

Appendix 2: Information and data collection package

Participating hospitals were provided with the following data collection packages and information for distribution to interviewers and patients.

A2.1 Survey methodology

1. Patient selection

All patients who are admitted and are in hospital can be part of the sample. This includes 'day only' patients, who are admitted to hospital but do not stay overnight. The exceptions are:

- patients considered by the person in charge of the ward to be not well enough or not competent enough to give informed consent to be part of the study; and
- people in Intensive Care Units.

The patient's informed consent is to be sought before the interview. Patients under the age of 18 are considered eligible, provided that parental or guardian consent is obtained.

To achieve a complete and representative sample for the hospital under study, patients should be selected to get a balanced proportion of day only and longer stay admissions similar to that of the hospital overall.

The sample should also cover all wards and parts of the hospital, with the possible exception of areas where restrictions are necessary for medical reasons of patient care, such as the intensive care units.

In practice, a patient might have multiple admissions during the interview period. In these cases, the patient should only be interviewed once.

In order to help the patients understand the importance of this study and to encourage patients to participate, the AIHW has designed a patients' information brochure. It is suggested that hospitals distribute these materials to patients during the interview period.

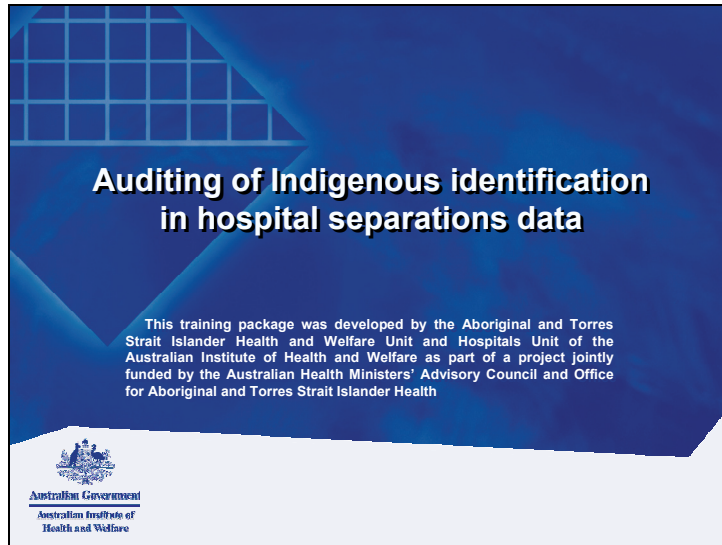
2. Interview Questions

Interviewers should read through the patient information sheet with the patient before asking for the patient's consent. The interview should only proceed after consent is given. Each interview consists of six questions. Those questions should be asked exactly as worded. Interviewers should not guess or force the answers. The interviewers should record whether a patient has given the consent to participate, the answers to the six questions, and some other information about the interview, as requested in the questionnaire. The AIHW has also produced the interviewers' information in PowerPoint format. Hospitals can use this file as training materials for the interviewers. Additional information for trainers is provided in the PowerPoint file.

3. Report the results


Each hospital should appoint at least one person to report the comparison between interview results and hospital records, using the provided Excel file 'report sheet'. For detailed instructions of filling out the sheet, please see the worksheet named 'notes' in the 'report sheet' file.

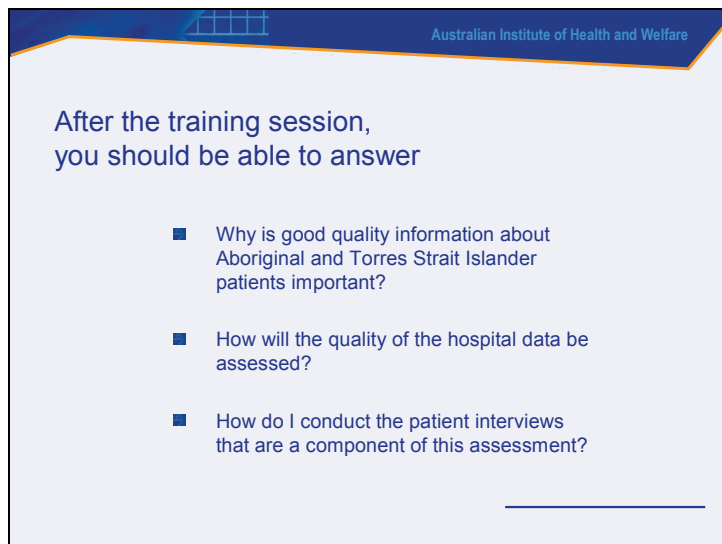
A2.2 Interviewers' information



**Auditing of Indigenous identification
in hospital separations data**

This training package was developed by the Aboriginal and Torres Strait Islander Health and Welfare Unit and Hospitals Unit of the Australian Institute of Health and Welfare as part of a project jointly funded by the Australian Health Ministers' Advisory Council and Office for Aboriginal and Torres Strait Islander Health


Australian Government
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After the training session,
you should be able to answer

- Why is good quality information about Aboriginal and Torres Strait Islander patients important?
- How will the quality of the hospital data be assessed?
- How do I conduct the patient interviews that are a component of this assessment?

