Improving identification of Aboriginal and Torres Strait Islander peoples in health data

Working paper

August 2009

Australian Institute of Health and Welfare
Canberra

Contents

Acknowledgments

The main authors of this report are Fadwa Al-Yaman and Michelle Gourley. We wish to acknowledge the assistance of a number of staff within the Australian Institute of Health and Welfare (AIHW), Social and Indigenous Group for their contribution to these guidelines, in particular Mieke Van Doeland, Denise Arnold, Deanne Pagnini and Michelle Wallis. Special thanks are extended to Jim Pearce.

Thanks are also due to the Steering Committee who gave advice on the development of these guidelines which comprised Andrew Webster, Kerryn Pholi and Dan Black (ABS), Joy Eshpeter and Brendan Gibson (OATSIH), Paul Basso (Statistical Information Management Committee), Steve Larkin and Graham Henderson (National Advisory Group on Health Information and Data), Barbara Whitlock (Department of Health and Ageing), Nicki Tafe (Medicare Australia), Steve Morris and Ian McHenry (Australian Division of General Practice), Jenny Reath (Royal Australian College of General Practice) and Yin Paradies and Noel Hayman (National Health and Medical Research Council). Further we would like to thank the members of NAGATSIHID who provided comments on these guidelines.

Special thanks are extended to the State and Territory Health Departments who provided comments on these guidelines and assisted in the organisation of focus group sessions which helped to inform these guidelines. In particular, thanks are extended to Mary Sullivan and John Willis (Victorian Department of Human Services), Peter Brandt and Maria Kokkoris (NSW Department of Health), Paul Basso (South Australian Department of Health), Susan Colwell (ACT Health), Inge Young and Jordan Kelly (WA Department of Health), Martha Davies (NT Department of Health and Community Services), Melinda Tonks and Peter Mansfield (Tasmania Department of Health and Human Services).

We would also like to acknowledge the following national data custodians for their input into these guidelines: Elizabeth Sullivan, Helena Britt, George Bodilsen and Katrina Burgess (AIHW) and Michaela McGuigan (Australian Bureau of Statistics).

A number of frontline staff working in hospitals such as admission clerks, ward clerks, and midwives, data managers and general practitioners in various states and territories also had input into these guidelines.

This work received financial support from the Commonwealth Department of Health and Ageing Office for Aboriginal and Torres Strait Islander Health and the National Health and Medical Research Council.

Introduction

Why do we need Best Practice Guidelines?

Accurate identification of Aboriginal and Torres Strait Islander people in health related data collections is vital for understanding trends and disparities in health status and access to health services and planning for the provision of services to Aboriginal or Torres Strait Islander Australians. Despite improvements in recent years, there are continuing problems with under-identification of Indigenous people in many national health data collections. The Best Practice Guidelines have been developed to improve the collection of information on Aboriginal or Torres Strait Islander people in key national health data sets, through setting out best practices that can be implemented by data collectors, data managers and data custodians.

Why improve Aboriginal and Torres Strait Islander identification in national health data collections?

It is widely recognised that Aboriginal and Torres Strait Islander people have much more ill health than other Australians. They die at much younger ages and are more likely to experience disability and reduced quality of life due to ill health (ABS & AIHW 2008).

Data from a number of sources indicate that Aboriginal and Torres Strait Islander people suffer from disadvantage across a range of socioeconomic factors that affect health. In 2002, Aboriginal and Torres Strait Islander people reported lower incomes than other Australians, higher rates of unemployment, poorer education achievements and lower rates of home ownership (ABS 2004).

Aboriginal and Torres Strait Islander people also have higher levels of health risk behaviours such as smoking and alcohol misuse, and other risk factors such as poor housing and exposure to violence are also important determinants of Indigenous health. Numerous other aspects of the living and social conditions of Indigenous Australians, along with a reduced sense of control over their own lives, may also explain the poor health of Aboriginal and Torres Strait Islander people (Ring & Brown 2002). Issues such as the impact of colonisation, racism, and forced removal policies also affect the health of Indigenous Australians today (Morgan & Allen 1998). All of these factors also influence whether Indigenous Australians will self-identify when asked.

Information on the extent of ill-health and disadvantage for Aboriginal and Torres Strait Islander people in Australia is a vital prerequisite for public health interventions aimed at improving the health of Aboriginal and Torres Strait Islander people in Australia. The accuracy of this information depends on our ability to identify members of the Aboriginal and Torres Strait Islander community when they seek services in the health, education, employment, housing and other sectors, or participate in surveys. While these guidelines focus on the administrative processes supporting improved identification, they also recognise that individuals have the right to decide for themselves whether or not to identify as Aboriginal and/or Torres Strait Islander in any given situation. Thus, ensuring that people understand why the question is being asked and why it is important is crucial to promoting an environment in which people feel comfortable answering questions regarding their Indigenous status.

For example, information on a person's gender and age are collected when they come into contact with the health system in order to understand the health of men compared to women and young people compared to older people and to design specific public health interventions to tack health inequalities across these groups. In the same way, a question on a person's Aboriginal and Torres Strait Islander status provides a picture of the health status of Aboriginal and Torres Strait Islander people as an important population group in Australia.

These guidelines are focused on improving the quality and completeness of identification of Aboriginal and Torres Strait Islander people in national health data collections so that high quality information on the health and social disadvantage suffered by Aboriginal and Torres Strait Islander people is available to planners and policy and decision-makers in health and other sectors.

Barriers to Aboriginal and Torres Strait Islander identification

A number of studies have highlighted barriers to Aboriginal and Torres Strait Islander identification. Some of these studies have also made recommendations on how Aboriginal and Torres Strait Islander identification can be improved. These studies are summarised below.

A survey of staff in ACT public hospitals in 2005 which examined how staff attitudes about Indigenous status data collection impact on the accuracy of Indigenous status in admission data found that negative attitudes to collecting Aboriginal and Torres Strait Islander identity information in hospitals from frontline staff exist. Specifically, some staff 'fear' asking people accessing hospital whether they are Indigenous because of aggressive responses by both Indigenous and non-Indigenous people. The study also reported that many staff indicated that the purpose of asking people if they were Indigenous was related to funding and justified the irrelevance of collecting information on client ethnicity by stating that they believed that everyone should be treated equally, implying that ethnic groups in Australia may receive preferential treatment (Lovett 2006).

Three studies have examined Aboriginal and Torres Strait Islander identification in general practice (NCIRS 2003; Riley et al 2004; Kehoe 2007). Each found that only a minority of GPs had routine identification processes. Many practices made assumptions based on appearance, or expected that patients would disclose their Aboriginal and or Torres Strait Islander identity without asking. Many GPs had the view that asking the question might offend patients and that since Aboriginal and or Torres Strait Islander patients were likely to be a minimal proportion of their practice population, it was impractical to ask all patients the identity question. Similar to the study of ACT public hospitals in 2005 (Lovett 2006), some GPs felt that all patients should be treated equally and that no impact would or should derive from identification and thus identification served no purpose. A study undertaken by the ACT Division of General Practice also found that there was widespread confusion amongst GPs about the criteria for Aboriginal and Torres Strait Islander status (eg questions about 'half-castes' and 'part-Aborigines' were common); that there was lack of knowledge of the Aboriginal and Torres Strait Islander health assessments or other GP-mediated Aboriginal and Torres Strait Islander specific health initiatives; and that GPs believed that the reasons behind obtaining information on Aboriginal and Torres Strait Islander identity are bureaucratically driven and not beneficial to the patients (Kehoe 2007).

A study on improving Indigenous identification in communicable disease reporting systems also reported a number of major limitations to improving the quality of Indigenous identification. Reported limitations arose from differences across jurisdictions in notification and reporting systems, reluctance of Aboriginal and Torres Strait Islander Indigenous people to identify, incomplete identification, non-use of the standard ABS question on identity, lack of public health awareness, limited training to collect and value Aboriginal and Torres Strait Islander identity information and non-integrated information and services (DoHA 2004). This report made a number of recommended actions to improve reporting of Indigenous identification in communicable disease data collections in all jurisdictions. Recommendations ranged from making collection and reporting of Indigenous identification a mandatory requirement in all communicable disease health policies; revising national funding agreements and reporting to introduce incentives in relation to the quality of Indigenous identification; routinely monitor and report completeness of Indigenous identification data in communicable diseases through Communicable Disease Network of Australia; implementing Indigenous identification as part of standard demographic data gathered on all health care users; and ensuring sharing of available Indigenous identification data across health information systems (DoHA 2004).

While these studies focused primarily on systemic barriers, it is important to note that there are complex social and historical reasons why Indigenous people themselves may be reluctant to identify as Aboriginal and/or Torres Strait Islander. Some may be concerned about being discriminated against if they identify. Although the policy of the forced removal of Indigenous children is no longer in place, the impact of this policy is still being felt within Indigenous communities and families, and people are often suspicious of why a person “in authority” would want to know if they are an Aboriginal or Torres Strait Islander.

Background to the Best Practice Guidelines

Despite continuing improvement in the collection and recording of Aboriginal and Torres Strait Islander clients of health and welfare services, investigations into the quality of data related to Aboriginal or Torres Strait Islander identification carried out in recent years indicate that problems still exist. There is a lack of basic and comparable data on the health of Aboriginal or Torres Strait Islander people due failure to record clients’ Aboriginal or Torres Strait Islander status, differences in methods for determining Aboriginal or Torres Strait Islander status, and inconsistencies in the way this information is recorded. There are also variations in the extent to which people feel comfortable self-identifying as Aboriginal or Torres Strait Islander, and they have the right not to identify as such if they so choose.

The guidelines were commissioned by the National Health and Medical Research Council (NHMRC) and developed by the Australian Institute of Health and Welfare (AIHW). The project was funded by the NHMRC and the Office of Aboriginal and Torres Strait Islander Health (OATSIH), within the Australian Government Department of Health and Ageing (DoHA). A Steering Committee with representation from the AIHW, the Australian Bureau of Statistics (ABS), DoHA, OATSIH, NHMRC, the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data, Medicare Australia, the Royal

Australian College of General Practitioners, the Australian General Practice Network and the Statistical Information Management Committee gave advice on the different stages of this project.

Some states and territories have developed guidelines for collecting and recording information on Aboriginal and Torres Strait Islander clients attending health services to improve the quality of data on Aboriginal or Torres Strait Islander Australians for the purposes of reviewing and monitoring access to services and health status (See appendix 3). The guidelines outlined in this report have built upon existing guidelines and have been developed as a basis for national best practice in collecting accurate information on the Aboriginal or Torres Strait Islander status of clients. They are intended to assist health service staff and managers in providing good quality data that will support the implementation of strategies relevant to the health of Aboriginal or Torres Strait Islander Australians, and may be used as a basis for systematic evaluation.

