Australian Health Ministers' Advisory Council

AIHW

The Aboriginal and Torres Strait Islander Health Information Plan

...This time, let's make it happen

A report prepared for Australian Health Ministers' Advisory Council by the Aboriginal and Torres Strait Islander Health and Welfare Information Unit, a joint program of the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

October 1997

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FOREWORD

In 1994 the Australian Health Ministers' Advisory Council (AHMAC) endorsed the recommendation of the national body responsible for national health information, that the highest national priority was to:

> *"Work with Aboriginal and Torres Strait Islander peoples to develop a plan to improve all aspects of information about their health and health services."*

Funds were provided to implement that recommendation and develop a plan.

After extensive consultation, particularly with Aboriginal and Torres Strait Islander people, their communities and organisations, this report : *"This time, let's make it happen"* was presented to AHMAC in October 1997. AHMAC has agreed to the recommendations of this Report and asked the National Health Information Management Group to oversee the implementation. As much of the implementation will be in the hands of the individual governments and their health authorities, the Management Group has set up an implementation group including Indigenous health organisations and stakeholders to manage the process.

Australian Health Ministers have agreed to the publication of this Report.

"This time, let's make it happen" describes the shortcomings in the current collection, processing and use of Indigenous health information. The major deficiency is the poor quality of Indigenous identification in administrative data collections. As the Report notes, there is little new in its findings or recommendations; most have been the subject of previous reviews. The Report identifies lack of commitment and effective flow-through as the most important reasons for the lack of improvement following earlier reports. Recommendations therefore stress that effective implementation relies on building and maintaining commitment among the key agencies and groups. The implementation group recognises this as its major task.

Implementation will require persistence and commitment for all the major players. A number of the solutions call for changes in attitudes as well as collection of better information. Members of AHMAC have expressed their determination to achieve the proposed improvements in Aboriginal and Torres Strait Islander health information and will seek to implement the recommendations through the mainstream health information systems and collections.

In releasing this report, AHMAC calls for a cooperative effort from the many organisations, interests and people concerned, especially those in the Australian health system.

David Butt
CHAIR, AHMAC

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List of Abbreviations

AEDP	Aboriginal Employment Development Program
ABS	Australian Bureau of Statistics
AHLO	Aboriginal Hospital Liaison Officer
AHMAC	Australian Health Ministers' Advisory Council
AHRC	Aboriginal Health Resource Co-operative
AIHW	Australian Institute of Health and Welfare
ALO	Aboriginal Liaison Officer
AMS	Aboriginal Medical Service(s)
ATSIC	Aboriginal and Torres Strait Islander Commission
ATSIHWIU	Aboriginal & Torres Strait Islander Health and Welfare Information Unit
CEP	Community Employment Program
COAG	Council of Australian Governments
HAHU	Heads of Aboriginal Health Units (Commonwealth & State health)
HCINS	Housing and Community Infrastructure Needs Survey
KAMSC	Kimberley Aboriginal Medical Services Council
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Survey
NATSIS	National Aboriginal and Torres Strait Islander Survey
NCATSIS	National Centre for Aboriginal and Torres Strait Islander Statistics
NHDD	National Health Data Dictionary
NHIMG	National Health Information Management Group
NHMRC	National Health and Medical Research Council
NHS	National Health Survey
OATSIHS	Office of Aboriginal and Torres Strait Islander Health Services
SAHC	South Australian Health Commission
VACCHO	Victorian Aboriginal Community Controlled Health Organisation

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Many people have contributed to this review of Indigenous health information and the subsequent development of recommendations and a National Aboriginal and Torres Strait Islander Health Information Plan.

The authors are indebted to the many individuals who participated in the development of this plan in a variety of ways – through opening up their agencies to visits from project staff and consultants, their attendance and valuable contributions at consultative seminars and meetings, and in reading and commenting on draft reports and recommendations. This is your report – you provided much of its content through your thoughtful and timely suggestions, advice and critique.

Thanks are also due to the project consultants, Ali Nur and Jennie Lyons, for undertaking the national consultations and drawing together the research findings into consolidated reports and recommendations. Other key individuals include Tony Barnes, for his timely direction, support and additional research, and Robyn James, who assisted with editing on several chapters.

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Lastly, the authors are grateful to the members of the Australian Health Ministers' Advisory Council (AHMAC), who had the foresight and direction to commission this work, without which there would still be no National Aboriginal and Torres Strait Islander Health Information Plan.

Executive Summary

Background

The need to improve the quality of Indigenous health information was identified as the major national priority in the 1994 National Health Information Development Plan. Funds were made available by Australian Health Ministers' Advisory Council (AHMAC) to the Australian Institute of Health and Welfare (AIHW) to undertake the development of a national Indigenous health information plan. The Aboriginal and Torres Strait Islander Health and Welfare Information Unit (ATSIHWIU - a joint initiative of the AIHW and the Australian Bureau of Statistics) has managed the project on behalf of AIHW and AHMAC. The project is overseen by the ATSIHWIU Advisory Group.

Project methodology

The project was undertaken in two phases. The first phase, beginning in mid-1996, involved project planning and a national consultation involving visits to all states and territories, in order to prepare a series of individual state and territory reports on current activities and issues. All Aboriginal Medical Services and related organisations in each state were written to at this time, and invited to participate in the project. Consultative meetings were subsequently held with all Commonwealth, state and territory health departments, relevant national organisations, and also with approximately 30 Aboriginal medical services and organisations across most states and territories. Draft reports on the outcomes of these consultations, with discussion on the range of collections in each jurisdiction and their relevance for Indigenous health information, were prepared, and subsequently returned to the agencies consulted for comment and amendment

The second phase of the review involved the preparation of two reports – a draft summary report (upon which a further round of national consultation occurred) and a final report. This phase included identifying case studies which represent innovative or effective practices across Indigenous health information interests. These case studies are presented throughout this report, and are drawn upon to illustrate relevant discussion points.

The draft summary report was released for widespread national consultation in May 1997.
A series of state consultations was conducted in almost all states and territories with a range of national and state/territory government and community interests (with consultations in Tasmania yet to be finalised). State and territory health authorities, sometimes in conjunction with state National Aboriginal Community Controlled Health Organisation (NACCHO) affiliated agencies and representatives, were actively involved in the organisation and preparation of the fourteen state seminars and meetings. The purpose of the second round of consultation was to discuss the project's findings and preliminary recommendations, and to provide an opportunity for stakeholders to consider the application of the recommendations and any implications for them or their agencies. A primary aim of this consultation phase was to seek consensus amongst all interest groups about the actions needed to improve the quality of Indigenous health information, prior to finalising the report and presenting it to AHMAC. Over 300 participants attended these meetings. Additionally, consultative meetings were held with the National Health Information Management Group and the NACCHO Executive. Written submissions were also received from 15 organisations and individuals.

The review findings

Gaps in data about the health of Aboriginal and Torres Strait Islander Peoples

Some of the most relevant statistics about the health and welfare of Aboriginal and Torres Strait Islander peoples are not reported at all, or are inadequately reported. For instance, mortality is not adequately reported for two thirds of the Indigenous population, that is for those Indigenous peoples who live in the eastern states of Australia, particularly Queensland, New South Wales, Victoria, and Tasmania. Because of this, there is a tendency for data from other jurisdictions (namely Western Australia, South Australia and the Northern Territory) to be used as proxies for making generalisations about Indigenous health issues across the country. The significant potential for this to mask differing population characteristics, needs and services utilisation patterns means that it is no longer appropriate or acceptable to use data from these states in this way.

Further, the reporting on morbidity issues relies heavily on hospital separations data which have generally not been assessed for the completeness of recording of Indigenous status. The capacity of Commonwealth, state and territory governments to report on issues such as the health status, service use and access to services by Indigenous peoples is totally reliant on one factor – being able to accurately identify Indigenous clients. Without accurate identification of Indigenous status, there is little capacity to monitor changes in health status, make comparisons between Indigenous and non-Indigenous Australians, evaluate access to services and the responsiveness of health services to addressing needs, or to quantify the resources expended on health services for Indigenous peoples.

Limitations of current efforts in Indigenous health information

The process undertaken to develop this report has identified numerous shortcomings in the current information collection systems, and as well as the processing and use of resulting statistics – all of which undermine Australia's capacity to accurately capture and report on Indigenous health information. In particular, the quality of Indigenous identification in most collections at all levels and agencies needs to be significantly improved if they are expected to meet the recommendations of the National Aboriginal Health Strategy.

Over and above the limitations identified below, the most significant finding from this review is that Australian jurisdictions have known – for many years – the factors affecting the quality of Indigenous information and the actions needed to address these limitations. Indeed, these can be found in an array of government reviews, reports, recommendations and national workshops. The missing component in all of these has been the lack of commitment and follow-through to implement the recommendations. Thus, little of what follows below and in the main body of this report is new – much has been heard and recommended before. What is new this time around is a suggested process for building and maintaining commitment to, and an emphasis, on action amongst the key agencies – at all levels of government and community interest.

The other major limitations affecting Australia's capacity to collect good quality information about, and report on, Indigenous health include:

- ***Poor and uncertain levels of identification of Indigenous peoples in existing collections,*** including vital statistics (particularly death data), hospital separations, perinatal collections, and community health collections. The reasons for this are two-fold – there appears to be both a reluctance by (or lack of awareness of the need for) clients to self-identify their Indigenous status, as well as of clinical and administrative staff to seek information about Indigenous status. Additionally, the degree of incompleteness of identification is largely untested and, therefore, unknown in most collections.

- ***Inconsistent use of classification standards and collection protocols*** – both across and within jurisdictions. There is a general lack of awareness or use of existing standard definitions across health services collections. This severely limits the capacity to make comparative assessments. The current coding procedures in most collections do not adequately capture Indigenous status information, with some collections containing no capacity for Indigenous identification at all. Additionally, the procedures used by front line staff to capture identifying information often deliberately overlook any requirements to ask all clients about Indigenous status (where these exist), with many staff choosing to make assumptions about race on the basis of local knowledge or the presenting client's appearance.

- ***Limited systemic efforts towards validation of data and quality control mechanisms*** – without testing the level of under-recording of Indigenous status in a data set, no corrections can be made to remove bias from the resulting statistics.

- ***A general lack of guidelines or protocols concerning the ownership, usage and confidentiality of data***, for the exchange of information between Indigenous communities and health services and other agencies.

- ***Little attention to the information needs of Indigenous communities*** – there was a widespread perception amongst many Indigenous communities and health agencies that data and information provided to funding bodies, governments and researchers were:
  - ⇒ not fed back to communities (at all, let alone in culturally appropriate ways);
  - ⇒ not used at all (this appears to hold some truth, particular in terms of grant-related information provided to government funding agencies); and
  - ⇒ that requests for information are not co-ordinated (thereby imposing a considerable burden on already-stretched community resources).

- ***A general dearth of appropriate information management skills*** amongst community health staff in both mainstream and community-controlled services. In some instances, the information system was dependent upon the skills and goodwill of an individual who, at some time in the past (or present) held a position of authority in the local health service or clinic, and who had a personal interest in information technology – but the systems initiated by such individuals were often not maintained after the individual moved on. This common situation is neither reliable nor sustainable. Significant, co-ordinated and sustained investment by governments in the development of skills and capital equipment may be required in order to effect systemic improvement in this area.

- ***A generally poor willingness and few mechanisms to share relevant data*** between levels in the system, and also between similar agencies at the same level – as well as no rewards for doing so.

- ***Little evidence of an 'information culture'*** within community health services in general, and in Indigenous health in particular.

- ***Apparently little appreciation (with some notable exceptions) amongst communities and services of the potential power that information has*** – and how it can be used to effect change, generate resources, support advocacy, and generally make things happen. Importantly, there also seems to be few structures or mechanisms in place to support communities to use information in such ways.

Issues arising from consultation on the draft recommendations

Issues raised unanimously across many of the state and territory seminars, and which were of particular concern to Indigenous community interests, included the need for safeguards against the potential misuse of information, and the need to support communities and services at the local level to collect and use information for their own needs. Participants generally recognised and supported the need for accurate data about Indigenous people, but there appeared to be an undercurrent of concern that such information could be used against Indigenous people and their agencies (indeed, past examples were readily provided).

Therefore, first and foremost was a call for protocols to be developed and agreed to amongst all parties for the appropriate use of information about Indigenous people.

Secondly, participants urged that the future emphasis must be on supporting the development of good quality local information, for use at the local community level, but which is of sufficient quality to allow use and reporting at state and national levels – again, with the provisos that due attention and care is accorded to guarding against the potential misuse of data, that protocols are developed and observed, and that there is appropriate feedback of information to the source communities.

Thus, the recommendations in this final report have been revised to reflect this emphasis. The recommendations as outlined below in the National Aboriginal and Torres Strait Islander Health Information Plan (and detailed in Part 5 of this report), are within two main categories – to ***develop a supportive infrastructure***, as well as attending to ***technical improvements*** in information collection and reporting.

A third set of recommendations relates to the need to ensure that processes exist to facilitate ongoing ***national co-ordination, commitment and review of efforts*** to improve Indigenous health information. Poor national commitment and follow-through of recommendations has been the key factor hampering past efforts to improve Indigenous health information.

National Aboriginal & Torres Strait Islander Health Information Plan

GOALS & OBJECTIVES	MAJOR STRATEGIES	RESPONSIBILITY FOR ACTION	MONITORING PERFORMANCE
GOAL 1: DEVELOP A SUPPORTIVE BASE AND INFRASTRUCTURE FOR IMPROVING INDIGENOUS HEALTH INFORMATION			
1.1 **Address issues concerning the ethics, ownership and use of data about Indigenous peoples**	Develop national and locally-specific protocols for the sensitive handling of data concerning Indigenous peoples, with the active involvement of communities, and addressing, as a minimum: ➢ ownership of data ➢ the appropriate use and handling of data (including who has access, and under what circumstances) ➢ principles and mechanisms for returning information to communities promptly and in culturally appropriate ways	The National Health Information Management Group to commission and oversee work to develop national protocols for handling of Indigenous-related data by government agencies The work must be undertaken as a partnership approach, with the active involvement of NACCHO, HAHU and ATSIHWIU Advisory Group, in the context of the Framework Agreements where these exist	A formal process to develop national protocols commenced by 1 July 1998 National protocols developed and ratified by relevant Commonwealth, state and territory government agencies and NACCHO by 30 June 1999 State and locally-specific protocols, based on the national protocols, to be developed and ratified by 31 December 1999
1.2 **Develop and support information management skills and processes in community health services and hospitals (an 'information culture')**	Build and continue to support the capacity of communities to collect and use local information for local needs, including attention to: ➢ training, materials, capital equipment and software, central advisory support ➢ mechanisms for joint local planning and service delivery amongst services ➢ promotion of training in the use and application of information to support local needs in planning and monitoring	All government health agencies which expect community health services, hospitals and AMSs to provide regular information about their services and clients are to ensure that such facilities have the necessary staff skills base, equipment and ongoing support with which to fulfil these functions Such an initiative may warrant targeted developmental support under the proposed national/state cost-shared program (Refer 3.1)	Commonwealth, state and territory health authorities to report on activities in this area in conjunction with annual performance reporting on Indigenous health information to AHMAC

1.3 **Promote information dissemination and communication**	1) Develop and implement procedures to ensure that locally relevant information and research findings are returned to Indigenous communities promptly and in ways which communities find useful 2) Develop campaigns, resource materials and initiate other strategies to promote the importance of collecting accurate data about Indigenous peoples amongst: ➢ health agencies ➢ non-health information collectors ➢ Indigenous communities	Governments and health agencies at all levels are responsible for implementing this strategy in their jurisdictions Funding agencies to ensure that contractual agreements with researchers reflect requirements to promptly return information collected from Indigenous communities National and state promotional activities may be supported under the proposed national/state cost-shared program (Refer 3.1)	Commonwealth, state and territory health authorities to report on activities in this area in conjunction with annual performance reporting on Indigenous health information to AHMAC
1.4 **Develop a strong and supported Indigenous workforce to facilitate improvements in the coverage and quality of Indigenous health information**	1) Establish permanent and long-term positions for Indigenous personnel, to facilitate substantial improvements in the quality of Indigenous health and related information, including, as a minimum: ➢ Hospital-based Indigenous officers who are able to deal with Indigenous issues across all levels of care, including understanding and improving information; ➢ Sufficient permanent Indigenous staff located in state and territory offices of the ABS, to promote willingness to identify amongst Indigenous people and to facilitate community co-operation with Census and other surveys 2) Provide ongoing training, resources and support for Aboriginal Medical Services staff in the collection, analysis, application and reporting of information about health issues in their communities	State and territory health authorities, area health authorities and hospitals to recruit and train Indigenous officers to facilitate links between local communities and the hospital and for enhancing information quality Australian Bureau of Statistics to provide permanent employment opportunities and training of Indigenous staff to work with local Indigenous communities on Census and other surveys affecting Indigenous communities All jurisdictions to initiate workforce development programs for AMS and other staff in handling data about Indigenous peoples	All hospitals with an Indigenous catchment population in the order of 500 persons to aim to have in place by December 1998 an officer with responsibility for facilitating links between local communities and the hospital and for enhancing information quality The Australian Bureau of Statistics to have Indigenous persons appointed to Census and related survey positions in all state and territory offices at least six months before the 2001 Census Commonwealth, state and territory health authorities to report on activities in this area in conjunction with annual performance reporting on Indigenous health information to AHMAC

GOALS & OBJECTIVES	MAJOR STRATEGIES	RESPONSIBILITY FOR ACTION	MONITORING PERFORMANCE
GOAL 2: IMPROVE THE TECHNICAL ASPECTS REQUIRED TO FACILITATE QUALITY INDIGENOUS HEALTH INFORMATION			
***2.1* Improve the capacity of major health and related data collections to separately identify Indigenous persons**	*1)* Major health and related collections in all jurisdictions to be able to separately identify Indigenous persons, and have appropriate quality control checks and reporting processes in place *2)* All major collections to use common identification classifications and collection protocols, including: ➢ adoption of a common classification standard, as incorporated in National Health Data Dictionary ➢ processes to ensure the mandatory seeking of information about the Indigenous status of clients (i.e. all clients should be given the opportunity to self-identify as Indigenous if they so choose, rather than having service staff make assumptions on the basis of clients' appearance) ➢ development and promotion of less-threatening (for staff and clients) strategies for seeking information ➢ widespread promotion of the need for improved Indigenous identification in data collections amongst health services, information collectors, and Indigenous communities	All jurisdictions to initiate and/or facilitate continued action to improve the coverage and quality of information about Indigenous persons in major data collections – specifically Registrars responsible for collecting Indigenous vitals statistics, and Health Departments and community controlled organisations for collecting other health data ATSIHWIU to facilitate support and sharing of 'best practice' information amongst jurisdictions ABS to lead and report on efforts towards complete identification in vitals data collected by Registrars, with the Regional Directors to take a close personal interest in improving the quality of vital statistics data in their respective states and territories AIHW to lead and report on efforts towards complete identification in hospital, perinatal and other health services collections	All vital statistics collections to correctly identify 90% of expected Indigenous births and deaths by 31 December 1999 All states and territories to have derived an estimate of the completeness of the Indigenous information in their perinatal collections by 31 December 1998, and in their hospital separations data sets by 31 December 1999 Commonwealth, state and territory health authorities to report on activities in this area in conjunction with annual performance reporting on Indigenous health information to AHMAC
***2.2* Establish and, if necessary, improve the quality of the population estimates of Indigenous persons**	1)Review the suitability of definitions used and estimates for deriving Indigenous statistics 2)Undertake regular assessments of the quality of population estimates, including: ➢ establishing accurate baseline estimations ➢ researching differences, and the reasons for such differences, between ABS Census counts and community perceptions ➢ estimates of the Torres Strait Islander population	The Australian Bureau of Statistics and the Australian Institute of Health and Welfare to take responsibility for activities in this area, with appropriate advice and support from state and territory agencies and Indigenous communities and their representatives	Report on review by December 1998 Estimations of Indigenous population by 2001 predicted with accuracy in preceding years Torres Strait Islander population estimates by 31 December 2000

2.3 **Foster long-term commitment to major special purpose collections to obtain essential information unable to be obtained from administrative data sources**	As far as practicable, develop a national survey collection system which, in conjunction with administration collections, provides all essential national and state Indigenous statistics at sufficient frequency to allow jurisdictions to adequately report on nationally agreed performance indicators, and comparisons to be made between Indigenous and non-Indigenous persons and between jurisdictions	The NHIMG, in conjunction with the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, and the ATSIHWIU Advisory Committee, to oversee and undertake work in this area	Strategy developed by 30 June 1999

GOALS & OBJECTIVES	MAJOR STRATEGIES	RESPONSIBILITY FOR ACTION	MONITORING PERFORMANCE
GOAL 3: NATIONAL COMMITMENT TO IMPLEMENT RECOMMENDATIONS TO IMPROVE INDIGENOUS INFORMATION			
***3.1* Ensure national and state/territory processes are in place to oversee implementation of strategies to improve Indigenous health and related information**	Initiate processes to facilitate and oversee implementation of the plan's recommendations in a cohesive, co-ordinated and partnership manner, including: ➢ a formal process for national leadership (in partnership with national, state and community interests), to facilitate support of jurisdictional initiatives, benchmarking, co-ordination and review ➢ appropriate partnerships at the state/territory level to facilitate and support developments in line with the Framework Agreements on Aboriginal and Torres Strait Islander Health ➢ consideration of the possibility of providing resources and commitment to enable action – e.g. through a cost-shared Indigenous Health Information Enhancement Program (with a minimum of five-years funding), ➢ consideration of the potential for providing resources for a person, attached to the AHMAC Executive, and/or a high level Indigenous Information Task Force, to facilitate, co-ordinate and oversee national activity in this area ➢ clear delineation of roles and responsibilities amongst the major stakeholders	National leadership and oversighting of jurisdictional progress to improve Indigenous health information to be undertaken by NHIMG in a joint partnership arrangement involving, as a minimum, HAHU, NACCHO, and the ATSIHWIU Advisory Committee AIHW to provide secretariat resources to support a greater Indigenous information presence within NHIMG NHIMG to have principal carriage for reporting on progress to Health Ministers and AHMAC The ATSIHWIU Advisory Committee to oversee operational developments to improve Indigenous health and related information AHMAC, in conjunction with NHIMG, to continue to commit resources - to support developmental and other activities to improve Indigenous health information All jurisdictions to explore and establish financial and other incentives to encourage improvements in Indigenous information provided by hospitals, funeral directors, Births and Deaths Registrars, and others	Commonwealth, state and territory health authorities to report on activities in this area in conjunction with annual performance reporting on Indigenous health information to AHMAC, and also to NHIMG Additional targeted secretariat resources provided by AIHW to support NHIMG activities in Indigenous health information An Indigenous Information Officer appointed and situated with the AHMAC Executive and/or a Task Force established and functioning by 30 June 1998

Part 1 The Review

1 Introduction

> ***The essence of these resolutions, decisions and recommendations is that comprehensive routine Indigenous health statistics should be available nationally – that is, coverage should extend over the whole country, and, at least for an agreed basic data set, there should be comparability and compatibility in the information collected. Some of the individual states and territories have indeed pushed ahead, as a result of initiatives in individual administrations, or the particular interest taken by key individuals. But, in the Australian context, with health care delivery basically a state and territory responsibility, a national effort implies that the Commonwealth accepts responsibility for co–ordination and integration. The missing component has been an administrative framework for doing so.***
>
> *Smith, LR. (1978)* ***Aboriginal health statistics in Australia - a survey and a plan.*** *Third revision. Health Research Group, Australian National University, Canberra*

The above observation appeared in a 1978 report to the then Commonwealth Department of Health, along with a recommended national plan for collecting and reporting on Indigenous health statistics. Almost 20 years later, such sentiment is still pertinent. That so little advance has been made since this statement is an indictment of the relative inaction in relation to health information about Aboriginal and Torres Strait Islander peoples over the past two decades. Time and again, there has been a lack of commitment by agencies to implement procedures to achieve the comprehensive information which all major parties agree is necessary.

Of course, the last two decades have seen some significant advances in the availability and quality of Indigenous health information. This is particularly so in relation to improved identification of Indigenous peoples in vital statistics from Western Australia, South Australia and the Northern Territory, as well as in some health services collections, and the increasing adoption of a single standard against which such classifications are made.

The obvious successes in some states and territories notwithstanding, the current state of Indigenous health information is, in many respects, a legacy of Australia's fragmented health services funding and delivery systems. Thus, it is still characterised by:

- inadequate identification of Indigenous peoples in many collections, particularly in relation to hospital morbidity in most states and territories, and also in birth and death registrations in some states;

- inconsistent definitions and instruments for collecting Indigenous health information across states and territories and even across data collections held within individual states and territories;

- no – or inadequate – systematic quality control mechanisms to check the validity of Indigenous identification in current collections;

- little commitment by funding agencies and government bodies to returning information to communities, or to sharing information in general – at all, let alone in culturally sensitive or appropriate ways;

- no guidelines (particularly amongst government agencies) about the ownership, or ethical and appropriate use of data about Indigenous peoples – an issue of major importance to Indigenous peoples and Aboriginal medical services;

- limited appreciation of the power and value of information, and how information can be used to improve health services at the local level;

- a complicated web of obscure accountability lines and reporting requirements for Indigenous community–controlled health agencies, due largely to the plethora of funding sources and programs under which they are resourced; and

- a health workforce which is relatively ill–equipped in terms of the necessary skills, knowledge, resources and support required to collect, analyse, report and act upon the information about Indigenous health – an observation which applies equally across both clinical and administrative staff at each jurisdiction (including state, territory and Commonwealth government agencies, and both government and community–controlled health services).

And while there is some prospect of improvements in Indigenous health information at the national level as a result of the recent establishment of the Aboriginal and Torres Strait Islander Health and Welfare Information Unit (ATSIHWIU) and initiatives under the National Health Information Management Group (NHIMG), there exists no obvious structure or process in the current system for providing high level leadership, managing change or reporting on progress towards the development of a national Indigenous health information system. The need for this leadership will become even more urgent as improvements in Indigenous health data are demanded to fulfil the reporting requirements of the Aboriginal and Torres Strait Islander Health Performance Indicators and Targets, against which Australian Health Ministers recently committed to annually report on progress.

This review is merely the latest in a long line of recommendations, reviews, reports, discussion papers, strategies and national workshops stretching across more than three decades. One common element amongst many of these earlier initiatives is the apparent inattention to implementing recommendations – at all, let alone in a planned, cohesive and nationally co–ordinated way. Accordingly, this review and its proposed national plan provide little in the way of new information and recommendations, for much of that which has gone before still applies today. The difference is a proposed process for ensuring that this plan, if agreed and endorsed by the major interest groups, is transformed into action on the ground.

The recommendations herein highlight requirements in terms of improving technical aspects of Indigenous health information, and also in terms of processes and structures needed to build the capacity of the system to support better quality health information.

Together with the existing activities underway in Australia (*refer Part 2, Section2 of this report*), the recommendations constitute the set of tasks which comprise a proposed national plan and processes for improving Indigenous health information in Australia.

Effective attention and commitment now to an agreed formal process for enacting a national plan for Indigenous health information is the best defence against ensuring that future reviews do not repeat these findings. As such, establishing and maintaining the commitment of all jurisdictions to an ongoing national process of implementation and review remains the highest priority within a range of important recommendations for improving Australia's Indigenous health information effort.

2 Background

In early 1996, the Australian Health Ministers' Advisory Council (AHMAC) commissioned the Australian Institute of Health and Welfare (AIHW) to, in conjunction with stakeholders, conduct a review of and develop a National Plan for Aboriginal and Torres Strait Islander Health Information. The need for a plan which would improve all aspects of Indigenous health information was identified as the highest priority of the 1994 National Health Information Plan forum.

The task was referred to the Aboriginal and Torres Strait Islander Health and Welfare Information Unit (ATSIHWIU) – a joint program of the AIHW and the Australian Bureau of Statistics (ABS), based within the ABS's National Centre for Aboriginal and Torres Strait Islander Statistics in Darwin. The steering function for this project was provided by the advisory committee to the ATSIHWIU, which also assisted with the preparation of specific recommendations.

2.1 Terms of reference

The purpose of this project was to develop a plan to improve all aspects of information about Aboriginal and Torres Strait Islander health and health services, in conjunction with Indigenous peoples and agencies involved in all tiers of their health services.

The project's terms of reference were to:

a) Analyse the extent to which the information plans outlined in the National Aboriginal Health Strategy of 1987 have been implemented;

b) Undertake consultations with State/Territory, Commonwealth and non–government Indigenous health stakeholders to determine desired modifications to the information proposals in the National Aboriginal Health Strategy;

c) Record examples of 'excellence' and 'success' in the field of health information, through consultations with State/Territory, Commonwealth and non–government health agencies, paying particular attention to methods of presenting information to different audiences;

d) Analyse the information collected under (c) to determine current 'best practice' and major gaps in different areas of Indigenous health information;

e) Establish a set of highest priority Indigenous health information needs based on the needs of both government and non–government sectors;

f) Determine options and proposals for data collection, processing and the reporting necessary to meet these highest priority information needs; and

g) Prepare a preliminary report on a proposed integrated strategic information plan, (bringing together ideas and information collected and analysed in (a) – (f)).

2.2 Methodology

The project was undertaken in two phases. The first phase (from June 1996 to February 1997) involved project planning and a national consultation involving visits to all states and territories, in order to prepare a series of individual state and territory reports on current activities and issues.

Letters explaining the project and inviting input were distributed in July 1996 to key national, state and community-controlled agencies involved in Indigenous peoples' health and health services. These included all state and territory government health authorities and Commonwealth funded Aboriginal Medical Services (AMSs). Consultations were subsequently held with Commonwealth, state and territory health departments and relevant national organisations. Parallel consultations were also held with approximately 30 AMSs across most states and territories. A few consultations have yet to be completed – these include AMSs in New South Wales and all services in the Torres Strait Islands (however the latter are scheduled for September 1997).

Participants at these consultations were asked about the health information collections that they and others in their state or territory generate, analyse and report on. Awareness of the National Aboriginal Health Strategy (NAHS) was also explored, particularly in relation to compliance with the Strategy's information recommendations. Opinions and suggestions were also sought for improvements in Indigenous information issues.

Draft reports on the outcomes of these consultations were prepared for each jurisdiction, and subsequently returned to the agencies consulted and all persons interviewed in the respective state or territory, for comment and amendment. Suggested amendments have since been incorporated.

The second phase of the review (from February 1997 to August 1997) involved the preparation of two reports – an extensive national report, and a summary report. This phase also included the identification of case studies which represent innovative and/or effective practices across the range of Indigenous health information interests. These case studies are presented and drawn upon throughout this report to illustrate relevant discussion points. Thus, the information provided in these reports was developed from a combination of a review of the literature, from consultations with key individuals and agencies in each state and territory, and from feedback provided on earlier state and territory summary reports.

2.3 National consultation

The release of a draft summary report in May 1997 marked the beginning of a second national consultative stage. The summary report was prepared primarily for the purpose of facilitating consultation on the project's draft recommendations. The second round of consultation again involved visits to most states and territories. While visits were unable to be scheduled in Tasmania and in the Torres Strait Islands during this consultative phase, they are planned for the near future. Nevertheless, stakeholders in these areas were provided with copies of the report in order to make written submissions, prior to formal meetings being scheduled in these jurisdictions.

Meetings and workshops were held with government and community interests to discuss the project's findings and recommendations, and to provide an opportunity for stakeholders to consider the application of the recommendations and any implications for them or their agencies. A primary aim of this consultation phase was to seek consensus amongst all interest groups about the priority actions needed to improve the quality of Indigenous health information and to achieve commitment for this purpose, prior to finalising the report and presenting it to AHMAC in October 1997.

Fourteen meetings and/or seminars were held in each of Brisbane, Canberra, Darwin, Perth, Melbourne, Adelaide and Sydney. These attracted over 300 participants, representing a range of interests including Commonwealth and state and territory health authority officials (such as senior managers, and those in Aboriginal health units, public health programs and information related areas), officers of state and Commonwealth government statistics and/or health information agencies, Registrar–Generals and officials from birth and deaths registries, staff and/or senior managers of Aboriginal medical services and community controlled services, and academic researchers.

Additional seminars and meetings were held with the National Health Information Management Group, the Executive of the National Aboriginal Community Controlled Health Organisation (NACCHO), the Commonwealth, State and Territory Heads of Aboriginal Health Units (HAHU), the national health portfolio representative on the Aboriginal and Torres Strait Islander Commission (ATSIC), and at an Aboriginal health workers conference. In addition to feedback received through workshop participation, written submissions were also received from 15 organisations and/or individuals.

The draft recommendations and directions were generally very well received. Additionally, seminar participants (particularly the Indigenous community interests) were unanimous in their call for the introduction of safeguards against the potential misuse of information, and also for the need to support communities and services at the local level to collect and use information for their own needs. Participants generally recognised and supported the need for accurate data about Indigenous people, but there appeared to be an undercurrent of concern that such information could be used against Indigenous people and their agencies (indeed, past examples were readily provided).

Therefore, consultation participants agreed that – first and foremost – there was a need for all parties to develop agreed protocols for the appropriate use of information about Indigenous people.

Secondly, participants urged that the future emphasis must be on supporting the development of the necessary skills, resources and processes which will lead to good quality local information, for use at the local community level, but which is of sufficient quality to allow use and reporting at state and national levels. Again, this was with the provisos that due attention and care is accorded to guarding against the potential misuse of data, that protocols are developed and observed, and that there is appropriate feedback of information to the source communities.

A third opportunity for comment from stakeholders was provided in September 1997, at which time the penultimate national report and recommendations were circulated once more to key organisations, including Commonwealth and state and territory government agencies, and also to all participants to date, for final review and comment prior to submitting the report to AHMAC for consideration and endorsement in October.

2.4 Scope of the project

The commonly adopted definition of Indigenous health refers to the social, emotional, spiritual and cultural wellbeing of the whole community, rather than merely being concerned with an individual's physical wellbeing. Thus, it is a whole–of–life view which includes the cyclical concept of life–death–life. As such, the importance of ensuring that information about the health of Australia's Indigenous peoples encompasses the range of health determinants is clearly recognised and acknowledged.

However, this project has focused predominantly on the data collections which are held by health authorities and others necessary for calculating health information and population estimates (e.g. birth and death registrations and census collections). This was a deliberate decision taken at the beginning of the project, in an effort to focus initial attention on the core health data in relation to mortality, morbidity, and health services use (where such data are available). Thus, issues such as environmental health aspects and infrastructure, welfare, housing, and transport information, have not been included. Nevertheless, thus does not negate the importance of collecting quality data on these broader determinants of health. Indeed, it is desirable that an extended plan covering these data will be developed in the future.

Another major focus of attention in this project was the need to consider the requirements of users at all levels of health information (including local community and clinic level, hospital level, state/territory, and national levels; the emerging need for making international comparisons was also recognised). This was recognised at the earliest planning stages, and has continued to be a prime focus throughout the life of the project.

Part 2 Setting The Context

1 The myth of homogeneity

1.1 "The Aboriginal community"

Despite the common stereotypical misconceptions to the contrary, there is no single "Aboriginal and Torres Strait Islander community". Rather, Australia's Indigenous population comprises a diverse range of peoples who "live in a spectrum of ecological zones, speak several hundred languages, and have differing religious and healing practices, diets, family traditions, political structures and economic strategies".[1] This is no less true today as it was before European colonisation of Australia.

This review experienced many instances which have highlighted this diversity, particularly during the public consultative meetings, where some participants noted that many people are of the mistaken belief that Indigenous Australians comprise one homogenous group. In other cases, comments made by participants actually reflected such a poor understanding of the diversity that is Indigenous Australia. On another level, there were instances during the consultation where, for each respondent who argued that a particular recommendation or strategy was inappropriate, say, due to poor literacy levels of remote Indigenous persons, another has pointed to the significantly higher literacy and educational levels attained by many Aboriginals and Torres Strait Islanders who live and work in Australian cities.

Australia's Indigenous peoples are a very heterogeneous population group, and as such should not be viewed as a single entity. For instance, the health services needs of Aboriginal people in the Kimberley region of Western Australia may be very different to those in Sydney's inner-city suburb of Redfern. Similarly, strategies which may be appropriate for addressing a particular health issue in a remote Aboriginal community in Central Australia may be inappropriate when working with Indigenous persons in Canberra.

The heterogeneity of Australia's Indigenous peoples must be recognised and acknowledged when considering strategies for a national Indigenous health information plan. It is clearly inappropriate to apply a given strategy equally and expect it to be effective across all communities. Rather, the national plan requires considerable locally-focused and contextually appropriate activities, albeit co-ordinated at higher – state/territory and/or national – level.

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[1] Reid J & Lupton D. (1991) *Introduction*, in Reid J & Trompf P (Eds.) **The Health of Aboriginal Australia**, Harcourt Brace Jovanovich; cited in Golds M, King R, Meiklejohn B, Campion S & Wise M, *Healthy Aboriginal Communities*, in **Australian & New Zealand Journal of Public Health**, 1997, In press.

1.2 The use of health services by Indigenous persons

Just as there is no uniform 'Indigenous persons' entity, there is similarly no uniform approach to the ways in which Indigenous persons interact with health services. Additionally, there are different approaches and services provided between urban and rural or remote localities and, within this, services may be community controlled AMSs, state-run clinics, or part of the mainstream health services sector.

Urban and rural services

The primary health care needs of many remote Indigenous communities are often serviced by a single health clinic or health service. Depending on their size, these clinics and services employ a range of health practitioners to provide basic clinical, counselling and preventive services to Indigenous persons in the local community. This style of service can provide almost all of the primary health care services to Indigenous persons in remote areas – often because there are no or few other services available and, as such, there is a 'captive population'.

However, this is not the case in many urban and provincial centres, where Indigenous persons sometimes have a choice of attending mainstream health services in addition to – or instead of – local AMSs or clinics. In this case, 'mainstream' services include all services provided for the general community, such as private and public medical practitioners (both general practitioners and medical specialists), hospitals, community health services, and specific public health programs such as alternative birthing initiatives, dental health, substance abuse and communicable diseases programs.

Community controlled AMSs and state-run clinics

Some of the rural and remote Indigenous health services are managed by the relevant state or territory health authority, while others are Indigenous community-controlled health organisations or Aboriginal Medical Services (AMSs). The latter are predominantly funded by the Commonwealth Department of Health and Family Services (often with additional State/Territory Government funding for both services provision and to undertake additional targeted programs). These AMSs are usually managed by a board, comprising members of the local Indigenous community.

