

# To be or not to be: recording Aboriginal identity on hospital records

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## Abstract

Accurate health information is a key component in the development of health improvement strategies. This paper provides a discussion of the challenges in improving hospital information systems in relation to indigenous patients. Based on interviews with both staff and patients of a major city hospital complex, a picture emerges of the need for bottom-up approaches to understanding perceptions of identity. Indigenous patients were found to be generally comfortable about identifying themselves on hospital records (if asked), but were often not clear why such questions were asked. On the other hand hospital staff were often uncomfortable about asking and were equally not always clear why such information was needed. Issues of accurate hospital record administration are discussed in relation to the attitudes and perceptions of both staff and patients.

**Indigenous patients were found to be generally comfortable about identifying themselves on hospital records (if asked), but were often not clear why such questions were asked.**

## Introduction

The poor health status of indigenous Australians has been widely documented<sup>1,2,3</sup>. However a complete analysis of indigenous health data remains problematic given the uneven quality of health information systems across Australia<sup>4</sup>. A major cause for concern relates to the identification of Aboriginal and Torres Strait Islander

people on hospital records. Although public hospitals across Australia have for some time been attempting to identify their indigenous patients on records, there has often been a lack of consistency in approach. Concerns have been expressed from many quarters regarding under-reporting within hospital based indigenous health information<sup>5</sup>.

Improvement in indigenous health information has been very slow in coming. Thomson<sup>6</sup> has noted that despite calls for a consistent national approach to the collection of Aboriginal Health statistics dating back as far as the 1950s, it was not until well into the 1980s that any significant progress was made. A number of key workshops held by the Australian Bureau of Statistics in 1986, 1993 and 1996 all went some of the way in highlighting progress as well as setting agendas for improvement. However the recommendation by the National Aboriginal Health Strategy in 1986 for the 'establishment of a system for the collection and collation of sound and valid

national Aboriginal and Islander vital statistics'<sup>7</sup> is still to be realised with the National Aboriginal Health Strategy Evaluation Committee<sup>8</sup> noting only a partial attainment of this objective. Even more recently the Australian Institute of Health and Welfare report entitled *The Aboriginal and Torres Strait Islander Health Information Plan:...This time, let's make it happen* (1997) still noted enormous gaps in the quality of indigenous health data including for example the lack of accurate reporting of mortality for two thirds of the Australian indigenous population and a continued reliance on morbidity figures based on hospital separations data which generally had not been assessed for their completeness.

A major obstacle in the development of a national data collection system relates to the highly variable systems in place across Australia's states and territories. Since the late 80s the states and territories have gradually developed stronger policy positions in relation to the inclusion of indigenous identifiers on birth and death notification forms, death certificates, hospital in-patient collections as well as specific maternal/perinatal, cancer and communicable disease collections. However these sorts of improvements only tell part of the story, since the issue of

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identification ultimately boils down to one of interpersonal communication. As Richard Madden<sup>9</sup> from the Australian Institute of Health and Welfare has pointed out:

While a bureaucratic and technical exercise, the identification of Indigenous people in administrative data collections used by Australian government is also about working out how to convince and motivate people about its importance - Aboriginal people and non-Aboriginal people, including doctors, funeral directors, people at the front desks of hospitals and health information managers.

This point is exemplified in the study by Robertson<sup>10</sup> who found that midwives often reported feeling embarrassed about asking about patients indigenous identity, preferring to not raise the question unless the patient's physical appearance or name suggested Aboriginality. Many midwives felt that asking about Aboriginality had the potential to damage their relationship with both Aboriginal and non-Aboriginal patients. Some felt it could be seen as discriminatory, whilst others felt 'stupid' asking women they perceived as 'obviously' Asian or European.

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Improving indigenous data collection requires then not only attention to the design of forms and computer databases, but also to the very human dimension of inquiring about an individual's cultural identity. This paper reports on a project conducted within a major Brisbane Public Hospital complex (The Royal Brisbane Hospital, The Royal Women's Hospital and The Royal Children's Hospital co-located at Herston). The study focuses not only on the technical aspects of indigenous data collection, but also on the attitudes of both staff and patients regarding the identity question on the admission form. This paper reports on the results of a project which investigated the collection of indigenous data on hospital admission records.