Although these guidelines were developed to address issues of identification of Aboriginal or Torres Strait Islander Australians in key national health data sets, many of these guidelines and recommendations may be applied to other data collections in both the health education and community services sectors in the future.

The project to develop the guidelines has involved five stages:

The first stage involved analysis of the quality of Aboriginal or Torres Strait Islander data in the key health data sets. Key findings are presented in the section Issues in Aboriginal or Torres Strait Islander identification in national data collections.

The second stage involved examination of how information flows from the point of service to the national data collection. Key features of these flows are also presented in the section Issues in Aboriginal or Torres Strait Islander identification in national data collections.

The third stage of the project involved focus group sessions with health care personnel at the point of service (e.g. hospital staff and midwives) and data managers, followed up by a survey of frontline hospital staff. Focus groups included people from all States and Territories.

The fourth stage of the project involved interviews with key people who administer the national data collections.

The final stage of the project was to develop these Best Practice Guidelines based on all the information collection in the previous stages. Separate reports from these stages have been produced and are described and summarised in Appendix 3—Other practice guidelines and relevant material.

The project has identified barriers to obtaining accurate Aboriginal or Torres Strait Islander status information. These include lack of training of staff, staff reluctance to ask the question, client refusal to answer the question, Aboriginal or Torres Strait Islander and other clients not wanting to identify, lack of privacy when answering the question, minimal checking/validating of data or follow up of missing information, and system inadequacies. These guidelines aim to address these barriers.

National data collections to which these guidelines apply

These guidelines are targeted at the following national data collections:

- Perinatal National Minimum Data Set (NMDS)
- Birth registrations
- Death registrations
- Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice
- Registration with Medicare
- National hospital-based data collections, including the Admitted Patient Care NMDS (National Morbidity Data Collection), Admitted Patient Mental Health Care NMDS, Admitted Patient Palliative Care NMDS, Alcohol and Other Drug Treatment Services NMDS, Non-admitted Patient Emergency Department Care NMDS

However, most of the guidelines may be applicable to all other data collections designed to capture the Aboriginal or Torres Strait Islander status of participants.

What services are covered by these guidelines?

These guidelines apply to all services that contribute data to the national data collections listed above. These services include, but are not limited to:

- Public hospitals (including psychiatric hospitals)[1]
- Private hospitals and Day Procedure Centres
- Multi-Purpose Services
- Offices of Registrars of Births, Deaths and Marriages
- Medical practitioners, coroners, funeral directors/undertakers or other services involved in notifying/registering the death of an individual
- Medicare offices
- Public and private practice midwifery services
- General practices
- Aboriginal Community Controlled Health Organisations.

Who should use these guidelines?

All persons involved in the collection, recording and validation of information on Aboriginal or Torres Strait Islander identity should use these guidelines, particularly those involved in the national data collections listed earlier. This would include staff at first point of contact (that is, staff who are the first point of contact in health services), staff responsible for follow up of missing data, and data managers. Target audiences for these guidelines are listed below.

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[1] This applies to all ‘entry points’ for the registration of clients within a centralised client registration database, including admitted patient services, emergency departments, outpatient departments and community health services.

Staff involved in obtaining client demographic information at the point of service, including:

- All staff involved in the registration of clients in hospitals and other 'entry points' for client registration in centralised client registration systems. This includes, but is not limited to, hospital admission officers, intake officers, triage nurses, and clinicians and administrative staff registering patients in emergency departments, outpatient departments and community health services
- Ward clerks with a responsibility of gathering/updating patient information
- Midwives providing services within health facilities or in clients' homes
- Aboriginal Liaison Officers and Aboriginal Health Workers
- GPs, practice managers, practice nurses and reception staff in GP offices or medical centres
- Staff of Medicare Offices involved in registering new clients and/or updating client details over the telephone
- Medical practitioners/coroners assessing the cause of death of a person
- Funeral directors/undertakers compiling a death certificate
- Any other professional notifying a birth or death of a person.

Data custodians or staff involved in preparing/collating data for reporting purposes, including:

- Data co-ordinators (these include co-ordinators of specific collections, or co-ordinators of client data for reporting to various data collections)
- State and territory data custodians
- National data custodians.

These guidelines are not only aimed at those who are new to the field and require guidance but will also be useful to people who are experienced in working in the health and other sectors.

How are the guidelines organised?

These guidelines start by giving some introductory demographic information on Aboriginal and Torres Strait Islander people in Australia. The guidelines are divided into four main parts:

Part A Guidelines for data collection deals with data collection and the question to be asked when ascertaining Aboriginal or Torres Strait Islander identity, issues that may arise in relation to asking the question or determining Aboriginal or Torres Strait Islander identity and follow-up of missing information as part of the data collection process. This section is designed mainly for point of service staff or other staff responsible for the collection of Aboriginal or Torres Strait Islander identity data.

Part B Guidelines for data custodians is intended for data custodians at local, state and territory level and provides information on the categories used for reporting Aboriginal or Torres Strait Islander identity at a national level, how to map state/territory categories to the national standard, the categories recommended for use at a local service level and advice on the use of a mandatory field for Aboriginal or Torres Strait Islander identification.

Part C Data validation protocols includes suggestions for validation of data at local, state and territory, and national levels.

Part D Training and education incorporates ideas on training for staff and the provision of information to the Aboriginal or Torres Strait Islander and wider communities about the importance of collecting Aboriginal or Torres Strait Islander status information, including what the data is used for. It also includes ideas for promotional material aimed at identifying service usage by Aboriginal or Torres Strait Islander individuals.

This guide also includes three additional appendices which readers may find useful:

Appendix 1: National, jurisdictional and organisational processes

Appendix 2: Other practice guidelines and relevant material

Appendix 1 makes recommendations in relation to policies and processes needed by organisations and jurisdictions for improving data relating to monitoring health status and service usage by Aboriginal or Torres Strait Islander people.

Appendix 2 includes links to other materials that may also be useful in data collection processes aimed at understanding service usage by, and monitoring the health status of, Aboriginal or Torres Strait Islander people. It also includes a description and summary of papers produced from the various stages of the project leading to the development of these guidelines. This appendix will be available online only at www.aihw.gov.au so that it can be updated as new information becomes available.

Aboriginal and Torres Strait Islander people in Australia

Definitions and terminology

The three components of the Commonwealth definition for identifying an Aboriginal or Torres Strait Islander citizen are:

- Aboriginal or Torres Strait Islander descent
- self-identification as an Aboriginal or Torres Strait Islander person, and
- acceptance of the person as an Aboriginal or Torres Strait Islander by the community in which he or she lives (AIHW 2003).

In practice, the collection of information on the community acceptance part of this definition in general-purpose statistical and administrative collections is controversial and often not feasible. Therefore, standard questions on Aboriginal or Torres Strait Islander identity relate to descent and self-identification only and only these are included in the ABS standard (AIHW and ABS 2005).

The term ‘Indigenous’ is also controversial amongst some members of the community, with Aboriginal or Torres Strait Islander the preferred identification term. Therefore, when interviewing an individual it is accepted protocol to ask the individual whether or not they identify as an Aboriginal or Torres Strait Islander person.

Demographic characteristics

At 30 June 2006, there were an estimated 517,000 Aboriginal and Torres Strait Islander people resident in Australia, representing 2.5% of the total Australian population. In terms of absolute numbers, New South Wales (152,700) and Queensland (144,900) had the largest Aboriginal or Torres Strait Islander estimated resident populations followed by Western Australia (71,000) and the Northern Territory (64,000) (ABS 2008b).

Ninety percent (463,700) of the Aboriginal or Torres Strait Islander population were estimated to be of Aboriginal origin only, 6% (33,300) of Torres Strait Islander origin only, and 4% (20,100) were of both Aboriginal and Torres Strait Islander origin.

Aboriginal and Torres Strait Islander people are estimated to represent 30% of the Northern Territory resident population. In all other states/territories Indigenous Australians represent less than 4% of the population. Victoria has the lowest proportion of people of Aboriginal or Torres Strait Islander origin at 0.6% of the total state population identifying as either Aboriginal or Torres Strait Islander people (ABS 2008b).

In 2006, 32% of Aboriginal or Torres Strait Islander people lived in Major Cities, 21% in Inner Regional, 22% in Outer Regional and 26% in Remote/Very Remote Australia. States with a relatively high proportion of Aboriginal or Torres Strait Islander people living in Major Cities included South Australia (49%), Victoria (50%) and New South Wales (43%). In contrast, 80% of the Aboriginal or Torres Strait Islander population living in the Northern Territory lived in Remote/Very Remote areas. In Western Australia, 42% of the Aboriginal or Torres Strait Islander population lived in Remote/Very Remote areas (ABS 2008b).

The Aboriginal or Torres Strait Islander population has a relatively younger profile compared with the non-Indigenous population. An estimated 37% of Aboriginal or Torres Strait Islander people were under 15 years of age in 2006, compared with 19% of non-Indigenous people. People aged 65 years or over comprised 3% of the total Aboriginal or Torres Strait Islander population, compared with 13% of the non-Indigenous population (ABS & AIHW 2008).

Part A: Guidelines for data collection

A1 What question should be asked and how should responses be recorded?

The following should be used when establishing a client's Aboriginal and Torres Strait Islander identity:

"Are you [is the person] of Aboriginal or Torres Strait Islander origin?"

The standard response options for this question are:

☐ No

☐ Yes, Aboriginal

☐ Yes, Torres Strait Islander

For clients of both Aboriginal and Torres Strait Islander origin, both 'Yes' boxes should be marked.

This approach may be problematical in some data collections, for example when data are collected by interview or using screen based data capture systems. An additional response category may be included if this better suits the data collection practices of the agency or establishment concerned:

☐ Yes, both Aboriginal and Torres Strait Islander

The question can be asked verbally or included on a form. All verbal requests and client registration forms should be consistent with this standard.