Principles of Community Control

Reproduced in full from the Kimberley Aboriginal Medical Services Council [2]

'Community control' is the managerial hallmark of an Aboriginal Medical Service (AMS). While operating alongside mainstream service providers, AMSs allow Aboriginal people to control their destiny and accept responsibility for their own decision making. The mechanism for community control is a health committee composed of elected members from the community.

There is no such entity as a generic AMS. Aboriginal community controlled health organisations (ACCHOs) are distinct, independent local health services owned and run by local Aboriginal communities according to that community's priorities. ACCHOs are in effect general practices owned by communities. Networks between ACCHOs are generally loose and informal.

Hospitals and state community health services, on the other hand, are part of a state-wide service structure with management hierarchies extending back to (a city-based central office), bound by government protocol and policy. There is no mechanism for Aboriginal management or control among any of the government health services in the Kimberley.

At a local level, there are many excellent individual workers in government services who consistently deliver culturally sensitive and thoroughly competent health care to Aboriginal people. There are also the bigots, the mediocre and the ignorant.

Without a strong Aboriginal voice, there can be no effective accountability for the quality and effectiveness of health care services provided to Aboriginal people. There is also no hope of realising the health benefits which flow from Aboriginal ownership of Aboriginal problems (the primary health care concept). ACCHOs and government services are not the A and B teams – they are chalk and cheese. At the same time there is a strong and complementary role for mainstream government services and ACCHOs.

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2 Kimberley Aboriginal Medical Services Council. (1977) **Principles of Community Control**, published at http://www.hcn.net.au/kamsc/commcont.htm

Community controlled Aboriginal health services

A recent review of community controlled Aboriginal health services for the National Aboriginal Health Strategy evaluation developed the following categorisation of AMSs:

Category 1 – these are AMSs which have a medical service within their own organisation, with a medical officer under the control of the service. There are three sub-categories:

1(a) The regional AMSs;
1(b) The large AMSs operating in communities with very large Indigenous populations – often, but not always, in major urban centres. Comprehensive service provision includes primary medical care, health promotion, prevention, education, and counselling services;
1(c) A group of AMSs whose services range in comprehensiveness from expanded general practice to a range of complexity (with annual budgets ranging from under $400,000 to $1million).

Category 2 – this refers to community controlled Aboriginal health services which provide clinical services but do not have a medical service within their own organisation.

Category 3 – covers health services which provide services such as counselling or perhaps screening services, but do not play an active clinical illness management role.

The review considered that there were 49 AMSs in Category 1, 22 in Category 2, and 17 in Category 3.

Sociocultural and mental health problems were widespread in the communities serviced by these agencies. Urban health services identified (in order of significance) alcohol, diabetes and mental health as their greatest problem areas, followed by sexually transmitted diseases, child abuse, sexual abuse and neglect, heart disease and hypertension, and domestic violence. In rural and remote communities education rated highly, as did social and behavioural problems.

Indigenous peoples' use of mainstream services was primarily determined by the AMS location and availability of other services in the area. Some AMSs provided additional services to facilitate the use of mainstream health services by Indigenous people, such as support and advocacy, hospital liaison, and the use of Aboriginal health workers. However, the majority of AMSs surveyed considered that mainstream services did little to encourage or support Indigenous people to use their services, citing little attention to providing culturally appropriate services being a major factor in the reluctance of Indigenous people to avail themselves of mainstream health services.

Adapted from Swan P & Raphael B (1995) [3]

[3] Swan P & Raphael B. (1995) **Ways Forward.** National Consultancy Report on Aboriginal & Torres Strait Islander Mental Health (Parts 1 & 2). National Mental Health Strategy. Australian Government Publishing Service, Canberra; citing an evaluation report by Wronski et al (1994), commissioned by ATSIC for the National Aboriginal Health Strategy Evaluation.

2 Why collect health information?

Information is collected about a diverse range of issues and used for an equally diverse range of purposes – at all levels in the community, including at the national, state/territory, regional or area, and local community levels. Some of the major uses of information include:

- Monitoring and surveillance of baseline data and trends in population health status, health outcomes, determinants of health (including health knowledge, attitudes, beliefs, risk factors, environmental conditions), and health inequities across population sub-groups, to detect changes and monitor progress;

- Monitoring and surveillance of communicable diseases and early identification of disease outbreaks or epidemics;

- Planning and development of policies, programs and services – at all levels in the system, from national Commonwealth Government programs to the services which need to be provided by an AMS to the local community;

- Evaluation of the impact and effectiveness of policies, programs and delivery of services, to inform audit or accreditation reviews, and to obtain feedback on work undertaken and services provided – the flip side of planning and development at all levels of interest;

- Monitoring of the utilisation of resources, access to services, and the range of health interventions or health services provided – that is, to assess what services are being provided and to whom and, importantly, to assess whether some groups are not accessing the services they need;

- Determining whether funding is adequate, distributed equitably, and used effectively and efficiently, and also to support arguments for increased investment to meet identified community need, informing choices amongst alternative courses of action, and to optimise the use of available resources and value for funds expended;

- Administrative accountability, funding acquittals, accounting for what has been done, substantiating resource costs, and progress reporting;

- As a tool for advocacy on behalf of identified community needs to support arguments for funding;

- Raising community (i.e. individuals, local communities, and national) awareness about health concerns, as a strategy for informing concerned individuals or for community action and health promotion, or even for keeping the issue of health disadvantage on political agendas; and

- Supporting public health research, that is, the creation of new knowledge or to generalise existing knowledge to other areas, and to test theories and potential solutions to address public health problems.

Different information users may have different requirements for each type of information, and these may change according to the specific context at a given time. For instance, all agencies, whether government departments or local clinics or AMSs are accountable to others for the services they provide with the funds made available to them. As clinics or AMSs need to provide information to their funding agencies, so too are they accountable for their actions to their staff, their clients and to their local communities. Likewise, government departments are accountable to their Ministers, Cabinet, the Parliament and, vicariously, to the Australian public.

Similarly, each level of interest may focus primarily on one or more information types and uses rather than those considered important at other levels. For instance:

- On an international level, Governments and community agencies alike are more likely to be interested in the capacity to make meaningful comparisons between Australia's Indigenous population and those of other similar countries (such as New Zealand, Canada, and the United States of America);
- At the national level, information is required to fulfil the Commonwealth government's commitment to monitor progress on improving Aboriginal health, and also to facilitate a nationally consistent approach – that is, to ensure that resources are distributed equitably across the country and/or directed to populations or areas of most need;
- Similarly, State and Territory governments need accurate information in order to fulfil commitments to improving Aboriginal health in their own jurisdictions;
- Individual hospitals and area health services need information about their services and clients served to effectively plan, deliver and evaluate service delivery in line with identified community need, and also to contribute data to national and/or statewide collections – thus, consistent information collection and reporting formats are needed;
- Local community health services (including AMSs) and workers may be more interested in obtaining information about the comparative health of their community (that is, against other communities), and also about the impact and reach of their services, to enable more effective planning and discharge of their duties and services;
- Local communities themselves are likely to want information about their capacity to receive and use health information to influence local services, and/or to be better informed about the health status and risk factor prevalence in their community – and where they stand against other communities.

However, while the interests in information vary according to levels in the system or the specific issue at hand, all rely on several key factors. These are the existence of good quality locally-specific information, and the capacity to make comparisons – over time, between individual Indigenous communities, and also between Indigenous and non-Indigenous populations. The capacity to make sensible comparisons over time and between different groups in turn relies on the use of similar or compatible definitions and indicators over time and across all jurisdictions. Meaningful statistical calculations can only be drawn from comparisons if sample sizes are large enough. Some comparisons can only be made by means of statistics derived from specific data sets (i.e. local health service data, or administrative collections, or surveys).

Finally, whatever the intended application, all information collected or provided must serve a useful purpose and, ultimately, contribute to improving health services delivery and/or identified health outcomes. Where this is not the case, its continued collection must be questioned.

3 Aboriginal and Torres Strait Islander health disadvantage

As noted previously, accurate information about population health issues and demographic and other client related details is essential in order to effectively plan, deliver and monitor the impact of health programs and services.

The need for such information is even more critical if governments and community health agencies alike are to address health inequities – such as those experienced by Australian Aboriginal and Torres Strait Islander people.

Australia's Indigenous population suffers the worst health of all population sub-groups in the country – and this is true of almost every indicator. Indeed, the recently released publication, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, reports that "the health disadvantage of Indigenous Australians begins early in life and continues throughout the life cycle".[4] This report is merely the latest and most detailed in a long line of publications which have documented the unacceptable health disadvantage of this population group.

The report notes that, compared to non-Indigenous people, Indigenous Australians:

- live an average of 15 to 20 years less;
- are two to three times more likely to give birth to low birthweight infants;
- are two to four times more likely to die at birth;
- are two to three times more likely to be hospitalised – particularly for respiratory conditions and injury;
- are 15 to 18 times more likely to die of infectious diseases; and
- experience significantly higher death rates at each age group, with the greatest differential being six to eight times higher amongst adults aged 25 to 54 years.[5]

Even more significantly, the health of Australia's Indigenous populations has not improved in line with that in other comparable countries.[6,7] Health differentials between Indigenous and non-Indigenous populations in other industrialised countries have decreased significantly in recent decades, to the point where the Indigenous health status is "approaching the average health of those nations".[8] Yet, no such change has occurred in Australia.

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4 Australian Bureau of Statistics (ABS) & Australian Institute of Health and Welfare (AIHW). (1997) **The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples**. Australian Government Publishing Service, Canberra.

5 ABS & AIHW, ibid.

6 Hogg R. (1992) *Indigenous mortality: Placing Australian Aboriginal mortality within a broader context*, in **Social Science Medicine**, 35(3):335-46.

7 Kunitz S & Brady M. (1995) *Health care policy for Aboriginal Australians: the relevance of the American Indian experience*, in the **Australian Journal of Public Health**, 19(6): 549-58.

8 National Aboriginal Health Strategy Evaluation Committee. (1994) **The National Aboriginal Health Strategy: an evaluation**. Aboriginal and Torres Strait Islander Commission, Canberra.

4 Why collect information about Indigenous peoples' health?

There can be no greater justification for improving the coverage and quality of information about Indigenous people in Australia than its contribution to the process of reducing Indigenous health disadvantage. Such effort is vital both in terms of improving knowledge about the trends in health status of Indigenous people and also to help safeguard funding for Indigenous health initiatives. The latter is increasingly important in the current economic and socio-political climate, where funding of affirmative action initiatives, particularly for Indigenous peoples, is increasingly called into question by both community and political interests alike. Failure to improve information and to demonstrate what is achieved with the available funds could result in funding cuts.

A key issue in improving the quality and coverage of information about Indigenous people is the extent to which they are accurately identified in data collections, or, in the case of single surveys, the sample sizes are sufficiently large to provide meaningful information.

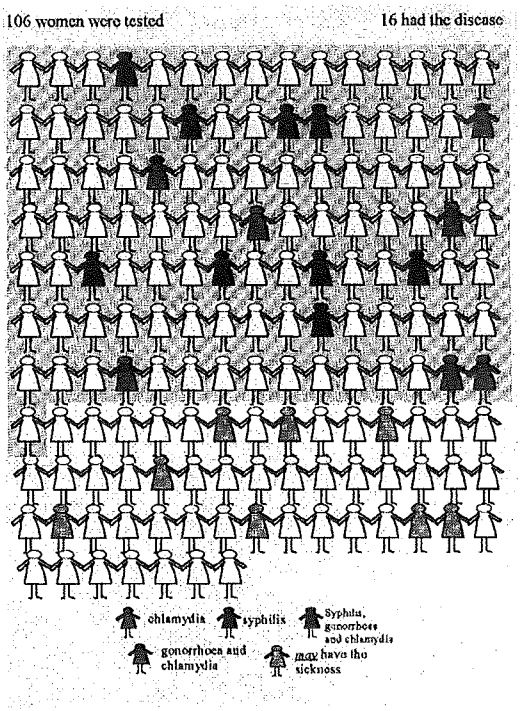
Thus, the need for accurately identifying Indigenous persons in major health and related collections is critical in terms of providing supportive evidence for – and assessing the impact of – affirmative action programs to target identified need and address significant health inequities.

5 What becomes of the information collected?

The information collected about Indigenous persons is used and reported differently, depending on the reason for collection, and the level of interest. For instance, many AMSs and community health agencies collect information about the clients they serve and the services provided to them. The primary reason for doing this should be to monitor and, where necessary, improve health service activities and outcomes. This type of information may also be provided in the form of performance information to funding bodies to satisfy contractual obligations. Similar information may be provided by a local service to demonstrate to its local community the activities of the service over the previous year and the range of services provided. Either way, this is a form of demonstrating accountability to those which have an interest – whether this is a financial one (as in the case of the funding agency) or of being accountable to the local constituencies.

On another level, hospitals and health services provide information about their clients to a central agency – usually the state health authority – for reporting on a state-wide and/or national level about services provided, access to services, and other relevant statistics. Such information is then used to monitor health trends, performance and to identify need for new programs and initiatives.

Likewise, the formats for providing this information vary according to the purpose and level of interest. Information about services and people may be presented in evaluation reports, audit reports, annual reports (for instance by individual AMSs, and also by state or Commonwealth health authorities), performance statements and progress reports to funding agencies, and even to Parliamentary committees of enquiry (such as the current inquiry into Indigenous health by the House of Representatives Standing Committee on Family and Community Affairs, or Senate Estimates Committees and state equivalents).



In each case, the format can be adapted according to the specific needs of interests of the constituencies served. For instance, such information does not have to consist of pages of complicated tables and statistical data. Indeed, such a format may be quite inappropriate for some community groups, who may feel bewildered at being presented information in this way. For example, the Nganampa Health Council in Central Australia recognises the need to be accountable to its local traditional community – and as such, aims to present statistical information simply and effectively about the local population, their health issues and patterns of service. An example of this approach, using simple graphics and colour to depict the prevalence of certain sexually transmissible diseases in a local female population, is shown here.

A further innovative way of presenting information about Indigenous health issues is through the use of the Internet. A number of case studies are presented below.

Indigenous Health Information on the 'Net'

The multimedia boom of the 1990s has opened up a range of new and exciting opportunities for promoting awareness and sharing information about Indigenous health issues. A small selection of innovative Australian sites are showcased below.

Kimberley Aboriginal Medical Services Council **http://www.hcn.net.au/kamsc/**

This particularly informative site is maintained by the Kimberley Aboriginal Medical Services Council (KAMSC) of Broome in Western Australia. It provides a wealth of information about the KAMSC and the regional Aboriginal community-controlled health services (including positions vacant and training opportunities), as well as useful links to other Indigenous health related sites.

However, its strength lies in the KAMSC's use of this site as an advocacy tool for informing others about the plight of Aboriginal health and health services conditions – in short, it is a valuable strategy for presenting available information in a variety of formats to raise awareness and facilitate informed debate about Indigenous health.

The site presents a range of discussion papers, media releases and other resources relating to Indigenous health issues, including:

- copies of submissions and responses to government policy initiatives;
- the use of stories to highlight practical aspects of Indigenous health and primary health care; and
- documents detailing policies and issues of importance, such as information technology and the delivery of outstation health services, issues for Aboriginal controlled health services in the Kimberley, and principles of community control (the latter reproduced earlier in this report).

Aboriginal and Torres Strait Islander Health Research Homepage
http://www.cowan.edu.au/hhs/health/absti/absti.htm

This site is maintained at Edith Cowan University in Perth, Western Australia. It provides an Australian-focused clearinghouse of resources and a forum for health researchers and others interested in Indigenous health to exchange information. The site provides information about data sources, bibliographic references, theses and reports, current research initiatives, conferences, an Indigenous health research listserver, and an Aboriginal and Torres Strait Islander electronic health bulletin.

Indigenous Peoples **http://www.ens.gu.edu.au/eberhard/indigen.htm**

This site is maintained privately by Eberhard Wenzel, an academic researcher based at Griffith University in Brisbane, Queensland. It provides an extensive array of links to world-wide sites about Indigenous peoples throughout many countries. While the focus is predominantly Indigenous health-related, the links include broader topics of relevance to Indigenous persons, such as the environment, culture, history and spirituality.

However, the issue of information collected being returned to and shared with communities appears to be a major issue of contention. There is a widely held perception amongst Indigenous communities and those involved in providing local services that data and information provided to funding bodies, government agencies and academic researchers are often not used appropriately, nor the results fed back to communities (at all, let alone in culturally appropriate ways or in a timely fashion), and also that the many requests for information are not co-ordinated. Indeed, many people consulted complained of the practices of some government agencies (for instance the Australian Bureau of Statistics) to sell the repackaged data back to the source communities, or to present information to communities in socially inappropriate ways. Clearly, more consideration and commitment is required on behalf of government agencies and researchers alike to returning information to communities, as are strategies for presenting such data in a range of appropriate formats. An example of one approach, suitable for use with traditional Aboriginal communities, is presented overleaf ('Health Information for Community Action').

Concern was also expressed by some community controlled agencies that information provided to funding agencies could be misused for cost-cutting or other inappropriate purposes. Aboriginal and Torres Strait Islander communities were particularly concerned about the use of information about Indigenous persons – particularly, what information is collected, by whom, how it is used, who owns the data, who has access to it, and under what circumstances?

These issues have the potential to be a major stumbling block to facilitating Indigenous peoples' acceptance of and co-operation with strategies to improve the quality of Indigenous health data. As such, no government agency can afford to ignore these concerns – indeed, the development of appropriate guidelines and safeguards concerning the ethical use of data about Indigenous persons must be addressed as a critical priority as an integral component of any further significant action in this area. This has been recognised by those seeking to improve Indigenous health information in New South Wales, as indicated in the case study below.

Ironing out the ground rules for using Indigenous information

In New South Wales, the Aboriginal Health Information Management Group – a partnership involving that state's Aboriginal Health Resource Co-operative (AHRC) and NSW Health – has been established to oversee activities to improve Indigenous health information.

The group has recognised the overwhelming importance of working through issues of data ownership and developing and putting in place protocols for the ethical use of information about Indigenous persons as the highest priority. Only when these issues have been ironed out to the satisfaction of all players will the group begin to assess the problems affecting the collection and reporting of Indigenous health information in that state, or start to decide on priority issues and actions to be initiated.

Health Information for Community Action

The 'Adult Aboriginal Mortality Project'[9,10,11,12] was undertaken in the Northern Territory between 1991 and 1995. One aspect of the project involved the practical application of the "Land, Body and Spirit" concept as a way of classifying causes of death in local Aboriginal communities and facilitating discussion about adult deaths at the local community level.

The project attempted to bridge traditional Aboriginal and Western systems of assigning causation, and allowed emphasis to be given to the social and community factors underlying the medical causes of death. Thus, the "underlying causes" approach was considered more appropriate and culturally relevant than a standard disease-based approach to considering information and planning broad-based community initiatives to address local health issues.

The classifications of "Land", "Body", "Spirit" and also "Smoking", together with a simple statistic (the 'proportional mortality ratio' – used for illustrating comparative information), were used to feed back information to the local community in the form of pie charts. For example, "Land" issues such as poor living conditions, overcrowding, inadequate housing and lack of clean water and sanitation were identified as contributing to chest infections, diarrhoea, and skin, ear and eye infections. Conditions such as diabetes and heart disease were explained by the "Body" factors of poor quality Western food and too little regular exercise. "Spirit" aspects included cultural conflict, forced assimilation, loss of traditional lands, educational disadvantage, unemployment and poverty – all seen as major contributors to substance abuse problems, violence and poor mental health.

The researchers recognised that, while information can equate to power, it can also disempower by overwhelming or depressing people. Thus, simplicity of information feedback was vital, as was a focus on positive information and sharing of "good stories". For example, team members would insist that adverse health outcomes were not inevitable, and that not all Aboriginal people die at a younger age. Similarly, positive reaffirming stories, such as the active role of Aboriginal people in reducing Aboriginal infant mortality rates in recent decades, were also promoted.

This strategy sought to demystify major health issues as well as to encourage people to talk about them – that is, to get people talking, to share their views about what was causing these health problems, and even to encourage discussion about the myths that may have enveloped an issue, in the hope that these could then be countered. By raising a community's awareness about a health problem and allowing exploration of the underlying causes, communities are better placed to identify their own practical strategies with which to address local problems and issues.

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[9] Weeramanthri T. *Health information for community action*, in the **Aboriginal and Islander Health Worker Journal**, pp 10 – 12, publication dates not known.

[10] Weeramanthri T. (1996) *Knowledge, Language and Mortality: Communicating health information in Aboriginal communities in the Northern Territory*, in the **Australian Journal of Primary Health** – Interchange, 2(2): 3 – 11.

[11] Weeramanthri T. (1995) *Aboriginal Deaths*, in the **Aboriginal and Torres Strait Islander Health Information Bulletin**, Vol. 21, pp 73 – 76.

[12] Menzies School of Health Research. **Adult Aboriginal Mortality Project (1991 – 1995): Community Feedback Package**. Menzies School of Health Research, Darwin, publication dates not known.

This method proved culturally acceptable and enhanced the process of communicating complex health information in community feedback sessions and workshops.

6 "But this has been done before"

This review of current practices to collect and report on Indigenous health information has uncovered a widespread perception, particularly amongst Aboriginal and Torres Strait Islander communities, that reviews such as this "has been done before". That is, that Indigenous health is a particularly well researched field, with much information generated – but that there never seems to be any results or follow-up action.

A similar issue identified by participants concerns the seemingly limited capacity of national initiatives – including the National Aboriginal Health Strategy – to successfully make the transition from a national policy to effective and sustainable implementation at the grassroots level.

Regrettably, much of the frustration expressed by Indigenous communities and AMSs is not without foundation. For too long Indigenous people have been passive recipients in a seemingly never-ending array of research initiatives, and have witnessed countless public outcries about the state of Indigenous health and the socioeconomic and environmental living conditions, accompanied by promises of action – all apparently (to those experiencing the frustration) to little avail, at least in terms of changes in outcomes.

Nevertheless, the National Aboriginal Health Strategy evaluation report appropriately identified a "great need for more and better information about the health and welfare of Aboriginal and Torres Strait Islander peoples", for the purposes of:

- identifying health and welfare problems and at-risk groups;
- setting priorities for interventions and policies;
- planning programs and policies;
- monitoring changes over time; and
- evaluating the effectiveness of interventions.[13]

The report went on to assert that:

> *It is true that available data is* (sic) *inadequate to accurately define what needs to be done, in what order of priority, with whom and by whom. If we wait until such perfect data is* (sic) *available, we will wait forever – at least beyond the point when any decent solution could be implemented.*[14]

This raises several pertinent issues, namely that:

1. There is little point in agencies (government and community controlled) in continuing to collect irrelevant information about Indigenous persons, or information that clearly serves no purpose. Where this practice exists, it must stop – as a matter of priority.
2. Similarly, if the knowledge gained through the collection of such information is not put to use, then why continue to collect it?

Clearly, a visible and ongoing commitment to acting on the information collected – by all major stakeholders – is long overdue. This factor is the single most important finding of this review, and as such, is a major component of this report's recommendations and the National Aboriginal and Torres Strait Islander Health Information Plan.

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[13] National Aboriginal Health Strategy Evaluation Committee, op cit.

[14] National Aboriginal Health Strategy Evaluation Committee, ibid.

Part 3 The State of the Nation

1 State and Territory Health Information Activity

1.1 Introduction

Like previous reviews, this project has identified major shortcomings in the coverage and quality of Indigenous health information in Australia in the 1990s. However, in considering the efforts required by all Australian jurisdictions to improve the capacity to report effectively on Indigenous health trends, it's also important to reflect on the achievements that have occurred in a relatively short period of time. Just twenty years ago, no Australian jurisdiction separately identified Indigenous persons in birth or death registrations, and only one jurisdiction (the Northern Territory) had just begun to record Aboriginality in their hospital collections. Two decades on – by the end of 1997 – all major vital statistics and hospital-related collections have practices in place to collect, record and report on the Indigenous status of persons who are born, die or are admitted to hospital in every Australian jurisdiction. Further, those responsible for population estimates, birth and death data, and most health collections have recently committed themselves to using common definitions. Thus, although there is a way to go to enhance the quality of health information, the capacity of Australian states and territories to adequately report on the health status and health services utilisation of Aboriginal and Torres Strait Islanders has substantially improved over the past two decades.

This section provides a national overview of current activity and mechanisms to collect and report on information about Aboriginal and Torres Strait Islanders in the major Australian administrative and health services data collections. In so doing, it documents the range of practices in place to improve the quality and coverage of information about Indigenous persons, and showcases several particularly innovative attempts in some jurisdictions. More detail about individual jurisdictions may be found in the individual state and territory summary chapters, at Attachments 2.1 through 2.8 of this report.

1.2 Introduction of an Indigenous Identifier in Major Collections

Table 1 overleaf details the years in which Indigenous identifiers were first introduced in state and territory health and vital statistics collections – i.e. births and deaths registrations (including medical certificates of cause of death), hospital separations, maternal/perinatal collections, cancer registries and notifiable communicable diseases collections.

Vital statistics

In 1984, the Australian Capital Territory (ACT) became the first jurisdiction to begin separate identification of Aboriginal and Torres Strait Islander persons in births and deaths registrations. This was followed by the Northern Territory (NT) and Western Australia (WA) in 1985 (deaths only in WA), South Australia (SA) and New South Wales (NSW) in 1986, Victoria in 1987, and Tasmania in 1988, and births registrations in WA in 1991. Queensland was the last jurisdiction to introduce separate Indigenous identification in birth and death registrations, in 1996 – and, in doing so, has clearly demonstrated that major inroads can be achieved in a relatively short period of time, given the will and commitment toimproving the coverage and quality of information. (The Queensland experience is documented below.)

Table 1 Introduction of an Indigenous Identifier in Administrative Data Sets

Type of collection	Date of Introduction of Indigenous Identifier							
	NSW	Vic	Qld	SA	WA	Tas	NT	ACT
Vital Statistics Collections								
Birth registrations/notifications	1986	1987	1996	1986	1991	1988	pre-1985	1984
Death registrations/notifications	1986	1987	1996	1986	1985	1988	pre-1985	1984
Medical certificates - cause of death	No	1987	1996	Yes	1983	No	1988	No
Health Services Collections								
Hospital separations	1979	1986 (b)	1993 (c)	1984	1981	1997 (d)	1976	1981
Maternal/perinatal collections	1986	1982	1987	1981	1980	1996	1986	1989
Cancer registries	1992	1982	1988	No (e)	No (e)	1991	1981	1992
Communicable diseases collections	1991	No (f)	Yes	Yes	1988	Yes	pre-1980	1991

Notes:
(a) If date of first collection is unknown, current status is shown (indicated by 'Yes')
(b) Extended to private hospitals in 1993(c) Partial introduction in 1988
(d) Proposed for end 1997
(e) While the notification system does not record Aboriginality, the collection does as the dataset is linked (or can be manually matched) to other sources which do record Aboriginality
(f) HIV/AIDS is the only notifiable communicable disease in Victoria which has capacity to record Indigenous status

Source: Australian Bureau of Statistics / Australian Institute of Health and Welfare (1997) **Indigenous Identification in Administrative Data Collections – Best Practice and Quality Assurance.** Report on Workshop Proceedings – November 1996. Australian Bureau of Statistics, Canberra. *(From information provided by State and Territory health departments and Registrars in January 1997).*

Hospital separations and morbidity collections

The Northern Territory was the first jurisdiction to introduce an Indigenous identifier in its hospital separations collection, in 1976. NSW followed in 1979, WA and the ACT in 1981, SA in 1984, Victoria in 1986, and Queensland introduced the first stage of a separate identification process in 1988 – with a more comprehensive approach following later in 1993. Tasmania remains the only jurisdiction without formal identification processes for Aboriginal and Torres Strait Islander peoples in hospital collections, however there are plans to introduce this from late 1997.

The history of separately identifying Aboriginal and Torres Strait Islanders in maternal and perinatal collections demonstrates a more targeted national approach to improving data collections than the ad-hoc incremental processes adopted by individual jurisdictions for mainstream hospital collections. This followed national agreement of jurisdictions in the early to mid-1980s to, amongst other issues, seek to collect a range of perinatal-related information for all pregnancies in Australia. Amongst the data collected were risk factors for high infant mortality and morbidity and, amongst these, the mothers' Indigenous status. Specially-trained midwives were employed in all states and territories to visit all hospital records and obstetric units and work with staff to initiate and maintain the collection of these data, including the Indigenous status of mothers. Prior to this, only WA, SA and Victoria had processes in place for Indigenous identification in perinatal collections (introduced in 1980, 1981 and 1982 respectively). Following the targeted effort of site visits to all hospitals, almost all other states and territories followed suit in the ensuing years – NSW and NT in 1986, Queensland in 1987, and the ACT in 1989. Tasmania was the last state to initiate separate Indigenous identification in perinatal collections, in 1996.

1.3 Operational procedures for gathering information about Indigenous persons

Vital statistics

Agreement has been reached amongst all state and territory Registrars-General (as well as by the Australian Bureau of Statistics [ABS]) to use the National Health Data Dictionary Version 6 operational question about Indigenous status, namely:

> *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* .....

This standard allows for the separate identification of both Aboriginal persons and Torres Strait Islanders from non-Indigenous persons, in addition to capturing those individuals who identify as being of both Aboriginal and Torres Strait Islanders.

However, as indicated in Table 2 (later in this chapter), the Indigenous identification questions vary amongst the states for birth and death notifications. Indeed, there are even different questions asked of birth and death notifications within two jurisdictions (WA and the ACT). For instance:

- the above standard is applied for both births and deaths in NSW, Queensland and SA, and for births only in the ACT;
- a combined Aboriginal and Torres Strait Islander origin question (without the scope to identify separately or as of both origin) is asked in relation to all births and deaths in Vic, NT, and for births in WA, and for deaths in the ACT;
- Tasmania asks a question only of Australian Aboriginality origin (self-selected among a range of racial groups including European and Asian) of both birth and death notifications, while WA also asks only about Aboriginality in relation to deaths.

In relation to birth notifications, details of Indigenous status are sought from both parents. In almost all states, the parents are required to complete the birth notification/registration form. However, in some cases (for instance in some traditional communities in the Northern Territory), health workers may be called upon to complete the birth notification forms on behalf of the parents.

Death notification forms are usually completed by the funeral director responsible for arranging the burial or cremation of the deceased person, however this is almost always done with the assistance of an informant, usually a close relative of the deceased person.

Figures 1 and 2, overleaf, indicate the ratio of actual registered Indigenous births and deaths to those expected, based on ABS population projections for each state and territory for the full years 1992 to 1995. This clearly demonstrates that, while coverage of Indigenous birth registrations is over 80 or 90% in most jurisdictions, less than half of all Indigenous deaths are registered as such throughout Eastern Australia. Further, while NSW and Victoria currently identify between 40 and 50% of Indigenous deaths each year, in Tasmania the figure is less than 10%. Such is the poor quality of these data, the ABS considers that only WA, SA, NT and ACT death registrations data are of publishable quality, resulting in the use of Indigenous death data from WA, NT and SA as proxy data for the Eastern states.

Figure 1 Ratio of Registered to Expected Births, by State and Territory, 1992-1995

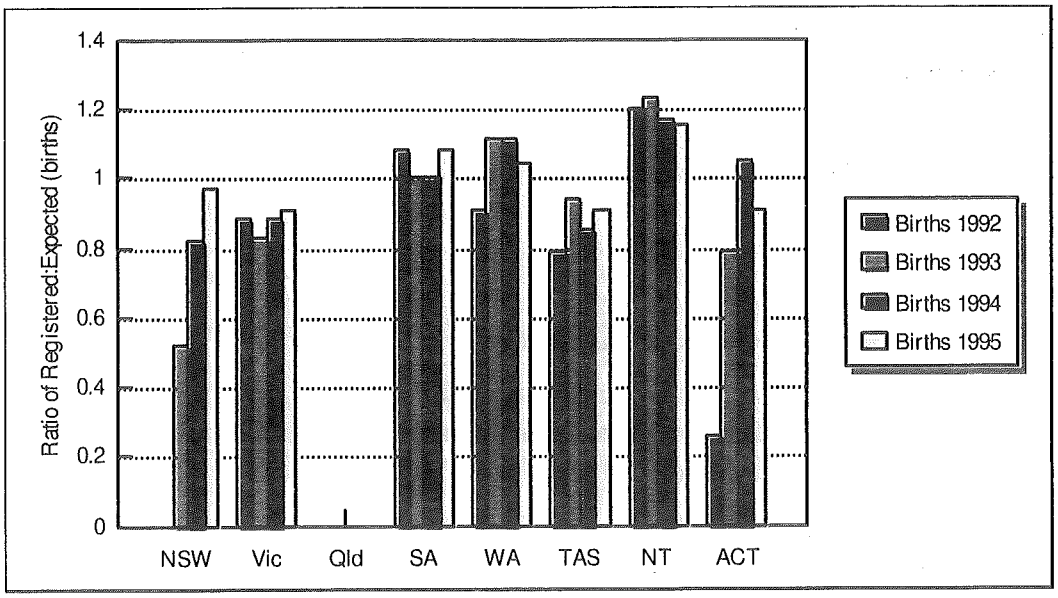
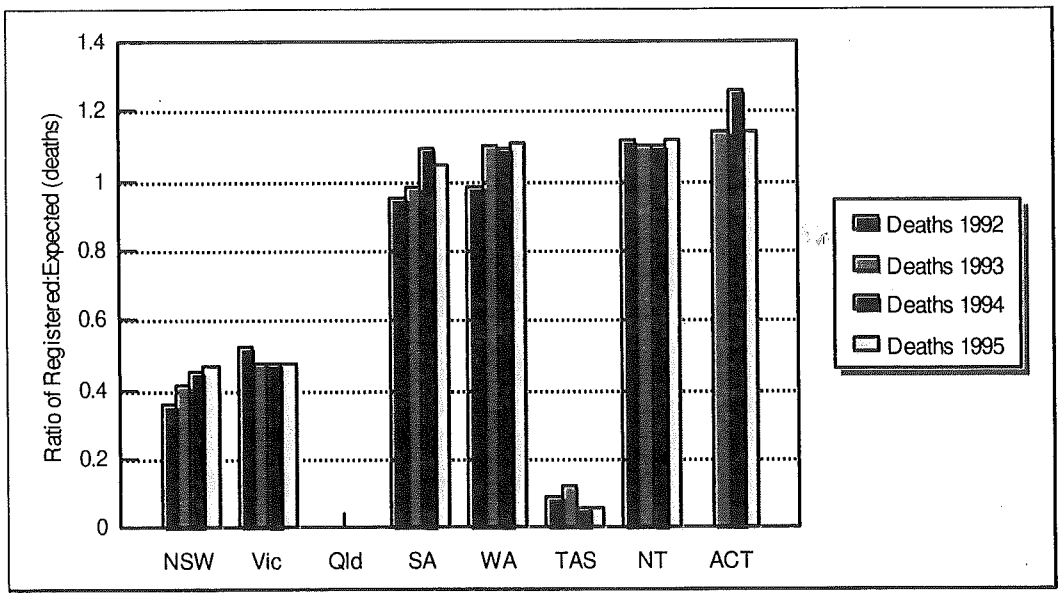


Figure 2 Ratio of Registered to Expected Deaths, by State and Territory, 1992-1995



The data on birth and death registrations in Figures 1 and 2 suggest that Queensland does not collect or report separately on Indigenous births and deaths. However, Queensland was the last state to initiate collection of Indigenous births and deaths data throughout the state, which began from 1 January 1996. As such, there is only one full year of data to report – and, given the normal difficulties associated with initiating new data collection and recording practices, it is possible to expect that comprehensive reporting of Indigenous birth and deaths data may take several years to achieve.

Nevertheless, preliminary analysis of the 1996 Queensland registrations indicates comprehensive compliance with identifying Indigenous status in birth registrations – so much so, that the actual Indigenous birth registrations totalled almost 3,500, some 38% higher than the 1996 population estimates figures (high series). Quality checks on these data suggest that the information supplied is reliable. However, while vast improvements have also been achieved for Indigenous identification in deaths registrations, this has not met with the same level of success as the births data. Nevertheless, the recent Queensland experience clearly demonstrates to the other eastern states the substantial inroads that can be achieved in a short period of time, given the appropriate level of commitment and the will to do so. The strategies adopted in Queensland are provided in the case study below.

Separate identification of Indigenous persons in births and deaths data
– the Queensland experience –

While Queensland only introduced an Indigenous identifier in vital statistics collections for the first time in 1996, many of the lessons learned from the Queensland experience are applicable to other jurisdictions.

Summary of action taken:

- New births and deaths registration forms were produced for use from 1 January 1996, with provision for identification of Indigenous status of the registrant.
- A Working Group was established by the ABS Queensland Office and met monthly to monitor the implementation of the new forms (a role which later expanded to include improving the quality of the data reported). Representatives include the ABS, the Qld Government Statistician's Office, Registrar-General's Office, Qld Department of Health (including the Aboriginal Health Unit), the Indigenous Health Program (University of Qld), the Department of Families, Youth and Community Care, and community representatives.
- Interim forms were distributed to court houses (for use from January 1996) with a covering explaining the changed form. Samples of the forms (with covering letters) were also sent to hospitals, funeral directors' associations, etc.
- Use of the forms was closely monitored in the first six months, and follow up phone calls made as appropriate to encourage those not using the forms to do so.
- A more targeted (and highly successful) strategy was adopted for the final forms, in July 1996. Bulk copies of these forms were widely distributed to hospitals, courthouses, general practitioners, individual funeral directors (rather than only to their professional associations), and any other potential users. In addition to the covering letters, brochures were also included explaining the need to complete the Indigenous identification section of the form. These brochures were redistributed a further time in November to metropolitan funeral directors (where compliance with completing the question appears to be slower).
- Further communications activity occurred through a representative of the Registrar-General's Office addressing the funeral directors' annual conference on the importance of using the new forms and completing the Indigenous identification question.
- While monitoring has continued, compliance now appears very high, with little recourse to follow up telephone contact required.

Information provided by Malcolm Greig, ABS Queensland Office

Completion of the Indigenous status question in birth and death registrations vary across Australia, however, most jurisdictions report high coverage in terms of response to the Indigenous identification question on birth notification forms. Death registrations are another story however, even then, wide variations occur across states. For instance, WA has 95% completion rates while, in Victoria, almost one third of all death registration forms contain no response to the Indigenous identification question

While no jurisdiction follows up informants where there is no response to Indigenous identification questions in relation to births and deaths, some (e.g. NT) initiate follow up action where it is believed that the information provided may be incorrect (e.g. on the basis of local knowledge, the name of the birth or death registrant, or the place of residence).

