; Riley et al. 2004). The barriers to improved Indigenous identification, which have been described by these and other investigations (IIICDRP 2004; Kelaher et al. 2010), impede both access to health interventions specific to Aboriginal and Torres Strait Islander people mediated by general practice and contributions made by general practice to national data collection. These barriers, relevant reforms made to date and next steps are outlined in Table 5.1.

As highlighted in Table 5.1, some challenges have been at least partly addressed by recent developments, while others require further work. The complexity of the sector, including the wide range of relevant stakeholders, can be a barrier to full realisation of the potential impact of all initiatives at the national level. Better coordination at the national level would assist to integrate existing reforms and address outstanding barriers.

Recognising these issues, the AIHW convened national workshops in December 2011 and November 2012 to bring stakeholders together. The workshops promoted better communication across the range of government and non-government agencies involved to share best practice and leverage existing activities. The full report of the workshops and other work undertaken in this sector will be available in 2013 (AIHW forthcoming 2013b).

Table 5.1: Indigenous identification in general practice: status and next steps

Pre-2008 status	Current status	Start date	Next steps
No nationally funded positions or focus on Indigenous health in Divisions of General Practice, now Medicare Locals	Medicare Locals funded for 86 Aboriginal and Torres Strait Islander Outreach Workers, and 86 Indigenous Health Project Officers	Outreach workers: 2010 Project officers: 2009	Maximise potential and coordination of new positions
No financial support/incentives for practice change	Practice Incentive Program Indigenous Health Initiative (PIP IHI) started	From May 2010	Monitor effects of the PIP IHI participation: refine as needed
General practice accreditation standards did not mandate routine identification	Routine Aboriginal and Torres Strait Islander identification mandated in accreditation standards	Fourth (4 th) edition, from December 2011; will be gradually implemented over time as practices seek renewal of accreditation	Monitor uptake and impact
No requirement for practices to undertake cultural training	Introductory cultural awareness training developed by the RACGP and required for participation in the PIP IHI	From 2011	Need to build on basic introductory material
Diversity of clinical information systems: no standardisation of identification or links to service delivery required	Opportunity for improvements to be made via e-health agenda	Personally controlled Electronic Health Record (PCEHR) registration open to all Australians from July 2012	Need to optimise Aboriginal and Torres Strait Islander identification for data collection and service delivery in e-health; improvements needed to clinical information systems
Pathology processes generally do not include Indigenous status, so data collection via pathology processes undermined	Pathology Business Case prepared by the AIHW; currently e-pathology processes do not mandate inclusion of Indigenous status	Some improvements made at jurisdiction level; no national requirements for Indigenous status collection in paper or e-processes	AIHW to liaise with relevant agencies to ensure Indigenous status is identified in e-pathology processes; need to monitor progress
Lack of national coordination	AIHW contribution via convening national workshops with relevant stakeholders	n.a.	Requires recognition
Lack of single point of reference for all Indigenous-specific health interventions mediated by general practice	Some work done through the Indigenous Chronic Disease Package but incomplete	2010	The AIHW will seek to address via national web resource for information sharing
Lack of awareness-raising for Aboriginal and Torres Strait Islander people	A component of Indigenous Outreach Workers' role	2010	Requires additional work
Lack of awareness-raising for non-Indigenous people	Role not allocated or funded	n.a.	Requires recognition

5.3 Improving identification in e-health systems

National reforms are underway to develop and progress national e-health systems in Australia, as mandated and funded by COAG.

Personally Controlled Electronic Health Record

The Australian Government approved the development of the Personally Controlled Electronic Health Record (PCEHR) system in 2010, and allocated funding to build key national components of this system by July 2012. The 2012–13 Budget announced further

funding over 2 years to operate the system's national infrastructure. Since July 2012, consumers can register for an e-health record.

The project conducted a detailed analysis of the PCEHR and e-pathology programs to investigate the extent to which these initiatives support improved Indigenous status collection and transmission. The investigation indicated Indigenous status had not been included in a standardised way in PCEHR clinical documents (Table 5.2).