The Aboriginal or Torres Strait Islander identity question allows for more than one response. The procedure for coding responses is as follows:

Response	**Recording category**
'Yes, Aboriginal' is ticked but Torres Strait Islander is not ticked	Aboriginal but not Torres Strait Islander origin
'Yes, Torres Strait Islander' is ticked but 'Yes, Aboriginal' is not ticked	Torres Strait Islander but not Aboriginal origin
'Yes, Aboriginal' is ticked and 'Yes Torres Strait Islander' is also ticked	Both Aboriginal and Torres Strait Islander origin
'No' is ticked	No, neither Aboriginal nor Torres Strait Islander origin
'No' is ticked and either or both 'Yes, Aboriginal', and 'Yes Torres Strait Islander' are ticked	Disregard 'No' response and record the other category ticked.
Client is capable of responding but declines to respond following prompting/follow-up	'Not stated/inadequately described'
Where it is impossible for the question to be asked during the contact episode	'Not stated/inadequately described'.
Response to the question has been left blank or is incomplete	'Not stated/inadequately described'.

In asking the question verbally or on a form, *only* the three standard responses (or four responses including the additional response category) identified above should be offered as the available responses. If using a form, response options of 'Unknown' or 'Not stated' should *not* be included on the form.

If a client declines to respond to the question, or cannot answer the question for reasons outlined later in this document and cannot be followed up, the response to the Aboriginal or Torres Strait Islander status question is considered as incomplete. Responses that are incomplete *must not* be recorded or coded as No 'or'Neither Aboriginal nor Torres Strait Islander. Instead, 'Not stated/inadequately described' should be recorded.

It is essential that all data collections adopt the national standard, that is, the question and codes used by the Australian Bureau of Statistics (ABS) in the population census for collecting Aboriginal or Torres Strait Islander status information (i.e. those shown in the box above). Variations in the question used to ascertain a client's Aboriginal or Torres Strait Islander identity can lead to different responses and over time, result in inconsistencies in data collections. Use of the standard for Aboriginal or Torres Strait Islander status ensures that consistent and comparable data are collected across statistical and administrative collections and for all government and non-government data collections. It also provides the basis for comparability of information collected within and between agencies.

The ABS standard question is based on the Commonwealth definition for identifying an Aboriginal or Torres Strait Islander citizen. That is, an Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives'.

There are three components to the Commonwealth definition: descent, self-identification, and community acceptance. In practice, as discussed in the background of these guidelines, it is not feasible for mainstream organisations (or non-Aboriginal controlled organisations) to collect information on the community acceptance part of this definition in general purpose statistical and administrative collections. Therefore the standard question on Aboriginal or Torres Strait Islander identity is based on the 'operational definition' (AIHW and ABS 2005). The operational definition of Aboriginal or Torres Strait Islander identity used by the ABS is: indicates whether or not a person identifies as being of Aboriginal or Torres Strait Islander origin. The term 'origin', when used in the context of the operational definition, is considered to relate to people's Australian Aboriginal or Torres Strait Islander descent

When Aboriginal and Torres Strait Islander identity information is reported and recorded the resulting data item is known as the client's self-identified Aboriginal and Torres Strait Islander status.

A2 Why should the question be asked?

The aim is to provide better services for Aboriginal and Torres Strait Islander peoples.

Better data to improve service planning and delivery

- Accurate information on Aboriginal and Torres Strait Islander identity is necessary for the government and services to plan and deliver appropriate health services for all Australians, to assess the impact of services on particular groups in the community, to improve health care and to monitor changes in health and wellbeing over time.

Better immediate service delivery and care

- Collecting data will assist GPs and other health care providers to determine client eligibility for targeted population health strategies and services such as specific immunisation considerations, Indigenous health check items and Aboriginal and Torres Strait Islander PBS listings. These services are only available for clients who wish to identify as Aboriginal and Torres Strait Islander. It is important to note that it is the individual's choice as to whether they self-identify or not and as to whether these services are provided to them or not.
- Information on Aboriginal and Torres Strait Islander identity helps staff to provide better and culturally safe care, identify potential language barriers and refer clients to culturally appropriate services[2] such as Aboriginal Liaison Officers, Aboriginal Health Workers, Aboriginal Health Services and Aboriginal Community Controlled Health Organisations (Aboriginal Medical Services) as appropriate or identified by the person as a desired option.

It is not possible for staff to determine whether a person is of Aboriginal or Torres Strait Islander origin without asking the person or to know whether a person wishes to identify as such for this purpose. Assumptions should not be made based on appearance or on prior knowledge of the person's family history or background.

It is the right of the individual to self-identify or not as Aboriginal or Torres Strait Islander. This should be an informed choice.

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[2] Culturally appropriate services are services tailored to meet the cultural, social and linguistic needs and respect the values and beliefs of a particular group in society. For Aboriginal and Torres Strait Islander peoples, examples of such services include Aboriginal Health Services and Aboriginal Community Controlled Health Organisations (ACCHOs). General practitioners, clinicians and hospitals can refer Indigenous patients to these services—the contact details of all ACCHOs in Australia can be found on the DoHA website.

A3 In what context should the question be asked and what information should be given before asking the question?

The following sentence is recommended to be used before asking a client any information related to cultural background and identity:

"I now need to ask you some questions which we ask of all clients to help staff to tailor and provide appropriate care to all clients and to help the government to plan and provide improved health care and services for all Australians."

A variation of this preamble could be used by funeral directors:

"I now need to ask you some questions regarding the deceased which will help the government to plan and provide improved health care and services for all Australians."

Ideally, staff should keep this preamble in front of them when asking questions, on a piece of paper or on the computer screen, so that it is not forgotten and is phrased correctly and consistently. If staff are unable to easily adopt this exact phrase they should be instructed of the crucial elements to remember:

- Ask all patients
- The question is asked to assist with appropriate care

The question is asked to assist with health service planning by providing accurate information on the current state of health of different population groups living in Australia.

If a form is used, a preamble can also be included to introduce questions related to cultural background and identity however this is not a requirement. The following sentence is recommended:

"The following information will assist in the planning and provision of appropriate and improved health care and services".

The Aboriginal or Torres Strait Islander status question should be placed within the context of other questions related to cultural background and identity, such as country of birth and main language spoken.

Recent evidence from a survey of general practice and focus groups with health care personnel suggests that asking the Aboriginal or Torres Strait Islander identity question in the context of other questions related to cultural background and identity can improve staff willingness to ask the question and client willingness to answer the question (AIHW: Britt et al 2003; AIHW unpublished).

Staff asking the question need to be aware that Aboriginal or Torres Strait Islander clients may have received unfavourable treatment in the past and/or may have concerns about what this information will be used for. Aboriginal or Torres Strait Islander clients may therefore be reluctant to answer 'Yes' to the question. Staff should have an understanding of the reasons why the question needs to be asked, and be able to explain those reasons. The choices and position taken by the person being interviewed need to be respected.

A4 Who should the question be asked of?

The Aboriginal or Torres Strait Islander identification question should be asked:

- Of every client of a health service, irrespective of appearance, country of birth or whether staff know the client or their family background.
- Of all persons for whom a Medicare enrolment form is submitted (including newborn babies), or persons applying to copy or transfer from one Medicare Card to another. Aboriginal or Torres Strait Islander identity can also be notified voluntarily to Medicare by submitting a Voluntary Indigenous Identifier form.
- In relation to every birth registered with state/territory Registrars of Births, Deaths and Marriages.
- In relation to every person who has died, for whom a Death Registration Form is submitted to a state/territory Registrar of Births, Deaths and Marriages by a funeral director/undertaker or other person arranging to notify the family or the State of the person's death, and for whom a medical practitioner or coroner has submitted a Cause of Death Certificate.

It is essential that the self-identification of an individual as Aboriginal or Torres Strait Islander be recorded (as per the Commonwealth definition specified in section A1 What question should be asked?), except in circumstances where the individual cannot directly answer the question for reasons listed below. The opinion of staff members should not be the basis of recording the responses to the standard question.

Whilst staff may know their clients' family background, particularly in small country towns, this should not be a reason for staff to not ask the question. Not all members of the same family may wish to identify themselves as Aboriginal or Torres Strait Islander individuals. An individual makes the choice and is the agent for supplying the answer to the question.

Staff should not assume that people born outside of Australia are neither Aboriginal nor Torres Strait Islander. While the majority of Aboriginal or Torres Strait Islander people are born in Australia, some may be born outside of Australia and this is likely to become increasingly common as more Aboriginal or Torres Strait Islander people travel and work overseas.

A5 Who should answer the question?

Clients of a health service should be asked the question directly or be asked to complete a form with this question included and should answer the question themselves.

There are some situations in which the client will be unable to answer the question or in the case of birth and death registrations, the person for whom the registration is for is unable to answer the question. Such situations include:

- Where the client is a newborn baby
- Where the client is a baby (other than a newborn) or child aged under 15 years
- Where the client is too ill, unconscious or incapable due to a psychiatric condition or dementia
- Where the client does not speak English or cannot read or write
- Where the client is deceased.

In these instances, it is acceptable for others to be asked the question and answer the question on the client's behalf, as prescribed below.

A5.1 If the client is a newborn baby

In hospitals, the Aboriginal or Torres Strait Islander identity of the mother and newborn baby should be separately ascertained and recorded. The mother should be asked to identify herself and her baby. It should not be assumed that the baby's Aboriginal or Torres Strait Islander identity is the same as that of the mother. Staff should not assume that the newborn baby is not Aboriginal or Torres Strait Islander when the mother has not identified as being of Aboriginal or Torres Strait Islander origin.

Birth registration forms are prepared and submitted by the parents of a newborn baby. Birth registration forms should allow the Aboriginal or Torres Strait Islander identity of the mother, father and newborn baby to be separately identified. If the baby's Aboriginal or Torres Strait Islander identity has not been indicated on the form, then if either the mother or father is identified as Aboriginal or Torres Strait Islander, the baby should be identified as Aboriginal or Torres Strait Islander by the state/territory Registrar of Births, Deaths and Marriages.

A5.2 If the client is a baby (other than a newborn) or child under 15 years of age

Where the client is a baby (other than a newborn, for newborns, see guideline above) or child under 15 years of age, the parent or guardian is asked to declare the Aboriginal or Torres Strait Islander identity of the baby or child.

If the parent or guardian is not available, a close relative, friend, or another member of the household accompanying the child should be asked to provide this information.

If this is not possible (for example the child is too young), the parent/guardian could be contacted to confirm whether they identify the child as being Aboriginal or Torres Strait Islander.

A5.3 If the client is too ill to be asked the question or is not able to answer the question

Where the client is unable to respond to the question about the identity of the person because they are too ill, unconscious, or incapable due to a psychiatric condition or dementia, in the first instance the staff member should ask the client's carer, relative, or any other person who is accompanying the client for this information. If the person accompanying the client does not know the client's identity then the client should be asked the question directly when they are capable of responding.