## Methodology

In order to expose potential weaknesses in the identification system, in mid 1996 a hospital census was conducted which sought to independently record the cultural identity of hospital patients. Wards were randomly selected and then visited by an interviewer who sought interviews with as many patients as possible. Using this method it was possible to locate indigenous patients independently of the hospital admissions records.

Patients who identified as indigenous could then be checked against the hospital data so that two groups of indigenous patients within the hospital could be defined - those correctly identified on admission records - and those incorrectly identified on admission records. The census was also used to ascertain patients attitudes toward being asked about their cultural identity.

A very brief census questionnaire of about five minutes duration was designed so that interviewers would minimise disturbance to patients and maximise participation. Indigenous patients were then asked if they would be willing to participate in a longer semi-structured interview (of about 30 minutes duration) which focused on their perceptions of the identity question. Answers to these questions were coded and entered onto SPSS for statistical analysis. Significant differences in frequencies of responses were identified by Chisquare tests.

In addition to the census, interviews were also conducted with the Aboriginal Hospital Liaison Officer, hospital managers, nursing staff, and admissions clerks in order to fully understand relevant administrative procedures and also to describe staff attitudes toward the identity question

## Results of staff interviews

### The administrative process

At the time of the study all three hospitals had a policy which acknowledged the need to collect indigenous identity on admission records. The same identification question was used by each of the hospitals on their admission forms. The question asked patients to tick a box against the following possibilities: (a) Caucasian (b) Aboriginal © Torres Strait Islander (d) Asian (e) Other, and (f) Unknown. The logic of such a question clearly 'targets' indigenous identity since all other identities are either lumped into large amorphous categories like Caucasian or Asian, or are simply ignored (eg African, South American). Commonly hospital staff filled in admissions forms, verbally seeking information from the patient and or their family.

### Staff perceptions

Whilst senior managers generally reported official policy positions regarding the ethnicity question, clerical and nursing staff were able to report the difficulties they felt in asking about a patient's cultural identity. Interestingly

**Table 1.**

| Indigenous Patients       | Identified Correctly | Identified Incorrectly | Other         | Total     |
|---------------------------|----------------------|------------------------|---------------|-----------|
| Royal Children's Hospital | 10                   | 9                      | 1*            | 20        |
| Royal Brisbane Hospital   | 1                    | 4                      |               | 5         |
| <b>Total</b>              | <b>11 (44%)</b>      | <b>13 (52%)</b>        | <b>1 (4%)</b> | <b>25</b> |

\* One had self-identified as 'other' because they wanted to be considered both Aboriginal and Torres Strait Islander, but could not choose both in the 'either or' question on the form.

staff in the two adult hospitals felt the identity question was much more problematic than staff in the children's hospital. Children's hospital staff generally felt more comfortable in asking a parent or guardian about their child's ethnicity than staff in the adult hospital's felt in asking an adult patient directly.

Some staff reported that the ethnicity question was a sensitive question because patient's do not see the relevance of ethnicity to their treatment and so are reluctant to answer. A number of staff felt that the ambiguity surrounding the ethnicity identifiers caused some patients to feel irritated. Caucasian was felt to have little practical meaning and many cultural identities simply were left out. It was for these sorts of reasons that some staff reported on occasions either guessing ethnicity or ticking 'other'. Staff also reported that they often found themselves asking questions in relatively open spaces and felt the lack of confidentiality made the situation worse.

The Aboriginal Hospital Liaison Officer expressed concerns about the lack of accurate identification, since her support work was reliant on hospital data, though informal networks often lead to the Liaison Officer 'finding' many more indigenous patients than formally noted on the hospital data base. 'Guessing' ethnicity also caused problems for the Liaison officer who reported instances of being sent to the bed of Papuans or Pacific Islanders or other non Aboriginal patients who had been incorrectly 'guessed' by hospital staff.

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## Results of bed census survey

### Description of the Sample Group Interviewed - Overall Completion of the Admission Forms

The interview team consisted of 4 people, two non-indigenous women and two indigenous men. However, over 90% of the interviews were performed by one man and one woman. Seven wards were visited in the Royal Children's Hospital, while patients were interviewed at 12 wards in the Royal Brisbane Hospital (The Women's Hospital could not be included due to resource constraints).

