

# **Improving Indigenous identification in communicable disease reporting systems**

A discussion paper prepared by the Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee for the Australian Government Department of Health and Ageing

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Secretariat and research officer support:



**PHIDU**

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The views expressed in this report are solely those of the authors and should not be attributed to the Department of Health and Ageing or the Minister for Health and Ageing.

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## Acronyms

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ACCHS	Aboriginal Community Controlled Health Service
ATSIHWIU	Aboriginal and Torres Strait Islander Health and Welfare Information Unit
CDNA	Communicable Diseases Network of Australia
DoHA	Department of Health and Ageing, Australian Government
GP	General Practitioner
HIC	Health Insurance Commission
IASHC	Indigenous Australians' Sexual Health Committee
IT	Information Technology
MBS	Medicare Benefits Schedule
NACCHO	National Aboriginal Community Controlled Health Organisation
NAGATSIHID	National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data
NHDD	National Health Data Dictionary
NNDSS	National Notifiable Diseases Surveillance System
OATSIH	Office for Aboriginal and Torres Strait Islander Health
PHD	Population Health Division, DoHA
PHOFA	Public Health Outcome Funding Agreement
SCATSIH	Standing Committee on Aboriginal and Torres Strait Islander Health
STI	Sexually transmissible infection
STD	Sexually transmitted disease
TSIAB	Torres Strait Islander Advisory Board



## Foreword

The need to improve the quality of Aboriginal and Torres Strait Islander peoples' health information remains a national priority, as it provides the evidence base necessary for effective health policy development and program implementation. This is particularly important for Aboriginal and Torres Strait Islander peoples, who experience a significantly lower health status than that of the wider Australian population. This situation is further compounded by the difficulty in identifying Aboriginal and Torres Strait Islanders from other Australians in the information streaming from health and welfare services across the sector. *The Aboriginal and Torres Strait Islander Health Information Plan...This time, let's make it happen* (ATSIHWIU, 1997) highlights this situation, determining that the quality of Indigenous identification in most data collections at all levels needs to be improved significantly.

More specifically, the need to improve Indigenous identification in communicable disease reporting has been noted as an issue of increasing importance by a number of key stakeholders including: the National Health Information Management Group Subcommittee; the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data; the National Public Health Partnership Group's Aboriginal and Torres Strait Islander Working Group; the Office for Aboriginal and Torres Strait Islander Health; and the Communicable Diseases Network of Australia.

This discussion paper aims to provide some insight into how Indigenous identification can be improved in communicable disease reporting by putting forward a number of achievable strategies that are short, medium and longer term.

The Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee believes that this paper will provide effective strategies for all those interested in improving Indigenous communicable disease reporting to assist in reducing the number of Aboriginal and Torres Strait Islander Australians affected by communicable diseases.

Throughout the development of this paper, the Steering Committee has placed the importance of data principles and protocols when using or reporting on Indigenous information, at the forefront of its deliberations. These underpinning values are embedded in the paper to ensure that the Indigenous culture is respected, in line with the strong recognition of the Aboriginal and Torres Strait Islander community's ownership of data relating to their community. This involves the protection and constructive use of the information as well as consideration about data quality issues and the accurate identification of clients as Aboriginal and Torres Strait Islander people in data collections.

Debra Reid

Chair

Improving Indigenous Identification in Communicable  
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Details on length of membership and other participants in Steering Committee meetings are provided at Attachment D.

# Executive Summary

## *Background*

The Aboriginal and Torres Strait Islander population is one of the most disadvantaged groups in Australia and - despite some good news stories - has a significantly lower status of health and well-being than the wider population. Aboriginal and Torres Strait Islanders have a much higher prevalence of a range of communicable diseases, and higher related morbidity and mortality, than non-Indigenous Australians.

The need to improve the quality of Aboriginal and Torres Strait Islander health information remains a national priority. The Population Health Division of the Australian Government Department of Health and Ageing made resources available for the *Improving Indigenous Identification in Communicable Disease Reporting Project* to

develop a Draft Discussion Paper with recommendations to the Department of Health and Ageing for future action to improve Indigenous identification in communicable disease reporting systems.

The Project Auspice is the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID). The Project Steering Committee convened to oversee the development of the Draft Discussion Paper has a majority representation of Aboriginal and Torres Strait Islander Australians, is chaired by an Indigenous Australian, and includes representation from the Aboriginal and Torres Strait Islander community controlled health sector. Reporting is to NAGATSIHID and the National Public Health Information Working Group. The Project Secretariat is provided by the Public Health Information Development Unit (PHIDU), The University of Adelaide, and is funded by the Population Health Division, Australian Government Department of Health and Ageing.

## *Project methodology*

The Discussion Paper was produced from August 2003 to June 2004 under the guidance of the *Improving Indigenous Identification in Communicable Disease Reporting Project* (IIICDRP) Steering Committee and through the participation of many people, of Aboriginal and Torres Strait Islander, and non-Indigenous origins. The Steering Committee's work was based on four methods: a survey of relevant literature reported since 1997 to identify key background documentation; work with jurisdictions through nominated Contact Officers providing up-to-date information on current jurisdictional situations; interviews and surveys with key stakeholders; and preparation of the Discussion Paper.

## *Benefits of improving Indigenous identification in communicable disease reporting*

In summary, the major benefit of improving the quality of Indigenous identification in communicable disease reporting identified in interviews with stakeholders was to make a contribution to better health for Aboriginal and Torres Strait Islander peoples. Stakeholders reported that benefits arise from better data collection leading to better quality data, and a clearer picture and understanding leading to better use of data and actions to address communicable diseases in Aboriginal and Torres Strait Islander populations, and enabling the measurement of change over time. However it is important to note that one of the major

contextual challenges to these identified benefits, especially for Indigenous people with communicable diseases, is diagnosis and data capture at the outset.

### ***Current situation***

Systems for communicable disease reporting differ around the country and are increasingly reliant on pathology based reporting. Notification of communicable diseases is a jurisdictional responsibility with medical practitioners and/or pathology laboratories required to report certain communicable diseases to State/Territory authorities responsible for addressing outbreaks, infection control, and other public health responses to minimise and prevent infectious disease in the population. An overview of key differences across the jurisdictions is shown below in Table A.

**Table A Best practice in jurisdictions**

State or Territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Legislated authority/requirement to collect Indigenous identification in communicable disease notifications	-	✓	-	-	✓	✓	-	□
Indigenous identification required for <i>all</i> notifiable communicable diseases	✓	✓	✓	✓	✓	✓	-	✓
Proportion notified by medical practitioners*	10%	60%	1-5%	66%	75%	5-10%	5%	5-10%
ABS standard collected by CDUs from primary data collectors (medical practitioners)	-	✓	✓	-	✓	✓	-	✓**
ABS standard reported (by CDUs to NNDSS)	-	✓	✓	-	✓	✓	-	-
Data matching with hospital information system (nearly all notifications)	-	-	-	-	-	-	-	✓
Indigenous identification completion rate above 50% in 2002 (able to be reported nationally)	-	-	-	55%	72%	-	-	92%

\* Proportion (estimate) notified by medical practitioners that could potentially report Indigenous identification in the first instance.

\*\* Hospitals only, not on CDU notifications.

CDU = Communicable disease units in the States and Territories. NNDSS = National Notifiable Disease Surveillance System.

### ***Limitations***

In summary, the following major limitations to improving the quality of Indigenous identification in communicable disease reporting were identified in interviews with stakeholders. There are limitations that arise from differences across the jurisdictions - in legislation, notification and reporting systems, regional reporting structures, core business viewpoints, and concerns about data sharing. Aboriginal and Torres Strait Islander populations are diverse, and there is limited capacity to engage with these diverse populations. There are deficiencies in systems (e.g. pathology), in services - especially in rural/remote areas - and in resources. There are deficiencies in primary data collections (e.g. GP collections) and baseline information - in urban areas particularly - and in data not being transferred especially to and from pathology. There are deficiencies in Aboriginal and Torres Strait Islander people not identifying, and deficiencies in cultural care. National information on non-notifiable communicable disease is not readily available.

Data that is collected or held also has limitations – it is incomplete, of dubious quality, not to national standard, and not of a holistic nature. Data collections lack quality assurance and do not account for population mobility or cross-border issues. Organisational and cultural issues identified include: limited training to collect and value information, lack of public

health awareness, and non-integrated information (e.g. environmental health) and services (e.g. prisons).

### *Options to improve*

There is little work currently being undertaken to examine and improve Indigenous identification in communicable disease systems. However a body of related work on Indigenous identification mainly in hospitals was surveyed for relevant options to improve Indigenous identification in communicable disease systems. In summary, these address the need to: build capacity at the local level; improve data collection processes; implement data principles and protocols; report useable information to communities; use data to improve Aboriginal and Torres Strait Islander health; change organisational culture/values; and improve conformity with national standards.

However, the majority of communicable disease reporting is the notification of cases of infections, from pathology laboratories and/or medical practitioners to State and Territory health officials, who are authorised to take required public health actions. Medical practitioners in hospitals report only a small proportion of notifications as the majority of people with communicable disease are not treated in hospital.

Stakeholders interviewed for the project suggested many options for improving the quality of Indigenous identification in communicable disease reporting. The options can be categorised into the areas of: developing **Policy**, creating **Incentives**, improving **Reporting**, introducing **Workplace Reforms**, and enhancing **Information Systems**. In addition, a number of initiatives were proposed to provide additional targeted gains.

### *Consistent national approach*

Most stakeholders were in favour of a consistent approach nationally and saw merit in building on the steps already taken to achieve one, such as the Communicable Diseases Network of Australia and the national case definitions for notifiable communicable diseases. Some respondents thought there would be more value in having targeted approaches than in spending the effort universally improving national surveillance across the board. Key questions put forward were – what is the purpose of national surveillance, and to achieve improved outcomes for Aboriginal and Torres Strait Islander health what is the best way to do it? For instance, for the purpose of identifying trends, the use of sentinel sites could be more effective. A national approach could be more usefully targeted to certain diseases, such as vaccine preventable diseases and sexually transmissible infections.

## **Key Recommendations**

The Steering Committee clearly wanted to see *sustained* improvement in Indigenous identification in communicable disease reporting that is supported by the Australian Government and jurisdictions. The Steering Committee recognises that improvements and changes can only be sustained if they happen through a number of processes, for example in Australian Government policy, in State and Territory legislation, and in developing working partnerships with key stakeholders.

Collecting and reporting Indigenous identification in all communicable diseases collections in all jurisdictions as a standardised process is the highest order recommendation made by the Steering Committee. This can be achieved through action in: developing **Policy**, creating

**Incentives**, improving **Reporting**, introducing **Workplace Reforms**, enhancing **Information Systems** and in exploring initiatives for targeted change.

The recommendations to the Australian Government Department of Health and Ageing are for actions in these six areas. Recommendations are addressed to all, to the Australian Government and to the jurisdictions, and are set out over the short (within 1-2 years), over the medium (within 2-4 years) and over the longer term (within 4-6 years).

***Recommendations***

<p><b>Policy</b></p> <p>Short Term</p> <p>Medium Term</p> <p>Long Term</p>	<p><i>All:</i> Make collection &amp; reporting of Indigenous identification a mandatory requirement in all communicable disease health policies.</p> <p><i>Australian Government:</i> Set benchmarks &amp; milestones to reward gains in Indigenous identification (II) made by the jurisdictions; &amp; provide model public health instruments for legislative change (moving towards national public health legislation over the longer term).</p> <p><i>Jurisdictions:</i> Legislate the collection &amp; reporting of II as a mandatory requirement in all health policies relevant to communicable disease.</p> <p><i>All:</i> Implement a standardised process that incorporates the Indigenous identification standard into all collections on communicable diseases (CDs) through CDNA.</p> <p><i>Australian Government:</i> Provide support for jurisdictions to develop &amp; implement the ABS standard for the collection of II in CD reporting; Negotiate changes to pathology reporting systems to include II data from primary collectors.</p> <p><i>Jurisdictions:</i> Develop &amp; implement (with support from the Australian Government) collection of national standard II into all communicable disease collections.</p> <p><i>All:</i> Use information on Indigenous identification in communicable disease reporting in a constructive way to improve the health of Aboriginal &amp; Torres Strait Islanders through effective planning, development &amp; resourcing of treatment &amp; prevention services for communicable diseases.</p> <p><i>Australian Government:</i> Introduce National Public Health Legislation that mandates collection &amp; reporting of II in CD notifications.</p>
<p><b>Incentives</b></p> <p>Short Term</p> <p>Medium Term</p> <p>Long Term</p>	<p><i>All:</i> Continue to fund proven best gains &amp; prevention (e.g. immunisation, donovanosis eradication).</p> <p><i>Australian Government:</i> Fund ‘field officers’ to work in jurisdictional Public Health Units &amp; with primary data collectors (e.g. GPs, AMSs); Provide nominal incentives to software providers to accelerate software changes to bring Indigenous identification to the national standard, as a non-defaulting, mandatory data item.</p> <p><i>Jurisdictions:</i> Work with the Australian Government funded field officers; Continue/explore/-evaluate the use of incentives (such as casemix) &amp; ‘performance agreements’ with health service providers to improve II.</p> <p><i>All:</i> Nationally equitable funding (all jurisdictions) - demonstrated high need receives funding priority &amp; additional resourcing to ‘close the gap’.</p> <p><i>Australian Government:</i> Revise national funding agreements &amp; reporting to introduce incentives in relation to the quality of Indigenous identification (e.g. Public Health Outcome Funding Agreement, Primary Health Care Access Program, Health Care Agreements).</p> <p><i>All:</i> Achieve &amp; sustain, satisfactory II completion rates in communicable disease reporting.</p> <p><i>Australian Government:</i> Work through the National Public Health Partnership to ensure funding is linked to satisfactory &amp; sustained gains in II in CD reporting; Develop a funding arrangement to support infrastructure maintenance &amp; development in CD reporting systems to assist jurisdictions to meet national standards.</p>
<p><b>Reporting</b></p>	<p><i>All:</i> Routinely monitor &amp; report completeness of Indigenous identification data in</p>

### **Recommendations**

Short Term	<p>communicable diseases through CDNA; Identify key policy-relevant &amp;/or program development networks &amp; agencies &amp; disseminate information to get II onto their agendas; Publish the data in cooperation with Indigenous organisations.</p> <p><i>Australian Government &amp; Jurisdictions:</i> Identify leading jurisdictions as models for best quality administrative performance &amp; use a national approach to move towards best model.</p> <p><i>Australian Government:</i> Fund a permanent Secretariat to monitor &amp; review progress on the actions set out in these recommendations.</p> <p><i>Jurisdictions:</i> Investigate multi-jurisdictional areas &amp; methods for CD surveillance &amp; action.</p>
Medium Term	<p><i>All:</i> Report the data in context, to show a more complex picture (e.g. including under-pinning determinants e.g. poverty, over-crowding, lack of education) rather than focusing only on Indigenous status.</p> <p><i>Australian Government:</i> National reporting on CDs affecting Aboriginal and Torres Strait Islander people by urban/rural/remote regions (geographically sensitive - does not identify individual communities); &amp; by age &amp; sex groups; Manage NNDSS II data categories to improve correspondence with jurisdictional data (for jurisdictions not to standard); Collate existing material on non-notifiable communicable diseases with high Indigenous impact (e.g. results of studies, existence of state-wide registers, programs, conditions such as rheumatic fever); Investigate collection of denominators for pathology testing.</p> <p><i>Jurisdictions:</i> Better connections between Aboriginal and Torres Strait Islander health &amp; environmental health data &amp; programs.</p>
Long Term	<p><i>All:</i> Develop &amp; implement a process &amp; mechanism that enables reporting back to Aboriginal and Torres Strait Islander communities, useable information about communicable diseases.</p> <p><i>Australian Government:</i> Develop a nationally accepted set of rules for reporting Aboriginal and Torres Strait Islander data (National Data Principles &amp; Protocols); Support longer term work on how the information is used nationally in a constructive manner – as a standardised II process is implemented.</p>
<b>Workplace reforms</b>	<p><i>All:</i> Implement Indigenous identification as part of standard demographic data gathered on all health care users; include II in staff development &amp; training programs; Improve GP capacity to collect standard demographic data including II, &amp; encourage/fund education &amp; awareness initiatives with professional bodies.</p>
Short Term	<p><i>Australian Government:</i> Under-write provision of standard brochures &amp; training material (e.g. ABS, HIC), national ‘train the trainer’ program &amp; materials; community &amp; professional II campaigns; Negotiate changes to health professionals’ training with relevant colleges (e.g. Royal Australian College of General Practitioners) &amp; professional groups (e.g. Divisions of General Practice).</p> <p><i>Jurisdictions:</i> Continue/initiate training &amp; support for primary data collectors (e.g. GPs, hospital patient administration); Actively seek opportunistic ways to implement change towards ABS standard for II in communicable disease reporting.</p>
Medium Term	<p><i>All:</i> Establish minimum data standard for a set of demographic data to be used in all health collections (including GPs, pathology).</p> <p><i>Jurisdictions:</i> Audit Indigenous identification completion rates &amp; data accuracy in communicable diseases, &amp; quality assure data collection methods against best practice; Set data standards for transfer of demographic data in health.</p>
<b>Information systems</b>	<p><i>All:</i> Enable sharing* of available Indigenous identification data across health information systems.</p>
Short Term	<p><i>Australian Government:</i> Continue HIC program of voluntary Medicare indigenous self-identification; Liaise with software companies making GP client-based information systems</p>

\* with appropriate privacy and security, and due consideration given to Indigenous cultural sensitivities.

### *Recommendations*

Medium Term	<p>(e.g. Medical Director) to improve &amp; standardise data fields for Indigenous identification. See also, Provide nominal incentives to software providers, under <b>Incentives</b> above.</p> <p><i>Jurisdictions:</i> Continue/explore data sharing, data matching* across health information systems (e.g. hospital patient administration, pathology, emergency; hospital patient registers &amp; CD notifications).</p> <p><i>All:</i> Aim for ‘once only’ collection &amp; increase electronic transfer of demographic data including Indigenous identification.</p> <p><i>Australian Government:</i> Provide model instruments to enable data sharing &amp; support &amp; encourage such initiatives in jurisdictions; Lead with standards for data transfer of health information (from GPs to pathology to state CD units); support &amp; encourage IT enhancements to ABS standard (e.g. GP practice software, pathology corporate IT systems).</p> <p><i>Jurisdictions:</i> Exploit potential to increase automated /electronic transfer of already collected data (eliminate multiple re-writing &amp; re-keying); Explore data linkage* (research purposes).</p>
Long Term	<p><i>All:</i> Electronic health record (e.g. HealthConnect).</p>
<b>Initiatives</b>	<p><i>All:</i> Explore a range of proposed initiatives to improve the quality of Indigenous identification in communicable disease reporting, as detailed in Table 11.</p>

The recommendations put forward in this paper can be categorised into two main areas: those strategies that directly aim to improve Indigenous identification on communicable disease reporting, and those strategies aimed at addressing wider issues that also impact on Indigenous identification in communicable disease and the reporting processes. The Steering Committee has recommended a process of communicable disease notification that works more effectively, allows proactive planning and more effective interventions, and that fits within the broader picture of the ‘*surveillance loop*’ using data to improve action in communicable diseases affecting Aboriginal and Torres Strait Islander peoples.

The Steering Committee recognises that many gains have already been made, and that there are opportunities for further gains over a range of time scales. The immediate priority is to promulgate Indigenous identification in communicable disease reporting as a standard practice to be adopted by all those involved in gathering this information. This can be achieved by establishing a forum for government, key organisations and academia to work in partnership to facilitate discussion, form closer links, provide a platform for decision making/priority setting and sharing information to specifically address the issues associated with Indigenous identification in communicable disease reporting.

#### *Underlying principle*

**A fundamental principle underlying the actions required is the need to work together with Indigenous organisations representing Aboriginal and Torres Strait Islander peoples, in strong partnership arrangements where relevant to the recommendations.**

The recommendations addressed to different sectors (to all, to the Australian Government, and to the jurisdictions) are further explored in Section 7, and summarised in the tables that conclude that Section (Table 10 *Recommendations*, Table 11 *Proposed Initiatives*).

# 1 Background

Baseline key statistics describe the general health, communicable diseases affecting, and other aspects of the situation of Aboriginal and Torres Strait Islander peoples in Australia today. An overview of the project including the methodology used follows, and the scope and definitions used in this Discussion Paper completes this section.

## 1.1 Communicable diseases and Indigenous health

‘Australians in general are one of the healthiest populations of any developed country and have access to a world-class health system. Indigenous Australians in general are the least healthy of all Indigenous populations within comparable developed countries and have a significantly lower level of access to appropriate health care than non-Indigenous Australians. Current mortality and morbidity data shows that the health of the Aboriginal and Torres Strait Islander population is the worst of any population in Australia, including groups of similar socio-economic status and non-English speaking migrant populations.’ (NATSIHC 2003a, p. 6)

The Aboriginal and Torres Strait Islander population experiences life expectancy far below that of other Australians (a difference of 21 years for males and 19 years for females), deaths and low birth weights of new born babies twice as likely as other Australians, much higher prevalence of diseases such as diabetes, hypertension, and a much higher prevalence of a *range of communicable diseases* (NATSIHC 2003a, p. 6).

*The Health and Welfare of Australia’s Aboriginal and Torres Strait Islander Peoples 2003* states that the ‘burden of communicable diseases in Indigenous Australians is far greater than that of non-Indigenous Australians’ (ABS & AIHW 2003, p 144). This is illustrated in the following two tables (Table 1 and Table 2) that show how much higher hospitalisation and communicable disease notification rates are for Aboriginal and Torres Strait Islander than for non-Indigenous people.

Age-specific hospital separation rates show higher rates for Aboriginal and Torres Strait Islander patients at all ages (except males aged 75 years and over). Age-standardised separation rates are higher than those for non-Indigenous people for many principal diagnoses including infectious and parasitic diseases. Aboriginal and Torres Strait Islander males and females were more than two and a half times more likely to be hospitalised for infectious and parasitic diseases and other communicable diseases. For example, as Table 1 following shows, ‘Indigenous Australians were four times more likely to require a hospital visit for the treatment of pneumonia than non-Indigenous Australians’ and rates for pneumococcal pneumonia were even higher, particularly in females. ‘*Despite the under-identification of Indigenous persons in hospitalisation data*, the data available indicate that the Indigenous population experiences a higher burden of illness and disease resulting in hospitalisation than does the rest of the population’ (ABS & AIHW 2003, pp.79-80, 147-148, our *emphasis*).

**Table 1 Hospital separations: major communicable illnesses 2000-01 (ABS & AIHW 2003)**

Selected infectious and parasitic diseases	Indigenous males				Indigenous females			
	no.	%(b)	rate(c)	rate ratio(d)	no.	%(b)	rate(c)	rate ratio(d)
<b>Infectious and parasitic diseases</b>								
Intestinal infectious diseases	1,369	1.8	3.9	2.3	1,298	1.3	4.3	2.3
Tuberculosis	21	0.0	0.2	4.5	18	0.0	0.1	2.5
Other bacterial diseases	311	0.4	2.5	3.4	330	0.3	2.4	4.3
Septicaemia	233	0.3	2.3	4.0	277	0.3	2.2	5.2
Pneumococcal septicaemia	20	0.0	0.1	5.2	17	0.0	0.1	3.9
Infections, sexual transmission	37	0.0	0.2	2.6	129	0.1	0.6	4.7
Viral infections	168	0.2	0.7	1.0	161	0.2	0.7	1.2
Viral hepatitis	40	0.1	0.2	1.1	24	0.0	0.1	1.4
Other & unspecified infectious & parasitic diseases	712	0.9	3.0	2.2	736	0.7	3.3	2.7
Meningitis	45	0.1	0.2	3.2	31	0.0	0.1	2.0
Influenza	68	0.1	0.4	3.5	87	0.1	0.5	3.8
Pneumonia	2,335	3.1	13.6	4.4	2,034	2.0	11.6	5.0
Pneumococcal pneumonia	126	0.2	0.7	7.8	101	0.1	0.7	9.9
Kidney infections	66	0.1	0.5	3.5	429	0.4	2.4	3.9
<b>Total</b>	<b>5,132</b>	<b>6.7</b>	<b>27.3</b>	<b>2.7</b>	<b>5,253</b>	<b>5.2</b>	<b>28.1</b>	<b>3.1</b>

(a) Data are for public and most private hospitals. Categories based on ICD-10-AM codes A00–B99, G00–G03, J10–J18, N10–N12, N13.6 and N15.1; (b) Percentage of all Indigenous hospital separations in 2000–01; (c) Per 1,000 population. Directly age-standardised using the total Australian population as at 30 June 1991; (d) Rate ratio is equal to the rate of Indigenous separations divided by the rate of non-Indigenous separations.

Source of data: AIHW National Hospital Morbidity Database; Source of table: ABS & AIHW 2003, p 147.

However, most cases of a communicable disease do not result in hospitalisation. Higher prevalence of a range of communicable diseases is also shown in notifiable communicable disease rates in Table 2 following that describes data from 2002 reported to the National Notifiable Diseases Surveillance System (NNDSS) for South Australia, Western Australia and the Northern Territory combined (NNDSS 2004).

#### Caveats on the data shown in Table 2 (following)

The data shown in Table 2 should be regarded as indicative rather than actual, as it represents the best data available at the present time from those jurisdictions that achieved a rate of Indigenous identification completion of more than 50% across all communicable diseases. The data presented need to be used/interpreted with caution and understood in the light of the following caveats (ABS & AIHW 2003, p 144):

- there is incomplete identification of Aboriginal peoples and Torres Strait Islanders in data collections, even in those states and territories (Western Australia, South Australia, Northern Territory) regarded as holding the most complete Indigenous identification data;
- there is incomplete notification of communicable diseases, with the proportion notified varying across diseases and according to factors such as the seriousness of the condition (less serious cases are less likely to be notified); and
- where high proportions of Aboriginal and Torres Strait Islander populations are screened for communicable diseases, apparent increases in rates may be a byproduct of screening processes (i.e. a process artefact) rather than an increase in the disease.

**Table 2 Notified communicable diseases 2002: SA, WA, NT combined (NNDSS)**

Disease	Notifications no.	Proportion of notifications* identified as			Crude rate per 100,000 population(a)		
		Indigenous %	Non-Indigenous %	Unknown %	Indigenous	Non-Indigenous	Rate ratio(b)
<b>Bloodborne infections</b>							
Hepatitis B (incident)	61	16.4	57.4	26.2	7.5	1.1	7.0
Hepatitis B (unspecified)	647	11.6	66.0	22.4	56.5	13.2	4.3
Hepatitis C (incident)	181	17.7	57.5	24.9	24.1	3.2	7.5
Hepatitis C (unspecified)	1895	6.6	57.9	35.5	94.2	33.9	2.8
<b>Foodborne diseases</b>							
Campylobacteriosis	4867	2.7	58.2	39.1	98.0	87.6	1.1
Cryptosporidiosis	568	32.6	37.7	29.8	139.4	6.6	21.1
Haemolytic uraemic syndrome	1	100.0	0.0	0.0	0.8	0.0	-
Hepatitis A	95	30.5	62.1	7.4	21.9	1.8	12.0
Listeriosis	15	20.0	60.0	20.0	2.3	0.3	8.1
Salmonellosis (NEC)	1572	14.6	53.3	32.1	173.3	25.9	6.7
Shigellosis	256	62.5	23.4	14.1	120.6	1.9	65.0
SLTEC,VTEC	43	0.0	74.4	25.6	0.0	1.0	0.0
Typhoid	14	0.0	85.7	14.3	0.0	0.4	0.0
<b>Sexually transmissible infections</b>							
Chlamydial (NEC)	6309	27.1	46.9	26.1	1286.3	91.4	14.1
Donovanosis	11	90.9	9.1	0.0	7.5	0.0	243.7
Gonococcal infection	3107	68.9	19.3	11.8	1613.3	18.6	87.0
CGN Syphilis	13	92.3	0.0	7.7	9.0	0.0	-
Syphilis	634	78.5	10.9	10.6	375.3	2.1	175.9
<b>Vaccine preventable diseases</b>							
Haemophilus influenzae type b	11	63.6	36.4	0.0	5.3	0.1	42.6
Influenza (laboratory confirmed)	891	5.1	21.2	73.7	33.9	5.8	5.8
Measles	2	0.0	50.0	50.0	0.0	0.0	0.0
Mumps	24	8.3	62.5	29.2	1.5	0.5	3.2
Pertussis	739	4.5	67.3	28.3	24.9	15.4	1.6
Pneumococcal disease(invasive)	456	19.5	72.8	7.7	67.1	10.3	6.5
CGN Rubella	1	0.0	100.0	0.0	0.0	0.0	0.0
Rubella	9	0.0	55.6	44.4	0.0	0.2	0.0
Tetanus	1	0.0	100.0	0.0	0.0	0.0	0.0
<b>Vector borne diseases</b>							
Barmah Forest virus infection	65	7.7	55.4	36.9	3.8	1.1	3.4
Dengue	58	0.0	79.3	20.7	0.0	1.4	0.0
Malaria	65	0.0	86.2	13.8	0.0	1.7	0.0
Murray Valley encephalitis	2	0.0	50.0	50.0	0.0	0.0	0.0
Ross River virus infection	232	9.9	54.3	35.8	17.3	3.9	4.4
<b>Zoonoses</b>							
Brucellosis	1	0.0	100.0	0.0	0.0	0.0	0.0
Leptospirosis	8	0.0	87.5	12.5	0.0	0.2	0.0
Ornithosis	11	0.0	81.8	18.2	0.0	0.3	0.0
Q fever	47	4.3	72.3	23.4	1.5	1.1	1.4
<b>Other bacterial infections</b>							
Legionellosis	124	3.2	71.8	25.0	3.0	2.8	1.1
Leprosy	3	66.7	33.3	0.0	1.5	0.0	48.7
Meningococcal infection	107	13.1	78.5	8.4	10.5	2.6	4.1
Tuberculosis	136	18.4	77.2	4.4	18.8	3.2	5.8

\*Data extracted 10 March 2004 (a) Based on 2001 Census (ABS) (b) Rate ratio is equal to the rate of Indigenous notifications divided by the rate of non-Indigenous notifications and does not include notifications where Indigenous status was not known.

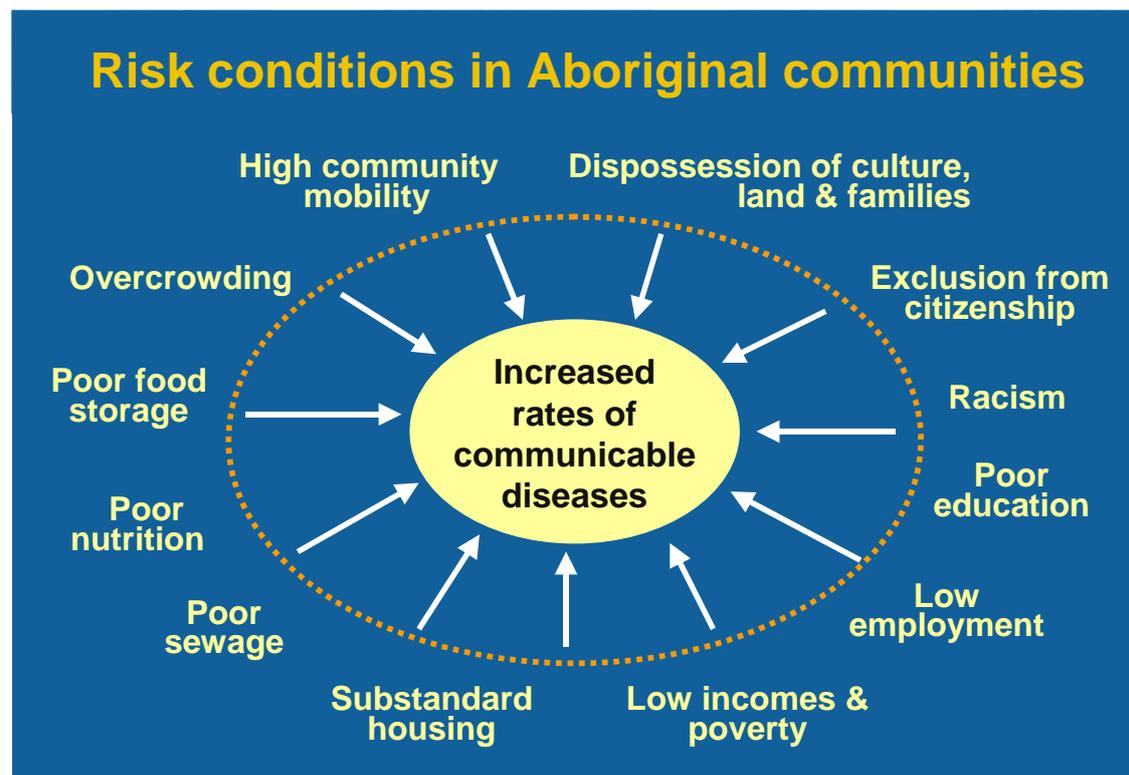
Source: National Notifiable Diseases Surveillance System. A number of communicable diseases and conditions, of public health importance, are nationally notifiable under legislation; data notified to state and territory health authorities by hospitals, general practitioners, pathology laboratories, is forwarded to the NNDSS. The proportion of diseases notified varies across diseases and according to factors such as the seriousness of the condition (less serious cases are less likely to be notified).

The environmental and living conditions contexts need to be considered when examining rates of communicable diseases and the large population rate ratio variations between Aboriginal and Torres Strait Islander and non-Indigenous Australians.

‘There is evidence that Aboriginal and Torres Strait Islander populations suffer a disproportionate impact from both increased exposure to environmental hazards and decreased access to environmental health services. Aboriginal and Torres Strait Islander peoples are more likely to live in conditions considered to be unacceptable by general Australian standards. This includes overcrowding, poorly maintained buildings, high housing costs relative to income, and a lack of basic environmental health infrastructure, such as adequate sanitation, water supplies and appropriate housing.’ (NATSIHC 2003a, p. 6)

A wider range of risk conditions or underlying determinants affecting the health of Aboriginal and Torres Strait Islander communities expands the context for actions to prevent and treat communicable diseases. An example of the range of contextual factors is shown in Box 1 below (Black 2004).

**Box 1 An example of contextual factors (Black 2004)**



Source: Black, M 2004, 'Communicable diseases in Aboriginal communities', NSW Health, Sydney.

About 2.4% of Australia's total population<sup>1</sup> self-identified as being 'of Aboriginal or Torres Strait Islander origin' in the 2001 Census, with the largest numbers (and proportions of the total Aboriginal and Torres Strait Islander population) living in New South Wales, Queensland, Western Australia and the Northern Territory as shown in Table 3 below (ABS 2004). People of 'Aboriginal origin only' made up around 90% of the total Aboriginal and Torres Strait Islander population, while people of 'Torres Strait Islander origin only' were around 6%, and people of 'Both Aboriginal and Torres Strait Islander origin' around 4% of this total. The number of Torres Strait Islanders in the Torres Strait Area was estimated at around 6,900 (about 24% of the Torres Strait Islander population of Queensland or 14% of all Torres Strait Islanders in Australia) (ABS 2003).