The question of why the seeking of a person's Indigenous status should prove difficult in relation to deaths but not for births needs to be considered. Some states report considerable resistance from funeral directors to comply with the request to ask about the Indigenous status of all deceased persons, citing the main reasons as fear of offending bereaved persons or discomfort at asking seemingly irrelevant questions at a time of grief. Another reason offered is that more mistakes in reporting this information may be more likely for deaths notifications due to the grief and stress experienced at this time.[1]

Either way, many states have realised the importance of working with funeral directors to encourage collection of information about the Indigenous status of deceased persons, and have targeted efforts in this direction. Specific initiatives include educational resources and promotional leaflets targeting funeral directors explaining the importance of such information and the reasons for collecting these data, and also redesigning the notification forms to highlight the Indigenous information question (to prevent accidental omission).

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[1] Graham Crawley, General Manager Australian Funeral Directors Association (Queensland), in Australian Bureau of Statistics / Australian Institute of Health and Welfare (1997) **Indigenous Identification in Administrative Data Collections – Best Practice and Quality Assurance**. Report on Workshop Proceedings – November 1996. Australian Bureau of Statistics, Canberra.

Why are ACT Indigenous death registrations data so comprehensive?

The ACT is worthy of particular mention in relation to coverage of Indigenous death data. Why, when the surrounding/nearest states of NSW and Victoria are achieving less than 50% coverage, is the ACT consistently recording close to or in excess of 13% of the expected number of deaths? Why are the difficulties associated with encouraging self-identification in the major cities in NSW and Victoria not carried through to the ACT – which is merely a geographic island surrounded by NSW? Shouldn't the ACT experience similar problems?

The limited research undertaken as part of this project has revealed that the ACT Registrar-General's Office's procedures for identifying the Indigenous status of births and deaths registrants are no different to those in NSW and Victoria. Indeed, the ACT takes no action to follow up informants where there is no response to Indigenous identification questions on death notifications forms.

When questioned about this phenomenon, ACT respondents considered that demographic and socioeconomic issues may explain the high rate of self-identification amongst Indigenous residents in the ACT. That is, a high proportion of the ACT's Indigenous population are more highly educated and have greater incomes than their counterparts in other states. Many are also employed – or their family members are employed – in government agencies, particularly in the Aboriginal and Torres Strait Islander Commission (ATSIC) or in Aboriginal policy or program areas – this, it was suggested, made many of the ACT's Indigenous persons acutely aware of the importance of Indigenous self-identification. Indeed, one Indigenous respondent related her experience of attending an ACT Indigenous community meeting for the first time after transferring from interstate, at which participants were constantly reminded of their duty "to stand up and be counted" at every opportunity. The respondent noted that she had never before witnessed such sentiment in any other community.

Whether the ACT differences can be explained by social influences, or whether there are other determinants, remains uncertain. However, the issue does warrant further detailed research.

Hospital collections

All states and territories maintain central collections detailing data about hospital separations and hospital-related morbidity. Additionally, all jurisdictions have perinatal / maternal (midwives) collections, while many have other hospital-based collections such as for mental health services or elective surgery waiting lists. Each of the state hospital separations and perinatal collections have the capacity to record the Indigenous status of inpatients, however, like birth and deaths notifications, the actual definitions and questions differ across the country. (The range of questions used are listed in Table 2 at the end of this chapter.)

All public – and most private – hospitals are required to provide information about the Indigenous identity of patients. Instruments for encouraging compliance with the seeking and provision of such data include performance agreements (e.g. with area health boards and/or individual hospitals), legislation (e.g. for NSW private hospitals), and funding or service agreements. A further (and recent) initiative which, while not intended for this purpose, is expected to result in significantly improved identification of Indigenous patients, is the introduction of a 30% casemix funding weight for treatment of Indigenous patients in South Australian hospitals.

Incentives for Improving Indigenous Status Information

Financial incentives

In recognition of the often higher costs associated with providing health services to Indigenous patients, the South Australian Health Commission (SAHC) has this year introduced a loading for treatment provided to Indigenous patients in South Australian hospitals. Some millions of dollars annually has been allocated to cover the Indigenous casemix weights. Thus, although intended as a measure to address inequities in the costs of service provision, an unintended consequence of this initiative is likely to be an unprecedented level of activity by South Australian hospitals to improve its data collection procedures in order to enhance the quality of Indigenous status information. Indeed, the financial incentives to do so are of a considerably higher order of magnitude than any previous incentives to improve Indigenous data collection. Already, hospitals are modifying their information systems and putting in place operational procedures to encourage staff to complete the Indigenous status identification question for all hospital admissions.

However, respondents in the SAHC also recognise this 'opportunity' as potentially problematic, in that nobody is really able to anticipate the likely impact of the financial incentive to improve Indigenous identification in hospital information collections. Indeed, there is a fear that this may result in overenumeration of Indigenous patients – or cases where non-Indigenous patients are incorrectly recorded as Indigenous. As such, SAHC executives will be eagerly awaiting preliminary results of the impact of the new Indigenous casemix weights over the coming months.

Nevertheless, the issue of providing incentives – financial or otherwise – warrants serious consideration in other jurisdictions

Non-financial incentives

Another potential strategy for encouraging greater efforts amongst health services to improve Indigenous data collection includes the use of accreditation systems, such as the Australian Council on Healthcare Standards (ACHS)[2] in hospitals, and the Community Health Accreditation and Standards Program (CHASP)[3] for community-based health services and programs – both of which seek to improve and assure the quality of health services by assessing the capacity with which institutions and services meet prescribed quality standards. Consideration could be given to working with these major agencies to include new standards for Indigenous health information when these are next reviewed.

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[2] Australian Council on Healthcare Standards (ACHS) Care Evaluation Program, Melbourne, contact (03) 9417 5488.

[3] Australian Community Health Association. (1993) **Manual of Standards for Community and Other Primary Health Care Services**. Community Health Accreditation and Standards Program, ACHA, Sydney.

However, while almost all state and territory health authorities had policies in place for asking about the Indigenous status of all patients, the actual practices for collecting and recording this information varies enormously between states – and also between hospitals within states. Common approaches include any one or a combination of:

- the direct questioning of all patients about their Indigenous status;
- the direct questioning of only those patients who hospital staff thought were of Aboriginal or Torres Strait Islander appearance;
- patient self-completion of admission forms containing an Indigenous identity question;
- assumptions made by hospital staff based on the patient's appearance or local knowledge; and
- prominently displaying in waiting rooms the procedures for seeking information about clients' Indigenous status, for the purpose of encouraging people to self-identify.

During the consultations on this review, many hospital and health services staff expressed concerns about asking patients questions concerning their Indigenous status, often citing the fear of causing offence to patients (both Indigenous and non-Indigenous). Still others reported that many Indigenous persons were afraid to self-identify as such for fear of being discriminated against or receiving different treatment. These concerns are highlighted in the case study overleaf of Victorian midwives' attitudes to asking mothers about Indigenous identity, however, the experience of this review suggests that such attitudes and practices are widespread throughout Australian hospitals, and particularly in Eastern states.

In the case of perinatal collections, maternal self-identification is the sole method of determining an infant's Indigenous status. A midwives' data collection form is completed for all births by the attending midwife. The mother's self-identification of ethnic origin is automatically recorded as the baby's identity. Consequently, all perinatal collections are likely to under-record Aboriginality for Indigenous mothers who do not identify themselves as such and for Indigenous Aboriginal babies born to non-Indigenous mothers.

However, one state in particular – Western Australia – has met with considerable success in terms ensuring high quality of Indigenous status information in its perinatal collection through linking birth notifications with records contained in perinatal collections, as highlighted overleaf. However, it is also pertinent to acknowledge that, while data linkage provides a useful quality assurance tool, it also raises considerable issues concerning confidentiality and privacy concerns.

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Issues affecting quality of identification in perinatal collections

A Victorian study[4] surveyed 54 hospital-based midwives to ascertain how they completed perinatal forms and whether they experienced any difficulty seeking information about the Indigenous status of mothers.

The study found that:

- Midwives did not ask the Indigenous identifier question of every mother – rather, the midwives would only ask it if they thought that the woman (and/or the person accompanying her) was of Aboriginal or Torres Strait Islander appearance;
- The only exception was one hospital where midwives reported that they felt comfortable asking the question of all women because, and that they knew the Indigenous persons living in the area and were aware of their general pride in being identified as Koori;
- The major reasons cited by midwives for not asking the question was that they did not understand the relevance of the question, that having to ask the question made the midwives feel uncomfortable, and that they felt it would make the women in their care uncomfortable;
- Reasons why the question made the midwives feel uncomfortable included: the fear that the question would cause offence to be Indigenous and non-Indigenous women, the fear that it may have an adverse effect on their relationship with the women, a fear of verbal or physical abuse by offended women and/or their partners, and that they felt "stupid" for asking the question of all women (especially those who had an obvious European or Asian appearance);
- Other midwives expressed annoyance or concern about having to make a special case for Aboriginal services and considered that Indigenous persons should assimilate with the rest of the community.

Achieving High Quality Indigenous Identification Information in Perinatal Statistics

Western Australia is renowned for having achieved highly accurate Indigenous status information in perinatal statistics collections. Further, the high quality of these data has been demonstrated through several studies, with less than 2% of cases found to have been incorrectly recorded.

The Western Australian Midwives' Notification System is the core component of the Western Australian Maternal and Child Health Research Data Base. In addition to the data from the Midwives' Notification System, the Data Base includes birth and death information from the WA Registrar-General and the Australian Bureau of Statistics, and hospital discharge data for all public and private hospitals in the state. Information about deaths and hospital admissions are complete for all children to age 15 years, and all data are linked to individual mother and child pairs. Additionally, 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.

Adapted from Read and Garfield (1997) [5]

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[4] Robertson H. (1994) **Koori Health Counts: How midwives identify women as Aboriginal or Torres Strait Islanders.** Koori Health Section, Department of Health and Community Services, Melbourne.

[5] Read A & Garfield C. (1997) *Indigenous identification in maternal and child health research in Western Australia*, in the ABS/AIHW publication, **Indigenous Identification in Administrative Data Collections – Best Practice and Quality Assurance**, Report on Workshop Proceedings, Nov. 1996.

This review found, in general, hospital admission procedures for collecting information about patients' Indigenous identity to be as haphazard and subjective as those illustrated in the study on the previous page – including even in the Northern Territory, which is considered to have one of the best hospital separations collections in terms of high quality coverage of Indigenous-related information. Indigenous respondents there reported that they had rarely been asked to self-identify during interactions with health services – likewise, staff consulted said that they rarely asked, noting that they tend to identify clients' Indigenous status based on their physical appearance or on local knowledge. Thus, the quality and coverage of Territorian collections was attributed by some respondents to "good luck rather than good management" – due largely to the particularly distinctive "Aboriginal" appearance of many Indigenous people in the NT.

However, as the case study overleaf clearly demonstrates, the widespread "fear of causing offence", cited by many hospital staff for not asking about Indigenous status, appears to be groundless. This study found that none of the Indigenous patients interviewed complained of feeling affronted at being asked about their identity – indeed, many expressed a feeling of pride at being asked or given the opportunity to identify as an Indigenous person.

This highlights the obvious need for widespread cross-cultural awareness training of health services staff who are responsible for seeking information about the Indigenous identity of patients.

Attitudes to asking and being asked questions about Indigenous status in hospitals[6]

A recent Queensland study has provided some interesting insight into the attitudes of both hospital staff and Indigenous clients concerning the seeking of information about patients' Indigenous status. Researchers concluded that asking about cultural identity appears to be much less problematic than many staff believed it to be, and that the critical factor was a lack of appropriate administrative process for seeking and recording information about identity, rather than risk of causing offence to patients. Interviews were conducted retrospectively with patients at selected major Brisbane hospitals to ascertain whether or not they were asked questions about identification, how they were asked, how they responded to it, and why. Interviews were also conducted with admission clerks and other admission-related hospital staff and Aboriginal hospital liaison workers.

Findings - Perceptions of Indigenous identity:

- Not one Indigenous patient expressed concern regarding being asked about their identity;
- Many strongly voiced their pride in answering the identity question;
- Most did not understand why they were asked but, since they were asked, would answer;
- A few felt that there were medical reasons why they were asked, noting that Indigenous people were more likely to experience some conditions, therefore maybe they require different treatment;
- One respondent explained that such information was very important for developing solutions to Indigenous health and also aided patients in receiving support from hospital liaison staff; all Indigenous patients interviewed felt that they were treated equally to other patients;
- However, almost all complained of feeling isolated within the hospital environment, with comments relating to the general shyness of Indigenous persons, and the difficulty conversing on the same level as hospital staff and therefore preferring to have Aboriginal staff to talk to;
- Indigenous identity shone through very strongly in almost all situations, with all respondents commenting that they would always answer an identity question.

Findings – Hospital admission processes and attitudes of staff:

- In general, staff reported that patients often completed their own admission forms;
- Where this is not the case, the admission clerk (or, occasionally, ward staff) verbally asks the questions and completes the form (often directly on to the computer file);
- Staff responded that they "usually" ask the identity question (however staff at one hospital, with a higher rate of referred private patients, responded that the ethnicity question was not asked "as it was perceived as unimportant");
- When staff don't ask, they "sometimes" decide on the basis of visual judgement on appearance;
- Admission staff responded that patients often do not answer the ethnicity question – noting that, when they had attempted to follow up on this omission patients often objected, resulting in staff ticking the 'other' category or making a visual assessment.

Recommendations for improving Indigenous data in hospital information systems:

- All patients should be asked about cultural identity – visual judgements should never be made; hospital staff should be trained in how to ask about identity, and also in the importance of public health information;
- Liaison Officers should be employed by Queensland Health to support state hospitals to implement changes to their information systems.

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[6] Shannon C, Brough M & Haswell-Elkins M. (1997) **Identifying Aboriginal and Torres Strait Islander People on Hospital Records – Problems and solutions in public health information.** Indigenous Health Program, The University of Queensland & the Queensland Institute of Medical Research, Brisbane.

Other major health collections

Almost all state and territory cancer registries and notifiable communicable disease collections have the capacity to separately record Indigenous status, however, with very few exceptions, the Indigenous status data in these collections are known to be patchy at best. This is due to these collections' secondary data source status, in that, the collections rely on data referred from other sources – usually primary care practitioners, pathology laboratories and hospitals. Thus, the collections are reliant on the vigilance of others to collect and report information about the Indigenous status of persons at every step in the process – that is, for individual private practitioners to ask patients to self-identify, to record this information on the pathology or hospital or disease notification forms, for staff at the laboratory or other facility to transfer this information to their records, and then to forward the information further to the cancer registry or communicable diseases notification system.

As has been illustrated elsewhere in this report, formal and methodical guidelines and procedures to collect and record information about individuals' Indigenous status are few and far between (particularly in health services institutions' collections). But the cancer and communicable diseases collections rely on several steps and data sources – where, at any point the system may break down. In the absence of due care at each step in the collection and reporting process, or the initiation of systematic or one-off data matching exercises, little reliance can be placed in the data quality of these collections.

The quality of the recording of Indigenous status in most community-based health collections, such as those of community health centres and services, was generally quite poor.

While some had the capacity to collect information about the Indigenous identity of clients, this was limited by the generally ad-hoc nature of community health information in general – that is, poorly designed information systems, antiquated and incompatible equipment and software, and little capacity to extract and analyse information collected. Of course, the problems relating to obtaining quality data about Indigenous persons in vital statistics and hospital collections – such as inattention to standard procedures for collecting, recording and reporting on Indigenous identity – also apply to community health collections. It also needs to be acknowledged that many Indigenous persons harbour concerns about the reporting of data about sexually transmissible diseases – particularly at the local level.

However, four states are currently collaborating to develop a Community Health Information System (CHIS) which will fully capture information about people's usage of and access to wider community health services, including those for Indigenous people. This system is being developed in partnership between NSW Health, the South Australian Health Commission, Queensland Health and the ACT Department of Community Care. Other states and the Northern Territory are also actively developing their own systems.

1.4 Initiatives to improve data quality

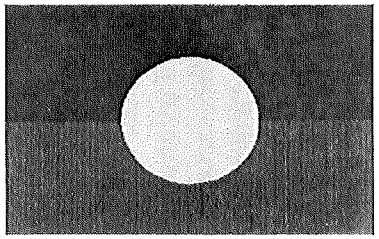
This review found few systematic mechanisms in place to check the quality of Indigenous data in the various collections. However, many collections have adopted a range of one-off or short term strategies to assess the quality of the data. These include:

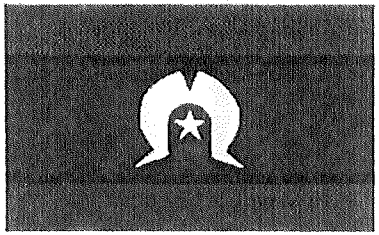
- Benchmarking – that is, using the Census figures or preferably ABS population estimates as denominators for calculating expected rates, and comparing these with Indigenous coverage in existing collections;
- Cross-checking data with other sources – matching records from two or more datasets;
- Using Indigenous Hospital Liaison Officers to assist in collecting Indigenous status data from patients and comparing these with information about Indigenous persons in hospital records;
- Checking medical certificates against communicable disease notification forms, and also checking medical certificates of cause of death against death notifications;
- Assessing the quality of Indigenous status information transfer from primary data sources to final data sets;
- Direct follow up with funeral directors who submit incomplete notification forms; and promoting awareness amongst information collectors (e.g. hospital admission clerks, funeral directors, etc.) of the importance of collecting information about Indigenous identity, and providing them with training and support in the appropriate strategies with which to do so.

Other strategies to improve the quality of information about Indigenous persons in major collections relate to finding less threatening ways of seeking this information. As noted previously, this is a major issue – particularly for health services staff. Therefore, strategies need to be identified and implemented to facilitate easier ways of seeking information about clients' Indigenous identity. Three strategies warrant particular mention here, as each were found to be highly acceptable to both Indigenous persons and to health services staff – and they had the added advantage of substantially increasing people's willingness to self-identify as Indigenous. These include the use of:

- Employing Aboriginal Hospital Liaison Officers – this strategy, more than any other, has been found to greatly enhance the quality of Indigenous identity information, as well as facilitate greater cross-cultural understanding and awareness between Indigenous persons and hospital staff, and generally ease Indigenous patients' concerns about being admitted to hospital;
- Self-completed forms containing an Indigenous identity question (that is, rather than direct asking of patients) – the completion of pre-admission forms in the privacy of people's own homes, where possible (it is noted that such forms may also need to be completed with the assistance of Aboriginal Hospital Liaison Officers and/or Aboriginal Health Workers where literacy may be a problem);
- Explanation of the reasons for collecting Indigenous status information as a general strategy for reducing apprehension; and
- promotional material highlighting the importance of self-identification amongst Indigenous persons, including the use of clearly visible posters and other material in hospital waiting rooms, Registrar-General's Offices and any other appropriate venues. (An example is provided overleaf.)

Australian Bureau of Statistics





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

WHY IS THIS QUESTION IMPORTANT FOR HEALTH INFORMATION?

Why is this question important for health information?

When people go to hospital because they are sick or because they are going to have a baby they are asked a lot of questions. One question that is very important is;

"Are you of Aboriginal and/or Torres Strait Islander origin?"

If you are not asked this question it is very difficult to find out how many Aboriginal and Torres Strait Islander people are going to hospital and for what reasons. Also it is hard to find out how many Aboriginal and Torres Strait Islander people are dying and what are the causes of death. This will help us to understand if Aboriginal and Torres Strait Islander people are getting better or worse, health wise.

A lot of people from government and Aboriginal and Torres Strait Islander organisations around Australia are working to improve the identification of Aboriginal and Torres Strait Islander people so that better information can be obtained.

Why is this information needed?

The health of Aboriginal and Torres Strait Islander people is worse than the health of the rest of the Australian community. Aboriginal and Torres Strait Islander people don't live as long; about 20 years less than for other Australians. We need to know more about the causes of ill health and death among Aboriginal and Torres Strait Islander people. Why? To make sure health services are properly resourced and to work out if things are improving or getting worse.

Is it discriminatory to ask this question?

No, it's not, but sometimes people feel embarrassed or wonder why this question is asked. The information is used for statistical purposes to measure the health and well being of Aboriginal and Torres Strait Islander people. It's a message about your health. It could be regarded as discriminatory not to ask this question, as this important information would not be available for decision makers working towards improving health and well being of Aboriginal and Torres Strait Islander people.

Table 2 Current Operational Questions and Procedures for Collecting and Recording of Information About Indigenous Identification

State	Wording of Indigenous Identification Question/s
	Birth Notifications
NSW	Is the mother/father of Aboriginal or Torres Strait Islander origin? Yes/No (For persons of mixed origin, tick both 'Yes' boxes)
Vic	Is the child's mother/father of Aboriginal or Torres Strait Islander origin? Yes/No
Qld	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	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)
WA	Aboriginal or Torres Strait Islander? Yes/No (Completed by mother and father)
Tas	Origin: Mother/father – Australian Non-Aboriginal, Australian Aboriginal, European, Asian, Other (Specify)? Tick appropriate box (self identification)
NT	Is the child's mother/father of Australian Aboriginal or Torres Strait Islander origin? Yes/No
ACT	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 Notifications
NSW	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (For persons of mixed origin, tick both 'Yes' boxes)
Vic	Was the deceased of Aboriginal or Torres Strait Islander origin? Text answer
Qld	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (If both Aboriginal and Torres Strait Islander, tick both 'Yes' boxes)
SA	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No (If of both Aboriginal and Torres Strait Islander, tick both 'Yes' boxes)
WA	Aboriginal? Yes/No
Tas	Origin of deceased: Australian Non-Aboriginal, Australian Aboriginal, European, Asian, Other (Specify)? Tick appropriate box
NT	Was the deceased of Aboriginal or Torres Strait Islander origin? Yes/No
ACT	Was the deceased an Australian Aboriginal or Torres Strait Islander? Yes/No
	Hospital admissions
NSW	Indigenous status: Aboriginal, Torres Strait Islander, Both Aboriginal and Torres Strait Islander, Neither Aboriginal or Torres Strait Islander? Tick appropriate box
Vic	Aboriginality: Aboriginal or Torres Strait Islander, Not Aboriginal or Torres Strait Islander? Tick appropriate box
Qld	Ethnic origin: Caucasian/European, Aboriginal, Torres Strait Islander, Asian, Other, Not stated/Unknown? Tick appropriate box
SA	Race: Caucasian, Aboriginal, Asian, Other, Torres Strait Islander, Both Aboriginal and Torres Strait Islander, Unknown? Tick appropriate box
WA	Aboriginality? Yes/No
Tas	Question proposed to be implemented end 1997
NT	Aboriginal or Other? Tick appropriate box
ACT	Ethnic origin: Aboriginal, Non-Aboriginal? Tick appropriate box
	Perinatal forms
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: Australian Bureau of Statistics / Australian Institute of Health and Welfare (1997) **Indigenous Identification in Administrative Data Collections – Best Practice and Quality Assurance.** Report on Workshop Proceedings – November 1996. Australian Bureau of Statistics, Canberra. (*From information provided by State and Territory health departments and Registrars in January 1997*).

2 National initiatives in Indigenous health-related information

The 1990s have witnessed increasing and unprecedented awareness in, and activities to improve, information and data collection – across health services and publicly funded programs in general, as well as in relation to Indigenous issues in particular.

This has, in part, developed from heightened community and government concerns to strengthen accountability for public expenditure, and the accompanying need to know what moneys are spent, by whom, for what services, which population groups receive the services (and, even more importantly, who is missing out), and whether the services resulted in any identifiable improvements.

Additionally, and in the case of Indigenous peoples and their health in particular, calls for improved information follow increasing government and community awareness of the need for increased commitment to affirmative action initiatives across a range of endeavours, in an attempt to redress the significant – and worsening – health and socioeconomic differentials between Indigenous and non-Indigenous Australians. Therefore, accurate information is required about the number of Indigenous persons residing in a given area, demographic details and health status, and also their requirements, in order to more appropriately and effectively fund, plan, deliver and monitor local services.

At the national level (and to a lesser extent, the state and territory level), this need to monitor health status, program expenditure and outcomes, is reliant on the existence of standard practices across all jurisdictions for the collection and reporting on the required information, so that national reporting is accurate, and based on consistent standards, indicators and procedures.

2.1 National Health Information Agreement and related initiatives

The key mechanism through which the process to improve the uniform collection, quality and dissemination of national health data is the ***National Health Information Agreement (NHIA)***, which commenced operation in June 1993, and to which the heads of the Commonwealth, and state and territory health authorities, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare are signatories. In addition to improving data, the NHIA also provides the framework and mechanism through which to promote sharing of national health information, and co-operation in the provision of resources to address information development priorities.

The major implementation mechanism of the NHIA is the ***National Health Information Work Program***, which details priority health information activities and development requirements, and processes for their implementation. One initiative developed under the work program is the ***National Health Data Dictionary***, under the guidance of the ***National Health Data Committee (NHDC)***, which provides national standards for use in Australian health data collections.

The implementation of the work program is overseen by the ***National Health Information Management Group (NHIMG)***, which comprises representatives of all major health information interest groups. The NHIMG is also responsible for reporting on health information development and progress to the Australian Health Ministers' Advisory Council (AHMAC). Secretariat support to the NHIMG is provided by the Australian Institute of Health and Welfare (AIHW).

Under the auspices of these initiatives, the AIHW organised the ***National Health Information Forum*** in 1994. This forum recommended that the highest national priority in information development was the need for a ***National Indigenous Health Information Plan***, thus, leading to this review and report. This point was also included in the ***National Health Information Development Plan***, which was developed by the NHIMG following the Forum, and subsequently endorsed by the Australian Health Ministers' Advisory Council (AHMAC). It was this Forum and the subsequent Development Plan that recognised that Indigenous information was the highest priority for health information development in Australia. This recognition led to the development of this review and National Indigenous Health Information Plan.

It is important to recognise the significant gains that have occurred in relation to information development over recent years, which are due predominantly to this ongoing and effective national committee infrastructure to support improvements in information quality.

Thus, there is every reason to consider that, due to the existence of these initiatives and the heightened awareness of the need for quality information in the health sector, the potential for implementing this review's recommendations is considerably greater than for those reviews which have gone before.

However, these processes were established for the purpose of streamlining information collection and reporting amongst Commonwealth, state and territory government health and related agencies. There is little, if any, scope at present for involvement of Indigenous or any other community interests in the activities and decision-making processes undertaken under the auspices of the National Health Information Agreement and the National Health Information Management Group.

Yet, it is the position of this review that the National Health Information Management Group, comprising all senior government health interests, must take a lead role in improving the quality and coverage of Indigenous health information in all Australian jurisdictions. As such, it behoves the NHIMG and other key interest groups to establish mechanisms which facilitate the active participation of agencies such as the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Heads of Aboriginal Health Units (in government health agencies – HAHU) in making decisions and leading Australia's efforts to improve Indigenous health information.

2.2 Clarification of responsibilities and frameworks for Indigenous health services

Responsibility for funding Indigenous health services and programs is shared between the Commonwealth and state/territory governments. The provision of services is the responsibility of the state and territory health authorities and some Indigenous community-controlled health organisations. At the national level, funding and administration of Indigenous health programs transferred from the Aboriginal and Torres Strait Islander Commission (ATSIC) to the Commonwealth Department of Health and Family Services (DHFS) in July 1995. The respective roles and responsibilities of both these agencies in relation to Indigenous issues, including the monitoring of program effectiveness, is established in a ***Memorandum of Understanding*** [7] (MOU) between the two agencies. The MOU stipulates that all activities undertaken by the respective agencies must observe the principles espoused in the National Aboriginal Health Strategy, namely:

- acknowledgement and acceptance of Aboriginal and Torres Strait Islander peoples' holistic view of health;
- recognition of the importance of Indigenous community control and participation; and
- the importance of intersectoral collaboration.

On another level, the principles and arrangements for the planning, service delivery and accountability for Indigenous health services provision at the state and territory level, are being effected through ***Framework Agreements on Aboriginal and Torres Strait Islander Health***,[8] which are in the process of being negotiated and signed. At this point in time, Framework Agreements have been signed between the relevant parties in all but two states/territories.

The Agreements are negotiated individually but many cover common ground. An example of such an Agreement states its aims as improving health outcomes for Aboriginal and Torres Strait Islander peoples through:

- improving access to both mainstream and Aboriginal and Torres Strait Islander specific health and health-related programs which reflect the level of need;
- increasing the level of resources allocated to reflect the higher level of need of Aboriginal and Torres Strait Islander peoples, including within mainstream services, and transparent and regular reporting for all services and programs; and
- joint planning processes which will inform the allocation of resources and allow for:
  - ⇒ full and formal Aboriginal and Torres Strait Islander participation in decision making and determination of priorities;
  - ⇒ improved co-operation and co-ordination of current services delivery, both Aboriginal and Torres Strait Islander specific services and mainstream services, by all spheres of government;
  - ⇒ and increased clarity with respect to the roles and responsibilities of the key stakeholders.[9]

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[7] ATSIC & DHSH. (1995) **Memorandum of Understanding** – Between: The Chairperson of the Aboriginal and Torres Strait Islander Commission, and the Commonwealth Minister of State for Human Services and Health, Canberra.

[8] Department of Health & Family Services. (1996) **Agreement on Aboriginal and Torres Strait Islander Health** – Between: (State) Minister for Health, the Commonwealth Minister of State for Health and Family Services, the Chairperson of the Aboriginal and Torres Strait Islander Commission, and the (State) Aboriginal Community-Controlled Health Organisation, Canberra.

[9] Department of Health and Family Services, ibid., Section 2.

This Agreement emphasises considerable collaborative action between all signatories in order to improve information, in both explicit and implicit terms. The following points reflect some of the information-related requirements of the partners under the Agreement:

- 3.1 (a) – to increase current levels of resources and commitment to improve health outcomes for Aboriginal and Torres Strait Islander peoples (this implies the capacity to accurately identify and monitor expenditure);

- 3.1 (b) – to identify and publicly report through a range of mechanisms … on current levels of funding for Indigenous specific and mainstream health and related services for Indigenous peoples;

- 3.1 (c) – undertake joint, needs-based planning processes (this implies having access to a range of accurate information upon which to plan on the basis of need);

- 3.2 (d) – to simplify administrative processes for Indigenous community controlled services in order to consolidate grant application and reporting processes;

- 3.8 (b) – to ensure Indigenous persons' access to both mainstream and Indigenous specific health and related service, by publicly reporting on accountability against enforceable service standards;

- 3.12 – to establish culturally sensitive and ethical privacy and confidentiality protocols for the routine collection of standardised data on Indigenous health, with such protocols recognising Indigenous ownership of the data and clarifying issues concerning use of the data;

- 3.13 – to improve the quality of relevant data available on the provision to and utilisation of mainstream health services by Indigenous persons;

- 3.14 – to develop appropriate health outcome indicators to measure progress in improving the health of Indigenous peoples and develop mechanisms for reporting specifically on health outcome indicators; and

- 6.2 – to publicly report every six months on progress in implementing commitments under the Agreement, including (as a minimum) funding for community controlled health services, improved outcomes for mainstream services, and linkages between community controlled and mainstream services.

Many people consulted during the development of this national Indigenous health information plan spoke very favourably about the Framework Agreements as the first constructive step in forging more effective partnerships between community-controlled interested and levels of government to jointly improve the health of and services provision to Aboriginal and Torres Strait Islanders.

2.3 Activities to improve aspects of Indigenous health information

In addition to the development of this ***National Plan for Indigenous Health Information***, there are several important and complementary Indigenous health initiatives currently underway, all of which will be finalised in the coming months. Many of these are supported by the DHFS as part of an overall intention to address a series of information shortcomings in relation to Indigenous health. These include:

- A project to assess ***Aboriginal and Torres Strait Islander Health Allocation and Expenditure***, which seeks to identify baseline data on the allocation and expenditure of funds on Indigenous health by the Commonwealth and state and territory governments, and develop mechanisms for the continuing collection and reporting of such data to inform the planning, monitoring and evaluation of resource allocation and expenditure;

- The development of ***Data Protocols*** by the DHFS, in conjunction with the community sector, to govern the privacy and confidentiality concerns surrounding community service level health information; and

- Two initiatives to develop common standards and processes for reporting on activities and outcomes in relation to Aboriginal and Torres Strait Islander health – ***National Performance Indicators and Targets in Aboriginal Health*** (for government health authorities) and ***Service Activity Reporting Requirements*** (for Commonwealth-funded AMSs).

The national, state and territory government health agencies are expected to report against the National Performance Indicators and Targets in Aboriginal Health on an annual basis to AHMAC. Further, Australian Health Ministers agreed at their August 1997 meeting that Commonwealth, state and territory jurisdictions would be held accountable for improving Indigenous health, through this annual process of publicly reporting on progress against these indicators. The indicators, which are still being refined, relate to health outcomes and health status, access to health services, health services outputs (including screening and immunisation rates), workforce issues, disease and injury risk factors, intersectoral issues (such as housing and poverty), community involvement in planning and services delivery, and the quality of services provided.

The process to develop Service Activity Reporting Requirements for AMSs is a separate – although complementary – one to the government agencies' performance indicators initiative outlined above. These standards focus predominantly on information about the range of services provided by AMSs on behalf of the DHFS. While it is ultimately intended to develop a common reporting system for all community health services, at this stage, the project focuses primarily on programs funded by the DHFS. This process also seeks to rationalise the existing web of reporting and accountability requirements expected of Indigenous health services.

However, there was some disquiet expressed in the recent national consultations undertaken for this review about the expectation that everything that AMSs do can be wrapped up neatly in the Service Activity Reporting Requirements. Indeed, as the case study overleaf indicates, there was concern that important social and cultural activities provided in or by AMSs could be overlooked or devalued in this attempt to quantify activities into a relatively small and manageable number of performance indicators.

The holistic approach of the Aboriginal Medical Service – Issues in measuring effectiveness

Most people agree on the importance of AMSs and government agencies alike in being able to demonstrate the effectiveness and efficiency of health services provision to Indigenous people.

However, this in turn relies on the existence of performance indicators which appropriately and simply measure the entire holistic concept of 'the AMS approach'. The AMS is more than merely an extension of a general practice surgery or small-scale community health centre – for many, it is a way of life and a focus for community activity and fostering cultural identity.

First and foremost, AMSs envelope the 'primary health care approach' to providing services in line with the identified needs of the local community, namely through:

- collaborative networking – health as a concept is holistic, and achieved in partnership, rather than in unequal doctor-patient relationships;
- the active participation of consumers and the wider community in all aspects of the AMS' operation, including planning, service delivery, evaluation, research, and management;
- seeking to address the macro and longer term considerations as well as the micro and immediate problems and concerns;
- offering comprehensive and holistic management of health problems – including attention to the physical, emotional, environmental and social aspects, and also to the health of families, communities and populations, as well as that of individuals;
- involving a partnership relationship – across the primary health care sector, with the secondary and tertiary sectors, with other members of the health service team, and with the community;
- providing services which are culturally appropriate and responsive to the needs and values of the local Indigenous community;
- supporting informed, accountable and organised community involvement in decision-making at the agency and community level;
- focusing on prevention and wellbeing as well as diagnosis and care.

But there is yet another level to the AMS – and that is the provision of a safe community-focused place where people can come together to share stories and information. The AMS serves the role of a neighbourhood house – a central meeting place which is used for a variety of activities, including for recreational, educational, political, cultural, health enhancing and advocacy purposes. It can also become the focal point for community development activities, as well as providing child care, skills development, information and referral, and for group discussions.

As such, the AMS promotes collective action to promote and protect health, fosters self-determination and social justice, and collective decision-making. It is much more than an expanded general practice surgery – more of a way of life and a focal point for strengthening community and cultural identity.

But how do you translate such a range of community-focused activities into a limited number of performance indicators – without losing much of the meaning in the translation process?

Adapted from concepts and principles espoused in several publications [10,11,12,13]

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[10] Legge D, McDonald D & Benger C. (1992) **Improving Australia's health: the role of primary health care.** Final report of the Review of the Role of Primary Health Care in Health Promotion in Australia. National Centre for Epidemiology and Population Health, ANU, Canberra.

[11] Kenny S. (1994) **Developing communities for the future: Community development in Australia.** Thomas Nelson Australia, Melbourne.

[12] Ryan P. (1992) **Cases for change: CHASP in practice.** Community Health Accreditation and Standards Program, Australian Community Health Association, Sydney.

[13] Ife J. (1996) **Community development: Creating community alternatives – vision, analysis and practice.** Addison Wesley Longman Australia, Melbourne.

2.4 Other national health information developments

A number of other health information initiatives currently have relevance for Indigenous health. These include the ***Disability Data Reference Advisory Group (DDRAG)***, the new ***National Community Services Information Management Groups*** and the ***National Community Services Data Committee***, and any information agreements which result from the current work to develop a ***National Public Health Partnership***.

Additionally, there are implications for Indigenous health information arising from a number of recent stand-alone national program initiatives, including in relation to Indigenous sexual health[14] and Indigenous mental health.[15] Both of these documents make recommendations in relation to Indigenous health information. Clearly, some consideration needs to be given to how any implementation of these recommendations will be co-ordinated with this and other health information initiatives

2.5 National data sources

Administrative data collections, such as birth and death registrations, hospital separations, or disease notifications result from standard records, each of which is kept primarily for the purposes of providing services to individuals with diseases or health conditions; or they are kept primarily for the purpose of official notification or legal registration of significant events in the life of individuals. In neither case are the records kept primarily for the purposes of providing statistics – let alone statistics about Indigenous people. The statistical pictures which can be painted from data sets such as these are therefore completely determined by the information needs of the services being provided to the individuals by the service provision agency or by the legal or regulatory needs. The data needs for these purpose are generally very limited and fall far short of even a sparse set of variables which describe the full gamut of health information for which health statistics might be required. If statistics are required on variables which go beyond the narrow set collected for administrations reasons then special data collections, which have as their primary purpose the generation of statistics, are required.

Sample household surveys are one important type of special data collection for gathering certain kinds of information about Indigenous people at the state/national level. Surveys are the only useful approach for a wide variety of statistics such as perceptions and attitudes about health, some aspects of access to services, and a range of morbidity issues which cannot be captured from hospital data collections, either because the condition does not result in hospitalisation or because data quality from non-survey sources is suspect.