Among the total of 451 patients interviewed at the two hospitals, 25 (5.5%) identified as Aboriginal or Torres Strait Islander. Of the 313 parents or guardians of patients interviewed at the Royal Children's Hospital, 20 (6.4%) identified the child as Aboriginal or Torres Strait Islander. Five (3.6%) of the 138 contacted at the Royal Brisbane Hospital identified as indigenous.

Overall, 267 of the 451 interviewees (59.2%) recalled filling in the questions on the admission form, while 181 (40.1%) said they did not remember. A higher percentage of patients at the Royal Brisbane Hospital (50%) than at the Children's Hospital (36%) said they did not remember the form.

Among the 25 indigenous patients, 11 (44%) remembered answering the form. Of these 11, 7 said family members had filled out their forms. A cross-check with hospital records revealed significant gaps in the accuracy of recording indigenous identity as shown in Table 1.

**Table 2**

| Hospital                  | Indigenous patients identified in this study (%) | Indigenous patients recorded in hospital inpatient separations data (%) |
|---------------------------|--|---|
| Royal Children's Hospital | 6.4  | 3.6   |
| Royal Brisbane Hospital   | 2.7  | .96   |

**Table 3.**

| <i>"What is your ETHNICITY"</i> | Those asked the identity question<br><i>"How did you answer the question?"</i> | Those not asked or didn't answer<br><i>"How would you have answered if you'd been asked?"</i> | Total Group |
|---------------------------------|--|---|-------------|
| Caucasian                       | 100 (60.6%)  | 147 (51.3%)   | 247         |
| Aboriginal                      | 6 (3.6%)   | 14 (4.9%)   | 20          |
| Torres Strait Islander          | 1 (0.6%)   | 3 (1.0%)  | 4           |
| Asian                           | 1 (0.6%)   | 2 (0.7%)  | 3           |
| Other                           | 40 (24.2%)   | 98 (34.2%)  | 138         |
| None                            | 17 (10.3%)   | 22 (7.7%)   | 39          |
| <b>Total</b>                    | <b>165</b>   | <b>286</b>  | <b>451</b>  |

This potential for under-reporting of indigenous patients can also be seen by comparing the results of this study with the 'official' level of reporting of indigenous patients for the 1994/95 year as shown in Table 2.

### The ethnicity question

Of the 451 people asked whether or not they remembered being asked their ethnicity, 165 people (36.6%) said yes, 270 (59.9%) said no. Sixteen people did not answer this question. Only 15.6% of Royal Brisbane Hospital patients said yes, while 48% of parents/guardians of Royal Children's Hospital patients said yes. This difference is highly significant (Chisquare test,  $p < 0.001$ ). Among the 25 indigenous patients interviewed, 8 (32%) said they recalled being asked this question; a similar proportion (38.3%) of non-indigenous patients recalled being asked ( $p > 0.05$ ).

Among the 267 who remembered the form, 57% said they were asked the question. The interviewees who answered that they had been asked the question were asked to indicate how they actually did answer. Those who said they did not remember being asked were requested to say how they would have answered it if they had been asked. Table 3 shows the distribution of answers to this question.

There was no significant difference in response patterns between those who were and were not asked the ethnicity question. The largest number said that they had, or would have, answered Category 1: Caucasian. The distribution of answers was generally similar across the groups stratified by whether they had been asked the identity question during admission. However, there was an increase in the number saying they would have answered "Other" and a corresponding decrease in the number saying they would have answered "Caucasian". This shift may reflect a dissatisfac-

tion with the Category "Caucasian" as described below, and a tendency not to choose that answer if given more time to consider the answer. While being asked this question during the interview, many people went on to describe their ethnicity in detail, which would not have been possible during admission procedures.

When asked whether the patient or parent/guardian considered the answer they gave, or would have given, about their ethnicity to be accurate, 235 (54.4%) replied that it was accurate, while 196 said it was not accurate.

### Attitudes towards the cultural identity question

Patients were asked to indicate whether they:

*Agreed a Lot*                      *Agreed a Little*  
*Disagreed a Little*                *Disagreed a Lot*

with the following statements as read by the interviewer.