**Table 3 Aboriginal and Torres Strait Islander population\* by jurisdictions (ABS 2004)**

	Total population '000	Indigenous population		
		Number '000	Proportion of state & territory population %	Proportion of total Indigenous population %
New South Wales	6,575.2	134.9	2.1	29.4
Victoria	4,804.7	27.8	0.6	6.1
Queensland	3,628.9	125.9	3.5	27.5
South Australia	1,511.7	25.5	1.7	5.6
Western Australia	1,901.2	65.9	3.5	14.4
Tasmania	471.8	17.4	3.7	3.8
Northern Territory	197.8	56.9	28.8	12.4
Australian Capital Territory	319.3	3.9	1.2	0.9
<b>Australia (a)</b>	<b>19,413.2</b>	<b>458.5</b>	<b>2.4</b>	<b>100.0</b>

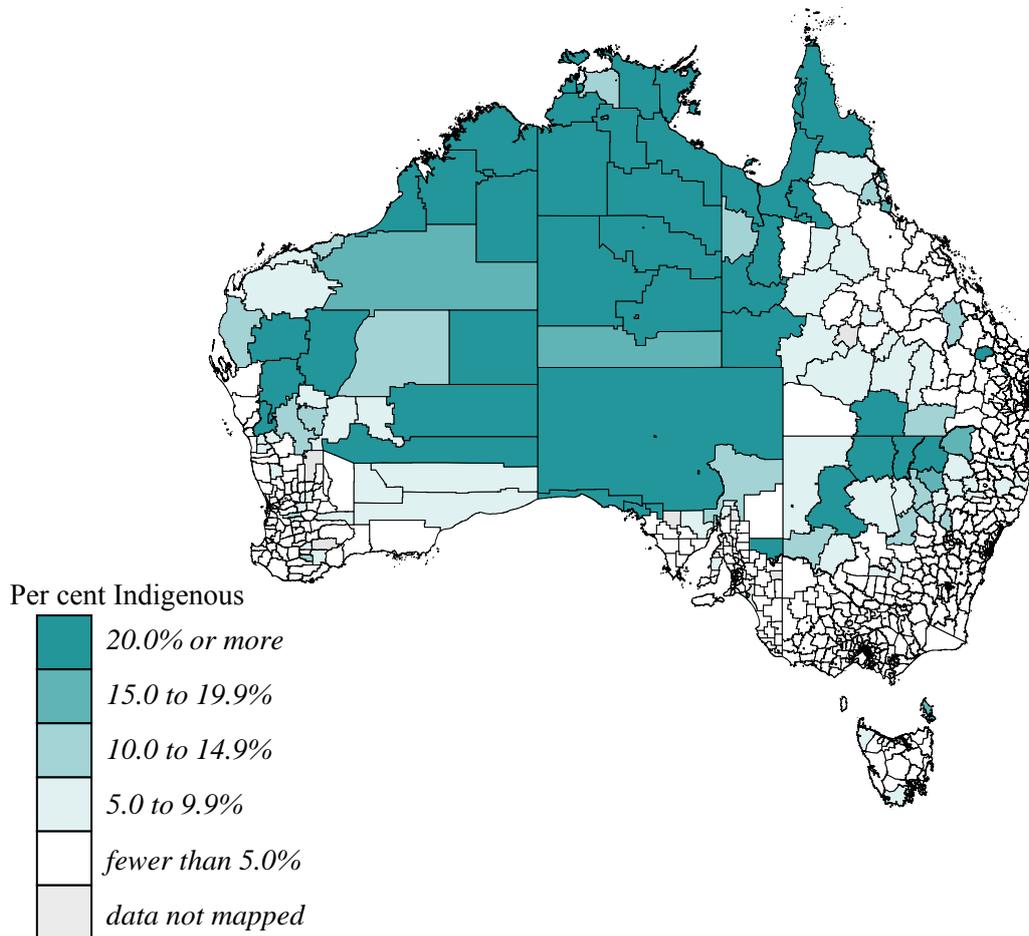
(a) Includes Other Territories.

\* estimated resident population

Most of the Australian population is concentrated along the eastern and southwest coasts in the most densely settled areas of the continent. Aboriginal and Torres Strait Islander peoples are more widely spread in areas covering most of the continent, reflecting their lower level of urbanisation (30% compared to 67% non-Indigenous), and the greater likelihood of Aboriginal and Torres Strait Islanders to live in very remote areas (ABS 2004).

<sup>1</sup> Estimated resident population, derived from the Census 2001. ABS notes that the 'Indigenous origin question is more comprehensively answered than most other Census variables. Nevertheless, the question non-response rate for Indigenous status has increased slightly from 1.7% in the 1996 Census to 2.0% in 2001. Some of the people who did not have a response provided for them will be Indigenous, although the proportion that is actually Indigenous is not known' (ABS 2002).

**Map 1 Distribution of Aboriginal and Torres Strait Islander Population (ABS, PHIDU)**



*Source: data ABS; map PHIDU.*

Aboriginal and Torres Strait Islander people are far less likely to live in the Major Cities areas (with 30.1% in these areas compared with 65.5% for the total Australian population), and much more likely to live in the remote areas (28.0% in the combined Remote plus Very Remote classes, compared with 3.0%) or in regional areas, in particular areas in the Outer Regional class (23.2% compared with 10.0%) (Glover et al. 2004).

The proportion of Aboriginal and Torres Strait Islanders in the total population rises with increasing geographic remoteness - from 1% of the total population living in Major Cities to 45% in areas that were Very Remote (ABS 2003). This differential distribution is shown in the map above.

Access to health services is proportionally more difficult for Aboriginal and Torres Strait Islander people living in remote areas in comparison to their non-Indigenous counterparts, and therefore, the overall availability of health information is affected.

## **1.2 Project background**

In 1997 *The Aboriginal and Torres Strait Islander Health Information Plan... This time, let's make it happen* recommended that 'all major health and related collections include accurate Indigenous identification', an Indigenous identification field be included in all future health collections, and that a 'single classification standard' be used 'throughout all jurisdictions and health services' (ATSIHWIU 1997, p. 34). That standard - the National Health Data Dictionary - was then in version 6 (the current version is 10) but the ABS standard question 'for seeking the Indigenous status of clients' remains the same (ABS 1999).

In 2003 all Health Ministers signed the National Strategic Framework for Aboriginal and Torres Strait Islander Health. The first recommendation is to 'Implement the 1997 *National Aboriginal and Torres Strait Islander Health Information Plan*'<sup>2</sup> including the Australian Bureau of Statistics (ABS) standard for Aboriginal and Torres Strait Islander identification in all data collections (NATSIHC 2003a, b).

This Discussion Paper was produced from August 2003 to June 2004 under the guidance of the Improving Indigenous Identification in Communicable Disease Reporting Project (IIICDRP) Steering Committee and through the participation of many people, of Aboriginal and Torres Strait Islander and non-Indigenous origins.

This document offers information on the current situation of Indigenous identification in communicable disease reporting in all jurisdictions and nationally. It has been produced in association with jurisdictionally nominated contact officers and incorporates the views of key stakeholders from interviews and surveys. Information was collected on a range of issues including: limitations in the current situation; the benefits of improving Indigenous identification in communicable disease reporting; options to improve (including a summary of options previously identified in the literature survey); as well as views on barriers to, and opportunities for, a consistent national approach.

The IIICDRP Steering Committee has identified recommendations for action in the short (over 1-2 years), medium (over 2-4 years) and long term (over 4-6+ years) that detail the strategies and initiatives that are required to be undertaken by both the Australian Government and jurisdictions to improve the identification of Indigenous status in communicable diseases. These recommendations incorporate the views, opinions and advice that have been provided in the processes of working with the jurisdictions, interviewing and surveying stakeholders, and in preparing this Discussion Paper.

## **1.3 Project Overview**

The role of the *Improving Indigenous Identification in Communicable Disease Reporting Project* (IIICDRP) is to:

develop a Draft Discussion Paper with recommendations to the Department of Health and Ageing for future action to improve Indigenous identification in communicable disease reporting systems.

The IIICDRP Steering Committee's Terms of Reference state that: 'the process implemented to develop the discussion paper will foster Indigenous ownership and self-

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<sup>2</sup> Aboriginal and Torres Strait Islander Health and Welfare Information Unit, *The Aboriginal and Torres Strait Islander Health Information Plan*, Australian Health Ministers' Advisory Council and Australian Institute of Health and Welfare, Canberra 1997.

determination. Although the scope of the project focuses specifically on one area of Indigenous health and well-being (namely, improving Indigenous identification in communicable diseases reporting), its overarching aim is to improve the health and general well-being of Indigenous people, and will therefore be clearly viewed within this wider aim.’

The project Auspice is the National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID). Associate Professor Ted Wilkes (Professorial Fellow in Aboriginal Health with the Centre for Developmental Health at Curtin University, in conjunction with the Telethon Institute for Child Health Research) represents NAGATSIHID on the IICDRP Steering Committee.

The IICDRP Steering Committee has a majority representation of Aboriginal and Torres Strait Islander Australians, is chaired by an Indigenous Australian, Ms Debra Reid, Office for Aboriginal and Torres Strait Islander Health (OATSIH) and members include representatives of: the National Aboriginal Community Controlled Health Organisation (NACCHO); Queensland Health; Indigenous Australians’ Sexual Health Committee (IASHC); Population Health Division, Australian Government Department of Health and Ageing (PHD, DoHA); the Torres Strait Islander Advisory Board (TSIAB); NSW Health; NT Health; and the Communicable Diseases Network of Australia (CDNA).

Project reporting is to NAGATSIHID and NPFIWG. The project Secretariat is provided by the Public Health Information Development Unit (PHIDU), The University of Adelaide and is funded by PHD, DoHA.

## **1.4 Project Methodology**

The Draft Discussion Paper was developed through input and advice from the IICDRP Steering Committee, which met monthly by teleconference and was supported by the PHIDU research officer. Four methods were used to investigate the issues:

- a survey of relevant literature reported since 1997 to identify key material to use as background documentation and to brief the Steering Committee;
- work with jurisdictions through their nominated Contact Officers assisting the Steering Committee with up-to-date information on the current situation in their jurisdictions;
- interviews and surveys with key stakeholders with the primary stakeholder for the Project identified as Aboriginal and Torres Strait Islander stakeholders
- preparation of the draft Discussion Paper (3 drafts) and early release for comment to participating stakeholders, endorsement by NAGATSIHID, and final version endorsed by the Steering Committee before presentation to DoHA.

These components of the project methodology are described in more detail in Appendix C *Project Methodology*.

## **1.5 Scope and definitions**

Definitions of important terms and concepts follow.

### ***Communicable diseases***

In general discussions with stakeholders and others, there was a tendency to interpret ‘communicable diseases’ as equivalent to ‘notifiable communicable diseases’ – those diseases that a pathologist and/or a medical practitioner is required to report to state health authorities so that they can take any necessary public health actions in response. (Nationally notifiable communicable diseases are shown in Box 6 in Section 2.2 *Situation nationally*.) The Steering Committee debated the inclusion of *non-notifiable* communicable diseases and the effect these had on the Aboriginal and Torres Strait Islander population determining that they should be included in the scope of the project. The main focus, however, is on notifiable communicable diseases.

### ***Use of ‘Indigenous’ to mean Aboriginal and Torres Strait Islander***

Discussions with Steering Committee Members and with stakeholders revealed that there was a preference for the term ‘Aboriginal and Torres Strait Islander peoples/Australians’ rather than ‘Indigenous peoples/Australians’. Although both terms are used in this Discussion Paper, ‘Aboriginal and Torres Strait Islander peoples/Australians’ has been preferred. Where the term ‘Indigenous’ is used (for instance, in the title of this Discussion Paper, in quoting other people, or in program names) it should be understood as referring to Aboriginal and Torres Strait Islander peoples.

### ***Use of ‘Indigenous identification’ and ‘Indigenous status’***

The term ‘Indigenous identification’ is used to refer to the entire process by which health care users are asked to self-identify as being of Aboriginal and Torres Strait Islander origin, and their identification is recorded and reported in health information systems. The resulting data item is known as ‘Indigenous status’.

### ***Indigenous identification – the ABS standard***

Box 2 below provides an overview of the Australian Bureau of Statistics (ABS) standard question on Indigenous identification, as set out in the National Health Data Dictionary (data element *Indigenous status*), which details data categories, standard outputs and the relationship to the ‘Australian Government working definition’ (ABS & AIHW 2003).

## Box 2 ABS standard question on Indigenous identification (ABS & AIHW 2003)

In 1995, the ABS formally adopted the following question as the standard for identifying persons as members of the Indigenous population:

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

The categories expected to be used in collecting Indigenous status data are derived from the answers to the relevant question in the question module, but include the supplementary category 'Not stated/inadequately described', where applicable:

1. No
2. Yes, Aboriginal
3. Yes, Torres Strait Islander
4. Not stated/inadequately described

However, these 'input' categories do not include the category 'Both Aboriginal and Torres Strait Islander Origin' because that category is defined when both the 'Yes' boxes are ticked. When this occurs the results are amalgamated and appear in the standard output.

The 'output' categories are the same as the categories agreed for use in the collection protocol for Indigenous status in the National Health Data Dictionary and the National Community Services Data Dictionary, and create the following output data:

1. Aboriginal but not Torres Strait Islander origin
2. Torres Strait Islander but not Aboriginal origin
3. Both Aboriginal and Torres Strait Islander origin
4. Neither Aboriginal nor Torres Strait Islander origin
5. Not stated/inadequately described

The ABS standard question is based upon the 'Australian Government working definition' but does not include the third element of the Australian Government definition, namely that 'an Aboriginal or Torres Strait Islander is a person who is accepted as such by the community in which he or she lives'. Collecting information on the basis of community acceptance is often impractical and can lead to inaccuracies, and for these reasons it is not included in the ABS standard.

Source: ABS & AIHW 2003, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, ABS Cat. No. 4704.0, ABS, Canberra, p. 227.

## **2 Indigenous identification in communicable disease reporting systems**

Systems for communicable disease reporting (notifications) differ around the country and are increasingly reliant on pathology-based reporting. Notification of communicable diseases is a jurisdictional responsibility, with medical practitioners and/or pathology laboratories required to report certain communicable diseases to State/Territory health authorities. These authorities are responsible for addressing outbreaks, infection control, and other public health responses to communicable diseases in the population.

The current varying situations for Indigenous identification in communicable diseases reporting systems across the jurisdictions and nationally are described in this section. A range of agreements and stated national objectives related to the collection of Indigenous identification data in communicable disease reporting systems is also reported.

### **2.1 Situation in the States and Territories**

Up-to-date information on the current situation for Indigenous identification in jurisdictional communicable disease reporting systems was sought and received from all States and Territories through jurisdictionally nominated Contact Officers assisting the Project.

The current practices/situations of the eight States and Territories vary with regard to:

- (1) legislation enabling the collection and reporting of communicable disease information,
- (2) who collects Indigenous identification and how it is collected,
- (3) whether collection and reporting to the ABS standard is fully implemented, and
- (4) Indigenous identification data completion rates and recent improvements in rates.

#### ***Best practice***

From a national perspective, the jurisdictions are crudely assessed against a set of possible measures of best practice (shown in Table 4, following), to provide an overview of important variables and differences in data collection and communicable disease notification practices.<sup>3</sup> If the desired end result is for Indigenous identification in communicable diseases to be reported nationally (i.e. jurisdictions with an overall Indigenous identification completion rate above 50%), there are three jurisdictions that currently meet this standard. (Note that Victoria was also rapidly approaching the reporting standard in 2003.)

The Northern Territory is notable for having both the highest Indigenous identification completion rate (92% in 2002) and for its use of data matching with the hospital information system for nearly all notifications. South Australia is distinguished both by its relatively high Indigenous identification completion rate (72% in 2002) and in having the highest proportion of communicable disease notified by medical practitioners.

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<sup>3</sup> See Adams, J et al. 2004 for an assessment of best practice guidelines for collecting data on Indigenous status at a health service level.

**Table 4 Best practice in the jurisdictions**

State or Territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Legislated authority/requirement to collect Indigenous identification in communicable disease notifications	-	✓	-	-	✓	✓	-	☐
Indigenous identification required for <i>all</i> notifiable communicable diseases	✓	✓	✓	✓	✓	✓	-	✓
Proportion notified by medical practitioners*	10%	60%	1-5%	66%	75%	5-10%	5%	5-10%
ABS standard collected by CDUs from primary data collectors (medical practitioners)	-	✓	✓	-	✓	✓	-	✓**
ABS standard reported (by CDUs to NNDSS)	-	✓	✓	-	✓	✓	-	-
Data matching with hospital information system (nearly all notifications)	-	-	-	-	-	-	-	✓
Indigenous identification completion rate above 50% in 2002 (able to be reported nationally)	-	-	-	55%	72%	-	-	92%

\* Proportion (estimate) notified by medical practitioners that could potentially report Indigenous identification in the first instance.

\*\* Hospitals only, not on CDU notifications.

CDU = Communicable disease units in the States and Territories. NNDSS = National Notifiable Disease Surveillance System.

### **Legislation**

The two jurisdictions (Northern Territory and Victoria) that have revised their legislation since 1999 both included changes to require reporting of Indigenous identification. South Australia has broad authority to collect information of relevance (and has implemented Indigenous identification in notification forms and data systems). Tasmania has similar indirect authority, expressed in guidelines. Improvements in Indigenous identification completion rates have been especially noticeable in Victoria (see Table 8) as the Northern Territory already had relatively high completion rates. Western Australia anticipates changing their legislation in 2004 to mandate the notification of communicable diseases by pathologists (currently reporting on a voluntary basis). This would include the requirement to report Aboriginality (as per the notification form), although it is recognised that pathologists currently do not collect or hold information on Indigenous identification and so are unable to report it. Queensland also plans changes to its legislation and may consider including the requirement for Indigenous identification in notifications of communicable diseases.

There is currently no national legislation that requires jurisdictions to adopt one model or a set standard; each must introduce legislation separately and inevitably differences arise.

**Table 5 Legislation across jurisdictions**

State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
<b>Legislation enabling collection and reporting of communicable disease information</b>	Public Health Act 1991 and Regulations	Health (Infectious Diseases) Regulations 2001	Health Act 1937 and Health Regulations	Health Act (1911)	Public and Environmental Health Act (1987)	Public Health Act 1997 and guidelines (2003)	Public Health Act 1997	Notifiable Diseases Act 1999
<b>Legislation includes reporting of Indigenous identification</b>	No	Yes	No but considering	No but planned for 2004	Yes, indirectly (determined by Dept)	Yes, indirectly (in guidelines)	No	Yes
<b>Changes made since 1997 that impact on Indigenous identification.</b>	Nil known	2001, mandated GPs to report Indigenous status (was voluntary)	Nil	Nil		None	Nil	1999 - legal requirement to report 'Aboriginal / Non-Aboriginal' with disease notifications
<b>Future changes planned to include Indigenous identification.</b>	Nil known	No changes	Currently revising legislation in the Public Health Bill 2004	Yes – early 2004 - A Health Amendment Bill will specify that practitioners and laboratories should notify information as appears on relevant notification forms including Aboriginality.	None planned	None	Nil	Changing 'Aboriginal/non-Aboriginal' to 'Indigenous status' in schedule of items collected.

### ***Who notifies***

All jurisdictions receive communicable disease notifications from medical practitioners and/or pathology laboratories. However, as the following table describes, most jurisdictions rely mostly on ‘pathology-based’ reporting systems with more than 90% of notifiable communicable disease in those jurisdictions reported *solely* from pathology laboratories. The remainder is reported by medical practitioners. Any data on Indigenous identification held by test-requesting medical practitioners and not reported in pathology-based notifications is only available through public health follow-up of practitioners (usually for specified diseases only).

Three States (Victoria, Western Australia, South Australia) have ‘dual reporting’ systems that require medical practitioners (with or without pathology) to notify the majority of communicable diseases (ranging from approximately 60% in Victoria, 66% in Western Australia (where pathologists have additionally been voluntarily notifying for the last few years) to 70% in South Australia). Western Australia observes that adding pathology-based notifications has increased case ascertainment but decreased the Indigenous identification rate.

The term ‘medical practitioners’ includes General Practitioners (GPs) in private practice, and doctors in Aboriginal Medical Services, in prisons, clinicians in hospitals, etc. In most States GPs provide the bulk of notifications from medical practitioners (however that rate varies markedly across States) as is shown in Table 6. Nurse practitioners are not included in the definition of medical practitioners.

Some diseases of particular public health importance are followed up in enhanced surveillance where additional information related to risk is sought from notifying or responsible medical practitioners by communicable disease units in the jurisdictions. Indigenous identification data completion rates can vary greatly by disease (except in the Northern Territory). Diseases that are followed up (to collect supplementary information) generally have higher Indigenous identification completion rates in most jurisdictions as this information is sought if it is not already held.

Information from the random sample of GPs and their clients in the BEACH study suggests that Aboriginal and Torres Strait Islander clients (at about 1% of all clients) are ‘clearly’ under-reported by GPs. However, when the question is asked in the context of a series of questions about origin, around 2.2% of patients identify as being of Aboriginal or Torres Strait Islander origin (Britt et al. 2003, p. 135; see Box 3 below).

#### **Box 3 Some lessons from BEACH and SAND – identification data from GPs**

“[BEACH] annual estimates on the proportion of all GP encounters with Indigenous people (around 1% per annum) are clearly an under-representation. *The SAND substudy found that if the question is asked of the patient within the context of a series of questions about origin, 2.2% will identify as Aboriginal or Torres Strait Island people.* It is possible that where GPs are offered a simple yes/no tick box for this question at every encounter, they often do not ask the patient the question. However, there is remarkable consistency in the age–sex distribution of these patients each year, and in the patterns of problems managed. These patterns also reflect what is known from other sources about the prevalence of certain diseases in the Indigenous population. Therefore, while the reader should keep the *under-representation* of these encounters in mind, there is *no reason to believe it is biased in any consistent way.*” [our emphasis]

Source: Britt et al. 2003, *General practice activity in Australia 2002–03*, AIHW, Canberra, p. 135.

A recent Queensland Health study (2003a) found that while there was high acceptability for the Indigenous identification question (survey responses and focus group discussions), service providers were still concerned about the 10-16% of people who 'disliked the question'. Another recent study at a Sydney hospital found that only 1% of non-Indigenous women objected to being asked the question (Jackson Pulver et al. 2003).

**Box 4 GPs and Indigenous identification (Brisbane North Div GP 2003)**

The Brisbane North Division of General Practice conducted a survey in 2003 of the large group of GPs it supports (over 700 GPs). Of the 195 (28%) GPs which responded to the survey 62% had at least one Indigenous client and the average was eight Indigenous clients. Of this group of GPs, 40% reported that they used Indigenous identifiers. The reasons offered for not using identifiers included:

- feeling uncomfortable
- not knowing who to ask
- identifiers not being necessary
- identifying these patients seen as discriminatory
- no place on patient record/medical software to record this.

Source: Brisbane North Division of General Practice 2003, Survey, unpublished data.

General practice software offers some facility to collect Indigenous identification in terms of patient demographics, but does not appear to meet the national standard (see Box 2).

Pathology reporting in almost all jurisdictions does not include Indigenous identification. Medical practitioners may collect this information but it is not passed on in requests for pathology tests. Two jurisdictions have linked/can match public pathology data with hospital patient registration systems to improve Indigenous identification rates in public hospital data. Private pathology remains outside these systems. In most states a few pathology companies do the majority of tests. There is increasing corporatisation of private pathologists into 'federations' that plan to, or do, share corporate IT systems. There are some moves to enhance electronic data transfer (both from GPs to pathology laboratories, and from pathology laboratories to state communicable disease units (notifications). It is not known how many of these initiatives meet national health information standards.

**Table 6 Who collects and how collected**

State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
<p><b>How and by whom is notifiable communicable disease reported?</b></p> <p><i>estimates of proportional data inflows (note that these are <u>overall</u> estimates whereas actuals are disease dependent)</i></p>	<p>Pathology laboratories: 90%</p> <p>Medical practitioners: 10%</p>	<p>Both medical practitioners &amp; laboratories: 50%</p> <p>Medical practitioners: 10%</p> <p>Pathology laboratories: 40%</p>	<p>Pathology laboratories: 99%</p> <p>Medical practitioners: &lt;1-5%</p>	<p>Both medical practitioners &amp; laboratories: 33%</p> <p>Medical practitioners: 33%</p> <p>Pathology laboratories: 30-40%</p>	<p>Both medical practitioners &amp; laboratories: 70%</p> <p>Medical practitioners: &lt;5%</p> <p>Pathology laboratories: 25-30%</p>	<p>Pathology laboratories: 90-95%</p> <p>Medical practitioners: 5-10%</p>	<p>Pathology laboratories: 95%</p> <p>Medical practitioners: 5%</p>	<p>Pathology laboratories: 90-95%</p> <p>Medical practitioners: 5-10%</p>
<p><b>How and by whom is Indigenous identification data collected for notifiable communicable diseases?</b></p>	<p>GPs &amp; other medical practitioners notifying</p>	<p>GPs &amp; other medical practitioners notifying.</p>	<p>GPs &amp; other medical practitioners notifying.</p> <p>Public pathology lab provides this data routinely in recent years querying hospital systems data missing from pathology request form.</p>	<p>GPs &amp; other medical practitioners notifying.</p> <p>Potential for data matching/sharing with hospital patient register to provide additional Indigenous identification.</p>	<p>GPs &amp; other medical practitioners notifying.</p> <p>CDCU follow up missing II with notifying Dr for meningococcal &amp; pneumococcal diseases; &amp; by STD Services for gonococcal infection, HIV, chlamydia infection, syphilis, hepatitis B &amp; C.</p>	<p>Public health officers send out follow-up standard questionnaires to medical practices.</p>	<p>Public health officers collect from GP or patient during follow-up investigations.</p>	<p>Data matching with hospital information system (nearly all notifications).</p> <p>Notifying medical practitioners.</p> <p>Enhanced surveillance followed up by other means.</p>
<p><b>Communicable disease reporting systems that do not collect Indigenous identification data.</b></p>	<p>Laboratory reporting systems</p>	<p>Laboratory reporting systems</p>	<p>Private laboratory reporting systems</p>	<p>Laboratory reporting systems</p>	<p>Laboratory reporting systems</p>	<p>Laboratory reporting systems</p> <p>GPs &amp; other medical practitioners notifying CDs</p>	<p>Laboratory reporting systems</p> <p>GPs &amp; other medical practitioners notifying CDs</p>	<p>Laboratory reporting systems</p>

### ***Implementation of the ABS standard question***

Five jurisdictions have implemented the ABS Indigenous identification standard in communicable disease notifications (four can currently record it in the standard categories, one will be able to after system changes; there are subtle differences – see Table 7 following). Most jurisdictions require some form of Indigenous identification data to be reported for *all* notifiable communicable diseases, with the exception of Tasmania and the Australian Capital Territory which require it only for selected diseases. Tasmania and the Australian Capital Territory collect Indigenous identification in follow-up for a small number of diseases requiring enhanced surveillance and further investigation.

Although most of the training and audit effort to date on Indigenous identification in the health system has been concentrated on hospitals, and the quality of hospital data has improved over time, only three jurisdictions (the Northern Territory, South Australia, and Western Australia) reported satisfactory Indigenous status in hospital separations data for 2001-2002 (AIHW 2003, p. 123). This was however an improvement on 1999-2000 when only two jurisdictions (the Northern Territory and South Australia) reported acceptable Indigenous status (Lehoczky et al. 2002, p. 62). Improvements in hospital data quality are attributed to the use of the *National Health Data Dictionary* definitions by all jurisdictions (AIHW 2003, p. 123).

The National Health Data Dictionary (NHDD) data element ‘Indigenous status’ is based on the ABS standard for Indigenous status (ABS 1999). The standard question form is:

[Are you] [Is the person] [Is (name)] 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

‘It is strongly recommended that the question be asked directly wherever possible. The question must always be asked regardless of data collectors’ perceptions based on appearance or other factors’ (ABS 1999).

The classification for *Indigenous status* has two levels.

Indigenous:

- Aboriginal but not Torres Strait Islander Origin
- Torres Strait Islander but not Aboriginal Origin
- Both Aboriginal and Torres Strait Islander Origin

Non-indigenous:

- Neither Aboriginal nor Torres Strait Islander Origin

The additional category of ‘Not stated/ inadequately described’ is not a valid response, but is intended for use: when importing un-mappable data from other collections; where an answer was refused; or where the question was unable to be asked for some reason (e.g. the person was unable to communicate or someone who knew the person was not available) (ABS 1999).

See Box 2 for an overview of the ABS standard question, response and output categories.

Further information:

The (AIHW 2004) National Health Data Dictionary data element *Indigenous status* is at: <http://meteor.aihw.gov.au/content/index.phtml/itemId/291036> (viewed 13 December 2005).

The ABS standard (the source of the National Health Data Dictionary data element *Indigenous status*) is: Australian Bureau of Statistics 1999, *Standards for Social, Labour and Demographic Variables: Cultural Diversity Variables: Indigenous Status*, [Statistical Concepts Library] ABS, Canberra, viewed 13 December 2005, <http://www.abs.gov.au/Ausstats/abs%40.nsf/66f306f503e529a5ca25697e0017661f/204de801c48453e4ca25697e0018fe46!OpenDocument>.

**Table 7 Whether ABS Standard question implemented**

State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
<b>Communicable disease reporting systems that <i>do</i> collect Indigenous identification data.</b>	HIV/AIDS database (records HIV & AIDS notifications only).  Notifiable Diseases Data System (NDD) (records all other notifiable infectious diseases).	Notifiable Infectious Diseases Surveillance System.	Notifiable diseases surveillance system (NOCS) records indigenous status where provided. Reasonable data is available for specific diseases (with follow-up of patient details) including: invasive pneumococcal & meningococcal, pertussis <5s (all pertussis in N Qld), measles, HIV/AIDS, tuberculosis, hepatitis A, syphilis.	Notifiable diseases system – all diseases (including enhanced surveillance for selected diseases e.g. HIV/AIDS, gonococcal infection, Hepatitis C, pneumococcal disease, invasive Haemophilus influenzae type B [Hib] infection, TB and others).	Notifiable Diseases Database Management System (NDDMS).	Only collected for those diseases that require follow-up investigation: Hepatitis B & C, HIV, Streptococcal pneumonia, Tuberculosis, Gonorrhoea, Meningococcal, Chlamydia, Syphilis.	Only collected for those diseases that require follow-up investigation, eg HIV, acute Hepatitis C, vaccine preventable diseases.	Centre for Disease Control (CDC) notifiable disease database.
<b>Whether ABS standard collected/recorded</b>	No	Yes	Yes	No	Yes	Yes	No	Yes in hospitals Will be recorded from 01/07/04
<b><i>Detail the Indigenous identifier that is collected.</i></b>	Aboriginal or Torres Strait Islander - Yes/No/Unknown  Both databases currently under review	ABS standard recorded as: 1. No 2. Yes, Aboriginal 3. Yes, Torres Strait Islander 4. Yes, both Aboriginal and Torres Strait Islander	Aboriginal, Torres Strait Islander, Both Aboriginal and Torres Strait Islander, Neither Aboriginal or Torres Strait Islander, Unknown	Doctors form: 'Ethnicity' - Aboriginal/TSI or other.  Enhanced surveillance form: 'Ethnicity' (most commonly) Aboriginal/Non-Aboriginal/Unknown.  HIV/AIDS form: 'Aboriginal' - Yes/No/Unknown	1. Indigenous – Aboriginal but not TSI origin 2. Indigenous – TSI but not Aboriginal origin 3. Indigenous – Aboriginal and TSI origin 4. Not Indigenous 5. Not stated Considering breaking 5 into: 5A – field on form completed, versus 5B – field not completed.	ABS standard	Aboriginal or Torres Strait Islander	ABS standard collected; currently recorded as:  Indigenous status - Aboriginal/ Non-Aboriginal/ Unknown.  From 01/07/04 will record Indigenous status in the ABS format

### ***Indigenous identification completion rates***

In 2002, jurisdictional completion rates overall (for all communicable diseases notified) ranged from 26% (New South Wales and Queensland) to 92% (Northern Territory) (note that Australian Capital Territory and Tasmania could not report). Most jurisdictions have recorded, and continue to record, improvements in their Indigenous identification completion rates (e.g. Queensland improved from 15% in 1998 to 32% in 2003, Victoria from 19% in 1999 to 46% in 2003, South Australia from 46% in 1996 to 73% in 2003, and the Northern Territory from 87% in 1997 to 92% in 2002). New South Wales reports no change and Western Australia reports a decrease in line with increased pathology notifications (see Box 5 below).

Indigenous identification completion rates are highly variable across diseases as well as jurisdictions.

The National Notifiable Disease Surveillance System (NNDSS) only reports communicable diseases by Indigenous and non-Indigenous status where the Indigenous identification completion rate in the jurisdiction is above 50%. In 2002, there were three jurisdictions that achieved a 50% or higher completion rate, and these were: Western Australia, South Australia, and the Northern Territory.

Nationally, Indigenous identification rates are generally higher overall for sexually transmissible infections, vaccine preventable and certain other diseases (usually of low case numbers) that are followed up in enhanced surveillance, with most States and Territories reporting cases achieving a 50% or more Indigenous identification rate.

#### **Box 5 Situation summary illustrating the impact of pathology-notified cases**

“The following is a brief description of the epidemiology of hepatitis C in WA from 1990 to 2000. The total number of hepatitis C (incident + unspecified disease status) notifications in WA remained fairly stable from 1993 to 1999 at around 1,200 cases per year. *More than 1,800 cases were notified in 2000, following the addition of laboratory-notified cases, which suggests there had previously been substantial under-notification by diagnosing doctors.* ... Since hepatitis C became a notifiable disease in 1993, notifications have predominantly been reported from the Perth metropolitan area (on average, 72% of all notifications). The crude notification rate in WA in 2000 was three times greater in Aboriginal than in non-Aboriginal people (rate ratio = 3:1), but these results must be *interpreted with caution as the Aboriginal status of 63% of notified hepatitis C cases in 2000 was unknown.*” [our emphasis]

Source: Atthowe JM, Thompson SC, Giele CM 2003, *The Epidemiology of Notifiable Sexually Transmitted Infections and Blood-Borne Viruses in Western Australia 1990 to 2000*, Department of Health, Perth, Western Australia.

### ***Initiatives***

All jurisdictions have implemented and/or plan to implement a range of initiatives to improve Indigenous identification in communicable disease reporting or related reporting systems. Information on jurisdictional continuous improvement activities and initiatives can be found in Appendix G.

**Table 8 Indigenous identification data completion rates**

State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
<b>Proportion &amp; number of communicable disease notifications that include Indigenous identification data in 2002 (completion rate)</b>	26% 7,935 of 30,501 notifications	44% 10,305 out of 23,489 notifications	26%	55% 6,697 of 12,115 notifications	72% 4,005 of 5,579 notifications	Results not yet available.	Very few notifications with Indigenous identification were recorded during 2002.	92% 5,831 of 6,350 notifications
<b>How do you establish this proportion?</b>	Aboriginal or Torres Strait Islander =Y+N / Total number of notifications	All less Declined to answer, Not Stated, Question not able to be asked / Total	Proportion of Unknown cases compared with total number of cases	Notifications with Ethnicity information / Total	Reported cases, with Indigenous status set / Total	Indigenous / Total	-	Notifications with Indigenous status recorded / Total
<b>Whether this proportion has changed over time</b>	No	Yes Increase from 19% in 1999 to 46% in 2003.	Yes Increase from 15% in 1998 to 32% in 2003.	Yes Increase in 1990s, decrease from 2000.	Yes Increase from 46% in 1996 to 73% in 2003.	Not known	-	Yes Increase from 87% in 1997 to 92% in 2002.
<b>Reasons for the change/s</b>	No significant change over time.	Legislation enacted in 2001, mandated GPs to report Indigenous status (was voluntary previously).	Improved recording from public system, changes to the data set in 2001, and integration with vaccination register that also records Indigenous status.	Improvement through 1990's in doctor completion of notification forms resulted in improvement in reporting of Aboriginality. Decline overall and for most diseases from 2000 due to inclusion of lab notifications.	Main reason is an acknowledgement within the CDCB that good demographic data (including Indigenous status) are helpful when investigating clusters of cases.	Not known.	-	A substantial reduction in 'unknown' occurred after 1999 may relate to increased attention to recording Indigenous status within hospitals and increased computer access to this information for CDC notifiable disease data entry staff.

## **2.2 Situation nationally**

This section describes Indigenous identification in national communicable disease reporting systems.

### ***The National Notifiable Diseases Surveillance System (NNDSS)***

The States and Territories voluntarily provide information on 66 notifiable communicable diseases of national public health concern, to the National Notifiable Diseases Surveillance System (NNDSS) (see Box 6). For NNDSS overall, there is a low Indigenous identification rate which varies by jurisdiction, by disease, and over time, depending on the processes that individual States and Territories have in place to obtain the information. The low overall completion rate for Indigenous identification reflects the fact that this is not a routine data item in some jurisdictions.

The low overall rate of Indigenous identification in NNDSS also reflects the predominance of passive surveillance of communicable diseases based on pathology notifications in Australia, and the limited capacity to transfer Indigenous identification – along with other demographic details – routinely from requesting medical practitioners to pathology laboratories and on to communicable disease units conducting surveillance and public health responses in the jurisdictions.

