

Aboriginal and Torres Strait Islander Origin - Recording of Information of Patients and Clients

- **Summary** The policy directive outlines the requirements for collecting and recording accurate information on the Aboriginal and Torres Strait Islander status of all clients of public health services in NSW.
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Secretary, NSW Health

This Policy Directive may be varied, withdrawn or replaced at any time. Compliance with this directive is mandatory for NSW Health and is a condition of subsidy for public health organisations.



Aboriginal and Torres Strait Islander People – Recording of Information of Patients and Clients

PURPOSE

The policy directive and the associated procedures document outlines the requirements for collecting and recording accurate information on whether clients of NSW Health services are Aboriginal and/or Torres Strait Islander. Aboriginal and Torres Strait Islander people are under-reported in many health related data collections in NSW. Self-report in response to the standard Australian Bureau of Statistics question about a person's Aboriginality is the most accurate means of ascertaining whether a client is Aboriginal and/or Torres Strait islander. The standard question must be asked of all clients of NSW Health services, and the information needs to be recorded accurately according to national standards.

MANDATORY REQUIREMENTS

- 1. All NSW Health services are required to collect consistent and comprehensive data on Aboriginal and Torres Strait Islander health.
- The Aboriginal and Torres Strait Islander Origin Recording of Information of Patients and Clients: Procedures document describes the standards required for the accurate collection and recording of data.
- 3. The standard question seeking information about a person's Aboriginality should be asked of all clients of NSW Health services to establish whether they are Aboriginal and / or Torres Strait Islander:

'Are you (is the person) of Aboriginal or Torres Strait Islander origin?"

- 4. These standard response options should be provided to the clients to answer the questions (either verbally or on a written form):
 - 🗆 No
 - □ Yes, Aboriginal
 - □ Yes, Torres Strait Islander
 - □ Yes, both Aboriginal and Torres Strait Islander
- 5. Asking the question:
 - Staff responsible for registering a client should ask the standard 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 or not the staff know the client or their family background
 - 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.
 - Specific situations related to asking the question are described in Section 2 and Section 4 of the Procedures document.



6. Recording the Information:

- Information systems should record whether a client is Aboriginal or Torres Strait Islander using the standard categories, which are outlined in Section 3 in the Procedures document.
- Responses to the standard questions should be coded as described in Section 3 in the Procedures document.
- A response to the standard question should be a mandatory requirement when registering or entering client details in electronic recording systems.
- Local data management systems must be able to identify those records that are coded as not stated / inadequately described which require follow-up.

7. Training in the correct and consistent recording of whether a client is Aboriginal and/or Torres Strait Islander must be delivered to all staff. See Section 5 in the Procedures document.

8. Data quality assurance and validation activities must be undertaken at the local level (Section 6 Procedures document) and by NSW Ministry of Health (Section 7 Procedures document).

IMPLEMENTATION

- 1. Roles and Responsibilities of NSW Health agencies:
 - Chief Executives, Health Service Executives, and Managers are responsible for the implementation of this policy and procedures at the local level.
 - All NSW Health employees are responsible for the accurate recording of Aboriginality when ever this is part of their role.

2. Roles and Responsibilities of NSW Ministry of Health:

 NSW Ministry of Health is responsible for providing the mandatory requirements and procedures, and to support the implementation and evaluation of this policy.

3. Activity Based Funding

With the implementation of activity based funding in July 2012, accurate and consistent recording of Aboriginality is essential for the effective application of associated weighting and will enable LHDs/SHNs to:

- Monitor expenditure on health care against funding for Aboriginal clients
- Enable clinicians and managers to understand the factors contributing to cost variations including the extent to which these relate to patient complexity or differences in the way services are delivered to Aboriginal clients
- Make decisions about where to invest additional resources to meet increasing demand in the most cost effective way for Aboriginal clients.
- Contribute information about costs to the national "price setter", the Independent Hospital Pricing Authority.
- Be appropriately funded according to the efficient pricing for treating Aboriginal patients.



