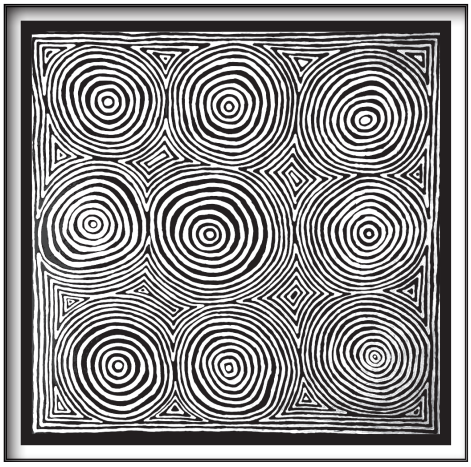
Australian Government

Australian Institute of Health and Welfare

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



Cover artwork: **Jackie Kurltjunyintja Giles, *Tjumu Tjumu 2009***,
152 x 152cm acrylic on linen, Kayili Artists, © Jackie Kurltjunyintja Giles
art@kayili.com.au

Tjamu Tjamu is east of Kiwirrkurra. It is the artists fathers country and part of the tingarri*. There is a rockhole there and it is the place a group of ladies camped with one wati (man). He was the kangaroo ancestor and the ladies were his sisters, aunties, mothers and grandmothers. He wanted all the ladies to be his wifes. He came along from the north and called the ladies to come and camp with him. They wanted to call him Tjamu Tjamu (grandfather, grandson) but he wanted to be called Kurril Kurril (keep as a spouse someone who is not eligible; IAD Press) which is the name given to a rockhole at this place. The kangaroo- malu tjukurrpa continues travelling to Tjutalpi, Witunkuntja, Wirti, Makarra, Millmillpa and Kurryl, this is the artists tjukurrpa.

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Canberra

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Please note that there is the potential for minor revisions of data in this report.

Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

These appendixes can be found at <http://www.aihw.gov.au/publication-detail/?id=6442468342>.

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

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Summary

Aboriginal and Torres Strait Islander people are under-identified in many health-related data collections. Self-report in response to the standard Indigenous status question is the most accurate means of ascertaining a client's Indigenous or non-Indigenous status.

The development of the best practice guidelines

- The Best Practice Guidelines document the recommended national approach for collecting and recording accurate information on the Indigenous status of clients.
- The guidelines were informed by a review of previous research into Indigenous under-identification in administrative data collections, consultation with key stakeholders, service providers, health authorities and data custodians for the range of key health data collections covered by the guidelines.
- The guidelines address the need for a more systematic national approach to ensure the standard Indigenous status question is asked correctly and consistently of all clients of health services, and that this information is recorded properly.
- They comprise three parts—*Part A: Asking the question*, *Part B: Recording responses* and *Part C: Putting the guidelines into practice*.

Other recommendations

- This report also includes recommendations for supporting the implementation of the Best Practice Guidelines through staff training, as well as data quality assurance strategies for service providers and data custodians.
- The report notes the need to promote guidelines widely so that their use becomes routine across various service provision settings and client groups.
- The promotion of these guidelines needs to address prevailing beliefs and attitudes amongst both staff and clients of health services that may undermine best practice at the point of data collection.
- The Council of Australian Governments (COAG) National Indigenous Reform Agreement sets out a timeline for all jurisdictions to complete implementation of the guidelines by December 2012.
- The AIHW's National Indigenous Data Improvement Support Centre (NIDISC) has been established to support jurisdictions and service providers to implement the guidelines.

Introduction

Despite improvements in recent years, there are continuing problems with the under-identification of Aboriginal and Torres Strait Islander people in many health-related data collections. A more systematic approach is required to ensure the standard Indigenous status question is asked correctly and consistently of all clients, and that this information is recorded accurately.

Reliable data on the health of Indigenous Australians is essential for measuring the effectiveness of health services in meeting the needs of Aboriginal and Torres Strait Islander people, and for further policy development, planning and improvement in service delivery. The correct and consistent collection and recording of Indigenous and non-Indigenous status in administrative processes is also an important practice in upholding the rights of all clients of health services.

Aboriginal and Torres Strait Islander clients of health services should be provided with the option of accessing information and services specifically designed to meet their needs; this can only be ensured if all clients of a service are given an opportunity to respond to the standard Indigenous status question. Furthermore, all clients have the right to decide for themselves whether they wish to report their status as Aboriginal, Torres Strait Islander, both Aboriginal and Torres Strait Islander or neither Aboriginal nor Torres Strait Islander in a given situation, and they must be asked the standard question for this right to be exercised.

The Best Practice Guidelines detailed in this publication were developed to improve the collection and recording of Indigenous status in key national health data sets. They set out best practices in collecting and recording this item, and strategies for supporting best practice that can be implemented by data collectors, data managers and data custodians. Although these guidelines were developed to address issues for specific health data sets, most of these guidelines and recommendations could be readily applied to other data collections in health, education and community services sectors.