There are positives and negatives to the dominance of pathology-based notifications of communicable diseases. On the plus side, total ascertainment of cases is likely to be greater, and laboratory tests are regarded as a more reliable (and definitive) source of data on communicable diseases than clinical examination alone, for the majority of nationally notifiable diseases. On the downside, patient information from laboratories notifying communicable diseases is limited. More detailed or complete data can only be provided by the requesting medical practitioner or the patient. This requires additional activity in ‘enhanced surveillance’ with follow-up calls for additional data, which can be expensive and time consuming for public health staff and medical practitioners.

It must be remembered that States and Territories reporting to NNDSS do so on a voluntary basis. The collection of *national* data has been achieved over time (NNDSS started in 1990) and through the collaboration of the Australian Government and the State and Territory governments through the Communicable Diseases Network of Australia (CDNA). However, as a voluntary system it has no capacity to *require* that (mandatory) standards (such as the ABS standard for Indigenous identification) be met by the States and Territories contributing data to the national system. It takes time for all jurisdictions to reach agreement, and additional time is needed to implement agreed changes; for instance, negotiating the national case definitions took around three years, and for all jurisdictions to achieve the national case definitions will take longer.

### ***NNDSS criteria for a nationally notifiable disease***

The criteria used by NNDSS to determine whether a disease should be nationally notifiable are:

- Feasibility of collection - how easy/hard is it to collect the notification data?
- Priority (State/Territory vs. national policies/interests) - generally collect only diseases that are of national importance
- Immediacy of an intervention that is possible and/or required
- Outbreak potential of the disease
- Potential for new disease control programs or for refinement of existing programs
- Potential for a high-case fatality rate - a high number of people who are infected end up dying from the diseases
- Community/political concerns
- International concern - does the World Health Organisation collect data on this disease?
- Maintenance and evaluation of existing and future communicable disease control programs
- Importance to Indigenous Health (Miller 2004, pp. 18-19).

### ***Nationally notifiable communicable diseases***

In September 2003 the Communicable Diseases Network of Australia (CDNA) endorsed the following list (Box 6) of communicable diseases to be notified nationally. States and Territories are to work 'toward harmonisation' with the national notifiable diseases list.

CDNA explains that: 'Nationally consistent notification of infectious diseases provides data across all Australian States and Territories. These data provide a basis for the development of public health policy, a mechanism for the development of response to communicable disease outbreaks of national significance, and basic information relating to the development and implementation of a communicable disease control policy' (CDNA 2004).

### ***The HIV/AIDS national register***

HIV/AIDS data is reported direct from States and Territories to the National Centre for HIV Epidemiology and Clinical Research (NCHECR). Information is reported in a 'name code' that together with data of birth is sufficient to track unique individuals in the register whilst retaining their privacy and the confidentiality of related data. The data is reported nationally in the NCHECR Annual Report (NCHECR 2003b). NCHECR is widely regarded as a model for quality data collection which includes being able to guarantee privacy and confidentiality while maintaining a register of cases of this major communicable disease. Its negotiated reporting arrangements and strong partnerships with different Aboriginal and Torres Strait Islander organisations in different jurisdictions, and the trust it has built up over the long term, provides an effective learning model for improving Indigenous identification in communicable disease reporting. In 2003, NCHECR reported data by Indigenous status for the first time, identifying differences in patterns of HIV transmission between Aboriginal and Torres Strait Islander and non-Indigenous people that would need to be incorporated into successful prevention strategies (NCHECR 2003b).

**Box 6 Nationally notifiable communicable diseases (as at September 2003)**

Acquired immunodeficiency syndrome (AIDS)	Kunjin virus infection
Anthrax	Legionellosis
Australian bat lyssavirus	Leprosy (Hansen's disease)
Barmah Forest virus infection	Leptospirosis
Botulism	Listeriosis
Brucellosis	Lyssavirus - unspecified
Campylobacteriosis (not notified in NSW)	Malaria
Chlamydia	Measles
Cholera	Meningococcal disease (invasive)
Congenital rubella syndrome	Mumps
Congenital syphilis	Murray Valley Encephalitis virus infection
Creutzfeldt-Jakob disease (CJD)	Pertussis
Cryptosporidiosis	Plague
Dengue fever	Pneumococcal disease - invasive
Diphtheria	Poliomyelitis (wild-type and vaccine-associated)
Donovanosis	Psittacosis (ornithosis)
Flavivirus infection - unspecified	Q fever
Gonococcal infection	Rabies
Haemolytic uraemic syndrome (HUS)	Ross River virus infection
Haemophilus influenzae type B (Hib) infection - invasive	Rubella
Hepatitis A	Salmonellosis
Hepatitis B – newly acquired	Severe acute respiratory syndrome (SARS)
Hepatitis B – unspecified	Shiga toxin- and verocytotoxin-producing <i>Escherichia coli</i> (STEC/VTEC)
Hepatitis C - newly acquired	Shigellosis
Hepatitis C - unspecified	Smallpox
Hepatitis D	Syphilis – infectious (primary, secondary and early latent), less than 2 years duration
Hepatitis E	Syphilis – more than 2 years or unknown duration
Hepatitis - not otherwise specified (not notified in WA)	Tetanus
Human immunodeficiency virus (HIV) – individuals less than 18 months of age	Tuberculosis
Human immunodeficiency virus (HIV) – newly acquired	Tularemia
Human immunodeficiency virus (HIV) - unspecified individuals over 18 months of age	Typhoid fever
Influenza laboratory-confirmed	Viral haemorrhagic fevers (quarantinable)
Japanese Encephalitis virus infection	Yellow fever
	(Source: Australian National Notifiable Diseases <a href="http://www.health.gov.au/internet/wcms/publishing.nsf/Content/cda_surveil-ndss-dislist.htm">www.health.gov.au/internet/wcms/publishing.nsf/Content/cda_surveil-ndss-dislist.htm</a> accessed 13 December 2005.)

## 2.3 Present agreements and stated objectives

There are a number of agreements that may be related to the collection of Indigenous identification data in communicable disease reporting systems. Additional information can be found in Appendix H. Present agreements at a national level include—

The *National Aboriginal and Torres Strait Islander Health Information Plan* (ATSIHWIU 1997) which recommends ‘that all major health and related collections include accurate Indigenous identification’, that an Indigenous identification field be included in all future health collections, and that a ‘single classification standard’ be used ‘throughout all jurisdictions and health services’ (ATSIHWIU 1997, p. 34). That standard - the ABS standard - as documented in the National Health Data Dictionary was then in version 6 (the current version is 10); the ABS standard question ‘for seeking the Indigenous status of clients’ is the same (ABS 1999).

The Australian Government Department of Health and Ageing *Budget 2003-04* (DoHA 2003) states that the ‘Department is committed to raising the health status of Aboriginal and Torres Strait Islander peoples by working in partnership with communities to provide access to high quality comprehensive primary health care and population health programs’. A ‘two pronged’ approach aims to: ‘improve accessibility and responsiveness of the mainstream health system; and provide complementary action through Indigenous specific health programs’. It also states that ‘although many initiatives are coordinated through the Office for Aboriginal and Torres Strait Islander Health (OATSIH), all programs within the Department have a responsibility to meet the specific health needs and circumstances of Indigenous Australians’ (DoHA 2003, p. 201).

*National Strategic Framework for Aboriginal and Torres Strait Islander Health* (NATSIHC 2003a, 2003b) endorsed by Australian, States and Territory governments and signed by all Health Ministers in July 2003, in its *Key Result Area Seven: Data, Research and evidence* ‘aims to develop a more strategic approach to improving information about how well the health sector is meeting the need of Aboriginal and Torres Strait Islander peoples, including data collection, evaluation of interventions and research processes. It aims to ensure that data is consistent, analysed, published and is collected in such a way to enable comparison across jurisdictions. It aims to improve research processes and data collections about Aboriginal and Torres Strait Islander peoples so that they inform approaches to improving Aboriginal and Torres Strait Islander health’ (NATSIHC 2003a, p. 31). The first recommendation is to ‘Implement the 1997 *National Aboriginal and Torres Strait Islander Health Information Plan*’<sup>4</sup> through a number of activities including using the ABS standard for Aboriginal and Torres Strait Islander identification in all data collections.

The *Agreement on Aboriginal and Torres Strait Islander Health* (Framework Agreement). Under a Health Memorandum of Understanding the Framework Agreements have been drawn up between the government of each jurisdiction, the Australian Government, the Aboriginal and Torres Strait Islander Commission and the state or territory affiliate of the National Aboriginal Community Controlled

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<sup>4</sup> Aboriginal and Torres Strait Islander Health and Welfare Information Unit, *The Aboriginal and Torres Strait Islander Health Information Plan*, Australian Health Ministers’ Advisory Council and Australian Institute of Health and Welfare, Canberra 1997.

Health Organisation (NACCHO). The first Framework Agreements were signed between 1996 and 1998, and have since been renegotiated. Essentially ‘process agreements’, they ‘generally bind parties to adhere to certain processes rather than to substantive issues’ (ATNS 2003). The key commitments made by the Framework Agreement partners were to: an increased level of resources allocated to reflect the level of need; joint planning; access to both mainstream and Aboriginal and Torres Strait Islander specific health and health related services which reflect their higher level of need; and improved data collection and evaluation (ATSIC 2001).

NACCHO ‘*Position on Socially Communicable Diseases*’. The ‘salient points’ are: to eliminate socially communicable diseases in Aboriginal peoples; to establish Aboriginal community controlled primary health care services in all Aboriginal communities; and to develop effective socially communicable disease programs as part of the primary health care role of Aboriginal community controlled health services’ (NACCHO 2003).

*National Performance Indicators for Aboriginal and Torres Strait Islander Health* (OATSIH 1998, 2000). These indicators have been agreed to by all governments and reported against since 1997. Revised indicators (2000) were to be used for reporting from 2001 onwards<sup>5</sup> and include an indicator on jurisdictional efforts to improve identification of Indigenous people in administrative data collections (CRCATH [Mackerras] 2000).

The *Public Health Outcome Funding Agreements* (PHOFAs) - bilateral funding agreements between the Australian Government and State and Territory Governments that provide broadbanded funding to States and Territories to meet public health needs and priorities in specific public health program areas. Total Australian Government funding provided under the PHOFAs for 1999-2000 was \$178 million. The eight broadbanded program areas are the: National Drug Strategy; National HIV/AIDS Strategy; National Immunisation Program; BreastScreen Australia; National Cervical Screening Program; National Women's Health Program; National Education Program on Female Genital Mutilation; and Alternative Birthing Program (DoHA 2002).

*Australian Health Care Agreements* - basis for the Australian Government Government’s financial contribution to public hospitals - generally thought of as funding agreements, the Australian Health Care Agreements also have an important role in guiding reform in the public hospital sector.

*National Health Data Dictionary* (AIHW) – sets out the ABS standard and the associated source documents that provide information on the conceptual underpinnings, guidance for data collection and recording, and technical information.

The *National Indigenous Australians’ Sexual Health Strategy* 1996-97 to 1998-99 (NIASHS), launched by the Federal Minister for Health in March 1997, has ‘since become the benchmark by which all Indigenous sexual health programs are evaluated’ (Queensland Health 2003b). The NIASHS has been extended to 2003-04 to match the duration of the fourth *National HIV/AIDS Strategy*. The *Strategy* provides a policy framework for addressing STD control among Aboriginal and Torres Strait Islander people.

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<sup>5</sup> Source: OATSIH website <http://www.health.gov.au/oatsih/pubs/mpi.htm>.

*The National Indigenous Australians' Sexual Health Strategy (NIASHS): Implementation plan for 2001/02 to 2003/04* (IASHC 2002) identifies key action areas and ways to build the capacity of services and organisations, sets out the principles that underpin effective collaboration and proposes recommendations to support shared planning processes under partnership arrangements. A major emphasis is on building the evidence base of good practice through monitoring, research, and reporting and evaluation.

The *National Indigenous Pneumococcal and Influenza Immunisation Program* provides free vaccines to Aboriginal and Torres Strait Islander people through community controlled Aboriginal Medical Services, State/Territory immunisation clinics and General Practitioners, to protect them from two communicable respiratory illnesses, pneumococcal disease and influenza. The Program aims to increase immunisation levels for influenza and pneumococcal disease to reduce the Indigenous community's burden of acute respiratory illness and death.

New Medicare Benefits Schedule (MBS) Item for Well Persons' Health Checks for Aboriginal and Torres Strait Islanders every two years, and *MedicarePlus* - employing an Aboriginal health worker. 'In November 2003, the Australian Government announced a range of initiatives known as *MedicarePlus*. One Practice Incentive Program initiative being implemented as part of the *MedicarePlus* package is the Practice Nurse and Allied Health Worker initiative. The initiative allows for the employment of an Aboriginal health worker in place of or as well as a practice nurse in either a general practice or Aboriginal Medical Service (AMS) (HIC 2004).'

*Indigenous PCR drug testing and replacement program* pays for tests and drugs – jurisdictions have individual agreements with the Australian Government for testing. Jurisdictions may have additional arrangements, e.g. Queensland Health has a program for replacing any drugs used (in formal program, no formal agreement with pathology laboratories) so organisations that use it are encouraged to identify their Aboriginal and Torres Strait Islander clients.

*National Donovanosis Eradication (Elimination) Project, 2001–2004*. Funded by the Australian Government Department of Health and Ageing's Office for Aboriginal and Torres Strait Islander Health (OATSIH) through the *National Indigenous Australians' Sexual Health Strategy* (NCHECR 2003a). (See Box 9.)

### 3 Benefits

Significant benefits could be achieved through improving the quality of Indigenous identification in communicable disease reporting systems. The following major benefits were reported in interviews and surveys with key stakeholders assisting the project (quoted material from stakeholders is shown in *italics*). In summary, benefits include: better health for Aboriginal and Torres Strait Islanders; better data collection leading to better quality data and a clearer picture of communicable diseases affecting Aboriginal and Torres Strait Islander populations; and better use of data to improve actions to address communicable diseases in these populations, and enable the measurement of change over time.

These benefits are reported more extensively below. A variety of specific good news stories where improved data has led to an improved public health response and actual health gains in Aboriginal and Torres Strait Islanders in relation to communicable diseases were attested by stakeholders and conclude this section.

#### *Better health outcomes*

The major benefit anticipated is in health gains for Aboriginal and Torres Strait Islander people (e.g. reductions in health inequalities, increases in health and well-being) and in improving the health of Aboriginal and Torres Strait Islander people by tying data back into action ('closing the surveillance loop' – see Box 8), using the data to improve health (not collecting data for data's sake).

#### *Better quality data*

The benefits of better quality data giving a clearer picture and more certainty regarding data accuracy, should mean increased understanding of communicable diseases and how they impact on Aboriginal and Torres Strait Islander populations and communities. This leads to planning and policy change, development of more appropriate programs and improved resource allocation, timely assessment of emerging issues, and generally better use of information in constructive ways. Specific outcomes include better response to outbreaks, and implementing better treatment programs as well as programs to prevent the spread of communicable diseases.

While there are many notifications for which Indigenous status is unknown, and differential ascertainment of Indigenous status (e.g. across jurisdictions, across diseases), disease rates calculated on the basis of known Indigenous status may be misleading. Better quality and more complete data would mean more accurate calculation of rates of communicable disease for Aboriginal and Torres Strait Islander and non-Indigenous Australians.

Benefits include more accurate information on the burden of disease in Aboriginal and Torres Strait Islander groups and communities rather than inaccurate information through using proxy indicators such as usual residence. The major benefits of improving the quality of Indigenous identification in communicable disease reporting systems are to

*'See the real size of a problem, that is the prevalence of disease e.g. Chlamydia.  
Target appropriate treatments and programs to areas where problems are identified.  
Target PREVENTION.'*

### *Better use of information*

Respondents identified that the fundamental problem is how government uses information. Three main areas of use are identified: program planning, policy development, and service delivery. The real question is how to improve outcomes? One strategy is having better information, for instance, achieving 100% Indigenous identification in the difficult and highly sensitive areas of communicable diseases while safeguarding the privacy and confidentiality requirements of individuals.

Benefits to Aboriginal and Torres Strait Islander people include: better resourcing, better targeting of resource allocation, and more appropriate programs to address communicable disease.

### *An informed partnership*

An informed partnership working together to improve the quality of Indigenous identification in communicable disease information would encourage ownership of the process by Aboriginal and Torres Strait Islanders who have the power of knowledge and of knowing communicable diseases can be treated and fixed. In addition, Aboriginal and Torres Strait Islander people would have the ability to advise jurisdictions on required health policy development through an informed partnership with the Aboriginal and Torres Strait Islander community sector. Organisations would be better able to respond to Aboriginal and Torres Strait Islander health needs when providing health services. An informed partnership would result in better-informed policy makers and program implementers.

### *Improved response, better action*

Effective reporting on Aboriginal and Torres Strait Islanders who present with communicable diseases to medical practitioners and at health services, means faster response times, improved planning data to fund improved programs, and data directly linked to outcomes.

### *Better data collection leading to improved data quality*

The benefits of standardising the process nationally are that skilled health staff are aware of how to sensitively ask the ABS standard question, and the population is relaxed and comfortable about being asked the question.

### **Box 7 NSW Aboriginal Health Information Guidelines (1998)**

The *NSW Aboriginal Health Information Guidelines* recognise explicitly 'that information is a resource, the value of which is determined by the contribution it makes to the ultimate goal of improving Aboriginal health and the priorities of the health system in addressing that goal. In this context, accurate, reliable and meaningful health information fulfils an important role in the planning and delivery of health services for Aboriginal peoples' (NSW Health & NSW AHRC 1998, p. 2).

The *Guidelines* also state that 'the value of collecting and recording Aboriginal health information is fully realised only when that information is shared and used to benefit Aboriginal peoples and communities' (NSW Health & NSW AHRC 1998, p. 5).

### *Ability to see change over time*

Improved Indigenous identification in communicable disease reporting would enable monitoring of change over time. Most Aboriginal and Torres Strait Islander health issues do not change quickly over time. Infectious diseases, however, are one area that can change relatively quickly – therefore knowing disease rates prior to introducing a vaccine would enable better monitoring of change after the vaccine is introduced.

### *Knowing what's happening*

With good quality data there is information about what's happening and strategies can be developed that are effective and consistent with population health approaches, *'if we don't [know what's happening] we're just putting on bandages and working in the dark'*. Examples where good quality data is needed include Hepatitis C in Aboriginal and Torres Strait Islander communities, and skin infections, considered to be far more prevalent than the data suggest. Good quality data on these infections would enable targeting public health programs in schools, and tackling related issues of overcrowding in homes, and poor general health in communities.

There are other issues arising in infectious diseases, such as the emergence of MRSA (Methicillin-resistant *Staphylococcus aureus*) in Aboriginal and Torres Strait Islander communities, that would affect clinical treatment (e.g. need to use different antibiotic) and where there would be treatment benefits in knowing the prevalence and incidence in Aboriginal and Torres Strait Islander populations.

*'Biggest good news is immunisation... in general has reduced incidence and prevalence of a lot of infectious diseases, saved a lot of lives.'*

### *Better data to access mainstream resources*

There is a need to improve data on Aboriginal and Torres Strait Islander health to successfully mainstream the public health response to improve Aboriginal and Torres Strait Islander outcomes in communicable diseases.

### *Traditional surveillance benefits*

There is a range of benefits traditionally discussed as reasons for epidemiology and surveillance that could be delivered through improved data:

- raised awareness of health conditions and of health differentials (handled in an appropriate and sensitive manner) for the purpose of influencing decision makers,
- identification of factors that may be associated with disease causation,
- assisting in the planning and provision of appropriate services, and
- evaluation of services and interventions.

The 'surveillance loop' (shown in Box 8 following) uses data to get action to address the problem described and measured by the data, and then to evaluate the impact of interventions. Once service provision can be shown to have a benefit, data can be used to advocate with opinion makers or tell them they have done a good job.

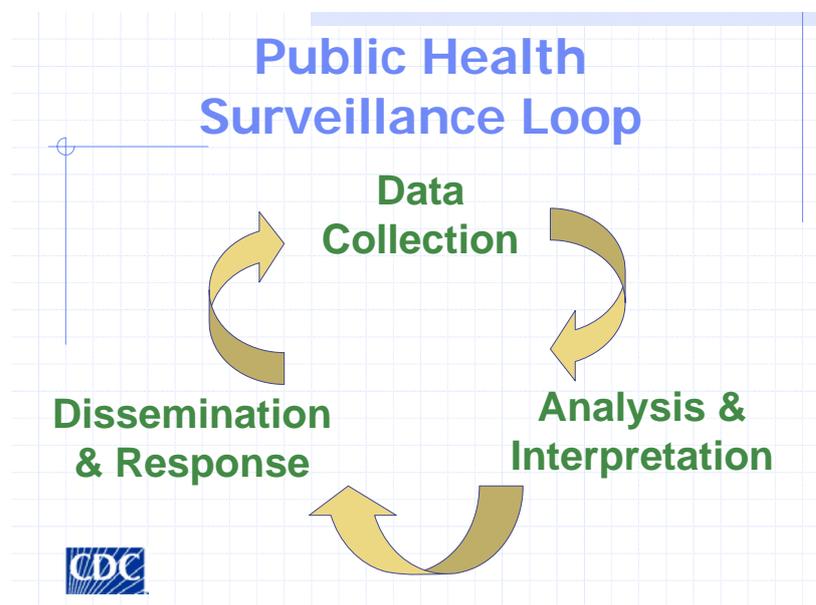
The surveillance loop uses data to address diseases that have a different epidemiology and different impact on Aboriginal and Torres Strait Islander and non-Indigenous populations – and to monitor interventions (e.g. new public health programs, new vaccines). Because the

Aboriginal and Torres Strait Islander population is such a small subset of the population as a whole, improvements in health related to communicable disease will not be seen unless this population is specifically identified and monitored. An example is pneumococcal disease, where although the rates of infection are higher in Aboriginal and Torres Strait Islander populations, the absolute numbers are higher in non-Indigenous populations. These larger numbers tend to swamp data on pneumococcal disease in Aboriginal and Torres Strait Islanders. To study the impact of preventive strategies on particular diseases affecting a small subset of the population (i.e. Aboriginal and Torres Strait Islander Australians) we must be able to identify and monitor that subset over time.

### Box 8 The Surveillance loop

'Infectious disease surveillance is an ongoing and dynamic process. GPs, hospital clinicians and laboratory scientists collect data on infectious diseases, which are then collated, analysed and interpreted by public health personnel. Information must then be disseminated to 'those who need to know' in order that action may be taken. The term **surveillance loop** is used to describe this process. A continuous 'loop' is required to ensure effective and efficient surveillance in the region, in order that:

- Outbreaks are detected, investigated and managed
- Trends in endemic disease are monitored
- Interventions, such as immunisation, are evaluated
- The progress of control measures are assessed
- The performance of public health programmes are measured
- Lessons are learned from outbreaks to inform future policy and practice and the prevention of future outbreaks.'



Sources: Eastern Regional Health Authority 2003, 'Introduction', Closing the Loop: Communicable Disease Bulletin, Issue 1; Sappenfield 2002, 'MCH Surveillance: Working the numbers...', Presentation.

### *Good news stories*

Examples identified by stakeholders where better data has directly benefited Aboriginal and Torres Strait Islander people, include vaccine preventable diseases, new ways of treating sexually transmissible infections, and programs for the eradication of certain diseases.

#### *Vaccine preventable diseases*

Examples range from measles (relatively easy) to Hepatitis B (trying to eliminate a chronic infection that does not manifest for decades). Effective immunisation strategies, tailored to populations, and their impact on vaccine preventable diseases include:

Far North Queensland—using public health data from pneumococcal disease monitoring over many years and through intensive surveillance of pneumococcal disease, determined that it was a serious cause of morbidity and mortality in Indigenous populations, and commenced vaccination. There was a large improvement in the rate of disease, and a program was consequently brought in for the rest of Australia. (Gratten et al. 1998, McIntyre et al. 2000, Hills et al. 2002)

Northern Territory—Haemophilus influenzae type b (Hib). There has been a huge impact on rates of disease in Aboriginal and Torres Strait Islander peoples in the Northern Territory since the introduction of the vaccine in 1993, after documenting that it was a problem causing serious morbidity. By 1998, public health staff could report that the ‘incidence of invasive Hib disease fell to a seventh of its pre-vaccine level in both Aboriginal and non-Aboriginal infants and in the most at-risk age-group’ (Markey 1998, p. 3, see Table 9 below).

**Table 9 Invasive Hib disease before and after the Hib vaccine (Markey 1998)**

	Pre-vaccination era		Post-vaccination era		Relative risk	95% CI
	Cases	Incidence	Cases	Incidence		
Aboriginal	84	278	9	37	0.13	0.07-0.26
Non-Aboriginal	23	50	3	8	0.16	0.05-0.52
Total	107	141	12	19	0.14	0.08-0.25

Source: Markey 1998, p.3.

Far North Queensland—Hepatitis A was identified as the cause of Aboriginal and Torres Strait Islander child deaths and a large number of hospital cases. A Hepatitis A vaccination program for Indigenous children was instigated, and authorities have since seen Hepatitis A disappear in children. (Hanna et al. 2000)

#### *Developments in treatment of sexually transmissible infections*

Introduction of less invasive testing techniques (e.g. PCR - polymerase chain reaction - urine tests) and community-wide screening and more comprehensive strategies in the treatment of sexually transmissible infections (STIs) have led to marked decreases in some diseases. For instance, a Nganampa Health Council program to improve diagnosis and treatment of gonorrhoea and chlamydial infection in remote Aboriginal communities reported that over two years the prevalence of gonorrhoea in people aged 12-40 years almost halved (from 14.3% to 7.7%) and chlamydial infection also fell. The immediate reduction in gonorrhoea prevalence was attributed to ‘reduced duration of infectiousness due to advances in diagnosis, increased testing activity and reduced interval to treatment rather than behaviour

change' (Miller et al. 1999). The program demonstrated effective control activities for STIs in remote communities with highly mobile populations.

Queensland Health reports that the combination of the new non-invasive technology PCR urine testing program for chlamydia and gonorrhoea, together with 'effective new one-dose treatment drugs', has had a major impact on the success of screening programs, and 'offers a real opportunity to reduce the overall disease burden of the two infections in Queensland Indigenous communities'. Early evidence of this successful approach is reported from a Far North Queensland community that took part in Well Person's Health Checks in 1998 and 2000, with regular screening by the local health service in the intervening period. At follow up, 'chlamydia prevalence among 15–35 year olds had reduced from 24.4% in 1998 to 11.8% in 2000 (p=0.059)' (Queensland Health 2003b, p. 11). The *Queensland Indigenous Sexual Health Strategy* retains a strong focus on the continued expansion and use of PCR testing and opportunistic screening.

Nganampa Health Council has prepared a manual for clinic workers (with OATSIH assistance) on *STD Control in Remote Aboriginal communities* (Miller 1999). The '8-way model' arising out of that development was set up as a comprehensive, multi-faceted strategy that addresses (among others): health hardware, good evaluation, clinical services with treatment and screening of men and women separate, confidentiality, privacy, and having good surveillance data sets in place. The 8-way model is about not focusing *solely* on clinical services or surveillance, but putting a range of strategies in place. The aim is to use resources intelligently and comprehensively. 'To have an effective STI program you have to do it holistically – you can't just choose and focus on one thing.'

A similar example (from New South Wales) involves sexual health screening in communities with a high burden of STIs, supported by treatment and education and prevention activities, using public health information to inform a public health intervention.

### *Eradication programs*

An example of a program to eradicate a preventable communicable disease is the program to eradicate donovanosis, described in Box 9 below.

#### **Box 9 Case Study: Donovanosis (Miller 2001, NCHECR 2003)**

'Donovanosis occurs globally in small endemic foci mainly in developing countries in association with poverty and poor access to diagnosis and treatment. In Australia it is found in small geographic clusters amongst Aboriginal and Torres Strait Islanders living in rural and remote communities in northern and central Australia' (Miller 2001, p. vii).

All 31 cases notified nationally in 1998 were from Western Australia, Northern Territory and Queensland (estimated 300 cases prevalent across northern Australia).

Bad news: "**Underdiagnosis and underreporting** limits the usefulness of the surveillance data."

Good news: "Despite the limitations of the data, it does appear that the **total number** of people **suffering from donovanosis in Australia is small and declining.**" (Miller 2001, p. vii)

**BENEFITS:** 'The **benefits** of improved control or eradication would include the reduction in morbidity, and social and emotional consequences for the individual; prevention of severe, extensive disease requiring hospitalisation; a reduction in duration of infection, repeat investigation, and repeated courses of treatment. In addition, the time and energy of remote clinic staff which is now devoted to the treatment and follow-up of donovanosis could be

directed elsewhere. The eradication of donovanosis would also reduce the risk of HIV transmission in rural and remote ATSI communities' (Miller 2001, p. viii).

**ACTION: The National Donovanosis Eradication Project (NDEP) 2001-4.** Strategies: 'targeted surveillance, high quality education and support for primary health care workers, intermittent or short course oral medication and new laboratory techniques' (NCHECR 2003, p. 1).

In 2001 four project officers (in Alice Springs, Darwin, Perth and Cairns) were appointed 'to support the activities of primary health care workers in areas where the disease was endemic'. The NDEP is funded by OATSIH through the National Indigenous Australians' Sexual Health Strategy. The National Donovanosis Eradication Team (a technical advisory team) supports the project officers to 'deliver a national approach to the project through national meetings and resource development' (NCHECR 2003, p. 4).

**GOALS: Elimination of donovanosis.** 'Achieved when regions that have previously notified donovanosis cases have no further notifications *while maintaining enhanced surveillance*' over two years (NCHECR 2003, p. 4, our *emphasis*).

**Reduction of a risk factor for HIV transmission.** 'The elimination of donovanosis will reduce at least one of the risk factors for HIV transmission in rural and remote communities' (NCHECR 2003, p. 4).

## 4 Limitations

There are a number of limitations in the existing communicable disease reporting systems that impact on the collection of accurate Indigenous status information.

In summary, the following major limitations were reported in interviews and surveys with key stakeholders assisting the project (quoted material from stakeholders is shown in *italics*): differences in legislation, notification and reporting systems; deficiencies in systems and in services especially in rural/remote areas; limitations in the data because it is incomplete, not holistic, or of dubious quality; and limitations arising from organisational and cultural issues. These limitations are reported more extensively below.

### *Jurisdictional differences*

Differences in enabling legislation, and in the systems for notifying and reporting communicable diseases, in all States and Territories, inhibit the production of nationally consistent data. Jurisdictions also differ in their degree of centralisation/decentralisation and in whether reporting of communicable diseases is to a central state agency or through regional public health units (or both). There are concerns regarding the impact of privacy legislation and requirements and who is mandated to provide information (and who could be sued for doing so). There are different viewpoints across the jurisdictions on the degree to which the reporting of Indigenous identification is part of their core business.

Aboriginal and Torres Strait Islanders are not homogenous populations and there are differences in these populations both within and between jurisdictions. Another major variable is the proportion of Aboriginal and Torres Strait Islander peoples in areas within jurisdictions (e.g. regions, zones) and in the different States and Territories. These factors affect the reporting of Indigenous identification.

### *Indigenous identification*

There is a general lack of Indigenous identification in all information systems, and particularly in health-related systems that contribute to communicable disease notifications, such as pathology systems (which in some States report the majority of communicable disease notifications) and in GP practice systems for recording patient details. These limitations are described in more detail below.

### *GP recording*

Many respondents identified poor GP collection and reporting of Indigenous identification. Three out of eight jurisdictions (Victoria, Western Australia, and South Australia) rely more on medical practitioners (primarily GPs) than on pathology laboratories to notify communicable diseases. These jurisdictions were more likely to think that medical practitioner reporting could be improved with some effort (such as reminders about their obligations under public health acts, follow-up calls for missing data, and education of '*recalcitrant GPs*'). One respondent commented that if GPs always receive forms back asking for missing Indigenous identification data then they will learn the need for compliance and get better at it – but '*if no feedback, no penalty, then [GPs] learn that it doesn't matter*'.

Those jurisdictions that relied most on pathology-based notifications found that GPs were more likely to be poor data collectors and reporters. They were also more likely to think that this situation was unchangeable and tended to see solutions in terms of improving data transfer from hospitals or GPs to pathology laboratories and thence on to jurisdictional communicable disease units.

Respondents identified limitations in the accuracy of Indigenous identification data collected and reported by GPs. It was frequently suggested (including by GPs themselves – see Box 4) that some GPs were more likely to make assumptions (e.g. on the basis of skin colour) than to ask the ABS standard question. Other reasons given for not asking the question included: *‘potentially embarrassing or intrusive and may cause offence, not relevant to the management of the patient, silly when the answer may appear to be obvious’*. Another respondent suggested that *‘people are embarrassed to ask the question because they think people will be embarrassed to answer it’*. Respondents from areas in which the majority or a substantial minority of the population was Aboriginal or Torres Strait Islander mentioned how silly it was asking the question when everyone knew and there was no doubt about peoples’ Indigenous status.

Information from the BEACH study suggests that Aboriginal and Torres Strait Islander clients are under-reported generally by GPs but also that this reporting can be easily improved when the Indigenous status question is asked in the context of a series of questions about origin (Britt et al. 2003; see Box 3).

Queensland Health (2003a) evaluated the effectiveness of a number of strategies and found that while there was high acceptability for the Indigenous identification question (survey responses and focus group discussions), there was concern about the 10-16% of people who *‘disliked the question’*, as well as concern for people being *‘repeatedly asked about Indigenous status at different services’*, and that *‘despite efforts at client education through the use of printed materials, lack of awareness and misconception about the reasons for asking the question remain in the community’*. These included widespread *‘beliefs that Indigenous clients and Indigenous services receive preferential treatment’* (Queensland Health 2003a, pp.18-19).

#### *Data quality*

Respondents queried the quality of current Indigenous identification data, even when the apparent completion rate is high. They asked whether doctors and/or hospitals were actually asking their patients the ABS standard question, or whether assumptions were being made based on, for example, skin colour or name.

#### *Reluctance of Aboriginal and Torres Strait Islander people to identify*

The reluctance of some Aboriginal and Torres Strait Islanders to identify as such when asked about their Indigenous status in health settings was mentioned by many stakeholders, and there was a range of opinion as to the degree of this limitation. Some stakeholders viewed this as a major limitation, others thought that it was over-rated as a limitation while accepting that *some* Aboriginal and Torres Strait Islanders in *some* circumstances might be reluctant to self-identify. Settings and situations where Aboriginal and Torres Strait Islanders might prefer *not* to identify could include sexual health clinics, and at GP attendances for a sexually transmitted infection. It was thought that older Aboriginal and Torres Strait Islanders might be less willing to identify because of the relative recency of, and strong oral history about, colonial penalties for identifying as Aboriginal or Torres Strait Islander (e.g. removal from

the community and possible inhibitions on movement around the country). Concerns about the insensitive use of the data, actual instances where there had been breaches of privacy, and the stigmatising and stereotyping of Aboriginal and Torres Strait Islanders in relation to communicable diseases, especially sexually transmitted diseases, were also raised as disincentives to self-identify.

#### *Pathology-based notifications*

The majority of jurisdictions in Australia rely primarily on pathology-based notifications of communicable diseases. The current inability to transfer Indigenous identification data (that may be held by GPs) – along with other patient demographic details – from requesting medical practitioners to pathology laboratories, and from pathology laboratories to state communicable disease units conducting surveillance in the jurisdictions was consistently identified as the major limitation to improving Indigenous identification.

#### *Passive reporting*

There is an over-reliance on passive reporting in most jurisdictions, and there is no systematic follow-up of medical practitioners for Indigenous status when this is omitted from communicable disease notifications or where there is no clinical report (i.e. pathology laboratory notification only).

#### *Using the ABS standard question*

States and Territories determine the standards for demographic items requested in notifications of communicable diseases. The national standard as set out in the National Health Data Dictionary is the ABS standard question which is used in the Census and in major surveys (see Box 2). Not all jurisdictions request the ABS standard from notifying practitioners, and as a consequence, Indigenous identification data is not uniform in the National Notifiable Diseases Surveillance System (NNDSS).