Table 5.2: Features of currently proposed PCEHR clinical documents

Clinical document name	Who provides to PCEHR	NEHTA data specification template available	Indigenous status required	Release date
Shared health summaries	Author of the information only	Yes Embedded in the PCEHR; not a document to be uploaded	Yes	June 2012
Event summaries	Author of the information only	Yes Embedded in the PCEHR; not a document to be uploaded	Yes	June 2012
Discharge summaries	Author of the information only	Yes	No	June 2012
Specialist letters	Author of the information only	Yes	No	June 2012
Referrals	Author of the information only	Yes	Yes	June 2012
Prescribing and Dispensing Information	Author of the information only	No; not finalised	Template not finalised	June 2013
Pathology Result Reports	Author of the information only	No; not required as already using Australian Standards for messaging	Optional field in the current HL7 messaging standard; not a required element	June 2013

Note: 'Required' in this case means that a value must be entered. If a value is not entered, the document will not be able to be loaded to the PCEHR, and will return to the health-care provider for a corrected version.

The second release of the PCEHR system in November 2012 allowed consumers to record their Indigenous status when they register for PCHER. This information is sought from registrants directly and is available for accessing providers to view. The information is collected according to the National Health Data Dictionary standard codes. This development will need to be monitored to investigate its capacity to increase access to specific health services for Aboriginal and Torres Strait Islander people and improve Indigenous status collection in health data.

Pathology processes

Currently, most pathology request forms do not include an Indigenous status identifier. This means Indigenous identification data cannot flow from medical practitioners and hospitals to pathology laboratories and from pathology laboratories to the state and territory health registers. This is a major limitation to improving Indigenous identification in communicable disease and cervical screening data, which largely rely on pathology to obtain patient information. It is also a limitation to improving Aboriginal and Torres Strait Islander identification in cancer data.

Improving Indigenous identification by including Aboriginal and Torres Strait Islander identification on pathology forms has been a priority area on NAGATSIHID's work plan for

a number of years; the AIHW was tasked with investigating these issues under Schedule F of NIRA (Appendix A). The AIHW's business case for including Indigenous status on pathology request forms, to be published in 2013, recommended both longer term work at the national level and shorter term efforts at the jurisdictional level to improve data transfer via pathology processes.

E-pathology program

Indigenous status is currently an optional, not mandatory, requirement in the Australian Standard for health messaging (AS 4700.2). Changing this requirement to a mandatory element would not only begin to improve Indigenous status data in pathology-generated data, but also would support other developments in the general practice sector to drive improved identification processes at the point of care.

As health-related work increasingly moves to electronic format, new opportunities will become available to improve Indigenous data collection. The analysis of Indigenous status in e-health processes has informed discussions with both NEHTA and DoHA in raising awareness of these issues and their broader context. Subsequent to these processes, in June 2012 the AIHW provided advice to both agencies regarding the need for improvements in Indigenous status information collection and transfer. The AIHW also briefed both NAGATSIHID and NATSIHSC on these issues to ensure common understanding of the current situation regarding Indigenous status in e-health.

5.4 Discussion

Identification of Indigenous status in the general practice sector is an ongoing challenge. In recent times, both the Australian Government and non-government organisations have implemented relevant reforms with the potential to drive improved practices. The complexity of the sector means that greater coordination is needed to ensure the potential of these reforms is fully realised.

There are a range of government and non-government stakeholders with interests in improving Indigenous identification in the general practice sector. Although the AIHW is one such stakeholder, it has limited capacity to directly influence this process. In responding to the range of issues raised by the general practice workshop and other work in the sector, the AIHW will undertake the following activities as part of phases 2 and 3 of the evaluation and support project:

- advocate for changes to improve identification in general practice software and e-health through liaison with DoHA and NEHTA and relevant national committees
- provide targeted support to the general practice sector as project resources allow
- promote national coordination through liaison with relevant stakeholders.

6 Conclusions and next steps

6.1 Summary of current state of play

By participating in the NIRA, jurisdictions agreed to implement the Guidelines throughout the health sector. However, their capacity to do so varies across different health settings. Guidelines implementation processes and data improvement outcomes vary across the health sectors and data sets in scope for the project, as summarised below.