The collection of Indigenous status

National standards

Adherence to national standards for items in data collections helps to ensure consistency and promote confidence that the same concept is being measured in each collection. Self-report is the most accurate means of ascertaining an individual's Indigenous or non-Indigenous status, and a standard question is used to collect this item in the Census, Australian Bureau of Statistics (ABS) household surveys and in national administrative datasets. There is also a national standard for the recording of responses to this question. In order to collect accurate data, the standard question must be asked of the respondent as it is worded, and the response must be recorded correctly.

The impact of under-identification

Under-identification occurs when Indigenous status is not correctly collected or accurately recorded for all clients. Incorrect or inconsistent data collection can lead to Aboriginal and Torres Strait Islander clients being incorrectly reported as non-Indigenous, or as 'not stated'. These records are not included in systems for monitoring and understanding the health of Aboriginal and Torres Strait Islander Australians, which raises problems for conducting analysis and drawing conclusions from the data available. It is unknown whether the characteristics of these 'missing' Aboriginal and Torres Strait Islander clients are different or similar to those that have been reported as Aboriginal and/or Torres Strait Islander, therefore it is difficult to determine whether the available data are representative of Aboriginal and Torres Strait Islander service users overall, or whether the data contain certain biases.

The degree of under-identification in data sets can vary across different jurisdictions, sectors and service providers, due to varying standards of data collection practices and systems. Overall under-identification, and variations in the degree of under-identification across collections, can create difficulties for measuring the gap in health outcomes between Indigenous and non-Indigenous Australians, and for monitoring progress in closing the gap.

The unknown numbers and characteristics of 'missing' Aboriginal and Torres Strait Islander service users in administrative datasets, and the subsequent inability to identify and control for biases, affects the accurate monitoring of specific health conditions and health outcomes in the Indigenous population. For example, it is unknown whether Aboriginal and Torres Strait Islander clients presenting with certain conditions are more likely to have their Indigenous status correctly recorded than those presenting with other conditions, making the prevalence of specific health conditions and outcomes of interventions in the Indigenous population difficult to accurately monitor using administrative datasets. It is also difficult to determine whether sub-groups that appear more frequently as users of health services are those with the poorest health in the Indigenous population, or whether they are more likely than some other Aboriginal and Torres Strait Islander clients to have their Indigenous status recorded correctly when they present to a health service, or both.

Under-identification also creates difficulties in using administrative data to better understand Aboriginal and Torres Strait Islander people's preferences in the health services they access, and which services and policy interventions produce the best outcomes. This limits the degree to which researchers and policy-makers are able to identify and understand what works, or what *could* work, to overcome Indigenous disadvantage and improve health outcomes.

The extent of under-identification

The unknowns surrounding Indigenous under-identification create difficulties for measuring the extent of the problem. One method for estimating the extent of Indigenous under-identification in various datasets is analysis of the proportion of records where Indigenous status is not recorded, and how this varies by age, sex, jurisdiction, region and other relevant variables. The AIHW's analysis of the quality of Indigenous identification in key health datasets, undertaken as part of this project, found that the overall proportion of 'not stated' records has remained

relatively unchanged in most collections over the last few years. It ranged from below 0.1% in the National Perinatal Data Collection to 12% in the BEACH survey of general practice (Appendix A).

For those records where Indigenous status was recorded (i.e. records which indicated that the client is non-Indigenous, Aboriginal, Torres Strait Islander or both Aboriginal and Torres Strait Islander), data analysis cannot determine whether this status was recorded as a result of directly asking the client their status, and if it was, whether the standard Indigenous status question was used. Methods for exploring the practices of service providers in the collection of Indigenous status include data quality audits, staff and/or client surveys and focus groups with health service staff responsible for data collection.

Issues affecting the collection of Indigenous information

Several studies have been conducted to identify issues that affect the correct and consistent collection of Indigenous status in administrative datasets. More detailed information on these studies is provided in Appendix B.

A survey of staff in Australian Capital Territory (ACT) public hospitals in 2005, which examined attitudes towards asking the Indigenous status question of clients and the impact of these attitudes on the accuracy of Indigenous status in admission data, found that some frontline staff in hospitals had negative attitudes toward collecting Indigenous status information. Specifically, some staff fear asking presenting patients whether they are Aboriginal or Torres Strait Islander because of concerns about provoking aggressive responses from both Indigenous and non-Indigenous people. The study also reported that a number of staff felt the purpose of asking people if they were Indigenous was related to funding, and justified the irrelevance of collecting this information by stating that they believed that everyone should be treated equally, suggesting a belief amongst some staff that Indigenous Australians may receive unwarranted preferential treatment (Lovett 2006).

A number of participants in the study expressed a firm belief that their service 'treated everyone the same', and that collection of Indigenous status was not in keeping with such an ethos of equality. It should be noted that, firstly, a failure to ask the Indigenous status question correctly and consistently of all clients is in fact a failure to 'treat everyone the same'. Secondly, a client's response to the standard Indigenous status question should have no bearing on the standard of the treatment they receive. The collection of Indigenous status as a routine administrative procedure does not in itself contravene a service's commitment to equitable service provision.