The identity nominated should always be verified with the client when they have recovered sufficiently to be able to answer the question.

A5.4 What if the client does not speak English or cannot read or write?

If a client does not speak English but is accompanied by someone who can interpret for them, then it is recommended that the person accompanying them is asked to interpret the question for the client and their response.

If there is no one with the client who can speak English, it is recommended that an interpreter or Aboriginal or Torres Strait Islander Liaison Officer who can interpret the relevant Aboriginal or Torres Strait Islander language being used by the client be called to assist the client.

If a form is to be completed and the client cannot read or write, it is recommended that an appropriate staff member (e.g. an interpreter or Aboriginal or Torres Strait Islander Liaison Officer/ Health Worker) go through the questions with the client.

A5.5 If the client is deceased

Where a client is deceased, Aboriginal or Torres Strait Islander identity information should be obtained from the next of kin in the first instance. If no next of kin has been identified or available, then the question should be asked of the broader family. If this information is not able to be obtained from either of these sources, another person who knew the client well may be asked to provide this information.

A6 Who should ask the question?

Staff responsible for registering a client or updating their information should ask the question when the client is first registered with the service (see section *Who should use these guidelines*).

For perinatal data collections, the midwife should undertake to identify mothers and their babies as being Aboriginal or Torres Strait Islander by obtaining this information directly from the mother, regardless of the information separately recorded in the hospital database.

In general practices, GPs and practice nurses should collect information on the Aboriginal or Torres Strait Islander identity of the patient as part of routine medical history taking if this information has not already been noted by reception staff.

Funeral directors, undertakers, medical practitioners and coroners responsible for registering a death or assessing the cause of death must ask the next of kin (or other appropriate person) about the Aboriginal or Torres Strait Islander identity of the deceased.

A7 When should the question be asked?

The question should be asked when the client first registers with a service (e.g. at a new patient consultation, booking into hospital), which may occur over the telephone or at first presentation. If it is not practical to collect this information over the phone then this information must be obtained on the first contact with the service. It is essential to collect the correct information on Aboriginal or Torres Strait Islander identity initially, as asking the question of the same client numerous times can be tedious for staff and clients.

On subsequent presentations, the question should be asked if the information is missing or appears to be incorrect. Regular attempts should be made to update this information when the opportunity arises. Clients should have an opportunity to confirm or update their status on a regular basis.

For perinatal data collections, the midwife should ascertain the Aboriginal or Torres Strait Islander status of the mother at the time that she presents for the delivery or soon after, and as soon as appropriate after the birth of the baby.

In general practices, if the information is missing on the medical registration form, the GP or practice nurse should ask the question as part of routine medical history taking. This could be linked to an enquiry about the provision of an Indigenous Adult or Child Indigenous Health Check, Aboriginal or Torres Strait Islander specific Immunisation Schedules or Aboriginal and Torres Strait Islander PBS listings, because as discussed previously, the purpose of the interest in the identity of the individual is to provide relevant targeted health services.

For Death Registrations, Medical practitioners or coroners issuing a Cause of Death Certificate should ask the family or next of kin as to the Aboriginal or Torres Strait Islander identity of the deceased at the time of issuing the certificate. Funeral directors/undertakers registering a death should also ask the family of the deceased person or their next of kin as to the Aboriginal or Torres Strait Islander identity of the deceased person at the time that the body is received or soon afterwards (i.e. on first contact with the family or next of kin).

A8 What if a client complains about being asked, or wants to know why they are being asked the question?

If a client reacts negatively to being asked the Aboriginal or Torres Strait Islander status question or wants to know why they are being asked, the following should be explained:

- The Aboriginal or Torres Strait Islander identity question is one of several questions related to a client's origin and demographic characteristics asked of all clients who attend a health service, enrol with Medicare or are involved in the registration of a birth or death.
- Identification is voluntary, but this information is needed to improve the health of Aboriginal and Torres Strait Islander peoples in the same way that other demographic information is used to improve the health of the total Australian population. For example, information about age is used to assess whether particular age groups have greater health needs than others.
- All clients are asked their Aboriginal or Torres Strait Islander status in order to collect accurate information about health status and service use to assist with the planning and delivery of services for all Australians. Aboriginal and Torres Strait Islander status is also collected for all newborn babies and recently deceased for similar reasons as outlined above—to gain a better understanding of the health status of Australians as well as birth and mortality patterns to help the government to plan and provide improved services.
- The response to this question is aimed at establishing the person's choice of services. It will assist staff to offer and provide culturally safe care and refer Aboriginal or Torres Strait Islander people to culturally appropriate services if the client so wishes, such as Aboriginal Liaison Officers and Aboriginal Health Workers.
- The response to this question may result in access to initiatives targeted to particular needs of the Aboriginal and Torres Strait Islander people such as Health Checks, specific immunisation considerations, and Aboriginal and Torres Strait Islander specific PBS listings.
- All personal information is protected by a strict Privacy Act—the use of personal information for reasons other than the purpose for which it was collected is strictly prohibited unless consent is given. Aboriginal or Torres Strait Islander status information is used by local health services to improve care and in de-identified form is used to improve information on the health of Aboriginal or Torres Strait Islander and non-Indigenous population groups.
- Security measures are taken to protect personal information against loss, misuse and unauthorised access.

The explanations outlined above are important to both Aboriginal or Torres Strait Islander and non-Indigenous clients who question why they are being asked their Aboriginal or Torres Strait Islander status. It could be further explained that the health of Aboriginal and Torres Strait Islander peoples is significantly poorer than that of non-Indigenous Australians and that accurate information will help to improve the health of Aboriginal and Torres Strait Islander peoples through the provision of better and more appropriate care and improved planning of, and access to, health services.

A9 What if a client declines to answer?

Every client has a right to decline to answer the standard question. Clients should be informed of this right and that their level of care and access to services will not be affected if they choose not to answer the question.

If a client declines to answer, this should be recorded in the 'Not stated/inadequately described' category. It should not be recorded in the 'No', 'Neither Aboriginal nor Torres Strait Islander' or any other local 'Non-Indigenous' categories.

A10 What if a client wishes to change their Aboriginal or Torres Strait Islander status?

The client should be allowed the opportunity to confirm or change any previously recorded identification.

While a person's Aboriginal or Torres Strait Islander identity does not change over time, their willingness or ability to identify may vary over time and in different circumstances. Even though the aim of these guidelines is to improve information about access to services, and usage of services, by Aboriginal and Torres Strait Islander people, the fundamental principle is acknowledgement of the choice, or not, of a person to identify, or be identified, as an Aboriginal or Torres Strait Islander.

A11 Follow-up of missing information

It is recommended that procedures for the follow-up of missing information be undertaken by relevant organisations and appropriate bodies (e.g. Australian Funeral Directors Association; State/territory health authorities; Area Health Services).

If procedures for the follow-up of missing Aboriginal or Torres Strait Islander status information have not already been developed by relevant organisations, health services and providers should consider developing procedures to ensure that where information on Aboriginal or Torres Strait Islander status was unable to be obtained at the initial contact with the service, an appropriate staff member is assigned the role to follow-up with the client or respondent. If possible, this should occur before the client has left the service.

Business rules can be constructed which differentiate between people who were not asked about their Indigenous status and need to be followed up, and those who exercise their rights not to answer the question. In the first scenario, protocols can be developed so that reminders are generated (e.g. their record is flagged to ask the question again at a more appropriate time), while in the second scenario that protocol would not be appropriate.

In general practices and medical centres, if Aboriginal or Torres Strait Islander status is missing on a patient's record, this information should either be collected by the GP as part of routine medical history taking or when demographic/contact information is updated at the time of the next consultation.

Where forms are completed and handed into the service, if Aboriginal or Torres Strait Islander status is missing, this should be confirmed with the client. If forms are mailed to the service, the client should be contacted to obtain information where this item has not been.

In the case of Death Registration data, if Aboriginal or Torres Strait Islander status is missing on the Death Registration Form, then the funeral director should follow it up with the family before the form is sent to the Registry. . Similarly, medical practitioners or the coroner responsible should attempt to complete the identity question before the form is sent to the Registry.

Despite attempts to complete missing information, there may still be occasions where the information cannot be obtained. In such cases, the category 'Not stated/inadequately described' should be recorded in the system. Where local systems do not have this category, the category that is closest to this should be used. The category 'Neither Aboriginal nor Torres Strait Islander' or any other local 'Non-Indigenous' category should *not* be used (See B1 for more information on the categories used to record Aboriginal and Torres Strait Islander identity).

There are situations where information on Aboriginal or Torres Strait Islander status is unable to be obtained initially. For example:

- the client may be too ill, unconscious or incapable due to a psychiatric condition or dementia
- a 'quick' registration is required such as in an emergency or disaster situation
- the registration is incomplete because staff have not asked the question.

In these situations it is important that effective follow-up procedures and practices are in place to ensure that this information is obtained at a later stage wherever possible, preferably before the client has left the service (e.g. before discharge from the hospital).

Resources will need to be targeted by jurisdictions to ensure correct identification and follow up of Aboriginal or Torres Strait Islander status, for example, the employment of Aboriginal Liaison Officers. Follow-up procedures to obtain missing Aboriginal or Torres Strait Islander identity information may include:

- Clients could be handed a print out of their personal details sheet (eg at the time of a follow-up service) and asked to check if these details are correct. If the Aboriginal or Torres Strait Islander status of the client was not stated, this provides an opportunity for the client to update this information.
- Ward clerks could collect missing information while the client is still on the ward, ie before they leave the service.
- If Aboriginal Liaison Officers (ALOs) or Aboriginal Health Workers (AHWs) are employed in a service they may have a role in updating records. If this is part of their role, a list of clients with a 'Not stated' or missing Aboriginal or Torres Strait Islander status could be provided to the ALO or AHW daily to follow-up.
- GPs and clinicians could ask their client their Aboriginal or Torres Strait Islander identity as part of routine medical history taking if this information is missing on the record, and record this information themselves and/or pass this information on to an appropriate person who has the authority to update the record.
- If computer software programmes have in built prompts regarding missing information such as pop-up reminders that appear on the screen when a patient presents to the service and their Aboriginal or Torres Strait Islander identity is not complete, then staff should take note.
- Staff could check whether Aboriginal or Torres Strait Islander identity had been recorded on any accompanying documentation to the client's registration, such as a discharge letter or emergency department triage notes or some other documentation.