The primary statistical information derived from the five yearly Australian Censuses of Population and Housing Censuses is counts of the Indigenous (and total Australian) population at the national, state and territory, regional and local community levels. In addition, Censuses provide information on precursors of health and social-well being such as socioeconomic status, housing and transport issues, educational and labour force statistics.

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[14] ANCARD Working Party on Indigenous Australians' Sexual Health. (1997) **National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99**. Commonwealth Department of Health and Family Services, Canberra.

[15] Swan P & Raphael B. (1995) **Ways Forward: National consultancy report on Aboriginal and Torres Strait Islander Mental Health (Parts 1 & 2)**. National Mental Health Strategy. Australian Government Publishing Service, Canberra.

The all important factor about Census data is that it can provide statistics at all levels (national, state/territory, regional, right down to communities of 80 or so people). No other data set can do this for all parts of Australia. For this reason the Census is an extremely important data sources for health information purposes, quite separately from its role in population estimation (which is discussed below), despite the fact that it does not collect any health data.

Other special purpose collections such as specialised epidemiological research studies and detailed local cross-sectional surveys provide detailed information on a wide range of issues, for instance, health status, risk factor prevalence, health knowledge and practices and attitudes. As such, special purpose collections provide a vital range of supplementary health and related information.

Earlier discussions point to the need for accurate identification of Indigenous peoples in birth and death data, hospitals separations collections and other administrative data sets. The issues of accurate and complete identification of Indigenous people (and the use of consistent standards) is just as important for major national surveys, Censuses or small detailed local studies as it is for administrative collections. It is quite possible that, as a general rule, Indigenous identification is better and more complete in these specialised data collections than for administrative collections but this does not diminish the importance of focusing on the importance of achieving high levels of identification; and, in all cases taking steps to assess and measure the extent to which completeness has been achieved; and, once this is know, to use this information to correct for any under-recording to produce reliable unbiased statistics.

This review recognises that, in addition to the types of data collected by Censuses, regular national surveys are the only viable source of a number of essential groups of health related data. These include:

- data which will allow national (or even state and territory) levels of morbidity level outside hospitals to be measured,
- data which allow national (or even state and territory) attitudes and perceptions about health and health services to be measured;
- data which allow some national (or even state and territory) health risk factors to be measured; and
- data which allow the use of a range of services at the national (or even state and territory) level to be measured.

In the past, this type of data has been collected by two major survey vehicles, the National Aboriginal and Torres Strait Islander Survey (NATSIS) in 1994, and the National Health Survey (NHS) in 1989 and 1995. The former survey targeted just Indigenous people and engaged a range of special techniques and processes (including extensive consultation with the Indigenous community and key Indigenous leaders), the employment of Indigenous interviewers to undertake survey fieldwork, the construction of appropriately worded questions and special feedback and dissemination processes. These measures are believed to have assisted the achievement of high data quality. The latter survey included all people in Australia within its scope and did not employ special procedures. The prospect of achieving high quality data may been lower for the NHS than the NATSIS as a consequence.

A wide range of useful statistics have been published from the NATSIS. The results of the first NHS proved to be of too doubtful quality because of the relatively small sample and the results of the second survey are currently undergoing analysis to assess their quality prior to publication of Indigenous statistics from the survey.

It is recommended that, as far as practicable, a national survey collection system be developed (with allocated resources) which, in conjunction with administration collections, provides all essential data. This survey program should yield statistics of sufficient quality to allow national, and state and territory estimates to be derived, which can be used to make comparisons between successive surveys and also between various sections of the Indigenous and Australian non-Indigenous population. Coverage of these surveys should be extended to all sections of the Indigenous population which have been shown to yield sufficiently reliable data for useful health and health-related statistics to be produced. In this regard the evaluation of the enhanced sample of Indigenous people from the 1995 National Health Survey will provide valuable information. Where it has been displayed that no useful data can be produced, more culturally appropriate collections should be undertaken at regular intervals for these populations (i.e. separate collections, but only where these cannot be accommodated in major surveys).

It is also recognised that there are considerable demands for community level health information particularly in remote areas on issues such as environmental determinants of health including information on housing quality and type, infrastructure needs, health services provided to communities, and indicators of the level of morbidity within the community. This need is frequently expressed by national and state and territory health service funders and arises in part because there is a need to measure and record differences between individual communities and types of communities. Thus there is need to make comparisons between individual communities, and between groups of communities; and to rank communities according to various health related criteria. Demand for this type of data comes from service providers, administrators and community leaders. This is a very reasonable demand and consistent with the stated goals of health service funders.

Furthermore, if local communities and their health service managers are to be empowered, they need access to good information to enable them to be in a position to engage in informed decision making on health related issues in their community. After all, "community control", by definition, exists at the community level.

Census data will supply some of this information through the ABS's series of approximately 1000 Indigenous Census Profiles (to be released for the 1996 Census in late 1997). The information available from the Census is very limited. Local data can, of course, be collected at the local level in clinics and services but is rarely comparable across communities.

The Housing and Community Infrastructure Needs Survey (HCINS), conducted in 1992 for ATSIC has proved to be capable of meeting these demands to some extent despite some doubts about the quality of some field collection operations. The HCINS is, in fact, misnamed and is a census rather than a survey. The data collection method, by observation and by interviewing service providers and community leaders could be a preferable alternative for some types of data in remote community settings. There is an urgent need for better quality and more up-to-date data of this type, especially if it can be enhanced by collection of some health data from the community's health service providers.

There is an urgent need for a commitment to be given to repeat, as soon as feasible, an enhanced HCINS throughout all remote area communities of Australia. The commitment should be extended to repeat the conduct of the HCINS every five years. The enhancements should include a capacity to record some health information by interviewing local community clinic personnel. The objectives of future HCINS data collections should be dovetailed and integrated as far as possible with the design of sample household surveys which collect Indigenous health information. Further, there is scope for some mutually beneficial integration of the design and field operations of future HCINS and the preparations for the Census of Population and Housing in remote areas. This could have benefits in terms of both efficiency and data quality for both collections.

Given the central importance of certain risk factors to Indigenous health morbidity and mortality patterns, regular surveys must be conducted to monitor changes in, as a minimum, nutritional issues, tobacco smoking, and alcohol consumption patterns in both urban and rural settings.

One area of particular concern - and about which there are little quantitative data - is the burden of debilitating illness and disability in Indigenous communities. Several local epidemiological studies and anecdotal data from health services highlight the widespread prevalence of a range of diseases which are readily treatable in their early stages but, if treatment is delayed too long, can result in severe disabilities. However, since such conditions (for instance, otitis media and diarrhoea) are generally underrepresented amongst hospital patients, because the conditions are usually treated at the community level or not at all, hospital separation statistics give a very poor indication of the level of morbidity associated with these conditions. This even applies to some notifiable conditions and diseases which may be poorly recorded. Yet, such conditions can be responsible for major disability, such as hearing loss in the case of otitis media – which, in turn, has the devastating socioeconomic effects of increased isolation and reduced educational and employment opportunities and life chances.

At present, some potentially useful work is being done in a number of areas where population based registers are being used to record the service interventions at the community clinic level. As these improve over the coming years they offer great potential for providing, at least snapshots of the required community level data. Considerable effort should be devoted towards constructing suitable population registers which avoid duplication and are complete in their coverage to enable statistics to be reported from these registers at the state and territory level.

Another potentially useful approach is to capture systematically the quantitative and anecdotal knowledge possessed by the experienced locally-based health service providers about the collective burden of these diseases and conditions in their communities. After all, these people must be the most knowledgeable about the patterns of morbidity in the community. The full community coverage approach of the HCINS (above) type data collection offers one approach to capturing data of this type.

Population counts and population estimates

Accurate estimation of the population of Australia's Indigenous population (at the national and state and territory level) is fundamental to deriving any usable health statistics. Without this there is little point in devoting substantial effort to collecting and analysing any data on health events in Indigenous peoples. Estimates at the regional and community level are also important. Advances have been made in the mid- 1990s with the publication of ABS's Experimental Estimates of the Population of Aboriginal and Torres Strait Islander Peoples (ABS Cat No 3020.0). These are advisedly referred to as 'experimental' because there still are uncertainties about the estimation of this population. Further, Indigenous population estimates for 1996 have recently been published by the ABS based on the results of the 1996 Census (ABS Cat No 3101.0). These new estimates of the 1996 Indigenous population are much higher than 1996 projections made from the 1991 Census. The discrepancies are not uniform with almost no discrepancies for populations in remote central and northern Australia but discrepancies of up to 50 percent and more in metropolitan areas throughout Australia.

The usual method of assessing the quality of birth and death data is by comparing the actual numbers of Indigenous birth and death registrations with those expected within a given community in a specified period of time - that is, against the population projections derived from the experimental estimates. Thus, assessing the accuracy of the birth and death data is totally dependent on the reliability of the population projections. The ABS proposes, in projections to be calculated in 1998, to incorporate some elements of the changing propensity to identify as Indigenous.

Considerable effort needs to be directed to work with Indigenous communities to investigate the basis for, and addressing if necessary, differences between ABS Indigenous Census counts (and, at the state and territory level, population estimates) and the communities' understanding of the numbers of people living in their communities. If discrepancies are found to be due to incorrect perceptions of the communities then a program should be implemented to help people understand where their perceptions have misled them. If, however, discrepancies are identified as due to Census counts being too low then the reason for the low estimates should be identified and acknowledged. It is still too early to assess the impact of increases in Census counts of Indigenous people on Indigenous community perceptions about these figures. Nevertheless, if discrepancies are identified as due to Census procedures, these should be taken into account when planning future Censuses.

While it is recognised that the methodology underlying the ABS population estimates is the best currently available it is uncertain, whether these methods fully cope with all the difficulties inherent in estimating Indigenous populations. Resources therefore need to be committed (and used by ABS or others) to investigate current methods and explore potential improvements for estimating the size, geographic distribution and age and sex structure of the Indigenous community and how these change over time. Particular attention should be devoted to deriving methodologies which are capable of estimating populations from the results of successive Censuses, in the presence of changing propensity to identify amongst Indigenous people. An additional requirement is to derive methods to estimate the extent to which Indigenous people change their identification.

Indications from the 1996 Census are that significant discrepancies exist between 1991- and 1996-based population estimates for 1996 for some southern and eastern states. For some states, particularly in metropolitan areas, 1996 Indigenous population counts are as much as 40 percent higher than expected based on the natural increase since the 1991 Census. The unexplained increases are largely due to changes in the way some people chose to classify themselves in the 1991 Census compared with the 1996 Census. These unpredictable changes, which seem to be absent or smaller in remote area Indigenous populations, compromise the interpretation of rate and ratio statistics. There is an urgent need to improve our understanding, and investigate methods of reliably monitoring, the ways in which Indigenous people change their identification (as recorded in data collections) with the passage of time. If identification changes over time in a data collection, this will influence the Indigenous statistics derived from the collection. Furthermore, unless the changes that do occur in identification are the same in different collections, we can not be confident about the interpretation of any Indigenous statistics derived from such collections.

Torres Strait Islanders are keen to be able to obtain separate health statistics pertaining to their population group. There are sound epidemiological reasons for doing this because available information suggest there are considerable differences in the health profile of this group compared with Aboriginal peoples. Furthermore, there are some reasons to believe that the health profiles and prospects of Torres Strait Islanders who are resident within Torres Strait may be somewhat different to Torres Strait Islanders who are now resident on the Australian mainland.

The extent to which health statistics for this population group can be explored and studied is extremely limited because of the absence of recognised population estimates for this group, either in total or divided between Island and mainland residents. Depending upon the purpose for which Torres Strait Island(er)s population estimates are required, the definition of the population group may differ. Population group definitions that may be required include:

a) all people with Torres Strait Islander origins living in Australia;

b) as a) may be difficult to estimate, restricting population estimates to Queensland may be more appropriate;

c) separate population estimates may be required for Torres Strait Islanders resident in the Torres Strait Islands and Torres Strait Islanders resident in mainland Queensland (or Australia);

d) there are important differences between the geographical entities of Torres Strait Islands, Torres Strait Area, and the Torres Strait Shire; and

e) further, for some purposes estimates will be required of all people resident in one or other geographic entities in d).

The review recognises that there are considerable technical difficulties in attempting to construct such estimates, not least because of the volatility and high levels of 'category swapping' that have been observed at Census enumerations in the past. An added complication is the change in the allowable responses to the Indigenous origin question at the 1996 Census. People may now choose to classify themselves as both Aboriginal AND Torres Strait Islander, whereas in earlier Censuses this was not possible. Evidence from other sources of data suggests that a substantial proportion of Torres Strait Islanders choose to classify themselves in this way. It is not clear how these people would have self-classified themselves if a 'both' category were not allowed.

3 Information activities of community controlled services

All community controlled health organisations keep patient medical records for patient care management purposes. Each patient record contains demographic information such as name, address, age and/or date of birth, and clinic information such as investigations undertaken, diagnosis, treatments and follow up, and recalls.

Most AMSs record patient information in paper-based systems, although in some cases the data are entered later into a PC-based information system. However, like mainstream community health services throughout the country, there is no consistent approach to the design and use of computerised information systems. There is a plethora of accounting and patient records management software programs in use – including several purpose built systems for AMSs (see, for example, the Miwatj and Health Planner case study overleaf). Indeed, several organisations (such as Miwatj) exist primarily as a resource and information support service to AMSs within defined regions – in these cases, the information collection and reporting mechanisms are relatively sophisticated. However, these are in the minority.

As detailed elsewhere in this report, the capacity with which most AMSs can effectively collect, analyse, use and report on data about client services patterns and health status is severely limited. This is largely due to the lack of a co-ordinated purpose built information system and equipment (as highlighted above), insufficient training and skills development in information for both administrative and clinical staff. In many cases, systems had been initiated (almost always by an individual with an interest in doing so) but these were no longer maintained or used (often because the individual had since left the agency, usually taking all of the knowledge and skills with them). Indeed, during the consultations with AMSs as part of this review, the consultants were shown 'the computer' – sitting in a disused corner and covered in dust.

In some states however, for instance, in Western Australia, the health authority is in the process of negotiating with AMSs to jointly develop a computer based information system, with the aim of the new system going some way towards meeting the information needs of both the AMSs and the state health authority.

Like all publicly accountable agencies, AMSs produce annual reports. These are presented at their Annual General Meetings and then released for public use, with copies forwarded to funding agencies. With some notable exceptions, for example Nganampa Health Service's annual reports, these rarely provide much useful health or health activity statistical information.

Another major information-related issue affecting AMSs which has not been addressed anywhere else in this report concerns research and information requests – both of the AMS and of the community it serves. Many respondents complained of the constant bombardment of such requests from an array of sources, including university researchers, government information collectors, and funding agencies.

Better clinical management with population registers – Miwatj and 'Health Planner'

The Miwatj Health Aboriginal Corporation is an umbrella organisation for three Aboriginal Community Controlled Health Organisation in the East Arnhem region. The corporation manages health information data for the affiliated Aboriginal health services in the region. Patient records are managed in a computerised medical records 'Health Planner' system, which originated from an information system in use in other AMSs in Australia and has been adapted for local needs. The central data base is administered at the Miwatj office in East Arnhem Land, and connected by modem to outlying clinics. In addition, the Health Planner information is copied to five laptops weekly, for use by clinical staff to review patient files.

Almost all of the Aboriginal health services affiliated with Miwatj send their patient information to a central location on paper forms – only one clinic does its own data entry. The organisation employs 1.25 full time equivalent staff for data entry into the Health Planner. The Health Planner information is grouped into demographic, diseases, medication, examination, and pathology files. Clinical staff describe it as an excellent tool for patient recalls, follow up and opportunistic screening of diseases. The system generates frequencies and disease prevalence on colourful and easy to read graphics which are used for health promotion and services planning.

Although used primarily as a population register for follow-up management and for recording clients' clinical data, the client database is also used for practice management applications such as file keeping and patient accounting. The system involves the 60 health care processes that include immunisations, developmental checks, examinations (weight, blood pressure etc), investigations (Pap smears, blood tests) and treatments.

Lists based on variables such as age, sex, past history, current therapy, pathology or geo-social or economic factors can be generated for recall purposes. When made dynamic by the addition of time, an individual health plan is generated. These recall patterns can be varied by the user, based on local disease spread, practices and demographics.

An individual's health plan can be generated at the point of contact and used by doctors and health workers to assist in management decisions. These are used to build up a picture of screening or preventive activities due in any given community location or for a family or any other demographic variable. These lists have been used to drive immunisation programs, syphilis serology follow-up, Pap smear screening and specific disease programs such as for diabetes, rheumatic heart disease and hypertension.

The system is capable of generating useful graphically displayed local community health status and activity statistics of considerable flexibility, only limited by the technical skills of the users.

Information adapted from KAMSC,[16] and provided from consultations with Miwatj

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[16] Kimberley Aboriginal Medical Services Council. (1997) **Healthplanner**. (http://www.hcn.net.au/kamsc/hlthplan.htm)

Some of the larger AMSs have taken a more proactive approach to research, with some turning requests for research into something tangible for community participants, so that all parties have something to gain. Two examples are provided here (below and in the case study overleaf) from Nganampa Health Council (in Central Australia), where researchers are given access to the community in order to undertake their research only after the AMS has had the opportunity to 'massage' the research questions so that they are able to obtain information of interest and relevance to their community, and have received assurances that the research participants will have received something in return for their participation.

> *Recently Nganampa was approached by an urban research institute interested in conducting research on housing. Nganampa redirected the research in the planning phase. The methods were revised: the siting of waste water removal systems, vermin control and yard lighting were added to the issues to be examined. The aims were redefined, and made more concrete, immediate and useful. They now include provision of a yard kit to householders participating in the survey; it includes a garden hose, tap connectors, rake, trees, vegetable seeds, and shelving for verandah areas. These are all practical measures aimed at improving the yard facilities and meeting identified needs. This process can improve the relevance and quality of the research.*[17]

Nganampa's approach to managing research itself – as well as maximising opportunities from external research requests – is highlighted in the case study overleaf. This is a particularly proactive and constructive approach by an AMS to gaining information about their local community, however, it should also be acknowledged that such control over research is much easier managed in traditional and remote locations (where external access to the community is more difficult) than in urban areas. Nevertheless, a further case study is provided of the Victorian Aboriginal Health Service's participatory approach to co-ordinating research requests in a major urban centre – this clearly demonstrates what can be achieved to provide more community control over information requests of local communities in more populous areas.

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[17] Miller P & Rainow S. (1997) *Commentary: Don't forget the plumber – research in remote Aboriginal communities*, in the **Australian and New Zealand Journal of Public Health**, 21(1):96-97, page 96.

An alternative approach to Indigenous research – Nganampa Health Council

Nganampa Health Council, an independent community controlled health service in the far north west of South Australia, has a practical approach to conducting research in remote Indigenous communities – however they note that it is one that may not necessarily be generalisable to other remote communities.

In addition to receiving regular requests from external researchers to undertake specific research with local communities, Nganampa also conducts its own research, surveys and evaluations on major health issues. In all cases, the following questions are often considered in relation to the proposed research:

- Will the research contribute to an improvement in Aboriginal health?
- Who set the research agenda? (In an ideal world, instead of researchers approaching AMSs and Indigenous communities to explore an issue of researcher-generated interest, perhaps the reverse should be the standard approach? That is, Indigenous interests would have a research question about which they required information, and with which they would initiate contact with researchers and academic institutions – thereby changing the dynamic for researchers from external researcher to hired consultant.)
- Does the research question deal with the community's immediate health problems? Nganampa staff note that many Indigenous groups approve research proposals that have immediate relevance but are less interested in – and sometimes hostile to – research that ignores the community's immediate health problems.
- Does the research seek to address people's immediate needs – rather than just documenting them? Nganampa suggests budgeting in a little additional time and money into research strategies to enable the undertaking of 'ethical surveys'. For instance, being prepared to collect firewood if surveying old people's needs, or taking along a plumber on a survey of toilets to enable the broken ones to be repaired.
- Is the research respectful of the community's cultural and other values? For instance, is the methodology mindful of traditional Indigenous concepts of time, or their need for confidentiality? And how does the researcher intend to return the information gained back to the community, and in what format?

Over and above these principles, Nganampa Health Council has a strong history of being prepared to undertake or commission its own research, as a way of negotiating and taking control over research in the local community. The Council's board takes a proactive role in directing and subsequently owning the resulting research, and has employed several anthropological and health researchers. Protocols are in place for managing research and even for publishing or discussing findings with the mass media, with no automatic rights of publication. Ownership of data rests with the community, and all requests for approval to publish research findings must be approved by the Nganampa management board.

Miller P & Rainow S [18,19]

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[18] Miller P & Rainow S, op cit.

[19] Miller P, personal communication.

A proactive approach to research by the Victorian Aboriginal Health Service

The Victorian Aboriginal Health Service (VAHS) was established in 1974, to provide clinical and preventive health care services to the Melbourne Aboriginal community. Concerned about the increasing frequency of requests to undertake research amongst Victoria's Koori population and the simultaneous lack of protocols for conducting such research, the VAHS is developing its capacity to undertake its own community-focused research and evaluation as well as initiating mechanisms to improve the quality and appropriateness of research involving Indigenous peoples.

The VAHS established an Institutional Research Ethics Committee to consider and approve research requests and monitor the ethical aspects of research studies conducted by the VAHS. It is constituted according to the National Health and Medical Research Council guidelines for conducting research with and about Indigenous persons, and is officially registered with the Australian Health Ethics Committee in Canberra. The committee comprises three male community members, three female community members, a medical practitioner with research experience, a lawyer, and a community elder.

A more recent initiative is the establishment of the Victorian Aboriginal Research Network – again, initiated by the VAHS. This network comprises a wide range of agencies interested in Indigenous health research, including Victorian Aboriginal community organisations and co-operatives, the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), the Koori Health Unit (state health authority), the VAHS Health Promotion and Research Unit, ATSIC, Department of Aboriginal Affairs, and the four major Melbourne academic institutions. The Network seeks to facilitate:

- Aboriginal control of research activity, through channelling all research requests through a registered Aboriginal Ethics Committee;
- a co-ordinated approach to Indigenous research efforts, including reducing duplication of effort;
- the maximal use of research and health promotion funds;
- higher quality research – and reduced occurrence of inappropriate or unethical research;
- improved consultation with community interests in the development and undertaking of research;
- improved community confidence in the process of research; and
- greater communication and awareness about the range of current and planned research initiatives amongst all organisations involved in research with Indigenous people.

The Network has established protocols for developing research proposals, which involves preliminary consultation with appropriate community organisations and then distributing a draft proposal to all Network members for consideration. After consultation and amendment (as appropriate), the proposal is then submitted to the ethics committee for ethical clearance.

Other protocols developed by the Victorian Aboriginal Research Network include procedures for external (i.e. non-VAHS) researchers seeking to undertake research in the Melbourne Koori community, for research by clinical workers, and for publishing details of research.

Victorian Aboriginal Health Service [20]

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[20] Victorian Aboriginal Research Network. (1996) **Proposal for a Victorian Aboriginal Research Network: Discussion document**. Victorian Aboriginal Health Service, Melbourne.

Part 4 Overview of Issues Affecting Indigenous Health Information

1 Introduction

Several factors affecting the capacity of an information system – be it an Indigenous health information system or any other – to capture and report on data efficiently and effectively have been identified through the processes to develop this report.

Essentially, an effective information system is one which:

- seeks to maintain and enhance existing systems and structures, rather than to establish new ones, (that is, unless existing structures cannot be made to work effectively);
- recognises the critical importance of trained, knowledgeable, informed, involved, and supported health professionals, non-clinical information collectors, and communities;
- seeks to fulfil a useful purpose for communities, health services and governments alike;
- is able to measure progress and performance across all areas of interest, including program and services evaluation, cost-effectiveness, accessibility and reach of programs and services, and comparative differentials across Indigenous communities and also between Indigenous and non-Indigenous peoples; and
- importantly, is able to measure change accurately and consistently over time.

Part four of this report seeks to describe the characteristics of Australian information systems and data sources and analyses its capacity to meet the above challenges in relation to Indigenous health information.

In particular, the limitations of current efforts in – and also some initiatives in place to improve – Indigenous health information will be explored.

2 Limitations of current efforts in Indigenous health information

2.1 Gaps in information about Indigenous health

Some of the most relevant statistics about the health and welfare of Aboriginal and Torres Strait Islander peoples are not reported at all, or are inadequately reported.

For instance, mortality is not currently reported for two thirds of the Indigenous population, that is for those Indigenous peoples who live in the eastern states of Australia, particularly Queensland, New South Wales, Victoria, and Tasmania (due to the poor recording of Indigenous status in death data in these states). The latest available figures for NSW and Victoria suggest that approximately half the deaths in 1995 among the Indigenous population were not recorded as Indigenous. In Tasmania and Queensland the situation was worse, with next to no Indigenous deaths being correctly recorded. Queensland, however, should be commended for its promising start in improving the recording of Indigenous mortality in 1996. Indeed, their rapid (but as yet incomplete) progress in achieving death information of reportable quality for Indigenous people is demonstrates that major outstanding data quality issues can be effectively solved in a relatively short time given the right commitment to do so.

Additionally, there is a wide range of diseases and conditions which are difficult or impossible to measure on a national scale - many of these are of particular public health significance among Indigenous communities. The reporting on morbidity issues relies heavily on somewhat incomplete hospital separations data, mainly from four states and territories. Additionally, even if hospital reporting were perfect, any disease or condition which does not normally result in hospitalisation will be inadequately reported. Notable amongst these are the often undiagnosed and untreated infectious diseases of childhood which exhibit as cycles of repeating or even continuous episodes of disease among some groups of Indigenous children.

Similarly, there are no accurate national data on issues such as emotional and social wellbeing, or reliable data on patterns and levels of nutritional intake, or even the prevalence of different types of disability among Indigenous people. Many of these diseases and conditions are often not life-threatening in themselves but, taken together, they can be responsible for very high levels of 'low grade' chronic morbidity and social disadvantage.

It is well recognised that the causes of the poor state of Indigenous health and high level of welfare dependence are, in large part, intimately linked with the social and cultural history of Indigenous people over the past two hundred years. The linkage occurs through the consequent legacy of dispossession and disempowerment, leading to today's high levels of unemployment, poor educational attainment, and low self-esteem. All these factors are determinants of the health and welfare of Australia's Aboriginal and Torres Strait Islander peoples, but there is little scope for informative reporting on these issues. Although some of these factors, such as employment and poor educational attainment, can be reported quite well in statistical terms, there are few prospects for reporting at a national level on the more intangible issues such as self-esteem and social and emotional wellbeing.

These gaps in the information about the health of Aboriginal and Torres Strait Islander peoples are predominantly due to two main factors, namely that:

1 Some collections do not attempt to collect information about the Indigenous status of clients; and

2 Even when collections have Indigenous identifiers, the process to collect, record and/or report on Indigenous status breaks down – that is, it doesn't work in practice.

In the latter case, that is, where the systems to collect and record Indigenous status break down, the reasons for such problems can usually be attributed to either:

- information system design faults or technical failures, for example, in the case of secondary data collections such as Cancer Registries, which rely on information collected from other sources; or
- problems of a social or cultural nature, including:
  - ⇒ *factors generally affecting the quality of data*, such as:
    - i) the importance of confidentiality and privacy in Indigenous cultures, and the difficulty of maintaining confidentiality standards when data relate to small, local community and/or widely dispersed populations;
    - ii) impact of language difficulties (English may not be the first language, particularly in remote communities);
    - iii) differing concepts of numeracy, particularly in some remote, traditional communities;
  - ⇒ *and factors affecting the willingness of an individual to self-identify or their capacity to be identified,* including:
    - i) the impact of individuals' multiple names (due to Aboriginal calling names, limited literacy or spelling skills, or name change following family/community death);
    - ii) the expectation that information gathering should be an exchange process, thus the importance of reporting information back to communities;
    - iii) the potential embarrassment of direct questioning, particularly by strangers (such as hospital admission staff);
    - iv) issues relating to ownership and use of information;
    - v) fear of discriminatory treatment or misunderstanding of the need for Indigenous identification, as reasons for not self-identifying.

2.2 Standards for identifying and recording an individual's Indigenous status

Identification of Indigenous people in information collections

In late 1996, the Prime Minister wrote to all state premiers and territory chief ministers, highlighting the urgent need for all mainstream government-funded programs to be responsive to the requirements of their Indigenous clients, and pointing to the lack of available information in this area. The letter drew particular attention to the need for publicly-funded services to report on their performance in terms of Indigenous clients' needs, and that this would be an important area for attention and development through Council of Australian Governments (COAG) processes.

This action, above all else, highlights the critical importance with which Indigenous information issues are currently viewed in Australia – and not only in health, but across all government portfolios.

However, the capacity to report on issues such as health status, service use and access to services is totally reliant on one factor – being able to accurately identify Indigenous clients. Without accurate identification of Indigenous status, there is little capacity to monitor changes in health status, make comparisons between Indigenous and non-Indigenous Australians, evaluate access to services and the responsiveness of health services to addressing needs, or even to begin to quantify the resources expended on health services and programs for Indigenous peoples.

Government accountability and performance monitoring on Indigenous health has recently received a further major boost. In August 1997, Australia's Health Ministers agreed that all jurisdictions should report annually on a range of performance indicators relating to Indigenous health outcomes, use of services and access issues. These are currently being refined. Where data are inadequate, Ministers agreed that efforts to improve data quality should be reported.

As discussed in the previous chapter, the coverage of information about the Indigenous status of people in existing collections – including vital statistics (particularly death data), hospital separations, perinatal collections, and community health collections – is limited. Additionally, the degree of incompleteness of identification is largely untested and, therefore, unknown; this is just as important an issue for most collections (the issue of data quality is discussed in the relevant section below).

Three jurisdictions in particular are recognised as having relatively accurate or good quality vital statistics data in relation to Indigenous peoples (namely Western Australia, South Australia and the Northern Territory). Because of this, however, there is a tendency for data from these jurisdictions to be used as proxies for making generalisations about Indigenous health issues across the country. The significant potential for this to mask differing population characteristics, needs and services utilisation patterns means that it is no longer appropriate or acceptable to use data from these states in this way.

The reasons for the lack of Indigenous identification are two-fold, in that there appears to be both a reluctance amongst (or lack of awareness of the need for) clients to self-identify their Indigenous status, as well as of clinical and administrative staff in health and related agencies to seek information about their clients' Indigenous status.

Standardising the identification definitions and procedures

This review has found a multitude of classifications, definitions, questions and collection protocols for capturing information about Indigenous status – both across and within state and territory jurisdictions. There also appears to be limited awareness of the existence of standard definitions for collecting information about the Indigenous status of people.

The use of a single classification and standard definition by all jurisdictions and agencies allows more accurate comparisons to be made across states, Indigenous communities and data collections. However, the current coding procedures in most collections do not adequately capture Indigenous status information, with some collections containing no capacity for Indigenous identification at all.

Additionally, the procedures used by front line staff to capture identifying information often deliberately overlook any requirements to ask all clients about Indigenous status (where these exist), with many staff choosing to make assumptions about race on the basis of local knowledge or the presenting client's appearance.

Nevertheless, the review found that one particular standard for capturing and recording Indigenous status has increasingly been adopted by many jurisdictions across Australia, including the Australian Bureau of Statistics (for use in the 1996 population census and the first National Aboriginal and Torres Strait Islander Health Survey[1]), and all Registrars-General throughout Australia (for birth and death registrations). Importantly, the same standard is recognised by the National Health Information Management Group for use in the National Health Data Dictionary Version 6. This review found that, by virtue of this latter status, it was the intention in many jurisdictions to apply this standard when developing new, or upgrading existing, information collection systems and protocols.

This review accepts that there may be some disagreement with the use of this standard and that it may, in the future, need revision. It does not capture all three aspects of the accepted 'Commonwealth definition' (that is, Indigenous origin, individual identification and community acceptance of Indigenous status). Nevertheless, given it is, at present, the standard most widely used and promulgated, the review considers that this be the standard adopted in all jurisdictions unless – and until – an authoritative assessment recommends a better alternative.

Quality assurance – how accurate are the data?

This review found little evidence of formal or systematic quality control mechanisms in place to assess the quality of existing data collections in accurately identifying Indigenous status. Where these occurred, they were often as one-off epidemiological studies or data-matching exercises between two or more datasets. In some cases, individual hospitals used Indigenous Hospital Liaison Officers to talk informally with clients to establish their Indigenous status and to check the records of known Indigenous clients to ensure that their Indigenous status was correctly recorded.

Without testing the level of under-recording of Indigenous status, no corrections can be made, and this can result in biased statistics. Therefore, more formal quality control mechanisms, such as data matching between two or more data sets, and validation studies are required in order to monitor the effectiveness of data collection processes in accurately capturing Indigenous status.

Of course, the issue of data matching raises specific concerns about the need for privacy and confidentiality provisions, to safeguard against the potential (or at least perceptions of) misuse of data. This review found the issue of privacy to be of particular concern to Indigenous peoples and community-controlled services. However, as noted elsewhere in this report, few policies or guidelines exist for the appropriate and culturally sensitive use of data. Clearly, this issue must be addressed before consideration can be given to introducing some forms of system-wide quality control mechanisms.

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1 Australian Bureau of Statistics. (1995) National Aboriginal and Torres Strait Islander Survey: DetailedFindings.Catalogue No. 4190.0, Australian Bureau of Statistics, Canberra.

2.3 Social, cultural and structural impediments to quality Indigenous information

The process undertaken to develop this report has identified several other shortcomings affecting the processing and use of statistics – all of which undermine Australia's capacity to accurately capture and report on Indigenous health information. Unlike issues of a more technical or definitional nature (as outlined above), other factors concern the social and structural conditions within which information is collected, processed and analysed. It is this latter aspect which is explored below.

Mechanisms for collecting information about Indigenous status

As identified elsewhere in this report, the practices used to collect information about people's Indigenous status are largely ad hoc – with many assumptions made merely on the basis of appearance, particularly skin colour. However, making assumptions in this way is misleading, and can cause inaccurate reporting (both under- and over-reporting) of Indigenous status. It is recognised that some health services staff feel embarrassment or resistance toward asking clients about Indigenous status. Sometimes this is based on previous abusive remarks from clients who feel angered or offended at being asked whether they are of an Aboriginal and/or Torres Strait Islander origin. Such staff are less likely to ask clients to self-identify, preferring to either guess their Indigenous status on the basis of appearance or local knowledge, or to ignore the requirement to ask the question at all. Conversely, Indigenous clients may refuse to self-identify as such – due, in part, to the fear of potential racial prejudice or being treated differently to others.

Therefore, mechanisms need to be developed for use in health services to promote Indigenous identification in ways which are less threatening or confronting for both staff and clients alike. A key issue may be increasing people's understanding of why Indigenous status information is collected.

The review found that a higher frequency of Indigenous identification in hospital collections was obtained where the information was sought in writing from clients, for instance, by asking presenting clients to complete a card (that is, rather than being asked verbally in a public area), or by completing pre-admission forms in the privacy of their own homes. Identification was also higher where Indigenous Hospital Liaison Officers were employed to work with local communities, for instance by following up Indigenous inpatients, cross-checking admissions data to ensure accurate recording of Indigenous status, and generally encouraging clients to self-identify.

Another factor was that, in almost all relevant data collections, the database fields for recording Indigenous status was optional. Inadequate or absent instructions in health services policies and procedures for seeking information about Indigenous status, and poor attention to inputting of such data into database fields, are considered to be factors in the under-reporting of Indigenous status. The absence of mandatory directives renders administrative officers and other staff responsible for collecting this information less inclined to ask the question of all clients.

Commitment to sharing information

This review found little evidence of commitment by funding agencies, governments and researchers to returning information to, and sharing information with, the communities and services from which the initial data were obtained. In fact, there appeared to be a widely held view amongst many Indigenous communities and community controlled services that data and information provided to others were not fed back to communities appropriately (at all, let alone in useful ways), and a perception that such information may not even be used at all. It appears that this latter perception may hold some truth, particular in terms of grant-related information provided to government funding agencies.

Commitment to regular, timely and culturally appropriate reporting of Indigenous health information must be a fundamental requirement of all parties seeking information from and about Indigenous communities and their health agencies.

The relatively poor awareness amongst a range of community and professional interests of the reasons for separately identifying Indigenous peoples in health and related collections is considered to be a major factor affecting the quality of existing data collections. Few people – including senior government officials, front line data collectors, health workers, and Indigenous community members – have any real understanding of the importance of Indigenous identification and why accurate data are needed to inform planning and better targeting of health services toward areas of greatest need.

Significant attention is required to developing programs at all levels to improve community understanding of the importance of collecting identification information and to promote greater self-identification. In particular, all people collecting Indigenous status data should be able to explain to clients why it is needed.

In addition to promoting greater community awareness of the importance of capturing quality Indigenous health information, it is also necessary to promote greater awareness of national and local efforts to improve information quality. Implementation of a national Indigenous health information plan doesn't just happen with the release of the plan itself – there must be a commitment and identified processes for ensuring that action occurs.

Awareness about the applications of information – building an information culture

The review found a general dearth of appropriate information management skills or even an 'information culture' within community health services in general, as well as in Indigenous health services in particular. In some instances, information systems depended on the skills and goodwill of individual officers or managers with a personal interest in information technology – with the use of any applications or systems developed lapsing when the individual moved on. This is neither reliable nor sustainable. Significant co-ordinated and sustained investment by governments in the development of skills and capital equipment may be needed to effect improvements in this area.

There is an urgent need to build and sustain the technical capacity needed to support quality Indigenous health data collection and reporting. It is often the case that information systems and initiatives are developed and expected to be implemented, with no attention given to developing and maintaining the necessary skill levels and technical capacity. Little support is provided to assist the implementation of new initiatives, or to improving the relative literacy and skills levels amongst those individuals who are expected to implement them.

There also appears to be little appreciation amongst Indigenous communities and community health agencies of the potential power that information has, and how it can be used to effect change, generate resources, support advocacy, and generally 'make things happen'. Importantly, there also seems to be few structures or mechanisms in place to support communities to use information in such ways.

Paramount in any effort to improve information collection and reporting systems about Indigenous health is the active involvement of Indigenous communities and community-controlled health agencies in every facet of development, implementation and review. However, there are few mechanisms at the community level for supporting community involvement in planning and co-ordination activities to improve health services delivery, develop more effective communication networks, collect and share information, and monitor and report on the progress of local initiatives. Similarly, the review found a generally poor willingness to share relevant data between agencies at the local community level, which the review considers is due, in part, to there being few mechanisms through which to do so.