REVISION HISTORY

| Version | Approved by | Amendment notes |
|-----------------------------|--|---|
| July-2012 (PD2012_042) | Deputy Director General, Population Health, and Chief Health Officer | Replaces PD 2005_547 |
| March 2005 (PD 2005_547) | Director-General | Originally issued as Circular 2000/38. Replaced Circular 85/25 and Information Bulletin 94/3. |

ATTACHMENTS

1. Aboriginal and Torres Strait Islander Origin – Recording of Information of Patients and Clients: Procedures.

Aboriginal and Torres Strait Islander Origin – Recording of Information of Patients and Clients



Issue date: July-2012 PD2012_042

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1 BACKGROUND

1.1 About this document

This Policy Directive replaces Policy Directive PD2005_547 'Aboriginal and Torres Strait Islander Origin- Recording of Information of Patients and Clients'. This policy directive revises and updates the previous policy.

1.2 Legal and legislative framework

The '*National best practice guidelines for collecting Indigenous status in health data sets*' (AIHW, 2010) documents the national approach for collecting and recording accurate information on whether a client is Aboriginal and/or Torres Strait Islander.

The Council of Australian Governments (COAG) National Indigenous Reform Agreement requires all jurisdictions, including NSW, to implement the National Best Practice Guidelines.

This policy and procedures document incorporate the activities outlined in the National Best Practice Guidelines. The implementation of these will ensure NSW meets their National Indigenous Reform Agreement obligations in relation to identification of Aboriginal and Torres Strait Islander people.



2 ASKING THE QUESTION

2.1 The Standard Aboriginal and Torres Strait Islander Origin Question

The following question should be asked of all clients to establish whether they are Aboriginal and / or Torres Strait Islander:

'Are you (is the person) of Aboriginal or Torres Strait Islander origin?"

2.2 The standard response options

- 2.2.1 Three standard response options should be provided to the clients to answer the questions (either verbally or on a written form):
 - □ No
 - □ Yes, Aboriginal
 - □ Yes, Torres Strait Islander
 - □ Yes, both Aboriginal and Torres Strait Islander
- 2.2.2 If the question has not been completed on a returned form, this should be followed up and confirmed with the client.

2.3 How to ask the question

- 2.3.1 Staff responsible for registering a client should ask the standard question seeking information about a person's Aboriginality when the client is first registered with the service.
- 2.3.2 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
- 2.3.3 The question should be placed within the context of other questions related to cultural background, such as country of birth and main language spoken.
- 2.3.4 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.
- 2.3.5 In some situations (such as in the case of birth and death registrations) the client will be unable to answer the question themselves. In this case it is acceptable for certain others (such as mother, father, close friend, relative, or household member) to be asked the question and to answer the question on the client's behalf if they feel confident to provide accurate information.
- 2.3.6 In instances where the client is temporarily unable to answer the question, it is 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.



3 RECORDING RESPONSES

3.1 How to record responses

- 3.1.1. Information systems should record information on whether a client is Aboriginal and/or Torres Strait Islander using the standard national categories, which 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

In addition databases in NSW should use the following additional category:

8. Declines to respond

3.1.2 Responses to the standard questions should be coded to the following national standards.

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

(Note these categories represent national standards, with the addition of the code 8, used by NSW to identify clients who have declined to respond. In the national categories, the NSW Code 8 would be coded as 9. See Section 3.3 for further information).

3.2 Mandatory completion

A response to the standard question on a person's Aboriginality should be a mandatory requirement when registering or entering client details in electronic recording systems. Staff registering or entering details of a client should not be able to proceed with registration until a response has been completed.



3.3 Identifying records for follow up

- 3.3.1 Local data management systems should be able to identify those records that require follow up. In NSW the code 8 is used (as described in 3.1.2) to identify clients who have declined to answer, and therefore do not require follow up. Client's 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, require follow up with the client, to determine the correct code.
- 3.3.2 Additional categories used by NSW or in local systems for the purposes of workflow management and follow-up must be mapped to the correct national category (Categories 1, 2, 3, 4, and 9) before the data are provided to the national data custodian. In NSW, data coded as category 8 (declined to respond) must be recoded to category 9 before submission to national data custodians.



