Report on Workshop Proceedings – November 1996

Australian
Bureau of
Statistics

AUSTRALIAN INSTITUTE OF
HEALTH & WELFARE

Indigenous Identification in Administrative Data Collections

Best Practice and Quality Assurance

INDIGENOUS IDENTIFICATION IN ADMINISTRATIVE DATA COLLECTIONS - BEST PRACTICE AND QUALITY ASSURANCE

Report on Proceedings of the Brisbane Workshop - November 1996

A JOINT PROGRAM OF AUSTRALIAN BUREAU OF STATISTICS
AND AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE

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FOREWORD TO WORKSHOP PROCEEDINGS ..

The workshop was organised by the National Centre for Aboriginal and Torres Strait Islander Statistics (NCATSIS) of the Australian Bureau of Statistics (ABS), and hosted by the Queensland office of the ABS over two full days on the 26-27th November 1996. The initiative was part of the ongoing work plan of the Aboriginal and Torres Strait Islander Health and Welfare Information Unit of NCATSIS. The Unit is a joint project between the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

Complete and correct identification of Aboriginal and Torres Strait Islander people, using a common approach, is the key to high quality Aboriginal and Torres Strait Islander statistics from administrative data sets. This has been recognised for decades and has been the subject of numerous government initiatives including a plan sponsored by a House of Representative Standing Committee, a high level task force held in the mid 1980's and two workshops on Aboriginal Health Statistics (see the paper by Neil Thomson in this report for more details).

Of the previous initiatives it is arguable that the task force on Aboriginal health statistics has been the most effective initiative in bringing about change. Many Health Departments and Registrars of Births, Deaths and Marriages commenced efforts to record Aboriginality in some of their major collections following the work of the task force. Today nearly all important health data sets have incorporated a capacity to collect Aboriginality in one form or another.

Papers presented in this workshop will show, for instance that some States and Territories have achieved reportable quality birth and death statistics for Aboriginal and Torres Strait Islander people. In addition, at least one state, Western Australia, may well have very high quality hospital separation and perinatal statistics. However, many collections, particularly those in the south eastern states, apparently remain stubbornly resistant to a range of efforts to improve their quality to a level which would allow reporting of reliable Aboriginal and Torres Strait Islander health statistics.

Nevertheless, some significant advances have been made since the last workshop. Many of these are discussed in greater detail in the workshop papers and were debated at length during workshop discussions. These include:

☐ The development of an ABS standard for identifying Indigenous people in collections

☐ The widespread adoption of this standard by Registrars of Births, Deaths and Marriages, and by the National Health Data Dictionary

☐ The gradual improvement in the completeness of identification of Indigenous people in some jurisdiction's birth notification collections

☐ The achievement of reportable quality death data for the Australian Capital Territory

☐ The notable achievements of Queensland in the early stages of their push to identify Indigenous people in their birth and death collections.

In addition, there have been some very thorough studies detailing how Aboriginality is recorded in practice, other studies have documented barriers to best practice, and others have investigated the quality of sub-sets of collections by painstaking re-examination of records or re-questioning of respondents. Some of these results are encouraging, suggesting data quality can be high. Other results confirm what many have suspected, that there are still important gaps where little, if any, effort is devoted to capturing information about Aboriginal and Torres Strait Islander identity.

This workshop occurs at a time when there is demonstrated renewed commitment by Australian governments to improve the quality of Aboriginal and Torres Strait Islander health information. Since the last workshop in Brisbane in 1993 the Commonwealth government has increased its commitment of resources to Aboriginal Torres Strait Islander health and welfare information by three-fold. The review of the National Aboriginal Health Strategy called for improved health statistics in order to effectively monitor and evaluate the nations future efforts to improve Indigenous health.

The Australian Health Ministers Advisory Committee (AHMAC) has recently commissioned the development of a full set of performance indicators for Aboriginal and Torres Strait Islander health and health service issues. The performance indicators which are to be reported on by all jurisdictions, will require high quality data in all the collections discussed at the workshop for all States and Territories. AHMAC have also recognised that the central data quality issue for performance indicators is the degree to which Aboriginal and Torres Strait Islander people are identified. AHMAC have also commissioned the development of a national plan for Aboriginal and Torres Strait Islander health information which will heavily feature the need for high quality identification of Aboriginal and Torres Strait Islander people in health collections.

In short, the identification of Aboriginal and Torres Strait Islander people in health collections is more than ever before on centre stage as a national health information priority.

The scope of this workshop was intentionally made narrower than the two previous workshops on Aboriginal health statistics. The workshop focused primarily on just two issues:

☐ How should information which identifies Aboriginal and Torres Strait Islander people be collected by those who capture health data, and how is this done in practice?

☐ How should the quality of this information be assessed in health data-sets, and how can this be most effectively achieved?

Subsidiary questions which the workshop considered included:

☐ What is it that some States and Territories do well, which lead to good quality Aboriginal and Torres Strait Islander death statistics, but other States do not do as well leading to poor quality statistics?

☐ What sets of practices should be promoted as "best practice" for collecting Indigenous status information in different data-sets?

☐ What are the most efficient and effective methods for estimating the completeness of Indigenous identification in different collections?

☐ Can estimates of completeness be used to derive statistics about Aboriginal and Torres Strait Islander people?

The participants attending the workshop reflect the collection and quality assessment focus of the workshop. Most participants who took part in this workshop fell into one of three categories:

☐ Representatives of the government agencies responsible for data collection i.e. Registrars General and Health Departments (including Aboriginal Health Units) from each State and Territory

☐ Experts in the collection and assessment of data quality in Aboriginal health information

☐ ABS personnel from the National Centre for Aboriginal and Torres Strait Islander Statistics and from each State and Territory Office.

A major aim of the workshop was to foster the development of a small local network of people in each State and Territory interested in issues of identification of Aboriginal and Torres Strait Islander people. These networks should include at least representatives of the offices of the local Registrar General, the Department of Health and local ABS office, and might also include any locally based experts. These networks will be the focus of future efforts to improve identification of Aboriginal and Torres Strait Islander people in health collections.

These Proceedings will be used to develop a strategy and associated program of work to address, on a state by state basis in conjunction with the local networks, the major outstanding issues in this area. These activities will be facilitated at a national level by NCATSIS of ABS with support from the Australian Institute of Health and Welfare (AIHW) and will call on advice and support of a broadly based informal working group which was formed at the workshop (see resolutions).

The following resolutions and recommendations, drafted at the workshop, were submitted for consideration to the Australian Health Ministers Advisory Council (AHMAC) meeting on Thursday 20th February 1997, through the Heads of Aboriginal Health Units and the AIHW. In response, the AHMAC meeting minutes noted the resolutions and AHMAC members agreed that "Indigenous origin", as defined in the National Health Data Dictionary (1) be used in administrative health data collections used by Australian Governments. Further, AHMAC members requested the National Health Information Management Group (NHIMG) to consider and take urgent action on the resolutions.

At this same AHMAC meeting it was agreed that all jurisdictions should take immediate steps to improve the quality of data related to Aboriginal and Torres Strait Islander health to enable reporting against agreed performance indicators. Jurisdictions would also report in six months time on their ability to report against the performance indicators and on their progress in developing the capacity to report where they are currently unable to report due to inadequate data.

1. Note that the "Indigenous origin" definition as defined in the National Health Data Dictionary is based on the ABS standard Indigenous status definition.

I am grateful to Brian Doyle, Regional Director of the Queensland ABS office, for hosting the workshop and to Malcolm Greig and all the staff of the Queensland office who assisted with preparations and ensured the smooth running of the workshop. I would also like to thank Chris Davis, Kylie Freer, Tammy White, Barbara Gray, and Jennifer Isaacs for their assistance in preparations for the workshop and for preparing these proceedings for publication.

Tony Barnes

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Darwin.

ABBREVIATIONS

ABS	Australian Bureau of Statistics
AHLO	Aboriginal Hospital Liaison Officer
AHMAC	Australian Health Ministers Advisory Council
AIH	Australian Institute of Health
AIHW	Australian Institute of Health and Welfare
ALO'S	Aboriginal Liaison Officers
AMA	Australian Medical Association
ANU	Australian National University
ATSIC	Aboriginal Torres Strait Islander Commission
CEP	Community Employment Program
CHSS	Community Health Statistical System
DAA	Department of Aboriginal Affairs
DCHS	Department of Community and Health Services
DSU	Data Services Unit
GSO	Government Statistician's Office
HAHU	Heads of Aboriginal Health Units (Commonwealth, State, Territory)
HIM	Health Information Manager
HIMAA	Health Information Managers Association of Australia
HRSCAA	House of Representatives Standing Committee on Aboriginal Affairs
MRA	Medical Record Administrator
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHSEC	National Aboriginal Health Strategy Evaluation Committee
NATSIS	National Aboriginal Torres Strait Islander Survey
NCATSIS	National Centre for Aboriginal and Torres Strait Islander Statistics
NHDD	National Health Data Dictionary
NHMRC	National Health Medical Research Council
PDC	Patient Data Collection
PDCU	Perinatal Data Collection Unit
PRISM	Psychiatric Records Information Systems Manager
QHAPDC	Queensland Hospital Admitted Patient Data Collection

SAHC	South Australian Health Commission
THS	Territory Health Services (NT)
TSI	Torres Strait Islander
VEMD	Victorian Emergency Minimum Database
VIMD	Victorian Inpatient Minimum Database

WORKSHOP RESOLUTIONS

INTRODUCTION

The outcomes from the proceedings were summarised to form the following workshop resolutions and recommendations. The workshop noted that many of the recommendations and resolutions of previous workshops on Aboriginal and Torres Strait Islander health information and statistics were still relevant today. The resolutions from this workshop are grouped into five sections:

☐ Commitment and consultations between Aboriginal and Torres Strait Islander peoples and agencies

☐ Education amongst senior officials and health information managers in health agencies and Registrar General's offices

☐ Standard Questions implemented prior to the 2001 Census

☐ Specific Resolutions

☐ Process for ongoing focus on identification of Aboriginal and Torres Strait Islander people in administrative collections.

COMMITMENT AND CONSULTATION

Best practice in the identification of Aboriginal and Torres Strait Islander peoples in administrative data system relevant to health requires:

☐ Strong and explicit COMMITMENT by all agencies concerned, including:

- State and Territory Health Departments
- Other health care providers
- Registrars of births and deaths
- Australian Bureau of Statistics
- Australian Institute of Health and Welfare
- National Health Information Management Group
- Health Information Management Association of Australia
- Australian Medical Association
- Funeral Directors Associations.

☐ Ongoing CONSULTATION with Aboriginal and Torres Strait Islander organisations and agencies about all aspects of identification, including issues of:

- Definition
- Best practice in collecting data
- Involvement of Aboriginal and Torres Strait Islander people in data collection

- Assessment of completeness of identification

- Feedback of statistics from collections .

EDUCATION

Continuing education and awareness raising is required for:

☐ Senior officials in health agencies (including Health Departments, AMA, HIMAA) and offices of Registrars General in order to promote strong organisational commitment and support

☐ Front line data collectors (eg admission clerks, doctors and funeral directors) in order to equip them with the means to deal with sensitivities and potential misunderstandings surrounding identification processes.

The continuing education should include broad based cross-cultural training, the need for and use of health statistics, and issues arising in identification of Indigenous people in administrative collections relevant to these statistics.

Indigenous communities, and their representatives, and the wider Australian community need to be provided with information explaining the benefits of identification for improving Indigenous health and why this involves *all* Australians, not just Indigenous peoples.

STANDARD QUESTIONS

In the lead up to the 2001 Census ABS should undertake a process of consultation particularly with the Indigenous community to examine all aspects of the definition of Indigenous people as it relates to administrative data systems.

In order to produce consistent health statistics the ABS standard, as adopted by the National Health Data Dictionary Version 6, should be used in administrative collections for recording Indigenous status. This should be the preferred questioning approach at least until this standard or the Census question is modified.

This standard involves:

☐ A question which addresses Indigenous origin and not a broader concept of ethnicity or cultural background

☐ Separate identification of people of Aboriginal origin, Torres Strait Islander origin or both

☐ Identification questions should be mandatory

☐ Except where identification information is transferred from one record system to another, there should be no "not stated" category

☐ Questioning of all service clients (or their family members) and avoiding adhoc or visual means of identification.

In the interests of high data quality and to allow for possible identification changes, data recorders are encouraged to ask the standard question on each service delivery encounter.

SPECIFIC RESOLUTIONS

Resolution 1:

Birth registration and midwives notification systems in each State and Territory should identify Aboriginal and Torres Strait Islander status of mothers and fathers.

Resolution 2:

Special efforts are needed urgently in States in which the quality of Indigenous identification in death registration remains poor.

Resolution 3:

ABS and other data-gathering agencies should release data relating to Indigenous health on an annual or other appropriate regular basis, even if coverage is assessed as being incomplete, to inform all concerned about current data quality in data sets and to assist and encourage research to improve quality.

Resolution 4:

For data collection, where completeness is not known, ABS/AIHW should co-ordinate efforts to assess, monitor, and report this aspect of quality.

PROCESS FOR ONGOING FOCUS ON IDENTIFICATION

The resolutions of this workshop should be presented to AHMAC for endorsement, through the Heads of Aboriginal Health Units and AIHW.

The AIHW and ABS should convene a reference group of "minders of best practice" to monitor processes of implementation of Indigenous identification in government collections of birth, death and perinatal registration, midwives notification and hospital inpatient systems and related collections.

Suggested membership of the reference group should include representatives of:

- HAHU
- NACCHO
- Registrars General
- Perinatal data units
- HIMAA
- AMA
- AIHW
- ABS.

In recognition of the highest priority this issue has for health information for Australian governments this group should be chaired by the Director of AIHW, the country's premier health information agency.

CHAPTER 1

OPENING AND HISTORICAL OVERVIEW

The workshop was formally opened by a brief welcome from the Head of the Queensland Office of the Australian Bureau of Statistics, Mr Brian Doyle. Brian's welcome was followed by short opening addresses given by Mr Sol Bellear on behalf of Heads of Aboriginal Health Units and Dr Richard Madden, Director of the Australian Institute of Health and Welfare. A third opening address from Mr Don Fraser, a representative of the National Aboriginal Community Control Health Organisation (NACCHO) could not go ahead due to illness of the presenter. However, the chairperson of NACCHO, Mr Puggy Hunter, has indicated his support for processes which will lead to better health statistics for Aboriginal and Torres Strait Islander people.

The opening addresses were followed by a presentation from Dr Neil Thomson on the history of efforts to improve Aboriginal and Torres Strait Islander health statistics.

INTRODUCTION TO THE INDIGENOUS IDENTIFICATION WORKSHOP

By Sol Bellear, Representative of Head of Aboriginal Health Units

The death rates for Indigenous people are not known in the Eastern States. Statistics on Aboriginal and Torres Strait Islander health are predominantly from WA, NT and perhaps SA. It seems that politicians view "real" Aboriginal people as living in those areas on which there are statistics available. This has implications for service delivery, e.g. the recent Federal Government infrastructure program with the army targeting NT and WA.

It is important for Aboriginal people to elect to be counted. NSW Health has a poster called "Don't wait to be counted...tell them you are Aboriginal or Torres Strait Islander". Some health workers have found in Queensland hospitals that non-Indigenous counter staff make assumptions on whether patients are Indigenous Australians on the basis of appearance. This means, for example, that a Fijian, Tongan, black African or African American may be classified automatically as an Aboriginal or Torres Strait Islander person. While it may be embarrassing for some counter staff to ask 'Are you an Aboriginal person or are you of Aboriginal or Torres Strait Islander descent', Aboriginal people are conscious of participating and aware of where the figures end up.

Recently, the National Aboriginal Community Controlled Health Organisation (NACCHO) was very scathing of the ABS and questioned whether the figures were accurate. While the bureaucracy may view this as a technical exercise, Aboriginal people in both community control and bureaucracy must be involved at all levels. If they are not, many will be reluctant to participate. However, at the same time, the roles of State and Territory governments, in particular health departments, should not be discounted.

The failure to implement the National Aboriginal Health Strategy properly has been due to the failure of governments at both the State and Federal levels to collaborate intersectorally and to sit down and talk about joint responsibilities. The other issue is that of infrastructure. Aboriginal people are now just starting to put health on the agenda as their number one priority. It has never been the priority before because successive governments on both levels have acted on 'flavour of the month' decisions, usually drug and alcohol programs that did not work. Now that has turned around and there are a lot of communities who have taken up the Aboriginal health issue 'by the throat' and made it a priority.

I frequently get asked "What are you (as a Health manager) going to do for us". This question, together with "What are governments going to do for communities", is common. As long as people themselves make certain issues the priorities, they can be put into place. However government cannot stop people from smoking, the number one killer risk factor; or stop them drinking; or stop people from beating up on their community or their partners. Those are probably the three biggest areas of Aboriginal health - the major contributing factors to ill health. Some 80% of evacuations in the north of Queensland are through some form of violence. The issues relating to health, such as smoking, are appalling. ABS is not needed to give those figures because they have been around for years.

With the assistance of NHMRC and Ian Ring, epidemiologist with Queensland Health, the "killer diseases" have been established. To attack seven or eight of the top killer diseases amongst Aboriginal communities, the type of exercise proposed through the workshop is needed. This needed to happen years ago and the Heads of Aboriginal Health Units will support it, although workshop participants will need to put pressure on State and Territory governments. More importantly, Aboriginal people will need to be involved at all levels. While it is a bureaucratic exercise because it is a bureaucratic problem, Aboriginal people are there to help and will do so.

PRESENTATION TO THE INDIGENOUS IDENTIFICATION WORKSHOP

By Richard Madden, Australian Institute of Health and Welfare

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 hospital and health information managers. This is imperative to solving the problem, in particular in south eastern Australia where the number of Aboriginal and Torres Strait Islander people coming past any one of those busy people is likely to be small. In fact, the major task is raising consciousness about the issue.

I first encountered this problem in 1985, when I was running the NT Treasury and was responsible for statistical coordination in the NT. At a meeting, representatives from Commonwealth Health, ABS and DAA in Canberra asked me to identify Aboriginal people in birth and death collections. Convinced it was a worthwhile issue, the NT Government made a commitment and within six months had useable data for both births and deaths. Other places have been more difficult but Ian Ring has worked hard in Queensland and the exercise seems to be going well.

As the ABS has found with its work over the past several years since identification started, it is very difficult to get good information. Deaths in custody is one collection where Aboriginal identification seems complete and gets action in Aboriginal policy through the efforts of the Royal Commission into Aboriginal Deaths in Custody. This shows that when something is significant, identification is possible. Aboriginal deaths, whatever the cause, are just important as deaths in custody and there ought to be the same approach and urgency. Identifying Aboriginal people in births is also just as important.

The Aboriginal deaths statistics that have been published by the ABS for the States and Territory show how big the problem is. John Condon in the NT has done some work using that data to show regional variations within the NT. His presentation at the North Australian Statistics Workshop in 1995 showed that death rates in the Top End of the NT were significantly worse than in the Centre, and this has caused people to question the way they were approaching problems. Aboriginal identification in death data is not just about showing there is a high death rate, but also provides the basis for research on regional variations and variations in different causes of death. It also enables measurement of effect because once there is good identification, you start to get time series data and can monitor whether there are changes. It is only in complete collections like vitals statistics that these sort of variations can be seen. There are no sampling problems and relatively small variations in rates can be detected, this is important to policy makers to enable them to check whether their policies are having any effect.

This is a hard issue and progress has been made. In the States and NT where work has been done, an application of effort has been shown to work. In the NT, where there is a higher proportion of Aboriginal people in the population, it is simpler than NSW and Victoria. What has been learnt has been valuable and provides the basis for approaches which might work elsewhere. At the workshop, hopefully some best practice will be found, taken away and applied. Also, it is important to talk about how to get through to all the different parties that need to be convinced that this is really their problem and part of their job.

It is essential to look at change over time and there has to be a decent basis for research. The Australian Institute of Health and Welfare (AIHW) supports the National Centre for Aboriginal and Torres Islander Statistics (NCATSIS), which is a joint unit of the ABS and the AIHW funded by the Department of Health and Family Services, because skills in this area are at a premium and it is important to focus efforts on this problem. Finally, I would like to acknowledge that Tony Barnes has done a great job in revitalising the National Aboriginal Statistics Unit, and pay tribute to all staff in NCATSIS.

So let us all commit to a major effort to get Indigenous identification right. All the interests that need to be involved are here at this workshop. We do not want to have to meet again to solve the problem.

AN HISTORICAL OVERVIEW OF THE DEVELOPMENT OF INDIGENOUS HEALTH STATISTICS

By Neil Thomson, Visiting Senior Fellow, School of Health Studies, Edith Cowan University

Background

The need for health statistics about Australian Aboriginals and Torres Strait Islanders has been recognised since at least 1955 when the National Health and Medical Research Council drew attention to the fact that despite indigenous mortality and morbidity in parts of Australia being:

"*So high as to attract official attention from time to time, no precise information is available to indicate the extent or even the nature of the diseases concerned and no satisfactory means exist for studying their incidence for readily undertaking appropriate measures*" (NHMRC 1955, cited in Smith 1978).

Shortly after this, the Northern Territory Administration initiated in 1957 the first collection of indigenous data on a regular basis when it started to publish information about indigenous infant mortality (House of Representatives Standing Committee on Aboriginal Affairs (HRSCAA) 1979). But, "this was for many years the only published information on the state of Aboriginal health" (HRSCAA 1979:30).

Initial responses

Partly in response to a series of NHMRC resolutions during the 1960s and early 1970s, the Commonwealth and State Health Ministers endorsed in 1973 a policy of collecting national Aboriginal health statistics. This endorsement was consistent with, and supported by, reports by the NHMRC, the National Population Inquiry, the Commission of Inquiry into Poverty, the Senate Select Committee on Aboriginal and Torres Strait Islanders, the House of Representatives Standing Committee on Aboriginal Affairs, the Workshop on Aboriginal Medical Services (held in 1974), the National Aboriginal Consultative Committee and the National Aboriginal Conference Executive (HRSCAA 1979).

In 1975, the Commonwealth Department of Health (1) commissioned Dr Len Smith (2), Research Fellow, Health Research Group, Australian National University to "develop a plan for the collection, interpretation and dissemination of Aboriginal health statistics on a national basis " (HRSCAA 1979: 30). Dr Smith's "Aboriginal health statistics in Australia - a survey and a plan" (Smith, 1978) was the blueprint for attempts in the late 1970s and early 1980s to foster the identification of indigenous people in the registration of vital events (that is, births and deaths), in key collections maintained by the State health authorities and in a variety of other data sources.

But progress was painfully slow. In the early 1980s, no jurisdiction provided for the identification of indigenous people in birth registrations and only New South Wales did so for death registrations (Achanfuo-Yeboah 1995). A number of the collections maintained by State and Territory health authorities did provide for the identification of indigenous people, but the adequacy of identification was unknown and little useful information was produced.

Task Force on Aboriginal Health Statistics

In 1984, the lack of real progress on the development of indigenous health statistics prompted the establishment by the Treasurer and the Ministers for Health and Aboriginal Affairs of a high-level Commonwealth Task Force on Aboriginal Health Statistics. The

Task Force, comprising Deputy Secretary-level Commonwealth officials from the Australian Bureau of Statistics and the Departments of Health and Aboriginal Affairs (3), met with senior officials from each State and Territory except Queensland (4). In discussions with the States and Territories the Task Force focused on four collections identified as priorities in the development of national indigenous health statistics - the births and deaths registration systems and the maternal/perinatal and hospital in-patient collections (5). In these meetings, broad agreement was reached on the inclusion of an indigenous identifier in most of these collections (see Table 1.1 for a summary of the outcomes of the Task Forces meeting with the States and Territories).

Some States and Territories moved quite quickly to implement the agreements reached with the Task Force, but progress on the implementation of some of the agreements was extremely slow. As well, the momentum established by the Task Force was not maintained by the Commonwealth. This occurred partly because the high-level interest at Commonwealth level virtually lapsed as soon as the Task Force had completed its work, with the result that there was inadequate, or ineffectual, pressure on States and Territories to implement the agreements reached.

The Commonwealth compounded this lack of continued high-level involvement by offering the States and Territories inappropriate support for their efforts to collate and analyse or validate available indigenous health statistics. Rather than provide States and Territories with suitable staff to undertake such specialised statistical functions, the Commonwealth arranged for short-term staff resources to be made available under the Community Employment Program (CEP) - one of its schemes for long-term unemployed people. It is testimony to the commitment of some staff at State and Territory level, particularly in South Australia and the Northern Territory, and good fortune (rather than good design), that some suitable staff were recruited under the scheme. As a result, some useful studies were undertaken during the 30 week projects possible under the CEP (see for example, Aboriginal Health Organisation of SA, 1986; Devanesen et al. 1986; Thomson, Paden and Cassidy, 1990).

Structural changes at the Commonwealth level around this time militated also against effective coordination of the development of national indigenous health statistics. The Commonwealth Department of Health had provided leadership in the area during the 1970s and early 1980s, and was an important force in the establishment and conduct of the work of the Task Force. In late 1985, responsibility for indigenous health statistics was given to the newly established Australian Institute of Health (AIH) (6). The early work of the AIH, including its work on indigenous health statistics, was somewhat restricted because of antagonism from parts of the Commonwealth Department of Health and the reluctance of some States and Territories to cooperate fully until the Institutes roles and responsibilities were spelled out clearly, as was done in the legislation establishing it as a statutory authority in July 1987. In 1986, the Commonwealth Department of Health's involvement in indigenous health was diminished further when responsibility for other aspects on indigenous health was passed to the Department of Aboriginal Affairs.

Darwin workshop, 1986

The Darwin workshop brought together people working largely in the health area to "permit an exchange of experiences in the development of Aboriginal health statistics, with an emphasis on the CEP projects" (Thomson, 1986:vii). Representation from the

Australian Bureau of Statistics and the State and Territory registrars responsible for birth and death registration was minimal, with only Darwin-based people being involved.

Partly in response to the short-term nature of the CEP projects, the workshop resolutions emphasised the need for long-term approaches. For example, a key resolution was that:

"The Commonwealth Government in consultation with State/Territory governments and Aboriginal communities should develop long-term strategies consistent with a real and lasting commitment to the development of national Aboriginal health statistics". (Thomson, 1986: ix).

The call for "long-term strategies" and "lasting commitment" fell largely on deaf ears, as evidenced by the patchy implementation of the changes necessary to provide for indigenous identification in vital statistics registrations and key health-related collections (see Table 1.2).

National Aboriginal Health Strategy and its evaluation

The National Aboriginal Health Strategy Working Party re-iterated the need for reliable data and called on the Ministerial Forum for Aboriginal Affairs (7) to "reaffirm and give renewed commitment to the establishment of a system for the collection and collation of sound and valid national Aboriginal and Islander vital statistics", with particular attention to the recording of indigenous status on hospital admissions and on notifications of births, stillbirths and deaths. (National Aboriginal Health Strategy Working Party, 1989:225)

In the limited implementation of the National Aboriginal Health Strategy it was decided that "an appropriate level of resources be made available to the Australian Institute of Health to enable comprehensive Aboriginal health statistics data collection, analysis and reporting" (National Aboriginal Health Strategy Evaluation Committee, 1994:69). The Commonwealth Department of Human Services and Health was required to provide an additional $0.56 million to the Institute over a five-year period, but instead provided a total of $0.28 million and left the Institute to find the remainder out of its core budget. The National Aboriginal Health Strategy Evaluation Committee (1994:70) concluded that the Institute had made "only limited progress in improving the quality and content of national collections and in developing a national database of Aboriginal and Torres Strait Islander health".