- In the hospital sector, Indigenous data have been verified by the under-identification assessment project. This demonstrated that 6 jurisdictions – together covering 96% of the Aboriginal and Torres Strait Islander population – achieved 80% or higher of Aboriginal and Torres Strait Islander identification. Improvements to data collections, such as the addition of Indigenous status of the baby to the National Perinatal Data Collection, are continuing.
- Alcohol and other drug treatment services are a mix of both government and non-government services. Some jurisdictions have undertaken data improvement activities in the sector and distributed the Guidelines, but there is scope for more work on implementation in the sector.
- The mental health sector has recently undergone major reforms which have implications for data collection. National support for Guidelines implementation will be considered during the next phase of the project as these changes are embedded. Given the links between mental and physical health, accurate data on service provision in this sector is important to achieving COAG commitments to Closing the Gap between the life expectancies of Indigenous and non-Indigenous people.
- Records of Indigenous status in cancer registries are contingent on good practices at a number of points in the information supply chain to ensure these data are transferred from patient to pathology laboratories to registers. Improvements in these registries largely depend on achieving the long-standing goal of requiring Indigenous status data in pathology request forms. This work can be supported by national-level efforts to ensure Indigenous status is included as a mandatory element in e-pathology processes.
- In its current form, the National Diabetes Register has limited coverage of diabetes in the Aboriginal and Torres Strait Islander population.
- The general practice sector is complex with a range of diverse stakeholders. This makes improving identification difficult, though this is critical for both improved service delivery and data collection. Both the Australian Government and non-government organisations have implemented relevant reforms with the potential to improve the collection of Aboriginal and Torres Strait Islander status for all patients. More work is needed to address barriers to implementation. This would involve strengthening national coordination of effort, addressing practice software barriers and improving pathology reporting systems.

Table 6.1: Stage of Guidelines implementation in sectors/data sets, and implications for the project

Sectors and data sets	Current status and issues	Project response
Hospitals sector (National Hospital Morbidity Database, National Perinatal Data Collection)	Data are generally of high quality. An audit of data quality was undertaken in 2012 and another audit is likely in 2 years.	Additional support not required
Alcohol and Other Drug Treatment Services National Minimum Data Set	Mix of government and non-government providers. Services specific to Aboriginal and Torres Strait Islander people report separately via the OSR.	Support will be considered in later stages
Mental Health Care services sector (National Residential and Community Care databases)	Recent reforms to data collections nearing completion. Services specific to Aboriginal and Torres Strait Islander people report separately via the OSR.	Support will be considered in later stages
National Diabetes Register	Substantive structural limitations in relation to diabetes in the Aboriginal and Torres Strait Islander population.	Limited coverage of data collection: no support required at this stage
Cancer registries	State and territory registries have limited influence on data quality. Upstream work in the general practice sector and pathology messaging needed to improve identification.	Targeted support in pathology in phases 1 and 2
General practice sector	Challenging but important sector due to: <ul style="list-style-type: none"> • the importance of identification for service delivery • the large number of stakeholders and complexity of sector • the ongoing implementation of a range of reforms since 2008 • the opportunities for improvement offered by e-health reforms. 	Targeted support in phases 1 and 2

6.2 Areas for further work

This report completes Phase 1 of the support and evaluation of the *National best practice guidelines for collecting Indigenous data in health data sets*. Its findings indicate that further implementation of the Guidelines would be facilitated by the following.

- **Recognition of non-jurisdiction stakeholders** as essential partners in the implementation of the Guidelines, as the capacity of jurisdictions to implement the Guidelines varies across health sectors. For example, liaison with provider organisations and their representative bodies would assist in identifying and addressing barriers to implementation at the provider–patient/client level.
- **Supporting jurisdictional implementation processes:** for example, by strengthening national reporting mechanisms through more detailed description of Guidelines implementation activities. This would assist in determining overall progress of Guidelines implementation and in highlighting emerging issues.
- **Provision of targeted support by the AIHW to assist in systematic implementation of the Guidelines.** Efforts to implement the Guidelines, whether by jurisdictions or other bodies, would be assisted by tailored support in selected areas to embed processes that comply with the Guidelines.
- **Fostering national coordination in the general practice sector.** For example, enhanced coordination across programs for services specific to Aboriginal and Torres Strait Islander people would build momentum for improvements. Likewise, closer liaison between service delivery, data collection and e-health programs would optimise the collection and use of Indigenous data.