4 IMPLEMENTING THE PROCEDURES IN SPECIFIC SITUATIONS

4.1 In the event of a birth

- 4.1.1 For perinatal data collections, the standard questions on whether a client is Aboriginal and/or Torres Strait Islander should be asked directly of the mother, regardless of the information separately recorded in the hospital database.
- 4.1.2 In NSW, information on whether the mother and the newborn baby are Aboriginal and/or Torres Strait Islander must be recorded in the NSW Perinatal Data Collection (See NSW Policy Directive PD2010_072).
- 4.1.3 The mother should be asked to provide the information on whether her baby is Aboriginal and/or Torres Strait Islander in addition to her own Aboriginality.
- 4.1.4 It should not be assumed that the baby will share the mother's origin. In particular, if the mother does not report her origin as Aboriginal and/or Torres Strait Islander, it should not be assumed that the newborn is therefore not Aboriginal or Torres Strait Islander.

4.2 If the client is a child under 15

- 4.2.1 Where the client is a child under 15 years of age, the parent or guardian is asked to declare whether the client is Aboriginal and/or Torres Strait Islander on their behalf.
- 4.2.2 If the parent or guardian is not available, certain others may be asked to provide this information (see 2.3.4)
- 4.2.3 If the accompanying adult is unable to provide this information, the child's parent / guardian should be contacted as follow-up to establish whether the child is Aboriginal and/or Torres Strait Islander.

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

- 4.3.1 When the client is unable to respond to the standard question because they are too ill, unconscious, or too ill due to 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 (see 2.3.4).
- 4.3.2 The response provided by this person should be verified with the client when they have recovered sufficiently to be able to answer the questions themselves.
- 4.3.3 If the person accompanying the client does not know whether the client is Aboriginal and/or Torres Strait Islander, the client should be asked the question directly when they are capable of responding.
- 4.3.4 In the event that the person accompanying the client does not know whether the client is Aboriginal and/or Torres Strait Islander and the client does not recover



sufficiently to provide this information, the answer to the standard question on Aboriginality should be recorded as a non-response.

4.4 If the client does not speak English, or cannot read or write

- 4.4.1 If the 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.
- 4.4.2 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.
- 4.4.3 If a form is to be provided 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) go through the questions with the client.
- 4.4.4 All clients' should be given the opportunity to respond to the standard Aboriginality question for themselves. While a client who speaks an Aboriginal language may be highly likely to be an Aboriginal person, their Aboriginality cannot be assumed; the client may be of both Aboriginal and Torres Strait Islander for example.
- 4.4.5 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 standard question.

4.5 If the client is deceased

- 4.5.1 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 whether the deceased is Aboriginal and/or Torres Strait Islander. 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.
- 4.5.2 If information on whether the deceased is Aboriginal and/or Torres Strait Islander is missing on the death registration form, the funeral director should follow 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.

4.6 If staff are reluctant to ask the question

4.6.1 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 standard question on a



person's Aboriginality as no more or less sensitive or problematic than other items of personal data routinely collected from clients.

- 4.6.2 All client's, whether Aboriginal, Torres Strait Islander, or non-Aboriginal or Torres Strait Islander, have the right to self-report, rather than have their identity assumed and recorded on their behalf. To refrain from asking any client the standard question on a client's Aboriginality is an act of discrimination which infringes upon the client's right to respond to this question for themselves.
- 4.6.3 Staff should not modify the standard question in any way. The question should be asked correctly, consistently, and uniformly of all clients, using the wording precisely as stated in this policy and procedure.

4.7 If the client wants to know why they are being asked the question

- 4.7.1 The following provides several responses that may assist staff in explaining to clients the reasons for asking the standard question on a client's Aboriginality:
 - a. The question on whether a person is Aboriginal and/or Torres Strait Islander is one of several questions related to a client's identity 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.
 - b. The collection of information on whether a person is Aboriginal and Torres Strait Islander is necessary for government and other services to plan and deliver appropriate 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.
 - c. 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.
 - d. Service providers cannot make assumptions about whether a person is Aboriginal, Torres Strait Islander, or non- Aboriginal and Torres Strait Islander, therefore this information can only be determined by asking the client the standard question.
 - e. All personal information is protected by privacy law. The NSW Health Privacy Manual (Version 2) (Policy Directive PD2005_593) provides operational guidance for health service staff to the legislative obligations imposed by the Health Records and Information Privacy Act 2002, and outlines procedures to support compliance with the Act in any activity that involves personal health information.