In its submission to the Evaluation Committee, the Australian Institute of Health and Welfare requested additional funding from 1994-95, to enable both expansion of its Aboriginal and Torres Strait Islander Health Unit and the Units relocation from Canberra to Darwin (NAHSEC, 1994). One reason for the proposed relocation was to allow more effective coordination with the Australian Bureau of Statistics Aboriginal Unit, but the Evaluation Committee doubted "whether relocation would provide a solution to the identified problems related to the quality of data collections from the States" (NAHSEC, 1994: 70).

Brisbane workshop, 1993

The Brisbane workshop, which was convened by the Australian Institute of Health and Welfare "to bring together Aboriginal and non-Aboriginal people working in the area of Aboriginal health" (AIHW, 1995:1), confirmed the real progress that had been made in most States and Territories since the Darwin workshop. Most presentations took a broader view than demonstrated at Darwin, where the focus had been largely on the collections identified as priorities by the Task Force on Aboriginal Health Statistics.

Another positive feature that became evident at the Brisbane workshop was the placement of the development of indigenous health statistics within the framework of the National Health Information Agreement. The Agreement, which had been endorsed in April 1993 by the Australian Health Ministers Advisory Council, "provides the basis for the development, sharing and analysis of national health data" and includes a work program incorporating "agreed health information priority areas" (English, 1995:78). The fact that indigenous identification is a major consideration in the draft work program suggests that the range of people with an interest in the improvement of indigenous health statistics will be much wider than evident from the participation at the Darwin and Brisbane workshops.

Despite the positive aspects, the Brisbane workshop, like the one in Darwin seven years earlier, had limited representation from the Australian Bureau of Statistics and there were, in fact, no representatives from the State and Territory registrars.

Recent developments

Partly in response to proposals to the National Aboriginal Health Strategy Evaluation Committee and to its recommendation that "agreement should be reached concerning the responsibilities of AIHW and the Australian Bureau of Statistics in data collections on Aboriginal health" (NAHSEC, 1994:70), the Commonwealth Department of Human Services and Health provided the Institute with substantial funds to operate an Aboriginal and Torres Strait Islander Health and Welfare Information and Statistics Project (AIHW, 1996). The project was funded to operate for 1995-96 and 1996-97, with an evaluation scheduled in the second year.

The Institute contracted the ABS to undertake the work of the project, and the funds enabled the Darwin-based ABS Aboriginal Statistics Unit to be expanded in July 1995 to become the National Centre for Aboriginal and Torres Strait Islander Statistics. An advantage of this arrangement is that "no physical boundary divides ABS resources applied to the Institutes project from those applied to the National Centre's other activities" (AIHW, 1996:42). The project's work program, which is agreed between the Director of the Institute and the Australian Statistician, is assisted by a broad-based advisory group.

This AIHW-ABS collaboration has already produced some useful publications, including an analysis of indigenous mortality (Anderson, Bhatia and Cunningham, 1996), and the first of a planned series of biennial reports on Aboriginal and Torres Strait Islander health is scheduled for release in April 1997.

And, of course, this workshop has been organised as part of the enhanced focus on indigenous health statistics by the ABS and the AIHW.

Summary

Almost a quarter of a century since the Commonwealth and State Health Ministers first endorsed a policy of collecting national Aboriginal health statistics, Australia still does not have national indigenous health statistics.

Progress on the development of indigenous health statistics has been sporadic over the period, largely because of the lack of sustained commitment by the Commonwealth

State and Territory governments. The very occasional demonstration of commitment, such as occurred with the Task Force on Aboriginal Health Statistics in 1984, did trigger some development.

The restricted range of people and organisations involved in the consideration of indigenous health statistics, as occurred at the Darwin and Brisbane workshops, has been a limiting factor also on the development of State and Territory, and hence national, indigenous health statistics. The lack of participation of ABS officers from around the country and of representatives from each State and Territory registrar of birth and deaths has meant that most meetings have involved preaching to the converted. (8)

Against this backdrop, the recent development involving the ABS and the AIHW is most encouraging, as is the wide range of participants at this workshop. The financial support for Aboriginal and Torres Strait Islander Health and Welfare Information and Statistics Project is the first time that the Commonwealth has matched its stated intentions in the area of indigenous health statistics with adequate resources to permit sustained development. This suggests that there is, for the first time for many years, a real commitment to achieve a policy first endorsed in 1973.

Equally as important for sustained development of indigenous health statistics is the range of people now included in the process. Unlike the restricted range of participants at the Darwin and Brisbane workshops, it is most encouraging to see that all offices of the Australian Bureau of Statistics are represented at this meeting, as are all State and Territory registrars of births and deaths.

The combination of government commitment and the participation of all key agencies and individuals should ensure that we may achieve in the few years remaining to the year 2000 more than has been achieved in the last quarter of a century.

Endnotes

1) Throughout this paper, organisations are referred to with the name they had at the time. The current names of the relevant Commonwealth agencies are the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, the Department of Health and Family Services and the Aboriginal and Torres Strait Islander Commission.

2) Many years later, Dr Smith was in 1987 appointed Director of the Australian Institute of Health, a position he held until late 1992.

3) The main Commonwealth officials involved were Mrs Ann Kern, Deputy Secretary, Commonwealth Department of Health, Mr Harvey Jacka, Deputy Secretary, Department of Aboriginal Affairs and Mr Fred Bagley, First Assistant Statistician, Australian Bureau of Statistics.

4) The reason why the Task Force did not meet with Queensland officials is not clear. People associated with the Task Force reported that Queensland officials declined to meet with the Task Force. Queensland officials maintained that the specific dates suggested for meetings were not convenient, but that they would have met with the Task Force on a mutually acceptable date.

5) Given the breadth taken by Smith in his plan for Aboriginal health statistics (Smith, 1978), it is somewhat surprising that the Task Force restricted its attention mainly to these four collections.

6) The AIH was established around the middle of 1985 as a part of the Commonwealth Department of Health, and did not assume its current status until July 1987, when it became a statutory authority within the Commonwealth health portfolio.

7) This rather unique Forum, comprising Commonwealth, State and Territory Ministers for Health and Aboriginal Affairs, offered the hope of real commitment to indigenous health, but unfortunately met only two or three times.

8) Generally, the lack of participation was due to their not being invited rather than their reluctance to attend.

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1.1 OUTCOMES OF THE MEETINGS OF THE TASK FORCE ON ABORIGINAL HEALTH STATISTICS WITH STATE AND TERRITORY HEALTH AUTHORITIES, OCTOBER 1984

Provision for the identification of indigenous people	NSW	Vic.	WA	SA	Tas.	ACT	NT
Birth notification forms	Agree in principle	Agree	Disagree	Agree	Agree	Agree	Agree in principle
Death notification forms	In place	Agree	Will consider	Agree	Agree	Agree	Agree in principle
Medical certificates of causes of death	Will consider	Agree	In place	Disagree	Disagree	Defer	Inconclusive
Medical certificates of cause of perinatal death	In place	Agree	In place	In place	In place	In place	Agree in principle
Hospital in-patient collection	In place	In place	In place	In place	No collection	In place	In place
Maternal/perinatal collection	In place	In place	In place	In place	In place	In place	No collection

Source: Modified from Task Force on Aboriginal Health Statistics, 1985.

1.2 YEARS IN WHICH THE IDENTIFICATION OF INDIGENOUS PEOPLE WAS PROVIDED FOR IN SELECTED HEALTH-RELATED COLLECTIONS

Type of collection	NSW	Vic.	Qld.	WA	SA	Tas.	ACT	NT
Birth notification forms	1991	1986	1996	1991	1985	1988	1985	1988
Death notification forms	1981	1986	1996	1985	1985	1988	1985	1988
Medical certificates of cause of death	No	1986	No	1983	No	No	No	In place
Medical certificates of cause of perinatal death	1981	No	No	1983	In place	In place	In place	In place
Hospital in-patient collection	1976	Late 1970's	1992	1971	1968	Proposed	1979?	1971
Maternal/perinatal collection	1981	In place	1986	1970's	1981	In place	In place	1972
Cancer registration	1992	1982	1992	1982	1977	No	1992	1981
Communicable diseases notifications	No	No	1970's	1988	No	No	No	1970's

Source: Smith, 1978; Achanfuo-Yeboah 1993.

Note: It has been beyond the scope of this paper to confirm the precise years in which the provision for indigenous identification was added to each collection. It has not been possible to provide even a rough estimate for some collections, in which case it is recorded simply that the provision is "in place".

CHAPTER 2

REPORTS FROM STATE AND TERRITORY REGISTRARS GENERAL

In this section of the Workshop the Registrars General, or their representatives from each State and Territory, presented a brief information paper on the identification of Aboriginal and Torres Strait Islander people in the records of births and deaths for which they are responsible. Information on the questions and methods used to identify Indigenous people was provided by speakers and comments on data quality and the date when identification commenced was also sought.

For ease of reference a small amount of information about progress towards high quality identification has been extracted from the pages which follow or confirmed with the authors. Tables 2.1 and 2.2 and 2.3 below summarise the form of the questions and responses used and provide some information on the commencement date of collection.

2.1 ADMINISTRATIVE DATA SETS RELEVANT TO INDIGENOUS HEALTH(a)

	DATE OF FIRST							
Type of collection	*NSW*	*Vic.*	*Qld*	*SA*	*WA*	*Tas.*	*NT*	*ACT*
Birth notification forms	1986	1987	1996	1986	1991	1988	1988	1984
Death notification forms	1986	1987	1996	1986	1985	1988	1988	1984
Medical certificates								
Cause of death	No	1987	1996	In place	1983	No	1988	No
Medical certificates								
Cause of perinatal deaths	No	1995	1996	In place	1983	No	1988	No

(a) Note that there are some inconsistencies between information in this table and tables 1.1 and 1.2 which are obtained from earlier published sources.

(b) If date of first collection is unknown, current status is shown.

Source: Information provided by State and Territory health departments and Registrars. (Current at January 1997).

2.2 HISTORICAL COMPARISONS ON THE REGISTRATION FORMS

State	Year	Wording of Indigenous identification question on form
		BIRTH NOTIFICATION FORM
NSW	1986-October 1996	Is the child's mother/father considered to be an Australian Aboriginal or Torres Strait Islander ? Yes/No
	November 1996 to present	Is the mother/father of Aboriginal or Torres Strait Islander origin? Yes/No (For persons of mixed origin, tick both 'Yes' boxes)
Vic.	1987 to present	Is the child's mother/father of Aboriginal or Torres Strait Islander origin? Yes/No
Qld.	January 1996 to present	Is the mother/father of Aboriginal or Torres Strait Islander origin? Yes/No (If of both Aboriginal and Torres Strait Islander origin tick both 'Yes' boxes)
SA	1986–1995	Is the mother/father of Aboriginal/Torres Strait Islander? Yes/No
	1996 to present	Is the mother/father of Aboriginal or Torres Strait Islander origin? Yes\No (If of both Aboriginal and Torres Strait Islande origin tick both 'Yes' boxes)
WA	1991 to present	Aboriginal or Torres Strait Islander? Yes/No (Completed by mother and father)
Tas.	1988 to present	Origin: Mother/father-Australian Non Aboriginal, Australian Aboriginal, European, Asian, other (specify)? Tick appropriate box (self identification)
NT	1988 to present	Is the child's mother/father of Australian Aboriginal or Torres Strait Islander origin? Yes/No
ACT	1984-April 1995	Is the mother/father Aboriginal? Yes/No Is the mother/father Torres Strait Islander? Yes/No
	May 1995 to present	Is the mother/father Aboriginal? Yes/No Is the mother/father Torres Strait Islander? Yes/No Is the mother/father both Aboriginal and Torres Strait Islander? Yes/No
		DEATH NOTIFICATION FORM
NSW	1986-1989	Was the deceased considered to be an Australian Aborigine? Yes/No
	1989-April 1996	Was the deceased considered to be an Australian Aborigine or Torres Strait Islander? Yes/No
	May 1996 to present	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (For persons of mixed origin, tick both 'Yes' boxes)
Vic.	1987 to present	Was the deceased of Aboriginal or Torres Strait Islander origin? Text answer
Qld.	January–June 1996	Is the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (If of both Aboriginal and Torres strait Islander origin tick both 'Yes' boxes)
	July 1996 to present	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (If both Aboriginal and Torres Strait Islander origin, tick both 'Yes' boxes)
SA	1986-1995	Was the deceased of Aboriginal/Torres Strait Islander origin? Yes/No
	1996 to present	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (If of both Aboriginal and Torres Strait Islander origin tick both 'Yes' boxes)
WA	1985 to present	Aboriginal? Yes/No
Tas.	1988 to present	Origin of deceased: Australian Non Aboriginal, Australian Aboriginal, European, Asian, Other (specify)? Tick appropriat box
NT	1988 to present	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No
ACT	1984 to present	Was the deceased an Australian Aboriginal or Torres Strait Islander? Yes/No

Source: Information provided by State and Territory Registrars. (Current at January 1997).

2.3 CURRENT WORDING ON THE MEDICAL CERTIFICATE - CAUSE OF DEATH

State	Wording on Indigenous identification question on form
NSW	Not collected
Vic.	Was the deceased of Aboriginal or Torres Strait Islander origin? Text answer
Qld.	Was the deceased of Aboriginal or Torres Strait Islander origin? (If of both Aboriginal and Torres Strait Islander origin tick both 'Yes' boxes)
SA	Of Aboriginal or Torres Strait Islander origin? (No, Yes Aboriginal, Yes Torres Strait Islander)
WA	Aboriginal? Yes/No
Tas.	Not collected
NT	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No
ACT	Not collected

Source: Information provided by State and Territory Registrars. (Current at January 1997).

NEW SOUTH WALES

NSW REGISTRY OF BIRTHS, DEATHS & MARRIAGES - IDENTIFICATION OF INDIGENOUS PEOPLE IN DATA COLLECTIONS

By Trevor Stacey, Registrar

History of collection

An indigenous identifier question has been included on birth and death registration forms since the late 1980s. However, the NSW Registry was unable to capture the information electronically until the introduction of the LIFEDATA computer system in 1992.

Since that time (first full year 1993) the Registry has collected and provided indigenous births and deaths information to the Australian Bureau of Statistics (ABS).

Two important strategies have been directed to improving the identification of indigenous people within our data collection since that time.

In 1994/95 , the NSW Demography section of ABS undertook an analysis of the accuracy and completeness of NSW coverage of the indigenous population. This involved both comparison against Census based population estimates and sampling of actual registration forms to determine keying errors/degree of client completion. The results of this analysis have been applied to determine appropriate follow-up action for no response, and review form design.

In 1996 new birth and death registration forms were introduced, with the indigenous identifier question rephrased and question structure made clearer by using tick boxes and improving location on the form. The new death registration form (question 15) was introduced from May, 1996 and appears to be having an impact on the completion rate for this item. The new birth registration form (questions 22 and 31) was introduced in November and similar results for parental identification are expected.

The NSW Registry is aiming to enhance the accuracy of information collected with information programs for funeral directors explaining the reasons for collecting this information.

Medical certificates

There is no indigenous identifier currently included on these forms (*Medical Certificate of Cause of Death* and *Medical Certificate of Cause of Perinatal Death)* in NSW. However, NSW will be reviewing its cause of death forms, in line with the recent review in South Australia, and subsequent inclusion of an identifier (as a cross-check against the information collected on the registration form) is likely.

Terminology

The current wording on NSW registration forms for indigenous identification is provided below.

Births (since November 1996)

Is the mother of Aboriginal or Torres Strait Islander origin? (For persons of mixed origin, tick both "Yes" boxes).

Is the father of Aboriginal or Torres Strait Islander origin? (For persons of mixed origin, tick both "Yes" boxes).

If the answer is "Yes" to either question then the birth is coded as Aboriginal or Torres Strait Islander.

With the new registration form, the form is likely to be completed by both parents in most cases - previously the informant was the mother alone in the majority of cases.

Deaths (since May 1996)

Was the deceased of Aboriginal or Torres Strait Islander origin? (For persons of mixed origin, tick both "Yes" boxes).

Normally the death registration information is provided by a relative of the deceased person.

Some resistance has been noted from funeral directors in asking this question - have held meetings and information sessions with the Australian Funeral Directors Association to explain the purposes of the new questions and design of the form. A further education campaign is planned for 1997.

2.4 NEW SOUTH WALES BIRTHS DATA

	1994 %	1995 %	1996 to date %
Not ATSI	Balance	92.0	91.0
Both parents	0.7	0.8	0.8
Mother only	0.9	1.1	1.2
Father only	0.8	0.9	1.0
No response	Not separately measured	4.9	5.5

VICTORIA

VICTORIAN REGISTRY OF BIRTHS, DEATHS & MARRIAGES

REPORT ON DATA COLLECTION RELATING TO INDIGENOUS PERSONS

By Ian Bowler, Registrations Manager

History of reporting

The Victorian Registry has been collecting data on the births and deaths of Indigenous persons for the Australian Bureau of Statistics since 1987.

This information is collected through questions appearing on birth and death notification forms and on medical certificates relating to deaths.

However, while being careful in the recording of information received, the Registry does not take any action where the informant does not answer the question on the form.

Comparison of years

In an attempt to get an understanding of response success, a comparison has been made of all registered births and deaths occurring in the years 1994, 1995, and 1996 (see attachment 1).

Births

In 1994 and 1995 the number of parents not answering this question on a birth notification form was around 70%. However, in 1996 the number not answering the question on births (registered to 20 November) had dropped to 36.5%.

This is recognised as having occurred because of the release on December 1995 of a new birth notification form which, although the same design as the previous form, has a coloured background, therefore highlighting the areas where responses to all questions are required.

Deaths

In 1994 the number of doctors and informants not answering this question on death forms was 31.9%, in 1995 28.74% and in 1996 (to 20 November) 28.92%.

The improvement between 1994 and 1995 would have to be due to a brochure on collecting these statistics that was prepared for funeral directors by Dr Sarah Berg of the Victorian Koori Health Unit, one of the presenters during this Workshop.

The Registry has just had a new Act passed by Parliament, which means that the layout of all registration forms will be reviewed over the next few months and hopefully improved in some areas.

Comparison with other reports

As well as these activities, in early 1995 Dr Berg provided a list of 65 deaths that occurred in 1994 and had been reported to the Koori Health Unit by Koori hospital liaison officers. The list was compared against deaths registered at the Registry.

This was then repeated in October 1996 with reported deaths for 1995.

See attachment 2 for the results of the comparisons for both 1994 and 1995 deaths.

ATTACHMENT 1

2.5 IDENTIFICATION OF INDIGENOUS PEOPLE IN DATA COLLECTION
COMPARISON OF REGISTERED BIRTHS OCCURRING IN THE YEARS 1994 TO 1996

		1994		1995		1996 (to 20/11/96)	
ABS code	Description of parents	No. of records	% of total	No. of records	% of total	No. of records	% of total
	Recording error (in each case - "Both parents not stated")	559	0.87	416	0.66	170	0.35
0	Both parents not Indigenous	15613	24.34	18489	29.40	30 144	62.27
1	Both parents Indigenous	155	0.24	143	0.23	109	0.23
2	Mother Indigenous, father not Indigenous	204	0.32	217	0.35	167	0.34
3	Mother Indigenous, father not stated	38	0.06	26	0.04	3	0.01
4	Mother not Indigenous, father Indigenous	155	0.24	165	0.26	111	0.23
5	Mother not Indigenous, father not stated	119	0.19	30	0.05	15	0.03
6	Mother not stated, father not Indigenous	6	0.01	9	0.01	17	0.04
7	Mother not stated, father Indigenous	34	0.05	13	0.02	3	0.01
8	Number not used						
9	Both parents not stated	47 258	73.68	43 381	68.98	17 672	36.50
	Total records	64141		62 889		48 411	
	Total records recording Indigenous parent(s)	586	0.91	564	0.90	393	0.81

2.6 IDENTIFICATION OF INDIGENOUS PEOPLE IN DATA COLLECTION
COMPARISON OF REGISTERED DEATHS OCCURRING IN THE YEARS 1994 TO 1996

		1994		1995		1996 (to 20/11/96)	
ABS code	Description of deceased	No. of records	% of total	No. of records	% of total	No. of records	% of total
Blank	Not Indigenous	21924	67.90	23 010	71.08	19287	70.93
A	Indigenous	58	0.18	59	0.18	35	0.13
N	Not stated	10306	31.92	9303	28.74	7 869	28.94
	Total records	32 288		32 372		27 191	

ATTACHMENT 2

2.7 COMPARISON OF REPORTS BY KOORI HOSPITAL LIAISON OFFICERS AGAINST DEATH REGISTRATION

	1994	1995
Number of deaths reported by Koori hospital liaison officers	65	59
Number of deaths registered as Aboriginal/Torres Strait Islander (these figures represent the final adjustment after comparison with report)	56	59
Awaiting registration at time of comparison - confirmed as Aboriginal/Torres Strait Islander	9	6
COMPARISONS BEFORE REGISTRATIONS ADJUSTED		
Deceased registered as appears on report list	28	33
Deceased registered under a different name to list (1995 - one deceased is registered as not Aboriginal/Torres Strait Islander)	2	5
Registered but not stated whether deceased was an Aboriginal/Torres Strait Islander	6	5
Deceased registered as not Aboriginal/Torres Strait Islander	2	2
Death relates to different year	(1993) 1	(1994) 1
Awaiting registration forms from funeral director at time of comparison	9	6
Insufficient information on report list to confirm registration	3	-
No record of death held at Registry	13	5
Confirmed that death was outside of Victoria (in New South Wales)	1	2
Number registered as Aboriginal/Torres Strait Islander, but not on list of deaths reported by liaison officers	20	17

QUEENSLAND

QUEENSLAND REGISTRY OF BIRTHS, DEATHS & MARRIAGES

COLLECTION OF ABORIGINAL AND TORRES STRAIT ISLANDER DATA

BIRTH & DEATH REGISTRATION FORMS

By Desmond Tanner, Registrar

The Queensland Registry of Births, Deaths & Marriages commenced the collection of Aboriginal and Torres Strait Islander data on 1 January 1996.

Death registration forms were altered slightly to include a question on whether the deceased was of Aboriginal or Torres Strait Islander origin (or of both Aboriginal and Torres Strait Islander origin).

Birth registration forms were altered to seek similar information regarding the child's father and mother.

The question was framed in a similar manner to that contained in the 1996 Census form.

The forms were supplied to all regional Offices of the Registry and circulars were sent to all hospitals and Funeral Directors' associations advising that revised forms were available and were to be used immediately.

The uptake of these forms was slow and it was some months before they were being used in large quantities throughout the State.

To coincide with the introduction of a new computer system, both the birth and death registration forms were completely re-designed. The Aboriginal and Torres Strait Islander question remained unchanged.

In an endeavour to improve the uptake of the latest forms, supplies were sent to all hospitals and Funeral Directors as well as to regional offices. Usage of the latest forms is now running at about 98% of all registrations.

Since the Aboriginal and Torres Strait Islander information is not used for birth and death registration purposes its accuracy is not questioned nor any omissions followed up by the Registry.

The Aboriginal and Torres Strait Islander information is not held in the birth and death registers, does not appear on any certificates and is not processed in any way by the Registry.

The information is forwarded weekly to the Queensland Department of Health and to the Australian Bureau of Statistics for statistical analysis.

Recently, all Funeral Directors in Brisbane and surrounding shires were contacted to reinforce the importance of completion of the Aboriginal and Torres Strait Islander question.

SOUTH AUSTRALIA

SOUTH AUSTRALIA BIRTHS, DEATHS & MARRIAGES REGISTRATION OFFICE

COLLECTION OF ABORIGINAL AND TORRES STRAIT ISLANDER STATISTICS

By Kim Potoczky, Registrar

History of collection

The South Australian Births, Deaths & Marriages Registration Office collects Aboriginal and Torres Strait Islander statistics for both births and deaths as recommended by the Australian Bureau of Statistics. This information has been collected since 1986, until recently there was only one box indicating Aboriginal or Torres Strait Islander Origin. The questions have been rephrased with the facility to indicate either or both (as shown below).

Data collection

Births

The Birth Registration Statement is required to be completed by medical staff and both parents after the birth of a child and then is forwarded to this office for the birth to be registered.

Both parents are required to provide their details which include the following:

Is the mother of Aboriginal or Torres Strait Islander Origin?

No ☐ Yes, Aboriginal ☐

Yes,Torres Trait Islander Origin ☐

Is the father of Aboriginal or Torres Strait Islander Origin?

No ☐ Yes, Aboriginal ☐

Yes, Torres Trait Islander Origin ☐

Deaths

The Death Registration Statement is completed by the funeral director responsible for the arrangements of the burial/cremation of the deceased. The statement is completed with the assistance of an informant who is usually a relative and then returned to this office for registration.

Details of the deceased required on the statement include:

Was the deceased of Aboriginal or Torres Strait Islander Origin? No ☐

Yes, Aboriginal Origin ☐

Yes, Torres Trait Islander origin ☐

The Doctor's Certificate of Cause of Death which is completed by a medical practitioner certifying death also required the above questions to be answered.

Perinatal deaths

Question 4 asks the Mother's Race Aboriginal/Torres Strait Islander. This question will be changed in line with ABS standards once the current stock runs out.

Reliability of data collected

Data entry of registrations for both births and deaths is outsourced by the registry to a private contractor. BDM staff prepare documentation for keying and highlight the indicator to ensure it is keyed by the contractor.

ABS receive data on a monthly basis on disc and have access to the Doctor's Certificates of Cause of Deaths for further matching of information. ABS staff do checking and have given feedback to the Registrar on the quality of data being captured.

It is difficult to measure the reliability of the data as we are relying on the informant to answer the questions and in the case of deaths on the funeral director and their informant.

WESTERN AUSTRALIA

REGISTRY OF BIRTHS, DEATHS AND MARRIAGES

COLLECTION OF ABORIGINAL AND TORRES STRAIT ISLANDER STATISTICS

By Don Stockins, Registrar

The current status of the collection of Indigenous identifying information in Western Australia

Births

The information is provided by parents off new born children on a Birth Information Paper (recently renamed Notification of Birth).

The question asked is simply - "Aboriginal or Torres Strait Islander? Yes /No" (a mark in the accompanying box suffices).

No query is made if the question is not answered.

There is better than 95% completion rate.

Deaths

Death information papers:

- ☐ The death information is provided by Funeral Directors who obtain details from the next of kin
- ☐ A section on the form asks: "Aboriginal Yes No" and the funeral director's staff type a "X" in the appropriate box

Medical certificate of cause of death:

- ☐ The certificate is completed by the Medical Practitioner who was in attendance during the deceased's last illness
- ☐ Same question as Information paper
- ☐ No query is made if the question is not answered
- ☐ There is a better than 95% completion rate

No comparison is made of information supplied by a doctor to information provided by a funeral director. The data entry is taken form the funeral director's information.

Information gathered on the Registration Database is down loaded monthly onto magnetic tape and supplied to the ABS. The information in regard to Indigenous identification is only stored as: "Aboriginal Yes or No" for both Birth and Death records.