Next steps in the support and evaluation project

The AIHW will continue to monitor Guidelines implementation and data quality and to identify barriers to and facilitators for improved data collection. This effort will incorporate:

- continuing to collect information from jurisdictions on data improvement activities, including Guidelines implementation
- monitoring improvements in the quality of Indigenous data in data collections in scope for the project
- identifying barriers and facilitators.

The project will also provide targeted support for implementation in selected sectors and jurisdictions. Support activities could be tailored to the needs of jurisdictions with smaller Indigenous populations, in order to assist with Guidelines implementation issues in those contexts.

In addition, the project could develop supporting material to assist both government and non-government agencies undertake structured processes for to implement the Guidelines. This may include a resource such as a checklist both to self-audit factors affecting readiness for Guidelines implementation, and to support additional systematic and multi-layered implementation activities where needed.

More work is needed to improve Indigenous identification in cancer registries through a focus on upstream points in the information supply chain, including general practitioners and pathology laboratories.

Further implementation of the Guidelines in the general practice sector would be assisted through more centralised coordination and an integrated strategy to address under-identification. The AIHW has committed to undertaking further work in this sector as resources allow. Such efforts would include:

- advocating for changes to general practice software and e-health through liaison with DoHA and NEHTA and relevant national committees
- providing support targeted to the needs of the general practice sector and promoting national coordination of effort through holding an annual forum.

The distribution of the Guidelines and supporting material through the NIDISC will continue throughout the project. A final report on the project will be published at the end of 2014.

Appendix A: National Indigenous Reform Agreement, Schedule F

Agreed data quality improvements

F1 In the period up to 30 June 2013, the Commonwealth and States and Territories will undertake the following actions to improve the performance indicator data required under this Agreement.

F2 A schedule to each jurisdiction's Overarching Bilateral Indigenous Plan will clearly articulate the activities that jurisdiction will undertake, in the period up to 30 June 2013, against each action for which that jurisdiction is responsible. Plans will need to include concrete, objectively verifiable activities.

F3 Actions will be implemented consistent with the Closing the Data Gaps workplans.

Agreed data quality improvements	Agreed action Responsible jurisdiction/agency
The ABS will implement improvements to Census Indigenous enumeration procedures to improve the quality of the Census count of Indigenous Australians.	Commonwealth Government/Australian Bureau of Statistics
The ABS will expand the scope of the Census Post Enumeration Survey to include very remote areas and discrete Indigenous communities.	Commonwealth Government/Australian Bureau of Statistics
The ABS and AIHW will lead analysis of the level of Indigenous identification in key data sets, including a baseline report and ongoing five-yearly studies to monitor identification levels over time.	<p>The ABS and AIHW will work in partnership with all jurisdictions to assess the extent to which the Indigenous population is accurately identified in key data sets and to develop the evidence base on what strategies are likely to positively impact on the Indigenous population's propensity to identify.</p> <p>The ABS and AIHW will establish governance arrangements to oversee the development of the data quality studies which will include members from appropriate data committees, (such as NAGATSIHID), the States and Territories, and other stakeholders.</p> <p>The ABS and AIHW will be responsible for the sampling strategies, methodology, and assessment of the level of under-identification in each data set.</p> <p>Timelines: A baseline report will be published in 2010 with recommendations on how to adjust each data set for more accurate data and on strategies to continue improving identification of Indigenous status through an ongoing program of work.</p>
All jurisdictions will adopt the standard ABS Indigenous status question and recording categories on data collection forms and information systems for key data sets.	All jurisdictions.