Part B: Guidelines for data custodians

B1 Mapping of categories for recording Aboriginal or Torres Strait Islander status

As recommended in A1 of these guidelines, local information systems should record Aboriginal and Torres Strait Islander identity information using the national categories for recording Aboriginal and/or Torres Strait Islander identity as set out in the National Health Data Dictionary (AIHW 2003). These are:

1. Aboriginal but not Torres Strait Islander origin
2. Torres Strait Islander but not Aboriginal origin
3. Both Aboriginal and Torres Strait Islander origin
4. Neither Aboriginal nor Torres Strait Islander origin
9. Not stated/inadequately described.

If local recording systems have not provided Aboriginal and Torres Strait Islander identity data in this format, this should be queried with the local service and the categories used mapped to the national categories. Records for which the response to the Aboriginal or Torres Strait Islander identity question is missing should be recorded as 'Not stated/inadequately described'. These records must *not* be coded to the category 'Neither Aboriginal nor Torres Strait Islander'.

While some states and territories include two additional local categories—'Declined to answer' and 'Question unable to be asked'—these are not recommended in the national guidelines as they deviate from the national standard. It is recognised however that these categories may be useful to record identity information at the local level. If these two categories are used in local reporting systems, responses must be mapped to the national category of 'not stated/inadequately described'. They should *not* be mapped to the 'Neither Aboriginal nor Torres Strait Islander' category.

B2 Is the Aboriginal or Torres Strait Islander status data item mandatory?

The Aboriginal or Torres Strait Islander identity data item should be included in all data recording systems contributing data to national minimum datasets in which Aboriginal or Torres Strait Islander identity is a required data item. Data custodians should also consider including the Aboriginal or Torres Strait Islander identity data item in all other data systems recording client demographic information.

Recording a response to the Aboriginal or Torres Strait Islander identity item should be mandatory when registering client details in data recording systems. A default response, such as 'Not stated' or 'No' or 'Neither Aboriginal nor Torres Strait Islander' *should not* be set in computerised systems. Staff registering details of a client should not be able to complete the registration until a response of the Aboriginal or Torres Strait Islander identity item has been completed.

Part C: Data validation protocols

A strategy for the validation of Aboriginal or Torres Strait Islander identity data should be developed by each individual service and state/territory. Aboriginal or Torres Strait Islander identity data should be validated as a component of all data validation checks, with some edits specific to Aboriginal or Torres Strait Islander identity only, and where possible should be checked before the client leaves the service.

Recommendations and guidelines regarding validation of Aboriginal or Torres Strait Islander identity data at the local service, state/territory and national level are discussed below. The local service level protocols are relevant to hospitals and general practices. State/territory level protocols are relevant to state/territory health authorities and Registrars of Births, Deaths and Marriages. National level protocols are relevant to national agencies that house particular data collections such as the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and Medicare Australia.

C1 Local service level data validation protocols

Local services should establish protocols for monitoring, improving and maintaining the quality of data collected related to the Aboriginal and/or Torres Strait Islander identity question.

Protocols will vary with local circumstances but could include:

- Review of local policies, procedures, form layout and data recording systems to ensure that these are consistent with these Guidelines with respect to the Aboriginal or Torres Strait Islander identity question.
- Comparing information obtained by Aboriginal Liaison Officers or Aboriginal Health Workers who may have a role in asking clients their Aboriginal or Torres Strait Islander identity with the data recorded in the recording system. Note that it is the choice of the individual to provide identity information to ALO's, AHW's and other staff.
- Checking whether clients who have been referred from Aboriginal and Torres Strait Islander health services are recorded as Aboriginal or Torres Strait Islander.
- Comparing the number and proportion of Aboriginal or Torres Strait Islander records for the local service with the previous year's data to determine whether there have been any obvious errors in coding (e.g. an unusually large increase or decline in the number of Indigenous records). While it is expected that there will be some variation in the number of Indigenous records from one year to the next or a substantial difference between years should be cause for investigation.
- Establishing protocols for following up records with missing Aboriginal or Torres Strait Islander status (see A11).
- Development of business rules to cope with different identifications when there are two sources of data (e.g. cause of death forms and death registrations). For example, if Aboriginal and/or Torres Strait Islander status appears on any form, then they are coded as being of Aboriginal and/or Torres Strait Islander origin.
- Health providers prompted to check demographic details including Aboriginal or Torres Strait Islander status where relevant or where such information is missing.
- Comparing the levels of 'Not stated' from Funeral Directors to determine whether further education or assistance is required.

Protocols relevant to General Practice data only:

- General Practice organisations should be involved in setting up protocols for auditing and to assist practices to achieve collection targets for Aboriginal or Torres Strait Islander status information if funded to do so. Some GPs through the National Primary Care Collaborative have already been engaged in data collection, cleansing and reporting.
- Audits to check the completeness of Aboriginal or Torres Strait Islander identity data could be part of general practice quality assurance and professional development activities (e.g. Active Learning Modules).

C2 State/territory level data validation protocols

State/territory data custodians are encouraged to establish protocols for monitoring, improving and maintaining the quality of data collected related to the Aboriginal or Torres Strait Islander identity questions. At a minimum, protocols should include:

- Regular monitoring of Aboriginal or Torres Strait Islander identity information and provision of continuing feedback on data quality to local services.
- Regular checks that codes used for recording Aboriginal or Torres Strait Islander identity in local systems are consistent with these Guidelines—in particular, that invalid or inappropriate codes are not being used.
- Regular checks that local services have not set default values for the Aboriginal or Torres Strait Islander identity, for example evidenced by no reporting of records with a 'Not stated' response to the Aboriginal or Torres Strait Islander identity item.
- For each local service, the number and proportion of Aboriginal or Torres Strait Islander records should be compared with the previous year's data to determine whether there have been any obvious errors in coding (eg an unusually large increase or decline in the number of Indigenous records) (See C1, point 4 for further explanation).
- Compare data for Aboriginal or Torres Strait Islander clients with variables such as country of birth, language spoken and Medicare eligibility status so that mismatches can be queried with local services[3].

State/territory data providers should inform the national data custodian of any events or issues that may have impacted on the quality of the Aboriginal or Torres Strait Islander data.

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[3] Most Aboriginal and Torres Strait Islander peoples are eligible for Medicare. Although at present, most Indigenous people are born in Australia and speak English or an Australian Aboriginal language, it is becoming increasingly common for Aboriginal and Torres Strait Islander peoples to be born overseas as travelling and migrating become more common among the Indigenous population. Therefore, it is important that records for Indigenous persons recorded with an overseas country of birth or foreign language as main language spoken are not changed automatically but are cause for investigation only.

Additional protocols could include:

- Data quality surveys involving direct surveys or interviews with clients, undertaken to determine accuracy of Aboriginal or Torres Strait Islander identity in the relevant data collection and estimate of the level of under-identification.
- Government Departments could establish processes to review and audit Aboriginal or Torres Strait Islander identity data.

C3 National level data validation protocols

National data custodians should establish protocols for monitoring, improving and maintaining the quality of data collected related to the Aboriginal or Torres Strait Islander identity questions. At a minimum data validation at the national level should be undertaken on an annual basis, although quarterly or monthly data validation may be appropriate. At a minimum, protocols should include:

- Data providers are informed of all data checks and edits that will be carried out on the provided data.
- Check that invalid codes have not been used for recording Aboriginal or Torres Strait Islander identity.
- Check that 'Not stated' is reported separately and not included in 'No, neither Aboriginal nor Torres Strait Islander'.
- The number and proportion of Aboriginal or Torres Strait Islander records should be compared with the previous year's data to determine whether there have been any obvious errors in coding (e.g. an unusually large increase or decline in the number of Indigenous records) Comparison should be undertaken at the state/territory level and other levels if feasible (See C1, point 4 for further explanation).

All validation queries should be sent back to the data provider for follow-up. Errors should be corrected and re-supplied to the national data custodian. The re-supplied data should then be reassessed to identify any remaining data quality issues. If practical, the finalised data set should then be sent back to the data provider.

Depending on the specific data collection, additional protocols could include:

- Compare data for Aboriginal or Torres Strait Islander persons with variables such as country of birth, language spoken and Medicare eligibility status so that mismatches can be queried with states/territories and investigated[4].
- Comparing Aboriginal and Torres Strait Islander identification in one data collection with that recorded in, or by linking to, a related data set only under the provision that ethical approval is obtained and noting that such analyses is subject to privacy legislation as well as other relevant legislation underpinning various datasets. This information will be used to assess the extent of under identification to help providing better estimates of the Indigenous population using relevant services.
- To avoid misleading information, the quality of Indigenous identification in each data set should be assessed and the conditions and rules under which it can and can not be used should be clearly stated for each data set.

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[4] See footnote 4.

Some restrictions should be placed on the release or publication of Aboriginal or Torres Strait Islander identity data that has known data quality issues. For example, numbers and corresponding rates where the cell size is less than 5 should be suppressed and state/territories with a high level or under-reporting of Aboriginal or Torres Strait Islander status should be considered to be excluded from data analysis.

Part D: Training and education

D1 Staff training

All persons responsible for collecting, recording and validating Aboriginal or Torres Strait Islander identity information should be provided with appropriate training to ensure that these tasks are carried out effectively. Training on Aboriginal or Torres Strait Islander identification may best be delivered as part of a training program that focuses on overall data collection and quality. Staff should understand that a question on Aboriginal and Torres Strait Islander identity is one of many questions that should be asked of all clients attending or registering with a service with two main aims in mind—better data collection and better service delivery and care. Staff who could undertake training include point of service staff, clinical staff and data managers.

These Guidelines could be used as the basis for training of staff in the identification of Aboriginal or Torres Strait Islander people. Training should include topics to ensure that staff:

- Understand why the information is needed.
- Understand the importance of collecting accurate and complete information.
- Are aware of the standard ABS question and understand that the question must be asked of all clients on first contact or presentation to the service.
- Are able to clearly explain to clients the reasons for collecting this information.
- Can respond appropriately to clients who ask why the information is needed.
- Are equipped to deal with difficult situations related to asking the question.
- Understand and are aware of follow-up procedures for obtaining missing information and ways in which data collection and data quality can be improved.
- Understand that it is the client's choice as to whether they identify or not and that all clients have the right to decline to supply this information.
- Understand and are aware of the importance of confidentiality.
- Are trained in cultural safety issues and cultural sensitivities. Staff should be aware that for some clients English is not their first language and that an interpreter and/or Aboriginal Liaison Officer may be of assistance.
- Know how to record Aboriginal or Torres Strait Islander identity information correctly either on paper form or in computerised systems.
- Are knowledgeable of specific health issues of concern and relevance to Aboriginal or Torres Strait Islander populations.