TASMANIA

REGISTRY OF BIRTHS, DEATHS AND MARRIAGES

PROVISION OF STATISTICS TO THE AUSTRALIAN BUREAU OF STATISTICS AND RECORDING OF INDIGENOUS STATISTICS

By John Jameson, Registrar - General

Registration function

Events of Births and Deaths in Tasmania are registered under the *Registration of Births and Deaths Act 1895* (as amended), this legislation is administered by Registration Services (Registry of Births Deaths & Marriages), a Division of the Department of Justice.

The Registry's primary role is the registration of births, deaths, marriages, and other events provided for under the legislation administered by the Registrar-General.

Secondary objectives include the supply of "non core" data to other agencies and bodies such as the Australian Bureau of Statistics. Unfortunately the electronic system used by the registry was not designed to extract this information.

Regulations are provided for by section 48 of the Act, (*Registration of Births and Deaths Regulations 1969*) which, amongst other things, provide for various prescribed forms including:

a) Form 1	Record of Birth
b) Form 2	Record of Death
c) Form 3	Notice of Birth
d) Form 4	Statutory Declaration of Birth
e) Form 5	Notice of Death

Forms 1 and 2 describe the format and content of the "Register" (now in electronic format). Forms 3, 4 and 5 are papers or notices required to be completed by an informant. The Registers are compiled from these notices.

Recording of statistics

Following consultation with the Australian Bureau of Statistics the Regulations were amended in 1988 to include additional statistical information on forms 3, 4 and 5. This additional information relates to:

- Birth intervals of previous children
- Previous children of the mother
- Details of the origin of the parents in the case of a birth and the deceased's origin in the case of a death.

The extra data collected for statistical and research purposes is not recorded on the Record of Births and Deaths (the Register), nor is it revealed on any certificates issued. Information supplied on the notice papers relating to this data is not coded in any manner. The information therefor is not readily available to any individual or organisation other than the ABS.

Registration system

The Tasmanian Registry of Births and Deaths uses a database program "dataflex" to record and store data relating to it's registration function. Within dataflex, there is provision to enter "registration data" and data for "ABS Statistics".

To date, the statistical data has not been entered on the Register as the current system would need to be augmented. As this is not a statutory core function, resources have not been made available for any enhancement to the system.

The system does not have the capacity to automatically link events or individuals. It is therefore not easy to cross match information about an individual with information about parents, siblings, children or marital partners.

Dissemination of information to ABS

At present no suitable method of extracting the data, in an electronic format useful to the ABS, is available. Tasmanian information is supplied to the ABS by means of photocopied notice papers.

This matter is being investigated with the ABS to determine the feasibility and cost/effectiveness of supplying the data in electronic format. Any such augmentation would need to be capable of extracting all the necessary detail from the record.

Recording of origins of parents/or individual

The Notice of Birth form completed by all parents includes provision for statistical information relating to:

- Australian Non Aboriginal

- Australian Aboriginal

- European

- Asian

- Other (specify).

Similar information is requested on the Notice of Death form. This form is however, normally completed by the Funeral Director on behalf of family or executors.

Note is made on both Notice Forms that the information is for statistical purposes only. There is no statutory obligation to complete the section. If the section is not completed, or abusive comments are made such as "none of your business", no follow up action is taken by the Registry.

The ratio of completed questions to unanswered is very low in Tasmania, especially for deaths. However to follow up with new parents on statistical questions where there is no statutory power to demand information, can have adverse impacts. Death information can be followed up with funeral directors. However, they will not always be aware of racial origins and care must be taken at a time of family grief to avoid what may be seen as unwarranted bureaucratic pressure to answer unimportant questions.

Self identification

The information is *self identifying* by the parents or informants as the case may be. It should also be noted that the birth information relates to the parents, not the child.

There is no guarantee that the child will, or will not, at maturity identify themselves as having the same origins as their parents.

It is also possible that a particular family may record their origins differently for different children. The Registry does not cross check information on Birth Notices with information provided for the registration of previous issue. This could only be done at significant cost.

The informant for a death notification may or may not be aware of details of the deceased's origins. Furthermore, some informants may deliberately provide inaccurate information for the statistical section.

The rate of self identification as Aboriginal in Tasmania may vary between births and deaths as there appears to be a lower level of self identification in the older age groups.

Determination of Aboriginality

It is not the responsibility of the Registry in Tasmania to determine Aboriginality; to comment on what determines Aboriginality; or to develop guidelines for determination.

For the information of the meeting, definitions used in Tasmania include that contained in the Tasmanian *Aboriginal Lands Act* 1995 which refers to the Commonwealth *Aboriginal and Torres Strait Islander Commission Act* 1989 for a definition of Aboriginal person. In simple terms this is defined as a person of the Aboriginal race of Australia.

In *Gibbs V Capewell (Drummond J.)* Federal Court ALR128 577,(see attachment 1) the determination was that a person must be able to show a direct line of descent to Aboriginal society. Dependent on the degree of aboriginal descent, the person should also be accepted by the Aboriginal community as an Aboriginal. This concept is also the basis of the Tasmanian Chief Electoral Officer's guidelines under Section 9(3) of the Tasmanian *Aboriginal Lands Act* 1995.

There are, however, no guidelines under the *Registration of Births and Deaths Act* 1895 for determining Aboriginality. As mentioned previously origin status is self identifying. The Registry has no power or capacity to inquire into or require proof of a persons origins.

Origin status as provided on the notification forms would appear to have no bearing on any other organisation's determination of an individual's Aboriginal status. Information as to parentage, which is comprises an essential part of the Register, does of course provide an implied "family history/genetic link" and may be used to assist in determining Aboriginal status. This is not the responsibility of the Registry.

Problems with current system

The Notice Form asks "origins." It infers genetic origins, but there is no guarantee that respondents are aware of their genetic as opposed to social links. There is no information sought on acceptance of heritage, or acceptance as a member of any particular community.

The accuracy of the information is not checked. This would be difficult to achieve. Record keeping by previous generations did not necessarily make the distinctions we are now concerned with. Definitions of the origins of families in the nineteenth century may therefor be dependent on hearsay rather than fact. If self identification is to some extent dependent on data that might not be reliable then the accuracy of the self identified data could be questioned.

The purpose for which the information is being collected will differ between agencies. The current self identifying system may well be acceptable for broad statistical purposes, but quite inappropriate if used to determine an individual's origins.

The information collected by the Registry specifically on Origins is not, and never should be, used to determine eligibility to access programs. The accuracy of the information is not sufficient for this purpose and for this reason does not form part of the Register.

As outlined in the section "Recording of origins of parents/or individual" the origins questions have a low response rate. This is a greater problem with death information than with births. Action is being taken to discuss the issue with funeral directors to attempt to ensure a completion rate that exceeds 85%. Liaison with health authorities has commenced to maximise the efficiency of data flows between the Registry and health authorities. This should also improve the collection of statistical data.

Conclusion

The Registry in Tasmania:

- Collects information relating to the origins of individuals for statistical and research purposes
- This information is not part of the register
- The information is self identifying and is not verified
- The information is passed to the ABS in hard copy format
- The Registry's computer system is not able to provide the information electronically
- The information is not passed onto third parties other than the ABS
- The method of collecting information may differ dependent upon the reason for collecting the information and use that it is put to
- Action needs to be taken to improve the response rate to origin questions.

ATTACHMENT 1

GIBBS V CAPEWELL AND OTHERS

FEDERAL COURT OF AUSTRALIA - GENERAL DIVISION

DRUMMOND J

30 June 1994, 3 February 1995 - Brisbane

Aboriginals and Torres Strait Islanders - Elections - Meaning of "Aboriginal person" for purposes of election under Aboriginal and Torres Strait Islander Commission Act - (CTH) Aboriginal and Torres Strait Islander Commission Act 1989 ss 101, 102.

Words and phrases - "Aboriginal person"

G sought an order under cl 10 of Sch 4 of the Aboriginal and Torres Strait Islander Commission Act 1989 (Cth) that an election under the Act be declared void on the grounds that (i) the first respondent was not qualified to stand for election under s 102 of the Act because he was not an "Aboriginal person" as required by the Act; and (ii) votes were cast by persons who were not entitled to vote because they were not "Aboriginal persons" as required by s 101 of the Act.

Drummond J directed that the true meaning of the expression "Aboriginal person" be determined as a preliminary issue.

Held

(i) The expression "Aboriginal person" within the meaning of the Act is not confined to full blood descendants of pre-European settlement inhabitants of Australia but comprehends persons of mixed descent.

(ii) The Act indicates that the expression should bear the meaning it has in current community parlance.

(iii) Some degree of Aboriginal descent is necessary, but it will only be sufficient to require a person to be regarded as an "Aboriginal person" where it is "substantial".

(iv) Where a person has only a small degree of Aboriginal descent but genuinely identifies him or herself as an Aboriginal person and is recognised as such by an Aboriginal community, such a person is an Aboriginal person as a matter of ordinary speech and for the purposes of the Act.

(v) Where a person has only a small degree of Aboriginal descent, genuine self-identification as an Aboriginal alone or communal recognition as such by itself may suffice, according to the circumstances, for such a person to be regarded as an Aboriginal person.

Attorney - General (Cth) v Queensland (1990) 94 ALR 515, followed.

Commonwealth v Tasmania (1983) 158 CLR 1; 46 ALR 625, considered.

Petition

This was a determination of a preliminary issue arising in a petition for an order that the election of the Roma Ward of the Roma Regional Council of the Aboriginal and Torres Strait Islander Commission be declared void or that the election of the first respondent be declared void.

K F Holyoak for the petitioner.

P S Hardcastle for the first respondent.

NORTHERN TERRITORY

NORTHERN TERRITORY REGISTRY OF BIRTHS, DEATHS AND MARRIAGES

By Philip Timney, Registrar-General

Summary report on Indigenous identification issues and current status in administrative collections

Indigenous identification officially began in the Northern Territory Births, Deaths and Marriages Registry in 1988. Prior to this informal assessments were made of a person' s Aboriginality from particulars provided from the various registration forms.

Details of indigenous identification are included on Northern Territory registration forms as per Attachment 1.

The details taken from the various registration forms are compiled into the official entry in the respective birth and death registers. Registry officers will initiate follow-up action on missing identification data only where they believe an actual error has occurred. The most important consideration when determining whether a person is of Aboriginal or Torres Strait Islander origin is self identification by the parents in the case of a birth, or identification by the deceased's immediate relatives in the case of a death.

The details of Aboriginality collected by the Registry Office remain confidential to Registry staff. Information is forwarded to ABS along with other registration data for the purposes of compiling national statistics. Similar details may be released for purposes such as maintaining the National Death Index or other medical research in line with the Registrar' s access policy. Current certificates issued from the birth or death Registers do not contain reference to a person's racial origin.

The Registry works closely with the ABS in developing the wording and descriptions of indigenous identification on registration forms and relies on the expertise of the ABS in this area.

There have been no significant client problems with either the method of collection of the data or the wording of the statements.

The new Births, Deaths and Marriages Registration Act commenced on 1 January 1997. The forms developed as part of the Regulations under the Act basically conform to the standardised format adopted by NSW and SA. Operational procedures will not be significantly affected by the changes. The Registry Office welcomes additional input into the preferred identifier descriptions in accordance with the resolutions and outcomes of the Brisbane workshop.

ATTACHMENT 1

2.8 INDIGENOUS IDENTIFICATION ON NORTHERN TERRITORY REGISTRATION FORMS

Form	Question asked of	Description
Information form - birth Completed by parents or in some cases, health workers on behalf of the parents	Mother, Father, Child	Is the child (mother, father) of Australian Aboriginal or Torres Strait Islander origin? (definition provided on form)
Hospital notification form - births Completed by medical staff	Mother	A: Aboriginal O: Other
Information form - deaths Mostly completed by relatives, or funeral directors/health workers on behalf of relatives	Deceased person	Was the deceased an Aboriginal or Torres Strait Islander? (definition provided on reverse of form)
Hospital notification form -deaths Completed by medical staff	Deceased person	A: Aboriginal O: Other
Medical certificate of cause of death - adults Completed by doctors	Deceased person	Was the deceased an Aboriginal or Torres Strait Islander? (definition provided on reverse of form)
Medical certificate of cause of death - children Completed by doctors	Mother	Is the mother considered to be of Aboriginal or Torres Strait Islander origin? (definition provided on reverse of form)

AUSTRALIAN CAPITAL TERRITORY

REPORT OF ACT REGISTRAR GENERAL'S OFFICE

By Dalma Jacobs, Australian Bureau of Statistics on behalf of the Acting Registrar Andrew Taylor

The ACT Birth and Death Information Forms both request the information to provide statistical information relating to indigenous persons.

The information requested in Part B of the Birth Information Form is for statistical purposes only and is given to the Australian Bureau of Statistics. It does not appear in the Register of Births or on any certificate issued by the Registrar-General. Office policy is that if the informant does not complete Part B(2) of the form, it is not followed up.

The Death Information form similarly requests the information to provide statistical information relating to indigenous people and is not required to be completed if left blank.

The ACT is interested in developments made by NSW and Queensland in the redesign of their Birth and Death forms.

The ACT Registration of Births, Deaths and Marriages Act presently prescribes the form and content of Birth and Death Information forms which prevents us making it compulsory for an informant to complete such details. It is, however, proposed to amend the Act to permit the Registrar-General discretion to determine the format and content of such forms and to require such details to be completed.

As part of the Annual Conference of Registrar of Births, Deaths and marriages we are committed to re-designing forms on a uniform basis and the adoption of model Birth, Death and Marriage legislation by each jurisdiction will facilitate this.

The ACT does not have a high population of Aboriginal or Torres Strait Islander peoples, however, we register Births and Deaths occurring within Jervis Bay Territory on behalf of the Commonwealth. The Jervis Bay Territory has pockets of Aboriginal and Torres Strait Islander settlement.

ABS comments

The question described on the current ACT Birth Information Form is far more effective than that on the ACT Death Information form. The "Deaths" question has no facility to separately record (a) Aboriginal origin, (b) Torres Strait Islander origin, or (c) Both Aboriginal and Torres Strait Islander origin, whereas the 'Birth' question is in three parts to facilitate this separate identification. This is one area where modification of the ACT Death question should be amended to improve data quality. The tick both "Yes" boxes method could be adopted if space on the form is a problem.

CHAPTER **3**

REPORTS FROM STATE AND TERRITORY HEALTH DEPARTMENTS

In this section of the Workshop brief reports from each State and Territory Health Department were presented concerning their data collections which identify Aboriginal and Torres Strait Islander people. Reports differed in emphasis, some concentrating on the range of collections which incorporate identifiers, some considered issues of data quality to a greater extent, while others discussed the central issue of the methods by which Indigenous people are identified.

As with Chapter 2 some useful summary information about some of the more important collections have been brought together in Tables 3.1, 3.2 and 3.3.

3.1 ADMINISTRATIVE DATA SETS RELEVANT TO INDIGENOUS HEALTH(a)

	DATE OF FIRST							
Type of collection	*NSW*	*Vic.*	*Qld*	*SA*	*WA*	*Tas.*	*NT*	*ACT*
Hospital separations	1979	1986	(c)1993	1984	1981	(d)1997	1976	1981
Maternal/perinatal collections	1986	1982	1987	1981	1980	1996	1986	1989
Cancer registrations	1992	1982	1988	1977	1981	1991	1981	1992
Communicable diseases notification forms	1991	No	In place	In place	1988	In place	Before 1980	1991

(a) Note that there are some inconsistencies between information in this table and tables 1.1 and 1.2 which are obtained from earlier published sources.

(b) If date of first collection is unknown, current status is shown.

(c) Partial in 1988.

(d) Proposed for end 1997.

Source: Information provided by State and Territory health departments and Registrars. (Current at January 1997).

3.2 HISTORICAL COMPARISON ON THE HOSPITAL SEPARATION FORM

State	Year	Wording of Indigenous identification question on form
NSW	1979–June 1993	Aborigine? Yes/No
	July 1993–June 1996	Aboriginality: Aborigine, Torres Strait Islander, Neither? Tick appropriate box
	July 1996 to present	Indigenous status: Aboriginal, Torres Strait Islander, Both Aboriginal and Torres Strait Islander, Neither Aboriginal or Torres Strait Islander? Tick appropriate box
Vic.	1986–1993	Country of birth: Aboriginal/Torres Strait Islander? Yes/No
	July 1993 to present	Aboriginality: Aboriginal or Torres Strait Islander, Not Aboriginal or Torres Strait Islander? Tick appropriate box
Qld.	1988 to present	Ethnic origin: Caucasian/European, Aboriginal, Torres Strait Islander, Asian, Other, Not stated/unknown? Tick appropriate box
SA	1984–June 1996	Race: Caucasian, Aboriginal, Asian, Other? Tick appropriate box
	July 1996 to present	Race: Caucasian, Aboriginal, Asian, Other, Torres Strait Islander, Both Aboriginal and Torres Strait Islander, Unknown? Tick appropriate box
WA	1981–1993	Race: Aboriginal, Non-Aboriginal? Tick appropriate box
	1993 to present	Aboriginality? Yes/No
Tas.	Question proposed to be implemented end 1997	
NT	1976 to present	Aboriginal or Other? Tick appropriate box
ACT	1981 to present	Ethnic origin: Aboriginal, Non Aboriginal? Tick appropriate box

Source: Information provided by State and Territory Health Departments. (Current at January 1997).

3.3 CURRENT WORDING ON THE PERINATAL COLLECTION FORM

State	Wording on Indigenous identification question on form
NSW	Race: Caucasian, Aboriginal, Asian, Other(specify)? Tick appropriate box
Vic.	Aboriginal? Yes/No
Qld.	Ethnic origin: Caucasian, Aboriginal, Torres Strait Islander, Asian, Other (specify)? Tick appropriate box
SA	Race: Caucasian, Aboriginal, Asian, Other(specify)? Tick appropriate box
WA	Race: Caucasian, Aboriginal(full or part), Other(specify)? Tick appropriate box
Tas.	Race: Aboriginal/Torres Strait Islander? Yes/No
NT	Aboriginality: Aboriginal, Non-Aboriginal? Tick appropriate box
ACT	Ethnic origin: Aboriginal or Non-Aboriginal? Tick appropriate box (self identification)

Source: Information provided by State and Territory Health Departments. (Current at January 1997).

NEW SOUTH WALES

THE STATUS OF ABORIGINAL HEALTH STATISTICS IN NEW SOUTH WALES

By Greg Curry, NSW Department of Health

Indigenous status is identified in most NSW Health data collections, however not all of these separately identify Aboriginals and Torres Strait Islanders. Collections which collect indigenous status include:

- Inpatients Statistics Collection
- Midwives Data Collection
- Emergency Departments Information System
- Child and Adult Sexual Assault Collections
- AIDS Register
- Infectious Diseases Surveillance System
- Drug and Alcohol School Surveys
- Methadone Database
- Census of Long Stay Patients
- Clients at Residential Agencies
- Clients at Non-Residential Treatment Agencies
- Census of Inpatients in Mental Health Facilities or Drug and Alcohol Facilities
- Census of Residents of Group Homes and Hostels.

In addition, a number of collections that have been set up in local areas to meet specific business requirements also include the identification of Aboriginals and Torres Strait Islanders.

While it appears that the under-reporting of indigenous status in many health information systems in NSW and other States and Territories is persisting, NSW Health has made some efforts towards quantifying the problem, and developing strategies towards a solution.

A review of various admission activities and practices among 22 hospitals in NSW, which was undertaken by NSW Health in 1994, indicated that all hospitals recorded the indigenous status of patients on admission, however they used diverse procedures to do so. In some hospitals people were asked a direct question about their indigenous status; some hospitals relied on self identification; others made an assumption based on the person's appearance; several hospitals used a combination of these methods; while two hospitals stated that all indigenous persons in the community were known to them. Staff interviewed during the review reported that many indigenous people were afraid to self-identify for fear of discrimination or for fear of other adverse consequences. While direct questioning of indigenous status would seem an expeditious alternative, some admissions staff and non-indigenous patients appeared to have difficulties with this approach.

NSW Health has undertaken the development of an Aboriginal Cultural Awareness Training course, aimed at hospital staff, management, clinical service deliverers and public contact personnel, which is scheduled for release shortly. The objectives of the course include developing an appreciation and understanding of traditional social structures and priorities in indigenous societies; promoting indigenous health as a holistic philosophy; informing participants of the key focus currently on Aboriginal health by the Department; and increasing the understanding of the factors which impact on indigenous people accessing mainstream public health services.

At the same time NSW Health has been working towards the introduction of performance contracts with all Area Health Services, due for implementation in the 1996/97 financial year. The quality of data captured at the local level will become increasingly significant to all Area Health Services. This will be particularly true of data pertaining to indigenous people - improving Aboriginal health is a key focus area for the Department and performance contracts include a number of specific targets for indigenous people.

The Department also has a partnership agreement with the Aboriginal Health Resource Cooperative (AHRC), the peak body representing Aboriginal community controlled organisations in NSW, to jointly advise the Minister on health policy, strategic planning and resource allocation principles. Work has recently commenced on a collaborative project with the AHRC which aims to improve the quality of Aboriginal health information in NSW. While the project is only in the initial stages, three important issues that are likely to be included are: improving the quality of Aboriginal health information collected by the public health sector; providing support to Aboriginal community controlled health services in the development of information systems which will facilitate planning and delivery of health services; and developing and implementing a code of practice regarding Aboriginal health information which will include factors such as data ownership and use.

Conclusion

Under-reporting of indigenous status, and the factors contributing to this problem, have been well documented at least since 1986. The same problem and contributing factors appear to exist 10 years later. NSW Health is committed to finding and implementing a long-term solution, and is currently exploring strategies that may facilitate improved health data on indigenous people. Establishing sufficient resources to replicate such efforts state-wide remains the greatest challenge.

NSW Health has designated improvement in Aboriginal health as a key focus area in its business plan. In working to improve information to support improved Aboriginal health, an appropriate balance must be achieved between expending resources on service delivery and data collection. In relation to data quality, the emphasis must be on achieving a level of quality that is appropriate to the purpose for which the data are to be collected. Identification of the "appropriate" level of data quality is one of the issues NSW Health is currently examining.

VICTORIA

VICTORIAN STATE - WIDE HEALTH DATA COLLECTIONS

By Irene Kearsey, Department of Human Services

These notes provide some background to certain Victorian State-wide health data collections. The Cancer Registry is the responsibility of the Anti-Cancer Council of Victoria; the other collections listed are the responsibility of the Department of Human Services, Victoria.

Cancer registry

The Registry records Aboriginal or Torres Strait Islander status according to Yes/No/Unknown but most of the data are provided by hospitals and therefore subject to the same data quality problems noted below.

Communicable diseases

With one exception, information about Aboriginality is not covered by the current regulatory process. HIV, the most recent to be made notifiable, requires Aboriginality to be recorded. It was decided to include this item after a lengthy consultation process involving, amongst others, the Department's Aboriginal Health Unit and Aboriginal Health Services. A regulation review process has begun and a working group will consider inclusion of this item for *all* infectious diseases; a similar consultation process will be required.

Data collections of service provision

Three data collections cover service provision (PRISM is also a patient management system):

- VIMD Victorian Inpatient Minimum Database (the "morbidity" collection)

- VEMD Victorian Emergency Minimum Database

- PRISM Psychiatric Records Information Systems Manager.

These will be described together under topic headings.

Coverage

VIMD

From public and private hospitals. Collects admitted patient episodes. From 1.7.95, also collects on *all* babies born in public hospitals (not just those qualified to be admitted).

VEMD

From public hospitals with Emergency Departments. Collects Emergency Department attendances.

PRISM

From public sector psychiatric services which operate under the *Mental Health Act 1986*. Collects psychiatric admitted patient episodes and, for community clients, at each 12 monthly review.

(VIMD, to some extent, duplicates PRISM reporting where psychiatric services have been integrated into general hospitals.)

Background to collections

VIMD

Electronic transfer to the Department's computer bureau of selected data items in Department specified format from hospital's own patient management system (therefore there is no paper form specified). The hospital's system must have an interface which maps the hospital's fields and codes into the VIMD codes and field sequence. The system is documented in the *PRS/2 Manual*.

The day following each transmission, after the editing process, a control report is returned to the hospital listing records which have definite errors (record rejected) and records which have possible errors (record accepted). The report gives edit identification numbers and the *PRS/2 Manual* provides full descriptions of each edit number, stating what is incorrect and how to correct the data. Hospitals must resubmit rejected records (after correction) and can correct any other record if there was an error.

The Department does not specify what patient management system the hospitals must use.

Deadlines for submission of data:

- Within 21 days after the end of the month of separation for episode details
- Within 1 month and 21 days after the end of the month of separation for diagnosis/procedure details.

Data are use to fund public hospitals by the Casemix system.

VEMD

Hospitals started to collect data during 1995/96 but a central collection is not yet established. Some pooling of data is underway. The intention is for electronic transfer of data to the Department (as occurs for the VIMD). The system is documented in the *Victorian Emergency Minimum Dataset* manual.

The intention is that clinical staff (doctors, nurses) enter data *during* the attendance rather than have clerical data entry from a handwritten record *after* the attendance.

The Department does not specify what patient management system the hospitals must use.

PRISM

Developed from an online computerised patient management system, started in 1983 for admitted patients, extended to outpatient and community services in 1985. Started in 1992, PRISM is a comprehensive computerised clinical records management system for all public sector admitted patient and community psychiatric services.

The Department does specify the system the hospitals and community services must use.

Identifier used

VIMD and VEMD

Hospital's Unit Record number. Data items include Medicare Number.

PRISM

Full identification details plus a state-wide unique identifier.

Definition

None of the collections have a broader 'Race/Ethnicity' question.

VIMD and VEMD

(Definition in National Health Data Dictionary, from the Department of Aboriginal Affairs, Constitutional Section 1981):

"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 with which he or she is associated."

PRISM

"An Aboriginal or Torres Strait Islander is any person of Aboriginal or Torres Strait Islander descent and who regards himself/herself as an Aboriginal or Torres Strait Islander."

Codes

In all collections, the field is mandatory.

Only two options permitted:

- Aboriginal or Torres Strait Islander
- Not Aboriginal or Torres Strait Islander.

How Aboriginality is collected

VIMD

Hospitals are advised to ask first "What is your country of birth?" then, if the answer is "Australia", to proceed with "Are you to Aboriginal or Torres Strait Islander descent?". For newborns, the mother is asked "Are you or the baby's father of Aboriginal or Torres Strait Islander descent?".

This may risk missing some Aboriginals but reduces potential problems.

VEMD and PRISM

No specific advice given.

Edits applied

VIMD

If *Aboriginality* is "Yes" but *Country of birth* is not Australia, then a warning is given that this combination is rare although still possible.

VEMD

No central collection yet so no editing.

PRISM

No editing applied.

Validation

VIMD

Cross tabulation of *Country of birth* against *Aboriginality* showed some unexpected combinations. Hence, introduction of edit.

VEMD

No central collection yet so no validation.

PRISM

Cross tabulation of *Language spoken at home* against *Aboriginality* showed some unexpected combinations. Cross tabulation is planned for *Suburb* against *Aboriginality* after obtaining ABS population figures.

Influences on quality

Specific data quality activities are coved in detail by Dr Sarah Berg in another paper.