Three studies have examined Aboriginal and Torres Strait Islander identification in general practice (Kehoe 2007; NCIRS 2003; Riley et al. 2004). Each found that only a minority of general practitioners (GPs) routinely collected the Indigenous status of patients. Many practices made assumptions based on appearance, or expected that patients would disclose their Indigenous status without being asked. Many GPs held the view that asking the question might offend patients and that since Aboriginal and Torres Strait Islander patients were likely to be a minimal proportion of their practice population, it was impractical to ask all patients their Indigenous status. Some GPs also felt that all patients should be treated equally and that no impact would or should derive from identification, and thus identification served no purpose.

The study undertaken by the ACT Division of General Practice found that there was widespread confusion amongst GPs about the criteria for Indigenous status (for example, questions about 'half-castes' and 'part-Aborigines' were common). The study also found that there was lack of knowledge of the Aboriginal and Torres Strait Islander health assessments or other available GP-mediated Indigenous–specific health initiatives, and that GPs believed that the reasons behind obtaining information on Indigenous status were bureaucratically driven and not beneficial to the patients (Kehoe 2007).

A study on improving Indigenous identification in communicable disease reporting systems also found a number of issues affecting the quality of Indigenous data. The issues reported were differences across jurisdictions in notification and reporting systems, limited understanding amongst practitioners of data collection obligations, limited understanding amongst both practitioners and clients of the reasons for collecting data and the uses of data, non-use of the standard Indigenous status question, lack of quality assurance measures and a perception of reluctance among Aboriginal and Torres Strait Islander people to disclose their Indigenous status (IIICDRPSC 2004).

The development of the best practice guidelines

The guidelines were commissioned by the National Health and Medical Research Council (NHMRC) and developed by the AIHW. The project was funded by both the NHMRC and the Office for 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 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 then Statistical Information Management Committee gave advice on the different stages of this project.

The project to develop the guidelines involved five separate stages outlined below. (More detailed information about each stage of the project is provided in Appendix C.)

- **Stage 1** analysed the quality of Aboriginal and Torres Strait Islander data in key health data sets.
- **Stage 2** examined how information flows from the point of service to the national data collection. (A report on this stage of the project is provided in Appendix D.)
- **Stage 3** involved focus group sessions with health-care personnel at the point of service (for example, 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.
- **Stage 4** involved interviews with key people who administer the national data collections.
- **Stage 5** involved the development of the Best Practice Guidelines based on all the information collected in the previous stages. This report completes Stage 5 of the project.

The research conducted in the development of these guidelines identified a range of issues affecting the correct and consistent collection and recording of Indigenous status. Many of these issues were similar to those found in previous studies. They were:

- lack of awareness and training of staff
- staff reluctance to ask the question
- client refusal to answer the question
- staff perceptions about Aboriginal and Torres Strait Islander clients not wanting to disclose their status
- lack of privacy when answering the question
- minimal checking/validating of data and follow-up of missing information
- inadequate data management systems.

The guidelines were developed to address these issues and to ensure that Indigenous status is routinely collected in a correct and consistent manner.

Some states and territories have developed their own guidelines for collecting and recording information on the Indigenous status of clients attending health services, and to improve the quality of data on Aboriginal and Torres Strait Islander Australians. These initiatives also informed the development of the national Best Practice Guidelines.

The COAG (2008) National Indigenous Reform Agreement (NIRA) strongly emphasises the need for improvement in data quality across a number of sectors including health, education and employment. COAG has agreed to a number of data quality improvements that Australian Government agencies, including the ABS and AIHW, and states and territories will undertake. All jurisdictions have committed in the NIRA to implementing these Best Practice Guidelines in health data collections by December 2012.

National data collections to which these guidelines apply

These guidelines were developed for the following national data collections:

- Perinatal National Minimum Data Set (NMDS)
- Bettering the Evaluation and Care of Health (BEACH) survey of general practice
- Medicare Australia registrations
- National Mortality Database
- 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 and Non-admitted Patient Emergency Department Care NMDS.

While the guidelines were developed for specific national health data collections, the guidelines and recommendations in this report are relevant to other data collection processes, such as the registration of births and deaths, and other areas of data collection, such as education.

Structure of this report

There are three further parts to this report.

Best practice guidelines for collecting and recording Indigenous status

Comprises three parts:

- *Part A—Asking the question*
- *Part B—Recording responses*
- *Part C—Putting the guidelines into practice.*

Recommendations to support the use of the best practice guidelines

Includes recommendations for service providers and data custodians to support the use of the guidelines. There are recommendations on staff training and data quality assurance and validation at the local, state and territory and national levels.

Promoting the best practice guidelines

Outlines the next steps for promoting the Best Practice Guidelines and supporting their implementation for key national health data collections and other collections.

Additional reports

Appendixes to this report, providing more detailed information about the extent of Indigenous under-identification in various key datasets and related issues, are available online at <http://www.aihw.gov.au/publication-detail/?id=6442468342>.