Training could be incorporated into standard orientation/induction and training programs conducted by services on a regular basis. Where attendance at a training program is difficult, alternatives should be considered including video conferencing or self-paced learning using online training, DVD or other media. Induction programs could include information about the local Aboriginal or Torres Strait Islander population if applicable.

D1 Staff training, Continue

Professional development programs should be available to equip point of service staff with the skills needed to deal with clients if difficult situations arise, particularly when asking questions that could be perceived as sensitive.

The local organisation should determine who could provide training and consider using experts within Aboriginal Health Services, Aboriginal Medical Services and Aboriginal Health Organisations who have had experience dealing with Aboriginal or Torres Strait Islander patients and are knowledgeable of Aboriginal or Torres Strait Islander-specific issues; state/territory health departments, as well as local Aboriginal people. Organisations should also make use of, and be aware of, current training programmes already developed by states/territories, health authorities, the Aboriginal Health Council of Western Australia in collaboration with the Royal Australian College of General Practitioners, Divisions of General Practice and Aboriginal organisations (see below).

Periodic assessments of the adequacy and effectiveness of training could be considered by means of direct evaluation of training outcomes and audits of Aboriginal or Torres Strait Islander identification.

Training programs that have already been developed by the states and territories and national organisations include:

- Collecting patient registration information training program (NSW Health) (http://www.health.nsw.gov.au/im/ahisu/training/pr_manual.pdf)
- The Indigenous identification staff awareness package (Queensland Department of Families).
- Contact statsfeedback@families.qld.gov.au for information on this package.
- Collecting Indigenous Status for Data Collectors in WA Health Services (WA Australian Bureau of Statistics).

Training sessions can be arranged by contacting the ABS Indigenous Unit on 08 9360 5110 or through the Department of Health WA.

Queensland Health has also produced two training presentations:

- Indigenous identification in health data collections: For data collectors and service providers in health services (Queensland Health)
- Collecting personal health information: A presentation for data collectors and health service providers

Copies of these training presentations are available from the Data Services Unit, Queensland Health, GPO Box 48, Brisbane QLD 4001; ph. 07 3234 0922.

- A Doctor training video has been developed by health services and Aboriginal organisations within Victoria for the training of junior doctors and other medical staff in culturally safe work practices with Aboriginal patients. This is being trialled in 2007 and once completed will be made available to health services across Victoria.

For more information on this video contact Koori Human Services Unit, Department of Human Services (email: koori@dhs.vic.gov.au)

- ‘GP training program’ run by James Cook University includes a cross cultural training workshop.

- Cultural Safety training modules for GPs entitled 'Working better in Aboriginal and Torres Strait Islander Health' have been developed by the Aboriginal Health Council of WA (AHCWA). This program was commissioned by the Royal Australian College of General Practitioners (RACGP) with funding provided by the Australian Government Department of Health and Ageing. These modules were pilot tested in 2007 as part of the Active Learning Programs run by the RACGP and it was recommended that this program be delivered across Australia in association with the National Aboriginal Community Controlled Health Organisation. For more information on these modules (contact AHCWA project officer Juliette Hubbard on 08 9227 1631; Juliette.Hubbard@ahcwa.org or visit www.racgp.org.au/aboriginalhealth unit/previous projects).
- General practice training in Aboriginal and Torres Strait Islander health run by regional training providers (see General Practice Education and Training (GPET) booklet: Training in Indigenous Health – Making a difference AND gaining invaluable General Practice Skills).

http://www.agpt.com.au/pdf/Training%20In%20Aboriginal%20and%20Torres%20Strait%20Islander%20Health1.pdf

- Aboriginal Health videos/dvds—'Doctors in Aboriginal Health, Aboriginal Health Workers, Cross-Cultural Awareness, Insight into Aboriginal Community Control' produced by Aboriginal Nations Australia and available in the RACGP website (http://www.racgp.org.au/aboriginalhealthunit/video).

D2 Community education

National and state/territory authorities should consider supporting Aboriginal communities and representative bodies to implement appropriate community education programs targeted at both the Aboriginal or Torres Strait Islander community and the wider community focusing on the importance of collecting Aboriginal or Torres Strait Islander identity information.

There may be concerns in Aboriginal or Torres Strait Islander communities about the possible uses of data and myths in the non-Indigenous community about better services for Aboriginal and Torres Strait Islander peoples that can affect the collection of data on Aboriginal or Torres Strait Islander status.

An effective community education program will assist staff to overcome some of the barriers experienced when collecting Aboriginal or Torres Strait Islander status information. For example non-Indigenous clients are less likely to object to being asked the question if they have an understanding that the question needs to be asked of everyone and why it is being asked.

Aboriginal Health Services, GPs and other primary health care services can play a vital role in improving the identification of Aboriginal or Torres Strait Islander Australians in health data by informing their clients of the importance of identifying, the reasons for identifying and encouraging Aboriginal or Torres Strait Islander clients to identify in other health services. Understanding of the reasons for being asked should lead to increased willingness on the part of Aboriginal and Torres Strait people to identify. These services can also inform the Aboriginal or Torres Strait Islander population of the specific benefits of identifying as Aboriginal or Torres Strait Islander such as additional Medicare item numbers (Adult and Child Health Checks), improved access to medications, and the option of bulk-billing in some areas. The use of promotional material is suggested as a means for education of clients attending these services.

D3 Promotional material

Promotional material aimed at addressing issues of Aboriginal or Torres Strait Islander identification could be developed and shared by national bodies, state and territory health authorities and other service providers.

A useful approach may be to aim such promotional material at the whole community, not just Aboriginal or Torres Strait Islander Australians.

The material could focus specifically on Aboriginal and Torres Strait Islander identification or on the importance of a number of data items of importance to service delivery, care and the planning of health services including Aboriginal or Torres Strait Islander identity.

The material would be most effective using modern media, tailored to suit different audiences, including those with low literacy skills or different language groups.

Material that has had input from and uses the faces of Aboriginal and Torres Strait Islander people of different appearances can be effective, particularly in illustrating that assumptions about identity should not be based on appearance.

Promotional material could provide information on the importance of accurate data, including Aboriginal or Torres Strait Islander identity information, why the Aboriginal or Torres Strait Islander identity question needs to be asked of all people (as well as other important questions), how family background may be important for improved medical care, the services that are available to Aboriginal and Torres Strait Islander peoples such as Aboriginal Liaison Officers, Aboriginal Health Workers and annual child and adult Health Checks. It should encourage Aboriginal and Torres Strait Islander people to identify when attending health services and should be positive rather than simply reiterating the poorer health status of Aboriginal or Torres Strait Islander people.

The type of promotional material that could be used will depend on the available resources of the individual service. Some examples of promotional material that could be developed are:

- Cartoons or pictograms that appeal to younger people.
- Posters displayed in prominent areas such as reception, waiting areas (such as in emergency or outpatient departments and general practices) and wards.
- DVDs/videos played on TV screens in waiting areas and wards.
- Educational and health promotional material played over the phone whilst clients are on hold.
- Television advertisements or community messages.

State/territory health authorities, Area Health Services, general practice organisations and local divisions could promote material developed within their local area.

Material that has already been developed by services and states/territories include:

- Locally produced Aboriginal identity posters developed by health services in Victoria aimed at improving the identification of Aboriginal or Torres Strait Islander patients at admission. Many include photos and contact details of Aboriginal community members and staff members and are entitled ‘Are you Aboriginal or Torres Strait islander? If you are, please let us know so we can use this information to plan and deliver improved services. To obtain a copy of such posters you can contact Bendigo Health, Victoria or the Koori Human Services Unit, Department of Human Services (email: koori@dhs.vic.gov.au)

- Posters and pamphlets which provide information to clients on why they are asked the question and for staff on why they need to ask the question. Such material have been produced by the ABS and are entitled:
  - *Aboriginal? Torres Strait Islander? Do you know? Please always ask: "Are you of Aboriginal or Torres Strait Islander origin?" Brochure aimed at health professionals*
  - *Are you Aboriginal? Torres Strait Islander? To find out we need to ask you "Are you of Aboriginal or Torres Strait Islander origin?" Brochure and poster aimed at individuals*

  Further information about, and copies of, the materials listed here can be obtained from the National Centre for Aboriginal and Torres Strait Islander Statistics; ph. 08 8943 2111 or email: ncatsis@abs.gov.au.

- The Flinders and Far North Division of General Practice have created their own poster and pamphlet with local faces which have adapted from the ABS resources, entitled 'Are you of Aboriginal or Torres Strait Islander origin?. Any of these people could be of Aboriginal or Torres Strait Islander origin. To find out we need to ask! Please answer this question. Your answers are used to plan and deliver Australia's health services'.

  To obtain copies of this material contact (08) 8642 3166.

- Similar material has been developed by Queensland Health and Queensland Department of Aboriginal and Torres Strait Islander Policy. These are listed below.
  - *Are you of Aboriginal or Torres Strait Islander origin? Why you are asked this question? For copies of the brochure and poster, contact the Office of Economic and Statistical Research; ph. 1800 068 587; email: oesr@treasury.qld.gov.au.*
  - *Who's Indigenous? What does it mean? Who wants to know and Why? This brochure can be found at: http://www.health.qld.gov.au/brochure/indigenous.asp*
- Posters which aim to encourage Aboriginal and Torres Strait Islander people to identify through Medicare enrolments (contact Medicare: Medicare@medicareaustralia.gov.au)

References

ABS 2004. National Aboriginal and Torres Strait Islander Social Survey 2002. ABS cat. No. 4714.0. Canberra: ABS.

ABS 2007. Births Australia 2006. ABS cat. No. 3301.0. Canberra: ABS.

ABS 2008. Population characteristics, Aboriginal and Torres Strait Islander Australians, 2006. ABS cat. No. 4713.0. Canberra: ABS.

ABS 2008b. Experimental estimates of Aboriginal and Torres Strait Islander Australians, June 2006. ABS cat. No. 3238.0.55.001

ABS and AIHW (Australian Bureau of Statistics & Australian Institute of Health and Welfare) 2005. The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005. ABS cat. no. 4704.0; AIHW cat. no. IHW14. Canberra: ABS & AIHW.

ABS and AIHW 2008. The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2008. ABS cat. no. 4704.0; AIHW cat. no. IHW21. Canberra: ABS & AIHW.

AIHW 2003. National Health Data Dictionary, version 12. AIHW cat. no. HWI 4344SET. Canberra: AIHW.

AIHW 2005. Improving the quality of Indigenous identification in hospital separations data. AIHW cat. no. HSE 101. Health Services Series no. 25. Canberra: AIHW.