VIMD

☐ Generally admission data is collected and entered by *clerical* staff. Most public hospitals have a qualified health information manager (HIM, previously known as medical record administrator, MRA) on staff or (small hospitals) on a visiting basis who is either in charge of admission clerical staff or has some influence over such staff. The Department employs a team of HIMs who use this network of hospital colleagues. HIMs are usually keen to improve data quality and provide training to clerical staff.

☐ VIMD is revised annually; this cycle of forums and documentation for hospitals and software suppliers provides an opportunity to promote data quality.

☐ The Department provides a HelpDesk telephone line.

☐ Private hospitals' industry association lobbied for exemption from reporting Aboriginality, but the Department made clear there was no exemption.

VEMD

☐ The intention is that data be collected and entered by *clinical* staff so it may be harder to negotiate improvement in data quality.

☐ VEMD will be revised from 1.7.97 which will provide an opportunity to promote data quality.

☐ No central collection yet so no assessment of quality.

PRISM

☐ For integrated services, see first dot point under VIMD.

☐ For other psychiatric services, the Department employs a HIM who provides training and advice to clerical staff.

QUEENSLAND

IDENTIFYING INDIGENOUS PEOPLE IN QUEENSLAND HEALTH COLLECTIONS

By Sandra Martyn, QLD Department of Health

Current status

The following Queensland health administrative data collections managed by the Data Services Unit (DSU) currently include Indigenous identification.

Collection:

- Queensland Cancer Registry
- Queensland Hospital Admitted Patient Data Collection
- Perinatal Data Collection.

There are other collections within the Department that include Indigenous identification, e.g. Geriatric assessment team client database, Hansen's disease register, etc. This paper will concentrate on those collections managed by the DSU.

Perinatal data collection (PDC)

This collection has been identifying the Aboriginality of the mother since 1987. The collection form asks for ethnic origin, with the options : Caucasian, Aboriginal, Torres Strait Islander, Asian, Other.

Hospitals are encouraged to either ask a standard question or to have the mother complete her own form details. It is thought that the extended, planned nature of caring for most pregnant women means that more women are given the opportunity to self identify.

The item is treated as mandatory and hospitals are queried if details are not stated. In addition, queries are raised if the mother is identified as Aboriginal and country of birth is not Australia, or if identified as Torres Strait Islander and country of birth is not Australia or Papua New Guinea.

Where possible, output checks are also done on historical data, to ensure that the ethnicity details of multigravidas birthing within the same hospital over a period of time are recorded consistently.

There are plans to investigate the use of pre-admission forms and the effect this can have on the accuracy of indigenous identification. In addition, quality assurance studies will be undertaken between the PDC and the Queensland Hospital Admitted Patient Data Collection. Where there is significant variation between the two data sources, hospital chart audits may be undertaken.

Finally, the availability of an indigenous identifier on birth and death certificates will mean that we will attempt to use this information for quality assurance exercises against the PDC data. Of particular interest will be the identification of babies of Aboriginal or Torres Strait Islander origin where the mother has not identified as such. This will indicate the need to add an indigenous identifier for either the father or the baby on the PDC form.

Queensland hospital admitted patient data collection

This collection has been identifying the Aboriginality of the patient since 1988, although complete coverage for all hospitals was only attempted from 1993. The collection form asks for ethnic origin, with the options : Caucasian, Aboriginal, Torres Strait Islander, Asian, Other.

The item is treated as mandatory and hospitals are queried if details are not stated. In addition, queries are raised if the patient is identified as Aboriginal and country of birth is not Australia, or if identified as Torres Strait Islander and country of birth is not Australia or Papua New Guinea.

The size of the collection means that to date it has not been feasible to undertake checks on the consistency of reporting ethnicity details over time. However, all public hospital data is now received electronically and therefore, at least within a hospital, patient details should be reported consistently as they are system generated.

Although formal audits have not been conducted by DSU, analysis of output indicates that there is probably under identification of indigenous people, particularly in SE Queensland. Further investigation is required, but standardised separation ratios for SE Queensland for selected conditions, such as diabetes, cerebrovascular disease, pneumonia, tuberculosis, hypertensive disease, nephritis, etc. are significantly lower than for the rest of Queensland and this is unlikely to be a result of their physical location. Interestingly, congenital anomalies and certain perinatal conditions give similar standardised separation rations for the two areas, which further supports the proposition that the PDC is reasonably accurate.

Queensland cancer registry

This collection has been identifying the Aboriginality of the patient since 1988. The collection form asks for ethnic origin, with the options : Caucasian, Aboriginal, Torres Strait Islander, Asian, Other.

The item has not been treated as mandatory to date, although there are plans to introduce querying of missing or unlikely combinations from July 1997 for hospital notifications.

The collection has a significant backlog of notifications and the focus is to get up to date with processing prior to implementing new quality assurance exercises. We are now encouraging electronic notifications from hospitals and this should mean that indigenous identification will be as reliable as the QHAPDC database. Additionally, matching is undertaken between the Registry and death certificates so the addition of an indigenous identifier will enable quality assurance work to be undertaken with these two data sources.

SOUTH AUSTRALIA

SOUTH AUSTRALIAN HEALTH COMMISSION INDIGENOUS IDENTIFICATION ISSUES

By John O'Brien, SA Health Commission

Current central collections

The main collections administered centrally by the SAHC are the hospital morbidity database for admitted patients (called ISAAC) and the Community Health Statistical System (CHSS).

The current hospital admission forms include a field which since 1st July 1996 has collected "Race" in the following format:

1. Caucasian

2. Aboriginal

3. Asian

4. Other

5. TSI

6. Both Aboriginal and TSI

9. Unknown.

Prior to this financial year, and since 1984, the collection was limited to: Caucasian, Aboriginal, Asian, Other.

The proportions of Aboriginal and Torres Straight Islanders admitted to hospital are understated due to variability in approach by Admitting Office staff.

The CHSS data base does not include details on Aboriginality. Individual Community Health Centres do record Country of Birth and use a self determination style question to record Aboriginality.

Other community based agencies follow varied practices which are site determined and in many cases limited to a yes/no response on the registration forms. These are often not filled out by the client but by the worker completing the registration details and in some cases are completed during, or following, a phone referral.

Statutory data collections such as the Cancer Registry and Perinatal Statistics Collection (1) and Communicable Diseases (2) record details as follows:

(1.) RACE	1. Caucasian
	2. Aboriginal
	3. Asian
	4. Other
(2.) ABORIGINAL	Yes/No

From 1/7/97 the Perinatal Statistics Collection will be converted to record information as required by the National Health Data Dictionary.

Proposed collections

Several statewide minimum data sets are under development e.g. Palliative Care. Any new work such as this is being guided by the items and definitions contained in the National Health Data Dictionary.

Other issues

From discussions with Health Unit staff it is apparent that there are two issues.

The first is the variability of the data due in part to differing emphasis and/or approach to the collecting of accurate information about Aboriginality.

The second is the perceived need to increase acceptance by Aboriginal people of the services offered. Health Units, where information in support of the Aboriginal culture was displayed, found services were accessed more frequently even if a specific Aboriginal worker was not available. Other community based services have recognised the need to employ Aboriginal reception staff to increase the feeling of support and sensitivity to the needs of their Aboriginal clients.

WESTERN AUSTRALIA

STATUS OF HEALTH COLLECTIONS IN WESTERN AUSTRALIA - HEALTH DEPARTMENT OF WESTERN AUSTRALIA

By Peta Williams, Office of Aboriginal Health

The Health Department has a number of health data collections. The identification of Aboriginal people on the health data collections ranges from very good for perinatal and morbidity data to less than adequate for collections such as communicable diseases.

Aboriginality is mandatory

The following health collections have Aboriginality as a mandatory data item and as such unknown cases or cases that fail the edit checks are returned for clarification.

Maternal/Perinatal Health (midwives notification system)

This system has been identifying the Aboriginality of the mother since 1980. The notification form is set up as Race with the alternatives: Caucasian, Aboriginal (full or part), Other. This question is mandatory and the form is sent back if it is not completed. The midwife is supposed to ask the mother the question however, there is variability of approach and observation is often used in combination with a face to face interview. Local knowledge of the family may be used, particularly in country areas.

There was a validation of the Midwives Notification System in 1992. More recently, the Western Australian Research Institute for Child Health selected those mothers identified as Aboriginal in 1994/95 and, after individual interviews, found a misclassification rate of 2%. The rate of mothers wrongly classified as non-Aboriginal was not examined due to the large sample required.

Hospital morbidity system

The WA Hospital Morbidity System has been identifying the Aboriginality of inpatients since 1981. From 1981 to 1993, the inpatient form was set up as Race with the alternatives: Aboriginal, non-Aboriginal. Since 1993, the form was set up as Aboriginality: "No" or "Yes". This is a mandatory data field and when not filled out the form is sent back for completion. In addition, there are edit checks within the Morbidity System e.g. Aboriginality is checked against Country of Birth. Any case which fails the edit check is sent back for clarification. Aboriginality is supposed to be asked by the Admitting Clerk, however, there is variability of approach with observation and knowledge of the family, particularly in country areas, the usual method.

There has been little validation of Aboriginality on the Morbidity System. The Institute for Child Health Research has done some research to validate its use of the Hospital Morbidity System. A comparison of computer versus paper records in 889 children admitted under 2 years reported that the child's indigenous status was incorrect on the computer file in 0.4% of cases (n=4). In addition, a 1993 examination comparing the Midwives Notification and Hospital Morbidity Systems in children aged up to 14 years found that 0.7% of children were recorded as non-indigenous on the Midwives System and indigenous on the Morbidity System and 7% of children were recorded as indigenous on the Midwives System and non-indigenous on the Morbidity System. However, only the indigenous status of the mother is recorded on the Midwives System.

Aboriginality not mandatory but linked

In the cancer database, Aboriginality is not a mandatory data item but the cases are linked to both the Mortality Register and the Hospital Morbidity System. Therefore, identification in this database can only be as good as the Mortality and Morbidity databases.

Cancer

The cancer notification (pathology) form does not routinely contain information on Aboriginality. However, the database is manually linked to the hospital morbidity and mortality databases. The cancer mortality data is substantially complete with respect to Aboriginality. However, the incidence data is less complete with approximately 5-12% of cancer cases unable to be identified from the hospital morbidity system for the years 1992-95. An on-line linkage system is currently being developed.

Aboriginality not mandatory and not linked

In the Communicable Diseases Registry, "Aboriginality" is not a mandatory data item, and the database is not linked to the Mortality Register or the Morbidity System. This impacts directly on the quality of the database and its ability to adequately reflect differences in communicable diseases between Aboriginal and non-Aboriginal people.

Communicable diseases (Infectious diseases and STDs)

The collection has identified Aboriginality since 1988. The form is set up as Ethnicity with the alternatives: Aboriginal, Non-Aboriginal, Asian, Other. While the question is on the notification form, it is poorly filled out and it is not chased up if it is incomplete. Consequently, there is a large proportion of cases of unknown Aboriginality, for example between 34% and 56% of cases were unknown for the years 1990 to 1993. The database has never been validated with respect to Aboriginality.

TASMANIA

TASMANIAN DEPARTMENT OF COMMUNITY AND HEALTH SERVICES - SUMMARY REPORT ON THE MAIN IDENTIFICATION ISSUES AND CURRENT STANDARDS

By Marita Hargraves, Department of Community and Health Services

The Department of Community and Health Services Tasmania is the biggest Department in the State Government structure.

Output groups

Services are delivered through the following output groups:

- Aged & Disability Support Services
- Acute Healthcare Services
- Population Health
- Child, Family & Community Support
- Mental Health
- Ambulance
- Housing.

Corporate goals and priorities

The Department has identified a range of corporate goals and priorities, the most relevant to this Workshop being the following.

Service delivery based on need:

☐ To identify which customer groups access our services, and how customers access different service types. Using this information to identify gaps and the extent of services provided by the Department

☐ To develop an agreed needs based methodology for service delivery

If the Department is going to be able to analyse the needs of the indigenous population within Tasmania and to develop services to meet the needs of that group, then stability of identification mechanisms as well as appropriate training and awareness raising of the value of such data collection activity will be critical.

Main identification issues in Tasmania

Community identification issues

Within the indigenous community in Tasmania confusion exists as to who is legally recognised as an Aboriginal or Torres Strait Islander. Some people who have thought of themselves as being Aboriginal and have received benefits accordingly for many years are now being asked by certain indigenous community leaders for proof of indigenous status and are having their authenticity publicly questioned.

Schisms within the community came to a head recently and exposed a range of points of dissension within the community over self-identification in comparison with "authorised" identification.

Such issues make it doubly important that any statistical collection activities which health and welfare professionals or other collectors of vital statistics undertake are based on asking the right questions.

We will obtain completely different data if we ask:

"Do you identify as being an Aboriginal or Torres Strait Islander"

instead of

"Do you identify as being an Aboriginal or Torres Strait Islander and are you accepted by that community? Can you show me proof?"

"Are you Aboriginal or a Torres Strait Islander?"

will give us completely different results than the question

"Are you of Aboriginal or Torres Strait Islander descent?"

Attitudinal issues and lack of training

There is a marked reluctance in many areas to ask people questions about their indigenous status.

The Department has appointed a Policy Officer in Aboriginal Health in Corporate Office and three Regional Aboriginal Liaison Officers (ALOs) who are working within the main acute hospitals.

The ALOs have been working with pre-admission staff to encourage and promote data collection at that point and will work with the Information Management Division to ensure that performance indicators endorsed nationally will be implemented consistently at such data collection points.

The State Morbidity Collection statistics indicate a slight but gradual increase in the identification of Aboriginal and Torres Strait Islanders in Tasmanian hospital admissions, increasing from a total of 4 in 1989 to 253 in the year to date. The difference between 1995 and 1996 public hospital data is very noticeable and probably attributable to the ALOs' work in the Regions.

Definitional issues

I have already referred to the local problems within the indigenous community of self-identification in comparison with "authorised" identification. This is a definitional issue in itself.

The variety of national definitions and the changes in national definitions over time are reflected in the inconsistency of definitions in legacy collections.

Within the administrative collections maintained by DCHS, the definitional issues relate to the legacy systems, both manual and computerised, which were developed individually and have not been standardised due to the high number of them and also due to the lack of awareness that standards do exist and data comparability is diminished if they are not used.

A Client Data Inventory was carried out by the Information and Statistics Branch of the Information Management Division In 1994 to identify what client information elements were being collected in which areas of the Department for what purpose and using what form of questions and classifications to record the answers.

Issues relevant to indigenous status which were found during that Inventory are:

☐ Some collections do not ask nor infer anything about indigenous status

☐ Those which do record indigenous status vary in the collection method - some specifically ask the individual, others ask the reporter, others infer the result

☐ Those which ask a question vary in the content of the question, e.g.:

- Are you an Aboriginal or Torres Strait Islander?
- Do you consider yourself to be of Aboriginal or Torres Strait Islander origin?
- Does the client identify themselves as an Aboriginal or Torres Strait Islander person?
- Is the child Aboriginal or Torres Strait Islander?

Those which infer the result vary in the attribution:

☐ Some record "Aboriginality" as yes/no

☐ Others record "Aboriginal/TSI" as yes/no

☐ And so on.

Collection instrument and coding issues

The Client Data Inventory project demonstrated the range of questions which are being asked or the form/screen prompts which are available to data collectors across the Department to identify indigenous status (or their absence).

These non-standard questions are leading to unanticipated results - either under - or over-reporting - and an inability to distinguish Aboriginal from Torres Strait Islander people.

Standardisation of questions and prompts is highly desirable.

The version of the software upgrade which is being installed over the next few months in the major public hospitals will enable the Aboriginal or Torres Strait Islander category to be broken down into:

- Aboriginal
- Torres Strait Islander
- But not both, although that is being worked on at present.

Lack of integration of collections

Lack of integration of collections results in some people being coded as being indigenous in some collections but not in others due to the different demographic data attached to each or the different forms of questions being asked.

It is conceivable that a common client front-end to Departmental operational databases may improve the statistical reliability of identifying indigenous status in relation to services accessed (or it may not!).

Where to from here?

Actions by the Department

The DCHS Information Management Division is working with the Aboriginal Health Unit and the Aboriginal Liaison Officers to develop a strategy which will:

☐ Highlight the need for better collection of data on indigenous status

☐ Lead to the standardisation of data collection instruments and definitions in regard to indigenous status

☐ Implement the national performance indicator agendas in a standard way across the State

☐ Educate and raise awareness in both staff and the general public about the reasons for the collection of indigenous data

☐ Decrease the reluctance of staff to ask the necessary questions in order to collect the data.

Actions required nationally

It is crucial that any State or local strategies are backed up by national agreement on and use of a stable definitional framework and an agreed set of questions so that we are all collecting the same type of information.

It is also vital that there is a national education and awareness campaign so that the general community and all the relevant Departmental officers start from the same basis of understanding about the need for and appropriateness of collecting such data.

Without a national general awareness campaign, the cultural and interpersonal barriers which have militated against the collection of indigenous data in health and welfare collections as a routine and appropriate action will continue to impede the national agenda for improvement in data collections and consequent improvement in planning for appropriate services to the indigenous communities.

Thanks to:

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NORTHERN TERRITORY

IDENTIFICATION OF INDIGENOUS STATUS IN HEALTH & COMMUNITY SERVICES ADMINISTRATIVE INFORMATION SYSTEMS IN THE NORTHERN TERRITORY

By Dr John Condon, Territory Health Services

Identification of Indigenous status in Northern Territory administrative health data is in most cases the best of any state. This is largely a result of the fact that Aboriginal people comprise over a quarter of the NT population and the vast majority of Aboriginal people are distinctive in many ways within NT society.

However, there are deficiencies in identification of long-standing urban residents of mixed descent, which are probably due to similar factors as in other parts of Australia. A national approach to assessing the quality of Indigenous status identification would be as beneficial in the NT as in states where improvement in data quality is a much more difficult challenge.

Health services have a long-standing emphasis on identification of Aboriginal status in administrative data collections, although not always for reasons that Aboriginal people regarded as benign. Administrative data collections operate in an environment of a particular and increasing emphasis on health services to Aboriginal people, increasing status and authority of Aboriginal health professionals, and specific initiatives such as development of cross-cultural training programs which all THS staff will undertake in some form (even the central office accountants). Aboriginality is an every day issue, and is prominent in the minds of all health professionals and support staff.

However, there are currently no particular administrative procedures, staff training programs or data quality audits that specifically address the identification of Indigenous status.

Current practices in identification of Indigenous status:

☐ Separate identification of Aborigines and Torres Strait Islanders - currently Indigenous status is recorded as a single category including both Aborigines and Torres Strait Islanders. Awareness of Torres Strait Islanders as a distinct population is poor.

☐ Labelling of the Indigenous status field in information systems - the Indigenous status field in some information systems is labelled as "race" or "ethnicity", especially in systems purchased from commercial vendors, some of which originate overseas. This field is sometimes used as a single indicator of Indigenous status, sometimes as one category in a list of ethnic groups.

☐ Coverage of collections - essentially all administrative collections include Indigenous identification.

☐ Completeness of identification - identification of Indigenous people is known to be very high - approx 50% of deaths in the NT are identified as Indigenous, as are 40% of hospital separations. Formal validation studies have not been done, although one validation study of a method of inferring Indigenous status from other information on death certificates (name of deceased, name of parents, place of birth, place of residence, place of burial, person who presided at burial, country of birth) found only

12 disagreements between Indigenous status as reported on 349 death certificates and the inferral method. This did not directly test the completeness of identification on death certificates, but gives some confidence that the degree of identification is not seriously deficient. (1)

The reason identification is so complete in the NT is not to do with any special administrative efforts or staff training. The main reason is simply that Aboriginal people comprise over a quarter of the population, and a higher proportion of clients of health services (eg. over 40% of hospital admissions), and that the vast majority of Aboriginal people in the NT are obviously Aboriginal by 'observation' - most have distinctively Aboriginal features (skin colour, other physical features, apparel), they speak a distinctive Aboriginal language (including Creole), etc. The majority also reside in distinct Aboriginal communities, either remote or in urban areas (70% live outside the 6 main urban centres). Admissions staff would find it very difficult not to recognise the majority of Aboriginal people!

In addition, Aboriginal people are so prominent a part of NT society that non-Aboriginal people are generally comfortable in dealing with them, and in considering the issue of Indigenous status.

However, there is evidence that identification of Aboriginal people of mixed descent, particularly those who have been urban residents for 2 or 3 generations, and whose appearance is not obviously distinguishable from other urban residents, is not as good as that of other Aboriginal people.

In undertaking data cleaning of the NT Cancer Register database earlier this year, over twenty people with surnames of notable Aboriginal families in Darwin were found to be identified in the hospital information system as non-Aboriginal. However, when checked all but two were found to be Aboriginal (the other two were non-Aboriginal spouses). Some of this mis-identification may be due to a change in the self-identification of some people - the data in the hospital information system derives from old paper records going back many years, and may not have been updated as people attended hospital in more recent years.

Admissions procedures in NT hospitals are variable. One of our major hospitals does not ask patients what their Indigenous status is, the other has patients complete their own information on an admissions form, although many illiterate and older people would need assistance.

Several areas that need attention include:

☐ Separate identification of Aborigines and Torres Strait Islanders, and increased awareness of Torres Strait Islanders as a distinct people.

☐ Identification of people who are not Aboriginal or Torres Strait Islanders but may be superficially confused as such (eg pacific islanders).

☐ Improved procedures by patient registration staff to ensure that people are given the opportunity to identify their Indigenous status, either verbally or in writing, or by acknowledgment of referral information from primary care staff who know individuals better than hospitals and other secondary care institutions do.

☐ Validation of data quality - the Epidemiology Branch of THS is planning to undertake data quality audits of administrative data collections, and Indigenous status would be a high priority in such audits. Hospital information systems would be the first to be considered.

A standard methodology for monitoring data quality of Indigenous status would be useful in the NT, since we do need to monitor quality despite a high level of identification, and for comparison with other states. A reliable estimate of incomplete identification would enable adjustment of Indigenous health statistics in states with poor identification to provide an estimate of the true state of Indigenous health in these areas, as well as providing a useful motivator for us all to improve our data quality.

1. Plant AJ, Condon JR, Durling G. Northern Territory Health Outcomes, Morbidity and Mortality 1979-91. Department of Health and Community Services, Darwin 1995.

AUSTRALIAN CAPITAL TERRITORY

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE IN THE ACT

By Norma Briscoe, ACT Department of Health

Introduction

The health of Aboriginal and Torres Strait Islander peoples is a major concern for all levels of government. The ACT Department of Health and Community Care recognises the fact that Aboriginal and Torres Strait Islander people have the worst health of all Australians and has responded by progressively implementing the recommendations of the Royal Commission into Aboriginal Deaths in Custody regarding data collection. During the 1996/97 financial year the Department will implement the framework Agreement on Aboriginal and Torres Strait Islander Health between the Australian Capital Territory, the Commonwealth Department of Health and Family Services, and the Aboriginal and Torres Strait Islander Commission. The agreement aims to improve the coordination and delivery of programs and services at all levels of ACT government, and to facilitate better health outcomes for Aboriginal and Torres Strait Islander peoples.

One of the objectives of the agreement is to increase the level of resources allocated to Aboriginal and Torres Strait Islander services, including those located within mainstream services, and to facilitate regular reporting of all services and programs. The Department is currently implementing the Agreement through the development of a 5-year strategic plan on Aboriginal and Torres Strait Islander health and the appointment of an Aboriginal health policy officer within the Department's Health Outcomes Policy and Planning Branch. Under the Agreement, the Commonwealth and Australian Capital Territory agree to develop in partnership with ATSIC, Aboriginal and Torres Strait Islander community services contracts which are outcome oriented and which include the evaluation of services to be implemented, including mechanisms to simplify reporting processes.

The Department has agreed that in partnership with the Commonwealth and the Winnunga Nimmityj'ah Health Service it will establish culturally sensitive and ethical privacy and confidentiality protocols in line with the Privacy Act, for the routine collection of standardised data on Aboriginal and Torres Strait Islander health. These protocols will recognise Aboriginal and Torres Strait Islander ownership regarding the use of the data. Of particular relevance to this workshop is the understanding that the Commonwealth and the Australian Capital Territory in partnership with ATSIC, NACCHO and the Winnunga Nimityjah Health Service will work towards improving the quality of relevant data available. The participating bodies have agreed to develop appropriate health outcome indicators and to report regularly on a six monthly basis.

How Aboriginal people are identified

The ACT Department of Health and Community Care considers that identifying Aboriginal and Torres Strait Islander peoples within the health system is crucial for monitoring health status and service utilisation.

It has adopted the 1993 National health data dictionary (National Health Data Committee 1993) definition of an Aboriginal person: "*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 with which he or she is associated.*"

Data collection

The following is a summary of the current status of Aboriginal and Torres Strait Islander vital statistics data in the Australian Capital Territory.

Hospital admission data

There is a question on the admission forms of the major hospitals in the ACT asking whether a person is of Aboriginal or Torres Strait Islander descent or not. Admission forms are normally sent to the patient at home for completion, thus allowing the patient to identify as an Aboriginal or Torres Strait Islander person if they wish to. However, problems seem to arise when patients are admitted through the Emergency Department - although there is provision for identification of Aboriginal and Torres Strait Islander persons hospital personnel tend not to ask the question because in the past some people have found the question offensive. If not answered the system defaults to no. However, this problem is not unique to Aboriginal data collections. The Australian Bureau of Statistics encounter these sorts of problems all the time with their surveys, and they do have mechanisms for getting around the problems of asking sensitive questions. Indirect methods can be used such as showing the respondent a card with the question on rather than directly asking the question. These sorts of techniques now need to be incorporated into Aboriginal data collection methodology to improve the quality of the data.

In an attempt to validate the Aboriginal field within the ACT morbidity file a cross tabulation was computed. We selected Aboriginal patients who had inpatient episodes during two consecutive years, and although the numbers were small the results were interesting. In 1993/94 260 persons identified as Aboriginal or Torres Strait Islander and in 1994/95 313 persons identified. A subset of those persons who had episodes in both years were selected, and the results showed that of the 52 persons from the first year who identified as Aboriginal or Torres Strait Islanders only 39 identified in the second year, and 10 out of the 49 persons in the second year had not identified in the previous year. This small exercise highlights the problem of reliability in self identification which is likely to be an ongoing problem in data collection.

Aboriginality is also included in mental health data collections on Woden Valley Hospital admission forms and on immunisation forms. Mental health services record the occasions of service of Aboriginal people using mental health services.

Birth and death registrations

Aboriginal and Torres Strait Islander persons are identified on both birth and death registration forms in the Australian Capital Territory. The racial origin of the mother and father is asked of the person filling in birth registration, and the family of the deceased are asked the racial origin of the deceased. Births, Deaths and Marriages spokesperson commented that this field often was not completed, and as in most other systems if the field is not completed the system defaults to no.

Perinatal and maternal collections

There is a field on the midwives collection form for the self-identification of the mother as being of Aboriginal or non-Aboriginal descent.