Agreed data quality improvements	Agreed action Responsible jurisdiction/agency
<p>All jurisdictions will improve procedures for collecting Indigenous status information in health and education data by training staff in key data collection positions about how and why to ask the Indigenous status question and to raise awareness about its importance.</p>	<p>All jurisdictions</p> <p>There will likely be a need for staff in key data collection positions (such as hospital admissions staff and funeral directors) to undergo training which will need to be coordinated by the States and Territories.</p> <p>The scale and form of such a program will be for each State and Territory to determine. Information system changes may also be needed in some jurisdictions.</p> <p>Timelines: Implementation by all jurisdictions of the AIHW's Best Practice Guidelines in the health sector is to be completed by December 2012. After 12 months, it is proposed that the AIHW and ABS would undertake periodic evaluations of how the Guidelines have been implemented in the jurisdictions across the various health data collections. The AIHW and ABS would need to work closely with the states and territories to undertake these evaluations.</p>
<p>All jurisdictions will develop and implement initiatives to raise the Indigenous community's awareness about the importance of identifying as Indigenous when accessing services and to therefore raise the propensity for identification.</p>	<p>All jurisdictions.</p> <p>All jurisdictions will develop and implement a program to raise the Indigenous community's awareness about the importance of identifying as Indigenous when accessing services, with the aim of raising the Indigenous community's propensity to identify. The program could include a variety of measures at the local, regional and/or state level and could build on existing engagement and consultation mechanisms. The scale and form of such a program will be for each State and Territory to determine.</p>
<p>The ABS will link Census records with death registration records to assess under identification of Indigenous mortality for use in the compilation of Indigenous life expectancy estimates.</p>	<p>The ABS will establish protocols with States and Territories for linking deaths data to Census records.</p>
<p>The AIHW and ABS will lead, in partnership with the States and Territories, the development of national best practice guidelines for data linkage and an examination of current and planned data linkage work (Commonwealth and State and Territory) relevant to Indigenous identification.</p>	<p>The ABS and AIHW will work in partnership with all jurisdictions to develop and implement national best practice guidelines for linking data relating to Indigenous people. The guidelines for linking Indigenous data will cover linkage methods and protocols, privacy protocols, quality standards, and procedures.</p> <p>Involvement of jurisdictions, and other stakeholders, in the governance arrangements for overseeing the work will help to ensure a consistent and informed program of data linkage work is carried out across Australia. Input from the Steering Committee will be sought in all phases of the proposed work including the development of agreed procedures, methods and protocols. This will help identify the need for any ongoing data linkage work.</p> <p>This project will need to take into account existing and planned data linkage work across all jurisdictions (including the methods currently being used, and the results from any completed work). This will help inform the development of national guidelines.</p> <p>In addition, the AIHW will build on its Indigenous Mortality Data Linkage Project. Currently, the project is a one-off data linkage process. This work will be continued with the aim of improving the estimates of Indigenous mortality and life expectancy on an ongoing basis. This would require jurisdictions to be prepared to supply relevant data, and to consider streamlining of data access protocols.</p> <p>Timelines: It is estimated that best practice guidelines and a report on current and planned data linkage work relevant to Indigenous identification could be produced by December 2010.</p>