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

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

Appendix B: An overview of the under-identification of Indigenous Australians in administrative data collections

Appendix B provides an overview of past and current projects on the under-identification of Indigenous Australians in administrative data

Appendix C: The five stages of the Best Practice Guidelines project

Appendix C provides information on the projects conducted to inform the development of the Best Practice Guidelines

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

Appendix D briefly explores the data pathway in each of the six health data sets examined for their flow of information on Indigenous status, and the factors that could affect the quality of these data at each step along the pathway.

Best practice guidelines

The Best Practice Guidelines comprise three parts:

- *Part A—Asking the question*
- *Part B—Recording responses*
- *Part C—Putting the guidelines into practice.*

The first two parts provide clear and concise information on how to correctly ask the Indigenous status question (Part A) and to record responses to this question (Part B).

Part C provides practical advice for dealing with the more common scenarios that are likely to arise when putting the guidelines into practice. Advice is provided on what to do:

- in the event of a birth
- if the client is a child under 15
- if the client is too ill to be questioned or is unable to respond to questions
- if the client does not speak English or cannot read or write
- if the client is deceased
- if staff are reluctant to ask the question
- if the client wants to know why they are being asked the question
- if a client objects to the question or declines to answer
- if the client chooses not to answer the question 'correctly'
- if a client wishes to change their previously recorded Indigenous status.

Part A: Asking the question

The standard Indigenous status question

The following question should be asked of all clients to establish their Aboriginal and/or Torres Strait Islander or non-Indigenous status:

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

The standard response options

Three standard response options should be provided to clients to answer the question (either verbally or on a written form):

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

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

Alternatively, a fourth response category may also be included if this better suits the data collection practices of the agency or establishment concerned:

- ☐ Yes, both Aboriginal and Torres Strait Islander

If the question has not been completed on a returned form, this should be followed up and confirmed with the client.

How to ask the question

Staff responsible for registering a client should ask the Indigenous status question when the client is first registered with the service. The question should be asked of *all* clients irrespective of appearance, country of birth or whether the staff know of the client or their family background.

The question should be placed within the context of other questions related to cultural background, such as country of birth and main language spoken. If a form is used, a preamble may be included to introduce questions related to cultural background and identity, however this is not a requirement. Should service providers feel a preamble is necessary, the following statement is suggested:

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

Clients may be asked the question directly, or asked to complete a form with the question included, and the client should answer this question themselves. There are some situations, such as in the case of birth and death registrations, when the client will be unable to answer the question. In these instances it is acceptable for certain others—such as a close friend, relative or member of the household—to be asked the question and to answer the question on the client's behalf if they feel confident to provide accurate information. In instances when a client may be temporarily unable to answer the question, it also acceptable for certain others who know the client well to respond on their behalf; however, this response should be verified with the client wherever possible.

Part B: Recording responses

How to record responses

Information systems should record Aboriginal and/or Torres Strait Islander or non-Indigenous status information using the national categories for recording Indigenous status as set out in the *National health data dictionary*. These categories 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

Responses should be coded as follows:

Response	Coding category
'Yes, Aboriginal' is ticked but 'Yes, Torres Strait Islander' is not ticked	1
'Yes, Torres Strait Islander' is ticked but 'Yes, Aboriginal' is not ticked	2
'Yes, Aboriginal' is ticked and 'Yes, Torres Strait Islander' is also ticked	3
'No' is ticked	4
'No' is ticked and either or both 'Yes, Aboriginal', and 'Yes, Torres Strait Islander' are ticked	9
Client is capable of responding but declines to respond following prompting/ follow-up	9
Where it is impossible for the question to be asked during the contact episode	9
Response to the question has been left blank or is incomplete	9

Mandatory completion

A response to the Indigenous status item should be a mandatory requirement when registering or entering client details in electronic data recording systems. Staff registering or entering details of a client should not be able to complete the registration until a response for the Indigenous status item has been completed.

Identifying records for follow-up

Local data management systems should be able to identify those records that are coded as 9 (Not stated/inadequately described), because of situations where it was impossible for the question to be asked during the contact episode and other situations where the response was left blank or incomplete. These records require follow-up and therefore should be distinguished from records that were coded as 9 because the client had declined to respond.

While additional categories could be used in local systems for the purposes of workflow management and follow-up, finalised records must be mapped to the correct national category before the data are provided to the state, territory or national data custodian.

Part C: Putting the guidelines into practice

In the event of a birth

For perinatal data collections, the mother's Indigenous status should be asked directly of the mother, regardless of the information separately recorded in the hospital database.

Some service providers in some jurisdictions separately ascertain and record the Indigenous status of both the mother and of the newborn baby. While the Indigenous status of the baby is not currently a requirement for perinatal data collections, this may become a requirement in future. If the Indigenous status of the newborn is to be collected, the mother should be asked to provide this information for herself and for her baby. It should not be assumed that the baby's status is the same as that of the mother. If the mother has not reported her status as Aboriginal or Torres Strait Islander, it should not be assumed that the newborn is therefore not of Aboriginal and/or Torres Strait Islander origin.