Cancer notification

At present there is a question on the notification form which asks if the patient is Aborigine/TSI with a tick box for yes/no. The ACT cancer notifications are processed by the NSW Cancer Council and the data manager there maintains that the quality of the data is very poor. This is mainly because the information on these forms is derived from the hospital admission forms, and if the information is not actively collected at admission then the information does not flow on. Because the quality of the data is known to be poor this has a flow on effect that the update of this field is not actively pursued, thus compounding the problem. The NSW Cancer Council is currently designing a new form which will incorporate the directive from the NSW Department of Health that from 1 July 1996 the forms should have the following on their notification forms 1. Aborigine 2. Torres Strait Islander 3. Both 4. Neither Aboriginal or Torres Strait Islander. This will be incorporated on ACT notifications on the next print run. Women attending the ACT Breast Screening clinic are asked whether they are Aboriginal or Torres Strait Islander.

CHAPTER 4 DATA COLLECTION ISSUES

INDIGENOUS PEOPLE IN GOVERNMENT STATISTICS - CURRENT AUSTRALIAN BUREAU OF STATISTICS STANDARD

By Tony Barnes, Tammy White, Kate Ross, National Centre for Aboriginal and Torres Strait Islander Statistics, Australian Bureau of Statistics

Indigenous identification over the past 30 years

Over the years since European colonisation of Australia Aboriginality has been classified and defined in very many ways. McCorquodale (1985) noted 67 different classifications, descriptions and definitions in some 700 pieces of legislation since white settlement of Australia began. Fortunately, there has been greater stability of classification over the past 30 years in statistical data sources.

In the years immediately following the 1967 referendum a definition of Indigenous people, loosely referred to as the Commonwealth definition, has been developed which has gained widespread but not universal acceptance. This definition has effectively replaced the interpretation based on preponderance of Aboriginal blood which had previously been use to interpret relevant sections of the Constitution.

The Commonwealth definition is based on the idea that an Aboriginal person 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.

There are three components to the definition:

- Descent or origin

- Self-identification

- Community acceptance.

The Commonwealth definition took a decade to receive Cabinet endorsement during which time some issues were clarified. This government process which led to Cabinet endorsement was reviewed by the Department of Aboriginal Affairs in 1981. A summary of the ten year process is provided below.

1968 - 'An Aboriginal is anyone with some Aboriginal blood who considers himself an Aboriginal'. (Minister-in-Charge of Aboriginal Affairs, Honourable W. C. Wentworth, March 1968).

1968 - 'An Aboriginal is a person of whole or partial Aboriginal descent, who claims to be an Aboriginal and is accepted as such by the community with which he is associated'. (W. C. Wentworth, Cabinet Submission, May 1968).

1971 - 'An Aboriginal is a person of Aboriginal descent who claims to be an Aboriginal and is accepted as such by the community with which he is associated.'
(September 1971).

1972 - 'An "Aboriginal" or "Torres Strait Islander" is a person of Aboriginal or Islander descent who identifies as an Aboriginal or Islander and is accepted as such by the community with which he is associated'.

1973 - Senator J. L. Cavanagh, Minister for Aboriginal Affairs endorses definition.

1973 - Extension to South Sea Islanders considered.

1975 - Interdepartmental Committee set up to assess whether to extend special benefits to South Sea Islanders.

1975 - '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 lives.'

1977 - Minister endorses definition (June 1977).

1978 - Cabinet decides not to extend benefits to South Sea Islanders (June 1978).

1978 - Cabinet endorses definition (October 1978).

Legal backing for the Commonwealth definition as a suitable basis for a standard definition was given in a High Court judgement in the case of Commonwealth v Tasmania (1983) 46 ALR 625.

Another much more recent judgement (Gibbs v Capewell and others (1995), 128ARL577), considered the meaning of "Aboriginal person" in the context of elections under the Aboriginal and Torres Strait Islander Commission Act 1989. This judgement broadly endorsed the Commonwealth view, with some qualifications, and appears to indicate that, of the three criteria in the definition, "Aboriginal descent" is the only criteria which is necessary under all circumstances for this Act. However, the judgement indicates that "Aboriginal descent" may not be sufficient in some circumstances, in which case evidence of the second and/or third criteria may be required.

In recent years the Draft United Nations Declarations on Human Rights and similar documents, to which Australia is a signatory, have endorsed the notion of self-identification as the basis for establishing whether a person is an indigenous person or not, (Aboriginal and Torres Strait Islander Commission, 1995).

Operational definition

The operational approach to Indigenous identification used in recent decades by the Australian Bureau of Statistic's Censuses has been based on the descent/origin component of the definition. In the 1976 Census, the question asked was "*What is each person's racial origin?*". Since then all Censuses have asked "*Are you of Aboriginal or Torres Strait Islander origin?*". Prior to the 1996 Census respondents could not record dual Aboriginal and Torres Strait Islander origin.

In many data collections this information is not recorded as the response to a specific written question which is read by, or read to, respondents. On the contrary, record clerks are often simply required to tick one of a number of boxes, for example, labelled "Aboriginal", "Torres Strait Islander" and "non-Indigenous", possibly with no specific instructions about how to acquire this information. Still other collections capture Indigenous status data by transfer from other record sources to another with no contact with or input from the subject.

The ABS standard classification for Indigenous status

In all other situations the underlying principle for this proposed operational standard for capturing Indigenous identification is to question respondents directly wherever possible. Where this is not possible questioning close relatives is the preferred approach. Where information is transferred from one collection to another, it should be captured in the first place by a direct question.

The following are the standard questionnaire modules for Indigenous Status for five different situations. It is our understanding that all Australia's Registrars of Births, Deaths and Marriages recently agreed to adopt this standard and that this will be reflected in future form redesigns.

(i) Respondent present and answers:

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

This question is recommended for household based interviewer conducted collections or self-enumerated collections where it is known that the person filling in the form is the subject.

(ii) Person not present and someone else who knows the person well answers:

e.g. Another member of the household answers for the person, parents answering for children, relatives answering in hospital situations.

Is the person 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

(iii) Person is dead and someone else answers e.g. death information form:

In these circumstances a close relative or friend should answer, only if a relative or friend is unavailable should the undertaker or other such person answer. This question should always be asked even if the person doesn't "look" Aboriginal or Torres Strait Islander.

Was the person 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

(iv) Person not present and someone else transcribes response from administrative data:

e.g. Criminal justice collections, hospital records, schools data.

Is the person 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

☐ Not Known/Not Stated

The above is the preferred form of question for the receiving data collections.

(v) Person is an infant e.g. perinatal information form:

Obviously babies cannot answer on their own behalf. Thus parents should be asked.

Is the baby's mother 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

and

Is the baby's father 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

The National Health Data Dictionary standard for Indigenous identification

In keeping with the approach adopted by the Census at that time, the 1984 Taskforce on Aboriginal Health Statistics recommended that the ABS Census "origin"- based question be used for determining and recording "Aboriginality". This approach is the entry in the current published (version 5) National Health Data Dictionary (NHDD), which documents the recommended practice for all Australian jurisdictions for recording and coding health related variables such as Indigenous status. However, in keeping with the slight change in the Census question in 1996 to allow for dual Aboriginal and Torres Strait Islander status which is included in the new ABS standard, the next NHDD (version 6) will adopt the approach of the ABS standard for its revised 'Indigenous Status' standard.

Like the ABS standard, the NHDD will allow "not stated" as an acceptable category in one specific situation. This is required where the only source of information about a person's Indigenous status is an existing record system which might have incomplete collection of Indigenous status. In these circumstances it is possible for there to be no record of the Indigenous status. If the original data capture was incomplete it is preferable that the blank or missing record from the original record system should be recorded as "not stated" in the current system. A "not stated" category should not be used when the subject or a close relative is the source of information.

Despite the existence of the NHDD there appears to have been a range of different approaches to identifying Indigenous people in health data collections over the years. The extent to which there is now uniformity of approach and practice should become clearer as a consequence of this workshop. Some jurisdictions have used approaches based on questions similar to the Census "origin" question being asked of clients, while other jurisdictions ask different question. Some Health Departments' data capture forms indicate no specific question and it is likely that admission clerk's personal knowledge and/or interpretations based on their own observations are the basis of most or at least some entries. With the growing use of direct computer data entry by admission clerks this practice may be increasing.

Why is it important to standardise?

The single most important type of Indigenous health statistic is of the "ratio" or "rate" type, i.e. death rates, hospitalisation rates, incidence rates. Such statistics are usually derived from an ABS experimental population estimate (based on Census counts from the most recent Census) as a denominator, and a numerator which is typically a statistic derived from a non-ABS administrative collection, i.e. numbers of Indigenous deaths, hospital separations etc. Meaningful Indigenous statistics can only be derived if numerator and denominator are based on similar, preferably identical, methods of determining Indigenous status. Where this does not occur rate and ratio statistics can be biased and should be treated with caution.

That this is a non-trivial issue is well illustrated by an example from New Zealand's 1991 census which illustrates how sensitive population estimates can be to apparently slight changes in the form of the question(s) asked. The 1991 census recorded people as "Maori" through two different questions: one concerned with racial origin/ancestry and the other with self reported ethnic identity. Research indicated people understood the distinction between these approaches.

The number of people reporting Maori ancestry was 511,278. This compares with 434,850 people who stated they identified as Maori, while only 323,493 people stated they identified solely as Maori, Gould (1992). The extent of possible biases in a ratio statistic, in which the denominator and numerator are derived from collections which use classification approaches which differ as much as these, is obvious.

Indigenous identification in the future

Since the 1996 Census used the single "origin" question, all population estimates and thus denominators in rate statistics will be based on this approach to Indigenous identification up to 2001. To ensure reliable statistics, particularly those which are used to monitor trends over time, numerators should also use this approach. It would therefore be wise to maintain the existing definitions and work towards achieving good compliance to them at least until 2001 and to resist any efforts to modify or improve the definition, as used in administrative collections, until that date.

Having said this it is necessary to recognise that Indigenous identification is not foremost a statistical issue. The statistical advantages of constancy and simplicity in an operational methodology may be challenged by other requirements - not least those of Indigenous people themselves who have obvious authority and rights on this issue. Also, the desires of governments for statistics to more closely reflect their working definitions or accepted legal interpretations could lead to pressure to review the ABS standard. In particular, the future may bring demands for the operational approach to be broadened to include a self-identification question as well as an "origin" question. Provided field testing confirms that this approach is feasible, a persuasive case could be made for its adoption into major survey and Census data collections.

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THE 3 R'S : LESSONS LEARNED DOWN SOUTH ABOUT PROMOTING GOOD PRACTICE IN RECORDING ABORIGINALITY OF PERSONS ADMITTED TO HOSPITAL

By Dr Sarah Berg, Koorie Health Unit, Department of Human Services

Background

There has been provision for public hospitals in Victoria to record admissions to hospital for Aboriginal and Torres Strait Islander people since 1979, but in practice, recording of Aboriginality of persons admitted to hospital was an "optional" data item, and there was ample evidence that hospitals were not recording Aboriginality accurately.

The importance of recording Aboriginality in Victorian hospitals was the focus of a publicity campaign directed at hospital staff and members of the Koori community in 1984-5, following concerns expressed by Aboriginal community organisations and Aboriginal community medical services who were members of the Victorian Aboriginal Health Resources Consultative Group. The members of this advisory group on Koori health had asked for action to be taken to improve the availability of accurate information on the health of Koori people in Victoria.

However, there was evidence of ongoing significant under-reporting and inaccurate reporting of Aboriginality, and in hospitals with a position for an Aboriginal Hospital Liaison Officer (AHLO), striking comparisons could be made between the admissions to Aboriginal and Torres Strait Islander persons as recorded by hospital admission staff, and by the AHLO.

The first 'R' - Rules

Recording of Aboriginality was made a *mandatory* data item on the Victorian Inpatient Minimum Database for both public and private hospitals in Victoria, from 1 July 1993, and from this time the requirement to ask persons admitted to hospital whether they are of Aboriginal or Torres Strait Islander descent has been included in public hospital funding and service agreements.

The second 'R' - Reviews

In order to monitor the implementation of recording Aboriginality of persons admitted to hospital, and to enable early documentation of any difficulties experienced by hospitals, Medical Records Administrators at forty-five public hospitals were contacted by phone by staff of the Koori Health Unit, in March 1994.

The results of this survey showed:

☐ There were significant difficulties reported by hospitals in regard to recording Aboriginality

☐ Staff compliance with asking every person admitted to hospital "Are you of Aboriginal or Torres Strait Islander descent?" was uncertain

☐ The field for recording Aboriginality was not a mandatory field in more than half of the hospital computerised patient admissions systems. This meant that if a response was not entered in the field, the patient would be recorded as being "non-Aboriginal" by default

☐ Aboriginality was not likely to be recorded in the circumstances of an emergency admission

☐ Aboriginality was being recorded on the Patient Master Index, and the Aboriginality question was not being asked at every admission.

Recommendations following the initial survey included:

☐ The need to provide regular feedback and reports on the numbers of admissions of persons of Aboriginal or Torres Strait Islander descent to regional offices and hospitals

☐ The need to provide promotional material and staff training material about recording Aboriginality

☐ The need for changes to hospital computer systems and hospital forms, and

☐ The need for quality assurance checks on the Aboriginality data item.

In October-November 1994, staff of the Koori Health Unit surveyed every public and private hospital in Victoria to determine the extent to which recommendations of the initial survey had been carried out. The survey results across Victoria showed:

☐ 7% public hospitals and 30% private hospitals reported that staff were not asking the Aboriginality question

☐ The computer system at 16% public hospitals and 26% private hospitals allowed for the Aboriginality field to be by-passed if no response was entered, and the patient would then be recorded by default as being "non-Aboriginal"

☐ Aboriginality was still being stored on the Patient Master Index database

☐ Only half of the hospitals with a position for an AHLO were using the monthly reports of the AHLO as a cross check on the recording of Aboriginality by hospital staff

☐ Very few hospitals had attempted to establish quality assurance checks on the Aboriginality data item.

Recommendations of the state-wide survey included:

☐ The need for annual reports from regional offices on action being taken to improve the recording of Aboriginality by hospitals in the region

☐ The need to document "best practice strategy" models in regard to recording Aboriginality, for sharing amongst hospitals

☐ The need to provide training for regional office staff and relevant hospital staff on Koori health issues, and the importance of accurately recording Aboriginality

☐ The need for changes to hospital computer systems.

The third 'R' - Rewards

In 1996, case studies of "best practice" in regard to recording Aboriginality were published, in order to reduce the negative comments and attitudes which were identified during the surveys as resulting in a barrier to achieving accurate recording of Aboriginality.

Certificates of *Achievement in Pursuit of Excellence* were presented to two hospitals for *"directly contributing to increasing the availability of accurate information on the health status of Aboriginal and Torres Strait Islander people in Victoria by acknowledging the need to accurately record whether patients admitted to hospital are* *of Aboriginal or Torres Strait Islander descent' and for implementing appropriate staff training, admissions protocols, and quality assurance checks on the Aboriginality data item*". The certificates were signed by the Victorian Minister for Health and the Minister responsible for Aboriginal Affairs in Victoria. The certificates were presented by the Ministers at an official ceremony.

A fourth and fifth 'R' - Retain Reservations

There has been a great deal achieved in regard to the recording of Aboriginality of persons admitted to hospitals in Victoria in recent years. However, the limitations of the data are acknowledged. There is still evidence of ongoing under-reporting and inaccurate recording of Aboriginality as reflected by analyses of the country of birth for persons recorded as being of Aboriginal or Torres Strait Islander descent at the time of admission to hospitals in Victoria; comparisons of the number of births recorded to mothers of Aboriginal or Torres Strait Islander descent as recorded by hospital staff, and by midwives for the Perinatal Data Collection; and from the monthly reports of Aboriginal Hospital Liaison Officers.

A final 'R' - Remember the importance of the role played by Aboriginal Hospital Liaison Officers

There are eighteen positions for Aboriginal Hospital Liaison Officers in Victoria. These staff play an extremely important role in improving the quality of information which is available in regard to recording admissions to Victorian hospitals of persons of Aboriginal or Torres Strait Islander descent.

The workshop participants were provided with a range of examples of the commitment of Aboriginal Hospital Liaison Officers to the need to accurately record Aboriginality, and of the assistance which has been provided by these staff at various stages, to improve the accuracy of identification of Aboriginal and Torres Strait Islander people admitted to hospital.

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PRESENTATION FROM THE AUSTRALIAN FUNERAL DIRECTORS ASSOCIATION

By Graham Crawley, General Manager Queensland - Operations

My observations are made from my many years of funeral service involvement. During this time I am led to believe, that regardless of whether you are anticipating a death or if it is a sudden death because of one's emotional grief make-up it is difficult to remember even the most simple of current events at this time, let alone trying to recall with accuracy information to which, at this point of time seems quite irrelevant. (Maiden surname, occupation of relatives, places of marriages etc). The only question on everyone's mind at the point of funeral arrangement is the time and the location of where the service is going to be held.

I cannot substantiate it, but I would be surprised if there were as many mistakes made with information recorded as "unknown" with births and marriages as compared to funerals. This I would suggest can be attributed wholly to the grief factor.

The most common problems experienced at the time of funeral arrangements are:

- A .The Aboriginality is uncertain or perhaps not admitted
- B. Mother's name is unknown
- C. Father's name is unknown
- D. Actual marital status is often unknown or not admitted
- E. Previous marriage details are unknown or not admitted
- F. Children's names and dates of birth are not known
- G. Place of death of husband or wife are often unknown
- H. These problems are common to all persons regardless of birth right.

Often the person who is arranging the funeral is not a close relative so the information is not known to the informant. As it is not in the province of the funeral director to record any information based on his or her own observations, the information can only be provided by the person authorising the funeral.

On some occasions there are no known relatives and without someone to provide this information the Aboriginality of the deceased is recorded along with most other details as being unknown to the informant. The only solution for these difficulties in the long term, is by ensuring that the community at large are educated for the need of such information being recorded accurately.

It would be, therefore, my suggestion that this information is likely to be more accurate if gathered some days immediately after the day of the funeral rather than the practice now, which is at the time of the funeral arrangement.

If the person who is authorising the funeral could also be charged with the responsibility for forwarding the relevant information to respective registrars in each state re; Form C (as in Qld) after the burial or cremation then all parties concerned could view the process with some objectivity.

Generally speaking I believe most of the Australian community are informed and understand the need for collation of accurate data. Most persons daily in their routines, thanks to science and technology, use automatic teller machines, mobile phones, faxes, credit cards etc. However, what we all have difficulty in understanding is the relevance of some information that is required to be furnished at the time of the persons death. Surely government departments can use this technology to find a satisfactory collection solution.

A more suitable time frame after the funeral has been completed for the collection of this data needs further investigation.

More than 3/4 of Australian families choose an AFDA member firm to effect funeral services for a deceased family member. Our members are willing to participate wherever possible to find a satisfactory solution to a long standing problem.

PRESENTATION FROM THE AUSTRALIAN MEDICAL ASSOCIATION

By Steve Larkin, Australian Medical Association

What are the issues doctor's face when completing death certificates, hospital records and other health records, when dealing with Aboriginal and Torres Strait Islander people? How do they get their information?

a) Death certificates

There has to have been a regular doctor/patient relationship during the last illness prior to the death before a doctor can sign the certificate. The forms actually ask for the length of this relationship (eg how long has the doctor known the patient). This is a legislative requirement in each state/territory. Doctors are not permitted to sign if this is has not been the case. If there is a medical practitioner present at the time who has knowledge of the person, then it may be possible for this doctor to sign the certificate.

Implications

If the doctor only vaguely knows the person, there is a risk that the quality of information recorded is suspect as the signing doctor is unlikely to be familiar with the deceased medical history.

If the doctor doesn't know the deceased has had an underlying illness, they are only going to record the cause of death and omit the underlying problems/causes (eg cause of death is Pneumonia but secondary to HIV/AIDS).

Another significant issue is the lack of opportunities afforded to Aboriginal people and doctors to form ongoing doctor/patient relationships. As such, there is not usually an intimacy of knowledge held by the doctor about the patient. This is a particular problem for rural and remote communities due to the lack of doctors in these areas. Reluctance by Aboriginal and Torres Strait Islander people to utilise the western European health system is also a contributing factor.

b) Hospital records

Under the Casemix system, doctors are meant to note all diseases on the front part of medical records.

Aboriginal and Torres Strait Islander people become disadvantaged in terms of information under this system as it is generally the case that these forms are left incomplete. This is largely due to an inability, reluctance or unfamiliarity on the part of Aboriginal and Torres Strait Islander people to access the hospital system. They are therefore disadvantaged when it is this information which provides the basis of funding allocation decisions etc.

The information may also be hard to obtain because doctor's work schedules in hospitals generally restrict the amount of time that might be taken in acquiring a comprehensive case history.

The implication of all the above is that the hospital system doesn't know the causes of Aboriginal and Torres Strait Islander people morbidity and mortality. As a consequence, this information may not inform funding allocation decisions.

Suggestions to improve data collection for Aboriginal and Torres Strait Islander people

a) Ideally, some form of patient held medical records contained/attached to a Medicare card (although acknowledging the current problems associated with these cards) would alleviate a number of the present difficulties. It would certainly address a number of issues connected with communication in remote communities in particular. As stated, the current difficulties associated with Medicare cards together with a lack of awareness by Aboriginal and Torres Strait Islander persons as to the importance of retaining the card on their person are immediate complicating factors.

b) A comprehensively linked on-line information system is another possibility. This would involve a central repository centre which could be widely accessed. The main issue inherent with this proposal is to do with confidentiality. In this sense, the dilemma concerns the tension between public benefit versus privacy rights.

c) The AMA believes it may be necessary to increase the level of awareness among Aboriginal people as to the importance of ascertaining the reason(s) for a person's death. If this is recorded accurately, it increases the likelihood that appropriate funding will be allocated. This information may also allow the identification of new trends in morbidity and mortality, eg are there any new diseases/illnesses that are responsible for why people are dying or getting sick?

Role of the AMA

The AMA recognises the importance of the issues discussed in this paper and would like to see these problems resolved. The AMA is therefore committed to being part of any process which aims to address these issues. In this sense, the AMA may be able to provide assistance in negotiations with Ministers and their departments or to apply political pressure if necessary.

It is worth noting that the AMA has a number of publications which it distributes to members. These include Australian Medicine, The Medical Journal of Australia plus other state branch newsletters. Consideration should be given to how these can be best utilised when strategising for reforms.

Finally, as both the national adviser to the AMA on Aboriginal health matters and also in my capacity as a member of the National Aboriginal and Torres Strait Islander Health Council, I am prepared to lend my support in whatever way is deemed effective in the pursuit of an improved data collection system.

CHAPTER 5

ASSESSING COMPLETENESS AND QUALITY OF IDENTIFICATION

ASSESSING THE COMPLETENESS AND QUALITY OF INDIGENOUS IDENTIFICATION IN ADMINISTRATIVE DATA COLLECTIONS

By Barbara Gray and Joan Cunningham, National Centre for Aboriginal and Torres Strait Islander Statistics, Australian Bureau of Statistics

This paper examines the principles underlying the methodology for assessing the completeness of measurement techniques, in particular assessing the quality of Indigenous identification in administrative data collections. The paper presents a theoretical framework that may be of assistance for grappling with some of the practical issues faced by people who work with collecting and using this information every day.

Validity and reliability

The two basic questions to be asked when talking about a measurement tool are; how valid is it? and how reliable is it?

Validity refers to the extent to which the measurement procedures accurately reflect the variable to be measured. Does the measurement tool actually measure what it is supposed to measure? For example, the number of times a young child hits another during his/her day at pre-school might appear to be a good measurement of the personality trait of aggressiveness. But is it really a valid measure? It may be measuring one small aspect of aggressiveness or something about the child's environment and not personality at all. Some measurement tools clearly record what we want them to. Years since birth is obviously a valid measure of physical age. The validity of many measures is not always so obvious.

Reliability refers to whether the measurement procedures assign the same value to a characteristic each time it is measured under the same circumstances. Everyone wants a reliable measure. A wooden ruler is a reliable measurement tool for length. If you use it one day, and again a week later, you can be sure you'll get the same result. A ruler made of elastic, however, would not give you a reliable measure.

It is possible to estimate the validity and reliability of a measurement tool. A good measurement tool will have high validity and high reliability. High validity means you are measuring what you intend to measure; high reliability means you're going to obtain consistent results. What we're interested in, is ensuring our measures of whether people are Aboriginal and/or Torres Strait Islander, are both valid and reliable.

Aboriginal and Torres Strait Islander people

Better quality health and welfare information concerning Indigenous people is important. It is important to know about the health status and the use of health and welfare services by Aboriginal and Torres Strait Islander people. We are interested, for example, in measuring the number of Aboriginal and Torres Strait Islander people who go to hospital, who suffer various conditions, or who die.

The current Census question regarding Indigenous identification, which has been used for many years is "Are you of Aboriginal or Torres Strait Islander origin? " (The instructions on the 1996 Census form ask people of both Aboriginal and Torres Strait Islander origin, to mark both "Yes" boxes).

This way of framing the question can be discussed and debated and is likely to be the subject of discussion and consultation in the future. However at the moment, this is the accepted standard for the ABS and this question will be included in the next version of the National Health Data Dictionary.

In order to make use of health and Census based statistics, comparability between data sources is important. If the same definition and form of the question is used the consistency or reliability of the measurement tool can be improved.

Given a reasonable and, most importantly, an agreed definition, how is it possible to correctly identify people who are Aboriginal and/or Torres Strait Islanders? There are likely to be a number of ways that this is currently being done. This includes by looking or guessing, by asking friends or relatives or by asking the person directly. There may be other ways. Whenever possible people should be asked directly. Consistent, reliable results will be most likely if the agreed definition and similar procedures for asking the question arc used. This is not always easy or possible, but it is important.

Validity and reliability relate to the measurement tool itself (the question and the way it is asked). As well as aiming for high validity and reliability it is important that the quality of what is being produced is actually assessed. In order to discuss how to calculate the completeness and quality of identification in an administrative collection it is useful to consider this theoretical model:

5.1 THEORETICAL MODEL FOR ASSESSING COMPLETENESS AND QUALITY

Administrative collection	'Truth'		
	Indigenous	Non-Indigenous	Total
'Indigenous'	a	b	a+b
'Non-Indigenous'	c	d	c+d
Total	a+c	b+d	a+b+c+d

Notes: a = Indigenous people who are correctly classified
b = Non-Indigenous people incorrectly classified
c = Indigenous people incorrectly classified
d = Non-Indigenous people correctly classified

An administrative collection (such as hospital records) will have people classified as either Indigenous or non-Indigenous. Actually lying in the hospital bed or using the aged care service are people who are truly Indigenous or non-Indigenous. Ideally all people will be classified correctly. However, it is likely that some of the people classified as Indigenous will be in fact non-Indigenous, and some of the people who are classified as non-Indigenous will in fact be Indigenous. It is important to ensure that we:

- maximise the number of Indigenous people who are correctly classified (ie. those in cell "a").

- minimise the number of Indigenous people who are incorrectly classified (ie. those in cell "c").

We also want to ensure the same is true for non-Indigenous people, though this seems to be easier in practice.

The table above has "truth" as one axis, and this is what we are really trying to compare our labelling with. In practice, however, we don't usually get "truth" so we use another source of data to estimate "truth". There are a number of ways this alternative source of information can be obtained. People who are in hospital or attending a particular service could be asked, separately from the administrative collection processes, "Are you of Aboriginal or Torres Strait Islander origin?" In Victoria, for instance, the numbers of people being seen by Koori Hospital Liaison Officers are compared with the numbers of Aboriginal and/or Torres Strait Islander people on hospital records.