Agreed data quality improvements	Agreed action Responsible jurisdiction/agency
<p>The AIHW will lead the development of an enhanced Perinatal National Minimum Data Set collection to collect data in relation to smoking during pregnancy, child and maternal health and the Indigenous status of the baby.</p>	<p>The AIHW will work with all jurisdictions.</p> <p>Expanding the Perinatal National Minimum Data Set will involve assessing what is currently collected by States and Territories in regards to smoking during pregnancy, child and maternal health and the Indigenous status of the baby; and developing nationally consistent data elements. Once the data elements are included in the PNMDs their collection would be mandatory for all jurisdictions.</p> <p>This process would involve consultation with all jurisdictions, including a stakeholder workshop, drafting of data elements, and approval through the National Health Information Agreement governance process on the data elements. Once the proposed enhanced data elements have been drafted, jurisdictions will need to provide an assessment of the changes required to their processes and information systems.</p> <p>Changes for jurisdictions will be variable depending on what jurisdictions currently collect.</p> <p>Timelines: It is estimated that development of the indicators would take two years, with implementation for national collection in approximately three years. However this timeline will need to be flexible to address any jurisdiction-specific complexities.</p>
<p>The AIHW will, with stakeholders, review jurisdictional practices for collecting pathology information and develop a business case for the implementation of a nationally consistent pathology data collection, including Indigenous status.</p>	<p>The AIHW will work with all jurisdictions to develop a business case with options and costs for a national pathology data collection.</p> <p>The AIHW will undertake a review of the national data collections which largely rely on information recorded on pathology forms to obtain information on Indigenous status.</p> <p>To oversee the review, a steering committee needs to be established with key stakeholders and representatives from all jurisdictions. The review will involve investigating the pathology testing and notification processes in each State/Territory and the affected stakeholders (such as pathology labs, general practitioners/specialists, hospitals, software vendors/developers); with a view to understand potential implementation issues for consideration in the business case.</p> <p>Timelines: It is estimated that a Business Case which considers the costs and benefits of implementing a national pathology collection could be completed by June 2010, and would be considered by the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data and the National E-Health Information principle Committee.</p>
<p>The Commonwealth Department of Health and Ageing, in partnership with State and Territory health departments and in collaboration with AIHW, will develop national Key Performance Indicators for Indigenous-specific primary health care services: A coordinated data collection is also planned.</p>	<p>All jurisdictions, led by the Commonwealth Government.</p> <p>A national Key Performance Indicator (KPI) framework will be developed through consultations with jurisdictions beginning July 2009. Approval of data elements will be sought through the National Health Information Agreement governance process.</p> <p>It is intended that a web based reporting system will be progressively developed and provided to Indigenous primary health care services to collect data associated with the national KPI framework.</p> <p>Financial support to facilitate the web based reporting system for OATSIH-funded Indigenous primary health care services will begin in 2009–10.</p> <p>While it is intended that all Indigenous-specific primary health care services could use the web based system for annual reporting from 2011–12, this is subject to agreement from States and Territories to meet an agreed share of the cost of implementing changes for State and Territory-funded services.</p>

References

- ABS & AIHW (Australian Bureau of Statistics & Australian Institute of Health and Welfare) 2008. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2008. AIHW Cat. no. AIHW 21. Canberra: ABS.
- AHMAC (Australian Health Ministers' Advisory Council) 2011. Aboriginal and Torres Strait Islander Health Performance Framework Report 2010. Canberra: AHMAC.
- AHMAC 2012. Aboriginal and Torres Strait Islander Health Performance Framework Report 2011. Canberra:AHMAC.
- AIHW 2001. National Diabetes Register, statistical profile, December 2000. Diabetes series no. 2. Cat. no. CVD 18. Canberra: AIHW.
- AIHW 2010a. Australian hospital statistics report 2008–09. Health services series no. 34. Cat. no. HSE 84. Canberra: AIHW.
- AIHW 2010b. National best practice guidelines for collecting Indigenous status in health data sets. Cat. no. IHW 29. Canberra: AIHW.
- AIHW 2010c. Indigenous identification in hospital separations data – quality report. Health Services Series no. 35. Cat. no. HSE 85. Canberra: AIHW.
- AIHW 2011a. Australia's mothers and babies 2009. Perinatal statistics series no. 25. Cat. no. PER 52. Canberra: AIHW.
- AIHW 2011b. Insulin-treated diabetes in Australia 2000–07. Diabetes series no. 11. Cat. no. CVD 45. Canberra: AIHW.
- AIWH 2012a. Aboriginal and Torres Strait Islander health services report, 2010–11: OATSIH services reporting-key results. Cat. no. IHW 79. Canberra: AIHW.
- AIHW 2012b. Australian hospital statistics 2010–11. Health services series no. 43. Cat. no. HSE 117. Canberra: AIHW.
- AIHW 2012c. Cancer in Australia 2010: an overview. Cancer series no. 60. Cat. no. CAN 56. Canberra: AIHW.
- AIHW 2012d. Mapping paper on Indigenous status in e-health. Unpublished.
- AIHW 2012e. Mental health services in Australia. Canberra:AIHW
<mhsa.aihw.gov.au/home>.
- AIHW 2012f. National Health Data Dictionary. Version 16. Cat. no. HWI 119. Canberra: AIHW.
- AIHW 2012g. Alcohol and other drug treatment services in Australia 2010–11: report on the National Minimum Data Set. Drug treatment series no. 18. Cat. no. HSE 128. Canberra: AIHW.
- AIHW 2013. Indigenous identification in hospital separations data- Quality report. Cat. no. IHW 90. Canberra: AIHW.
- AIHW, forthcoming 2013a. Final business case for the inclusion of Indigenous status on pathology request forms as a way to improve Indigenous identification in national cancer, communicable disease and cervical screening registers. Canberra: AIHW.