AIHW 2008 forthcoming (web only). Report on the flow of Aboriginal and/or Torres Strait Islander status information in six health data sets. Canberra: AIHW.

AIHW forthcoming - AIHW Hospital audits study. AIHW: Britt H, Miller, GC, Knox, S, Charles J, Valenti L, Henderson J, Pan, Y, Bayram C & Harrison C 2003. General Practice Activity in Australia 2002–2003. Cat. no. GEP 14. General Practice Series no. 14. Canberra: AIHW.

AIHW: Leeds, K, Gourley, M, Laws, P, Zhang, J, Al-Yaman, F, Sullivan EA 2007. Indigenous mothers and their babies 2001–2004. AIHW cat. No. PER38. Perinatal Statistics Series no 19. Canberra: AIHW.

ATSIHWIU (Aboriginal and Torres Strait Islander Health and Welfare Information Unit) 1999. Assessing the quality of identification of Aboriginal and Torres Strait Islander people in hospital data, Australian Health Ministers' Advisory Council. Canberra: AIHW and ABS.

DoHA 2004. Improving Indigenous identification in communicable disease reporting systems. Public Health Information Development Unit: University of Adelaide.

Kehoe H, 2007. A call of action: Better Aboriginal and Torres Strait Islander health through better GP identification. Canberra: ACT Division of General Practice

Lovett R 2006. Bound Volume for Master of Applied Epidemiology (Indigenous Health) Chapter 4.

Morgan,D.L., & Allen,R.J. (1998). Indigenous health: a special moral imperative. Aust N.Z.J Public Health, 22(6), 731-732.

National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases 2004. Evaluation of National Indigenous Pneumococcal and Influenza Immunisation Program, 2003, (unpublished study)

Riley I, Williams G, Shannon C, et al. Needs Analysis of immunisation for Aboriginal and Torres Strait Islander people in Queensland, Final Report, September 2004, Centre for Indigenous Health, University of QLD

Ring IT & Brown N 2002. Indigenous health: chronically inadequate responses to damning statistics. Medical Journal of Australia 177(2/16): 629-31.

Young 2001. Assessing the quality of identification of Aboriginal and Torres Strait Islander people in Western Australian Hospital data, 2000. Health Information Centre Occasional paper 13. Health Department of Western Australia: Perth.

Appendix 1: National, jurisdictional and organisational processes

Policies and processes should be in place to support staff in collecting the Aboriginal or Torres Strait Islander status of clients and to implement improvements to work-practices to achieve greater consistency in the collection of this information. These policies and processes should be regularly reviewed to ensure that they remain effective.

National agencies, jurisdictions and general practice organisations should ensure relevant materials and resources, such as policies, procedure manuals, best practice guidelines and training packages are widely available, for example through an appropriate web site.

Strategies at the national or jurisdictional level that could be adopted to improve Aboriginal or Torres Strait Islander identification include the following:

- Ensure that forms are standardised for the collection of Aboriginal or Torres Strait Islander identity information within individual services and across services and recording systems are standardised to conform to the ABS question and categories recommended in this document.
- Consider liaising with computer software companies to ensure that Aboriginal or Torres Strait Islander status is a mandatory item in recording systems, to improve the ease with which Aboriginal or Torres Strait Islander identity data is recordable and accessible for checking and updating and to flag records where Aboriginal and Torres Strait Islander status is missing (e.g. pop-up reminders that appear on the screen when a patient presents to the service and their Aboriginal or Torres Strait Islander identity is not complete). Such improvements are currently being trialled for the general practice computer software program 'Medical Director'.
- Consider providing funding to assist in the training and support of services in the implementation of these national best practice guidelines.
- Ensure that consistent and regular training programmes on cultural sensitivity and the importance of collecting Aboriginal or Torres Strait Islander identity information are conducted for staff who are involved in the collecting and recording of Aboriginal or Torres Strait Islander identity (see Section D: Training and Education for more information on training.
- Consider providing funding to local services to employ Aboriginal Liaison Officers or Aboriginal Health Workers.
- Health authorities should consider conducting regular reviews of state-wide procedures for the collection, recording and verification of Aboriginal or Torres Strait Islander identity information as the basis for planning action to improve the quality of Aboriginal or Torres Strait Islander identity information.
- Consider mechanisms to increase management commitment to improved Aboriginal or Torres Strait Islander status data quality. For example, by incorporating requirements in service arrangements and identifying sources of funding to be directed at the adoption of arrangements to improve identification; financial loading given to services based on Aboriginal or Torres Strait Islander patients identified.
- Consider incentives for services and organisations to accurately collect and record Aboriginal or Torres Strait Islander identity information and undertake auditing. Ways in which incentives could be given include accurate recording of Aboriginal or Torres

Strait Islander identity linked to hospital and GP accreditation (collecting identity information is a requirement of the Royal Australian College of General Practitioners practice accreditation); higher Medicare rebates for Aboriginal or Torres Strait Islander clients recorded; Practice Incentive payments for completion of Aboriginal or Torres Strait Islander identity in practice records; and financial incentives provided for Aboriginal or Torres Strait Islander specific Medicare Items undertaken which would make it worth the effort for practices to review all patient demographics. In some states and territories, a 30% loading is applied to Aboriginal or Torres Strait Islander patients separated from public hospitals so that appropriate funding can be allocated to hospitals. Financial loading could be considered as an incentive to improve the accuracy of recording Aboriginal or Torres Strait Islander identity information.

Strategies at the local service level could include:

- All forms used should be consistent with the ABS standard question on Aboriginal or Torres Strait Islander status and the categories recommended for use in these guidelines included.
- Staff and individual managers should be accountable for collecting accurate Aboriginal or Torres Strait Islander identity information. Job descriptions and duty statements for staff involved in the collection, recording and validation of data could include responsibilities surrounding accurate data collection.
- Local training resources should be identified by organisations to facilitate training of staff and consider incorporating this into performance evaluation.
- Services should be encouraged to employ Aboriginal and Torres Strait Islander staff (e.g. Aboriginal Enrolled and Registered Nurses, administrative staff), Aboriginal Liaison Officers or Aboriginal Health Workers.
- Managers should maintain the enthusiasm of, and provide support to, staff to collect accurate Aboriginal or Torres Strait Islander identity information.
- Promotional material could be made available in waiting rooms and reception areas.
- Services should be encouraged to review the privacy of areas in which clients are interviewed to obtain Aboriginal or Torres Strait Islander identity and other information. For example, if private rooms are available, patients could be given the option of answering such questions in these rooms; nurses and GPs could ask personal details of patients in screening rooms as part of routine health screening; or forms could be used to record this information rather than asking the question verbally. While forms can overcome many privacy issues, it should be noted that they can pose problems for people who have low-level literacy skills or do not have English as their first language. Lack of privacy of interview areas may contribute to the reluctance of people to identify.

Appendix 2: Other practice guidelines and relevant material

Guidelines and documents that contain information on the collection and recording of Aboriginal or Torres Strait Islander identity

A number of documents are available that outline collection and recording practices regarding Aboriginal or Torres Strait Islander identity information. These are shown in the table below. Some states and territories also have data collection manuals which have a section on the Aboriginal or Torres Strait Islander identification data item which are also included below and can be requested from state and territory health departments.

Table A1: Policies, guidelines and data manuals that include information on the Aboriginal or Torres Strait Islander identity data item

State/territory	Policies/guidelines/manuals
National	• Improving the quality of Indigenous identification in hospital separation data (AIHW 2005). http://www.aihw.gov.au/publications/hse/iqiihs/iqiihs-c00.pdf • Fact sheet: The identification of Aboriginal and Torres Strait Islander people (RACGP 2006). http://www.racgp.org.au/Content/NavigationMenu/PracticeSupport/StandardsforGeneralPractices/RACGPStandards3rdEdFactSheets/200608Identificationofpatients.pdf • Information sheet for general practices: guidelines for Aboriginal and Torres Strait Islander identification of patients (DoHA, unpublished) • Guidelines for Aboriginal and Torres Strait Islander Identification of Patients (Flinders and Far North Division of General Practice, unpublished; adapted from DoHA guidelines)
NSW	• Better practice guidelines to improve the level of Aboriginal and Torres Strait Islander identification in the NSW public health system (NSW Health 2000) http://www.health.nsw.gov.au/pubs/2000/pdf/bprac-ab-id.pdf • Principles for recording Aboriginal and Torres Strait Islander Origin information of patients (NSW Health 2000) http://www.health.nsw.gov.au/pubs/2000/pdf/circular_2000_38.pdf • Improving Aboriginal and Torres Strait Islander origin information in NSW: Report of a pilot study. http://www.health.nsw.gov.au/pubs/1999/pdf/origin.pdf • Aboriginal health information guidelines • Aboriginal and Torres Strait Islander Origin—recording of Information of Patients and Clients (March 2005) http://www.health.nsw.gov.au/policies/pd/2005/pdf/PD2005_547.pdf • Aboriginal and Torres Strait islander Peoples—Preferred Terminology to be Used (January 2005) http://www.health.nsw.gov.au/policies/PD/2005/pdf/PD2005_319.pdf • Privacy of Personal information on Aboriginal Staff and Clients (January 2005, unpublished)
Vic	• Principles of recording Aboriginal status (Department of Human Services, Koori Human Services Unit 2007, unpublished). 2004 version can be found at: http://www.health.vic.gov.au/koori/status.pdf • 'Are you of Aboriginal or Torres Strait Islander descent?: information for staff involved in hospital admissions' (Department of Human Services, Koori Human Services Unit, 2006—unpublished) • Case studies in best practice of recording Aboriginality (Koori Health 1996) http://www.health.vic.gov.au/koori/archive/casestud/index.htm

(continued)

Table A1 (continued): Policies, guidelines and data manuals that include information on the Aboriginal or Torres Strait Islander identity data item

State/territory	Policies/guidelines/manuals
Qld	• Queensland Health Patient Admitted Data Collection (QHPADC) manual http://www.health.qld.gov.au/hic/qhapdc2005/QHAPDC%20Manual%2005-06dk.pdf
WA	• Hospital Morbidity Data System Reference Manual http://www.health.wa.gov.au/ICAM/publications/pubdocs/HMDS_Ref_Manual_July_2006.pdf
SA	• Integrated South Australian Activity Collection (ISAAC) manual http://www.health.sa.gov.au/isaac/
Tas	• Department of Health and Human Services information guidelines (unpublished)
NT	• Patient identification, registration, classification and charging guide (unpublished)

Other documents that informed these guidelines

The papers described and summarised below were compiled after the completion of each stage of the project on improving identification of Aboriginal and Torres Strait Islander peoples in health data sets in leading up to the development of these guidelines.