The provision of training and workforce development programs will go some way to ameliorating these problems. However, there is a high turnover of staff in community-controlled and mainstream community health services, particularly in rural and remote localities – thus, limiting the sustainability of a trained and 'information-aware' workforce in the agencies responsible for collecting data. Therefore, more systematic strategies must be adopted to address the urgent need of information skills development in health services. However, there are few mechanisms at the community level for supporting community involvement in the collection and sharing of information, the use of such information for planning and co-ordinating activities to improve health services delivery, and for monitoring and reporting on the progress of local initiatives. The process developed to promote several personal computer-based health information products, highlighted overleaf, may prove to be a useful model for training community health services staff to become more 'information aware'.

A related obstacle to collecting reliable data about Indigenous status concerns the fact that many information systems and databases in use in Australian health services are not sophisticated enough to extract data about clients' cultural backgrounds. In many cases fields to collect data on Indigenous status have been omitted from particular systems, or they are not comprehensive enough or standardised across a particular health service or region.[2] Further, existing data collections are not sophisticated enough to elicit data even where Indigenous status has been recorded – in these cases, all such data must be collected and reported on manually. A more systematic approach to designing, installing and supporting standardised information systems in Australian health services is warranted – without it there is little hope of adequate reporting on health information at the community level.

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2 Mooney G, Jan S, Palmer A & Wiseman V. (1996) **Feasibility Study into the Adequacy of Resources and the Development of a Funding Formula in Aboriginal and Torres Strait Islander Health.** Report to the NHMRC Aboriginal and Torres Strait Islander Standing Committee, Canberra

Learning how to use health information for the benefit of local communities

There are many computer-based health information products currently available. However, two products, the Health Education and Promotion System (HEAPS) and the HealthWIZ national social health database, are used as the basis of training workshops aimed at community health staff to develop skills in using information about local populations and demonstrating how this can be applied to assist everyday work.

The information software products were developed by Prometheus Information, with funding provided by the Commonwealth Department of Health and Family Services. HEAPS is a computerised national database containing details of health promotion resources, projects and programs – providing a comprehensive picture of current health promotion practice and a valuable means of sharing ideas and information. HealthWIZ is a national social health database which provides easy public access to key health and welfare information, with which users can design tables and analyse data on a wide array of information.

The value of such products is in their capacity to make health and related information readily accessible to a broad cross-section of users, to share information amongst a range of users, and for health and demographic profiles of a particular community to be developed quickly and easily.

However, a particular advantage of these products is that they are supported by action learning training workshops, which were developed by the Australian Community Health Association. The workshops are designed to enhance participants' understanding of key community health and information-related concepts, and to develop participants' skills in the application of these concepts to their work in the local community. A particular focus of the workshops is on how to use information to plan, document, implement and evaluate a range of activities in relation to a community's health. Additionally, the goals and activities of workshops can be personally tailored to meet locally specific needs and conditions.

So, while the training workshops were predominantly devised to assist in the promotion of these information products, they have successfully managed to promote greater awareness of how to use health information at the local community level.

Adapted from several publications [3,4,5]

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3 Department of Health and Family Services. (1997) *HEAPS and HealthWIZ*, in **Newsletter of the National Mental Health Stratergy**, Issue 5, p 10.

4 Prometheus Information. (1996) **What's happening in health promotion? -HEAPS for Windows.** Prometheus Information, Canberra.

5 For further details about the training workshops or products, contact Alison Miles at the Australian Community Health Association in Sydney on (02) 9389 1433, or Prometheus Information in Canberra (02) 6257 7356

Guidelines concerning confidentiality and the appropriate use of data about Indigenous peoples

This has been one of the most important issues raised in the public consultation processes undertaken to develop this report – particularly amongst, although not restricted to, Indigenous communities, AMSs and health clinics.

Indigenous people are concerned about how information that is collected about and from them is used. They seek assurances that the information will not be used for purposes other than for which it was collected, and also that the privacy of individuals about which data are collected is maintained. Importantly, Indigenous peoples also consider that the ownership of data about Indigenous persons should be vested with them – that is, not with government agencies.

Yet, this review found a general lack of guidelines or protocols concerning the ownership, usage and confidentiality of data, and also for the exchange of information between Indigenous communities and health services and other agencies. The only exception to this were protocols developed by individual AMSs or Indigenous community organisations (which had no or little status in government agencies) and guidelines for research conducted under the auspices of the National Health and Medical Research Council.[6] Additionally, staff in the major national government agencies (including the Australian Bureau of Statistics, the Australian Institute of Health and Welfare, and the Health Insurance Commission) are bound by legislation protecting the confidentiality and use of information collected – transgression of which can result in severe criminal and employment-related penalties.[7] While this does not negate the urgent need for protocols to be developed to guide the appropriate use of information about Indigenous peoples, these documents do indeed provide a useful starting place from which to develop such guidelines.

Community health information

It is recognised that many health sector information collections provide little indication of health services activity at the community level – which is, after all, where the majority of health services activity occurs. It is also recognised that the Medicare program and Pharmaceutical Benefits Scheme – both of which are premised upon notions of access and equity for those in need – are currently incapable of assessing such concepts in relation to Indigenous peoples, merely because no information is collected about the ethnicity of the registrants on these databases. Similarly, mandatory notifications of communicable diseases (a particularly important public health concern in many Indigenous communities), as well as cancer and cervical cytology registers, do not collect or report on Indigenous status.

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6 National Health and Medical Research Council. (1991) **Guidelines on ethical matters in Aboriginal and Torres Starit Islander research.** National Health and Medical Research Council, Canberra.

7 Examples of relevant legislation include (but are not limited to) the *Australian Bureau of Statistics Act 1975,* the *Census and Statistics Act 1905,* the *Statistics (Arrangements with States) Act 1956,* the *Australian Institute of Health and Welfare Act 1987,* and the *Health Insurance Act.*

2.4 Effective national leadership to improve Indigenous health information

As noted elsewhere in this report, there is no guarantee that action will result from a series of recommendations or national consensus on what needs to happen to resolve a given issue – and nowhere is this more pertinent than in relation to addressing the coverage and quality of health and related information about Indigenous peoples. Indeed, the relative inaction on previous recommendations, reviews, conferences and the like probably has few parallels. This situation must stop – and now.

Further, leadership, commitment and action must not rest only with one or two key agencies or jurisdictions. True, there is a significant role for government authorities. However, the actions to address the array of issues affecting the quality of information about the health of Aboriginal and Torres Strait Islanders clearly involves the active participation of many people and agencies – including government health and information agencies at all levels, AMSs and Aboriginal health clinics, hospitals, area health services, community health agencies, Indigenous community groups and leaders, Registrar-Generals, funeral directors, and many more.

Another issue which must be addressed is the identification of a process of some description which provides national leadership and supports – indeed galvanises – action on a number of levels and across jurisdictions.

The high level Task Force of the mid-1980s (to improve Indigenous identification in perinatal statistics collections) had what it took to galvanise such action across the country (see Attachment 1 for details). Although it operated for a relatively short time, it achieved much – with significant improvements in perinatal data in all states and territories. Importantly, this Task Force managed to involve government health administrators at the most senior levels – this level of commitment cannot be underestimated in the capacity of an initiative to achieve the desired results.

However, there is still much more to achieve in order to improve Indigenous health and related information – indeed, the Task Force left considerable unfinished business. And in its absence, there is no other process or structure in place in which responsibility for overseeing new work can be placed.

Had such a process been in place or initiated in conjunction with the release of the National Aboriginal Health Strategy, a more considered approach to its implementation may have occurred. But there is no such focus now – particularly for improving Indigenous health information (with the only exception being the Aboriginal and Torres Strait Islander Health and Welfare Information Unit's responsibility for improving aspects of technical capacity).

3 Initiatives to improve Indigenous health information

Case studies and examples of innovative approaches to collecting, analysing and reporting information about the health of Indigenous people are showcased throughout this report. These are merely the projects and initiatives about which the project consultants were informed during their consultations. As such, it is important to acknowledge that these are not the only examples of good practice – indeed, the scope for recording and disseminating instances of good practice is probably endless. A number of case studies concerning initiatives to improve aspects of Indigenous health information – and which have not been highlighted elsewhere in the report – are described briefly in this section. These refer to initiatives to encourage identification of Indigenous status in hospital collections, and others concerning the use of population-based registers as tools to support clinical preventive services, and disseminating examples of 'best practice' in Indigenous information itself.

One strategy to promote greater identification of Indigenous status amongst people admitted to hospitals is to reduce the isolationist approach to Aboriginality – that is, by broadening the issue to one of ethnicity. This was trialled at the Griffith Base Hospital in country New South Wales, where staff began asking all patients on admission to complete a short questionnaire about cultural backgrounds. This alone resulted in a 40 per cent increase in Indigenous identification in the first month of the questionnaire over the comparable period of time in the previous year.[8] Another effective measure is the use of Aboriginal Hospital Liaison Officers (AHLOs), as outlined overleaf.

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8 Mooney G et al. (1996) op cit.

Using Aboriginal Hospital Liaison Officers to Promote Information Exchange

Some hospitals, particularly those with a significant Indigenous catchment population, have appointed Aboriginal Hospital Liaison Officers (AHLOs) to enhance the quality of Indigenous identity information, as well as to facilitate greater cross-cultural understanding and awareness between Indigenous persons and hospital staff and generally ease Indigenous patients' concerns about being admitted to hospital. This case study documents the approach by the West Gippsland Hospital in Victoria [9]– an approach which is similar to many other AHLOs in Australian hospitals.

Regular print-outs of hospital admission details of patients identified as being of Aboriginal or Torres Strait Islander descent are provided to the AHLO, who compares the hospital's recordings with her own knowledge of local Koori community admissions. If the AHLO is aware of an admission of a Koori patient who has not been correctly recorded as such, s/he alerts hospital admissions staff as a quality control measure to ensure that the Indigenous identity question was actually asked at the time of admission. Quality assurance checks by the AHLO are considered by the hospital to be imperative in ensuring the legitimacy of the data about Indigenous patients, due to the high number and diverse range of staff who undertake and process hospital admissions. However, the hospital acknowledges that some Koori patients may choose not to be identified as such at the time of hospital admission. The AHLO also keeps records of Koori hospital patients, and provides monthly summary reports (containing de-identified information) to relevant areas of the hospital, such as the Medical Records Department. However, actual correction of incorrect records about individual patients occurs through direct contact between the AHLO and admissions staff (as described above).

The use of AHLOs is widely recognised as an effective strategy for improving the quality of hospital-based Indigenous information, and also for reducing barriers for Indigenous people so that they may be more likely to self-identify as being of Aboriginal and Torres Strait Islander descent. Importantly, it is a strategy that is Indigenous-centred and, therefore, more likely to be acceptable to local Indigenous communities. Sadly, the distribution of hospitals with AHLOs in Australia is inequitable – with the number not commensurate with need and the distribution of the Indigenous population.

The issue of population registers appeared to be of considerable interest to those working in AMSs and Indigenous health clinics, many of whom were keen to explore the use of such registers to support clinical management, preventive screening and recall services. Examples of such approaches include the Miwatj initiative in East Arnhem Land (highlighted in Part Three of this report) and the Fitzroy Valley Pap Smear Register and Cervical Screening Program developed in the Kimberley region of Western Australia (highlighted overleaf). Having pointed to the widespread interest amongst Indigenous communities in developing and using population-based registers, there also exists some uneasiness about the ways in which registers established by external agencies (for instance state and territory government cervical cytology registers) might be used. This remains another issue to be addressed in the development of guidelines for the use of information about Indigenous peoples.

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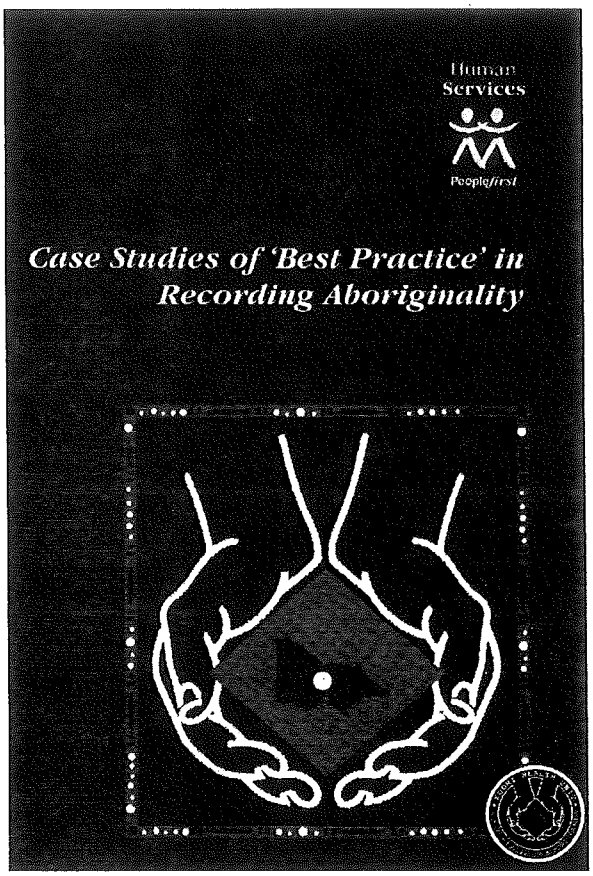
9 Department of Human Services (Vic). (1996) **Case Studies of 'Best Practice' in Recording Aboriginality.** Koori Health Unit, Department of Human Services, Melbourne.

The Fitzroy Valley Pap Smear Register and Cervical Screening Program[45,46,47]

This population-based register served as a useful example to demonstrate how such registers can inform and support the development of locally acceptable health strategies, in this case, for women at risk of developing cervical cancer. The initiative was developed with the active participation of the local community, and developed strong links with local health services to develop on-the-ground recruitment strategies in line with the identified needs and concerns of the women in the community. The program resulted in extensive coverage of the local Indigenous population (in excess of 86% of the local Aboriginal women aged 15 to 69 years), as well as significantly high cervical screening rates.

However, this case study also serves to indicate the need for such initiatives to be sustained. Within several years of its development, the program was defunded. The removal of the program had a negative impact on local health service delivery and screening rates – which has the potential, in the longer term, to adversely affect local cervical cancer incidence and mortality rates.

Another example of a positive approach to improving Indigenous information comes from the Koori Health Unit in the Victorian Department of Human Services – in the form of public recognition of effective practice in health services' recording of Aboriginality. Their publication of *Case Studies of 'Best Practice' in recording Aboriginality* [48] (pictured opposite) was published July 1996. The Koori Health Unit clearly sees its role as a proactive one in supporting and fostering effective practices through public recognition (and thus promotion, positive reinforcement, as well as public kudos for the agencies involved), and in disseminating case studies to other agencies as an educative and awareness-raising process. Indeed, the efforts of the Koori Health Unit highlights a key potential role for other state and national agencies (both government and community) in fostering and supporting agencies to adopt more effective practices in Indigenous health information.



[45] Mak D & Straton J. (1993) *The Fitzroy Valley Pap Smear Register – Cervical screening in a population of Australian Aboriginal women*, in the **Medical Journal of Australia**, Vol. 158: 163-166.

[46] Toussaint S. (1996) Marnin Business – **Cervical screenings and health-related issues in the Fitzroy Valley, Kimberley, Western Australia**. Report prepared for the Women's Cervical Cancer Prevention Program, Western Australian Health Department, Perth.

[47] Mak D & Straton A. (1997) *Effects and sustainability of a cervical screening program in remote Aboriginal Australia*, in the **Australian and New Zealand Journal of Public Health**, Vol. 21: 67-70.

[48] Department of Human Services (Vic). (1996) op cit.

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4 Some caveats

There is little point in government agencies demanding data and information about clients served or health services provided for them, unless there is an associated capacity to adequately collect the required data, or at least a corresponding effort to develop this capacity. Thus, the collection of quality health information is ultimately reliant on the existence of an infrastructure which supports data collection, analysis and dissemination across all levels of interest, and the skills and knowledge with which to effect this. Further, this situation is only likely to be developed if those collecting the data are also provided with the resulting statistics or, as a minimum, they are aware of and believe in the valuable uses to which the data are put. To expect anything else is unrealistic.

It is important to acknowledge that any recommendations to improve Indigenous health information in Australia cannot be effected in a vacuum. Any resulting improvements in information and reporting will also rely heavily on other support mechanisms, policies, structures and changes in the wider mainstream and Indigenous health services sectors. For instance, the success of developing and maintaining an information-skilled and knowledgeable workforce will be severely limited if measures are not introduced to address the high turnover of community health practitioners in Indigenous communities and the rapid burnout of Aboriginal health workers.

That is, while this review has identified a major need for training and development initiatives to increase the information skills of health workers, it makes poor economic sense to provide such training to staff who are unlikely to remain in those positions for any length of time. These broader health system issues are beyond the remit of this review. Nevertheless, the capacity of this plan's recommendations to improve Indigenous information in Australia are inextricably dependent upon addressing the wider health system's infrastructural problems. One avenue for addressing these issues is to provide training and longer-term employment opportunities in relation to health information for Indigenous peoples through the Community Development Employment Program and/or the Australian Public Service's Aboriginal Employment Development Program.

This review also acknowledges that certain costs will accompany the implementation of these recommendations. For instance, changes concerning the collection and analysis of data may entail additional processing costs, and additional time and resources with which to implement the changes, such as in updating program manuals, database reprogramming, redesign of collection forms and reprinting, and the education and training of staff in the new procedures.

Clearly, a balance needs to be found between the need for quality public health information on the one hand, and ensuring the efficient use of resources and minimal impact on the efficiency of administrative systems and procedures on the other.

It is also recognised that some states will require considerably more effort than others in order to improve their information systems to meet the minimum standards required for Indigenous identification and collection. Therefore, any national initiatives to implement this plan's recommendations should ensure that those jurisdictions which have already devoted resources to improving Indigenous identification in some of their collections are not penalised (financially or otherwise), and are not expected to cross-subsidise efforts to increase data quality in those states where significant work is required. Finances aside, however, it is expected that the experiences and effective practices of 'high-performing' states be used as valuable resources for other jurisdictions.

Part 5 Recommendations to Improve the Quality of Indigenous Information

1 Develop A Supportive Infrastructure

1.1 Develop guidelines for the protection and appropriate use of Indigenous health information

1.1.1 Protocols for handling data about Indigenous peoples

R1: It is recommended that national protocols be developed to address the appropriate use and handling of data, as a matter of priority. These should include a requirement for agencies which seek data from or about Indigenous communities or services to feed information back to the source communities, promptly and in culturally appropriate ways. The protocols must be developed with the active participation of Indigenous peoples and community agencies.

Responsibility for action:

National:

Establish a working group comprising the major Indigenous health partnership agencies DHFS, NHMRC, AIHW, NACCHO and relevant State agencies, to review the relevance of any existing jurisdictional policies (e.g. NHMRC Guidelines for Research with Indigenous Peoples), and to develop standards for use in National and State jurisdictions.

R2: It is further recommended that such protocols contain a capacity to be amended, as appropriate, for application by local health services and institutions, to reflect specific concerns and circumstances of individual communities.

Responsibility for action:

State and Local agencies to adapt in conjunction with Communities.

1.2 Develop information management skills in health services

1.2.1 Build community capacity to collect and use information

R3: It is recommended that specific strategies and programs be adopted to facilitate improved technical capacity amongst health agencies responsible for data collection. These might include providing access to technical and advisory support for data collection and information issues, budgets for appropriate staff training and materials (including capital equipment), information resource kits for front-line information collectors, and, where appropriate, electronic data transfer systems. Above all, attention must be devoted to raising information skills levels and awareness amongst health services personnel.

Responsibility for action:

DHFS and state and territory jurisdictions

R4: It is further recommended that the existing Indigenous co-ordinated health care trials being undertaken in Western Australia and the Northern Territory communities be evaluated to explicitly consider the success of their shared approach to information. If this approach is successful, then National and State health departments should provide financial and technical support to enable Indigenous communities, and community-controlled and other local health agencies to engage in joint planning, service delivery, and information sharing and review processes.

1.2.2 Towards a proactive information–aware culture in health service

R5: It is recommended that avenues which encourage staff to enquire about Indigenous status of all client contacts (or their families) be pursued, including:

- increasing staff accountability for obtaining identification data on all client contacts, through inclusion of mandatory requirements in policies and as a performance criterion in individual health services managers' performance contracts;
- negotiating with health services accreditation agencies (such as the Australian Council of Healthcare Standards [for hospitals], and the Community Health Accreditation and Standards Program [for community-based health services]) for the inclusion of an accreditation criterion concerning mandatory collection and reporting on Indigenous status of all clients.

Responsibility for action:

Relevant national agencies to negotiate with accreditation agencies, with appropriate input.

1.3 Promote information dissemination and communication

1.3.1 Commitment to returning information to communities

R6: It is recommended that governments and health services at all levels develop policies, standards and procedures to ensure that information and research findings are returned to communities and their health agencies in a timely and culturally appropriate manner.

Responsibility for action:

Unless otherwise stated, all agencies and jurisdictions which collect information are responsible for implementing all recommendations in Section 6.

R7: It is further recommended that the requirement to return information and disseminate research findings to communities and their agencies, be a formal condition of health departments' own information collection activities. It should also be a condition stipulated in contracts with funding agencies and also of research grants. Furthermore, research funding selection processes should take into consideration the applicants' previous history of appropriately conducting research with, and disseminating research findings to, Indigenous communities.

Responsibility for action:

National and State health departments, ATSIC, NHMRC, and other funding bodies (including research funding agencies) to amend all future contractual and grant applications documentation and selection processes to ensure adherence to this recommendation.

R8: It is further recommended that Commonwealth and state and territory governments, and major community-controlled health services, routinely publish information about Indigenous health status and the performance of their programs and services in addressing identified community concerns, on at least a biennial basis. This should be linked to the ongoing performance indicators which are to be reported on by states, territories and community controlled health services.

Responsibility for action:

All agencies providing health programs and services.

1.3.2 Promoting awareness of the importance of accurate data

R9: It is recommended that a national awareness program be developed to promote the importance of accurate Indigenous data collection and identification to health agencies, other information collectors and the community, and that additional jurisdictional and community-specific issues be addressed through supplementary initiatives, as appropriate, at these levels.

R10: It is further recommended that community controlled health services develop proactive approaches to identification amongst their clients; ie. to instigate identification processes in their clinics, and encourage those clients referred to hospitals and other services to be proactive about identifying when records are being taken in the hospital.

Responsibility for action:

Community awareness initiatives should be co-ordinated across all jurisdictions, to ensure co-ordination (rather than duplication). Agencies at State and National levels must ensure community involvement in the design of programs for local use.

R11: It is further recommended that relevant agencies and researchers work with Indigenous communities to:

Responsibility for action:

All AMSs

- understand the reasons why people choose not to self-identify;
- understand why the propensity to self-identify can change between contacts with services; and
- develop strategies for addressing these issues.

Responsibility for action:

ATSIHWIU

1.4 Develop the Indigenous health workforce

R12: It is recommended that Aboriginal Hospital Liaison Officers be recruited to all

Responsibility for action:
State and Territory health departments

hospitals which have sizeable numbers of Indigenous clients, to assist with the hospital's efforts to improve the quality of data from Indigenous people, particularly Indigenous status.

R13: It is further recommended that Indigenous staff be recruited on a permanent

Responsibility for action:
ABS to provide permanent employment opportunities and training as part of its efforts to improve Indigenous identification in collections

basis to all Australian Bureau of Statistics State and Territory Offices to assist with work to promote willingness to identify amongst Indigenous people in survey and Census collections.

Responsibility for action:
DHFS and state and territory jurisdictions to initiate workforce development programs for AMS and other staff in handling health data about Indigenous people

R14: It is further recommended that ongoing training, resources and support for Aboriginal Medical Services staff in the collection, analysis, application and reporting of information about health issues in their communities.

2 Technical requirements to improve Indigenous health information

2.1 Improve Indigenous identification capacity in major information collections

2.1.1 Indigenous identification in administrative data collections

R15: ***Ensure that all major health and related collections include accurate Indigenous identification***

It is recommended that Indigenous peoples be accurately identified in all relevant data collections, including, vital and other administrative registrations (including birth and death notifications, and cancer and related registries), medical certificates on causes of death (including perinatal deaths), hospital separations collections, and perinatal collections. This should be progressed through implementing recommendations at 2.1.3 below.

Vital statistics

It is recommended that in those states where Indigenous identification in birth or death registrations is incomplete, the Registrars of births and deaths seek to identify the causes of incompleteness and to address these deficiencies as a matter of urgency. This should be done with the assistance and support of the ABS, and all jurisdictions should aim to accurately identify at least 90 per cent of expected numbers (as devised by ABS) of Indigenous peoples in vital registrations by December 1999.

Hospital separations

It is recommended that all jurisdictions should have piloted a scheme for assessing the completeness of identification in hospital collections by December 1998. All jurisdictions should have undertaken sufficient assessment work to derive an estimate of the completeness of the hospital separations data sets for the states by December 1999.

Perinatal collections

It is recommended that all jurisdictions should have piloted a scheme for assessing the completeness of identification in perinatal collections, and have undertaken sufficient assessment work to derive an estimate of the completeness of the perinatal collections for the states by December 1998. It is further recommended that each jurisdiction adopt and implement the full ABS standard for indigenous identification, which explicitly requires that the identification of both mothers and fathers be collected in relation to all births.

Cancer registrations

It is recommended that standard Indigenous identifiers be introduced into cancer and related registries (including cervical cytology), with clients' Indigenous status being entered either from pathology forms or, if this is not present, inquiry of the hospital or other source of cancer notification, as appropriate. This may also require addressing underlying issues, such as Indigenous identification and recording for pathology and general practitioner services.

Responsibility for action:

State: Each jurisdiction should convene working groups of key agencies and individuals to oversee progress towards improving identification on vitals statistics, in hospital separations collections (including perinatal collections), and in cancer registrations, respectively. The groups should meet regularly and monitor, on a monthly basis, the extent of completeness in the respective collections, and the activities being undertaken to improve identification.

National: ATSIHWIU to facilitate the creation and servicing (with materials and advice) of these groups and assist communication nationally between the jurisdictional groups. AIHW and NPSU, with expert advice from NT and WA, to pilot schemes for achieving complete recording of both mothers' and fathers' identification. ABS to lead efforts towards complete identification in vital statistics collections. AIHW to lead efforts towards complete identification in hospital, perinatal collections (in conjunction with NPSU), and cancer registrations.

Community health collections

R16: It is recommended that all information systems which record contacts and other information concerning community health status and services utilisation patterns, be amended to identify clients' Indigenous status according to currently accepted procedures, including in:

- client records systems at all community health centres and Indigenous-controlled services;
- client record systems for dental and allied health services;
- in Medicare and Pharmaceutical Benefits Scheme databases;
- in all communicable disease notifications; and
- in all special registers (at both State and community clinic levels), such as for diabetes.

Responsibility for action:

State: Each jurisdiction should convene a working group of key agencies and individuals to oversee progress towards improving identification in community health registers and population registers, where the latter are used for health monitoring purposes. The group should meet regularly and monitor, on a monthly basis, the extent of completeness in perinatal collections, and the activities being undertaken to improve identification.

National: ATSIHWIU to facilitate the creation and servicing (with materials and advice) of this group and assist communication nationally between the jurisdictional groups.

DHFS and the Health Insurance Commission to develop and implement a process which seeks to capture Indigenous identification in Medicare and Pharmaceutical Benefits Scheme databases by December 1999.

Include an Indigenous identification field in all future health collections

R17: It is recommended that all new health and related information collections developed in the future include the standard Indigenous identifier (see 2.1.2), for example, the proposed national register of people with insulin-treated diabetes mellitus.

Responsibility for action:

All jurisdictions and agencies responsible for establishing new collections, with advice provided by ATSIHWIU.

Establish processes which promote quality and feeding back of community health information

R18: It is recommended that, where identifiers exist in data collections, there should also be written procedures for assessing the completeness with which Indigenous people are identified, reporting findings and feeding information back to collectors.

Responsibility for action:

All jurisdictions and agencies, with advice provided by ATSIHWIU.

2.1.2 Consistent identification classifications and collection protocols

In order to achieve national consistency, use a single classification standard throughout all jurisdictions and health services for seeking the Indigenous status of clients.

R19: It is recommended that jurisdictions move to implement processes to ensure the adoption in all existing collections of the already-agreed standard classification for identifying Indigenous peoples, as recognised in the National Health Data Dictionary Version 6 (and by the ABS), namely:

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 .....

Responsibility for action:

Unless otherwise stated, all jurisdictions and agencies are responsible for implementing all recommendations in Section 2.1.

2.1.3 Improve processes in health services for collecting Indigenous status information

Seeking Indigenous status of all clients should be a mandatory requirement

R20: It is recommended that health services staff and other collectors be required to ask about the Indigenous status of all clients. That is, all clients should be given the opportunity to self-identify as Indigenous should they so choose rather than having hospital staff make assumptions on the basis of clients' appearance. Accordingly, existing health services procedures manuals, collection forms and databases (other than those which use information transferred from another record system) should be amended to reflect this mandatory requirement.

Develop less-threatening strategies for seeking information about Indigenous status

R21: It is recommended that strategies be developed and piloted for use in all hospitals and health services settings, for seeking information about Indigenous identification in non-threatening ways. Such strategies could include the use of Indigenous Hospital Liaison Officers, promoting and explaining rationale for seeking the information, and/or written approaches to seeking such information, however, it is important to recognise that such approaches should not be seen as alternatives, but rather as supporting the standard question approach about origin.

Promote awareness of the reasons for collecting information about Indigenous status

R22: It is recommended that strategies be developed to promote better understanding among Indigenous peoples of the need for improved identification in data collections, provided appropriate safeguards for the use of data are put in place.

Responsibility for action:

ATSIHWIU to seek resources to let a research consultancy to review the evidence concerning best practice in Indigenous identification in health services settings, and to develop potential pilot projects.

2.1.4 Quality assurance

Ensure the data quality of all collections

R23: It is recommended that quality assessment work be undertaken on all collections on the premise that datasets which have not had the completeness of their Indigenous identification validated are unreliable as sources of statistics. Strategies for assessing data quality include:

- benchmarking of Indigenous client rates (mainly vital statistics) against population estimates and demographic characteristics;
- data matching of records across two or more datasets, e.g. hospital separations and perinatal collections, or cross-checking medical certificates on cause of death against death notification forms;
- comparison of one or more datasets with sample population surveys;
- cross-checking using Indigenous Hospital Liaison Officers and other sources of expert advice and information; and
- greater attention to following up Indigenous status non-responses for information submitted to vital statistics and health data collections (including with funeral directors where submitted forms have not captured this information).

Responsibility for action:

States:

All jurisdictions and agencies, with pilot tests to be completed by December 1998, and jurisdiction-wide assessments completed by December 1999.

National:

AIHW and ABS to work with agencies to facilitate the development and implementation of pilot assessment procedures and to develop nationally consistent methodological approaches.

ABS to assess the uncertainty attached to expected numbers of births and deaths it derives from its current methodology.

2.2 Establish the quality of population estimates

2.2.1 Review the suitability of definitions used and estimates for deriving Indigenous statistics

R24: It is recommended that a review be undertaken into the suitability of the currently used standard question for Indigenous data. This should be completed, along with appropriate consultation, prior to the finalisation of the 2001 Census.

Responsibility for action:

ABS to co-ordinate the consultation with representatives of the Indigenous community and users of Indigenous statistics

2.2.2 Assess the quality of population estimates

R25: It is recommended that efforts to assess and, if necessary, improve the accuracy of the experimental estimates of the Indigenous population be recognised as amongst the highest priority issues for improving Indigenous health statistics.

> *Responsibility for action:*
>
> Unless otherwise stated, ABS should be responsible for implementing all recommendations in Section 2.2, with appropriate advice and support from States and other National agencies.

Census counts versus community perceptions

R26: It is recommended that considerable effort be directed to working with Indigenous communities to investigate the basis for, and addressing if necessary, differences between ABS Census counts (and, at the state and territory level, population estimates) and the community's perceptions. If discrepancies are found to be due to incorrect community perceptions, then a program should be implemented to help people understand their mistaken perceptions. If, however, discrepancies are identified as due to incorrect Census counts, then the reason for the low estimates should be identified and corrected.

Accurate baseline estimations

R27: It is further recommended that the necessary resources be committed to test whether the current methodology for deriving Indigenous population estimates can be improved. This should include:

a) improved methods of partitioning the count of people who do not state their identification in Census counts between the Indigenous and non-Indigenous population,

b) methods for undercounting which are more appropriate than those currently used,

c) investigating alternative approaches to adjusting for differential undercounting amongst males and females of different ages

Torres Strait Islander estimates

R28: It is recommended that estimates of the Torres Strait Islander population, according to specifically selected definitions, are derived by the ABS, and the quality of these be investigated thoroughly with a view to disseminating them publicly if the quality is shown to be adequate for use as a denominator in rate and ratio statistics for this population group.

Whole population statistics as proxies for Indigenous health

R29: It is further recommended that, where geographic regions have proportionately large Indigenous populations, additional research be conducted into the use of health statistics for the whole population as proxies for Indigenous health statistics.

2.3 Foster ongoing commitment to special purpose collections

2.3.1 Long term commitment to regular Indigenous surveys at appropriate frequencies

Develop a national survey collection system

R30a: It is recommended that a national survey collection system be constituted which, when considered with administrative collections, provides all essential national, state and territory Indigenous health statistics at sufficient frequency for jurisdictions' reporting requirements on nationally agreed performance indicators. This implies comparisons between Indigenous and non-Indigenous peoples, comparisons in time, and comparisons between jurisdictions.

National Aboriginal and Torres Strait Islander Household Survey

R30b: Within any limitations of the above recommendation, it is recommended that there be a national five yearly commitment (with allocated resources) to a regular and appropriate household survey program for Indigenous peoples. This survey program should yield statistics of sufficient quality to allow national, and state and territory estimates to be derived, and which can be used to make comparisons between successive surveys and also between various sections of the Indigenous and Australian non-Indigenous populations.

Surveys of health status and risk factor prevalence

R31: It is further recommended that, given the central importance of certain risk factors in Indigenous health morbidity and mortality patterns, a regular survey program be designed to monitor changes in, as a minimum, nutritional issues, tobacco smoking, and alcohol consumption patterns in both urban and rural settings.

It is further recommended that resources be sought for adequate sample sizes in national surveys to enable the necessary comparisons between Indigenous and non-Indigenous Australians.

Responsibility for action:

National:

ABS to ensure ongoing commitment to each of these survey recommendations, with appropriate advice, support and resources from other Commonwealth agencies, States and appropriate community groups.

Housing and Community Infrastructure Needs Survey

R32: It is recommended that a commitment be given to repeat, as soon as feasible and then at five-yearly intervals, an enhanced Housing and Community Infrastructure Needs Survey (HCINS), to be conducted throughout all remote area communities of Australia. The enhancements should include a capacity to record some health information by interviewing local community clinic personnel to capture community level health data. The design of future HCINS data collections should be co-ordinated and integrated as far as possible with the design of sample household surveys which collect Indigenous health information.

R33: It is further recommended that a long term data collection strategy be developed, endorsed and funded which will enable the collection of the necessary survey data for monitoring changes in Indigenous health status and health service delivery issues for a generation or more. This strategy could be constructed around the HCINS, as per above sample household surveys.

Responsibility for action:

ATSIC to contine to fund surveys; ABS to ensure the most effectively co-ordinate data from HCINS and ABS household surveys

2.3.2 Comparative health surveys

Ensure that other health surveys attempt to capture Indigenous information

R34: It is recommended that strategies for capturing information about social and emotional wellbeing and other mental health issues of concern to Indigenous communities through the proposed National Mental Health Strategy and the Aboriginal and Torres Strait Islander Emotional and Social Wellbeing (Mental Health) Action Plan continue to be identified.

R35: It is further recommended that, in the event of future national disability surveys, strategies to enhance the information about disadvantage and handicap in Indigenous communities continue to be identified.

2.3.3 Information about illness in communities

Obtain information about the burden of illness in Indigenous communities

R36: It is recommended that consideration be given to the development of strategies for obtaining baseline data and monitoring trends about the burden of illness in Indigenous communities, including the measurement of differentials between Indigenous and non-Indigenous Australians.

Responsibility for action:

National:

NHMRC and other agencies to promote burden of illness studies for Indigenous peoples as an area of priority national research.

ABS, with ATSIC and DHFS support, to explore the possibility of HINCS as an appropriate vehicle for the systematic community-by-community collection of selected information about morbidity loads in communities.

2.3.4 Population-based disease registers

Investigate the potential uses for population-based disease registers

R37: It is recommended that the potential use of regional, state and/or national community-based Indigenous disease registers be explored, in terms of information as a useful by-product from registers established for other purposes, such as epidemiological tools, for screening and recall purposes, for health services evaluation, policy development and services planning, and to assist in the delivery of efficient health services.

Responsibility for action:

Collaboration between NACCHO, DHFS and the States.

R38: It is further recommended that these registers be explored as potential tools to assist in checking and verifying population estimates, for assisting in the process of reconciling community and service provider perceptions, and for estimates and counts of Indigenous people.

3 Effective national leadership and co-ordination

Preamble

R39: So, what is needed in order to effect these recommendations?

There is clearly a need for national leadership in relation to Indigenous health information. Currently, there is no obvious agency or process for marshalling national action or co-ordinating and monitoring the range of efforts required of the various national, state, territory, regional and community interests.

The consultation process uncovered widespread reluctance to the draft proposal that a further bureaucratic structure be created to oversee developments in Indigenous health information. However, there was also widespread agreement for the need to develop a process – i.e. rather than a formal structure – for overseeing and co-ordinating the development of Indigenous health information initiatives across the country. This process, which must be accountable to the Australian Health Ministers Advisory Council (AHMAC) and the Australian Health Ministers Conference (AHMC), should – as a minimum – include the following responsibilities:

- ***considering the outcomes of the other current national projects in Indigenous health information*** which are currently underway, and ensuring that their recommendations are complementary (with each other and also with broader health system information initiatives);
- ***developing an agreed process for implementing and reviewing progress*** in each of the areas of:
  - ⇒ accurate collection and recording of Indigenous status in administrative collections;
  - ⇒ the application of consistent classifications and collection protocols;
  - the development of appropriate quality assurance mechanisms;
  - ⇒ advising on information to be collected through surveys, population studies and registers;
  - ⇒ information dissemination and community awareness strategies; and
  - ⇒ workforce development initiatives;
- and ***evaluating the progress towards implementation*** of the recommendations, and a formal public reporting process.