- AIHW, forthcoming 2013b. Taking the next steps: Identification of Aboriginal and Torres Strait Islander status in general practice. Canberra: AIHW.
- AIHW & ABS 2012. National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people. Cat. no. IHW 74. Canberra: AIHW.
- Britt H, Miller GC, Charles J, Henderson J, Valenti L, Harrison C, Zhang C, Chamber T, Pollack AJ, Bayram C, O'Halloran J, Pan Y 2012. A decade of Australian general practice activity 2002–03 to 2011–12. General practice series no. 32. Sydney: Sydney University Press.
- COAG (Council of Australian Governments) 2011. National Indigenous Reform Agreement. Viewed February 2013. <www.coag.gov.au/closing_the_gap_in_indigenous_disadvantage>.
- Condon JR, Zhao Y, Armstrong B & Barnes A 2004. Northern Territory Cancer Registry: data quality, 1981-2001. Darwin: Northern Territory Department of Health and Community Services.
- Donnolley N & Li Z 2012. Perinatal National Minimum Data Set compliance evaluation 2006 to 2009. Perinatal statistics series no. 26. Cat. no. PER 54. Sydney: AIHW National Perinatal Epidemiology and Statistics Unit.
- Duckett S & Willcox S 2011. The Australian health care system. Melbourne: Oxford University Press.
- Foley M, Zhao Y & Condon J 2012. Demographic data quality assessment for Northern Territory public hospitals 2011. Darwin: Department of Health.
- IIICDRP (Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee) 2004. Improving Indigenous identification in communicable disease reporting systems. Public Health Information Development Unit, The University of Adelaide, South Australia.
- Kehoe H 2007. A call for action: better Aboriginal and Torres Strait Islander health through better GP identification. Canberra: ACT Division of General Practice.
- Kehoe H & Lovett R 2008. Aboriginal and Torres Strait Islander health assessments: barriers to improving uptake. *Australian Family Physician* 37:1033–38.
- Kelagher M, Parry A, Day S, Paradies Y, Lawlor J & Solomon L 2010. Improving the identification of Aboriginal and Torres Strait Islander people in mainstream general practice. Melbourne: The Lowitja Institute.
- Kelagher M, Parry A, Day S, Paradies Y, Lawlor J & Solomon L 2010. Improving the identification of Aboriginal and Torres Strait Islander people in mainstream general practice. Melbourne: The Lowitja Institute.
- Leeds K, Gourley M, Laws P, Zhang J, Al-Yaman F & Sullivan EA 2007. Indigenous mothers and their babies, Australia 2001–2004. Perinatal statistics series no. 19. Cat. no. PER 38. Canberra: AIHW.
- Li Z, McNally L, Hilder L & Sullivan EA 2011. Australia's mothers and babies 2009. Perinatal statistics series no. 25. Cat. no. PER 52. Sydney: AIHW National Perinatal Epidemiology and Statistics Unit.
- McDermott R, Tulip F & Schmidt B 2004. Diabetes care in remote northern Australian Indigenous communities. *Medical Journal of Australia* 180:512-516.

NHFA & AHHA (National Heart Foundation of Australia and Australian Healthcare and Hospitals Association) 2010. Better hospital care for Aboriginal and Torres Strait Islander people experiencing heart attack.

Norris T, McIntyre P & Menzies R 2004. 'Role of GPs in adult Indigenous immunisation – a national survey'. Paper presented at Proceedings of the 9th National Immunisation/1st PHAA Asia Pacific Vaccine Preventable Diseases Conference. Immunisation at the crossroads: challenges and strategies, Cairns, 19–20 August 2004.