Jurisdictions that do not currently meet the national standard identified the following limitations: GPs will not fill in the more complicated question (the ABS standard question), it is too large a data load; there are no Torres Strait Islanders or only a small number of Torres Strait Islanders in their jurisdiction; and/or that they have made a trade off between getting some data or no data from GPs by asking a simpler question to maximise the chance of it being answered.

However, the jurisdictions that do meet the national standard report that it is not a problem for their GP population. (Examples of jurisdictional notification forms that do meet the national standard can be found in Appendix E.)

#### *Training to collect Indigenous identification*

Related to the issues described above, respondents identified that they '*lack routine protocols for getting the information*'. Unlike the Census, which trains collectors in one way of collecting the data, jurisdictions differ in their approach and in their ability to influence the collection practices of primary data collectors. There was no evidence of a standard protocol implemented in any of the jurisdictions for collecting and recording Indigenous status.

Lack of support from management for frontline health staff asking the Indigenous identification question, deficits in frontline support and in training (including training maintenance structures that have not been developed in a constructive way), were also identified as limitations.

#### *Incomplete Indigenous identification*

Indigenous identification data is incomplete in all health-related data collections, including communicable disease notifications, hospital admissions, and death registrations. Only three jurisdictions nationally report communicable diseases notifications by Indigenous status. AIHW report that there are estimates of the completeness of Indigenous identification data in some data sets only, e.g. hospital data is reported as complete by three out of eight jurisdictions (South Australia, Western Australia, and the Northern Territory) but even these jurisdictions have some records with Indigenous status 'not stated'. Deaths data have a very high proportion of 'not stated' and data from only four jurisdictions (Queensland, Western Australia, South Australia and the Northern Territory<sup>6</sup>) is considered complete enough to report.

#### *Quality assurance*

Respondents identified the lack of quality assurance activities as a serious limitation. Population health units do not have a mechanism for querying suppliers of the data to request an improvement when Indigenous identification falls below a pre-determined quality standard; they lack '*a checker of the checker*'.

*'Proof of commitment is auditing'* one respondent pointed out, *'and if it's not audited then you're not committed'*.

#### *Data sharing*

When data on Indigenous status is collected, that data often cannot be transferred from one data set to another. For example, GPs cannot transfer data on Indigenous identification to pathology laboratories.

#### *Baseline data*

Without good baseline data it is difficult to show that the health of Aboriginal and Torres Strait Islander peoples has improved, that the gap with the non-Indigenous population in communicable diseases has closed, or that a particular intervention works or works better than another one.

#### *New South Wales and Queensland data*

The two States with the largest Aboriginal and Torres Strait Islander populations (New South Wales and Queensland) do not meet the reporting standard of 50% or more Indigenous identification completion rate. Their notifiable disease data is consequently not reported. Respondents suggested that the inclusion of these two States with the numerically largest Aboriginal and Torres Strait Islander populations, and Victoria, would be sufficient to meet the criteria of 'good baseline data' nationally (as the remaining jurisdictions, Tasmania and

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<sup>6</sup> See Glover et al. 2004.

the Australian Capital Territory would probably not alter the overall picture because their Aboriginal and Torres Strait Islander populations are small in number).

#### *Non-notifiable diseases*

The burden of non-notifiable diseases (e.g., scabies and parasitic infections, eye and ear disease, rheumatic fever) is largely unknown, both at jurisdictional levels and nationally. There is concern about non-notifiable communicable diseases, for which quality of life is an issue (rather than mortality/morbidity) and in relation to which there is a major gap in the environmental health response. The focus is more on treatment and care while for these communicable diseases there is a whole other sector response required that includes housing, education, and community infrastructure.

There is a lack of reporting on programs like the Aboriginal Hearing Program (otitis media) that has been good at screening children. There are long-term effects of failures to screen and report appropriately, as with scabies, and streptococcal infections. At least two jurisdictions maintain registers for rheumatic fever in order to better management its chronic effects, but there is no national approach.

#### *Cross border issues*

*‘Infections are no respecters of borders’*

At a minimum, cross border issues can lead to neither jurisdiction taking responsibility for a communicable disease issue, to serious concerns about the spread and tracking of communicable diseases. Several studies examining outbreaks of communicable disease in one area have demonstrated the need to look at interventions in other related communities before it can be transferred, or for screening or other interventions to occur at similar times.

*‘Population is not bounded by jurisdictional boundaries, and the communicable diseases they carry are not bounded by jurisdictions.’*

Several geographic areas have issues in common in Aboriginal and Torres Strait Islander communities and are perceived as obvious areas for coordination and for consideration as single communicable disease areas:

- Northern Australia - northern Western Australia, northern Northern Territory, and northern Queensland – issues have included e.g. Donovanosis eradication, syphilis outbreaks, Murray Valley encephalitis.
- Central Australia - lower end Northern Territory, Goldfields region Western Australia, northern South Australia and possibly parts of southwestern Queensland.
- Border areas between Papua New Guinea, the Torres Strait and northern Queensland.

Some cross border initiatives are in existence or have evolved, such as the tri-state arrangement (Northern Territory, South Australia, and Western Australia).

### *Cross boundary issues*

Tension between 'mainstream' health and Indigenous-focused health was a cross boundary issue identified by many stakeholders. There is a tendency for mainstream health to direct any and all Indigenous issues to Aboriginal and Torres Strait Islander health units. The perspective from Aboriginal and Torres Strait Islander units is that they are not there to deal with *all* Indigenous health issues: the health of the *whole* population *is* a mainstream issue. Indigenous identification needs to be '*a standardised part of a formal process*' across the whole health system, and the same is true of training and cultural care. These are issues that address '*changing the "us and other" mindset*', the mindset that relegates 'Aboriginal stuff' to over there... when the duty of care is a duty of care to the whole community and Aboriginal and Torres Strait Islanders are a part of that community. There was a strong argument for increasing commitment to Aboriginal and Torres Strait Islander outcomes through mainstream agreements and '*not sidelining Indigenous issues to Indigenous programs*'.

### *Denominator data*

Enumeration of Aboriginal and Torres Strait Islander people in the Census was questioned in terms of using the Census as the denominator to calculate rates of communicable disease.

The issue of whether a person who identified as Aboriginal in the Census also identifies as Aboriginal to a health care provider (who must first ask for the information) was also raised. This issue is also relevant to the voluntary Indigenous identification with the Medicare card program through the Health Insurance Commission.

The lack of an appropriate pathology denominator (the total number of pathology tests) limits usefulness of positive pathology, as they do not know whether rates change in tandem with changes in screening rates or other practices.

*'The system needs to know whether an increase in a disease like gonorrhoea in an Indigenous population is due to an increase in the number of people tested or a real increase in the rates of infection. To do that we would need to identify Indigenous status pre testing.'*

### *Identification versus origin*

The New South Wales Health report on *Improving Aboriginal and Torres Strait Islander origin information in New South Wales* (1999) notes that the ABS standard question, (Are you of Aboriginal or Torres Strait Islander origin?) 'refers to a person's origin, not self-identification' which it describes as 'a critical issue, and one that has not been well articulated to date' (New South Wales Health 1999, p. 4).

### *Too much bad news*

The focus ... is community-orientated information, and the need to provide a context for the official data. In Australia, Aboriginal community-controlled health services pioneered the application of new public health philosophy and the principles of the Ottawa Charter for Health Promotion. However, most health reports have remained illness-oriented – rarely exposing these positive primary health care initiatives and the intersectoral networking of Aboriginal Health Workers or Environmental Health Workers in conjunction with government instrumentalities. The result is a perspective on Aboriginal health which over-emphasises clinical and bio-medical profiles. While

important, they not only remain questionable owing to the contentious matter of Aboriginal identification in statistical collection, but they ultimately provide a limited cultural perspective which tends to have a negative impact on community members. In short, it is perceived as unbalanced. *“Too much Bad News!”* they say ... (Brice 1997, p. 23, our emphasis)

Similar views were expressed by stakeholders and evident in interviews, that is, lack of, or inappropriate, reporting to communities (information not useable). The over-emphasis in western medicine on clinical and medical aspects of illness (when *‘we’re talking about health and well-being’*) is not always useful, and *‘It’s not holistic’*. A too-narrow emphasis can mean that ‘single issue’ catastrophes dominate reporting. *‘Health has a habit of silo-ing diseases’* one respondent commented - giving the example of STIs - *‘It might work for treatment but not when comes to promotion’*.

#### *Engagement with Aboriginal and Torres Strait Islander populations*

Aboriginal and Torres Strait Islander populations are not homogenous across Australia or in any particular jurisdiction and there is a lack of capacity to engage with the full range of diversity across and within these populations. Lack of engagement is seen as having a negative influence on ability to collect, and the quality of collected, data.

#### *Urban areas*

Disease in urban areas generally, and ‘hidden’ or ‘invisible’ populations of Aboriginal and Torres Strait Islanders in the large urban areas (Sydney, Melbourne, Brisbane, etc) were identified as emerging issues. In the large urban areas *‘we’re invisible, we’re here but invisible... we’re constantly bombarded with images from the desert as if that’s the only Aboriginal authenticity’*. While residence (especially remote or rural) has been used as a proxy indicator when jurisdictions attempt to calculate the impact of communicable diseases in the Aboriginal and Torres Strait Islander population, this approach is not viable for the large urban areas. There is thus a lack of information on urban Aboriginal and Torres Strait Islander populations and the effects of communicable diseases in these settings.

#### *Remote and rural areas*

In remote and rural areas, the lack of health care services on the ground also limits the collection and quality of data in communicable diseases and other health areas. Data cannot be collected adequately unless health care services are first set up, staffed, resourced and supported. In small remote communities, close relationships can also place limitations on data quality through concern about possible abuses of privacy and confidentiality.

#### *Bush medicine*

Unstudied aspects of the use and impacts of bush medicines and traditional practices were identified as limitations in understanding.

#### *Cultural care in mainstream health*

Mainstream health services have to learn about *‘cultural security, and having respect for different cultures – not only Aboriginal culture’*.

*‘There should be protocols around cultural aspects – after all we’re supposed to be a multicultural country.’*

Cultural awareness and sensitivity should be part of the training of the entire health workforce, for instance, training on *'dealing with key cultural groups in a hospital setting'*, a manual at each nurse station that sets out procedures that are followed to show cultural respect. Couching sensitivity in terms of culture, in a context of broader respect should desensitise any one particular culture. Expressing cultural sensitivity as *'cultural care'* - a duty of care to a cultural group - could cover a range of issues, including the collection and retention of bodily samples for pathology testing in relation to communicable disease.

#### *Lack of public health awareness*

Respondents identified lack of a public health awareness or focus within health generally, as well as in the community, as an impediment to improvements in data collection, including Indigenous identification. This was also referred to as leading to the *'data for data's sake'* perspective and as indicating a need to work harder to *'close the loop'* in terms of getting actions in response to surveillance data and evaluating those actions with surveillance data, using *'data to make a difference'*.

#### *Prison health services*

Stakeholders identified the poor interface between prison health services and Health Departments as a limitation to improving Indigenous identification in communicable disease reporting. Aboriginal and Torres Strait Islander people are over-represented in prison populations (e.g. Aboriginal men form 20% of the prison population, women 23-27% of the jail population over Australia, with rates much higher in some areas).

Some prisons do not routinely test for communicable diseases in Aboriginal and Torres Strait Islander people (unless there is a specific reason to do so). Many do not follow best practice and test all Aboriginal and Torres Strait Islander inmates on reception and release. Prison health screening practices were described as *'either on or off'* and most were *'currently off'*.

It was suggested that the over-representation of Aboriginal and Torres Strait Islander people in prison populations presents an opportunity for screening and sampling to provide information on this *'sentinel'* population to give an indication of the likely upper bounds of rates of disease (could under-state HIV because different groups of people are at risk, however for Hepatitis C and most other infectious diseases there would be sufficient information).

#### *Collecting high quality data*

The collection of high quality data is limited by factors that include geography and availability of health services, and other factors that vary by disease. Disease rates for Aboriginal and Torres Strait Islander people cannot be calculated when the denominator is unknown or where Indigenous identification is not accurately recorded. Infectious diseases are increasingly a remote area issue – aside from Hepatitis C, HIV/AIDS, and injecting drug related transmissions (blood borne viruses).

## 5 Options

Previous work in this area has focused on improving the quality of the Indigenous status data of patients admitted to hospital. There has been little work examining Indigenous identification in communicable disease systems specifically<sup>7</sup>. However, the body of work related to Indigenous identification in health and vital statistics collections has been examined and options already identified are summarised in this section (and reported in more depth in Appendix F).

Seven broad strategies were identified from the review of the literature to improve identification of Indigenous status in health systems: build capacity at the local level; improve data collection processes; implement data principles and protocols; report useable information to communities; use data to improve Aboriginal and Torres Strait Islander health; change organisational culture and values; and introduce national measures.

The majority of this work arises out of, or in relation to, the development and implementation of strategies needed to apply the ABS standard question on Indigenous status in hospitals, and more recently, across the wider health system.

However, as described in Section 2.1 above, the majority of communicable disease reporting is notifications from pathology laboratories and/or medical practitioners (primarily private practice general practitioners) to State and Territory health officials so that those authorities can take the required public health action. Medical practitioners in hospitals report only a small proportion of all notified communicable diseases as the majority of people with communicable disease do not enter hospital.

Stakeholders interviewed for the project suggested many options for improving the quality of Indigenous identification in communicable disease reporting. The options have been categorised into the areas of: developing **Policy**, creating **Incentives**, improving **Reporting**, introducing **Workplace Reforms**, and enhancing **Information Systems**.

In addition, various initiatives were proposed to provide additional targeted gains improving the quality of Indigenous identification in communicable disease reporting, and are presented separately.

### 5.1 From the literature

The review conducted in 1996-97, which culminated in the production of *The Aboriginal and Torres Strait Islander Health Information Plan... This time, let's make it happen* found that there were 'few systematic mechanisms in place to check the quality of Indigenous data' (ATSIHWIU 1997, p. 34). However there were a variety of one-off or short-term strategies that included:

Benchmarking, cross checking data with other sources, using Hospital Liaison Officers, checking medical certificates against communicable disease notification forms, 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 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 (ATSIHWIU 1997, p. 34).

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<sup>7</sup> Exceptions are ABS & AIHW 1996, and ATSIHWIU 1997.

In 2004, there is little evidence of systematic mechanisms being in place to check the quality of Aboriginal and Torres Strait Islander data. There has been and continues to be a variety of one-off or short-term strategies, which were discovered through the literature survey prepared for this document. They have been grouped into seven broad strategies to improve identification of Indigenous status in health systems, by building capacity at the local level; improving data collection processes; implementing data principles and protocols; reporting useable information to communities; using data to improve Aboriginal and Torres Strait Islander health; changes in organisational culture and values; and introducing national measures.

The majority of options identified since the 1997 *Plan* arise out of specific data audits, usually of hospital morbidity data. The focus is on recommendations to improve training and awareness, and measures to increase data quality and conformance with standard practices. More recent recommendations include a focus on the need for change in organisational culture and values, recognising that these impact on the correctness and completion of routine demographic data including Indigenous identification, and on willingness to commit resources to monitor data quality and put enhancements in place. The most recent broader reports call for sustained capacity building at the local level, in both the collection and use of data to improve health outcomes for Aboriginal and Torres Strait Islander peoples. These are discussed further in Appendix F.

## **5.2 Identified by stakeholders**

This section reports on options for improving the quality of Indigenous identification in communicable disease reporting that were identified in interviews and surveys with key stakeholders. Quoted material from stakeholders is shown in *italics*. The various options identified have been placed within the categories of: developing **Policy**, creating **Incentives**, improving **Reporting**, introducing **Workplace Reforms**, and enhancing **Information Systems**.

Initiatives proposed to provide additional targeted gains in improving the quality of Indigenous identification in communicable disease reporting are presented separately and complete this section.

### **5.2.1 Policy**

#### ***Make it a policy requirement to report Indigenous identification***

The Australian Government and all State and Territory governments should implement a *policy requirement* to report Indigenous identification in communicable diseases reporting in a manner that is understood, accepted, and sustained. Efforts to improve Indigenous identification are often driven by individual ‘champions’ working with providers and need to be written into policy documents that survive staff changes.

Benefits: A consistent, sustainable, continuous, and integrated focus to support improvements in Indigenous identification over the long term.

Drawbacks: Requires political commitment and will, and needs to be under-pinned by needs-based resource commitments.

#### ***Implement a standardised process***

National implementation of a standardised process for Indigenous identification in data collection and reporting, and negotiation with all jurisdictions would ensure that the national Indigenous identification standard is incorporated into all communicable disease data collections. The Communicable Diseases Network of Australia (CDNA) is suggested as the preferred driver to ensure the focus is on communicable diseases and Indigenous identification. While CDNA is a voluntary network (and has no ability to compel the jurisdictions to comply) it does have a role in supporting and negotiating national standards and in encouraging jurisdictions to move towards them as opportunities present. It was also suggested that Indigenous identification should be part of the national case definitions for notifiable communicable diseases (finalised after three years' negotiation with the jurisdictions).

**Benefits:** National implementation of a standardised process would present a clearer national picture of communicable diseases affecting Aboriginal and Torres Strait Islander Australians. The focus on collecting better quality demographic data that includes Indigenous identification would diminish bias in systems and make the system work better for *all* Australians.

**Drawbacks:** Information may not be taken on board and used in a constructive way to plan, develop, and fund better services and outcomes in communicable diseases for Aboriginal and Torres Strait Islander peoples.

### ***Australian Government support for jurisdictions to develop collection of standardised Indigenous identification***

Australian Government cooperation with and support for jurisdictions will be required to assist in implementing standardised Indigenous identification in communicable disease reporting. Assistance could include planning and development for the required infrastructure, support in the required training, and support in how to use information in communicable diseases management, planning and development for the future, and in dealing with emerging issues.

**Benefits:** Australian Government and jurisdictions working together cooperatively to an agreed end.

**Drawbacks:** Jurisdictions may not be able to achieve a cooperative working arrangement and may not welcome perceived Australian Government 'interference'.

### ***National public health legislation***

National public health legislation to mandate the reporting of Indigenous identification in communicable disease notifications is a longer term option. The drafting of model public health legislation could provide additional short term gain for jurisdictions considering changes to their legislation. Jurisdictions that already have this legislative requirement have reported that it provides protection for data providers from perceived privacy and confidentiality constraints. This option would better enable the collection, reporting and sharing of data within the health sector.

The role of Aboriginal and Torres Strait Islander leadership is important because if Aboriginal and Torres Strait Islander organisations support this option, the Australian Government would be empowered to take a lead role in the modelling and eventual enactment of national public health legislation and associated instruments.

There are concerns that the legislative stick is *'too big a stick'* and that the *'penalties could be draconian'*. In practice, penalties are not used by jurisdictions that currently have such powers under legislation and the legislation is seen and used in an enabling rather than a punitive way.

Benefits: Legislation removes barriers at a minimum, and when other actions are taken in concert, can improve completeness of Indigenous identification in communicable disease reporting over time, as shown in the NT and Victoria.

Drawbacks: Legislation may be perceived as a stick rather than a comfort for health professionals. The legal requirement to report Indigenous identification may not make a change on its own as it only removes a barrier to reporting. To be more effective, other strategies identified in this document need to be implemented at the same time.

## **5.2.2 Incentives**

### ***Provision and use of incentives***

The Australian Government and jurisdictions could provide monetary or in-kind incentives to improve reporting of Indigenous identification. For example incentives to GPs have increased Aboriginal and Torres Strait Islander vaccination rates. The new MBS Item *Well Person's Health Check for Aboriginal and Torres Strait Islanders* may increase Indigenous identification of clients by GPs. Some States have previously made payments to GPs for notifications (ceasing when it became a legislated responsibility). One option is to explore use of an MBS Item to reward GPs for good quality reporting on communicable diseases (notifications, enhanced surveillance, interventions).

Another strategy currently in use in South Australia, Vic and NSW is to pay increased casemix loadings to hospitals for Aboriginal and Torres Strait Islander patients. It was suggested that acceptable implementation of the ABS standard question could be made a requirement of the hospital's contract and/or the CEO's performance agreement.

Another option is for the Australian Government to fund field officers in each jurisdiction to work on improving Indigenous identification in communicable diseases reporting. They could be placed 'on the ground' with appropriate Public Health Units or organisations. An additional option is for the Australian Government to continue to fund best gains and prevention for decreasing the impact of communicable diseases in Aboriginal and Torres Strait Islander populations. This option was raised to encourage jurisdictions to target certain areas to participate in nationally available, directed funding (e.g. funded vaccination programs that are tailored for Aboriginal and Torres Strait Islander populations, specific funding for nucleic acid tests for Aboriginal and Torres Strait Islander patients).

Benefits: All these incentives will increase reporting of Indigenous identification, some more directly than others. Current incentives to GPs that have the effect of increasing Indigenous identification have further potential and other options could be investigated for appropriateness and effect. There is the opportunity to examine jurisdictional experiences to date (e.g. evaluate casemix incentives) more closely to establish possible best practice. Australian Government funding of field officers and best gains nationally could be a motivator to the jurisdictions, and sends a strong message that the Australian Government means business in the area of improving the quality of Indigenous identification in communicable disease reporting.

Drawbacks: The cost to the Australian Government of funding field officers and best gains nationally as well as other incentives such as those to GPs could be a drawback. GPs are currently over-burdened with differential reporting/MBS claiming requirements and small per capita incentives may not provide sufficient motivation, and could be perceived as adding to the paperwork and 'red tape' burden. There is uneasiness about making incentive payments for legislated responsibilities and in selecting out duties/tasks such as notification of communicable diseases that are seen as intrinsically a part of general practice; and concern that such payments would set an unhealthy precedent.

Victoria and NSW report that although casemix incentives are offered, many hospitals are unaware of them and there has been no evidence of positive effect on reporting practices, although South Australia attributes improved Indigenous identification in hospital reporting to this incentive.

### ***Using national funding agreements and initiatives***

The Australian Government could use its over-arching requirements to revise national funding agreements and work through the National Public Health Partnership Group to ensure that they are linked to satisfactory achievements/sustained gains in the collection and reporting of Indigenous identification. A variety of mechanisms were suggested such as re-examination of funding allocations made by Population Health to the regions, or a pool of bonuses for those areas above a minimum completion rate (e.g., bonus in funding arrangements under PHOFAs for good Indigenous identification). For some jurisdictions, the regional level may be more appropriate, as large urban populations skew data (e.g. would have to achieve satisfactory Indigenous completion rates in more than 80% of regions).

Benefits: Reporting of Indigenous identification completion rates will provide transparency and ensure that the Australian Government receives valuable information for its funding investment. Requirements for good Indigenous identification in national funding programs could be seen as moves towards or a precursor for nationally equitable funding. A bonus structure could be used to reward those who have made an investment in good data practices.

Drawbacks: It will take time to think through and agree to appropriate incentives. There may be difficulties in making reporting simple, and in minimising gamesmanship and unintended consequences. The results must be monitored.

### ***Infrastructure development incentives***

The public health response to communicable disease is primarily a jurisdictional responsibility, however, the jurisdictions currently provide data to the Australian Government freely and voluntarily, through the National Notifiable Disease Surveillance System (NNDSS). The jurisdictions have also self-funded changes required by the redevelopment of NNDSS. It was suggested that the Australian Government could contribute to the continued development and maintenance of infrastructure in the jurisdictions that supports the national communicable disease reporting system, through funding arrangements between the Australian Government and the jurisdictions, that recognise the cost to the jurisdictions, of reporting to the national system.

Benefits: A funding arrangement would recognise and augment the contributions made by the jurisdictions, and provide the Australian Government with a means of enticing jurisdictions to more rapidly meet national Indigenous identification standards.

Drawbacks: An infrastructure support funding arrangement would fundamentally alter the relationship between the Australian Government and the jurisdictions in relation to communicable disease reporting.

### **5.2.3 Reporting**

#### ***Monitor and report***

The completeness of Indigenous identification data in communicable disease reporting should be routinely monitored and reported. Reporting completeness by jurisdictions, by diseases - whether rates are high or low - signals importance, focus on, and effort to improve. Some jurisdictions already do this as part of their effort to improve Indigenous identification (e.g. see Queensland Health 2003b).

Stakeholders perceived a clear link between the reporting of data and the collection of better quality data. There were pleas for *'More visible use of the data so that providers are able to see what's been done with it'* and calls for the reporting of data on interventions especially, including prevention, as well as data on communicable disease notifications, rates and prevalence in Aboriginal and Torres Strait Islander populations. Any extension of routine reporting that includes information on associated interventions has the potential to enrich understanding on what works and provide a practical link to 'on the ground' actions. Tying data more closely to action will assist in countering the viewpoint that *'data über alles'* (data is more important than anything else) - the perception that the collection of data is the end and only aim.

The larger jurisdictions were identified as a major gap in 'national' baseline information. Nationally, only three jurisdictions that achieve a 50% completion rate, report on communicable diseases in Aboriginal and Torres Strait Islander peoples. Larger jurisdictions should be able to justify a more systematic look at their data by Indigenous status but low completion rates currently prevent this.

Benefits: Improvements in Indigenous identification completion rates will become visible, as will 'no change' situations. Reporting on interventions and their impacts would extend information on the 'surveillance loop' and enable a more complex, evidence-based, and targeted focus for future effort.

Drawbacks: Unless there are improvements, reporting continued low completion rates could be de-motivating.

#### ***Report the data in context***

Reporting the data in context was an option proposed to allay fears about stigmatising and stereotyping of Aboriginal and Torres Strait Islander peoples in relation to communicable diseases. An example would be a focus on the under-pinning determinants (eg environmental health factors, social health factors) that can have more impact/consequence on disease than Indigenous status. Another suggestion was to report more complex, contextual information – without breaching confidentiality – by using vignettes or 'typical' case descriptions in research reporting.

Benefits: A more complex picture is presented of the wider issues associated with communicable diseases and Aboriginal and Torres Strait Islander communities. This would allow better 'connected' responses in communicable disease that cut across 'silos' of information and better inform treatment and especially prevention.

Drawbacks: More complex research and reporting are costly, and a limited skill base currently exists.

### ***Build more effective partnerships***

For example, build strong ties with GPs, act in partnership with Aboriginal and Torres Strait Islander organisations, mandate for Aboriginal and Torres Strait Islander representatives on health boards (e.g. hospitals, non-government organisations that represent patients). This addresses a way of working together, in building stronger, more effective partnerships. Effective partnerships are a pre-requisite for the publishing of Indigenous identification in communicable disease data.

Benefits: Working together to achieve negotiated aims, strong involvement of Aboriginal and Torres Strait Islander people and their representative organisations, on communicable diseases and in health generally, will result in many positive flow-on effects over time, including the quality of Indigenous identification.

Drawbacks: It can be time consuming to build partnerships as reaching agreement usually proceeds at the pace of the slowest, or least resourced, member.

### ***Publish the data, in cooperation with Indigenous organisations***

This option was frequently raised, and stakeholders identified the National Centre for HIV Epidemiology and Clinical Research (NCHECR) as a model to emulate. The National Centre has over a lengthy period of time, worked with Aboriginal and Torres Strait Islander organisations in the States and Territories and nationally, and with jurisdictional public health units, to ensure a level of comfort and agreement with data to be published on Aboriginal and Torres Strait Islanders. In 2003 for the first time, the NCHECR annual report included information on differences in transmission patterns for HIV between the Aboriginal and Torres Strait Islander and non-Indigenous populations (NCHECR 2003). This valuable information would not have been made public without the degree of trust built up over time and in partnership.

Benefits: The partnership approach progresses trust and collaborative effort and ensures that information is used in a constructive way.

Drawbacks: Initially it takes time and effort to progress understanding, to establish comfort with the concept of publicly available data, and agreement on what can be published.

### ***Put up leading jurisdictions as best practice models***

Identify the leading States and Territories as models for best practice and best quality administrative function or performance in Indigenous identification and use a national approach to bring all to best model. The major aim is to get communicable disease rates in Aboriginal and Torres Strait Islander populations back in line with those in non-Indigenous populations (to 'close the gap').

Although 'best practice' was not a focus of this project, various stakeholders spontaneously identified examples in several areas. South Australia was most frequently identified (by non-South Australia stakeholders) as an example of best practice in communicable disease reporting (including Indigenous identification). The Northern Territory was also identified as a best practice example by (non-Northern Territory) stakeholders, with the special advantages of small population, large proportion of Aboriginal and Torres Strait Islander

peoples in the population (many living remotely), limited number of health services (especially private, or servicing remote populations) and good connections and data sharing across health information systems. Victoria was also identified (by a non-Victorian stakeholder) as a model for communicable disease practices and data.

The 'dual reporting' jurisdictions (Victoria, Western Australia and South Australia) were suggested as a group that had best practice (i.e. with the majority of communicable disease notified by medical practitioners (with and without pathology test results). Western Australia, South Australia and Northern Territory are the three jurisdictions that currently exceed the national reporting 'best practice' requirement for 50% completion of Indigenous identification in communicable disease notifications (note also that Vic is approaching this completion rate with 46% in 2003).

The National Centre for HIV Epidemiology and Clinical Research was identified as a model of best practice for its sustained maintenance of privacy and confidentiality in a very sensitive area (HIV/AIDS cases); for sensitive, collaborative reporting of that data; and for its partnership arrangements built up over time with Aboriginal and Torres Strait Islander organisations at different levels (e.g. State, national) and with the jurisdictions ('*they never diss the states*').

Nganampa Health Council was identified as a model of best practice for community-wide screening and associated interventions, and their impact on sexually transmitted infections. The 'tri-state agreement' (*Tri-State HIV and STI Prevention Project*, jointly funded by the Australian Government Department of Health and Ageing and the South Australian, Western Australian and Northern Territory governments) was also nominated as a best practice in communicable disease surveillance and response in Aboriginal communities and as a driver for at least identifying best practice interventions among the individual jurisdictions participating.

Benefits: The ability to fast track improvements among the States and Territories by identifying best practice, sharing information and 'how to' on quality improvements, and benchmarking across jurisdictions.

Drawbacks: States and Territories may not be able to work together - some may not have equal commitment - to both identify best practice and to fast track the implementation of identified best practice measures.

### ***Changes to national communicable disease reporting***

In the interim, until the national standard is achieved by all jurisdictions, the National Notifiable Disease Surveillance System (NNDSS) should ensure that Indigenous status data accurately reflects differences in collection practices of jurisdictions that do not currently meet ABS standard. The new NNDSS Data Acquisition System (DAS) specifies Indigenous status according to the ABS standard. Jurisdictions are encouraged to follow that data specification. For jurisdictions that do not yet send data to the new DAS, NNDSS needs to ensure that the mapping of Indigenous status data variables in NNDSS reflects those differences.

Benefits: Accuracy of data categories is improved and there is better correspondence with actual data collected in jurisdictions.

Drawbacks: Additional category of Indigenous identification data in NNDSS.

National reporting of communicable diseases should show urban/rural/remote regions; and be available by sex and age groups. The NNDSS currently receives age, sex and postcode

data for all notifications reported by jurisdictions, and such reporting is therefore theoretically possible. The ability of NNDSS to report on communicable disease in Aboriginal and Torres Strait Islander populations in the finer classifications of age and sex and/or area (e.g. Australian Standard Geographical Classification Remoteness Areas) is dependent on underlying numbers, agreements on appropriate reporting with Aboriginal and Torres Strait Islander and jurisdictional partners, and sensitivity (including geographic sensitivity) to the reporting of low numbers to ensure that the identity of individual communities and the privacy and confidentiality of individuals are not inadvertently breached.

Benefits: Reporting by urban/rural/remote areas would allow identification of issues particular to geography/access to health services; reporting by sex and age groups would enable better analysis of and actions addressing communicable diseases in population sub-groups.

Drawbacks: Reporting may exceed capacity to act to address identified problems.

Inclusion in national reporting - although not necessarily in NNDSS - of other (non-notifiable) communicable diseases that particularly affect Aboriginal and Torres Strait Islanders, e.g. rheumatic fever, scabies and other parasitic infections, trachoma, otitis media.

Benefits: A more accurate picture of all communicable diseases that particularly affect Aboriginal and Torres Strait Islander peoples and better estimation of the impact of that total burden of disease.

Drawbacks: More bad news? Effort to collate and pull together the information some of which is already available in a variety of studies and screenings, which may not all sit within the health area (eg school screening, prison screening).

### ***Using communicable disease information nationally (improving the use of information)***

There is a need for longer-term work on how the information is used nationally. Improved evidence of communicable diseases affecting Aboriginal and Torres Strait Islander people will mean an initial increase in the numbers and rates recorded. We need to consider how that information is managed in a constructive manner, specifically, how more *accurate* information provides opportunities for better communicable disease management, treatment and especially prevention programs.

Benefits: Better understanding of communicable diseases and their impacts, and the opportunities for improved planning, development, health infrastructure, resource allocation, and programs to prevent, educate and treat, and respond to outbreaks.

Drawbacks: Governments and health services may not use improved evidence appropriately, or not use it to improve the situation on the ground.

### ***Better connections between Indigenous health and environmental health data***

Improving this connection is part of adopting a more holistic approach to Aboriginal and Torres Strait Islander health and wellbeing. This would make explicit the relationships between poor environmental health factors (e.g. dust, inadequate 'health hardware', overcrowded living conditions) and communicable diseases that thrive in such conditions. The medical focus on treatment at health centres and hospitals is good at returning people to

their community but when that community has poor environmental health conditions, re-infection occurs more easily and patients can go round and round in a downward spiral.<sup>8</sup>

Benefits: A more holistic understanding and better-connected actions on broader aspects of communicable disease prevention in Aboriginal and Torres Strait Islander communities.

Drawbacks: Takes commitment, money, resources, when many primary services are stretched. Extending the boundaries of existing programs is difficult when they have been designed as ‘silos’. For instance, a program to survey and fix up health hardware in existing housing does not address overcrowding or poor nutritional practices in that housing.

#### **5.2.4 Workplace reforms**

##### ***Support training in the collection and reporting of standardised Indigenous identification for primary data collectors***

Develop and implement training, support and awareness activities for health personnel who are primary data collectors (e.g. GPs, other medical practitioners, nurses, patient administration in hospitals). Training should focus on collecting routine demographic data generally, including Indigenous identification (e.g. as does the New South Wales training program (New South Wales Health 2003). Although this could be seen as primarily a jurisdictional responsibility, the Australian Government could assist in a number of ways that range from under-writing the provision of, or making standard brochures and training material available (e.g. through ABS and HIC), and through a national ‘train the trainer’ program and materials. Education campaigns with the general public, with Aboriginal and Torres Strait Islander communities, and with health professionals - about identifying and what it means - is another specific suggestion in this area.

There is an ongoing need for health staff to participate in Aboriginal and Torres Strait Islander cultural awareness/safety education and training. Education and training programs for collecting quality demographic data (including Indigenous status) on patients and clients should not be confused with Aboriginal and Torres Strait Islander cultural awareness/safety.

Benefits: Improved understanding of why data is important to collect, increased health staff comfort with Indigenous identification as a standard and routine part of gathering patient/client demographic details, increased comfort for Aboriginal and Torres Strait Islanders providing information, and improved quality of data collected. As trained health staff and health system users move around the health system, training in the standard has a flow on effect that will accelerate when it achieves critical mass. The focus on demographic data including Indigenous identification means the Indigenous identification question is destigmatised for health staff, Aboriginal and Torres Strait Islander people and especially the general population.

Drawbacks: Could be perceived as adding an extra load to frontline staff; difficulties in ensuring that *all* staff receive adequate training and follow-up with increased staff turnover, rotation and casualisation; overcoming cynicism and the perception that, even though staff are required to collect data, no one ever uses it, and views that data collection is unimportant.

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<sup>8</sup> The NSW Health *Housing for Health* program uses the story of Kylie’s first 2 years, when, after a range of infections and re-infections (gastroenteritis, otitis media, giardia) her growth (weight) had dropped from the nintieth to the tenth percentile for her age (Standen 2004).

### ***Improve GP capacity to collect data***

Regardless of which system a jurisdiction has implemented, medical practitioners are the primary data source for Indigenous identification in communicable diseases. GPs are often the major notifiers, and/or providers of data for enhanced surveillance, of communicable diseases. Data currently provided by GPs is assessed as poor in relation to the national standard (e.g. it is frequently assumed that GPs guess or assume the Indigenous identification of clients rather than asking). GPs are increasingly busy and find 'red tape' reporting burdensome. GP client information systems may not support collection of Indigenous identification and medical practice software may need to make changes to bring it into line with the national standard for Indigenous identification. Improving GP capacity to collect Indigenous identification is one of the most important options, and there were several ways identified.