Why is information about the health of Aboriginal and Torres Strait Islander people important?

- Most of us enjoy a good standard of living and a good level of health, unfortunately this is not true for all Australians
- Aboriginal and/or Torres Strait Islander peoples suffer much more ill health than other Australians, with a higher prevalence of many diseases such as diabetes, asthma and circulatory disorders.

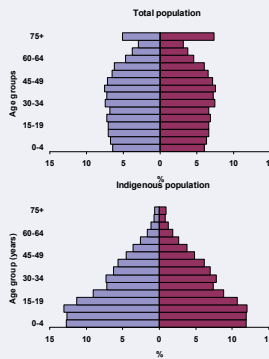
Did you know?

- Average life expectancy at birth is estimated to be 17 years lower for Aboriginal and Torres Strait Islander people than for non-Indigenous people.
- Mortality rate for Aboriginal and Torres Strait Islander infants is almost three times that of non-Indigenous infants.
- There has been slight improvement over the last 10 years

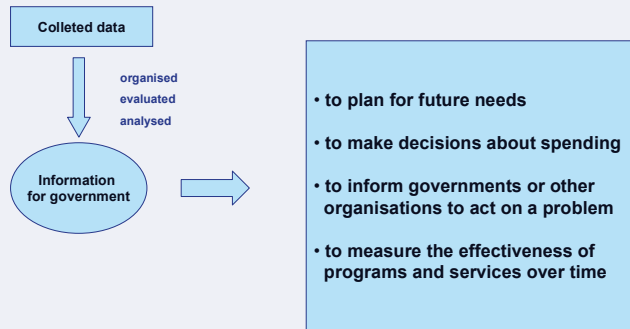
Estimated Resident Population 2005

Estimated total population (all Australians)
20,328,609

Estimated Aboriginal and Torres Strait Islander population
492,677



What happens to the hospital data collected

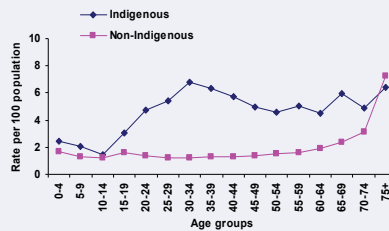


Why is the identification of Aboriginal and Torres Strait Islanders such an important issue?

- The ability of governments to report on issues such as the health status, service delivery and access to services by Aboriginal and Torres Strait Islander peoples is totally reliant on
 - the accurate identification of Aboriginal and Torres Strait Islander clients in data collections such as hospital separations.
- Without good quality information, decision makers are unable to
 - evaluate access to services,
 - evaluate responsiveness of health services to addressing health care needs and
 - accurately estimate the health expenditure necessary to adequately cover residents' medical needs

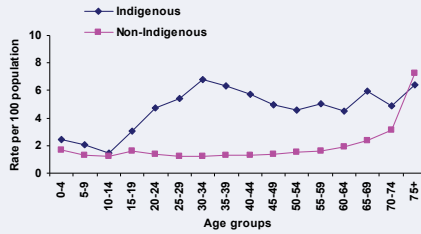
What happens to hospital data?

- Hospital separations, respiratory disease, male, 2004–05



Note: Data are only reported for Qld, WA, SA, and public hospitals in NT, where the quality of Indigenous identification is deemed to be at a satisfactory level

■ Hospital separations, injury and poisoning, female 2004–05



Note: Data are only reported for Qld, WA, SA, and public hospitals in NT, where the quality of Indigenous identification is deemed to be at a satisfactory level

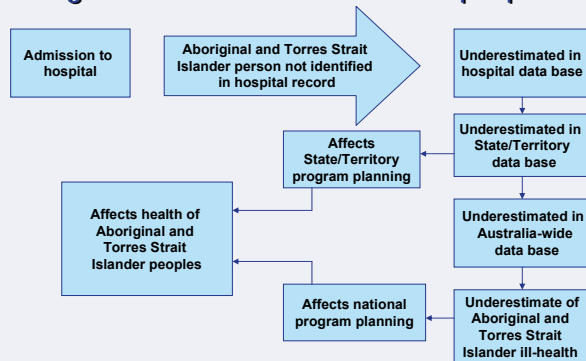
Previous studies have shown that the numbers of Aboriginal and Torres Strait people recorded in hospital data are less than the actual numbers in hospital