#### *I know what the question was really about*

Just over half of the patients interviewed, 50.8%, felt strongly that they knew what the question was about, while a further 29.3% agreed a little that they knew. Only 12% indicated they had no idea what the question was about. There was a significant difference in responses associated with the Hospitals ( $p < 0.001$ ), with more patients in the Royal Brisbane Hospital (74.6%) agreeing strongly with the statement, compared to the Children's, where 40.3% agreed strongly and 39% agreeing a little. Eleven out of the 25 indigenous patients (44%) strongly felt they knew what the question was about, while 16% indicated they did not know what it was about at all. This pattern of responses did not differ significantly with the non-indigenous group. Individual interviewees made a few comments about this question such as, "(the ethnicity question is) racist" or "I'd never

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thought about it".

#### *I found the question easy to answer*

A similar pattern of responses was given to this second question, with 54.3% indicating they strongly agreed with the statement. In the Royal Brisbane Hospital, very few people gave intermediate answers, with 76.8% saying they strongly agreed, while 13.8% indicated they strongly disagreed. In contrast, 44.4% and 35.1% of parents/guardians in the Royal Children's Hospital said they agreed a lot and a little, respectively, while roughly equal percentages (8.6% and 10.5%) indicated they disagreed a little and a lot, respectively.

Responses between ethnicity categories differed significantly in response to this question ( $p < 0.01$ ). While most of those who answered "Caucasian" (88.6%) expressed agreement [little or a lot], 56% of those identifying as Aboriginal, 100% of those identifying as Asian or Torres Strait Islander and 73% of those answering as "Other" agreed with the statement. Approximately 20% of Aboriginal and "Other" respondents disagreed a lot with the statement, and hence expressed difficulty in answering the ethnicity question.

This question raised a few comments, such as "I didn't answer the question", "I had to think about it", "European didn't apply to the responses so I had to add bits" and "It was a stupid question that shouldn't be asked".

#### *I was surprised to be asked such a question.*

Most people (64.5%) indicated they were not surprised by the question, while 23.7% indicated they were. The proportion who were surprised was roughly equal in the two hospitals, although again, those from the Royal Brisbane expressed fewer intermediate responses than those in the Children's. No significant difference was seen in patterns of responses by indigenous versus non-indigenous people or between those in differing ethnicity response groups.

#### *I felt comfortable about being asked*

Given the comments examined above, a surprisingly large majority of people (69.4%) strongly agreed that they felt comfortable about being asked the ethnicity question. Only 5.5% indicated that they disagreed a lot with the statement. Disagreement was slightly more frequent among indigenous patients, with 56% indicating no discomfort, and 16% indicating considerable disagreement with the statement, although 100% of Torres Strait Islanders answered with strong agreement. Those who answered the ethnicity question "Other" showed similar

acceptance [69% strongly agreed] as those who answered "Caucasian" [72.1% strongly agreed]. All those identifying as "Asian" agreed strongly with the statement.

#### *I know why the hospital would like such information*

Although a large percentage of patients indicated they knew what the question was about, few felt they knew why the hospital needs the information. Only 5.2% from the Royal Brisbane Hospital and 39.8% from the Children's Hospital said they agreed a lot or a little to the statement. Nearly 87% of the Royal Brisbane patients, but only 46% of Children's Hospital interviewees indicated they had no idea why the Hospital needs the information. This difference between hospitals is highly significant ( $p < 0.001$ ).

Patterns among indigenous patients reflected more closely those of the Children's Hospital [where most were interviewed], with 14 out of

25 (56%) indicating they strongly disagreed with the statement [and did not know why the hospital needs the information].

#### *Suggested Changes to the Question*

When asked whether the patient would like to see a change in the wording of the question, a surprisingly low percentage (25.9%) of interviewees indicated it should be changed. Only 16% of indigenous patients suggested changes should be made.

### **Results of semi-structured interviews with indigenous patients**

Indigenous patients identified through the census questionnaire were also interviewed in a longer format, semi-structured interview regarding their perceptions of the identity question. Given the concerns expressed by some staff about the sensitivity of the identity question, it was interesting to find that not one indigenous patient interviewed expressed any concern about being asked about their identity. Of those who remembered being asked the question, all felt very comfortable in answering. A number indicated they were proud of their identity and were more than happy to express this if asked.