Ways of measuring agreement

Given two sources of information, in this case our administrative collection and 'truth' (or our best estimate), there are a number of ways agreement can be measured. The proportion of people who are correctly classified can be calculated as(a+d)/(a+b+c+d). This method, however, is not satisfactory for measuring the completeness of the measurement of Indigenous and non-Indigenous people. This is because of the high numbers of non-Indigenous people compared to Indigenous people. In reality most non-Indigenous people are correctly classified. This is not the case for Indigenous people. In addition some correct classification will have occurred by chance. Some examples will make this clearer.

Sensitivity and specificity can also be calculated. Sensitivity refers to the proportion of people with a particular characteristic of interest who are correctly classified as having that characteristic. It is calculated as a/(a+c). A highly sensitive measure or test for a medical condition, for example, will not miss many people who have the condition. A highly sensitive measure of the number of Indigenous people will not miss many people who are Indigenous. It will show that a high proportion of Indigenous people are correctly classified as Indigenous people.

Specificity is the proportion of people without a particular characteristic of interest who are correctly classified as not having that characteristic. For example specificity is the proportion of non-Indigenous people who are correctly classified as non-Indigenous. This is calculated as d/(b+d).

In medical research, there is usually a trade off between sensitivity and specificity, but this is not the case in measuring Indigenous status. Specificity is high, because non-Indigenous people are rarely classified as Indigenous. There is, however, great potential to increase sensitivity.

Some examples.

In the first example there are 1000 people of whom, in "truth", 10% are Indigenous. The table below shows one way these people might get classified in an administrative data collection:

5.2 THEORETICAL MODEL - INDIGENOUS PEOPLE 10% OF THE POPULATION

Administrative collection	'Truth'		
	Indigenous	Non-Indigenous	Total
'Indigenous'	60 (a)	5 (b)	65 (a+b)
'Non-Indigenous'	40 (c)	895 (d)	935 (c+d)
Total	100 (a+c)	900 (b+d)	1 000 (a+b+c+d)

The proportion of all people correctly classified = a+d/a+b+c+d = 955/1000 = 95.5%

Specificity = d/(b+d) = 99 % that is 99% of non-Indigenous people were correctly classified.

Of the Indigenous people, however only 60 out of 100 have been correctly classified. Sensitivity = a/(a+c) = 60 %

As we are interested in information about Aboriginal and Torres Strait Islander people, this level of sensitivity is not good enough. If we were to use this information to make comparisons between Indigenous and non-Indigenous people, we could easily be misled, and our results may not be valid.

Similar results may arise, even when the proportion of Indigenous people is lower. In the second example there are 1000 people of whom, in "truth", 2% are indigenous.

5.3 THEORETICAL MODEL - INDIGENOUS PEOPLE 2% OF THE POPULATION

Administrative collection	'Truth'		
	Indigenous	Non-Indigenous	Total
'Indigenous'	15 (a)	2 (b)	17 (a+b)
'Non-Indigenous'	5 (c)	978 (d)	983 (c+d)
Total	20 (a+c)	980 (b+d)	1 000 (a+b+c+d)

The proportion of all people correctly classified is :

a+d/a+b+c+d = 993/1000 = 99.3%

Specificity = d/(b+d) = 99.7 % that is 99.7 % of non-Indigenous people were correctly classified.

While only 5 Indigenous people have been incorrectly classified, we have only achieved sensitivity of 75%. Sensitivity = a/(a+c) = 75 %

Again sensitivity is not high enough and the validity is not satisfactory.

Conclusion

It is important for the improved health of Aboriginal and Torres Strait Islander people that the sensitivity and validity of the measures in administrative collections is increased. It is important to get as close as possible to the "truth".

We need to increase the validity and reliability of our measure by using agreed definitions, questions and procedures. We need to assess the completeness and quality of administrative collections. In order to assess completeness and quality it is necessary to compare "truth" (or our best estimate of it in the form of another good source of information) with what is in the administrative collection. We need to calculate the sensitivity of our measure. In summary we want to use the information we obtain to maximise the sensitivity and validity of our measures of the numbers of Aboriginal and Torres Strait Islander people.

MEASURING THE COVERAGE OF INDIGENOUS BIRTHS AND DEATHS REGISTRATIONS

By Tim Carlton, Demography Section, Australian Bureau of Statistics

Aims and objectives

This paper uses ABS projections of Indigenous births and deaths to assess how complete the coverage was of Indigenous birth and death registrations collected by the State Registrars of Births, Deaths and Marriages between 1992 and 1996.

It will also assess how suitable the ABS projections are as benchmarks for this analysis. The final objective of the paper is to examine any geographic bias to registration rates of Indigenous births and deaths.

Main findings

There is no gold standard to which we can compare birth and death registrations. Given the data available at the time of the 1991 Census, estimates were made of birth and death registration coverage. Since then, birth registrations in NT, WA and Queensland have indicated that, at least in those States, the "expected" number of births was too low. When data becomes available from the 1996 Census this analysis will be undertaken again. Although again, there is no guarantee that the expected levels of births and deaths from this process will more accurately reflect reality.

While not all States produce Indigenous births data of publishable quality, there have been consistent improvements, and if these continue, high quality data should be available nationally in the relatively near future.

However, there have been relatively few improvements in the coverage of deaths data in the last few years. For some reason, people in Victoria and New South Wales are about twice as likely to be identified as being Aboriginal or Torres Strait Islander on the Census, as on a death registration form.

Births

Table 5.4 compares the number of births registered with the projected number of births.

When this analysis was first undertaken, in 1994 there were significantly more birth registrations in NT and WA than expected based on the projections. WA & NT had, on average, 16% more births registered than projected. Because of this, the ABS revised its assumptions about Indigenous fertility in WA and NT. Therefore, in this table the projected number of births is broadly comparable with the number registered in these States.

5.4 PROPORTION OF 'PROJECTED' BIRTHS REGISTERED

	1992	1993	1994	1995	1996	Expected births, 1996
	%	%	%	%	%	Number
New South Wales	-	54	83	96	104	2 477
Victoria	87	84	87	89	81	623
Queensland	-	-	-	-	121	2 520
South Australia	109	99	99	109	91	551
West Australia	80	99	100	93	97	1 630
Tasmania	78	93	85	89	83	312
Northern Territory	100	100	97	97	104	1 403
Australian Capital Territory	27	80	107	91	104	59
Australia	44	60	68	71	91	9 575

Notes: 1996 registered births have been estimated assuming the same number of total births as registered in 1995. (Nationally, 153,000 births had been registered and processed by the ABS by October 1996, 60% of the total number of births registered for 1995). Queensland births only relate to those months in which Indigenous births were captured (From July onwards). Therefore these estimates are based on an estimated 27% of the year's total births. This analysis makes no adjustment for registrations undertaken using the old form.

This analysis is currently regarded as the best available data on Indigenous births. On the basis of this, most States have quite high registration rates, and national birth registrations may rise above 90% in 1996, and therefore could be publishable. However, it is important to note that in 1997 ABS projections will be recalculated using the 1996 Census. This may mean significant changes in the projected numbers of births for some States.

As discussed above, based on the original set of projections, NT and WA projected births were, on average, 16% too low. The first Queensland Indigenous births processed by the ABS, were those registered in July 1996. Preliminary data from July to early October (an estimated 27% of the year's births) indicate that projections of Queensland births were also similarly low, as registrations are 21% higher than projected.

This suggests that the low numbers of births projected may not be restricted to NT and WA, but may also exist in other States. There are significant differences between the socio-economic profile, the extent of dispossession, and the culture of Indigenous people in different States, therefore the factors that led to an undercount of babies in the Census in NT, WA and Queensland, may not consistently apply to all States. However, for illustrative purposes table 5.5 shows the registration rates under the hypothetical assumption that projections of births in States other than NT and WA (which are already adjusted) are 16% too low.

Table 5.5 does not represent the official ABS benchmark and is provided merely to illustrate an extreme position. Births data will be published if it reaches a level of 90% of the projections in the previous table.

5.5 PROPORTION OF 'PROJECTED' BIRTHS REGISTERED, ADOPTING A 16% UPWARD ADJUSTMENT OF EXPECTED BIRTHS FROM PUBLISHED PROJECTIONS

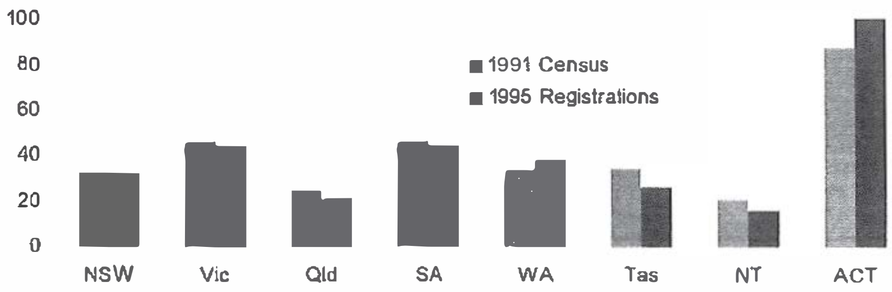
	1992	1993	1994	1995	1996	Expected births, 1996
	%	%	%	%	%	Number
New South Wales	-	46	72	83	89	2 873
Victoria	75	72	75	76	70	723
Queensland	-	-	-	-	105	2 923
South Australia	94	85	86	94	78	639
West Australia	80	99	100	93	97	1 630
Tasmania	68	80	73	76	72	362
Northern Territory	100	100	97	97	104	1 403
Australian Capital Territory	23	69	92	79	89	68
Australia	38	52	58	61	79	10622

Even if there was a 16% underestimate in the projections, most States have birth registration levels at, or approaching, publishable levels (more than 90% coverage).

Regardless of which measure is used, it is obvious that the transition from very low to very high coverage has been very rapid. NSW went from negligible to almost complete coverage in three years, WA in 2 years, and Queensland appears to have made the transition in a single year.

The proportion of Indigenous babies under one year old in capital cities counted in the 1991 Census gives some indication of the proportion of Indigenous births in capital cities. It is probably fairly safe to assume that between 1991 and 1995 there were no major falls in fertility, or rural-urban migration. Therefore we would expect the proportion of births registered in capital cities in 1995 to be similar to the proportion of babies under one year old in the 1991 Census in capital cities. This is what we find. Therefore, there is no evidence to suggest that babies born in capital cities are either more likely or less likely to be registered as Indigenous than those born in the rest of the State. However, this does not prove the accuracy of the registrations, only that they are broadly consistent with Census data.

5.6 PROPORTION OF REGISTERED INDIGENOUS BIRTHS IN CAPITAL CITY



Death

The transition from low levels of death registration to high levels is a much slower process than for births. Most States have shown no significant change in death registration rates in the last 4 years, although NSW appears to have experienced a slow increase in registration rates since 1992.

The estimates for 1996 are based on a proportion of the full year's data, and are therefore subject to significant revision. Specifically, South Australia and the ACT should not take these figures for 1996 as indicating a fall in performance from previous years. Some States are based on very small numbers of deaths, and therefore, the coverage rates here are unreliable. Queensland data are based on only 11% of the year's data, and should also be treated with caution.

5.7 PROPORTION OF 'EXPECTED' DEATHS REGISTERED

	1992	1993	1994	1995	1996	Expected deaths, 1996
	%	%	%	%	%	Number
New South Wales	35	41	44	47	46	476
Victoria	51	48	48	48	51	104
Queensland	-	-	-	-	66	550
South Australia	94	97	108	104	43	116
West Australia	97	109	108	110	97	348
Tasmania	10	12	6	6	4	51
Northern Territory	116	110	111	114	116	340
Australian Capital Territory	-	113	125	113	56	8
Australia	54	57	58	59	59	1 993

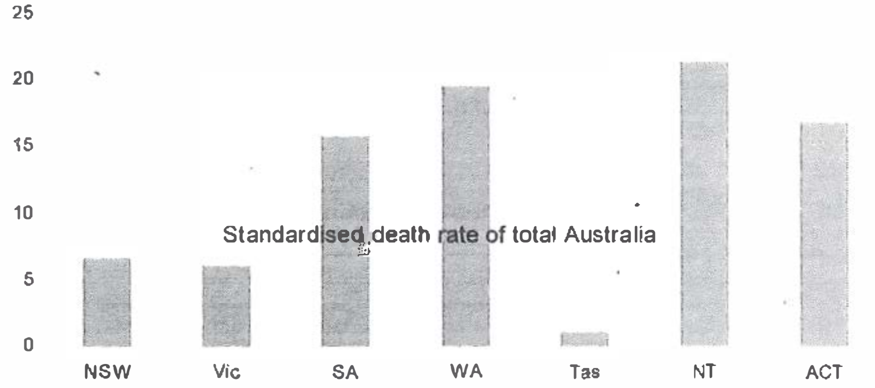
Note: Data for Queensland in 1996 makes no adjustment for use of old forms. 1996 registered deaths have been estimated by proportional adjustment of data available at the time of preparing this report.

Around 50% of the projected number of deaths are registered in NSW and Victoria each year, and this proportion is relatively stable. Tasmania has very low registration rates.

As with births, in some States, the number of deaths registered exceeds the number projected. However, as there are no States which are approaching the 90% cut-off (all States either have close to complete, or around 50-60% coverage), there would be little to be gained analytically from upward adjustment of the projected deaths.

Looking at the general stability of coverage rates in NSW and Victoria, one may be tempted to suggest that the projections are wrong, and that the registration system is relatively complete. However, if death registrations were complete, then Indigenous people in those States, would actually have standardised death rates lower than the total population; a theory which no other indicator of socio-economic status supports.

5.8 ILLUSTRATIVE STANDARDISED INDIGENOUS DEATH RATE(a), 1993–95



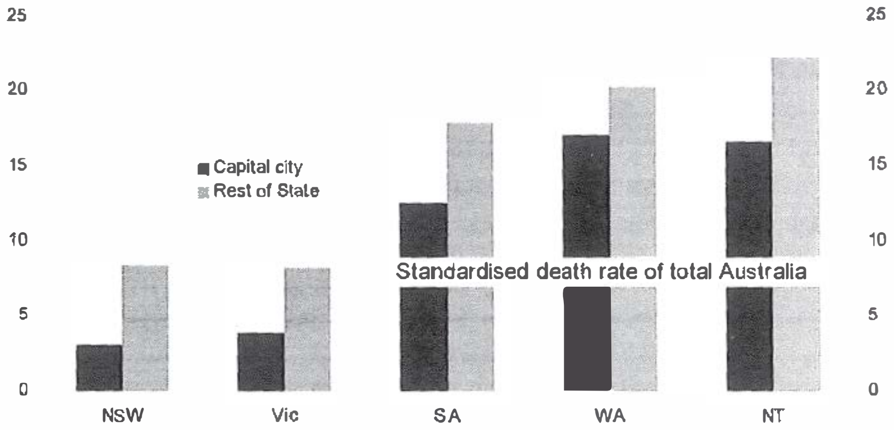
(a) Assuming complete coverage.

In all States, the Indigenous standardised death rate, as measured using death registrations, is lower in the capital city than the rest of the State, probably indicating the greater access to health services, and higher general socio-economic status.

In addition, according to registration data, the Indigenous death rate in Sydney and Melbourne is less than half that of rest of the respective States. While in South Australia, Western Australia and the Northern Territory, the differences in Indigenous death rates between Capital city and the rest of the State are much smaller.

The socio-economic status of Indigenous people in Sydney and Melbourne is significantly higher than that of Indigenous people in rural NSW and Victoria. For example the unemployment rates are around 60% higher in rural areas than in the Capital cities. However, it seems unlikely that the differences in socio-economic status and access to health care explain all of the difference between the urban and rural death rates. I suspect that there is a greater level of under-reporting of deaths in Sydney and Melbourne than in the rest of NSW and Victoria. Registrars in these States need to improve coverage both in the capital cities and in the rest of the State, but particular emphasis could be placed improving the capital city registration rates.

5.9 ILLUSTRATIVE STANDARDISED INDIGENOUS DEATH RATE(a), 1993-95



(a) Assuming complete coverage.

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Appendix 1: ABS projection techniques

Based on the difference between the populations enumerated in the 1986 and 1991 censuses, Alan Gray (ANU) calculated the average death rates for the period, using demographic techniques to adjust for the increasing propensity to identify and changes in level of enumeration.

Total births for 1991 has been calculated by adjusting the number of children under one year old for under-enumeration (about 7%). Age-specific fertility rates were then calculated by "allocating" these babies to "mothers" in the same proportion as registered in the birth registrations.

Various population projections were made based on different assumptions about changes in fertility and mortality, although these different assumptions do not make significant differences to the results of this analysis. This paper is based on constant fertility, and a 3% annual decline in mortality by 2001 (high series). From these data, the number of Indigenous births and deaths expected in each State can be calculated for each year, and this number compared to the number registered.

This method is designed to give a general indication of the accuracy of registration data. However, it is important to note that there are some inaccuracies inherent in using this method.

The expected number of births and deaths is based on set assumptions, and therefore is relatively constant, while the actual number (and the number registered) may be much more volatile. For example, in the ACT, in 1994 there were 107% of the expected number of births registered, compared with 91% in 1995. Much of this variability from year to year is due to a change in actual number of births, rather than to improvements in the registration process.

The projections are based on assumptions about changes in fertility and mortality, and a base population which may not accurately reflect the true picture. However, they are considered to give a reasonable indication of the coverage of Indigenous birth and death registrations.

When data from the 1996 Census becomes available, the projections of births and deaths will be rebased, and may be significantly different in some States.

INDIGENOUS IDENTIFICATION IN MATERNAL AND CHILD HEALTH RESEARCH IN WESTERN AUSTRALIA

By Anne Read and Carol Garfield, TVW Telethon, Institute for Child Health Research

In order to plan appropriate, evidence based policy for Aboriginal maternal and child health it is essential to have complete and correct identification of indigenous families. This is perhaps even more important in the case of analytical research, where risk factors for mortality and morbidity are being sought or where attempts are being made to ascertain etiology. In Western Australia (WA), the Midwives' Notification System (1) was established in July, 1974 and (following a validation study (2)) excellent, computerised data have been available from this source for all births since 1980 (3). In addition to information on antenatal and perinatal events, the Midwives' Notification of Case Attended Form 2 contains demographic information including whether the mother is identified as an indigenous person (3). This variable is categorised as Caucasian, Aboriginal/Torres Strait Islander or Other, the latter including any mothers not belonging to either of the other two groups.

The Western Australian Midwives' Notification System is the core component of the Western Australian Maternal and Child Health Research Data Base (4), which was established in the early 1980s and is held at the TVW Telethon Institute for Child Health Research. In addition to data from the Midwives' Notification System, the Data Base includes birth and death information from the Registrar-General of WA and the Australian Bureau of Statistics, and hospital discharge data for all public and private hospitals in WA from the Health Department of WA. Deaths and hospital admissions are complete for all children to age 15 years and all data are linked to individual mother/child pairs. In addition there are links to the Western Australian Birth Defects and Cerebral Palsy registers. The Data Base is complete for all births in WA from 1980 onwards with new birth cohorts being added on an annual basis (4).

Many research projects have been conducted using data from the Maternal and Child Health Research Data Base and a large number of these describe and/or analyse data according to indigenous status of mother or child. For most of these latter projects the Midwives' Notification System has been used to select mothers as "Aboriginal/Torres Strait Islander", and this has been assumed to accurately represent the indigenous background of the child as there is no information about the father on the Midwives' form. The Midwives' Notification of Case Attended Form 2 is a statutory requirement (1) and is completed for more than 99% of all births in WA, including home births. Due in part to the close contact that the midwives have with the mothers, the Midwives' Notification System has generally been considered to have accurate identification of the indigenous status of the mother. This was verified in a validation study conducted in 1992, where this variable had been recorded incorrectly in less than 2% of the forms. The validation study involved comparing the data for a sample of cases from the Midwives' Notification System with the information recorded in the hospital medical record (5).

As the birth information for each child on the Maternal and Child Health Research Data Base is linked to hospital discharges, for all children admitted we have the child's indigenous status recorded at each admission. These data have been validated by comparing a sample of admissions with the hospital paper records. This work was carried out for a research project investigating hospital admissions for children aged up to two years. As shown in Table 5.10, a total of 889 records were checked at teaching, suburban and remote hospitals. The child's indigenous status was incorrect on the computer file for four children in total, 0.4%.

On the Maternal and Child Health Research Data Base, it is possible that a child's indigenous status at hospital admission may differ from that at birth (where it is taken only from the mother's background). In research conducted to date, which has mostly involved the youngest children, we have found little difference in these two variables. With regard to older children, Table 5.11 shows the indigenous status of the child as taken from Midwives' Notifications compared with that taken from the Hospital Morbidity System. This table includes all children aged up to 14 years who were admitted to hospitals in WA during 1993. For the purpose of this paper and in order to simplify the data, the first admission only for each child in that year was taken to indicate the indigenous status of the child. In practice, we have found that children are rarely coded as "indigenous" at one admission and "non-indigenous" at another. Table 5.11 shows that, of the 34 376 children recorded as non-indigenous on Midwives' Notifications, 237 (0.7%) had been recorded as indigenous on the Hospital Morbidity System. These may be children with non-indigenous mothers and indigenous fathers who would have been missed as indigenous children by the Midwives' Notification System. Table 5.11 also shows 245 children recorded as indigenous on Midwives' Notifications and non-indigenous on the Hospital Morbidity System. This number comprises 7% of the total indigenous children as recorded by the Midwives' Notification System. Given that these data include children up to 14 years of age, it is possible that some of these children may have been identified at birth as being born to indigenous mothers but, as they approach adolescence, identification changes to non-indigenous. Clearly, self-identification is not possible for the child at birth. For all denominators used in our research, we use the indigenous background of the mother to identify Aboriginality of the child as we have this variable for all children from birth, whereas we have hospital discharge data only for those children admitted.

Cross-cultural marriages are now becoming increasingly common in the Aboriginal community (6). Thus, our method of using the indigenous status of the mother to define that of the child is becoming less accurate and a substantial proportion of the indigenous population might be excluded by missing those children with non-Aboriginal mothers and Aboriginal fathers. Since 1992, the indigenous background of both mother and father has been available from Birth Registrations. Thus, we can now add this latter variable to the details from the Midwives' forms to ascertain the indigenous status of both mother and father. This is extremely important as children with non-Aboriginal mothers and Aboriginal fathers may comprise a different group in terms of risk factors and health outcomes to those with Aboriginal mothers. Unfortunately, comparisons of the Birth Registration data with data from the Midwives' Notification System show that the former is less complete with more unknown values. Also, there is some disagreement in the recording of the mother's indigenous status between the two data collections.

Table 5.12 shows total WA births as recorded on the Midwives' Notification System and those registered with the Registrar-General of WA for children born in 1992 and 1993. In 1992 there were 548 less children registered than recorded on the Midwives' Notifications and, in 1993, this shortfall was 313 children. The numbers of records which linked in each year are shown in the second column. The unlinked records are strongly biased towards the indigenous children. In 1992 and 1993, approximately 16% of the

Midwives' Notifications for indigenous children did not link to a Birth Registration compared with 0.5% of the Midwives' Notifications for non-indigenous children.

Table 5.13 shows the 24 744 1992 births which had both a Midwives' Form and a Birth Registration. A major problem with Birth Registrations is the proportion with the indigenous status of the mother unknown, 12% for those children recorded as having indigenous mothers on Midwives' Notifications and 8% for those recorded as having non-indigenous mothers on this source. All the Midwives' Notifications were complete for this variable. Of the children recorded as having indigenous mothers on Midwives' Notifications, 3% were recorded as having non-indigenous mothers on the Birth Registration. This proportion agrees with results from the Midwives' Validation Study (5) and with a more recent validation discussed below. Of the children recorded as having non-indigenous mothers on Midwives' Notifications, 0.5% were recorded as having indigenous mothers on the Birth Registration. Table 5.14 shows similar data for the linked 1993 births. There were 24 991 births which had both a Midwives' Form and a Birth Registration. The proportion of Birth Registrations with indigenous status of the child's mother unknown appears to have improved and was less for those children recorded as having indigenous mothers on Midwives' Notifications (4%) than for those recorded as having non-indigenous mothers (5%).

To date we have not used the indigenous status of father in our maternal and child health research as this variable has only recently become available. However, as mentioned above, this is becoming an increasingly important area of research. It has been estimated that more than 80% of the children of cross-cultural marriages identify as indigenous (6). Table 5.15 shows the numbers of fathers recorded as indigenous on the Birth Registration where the mothers were recorded as non-indigenous on both the Midwives' Notification System and the Birth Registration. There were 201 and 216 fathers in 1992 and 1993 respectively. This is likely to be an underestimate as there were 827 fathers in this category in 1992 and 857 in 1993 with indigenous status unknown.

The ideal validation for any identification of indigenous people in statistical data collections is to ask the individuals concerned in a face to face interview if they identify themselves as indigenous. This has been done in recent research conducted at the TVW Telethon Institute for Child Health Research for a sample of mothers residing in the Perth metropolitan area, and has provided an assessment of the quality of the perinatal data collection. The interviews were conducted as part of a longitudinal cohort study. All mothers giving birth during a 15 month period who were recorded on the Midwives' Notification System as indigenous and residing in the Perth metropolitan area were included (n=660). Of these mothers, 15 (2.3%) identified themselves as non-indigenous and the remainder as indigenous. Of the 660 mothers, 47 could not be traced. If these mothers are excluded, 2.4% of the mothers contacted identified as non-indigenous. This result is in agreement with the Midwives' Validation Study conducted in 1992.

This recent project has also highlighted the value of built-in edits and careful checking of all records that appear dubious. Initial identification of mothers for the project was carried out using the copy of the Notification of Case Attended (Midwives') Form 2 which is required to be sent to the Health Department of WA within 48 hours after the child's birth. This was because early identification of the infants was required for the study purposes. When these early forms are received, all information is checked for completeness and accuracy by the Maternal and Child Health Studies Unit (3). Mothers for the research project were initially identified before this checking was complete and

60 of this group (9.1%) were found to be non-indigenous. The research project did not lead to any checks or procedures other than those which are normally carried out. Thus, the excellent checking and commitment of the staff at the Maternal and Child Health Studies Unit is in large part responsible for the complete and correct identification of indigenous mothers in the Western Australian Midwives' Notification System.

The most important conclusion from this work is that the Western Australian Midwives' Notification System provides complete and correct registration of births where the mother identifies as indigenous. This has also been recognised in a recent paper from Luther *et al.* where the Western Australian Midwives' Notifications were selected as the benchmark for the indigenous population of WA (7). Editing and constant checking by committed staff is vital to ensure the quality of such a system. Children with non-indigenous mothers and indigenous fathers are not identified by the Midwives' Notification System. Data from the Registrar-General/Australian Bureau of Statistics provides a useful adjunct to Midwives' data and can be used to identify the above group but coverage is incomplete. In view of the increasing importance of cross-cultural marriage in indigenous communities and the value of having this information available for the whole of Australia, efforts must be made to improve the national collection.