If the client is a child under 15

Where the client is a child under 15 years of age, the parent or guardian is asked to declare the client's Indigenous status on their behalf.

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 the accompanying adult is unable to provide this information, the child's parent/guardian should be contacted as follow-up to establish the Indigenous status of the child.

If the client is too ill to be questioned or is unable to respond to questions

Where the client is unable to respond to standard questions 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 accompanying the client who knows the client well and is confident of providing accurate information. The response provided by this person should always be verified with the client when they have recovered sufficiently to be able to answer the question themselves.

If the person accompanying the client does not know the client's Indigenous status, the client should be asked the question directly when they are capable of responding. In the event that the client does not recover sufficiently to provide their Indigenous status, the client's status should be recorded as a non-response.

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, it is recommended that the person accompanying them is asked to translate the question 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 spoken by the client) be called to assist.

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, social worker, Aboriginal or Torres Strait Islander liaison officer/health worker) go through the questions with the client.

All clients should be given the opportunity to respond to the Indigenous status question for themselves. While a client who speaks an Aboriginal language may be highly likely to be an Aboriginal person, their status cannot be assumed; the client may be of both Aboriginal and Torres Strait Islander origin, for example.

Non-English speaking clients from various cultural backgrounds should also be asked the question and given the opportunity to self-report in response to the Indigenous status question. Inclusion of the Indigenous status question in *all* data collections, with *all* clients, normalises the question and reinforces its consistent use as standard practice.

If the client is deceased

Funeral directors, undertakers, medical practitioners and coroners responsible for registering a death or assessing the cause of death must ask the next of kin about the Indigenous status of the deceased. If no next of kin is 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 deceased well may be asked to provide this information.

If Indigenous status is missing on the death registration form, the funeral director should follow it up with the next of kin before the form is sent to the registry. Similarly, medical practitioners or the coroner responsible should attempt to complete this item before the deceased's information is sent to the registry.

If staff are reluctant to ask the question

Staff should be encouraged to collect information from *all* clients in a professional and respectful manner, without anticipating or making assumptions about the client's identity or about how the client is likely to react or respond to any given question. Staff should be encouraged to regard the Indigenous status question as no more or less sensitive or problematic than other items of personal data routinely collected from clients.

All clients, whether Aboriginal, Torres Strait Islander or non-Indigenous, have the right to self-report their Indigenous status, rather than have their status assumed and recorded on their behalf. To refrain from asking any client the Indigenous status question is an act of discrimination which infringes upon the client's right to respond to this question for themselves.

Given that the question should be asked correctly, consistently and uniformly of all clients, staff should not attempt to modify the standard question in any way. The Indigenous status question in the Census, ABS household surveys and other major data collections is worded *precisely* as it is in these guidelines. Changing the question's wording, even slightly, has the potential to alter the question's meaning, and this may in turn influence the client's response.

If a client wants to know why they are being asked this question

Following are several responses that may assist staff in explaining to clients the reasons for asking the Indigenous status question.

- The Indigenous status question is one of several questions related to a client's origin and demographic characteristics that are asked of all clients who attend a health service, enrol with Medicare or are involved in the registration of a birth or death.
- The collection of Indigenous status is necessary for the government and other services to plan and deliver appropriate health services for all Australians, to assess the impact of services on particular groups in the community and to improve health care and to monitor changes in health and wellbeing over time.
- The response to this question allows service providers to ensure that Aboriginal and Torres Strait Islander clients have an opportunity to access relevant services—such as Aboriginal liaison officers and Aboriginal health workers, health checks, Aboriginal and Torres Strait Islander specific immunisation considerations and PBS listings—if they choose.
- Service providers cannot make assumptions about the Aboriginal, Torres Strait Islander or non-Indigenous status of any client, therefore Indigenous status can only be determined by asking each client this question.
- 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 the client's consent is given.
- Should a client request a more detailed explanation of where the data go or the ways they are used, staff may wish to refer the client to the Australian Institute of Health and Welfare website <www.aihw.gov.au> or the Australian Bureau of Statistics website <www.abs.gov.au>.

If a client objects to the question or declines to answer

Where a client objects to the question or declines to answer, they should be informed of their right to decline to answer the Indigenous status question and be advised that their level of care and access to services will not be affected if they choose not to answer the question.

While staff have a duty to collect and record Indigenous status information from all clients as correctly as possible, they are not obliged to convince a disgruntled, upset or unwilling client to respond to the question. Furthermore, while staff have a duty, if queried, to explain to clients why this question is being asked, they are not obliged to justify the use of standard question.

If the client chooses not to answer the question 'correctly'

There may be occasions where a client of a service is known to staff as an Aboriginal or Torres Strait Islander person, yet the client chooses not to report as such in response to the Indigenous status question. Conversely, there may be occasions where a known non-Indigenous client chooses to report themselves as Aboriginal or Torres Strait Islander in response to this question.