Further, a reflective analysis on the major national health initiatives in Australia which successfully made the transition from policy into practice reveals one common factor - committed funds from the Commonwealth and the states. Thus, it is this review's recommendation that AHMAC and NHIMG assess the potential value and scope for a dedicated program between the Commonwealth and states and territories to improve the national quality of Indigenous. This process has the advantage of providing commitment from all major parties, dedicated resources to provide incentive and facilitate action, and, by virtue of the shared financial commitment, scope for establishing and underwriting the activities of the national reference group to fulfil the above functions and responsibilities.

3.1 Establish processes to facilitate the national co-ordination and leadership

R40: It is recommended that the following processes be initiated to facilitate and oversee implementation of the plan's recommendations in a cohesive and co-ordinated manner:

- a formal process for national leadership (in partnership with national, state and community interests), to facilitate support of jurisdictional initiatives, benchmarking, co-ordination and review;
- appropriate partnerships at the state/territory level to facilitate and support developments in line with the Framework Agreements on Aboriginal and Torres Strait Islander Health;
- the provision of resources for a person, attached to the AHMAC Executive, and/or a high level Indigenous Information Task Force, to facilitate, co-ordinate and oversee national activity in this area; and
- clear delineation of roles and responsibilities amongst the major stakeholders.

Responsibility for action:

- NHIMG is the responsible agency for national leadership and to oversee jurisdictional progress to improve Indigenous health information, in active partnership with NACCHO, HAHU and the ATSIHWIU Advisory Committee
- The ATSIHWIU Advisory Group to oversee operational developments to improve Indigenous health and related information
- All jurisdictions to explore and establish financial and other incentives to encourage improvements in Indigenous information provided by hospitals, funeral directors, Births and Deaths Registrars, and others.

3.2 Ensure commitment to implementing recommendations to improve information

R41: It is recommended that resources be provided to ensure commitment and enable action to implement the recommendations in this plan, through a Commonwealth and State and Territory cost-shared Indigenous Health Information Enhancement Program. The program should be allocated a minimum of five-years funding, commencing in the 1998-99 financial year. The program should be used to fund national, state and local initiatives to effect:

- the accurate collection and recording of Indigenous status in health and related collections;
- the consistent application of classifications and collection protocols;
- the introduction of appropriate quality assurance mechanisms;
- the development of strategies to promote greater awareness amongst health industry staff and the general community, of the importance of Indigenous identification and quality health information; and
- the development of workforce development initiatives for improving the skills base required for quality information collection and analysis.

Suitable strategies to be supported under this program might include (but not limited to):

- employment by jurisdictions of clearly identified personnel to conduct site visits to hospitals and agencies, to facilitate the introduction of specific recommendations; and
- similar arrangements for technical and other advice to be provided by the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare, to state and territory health authorities and registry offices.

Responsibility for action:

AHMAC, in conjunction with NHIMG, to consider the potential value and scope for committing resources, through a Commonwealth/state cost-shared program, to support developmental and other activities to improve Indigenous health information

3.3 Promote the national Indigenous health information plan

R42: It is recommended that an organised strategy to promote the plan be developed and implemented, including, but not limited to:

- releasing the preliminary report and recommendations for a widespread public consultation process, including workshops and meetings in each state and territory;
- (following consultation and amendment), wide distribution of the final report to appropriate Commonwealth, state and government agencies, community-controlled organisations, and other interested agencies and individuals;
- development of two summary versions (targeting health and information agencies, and Indigenous communities and community-controlled health agency boards, respectively); and
- widespread targeted and opportunistic promotion of the review findings and strategy, through appropriate conferences, meetings, and professional and agency-specific publications.

Responsibility for action:

NHIMG to develop and oversee the implementation of a national communications strategy to promote the Indigenous health information recommendations and plan.

4 Delineation of roles and responsibilities

The Australian health system is a complicated web of structures, lines of accountability, and funding and service delivery arrangements. This has led to a perception that the system is fragmented, with resulting duplication - as well as gaps - in service delivery and program arrangements. Nowhere is this more evident that in the delivery of health and related services to Indigenous peoples - where, in addition to the above characteristics, there also appears to have been years of relative inaction relative to the high level of need. Efforts to improve aspects of Indigenous health appear to fall between the cracks of jurisdictional responsibility, landing firmly in the 'too hard basket'.

It is important to acknowledge that any work undertaken in the area of Indigenous health must be done in a co-operative and participative manner. Those working in the field must be mindful of both the need to ensure that principles of community control and Indigenous self-determination are adhered to, while also recognising the federal structure and associated responsibilities and interests within the Australian health sector. Thus, progress in this area is dependent upon all of these elements working together.

An important first step in seeking to improve the quality of Indigenous health information is to clarify the major interest groups, and delineate the various roles, responsibilities and inter-relationships. A minimum set of responsibilities is proposed below:

National responsibilities

In general, the responsibilities that are most appropriately managed at the national level (and which apply across all relevant national agencies), include:

- Leadership and co-ordination in the development of national standards and benchmarks, and strategic directions for improving Indigenous health information (in partnership with states and community interest groups);
- The establishment of nationally consistent processes by which the states and other agencies collect adequate Indigenous data;
- Funding of national programs and activities to promote Indigenous identification in collections and data quality;
- National interpretation of data for monitoring and evaluating progress across all jurisdictions;
- Implementing systems to accurately identify Indigenous peoples in all appropriate national data collections;
- Convening and supporting national working groups in the areas of:
  - ⇒ standards and methodological approaches for quality assurance;
  - ⇒ standards for the appropriate handling of Indigenous health data;
  - ⇒ national strategies to improve training and skills development in the collection and use of data in Indigenous health; and
  - ⇒ national communication strategies to promote the Indigenous health information plan and recommendations.
- Ensuring that, where agencies collect information from Indigenous communities and health services, this is returned to those communities in a timely and culturally appropriate manner.

Further to these national responsibilities:

- The ***Department of Health and Family Services*** is responsible for developing workforce training initiatives in the collection and use of data, in conjunction with other national agencies and states;
- The ***Australian Institute of Health and Welfare*** is responsible for leading national efforts to complete identification and validate Indigenous statistics in hospitals, perinatal and community health collections in all states; and for promoting the use of the National Health Data Dictionary as the standard to be attained in information technology development;
- The ***Australian Bureau of Statistics*** is responsible for leading national efforts to complete identification and validate Indigenous vitals data collected by Registrars of Births and Deaths in all states and territories; developing accurate Indigenous population estimates at census time and for inter-censal years; continuing to assess and revise the methodology for calculating expected numbers of births and deaths; and ensuring ongoing commitment to supporting regular Indigenous surveys (including a National Aboriginal and Torres Strait Islander Survey); and
- The ***National Aboriginal and Torres Strait Islander Health and Welfare Information Unit*** is responsible for facilitating communication between, and servicing of, national and state/territory working groups to increase accurate Indigenous identification in data collections.

State responsibilities

Unless otherwise specified, the prime responsibility for initiating and supporting these activities lies with the state and territory health authorities, with the involvement of other key agencies state and territory community agencies and the ABS state and territory officers:

- Setting strategic directions for state policies and programs in relation to improving the quality of Indigenous health information;
- Co-ordinating the planning, implementation and monitoring of state-wide initiatives in Indigenous health information, including implementing systems to accurately identify Indigenous peoples in all appropriate state and territory data collections;
- Supporting national initiatives to improve Indigenous health information;
- Collecting and reporting on statewide Indigenous health data;
- Collecting accurate births and deaths registration data about Indigenous people (the responsibility of Registrars of Births and Deaths);
- Convening and supporting state/territory working groups to progress Indigenous identification in collections concerning (ABS responsibility):
    - ⇒ vital statistics;
    - ⇒ hospital separations and perinatal collections;
    - ⇒ community health-based and population registers; and
    - ⇒ pathology and cancer registrations (ABS largely responsible for these roles);
- Ensuring that, where agencies collect information from Indigenous communities and health services, this is returned to those communities in a timely and culturally appropriate manner.

Hospital level responsibilities

Hospitals are responsible for:

- The collection of and reporting on hospital separations and perinatal data;
- Implementing systems to accurately identify Indigenous peoples in hospital separations and perinatal collections;
- Supporting state and national initiatives to improve Indigenous health information;
- Ensuring that, where information is collected from Indigenous communities and health services, this is returned to those communities in a timely and culturally appropriate manner.

Local health services responsibilities

Community health services, clinics and AMSs are responsible for:

- The collection of and reporting on local community health data;
- Implementing systems to accurately identify Indigenous peoples in all appropriate community-based data collections;
- Supporting local, state and national initiatives to improve Indigenous health information;
- Ensuring that, where information is collected from Indigenous communities, this is returned to those communities in a timely and culturally appropriate manner.

When will we believe that our community is healthy?

... When no-one will want to be researching us and give little or no return to the community. When a child born today will live as long as non-Aboriginal children, and will be able to drink clean water every day. When our people do not have the pressures to escape that lead to excess use of alcohol, drugs, or to suicide. When they have jobs, and high self-esteem. When they are able to travel to services, to visit friends and relatives, and to live in houses of their choosing.

How would we know when an Aboriginal community was healthy?

... When the environments, cultures, minds and bodies of all members of the community are healthy and conducive to Aboriginal people achieving pride, autonomy, longevity and freedom from disease.

Golds M, King R, Meiklejohn B, Campion S, & Wise M. (1997) *Healthy Aboriginal Communities, in the Australian and New Zealand Journal of Public Health,* Vol. 21: 386-90.

Attachment 1

An Historical Overview of the Development of Indigenous Health Statistics

Much of this chapter is summarised from a paper presented by Neil Thompson, Visiting Senior Fellow at the School of Health Studies, Edith Cowan University (Western Australia), at the November 1996 Brisbane workshop on Indigenous Identification in Administrative Data Collections.[1]

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[2]).

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. But, "this was for many years the only published information on the state of Aboriginal health".[3]

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.[4]

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1 Thompson N. (1997) *An historical overview of the development of Indigenous Health Statistics*, in Australian Bureau of Statistics & the Australian Institute of Health and Welfare, **Indigenous Identification in Administrative Data Collections: Best Practice and Quality Assurance**. Report on Workshop Proceedings, November 1996, Commonwealth of Australia, Canberra.

2 Smith, LR. (1978) **Aboriginal health statistics in Australia - a survey and a plan**. Third revision. Health Research Group, Australian National University, Canberra.

3 House of Representatives Standing Committee on Aboriginal Affairs (HRSCAA). (1979) **Aboriginal health**. Australian Government Publishing Service, Canberra.

4 HRSCAA, ibid., p30.

Attachment 1

In 1975, the Commonwealth Department of Health[5]commissioned the development of a "plan for the collection, interpretation and dissemination of Aboriginal health statistics on a national basis[6]

Dr Len Smith's *Aboriginal health statistics in Australia - a survey and a plan*[7] *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. For instance, in the early 1980s, no jurisdiction provided for the identification of Indigenous people in birth or death registrations.*[8] *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 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, met with senior officials from each State and Territory except Queensland. Four collections were 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. Broad agreement was reached on the inclusion of an Indigenous identifier in most of these collections.

Some States and Territories moved quickly to implement the agreements but, generally, progress was extremely slow. The momentum established by the Task Force virtually collapsed because the high-level interest at the Commonwealth 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.

Some useful studies, particularly in South Australia and the Northern Territory, were undertaken during a 30 week period under the CEP scheme resulting from the work of the Task Force (examples provided in references[9, 10, 11]).

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5 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.

6 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.

7 Smith, op cit.

8 Achanfuo-Yeboah DJ. (1995). *From Darwin to Brisbane: current status of Aboriginal health statistics and research*, in Australian Institute of Health and Welfare, **From Darwin to Brisbane: proceedings of a workshop on Aboriginal health statistics**, Brisbane, June 1993, Australian Government Publishing Service, Canberra.

9 Aboriginal Health Organisation of South Australia. (1986) A study of the accuracy of the hospital morbidity collection of South Australia with reference to Aboriginal patients. Aboriginal Health Organisation, Adelaide.

10 Devanesen D, Furber M, Hampton D, Honari M, Kinmonth N & Peach HG. (1986) **Health indicators in the Northern Territory**. Northern Territory Department of Health, Darwin.

Structural changes at the Commonwealth level around this time militated also against effective co-ordination 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). Immediate progress was slow, however, as the AIH determined its future role in health information in general.

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".[12] 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. 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.*[13]

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.

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 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.[14]

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".[15] 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.

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11 Thomson N, Paden F & Cassidy G. (1990) **Identification of Aborigines in hospital admissions in the North Coast Health Region, New South Wales**. Australian Institute of Health and North Coast Health Region of the New South Wales Department of Health.

12 Thomson N (Ed.). (1986) **Aboriginal health statistics: Proceedings of a workshop**. Darwin, April 1986, Australian Institute of Health, Canberra.

13 Thompson, ibid.

14 National Aboriginal Health Strategy Working Party. (1989) **A National Aboriginal Health Strategy**. Aboriginal and Torres Strait Islander Commission, Canberra.

15 National Aboriginal Health Strategy Evaluation Committee. (1994) **The National Aboriginal Health Strategy: an evaluation**. Aboriginal and Torres Strait Islander Commission, Canberra.

Attachment 1

The National Aboriginal Health Strategy Evaluation Committee 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".[16]

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 Unit's relocation from Canberra to Darwin.[17] One reason for the proposed relocation was to allow more effective co-ordination 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".[18]

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",[19] confirmed the real progress that had been made in most States and Territories since the Darwin workshop.

A 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".[20]

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.

Brisbane workshop, 1996

This workshop was sponsored by the newly created Aboriginal and Torres Strait Islander Health and Welfare Information Unit, the joint Australian Bureau of Statistics and Australian Institute of Health and Welfare based in Darwin. The workshop brought together representatives from almost all state and territory Registrars-General, health departments, the Australian Institute of Health and Welfare, all Australian Bureau of Statistics' state offices, and a range of other interest groups.

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16 National Aboriginal Health Strategy Evaluation Committee, ibid., p 70.

17 National Aboriginal Health Strategy Evaluation Committee, ibid.

18 National Aboriginal Health Strategy Evaluation Committee, ibid.

19 Australian Institute of Health and Welfare. (1995) **From Darwin to Brisbane: proceedings of a workshop on Aboriginal health statistics**. Brisbane, June 1993, Australian Government Publishing Service, Canberra.

20 English B. (1995) *The National Health Information Agreement*, in Australian Institute of Health and Welfare, **From Darwin to Brisbane: proceedings of a workshop on Aboriginal health statistics**. Brisbane, June 1993, Australian Government Publishing Service, Canberra.

The workshop's focus was specifically on establishing the current status of the Indigenous identification in health and vitals collections and to rekindle interest and maintain further improvements. The proceedings of the workshop (from which this chapter is taken) present an account from all Registrars-General and all health departments of the current position of identification in their collections.

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",[21] 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. This was established in conjunction with the Australian Bureau of Statistics.[22] The project was funded to operate for 1995-96 and 1996-97, with an evaluation scheduled in the second year. Subsequently, funding has been agreed for a further five years to 2001.

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".[23] The project's work program, which is agreed between the Director of the Institute and the Australian Statistician, is developed with the assistance of a broad-based advisory group.

This AIHW-ABS collaboration has already produced some useful publications, including an analysis of Indigenous mortality,[24] and the first of a planned series of comprehensive biennial reports on Aboriginal and Torres Strait Islander health was released in April 1997.[25]

Endnote:

i 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.

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21 National Aboriginal Health Strategy Evaluation Committee, op cit., p 70.

22 Australian Institute of Health and Welfare. (1996) **Annual Report 1995-96**. Australian Government Publishing Service, Canberra.

23 Australian Institute of Health and Welfare, ibid., p 42.

24 Anderson P, Bhatia K & Cunningham J. (1996) **Mortality of Indigenous Australians**. Occasional paper, Australian Bureau of Statistics and Australian Institute of Health and Welfare, Canberra.

25 ABS and AIHW. (1997) **The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples**. Australian Government Publishing Service, Canberra.

Attachment 2.1

State Summary of Health Information Collections
- NEW SOUTH WALES -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

The Birth Registration Form is usually completed by the mother after the birth of a child, and submitted to the Registrar of Births, Deaths and Marriages. Details are required of both parents, including whether either parent is of Aboriginal or Torres Strait Islander origin.

A Death Information Form is completed by the funeral director responsible for arranging the burial / cremation of the deceased. The form is completed with the assistance of an informant who is usually a relative, and then submitted to the Registrar of Births, Deaths and Marriages. The Death Information Form contains fields to record Indigenous status of the deceased person. However, the Doctor's Certificate of Cause of Death, which is completed by a medical practitioner, does not include information on the Indigenous status of the deceased.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

The NSW Health Department has performance contracts with each of its Area Health Boards, which are responsible for managing the state's public hospitals. All hospitals in NSW are required either by the performance agreement (for public hospitals) or under legislation (for private hospitals) to provide selected data items regarding inpatient admissions and discharges. Indigenous identification is one of the required data items. These data are centrally managed as the Inpatient Statistical Collection by the Information and Data Services Branch of the Department.

These data are provided in specified format from the hospitals' information systems to the Department predominantly through electronic transfer; however, not all sites report electronically at this time. These data are centrally managed by the Department's Information and Data Services Branch, as the Inpatient Statistical Collection.

Perinatal Collections

A Midwives Data Collection form is completed for all births by the attending midwife, and then submitted to the Department's Midwives' Data Collection Unit which manages the state-wide data collection. The Perinatal form contains demographic details of the mother such as age, address and country of birth, as well as information on the pregnancy characteristics, previous pregnancies and labour, sex, date and place of birth of the child, and the health status of the mother and the baby. All mothers are asked their country of birth and ethnic origin. The mother's self-identification of ethnic origin is recorded as either Caucasian, (Australian) Aboriginal, Asian, or Other.

The mother's ethnic identity is automatically recorded as the baby's identity. Consequently, the Midwives Data Collection will not record Aboriginality for Indigenous mothers who do not identify themselves as such and for Aboriginal babies born to non-Aboriginal mothers. The Midwives Data Collection produces regular reports, including information on Indigenous status from this collection.

Cancer Data Collection

The NSW Central Cancer Registry records Indigenous status only where this information is available from hospital admissions or death registrations.

Communicable Diseases Data Collections

The Infectious Diseases Surveillance System and the AIDS Register record Aboriginality – but, again, only where such information is made available from other sources.

1.3 Community-based Public Sector Collections

Major NSW collections include the capacity for Indigenous identification. These include: Child and Adult Sexual Assault Collections, Drug and Alcohol School Surveys and other substance-related collections, mental health collections, and various aged care and residential databases.

Respondents noted that the NSW community health clinics' activity data collections contain minimum information on Indigenous status. However, the Department is committed to the development of the Community Health Information System (CHIS) which will fully capture information about people's usage of and access to wider community health services, including those for Indigenous people. This system is being developed in partnership with NSW Health, the South Australian Health Commission, Queensland Health and the ACT Department of Community Care.

Aboriginal medical services provide clinical services to Aboriginal and Torres Strait Islander people in NSW. Additionally, Indigenous people receive services from the NSW Health Department and also from private sector providers such as general practitioners. The Aboriginal Health Resource Co-operative (AHRC) Ltd is the peak body for Aboriginal Medical Services and Aboriginal Community Controlled Health Organisations in NSW. Some of these organisations are members of the National Aboriginal Community Controlled Health Organisations (NACCHO). Aboriginal medical services receive funds from the Commonwealth and/or NSW State Government.

Attachment 2.1

The NSW Health Department has recently entered into a partnership agreement with the AHRC, under which the two organisations will jointly advise the Minister for Health on health policy, strategic planning and resources allocation issues concerning Indigenous health. Additionally, the Department has recently commenced a collaborative project with the AHRC to improve the quality of Aboriginal health information in NSW. The project also includes the development and implementation of a code of practice regarding Aboriginal health information which will include factors such as data ownership and use. Respondents pointed to the importance of addressing these issues and developing the partnership as a solid base from which to later identify Indigenous health information priorities and initiate specific actions.

Population health survey

The NSW Health Department is planning to carry out annual population health status telephone surveys (household surveys). The coverage and sampling methodologies are currently being discussed by a Steering Committee for the survey. The survey aims to capture information on health priority areas and the access and usage of health services in the state. It is recognised that Aboriginal people are not likely to be well canvassed by this method, particularly those living in rural and remote areas of NSW. Other options for collecting health information about Aboriginals are to be explored as part of a revised Aboriginal Health Information Project being undertaken by the Department.

1.4 Contribution to National Data Collections

The NSW Health Department provides information on cardiovascular diseases, injuries, diabetes, cancers and mental health to the Australian Institute of Health and Welfare as part of the National Health Priorities (formerly known as the National Health Goals and Targets) from its Inpatient Statistics Collection.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

Birth and death registration forms have included an Indigenous identifier question since 1986, and inpatient separations collections since 1979.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The number of registered Indigenous births in NSW in 1995 was almost 100% of that expected (on the basis of population projections and Census data). However, as in most Eastern states, the number of registered deaths attributed to Indigenous people in NSW in the same year was less than half the expected number of Indigenous deaths.

Respondents reports some resistance from funeral directors in asking the Indigenous identifier question of bereaved relatives and in completing the information on the deaths registration form.

Hospital collections

The NSW Health Department advises hospitals to first ask patients about their country of birth and then, if Australia, to ask whether the person is Aboriginal, Torres Strait Islander or both.

However, despite Departmental efforts to improve the completeness and accuracy of Indigenous identification in the Inpatient Statistics Collection, the information is still far from complete. There are major variations in practices and coverage between hospitals, with respondents noting the reluctance of some Indigenous people to self-identify. NSW Health will need to enhance their commitment to report on Aboriginal statistics if the NAHS Working Party recommendations concerning full reporting of Indigenous people in hospital morbidity, admissions and separation data collections are to be achieved.

An internal NSW Health review of admission activities and practices of 22 hospitals in 1994, found that all hospitals in the study recorded the Indigenous status of patients on admission. However they used diverse procedures to do so, including:

- some hospitals asked patients a direct question about their Indigenous status;
- some hospitals relied on self-identification by patients completing admission forms;
- others made assumptions based on the patient's appearance;
- several hospitals used a combination of these methods;
- two (small) hospitals stated that all Indigenous people in the community were known to them;
- hospital staff reported that many Indigenous people were afraid to self-identify for fear of discrimination; and
- some admissions staff felt embarrassed to directly question clients about their Indigenous status.

A Departmental Information Bulletin circulated to staff in 1994 stated that the Minister and the Department had received a number of complaints related to staff asking questions of a "sensitive nature" such as Aboriginality and religion. The NSW Health Department has since undertaken the development of an Aboriginal Cultural Awareness training course aimed at hospital staff. The objective of this course is to develop an appreciation and understanding of Indigenous cultural and social factors that could have implications for their health and health services.

Information and Data Services Branch staff reported that they believe that the completeness of Aboriginal identification in this collection will improve with the introduction of revised Area performance contracts.

Respondents also noted, however, that people cannot be forced to identify – and that this is a right protected in NSW by various Acts and the Information Privacy Code of Practice.

The quality and completeness of Indigenous status data captured at local and Area Health Services will reflect how well they are meeting their performance requirements.

Attachment 2.1

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

Consultations with the Aboriginal medical services in NSW has not been undertaken, pending approval from the Executive of the Aboriginal Health Resources Co-operative Ltd – their umbrella organisation. Until such time as this consultation occurs, there is no information about Indigenous community-controlled services and their data collections.

4. DATA QUALITY INITIATIVES

Respondents noted that the Inpatient Statistics Collection has a high level of accuracy following several Continuous Quality Improvement projects. However, there are no systematic mechanisms in place to check the quality of Indigenous data in other collections.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

The information collected by the Registrar on both the birth and death registration forms is provided to the Australian Bureau of Statistics (ABS) on a monthly basis.

While informal mechanisms exist through officer level contacts and co-operation between the Department and the Aboriginal Medical Services, particularly between the Department and Aboriginal Health Resource Co-operative, there is currently no joint system of compiling and reporting their information collections in Indigenous health.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

The NSW Health staff consulted reported having some understanding of the principles of the NAHS such as the holistic view of health by Indigenous people. However, most were not familiar with the Working Party's recommendations related to health information.

7. CURRENT AND FUTURE DEVELOPMENTS

A comprehensive strategy has recently been developed in partnership with the AHRC. The strategy comprises several projects including developing an Aboriginal Health Information Agreement to cover ownership and sharing of data, and confidentiality and privacy guidelines, consulting with the AHRC and the Aboriginal community controlled health sector in NSW regarding their information needs, and improving the under-reporting of Aboriginal and Torres Strait Islander status in mainstream health data collection systems.

Attachment 2.2

State Summary of Health Information Collections
- QUEENSLAND -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

Both birth and death registration forms were amended from January 1996 to include Indigenous status. Birth registration forms contain fields to record the Aboriginal or Torres Strait Island origin of both parents, while death registration forms contain fields to record whether the deceased person was of Aboriginal or Torres Strait Islander origin (or both).

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

All Queensland hospitals (public and private) are required to provide information on Indigenous status to the Queensland Hospital Admitted Patient Data Collection. Separate identifiers exist for Aboriginal and Torres Strait Islander persons. Data is received centrally from all public hospitals via electronic transmission.

Perinatal Collections

The Perinatal Data Collection uses the mother's self-reported ethnic origin. Central data managers reported that this collection under-reports Indigenous babies born to non-Indigenous mothers because the mother's ethnic identity is automatically recorded as the child's identity. Hospital staff are encouraged to either ask a standard self-identification question of all mothers or have the mothers themselves complete the forms.

Cancer Data Collection

The Queensland Cancer Registry, which is managed by Queensland Health, has the capacity to record ethnic origin. However, it relies on data derived from pathology results – which do not have Indigenous identifiers, despite the fact that the original clinical request may have contained the patient's Indigenous status. Respondents considered that the Cancer Registry contained incomplete information about Indigenous persons. For reporting purposes, periodical manual cross-checks are undertaken of names on the Cancer Registry with hospital and/or death records. This process is reported to be laborious and resource intensive. The Department plans to query missing data or improbable data field combinations from hospital notifications from July 1997.

Communicable Diseases Data Collections

Like the Cancer Registry, the Communicable Diseases Collection also has the capacity to record ethnic origin, but is subject to the same problems identified above.

Attachment 2.2

1.3 Community-based Public Sector Collections

Information on the activities at both district and community clinic levels is not reported centrally. At present, a Community Health Information System (CHIS) is being developed in collaboration with the South Australia Health Commission, the NSW Department of Health, and ACT Department of Community Care. Queensland Health is planning to make this information system available to government services throughout Queensland, and will also offer this to Aboriginal Medical Services without charge. This project is in early developmental stages.

At the time of consultation, the Tropical Public Health Unit based in Cairns was about to start an Aboriginal and Torres Strait Islander Community Health Information pilot project at in the Torres Strait region. An earlier pilot project to trial the same information system at another Aboriginal and Torres Strait Medical Service was abandoned due to a reported lack of technical skills and resources of the organisation.

Some community-based collections, such as the Geriatric Assessment Team Client Database and the Hansen's Disease Register, include an Indigenous identifier.

Torres Strait Health District

The Torres Strait Health District is currently undergoing a reorganisation to implement the Torres Strait Health Strategy, which also incorporates the Torres Strait Health Information Plan. This reorganisation will involve the partitioning of the current health services into two arms – a hospital based tertiary system, and an integrated primary health care system. The intention of the latter system is to deliver appropriate services and programs within the context of an information culture. That is, the level and type of services will be determined on a needs basis which will be decided through the collection and analysis of information, and the effectiveness and continuation of services will also be managed on the basis of information. To achieve this, it is recognised that considerable training and physical resources will be necessary to develop the required information system.

Regional Population Health Status Survey

Queensland Health carries out annual Regional Population Health Status Surveys. These household surveys are based on telephone interviewing of adults. The survey sample is approximately 800, stratified by health region, and covering rural and remote areas (although some over-sampling is reported in the state's south-east region). Survey information includes demographics, physical functioning, limitations due to physical problems, body pain, general health, vitality, limitations due to emotional problems, social functioning and mental health. The survey includes an Aboriginal and Torres Strait Islander identifier.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

The perinatal data collection was the first statewide data collection in the State to introduce an Indigenous identifier (in 1987). At that time, state government policy was not to record Indigenous identity in their information collections. The Queensland Hospital Admitted Patient Data Collection has been identifying patients' Aboriginality since 1988. However, complete coverage for all hospitals was only attempted in 1993.

Queensland was the last Australian state to commence recording of Indigenous status in birth and death registrations, which was initiated from 1 January 1996.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

Separate identification of Indigenous people in Queensland began in 1996. As such, there is only one full year of data to report. Given the normal difficulties associated with initiating new data collection and recording practices, comprehensive reporting of Indigenous birth and deaths data may take several years to achieve.

Nevertheless, preliminary analysis of 1996 registrations indicate comprehensive compliance with identifying Indigenous status in birth registrations – so much so, that the actual Indigenous birth registrations totalled almost 3,500, some 38% higher than the 1996 population estimates figures (high series). Quality checks on these data suggest that the information supplied is reliable. However, while vast improvements have also been achieved for Indigenous identification in deaths registrations, this has not met with the same level of success as the births data. Nevertheless, the recent Queensland experience clearly demonstrates to the other eastern states the substantial inroads that can be achieved in a short period of time, given the appropriate level of commitment and the will to do so.

Hospital collections

The completeness of Indigenous identification in hospital-related collections has steadily improved since the early 1990s. The identifier is treated as a mandatory requirement, with hospitals queried if details are not specified.

Departmental policy stipulates that hospital admission staff are to record the ethnic origin of the patient using one of the following codes: Australian, Aboriginal, Torres Strait Islander, Asian, or Other. The policy further instructs data collectors that the answer to the Indigenous data item "should be determined by the patient". Departmental policy is that "an Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community with which he/she is associated".

While some private hospitals introduced an Aboriginal and Torres Strait Islander identifier in 1991, others report this data as "not stated" for all patients. Follow up action is currently being undertaken to improve reporting on Indigenous status in hospital morbidity data collections.

Respondents reported further variations in the accuracy and completeness of Indigenous identification between data from public hospitals. This was further corroborated by a study commissioned by the Department's Health Information Centre on the quality of Indigenous identification for admitted patients in a number of hospitals. It was felt that the data variability was due largely to some admissions staff and patients feeling uncomfortable about the "sensitive nature" of questions concerning Aboriginal identity. Another reason cited was that staff often did not appreciate the importance of this data, and were therefore less likely to seek the information required. An example was given of one hospital which included a statement on admission forms to the effect that: "The Department requests that we ask your ethnicity if you are of Aboriginal or Torres Strait Islander descent". This was thought by some interviewees to indicate that the request was an external or Departmental request, rather than a request which was made or supported by the individual hospital.

Attachment 2.2

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

There are 13 community controlled medical services in Queensland which provide medical and other health services to Aboriginal and Torres Strait Islander people. These medical services form a loose umbrella coalition of the Queensland Aboriginal and Islander Health Forum (QAIHF). Some of these organisations are affiliated members of the National Aboriginal Community Controlled Health Organisation (NACCHO). The organisations are sometimes called Aboriginal Medical Services (AMS), and receive funds from the Commonwealth and/or State Government.

Six organisations were visited, including the Aboriginal and Islander Community Health Service (AICHS), Brisbane; AICHS, Ipswich; Goondir Aboriginal & Torres Strait Islander Corporation (Dalby); Yulu Burri Ba (North Stradbroke Island); Wu Chopperon Medical Service (Cairns); and Apunipima Cape York Health Council.

Five of the six community controlled organisations visited reported that they keep patient medical records; the organisation which does not collect patient medical records does not provide clinical services. These records are used in patient care management, with each record containing Indigenous identification, demographic information such as name, address, date of birth/age and clinical information including investigations undertaken, diagnosis, treatments and follow up and recalls.

Four organisations record client information on manual paper based information systems, while one uses a computer based system (GENESIS). Only one organisation records Aboriginal and Torres Strait Islander origin identification status in their clinical records; the organisation using GENESIS records Indigenous status only in their manual paper records. All organisations reported that all or most of their clients are Indigenous people and known to staff, and that they therefore did not see the importance or need for asking or recording Indigenous status.

The community organisations do not encourage non-Indigenous people to use their services, however they provide services to all who come to their organisation. For example, one organisation reported that 60% of the clients for their Needle Exchange Program were non-Indigenous.

The organisation which uses the GENESIS information system has been experiencing difficulties in generating reports from the system. They have a technical support contract with an interstate company but have experienced difficulties in meeting costs associated with bringing company staff from interstate. They suggested that local technical support would better meet their needs and be more cost effective.

All organisations reported that they receive funding from various Commonwealth and State agencies from a variety of programs. They provide activity reports to funding agencies along program lines. There is no co-ordination between programs and agencies' reporting requirements and time lines. All collect information on individual staff activities under specific programs. For example, one service receives funds for four Aboriginal Health Worker positions.

Each health worker records the number of people they serviced and the presenting health problems, on daily activity sheets. These are collected fortnightly by the CEO of the organisation, who produces monthly totals for each health worker (tabled at Board meetings), and quarterly activity totals for the Aboriginal Health Worker Program which are submitted to the funding agency with financial statements. This is all done manually and was reported as being "boring and laborious". It was suggested that computerisation would make it much more "tolerable".

4. DATA QUALITY INITIATIVES

Regular processes are in place to assess the quality of the new initiative to identify Indigenous births and deaths registrations. It is not known whether there are plans to continue these mechanisms in the longer term.

Hospitals are also queried if Indigenous data fields are incomplete or imply incorrect information on new data, however the size of the hospital morbidity collection means that it has not been feasible to undertake retrospective analysis of reporting consistency of ethnicity data over time.

Quality assurance studies are planned between perinatal data collections and the Queensland Hospital Admitted Patient Data Collection, with the potential for hospital chart audits to be undertaken where there is significant variation between the two data sources. Additionally, there are plans to investigate the effect of pre-admission forms on the accuracy of Indigenous identification.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) and to Queensland Health on a weekly basis.

There are useful informal mechanisms for the co-ordination of information systems through individual and officer level contacts. There is also co-operation between the Department and the Queensland Aboriginal and Islander Health Forum members. However, there is no existing joint system of compiling or aggregating their information collections in Indigenous health.

Queensland Health provides grants under specific programs to some community controlled organisations with specific requirements that the organisations provide the Department with prescribed data on the program. Most of these requirements relate to expenditure, and total number and demographics of people provided services under the program. Of the five organisations, four produce monthly totals of people consulted/treated in age groups and presenting medical problems. These totals are tabled at their board and management committee meetings and quarterly aggregates are then submitted to funding agencies with financial acquittals. It was reported by the Aboriginal Medical Services that, other than for the release of outstanding finance, taking note of prevalent medical issues in their communities and using their information for funding submissions, organisations receive no feedback on the information they provided to the Department.

Attachment 2.2

Respondents considered that, while funding agencies routinely collect a lot of information, they do not analyse it appropriately or opportunely, and do not provide appropriate, useful or timely feedback to Aboriginal Medical Services. One example given of how information could be used out of context was if the number of patients serviced was provided without additional information of the patients and the types medical problems presented, data could be wrongly compared with those of mainstream general practice as a measure of their performance. They stated that their role is much wider than providing direct medical care, as described by the Working Party for the NAHS. Hence, reporting on detailed information is considered useful as it enables a much broader understanding of the health and social status and broad-ranging needs of their client groups.

It was reported by community organisations that none of the annual reports that they generate are useful for population health purposes, and that they are not used for the purpose of planning or reviewing services delivered.

Confidentiality, Ethics and Ownership

All organisations reported concerns about the ownership, confidentiality, ethics and usage of information from their communities that they provide to funding agencies. They also strongly oppose information used purely for research purposes. At least three organisations reported receiving numerous requests from students and researchers for research projects with no apparent direct benefits for their communities.

There are currently no agreed guidelines on the ownership, confidentiality and ethics for the transfer of Indigenous health information between key stakeholders in Queensland. Although the National Health Information Agreement covers these issues, the Queensland Aboriginal and Islander Health Forum (QAIHF) is not part of this agreement.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Most Queensland Health staff consulted reported having a broad understanding of the principles of the NAHS, such as the holistic view of health by Indigenous people. However, most were unfamiliar with the Working Party's recommendations concerning health information, with many reporting that they were not aware of who was responsible for particular aspects of the Strategy. One interviewee stated: "we spent long nights discussing the strategy and how empowered I felt at the time ... but I haven't heard anybody talk about it now for a long time". Two others stated that they had read it some time before, but now remember little about it. Others suggested that there was never a commitment from governments and it was yet another "political exercise".

7. CURRENT AND FUTURE DEVELOPMENTS

As noted above, developments are proceeding in community health information, in conjunction with NSW, South Australia and the ACT health authorities.

Attachment 2.3

State Summary of Health Information Collections
- VICTORIA -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

A Birth Registration Form is required to be completed by medical staff and both parents after the birth of a child and submitted to the Births, Deaths and Marriages Registration Office. Details are required of both parents, including whether they are of Aboriginal or Torres Strait Islander origin.

Death Registration Statements are usually completed by the funeral director responsible for arranging the burial/cremation of the deceased. The statement is completed with the assistance of an informant who is usually a relative, and then submitted to the Births, Deaths and Marriages Registration Office. Requirements for Indigenous status of the deceased are the same as for birth registration. The death registration process is complemented by the Doctor's Certificate of Cause of Death, completed by a medical practitioner, and with similar requirements for recording Indigenous status.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

There are three main hospital collections, including the Victorian Inpatient Minimum Database (VIMD), the Victorian Emergency Minimum Database (VEMD), and the Psychiatric Records Information Systems Manager (PRISM). The VIMD records details of admitted patient episodes in both public and private hospitals, including (from 1 July 1995) all babies born in public hospitals. The VEMD records details of attendances at Accident and Emergency Departments at Victorian public hospitals. PRISM records details of public psychiatric services provided, including for all admitted patient episodes and community clients ate 12 monthly reviews. (Note that there may be some duplication between VIMD and PRISM). Collection of Victorian hospitals' morbidity data is centrally administered by the Department of Human Services. The Department requires all hospitals (public and private) to provide, through electronic transfer, selected data items in a specified format from their patient management information systems to the VIMD.

Perinatal Collections

Perinatal Forms are submitted to the Department's Perinatal Data Collection Unit by the midwives attending Victorian births. The perinatal forms contain demographic details of the mother such as age, address and country of birth, as well as information on the pregnancy and labour, the sex, date and place of birth of the child, and the health status of the mother and the baby. All mothers are asked if they identify as an Aboriginal or Torres Strait Islander. The mother's ethnic identity is automatically recorded as the baby's identity and therefore, it under-records Aboriginal babies born to mothers who identify themselves as non-Aboriginal.