Jurisdictions can remind GPs and other medical practitioners of their obligations under State and Territory public health legislation - to notify communicable diseases - and raise awareness of their importance in the public health response. Refreshing GPs on their reporting requirements, that include Indigenous identification in communicable disease notifications, is clearly a jurisdictional responsibility.

There is a role for the Australian Government to introduce, in cooperation with professional associations, education and training, accreditation and awareness initiatives in data collection generally, including Indigenous identification.

It would also be useful for the Australian Government to negotiate with software companies to ensure that GP client-based information systems (e.g. Medical Director) make changes to standardise data fields nationally for the recording of Indigenous identification.

The Australian Government and jurisdictions could explore all avenues with the potential to increase the automated or electronic transfer of already collected data (reducing the need to fill in forms) between GPs, pathology, and jurisdictional public health authorities.

Benefits: Improved quality and more professional collection of data. Better compliance of GPs with jurisdictional requirements. Increased automated or electronic transfer of data (including Indigenous identification) will reduce error and save time for medical practitioners.

Drawbacks: Workplace reform and changes to practice and information systems are required. There are difficulties in pushing training out to all GPs and other medical practitioners across the health system especially in competing for the scarce attention and time of busy practitioners. Many GPs are sceptical as to whether the many calls for information placed on them contribute to making a difference in the health of their patients. There are costs involved with making changes to medical practice software and other IT systems to increase electronic transfer of data.

### **5.2.5 Information systems**

#### ***Indigenous identification in all health-related information systems***

Indigenous identification needs to be implemented in *all* health information systems. Indigenous identification is already implemented to varying degrees in hospitals, death registrations, and in GP and other health practitioners' data but the effort needs to be sustained to increase the Indigenous identification completion rate in all health-related information systems. Improvements in Indigenous identification in any one system have the

potential to flow through to other systems over time (e.g., hospital data improvements can be shared with communicable diseases reporting systems as in the Northern Territory). There is a role for Aboriginal and Torres Strait Islander leadership to encourage and insist on good quality Indigenous identification. The Australian Government could lead by promulgating national standards, and by supporting and enabling changes that will be necessary to implement this option.

There is a role for the jurisdictions to enable health systems that collect Indigenous identification data to share the data (among authorised personnel) in relation to communicable diseases. Examples where this is already occurring include the Qld initiative to link pathology systems to patient registration details in public hospitals; and Northern Territory and Queensland data matching to augment Indigenous identification in communicable disease notifications from other data sources (such as hospitals). Where Indigenous identification data that has already been collected is unable to be shared in the health system, the only alternative is for public health authorities to do follow-up requests for information to medical practitioners and/or patients.

**Benefits:** Indigenous identification data once collected in the health system is able to be shared eliminating its repeated collection, and limiting calls on medical practitioners for missing information. Improvements in one system (e.g. hospitals) can improve Indigenous identification in other systems (e.g. communicable diseases) as is already occurring in a number of jurisdictions. The emphasis is on intelligent sharing of data across health-related information systems that have a need for it.

**Drawbacks:** While some jurisdictions have already initiated data sharing activities, others have attempted to do so and been refused. This option may require a change of philosophy within jurisdictional health departments; and may be of limited benefit where jurisdictions do not have patient/client master indexes. There may also be concerns about the safety of data sharing, and perceived risks to privacy and confidentiality.

### ***Indigenous identification in pathology systems***

Implement Indigenous identification in pathology systems including both public and private pathology systems through the *'inclusion of Indigenous identification on pathology request forms, and thence in pathology databases, and data provided as part of notification to public health authorities'*. Indigenous identification is absent in most pathology systems in all jurisdictions (except some public hospitals that can share patient registration data with pathology). Most jurisdictions depend heavily on pathology-based notifications of communicable diseases, and nationally notifiable communicable diseases are increasingly defined by pathology results. The option of implementing Indigenous identification in pathology systems was most frequently identified as a measure that requires urgent action.

Jurisdictions are responsible for changes in public pathology systems and some have/are in the process of implementing Indigenous identification in public pathology laboratories. In some jurisdictions there is a misconception that the Health Insurance Commission (HIC) prohibits the request of Indigenous identification on the pathology request form. While the HIC does not require this information, neither does it prohibit it; pathology laboratories may request additional information to that required by the HIC (personal communication, Mr D Marshall, HIC).

Private pathology is outside the control of the jurisdictions. In most states a few pathology companies do the majority of tests and identifying these may be an entry point for initiatives to improve Indigenous identification. The increasing corporatisation of previously 'stand

alone' private pathologists into larger associations or 'federations', which plan to implement or already share corporate information technology (IT) systems, presents opportunities to implement Indigenous identification, meet national health information standards, and enhance electronic data transfer systems - especially if requirements could be identified and progressed opportunistically over time as IT systems change. The Australian Government could kick start some change by making notional funding available to the first that are willing to make system changes to meet national standards. Once changes have been made to pathology databases, Indigenous identification data can be provided through changes to request forms or to labels. The option of *Making reporting easier*, below, addresses the GP-pathology interface more specifically.

**Benefits:** After the option of improving GP capacity to collect Indigenous identification, the option of including Indigenous identification on pathology requests and reporting would have the greatest impact on Indigenous identification completion rates in communicable disease notifications. The benefit would be greatest in jurisdictions that currently rely most on pathology-based reporting of communicable diseases, including New South Wales and Queensland – jurisdictions with large numbers of Aboriginal and Torres Strait Islander people, and low overall Indigenous identification completion rates.

**Drawbacks:** Getting pathology labs to change the pathology data set is seen as a major challenge initially, especially for private pathology; getting compliance over time is seen as an even bigger challenge. Diffusing change to all players at the frontline will need hard work and longer term activities - to disseminate, to educate and raise awareness, to remind, and to monitor and follow-up.

### ***Making reporting easier***

Once GPs are adequately collecting Indigenous identification data and notifying communicable diseases, *'the final step is to make the process easier'*. A system where doctors can use their practice software to notify public health authorities of pathology-confirmed communicable disease would be ideal. Improvements could be gained though GPs and/or hospitals adding Indigenous identification data to patient demographics printed on labels for attachment to pathology request forms, or printed on the forms themselves, so that pathology can report Indigenous identification with results.

Changes in general practice software to automate the doctor-pathology request/report function, and the electronic notification of communicable diseases to jurisdictional public health authorities are already being developed or considered in most jurisdictions. For GPs required to notify, improvements might be best gained through reminders and triggers (i.e. reminder that this disease is notifiable, trigger to include Indigenous identification if available, if not, to ask/have receptionist ask the question at next consultation, etc) that address the limitations of time-poor GPs.

The pathology request/report function is regarded as the next electronic enhancement for general practice software as many of the components are in place. Some plug in pathology request/report modules (pay per use) are available (e.g. Telepathy for Medical Director, Western Australia's PathCentre Direct). About 19 million 'episodes for pathology requests' are processed nationally according to Telepathy. About 100,000 communicable disease notifications are made annually. Around 15,000 doctors (85% of those who are computerised) use Medical Director general practice software, according to the maker, HCN.

Changing existing commercial software is likelier to be achieved if there is *one requirement nationally*, rather than a different requirement for each and every State and Territory. This is

an area where the Australian Government could usefully contribute, leading with standards and in jurisdictional and commercial negotiations, for instance with software providers.

Benefits: Making the reporting process easier may by itself bring gains in the completeness and quality of reporting. Transfer of electronic data avoids errors arising from re-writing and/or re-keying of data stored in GP patient practice software. Focus on easier reporting and implementing measures that save time and increase accuracy by automating routine processes helps busy GPs and enables value adding and productivity gains from the implementation of IT.

Drawbacks: Would require changes in general practice and related software (third parties). May need to use financial incentives to accelerate changes and to ensure changes are made to conform to the national standard.

### ***Improve capacity to electronically transfer data across health systems***

Explore all avenues with the potential to increase the transfer of automated or electronic data across health systems. This would include transferring patient demographic data (including Indigenous identification) into generated forms (electronic or paper) such as notifiable disease notifications and pathology test requests. Eliminate filling in forms by hand and multiple re-keying of data. Specifically, increase electronic transfer of data:

- (1) from GPs to pathology laboratories and back, and from pathology laboratories to jurisdictional public health authorities,
- (2) between different elements in hospital systems (eg patient registration, pathology, emergency department);
- (3) between different elements in health systems (eg sharing data to improve Indigenous identification between communicable disease and hospital patient registration systems).

Benefits: There are a range of reasonable medium term options to improve Indigenous identification in communicable disease reporting through improving/increasing electronic transfer of data between data users (GPs, pathology laboratories, hospitals, state public health authorities, and ultimately the NNDSS). In many cases the elements are in place and a connection would enable data sharing. Once Indigenous identification is on the agenda, adding it to existing systems can be done opportunistically (to take advantage of other changes). Over the longer term a true electronic health record (eg via HealthConnect) has enhanced potential.

Drawbacks: Getting different systems to reach agreement, resources needed to make changes to existing health systems. Many of the underpinning IT systems currently in use do not have any facility to receive/record/report Indigenous identification, are relatively inflexible, platform dependent, costly to change, have backlogs of changes waiting and IT systems themselves are used as an excuse and seem to act as a disincentive. Where capacity exists at one point (e.g. the GP may be able to use practice software to electronically request pathology) it is not carried through to *all* points of the system. There is '*Much work to be done, but also a lot of potential to improve*'.

### ***Use the Medicare number to improve Indigenous identification***

The Health Insurance Commission (HIC) is implementing a voluntary Indigenous identification program with Medicare. Several stakeholders suggested that wider use of the

Medicare number and associated voluntary identification could improve Indigenous identification in many systems including GP, pathology and pharmacy. A related option is to support the Medicare associated voluntary Indigenous identification program (HIC) for eventual use in data audits and/or data matching in other systems.

There is widespread mis-information around the HIC's voluntary identification project and its possible uses, with some stakeholders assuming that the Indigenous identification component would be determinable from the Medicare number, which is not so (personal communication, Ms C Levy, HIC). Although a substantial number of Aboriginal and Torres Strait Islanders have taken up the option to voluntarily self-identify in association with Medicare it could be years before coverage becomes sufficiently extensive to overcome data deficits in other areas. Potential uses of voluntary Indigenous identification information are in the process of being carefully structured and developed. Data matching, in research/audit programs rather than real-time functions, is a more likely use of this data. Any potential use of Medicare voluntary Indigenous identification data is subject to approval and needs to be in line with the stated purpose of collecting the information:

**The Aboriginal and Torres Strait Islander question is voluntary.** This information will be used to improve government health programs and outcomes for Indigenous people.

**Privacy Note:** The information provided on this form will be used to determine eligibility for Medicare benefits and to maintain a record of entitled persons for government programs administered by HIC. Collection of this information is authorised by law and may be disclosed to the Department of Health and Ageing, Centrelink, the Department of Veterans' Affairs and the Department of Immigration and Multicultural and Indigenous Affairs. Your HIC identification number and your eligibility for any benefit administered by HIC may be provided to a member of the staff when you use a hospital, medical practice or pharmacy. (HIC 2003, original emphasis.)

It is premature to suggest the use of Medicare associated voluntary Indigenous identification as an overall solution for the need to improve Indigenous identification in communicable disease reporting and across the board.

**Benefits:** In the short term, the use of the Medicare voluntary Indigenous identification data could be investigated as a means of cross-checking other data in relation to communicable diseases; over the longer term, improvements in Indigenous identification in one system should flow on and be used to improve Indigenous identification in communicable disease reporting systems.

**Drawbacks:** The program needs evaluation for its acceptability, current population coverage and attained Indigenous identification completion rate, and an estimated timeline to achieve varying proportions of coverage. Aboriginal and Torres Strait Islander people are faced with significant barriers to use of the MBS (and PBS) schemes, as noted by Anderson (2002) citing a 1997 study finding that 15-38% of Aboriginal and Torres Strait Islander Australians had 'no effective Medicare number or card', while in urban areas 15-20% had no 'access to current Medicare numbers' (Anderson 2002, p. 10; citing Keys Young 1997). There are concerns in some areas over what the data will be used for, and calls for more clarity in the *purpose* of collecting voluntary Indigenous identification in association with the Medicare card.

### 5.2.6 Initiatives

Stakeholders suggested a range of specific initiatives including initiatives to develop or pilot small scale prototype systems to improve Indigenous identification in communicable disease reporting *in depth* over the short to medium term (rather than across the entire health system over the longer term). Exploring multi-jurisdictional areas, and other models for health care delivery to Aboriginal and Torres Strait Islander Australians are other initiatives described below. These initiatives are not prescriptive and there will be more that could be explored with stakeholders for the purpose of improving Indigenous identification in communicable disease reporting, and with the ultimate aim of improving the health and well-being of Aboriginal and Torres Strait Islander peoples.

#### *Pilot a targeted surveillance programs*

Develop a targeted, active, surveillance system working in partnership with specific Aboriginal and Torres Strait Islander communities and their health service providers (e.g. Aboriginal Community Controlled Health Services (ACCHS), hospital outpatients, other health services that manage a number of Aboriginal and Torres Strait Islander people). The aim of the system would be the collection, collation, analysis, interpretation, and dissemination of information to the point in the system that can use that information to develop interventions (especially prevention), evaluate their impact, and provide feedback to the communities and public health on achievements. The system would actively work at ensuring that better Indigenous identification *does* lead to better action - a multi-component response to reduce the impact of and to eliminate communicable disease diseases from communities. The system would be underpinned by the understanding (or contract) that collection of data leads to action to improve the situation and that participants are culpable if they fail to act.

The initiative is suggested as an alternative or addition to blanket across the board improvements in Indigenous identification practices nation-wide. The initiative is envisaged as a prototype or pilot system developed in concert with Aboriginal and Torres Strait Islander communities and health services managing a number of people on a daily basis or whose existence depends on providing services to Aboriginal and Torres Strait Islander people.

The prototype system is seen as being voluntary in nature (not imposed), with agreement between all parties on a minimum (the 'lowest common denominator') of data to be collected and reported. Models that could be examined and emulated include the hospital-acquired Infection Control System (South Australia) - see Box 9 below - and OzFoodNet). The aim would be to get the best data from a subset of the population, rather than bad data on everything<sup>9</sup>. A strongly implemented feedback mechanism is an essential component to complete the active surveillance loop, which should include better-targeted strategies for disease control and prevention, and include an education and prevention function. Communities and organisations agreeing to participate could start by working together on minimum data in common, and build a useable system from the ground up, over time, together with the necessary trust and collaborative arrangements (estimate 4-5 years). A

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<sup>9</sup> Bonita (2003) of the World Health Organization sets out general guiding principles for simplified surveillance systems: *limited good information is better than large amounts of poor quality data or no data at all*, minimum sample size is that required by age and sex to detect trends, and data collection must be related to data use.

prototyping approach is suggested with the possibility that the system, if shown to be effective for participants over a reasonable timeframe, could be expanded to other areas.

Benefits: A targeted surveillance system could be a better use of resources and more effective in using surveillance information to improve the health and wellbeing of Aboriginal and Torres Strait Islander people than a blanket national activity with the drawbacks of the time required to make major changes to current practices (eg, in pathology laboratories, in GP reporting, in data transfer and interchange systems).

Drawbacks: A prototype or pilot will take time to develop, and even if well resourced adds extra load to pressured 'on the ground' services. The possibility of failure is a risk if the prototype is not seen as a priority and accordingly valued, or if the necessary quality human resources are not available.

### Box 10 Case Study: the South Australian Infection Control Service (ICS)

Responding to 'increasing concern at international, national and state levels [over] healthcare-associated infections and the spread of antibiotic-resistant organisms' the ICS was established in July 2001 with two main functions: 'the establishment and maintenance of state-wide surveillance systems for healthcare-associated infections (HAIs); and the promotion (in association with healthcare establishments) of appropriate interventions to reduce the rate of HAIs in South Australia' (Communicable Control Disease Branch 2003).

The ICS is a **voluntary network** or system of participation in state-wide healthcare-associated infection control. It is not a compulsory system.

'There is no legislation pertaining specifically to infection control in South Australia. The approach has been to work with healthcare institutions to develop safer practices through voluntary surveillance of healthcare-associated infections and provision of guidelines, education and specific assistance with interventions' (Internal documents provided by Dr C Cooper, Head of Infection Control Service).

Hospitals have duty of care requirements to minimise healthcare-acquired infection; these infections are very expensive to treat; any action to minimise costs is useful to hospitals.

ICS MISSION: 'To reduce the incidence of healthcare associated infections in all South Australian healthcare institutions.' To achieve this, the ICS **links surveillance and intervention strategies**. The philosophy is that surveillance should always inform interventions and vice versa' (Internal documents, as above).

The network now consists of all metropolitan public and private hospitals and all country hospitals (about 35-40). Initially two private and five public hospitals were asked if they would like to contribute data. They agreed and have been contributing since 1997. Other hospitals have approached ICS to ask if they also can contribute data and join the network.

PRODUCT: The ICS provides regular, timely reports that allow contributors to look at and benchmark their own data against the state-wide average.

PHILOSOPHY: **maximise benefits, minimise inputs**. Make data contribution as easy and attractive as possible and provide benefits for contributors. The ICS network value adds to the hospital data in a way that is clinically useful in a continuous improvement framework. The work of data input is reduced – initially contributors could for example, send in photocopied infection committee reports and the data was tidied up at the ICS end; over time standard data forms and indicators (16) have evolved.

ACTIVITIES: Meets 3 monthly with hospital CEOs for enhanced understanding. Holds 6-weekly meetings via the South Australia Nosocomial Infection Taskforce, attended by around 20-25 Infection Control Practitioners (ICPs) - started as a surveillance group and has developed into a general forum for a range of infection control issues. Training programs for country ICPs and infection control link nurses. A range of other continuous improvement activities.

OUTCOMES: MRSA (Methicillin-resistant *Staphylococcus aureus*) rates have halved in last two years meaning a reduction in hospital costs of treating. (US found a 30% decline over a 10 year period.) Attributed to regular feedback of data, and new hand washing techniques.

SUCCESS FACTORS: Voluntary system, of value to contributors. Value adding to existing data, making data provision easy. Very confidential information – no leaks to press.

### ***Pilot integrated monitoring in an urban setting***

Urban Aboriginal and Torres Strait Islander populations are identified as of particular concern and as an emerging issue. Although more than 30% live in the large urban areas (and ‘*wherever there’s a town there’s a Torres Strait Islander*’) they can become invisible in data collections as they form a very small proportion of the total urban population. Hence the option to pilot a study trial in an urban setting at an Aboriginal Community Controlled Health Service (ACCHS) to set up a system between the ACCHS, state public health authorities, and pharmacy to monitor the treatment outcomes of people presenting with a communicable disease. The trial could explore treatment, including patient medication history and compliance with treatment regime (eg, antibiotics). It could also cross-check public health and ACCHS information with that held by local pharmacies. Could be beneficial to investigate use of Master of Applied Epidemiology students as a potential resource for the pilot.

Benefits: Provision of information on an urban Aboriginal and Torres Strait Islander population - identified as an emerging issue and little information available to date. Benefits from additionally resourcing a connection between different elements of the health system to study an issue in common.

Drawbacks: Competing for resources.

### ***Geographically based, multi-jurisdictional, cross-border initiatives***

Cross-border and multi-jurisdictional issues related to the spread and containment of communicable diseases, and taking into account the mobility of Aboriginal and Torres Strait Islander populations were raised by stakeholders. Studies have demonstrated the need to intervene in wider areas when screening for and treating communicable disease in mobile populations. Variations in climate and rates of disease among the neighbours with whom we share borders and human migration paths (e.g. through the Torres Strait Islands to Papua New Guinea) also need to be considered. Several geographic regions have issues in common in Aboriginal and Torres Strait Islander communities and are perceived as obvious areas for coordination and consideration as a *single communicable disease area*. Further exploring the benefits of multi-jurisdictional, cross border initiatives is proposed, for instance initiatives across the areas of:

- Northern Australia - northern Western Australia, northern Northern Territory, and northern Queensland – issues have included e.g. donovanosis eradication, syphilis outbreaks, Murray Valley encephalitis.
- Central Australia - lower end Northern Territory, Goldfields region Western Australia, northern South Australia and possibly parts of southwest Queensland.
- Papua New Guinea, the Torres Strait and northern Queensland – issues have included e.g. HIV/AIDS, malaria.

Multi-jurisdictional initiatives would integrate communicable disease response across geographic areas that are affected by similar communicable disease profiles or describe Aboriginal and Torres Strait Islander mobility patterns. For instance, the *Queensland Indigenous Sexual Health Strategy 2003 to 2006* in describing how cross border issues affect service delivery, says that ‘given the nature of the travel of many Indigenous Queenslanders across international, state and territory borders, it will be necessary to work with a range of governments to improve service delivery to Indigenous people living in these areas. This

work should include efforts to better integrate services, improve access to early detection and treatment services, and improve data and monitoring systems. In particular, work needs to occur in the Torres Strait Treaty Zone and strengthening of Queensland's links to Papua New Guinea' (Queensland Health 2003b, p. 22).

Multi-jurisdictional approaches could address population mobility with the need for all within-area health services to provide communicable disease treatment and management services that are not compromised by population mobility (e.g. schedule screening, treatment and prevention/ education activities in concert and at similar times; ability to track patients and their treatment regimes across services on both sides of a border to ensure continuity, ability to eliminate multiple notifications for the same person in different areas).

Benefits: Better treatment and prevention effect for the same investment. Health services working together with Aboriginal and Torres Strait Islander communities to achieve a shared aim. Joining together in action may also have a benchmarking effect for the jurisdictions involved as the most efficient, cost-effective program available is identified and implemented more widely.

Drawbacks: Requires agreements of all jurisdictions involved on priorities and communicable disease issues that can usefully be tackled in multi-jurisdictional initiatives and similar commitment of resources both financial and human. There is a risk that the opportunity cost of *not* undertaking initiatives to develop multi-jurisdictional surveillance and response will not be considered.

### ***Exploring an adaptation of the Veterans' health care model***

The Veterans' health care model, administered by the Department of Veterans' Affairs provides a contrast to the universal service or 'mainstream' model that is, in some areas, still struggling to capture quality data on Indigenous identification. Australia has accepted the concept that returned service men and women, their spouses and families, have an entitlement to differential access to the health care system in recognition of their war service. Differential access is granted to '*card carrying members*' and includes special treatment arrangements, differential rebates and access to pharmacy. Veterans and their families form an identifiable subgroup with particular morbidities, for which the Australian Government and the community have accepted special responsibility. The population covered is approximately 340-520,000 (similar to the size of the Aboriginal and Torres Strait Islander population) with different levels of entitlement (there are white and gold cards). The Veterans' health care model has been able to provide tailored and appropriate services to veterans and their families in a sustained manner over a long period of time. A similar concept could be explored for the Aboriginal and Torres Strait Islander population, to concentrate substantial resources to improve Aboriginal and Torres Strait Islander health to the level of non-Indigenous health (to '*close the gap*') over the long term. At the least the Veterans' health care model could be explored for beneficial lessons relative to a sustained focus on improving the health of a population subgroup (e.g. use of a central repository of information).

Benefits: At the least, lessons on targeting health service delivery to a population subgroup over a long time; at most, delivering health services through such a model could be a more effective way to prioritise the health needs of Aboriginal and Torres Strait Islander Australians and concentrate on closing the gap.

Drawbacks: Acceptability to the Australian Government, to Aboriginal and Torres Strait Islander and non-Indigenous Australian communities. Costs of setting up and administering may divert money and resources from delivery of direct services.

## 6 A consistent approach nationally

Respondents were in favour of a consistent approach nationally and saw merit in building on the steps already taken to achieve one. The Communicable Diseases Network of Australia (CDNA), agreement on nationally notifiable diseases, and the national case definitions for notifiable communicable diseases, were identified as positive steps to be built on.

*‘National guidelines have overcome a lot of the variable reporting criteria caused by different definitions rather than different situations.’*

Respondents also believe there could be more value in having targeted approaches than in spending the effort universally improving national surveillance across the board. Key questions were the purpose of national surveillance and the best way to do it. For instance, for the purpose of identifying trends, the use of sentinel sites could be more effective than total population surveillance.

A national approach could then be more usefully targeted to certain diseases, such as STIs and vaccine preventable diseases.

It was also argued that the health of Aboriginal and Torres Strait Islanders in large urban centres has more in common with that of other urban populations that share similar determinants of health (e.g. poverty, overcrowding, low education). Rates of communicable diseases do ‘appear to be lower in urban areas than rural areas’ while there are various conditions that are almost exclusive to rural/remote Aboriginal and Torres Strait Islander communities, including rheumatic fever and heart disease, donovanosis, blinding trachoma, chronic suppurative otitis media and deafness (Black 2004). The focus should be on tackling communicable diseases in remote and rural populations with less access to health care services, poorer environmental health, and other barriers to treatment and prevention.

### *Alternatives to a consistent approach nationally*

A *prioritised* approach was raised as an alternative to a consistent national approach. The focus should be specifically on key diseases affecting Aboriginal and Torres Strait Islanders, and on key geographic areas (e.g. remote areas) that would benefit more from improvements in Indigenous health than others, and to put substantially more resources into those diseases and populations.

A related option was to concentrate on measuring major preventable diseases properly: e.g. STIs, meningococcal infection, pneumococcal infection and other vaccine preventable diseases; and to concentrate on diseases for which there are effective or new interventions (tests, vaccines, treatments) available.

Respondents also identified that there is a need for targeted strategies for specific diseases. Sentinel site surveillance could be used for diseases that are likely to be difficult to monitor nationally.

Prison populations were suggested as a sentinel population (due to the over representation of Aboriginal and Torres Strait Islander people<sup>10</sup>) because they would give a good indication of the upper bounds of rates of disease. While HIV/AIDS could be under-stated because it affects different groups of people, for Hepatitis C and most other infectious diseases the

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<sup>10</sup> Reportedly, Aboriginal men form 20% of the jail population, and Aboriginal women 23-27% of the jail population over Australia.

prison population would provide enough information. The sentinel practice idea has been used extensively in HIV monitoring in the non-Indigenous population (e.g. using St Vincents Hospital as a sentinel site has usefully enabled early information on HIV rate rises to be picked up). As a high risk population a good argument could be made for permanent (rather than stop-start) screening of people that enter and exit the prison system.

Cross sectional samples (e.g. one week) could be taken of common communicable diseases with high case numbers (e.g. Chlamydia, and rather than no follow-up), to follow up all cases in the sample for additional information including Indigenous identification. An alternative would be to follow-up a sample on a random or rolling callback basis.

### ***Points in favour of a nationally consistent approach***

*Nationally consistent data means a larger database that provides more quality information.*

With sufficient high quality consistent data, when a problem is different in two areas, there can be confidence that it is not because there is a difference in the way the data were collected, and that it must therefore be a *real* difference. Some consequences of this are: that an intervention can be piloted in one area that is known to be similar to others and outcomes can be meaningfully compared; and that it provides the ability to '*identify real consistency versus real differences in communicable diseases*'.

A large and consistent database allows comparison of interventions (e.g. which is the most successful) and the knowledge that apparent differences in success are not due to better data collection or other reporting artefacts, hence '*more opportunistic interventions are possible*'.

### *A more informed, nationally consistent approach*

Communicable disease issues differ as do Aboriginal and Torres Strait Islander communities across the country. A consistent approach nationally (meaning that all jurisdictions can report to a similar level, rather than some reporting and others not) is the only approach that makes sense if the purpose is to better inform policy and decisions relating to communicable diseases in Aboriginal and Torres Strait Islander populations. This would include the evaluation of programs nationally, improvements to surveillance generally, and the identification of areas of most need. It is '*better to be able to do it in all states not just some*', and although current national reporting is only for Western Australia, South Australia, Northern Territory, the majority of Aboriginal and Torres Strait Islander peoples live in the jurisdictions that are not reported nationally, and the risk is that decisions at a national level will be made based on incomplete jurisdictional data.

### *Equitable funding*

A nationally consistent approach (with *all jurisdictions* reporting and involved) is essential so that equitable national funding can be achieved. Equitable funding should be based on assessed need for e.g. prevention, management and treatment of communicable diseases in Aboriginal and Torres Strait Islander populations.

*Some system changes would work best at a national level*

For pathology systems, the requirement to report Indigenous identification on laboratory requests and results requires national engagement of the Australian Government and key stakeholder groups (e.g. Aboriginal Torres Strait Islander Commission, the Public Health Laboratory Network, The Royal College of Pathologists of Australasia). Any possible use of the voluntary Indigenous identification associated with Medicare similarly requires such engagement.

## **6.1 Barriers to a consistent approach nationally**

Barriers to a consistent approach nationally to Indigenous identification in communicable disease reporting systems were identified as:

- Federation! Differences between the States and Territories. Difficulties in getting agreement from all jurisdictions and nationally.
- Ability of the Australian Government and the States and Territories to work together, and to work together with similar levels of commitment.
- Legislation – communicable disease notifications legislation is different in every State and Territory. There are also issues re medical practitioners’ perceptions of new Australian Government privacy laws that affect collection of items like Indigenous status and risk factor information.

## **6.2 Opportunities for a consistent approach nationally**

Opportunities for a consistent approach nationally to Indigenous identification in communicable disease reporting systems were identified as:

- Build on the Communicable Diseases Network of Australia (CDNA) collaboration, and agreements such as the national case definitions, now that these moves towards national uniformity are underway. Use CDNA to drive the Indigenous identification issues onto jurisdictional and other communicable disease relevant agendas to increase the momentum.
- Now that the National Aboriginal Community Controlled Health Organisation (NACCHO) and Aboriginal and Torres Strait Islander health services are increasingly ‘seeing’ the value of Indigenous identification generally and of research, the momentum is greater and there is opportunity in the way in which information is gathered and used in the mainstream to recognise Aboriginal and Torres Strait Islander peoples’ sensitivities better.
- The existence of national professional organisations (e.g. the Royal College of Pathologists of Australasia, the National Public Health Laboratory Network) should facilitate work to bring about a nationally consistent approach (including Indigenous identification) to pathology reporting.
- Linking improvements to practical reconciliation could be used to piggyback greater uniformity among the jurisdictions.
- Disseminating information to the point in the system that can use that information – for the development of interventions, evaluation of interventions, and feedback to public health on achievements can be used to strengthen the national approach.

- Opportunity is also created through increased national recognition of the importance of better information on health inequalities. Health inequalities are well documented even with incomplete data (better, more complete data will show the same picture of health inequalities). Aboriginal and Torres Strait Islander health peak bodies - including Aboriginal Community Controlled Health Organisations - need to recognise the importance of the health inequalities shown in communicable disease reporting and drive improvements with appropriate government and other stakeholders.

## 7 Recommendations

The Steering Committee clearly wanted to see strategies/recommendations that created a *sustained* improvement in Indigenous identification in communicable disease reporting. This requires a sustained change process that is supported by the Australian Government and jurisdictions. The Steering Committee recognises that improvements and changes can only be sustained if they happen through a number of processes. Collecting and reporting Indigenous status in all communicable diseases collections in all jurisdictions must be a standardised process. This is the number one recommendation. This can be achieved through action in: developing **Policy**, creating **Incentives**, improving **Reporting**, introducing **Workplace Reforms**, enhancing **Information Systems**, and in exploring **Initiatives** for targeted change.

There are issues raised in this Draft Discussion Paper that may be perceived as being outside the scope of the Project. These wider issues impact on Indigenous identification in communicable disease and the reporting processes, and as such could not be ignored. The recommendations put forward in this paper may therefore be categorised into two main areas: those strategies that directly aim to improve Indigenous identification on communicable disease reporting, and those that focus on addressing wider issues that also impact on Indigenous identification in communicable disease and reporting processes.

This Committee has recommended a process of communicable disease notification that works more effectively, allows proactive planning, more effective interventions, that fits within the broader picture of the ‘surveillance loop’ using data to improve action in communicable diseases affecting Aboriginal and Torres Strait Islander Australians. The real backbone of communicable disease surveillance systems is the strong implementation of the feedback loop, so that the information does not end up in a ‘data graveyard’ but is actively used to base actions to address communicable disease occurrence. Feedback makes or breaks the system in the long term, and without feedback the system will lose the impetus of Aboriginal and Torres Strait Islander partners (as well as mainstream partners).

The Steering Committee has thus adopted a comprehensive approach that includes recommendations for changes in all the areas listed (in boldface) above. The Steering Committee recognises that many gains have already been made, and that there are opportunities for further gains over a range of time scales. The immediate priority is getting a commitment to the implementation of the recommendations on to all relevant agendas and across all sectors pertinent to communicable disease reporting, and an agreement for a structure to monitor and review actions arising from the recommendations as a result of this commitment.

### *Underlying principle*

**A fundamental principle underlying the actions required is the need to work together with Aboriginal and Torres Strait Islander organisations representing Aboriginal and Torres Strait Islander peoples in strong partnership arrangements where relevant to the recommendations.**

The recommendations to the Department of Health and Ageing are for actions in five areas. Recommendations are addressed to *All*, to the *Australian Government* and to the *Jurisdictions*, and are set out over the short (within 1-2 years), medium (within 2-4 years) and longer term (within 4-6years). Comprehensive tables setting out all recommendations (Table 10) and proposed initiatives (Table 11) conclude this section.

## **7.1 Policy**

In the short term (over one to two years) the recommendation (to all) is to make the collection and reporting of Indigenous identification a mandatory requirement in all health policies relevant to communicable disease.

The Australian Government is recommended to: set benchmarks and milestones to reward gains in Indigenous identification made by the jurisdictions; and to provide model public health instruments for legislative change (moving towards national public health legislation over the longer term).

Jurisdictions are recommended to legislate the collection and reporting of Indigenous identification as a mandatory requirement in all health policies relevant to communicable disease (jurisdictions that have not already done so and that are planning changes to public health legislation).

In the medium term (over two to four years) the recommendation (to all) is to implement a standardised process that incorporates the Indigenous identification standard into all collections on communicable diseases through Communicable Diseases Network of Australia (CDNA).

The Australian Government is recommended to: provide support for jurisdictions to develop and implement the ABS standard for the collection of Indigenous identification in communicable disease reporting; and negotiate changes to pathology reporting systems to include Indigenous identification from primary collectors (requesting medical practitioners).

Jurisdictions are recommended to develop and implement (with support from the Australian Government) collection of national standard Indigenous identification into all communicable disease collections.

In the longer term (over four to six years) the recommendation (to all) is to use information on Indigenous identification in communicable disease reporting in a constructive way to improve the health of Aboriginal and Torres Strait Islanders through effective planning, development and resourcing of treatment & prevention services for communicable diseases.

The Australian Government is recommended to introduce National Public Health Legislation that mandates collection and reporting of Indigenous identification in communicable diseases notifications.

## **7.2 Incentives**

In the short term (over one to two years) the recommendation (to all) is to continue to fund proven best gains and prevention (e.g. immunisation, Donovanosis eradication).

The Australian Government is recommended to fund 'field officers' to work in jurisdictional Public Health Units and with primary data collectors (e.g. GPs, ACCHSs). The jurisdictions are recommended to work with the field officers.

Jurisdictions are also recommended to continue or explore or evaluate the use of incentives (such as casemix) and 'performance agreements' with health service providers to improve Indigenous identification.

The Australian Government is also recommended to provide nominal incentives to software providers to accelerate software changes to bring Indigenous identification to the national standard, as a non-defaulting, mandatory data item.

In the medium term (over two to four years) the recommendation (to all) is for nationally

equitable funding (all jurisdictions) on a needs-assessed basis. The rationale is that as data completeness (enumeration) and quality improve, higher rates of communicable disease in Aboriginal and Torres Strait Islander populations are frequently demonstrated. Demonstrated high need should receive funding priority and additional resourcing to ‘close the gap’. Jurisdictions should aim to meet minimum standards for Indigenous identification data to participate in national programs designed to address demonstrated higher need, and to provide the additional resourcing required to bring Aboriginal and Torres Strait Islander health to the level of non-Indigenous health.