	Indigenous in hospital record	Non-Indigenous in hospital record	Unknown in hospital record	Total	% correctly recorded
Indigenous in interview	549	82	13	644	85.2%
Non-Indigenous in interview	15	7507	95	7617	98.6%
Not recorded	0	2	2	4	
Total	564	7591	110	8265	

Results from a 1998 study

Sex correctly recorded 99.4%
 Date of birth correctly recorded 96.1%
 Address correctly recorded 90.3%

What are the effects of non-identification of Aboriginal and Torres Strait Islander people?



Why ?

- would Aboriginal and Torres Strait Islander peoples not be identified accurately in hospital admission records?

Some answers

- people may feel awkward asking about Aboriginal and Torres Strait Islander origin
- people may feel it would upset patients to ask them about Indigenous status
- people may rely on who they think “looks” or has a name that “sounds” Aboriginal and Torres Strait Islander
- people may not correctly report their Indigenous status, in fear of unfair treatment. This may happen to both Indigenous and Non-Indigenous patients.

What is the definition of an Aboriginal and Torres Strait Islander Australian

- defined under a Commonwealth Government definition which was accepted by the High Court of Australia in the case of Commonwealth versus Tasmania (1983)
- This definition states that ‘An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives’

The standard question

Are you of Aboriginal or Torres Strait Islander origin?

For persons of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.

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

Assessing the completeness of the information collected by hospitals

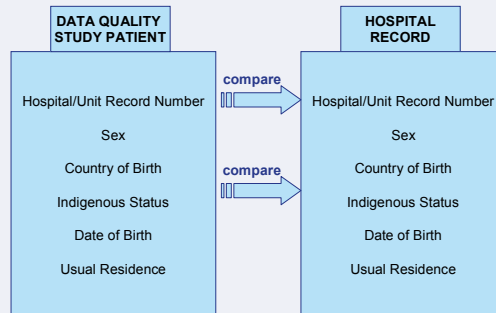
Past studies using this methodology

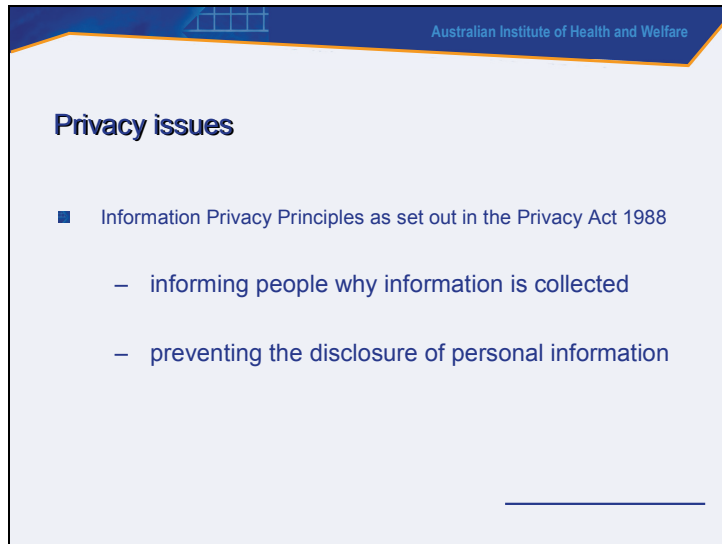
- 1997 Northern Territory
- 1998 ATSIHWIU pilot study
- 2000 Western Australian
- 2000 Queensland

In the current project

- Interviews will be conducted in selected public hospitals in NSW, Qld, WA, SA, and Tas
- AIHW will provide guidance, assistance, and analysis of the interview results

Assessing the completeness of hospital data





Information Privacy Principles (IPP)

- PP1 - Restricting collection of information to lawful purposes and by fair means
 - PP2 - Informing people why information is collected
 - PP3 - Ensuring personal information collected is of good quality and not too intrusive
 - PP4 - Ensuring proper security of personal information
 - PP5 - Allowing people to know what personal information is collected and why
 - PP6 - Allowing people access to their own records
 - PP7 - Ensuring that personal information stored is of good quality, including allowing people to obtain corrections where it is not
 - PP8 - Ensuring that personal information is of good quality before using it
 - PP9 - Ensuring that personal information is relevant before using it
 - PP10 - Limiting the use of personal information to the purposes for which it was collected
 - PP11 - Preventing the disclosure of personal information outside the agency
- (ComLaw 2009)

Beginning the task

- Obtain list of patients to be contacted
- Introduce yourself to the person in charge of the ward, explain you are doing the data quality study and ask permission to conduct interviews
- Ask if they would identify which patients are well enough, competent enough and available to be asked about participating in the study
- In the case of a minor (less than 18 years) it will be necessary to seek the consent of the parent or guardian.