Attachment 2.3

Cancer Data Collection

The Cancer Register, controlled by the Anti-Cancer Council of Victoria, collects information on Aboriginality and receives notifications from hospitals and pathology laboratories. Hospital notifications are subject to the same problems of data inaccuracy as the VIMD, and is often incomplete as the option 'Unknown' is permitted in data collection. The Cervical Cytology Register has no Indigenous identifier.

Communicable Diseases Data Collections

HIV/AIDS is the only communicable disease in the Communicable Diseases Data Collections which has an Indigenous identifier. This was achieved under an agreement between the Victorian Aboriginal Community Controlled Health Organisations and the Department. A review process is currently underway to consider the use of an Indigenous identifier for all notifiable communicable diseases.

1.3 Community-based Public Sector Collections

Community health clinics in Victoria are required to provide activity reports to the Department. These include the demographics of people provided with services and types of services delivered. However, individuals consulted reported very little confidence in the quality of the community health activity data collections.

1.4 Contribution to National Data Collections

The Victorian Department of Human Services provides information on all data to the Australian Institute of Health and Welfare (AIHW), as part of the National Health Priorities (formerly known as the National Health Goals and Targets) from the Hospital Morbidity and Separations Data Collections.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

Indigenous identification was first sought on all birth and death notifications, and on medical certificates of cause of death, in 1987. The capacity to record Aboriginality was introduced from the start of the VIMD collection in 1979, as a specific code in the 'Country of Birth' field. A specific – but optional – Indigenous identification field was introduced in 1986 for all public hospitals, and extended to private hospitals in July 1993.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The number of registered Indigenous births in Victoria in 1995 was just under 90% of that expected (on the basis of population projections and Census data). However, as in most Eastern states, the number of registered deaths attributed to Indigenous Victorians in the same year was less than half the expected number of Indigenous deaths.

Between 29 and 32% of all Victorian death registration forms submitted in the period 1994-1996 contained no responses to the Indigenous identification question. However, no action is taken to follow up informants when there is no response to Indigenous identification questions in relation to births and deaths.

Hospital collections

Admissions staff of all Victorian hospitals (private and public) are required to ask and record whether patients are of Aboriginal or Torres Strait Islander descent. This is now mandatory and the only options are 'Yes' or 'No'. Hospitals have been advised by the Department to first ask patients: *"What is your country of birth?"* then, if the answer is *"Australia"* to proceed with *"Are you of Aboriginal or Torres Strait Islander descent?"*

Provision of Indigenous identification is mandatory and any record with no code in that field is rejected by the VIMD. If a public hospital does not complete and resubmit the record, it does not receive payment for that episode of care.

VIMD managers report that the accuracy of Aboriginal identification in this collection has improved since 1993, but despite this reported improvement, the identification of Aboriginal people in the Victorian hospital system was far from accurate. The completeness and accuracy of Indigenous identification varies from hospital to hospital.

The reasons for incomplete data included the following. Some hospitals use a 'Patient Master Index' with incorrect and out of date identifying information, and do not seek to update patient information at each admission. Some admissions staff and some patients consider the specific questions of Indigenous identity to be of a 'sensitive' nature. The field for recording Aboriginality is not a mandatory field in more than half of the hospital computerised patient admission information systems – if the field is not completed, the patient would be recorded as non-Aboriginal by default. Lastly, Aboriginality tends not to be recorded in emergency admissions.

A recent study undertaken on how Victorian midwives identify women as Indigenous found that most midwives did not ask every mother – rather only those that they suspected may be Indigenous, e.g. on the basis of the woman's appearance, name, or if she was accompanied by Indigenous relatives. Reasons for not asking all women about their Indigenous status included poor awareness of the need for seeking such information, midwives' discomfort and fear of causing offence, and a perception amongst midwives that asking the question would cause discomfort to their patients.

The Department's Koori Health Unit funds Koori Hospital Liaison Officer positions in 18 public hospitals. These officers submit monthly activity sheets to the Unit, which include monthly Indigenous patient totals, age, sex, reason for admission, date of admission and discharge, and whether they visited the patient during this admission. The liaison officer also completes and submits separate forms with information on Koori births and deaths in their area. These forms contain date of birth, sex of the baby and if either the mother or the father of the baby is Koori. The death form also contains the date, place and cause of death. The relevant hospital is notified when differences are found between VIMD data and the information on the liaison officers' activities. Unit staff reported that some patients who are known to the officers as Koori choose not to identify themselves as such.

Attachment 2.3

Additionally, the Koori Health Unit has developed information and promotional materials for the improvement of Aboriginality data items in hospitals' admission records. The Unit introduced an incentive system, for which the Minister awards a 'Certificate of Achievement in Pursuit of Excellence' for hospitals that contribute directly to increasing the availability of accurate information on the health status of Aboriginal and Torres Strait Islander people. In order to raise awareness, the Unit has published a report on case studies of two hospitals which have 'best practice' strategy models for the improvement of the completeness of Aboriginality records.

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

Victorian Aboriginal Health Service

The VAHS provides medical and other health services to Aboriginal and Torres Strait Islander people in Victoria. Victorian Aboriginal medical services have formed a coalition of Victorian Aboriginal Community Controlled Health Organisations (VACCHO). Some of these organisations are members of the National Aboriginal Community Controlled Health Organisations (NACCHO). These organisations receive funds from the Commonwealth and/or State Governments.

The VAHS keeps patient medical records for use in patient management. Each patient record contains demographic information such as name, address, date of birth/age and clinical information such as investigations undertaken, diagnosis, treatments and follow up and recalls. Clinical information is recorded on simple paper based information systems by the health clinicians. No routine reports are generated from the information in these records.

Indigenous status is not recorded in any VAHS client records, however it was felt that this was not important since the service does not encourage non-Indigenous clients. They do however, provide services to all who come to their organisation (except for dental care which is provided strictly to Koori people due to the higher cost of dental care).

The VAHS maintains separate records for Dental Care services. These contain specialist dental and demographic information, similar to the patient medical records referred to above. Health Services staff reported that for people to receive dental care they should 'prove' their Koori identity. The consultation did not find any clear and standard means in which staff identify and individual's Koori identity. Practices reported included staff members to ask for proof from those they did not know to be from the local Koori community, or who did not "look Aboriginal".

The health services produce ad-hoc specific project reports and a regular community newsletter. They stated that they do not generate reports based on their health care data with the exception of specific public health research projects. The services could consider analysing and aggregating the health care data they routinely collect. Such an analysis could provide important information to assist in health care planning, over and above its current use of clinical care management.

4. DATA QUALITY INITIATIVES

There are no systematic mechanisms in place to check the quality of Indigenous data in the various collections, other than the return of forms to those hospitals where information submitted differs from that provided by the Koori hospital liaison officers (described above).

Koori death figures provided by Koori hospital liaison officers were compared in a one-off study with the official Indigenous death registrations. The results indicated that six of the 59 deaths reported by liaison officers during the study period were still awaiting registration forms from funeral directors at the time of comparison, while there was no record of the death at the Registry in a further five cases.

Respondents point to the significant role of Koori hospital liaison officers in improving Indigenous information in Victorian health collections. However, they are clearly under-resourced compared to the job at hand. While there are over 300 hospitals in Victoria, only 18 have Koori health workers – including only four positions for the entire Melbourne metropolitan area.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

There are useful informal mechanisms through individual and officer level contacts and co-operation between the Department and the Aboriginal Community Controlled Health Services in Victoria. However, there is no joint system of compiling and reporting their information collections in Indigenous health. Similarly, there are no mechanisms in place to link information systems of the Department with those of other agencies, such as the Aboriginal and Torres Strait Islander Commission (ATSIC).

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) on a monthly basis.

The VAHS staff reported that they receive funding from various Commonwealth and State agencies, and a variety of programs. However, they stated that they do not provide any information or data other than financial information to funding agencies. This is due to concerns that funding agencies may use the information out of context. Their concern is that traditional 'head counting' of people provided with health services would not accurately capture their broader community support responsibilities as described in the NAHS. The Health Services staff consulted stated that they would strongly oppose providing information to other agencies and would require proof of direct benefits to their communities before they would provide such information to anyone.

Attachment 2.3

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Health Services staff consulted considered that governments of all levels had failed to implement any of the recommendations of the NAHS Working Party. They stated that there had never been the political will to make governments accountable for their lack of action. Those consulted did not address specific recommendations related to Indigenous health information. They implied however, that responsibility for implementation of the NAHS rested solely with governments and not jointly with Aboriginal Community Controlled Health Organisations. In order to address these issues it would be important for stakeholders to jointly develop strategies to increase the level of understanding of the NAHS by the Indigenous communities and the wider public.

7. CURRENT AND FUTURE DEVELOPMENTS

The release of new birth registration forms in December 1995, with coloured background to highlight all areas where responses are required, appeared to generate fewer non-responses to the Indigenous identification question – in 1994 and 1995, this question attracted a non-response rate of 74% and 69% respectively, but dropped to 36% in 1996. The layout of the deaths notification forms are currently being reviewed in a similar way, and it is hoped that this will also reduce non-response rates.

A Victorian Aboriginal Research Network has recently been initiated to facilitate co-ordination and reduced duplication amongst researchers and research activity on Indigenous health issues. The network also aims to reduce the occurrence of inappropriate or unethical research, through enabling Indigenous control of research activity via a registered Aboriginal Ethics Committee.

Additionally, a Victorian Advisory Committee on Aboriginal Health, with representation from all major Koori health interests in Victoria, has been established. This may be an important mechanism for facilitating future developments to improve Indigenous health information.

Attachment 2.4

State Summary of Health Information Collections
- TASMANIA -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

The Tasmanian Birth Registration Form contains fields to record the "Australian / Aboriginal" origin of both parents. Similarly, the Death Registration Form contains fields to record whether the deceased was of "Australian / Aboriginal" origin.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

The Tasmanian Hospital Morbidity Collection currently brings together data from public and private hospitals in the State. It has fields for recording a patient's racial status as "Australian" (including "Aboriginal") and "Other". At the time of consultation, the Department of Community and Health Services was in the process of breaking down the "Aboriginal" category into "Aboriginal" or "Torres Strait Islander". However, there is no mandatory requirement for hospitals to seek this information.

Perinatal Collections

The Tasmanian Perinatal Data Collection uses the mother's self-identification to record Indigenous status of newborn babies. Self-identification was reported by respondents to be generally very good, but there is potential to under-report Aboriginal babies born to non-Aboriginal mothers. The Department does not report on Indigenous information from this collection, citing the relatively low numbers of Indigenous births.

Cancer Data Collection

The Menzies Centre for Population Health Research is contracted by the Department to manage the Tasmanian Cancer Registry. All data on cancers throughout the State are remitted to the Centre. The Cancer Registry records Indigenous status only where this information is available from hospital admissions and Death Registration Forms. The Menzies Centre does not report on the data of Indigenous people, primarily because the numbers are very low. The Centre does however, provide the Cancer Register data to the Australian Institute of Health and Welfare (AIHW) as part of the National Cancer Register maintained by the AIHW.

Attachment 2.4

Communicable Diseases Data Collections

The Tasmanian Communicable and Notifiable Diseases Data Collection records Aboriginality only where this information is available from the service provider, for example, a general practitioner, when a follow-up questionnaire is completed. Such questionnaires are sent to medical practitioners where patients have been diagnosed with Chlamydia, Syphilis, Gonorrhoea, HIV/AIDS, Hepatitis B, Hepatitis C and Tuberculosis. The Department does not routinely report on Aboriginal statistics from this collection as it contains very little information on Indigenous status. However, these data are provided to the national communicable diseases database as part of a standard format.

1.3 Community-based Public Sector Collections

Respondents reported that most of the Department's information collections on the activities of community clinic-level services are managed at a regional – rather than central – level. Consequently, coding and recording variations exist between regions and collections. The potential for these collections to accurately report on Indigenous health is limited as they contain little information on Indigenous status. The Department is currently addressing this issue by completing a one month "snapshot" of Aboriginal identifiers in nominated areas of the Department. It is intended that staff in community health clinics will in future be directed to request information about the Indigenous status of their clients.

1.4 Contribution to National Data Collections

The Department provides, where available, records, raw data and/or information on cardiovascular diseases, injuries, diabetes, cancers and mental health as part of the National Health Priorities (formerly known as National Health Goals and Targets) from the Hospital Morbidity and Separations Data, to the Australian Institute of Health and Welfare (AIHW).

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

An Indigenous identifier was introduced to Tasmanian birth and death registrations in 1988. Although there is capacity to record Aboriginality in the hospital morbidity collection, such information is not routinely sought, collected or reported on. However, it is proposed to formalise the collection and recording of such information later this year.

Attachment 2.4

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The number of registered Indigenous births in Tasmania in recent years was around 85 to 95% of that expected (on the basis of population projections and Census data). However, the achievement of such high rates is not extended to death data – with Tasmania providing the most incomplete death registration data for Indigenous peoples of any Australian state or territory. The number of registered deaths attributed to Indigenous Tasmanians in recent years is less than 10% of the expected number of Indigenous deaths.

Respondents note that a much lower level of self-identification amongst registration activities occurs amongst older age groups.

There is no follow-up of incomplete registration forms, and no verification checks within the system to assess whether children from the same family have their Indigenous status registered consistently.

Hospital collections

Respondents reported the generally poor attention to collection of Indigenous data in the health sector and, by default, the inadequate data quality of the various collections. They also pointed to a "marked reluctance" of staff in many areas to asking clients questions about Indigenous status.

In 1994, the Department carried out a Client Data Inventory to map the information being collected by the various areas of the Department, including the purpose and format of the collections. In relation to Indigenous data, the Inventory found that many collections do not seek or infer any information about Indigenous status, and that for those that do record such data, the collection method varies in that some specifically ask the individual, while others ask the reporter.

Further, those collections which sought to ask clients to self-identify vary in how the question is framed, for example:

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

Finally, some collections recorded only Aboriginality, while others gave the option of either "Aboriginality" or "Torres Strait Islander".

Respondents also report some confusion within Indigenous communities in Tasmania about who is 'legally' recognised as an Aboriginal or Torres Strait Islander. (This appears to be a particularly important issue for Tasmania, which has seen a number of significant court cases and judgements in this area in recent years.) This confusion is based on the difference between self-identification and community acceptance of someone as a member of their community.

Attachment 2.4

Since the introduction of the Client Data Inventory, the Department has created three Regional Aboriginal Health Liaison Officer positions, covering the three State health regions. Aboriginal Health Unit staff, as well as others consulted, reported that the completeness of Aboriginal identification in the State Hospital Morbidity Collection had improved since the engagement of the Liaison Officers. Despite this, however, the number of patients recorded as Aboriginal or Torres Strait Islander in hospital-based collections remains low.

The Department is currently supporting changes to its Inpatient Statistical Collection. The installation of a new data system is scheduled before the end of 1997. This will be complemented with requirements for staff to request information about Indigenous status at the time of initial patient contact, and will be supported by staff training about Aboriginal identifiers.

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

Two Aboriginal Medical Services were invited to provide details of the health information they collect on Indigenous people. The AMS in Hobart (sometimes called the Aboriginal Medical Centre) was visited and consulted.

The AMS has an Aboriginal identification question in their client characteristic forms but staff reported that they only ask the question when it is not known if a particular client is Aboriginal. The AMS asks clients for proof of Aboriginality; however, they are aware that this leads to incomplete data of Indigenous status. The AMS does not record or report on Aboriginality in any of their reports.

The patient medical records are used for patient medical care and management. Patient records contain demographic information such as name, address, date of birth/age and clinical information including: investigations undertaken, diagnosis, treatments, follow up and recalls. The AMS records these patient medical details in a Paradox-based computer information system as well as on a manual based records system.

The AMS produces monthly totals of people assisted and treated on the basis of age groups and the social and medical problems presented. These totals and quarterly aggregate figures are presented at board of management meetings, before being submitted to funding agencies with financial acquittals. This information is also used as a basis for health promotion activities and programs in raising community awareness of the major medical issues in the community. The AMS also produces an annual report for public use and forwards copies to funding agencies.

Records are also kept on childhood immunisations. In addition to producing monthly and quarterly totals of children vaccinated (with categories of vaccinations), the AMS is periodically required to complete cost reimbursement forms for funding agencies.

AMS representatives reported a belief that while funding agencies routinely collect a lot of information, they do not analyse it appropriately, nor do they provide appropriate, useful or timely feedback to Aboriginal medical services. The organisation stated very strongly their suspicion of, and objection to, providing information for research purposes and reported that they receive many requests for assistance in research that has no clearly stated benefits for their communities. It was further reported that, although funding agencies request information and data from Aboriginal medical services, they do not provide them with the funds and resources required to manage and maintain information systems.

4. DATA QUALITY INITIATIVES

There are no systematic mechanisms in place to check the quality of Indigenous data in the various collections. The current registry collection and recording mechanisms do not cater for any automatic cross-matching between events and individuals, e.g. between births and deaths data concerning parents, siblings, children, and spouses.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) on a monthly basis in photocopy format.

While there appears to be some useful officer-level contacts between the Department and the Aboriginal Medical Services, there remains some resistance to the exchange and sharing of information.

There are currently no agreed guidelines regarding the ownership, confidentiality and ethics for the transfer of Indigenous health information between key stakeholders. There is also an implied mistrust and fear that funding agencies may misuse information for purposes including cost saving measures.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Departmental representatives consulted stated that it was difficult to co-ordinate the implementation the NAHS because the Strategy was so broad and complex, and because of its implied cross-sectoral responsibilities. Some respondents were not familiar with Working Party recommendations concerning Indigenous health information.

Staff at the Aboriginal Medical Service in Hobart considered that governments were not committed to the implementation of the NAHS Working Party recommendations and as a result, little action had occurred.

7. CURRENT AND FUTURE DEVELOPMENTS

The feasibility and cost-effectiveness of supplying registry data to the ABS in electronic format is currently being investigated.

Attachment 2.5

State Summary of Health Information Collections
- SOUTH AUSTRALIA -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

Birth Registration Forms are required to be completed for all births by both medical staff and parents, and then submitted to the Births, Deaths and Marriages Registration Office. Details are required of both parents, including whether they are of Aboriginal or Torres Strait Islander origin.

Death Registration Statements are 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 submitted to the Registration Office. Indigenous status is recorded where this is obtained. This is complemented by the Doctor's Certificate of Cause of Death , completed by a medical practitioner, which has similar requirements for recording Indigenous status.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

South Australian hospital morbidity and separations data are centrally administered by the South Australian Health Commission (SAHC) in the ISAAC database, which records details of episodes of care for admitted patients. Full details concerning the operational recording of Indigenous identification data in hospital morbidity collections are provided in 2.2 below.

Perinatal Collections

South Australia's Perinatal Data Collection uses the mother's self-reported ethnic origin. The mothers' self-identification is considered to be generally very good, but the perinatal collection would not report as Indigenous any Aboriginal babies born to non-Aboriginal mothers. The SAHC produces regular reports from this collection and cross-checks their data with hospital morbidity, separations and birth register records to make their reports as accurate as possible. The Perinatal Statistics Collection was updated from 1 July 1997 to record information as required by the National Health Data Dictionary.

Cancer Data Collection

While Indigenous identification is included on cancer notification forms, the Cancer Register does not record ethnicity or Aboriginality as their data are derived predominantly from pathology results – which do not report this information to the Register, even where the original request contained the Indigenous status of the patient. To report on Indigenous statistics from this collection, the SAHC periodically engages an officer to cross-check data in their register with hospital and/or death records. However, this is reported to be a laborious and resource intensive exercise. Therefore, the Cancer Register is reported to have incomplete information on Aboriginal and Torres Strait Islander people.

Communicable Diseases Data Collections

The Infectious and Notifiable Diseases Collections have the capacity to record Aboriginality. However, these data collections are derived from pathology results, which have no identifiers even when the original request contained Indigenous status of the patient. To report on Indigenous statistics from these collections, the SAHC periodically engages an officer to cross-check data in their register with hospital and/or death records. Again, this is a laborious and resource intensive exercise, and results in incomplete information on Aboriginal and Torres Strait Islander people.

1.3 Community-based Public Sector Collections

Community health data

The SAHC's data on the activities at community health clinics are administered centrally in the Community Health Statistical System (CHSS) database. The system was designed to provide local health centres with activity and other client statistics to assist in the planning, management and measurement of service provision. Although CHSS does not record data on Aboriginality, individual community health centres tend to record country of birth and use a self-determination style question to record Aboriginality in their own records.

It was initially intended that the CHSS be used by the SAHC, the SA Aboriginal Health Council and Aboriginal Community Controlled Health Organisations to collect data on Aboriginal health throughout the State which would then be collated, analysed and reported on by the Aboriginal Health Council SA Inc. The System was initially accepted by all community controlled organisations in the State, following some for Aboriginal Medical Services several years ago. However, due to concerns about the ownership and confidentiality of information, no data were provided to the Aboriginal Health Council or the SAHC as intended.

Aboriginal Health Workers, Aboriginal Liaison Officers employed by the Commission, some public hospitals and the SA Aboriginal Health Council currently use the CHSS to record individual Aboriginal staff activities. They record client demographic details and health issues addressed. Fortnightly activity totals of number of people serviced and the types of services provided by each staff member are then submitted to the Council which produces aggregate quarterly summaries. However, it is not clear how this summary information is currently being used.

Most of the SAHC's sentinel health and primary health care programs are delivered outside hospitals and institutions. It was reported by the SAHC staff that there are no collections of Indigenous information on these programs in the CHSS database.

South Australia keeps a school dental statistics database, which has the capacity to record Aboriginality. The quality of these data is considered to be very good.

Attachment 2.5

Population-based surveys

The SAHC also carries out population health surveys (household surveys) twice yearly in metropolitan Adelaide. These take the form of 'health omnibus surveys', conducted by interviewers visiting households, or a computer-assisted telephone survey method (referred to as SERCIS). Interviews are completed with representative samples of adults living in households in each of the Adelaide Health Metropolitan Regions. From time to time the Commission also carries out other telephone surveys on specific health issues.

Those consulted considered that population health telephone surveys were a time- and cost-effective method of determining population health status. However, they also noted a number of limitations, including: no Indigenous identifier in the surveys, lack of rural/remote coverage, sampling issues concerning small and dispersed Indigenous populations, the reliability of self-assessment results, the availability and accessibility of telephones to disadvantaged groups, and language and cross cultural issues. SAHC Epidemiology Branch Staff would like to include Indigenous status in the surveys and to expand them to rural and remote residents, but reported that current resource levels would not allow for this extension.

1.4 Contribution to National Data Collections

The SAHC provides data on cardiovascular diseases, injuries, diabetes, cancers and mental health as part of the National Health Priorities (formerly known as the National Health Goals and Targets) from the ISAAC database to the Australian Institute of Health and Welfare.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

Indigenous identification in birth and death registrations began in 1986. An identifier was first introduced to the hospital morbidity collections in 1984, and later upgraded to its current form in 1996. However, the CHSS database does not have an Indigenous identifier.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The recording of Indigenous births is high in South Australia – with the number of registered Indigenous births in recent years around 100 to 110% of that expected (on the basis of population projections and Census data). Similarly, the number of registered deaths attributed to Indigenous South Australians is around the same as the expected number of Indigenous deaths.

Hospital collections

The current hospital patient forms include a field to record the patient's race with the following options: Caucasian, Aboriginal, Asian, Other, Torres Strait Islander, both Aboriginal and Torres Strait Islander, and Unknown. The SAHC's official definition of 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/she is associated".

Staff responsible for centrally managing hospital inpatient records reported that there are some variations in the accuracy and completeness of Indigenous identification between public hospitals' data, with the proportions of Indigenous patients probably understated. There is some anecdotal evidence that admissions staff and some patients consider the specific questions of Aboriginal identity to be of a 'sensitive' nature, e.g. staff not feeling comfortable with asking the identifier question and therefore determining Aboriginality based on appearances, or the patient not correctly self-identifying due to fear of discrimination within health services. However, SAHC staff reported that there have been some improvements in the completeness of Indigenous identification in the ISAAC database since 1994.

Some private hospitals in South Australia were reported by Commission staff as not having identified Aboriginal people in their morbidity and separations data. This has also contributed to incomplete hospital morbidity data in South Australia.

Examples of inconsistencies in the identification of Indigenous people in public hospitals morbidity data include: instances where 'race' is recorded as Aboriginal but country of birth was overseas, and less than expected admissions of Aboriginal people from the state's far north west – even when data from Alice Springs Hospital (where many access care) are added. However, Aboriginal communities in South Australia are well concentrated in the two main areas of Adelaide and Nganampa – these demographics assist in building a database of Aboriginal populations as well as improving data usage and linkage.

There is a perception amongst SAHC staff of a need to increase acceptance by Indigenous people of the services offered by the Commission. Experience has shown that health units which actively promote and display Indigenous-specific information or demonstrate cultural sensitivity in other ways are accessed more frequently – even in clinics where specific Aboriginal workers were 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 Indigenous clients.

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

There are six Aboriginal Community Controlled Medical Services in SA which provide medical and other health services to Aboriginal and Torres Strait Islander people. Of these six, four were visited and consulted: Nunkuwarrin Yinti of SA Inc. in Adelaide, and Port Lincoln Aboriginal Health Services, Pika Wiya Health Services in Port Augusta, and Nganampa Health Council in far North West of the state.

Attachment 2.5

These four organisations keep client medical records, for patient management use. Each patient record contains demographic information such as name, address, date of birth/age and clinical information including investigations undertaken, diagnosis, treatments, follow up, and recalls.

Two organisations record their patient/client details in the CHSS information system, another keeps records in Microsoft Access-based system, and the other in the Royal Australian College of General Practice Information System. This latter organisation was considering rejoining the CHSS system and was keen to trial the Family Planning version.

All organisations reported that, although they do not encourage non-Aboriginal people to use their services, they do provide services to all who come to their organisation. None of the organisations record Indigenous status in their medical records, although their client characteristic forms have self-identification questions. One organisation maintained a different colour coding system for Aboriginal and non-Aboriginal client files in the past, but abandoned it when some people were offended by inaccurate coding. This is the only one of the four organisations consulted that still records Aboriginality for those clients that staff know to be Aboriginal. However, they are aware that this data are incomplete, and therefore do not report Aboriginality in any of their reports. The other organisations reported that, although they do not record or report on Aboriginality, their reception staff (who complete client details at first contact) know 95-100% of their Aboriginal clients. For these reasons, most organisations consulted did not see the importance or need for recording the Indigenous identity of their clients.

All four organisations keep records on childhood immunisations – one using Microsoft Access, one on a Genesis computer based system, and the remaining two on a paper-based system. In addition to producing monthly and quarterly totals of children vaccinated with categories of vaccinations, organisations have to periodically complete cost reimbursement forms for funding agencies.

One of the organisations maintains a population register of residents in their communities, which is linked to their clinic activity records. This enables them to produce rates of contacts, health problems, referrals and evacuations. This organisation provides health services to a small, homogenous and geographically isolated population. There are no other generic health services that their community members could easily access. These factors assist in the maintenance of the population register.

A number of community organisations reported that they consider heart disease and diabetes to be the most common causes of disability and death in their communities. They suggested that a community based register for heart disease and diabetes with regional reporting would greatly enhance their capacity to better plan and target their services to community needs. Similarly, it was reported that many Indigenous people do not seek medical assistance for chronic diseases until the disease reaches an advanced stage. To address this, community organisations suggested that the SAHC explore options for the development of state-wide data collections on chronic diseases, survival rates of various cancers, drug abuse and mental health outside the psychiatric hospitals.

One of the organisations produces a very complete Annual report reporting on the health status of the client population and the activities of the clinics. The method of presentation of results appears to be very effective for traditional community populations.

All the Aboriginal Community Controlled Health Organisations have strong links and a co-operative relationship with the SA Aboriginal Health Council in matters of political and strategic importance and for advocating for better health services to Aboriginal people in the state. However, they maintain an 'arms length' relationship with the Council on matters of administration and management of health services including health information.

4. DATA QUALITY INITIATIVES

Data quality checks of the Perinatal Statistics Collections data are undertaken regularly by data matching with hospital morbidity, separations and birth registrations data. However, there are no systematic mechanisms in place to check the quality of Indigenous data in other collections, other than ad hoc periodic data quality checks.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) on a monthly basis. The ABS also has access to the Doctor's Certificate of Cause of Death for matching of information, upon which feedback is provided to the Registrar on the quality of the data captured.

There are also useful informal mechanisms through individual and officer level contacts and co-operation between the SAHC and the Aboriginal Community Controlled Medical Services. However, there is no joint system for compiling and reporting their information collections in Aboriginal health. There is no system in place to link the SAHC's information systems with other agencies' collections.

The SAHC provides grants under specific programs to some community controlled organisations, with specific requirements that the organisations provide it with prescribed data on the program. Most of these requirements relate to expenditure, and total number and demographics of people provided services under the program. It was reported by Aboriginal medical services that, other than release of outstanding finance, organisations receive no feedback on information they provide to the SAHC. Respondents considered that the provision of such feedback was important for gaining the commitment and co-operation of those collecting the information.

In addition to producing periodical activity and frequency reports, all community-controlled organisations produce annual reports which are presented at their annual general meetings and later released for public use. Copies are also provided to funding agencies. Annual reports often contain additional qualitative information which reflect agencies' wider community health responsibilities.

Attachment 2.5

One organisation is reported to produce quarterly reports with 'culturally appropriate' graphics for each clinic and community. These include the pictorial presentation of total number of contacts and people serviced by age, sex and illness categories, as well as on referrals, evacuations, trauma and petrol- and alcohol-related morbidity. These are presented to individual communities with the intent of promoting awareness of the major health issues in their community. Other organisations reported that they generally use their health information for funding submissions and select relevant extracts from their data collections as needed.

Two organisations have a dedicated employee to administer their information collections, and who is responsible for the data entry, analysis and reporting. For the other two organisations the centre co-ordinators administer and manage the information. These latter two expressed a need to establish designated staffing positions for the management of their health information, s well as for training and development of skills in data collection, analysis, presentation and reporting.

Confidentiality, Ethics and Ownership

Despite initial acceptance of the CHSS, concerns about the ownership and confidentiality of information have resulted in community organisations no longer being willing to provide data to the SA Aboriginal Health Council or the SAHC as was intended. Without particular reference to the Commission, organisations expressed some fear that funding agencies may use the information for other purposes or against the organisation for cost cutting measures. Three organisations stated very strongly their suspicion of, and objection to, providing information for research purposes and reported that they receive many requests for assistance in research that has no clear stated benefits for their communities. All organisations reported a belief that, while funding agencies routinely collect a lot of information, they do not analyse it appropriately or opportunely and most definitely to do not provide appropriate, useful or timely feedback to Aboriginal medical services.

There are no agreed guidelines on the ownership, confidentiality and ethics for the transfer of Indigenous health information between the key stakeholders in South Australia. While the National Health Information Agreement covers some of these issues, the Aboriginal medical services do not participate in this agreement.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Most SAHC staff consulted believed they had a broad understanding of the principles of the NAHS, mentioning particularly the holistic view of health by the Indigenous people. However, few were familiar with the NAHS Working Party's specific recommendations concerning health information. A similar lack of knowledge was noted in the consultations with Aboriginal community controlled health organisations.

Attachment 2.5

7. CURRENT AND FUTURE DEVELOPMENTS

In 1996, the Commonwealth and South Australian Governments, along with the Aboriginal and Torres Strait Islander Commission (ATSIC) and the SA Aboriginal Health Council, signed a Framework Agreement, in which they committed to establishing culturally sensitive, privacy and confidentiality protocols for the routine collection of standardised data on Aboriginal health. A commitment was also made to jointly improve the quality of relevant data available on the provision of mainstream health services to, and utilisation of mainstream health services by, Aboriginal people.

As part of their 'Info 2000 Project', the SAHC is currently undertaking to replace the CHSS with a new Community Health Information System (CHIS) in collaboration with the NSW Health Department, Queensland Health and the ACT Department of Community Care. Three community organisations consulted in South Australia reported a desire to improve their health information systems, noting that the development of CHIS was an opportune time to explore options to ensure that the new system fully and accurately captures data on Indigenous peoples' usage and access to wider community health services.

Work is currently underway to develop state-wide minimum datasets, for instance in palliative care. All new work is being guided by items and definitions in the National health Data Dictionary.

A 30% weighting for Aboriginality has been introduced in the 1997-98 financial year for casemix funding for South Australian hospitals. Although the rationale for this was to improve equity in the distribution of funding, it is expected that a by-product of this action will be increased incentive for individual hospitals to improve identification of Indigenous peoples.

Attachment 2.6

State Summary of Health Information Collections - WESTERN AUSTRALIA -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

Parents of newborn babies provide information on a Notification of Birth Form to the Registrar General's Office. The form has a field for recording Aboriginal or Torres Strait Islander status as 'Yes' or 'No'.

In the case of deaths, funeral directors responsible for the arrangements of the burial/cremation of the deceased provide Indigenous status information which this is obtained from the next of kin. The form contains similar Indigenous status fields as those for the Notification of Birth Forms. This is complemented by the Doctor's Certificate of Cause of Death which is completed by a medical practitioner and contains similar Indigenous status details.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

The Health Department of Western Australia's (HDWA) hospital morbidity and separations data are centrally administered in the WA Hospital Morbidity System. The current hospital inpatient forms include a field to record Aboriginality as 'Yes' or 'No'.

The Hospital Morbidity Data Collection has a Patient Master Index system across all major hospitals with demographic details for all patients admitted, including Indigenous status. This system is reported to be very comprehensive in terms of capturing data on the Aboriginality of hospital inpatients, as it combines data from both public and private hospitals in Western Australia.

Perinatal Collections

The Western Australian Perinatal Register (Midwives Notification System) uses the mother's self-reported Aboriginality to determine the baby's Indigenous status. The Perinatal Register has recorded mothers' Aboriginality since 1980. It contains a mandatory field to record the mother's 'Race' as Caucasian, Aboriginal (full or part), or Other.

Aboriginality data is cross-checked with the mother's 'Country of Birth' data and is also linked to and validated by the hospitals' 'Master Patient Index' and the 'Birth Register Database'. This enhances the accuracy and completeness of indigenous identification. Checks indicate that Indigenous status of births to Indigenous mothers is recorded with almost complete accuracy. However, as with all perinatal collections, Indigenous babies born to non-Indigenous mothers are not recorded as Indigenous, since perinatal statistics currently record no details about the Indigenous status of the father.

Under this collection, the Health Department of Western Australia (HDWA) supplies demographic details of Aboriginal births to the Western Australia Institute of Child Health, which is undertaking a follow-up study on child development and parenting in partnership with the Perth Aboriginal Medical Service. At the time of this report, the Institute was analysing data from the previous two years.

Cancer Data Collection

The Western Australian Cancer Register does not routinely record ethnicity or Aboriginality. Data is collected from pathology forms, which have no Indigenous identifiers. However, the Register is linked with the Patient Master Index and the Death Register, both of which have Aboriginal identifiers. The database is manually linked, but an on-line linkage system is currently under development. Respondents considered that data on Indigenous cancer-related mortality were substantially complete, but that Indigenous incidence data was probably much less complete.

Communicable Diseases Data Collections

The Notifiable Communicable Diseases Data Collection is based on either clinical and/or pathology results. It has the capacity to record Indigenous status, but is reliant on this information being provided by other sources. This collection identifies Aboriginal patients through the individual service provider who may be either a general practitioner or public health staff. Respondents from the Department's Public Health Branch and the Office of Aboriginal Health considered this to be the most incomplete of all Departmental information collections with respect to identification of Aboriginality (a view that was not shared by the Department's Disease Control Service). It was further noted that there was little value in collecting Indigenous status information in this data collection due to the difficulties in maintaining acceptable confidentiality standards for data concerning small and widely dispersed populations.

1.3 Community-based Public Sector Collections

Information currently collected on HDWA's sentinel health and primary health care programs are reportedly limited to child health, with information available on the mental health and communicable diseases services reported to be very limited.

HDWA has a state-wide 'Community Health Activities Data Collection', which records and reports on child health issues collected by Departmental community health nurses.

In 1995, the Department, with the co-operation of the Western Australian Municipal Association (WAMA) and local shires, undertook an assessment of environmental health services and environmental health risks in 155 Aboriginal communities in the state. Public health and environmental health issues were assessed, including water, sewerage, housing, animal and vector control. As an outcome, Aboriginal communities were graded on an environmental health risk rating, with major and minor works targeted to those 20 communities identified as having the most pressing environmental health needs. As part of this initiative, the Office of Aboriginal Health is undertaking detailed health screenings in several Aboriginal communities assessed as having the highest environmental heath risks.

Attachment 2.6

Mental Health Data Collection

The Mental Health Data Collection records clinic-based information. It has an Aboriginal identifier, similar to the Hospital Morbidity Data Collection. Respondents reported that this collection is incomplete because not all regions supply all of the information they collect. The Department's Office of Aboriginal Health also noted that this was one of the least complete State data collections concerning Indigenous identification.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

Indigenous identification in death registrations was introduced before 1985, and in birth registrations in 1991. The hospital morbidity collection began identifying Indigenous persons in 1981, and later upgraded to its current form in 1993. The perinatal collection has been identifying maternal Aboriginality since 1980.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The recording of Indigenous births is high in Western Australia – with the number of registered Indigenous births in recent years around 100 to 110% of that expected (on the basis of population projections from Census data). Similarly, the number of registered deaths attributed to Indigenous South Australians is around the same as or slightly above the expected number of Indigenous deaths.

Registry staff do not follow up informants when the birth and death registration forms' Indigenous questions remain unanswered. However, such cases are rare, as both forms experience a 95% completion rate on these questions. Data entry for deaths is only taken from death registrations data (i.e. from information supplied by the funeral directors and family informants), and not from information provided in the doctor's certificate of death.

Hospital collections

The recording of Aboriginality on hospital inpatient forms is mandatory, and incomplete forms are returned for completion. Aboriginality data are edit-checked within the morbidity system against 'Country of Birth' data.

However, the hospital inpatient forms do not specify how admissions staff are to determine the Aboriginality of patients. There is no standard practice for identifying Indigenous patients in Western Australian hospitals. One country hospital reported that they have a high proportion of Aboriginal clients and they are known to staff. Most hospital staff determine Aboriginality based on appearance or local knowledge of families.

Respondents reported some variations in the accuracy of Indigenous identification in some hospitals. This is reported to be due the lack of a standard and consistent practice for all hospitals in determining the Indigenous status of patients. There is also some reliance on old records, which may be incorrect. Another issue reported was the potential for inconsistent self-identification by some Indigenous persons at different episodes of contact with health services, due to fear of discrimination in service provision.