The Australian Government is recommended to revise national funding agreements and reporting to introduce incentives in relation to the quality of Indigenous identification (e.g. the Public Health Outcome Funding Agreement, the Primary Health Care Access Program, Health Care Agreements).

In the longer term (over four to six years) the recommendation (to all) is to achieve and sustain satisfactory Indigenous identification completion rates in communicable disease reporting.

The Australian Government is recommended to work through the National Public Health Partnership to ensure funding is linked to satisfactory and sustained gains in Indigenous identification.

The Australian Government is also recommended to develop a funding arrangement to support infrastructure maintenance and development in communicable disease reporting systems to assist jurisdictions to meet national standards.

### **7.3 Reporting**

In the short term (over one to two years) the recommendations (to all) are to: routinely monitor and report completeness of Indigenous identification data in communicable diseases through CDNA; identify key policy-relevant and/or program development networks and agencies and disseminate information to get improving Indigenous identification onto their agendas; and to publish communicable disease data in cooperation with Aboriginal and Torres Strait Islander organisations.

Both the Australian Government and jurisdictions are recommended to identify leading jurisdictions as models for best quality administrative function or performance and use a national approach to move towards best model.

Jurisdictions are also recommended to investigate multi-jurisdictional areas and methods for improved communicable disease surveillance and action to improve the related health of Aboriginal and Torres Strait Islanders.

The Australian Government is recommended to fund a permanent Secretariat to monitor and review progress on the actions set out in these recommendations.

In the medium term (over two to four years) the recommendation (to all) is to report the data in context, to show a more complex picture (e.g. including under-pinning determinants such as poverty, over-crowding, lack of education) rather than focusing only on Indigenous status.

The Australian Government is recommended to: report nationally on communicable diseases affecting Aboriginal and Torres Strait Islander people by urban/rural/remote regions (in a geographically sensitive manner that does not identify individual communities); and by age and sex groups; and to manage NNDSS Indigenous identification data categories to improve

correspondence with jurisdictional data (for jurisdictions that cannot yet meet the national standard).

The Australian Government is also recommended to collate existing material on *non-notifiable* communicable diseases with high impact on Aboriginal and Torres Strait Islander peoples (e.g. to collate the results of existing studies and screening; the existence of state-wide registers and programs, on conditions such as rheumatic fever, scabies and parasitic infections).

The Australian Government is recommended to investigate the collection of denominators for pathology testing.

Jurisdictions are recommended to make better connections between Aboriginal and Torres Strait Islander health and environmental health data and programs.

Over the longer term (within four to six years) the recommendation (to all) is to develop and implement a process and mechanism that enables reporting back to Aboriginal and Torres Strait Islander communities, useable information about communicable diseases.

The Australian Government is recommended to develop a nationally accepted set of rules for reporting Aboriginal and Torres Strait Islander data (National Data Principles and Protocols); and to support longer term work on how the information is used nationally in a constructive manner – as a standardised Indigenous identification process is implemented.

#### **7.4 Workplace Reforms**

Jurisdictions are recommended to: audit Indigenous identification completion rates and data accuracy in communicable diseases, and quality assure data collection methods against best practice; and to set data standards for transfer of demographic data in health.

In the short term (over one to two years) the recommendations (to all) are to: implement Indigenous identification as part of standard demographic data gathered on all health care users and include Indigenous identification in staff development and training programs; and improve General Practice capacity to collect standard demographic data and encourage/fund education and awareness initiatives with General Practice professional bodies.

The Australian Government is recommended to under-write provision of standard brochures and training material (e.g. ABS, HIC); a national ‘train the trainer’ program and materials; and community and professional Indigenous identification campaigns.

The Australian Government is also recommended to negotiate changes to health professionals’ training with relevant colleges (e.g. the Royal Australian College of General Practitioners) and professional groups (e.g. Divisions of General Practice).

Jurisdictions are recommended to continue or initiate training and support for primary data collectors (e.g. medical practitioners including GPs, hospital patient administration); and to actively seek out opportunistic ways to implement changes towards standard national Indigenous identification in communicable disease reporting.

In the medium term (over two to four years) the recommendation (to all) is to establish a minimum national data standard for the set of patient/client demographic data to be used in all health collections (including GPs, pathology).

## 7.5 Information Systems

In the short term (over one to two years) the recommendation (to all) is to enable sharing\* of available Indigenous identification data across health information systems.

The Australian Government is recommended to continue the Health Insurance Commission program of voluntary Medicare Indigenous self-identification.

The Australian Government is also recommended to liaise with software companies making GP client-based information systems (e.g. Medical Director) to improve and standardise data fields for Indigenous identification. (See also, *Provide nominal incentives to software providers*, under **Incentives** above.)

Jurisdictions are recommended to continue or explore data sharing and data matching\* across health information systems (e.g. hospital patient administration, pathology, emergency; hospital patient registers and communicable disease notifications) to improve Indigenous identification.

In the medium term (over two to four years) the recommendation (to all) is to aim for ‘once only’ data collection and to increase electronic transfer of collected demographic data (including Indigenous identification).

The Australian Government is recommended to provide model instruments to enable data sharing and support and encourage such initiatives in jurisdictions.

The Australian Government is also recommended to lead with standards for data transfer of health information (e.g. from GPs to pathology to jurisdictional public health units); and to support and encourage IT enhancements to meet national standards (e.g. GP practice software, pathology corporate IT systems).

In the medium term, jurisdictions are recommended to exploit potential to increase automated /electronic transfer of already collected data (i.e. to eliminate multiple re-writing and re-keying).

Jurisdictions are also recommended explore data linkage\* (for research purposes).

In the longer term (over four to six years) the recommendation (to all) is to work towards a national standard electronic health record (e.g. HealthConnect).

## 7.6 Initiatives

In the **short term** (over one to two years) the recommendation (to all) is to debate alternatives and/or additions to a consistent national approach, for example, targeted changes, sentinel sites, spot surveys; focus on key diseases (e.g. with effective treatments) and/or key geographic areas.

The Australian Government is recommended to:

- A. Develop a targeted surveillance system with Aboriginal and Torres Strait Islander partners and their health service providers, on a voluntary reporting model, to get the best data - including data on interventions and their evaluations - from a subset of population;

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\* with appropriate privacy and security, and due consideration given to Indigenous cultural sensitivities when data sharing/linking.

- B. Explore use of an MBS Item to reward GPs for good quality reporting on communicable diseases (notifications, enhanced surveillance, interventions);
- C. Explore the acceptability of, or see what might be beneficial from, other models such as the Veteran's health care model, with Aboriginal and Torres Strait Islander communities/ organisations and the wider community.

Jurisdictions are recommended to explore further multi-jurisdictional, cross border initiatives for geographic areas that can be considered as a single communicable disease area in terms of public health response, e.g.:

- Northern Australia - northern Western Australia , northern Northern Territory, and northern Queensland;
- Central Australia - lower end Northern Territory, Goldfields region Western Australia, northern South Australia and possibly parts of southwest Queensland;
- Papua New Guinea, the Torres Strait and northern Queensland; and
- Border areas (e.g. New South Wales, Queensland).

In the **medium term** (over two to four years) the recommendation (to all) is to determine the most effective way to prioritise the health needs of Aboriginal and Torres Strait Islander Australians to close the gap in communicable diseases.

The Australian Government is recommended to:

- A. Continue building the voluntary targeted surveillance system (estimate 3-4 years to build from ground up);
- B. Determine whether the other models explored would be a more effective way to prioritise the health needs of Aboriginal and Torres Strait Islander Australians;
- C. Pilot integrated monitoring in an urban setting (ACCHS, pharmacy, state public health unit);

Over the **longer term** (over four to six years) the recommendation (to all) is to explore a range of initiatives to improve the quality of Indigenous identification in communicable disease reporting.

The Australian Government is recommended to:

- A. Evaluate (if a trial) or enhance (if a prototype) the voluntary targeted surveillance system; and to
- B. Evaluate and/or implement Indigenous identification in pharmacy systems to monitor treatment for communicable diseases.

**Table 10 Recommendations**

Timeframe	Recommendations - to			
	All	Australian Government	Jurisdictions	
<b>Policy</b>	short term	Make the collection and reporting of Indigenous identification a mandatory requirement in all health policies relevant to communicable disease.	Set benchmarks and milestones to reward gains in Indigenous identification made by the jurisdictions; and provide model public health instruments for legislative change (moving towards national public health legislation over the longer term).	Legislate the collection and reporting of Indigenous identification as a mandatory requirement in all health policies relevant to communicable disease (jurisdictions that have not already done so and that are planning changes to public health legislation).
	medium term	Implement a standardised process that incorporates the Indigenous identification standard into all collections on communicable diseases through CDNA.	Provide support for jurisdictions to develop and implement the ABS standard for the collection of Indigenous identification in communicable disease reporting.  Negotiate changes to pathology reporting systems to include Indigenous identification data from primary collectors.	Develop and implement (with support from the Australian Government) collection of national standard Indigenous identification into all communicable disease collections.
	longer term	Use information on Indigenous identification in communicable disease reporting in a constructive way to improve the health of Aboriginal and Torres Strait Islanders through effective planning, development and resourcing of treatment & prevention services for communicable diseases.	Introduce National Public Health Legislation that mandates collection and reporting of Indigenous identification in communicable diseases notifications.	
<b>Incentives</b>	short term	Continue to fund proven best gains and prevention (e.g. immunisation, Donovanosis eradication).	Fund ‘field officers’ to work in jurisdictional Public Health Units and with primary data collectors (e.g. GPs, AMSs).  Provide nominal incentives to software providers to accelerate software changes to bring Indigenous identification to the national standard, as a non-defaulting, mandatory, data item.	Work with the Australian Government funded field officers.  Continue/explore/evaluate the use of incentives (such as casemix) & ‘performance agreements’ with health service providers to improve Indigenous identification.
	medium term	Nationally equitable funding (all jurisdictions) - demonstrated high need receives funding priority	Revise national funding agreements & reporting to introduce incentives in relation to the quality of	

Timeframe	Recommendations - to		
	All	Australian Government	Jurisdictions
longer term	<p>&amp; additional resourcing to 'close the gap'.</p> <p>Achieve and sustain, satisfactory Indigenous identification completion rates in communicable disease reporting.</p>	<p>Indigenous identification (e.g. Public Health Outcome Funding Agreement, Primary Health Care Access Program, Health Care Agreements).</p> <p>Work through the National Public Health Partnership to ensure funding is linked to satisfactory and sustained gains in Indigenous identification in communicable disease reporting.</p> <p>Develop a funding arrangement to support infrastructure maintenance &amp; development in communicable disease reporting systems to assist jurisdictions to meet national standards.</p>	
<p><b>Reporting</b></p> <p>short term</p> <p>medium term</p>	<p>Routinely monitor &amp; report completeness of Indigenous identification data in CDs through CDNA.</p> <p>Identify key policy-relevant and/or program development networks and agencies and disseminate information to get II onto their agendas.</p> <p>Publish the data in cooperation with Aboriginal and Torres Strait Islander organisations.</p> <p>Report the data in context, to show a more complex picture (e.g. including under-pinning determinants such as poverty, over-crowding, lack of education) rather than focusing only on Indigenous status.</p>	<p>Identify leading jurisdictions as models for best quality administrative function &amp; use a national approach to move towards best model.</p> <p>Fund a permanent Secretariat to monitor and review progress on the actions set out in these recommendations.</p> <p>National reporting on communicable diseases affecting Aboriginal and Torres Strait Islander peoples by urban/rural/remote regions (geographically sensitive - does not identify individual communities); and by age and sex groups.</p> <p>Manage NNDSS Indigenous identification data categories to improve correspondence with jurisdictional data (for jurisdictions not to standard).</p> <p>Collate existing material on non-notifiable communicable diseases with high Indigenous impact (e.g. results of studies, screening, existence of state-wide registers,</p>	<p>As for Australian Government</p> <p>Investigate multi-jurisdictional areas and methods for communicable disease surveillance &amp; action.</p> <p>Better connections between Aboriginal and Torres Strait Islander health and environmental health data and programs.</p>

Timeframe	Recommendations - to		
	All	Australian Government	Jurisdictions
longer term	Develop and implement a process and mechanism that enables reporting back to Aboriginal and Torres Strait Islander communities, useable information about communicable diseases.	<p>programs; on conditions such as rheumatic fever, scabies and parasitic infections).</p> <p>Investigate collection of denominators for pathology testing.</p> <p>Develop a nationally accepted set of rules for reporting Aboriginal and Torres Strait Islander data (National Data Principles and Protocols).</p> <p>Support longer term work on how the information is used nationally in a constructive manner – as a standardised Indigenous identification process is implemented.</p>	
<b>Workplace reforms</b>  short term   medium term	<p>Implement Indigenous identification (II) as part of standard demographic data gathered on all health care users; include II in staff development and training programs.</p> <p>Improve GP capacity to collect standard demographic data including II, and encourage/fund education &amp; awareness initiatives with professional bodies.</p> <p>Establish minimum data standard for set of demographic data to be used in all health collections (including GPs, pathology).</p>	<p>Under-write provision of standard brochures &amp; training material (e.g. ABS, HIC), national ‘train the trainer’ program &amp; materials; community &amp; professional II campaigns.</p> <p>Negotiate changes to health professional’s training with relevant colleges (e.g. Royal Australian College of General Practitioners) &amp; professional groups (e.g. Divisions of General Practice).</p>	<p>Continue/initiate training &amp; support for primary data collectors (e.g. medical practitioners including GPs, hospital patient administration).</p> <p>Actively seek opportunistic ways to implement change towards ABS standard for Indigenous identification in communicable disease reporting.</p> <p>Audit Indigenous identification completion rates &amp; data accuracy in communicable diseases, &amp; to quality assure data collection methods against best practice.</p> <p>Set data standards for transfer of demographic data in health.</p>
<b>Information systems</b>	Enable sharing* of available Indigenous identification data across health information systems.	Continue HIC program of voluntary Medicare indigenous self-identification;	Continue/explore data sharing, data matching* across health information systems (e.g. hospital patient

\* with appropriate privacy and security, and due consideration given to Indigenous cultural sensitivities when data sharing/linking.

Timeframe	Recommendations - to		
	All	Australian Government	Jurisdictions
short term		Liaise with software companies making GP client-based information systems (e.g. Medical Director) to improve & standardise data fields for Indigenous identification. See also, Provide nominal incentives to software providers, under <b>Incentives</b> above.	administration, pathology, emergency; hospital patient registers & CD notifications).
medium term	Aim for 'once only' collection and increase electronic transfer of demographic data including Indigenous identification.	Provide model instruments to enable data sharing and support & encourage such initiatives in jurisdictions. Lead with standards for data transfer of health information (from GPs to pathology to state CD units); support & encourage IT enhancements to ABS standard (e.g. GP practice software, pathology corporate IT systems).	Exploit potential to increase automated /electronic transfer of already collected data (eliminate multiple re-writing & re-keying). Explore data linkage* (research purposes).
longer term	Electronic health record (e.g. HealthConnect).		
<b>Initiatives</b>	Explore a range of proposed initiatives to improve the quality of Indigenous identification in communicable disease reporting.	As detailed in Table 11.	As detailed in Table 11.

AMS = Aboriginal Medical Service

CD = communicable disease

II = Indigenous identification

## Recommendation to explore a range of proposed initiatives to improve the quality of Indigenous identification in communicable disease reporting

In the interviews with key stakeholders a number of options were suggested that were of the nature of initiatives that could be explored: debated, piloted, trialed or prototyped, to improve the quality of Indigenous identification in communicable disease reporting and its purposive use, as broadly defined. The table below presents these exploratory initiatives but is not exclusive – there will be more initiatives that could be explored.

**Table 11 Proposed initiatives (not exclusive)**

	All	Australian Government	Jurisdictions
<p><b>Initiatives to debate, pilot, trial or prototype</b></p> <p>short term</p>	<p>Debate alternatives &amp;/or additions to a consistent national approach e.g. targeted changes, sentinel sites, spot surveys; focus on key diseases (e.g. with effective treatments) &amp;/or key geographic areas.</p>	<p>A. Develop a targeted surveillance system with Aboriginal and Torres Strait Islander partners &amp; their health service providers, on a voluntary reporting model, to get the best data from a subset of population and to include interventions and their evaluations.</p> <p>B. Explore use of an MBS Item to reward GPs for good quality reporting on communicable diseases (notifications, enhanced surveillance)</p> <p>C. Explore the acceptability of, or see what might be beneficial from, other models such as the Veteran’s health care model, with Aboriginal and Torres Strait Islander communities/ organisations &amp; the general public.</p>	<p>Explore further multi-jurisdictional, cross border initiatives for geographic areas that can be considered as a single communicable disease area, e.g.:</p> <ul style="list-style-type: none"> <li>▪ Northern Australia - northern WA, northern NT, &amp; northern Qld</li> <li>▪ Central Australia - lower end NT, Goldfields region WA, northern SA &amp; possibly parts of southwest Qld</li> <li>▪ Papua New Guinea, the Torres Strait and northern Qld</li> <li>▪ Border areas (eg NSW, Qld).</li> </ul>
<p>medium term</p>	<p>Determine most effective way to prioritise the health needs of Aboriginal and Torres Strait Islander Australians to close the gap in communicable diseases.</p>	<p>A. Continue building the voluntary targeted surveillance system (est. 4-6 yrs to build from ground up).</p> <p>C. Determine whether other models explored would be a more effective way to prioritise the health needs of Aboriginal and Torres Strait Islander Australians.</p> <p>D. Pilot integrated monitoring in an urban setting (AMS, pharmacy, state communicable disease unit).</p> <p>E. Evaluate/Implement Indigenous identification in pharmacy systems to monitor treatment for CDs</p>	
<p>longer term</p>		<p>A. Evaluate (if a trial) or enhance (if a prototype) the voluntary targeted surveillance system.</p>	

# Appendices

## Appendix A Terms of Reference

### *Terms of Reference*<sup>11</sup>

The Steering Committee for the *Improving Indigenous Identification in Communicable Disease Reporting Project* is convened to oversee the development of a Draft Discussion Paper for the Department of Health and Ageing.

The Draft Discussion Paper is to be developed under the auspice of the National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID). The process implemented to develop the discussion paper will foster Indigenous ownership and self-determination. Although the scope of the project focuses specifically on one area of Indigenous health and well-being (namely, improving Indigenous identification in communicable diseases reporting), its overarching aim is to improve the health and general well-being of Indigenous people, and will therefore be clearly viewed within this wider aim.

The discussion paper developed by the Steering Committee will include:

- a summary of current situation using existing documentation and stakeholder consultations, including a brief outline of the present agreements and stated objectives for the collection of Indigenous identification data in communicable disease reporting systems;
- the identification of limitations in the collection of Indigenous identification data in communicable disease reporting systems;
- the identification of the benefits of improving the quality of Indigenous identification in communicable disease reporting systems;
- consideration of a range of options for improving Indigenous identification in communicable disease reporting and outline of the benefits and drawbacks of the various options;
- the identification of barriers to, and opportunities for, a consistent approach nationally to Indigenous identification in communicable disease reporting systems;
- a summary of key statistics in communicable diseases affecting Indigenous Australians; and
- recommendations to the Department of Health and Ageing for future action.

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<sup>11</sup> Fourth draft endorsed as final at Steering Committee meeting of 10 December 2003.

## **Appendix B Project Brief**

### **1. BACKGROUND: PROCESS TO DEVELOP THIS PROJECT BRIEF**

#### **Deficiencies in data identified**

*The Aboriginal and Torres Strait Islander Health Information Plan ...this time, let's make it happen* (OHMIC & AIHW, 1997) determined that the quality of Indigenous identification in most data collections at all levels needs to be improved significantly.

#### **Need for action agreed by a number of key stakeholders**

The need to improve Indigenous identification in communicable disease reporting systems has been noted as an issue of increasing importance by a number of key stakeholders including: the National Health Information Management Group Subcommittee, charged with implementing the 1997 Aboriginal and Torres Strait Islander Health Information Plan (NAGATSIHID); National Public Health Partnership Group's Aboriginal and Torres Strait Islander Working Group (ATSIWG); Office for Aboriginal and Torres Strait Islander Health Services (OATSIH) and the Communicable Diseases Network of Australia (CDNA).

No clear view about how to progress preliminary work

It became apparent through communications between the Population Health Division (PHD), Australian Government Department of Health and Ageing (DoHA) and representatives from these abovementioned groups that there is no clear view about how to work in this area should be progressed.

Identification of resources to develop a project proposal

The PHD identified some resources within the Public Health Information Development Unit (PHIDU) (an independent unit based at the University of Adelaide, funded by the PHD) that could be made available to develop a project proposal.

#### **Project proposal presented to NAGATSIHID and OATSIH**

The project proposal was presented to the National Advisory Group Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) who agreed to take up the auspice for the project (with some minor amendments to the project proposal) and provide a representative on the Project Steering Committee. These minor amendments have subsequently been incorporated into the Project Brief provided below.

The proposal was also presented to the Office for Aboriginal and Torres Strait Islander Health who agreed to provide a representative on the project steering committee (with some minor amendments to the project proposal). These minor amendments have also subsequently been incorporated into the Project Brief provided below.

### **2. PROJECT BRIEF**

#### **Main Task**

To develop a Draft Discussion Paper with recommendations to the Department of Health and Ageing for future action to improve Indigenous identification in communicable disease reporting systems.

#### Resources Available

PHIDU will provide approximately 7 months project officer support for the project at 0.6 (3 days per week) as well as limited additional technical and research officer support as required. Limited funding is also available for some project officer travel.

#### **Importance of Engaging Key Indigenous Stakeholders**

In keeping with the clear recommendations from numerous studies, reports, policies and plans to improve the health of Aboriginal and Torres Strait Islander people the successful implementation of this proposed project requires ownership of the process by key Indigenous stakeholders at all phases of the project.

The literature surveyed in order to draft this proposal clearly substantiates this requirement. As stated in *The Aboriginal and Torres Strait Islander Health Information Plan ...this time, let's make it happen* (AHMAC & AIHW, 1997), Aboriginal and Torres Strait Islander communities have serious concerns regarding the use of health information about Indigenous persons – in particular, what information is collected, how is it used, who owns the data, who has access and under what circumstances.

In specific relation to health information and STD control the *National Indigenous Australian Sexual Health Strategy* (March 1997), which provides a framework for addressing HIV/AIDs and sexual health issues within Aboriginal and Torres Strait Islander communities, states that:

Data collection or 'surveillance' remains one of the most controversial aspects of sexual health policy, although there appears to be increasing agreement on the need for relevant data. Fundamental questions remain, however, in relation to collection methods, ownership of information, confidentiality, privacy, access to data and the ultimate use of data. (1997: 13).

Any project seeking to make recommendations for future action that covers an area so controversial must only proceed with a strong sense of ownership by Indigenous stakeholders. Initial key strategies to foster this ownership include the engagement of an organisation that has experience with and/or can demonstrate an understanding of the issues around improving Indigenous identification in communicable disease reporting, to auspice the proposed project and the formation of a Project Steering Committee comprising key Indigenous stakeholders and other key stakeholders.

#### **Auspice for Proposed Project**

Members of the National Advisory Group Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) recently agreed to auspice the project.

NAGATSIHID's role as the auspice of this project will primarily involve the provision of overall advice and guidance, for example:

- provision of comment or assessment of this Project Brief;
- provision of advice on how to foster ownership by key Indigenous stakeholders at all phases of the project;
- advice on the composition of the proposed Project Steering Committee;

- identification of key individuals and agencies which should be included in the proposed stakeholder interviews; and
- provision of comment or assessment of the proposed Draft Discussion Paper.

#### Project Steering Committee

In order to foster ownership of the project by Indigenous stakeholders the following criteria have been developed to guide the formation of the Project Steering Committee:

The Chair of the Project Steering Committee must be an Indigenous Australian;

There must be majority representation of Indigenous Australians;

Membership must include Aboriginal and Torres Strait Islander community-controlled health sector;

Members should ideally have expertise related to Indigenous health and communicable diseases.

Using the above criteria the Project Steering Committee should include representatives from the following key stakeholders groups:

NACCHO Aboriginal health/medical service working at community level (2)

State Aboriginal Health Division and State Communicable Diseases Unit (1-2)

NAGATSIHID (1)

CDNA (1)

Population Health Division (1)

ATSIHWIU (1)

National Public Health Partnership Working Group on Aboriginal and Torres Strait Islander Issues (1)

NPHIWG (1)

OATSIH (1)

Indigenous Australians' Sexual Health Committee (IASHC) (1)

Specific Torres Strait Islander representative organisation (1)

PHIDU to provide a research officer for project/research support.

Proposed that the Project Steering Committee meet monthly via teleconference.

If funding from the PHD is available, 'face to face' meetings at the start and finish of the project process should also be arranged.

If 'face to face' meetings at the start and finish of the process are arranged PHIDU has limited funding available to cover travel costs for the project officer.

#### **Draft Discussion Paper**

A suggested outline for the development of the proposed Draft Discussion Paper for consideration by the Project Auspice and the Project Steering Committee is:

- a summary of current situation using existing documentation and stakeholder consultations, including a brief outline of the present agreements and stated objectives for the collection of Indigenous identification data in communicable disease reporting systems;
- the identification of limitations in the collection of Indigenous identification data in communicable disease reporting systems;
- the identification of the benefits of improving the quality of Indigenous identification in communicable disease reporting systems;
- consideration of a range of options for improving Indigenous identification in communicable disease reporting and outline of the benefits and drawbacks of the various options;
- the identification of barriers to, and opportunities for, a consistent approach nationally to Indigenous identification in communicable disease reporting systems;
- (if endorsed for inclusion in Terms of Reference) a summary of key statistics in communicable diseases affecting Indigenous Australians; and
- recommendations to the Department of Health and Ageing for future action.

### **Proposed Process to Develop Draft Discussion Paper**

A proposed process to develop the Draft Discussion Paper for consideration by Project Auspice and the Project Steering Committee could include:

#### *Literature survey*

A brief literature survey to identify any key background papers/reports/strategies for the Project Steering Committee is proposed.

#### *Stakeholder Interviews*

Stakeholder interviews with key individuals and agencies as identified by the Project Auspice and Project Steering Committee are proposed in order to identify and develop potential strategies to improve Indigenous identification in communicable disease reporting systems. These interviews could be conducted using telephone and e-mail. It may be more appropriate to conduct 'face to face' visits with some stakeholders as identified by the Project Steering Committee. Any 'face to face' visits would be subject to the availability of funding.

#### *Drafting of Discussion Paper*

A Draft Discussion Paper on the outcomes of the stakeholder consultations will be prepared. The Draft Discussion Paper will be returned to the agencies and persons interviewed for additional comment and amendment. The final stage of the process would be Project Auspice and Project Steering Committee endorsement of the Draft Discussion Paper.

#### *Related Work*

The drafting of the Discussion Paper should take into consideration the work being undertaken by the STI Surveillance Committee (CDNA); the Data Principals Project (OATSIH); the Annual Surveillance Report of the National Centre in HIV Epidemiology and Clinical Research; and the National Performance Indicators (SCATSIH).

## **Appendix C Project Methodology**

The five methods used by the Project to develop the Draft Discussion Paper comprised:

- the formation of a Steering Committee with majority Aboriginal and Torres Strait Islander representation to carry out the work, which met monthly by teleconference and was supported by the PHIDU research officer;
- a survey of relevant literature reported since 1997 to identify key material to use as background documentation and to brief the Steering Committee;
- working with jurisdictions through their nominated Contact Officers assisting the Steering Committee with up-to-date information on the current situation in their jurisdictions;
- interviews and surveys with key stakeholders (the primary stakeholder for the Project was identified as Aboriginal and Torres Strait Islander stakeholders)
- drafting the draft Discussion Paper (3 drafts) and early release for comment to participating stakeholders; endorsement by the Project Auspice NAGATSIHID and by the Steering Committee.

These components of the Project are further described below.

It is important to stress that the exploratory nature of this project provides a discussion point for improving the quality of Indigenous identification in communicable disease reporting.

### ***Steering Committee***

A Project Steering Committee was formed in accordance with the stated criteria to foster ownership of the project by Aboriginal and Torres Strait Islander stakeholders.

The IIICDRP Steering Committee was auspiced by NAGATSIHID with PHIDU providing a part-time (3 days per week) research officer for project research and support in the secretariat function (funded by PHD, DoHA) initially for 7 months that extended to 12 months.

Meetings were held approximately monthly, by teleconference, from August 2003 to June 2004. Steering Committee members contributed to the project in many different ways. The final Draft Discussion Paper reflects the consensus view of all members forming the Steering Committee at 3 June 2004. All members and associated participants on the Steering Committee gave their time freely to attend teleconferences and participate in other discussions and paid their own associated administrative costs. Their contribution is recognised individually in the *Acknowledgements* (see Appendix D).

In order to foster ownership of the project by Aboriginal and Torres Strait Islander stakeholders the following criteria were developed to guide the formation of the Project Steering Committee:

- The Chair of the Project Steering Committee must be an Indigenous Australian;
- There must be majority representation of Indigenous Australians;
- Membership must include Aboriginal and Torres Strait Islander community-controlled health sector; and
- Members should ideally have expertise related to Indigenous health and communicable diseases.

Using the above criteria the Project Steering Committee was to include representatives from the following key stakeholders groups:

- National Aboriginal Community Controlled Health Organisation (NACCHO) Aboriginal health/medical service working at community level (2)
- State Aboriginal Health Division and State Communicable Diseases Unit (1-2)
- National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) (1)
- Communicable Diseases Network of Australia (CDNA) (1)
- Population Health Division, Australian Government Department of Health and Ageing (PHD, DoHA) (1)
- Aboriginal and Torres Strait Islander Health and Welfare Information Unit (ATSIHWIU) (1)
- National Public Health Partnership (NPHP) Working Group on Aboriginal and Torres Strait Islander Issues (ATSIWG) ((1)
- National Public Health Information Working Group (NPHIWG) (1)
- Office for Aboriginal and Torres Strait Islander Health (OATSIH) (1)
- Indigenous Australians' Sexual Health Committee (IASHC) (1)
- Specific Torres Strait Islander representative organisation (1)

Changes: ATSIHWIU advised that no representative was able to be nominated as ATSIHWIU had been de-funded, ATSIWG advised that no representative was to be nominated, and NACCHO's second representative was not nominated until the end of the project.

Chair of the Steering Committee: Ms Janine Engelhardt (NACCHO) and Mr Ted Wilkes (NAGATSIHID) acted as interim chairs prior to the election by acclaim of Ms Deb Reid (OATSIH) as permanent chair of the Committee, in accordance with the criteria above.

After formation of the Steering Committee, which first met in August, members' stated Indigenous/non-Indigenous status was reviewed to verify that the criterion ('there must be majority representation from Indigenous Australians') was met by the current combination of voting Steering Committee members, and some representatives were changed in order to meet the criteria.

A proposed process to develop the Draft Discussion Paper was considered by the Project Auspice and the Project Steering Committee, which endorsed the final version of the Project Brief in December 2003. The Project Terms of Reference and the Project brief can be found in Appendices A and B.

### ***Literature survey***

A brief literature survey to identify any key background papers/reports/strategies for the Project Steering Committee was prepared. More than 50 items were collated and summarised, including a variety of training and awareness material. The literature survey was discussed by the Steering Committee several times, and a summary of the options identified was prepared and reviewed in relation to the scope of the project. A synthesis of the material of relevance forms a component of this report (see Section 5.1 and Appendix F).

### ***Working with jurisdictions***

All States and Territories nominated Contact Officers to assist the Steering Committee. A working relationship was established and Contact Officers provided up-to-date information on Indigenous identification in communicable disease reporting systems in their jurisdictions, and additional information as required. Contact Officers also reviewed those sections of the Draft Discussion Paper that described the jurisdictional situation. Their contribution is recognised in the *Acknowledgements*.

### ***Interviews and surveys with key stakeholders***

A total of 56 interviews were held with, and/or completed surveys were received from, key stakeholders - individuals and agencies identified by the Project Auspice and Project Steering Committee to identify and develop potential strategies to improve Indigenous identification in communicable disease reporting systems. Limitations of time and money meant that the majority of interviews were conducted using telephone and e-mail. The interview format and process is shown in Box 11. The survey closely followed the format for the interview. Time spent in interview ranged from 15 minutes to 90 minutes; the average was 50 minutes. Notes of interviews were returned to participating stakeholders for any additional comment and amendment.

The range of potential stakeholders was much greater than those who were interviewed and surveyed for the project. Many more stakeholders were interested in, but had no time within the timeframe to participate, in the Project. Some key stakeholders were not able to be contacted during the time. Others who were contacted felt that there were more appropriate stakeholders to interview, and they mostly nominated other stakeholders. One stakeholder refused to participate.

A wide range of opinion on benefits and limitations, and of options to improve the quality of Indigenous identification in communicable disease reporting, were expressed by the participating stakeholders. The Discussion Paper was returned to participating stakeholders and other contributors for their information and comment prior to finalisation of the Draft Discussion Paper and its presentation to NAGATSIHID for endorsement.

### ***Drafting of Discussion Paper***

Sections of the Draft Discussion Paper were discussed by the Steering Committee as the Project progressed, including the literature survey, up-to-date information from the jurisdictions, and early analysis of material from the stakeholder consultations. Three drafts of the Discussion Paper were prepared and reshaped by the Committee over several meetings and additional out-of-session occasions. The Discussion Paper has been returned to the participating stakeholders for any additional comment and amendment. The final stage of the process will be its endorsement by the Project Auspice, NAGATSIHID, and by the Steering Committee, before presentation to DoHA for acceptance.

## Box 11 Interview format and process

### **Improving Indigenous Identification in Communicable Disease Reporting Project**

*Areas for discussion in the interview:*

***Current situation:***

summary of current situation including present agreements and stated objectives for the collection of Indigenous identification data in communicable disease reporting systems

***Limitations:***

in the collection of Indigenous identification data in communicable disease reporting systems

***Benefits:***

of improving the quality of Indigenous identification in communicable disease reporting systems

***Options:***

for improving the quality of Indigenous identification in communicable disease reporting

***Benefits / drawbacks*** of the various options

***Consistent approach nationally:*** including

***Barriers to / Opportunities for*** a consistent approach nationally to Indigenous identification in communicable disease reporting systems

Any other comments on related areas / issues

#### *Interview and Discussion Paper process*

Interviews will be set up ahead of time and at your convenience.

Your summarised comments will be returned to you in written form and a minimum of two weeks provided for any amendments/changes.

Interviews and surveys will be analysed as a group to provide information to the Discussion Paper (they will not be individually identified).

Your contribution (name, position, organisation) will be acknowledged in the Discussion Paper unless you prefer otherwise.

The draft Discussion Paper will be returned to the agencies and persons interviewed for additional comment and amendment.

The final stage of the process will be project Auspice and Steering Committee endorsement of the Draft Discussion paper, and acceptance by the, Department of Health and Ageing.

## **Appendix D Acknowledgements**

Many people contributed their time and knowledge to the Project, and are listed below in terms of their participation on the Steering Committee (either as a voting member, or observer), as a jurisdictionally nominated contact officer/s assisting, and/or as stakeholders interviewed for the Project. Many other people contributed background information and training material but as anonymous helpers are not individually listed, in particular staff of Medicare, the Health Insurance Commission, and the Australian Bureau of Statistics

We take this opportunity to thank all concerned.