Clients have a right to self-report their Indigenous status and staff should therefore always record the response that the client provides; they should not question or comment on the client's response. The client's recorded response should not be altered or annotated in any way to reflect the views of the staff member collecting the information.

Any client who self-reports as Aboriginal or Torres Strait Islander should be offered the services of Aboriginal liaison officers or Aboriginal health workers where available; however, the client's choice to engage or not engage with such services should be respected.

If a client wishes to change their previously recorded Indigenous status

All clients should have an opportunity to confirm or update any previously recorded personal information on a regular basis, including confirmation or alteration of their recorded Indigenous status.

The most convenient approach, particularly in general practice settings, may be to routinely provide clients with a copy of their personal details for verification, allowing an opportunity for clients to correct or update their Indigenous status.

Any changes should be received without comment and clients should not be required to provide a reason for changing their recorded Indigenous status.

Recommendations to support the best practice guidelines

As well as following the Best Practice Guidelines in the collection and recording of Indigenous status, there are a range of other strategies that service providers and data custodians can adopt to support best practice and maintain data quality. The National Indigenous Data Improvement Support Centre (NIDISC) has been established to assist jurisdictions and data custodians to implement these recommended strategies within their networks of service providers, for addressing under-identification and improving Indigenous data quality.

Recommendations for staff training

Training in the correct and consistent collection of Indigenous status may best be delivered as part of a training program that focuses on overall data collection and data quality. Staff should understand that this item is one of several that should be asked of all clients attending or registering with a service—for the purposes of useful and reliable data, effective policy and better service delivery.

While it is recommended that health services staff receive training in cultural safety for Aboriginal and Torres Strait Islander clients, such training should not be considered a prerequisite for the collection of Indigenous status using the standard question.

A frequently identified barrier to the collection of Indigenous status is a concern amongst staff that the question may provoke negative and aggressive reactions from some clients (particularly older, non-Indigenous clients). It is recommended that all staff in health service settings receive training in standard procedures for dealing with threatening or aggressive clients; however, this training should be conducted separately to training in the collection of Indigenous status. As stated in the guidelines, staff are required to ask the standard question correctly and consistently, and clients have a right to refuse to respond to this question. Beyond this, staff are not expected to tolerate or engage with aggressive clients in the interests of eliciting a response to this item.

Recommended staff competencies

In addition to the basic competencies in customer service, information management and confidentiality that are to be expected of staff working in health service settings, all persons responsible for collecting, recording and validating Indigenous status information should be able to demonstrate the following competencies:

- an ability to ask the standard question '*Are you of Aboriginal or Torres Strait Islander origin?*' correctly, and to correctly record responses on paper forms and/or computer systems
- an ability to clearly explain to clients the reasons for collecting this information
- an understanding of why it is important to collect and record Indigenous status for all clients

- an understanding of why it is important to collect this information correctly and consistently, using the standard question *'Are you of Aboriginal or Torres Strait Islander origin?'*
- an understanding of the voluntary nature of self-report of Indigenous status, and of a client's right to decline to answer this question or change their recorded status
- knowledge of available information and services for Aboriginal and Torres Strait Islander clients, and ability to convey this to clients as required
- knowledge of and ability to conduct follow-up procedures for obtaining missing information, including Indigenous status.

Recommendations for data quality assurance and validation

Local service providers such as hospitals, community health services and general practices are encouraged to establish strategies that support staff to correctly and consistently collect Indigenous status, and to monitor and validate their data to ensure it is of the best possible quality.

State- and territory-level health authorities and registries of births, deaths and marriages are encouraged to establish strategies for monitoring, improving and maintaining the quality of Aboriginal and Torres Strait Islander data, or to review their existing strategies to ensure they align with these guidelines. The Australian Institute of Health and Welfare is available to provide advice and guidance to health authorities, data custodians and service providers in these processes. The Australian Bureau of Statistics liaises with state and territory registries of births, deaths and marriages to ensure births and deaths data quality assurance strategies and business rules are correctly implemented

National-level strategies apply to national agencies housing data collections relevant to Aboriginal and Torres Strait Islander health, such as the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and Medicare Australia.

Recommended strategies for local service providers

- Review all forms and data recording systems to ensure the standard Indigenous status question is included and that coding categories are consistent with these guidelines.
- Provide appropriate training, supervision and support to staff in primary data collection and data management roles, to ensure data items such as Indigenous status are collected correctly and consistently.
- Ensure data collection processes and systems are as streamlined and user-friendly as possible for staff in data collection roles. Onerous data collection processes and time pressures increase the likelihood that items perceived as non-essential, such as Indigenous status, are omitted.
- Review client intake procedures to ensure client privacy is maintained, particularly in areas where clients are interviewed to obtain personal information. Lack of privacy of interview

areas may increase reluctance amongst staff to ask 'sensitive' questions, and may contribute to reluctance amongst clients to respond to this question.