4.7.2 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 <u>www.aihw.gov.au</u> or the Australian Bureau of Statistics website <u>www.abs.gov.au</u>.

4.8 If the client objects to the question or declines to answer

- 4.8.1 Where a client objects to the question or declines to answer they should be informed of their right to decline to answer the standard question on whether a client is a Aboriginal and/or Torres Strait Islander person and be advised that their level of care and access to services will not be affected if they choose not to answer the question.
- 4.8.2 While staff have a duty to collect and record information on whether a client is Aboriginal and/or Torres Strait Islander from all clients as correctly as possible, they are not obliged to convince a disgruntled, upset or unwilling client to respond to the question.
- 4.8.3 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 the standard question.



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

4.9.1 There may be occasions where a client 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 standard question. Conversely there may be occasions where a known non- Aboriginal or Torres Strait Islander person chooses to report themselves as Aboriginal or Torres Strait Islander in response to this question.

Clients have a right to self-report whether they are Aboriginal and/or Torres Strait Islander and staff should therefore always record the response that the client provides; they should not question or comment on the client's response.

4.9.2 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.

4.10 If a client identifies as Aboriginal and/ or Torres Strait Islander

- 4.10.1 Any client who self-reports as Aboriginal and/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.
- 4.10.2 Information about a person's Aboriginality should be included on the client's discharge summary.

4.11 If the client wishes to change personal information on their record

- 4.11.1 All clients should have the opportunity to confirm or update any previously recorded personal information on a regular basis, including confirmation or alteration of a record that they are Aboriginal and/or Torres Strait Islander.
- 4.11.2 The NSW Health Client Registration Policy (PD2007_094) describes when to update client registration details. Client / patient details, including information on Aboriginal and Torres Strait Islander origin, should be checked and confirmed or updated, as appropriate each time a client presents for a new phase of treatment.
- 4.11.3 Any changes to the previously recorded information on whether a client is Aboriginal and/or Torres Strait Islander should be received without comment and clients should not be required to provide a reason for changing their record.



5 STAFF TRAINING

- 5.1 Training in the correct and consistent collection of information on whether clients are Aboriginal and/or Torres Strait Islander must be delivered to all staff.
- 5.2 This training may be delivered as part of a training that focuses on overall data collection and data quality.
- 5.3 While it is recommended that all staff receive training in cultural safety for Aboriginal and /or Torres Strait Islander clients, such training should not be considered a pre-requisite for the collection of information on whether a client is an Aboriginal and/or Torres Strait Islander person using the standard question.
- 5.4 All staff must complete training requirements as outlined in the Respecting the Difference: An Aboriginal Cultural Training Framework for NSW Health (PD 2011_069).
- 5.5 All persons responsible for collecting, recording and validating information on whether clients are Aboriginal and/or Torres Strait Islander should be able to demonstrate the following competencies:
 - a. An ability to ask the standard questions *Are you of Aboriginal or Torres Strait islander origin?*' correctly, and to correctly record responses on paper forms and / or computer systems
 - b. An ability to clearly explain to clients the reason for collecting this information
 - c. An understanding of why it is important to collect and record information on whether all clients are Aboriginal and/or Torres Strait Islander.
 - d. An understanding of why it is important to collect this information correctly and consistently, using the standard question
 - e. An understanding of the voluntary nature of self-reporting a client's Aboriginality, and of a client's right to decline to answer this question or to change the information recorded.
 - f. Knowledge of available information and services for Aboriginal and Torres Strait Islander clients, and ability to convey this to clients as required.
 - g. Knowledge of and ability to conduct follow-up procedures for obtaining missing information, including whether a client is Aboriginal and/or Torres Strait Islander.