Patient information sheet

- It is important that patients understand the purpose of the study
- Read through the patient information sheet with each patient
- Answer any questions he or she has
- Leave the patient information with the patient
- Ask if they are willing to participate in the study
- Do not proceed with the questionnaire unless consent has been given

The questionnaire

- Questions should be asked exactly as worded
- If necessary repeat the question
- Do not guess if the answer is not heard or understood
- Exception – The sex question used to be offensive to some patients in past studies. Interviewers might fill the answer based on their own judgements.
- Do not force answers
- If prompts are necessary, it is important that they are neutral
- Record the answers accurately



How will the results of this study be used?

- The questionnaire will be compared to the original clerical admission records
 - A summary of the comparison will be sent to AIHW for analysis and
 - A report on the quality of the data will be produced to assist governments in the planning of health services
-



For staff responsible for filling the report sheets

- 'Hospital cover' sheet--enter hospital contact details, number of refusals, and other information as required.
 - 'Notes' sheet -- please read the detailed instructions on the before filling out the 'Report sheet'. And refer to it when you are not sure.
 - 'Report sheet'--report the interview answers and hospital records for patients who participate in the interview
-



Any further questions?

Thank you for your attendance

A2.3 Patient information sheet

The following information sheet was provided to participating hospitals for distribution to patients.

<Hospital Letterhead>

Patient information – Hospital data quality study

.....Hospital would like to know that the information that is collected on admission to the hospital is the right information. To do this, we would like to ask you some short questions.

If you agree to be part of this, we do not need to know, nor will we use your name.

Thank you

This project has been approved by the Ethics Committee of

Information already collected by the hospital and information collected for this study, but not your name or patient number, will also be used by the Australian Institute of Health and Welfare for a national report on hospital data quality.

For more information about this project, contact

A2.4 Patient information flyer

The following information sheet was provided to participating hospitals for distribution to patients.



We need your help to make sure that the data we collect are correct.

Will you help us by taking part in our survey?

The survey will enable us to check the accuracy of our records. The person-to-person interview will take only a few minutes of your time and is confidential. We will ask you six questions including your sex, date and place of birth, Indigenous status and your usual residence. We will not ask your name. The information will not be used to identify any person—it is only to check the accuracy (quality) of our records.

If you don't want to take part, you do not have to—it is your choice. There will be no difference to the care you receive if you say no.

What will happen to the information you provide?

Data items collected from the interview will be compared with the same items in the hospital records. The hospital record number, not your name, will be used to match the two records. When the record numbers are matched, the remaining items will be checked to see how they match. A summary of the comparison will be sent from the hospital to us for analysis. We will then produce a report on the quality of the data. This will allow hospitals and governments to work out the accuracy of all their data, and allow better planning and decision making.

Why is the quality of hospital data important?

It is easy to make mistakes, and a study in 1998 found that nearly one in ten records contained some incorrectly recorded data items.

This inaccurate data could mislead governments in their decision making, and could affect medical research. The decisions made by health services and hospitals, too, could be affected by inaccurate data. In fact, inaccurate information could have some effect on the way health services are delivered to everyone in Australia.

Who uses hospital data?

Hospital data are used by different organisations for different purposes. We analyse the data and publish the analyses in our reports, which help governments and community organisations develop health programs to meet the needs of the whole population or particular groups in Australia. We also put the data on our website, which can be accessed by research institutes, community organisations, government departments and the wider community. As an example, a government department may use the information to help them develop a program to prevent diseases that are more common in certain parts of the country, or among certain age groups, or among men rather than women. Medical institutes also need relevant information when trying to find the causes of diseases.

HOSPITAL RECORD		Match	?	Match	?	Match	?	Match	?
Hospital/unit record number	→	Match							
Sex	→	Match?							
Country of birth	→	Match?							
Indigenous status	→	Match?							
Date of birth	→	Match?							
Usual residence	→	Match?							