### ***Steering Committee***

Members and Observers participating in the Steering Committee from August 2003:

Chair:	Ms Debra Reid	Office for Aboriginal and Torres Strait Islander Health (OATSIH)	(Sep 03 – Aug 04)
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#### **Members:**

Ms Mary Beers	Communicable Diseases Network of Australia (CDNA)	(Aug 03 – Aug 04)
Assoc Prof Cindy Shannon	Indigenous Australians' Sexual Health Committee (IASHC)	(Aug 03 – Aug 04)
Mr Bernie Pearce	IASHC (proxy for Ms Shannon)	(Aug 03)
Ms Janine Engelhardt	National Aboriginal Community Controlled Health Organisation (NACCHO) (1)	(Aug 03 – Aug 04 and interim chair)
Ms Jill Gallagher	NACCHO (2)	(May 04 – Aug 04 )
Assoc Prof Ted Wilkes	National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID)	(Aug 03 – Aug 04 and interim chair)
Mr Mark Bartlett	NSW Health (proxy for NSW Health at the first Steering Committee meeting)	(Aug 03)
Mr Ray Mahoney	NSW Health	(Sep 03 – Aug 04)
Mr Peter Markey	NT Health	(Aug 03 – Aug 04)
Ms Trish Fagan	OATSIH (proxy for OATSIH at the first Steering Committee meeting)	(Aug 03)
Ms Moira McKinnon	Population Health Division (PHD), Australian Government Department of Health and	(Aug 03 – Aug 04)

		Ageing (DoHA)	
	Mr Craig Davis	Qld Health (replacing Ms Cardona)	(Sep 03 – Aug 04)
	Ms Magnolia Cardona	Qld Health / National Public Health Information Working Group (NPHIWG)	(Aug 03)
	Ms Samantha Faulkner	Torres Strait Islander Advisory Board (TSIAB) (replacing Ms Shibasaki)	(Jan – Aug 2004)
	Ms Sanchia Shibasaki	TSIAB (replacing Mr Bedford)	(Sep – Dec 2003)
	Mr Kenny Bedford	TSIAB	(Aug 03)
<b>PHIDU support</b>	Ms Su Gruszin	Public Health Information Development Unit, The University of Adelaide (PHIDU) (replacing Ms Ellickson)	(Sep 03 – Jun 04)
	Ms Cara Ellickson	PHIDU	(Aug – Oct 2003 & Jul – Oct 2004)
<b>Observers:</b>			
	Ms Kym Starr	OATSIH	
	Ms Karen Cirovski	OATSIH	
	Ms Joy Robinson	Communicable Disease Branch, PHD, DoHA	
	Ms Jill Guthrie	National Centre for Epidemiology and Public Health (NCEPH), Australian National University (ANU)	
	Ms Fiona Buzzacott	Aboriginal Health Council of South Australia (AHCSA)	
	Mr Kefle Yohannes	Surveillance and Epidemiology Section, PHD, DoHA	
	Mr Darryl Brooks	TSIAB	
	Mr Chris Lawrence	NCEPH, ANU (MAE graduate student)	
	Ms Wendy Hermeston	NCEPH, ANU (MAE graduate student)	
	Mr Jerry Moller	AHCSA	

## ***Jurisdictional Contact Officers***

State and Territory nominated Contact Officers assisting the Steering Committee:

New South Wales	Mr Mark Bartlett	Manager, Surveillance, Communicable Diseases Branch, NSW Health
Victoria	Ms Megan Counahan	Surveillance Manager, Communicable Diseases Section, Department of Human Services
Queensland	Mr Dion Tatow	Principal Program Advisor, Communicable Diseases Unit, Qld Health
Western Australia	Dr Gary Dowse	A/Director, Communicable Disease Control Directorate, Dept of Health
South Australia	Ms Leanne Colby	Senior Planning and Policy Officer, Aboriginal Services Division, SA Department of Human Services
Tasmania	Dr Avner Misrachi	Manager, Communicable Disease Prevention Unit, Dept of Health and Human Services, Tasmania
Australian Capital Territory	Ms Gail Byron, and Ms Hilary McClure	Senior Policy Officer, Aboriginal and Torres Strait Islander Health Unit, ACT Health Surveillance Officer, Communicable Disease Surveillance, Health Protection Service, ACT Health
Northern Territory	Dr Steven Skov	Acting Head, Surveillance Section, Centre for Disease Control, Dept of Health and Community Services, NT

## ***Key stakeholders participating in telephone interviews and surveys***

Alphabetical list of stakeholders participating (and agreeing to be listed):

Ms Fadwa	Al-Yaman	Unit Head, Aboriginal and Torres Strait Islander Health and Welfare Unit, Australian Institute of Health and Welfare (AIHW)
Mr Mark	Bartlett	Manager, Surveillance, Communicable Diseases Branch, NSW Health; and nominated jurisdictional Contact Officer
Ms Mary	Beers	Communicable Diseases Network of Australia (CDNA); Senior Lecturer, National Centre for Epidemiology and Population Health (NCEPH), The Australian National University (ANU); Steering Committee Member

Mr Dan	Black	Director, National Centre for Aboriginal and Torres Strait Islander Statistics (NCATSIS)
Prof Frank	Bowden	Chair, HIV/AIDS and Sexually Transmissible Infections (STIs) Committee; Professor of Medicine, ANU Medical School; Head, Academic Unit of Internal Medicine, The Canberra Hospital; Director, Canberra Sexual Health Centre, ACT
Ms Gail	Byron	Senior Policy Officer, Aboriginal and Torres Strait Islander Health Unit, ACT Health; and nominated jurisdictional Contact Officer
Ms Leanne	Colby	Senior Planning and Policy Officer, Aboriginal Services Division, SA Department of Human Services; and nominated jurisdictional Contact Officer
Dr Celia	Cooper	Manager, Infection Control Service, Communicable Disease Control Branch, Strategic Planning and Population Health Division, SA Department of Human Services
Ms Megan	Counahan	Surveillance Manager, Communicable Diseases Section, Department of Human Services, Victoria; and nominated jurisdictional Contact Officer
Ms Margaret	Culbong	Chief Executive Officer, Geraldton Regional Aboriginal Medical Service (GRAMS), WA
Dr John	Daniels	Medical Director, Redfern Aboriginal Medical Service, NSW
Mr Craig	Davis	Epidemiologist, Communicable Diseases Unit, Qld Health; Steering Committee Member
Dr Rod	Davison	Medical Director, Disease Control, Central Public Health Unit, Qld Health
Ms Noeleen	Dempsey	Indigenous Public Health Officer, Darling Downs Public Health Unit, Qld Health
Dr Gary	Dowse	A/Director, Communicable Disease Control Directorate, Dept of Health, WA; and nominated jurisdictional Contact Officer
Ms Samantha	Faulkner	Torres Strait Islander Advisory Board (TSIAB), Steering Committee Member
Dr Rod	Givney	Director, Communicable Disease Control Branch, Department of Human Services SA
Assoc Prof Andrew	Grulich	Head of HIV Epidemiology and Prevention Program, National Centre in HIV Epidemiology and Clinical Research (NCHECR)
Dr Bronwen	Harvey	Medical Adviser, General Practice Branch, Australian Government Department of Health and Ageing (DoHA)
Dr Noel	Hayman	Manager, Indigenous Health Program, Inala Indigenous Community Health Centre, Qld
Ms Sheila	Holcombe	Director, Secondary Use of Data Policy Section, Executive, Information and Communications Division, Australian Government Department of Health and Ageing (DoHA)
Dr. Caetlin	Jopson	General Practitioner, Indigenous Health Program, Chermiside Community Health Centre, and Brisbane North Division of General Practitioners

Mr Victor	Jose	Chief Executive Officer, National Secretariat of Torres Strait Islander Organisations Limited (NSTSIO)
Prof John	Kaldor	Deputy Director and Professor of Epidemiology, NCHECR
Ms Riemke	Kampen	Manager, Communicable Disease Surveillance Unit, ACT Health
Dr Chris	Kelman	Medical Adviser, Health Informatics, Information and Communications Division, Australian Government Department of Health and Ageing (DoHA)
Mr Darrell	Kickett	Chief Executive Officer, Western Australian Aboriginal Community Controlled Health Organisation (WAACHO)
Prof Susan	Kippax	Director National Centre in HIV Social Research (NCHSR), UNSW
Dr Vicki	Krause	Director of the NT Centre for Disease Control, NT Health
Chris	Lawrence	NCHECR; NCEPH, ANU; Steering Committee Observer
Dr. Tim	Leahy	Medical Policy Officer, WAACCHO
Mr Don	Lewis	Health Information Centre (HIC), Qld Health
Ms Ann Maree	Liddy	Chief Executive Officer, Queensland Divisions of General Practice
Mr Ray	Mahoney	Manager, Evaluation, Monitoring and Reporting Unit, Aboriginal Health Branch, NSW Department of Health; Steering Committee Member
Dr Peter	Markey	Head of Disease Surveillance, NT Centre for Disease Control, NT Health; Steering Committee Member
Ms Hilary	McClure	Surveillance Officer, Communicable Disease Surveillance, Health Protection Service, ACT Health; and nominated jurisdictional Contact Officer
Ms Ann	McDonald	Senior Research Officer, Surveillance Program, National Centre in HIV Epidemiology and Clinical Research (NCHECR)
Dr Moira	McKinnon	PHD, DoHA, Steering Committee Member
Ms Megge	Miller	Epidemiologist, Epidemiology and Surveillance Section, DoHA
Dr Avner	Misrachi	Manager, Communicable Disease Prevention Unit, Dept of Health and Human Services, Tasmania; and nominated jurisdictional Contact Officer
Dr Richard	Murray	Medical Director, Kimberley Aboriginal Medical Services Council Inc. (KAMSC), WA
Dr Graeme	Nimmo	Director, Microbiology, Qld Health Pathology Services, Princess Alexandra Hospital
Ms Debra	Reid	Office for Aboriginal and Torres Strait Islander Health (OATSIH); Chair of the Steering Committee
Dr Jenny	Robson	Pathologist, Sullivan Nicolaides Pathology
Assoc Prof Cindy	Shannon	Indigenous Australians' Sexual Health Committee (IASHC); Head of Indigenous Health, School of Population Health, University of Queensland; Steering Committee Member

Dr Steven	Skov	Acting Head, Surveillance Section, Centre for Disease Control, Dept of Health and Community Services, NT and nominated jurisdictional Contact Officer
Dr David	Smith	Department of Infectious Diseases, Pathcentre; Clinical Director, Division of Microbiology & Infectious Diseases, WA Centre for Pathology & Medical Research; Co-Director, Arbovirus Research & Surveillance Group, Department of Microbiology, University of WA
Dr Jenean	Spencer	Director, Surveillance & Epidemiology Section, DoHA
Mr Jeff	Standen	Manager, Aboriginal Environmental Health, Environmental Health Branch, NSW Health Department
Ms Mary	Sullivan	Koori Human Services (was Health) Unit, Dept of Human Services, Victoria
Mr Dion	Tatow	Principal Program Advisor, Communicable Diseases Unit, Qld Health; and nominated jurisdictional Contact Officer
Dr Sandy (Sandra)	Thompson	Medical Coordinator, Sexual Health Program, Health Dept of WA
Dr Angela	Todd	Senior Associate and Adjunct Senior Lecturer, Sydney Health Projects Group, School of Public Health, The University of Sydney
Clinical Assoc Prof Paul	Torzillo	Central Clinical School, University of Syd and Royal Prince Alfred Hospital
Mr Peter	Waples-Crowe	Policy Officer, Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
Dr Mark	Wenitong	Senior Medical Officer, WuChopperen Medical Service
Assoc Prof Ted	Wilkes	Professorial Fellow in Aboriginal Health with the Centre for Developmental Health at Curtin University, in conjunction with the Telethon Institute for Child Health Research; National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID); Steering Committee Member
Mr Michael	Wright	Communicable Disease Control Branch, Sexual Health and Blood-borne Viruses Program, Department of Health, Western Australia

### ***Other contributors***

Ms Megan	Black	NSW Public Health Officer Training Program
Ms Maxine	Clark	Program Manager, Indigenous Access, Health Insurance Commission (HIC)
Ms Megan	Collier	Program Coordinator Health Systems Improvement, Brisbane North Division of General Practice
Ms Louise	Cook	National Aboriginal Community Controlled Health Organisation (NACCHO)
Ms Lynette	Fergusson	Manager - Implementation Team, Queensland Divisions of

General Practice

Ms Helen	Gardiner	Aboriginal Health Branch, NSW Health
Mr John	Glover	Director, Public Health Information Development Unit, The University of Adelaide (PHIDU)
Mr Simon	Graham	Health Promotion Advisor, Australian Government Department of Veterans' Affairs
Mr Tony	Grivell	Acting Chief Executive Officer, Cooperative Research Centre Aboriginal Health Research, Darwin
Dr Di	Hetzel	Senior Researcher, PHIDU
Dr Geoff	Hogg	Microbiological Diagnostic Unit Public Health Laboratory, Microbiology and Immunology Department, The University of Melbourne
Ms Cheryl	Leavy	HIC Indigenous Communications Campaign, Health Insurance Commission (HIC)
Mr Doug	Marshall	Manager, Pathology, Health Insurance Commission (HIC)
Mr Robert	Menzies	Senior Research Officer, National Centre For Immunisation Research And Surveillance Of Vaccine Preventable Diseases (NCIR)
Ms Veronica	Scanlon	Medicare, Medicare Benefits Schedule (MBS)
Ms Cora	Shiroyama	Australian Government Department of Health and Ageing
Ms Kate	Silburn	Centre for Development and Innovation in Health, Australian Institute for Primary Care, La Trobe University
Mr Rod	Silburn	National Centre for Aboriginal and Torres Strait Islander Statistics (NCATSIS), Australian Bureau of Statistics (ABS)
Mr Fearnley	Szuster	PHIDU (for survey assistance)
Ms Sarah	Tennant	PHIDU (for the map)
Mr Neil	Thomson	Australian Indigenous HealthInfoNet, Centre for Public Health, Edith, Cowan University, Perth
Ms Kerrie	Tim	Aboriginal and Torres Strait Islander Services (ATSIS), Health and Welfare Branch
Mr Ian	Watts	National Manager - GP Advocacy and Support, Royal Australian College of General Practitioners (RACGP)

### ***Relevant agencies***

Wider circulation of the Discussion Paper could begin the important process of engaging in a dialogue with the relevant national groups, inter-governmental and inter-departmental structures, and additional stakeholders, to progress and report results.

These could include:

- the Communicable Diseases Network of Australia (CDNA),
- the National Public Health Partnership group,
- National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID),
- National Aboriginal Community Controlled Health Organisation (NACCHO),
- Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH),
- Intergovernmental Committee on AIDS, Hepatitis and Related Diseases (IGCAHRD),
- National Aboriginal and Torres Strait Islander Health Council,
- National Health & Medical Research Council (NH&MRC),
- Ministerial Advisory Committee on AIDS, Sexual Health & Hepatitis (MACASHH),
- Indigenous Australians' Sexual Health Committee (IASHC) (Subcommittee of MACASHH),
- Cross-Departmental Working Group on Indigenous Health<sup>12</sup>,
- State-based structures such as the SA Aboriginal Health Partnership and the Victorian Advisory Council on Koori Health.

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<sup>12</sup> Cross-Departmental Working Group on Indigenous Health; to improve portfolio coordination of Aboriginal and Torres Strait Islander health (DoHA 2003-04 budget papers).

## **Appendix E Notification of communicable disease forms**

South Australia and Victoria provide examples of notification of communicable disease forms that conform to the national standard for Indigenous identification.

# REPORT OF NOTIFIABLE DISEASE OR RELATED DEATH

**DEPARTMENT OF HUMAN SERVICES**

**CONFIDENTIAL**

PUBLIC AND ENVIRONMENTAL HEALTH ACT - 1987



**Government of South Australia**

*Do not use this form for AIDS, HIV, Hepatitis B or C or Sexually Transmitted Infections*

**DISEASE TO NOTIFY** (  Tick box below )

**Gastrointestinal Diseases**

- |   |   |
|---|---|
| <input type="checkbox"/> Botulism ☼         | <input type="checkbox"/> Paratyphoid ☼                              |
| <input type="checkbox"/> Campylobacteriosis | <input type="checkbox"/> Salmonellosis                              |
| <input type="checkbox"/> Cholera ☼          | <input type="checkbox"/> Shigellosis                                |
| <input type="checkbox"/> Cryptosporidiosis  | <input type="checkbox"/> STEC OR <input type="checkbox"/> HUS/TTP ☼ |
| <input type="checkbox"/> Food poisoning ☼   | <input type="checkbox"/> Typhoid ☼                                  |
| <input type="checkbox"/> Listeriosis        | <input type="checkbox"/> Yersiniosis                                |

1. Has the case been exposed to a potentially unsafe food, raw milk, water, swimming pools, or food outlet?

- Y  N  U

Specify .....

2. Has the case travelled recently?

- Y  N  U

Specify .....

**Vaccine Preventable and Invasive Diseases**

- Diphtheria ☼
- Invasive Haemophilus Influenzae ☼
- Invasive Meningococcal Disease ☼
- Invasive Pneumococcal Disease ☼
- Measles ☼
- Mumps
- Pertussis
- Poliomyelitis ☼
- Rubella OR  Congenital Rubella Syndrome
- Tetanus
- Varicella Zoster OR  Chicken Pox OR  Shingles

**Viral Hepatitis**

- Hepatitis A
- Hepatitis E
- Hepatitis Viral (non specific: not B, C or D)

**Legionellosis**

- L. Longbeachae
- L. Pneumophila ☼
- Other sp .....

**Mosquito Borne Infections**

- Murray Valley Encephalitis ☼
- Barmah Forest virus
- Dengue virus
- Kunjin virus
- Japanese Encephalitis ☼
- Malaria
- Ross River virus

What is the geographic location of infection?

Specify .....

**Zoonotic Infections**

- Australian bat lyssavirus ☼
- Brucellosis
- Hydatid
- Leptospirosis
- Psittacosis (Ornithosis)
- Q Fever
- Rabies ☼

**Mycobacterial Infections**

- \*\*Tuberculosis
- \*\*Non-Tuberculous Mycobacterial Disease
- Leprosy

\*\* Send to: SA Tuberculosis Service  
275 North Terrace  
ADELAIDE SA 5000 Ph: 8222 5483 Fax: 8222 5398

**Other Diseases**

- Anthrax ☼
- Yellow Fever ☼
- Plague ☼
- Viral Haemorrhagic Fever ☼

**CASE DETAILS** (Please print clearly.  Tick boxes where applicable)

LAST NAME: .....

GIVEN NAME: .....

RESIDENTIAL ADDRESS: .....

CONTACT PHONE NUMBER: .....

SEX:  M  F      DATE OF BIRTH:      /      /

IS THE CASE OF ABORIGINAL OR TORRES STRAIT ISLANDER ORIGIN?

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both Aboriginal & Torres Strait Islander
- Not stated

DOES THE CASE BELONG TO ANY OF THESE GROUPS?

- Commercial food handler
- Health care worker
- Child care worker

Occupation: .....

DATE OF ONSET:      HOSPITALISED:      DATE OF DEATH:

    /      /            Y  N  U           /      /

**DOCTOR/HOSPITAL DETAILS** (a stamp is acceptable)

NAME: .....

ADDRESS: .....

TELEPHONE:      PROVIDER NO: .....

SIGNATURE: .....

DATE:      /      /

**LABORATORY** – Positive pathology results received from:

- IMVS       WCH       GRIBBLES       OTHER
- SOUTH PATH       ABBOTTS       CLIN PATH

**CLINICAL COMMENTS** (Include others ill identified by case or identified by you)

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

*Please inform the patient that you have notified the Department of Human Services*

**Fax this form to 08 8226 7197**

OR send a reply paid envelope to  
CDC Branch, Reply Paid Service No 11  
Box 6 Rundle Mall PO Adelaide SA 5000

**Ring 08 8226 7177 as soon as possible if disease is marked with ☼**

Revised March 2002

# Confidential — Notification of Infectious Disease

Health (Infectious Diseases) Regulations 2001, Schedule 4  
July 2003, 2000/0030200, CDS0014.02



Diseases marked **(T)** (whether presumptive or confirmed) require immediate notification by telephoning **1300 651160**. All notifications must be sent within five (5) days of diagnosis to: Communicable Diseases Section, Human Services, Reply Paid 65937, Melbourne VIC 8060, or, Fax 1300 651170.

**Tick boxes where applicable. Please print clearly.**

## 1 Disease to Notify

### Sexually Transmitted Diseases (STIs)

Tick one or more boxes and complete sections 2, 4, and 5

- Chlamydia trachomatis infection (STI)
- Donovanosis (STI)
- Gonococcal infection (STI)
- Syphilis (STI) →  Congenital
  - Early (<2 years)
  - Late (>2 years)

### Other Infectious Diseases

Tick one or more boxes and complete sections 3, 4, and 5

- Anthrax **(T)**
- Arbovirus Infection
  - Australian arbo-encephalitis **(T)**
  - Japanese encephalitis **(T)**
  - Barmah Forest virus
  - Dengue virus
  - Flavivirus (other)
  - Kunjin virus
  - Ross River virus
- Botulism **(T)**
- Brucellosis
- Campylobacteriosis
- Cholera **(T)**
- Cryptosporidiosis
- Diphtheria **(T)**
- Food or water borne illness (2 or more related cases) **(T)**
- Giardiasis
- Haemolytic uraemic syndrome (HUS) **(T)**
- Haemophilus influenzae type b infection (Hib) **(T)**
- Hepatitis A
- Hepatitis B →  Acute  Non-acute
- Hepatitis C →  Acute  Non-acute
- Hepatitis D
- Hepatitis E
- Hepatitis viral (not further specified)
- Influenza (laboratory confirmed)
- Legionellosis **(T)**
- Leprosy
- Leptospirosis
- Listeriosis
- Lyssavirus →  Australian Bat lyssavirus
- Malaria
- Measles **(T)**
- Meningococcal infection **(T)**
- Mumps
- Paratyphoid **(T)**
- Pertussis
- Plaque **(T)**
- Pneumococcal infection (invasive)
- Poliomyelitis **(T)**
- Psittacosis (ornithosis)
- Rabies **(T)**
- Q fever
- Rubella →  Congenital rubella syndrome
- Salmonellosis
- Severe Acute Respiratory Syndrome (SARS) **(T)**
- Shigellosis
- Tetanus
- Tuberculosis
- Typhoid **(T)**
- Vero-toxin producing *Escherichia coli* (VTEC)
- Viral Haemorrhagic Fever **(T)**
- Yellow Fever **(T)**

## 2 Case Identification for Sexually Transmitted Infections (STIs)

First two letters only: Family Name First name Postcode of residence  
 \_\_\_\_\_ You MUST also complete sections 4 and 5

## 3 Case Identification for all Other Infectious Diseases

Patient Surname \_\_\_\_\_ First Name(s) \_\_\_\_\_  
 Patient Residential Address \_\_\_\_\_  
 City/Suburb/Town \_\_\_\_\_ Postcode of residence \_\_\_\_\_  
 Occupation and/or School and/or Child Care Attended \_\_\_\_\_

## 4 Details for ALL Notifiable Diseases

Date of Birth (or Age if DOB unknown) \_\_\_\_\_ Is the patient alive?  Alive  Deceased  
 Date of Onset of Illness \_\_\_\_\_  
 Sex (gender)  Female  Male Is the patient of Aboriginal or Torres Strait Islander origin?  
 No  Yes, Aboriginal  Yes, Torres Strait Islander  Yes, both Aboriginal and Torres Strait Islander  
 Risk factors \_\_\_\_\_  
 Suspected mode of transmission \_\_\_\_\_  
 Clinical comments \_\_\_\_\_  
 Has laboratory confirmation been requested?  
 No  Yes, pending at: \_\_\_\_\_  
 Yes, confirmed at: \_\_\_\_\_ Laboratory  
 May we contact your patient directly?  
 No  Yes, the patient's telephone number is: \_\_\_\_\_

## 5 Notifier Details

Name of Notifying Doctor, Laboratory or Hospital \_\_\_\_\_  
 Address \_\_\_\_\_  
 City/Suburb/Town \_\_\_\_\_ Postcode \_\_\_\_\_  
 Telephone \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

320  
 DHS Use Only Check: CC:

# Notifying Cases of Infectious Diseases in Victoria

## Your Requirement to Notify

Infectious diseases still occur frequently throughout the world, so constant vigilance is required to prevent the reappearance of diseases thought to have been conquered. Changes in lifestyle have also led to the emergence of new threats to public health from infection. Health authorities depend on medical practitioners and laboratories for information on the incidence of infectious diseases. Notification is vital in efforts to prevent or control the spread of infection.

Notifiable Infectious Diseases are included in Schedule 3 of the *Health (Infectious Diseases) Regulations 2001* and are divided into four groups on the basis of the method of notification and the information required. With the exception of HIV/AIDS, these groups are all included on this form (see reverse side).

**Group A** Diseases require immediate notification to the Department of Human Services by telephone or fax upon initial diagnosis (presumptive or confirmed), followed by written notification within five days. These diseases are underlined on the form and are marked with the  symbol.

**Group B** Diseases require written notification only, within five days of diagnosis.

**Group C** Diseases include the sexually transmitted infections (indicated on the form as STIs) and should be notified using the same form. To preclude identification of the patient, only the first two letters of the family and given name of the patient are required.

**Group D** Diseases include **HIV** (Human Immunodeficiency-virus) and **AIDS** (Acquired Immunodeficiency Syndrome) and written notification is required within five days of initial diagnosis. A **separate form** is used for this purpose due to the need to have national uniformity in collection of data. Copies of this form are forwarded to the diagnosing medical practitioner with the laboratory confirmation of HIV infection.

The Department provides pre-printed Reply Paid envelopes (no stamps required) and STD toll free telephone and facsimile numbers to make notifying as simple as possible. Copies of the form, information on diseases and outbreaks, media releases, disease data, privacy information and other publications are all available at the Department of Human Services Internet site "<http://www.dhs.vic.gov.au/phd>".

## Privacy Legislation

Commonwealth and State Privacy Legislation does not negate the responsibility to notify the specified diseases nor to provide the information requested on this form. Doctors have a responsibility to inform their patients that their information is being provided to the Department of Human Services. The Department is committed to protecting the confidentiality of the information it receives and is bound by strict policies. Further information about privacy and notifiable diseases is available from the Communicable Diseases Section.

## Further Information

All notifications and related inquiries should be directed to:

**Communicable Diseases Section**  
**Victorian Government Department of Human Services**  
**Reply Paid 65937, Melbourne VIC 8060**  
(No postage stamp required)  
**Telephone 1300 651160 Facsimile 1300 651170**  
(1300 numbers are charged at local call cost)  
**After Hours Contact the Duty Medical Officer**  
**via pager service 132222 and quote pager number 46870**

**Please PRINT clearly and retain a copy of  
the notification for your records. Thank you.**



CDS0014.02 - 2000/0030200

## **Appendix F Suggestions for improvement from the literature**

The review conducted in 1996-97, which culminated in the production of *The Aboriginal and Torres Strait Islander Health Information Plan... This time, let's make it happen* (ATSIHWIU 1997, p. 34), found that there were 'few systematic mechanisms in place to check the quality of Indigenous data'. However there were a variety of one-off or short-term strategies that included:

Benchmarking, cross checking data with other sources, using Hospital Liaison Officers, checking medical certificates against communicable disease notification forms, 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 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 (ATSIHWIU 1997, p. 34).

In 2004 although there are still few systematic mechanisms in place to check the quality of Aboriginal and Torres Strait Islander data, there has been/continues to be a variety of one-off or short-term strategies, which the literature survey prepared for the project document.

A range of options has been identified in a review of the literature survey for the project:

- Build capacity at the local level
- Improve data collection processes
- Implement data principles and protocols
- Report useable information to communities
- Use data to improve Aboriginal and Torres Strait Islander health
- Change organisational culture / values
- National measures.

These are discussed further below, together with specific options so far identified. The majority of options identified since the 1997 report (and reviewed in the literature survey) arise out of specific data audits, usually of hospital morbidity data. There is a focus on **improving training and awareness**, and measures to **increase data quality and conformance with standard practices**. More recent recommendations include a focus on the need for **change in organisational culture and values**, recognising that these impact on the correctness and completion of routine demographic data including Indigenous identification, and on willingness to **commit resources to monitor data quality** and put in place enhancements. The most recent broader reports (i.e. not limited to hospital administrative collections) call for **sustained capacity building at the local level**, in both the collection and use of data to improve health outcomes for Aboriginal and Torres Strait Islander Australians.

Note that social factors, reporting back to the community factors, organisational culture/values and other factors that impact on the quality of Aboriginal and Torres Strait Islander data, are out-of-scope for this project as the focus is on how to improve Indigenous identification in communicable disease reporting.

### ***Build capacity at the local level***

Options identified and in-scope include:

- development of effective confidentiality systems and local strategies (especially in relation to sexual health)
- enable local and regional level communities to develop data collection mechanisms that take account of mobility and cross-border demography and that are owned by communities (while this refers to state borders, it has implications for international borders in the Torres Strait where PNG nationals cross the border into Australia (the Torres Strait) often transmitting communicable diseases)
- involve communities in data collection systems development (especially re accuracy)
- ensure that relevant data collections are appropriate to the needs of Aboriginal and Torres Strait Islanders
- ensure appropriate data and best practice information is available to providers of sexual health services to Aboriginal and Torres Strait Islander people.

### ***Improve data collection processes***

The most common option identified was **improving health staff training and awareness** of the need for (1) Indigenous identification data and (2) consistency and compliance with national standards in its collection. As the quality of Indigenous identification in hospital data improves, the focus widens to expand training and awareness to other elements of the health system (eg, primary health care, pathology) and to other types of health professionals (eg, GPs, allied health). Training is specifically to improve staff ability to communicate with Aboriginal and Torres Strait Islander Australians, to handle ‘difficult’ patients, to manage clients’ queries, and to understand the importance of asking about Indigenous identification (rather than making assumptions based on apparent patient/client characteristics).

Other in-scope options identified that describe practices or changes to practices include (most arising from the hospital domain):

- improving health staff training and awareness of the need for (1) Indigenous identification data and (2) consistency and compliance with national standards in its collection
- expand training and awareness to other elements of the health system (eg, primary health care, pathology) and to other types of health professionals (eg, GPs, allied health)
- using easier, less threatening, more sensitive ways to seek information about patient Indigenous identification, eg,
  - self-complete forms completed at home before hospital admission (privacy)
  - showing respondents a card with the question on rather than directly asking the question
  - asking the Indigenous identification question after the Country of birth question
  - follow up by staff if the question is not completed
  - explaining reasons why Indigenous identification is collected, and
  - promoting the importance of Indigenous identification (prominent displays of promotional material)
- improve the collection of Indigenous identification within the context of improving patient registration (demographic) details generally (i.e., desensitise Indigenous identification as a separate/special issue)
- ensure admission staff check all detail in the hospital record on each patient admission
- update data collections if Indigenous identification becomes known after initial collection

- supervisors and managers support and reinforce frontline staff training and the importance of accurate patient registration and Indigenous identification
- appropriate organisational structures and processes in place support an information culture, including:
  - responsibility and accountability for collecting information clearly delegated to individual managers and staff
  - standard forms and Indigenous identification policies that conform to the ABS question in use across the health service
  - review all forms periodically to ensure conformance
  - audit data collections periodically to monitor completeness and accuracy
  - use post-discharge surveys to evaluate quality of Indigenous identification and identify need for further training
- training and support of health care staff in the importance and collection of Indigenous identification at all possible collection points (based on ABS work)
- improve communicable disease notifications by general practitioners
- investigate poor compliance by GPs
- modify pathology forms to allow recording of Indigenous identification
- address poor compliance by private laboratories (especially re notifiable conditions), starting points include:
  - provision of information on request forms
  - capability of systems to capture and on-transmit data
  - modifying legislation/regulation to provide ‘comfort’ re release of data considered ‘non-essential’ for patient care

### ***Implement data principles and protocols***

The majority of options identified in this section are concerned with the implementation and guaranteeing of established standards, such as the National Health Data Dictionary (ABS standard) question on Indigenous identification (origin). Implementing the standard means not only ensuring that the data is collected in an appropriate manner but that it is collected each time in a consistent way from all patients/clients, entered into computer systems that are correctly configured to support the standard, and monitored to ensure adequate quality against the standard or to identify improvement measures needed. The need for routine data quality assessment was the subject of many separately identified options in this area. A number of options also identify the need for the development and implementation of data and reporting protocols, especially in the areas of privacy and confidentiality.

Options identified and in-scope include:

- systematic mechanisms to check the quality and accuracy of Indigenous identification data, such as data quality assessment exercises and audits that are regularly conducted (to date most have been one-offs). A variety of mechanisms is identified, e.g.
- annual monitoring for hospital admission data against a sample of patients surveyed,
- spot audits to assess level of identification achieved by health facilities and collections,
- linking datasets to assess the completeness of identification
- following up a proportion of health facilities with high proportions of ‘not stated’

- monitor the percentage completion of the Indigenous identifier so that progress towards the goal (e.g., 90% completion) and maintenance at the goal level is known
- adopt a / the standard question on Indigenous identification; or use the ABS standard for Indigenous identification in all data collections
- standardise admission forms and procedures, revise manuals [Qld]
- ensure all new information systems and data collections conform to standards (and establish a committee to oversee the creation of new forms to ensure they conform to standards) [Qld]
- develop and use standard mechanisms to report on levels of Indigenous identification coverage
- develop protocols for the collection and use of health data including data on sexual health
- in remote communities especially, ensure privacy and confidentiality particularly in relation to sexually transmitted diseases
- develop legislative protection of confidentiality, and address confidentiality and privacy issues
- establish culturally sensitive and ethical privacy and confidentiality protocols that recognise Aboriginal and Torres Strait Islander peoples' ownership of data
- effective evaluation of process
- establish an accountable body to advise on matters relating to the collection, use, release and publishing of Aboriginal and Torres Strait Islander health information

### ***Changes in organisational culture / values***

Options identified that are in-scope and address general or specific values include:

- cultivate staff sense of ownership and responsibility for the data they collect
- Aboriginal Hospital Liaison Officers to raise cross-cultural awareness throughout hospitals
- hospital culture sensitive to cross-cultural issues – including Indigenous culture - and their impact on data quality
- develop organisational values of unity, excellence, compassion, justice and human dignity improve data quality generally, including Indigenous identification
- commitment to quality assurance in reporting Indigenous identification
- recruitment, training and retention of Aboriginal and Torres Strait Islander Australians by data collection, analysis and research organisations

### ***National measures***

Options identified and in-scope include:

- continued oversight of data quality issues by NAGATSIHID
- clarify the nature and purpose of existing data and identify and address information gaps – to inform planning, quality improvement practice, funding and delivery of primary health care services
- use existing mechanisms to improve the quality of data collection (e.g., State and Territory governments, AIHW, the National Health Information Plan, the National Centre for Disease Control and the National Centre for HIV Epidemiology and Clinical Research
- an effective national approach to address system issues that prevent or hamper accurate recording of Indigenous identification
- modify [State and Territory] health information systems to conform with national standards

- link data collection activities at all levels of government between health, housing and community and welfare programs to facilitate cross-sectoral activities and support preventative and environmental health activities
- develop primary health care minimum data sets for planning at all levels (local, regional and state/national levels)
- legislative changes to ensure recording of Indigenous identification on pathology forms
- jurisdictions report progress in improving Indigenous identification in data collection systems as part of performance indicator reporting
- continue involvement in national projects and activities to develop best practice models to improve Indigenous identification.

## **Appendix G Jurisdictional initiatives – past and planned**

Information on *Continuous improvement activities*, and on *Initiatives implemented and planned* to improve Indigenous identification in communicable disease reporting in the jurisdictions.

### **New South Wales**

#### ***Continuous improvement activities***

Quarterly Performance Indicator review of data completeness.

Completeness of Aboriginality recording assessed for meningococcal disease and syphilis. QA check on data entry (i.e. for diseases where follow up with the clinician occurs): QA target for Syphilis is >90% and meningococcal disease is >90% (Aboriginal or Torres Strait Islander =Y/N/Unk divided by Disease specific N of notifications).

#### ***Initiatives implemented to improve Indigenous identification***

None specific to Communicable diseases data collections, but the Aboriginal Health Information Strategy Unit, NSW Health, was created in 1997 and has as its overall goal the improvement of Aboriginal and Torres Strait Islander health information in NSW. One of the main strategies to achieve this goal has been the development and implementation of the *Collecting Patient Registration Information Training Program* targeted at NSW Health staff. This program separates collecting Indigenous status from Cultural Awareness Training and trains staff in how to collect Indigenous status as part of improving data quality.

The training package is available at <[www.health.nsw.gov.au/im/ahisu](http://www.health.nsw.gov.au/im/ahisu)>.

In 1998 and 2000, NSW Department of Health released the following documents to improve the Indigenous identification. While neither directly targeted Communicable Diseases they are aimed at the entire public health system.

- The Better Practice Guidelines to Improve the Level of Aboriginal and Torres Strait Islander Identification in the New South Wales public health system. <<http://www.health.nsw.gov.au/im/ahisu/pages/bprac-ab-id.pdf>>.
- Principles for Recording Aboriginal And Torres Strait Islander Origin Information of Patients and Clients. <[http://www.health.nsw.gov.au/im/ahisu/pages/circular\\_2000\\_38.pdf](http://www.health.nsw.gov.au/im/ahisu/pages/circular_2000_38.pdf)>.