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

There are 12 Aboriginal Community Controlled Medical Services in Western Australia which provide medical and other health services to Aboriginal and Torres Strait Islander people. Indigenous people also receive some services from the Health Department of Western Australian (HDWA) and private sector providers like general practitioners. Some of the medical services are members of the Western Australian Aboriginal Community Controlled Health Organisations (WAACCHO). The services are sometimes called Aboriginal Medical Services (AMS) and receive funds from the Commonwealth and/or State Government.

Three services were visited in 1996 as part of the preliminary research stage of this project – the Perth Aboriginal Medical Service, the Kimberley Aboriginal Medical Services Council (KAMSC) in Broome in the north of the state, and Ngaanyatjarra Health Services in the western desert area of the State, which is administered from Alice Springs in the Northern Territory.

The community controlled organisations visited reported that they keep patient medical records. They use these records for patient care management and each patient record contains Indigenous identifying and demographic information such as name, address, date of birth/age, and clinic information such as investigations undertaken, diagnosis, treatments and follow up, and recalls.

The AMSC is the central resource and umbrella organisation several Aboriginal Medical Services in the region, to which it provides support in public health policy, political advocacy, corporate services such as recruitment and skills retention, and the production of statistics and health information reporting.

One organisation currently uses the 'HealthPlanner' (AMFAC - Medrecord) computer based information system, but will soon move to using a Windows NT based update, "Ferret". This organisation also has an Internet site about their services (http://www.hcn.net.au/kamsc). Client registration details for medical services such as investigations and interventions, are recorded on their computer system. This system can generate 'heath process' summaries, which include periodic examination results or selected major health events driven by surveillance. It also has the capacity for billing, patient recalls, and for identifying individuals who are due for check-ups or preventive health services. Its best feature is reported to be its capacity to generate details of services required for individual clients at a given point in time.

Attachment 2.6

Other clinics record patient information on a paper-based system, and then enter data into an Apple Macintosh PC-based information system at their central office. These clinics are now in the process of changing their system to DOS EXCEL.

Another AMS currently records most of its health information on a paper based information system. They have a client/patient contact register for clinical activities. Under a recent agreement, this service received a grant from the Department for the staged development of a new computer-based information system, beginning with recording demographic details of new clients. This organisation also records selected service activities information for Department-funded programs, such as Pap smears, immunisations and heart health program activities.

4. DATA QUALITY INITIATIVES

A number of systematic mechanisms exist in Western Australia to check the quality of Indigenous data in the various collections. In all hospital based collections, Aboriginality information is checked against country of birth, with any records failing this check returned for clarification. Additionally, hospital admission forms which have not provided information on the patient's Indigenous status are returned for completion.

In addition to these formal initiatives, several studies have been undertaken to validate the Indigenous data in the Midwives Notification System (perinatal collection). In one study of mothers identified as Indigenous in 1994-95, only 2% were found to be incorrectly classified. The rate of mothers wrongly classified as non-indigenous has not been examined, due to the large sample size that such a study would require.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) on a monthly basis.

There appears to be close co-operation and liaison on issues related to Aboriginal health planning, at least between the key Western Australian government departments involved in Aboriginal services, such as the HDWA, Aboriginal Affairs Department, the Aboriginal and Torres Strait Islander Commission (ATSIC) and local government agencies. However, some operational aspects of a commitment to co-operate have yet to be realised.

Additionally, the Department currently receives information from some of the Aboriginal Community Controlled Health Organisations on Departmentally-funded programs such as heart disease monitoring and management, cervical cancer screening and childhood immunisation. This information consists mainly of activities data on individual programs. However, there are no standard definitions of activities and no uniform reporting systems. Additionally, the Department does not analyse, nor use this data because of the above limitations, and no feedback is given to the organisations providing the information.

HDWA's Office of Aboriginal Health is currently negotiating with a number of Aboriginal Medical Services to jointly develop a computer based information system, with the aim of the new system to meet the information needs of both these organisations and the Department. The Office of Aboriginal Health reached an agreement with the Perth Aboriginal Medical Service and provided some funds for the development of this system.

All Aboriginal Medical Services in Western Australia produce annual reports which are presented at their Annual General Meetings and then released for public use, with copies forwarded to funding agencies. One organisation transfers its program-specific data to the Department of Health on disc, with client identifying details such as name and address removed. All organisations supply quarterly expenditure acquittals to funding agencies.

The organisations in the Kimberley region produce periodic reports on selected health issues. These are either based on data from a specific medical service or from the combined services data. These reports are used for the opportunistic surveillance of diseases. Other uses for information from these organisations includes funding submissions, political lobbying and general health care advocacy.

Confidentiality, Ethics and Ownership

Some community organisations reported concerns about the ownership, confidentiality, ethics and usage of information from their communities and strongly opposed information used purely for research purposes. Community organisations consulted did not know how the information they provide to government agencies is used. One of the organisations expressed concerns that information they provided to funding agencies could be misused for cost cutting purposes by governments. There are no agreed protocols and guidelines on the ownership, confidentiality and ethics for the transfer of Aboriginal health information between agencies in Western Australia.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Most Departmental respondents reported having a broad understanding of the principles of the NAHS, such as the holistic view of health by Indigenous people. Most however, were not familiar with the Working Party's recommendations related to health information.

The community organisations consulted demonstrated good understanding of the principles stated in the NAHS. Again, however, there appeared to be poor familiarity with the NAHS Working Party recommendations on health information.

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7. CURRENT AND FUTURE DEVELOPMENTS

It was reported by community organisations that information on alcohol abuse, mental health and heart disease would assist them in their health care delivery and planning. It is not known whether any developmental work is likely in these areas at the current time.

Additionally, it would be useful if the Department progresses its existing plans of developing the Aboriginal Community Controlled Health Organisations' information system and explores the potential for expanding this to include those organisations that have developed their own systems.

An online linkage system is currently being developed between the cancer registry and hospital morbidity collections.

The 1997 Aboriginal Environmental Health Needs Survey is being conducted as a joint survey under the auspices of the Environmental Health Needs Co-ordinating Committee (EHNCC), representing ATSIC, Office of Aboriginal Health (Health Department of WA), Aboriginal Affairs Department, Commonwealth Department of Health and Family Services, Aboriginal Housing Directorate (Homeswest), and the WA Municipal Association. The EHNCC working group has identified common environmental information needs based on the HCINS, the HDWA's 1994-95 Statewide Environmental Health Survey and the Aboriginal Affairs Department's Aboriginal Community Profiles. The 1997 joint survey will decrease bureaucratic disruption to communities, and communities will see government agencies working together. Additionally, all levels of government will have access to the same quality information for planning and co-ordination of service delivery.

The University of Western Australia is considering running an Aboriginal Child Health Survey.

Attachment 2.7

State Summary of Health Information Collections
- NORTHERN TERRITORY -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

Indigenous identification is sought in relation to all birth and death registrations in the Northern Territory. In the case of birth registrations, the questions are asked of both the mother and father, and the forms completed by the parents – or sometimes by health workers on behalf of parents. Similar information is sought in relation to death registrations, in which case the form is completed by relatives, or by a funeral director or health worker on behalf of the relatives.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

The Territory Health Service's (THS) main hospital separations collections is the Hospital Morbidity Database. The THS uses a unique identifying number (a Hospital Registration Number – HRN), for each person admitted to hospital. The hospital information system containing the HRN and the identifying demographic details of each patient operates as the Patient Master Index. This system can operate with misspelt traditional names, and can also sort through multiple names (both traditional and Western). A practical limitation of the system reported by THS staff is the tendency for admissions staff to rely on old records rather than seeking to update the information at each admission.

The THS also maintains an Elective Surgery Waiting List. All hospital collections have the capacity to identify Indigenous people.

Perinatal Collections

The Midwives Data Collection uses the mothers' self-reported Aboriginality, however the process for obtaining this information varies. Some midwives complete forms for this data collection themselves, based on the mother's appearance and prior information contained in hospital records.

Cancer Data Collection

The THS' Cancer Register records Aboriginality only where this information is available from hospital admissions or death registration records. This collection is based on pathology results which do not identify Aboriginality, even if that information was provided in the original clinical request. THS staff are very keen to include Aboriginality in pathology results and they have been negotiating this inclusion with providers of pathology services in the Northern Territory.

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THS periodically engages officers to cross-check the details in their Cancer Register data with hospital and/or death records. To report on Aboriginal information from these data sources, THS also uses traditional names, place of residence and staff knowledge of individual clients from small and remote communities. However, this cross-checking activity is reported to be laborious and resource intensive.

Communicable Diseases Data Collections

Similarly, the Communicable Diseases Data Collections only record Aboriginality where the information is available from hospital admissions or other health care provider records. These collections are largely based on pathology results which do not identify Aboriginality.

1.3 Community-based Public Sector Collections

Most of the THS' sentinel health and primarily health care programs are delivered at Community Care and Community Health Centres or other agencies outside hospitals and institutions. At the time of the consultation, THS had no central data collection for the services provided at community health clinics and community care centres – where most non-hospital services are provided. However, development of such an information system is well advanced, and the THS is currently piloting a Rural Health Information System at a remote Aboriginal community.

Several other THS data collections exist but do not have any central management and reporting arrangements. The Chronic Disease Register is kept by remote area District Medical Officers (DMOs). This register has varying status amongst the districts, depending upon the commitment and length of stay of individual DMOs. Respondents noted that the Chronic Diseases data collections in Katherine and Darwin districts are more developed than others.

School dental statistics are reported to have good identification of Indigenous clients.

All THS data collections report separately on Aboriginal information, and all produce regular reports. Some (e.g. the Mental Health collection) report through the Department's Annual Report, while others (such as the Midwife Collection and the Cancer Register) report only when resources to do so are available.

Clinic activity data is recorded manually (pen and paper) in all Central Australian THS clinics and mailed to the administration centre in Alice Springs. Basic graphical monthly activity summaries are produced and returned to each clinic. A number of more sophisticated clinic level systems are also being piloted in NT community clinics.

Attachment 2.7

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

Indigenous identification on birth and death registrations began in the Northern Territory before 1985.

THS began recording Aboriginality of hospital patients in 1976 – and, as such, was the first of all Australian states and territories to do so.

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The identification of Indigenous people in the Northern Territory's birth and death registrations is consistently very high – with the numbers of both registered Indigenous births and deaths outnumbering the expected figures (based on the basis of population projections and Census data) by around 15–20%.

Follow up action on missing identification in birth and death registrations data only occurs when officers believe that an actual error has occurred (based on their knowledge of the person, including their name or place of residence).

Hospital collections

All THS data collections with an Indigenous identifier use the National Health Data Dictionary V.4 definition of Indigenous status (i.e. "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/she is associated"). However, there is no separate identification of Aboriginal and Torres Strait Islander peoples.

However, despite the long-standing emphasis on Indigenous identification in THS data collections, respondents reported that the actual application of these definitions vary greatly. For example, one service has the procedures for seeking Indigenous identification of clients prominently displayed in the reception area. Reception staff are given orientation and training, which includes details of the procedures for seeking information about Indigenous people. Despite these efforts, reception staff report that they tend to identify clients' Indigenous status based on their physical appearance. One officer consulted stated that it "would sound silly to ask a mother who looks Aboriginal, lives in a very remote Aboriginal community and does not speak English, whether she or her child was Aboriginal".

Respondents noted that the identification of Aboriginal people in THS data collections is assisted greatly by social and demographic factors in the Territory, which give considerable prominence to and visibility of Indigenous people and issues in the local community (compared to many other states). For instance, Indigenous people comprise 26% of the Territory's population (higher than all other states and territories), and most have a distinctively identifiable Aboriginal appearance and culture.

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Additionally, they comprise a high proportion of THS clients, and a high proportion of Aboriginal people live in identified Aboriginal communities in the Territory. Further, since Aboriginal people are so prominent part of the Northern Territory society, most non-Indigenous people are generally comfortable in dealing with them and in considering the issue of Indigenous identification. One respondent reported that, for these reasons, "admissions staff would find it very difficult not to recognise the majority of Aboriginal people". It is thought that these factors – rather than deliberate Departmental strategies – make Indigenous identification in THS information systems relatively accurate.

However, respondents also noted that there were deficiencies in the identification of long-standing urban residents of mixed descent – particularly those who have been urban residents for two to three generations and whose appearance is not so obviously distinctive from other urban residents. As such, while there is greater likelihood that more Indigenous people are identified in the Territory on the basis of physical or other characteristics (as above) than in other states, they are still subject to the same problems experienced by other states when attempting to identify Indigenous peoples of mixed origin and/or living in urban communities.

There is only one private hospital in the Northern Territory – the Darwin Private Hospital. It was reported by the THS staff consulted that private hospital does not provide their Morbidity and Separations data to either Territory Health Services or the Australian Institute of Health and Welfare (AIHW). This is reported to be due to concerns of confidentiality as the hospital is easily identifiable. As a result of Darwin Private Hospital not providing relevant data, the identification and recording of Indigenous status in all hospital morbidity and separations collections is incomplete.

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

Three Aboriginal Community Controlled Health Services in Northern Territory were visited and consulted, namely: the Central Australian Aboriginal Congress Incorporated in Alice Springs, Miwatj Health Aboriginal Corporation in Nhulunbuy and Wurli Wirlinjang in Katherine. A fourth, Anyingini Congress Aboriginal Corporation, provided written comments on their information collections.

The four organisations keep client medical records for the purpose of patient management. Each patient record contains demographic information such as name, address, date of birth/age and clinical information including investigations undertaken, diagnosis, treatments, follow up, and recalls.

The Miwatj Health Aboriginal Corporation is an umbrella organisation for three Aboriginal Community Controlled Health Organisation in the East Arnhem region. The corporation manages health information data for the affiliated Aboriginal health services in the region. Patient records are managed in a Fujitsu-based medical records 'Health Planner' system, which originated from an information system developed in a WA AMS and adapted for local needs. The central data base is administered at the Miwatj office in East Arnhem Land, and connected by modem to outlying clinics. In addition, the Health Planner information is copied to five laptops weekly, for use by clinical staff to review patient files.

Almost all of the Aboriginal health services affiliated with Miwatj send their patient information to a central location on paper forms – only one clinic does its own data entry. The organisation employs 1.25 full time equivalent staff for data entry into the Health Planner. The Health Planner information is grouped into demographic, diseases, medication, examination, and pathology files. The system was described by medical staff as an excellent tool for patient recalls, follow up and opportunistic screening of diseases. The system generates frequencies and disease prevalence on colourful and easy to read graphics which are used for health promotion and services planning. System limitations were reported to be that it is written on very old and out-dated computer language, it needs many cross references, and it is not "as user friendly as the prevailing more modern information system". The organisation has a technical support contract with a commercial firm based in Perth. The manager reported that in order to meet their community health information needs, they require additional technical support and training as well as updating the Health Planner to become more user friendly.

Another organisation has a computer-based (Microsoft Access) patient information system which was established by a keen doctor who has since left the organisation. There is little useful documentation and staff have had no training in how to generate reports from the system. There are a number of different databases which are not linked relationally. The consequences of this are that data are not presented as clearly as they need to be, data are under-utilised, and the production and use of summary reports are limited.

Yet another organisation is in the process of engaging consultants to develop a new computerised information system for the organisation. Currently, it has a clinical statistics sheet filled for each patient/client serviced. Data are then transferred into a computer system which generates monthly totals of numbers of patient seen by each doctor and Aboriginal Health Worker, and presenting problems. In addition to the routine medical services, the organisation undertakes an annual chronic diseases check list of all the patients who are 15 years of age or older. The screen covers health issues such as diabetics and hypertension. In addition to patient clinic data, there are information systems for dental care, the health of prisoners, mental health, welfare and transport, as well as data collections for aged people, people with disabilities, nutrition, school health, the health of children under five years of age, and communicable diseases information.

4. DATA QUALITY INITIATIVES

While there are no systematic mechanisms in place to check the quality of Indigenous data in the various collections, records which seem incorrect are identified (on the basis of an individual officer's local knowledge of the person, name, or place of residence) and returned for re-checking and revision.

For the reasons highlighted previously, Indigenous identification is thought to be very high in the Northern Territory health and vital statistics collections. Approximately 50% of all Territory deaths and 40% of hospital separations are identified as Indigenous.

One study undertaken to establish validation of Indigenous identification in death registrations, by inferring Indigenous status from other information on the death certificate (e.g. names, place of birth / residence / burial), found only 12 discrepancies amongst 349 death certificates.

Attachment 2.7

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided regularly by the Registrar to the Australian Bureau of Statistics (ABS).

There are useful informal mechanisms through individual and officer level contacts and co-operation between the Territory Health Services and the Aboriginal community controlled medical services. However, there is no joint system of compiling and reporting their information collections in Aboriginal health. There is no system in place that links information systems of the Territory Health Services with other agency collections such as those of the Aboriginal and Torres Strait Islander Commission (ATSIC) and the Office of Aboriginal and Torres Strait Islander Health Services (OATSIHS).

All organisations consulted in the Northern Territory reported a desire to improve their health information systems. The majority have information client information systems which require laborious tabulations to extract basic activity frequencies and tables to assess their community needs and funding agency requirements. Perhaps consideration could be given by OATSIHS, in consultation with Aboriginal Community Controlled Organisations and THS, to developing and/or purchasing an appropriate computer based record and data processing system/s. This should include appropriate resources including training and support as well as staffing positions dedicated for the management of the system/s. Where funding agencies require community organisations to maintain information systems they need to consider provision of necessary infrastructure and skills for information management at the level of community organisations.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Most THS staff consulted believed that they had a broad understanding of the principles of the NAHS, mentioning particularly the holistic view of health by the Indigenous people. Most however, were not familiar with the NAHS Working Party's specific recommendations related to health information. One senior community leader expressed some frustration at the lack of implementation of the NAHS. She stated that "we are the most researched people on earth... too much information is collected, taken away, (there is) no feedback, (and there are) no funds other than for more advisory committees". She gave an example of the ATSIC housing survey of 1992 (and the plan for another one next year) while Aboriginal housing needs remained as bad as they were in 1992. She also said "if recommendations are not addressed, the information is of no value to anyone".

7. CURRENT AND FUTURE DEVELOPMENTS

The THS' current operational environment is one of particular and increasing emphasis on the importance of providing culturally appropriate health services to Indigenous people, of facilitating increasing status and authority of Indigenous health practitioners, and of specific initiatives in cross-cultural training for all THS staff (including staff with no patient contact). However, at this stage, there are no particular plans for administrative procedures, staff training programs or data quality audits that specifically address the identification of Indigenous status of THS clients.

The THS' Epidemiology Branch is planning to undertake data quality audits of administrative data collections, with the accuracy of Indigenous status a high priority. Hospital information systems will be the first to be considered.

Attachment 2.8

State Summary of Health Information Collections
- AUSTRALIAN CAPITAL TERRITORY -

1. MAJOR COLLECTIONS HELD

1.1 Vital Statistics

Births and Deaths Registration

Birth registration details are required of both parents, including whether they are of Aboriginal or Torres Strait Islander origin, or both.

Details for death registrations are completed by the funeral director responsible for arranging the burial/cremation of the deceased. The statement is completed with the assistance of an informant who is usually a relative, and then submitted to the Births, Deaths and Marriages Registration Office. Requirements for recording the Indigenous status of the deceased are similar to birth registrations, with the exception that death registration forms do not allow the option of recording both Aboriginal and Torres Strait Islander origin.

1.2 Major Hospital and Health Services Collections

Hospital-based Collections

The main ACT hospital separations collection is the ACT Morbidity File, which has an Indigenous identifier. The ACT's major public hospital's admission form has a question about Indigenous status. Similarly, hospital-based mental health data collections record details of patients' Indigenous status.

Perinatal Collections

Like other states, the ACT's Midwives Collection form requires maternal self-identification as the sole method of determining infants' Indigenous status in perinatal collection records.

Cancer Data Collection

ACT Cancer notifications are processed by the NSW Cancer Council (which manages the NSW Cancer Registry). Although there is an Indigenous identifier question on the notification form, the quality of the data is known to be poor. The information is largely derived from hospital admission forms and, if the Indigenous identification data are not actively collected at hospital admission then it does not flow on to secondary collections. Non-responses to the Indigenous identification question are not actively pursued.

Patient records of ACT Breastscreen (the ACT's mammography screening clinic) have the capacity to record the Indigenous status of clients, but the question is not routinely asked by reception staff.

Attachment 2.8

Communicable Diseases Data Collections

Like many other states, while there is capacity to separately identify people of Aboriginal and Torres Strait Islander origins in the ACT's communicable diseases collections, the data is patchy – due largely to its reliance on other data sources (particularly pathology forms and primary medical practitioners). These data are not used to report on Indigenous health status in the ACT.

1.3 Community-based Public Sector Collections

Individual health services in the ACT maintain their own records on patient details, occasions of service and services provided. However, many of these are not linked, and there is little central reporting from these records. Consequently, it is not known the extent to which individual services and units collect information about the Indigenous status of their clients.

However, the ACT is currently collaborating with the state health authorities in Queensland, NSW and South Australia to develop an integrated community health information system. It is likely that demographic data, including Indigenous status, will form a component of this work.

Currently, Indigenous status is recorded for occasions of service of people using ACT Mental Health Services. There is also capacity on childhood immunisation forms for self-identification of Indigenous persons.

1.4 Contribution to National Data Collections

ACT Community Care provides information on all data to the Australian Institute of Health and Welfare (AIHW), as part of the National Health Priorities (formerly known as the National Health Goals and Targets) from the Hospital Morbidity and Separations Data Collections.

2. INDIGENOUS IDENTIFICATION IN DATA COLLECTIONS

2.1 Introduction of Indigenous Identifier

The ACT was the first of all Australian states and territories to include an Indigenous identifier in its birth and death registrations – beginning in 1984. Indigenous identification in hospital separations data began three years earlier, in 1981. The ACT perinatal collection began recording Indigenous identification in 1989.

Attachment 2.8

2.2 Operational Recording of Indigenous Identification

Birth and death registrations

The number of registered Indigenous births in the ACT in recent years has been within 10% under or over the expected figures (on the basis of population projections and Census data). (Such year-to-year fluctuations are not uncommon in the ACT, and are due to the relative small population numbers.) However, unlike most other Eastern states, the number of registered deaths attributed to Indigenous ACT residents has for the past few years been consistently in the range of the expected number of Indigenous deaths.

Where the Indigenous identification field is not completed, the system defaults to a 'no' response – signifying that the respondent is not an Aboriginal or Torres Strait Islander. Registry office policy is to take no action to follow up informants when there is no response to Indigenous identification questions in relation to births and deaths. However, there is currently a proposal to amend the legislation to permit the Registrar-General the discretion to determine the format and content of birth and death registration forms and to require Indigenous identification details to be completed.

Hospital collections

The ACT's major public hospital's admission forms contain an Indigenous identification question. However, the extent to which the question is completed is not known with any degree of certainty. Similarly, non-response to the question is not policed or followed up.

Respondents cited a trial undertaken in ACT public hospitals in the late 1980s of methods to improve Indigenous identification of patients. The study involved admission clerks directly asking 50% of patients whether or not they identified as an Aboriginal or Torres Strait Islander, while the other 50% were provided with admission forms for their self-completion (these included a question on identification). Staff reported that the direct questioning method "caused considerable aggravation for both hospital staff and patients alike".

This led to the adoption of a policy that, where possible, all patients should be given the admission papers for self-completion – and preferably mailed to the patient for completion and return prior to admission. Thus, questions about Indigenous status could be asked in this non-threatening way.

Respondents have reported that there is a relatively high rate of self-identification amongst elective admission patients, who are sent the hospital admission forms for self-completion and return prior to their admission. Respondents considered that the non-invasive nature of the self-completion of these forms – in the privacy of patients' homes, and without fear of the embarrassment or insensitivity of being verbally asked about race within earshot of strangers – was a major factor in the high completion rates amongst elective admissions.

Conversely, respondents note that hospital personnel tend not to ask about the Indigenous status of non-elective admissions – particularly of patients admitted via the Accident and Emergency Department. The most common reason cited for this remain s "the fear of causing offence".

Attachment 2.8

3. INDIGENOUS COMMUNITY-CONTROLLED SERVICES AND COLLECTIONS

The Winnunga Nimmityjah Aboriginal Medical Service provides services to Indigenous persons in the ACT, and is managed by a board which draws its members from the local Aboriginal community.

Consultations with the service has not yet been undertaken and, until such time as this consultation occurs, there is no information provided about the ACT's Indigenous community-controlled service and its data collections.

4. DATA QUALITY INITIATIVES

There are no systematic mechanisms in place to check the quality of Indigenous data in the ACT's various collections.

5. CO-ORDINATION, LINKAGE AND USAGE ISSUES

Information collected on both birth and death registrations is provided by the Registrar to the Australian Bureau of Statistics (ABS) on a monthly basis.

No other information was provided about co-ordination and linkage issues concerning Indigenous data in the ACT.

6. IMPLEMENTATION OF NATIONAL ABORIGINAL HEALTH STRATEGY (NAHS) INFORMATION RECOMMENDATIONS

Respondents seemed to be particularly familiar with the NAHS, including recommendations concerning information development.

7. CURRENT AND FUTURE DEVELOPMENTS

As noted above, the ACT Registrar-General's office is considering initiating a mandatory requirement for respondents to complete the Indigenous identification data questions on birth and death registration forms.

Attachment 3

National Indigenous Health Information Model

Prepared by the Australian Institute of Health and Welfare, Canberra; June 1997

Background

The Institute was approached by the authors of this report early in 1997 to produce a preliminary information model for Indigenous health (attached – National Indigenous Health Information Model Version 0.1). The Institute has acquired considerable experience in the field of information modelling in recent years, most specifically in the production of Version 1.0 of the National Health Information Model (NHIM), published in January 1996.[1]

The primary aim of the NHIM Version 1.0 was to provide the framework for all other developments in health information. In keeping with this aim, several national projects which are on the National Health Information Work Program (Non-admitted patients, Palliative care and Primary and community health services, national information management project) have developed information models using the NHIM as a basis for these activities. Three other projects currently underway are a National Public Health Information Model, a National Community Services Information Model and a national model for community health.

The Institute is currently working on the NHIM Version 2.0. Changes from Version 1.0 to Version 2.0 are aimed at enhancing acceptance of the model by non-technical users and to ensure that its coverage of health information is comprehensive. Version 2.0 is currently available on the AIHW Internet site (http://www.aihw.gov.au) but will also be published in hardcopy later in 1997.

Why develop an information model for Indigenous health?

In the broadest sense, the development of a National Indigenous Health Information Model will further contribute to the development of nationally consistent information frameworks, which in time should improve data coverage, quality and comparability across subject areas. It will also ensure that data development, data collection, development of information systems and the provision of data for national reporting purposes is undertaken in a planned and rational manner rather than being driven by the needs of specific interest groups, frequently working in isolation.

---

[1] Australian Institute of Health and Welfare. (1995) **National Health Information Model, Version 1**. Australian Government Publishing Service, Canberra.

Attachment 3

At a practical level, participation in the development of a subject-specific information model allows competing interests and differing perceptions about data to be discussed using a generic language (the same language appearing in different models), with the outcome of these discussions represented via an agreed graphical model. Once developed the model can be refined over time, it may challenge concepts used in the NHIM and other related models, and most importantly, by mapping existing data collections for Indigenous health to it, the process will identify (and document) existing gaps in the data and highlight deficiencies in data definitions.

How Version 0.1 of the National Indigenous Health Information Model was developed

The information sources described below formed the basis of the development of the National Indigenous Health Information Model. These sources provided information about health statistics, performance indicators and subject areas. This information was then 'mapped' to entities on the NHIM.

For example, an indicator such as the 'Death rate for diabetes among Indigenous Australian males aged 25–64 years' cannot be mapped directly to the model; it must be broken down into its components beforehand. The components comprise the 'raw' data that is collected and stored in information systems, such as 'Indigenous status' and 'sex'. The 'raw' data for this indicator and mappings to the National Indigenous Health Information Model are shown below:

> *The 'instance of a death' is mapped to the entity 'Death event'.*
>
> *The 'cause of death', although associated with the 'death event', is mapped to 'Physical wellbeing'. The reason for this separation is that a disease such as diabetes can be associated with 'other events' such as the detection of the disease or the recording of the presence of the disease at hospital admission.*
>
> *'Indigenous status' and 'sex' are mapped to the entity 'Demographic characteristic'.*
>
> *'Age' can be derived from information collected about a person's 'date of birth'. 'Date of birth' is mapped to the entity 'Demographic characteristic'.*

Once this information is collected, the data can be aggregated to form the population-based indicator of health status, mentioned above.

All of the boxes on the model for Indigenous health are entities (with some entities grouped as entities within entities). The entity is the foundation of the information modelling technique used to develop the NHIM. Entities are 'things that we need to know information or hold data about'.[2] For example, in the top left hand corner of the model is a large box titled '*Party*' with three smaller boxes inside it titled '*Person*', '*Party group*' and '*Organisation*'.

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[2] Australian Institute of Health and Welfare, ibid.

The smaller boxes are types of parties and represent the levels of information about a party that are desired i.e. information about persons (which once collected and aggregated can provide population based statistics, as in the example above), information about party groups such as families or communities and information about organisations such as health service providers.

Use of the word 'party' in the model is possibly contentious and alienating, but it has been used because it is a generic rather than a specific term such as 'patient' (which immediately begins to restrict the sort of information about a 'person' that might be required from an information system). The term 'party' has also been used because it is common across existing models. Commonality reflected in differing models highlights the commonality of information requirements across different subject areas. This latter reason also highlights the value in the technique of using entities rather than boxes (or other symbols) to graphically represent 'the real world'. Without a common approach, comparison and the identification of overlapping concepts between models is difficult.

Other large entities on the model include '*Party role*' (for example, information about a person in differing roles such as either a recipient of services or as a provider of services), '*Location*', '*Setting*' (such as a community health centre or within an Aboriginal community), '*Person characteristic*' (such as weight, employment status, type of housing), '*Health differential*', '*Outcome*', '*Event*' (such as information about a health service event or an event which happens to a person such as the date an injury occurred). Entities in the third column of the model relate to information which influences the interaction of 'parties' with the health and welfare system and include entities grouped according to 'Business factors', 'Environmental factors' and 'Enabling factors' (such as distance to a health service or awareness of the availability of, or eligibility for, a screening program).

The development of subject-specific models from the NHIM reflects a higher level of detail than occurs in the NHIM, hence the process inevitably involves the inclusion of entities on the new model which do not appear on the NHIM. Throughout the development of a subject-specific model a process of cross-checking also occurs to ensure that the concept underlying each entity is fundamentally different from all other entities (i.e. mutually exclusive). In practical terms, no data element should be able to be mapped to more than one entity on the model.

The process described above has resulted in all major entities from the NHIM appearing in the National Indigenous Health Information Model except '*Care plan*' and '*Need/Issue*'. The entity '*Health differential*' is a new entity on the National Indigenous Health Information Model and has been included to highlight the importance of collecting information about Indigenous health which is comparable (where appropriate) with information collected about the health of the non-Indigenous population. The inclusion of this entity 'breaks the rule' of mutual exclusivity in information modelling, but the concept is considered so important that the model would be incomplete without its representation.

Entity definitions normally accompany each of the entities depicted in a model. However definitions have not been provided in Version 0.1 of the National Indigenous Health Information Model as they are under review in the NHIM Version 2.0. Entities with the same name as occur in the NHIM, are taken as being the same as those in the NHIM and therefore must be defined similarly. Entities specific to the National Indigenous Health Information Model will need to be defined over time.

Attachment 3

Further consultation

The Institute believes that by aligning the National Indigenous Health Information Model with the NHIM, priority areas for Indigenous health information are more clearly delineated from the health information requirements of the total population. Areas of overlap are also emphasised. However, the true value of the information modelling technique employed to develop the National Indigenous Health Information Model Version 0.1 can only be assessed within a wider forum.

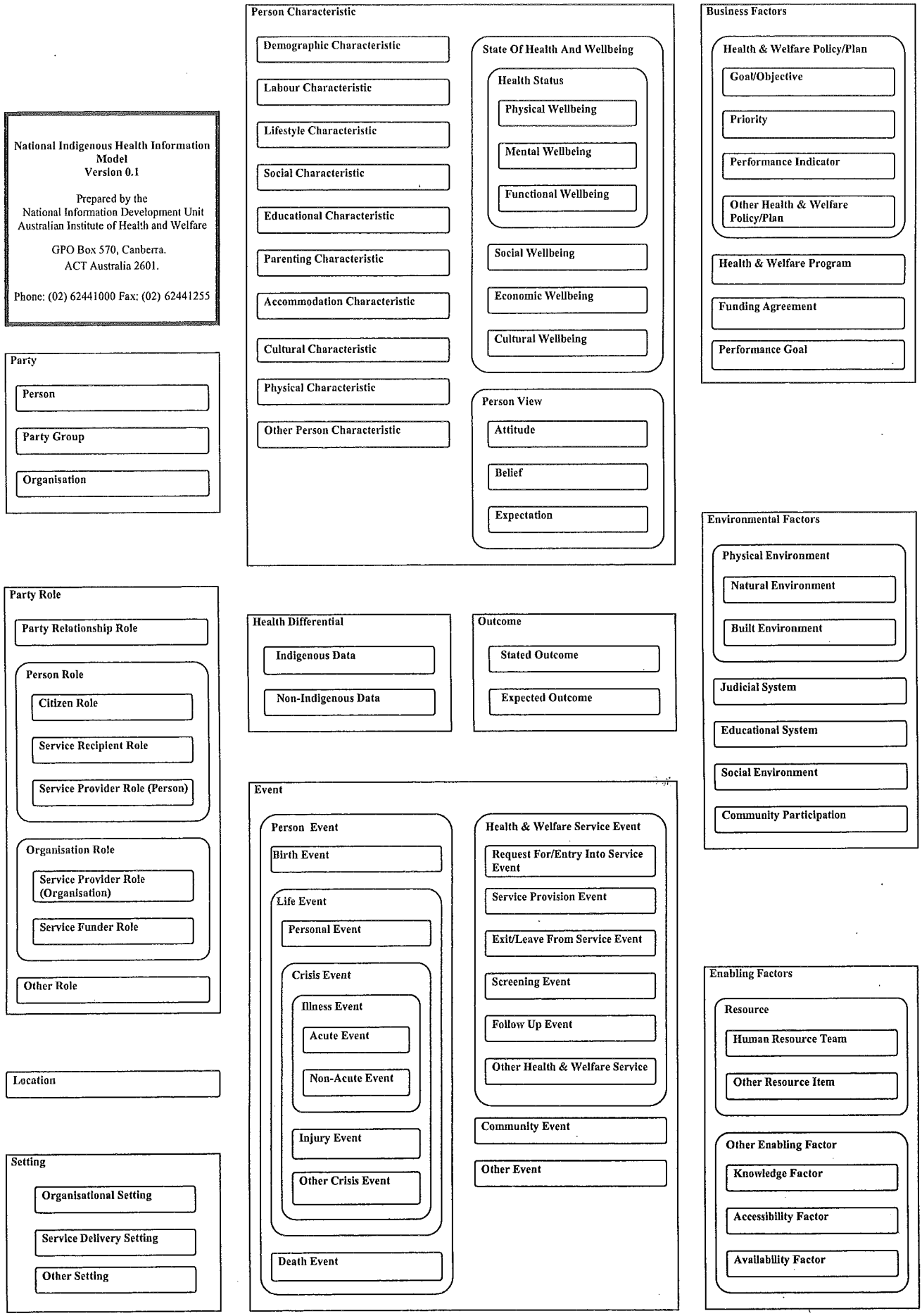
Specifically, the National Indigenous Health Information Model Version 0.1 requires further discussion and debate among interested stakeholders in relation to the following issues:

- its capture, coverage and completeness of Indigenous health information requirements;
- its ability to highlight gaps and specific areas of concern in the health information requirements of Indigenous peoples;
- its usefulness in communicating health information requirements to Indigenous communities; and
- its acceptance as an aid to the overall task of improving Indigenous health data collections and reporting of Indigenous health information.

Further work would also be required in relation to:

- consideration of the relationships between entities;
- development of entity definitions; and
- inclusion of entities for explanatory purposes which contravene the rule of mutual exclusivity.

The Institute will convene a national advisory group to consider national health information model development. Progress on model development will then be reported to the National Health Information Management Group (NHIMG). Consideration of the National Indigenous Health Information Model by this group would require endorsement of the project on the National Health Information Work Plan by NHIMG. This endorsement would facilitate national consultation and dissemination of the National Indigenous Health Information Model and in so doing ensure that the above-mentioned issues and further work are addressed within a national forum.


National Indigenous Health Information Model
Version 0.1
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Party
Person
Party Group
Organisation
Party Role
Party Relationship Role
Person Role
Citizen Role
Service Recipient Role
Service Provider Role (Person)
Organisation Role
Service Provider Role (Organisation)
Service Funder Role
Other Role
Location
Setting
Organisational Setting
Service Delivery Setting
Other Setting
Person Characteristic
Demographic Characteristic
Labour Characteristic
Lifestyle Characteristic
Social Characteristic
Educational Characteristic
Parenting Characteristic
Accommodation Characteristic
Cultural Characteristic
Physical Characteristic
Other Person Characteristic
State Of Health And Wellbeing
Health Status
Physical Wellbeing
Mental Wellbeing
Functional Wellbeing
Social Wellbeing
Economic Wellbeing
Cultural Wellbeing
Person View
Attitude
Belief
Expectation
Health Differential
Indigenous Data
Non-Indigenous Data
Outcome
Stated Outcome
Expected Outcome
Event
Person Event
Birth Event
Life Event
Personal Event
Crisis Event
Illness Event
Acute Event
Non-Acute Event
Injury Event
Other Crisis Event
Death Event
Health & Welfare Service Event
Request For/Entry Into Service Event
Service Provision Event
Exit/Leave From Service Event
Screening Event
Follow Up Event
Other Health & Welfare Service
Community Event
Other Event
Business Factors
Health & Welfare Policy/Plan
Goal/Objective
Priority
Performance Indicator
Other Health & Welfare Policy/Plan
Health & Welfare Program
Funding Agreement
Performance Goal
Environmental Factors
Physical Environment
Natural Environment
Built Environment
Judicial System
Educational System
Social Environment
Community Participation
Enabling Factors
Resource
Human Resource Team
Other Resource Item
Other Enabling Factor
Knowledge Factor
Accessibility Factor
Availability Factor