

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

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

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

The Best Practice Guidelines project involved five separate stages. This appendix provides information on the first four stages of the project. This report as a whole comprises the fifth stage of the project – the development of the Best Practice Guidelines.

Stage 1: Analysis of the quality of Aboriginal and Torres Strait Islander identification

Stage 1 of the Best Practice Guidelines project involved the analysis of the quality of Aboriginal and Torres Strait Islander identification in six national health data collections – the National Perinatal Data Collection, birth registrations, the BEACH survey of general practice, Medicare registration data, the National Hospital Morbidity Database and the National Mortality Database. The analyses examined the proportion of records where Indigenous status is not recorded, and how this varied by age, sex, jurisdiction, region, remoteness and, where possible, statistical division. The use of the ABS standard Indigenous status question and response categories in collection forms was also examined.

The main findings from the Stage 1 report were that the standard Indigenous status question and categories were used by most or all jurisdictions in the six health data sets examined. The proportion of records where Indigenous status was not recorded was low in some collections (e.g. below 0.1% in the National Perinatal Data Collection) and high in others (e.g. 12% in the BEACH survey).

The proportion of records with a ‘not stated/inadequately described’ Indigenous status varied by age, state/territory and remoteness for most data sets examined. It was 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. It was lowest in the older age groups, in states and territories with high Indigenous representation in the population (e.g. Northern Territory) and in remote areas.

The overall proportion of records where Indigenous status is not recorded has remained relatively stable over the last few years in most of the collections examined, but has showed a decline in some jurisdictions.

Stage 2: Report on the flow of Aboriginal and Torres Strait Islander identity information in six health data sets

Stage 2 of developing the guidelines involved an exploration of the data pathway for Indigenous status information in six health data sets (perinatal data, birth registrations, GP data via the BEACH survey, Medicare data, hospital data and death registrations), and the factors that could affect the quality of Indigenous status data at each step along the pathway. It assessed the information flow from the point of service, to an administrative data collection and to the final data collection. (Detailed findings on this stage of the project are provided in Appendix D.)

The main finding from this report was that, in general, information collected at the point of service is then submitted to state and territory collections and finally compiled in a national data collection. The exceptions to this are:

- birth registration data which bypass stage 1 of the information flow
- BEACH data which bypass stage 2
- Medicare data which bypass stages 1 and 2.

For most collections, data are collected initially on paper forms and then at various stages are entered into a data system, 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 at which the data is collected.

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/inadequately described' 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/inadequately described' 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 Indigenous status question 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, but 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, while 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.

What do these findings mean?

The differences in information flow between the data collections mean that some of the Best Practice Guidelines will need to be developed specifically for each collection. Information suggests that the use of the standard ABS question and categories for recording Indigenous status, practices for validating data, use of mandatory fields and default settings for recording Indigenous status, and follow-up of records with 'not stated' Indigenous status vary for each collection. They also vary by health service and state/territory within some collections. Development and implementation of standard practices in these areas could potentially improve the identification of Aboriginal and Torres Strait Islander people in these data sets.

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

Stage 3 of the Best Practice Guidelines project involved focus groups with point-of-service hospital staff across Australia, including midwives, health information managers and data administrators. The focus groups look at the identification of Aboriginal and Torres Strait Islander people in hospital and perinatal data.

The information presented in the report from this stage covers the usual practices for collecting and recording information on the Indigenous status of clients; barriers to obtaining information about a client's Indigenous status; and policies and guidelines, incentives, training and education, promotional material and suggestions for improving the identification of Aboriginal and Torres Strait Islander people in hospital and perinatal data.

Main findings from these focus groups are outlined below.

Collecting and recording Indigenous status

Usual practices for collecting and recording Indigenous status information vary substantially between hospitals and between the different states and 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, although 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 appear 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 usually undertaken 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, a perception that Indigenous patients may not want to disclose their Indigenous status, lack of privacy when answering the question, no checking/validating of data or follow-up of missing information, and system inadequacies (such as 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 requirements for the collection of Indigenous status. Staff are not always aware of the importance of collecting Indigenous status and are often not trained in how to respond to patients who object to the question or ask why this information is necessary.

Policies and guidelines

Most states and territories have policies and/or guidelines regarding the collection of information in hospitals, which may be specific to the Indigenous status item 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. However, 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. Some of these suggestions could be implemented in the short term with little difficulty, some could be implemented in the medium term with 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.

Stage 3: Input from general practice sector

Input from the general practice sector was also part of Stage 3 of the project. This was provided in the form of comments on relevant material proposed for inclusion in an initial draft of these guidelines.

The main comments provided revolved around the importance of emphasising that:

- correct and consistent collection of Indigenous status can improve care thorough provision of targeted health programs such as health checks and immunisation schedules
- the Indigenous status data item should be made mandatory in all general practice software
- the inclusion of the Indigenous status question on written forms are preferred to staff verbally asking the question
- it is impractical for staff to verbally confirm a patient's Indigenous status when that patient has answered a previous time
- accurate recording of Indigenous status should be promoted as part of general data cleaning and improvement
- motivators or incentives are required for practices to collect Indigenous status information and undertake auditing
- there are concerns about privacy in asking patients to disclose their Indigenous status.

Stage 4: Survey of national data custodians

Stage 4 of the Best Practice Guidelines project comprised a survey of the national data administrators of the six data collections, who were responsible for assessing the quality of information supplied. The survey was undertaken to obtain information on data validation processes undertaken, as well as general assessment of data quality within each collection. Administrators were surveyed from the following organisations: 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 are validated on a regular basis in some data collections (namely, birth registrations, death registrations and hospitalisations) but not in others (namely, National 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 particular edits and reports

that look specifically at Indigenous status. Follow-up of missing Indigenous status information is rarely undertaken by the national data administrators.