However few indigenous patients could think of any reason why they were asked about their cultural identity. Many accepted the question as part of usual 'bureaucratic red tape' and could offer no further explanation of why such a question was asked, whilst a few thought that it was 'for the record' or for 'stats' purposes. Two were a little more cynical, with one suggesting that 'they always put us down as being in hospital and its not always the

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Two indigenous patients suggested medical reasons were behind the question, noting that indigenous people were 'more likely to get Hep B and other diseases' and that perhaps different medical treatments are given to indigenous patients. One recalled that her baby had been given a TB shot because she was Aboriginal, and that perhaps this meant that there were other different needles or treatments needed for indigenous patients when they got older too. One very informed patient explained that such information was very important because it provided statistics which could be used to help prevent diseases among indigenous people, and that it was also important so that Aboriginal Hospital Liaison workers could be contacted to provide assistance to indigenous patients.

When asked about whether indigenous people might feel any differences about being hospital than non-indigenous people, several expressed their fears about the hospital environment, particularly those from outside of Brisbane. There were expressions of feeling isolated from friends and family. The outcome of this was explained by one indigenous mother: '*We are more reserved. We don't go with the flow*'. In a similar vein, a patient from far north Queensland explained:

You get tongue-tied when you talk. You need an Aboriginal to talk to. Some nurses are nice to joke with. But most you just can't understand what they're talking about.

Importantly none expressed any concern that they were given poorer treatment in hospital than their non-indigenous counterparts. All of those interviewed felt that treatment was equal. Some made a point about being very complimentary about hospital staff. Rather their feelings of isolation were founded on 'feeling different', on not seeing any 'black faces'.

It is important to note that those interviewed in this project were by definition those patients who felt comfortable in identifying to our interviewers their identity. The feelings of those who may not have identified either to hospital staff or our project interviewers, of course, remain unexplored and methodologically 'out of reach' within the bounds of this project. What was possible to explore though, was the issue of whether there was anything unique about the hospital situation which made it more or less likely for patients to identify themselves as

Aboriginal or Torres Strait Islanders. Again the strength of the indigenous identity shone through very strongly. Only one patient could describe a situation in which they didn't identify, and that was related to employment. Other than this example all expressed very strong desires to identify their Aboriginality, explaining that they were proud of their identity and would put it down on any form if asked. There was still some uncertainty about why such questions were asked, but if it was asked all said they would answer. Pride in identity over-rode other concerns, one female patient noting that:

I always fill in Aboriginality. Actually I often think, I am not filling this in, but then I do.

## Discussion

Contrary to some prevailing assumptions about indigenous people, it would seem that asking about cultural identity is not as problematic as some have suggested. At least among the sample of interviewees here (albeit very small), answering questions about Aboriginality is a source of pride. This is an important finding, since it

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demonstrates that there is community support for improving efforts to identify Aboriginal and Torres Strait Islanders on hospital records. This is not a surprising finding and is in line with national evidence that more people are choosing to identify themselves as Aboriginal and Torres Strait Islander<sup>11</sup>. The results of this study suggest that the critical factor in limiting the effective collection of Aboriginality on hospital records is lack of appropriate administrative processes. In this study only 57% of those who remembered the admission form, said they remembered being asked their identity.

Moreover administrative and nursing staff at times feel uncomfortable in asking about ethnicity, particularly with adult patients. Therefore it is not surprising that staff would regularly side-step the question by either guessing identity or simply marking 'other' or 'unknown'. Hospital staff should be reassured that the majority of patients - indigenous and non-indigenous - felt comfortable in being questioned about their cultural identity.

However it was also clear that although patients felt comfortable with the cultural identity question, they nevertheless did not know why such a question was being posed. Moreover a number of staff were not clear why the cultural identity question was included since 'all patients are treated the same'.

## Conclusion

Despite the existence of official policy on the need to collect Aboriginality data, lack of progress appears to relate to inadequate administrative processes and in particular inadequate training for hospital staff regarding both the importance of the identity question and practical support in how best to ask such a question. Equally patient education strategies are clearly required to ensure they know why they are asked.

Ultimately the problems raised in this paper suggest the need for better administrative checks and balances as it is clear that placing the identifier question on admission forms does not alone guarantee accurate collection of data. However the commitment to change required to bring about such changes requires more than official policy or central office directives, but also support throughout the hospital hierarchy and also sensitivity to the needs of both staff and patients.

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Man, when perfected, is the best of animals but, when separated from law and justice, he is the worst of all.

**Aristotle (384 - 322BC) in Politics I**