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5.10 VALIDATION OF WA HOSPITAL MORBIDITY DATA SYSTEM

		Total records checked	
Hospital	Computer file incorrect	Indigenous*	Non-Indigenous*
	n	n	n
Teaching	3	119	169
Suburban	0	78	166
Remote	1	262	95
Total	4	459	430

Computer files compared with hospital paper records. Children aged up to 2 years.
* as recorded on computer file

5.11 MIDWIVES' NOTIFICATION SYSTEM COMPARED WITH HOSPITAL MORBIDITY DATA SYSTEM

	Hospital Morbidity		
Midwives Notifications	Non-indigenous	Indigenous	Total
	n	n	n
Non-indigenous	34 139	237	34 376
Indigenous	245	3 107	3 352
Total	34384	3 344	37 728

Hospital admissions for 1993. First admission for each child in that year. Children aged up to 14 years. There were no records with indigenous status unknown.

5.12 MIDWIVES' NOTIFICATION SYSTEM AND REGISTRAR - GENERAL/ AUSTRALIAN BUREAU OF STATISTICS DATA

	Total births from MW	(Linked)	Total births from R-G*
	n	n	n
1992 births	25 324	(24 744)	24 776
1993 births	25337	(24 991)	25 024

* prior to processing by ABS

5.13 MIDWIVES' NOTIFICATION SYSTEM COMPARED WITH DATA FROM REGISTRAR - GENERAL/AUSTRALIAN BUREAU OF STATISTICS

1992 BIRTHS - INDIGENOUS IDENTIFICATION OF MOTHER

	Registrar-General			
Midwives'	Non-indigenous n	Indigenous n	Unknown n	Total n
Non-indigenous	21 519	119	1 912	23 550
Indigenous	33	1 015	146	1 194
Unknown	0	0	0	0
Total	21519	1 134	2 058	24 744

5.14 MIDWIVES' NOTIFICATION SYSTEM COMPARED WITH DATA FROM REGISTRAR - GENERAL/AUSTRALIAN BUREAU OF STATISTICS

1993 BIRTHS - INDIGENOUS IDENTIFICATION OF MOTHER

	Registrar-General			
Midwives'	Non-indigenous n	Indigenous n	Unknown n	Total n
Non-indigenous	22 431	138	1 195	23 764
Indigenous	57	1 118	52	1227
Unknown	0	0	0	0
Total	22 488	1 256	1 247	24 991

5.15 REGISTRAR - GENERAL/AUSTRALIAN BUREAU OF STATISTICS

Non- indigenous mothers*	Indigenous fathers n	Status father unknown n
1992 births	201	827
1993 births	216	857

* These are mothers coded as non-indigenous on both Midwives' Notifications and Registrar-General data

PROBLEMS IN THE RECORDING OF INDIGENOUS IDENTITY ON HOSPITAL RECORDS AT SELECTED HOSPITALS IN BRISBANE AND CAIRNS

By Associate Professor Cindy Shannon, Indigenous Health Program, The University of Queensland

Background and aim of the study

There is a serious lack of information on the health of Aboriginal and Torres Strait Islander people in Australia, especially in areas where indigenous people represent a small proportion of the population. This means that epidemiological patterns of health problems cannot be clearly described, which prevents the monitoring of disease trends over time, geographic location and among different groups in the community. The absence of information prevents the development of optimal, timely strategies for health promotion and disease prevention and control.

One of the major reasons for this lack of health information is very recent introduction of a question to record ethnicity on birth and death certificates, disease registries and hospital records. Hospital recording began in 1992-93 in Queensland and it is well recognised that the quality of these data are very poor and uneven, and likely the cause of substantial under reporting of ill health for Aboriginal and Torres Strait Islander people. This is clearly a complex issue, and many possible reasons could contribute to inaccurate reporting of indigenous identity on these records.

The basic goal of this study was to gain an understanding of the problems which prevent Aboriginal and Torres Strait Islander people from being identified on hospital records. Analysis of this information will be used to make practical recommendations which hospitals could implement in order to improve the accuracy of recording indigenous identity on their records.

Methodology

Prior to starting the collection of data, support was obtained from all levels of hospital administration and staff, working closely with their Aboriginal and Torres Strait Islander Health Units. The Aboriginal and Torres Strait Islander Hospital Liaison Officers played a crucial role in the project, since they represent the interface between indigenous patients and support services.

Both qualitative and quantitative methods were used to collect data from hospital patients, Aboriginal and Torres Strait Islander liaison officers and recording clerks at various entry points in wards in the Royal Brisbane and Royal Children's Hospitals in Brisbane and at Cairns Base Hospital in North Queensland.

A short questionnaire was administered on a bed-to-bed survey to quantify the numbers of people in selected wards who identified as Aboriginal or Torres Strait Islander, to determine the percentage of patients recorded accurately on their records and the proportion of people who recalled having been asked their ethnic background during admission procedures.

In-depth interviews were carried out with hospital staff to understand the procedures in place and the perceived and actual problems faced by those responsible for recording ethnicity on the forms. This required a clear understanding of the channels of entry for patients into the wards and an examination of the various types of admission forms in use at the various entry points. The Aboriginal and Torres Strait Islander Liaison Officers were also interviewed. This group was particularly concerned about recording, since their ability to offer support and services to indigenous patients requires an efficient identification procedure.

The project is nearly completed with analysis of data and final report preparation in progress. A thorough interview process among staff and patients within the Royal Brisbane Hospital and the Royal Children's Hospital has been completed. A similar study was recently conducted at Cairns Base Hospital as a student-directed research project, the findings of which are quite startling.

Some of the main findings from the Brisbane studies are summarised below.

Brisbane study

People who identified as Aboriginal or Torres Strait Islander represented 5.4% of the 462 patients interviewed in the bed surveys in the Royal Brisbane and Royal Children's Hospitals. There was a slightly higher proportion (6.1%) indigenous patients in the Children's Hospital than in the sample from the general hospital (3.6%). While only 15.6% of patients recalled being asked the identity question at the General Hospital, 49% of those in the Children's Hospital said that they had been asked this question. The higher proportion of patients being asked is also reflected in the percent identified correctly in their hospital records of the Children's Hospital (52.6% correct), compared to the Royal Brisbane Hospital (20%). Interviews conducted with patients in the Royal Women's Hospital were discontinued after finding virtually no women who had recalled being asked the indigenous identity question.

Preliminary analysis of interviews with the hospital staff about the indigenous identity question on the Hospital Admission forms is considered to be ill-conceived and in some instances, a cause of irritation or conflict. The forms tend to be filled out because it is mandatory, but staff devise ways to avoid a conflict by either getting patients to fill the form out, or by guessing their ethnic origin. This can be based upon a visual assessment, or from responses to questions like language group or country of birth. Both of these latter areas have a list of 90 to 100 choices available on the "help" menu. However, the ethnicity question has only 6 options, with no "help" menu available. This again points to the inadequate preparation accorded to this question.

The clerks expressed concern that the question seems irrelevant to the treatment of the patient, and sensed resentment from the various groups of non-indigenous people who are not Anglo-Saxon and do not accept being classified as "Caucasian". There was also a suggestion that not enough information about the public health significance of the question was provided to the clerks and the patients so they could understand why the question is important and how the information would be used. Some staff thought the question suggested they were not giving equal treatment to people of different ethnic backgrounds.

As a result of these problems, the Aboriginal and Torres Strait Islander identifier question is often either not asked (and assessed visually) or passed over (and classed as either "other" or "unknown"). The impact of this can be seen in the 1994/95 hospital inpatient separations by ethnic origin for the hospitals concerned. For example, while Aboriginal and Torres Strait Islander patients comprised 1% of separations, the "other" and "unknown" combined accounted for 6% of all separations. Similarly, in the Royal Women's Hospital, indigenous women accounted for 1.6% of separations, while the other/unknown category represented 29.3%.

Some hospital staff reported that the ethnic identity question is a less sensitive question than that about religion or marital status. However, they indicate that it is the limited choices available to the respondents, especially those non-indigenous, that has compounded its sensitive nature.

HOW MIDWIVES IDENTIFY WOMEN AS ABORIGINAL OR TORRES STRAIT ISLANDERS

By Helen Robertson, Judith Lumley, Sarah Berg, Perinatal Data Collection, Department of Human Services

Terminology

Koori: An Aboriginal language term used by Aboriginal people in Victoria, Tasmania and southern New South Wales to identify themselves. At the time of this project, midwives were advised to ask all women if they identified as an Aboriginal or Torres Strait Islander.

Introduction

At the present time we do not know if all women who have babies in Victoria and are Aboriginal or Torres Strait Islanders are identified on the Perinatal Morbidity Statistics Form. On the other hand our data collection has a higher number of women reported than other systems in Victoria .... we do not why this is so.

This study was undertaken to find out how midwives identify women as Aboriginal and Torres Strait Islanders. Midwives often did not ask women if they identified as Aboriginal or Torres Strait Islander because of the perceptions and assumptions they held about how women would feel if asked. These perceptions affect the quality of our data.

" *How midwives identify women as Aboriginal and Torres Strait Islanders.*"(1)

The Victorian Perinatal Data Collection Unit (PDCU) collects information on every baby that is born in Victoria. The perinatal form contains, amongst other items, the age, suburb/town of residence, country of birth and Aboriginality of the.mother. The guide to completing the form gives definitions and requests that every women is asked if she identifies as Aboriginal or Torres Strait Islander. Midwives complete a perinatal form for every baby born in Victoria.

In 1993 the Victorian Perinatal Data Collection Unit was asked by the Koori Health Unit of the Department of Health and Community Services to undertake a study to determine how midwives make this decision. The study was a special project for 1993 which was declared by the United Nations as the Year of the World's Indigenous Peoples.

Method

The study was facilitated by the author, who is a midwife, employed by the Perinatal Data Collection Unit to liaise with hospital staff about collecting information for the perinatal form. The project was conducted within the Victorian Perinatal Data Collection Unit's educational program and became part of routine liaison between August and December 1993. Consequently, state wide meetings were held in seven country and city hospitals and with student midwives at two universities. The hospitals ranged in size from 149 to 2,358 births per year.

I began by asking the Director of Nursing at the hospital where I was conducting an education program for permission to conduct a taped discussion with midwives about how they identify women as Aboriginal for the purpose of the PDCU form.

During the education session all the midwives present were asked if they would take part in a group discussion on "Aboriginality". They were advised that the information collected would be confidential and not identified as belonging to any particular institution or individual. No midwives refused to participate. The meetings were held in labour wards, staff rooms, classrooms, visitors' sitting areas and hospital boardrooms. The duration of the focus groups was between 20 and 40 minutes and overall fifty four midwives participated. It was hoped that the group discussion would allow midwives to disclose their own opinions.

The projects' aim was to find out why midwives felt uncomfortable about asking women if they were Aboriginal or Torres Strait Islanders. Focus group discussion allows for group interactions which produce a wide range of information and also have the potential for uncovering important unexpected findings (2). It was hoped that the group discussion would allow midwives to disclose their own opinion, attitudes to and perceptions of the problems with collecting Indigenous data. The process also enables the researcher to gain a broad understanding of why the participants think and act the way they do(2).

Although the focus group process is a good method for obtaining a wide range of opinions the responses of the group may not be independent of the group, the discussion may be directed by the dominant group member and some participants may find the group inhibitory(2, 3). We hope, in the future, to test the findings of the focus groups by sending questionnaires out to a further random sample of midwives. This will allow us to determine if the opinions expressed in the focus groups are the same as those expressed in an individually answered mail questionnaire.

Occasionally the midwives were inhibited when their charge nurse was present but this happened rarely as the groups were run as I tried to ensure that everyone had the opportunity to express their opinion. As we had been involved in an interactive education session prior to the focus we felt comfortable with each other and once the midwives started discussing the issues I had very little input.

The discussions were animated and the midwives shared their experiences, their opinions and ideas about Aboriginal people. All midwives involved said how they enjoyed participating in the groups.

The focus groups started with specific questions then moved to more open ended questions ... a type of funnelling effect which promoted interactive discussion . The groups allowed midwives the time to discuss "Aboriginality" and the discussion ranged from the basic question on how they actually filled out the form tho how they felt about nursing Aboriginal people.

Questions I asked were:

- What usually happens in this hospital about filling in this part of the form?
- Is every women asked formally?
- If not, what is done?
- Are there things about this process that make people uncomfortable?
- Are there any local factors that affect midwives' reporting?

At the conclusion of the focus group I summarised the main themes that had evolved out of the discussion and ended the session by advising the midwives of the importance of asking all women if they identify as Aboriginal or Torres Strait Islanders.

Immediately after the taping I wrote my impression of the group process and reviewed the tape. A summary was then sent to each individual hospital asking the participants if it represented a true record of the discussion. Finally all the tapes were analysed to determine how the midwives identify Aboriginal and Torres Strait Islander women and what factors influenced this process.

Results and discussion

What is the usual practice?

The midwives said that sometimes "Aboriginality" is entered on the form at the first antenatal admission by clerical or midwifery staff but most often it was recorded by the midwife when the woman was admitted to hospital in labour.

Do the midwives formally ask people?

Most mothers were not asked if they identified as Aboriginal or Torres Strait Islander. The initial reasons given were:

- The woman was not asked if she was born overseas
- The midwife knew her personally
- She was distressed in labour.

The midwives did ask woman who they thought were:

- "Aboriginal" by appearance and who were born in Australia
- They also asked women whose name suggested "Aboriginality"
- Women who were accompanied by Aboriginal or Torres Strait Islanders.

In two hospitals where clerical staff had already entered "Aboriginality" on the admission sheet the information was not utilised and often disregarded by midwives because:

- They believed that the mother may not tell clerical staff that she was Aboriginal (but they appeared to expect that the woman would confide in her midwife in labour ward)
- "Aboriginality" was not used because it took extra time to check back to the admission sheet
- Some midwives did not know that the information was available

At admission to hospital clerical staff were instructed to ask all women if they were Aboriginal or Torres Strait Islanders but, again, we do not know how many actually ask all women (4).

What is uncomfortable about reporting Aboriginal or Torres Strait Islanders?

Midwives did not ask about Aboriginality because they felt uncomfortable asking it. They felt uncomfortable because they expected both Aboriginal and non Aboriginal women to feel ill at ease when asked if they identified as Aboriginal or Torres Strait Islander for a variety of reasons.

☐ They frequently felt embarrassed asking women other questions for the perinatal form such as:

  - "Have you had an induced abortion?"
  - "What is your marital status?"
  - "Are you an intravenous drug user?".

Positive answers to these questions often carry a negative connotation in our society. They perceived the question about Aboriginality to be of the same kind, that is a positive answer has a negative connotation.

☐ They felt the question set Aboriginal women apart from non Aboriginal women. For instance they laughed with embarrassment when two midwives stated, unexpectedly, that they were of Aboriginal descent.

☐ Similarly all the groups wanted to know why the Perinatal Data Collection Unit required the information about whether a woman was Aboriginal or not - this was generally voiced at the start of taping and mostly in an aggressive and negative manner. Overall, midwives felt that the question would have an adverse effect on their relationship with the Aboriginal or non-Aboriginal woman having her baby.

☐ Midwives showed irritability and discomfort when discussing the need to present a special case for Aboriginal services. Often the same tone was used when they asked how people of Aboriginal or Torres Strait Islander descent made the decision to identify as Aboriginal. Many believed that Aboriginal people should assimilate into non Aboriginal society.

☐ Negative perceptions of Aboriginal people led the midwives to assume that Aboriginal and non Aboriginal women would be distressed if asked if they identified as Aboriginal or Torres Strait Islander.

These perceptions included discriminatory comments as follows:

- Aboriginal women get more social security
- Aboriginal people are generally drunk or in jail
- They do not attend private hospitals. If they do the women are so assimilated that they cannot be regarded as "real" Aboriginals or Torres Strait Islanders.

☐ Some midwives felt uneasy because they thought that all Aboriginal women would prefer not to answer or "own up", due to fear of the "stigma" attached to being Aboriginal or Torres Strait Islander within hospitals. This was also voiced by one Maori midwife and one midwife of Aboriginal descent.

☐ The midwives said they felt uncomfortable because in their experience Koori women would not want to answer a question about Aboriginality because:

- They were shy
- They had inferiority complexes
- They did not ask for attention
- They were quiet in labour
- They did not share information
- They often did not come in for antenatal care
- They left hospital early
- They were not to be found in private hospitals.

Many of the midwives saw Aboriginal women as problem patients because they did not communicate their needs to staff. Other midwives recognised that ignorance of Aboriginal women's needs made them feel uncomfortable when asking this question.

- ☐ Often midwives were uncomfortable because they believed that the hospital they worked in had very few Koori patients, although the midwives of Maori or Aboriginal descent stated that there had been more Koori woman than the non Aboriginal midwives thought.
- ☐ Midwives experienced prejudicial comments when asking women this question and consequently they felt afraid of physical or spoken abuse from women, or their partners. The midwives who did ask all women often made a joke of it to cover their embarrassment or fear at being subjected to discriminatory remarks, especially if the woman was born overseas or looked non Aboriginal.
- ☐ Some midwives felt the question discriminated against non Aboriginal women. They said the implication of the question was that the care may be different for Aboriginal and Torres Strait Islander women and not as good for other women.
- ☐ A few midwives said they felt stupid asking women they perceived as being of Asian or northern European appearance.

Work processes contributing to poor reporting

- ☐ The midwives said that the work processes associated with filling out the form meant few women were asked
- ☐ The form is constructed so that "Country of Birth" is filled in before Aboriginality: accordingly if the mother was born overseas she is not asked about Aboriginality
- ☐ Sometimes the form is filled in at some distance from the mother and the midwife neglects to get up and ask the mother

Although these may be valid excuses they may also reflect the reasons reported above for feeling uncomfortable about asking women.

Reasons why some midwives asked everyone

The few midwives who asked everyone did so because they recognised that Aboriginal and Torres Strait Islander people are of diverse appearance. There were also some midwives who understood that asking only women who looked Koori was discriminatory. They felt that all women should be asked and not just women singled out on appearance.

Occasionally a midwife would routinely inquire because it is a requirement of the Data Collection Unit. A few midwives knew that the collection of the information was important to improve the health of Aboriginal and Torres Strait Islander people. One midwife said that every woman should be asked as Aboriginality was part of our culture.

At only one hospital did the midwives feel entirely comfortable asking all the mothers. This was because the hospital staff had a strong relationship with the Koori Hospital Liaison Officer. The midwives were involved in the local Koori community and conducted antenatal education classes specifically for Aboriginal people. They also knew that a lot of people in their region have Aboriginal heritage.

Conclusions

☐ Midwives need to know the reason why they are requested to ask all women if they identify as Aboriginal or Torres Strait Islander.

☐ Major barriers to collecting information are often based on poor knowledge and understanding of definitions and issues.

■ There was strong evidence of the existence of underlying beliefs and perceptions about Aboriginal people which "inhibits" midwives from complying with our explicit advice on the collection of this information.

Recommendation

To improve the reporting of Indigenous statistics it is recommended that:

☐ Midwives and all data collectors understand the reasons why they are requested to ask all Australian born women if they are of Aboriginal or Torres Strait Islander descent. To facilitate this process I propose that:

1. ABS produce a video, for Australia wide distribution, aimed at informing data collectors of the importance of valid Indigenous statistics.
2. That each data collection agency devise educational programs to enable their data collectors to feel comfortable about asking if a person is of Aboriginal or Torres Strait Islander descent.
3. Health Departments in each State advised University Faculties and Departments of Medicine, Nursing, Midwifery and Health Sciences that they consider including in their curriculums courses to introduce students to the culture, living conditions and health problems of Aboriginal and Torres Strait Islander people.
4. Data collection agencies develop ongoing validation studies for the Indigenous data in their collections.
5. Research into issues concerning attitudinal change be undertaken by ABS.

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Many thanks to all the midwives who shared their experiences and feelings in the focus groups and to the Nursing Administrators who facilitated the project.

COLLECTION OF A STATISTICAL INDICATOR OF ABORIGINAL AND TORRES STRAIT ISLANDER ORIGIN ON BIRTH AND DEATH REGISTRATION FORMS - THE RECENT EXPERIENCE OF QUEENSLAND

By *Malcolm Greig, Population and Social Branch, Australian Bureau of Statistics*

Introduction

From 1 January 1996 an indigenous identifier has been included on the Queensland birth and death registration forms to determine whether persons are of Aboriginal or Torres Strait Islander origin.

A working group was set up, through the Queensland State Statistics Consultative Committee, to monitor the implementation of the interim and final forms. This group is chaired by the ABS and consisted of representatives from the ABS, the Queensland Government Statistician's Office (GSO), the Registrar-General's Office, the Queensland Department of Health (including the Aboriginal Health Unit), the Department of Families, Youth and Community Care, and the Indigenous Health Program (University of Qld). This working group met on a monthly basis to monitor and identify methods of improving the penetration in the use of the new (interim and final) forms and quality of the data reported.

The forms

The questions used for indigenous identification are:

Births

Is the mother of Aboriginal or Torres Strait Islander origin? (If of both Aboriginal and Torres Strait Islander origin, tick both "Yes" boxes).

Is the father of Aboriginal or Torres Strait Islander origin? (If of both Aboriginal and Torres Strait Islander origin, tick both "Yes" boxes).

If the answer is "Yes" to either of the above questions then the birth is coded as Aboriginal or Torres Strait Islander.

It is considered that in the majority of cases the mother is the person filling out the form.

Deaths

Was the deceased of Aboriginal or Torres Strait Islander origin? (If of both Aboriginal and Torres Strait Islander origin, tick both "Yes" boxes).

Normally the death information form is filled out by the funeral director in the company of the next of kin or someone close to the family.

1996 Census Question

Is the person of Aboriginal or Torres Strait Islander origin? (for persons of both Aboriginal and Torres Strait Islander origin, mark both "Yes" boxes).

The data

The question(s) were included on Interim forms from 1 January to 30 June and from 1 July on final forms. Indigenous data has been captured electronically by the ABS since 1 July. Indigenous data has been collected for the first 6 months but will need to be added to the data file.

It is also important to note that this paper is based on unprocessed data extracted directly from the Registrar General's records and presents the operational side of the collection of indigenous information. The paper "Measuring coverage of Indigenous births and deaths registrations" by Tim Carlton is based on ABS processed data and presents a summary of registration data compared to ABS experimental estimates and projections. As such the papers will not have the same set of statistics but should be consistent in what they show for Queensland.

Communicating the change

The interim forms were distributed with a covering letter to courthouses. Samples of the forms with a covering letter were also sent to hospitals, funeral director associations etc. No other promotional activities were carried out.

During the first six months use of the interim forms was monitored, and where necessary phone calls were made urging those not using the interim forms to start doing so.

An enhanced strategy was used for the distribution of the final forms. These final forms were distributed in bulk to hospitals, courthouses, GPs, individual funeral directors (rather than associations) and any other potential users of the forms. Accompanying the final forms was a letter and brochures explaining the need to fill in the indigenous identifier part of the form (see attachment 1). These brochures have been sent out again in November to metropolitan funeral directors.

A Registrar General's representative also attended the funeral directors conference to address them on the importance of using the new forms with particular mention to the importance of filling out the indigenous identifier questions correctly.

Since the introduction of the final forms monitoring of the usage has continued with little need to do any further phone contact.

Quality analysis

On a monthly basis two officers, one from the ABS and one from the GSO, went through every registered birth and death form and extracted the following information:

- Number of births received on the old and new (interim and final) forms respectively
- Number of new birth forms that had the indigenous identifier question blank or partially complete
- List of hospitals still using the old forms
- Number of deaths received on the old and new forms respectively
- Number of deaths received on the old and new forms respectively for six regions in Queensland identified as having as having a higher proportion of indigenous residents
- Number of new death forms that had the indigenous identifier question blank
- List of funeral directors still using the old forms.

The initial quality focus was to ensure that the new forms were being used

5.16 USAGE OF THE INTERIM/FINAL BIRTHS AND DEATHS REGISTRATION FORMS

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Births										
% use of interim/final forms	26.7	66.0	76.2	83.4	84.1	87.3	93.3	95.8	98.5	99.2
Deaths										
% use of interim/final forms	36.8	54.7	62.0	73.1	73.5	81.6	91.5	97.8	98.3	98.3

The use of the forms was initially slow but after 6 months the percentage use had risen to 87% and 82% respectively for births and deaths. Approaches to hospitals and funeral directors still using the old forms were made during this period to attempt to increase the usage of the interim forms.

With the introduction of the final forms from July 1, accompanied by a more intensive promotion, a further increase was achieved over the next 4 months. By October the number of births and deaths being recorded on the new forms were 99.2% and 98.9% respectively. This is expected climb to 100% gradually over time. However, due to circumstances in remote communities and late registrations there will always be the chance of an old form finding its way into the system.

It is now considered that the current penetration rate of the final forms is very acceptable and that there is no cause for concern on data quality in this respect.

Another aspect of data quality is - How often are the indigenous identifier questions filled out?

There are two aspects to this, whether the questions are filled in and whether the forms are entered correctly into the computer system.

With regard to the second aspect, an initial check was completed to see whether there were any forms ticked "Yes" as indigenous but entered incorrectly during data entry. This had been an issue in other states but after initial checking the number of errors detected were not significant and hence is not considered a major issue. A random check was also undertaken on October registrations. The results indicate that the high standard of data capture has been maintained.

In regard to the first aspect, the percentage of forms that had the indigenous identifiers blank or only partially completed are included Table 5.17 and 5.18.

5.17 FORMS WITH INDIGENOUS IDENTIFIERS BLANK OR PARTIALLY COMPLETED

	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Births									
Blank/partially complete (No)	181	186	166	183	259	388	450	476	446
Blank/partially complete (%)	6.0	6.0	5.3	5.0	7.7	9.9	11.1	11.4	10.5

As can be noted from the table the level initially hovered around the 5 to 6 per cent mark for the first 6 months for births with a significant increase over the July to October period where the percentages are 10% and over. This could be partially attributed to a printing error (shading problem) which was remedied quickly after the issuing of the final forms, however, this can not be quantified. These percentages will continue to be monitored closely and investigated over the next few months in an attempt to determine whether it was the shading problem or a general questionnaire design problem .

It is impossible to make assumptions on how many of these forms, that have the identifier either blank or partially complete are in respect of indigenous persons. However, irrespective of the levels, action needs be taken to increase the completion of these questions.

5.18 FORMS WITH INDIGENOUS IDENTIFIERS BLANK

	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Deaths									
Blank (No)	83	81	112	174	197	156	147	120	112
Blank (%)	7.8	8.0	9.5	11.6	13.7	7.2	6.4	5.8	5.6

For deaths, the percentages of forms with the indigenous identifier blank seem to have stabilised around the 6 to 7 per cent mark. This, as above, is of concern. Once again it is not known how many of these are of indigenous persons without further investigation. However, it does highlight the need for more promotional work to be done to ensure this field is filled in on all occasions.

Additionally, for deaths the indigenous identifier is included on the new medical certificate but is not normally used in cross checking the death information form. For October all death registration numbers were recorded, even where the indigenous identifier question on the death form was answered. The medical certificate was then checked to see if the indigenous identifier question was answered.

In summary the results were:

- ☐ 112 deaths (5.6% of all deaths) had the indigenous question blank on the death information form
- ☐ Of these, 59 (53%) had the indigenous question filled out on the medical certificate, 13 (12%) had the question blank on both and 40 (35%) were on an old medical certificate which did not have the indigenous question
- ☐ There were no cases where the medical certificate had the indigenous identifier question ticked "Yes" and left blank on the death information form
- ☐ There were actually 4 cases noted where the medical certificate said non-indigenous but the death information form said indigenous. There were also some minor differences between the recording of Aboriginal as opposed to Torres Strait Islander on both forms.