- Ensure staff across various levels and disciplines within the service (e.g. administration, medical staff, allied health) are prompted to check for and follow-up on missing personal details, including Indigenous status, in their contact with clients.
- Periodically provide regular clients with a copy of their personal details, including their recorded Indigenous status, for verification.
- In general practices, GPs and practice nurses should collect information on the Indigenous status of the patient as part of routine medical history-taking, to check and confirm information obtained by reception staff.
- Establish business rules for distinguishing between 'not stated/inadequately described' records that are the result of the client's inability to answer (and are therefore to be followed up) and 'not stated/inadequately described' records in which the client declined to answer (which do not require further follow-up).
- Establish policies and procedures for following up and correctly coding records with incomplete Indigenous status.
- Establish business rules for checking Indigenous status against other data items, particularly country of birth[1], language spoken and Medicare eligibility status[2].
- Monitor trends in the number and proportion of Indigenous records by comparing 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 records from one year to the next, a substantial difference between years should be cause for investigation.
- Conduct data quality surveys involving direct surveys or interviews with clients, to determine the consistency and accuracy of collection of Indigenous status (along with other client data items) and to develop estimates of the level of under-identification.

Recommended practices for state and territory data custodians

- Ensure data providers are aware of these guidelines and of other standards that are required for their provision of Aboriginal and Torres Strait Islander data (e.g. timeliness, formatting).
- Ensure the correct business rules are applied to cope with different identifications when there are two sources of data (e.g. cause of death forms and death registrations). For example, if one

1 Although, at present, most Aboriginal and Torres Strait Islander people are born in Australia and speak English or an Australian Aboriginal language, some Aboriginal and Torres Strait Islander people may be born overseas as travelling and migrating become more common among the Indigenous Australian population. Therefore, it is important that records in which a person has reported being of Aboriginal and/or Torres Strait Islander origin, and has also reported an overseas country of birth or foreign language as main language spoken, are investigated but are not changed automatically.

2 Most Aboriginal and Torres Strait Islander people are eligible for Medicare. A record should be investigated, but not automatically amended, if the client has reported as being of Aboriginal and/or Torres Strait Islander origin, yet is not eligible for Medicare.

data source identifies the client as Aboriginal and/or Torres Strait Islander, the record relating to this client should be coded accordingly.

- Regularly monitor Indigenous status information and provide continuing feedback on data quality to local services. In particular, monitor levels of 'not stated' reported from local service providers to determine whether further education or assistance is required.
- Regularly check that codes used for recording Indigenous status in local systems are consistent with these guidelines; in particular, check that invalid or inappropriate codes are not being used.
- Compare data for Aboriginal and Torres Strait Islander persons with variables such as country of birth, language spoken and Medicare eligibility status, and follow up with local service providers to ensure any issues are investigated.
- Regularly check that local services have not set default values for the Indigenous status item. (Default values are evidenced by no reporting of records with a 'not stated' response to the Indigenous status item. This would suggest that the data recording system defaults to the 'no, neither Aboriginal or Torres Strait Islander' response, and should be investigated.)
- For each local service, compare the number and proportion of Aboriginal and/or Torres Strait Islander records with the previous year's data to determine whether there have been any probable errors in coding (e.g. an unusually large increase or decline in the number of Indigenous records).
- Establish a system of review and audit of data collection processes and data quality for local service providers, including review and audit of Aboriginal and Torres Strait Islander data.
- Inform the national data custodian of any events or issues that may have affected the quality of the Aboriginal and Torres Strait Islander data for a given period.
- Establish a procedure for prompt investigation and response to data validation requests from the national data custodian.

Recommended practices for national data custodians

- Ensure relevant materials and resources, such as the Best Practice Guidelines and promotional material, are widely disseminated and readily available.
- Encourage state and territory data custodians and other data providers to access information, resources and advice from relevant data agencies such as the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, in order to implement these guidelines effectively.
- Ensure state and territory data custodians and other data providers are advised of all checks and edits that will be carried out on the data provided.
- At a minimum, undertake data validation at the national level on an annual basis, although quarterly or monthly data validation may be appropriate.
- Check the following in regular validation processes:
  - that invalid codes have not been used for recording Indigenous status
  - that 'not stated' is reported separately and not included in 'no, neither Aboriginal nor Torres Strait Islander'

  - that Aboriginal and Torres Strait Islander records with unexpected country of birth, language and Medicare eligibility items have been verified.
- Compare the number and proportion of Aboriginal and Torres Strait Islander records 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 records). Comparison should be undertaken at the state and territory level and other levels if feasible.
- Send back all validation queries to the data provider for follow-up. Errors should be corrected and re-supplied to the national data custodian. The confirmed or amended data returned by the provider 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.
- Assess and clearly state the quality of Aboriginal and Torres Strait Islander data published or provided (or the reliability of estimates derived from the data), and provide clear conditions and rules for the use of these data. Data custodians should also provide support services for users conducting analysis of Aboriginal and Torres Strait Islander data.
- Continue to engage with state- and territory-level data providers and other stakeholders in the development of strategies and protocols for data linkage, for the purposes of assessing the extent of under-identification and developing better estimates of service provision for Aboriginal and Torres Strait Islander people.