6 DATA QUALITY ASSURANCE AND VALIDATION AT LOCAL SERVICE LEVEL

For data quality assurance and validation at the local service level, local service providers must:

- 6.1 Review all forms and data recording systems to ensure the standard question on whether a client is Aboriginal and/or Torres Strait Islander is included and that coding categories are consistent with this policy and procedure.
- 6.2 Provide appropriate training, supervision and support to staff in primary data collection and data management roles, to ensure data items such as the item recording a client's Aboriginality are collected correctly and consistently
- 6.3 Ensure data collection processes and systems are streamlined and user friendly for staff in data collection roles.
- 6.4 Review client intake procedures to ensure client privacy is maintained, particularly in areas where clients are interviewed to obtain personal information.
- 6.5 Ensure staff across various levels and disciplines within the service are prompted to check for and follow up on missing client registration details, including information on a client's Aboriginality, in their contact with clients.
- 6.6 Establish business rules for distinguishing between 'not stated / inadequately described' records that are a result of a 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).
- 6.7 Establish policies and procedures for correctly following up and correctly coding records with incomplete information on whether a client is Aboriginal and/or Torres Strait Islander.
- 6.8 Establish business rules for checking information on a client's Aboriginality against other data items, particularly country of birth, language spoken, and Medicare eligibility.
- 6.9 Monitor trends in the number and proportion of Aboriginal and/or Torres Strait Islander clients by comparing with the previous year's data, to determine whether there have been any obvious errors in coding.
- 6.10 Conduct data quality surveys involving direct surveys or interviews with clients, to determine the consistency and accuracy of the collection of information on whether clients are Aboriginal and/or Torres Strait Islander and to develop estimates of under-reporting.



7 DATA QUALITY ASSURANCE AND VALIDATION AT NSW MINISTRY OF HEALTH

For data quality assurance and validation state-wide, NSW Ministry of Health must:

- 7.1 Ensure data providers are aware of the policy and procedure
- 7.2 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 data source identifies the client as Aboriginal or Torres Strait Islander, the record relating to this client should be coded accordingly.
- 7.3 Regularly monitor information on whether clients are Aboriginal and/or Torres Strait Islander 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.
- 7.4 Regularly check that codes used for recording a client's Aboriginality in local systems are consistent with the policy and procedures, in particular check that invalid or inappropriate codes are not being used.
- 7.5 Compare data for Aboriginal and Torres Strait Islander persons with variables such as country of birth, language spoken, and Medicare eligibility, and follow up with local service providers to ensure any issues are investigated.
- 7.6 Regularly check that local service providers have not set default values for the standard question seeking information on whether a client is Aboriginal and/or Torres Strait Islander. This would be evidenced by no reporting of records with a 'not stated' response to the standard question.
- 7.7 For each local service, compare the number and proportion of records with information indicating clients are Aboriginal and /or Torres Strait Islander with the previous year's data to determine whether there have been any probable errors in coding.
- 7.8 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.
- 7.9 Inform the national data custodian of any events or issues that may have affected the quality of data recording whether clients are Aboriginal and/or Torres Strait Islander for a given period.
- 7.10 Establish a procedure for the prompt investigation and response to data validation requests from the national data custodian.



8 MONITORING

Monitoring of the implementation and impact of this policy directive will be undertaken by NSW Ministry of Health and Local Health Districts:

- 8.1 In partnership with the Australian Institute of Health and Welfare, NSW Ministry of Health conducts a biannual survey which estimates the level of correct reporting of Aboriginal and Torres Strait Islander people in NSW public hospital data.
- 8.2 Local Health Districts will be required to determine appropriate indicators to monitor the adherence to this policy.

9 **REFERENCES**

- Australian Institute of Health and Welfare (2010). National best practice guidelines for collecting indigenous status in health data sets. Cat. No. IHW 29. Canberra: AIHW.
- NSW Health (2005). Privacy Manual (Version 2). Policy Directive PD2005_593
- NSW Health (2007). Client Registration Policy (PD2007_094)
- NSW Health (2011). Respecting the Difference: An Aboriginal Cultural Training Framework for NSW Health. Policy Directive PD2011_069.