#### ***Planned initiatives***

None specific to Communicable diseases data collections, but the Aboriginal Health Information Strategy Unit is currently undertaking a project to develop a Framework of Principles and Protocols for Cultural Awareness training for Area Health Service staff.

Project to enhance electronic notifications by pathology laboratories to State Public Health Unit. Consultant currently reviewing top 20 labs (80% of notifications) capacity to notify electronically. Opportunity to negotiate (with labs, with GPs) for Indigenous identification to be included on pathology request forms and pathology reporting formats. These forms currently do not support Indigenous identification.

Communicable Diseases would be supportive of exploring initiatives successfully implemented in other jurisdictions.

## Victoria

### *Continuous improvement activities*

The data are regularly looked at as part of the data quality within Communicable Diseases Section, however, one of the major barrier is the recording at health service providers.

**The quality of the data is better for those notifications that we receive in small numbers. This is because these notifications are followed up with individual patient or family rather than with a GP or hospital and the questions about ATSSIS are asked of the case.**

### *Initiatives implemented to improve Indigenous identification*

No initiatives to improve Indigenous identification in communicable disease specifically, however related initiatives are listed below.

Project by Ms Sandy Campbell on the level of ascertainment of Indigenous births in four Vic health information systems (conducted through NCEPH & the (then) Koori Health Unit, Department of Human Services). Showed significant under-reporting in all four systems.

Outcome: Koori health counts: update on Koori health information. March 2003.

Other material available:

Koori Health Unit 1996, *Case Studies of 'Best Practice' in Recording Aboriginality*, Victorian Government, Department of Health and Community Services, Melbourne, viewed 19 December 2003, <<http://koori.health.vic.gov.au/casestud/abbody.html>>.

Koori Health Unit 2001, *Are you of Aboriginal or Torres Strait Islander Descent?* Victorian Government, Department of Human Services, Melbourne.

### *Planned initiatives*

No, however, Communicable Diseases would be supportive of exploring initiative successfully implemented in other jurisdictions.

The Koori Human Services Unit (DHS) is responsible for managing the hospitalisation information (ICD10 Codes) of all admissions of identified Koori people. They have a liaison officer in each region of the state and it is planned to meet with them in early 2004 to improve reporting.

The Koori Human Services Unit is considering a reminder notice to refresh GPs on legislated requirements for reporting including communicable disease notifications.

## Queensland

### *Continuous improvement activities*

The data are regularly looked at as part of the data quality within Communicable Diseases Unit. CDU has previously had campaigns to improve Indigenous identification with vaccine service providers (most general practices) and routinely provides this information to new vaccine service providers. This sort of education is expensive (particularly in terms of staff resourcing).

No specific education programs for general practitioners occur through notifiable diseases surveillance (as there is no mechanism for this information to come via private laboratories),

although Indigenous status is routinely sought through follow-up of cases (where this is done - selected diseases only).

### ***Initiatives implemented to improve Indigenous identification***

In 1998, the Aboriginal and Torres Strait Islander Health Branch of Queensland Health funded the Communicable Disease Unit of the Public Health Services Branch to develop strategies for the accurate identification of Aboriginal and Torres Strait Islander peoples within public health systems. The first and second phases have been reported, recommendations formulated, and some actions taken to improve the quality of data on Indigenous status collected by clinicians, pathology laboratories and Queensland Health. Training and awareness raising promotional material is also listed below.

Queensland Health 1998, *Who's Indigenous? What's it mean? Who wants to know? ...and why?*

1998, *Public Health Systems, Indigenous Identifiers Project Phase 1*

1999, *You and Your Indigenous Patient*

2001, *Using health related data collections to monitor the health status of Aboriginal and Torres Strait Islander peoples in Queensland: Current Status*

2003, *Public Health Systems Indigenous Identifiers – Phase 2 Evaluation 2003*

### ***Planned initiatives***

Considering changes to legislation to require Indigenous identification in communicable disease notifications.

Changes in IT systems to enable data transfer/sharing where possible. Strategy of tackling what can be done in the public health system as first priority before extending changes.

Recommendations from the *Public Health Systems Indigenous Identifiers Phase 2* (see above) included:

- further training and support be provided to staff to encourage adherence to recommendations and to improve completeness of business databases;
- new and redeveloped databases to include the ABS recommended Indigenous identification field (some exceptions noted, e.g. Environmental Health Activity Database, Food Complaints database);
- periodic monitoring to assess compliance and accuracy;
- continue to inform the general and professional communities (e.g. at relevant meetings and conferences) of the planned uses of data – ultimately to improve Indigenous health - and the benefits of accurate identification; and
- continue involvement in national projects and activities to develop best practice models to improve Indigenous identification.

## **Western Australia**

### ***Continuous improvement activities***

Occasional reminders to staff in Public Health Units to endeavour to follow-up with doctors to complete indigenous status information for key diseases.

Completeness varies by disease. For those diseases with relatively more laboratory than doctor notification (e.g. hepatitis B and C, Ross River virus disease, etc) Indigenous status

information is less complete. By contrast, where there is relatively more doctor notification and/or effort by public health staff to follow-up and complete data (e.g. vaccine preventable diseases, meningococcal disease, HIV) Indigenous status reporting is complete or near complete.

### ***Initiatives implemented to improve Indigenous identification***

1. Improvement through 1990's in completion of notification forms by doctors resulted in improvement in reporting of Aboriginality. New design for doctor notification forms introduced in 1996 (and revised 2000). On doctor notification forms the desire was to keep the information collected as simple as possible. Hence, WA uses simple tickboxes, and does not differentiate Aboriginal and Torres Strait Islanders, given that the latter are likely to be very low in numbers in this state.
2. Analysed the quality of WA hospital data in 2001. Report (see below) included figures that could be used on a population basis to 'correct' statistics for various health measures; as well as comments & suggestions for improvement.

Young MJ 2001, *Assessing the quality of identification of Aboriginal and Torres Strait Islander people in Western Australian hospital data, 2000*.

2. Assessment of WA Cancer Registry indigenous status data with reference to Data Linkage Unit (2003)<sup>13</sup>.

Outcome: Accuracy of data improved: changed the recording of 135 non-Indigenous persons to Indigenous, and 100 Indigenous persons to non-Indigenous; and added 1388 Indigenous status codes for cases where there was no information.

3. Data Linkage Unit has become a key player in improving the quality of Indigenous status data in linked registries such as the WA Cancer Registry; however all data are collected passively from hospitals and other primary sources, and there is no information about accuracy for individual cases.

### ***Planned initiatives***

A Health Amendment Bill is planned for early 2004 which, if passed, will for the first time specify that practitioners and laboratories should notify information as appears on relevant notification forms. Hence, Aboriginality, which does appear on the forms, will by extension be a required field. In practice, it is unlikely that the change will have much influence on the quantity or quality of indigenous status reporting.

Consider inclusion of communicable diseases information in the scope of the Data Linkage Unit - to provide an avenue for assessing and ultimately improving the quality of data in communicable diseases. Privacy concerns and funding remain issues – it would be a considerable piece of work.

### ***Additional comments***

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<sup>13</sup> (WACR ref T030251)

There is a common perception among (some of) the Department's database managers that the questions concerning Indigenous status are unlikely to be routinely asked correctly in health-care situations, especially on repeated occasions of service – when, as per the definition, self-identification preference may have changed. This seems especially of concern for sexually-transmitted diseases and mental health data.

The relevance of the “Torres Strait Islander” identification to the Western Australian situation is low, and in some databases at least (Cancer Registry, for example, as well as the Communicable Diseases database), only “Indigenous status” is recorded, as yes/no/unknown – because we will not get better information than that, from our data providers. The fact that there is no code for “Aboriginal and/or Torres Strait Islander, but not sure if one or both” in the data domain for the national definition, is a serious shortcoming, from the WA point of view.

South Australia

### ***Continuous improvement activities***

Indigenous identification is reviewed at the end of each year and documented in annual reports.

The completion rate does vary somewhat from disease to disease. The diseases with the highest completion rates for the period 1996-2003 are as follows: Syphilis, HIV, Chlamydia infection, Hepatitis B, Hepatitis C, Gonococcal infection, Q fever, Meningococcal infection, Pneumococcal infection. The diseases with the lowest completion rates include Atypical Mycobacterium infection, Rubella, Listeria infection, and Legionella infection.

For specific conditions (meningococcal disease and pneumococcal disease), if the Indigenous identification field is not completed on the notification form, it is followed-up with the notifying doctor. For all the other notifiable conditions, a non-completed Indigenous identification field on the notification form is not routinely followed-up.

The follow-up of gonococcal infection, HIV, chlamydia infection, syphilis, hepatitis B and hepatitis C is performed by STD Services rather than by the Communicable Disease Control Branch, and the high completion rates for Indigenous identification for these 6 diseases suggests that STD Services routinely follow-up missing values regarding Indigenous identification.

### ***Initiatives implemented to improve Indigenous identification***

Improved engagement and relationship with General Practitioners (as instructed by Coroner) and increased attention on public health (through media reporting of food-related cases) has improved notification rate and data completeness including Indigenous identification.

### ***Planned initiatives***

Considering addressing completeness and quality of data supplied by GPs through pushing for more GPs to report, and by asking doctors generally to do the right thing; assess through a sample of doctors to see if they ask all patients the ABS standard question as is required. May focus on paediatricians (disproportionate amount of communicable diseases in children).

Considering breaking category 5 of the output categories (i.e. ‘not stated/inadequately described’) into 2 categories as follows:

- 5A – field on the notification form completed, denoting category 5; and
- 5B – field on the notification form not completed.

## **Tasmania**

### ***Continuous improvement activities***

Data quality varies – obtain a significant amount of unknowns because question not asked by notifier. Target certain diseases (Hepatitis B & C, HIV, S. Pneumonia, Tuberculosis, Gonorrhoea, Meningococcal, Chlamydia, Syphilis) and therefore expect better quality for enhanced data collection. Reliant on return rates from medical practices and lack of resources to specifically follow up Aboriginality for every notification.

### ***Initiatives implemented to improve Indigenous identification***

Modified standard questionnaires that Public Health Officers send out to medical practices to make them user friendly and a new data base (currently in development) will be to ABS standard.

### ***Planned initiatives***

Project in place on Indigenous sexual health, one aspect of this project is that GPs are being targeted to report on Indigenous status for STIs.

## **Australian Capital Territory**

### ***Initiatives implemented to improve Indigenous identification***

Putting the provision of Indigenous status into the new Code of Practice, but pathology laboratories may not be able to comply because they do not receive the data.

### ***Planned initiatives***

1. Data Utility Project – A review of the utility of the Aboriginal Medical Service client information for profiling the health status of the Aboriginal community in the ACT. The Population Health Research Centre of ACT Health will undertake this project in partnership with the ACT Aboriginal Medical Service in the ACT.

Outcome: The provision of a profile of the demographic characteristics, health status and health related behaviours of clients of the Aboriginal Medical Service.

2. The Aboriginal and Torres Strait Islander Health Unit of ACT Health recently developed its Business Plan a priority of which is a commitment to resource a Data Development Project. The Project has received executive endorsement.

The Project will map existing data sources and provide and prioritise recommendations to enhance the provision by ACT Health of comprehensive and valid Aboriginal and Torres Strait Islander health data.

Outcome: The Project is expected to:

- provide a strong evidence base for ACT Health in the development of policy, planning and purchasing of service for the ACT's Aboriginal community; and
- enhance ACT Health's ability to respond to national performance and financial measure accountabilities.

### ***Additional information***

In a Summary Response to the National Performance Indicators for Aboriginal and Torres Strait Islander Health reports for 2000-2001 and 2001-2002 the ACT stated the following:

“Under privacy legislation, the ACT is not in a position to provide data on disease prevalence where such data is potentially able to identify a client. Due to the ACT's relatively small Aboriginal population base, client identification would be possible.”

## **Northern Territory**

### ***Continuous improvement activities***

For notifications from laboratories, staff at the Centre for Disease Control (CDC) who collate notifiable diseases data, usually refer to the hospital information system to ascertain indigenous status of cases. In cases where this is not helpful, the information might be collected from health care providers, although they would only be contacted if enhanced surveillance of the case was required. For doctor notified cases the indigenous status is usually confirmed with the notifying doctor. Very occasionally, Aboriginality is assumed from the surname provided.

A substantial reduction in “unknown” occurred after 1999. This may relate to increased attention to recording Indigenous status within hospitals and increased computer access to this information for CDC notifiable disease data entry staff (see below).

Hospital staff who gather and record demographic information on patients use the ABS system and receive training on this matter. It is a standard data collection item for all people “entering” the public health system.

The quality and consistency of Indigenous identification data in the Northern Territory Hospital Morbidity Dataset was assessed in 1997,

Condon JR et al. 1998, Northern Territory Hospital Morbidity Dataset Validation of Demographic Data 1997, Territory Health Services Darwin, viewed 11 May 2004, <[http://www.nt.gov.au/health/health\\_gains/epidemiology/morbidity\\_dataset\\_1997.pdf](http://www.nt.gov.au/health/health_gains/epidemiology/morbidity_dataset_1997.pdf)>.

This review found that indigenous status in the hospital dataset was correct in 94% of cases. The small size of the NT and the local knowledge of people collecting this information also contributes to both the quality and quantity of indigenous identification. General impression is that the reliability of Indigenous identification data is high with the limitation that we only currently record Aboriginal/Non Aboriginal/Unknown. In the smaller centres of Katherine, Gove, Tennant Creek and probably Alice Springs it may be more reliable than in Darwin. The smaller size, fewer health service providers and subsequent greater familiarity and ease of checking means that the system of accurately determining Indigenous status probably works very well. In Darwin's larger more urban population with a larger number of providers, this is probably slightly less reliable. Since 1997 the mean proportion of “unknown” for Indigenous status each year was 11.3% for the NT as a whole, 5.1% for Alice Springs and 22% for Darwin (although down to 12% for Darwin in 2002, 2003)

### ***Initiatives implemented to improve Indigenous identification***

1. Centre for Disease Control data entry staff were given access to hospital demographic information to allow them to check details, including Indigenous status, when entering notifiable disease data.

Outcome: Reduced proportion of “unknowns”

2. An upgrade of the hospital information system in the mid-late 90s improved the quality of the information. A data quality project in 1997 made an assessment of the morbidity data.

Outcome: Reduced proportion of “unknowns”

3. Hospital staff who gather and record demographic data have been trained in the importance of recording Indigenous status and in the ABS recording system.

Outcome: Improved recording of Indigenous status

### ***Planned initiatives***

Incorporate ABS format for new notifiable disease database where that information available. The NT CDC notifiable disease database currently records Indigenous status as “Aboriginal/ Non-Aboriginal/unknown”. A new computer system is currently under construction and will record Indigenous status according to the ABS format. The new computer system will be implemented on 01/07/04. A program of Continuous Quality Improvement is planned for the new NT Notifiable Diseases System. However, there is no planned review of the data quality (with respect to indigenous status) in the hospital information system. It is not possible to say how reliable the information will be in relation to the ABS classification especially with respect to Torres Strait Islander status. At present there is no identified need in terms of service delivery planning to distinguish between Aboriginal and Torres Strait Islander people.

Planned outcome: Increase in proportion of notifications with Indigenous status in ABS format.

### ***Additional information***

The NT has a relatively high population of transient people who are not in the hospital system and are not regular clients of health services. This contributes to the proportion of “unknowns”.

To record Indigenous status according to the ABS standard for notifiable diseases (as opposed to our current Aboriginal / Non Aboriginal / “unknown”) would require an increase in work for primary care providers to gather the information in this way. Data entry staff do check hospital records for indigenous status but not all records have the data in ABS form.

Pathology companies *might* be persuaded to put a box on request forms for indigenous status (in ABS format) and doctors, nurses and Aboriginal Health Workers in the full range of primary care services *might* be able to be trained to gather this data and *might* fill it out routinely on pathology request forms. If they did, it *may* reduce the proportion of unknowns and increase the reliability of ascribing of indigenous status.

However, private pathology providers and many primary care agencies are beyond the immediate control of the health department. The cost of insisting on the ABS format for all notifiable disease notifications such changes would be high and the likely benefit to the NT seems low.

Overall in the NT there is already a high level of awareness of the need for and actual reporting of Indigenous status.

At present there is no identified need in terms of service delivery planning to distinguish between Aboriginal and Torres Strait Islander people.

## **Appendix H Present agreements**

Additional information on a range of *Present Agreements* discussed in Section 2.3.

### ***Health and Ageing Budget 2003-04 (DoHA 2003)***

The Australian Government Department of Health and Ageing Budget 2003-04 (DoHA 2003) Extract: 'The Department is committed to raising the health status of Aboriginal and Torres Strait Islander peoples by working in partnership with communities to provide access to high quality comprehensive primary health care and population health programs. It is pursuing a two pronged approach, which aims to:

- improve accessibility and responsiveness of the mainstream health system; and
- provide complementary action through Indigenous specific health programs.

Although many initiatives are coordinated through the Office for Aboriginal and Torres Strait Islander Health (OATSIH), all programs within the Department have a responsibility to meet the specific health needs and circumstances of Indigenous Australians.

The long-term strategic approach comprises:

- achieving comprehensive and effective health care for Aboriginal and Torres Strait Islander peoples through the development of infrastructure and resources;
- addressing key health issues and risk factors impacting on health status;
- improving the evidence base through effective data systems and evaluation and promoting the use of effective policy; and
- improving communication with service providers and the general population.

All policies relating to the health of Aboriginal and Torres Strait Islander peoples are based on the principles of community empowerment and participation in the development and delivery of health care services and a long term partnership approach with key stakeholders, including all levels of government and the Aboriginal community controlled health sector.'

Source: DoHA 2003, *2003-04 Portfolio Budget Statements*, Australian Government, Canberra, p. 201.

### ***National Strategic Framework for Aboriginal and Torres Strait Islander Health***

In the *National Strategic Framework for Aboriginal and Torres Strait Islander Health*, 'Key Result Area Seven' titled 'Data, research and evidence' develops a strategic approach to improving information on how well the health sector meets the needs of Indigenous Australians (NATSIHC 2003b, p. 31). The *National Strategic Framework...* is to make sure that data is consistent, analysed, published, and collected so as to enable comparison across jurisdictions.

It aims to improve data collections (and research processes) about Indigenous Australians that can inform ways of improving Aboriginal and Torres Strait Islander health.

Appropriate and practical data collection and research:

- 'Involves collaboration in the design, management, evaluation and dissemination phases of the research/data collection;
- Results in changes in policy, service delivery and people's behaviour;

- Includes a focus on communicating research/data collection findings in cross-cultural and non-academic contexts;
- Strengthens Aboriginal and Torres Strait Islander data collection and research capacity;
- Encourages multi-disciplinary and cross cultural skills and perspectives; and
- Tries to look at problems by evaluating health interventions and practices, instead of repeating the nature and scale of those problems' (NATSIHC 2003b, p. 31, our emphasis)

The *National Strategic Framework* sets three objectives and makes recommendations in four 'Action areas': Data availability and quality; Data development, information management and utilisation at the primary health care level; Research; and Knowledge translation (NATSIHC 2003b, pp. 31-34). The objectives are for:

- Improved quality of information and information management processes about the health of Aboriginal and Torres Strait Islander peoples.
- Improved information collection and utilisation of information on successful models of health care provision for Aboriginal and Torres Strait Islander peoples.
- Greater range and quality of research about the health of Aboriginal and Torres Strait Islander peoples with a focus on interventions to improve health outcomes.

The number one recommendation is to 'Implement the 1997 *National Aboriginal and Torres Strait Islander Health Information Plan*'<sup>14</sup>. Particular activities ('that will have a significant effect in improving data quality') include:

- using the Australian Bureau of Statistics (ABS) standard for Aboriginal and Torres Strait Islander identification in all data collections;
- introducing a voluntary Aboriginal and Torres Strait Islander identifier on the MBS;
- increasing training and support of health care staff to understand the importance of and how to collect data about Aboriginal and Torres Strait Islander status at all possible collection points – based on work underway by the ABS;
- encouraging data collection, analysis and research organisations to actively recruit, train and retain Aboriginal and Torres Strait Islander peoples;
- developing and using standard mechanisms to report on levels of Aboriginal and Torres Strait Islander status coverage;
- maintaining the ABS Survey and Census collection program;
- ensuring that all relevant data collections are developed in consultation with, and are appropriate to, the needs of Aboriginal and Torres Strait Islander peoples;
- where possible, ensuring "mainstream" data collections relevant to measuring Aboriginal and Torres Strait Islander health and related characteristics such as income, housing and employment, include adequate samples of Aboriginal and Torres Strait Islander peoples;

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<sup>14</sup> Aboriginal and Torres Strait Islander Health and Welfare Information Unit, *The Aboriginal and Torres Strait Islander Health Information Plan*, Australian Health Ministers' Advisory Council and Australian Institute of Health and Welfare, Canberra 1997.

- maintaining reporting of the annual Aboriginal and Torres Strait Islander National Performance Indicators with a particular emphasis on collecting data regarding the health of babies, infants and children which may have a later impact on developmental health, **chronic disease**, or educational outcomes; and
- continued oversight of data quality issues by the National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data.
- Develop consistent environmental health audit tools and environmental health indicators for Aboriginal and Torres Strait Islander communities.
- Where possible, link data collection activities at all levels of government between health services, housing agencies and other community and welfare programs to facilitate a cross-sectoral approach and support preventative and environmental health activities.
- Where there are important information gaps not covered by existing data collections (eg **oral health**) representative surveys should be conducted.
- Improve the quality, collection and management of health workforce data in mainstream services and Aboriginal community controlled health services.

#### Data development, information management and utilisation at the primary health care level

- Develop primary health care minimum data sets that are useful for planning at the local, regional and state/national levels.
- Develop a framework document that clarifies the nature and purpose of existing data and identifies and addresses information gaps, to inform planning, quality improvement practice, funding and delivery of primary health care services.
- Enhance data systems in primary health care services by investing in computers, software and staff skills development computerise patient records and support their use as a care-planning tool; and increase resources for evaluation and analysis of health system data.

#### **Research**

- Ensure that all health research about Aboriginal and Torres Strait Islander peoples complies with NHMRC ethical guidelines and is funded and conducted in line with processes identified by the NHMRC's Aboriginal and Torres Strait Islander Health Research Agenda Working Group.
- NHMRC review its procedures to ensure sufficient research funding is allocated to research aimed at improving Aboriginal and Torres Strait Islander health – noting that the *Health is Life*<sup>15</sup> report recommended that 5% of the total NHMRC research budget should be allocated to Aboriginal and Torres Strait Islander health research.
- Allocate government funding for research on Aboriginal and Torres Strait Islander health, in line with the research priorities and processes identified by the NHMRC's Aboriginal

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<sup>15</sup> HOR 2000, op cit

and Torres Strait Islander Health Research Agenda Working Group through the Strategic Framework for Indigenous Health Research.<sup>16</sup>

- Build research and evaluation capacity in the primary health care sector, particularly ACCHSs and increase Aboriginal and Torres Strait Islander participation in and control of research and research funding processes including in NHMRC funding decisions and as members of research teams.
- Increase the level of participation of Aboriginal and Torres Strait Islander peoples on NHMRC Council and Committees.

### ***Knowledge translation***

- Increase, collate and publish an evidence base on successful programs/interventions in Aboriginal and Torres Strait Islander health.
- Facilitate the translation of research into practice by close collaboration between researchers, government and the non-government sector.
- Identify and implement mechanisms for increasing awareness and understanding of data and research agendas, including that contained in this *National Strategic Framework*, amongst Aboriginal and Torres Strait Islander peoples.

### ***Some examples of successful programs and promising approaches identified in the National Strategic Framework:***

- ✓ Service Activity Reporting by Aboriginal and Torres Strait Islander primary health care services provides information on the client base, the extent of service they are providing, their staffing and funding levels. This information has been used to support additional funding to high priority areas identified on the basis of evidence about services, resources and use.
- ✓ Joint reports by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare combine information from a variety of sources to form an overall picture of mortality and morbidity, health service use and expenditure, health risk factors and wellbeing in Aboriginal and Torres Strait Islander populations. Future reports and surveys will provide an opportunity to assess progress in meeting the health and welfare needs of Aboriginal and Torres Strait Islander communities.
- ✓ The VicHealth Koori Health Research & Community Development Unit, funded by the Victorian Health Promotion Foundation, undertakes research strategies that bring together a number of research perspectives, including health, social science, history and policy, and provide for collaborative research strategies between researchers and Aboriginal and Torres Strait Islander health service providers. It aims to integrate research practice with community and policy development.
- ✓ The Kimberley Aboriginal Medical Services Council in Western Australia has published a textbook on primary health care within the context of Aboriginal community control that provides information for practitioners working in Aboriginal community controlled health services. The aim of the resource is to lessen isolation of practitioners in Aboriginal community-controlled health services, to speed up the acquisition of confidence in dealing with health problems more common in Aboriginal and Torres Strait Islander communities, and to reduce

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<sup>16</sup> NHMRC 2002, *The Research Agenda Working Group Road map: a strategic framework for Aboriginal and Torres Strait Islander health research*, Canberra 2002

unnecessary practice variation. The book is based on a systematic review of the literature, critical examination of studies, and experience in the delivery of health services within the Aboriginal community controlled sector.<sup>17</sup>

- ✓ The Cooperative Research Centre for Aboriginal and Tropical Health is a research partnership between the Menzies School of Health Research, Territory Health Services, Northern Territory University and two Aboriginal community controlled medical services (Danila Dilba Medical Service in Darwin and Central Australian Aboriginal Congress in Alice Springs). Its objective is to promote cooperation in research and education to improve Aboriginal and Tropical Health. It provides a new vehicle for developing cooperative research relationships, with control given to Aboriginal people, while ensuring that there is access to a broad range of expert advice.
- ✓ The Australian Government Department of Health and Ageing has collated information on promising approaches in primary health care for Aboriginal and Torres Strait Islander peoples.<sup>18</sup>

### ***The Framework Agreements***

The Framework Agreements (under a Health Memorandum of Understanding) have been drawn up between the government of each jurisdiction, the Australian Government, the Aboriginal and Torres Strait Islander Commission and the state or territory affiliate of the National Aboriginal Community Controlled Health Organisation (NACCHO). The first Framework Agreements were signed between 1996 and 1998, and have since been renegotiated. Essentially ‘process agreements’, they ‘generally bind parties to adhere to certain processes rather than to substantive issues’ (ATNS 2003). The key commitments made by the Framework Agreement partners were to: an increased level of resources allocated to reflect the level of need; joint planning; access to both mainstream and Aboriginal and Torres Strait Islander specific health and health related services which reflect their higher level of need; and improved data collection and evaluation (ATSIC 2001). Although their effectiveness varies between States and Territories, each of the Framework Agreements recognises a role in the decision-making process for both ATSIC and the state or territory affiliate of the National Aboriginal Community Controlled Health Organisation (NACCHO 1999).

#### Examples:

SA - *Aboriginal and Torres Strait Islander Health Framework Agreement* (South Australia) (2001) between the State of South Australia, the Australian Government of Australia, the Aboriginal and Torres Strait Islander Commission and the Aboriginal Health Council of South Australia)

Qld - *Agreement on Queensland Aboriginal and Torres Strait Islander Health* (the Framework Agreement) executed on 12 June 2002 - Parties to the Agreement: QAIHF; ATSIC; Australian Government; and Queensland Health

WA – *Western Australian Framework Agreement on Aboriginal and Torres Strait Islander Health* (July 2002) - between the State of Western Australia, the Australian Government of Australia, the Aboriginal and Torres Strait Islander Commission and the Western Australian Aboriginal Community Controlled Health Organisation.

Torres Strait - *Torres Strait Health Framework Agreement* between Australian Government and State Governments and the Torres Strait Regional Authority (TSRA) to jointly address the health issues in the Torres Strait through the implementation of projects and upgrading of services.

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<sup>17</sup> NACCHO 1999, op cit

<sup>18</sup> DHAC 2001, op cit.

NACCHO, in a 1999 *Report on the implementation of the framework agreements on Aboriginal and Torres Strait Islander Health* found that: ‘All of the indicators of socio-economic and health status (e.g. education, income and employment levels, infant mortality, life expectancy, adult morbidity and mortality rates) clearly show Aboriginal people to be by far the most disadvantaged group in Australia’ (NACCHO 1999, p. 4).

The latest reports on progress have found that ‘although some recommendations of the Framework Agreements remain outstanding, some states (such as NSW) actively require states and regional health providers, such as Area Health Authorities, to ensure input from the Indigenous community and open and accessible health facilities for Aboriginal and Torres Strait Islander people’ while in other jurisdictions, the Agreement ‘has resulted in little change or accountability in the way States provide health services to Indigenous people’ (ATSIC 2001). Audits by the Australian National Audit Office have raised the need for improved inter-agency coordination (ANAO 1998); NACCHO has stated that a lack of coordination between Federal and State Governments, with consequent “buck-passing” and difficulties in the relationship between Governments and Aboriginal organisations’ has been a major impediment to reform in Indigenous health, and that the Framework Agreements ‘attempt to address these issues’ (NACCHO 1999, ATSIC 2001).

### ***NACCHO Position on Socially Communicable Diseases***

The National Aboriginal Community Controlled Health Organisation (NACCHO) ‘Position on Socially Communicable Diseases’ states that:

‘The salient points are:

- To eliminate socially communicable diseases in Aboriginal peoples;
- To establish Aboriginal community controlled primary health care services in all Aboriginal communities;
- To develop effective socially communicable disease programs as part of the primary health care role of Aboriginal community controlled health services.’ (NACCHO 2003)

### ***National Performance Indicators for Aboriginal and Torres Strait Islander Health***

*National Performance Indicators for Aboriginal and Torres Strait Islander Health* (OATSIH 1998, 2000). National performance indicators have been agreed to by all governments and reported against since 1997. A revised set will be used for reporting from 2001 onwards. ‘National Performance Indicators for Aboriginal and Torres Strait Islander Health were first developed in 1996 by the Heads of Aboriginal Health Units (HAHU) at the direction of the Australian Health Ministers’ Advisory Council (AHMAC). The purpose was to provide a way of monitoring the performance of governments in improving the health of Aboriginal and Torres Strait Islander Australians. Interim indicators were accepted in 1997, and the first reports were submitted later that year. In March 1998, AHMAC asked the Australian Government to coordinate further refinement of the existing indicators. The Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) undertook this project on behalf of the Australian Institute of Health and Welfare, with work completed in September 2000’ (Cunningham et al. 2003). The revised indicators include an indicator on *jurisdictional efforts to improve identification of Indigenous people in administrative data collections* (Mackerras 2000). The indicator is listed under ‘Efforts to Improve Identification of Aboriginal and Torres Strait Islanders People in Data Collections’ as (OATSIH 2000, pp. 12-13):

Indicator number 1: Proposed definition: ‘A brief description of actions taken by jurisdictions to improve the identification of Aboriginal and Torres Strait Islander people in the datasets used for reporting on the indicators’ The indicator ‘Tells us about the adequacy of recording of Aboriginal and Torres Strait Islander status in health-related datasets, identifies datasets which are worth using now to provide information about Aboriginal and Torres Strait Islander health, and describes action taken to improve identification of Aboriginal and Torres Strait Islander peoples in health-related data’ (OATSIH 2000, p. 12).

Information required to report on indicators includes the following from the jurisdictions:

“every year the States and Territories should comment on actions being taken to improve the identification of Aboriginal and Torres Strait Islander people in their

- birth registrations
- death registrations
- hospital separation statistics
- Pap smear registries
- EEO and other workforce surveys
- **notifiable disease registries**
- **pathology forms**, and

every year States and Territories should report on progress towards including paternal identification in their Perinatal/Midwives collections” (OATSIH 2000, p. 13).

### ***The National Indigenous Australians’ Sexual Health Strategy***

The *National Indigenous Australians’ Sexual Health Strategy* 1996-97 to 1998-99 (NIASHS) was launched by the Federal Minister for Health in March 1997 and has ‘since become the benchmark by which all Indigenous sexual health programs are evaluated’ (Qld Health 2003b). The NIASHS has been extended to 2003-04 to match the duration of the fourth *National HIV/AIDS Strategy*. The *Strategy* provides a policy framework for addressing STD control among Aboriginal and Torres Strait Islander peoples.

In relation to data collection the *Strategy* states that: ‘to date, Indigenous Australians have had limited, if any, control over research and the collection of health data. A number of controversies have resulted from breaches of confidentiality and privacy from inadequate consultation in the development of research and data-collection processes. But research and data collection are very important if we are to respond effectively to the challenges posed by STDs, HIV/AIDS, hepatitis C and other related communicable diseases’. It recommends actions to improve collaboration between communities and research institutions, and ‘that there be greater attention to the ethical problems associated with data collection, as well as problems associated with the quality of health information systems’ (DHFS 1997, p. 17).

*The National Indigenous Australians’ Sexual Health Strategy (NIASHS): Implementation plan for 2001/02 to 2003/04* (IASHC 2002) identifies key areas in which action is needed and explores ways to build the capacity of services and organisations to initiate action in those areas, including specialist training for sexual health workforce and the provision of services to inmates of correctional services facilities and other specific populations. It identifies the key principals that underpin effective collaboration and proposes recommendations to support shared planning processes under the partnership arrangements. A major emphasis is on building the evidence base of good practice through monitoring, research, and reporting and evaluation.

### ***National Health Data Dictionary (AIHW)***

The National Health Data Dictionary (AIHW) context for the data element *Indigenous Status* includes: 'In the current climate of reconciliation, accurate and consistent statistics about Aboriginal and Torres Strait Islander peoples are needed in order to plan, promote and deliver essential services, to monitor changes in wellbeing and to account for government expenditure in this area' (AIHW 2004).

The standard Indigenous status question is in the National Health Data Dictionary (NHDD) and is part of National Minimum Data Sets for all the data collections that the Australian Institute of Health and Welfare (AIHW) holds (see table below).

The current version of the *Indigenous status* data element in the NHDD (version 5, as from September 2003) is available online through the AIHW's *Knowledgebase* (see below) and through the *National Health Data Dictionary, Version 10, 2001* (AIHW 2001), and linked corrigenda.

The *Knowledgebase* reports current data agreements that include the standard *Indigenous status* data element (all AIHW data collections\*) as shown in the table below (AIHW 2004). Data agreements are for both mandatory National Minimum Data Sets (NMDS) and optional Data Set Specifications (DSS).

\* The National Notifiable Diseases Surveillance System is held by the Australian Government Department of Health and Ageing, not the AIHW.

**Table 12 Data Agreements that include the *Indigenous Status* data element (AIHW 2004)**

NMDS - Admitted patient care	from - 01/JUL/2003	to -
NMDS - Admitted patient mental health care	from - 02/SEP/2003	to -
NMDS - Perinatal	from - 02/SEP/2003	to -
NMDS - Community mental health care	from - 02/SEP/2003	to -
NMDS - Admitted patient palliative care	from - 02/SEP/2003	to -
NMDS - Alcohol and other drug treatment services	from - 01/JUL/2003	to -
NMDS - Non-admitted patient emergency department care	from - 01/JUL/2003	to -
DSS - Cardiovascular disease (clinical)	from - 01/JAN/2003	to -
DSS - Diabetes (clinical)	from - 02/SEP/2003	to -
DSS - Health care client identification	from - 02/SEP/2003	to -
NMDS - Residential mental health care	from - 01/JUL/2004	to -

The Australian Institute of Health and Welfare (AIHW) reports that it is actively working on improving the quality of the Indigenous identifier in the different data.

### ***National Indigenous Pneumococcal and Influenza Immunisation Program***

The *National Indigenous Pneumococcal and Influenza Immunisation Program* provides free vaccines to Aboriginal and Torres Strait Islander peoples through community controlled Aboriginal Medical Services, State/ Territory immunisation clinics and General Practitioners, to protect them from two communicable respiratory illnesses, pneumococcal disease and influenza. See <<http://www.immunise.health.gov.au/indigenous.htm>> and <<http://www.health.gov.au/oatsih/pubs/immune.htm>> (viewed 11 May 2004) for additional information.



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