Promoting the best practice guidelines

The Best Practice Guidelines establish a more systematic national approach to improving Indigenous identification in key data sets, which will support jurisdictions in meeting their targets for improving Indigenous data quality as expressed in the COAG National Indigenous Reform Agreement. The guidelines provide information and recommendations on best practice in collecting and recording Indigenous status, using the standard Indigenous status question. They provide information on how to ask the question and how to record responses, and provide recommendations for managing data and ensuring data quality. They also provide advice on how to deal with a range of situations that may arise in implementing the guidelines.

Dissemination and ongoing support

The guidelines will be provided to key stakeholders involved in the funding and steering of the development of the Best Practice Guidelines, and will be presented to state and territory health departments, other relevant government agencies and data custodians for distribution throughout their networks. The guidelines will also be presented to a range of peak health organisations and peak Aboriginal and Torres Strait Islander organisations at the national and state and territory levels. The dissemination of the guidelines will be accompanied by information about the services and support available from the AIHW, and suggestions of ways the receiving agency could implement or support best practice in the collection of Indigenous status.

The AIHW's NIDISC service includes a dedicated helpdesk for responding to requests from data custodians, service providers and other stakeholders for further information or support in implementing the guidelines. This service will be promoted in the initial dissemination of the Best Practice Guidelines, in subsequent education and awareness campaigns targeting various stakeholders in the health sector, and in broader public education material.

While the Best Practice Guidelines establish the national standard for the collection of Indigenous status across various service provision settings and client groups, the guidelines themselves are limited in their potential to resolve broader issues that have been recognised as drivers of Indigenous under-identification. Research conducted by the AIHW in the development of these guidelines suggests that the major drivers of Indigenous under-identification—such as staff reluctance to ask the Indigenous status question and perceptions around Aboriginal and Torres Strait Islander people's willingness to self-report—may be manifestations of beliefs, attitudes and practices signifying broader issues in Australian society. These outcomes are in keeping with findings from other research projects.

The NIDISC service will provide guidance to jurisdictions in developing effective staff training approaches and other strategies for promoting the correct and consistent collection of Indigenous status. In keeping with the key messages of the guidelines, NIDISC's services and resources will frame the collection of Indigenous status as a simple and straightforward

administrative procedure, linking the correct and consistent collection of Indigenous status with the health sector's broader values of professional, ethical and patient-centred practice.

Along with supporting jurisdictions to meet the data quality improvement goals set out in the COAG National Indigenous Reform Agreement, the AIHW will conduct over-arching strategies in improving Indigenous data quality in key national data collections, to complement activities at the state and territory level. These key national collections include:

- Perinatal National Minimum Data Set (NMDS)
- Bettering the Evaluation and Care of Health (BEACH) survey of general practice
- Medicare Australia registrations
- 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 and Non-admitted Patient Emergency Department Care NMDS.

Evaluation

As expressed in the NIRA, the AIHW will work closely with the states and territories to evaluate the implementation of the guidelines across various health data collections. The evaluation will commence with a base-line assessment of current knowledge and competency in the collection of Indigenous status across a range of service providers, health professionals and jurisdictions. A follow-up assessment will be conducted 12 months after the agreed implementation phase has ended in December 2012, to determine the extent to which the implementation of the guidelines has led to an increase in knowledge and competency in the sector.

The evaluation process will determine whether increased knowledge and competency in collecting Indigenous status leads to a measurable improvement in correct and consistent data collection practices. The evaluation will also determine the degree to which any such improvements in data collection practices lead to improvements in Indigenous data quality. The outcomes of this evaluation should provide valuable insights for the analysis and reporting of Indigenous health data, and for directing future efforts in improving Indigenous data quality.

Further research

Much of the research to date has focussed on barriers to correct and consistent collection of Indigenous status. To assist in the promotion of the Best Practice Guidelines, research efforts should perhaps also be directed toward understanding motivators for attitudinal and behavioural change amongst various stakeholders.

Strategies for promoting best practice in the collection of Indigenous status can be based on the available evidence around beliefs, attitudes and behaviours of certain stakeholders; however, a significant stakeholder group is largely missing from the evidence base. The beliefs, attitudes and experiences of Aboriginal and Torres Strait Islander clients of health services remain, to a great extent, an unknown quantity.

Further research could explore the feelings and attitudes of Aboriginal and Torres Strait Islander clients towards being asked the Indigenous status question, and the ways that these clients may generally respond. Efforts to promote best practice and improve data quality could benefit from a greater understanding of whether Aboriginal and Torres Strait Islander clients are inclined to respond differently in different circumstances, and the factors that may influence any variations in responses.

Promotional campaigns would be enhanced by exploring perceptions within Aboriginal and Torres Strait Islander communities of the role and value of data, and by seeking feedback from clients and communities on ways that the problem of under-identification (if it is regarded as a problem) could best be addressed.

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