NSW Health 2011. Respecting the difference: an Aboriginal cultural training framework for NSW Health. Doc. no. PD2011_069. Sydney: NSW Health.

NSW Health 2012. Improved reporting of Aboriginal and Torres Strait Islander peoples on population datasets in New South Wales using record linkage – a feasibility study. Sydney: NSW Health.

Riley I, Williams G & Shannon C 2004. Needs analysis of immunisation for Aboriginal and Torres Strait Islander people in Queensland. Final report. Brisbane: Centre for Indigenous Health, University of Queensland.

Turner T, Misso M, Harris C & Green S 2008. Development of evidence-based clinical practice guidelines (CPGs): comparing approaches. *Implementation Science*, 3:45.

Zhang X, Condon JR, Rumbold AR, Cunningham J & Roder DM 2011. Estimating cancer incidence in Indigenous Australians. *Australian and New Zealand Journal of Public Health* 35(5): 477-85.

List of tables

Table 2.1:	Overview of the support and evaluation project	8
Table 2.2:	Health sectors and data sets in project scope (shaded), and responsibilities for implementation of the Guidelines.....	10
Table 2.3:	Number of requests for NIDISC resources by organisation type, Apr. 2010–Dec. 2012	12
Table 2.4:	NIDISC resources distributed, Apr. 2010–Dec. 2012	12
Table 2.5:	Liaison with relevant national committees	13
Table 2.6:	Liaison with data custodians	14
Table 3.1:	Sectors and data sets in scope	17
Table 3.2:	Number of hospital separations, by Indigenous status, 2010–11.....	20
Table 3.3:	Completeness and correction factors at jurisdiction level	21
Table 3.4:	Women who gave birth, Indigenous status, states and territories, 2009.....	24
Table 3.5:	Alcohol and other drug treatment closed episodes, Indigenous status, states and territories, 2009–10.....	27
Table 3.6:	Community mental-health-care service contacts, by Indigenous status and state and territory, 2009–10.....	30
Table 3.7:	Residential mental health-care episodes, by Indigenous status and state and territory, 2009–10.....	32
Table 3.8:	Summary of information regarding Indigenous status in jurisdictional cancer registries.....	34
Table 3.9:	Cancer incidence and mortality, by Indigenous status, selected states, 2003–07.....	36
Table 3.10:	Limitations of the National Diabetes Register in relation to Aboriginal and Torres Strait Islander people.....	39
Table 3.11:	National Diabetes Register registrants, Indigenous status, by states and territories, 2005–07	39
Table 3.12:	Structural limitations of data sets summary	40
Table 3.13:	Percentage of ‘not stated’ Indigenous status by data set.....	41
Table 3.14:	Assessments of Indigenous data quality specific to data sets	41
Table 4.1:	Summary of OBIP status and implementation, all jurisdictions.....	61
Table 5.1:	Indigenous identification in general practice: status and next steps.....	65
Table 5.2:	Features of currently proposed PCEHR clinical documents	66
Table 6.1:	Stage of Guidelines implementation in sectors/ data sets, and implications for the project	69

List of figures

- Figure 1.1: Aboriginal and Torres Strait Islander identification and COAG commitments4
- Figure 3.1: Data flow to National Hospital Morbidity Database.....19
- Figure 3.2: National Perinatal Data Collection data flowchart23
- Figure 3.3: Alcohol and other drug treatment data flowchart26
- Figure 3.4: Mental health data collection flowchart29
- Figure 3.5: Points at which Indigenous status may be collected or transferred to
cancer registries.....33
- Figure 3.6: Information transfer from pathology requests to cancer registries35
- Figure 3.7: National Diabetes Register patient data flowchart37

This report describes Phase 1 of the support and evaluation project of the AIHW's *National best practice guidelines for collecting Indigenous status in health data sets* (the Guidelines). It found that the processes for, and status of, Guidelines implementation varied across data sets and health sectors in scope for this project. The report identifies barriers to and facilitators for implementation across the various health sectors, and recommends how implementation processes could be improved.