Analysis of the quality of Aboriginal or Torres Strait Islander identification (Stage 1 report)

This paper presents analysis of the quality of the Aboriginal or Torres Strait Islander identifier in six health data collections—The Perinatal Data Collection, Births registrations, BEACH Survey of General Practice, Medicare data, the National Hospital Morbidity Database and the National Mortality Database—in terms of the proportion of records where Aboriginal or Torres Strait Islander identity is not recorded, and how this varies by age, sex, jurisdiction, region, remoteness, and where possible, statistical division. The use of the ABS standard question on Aboriginal and Torres Strait Islander identity and categories for responses in collection forms is also examined.

The main findings from this paper were that the ABS standard question and categories are used by most or all jurisdictions in the six health data sets examined. The proportion of records where Aboriginal or Torres Strait Islander identity is not recorded was low in some collections (e.g. below 0.1% in the Perinatal Data Collection) and high in others (eg 12% in BEACH Survey). The proportion of records with a 'not stated' Indigenous status varied by age, state/territory and remoteness for most data sets examined; being highest in the younger age groups, states and territories where there is a relatively small proportion of the population that is Indigenous (e.g. New South Wales), and in major cities; and lowest in the older age groups, states/territories with high Indigenous representation in the population (e.g. Northern Territory), and remote areas. The overall proportion of records where Aboriginal or Torres Strait Islander identity is not recorded has remained relatively stable over the last few years in most collections examined however has showed declines in some jurisdictions.

Report on the flow of Aboriginal or Torres Strait Islander identity information in six health data sets (Stage 2 report)

This paper briefly explores the data pathway regarding Aboriginal or Torres Strait Islander identity information in six health data sets (perinatal data, births registrations, GP data via the BEACH Survey of General Practice, Medicare data, hospital data and death registrations), and the factors that could affect the quality of Aboriginal or Torres Strait Islander status data at each step along the pathway. It assesses the information flow from the point of service, to an administrative data collection and to the final data collection.

The main findings from this paper were that in general, information collected at the point of service (stage 1), is submitted to state and territory collections (stage 2) and is finally compiled in a national data collection (stage 3). The exceptions to this are:

- the birth registration data which bypasses stage 1
- the BEACH data which bypasses stage 2
- the Medicare data which bypasses stages 1 and 2.

For most collections, data are collected initially on paper forms and then entered into a data system at various stages depending on the collection. In the hospital data collection and perinatal data collection, patient demographic information is often obtained verbally by staff and the information entered into a data system straight away. Once data have been entered into a data system the transfer of data to subsequent stages is usually in electronic format only. Not all data items are passed on to the next stage. The frequency that data are transferred to the next stage also varies from weekly to annually depending on the collection and the stage of collection.

The use of mandatory fields and default settings for recording Indigenous status; data validation procedures; and practices for the follow-up of records with not stated Indigenous status vary for each collection. In the hospital data collection, Indigenous status is a mandatory field in most states and territories and there is usually no default option. In the perinatal data collection, patient demographic information such as Indigenous status is commonly obtained from the hospital database in which case the collecting and recording of Indigenous status information is the same as in the hospital data collection. There is generally little validation of Indigenous status data or follow-up of not stated records undertaken by point of service personnel however this may be more commonly undertaken in the state/territory data collections.

Most forms use the standard ABS question on Indigenous status and the standard categories for recording this information. In cases where the question is asked verbally such as in hospitals, the standard question may not always be used. All national data collections use the standard codes to record Indigenous status however the recording codes used in the state/territory collections and the point of service databases can vary. The format in which the information is passed on to each of the stages can vary between jurisdictions. For example, in the hospital data collection, in some states and territories, hospitals will map Indigenous status data to the standard categories before sending it to the state/territory collection, and in other jurisdictions, the state/territory Health Authority will do this before sending the data to the AIHW for the national collection.

In most cases, training on the collection and recording of Indigenous status data is minimal and most states/territories do not have any official policies or guidelines regarding the collection of Indigenous status information.

This report will be made available on the Australian Institute of Health and Welfare Website in 2008.

Report on focus groups on the identification of Aboriginal and Torres Strait Islander people in hospital and perinatal data (Stage 3 report)

This paper presents the findings of focus group sessions which were conducted throughout Australia with point of service hospital staff, including midwives, health information managers and data administrators on the identification of Aboriginal and Torres Strait Islander people in hospital and perinatal data. The information presented covers the usual practices for collecting and recording information on the Aboriginal or Torres Strait Islander identity of clients; barriers to obtaining information about a client's Aboriginal or Torres Strait Islander identity; policies and guidelines, incentives, training and education, promotional material and suggestions for improving the identification of Aboriginal or Torres Strait Islander people in hospital and perinatal data.

A summary of the focus group findings is presented below.

Collecting and recording Indigenous status: Usual practices for collecting and recording Indigenous status information vary substantially between hospitals and states/territories. There appeared to be marked differences in 'how things work' between large metropolitan hospitals and smaller rural hospitals. This is partially due to hospital staff in rural areas knowing the patient or their family or because the question may be asked by clinical staff. In most hospitals, the information is asked verbally and recorded electronically, though in some hospitals the patient is asked to complete a form. It is clear that the wording of the question asked by staff is variable and may often not be the same as the standard ABS question. However, the categories collected mostly include the standard ABS codes, but there is also variation between hospitals and states/territories in whether and which additional codes are collected.

Validating/auditing: Validation of Indigenous status information and follow-up of missing data appears to be minimal in many hospitals. Aboriginal Liaison Officers are employed in some hospitals, and some have a role in updating or checking the Indigenous status information. Official auditing or evaluation of Indigenous status data appears to be undertaken usually by the state/territory health departments, but less so by hospitals.

Barriers: Participants discussed many barriers to obtaining accurate information on Indigenous status. These were mainly related to lack of training of staff, staff reluctance to ask the question, patient refusal to answer the question, Indigenous patients not wanting to identify, lack of privacy when answering the question, no checking/validating of data or follow up of missing information, and system inadequacies (e.g. outdated systems that require new staff to look up codes).

Training: In many hospitals there is no regular mandatory training of staff on cultural awareness issues or Indigenous identification. Staff are not always aware of the importance of collecting Indigenous status information and are often not trained in how to respond to patients who ask why this information is necessary or how to deal with difficult situations.

Policies and guidelines: Most states and territories have policies and/or guidelines regarding the collection of information in hospitals, which may be specific to Indigenous status information or may be relevant to all information collected within the hospital setting.

Incentives: In three states, Victoria, South Australia and New South Wales, a 30% loading is paid to public hospitals for Indigenous patients.

Promotional material: Promotional material aimed at improving the identification of Indigenous patients consists mostly of posters and pamphlets displayed in patient waiting areas. Many participants did not think these were overly useful for a range of reasons. On the other hand, in some hospitals this kind of material was seen as very useful, especially if produced locally and if used as part of a broader campaign to improve identification.

Suggestions for improving identification: Many suggestions for improving the identification of Indigenous people in hospitals were discussed along with practices that have proven effective in the collection and recording of Indigenous status information. Some of these suggestions could be implemented in the short-term with little difficulty, some could be implemented in the medium term requiring more cost and effort, and some may be feasible in the long-term but are dependent on other (national) developments. The suggestions for improvement fall under the categories of training and education of staff; education of GPs and primary health care services; education of the community; system improvements; administrative practices; and promotional material.

Input from General Practice sector (Stage 3)

Input from the GP sector was provided in the form of comments provided on relevant material proposed for inclusion in an initial draft of these guidelines.

The main comments provided revolved around the importance of emphasising that Indigenous identification information can improve care thorough provision of targeted health programs such as health checks and immunisation schedules; that Indigenous status should be made mandatory in all general practice software; that written forms are preferred to verbally asking the question by reception staff, GPs and Indigenous clients; that it is impractical for staff to verbally confirm a patient’s Indigenous status when they have answered a previous time; that accurate recording of Indigenous status should be promoted as part of general data cleaning and improvement; that motivators or incentives are required for practices to collect Indigenous status information and undertake auditing; and concerns about privacy in asking patients to provide their Indigenous identity.

Survey of national data custodians (Stage 4)

A survey was undertaken of the national data administrators of the six data collections who are responsible for assessing the quality of information to obtain information on data validation processes undertaken and general data quality within each collection. This included the ABS, Medicare Australia, and the AIHW (Hospitals Unit, National Perinatal Statistics Unit and the Australian General Practice Statistics and Classification Centre).

Responses to the survey showed that Indigenous status data is validated on a regular basis in some data collections (e.g. Birth registrations, Death registrations and Hospital database) but not in others (e.g. Perinatal Data Collection, Medicare registrations, BEACH survey). The main validations that are performed on Indigenous status data include comparing Indigenous status against the number or percentage of Indigenous records in the previous year’s data; and comparing Indigenous status against country of birth. Validation of Indigenous status data is generally undertaken as part of the general validation and edit procedures for all supplied records however there may be some specific edits and reports which look specifically at Indigenous status. Follow-up of missing Indigenous status information is rarely undertaken by the national data administrators.

Past and current projects on the under-identification of Indigenous Australians

This paper provides an overview of past and current projects on the under-identification of Indigenous Australians in administrative data collections including general practice data, perinatal data, hospital data, mortality data, communicable disease registries, pathology forms and community services. It reports on the main findings and recommendations made in the following reports and studies: Needs Analysis of Immunisation for Aboriginal and Torres Strait Islander People in Queensland; Evaluation of National Indigenous Pneumoccocal and Influenza Immunisation Program, 2003; A call for action: Better Aboriginal and Torres Strait Islander health through better GP identification; Improving the quality of Indigenous identification in hospital separations, State/territory and national studies that assess the level of under-identification of Indigenous people in hospital data; Case Studies of 'Best practice' in recording Aboriginality in Victorian hospitals; Attitudes about Indigenous status data collection in ACT public hospitals; Assessment of Indigenous status data quality in Perinatal data 1991–2004; Improving Indigenous identification in communicable diseases reporting systems; Feasibility study into increasing the completeness of the Aboriginal identifier in ACT Government registries; Report on the Data quality of Aboriginal and Torres Strait Islander identification: update on eight community services data collections 2006; Improving Indigenous identification in Home and Community Care.

This report will be made available on the Australian Institute of Health and Welfare Website in 2008.