The conclusion from this exercise is that looking at the medical certificate can provide a significant amount of extra information where the indigenous identifier is left blank on the death information form. However there appears to be some question on the accuracy (e.g. where the 2 forms disagree) and also, where the extra information is obtained it normally results in the answer being non-indigenous.

The final question to be dealt with is how accurate are the answers to the indigenous identifier questions

There are now 10 months of indigenous births and deaths data available. Given that the penetration rates for the use of the interim and final forms containing the indigenous identifier questions have been over 90% for the last 4 months, this data has been used below to estimate total expected births and deaths using a straight line extrapolation method. It should be noted that this is unedited data and that although data only from the last 4 months has been used the pattern has been consistent over the whole 10 months for births but more recently, for deaths, the pattern is more volatile. This is then compared with the ABS experimental projections released earlier this year, "Experimental Projections of the Aboriginal and Torres Strait Islander Population (3231.0)".

5.19 TOTAL ESTIMATED INDIGENOUS BIRTHS

	Jul 96	Aug 96	Sep 96	Oct 96	Total
Births					
Estimated total Indigenous births	296	283	283	267	1 129
All births	4 203	4 227	4 235	4 301	16966
Estimated % Indigenous/all births	7.0	6.7	6.7	6.2	6.7

See attachment 2 for expanded details

Using table 5.19 the total estimated indigenous births for the 4 months of 1996 is 1 129. At that rate the total for the full year would be 3 387 (1129 x 3). Note this method does not take into account any seasonal factor but the effect is not considered to be overly significant for this analysis.

The projected number of Queensland births for 1996 as published in the experimental estimates (p 25 - see attachment 3) is 2 520 for the high series (the low series estimate is

2 429). Clearly the 3 387 estimate for the number of births likely to be registered in 1996 is inconsistent with the ABS experimental Indigenous estimates and projections.

Comparisons with SA, WA and NT also provide cause to question the large number of indigenous births being registered in Queensland in 1996. However it must be noted that the WA and NT experimental estimates were revised and SA is running at 109% above the estimates. (See "Measuring the coverage of Indigenous births and deaths registrations")

The above suggests that the number of indigenous births is possibly over-reported and needs further investigation. A number of factors could be involved:

☐ The registration data being analysed in this paper is unprocessed and hence is not presented on a usual residence basis. When data is presented on this basis some reduction may occur but is hard to quantify at the moment.

☐ Non-indigenous births may be registered as indigenous (e.g. South Sea Islanders reporting as indigenous). Note that this analysis is based on unedited data so there may be cases where someone has reported as indigenous and this may conflict with country of birth data - thus final results may be lower than the current counts. However it is unlikely this could account for a large part of the difference.

☐ Is it possible that the allowance for only 1 partner being of indigenous origin has been underestimated in the methodology? Attachment 4 highlights the combination of parents indigenous status for the first 6 months indigenous births data. Of note is that 41% were where the mother was indigenous and the father not and 23% were where the mother was non-indigenous but the father was indigenous. The estimation methodology for the experimental estimates assume an Australian average of 22% for non-indigenous mothers. On this basis it would seem that this is not a causal effect for any difference in the experimental estimates and projections to actual registrations.

☐ There is certainly a difference between the way the indigenous persons are identified for birth registration and in the Census and this does account for some of the difference. For births the child is determined as indigenous if either one of the parents has identified as being indigenous. However, for the Census, the person filling out the form decides whether someone is indigenous or not.

5.20 TOTAL ESTIMATED INDIGENOUS DEATHS

	Jul 96	Aug 96	Sep 96	Oct 96	Total
Deaths					
Estimated total Indigenous deaths	25	55	37	69	186
All deaths	2 370	2 352	2 093	2 022	8 837
Estimated % Indigenous/all deaths	1.1	2.3	1.8	3.4	2.1

See attachment 5 for expanded details

The total estimated indigenous deaths for the 4 months of 1996 is 186. At that rate the total for the year will reach 558 (186 x 3). Note this method does not take into account any seasonal factor but it is not considered to be overly significant for this analysis.

The results for the months of August and October show substantial increases in the number of Indigenous deaths reported. These levels are not evident in July and September, particularly in the metropolitan area. It is worth noting that the August increase followed closely the mail out of promotional material on why this information was needed whilst there is no evident reason for the dip in September and rise again in October. Another promotional exercise will be conducted for November to see whether there is any impact on reporting indigenous deaths.

The expected number of indigenous deaths (using this simple extrapolation method) for Queensland in 1996 of 558 is now comparable with the experimental estimates high series of 550, however, still substantially below the low series estimate of 650 (see attachment 3). This would give a crude death rate for Qld in 1996 of 6.7, and compares favourably with the actual 1994 and 1995 rates for SA (6.6 and 6.2); WA (7.9 and 7.6); and NT (8.1 and 7.9).

On the surface it would appear that death information is being captured fairly successfully in Queensland, however, given the fluctuation in the number of deaths registered in the last 4 months care should be taken in interpreting the results. Further close monitoring is required.

Future action proposed

Deaths

It appears possible that promotional activities increased responses to the indigenous identifier question in the month of August. This occurred directly after the issuing of the final forms and brochures. The number of indigenous deaths reported in September dropped substantially again particularly in the metropolitan area however it rose again in October. Another promotional exercise will be undertaken at the beginning of November for the metropolitan area. The Aboriginal Health Unit of the Queensland Department of Health will also send out the promotional material to its Aboriginal Health teams at the same time to see if this helps in the country areas.

As mentioned above matching of medical certificate data against the death information form for October was completed to ascertain any differences. The results of this exercise need to be looked at further to determine whether there is any benefit in capturing the medical certificate indigenous information. It would be seen that the first course of action is to increase the use of the new medical certificate of cause of death form.

It is also proposed to seek attendance at the Funeral Directors Conference in March 1997 to explain the importance of filling in the information correctly.

Future action will also certainly focus on the use of Aboriginal specific forums and Aboriginal Health teams to promote the need to obtain accurate indigenous information. Exercises such as getting lists of Aboriginal deaths and checking them against registered deaths is an option that may be pursued.

Births

There seems to be no under-reporting of the number of births , quite the opposite. Future work will primarily focus on why there are such significant differences in the projection estimates to what is really happening. 1996 Census data will certainly provide the opportunity to do this.

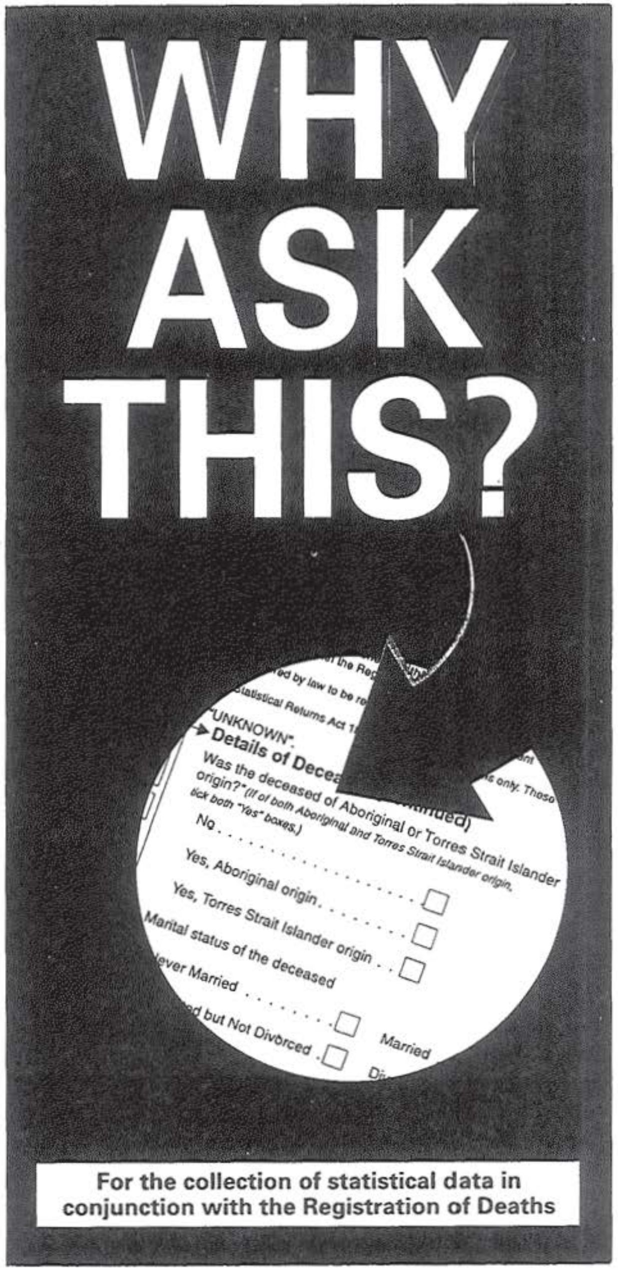
Conclusion

The introduction of the indigenous identifier questions on the birth and death registration forms must be considered a relatively successful exercise. There is obviously still work to be done but there are positive signs that the data is of acceptable quality.

The success has certainly been attained through the extreme co-operation of those involved on the working party. The model used is one we think that all data collectors should adopt when trying to collect indigenous information.

Finally I would like to acknowledge the work done by Sharon Spence (GSO) and Greg McNamara (ABS) over the last 10 months in extracting and reporting on the information contained in this report. Their work has been a valuable contribution to the success of this exercise.

ATTACHMENT 1



WHY ASK THIS?

"UNKNOWN".
Details of Decea
Was the deceased of Aboriginal or Torres Strait Islander origin?" (If of both Aboriginal and Torres Strait Islander origin, tick both "Yes" boxes.)
No . . . . ☐
Yes, Aboriginal origin . . . . ☐
Yes, Torres Strait Islander origin . . ☐
Marital status of the deceased

For the collection of statistical data in conjunction with the Registration of Deaths

Who needs to ask the question?

The question needs to be asked by those involved in the registration process. This will include undertakers and hospital staff, amongst others.

What if the next of kin is too upset to be asked?

This question (together with any other outstanding questions) should be followed up with the person(s) providing registration details as soon as is practical.

How should the question be asked?

All individuals providing registration details should be asked whether the deceased was of Aboriginal or Torres Strait Islander origin. The origin of the deceased is shown by a tick in the appropriate box (or boxes) -

No -	indicates the person was not of Aboriginal or Torres Strait Islander origin, or
Yes -	Aboriginal origin, or
Yes -	Torres Strait Islander origin, or
Yes -	ticks in both boxes, if the person was of both Aboriginal and Torres Strait Islander origin.

What if the person wants to know why the question is being asked?

Explain
that the information is collected for statistical purposes only. Information on Aboriginality will not be included in any official registration document.

Explain
that the information will be used to improve the health and thus life expectancy of Aboriginal and Torres Strait Islander people and will allow accurate estimates to be made of the numbers of Aboriginal and Torres Strait Islander people in Queensland.

Explain
that it is not possible to be certain if a person is of Aboriginal or Torres Strait Islander origin unless this question is actually asked.

For further information, contact

the Aboriginal and Torres Strait Islander Regional Health Coordinator at your local hospital or the Aboriginal and Torres Strait Islander Health Policy Branch, Queensland Health, on (07) 3234 0765.

QUEENSLAND GOVERNMENT

Is the person of Aboriginal or Torres Strait Islander Origin?

From 1 January 1996, Queensland introduced the collection of a statistical indicator of Aboriginal and Torres Strait Islander origin on birth and death registration forms. This allows, for the first time, an accurate means of producing birth and death statistics for Aboriginal and Torres Strait Islander people both in Queensland and nationally.

Why is this information needed?

This information is needed for a number of reasons. Currently, counts of Aboriginal and Torres Strait Islander people are available from the Census of Population and Housing which is conducted every five years. In the intervening periods, it has not been possible to accurately estimate the Aboriginal and Torres Strait Islander population, due to the lack of information concerning the birth and death rates amongst this group.

The collection of birth and death statistics for Aboriginal and Torres Strait Islander people will improve policy formulation and service delivery to all Queenslanders. It will also allow programs designed to address the needs of specific groups to be better targeted. In addition, forecasts can be prepared to plan services for these groups into the future.

Throughout Australia, the health of Aboriginal and Torres Strait Islander people is of a lower standard than the health of the general community. The life expectancy of Aboriginal and Torres Strait Islander people is some twenty years less than for other groups of Australians. This information needs to be available to ensure that appropriate action is taken to improve the health and thus life expectancy of this group of Queenslanders.

The availability of this information will also allow a more valid comparison to be made of relative local and State situations, in terms of both the general health of the population and funding requirements.

Who asked for this information to be collected?

The request to collect Aboriginal and Torres Strait Islander details with birth and death registrations has come from -

- Aboriginal and Torres Strait Islander groups,
- medical researchers, and
- government decision-makers (both State and Federal).

Is it discriminatory to be asking this question?

No. This information is being gathered for statistical purposes to improve the health of the Aboriginal and Torres Strait Islander community. Gathering this information will also allow accurate estimates to made of the number of Aboriginal and Torres Strait Islander people in Queensland now and in the future.

It could be regarded as being discriminatory to **not** ask this question as important information would not be available for decision-makers.

How is an Aboriginal or Torres Strait Islander person identified?

The official definition of an Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander origin who identifies as being Aboriginal or Torres Strait Islander and who is accepted as such by the community with which the person associates.

The important point is that the person must have identified themselves as being an Aboriginal or Torres Strait Islander, or be identified by their next of kin or other relevant person providing the registration details.

It is not possible for others to be certain whether a person is an Aboriginal or Torres Strait Islander unless this question is actually asked.

When is the question to be asked?

The question determining whether the deceased was of Aboriginal or Torres Strait Islander origin needs to be asked every time a death is registered to ensure that the opportunity is provided for the deceased to be correctly identified as an Aboriginal or Torres Strait Islander.

ATTACHMENT 2

5.21 ESTIMATED INDIGENOUS BIRTHS

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Births										
Metropolitan										
Indigenous Births Registered	17	44	46	37	56	64	65	58	65	69
% use of Interim/final forms	32.5	75.1	77.9	88.5	88.7	92.9	95.2	97.6	98.7	99.2
Estimated Indigenous Births (a)	52	59	59	42	63	69	68	59	66	70
All Births Registered	2 500	2 133	2 075	1 823	2 075	1 833	2 098	2 022	2 118	2 116
Estimated % of Indigenous/All Births	2.1	2.7	2.8	2.3	3.0	3.8	3.3	2.9	3.1	3.3
Country										
Indigenous Registered Births	38	118	153	142	199	192	209	211	213	195
% use of interim/final forms	20.9	58.3	74.6	78.4	79.8	82.3	91.5	94.0	98.3	99.1
Estimated Indigenous Births (a)	182	202	205	181	249	233	228	224	217	197
All Births Registered	2 500	2 445	2 017	1 901	2 289	2 021	2 105	2 205	2 117	2 185
Estimated % of Indigenous/All Births	7.3	8.3	10.2	9.5	10.9	11.5	10.9	10.2	10.2	9.0
Total										
Estimated Total Indigenous Births	234	261	264	223	312	302	296	283	283	267
All Births Registered	5 000	4 578	4 092	3 724	4 364	3 854	4 203	4 227	4 235	4 301
Estimated % of Indigenous/All Births	4.7	5.7	6.5	6.0	7.1	7.8	7.0	6.7	6.7	6.2

ATTACHMENT 3

5.22

EXPERIMENTAL PROJECTIONS OF THE ABORIGINAL AND TORRES STRAIT ISLANDER POPULATION, COMPONENTS OF POPULATION CHANGE, QUEENSLAND

Component of population change	*At 30 June* 1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
High Series										
Population	76 088	78019	80002	82028	84089	86 184	88318	90 494	92 712	94968
Births	2 334	2 389	2 442	2 486	2 520	2 556	2 597	2 641	2 685	2 726
Deaths	550	548	549	550	550	551	552	553	556	558
Natural Increase	1 784	1841	1 893	1 936	1 970	2 005	2 045	2 088	2 129	2 168
Net migration	90	90	90	90	90	90	90	90	90	90
Total Increase	1 874	1 931	1 983	2 026	2 060	2 095	2 135	2 178	2 219	2 258
Growth rate (%)	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.4
Medium series										
Population	76 060	77952	79887	81 860	83857	85 876	87926	90009	92 125	94 267
Births	2 334	2 389	2 441	2 485	2 520	2 553	2 594	2 637	2 680	2 719
Deaths	578	587	595	604	613	623	634	644	655	667
Natural increase	1 756	1 802	1 846	1 881	1 907	1 930	1 960	1 993	2 025	2 052
Net migration	90	90	90	90	90	90	90	90	90	90
Total increase	1 846	1 892	1 936	1 971	1 997	2 020	2 050	2 083	2 115	2 142
Growth rate (%)	2.5	2.5	2.5	2.5	2.4	2.4	2.4	2.4	2.3	2.3
Low series										
Population	76041	77 889	79 754	81 626	83 494	85 360	87 227	89097	90967	92 835
Births	2 324	2 359	2 392	2 415	2 429	2 443	2 462	2 483	2 502	2 519
Deaths	585	601	617	632	650	666	684	702	722	741
Natural Increase	1 739	1 758	1 775	1 783	1 779	1 777	1 778	1 781	1 780	1 778
Net migration	90	90	90	90	90	90	90	90	90	90
Total increase	1 829	1 848	1 865	1 873	1 869	1 867	1 868	1871	1870	1 868
Growth rate (%)	2.5	2.4	2.4	2.3	2.3	2.2	2.2	2.1	2.1	2.1

Source: ABS - 'Experimental Projections of the Aboriginal and Torres Strait Islander Population', 1991-2001, (Catalogue No. 3231.0).

ATTACHMENT 4

5.23 NUMBER OF INDIGENOUS BIRTHS REGISTERED IN QUEENSLAND

	Indigenous status of mother				
Indigenous status of father	Non-Indigenous	Aboriginal	Torres Strait Islander	Both	Total
Non-Indigenous	0	366	79	25	470
Aboriginal	212	237	12	12	473
Torres Strait Islander	36	22	88	4	150
Both	20	12	9	9	50
Total	268	637	188	50	1,143

Based on early data received during the first 6 months of the Indigenous data collection.

5.24 PROPORTION OF INDIGENOUS BIRTHS

	Indigenous status of mother				
Indigenous status of father	Non-Indigenous	Aboriginal	Torres Strait Islander	Both	Total
Non-Indigenous	0	32	7	2	41
Aboriginal	19	21	1	1	41
Torres Strait Islander	3	2	8	0	13
Both	2	1	1	1	4
Total	23	56	16	4	100

Based on early data received during the first 6 months of the Indigenous data collection.

ATTACHMENT 5

5.25 ESTIMATED INDIGENOUS DEATHS

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Deaths										
Metropolitan										
Indigenous Deaths Registered	1	6	3	4	4	5	7	16	5	19
% use of interim/final forms	55.1	66.8	79.0	85.0	88.0	89.7	95.5	98.4	98.2	98.7
Estimated Indigenous Deaths (a)	2	9	4	5	5	6	7	16	5	19
All Deaths Registered	750	1 021	881	918	1 029	925	1279	1 205	1 091	1 101
Estimated % of Indigenous/All Deaths	0.3	0.9	0.5	0.5	0.5	0.6	0.5	1.3	0.5	1.7
Country										
Indigenous Registered Deaths	1	9	13	19	18	14	16	38	31	50
% use of Interim/final forms	18.5	41.2	42.1	57.4	58.8	72.7	86.8	97.3	98.3	99.1
Estimated Indigenous Deaths (a)	5	22	31	33	31	19	18	39	32	50
All Deaths Registered	750	915	751	692	1 021	841	1 091	1 147	1 002	921
Estimated % of Indigenous/All Deaths	0.7	2.4	4.1	4.8	3.0	2.3	1.7	3.4	3.1	5.4
Total										
Estimated Total Indigenous Deaths	7	31	35	38	36	25	25	55	37	69
All Deaths Registered	1 500	1 936	1 632	1 610	2 050	1 766	2 370	2 352	2 093	2 022
Estimated % of Indigenous/All Deaths	0.5	1.6	2.1	2.3	1.8	1.4	1.1	2.3	1.8	3.4

APPENDIX 1 - WORKSHOP AGENDA

WORKSHOP AGENDA

Workshop:	On the identification of Indigenous people in administrative data collections, used by Australian governments.
Venue:	Queensland ABS State Office, 313 Adelaide Street, Brisbane, 21st Floor, training room.
Date:	26 - 27 November 1996.

DAY 1 - TUESDAY 26TH NOVEMBER 1996

9.00am	<u>Session 1: Opening addresses</u> Welcome by Brian Doyle, Regional Director - Qld ABS office. Introduction to the workshop by Sol Bellear, Heads of Aboriginal Health Unit Representative. Key note address by National Aboriginal Community Controlled Health Organisations Representative. Overview by Dr Richard Madden, Director of Australian Institute of Health and Welfare.
9.30 am	<u>Session 2: Reports from State and Territory Registrars General</u> Summary reports by representatives from each State and Territory. Representatives from Registrar General's Offices.
10.45 am	<u>Session 3: Reports from State and Territory Health Departments</u> Summary reports by representatives from each State and Territory. Representatives from Health Departments.
1.30 pm	<u>Session 4: Data collection issues</u> "Indigenous people in government statistics - current ABS standard." Presented by Tony Barnes and Tammy White, National Centre for Aboriginal and Torres Strait Islander Statistics, ABS. "The 3R's: lessons learned down south about promoting good practice in recording Aboriginality of persons admitted to hospital." Presented by Dr Sarah Berg - Koorie Health Unit, Department Health & Community Services, Victoria. Representative from the Australian Medical Association - Steve Larkin. Representative from the Australian Funeral Directors Association - Graham Crawley.

2.30 pm Break up into small groups for discussions on the best practice on Indigenous identification in the following areas:

- Death Certificates
- Hospital separations
- Other Health & Welfare
- Other.

4.00pm Report back.

Each group to report back to main group on outcomes of small group discussions.

DAY 2 - WEDNESDAY 27TH NOVEMBER 1996

9.00 am Session 5: Assessing completeness and quality of identification

"Assessing the completeness and quality of Indigenous identification in administrative data collections." Presented by Barbara Gray, Aboriginal and Torres Strait Islander Health & Welfare Information Unit, ABS.

"Measuring the coverage of Indigenous births and deaths registrations." Presented by Mal Greig on behalf of Demography Section, ABS.

"Indigenous identification in maternal and child health research in Western Australia." Presented by Dr Anne Read of the Institute of Child Health Research.

"Problems in the recording of Indigenous identity on hospital records at selected hospitals in Brisbane and Cairns." Presented by Cindy Shannon, University of Queensland.

"How midwives identify women as Aboriginal or Torres Strait Islanders." Presented by Helen Robertson, Department and Community Services, Vic.

10.45 am Small group discussion on monitoring completeness.

1.30 pm Developing best practice guidelines - Resolutions and Recommendations. Facilitated by Geoff Sims, AIHW.

"Collection of a statistical indicator of Aboriginal and Torres Strait origin on birth and death registration forms - The recent experience of Queensland." Presented by Malcolm Greig of population and Social Branch, ABS, Qld.

Review of work and discussions to date.

Where to from here?

5.00 pm Close of workshop.

APPENDIX 2 - WORKSHOP PARTICIPANTS ...

LIST OF WORKSHOP PARTICIPANTS

Participants	Organisation and Address
AUSTRALIAN BUREAU OF STATISTICS	
Tony Barnes Tammy White Barbara Gray Chris Davis Jennifer Isaacs	National Centre for Aboriginal and Torres Strait Islander Statistics Australian Bureau of Statistics G.P.O. Box 3796 Darwin, NT, 0801 T:(08) 89432190 F:(08) 89410715
Brian Doyle John Alexander Mal Greig David Jayne Greg McNamara Colleen Hill	Australian Bureau of Statistics G.P.O. Box 9817 Brisbane, QLD, 4001 T: (07) - 32226047 F: (07) - 32226038
Keith Churchill	Australian Bureau of Statistics G.P.O. Box 66a Hobart, TAS, 7001 T: (002) - 205832 F: (002) - 205824
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Geoff Dane	Australian Bureau of Statistics G.P.O. Box 3796 Darwin, NT, 0801 T: (08) 89432150 F: (08) 89410715
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Dalma Jacobs	Australian Bureau of Statistics 9th Floor FAI House Cnr London Cct & Akuna Street Civic, ACT, 2601 T: (06) 2070283 F: (06) 2070282

Participants	Organisation and Address
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Murray Klee Tanya Naeher	Education and Training Section Australian Bureau of Statistics Cameron Offices, Chandler Street Belconnen, ACT, 2616 T: (06) 2526751 F: (06) 2515486
STATE AND TERRITORY HEALTH DEPARTMENTS	
Peta Williams	Western Australian Health Office of Aboriginal Health G.P.O. Box 8172 Sterling Street Perth, WA, 6849 T: (09) 2224222 F: (09) 2224113
Ian Ring Sandra Martyn	Epidemiology & Health Information Branch Queensland Department of Health G.P.O. Box 48 Brisbane, QLD, 4000 T: (07) 32340929 F: (07) 32341529
Greg Curly Angela Todd Juanita Sherwood	Aboriginal Health Branch Information and Data Services NSW Health Department LMB 961 North Sydney, NSW, 2059 T: (02) 93919367 F: (02) 93919015
John O'Brien Vicki-Lee Knowles	S.A. Health Commission G.P.O. Box 65 Rundle Mall, SA, 5000 T: (08) 82266123 F: (08) 82266081
Marita Hargreaves	Information Management Department of Community and Health Services G.P.O. Box 1258 Hobart,TAS, 7001 T: (03) 62332483 F: (03) 62332899
Sarah Berg	Medical Officer Koori Health Unit Department of Human Services 555 Collins Street Melbourne, VIC, 3001 T: (03) 96167895 F: (03) 96168383

Participants	Organisation and Address
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Norma Briscoe	ACT Department of Health G.P.O Box 825 Canberra, ACT, 2601 T: (06) 2050917 F: (06) 2050866
REGISTRARS BIRTHS, DEATHS AND MARRIAGES	
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Trevor Stacey Margaret Kean	Registrar Registry of Birth, Deaths and Marriages 191 Thomas Street Haymarket, NSW, 2000 T: (02) 92438555 F: (02) 92438640
Ian Bowler	Registrations Manager Registry of Births Deaths and Marriages G.P.O. Box 4332 Melbourne, VIC, 3001 T: (03) 96035874 F: (03) 96706635
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John Jameson	Registrar General Registrar General's Division Justice Department G.P.O Box 198 Hobart, TAS, 7001 T: (03) 62333793 F: (03) 62240743
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Steve Larkin	Australian Medical Association G.P.O. Box E115 Queen Victoria Tce Parkes, ACT, 2600 T: (06) 2705479 F: (06) 2705499

Participants	Organisation and Address
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Graham Crawley	General Manager Queensland Operations Australian Funerals Pty Ltd 224 Newham Road Mount Gravatt, QLD, 4122 T: (07) 33499520
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