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graph TD
    A[Collected data] --> B[organised evaluated analysed]
    B --> C((Information for governments & research institutes))
    C --> D[• to make decisions about spending  
• to inform governments or research institutes to act on a problem  
• to measure the effectiveness of programs and services over time]
    
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A2.5 Instructions to interviewers

The following instructions were provided to participating hospitals for distribution to interviewers.

1. When contacting a patient, please read the patient information sheet, answer his/her questions, and ask for the patient's consent to participate in the interview. In answering his/her questions, you may use the following information:
 - This study is being conducted to find out how accurate the collected patient information is. This information is needed to plan health services and to monitor the health of the community.
 - The following questionnaire will ask details of the patient's gender, country of birth, date of birth, where he/she lives and whether he/she is of Aboriginal or Torres Strait Islander. His/her answers will be compared to the information already collected by the hospital at admission.
2. If the patient doesn't give his/her consent, please tick the appropriate box in the questionnaire and do not proceed below the line.
3. If the patient gives his/her consent, please:
 - record the patient's hospital record number before you proceed with the questions. This number will be needed to match the data you obtained from the questionnaire with the hospital records.And then,
 - go through the questionnaire with him/her. During the interviews, read the questions as worded to the patient, do not guess or force the answer. Exemption has been give to question two, the sex question. Since a patient might feel offended by being asked about his/her sex, interviewers can tick the answer to this question based on their own judgements.
4. At the end of the interview period, please count the total number of non-consents received, and record this number in the report sheet.

A2.6 Questionnaire

Patient interview information was collected by paper-based questionnaire (see below). The collected data were then compared to the hospital record, and the results collated into a de-identified database.

Questionnaire—Hospital data quality

Consent given

Yes No

Interviewer - do not proceed if consent is not given.

1. Hospital record number

Interviewer - please record number from patient's arm bracelet

2. Sex - Are you

Male

Or

Female

3. Were you born in Australia?

Yes

No

4. What is your date of birth?

Interviewer - if the patient cannot recall the date of birth, ask for an estimate of the year of birth or an estimate of the patient's age

Day/month/year

Or

What is your estimated year of birth?

Year

Or

What is your estimated age?

Years old

5. Are you of Aboriginal or Torres Strait Islander origin?

Interviewer - if both Aboriginal and Torres Strait Islander, tick both 'yes' boxes.

No

Yes, Aboriginal

Yes, Torres Strait Islander

6. Where do you usually live?

Number/street

Suburb/town

State or Territory/postcode

Thank you for participating!

Interviewer no. _____

Date: _____

Ward: _____

Time taken for interview: _____

Interviewer - note any changes to be made to hospital records at the conclusion of study

Comments: _____

A2.7 The report sheet

The following report sheet was provided to participating hospitals for collation of the compared patient records.

Record ID.	Sex		Born in Australia		Date birth			Indigenous status		Address of usual residence			
	Interview	Hospital record	Interview	Hospital record	Match or not	Year of birth (not estimated)	Estimated year of birth	Estimated age	Interview	Hospital record	Match or not	postcode	suburb

Notes (Please read before completing the report sheet)

- Record ID: This can be the patient record ID in the hospital records or another ID number separately generated by the hospital. If the number is generated by the hospital, it is important to make sure that a mapping is available such that each number in this column corresponds to a unique patient record ID in the hospital records.
- Sex: Please report the results from interview Question 2 and hospital record in the relevant column, using the following letters.
M – Male
F – Female
NS – Not stated
- Born in Australia: Please report the results from interview Question 3 and hospital record in the relevant column, using the following letters.

Y – Yes
N – No

NS – Not stated in the interview

4. Date of birth (DOB): If an exact DOB is obtained from interview Question 4, enter both of the following two items

(1) Match or not -- Is the DOB the same as hospital record?

Y – Yes

N – No

(2) Year of birth (not estimated) -- Enter the year of birth in 4 digits.

If an exact DOB is not obtained from interview, enter either of the following

(1) Estimated year of birth -- Enter the patient's estimated year of birth in four digits.

(2) Estimated age -- Enter the patient's estimated age.

5. Indigenous status: Please report the results from interview Question 5 and hospital record in the relevant column, using the following letters.

N – No, not Aboriginal or Torres Strait Islander

A – Yes, Aboriginal

TSI – Yes, Torres Strait Islander

ATSI – Yes, both Aboriginal and Torres Strait Islander

NS – Not stated

6. Address of usual residence: Match or not -- Is the address obtained from interview Question 6 the same as hospital record, at the postcode level?

Y – Yes

N – No

Postcode -- enter the postcode of the patient's usual residence address, or NS if it's not stated. This is needed to assess data quality by geographic area.

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