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## ■ Foreword

A meeting of the International Group for Indigenous Health Measurement was held in Canberra on 28–30 November 2006. The meeting brought together a range of people who are involved in this arena including people from indigenous organisations, national statistical agencies, departments of health, and research institutions from Australia, Canada, New Zealand, and the United States. The Australian Institute of Health and Welfare (AIHW) was honoured to host this meeting, which was co-sponsored by the Office for Aboriginal and Torres Strait Islander Health.

The purpose of the meeting was to further international collaboration to tackle health measurement issues for indigenous populations, building on the work that began at the inaugural meeting in Vancouver, Canada, in 2005.

The meeting highlighted the continued disparities between the health and wellbeing of the indigenous and non-indigenous populations in the four countries. The collection of high-quality data is essential to policy makers as it helps in monitoring and evaluating programs aimed at reducing these disparities. The value of the International Group for Indigenous Health Measurement was confirmed, and the commitment of the agencies represented to improving health information about indigenous people, for the benefit of indigenous people, was highlighted.

I would like to acknowledge the valuable contributions made by the participants during this meeting. Participants presented information on the work they are doing in their own countries to overcome current data deficiencies and to ensure that indigenous health is measured in appropriate ways and that all indigenous people are included in data collections. The importance of national level frameworks for data collection, health improvement and accountability underpinned many of the discussions.

I hope this report of the meeting is useful to participants and others with interest in indigenous health measurement issues.

*Penny Allbon*

Director

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## ■ Executive summary

This publication provides an overview of the second meeting of the International Group for Indigenous Health Measurement held in Canberra, Australia on 28–30 November 2006. The International Group for Indigenous Health Measurement includes a range of people who are involved in this arena, including people from indigenous organisations, national statistical agencies, departments of health, and research institutions from Australia, Canada, New Zealand, and the United States who are committed to working together to ensure the highest quality collection, dissemination, and use of data related to indigenous health.

The Introduction to this report describes the development of the International Group for Indigenous Health Measurement, then presents an overview of indigenous population statistics for each of the four countries, highlighting difficulties in data definitions and data collection processes, indigenous/non-indigenous disparities in infant mortality and life expectancy, and the differences in data governance and input into the collection and use of indigenous health data.

The proceedings from the Canberra meeting are included in Part A of the report. A summary of the meeting is presented, and the themes from the 34 presentations are organised into nine categories: Who counts whom?, capacity building, information governance issues, importance of collaborative efforts, the importance of the community seeing benefits from the data, the importance of cultural factors/holistic approach to well-being, data issues, international collaboration, and the way forward. The meeting agenda is included, along with abstracts from all the presentations, a list of meeting participants, and biographies of the presenters.

Part B goes beyond the meeting summary to present detailed information on data collection processes and data quality issues related to indigenous health measures in each of the four countries. The report includes information regarding the identification of indigenous people/households in the Census, vital statistics data (births and deaths), administrative data, health surveillance measures, and health related surveys, then ends with a comparative overview of indigenous data which includes developments in improving indigenous coverage and data quality.

The report continually highlights the necessity of collecting high-quality data of relevance to both policy organisations and indigenous people for reducing the health disparities between indigenous and non-indigenous people in all four countries.

## ■ Introduction

Indigenous and non-indigenous statisticians, researchers and organisations in numerous countries have been working to improve definitions, collection methods and uses of data on indigenous health, recognising the benefits of both high-quality data and the benefits of collaborating with colleagues in countries with similar issues. High-quality data are necessary to measure the health of indigenous people and to prioritise health needs. These data are fundamental to understanding the factors which underlie health disparities between indigenous and non-indigenous people. High-quality data can also guide public debate and ensure that policies and programs are evidence-based. Without high-quality data it is difficult to evaluate the effectiveness of health programs.

In 2004, discussions were held between health professionals in Australia and the United States on the establishment of a formal structure for working on indigenous health measurement issues. Canada and New Zealand subsequently joined the discussions, which led to the formation of the International Group for Indigenous Health Measurement (International Measurement Group).

At its inaugural meeting in Vancouver, Canada, in 2005, the International Measurement Group agreed that it would consist of participants from Australia, Canada, New Zealand and the United States, and that it would have two main purposes (AIHW 2006:11):

1. To improve the collection, analysis, interpretation and dissemination of information useful for improving the health of indigenous populations.
2. To develop an international network on indigenous health measurement that enables meaningful comparisons, exchange, mutual learning and collaborative projects that inform national policy making oriented to health gain.

The International Measurement Group considered the principles that should govern its development and operation, and agreed that indigenous people had a right to be counted, that indigenous people should be both leaders and participants (and thus needed increased capacity to assemble, analyse and use data), and that all data collection, analysis and dissemination should be linked to improvements in indigenous health.

The second meeting of the International Measurement Group was held in Canberra, Australia, in 2006. This report provides an account of the 2006 meeting in Part A, including the meeting agenda, abstracts, list of participants, and biographies of the presenters. Part B provides additional information on data related to indigenous health in Australia, New Zealand, Canada, and the United States, including census data, vital statistics, administrative data collections, health surveillance and health surveys. This introduction provides an overview of indigenous population statistics, including key indicators and issues related to data governance.

## Overview of indigenous population statistics

One of the most important factors in collecting high-quality data on indigenous health is the ability to define and identify the indigenous population in a consistent and meaningful way. Definitions are often determined by why the data are being collected. For example, if legal entitlements are linked to indigenous status, the question of ancestry or formal registration status with the government is likely to be used. For broader issues of health and wellbeing, the more socially meaningful measure of self-identification may be used.

Table 1 provides a summary of the size and composition of the indigenous populations in Australia, Canada, United States and New Zealand (the four countries constituting the International Measurement Group), along with relevant treaties or legal status definitions which affect the provision of health care or the collection of health-related statistics.

**Table 1: Overview of indigenous populations and treaty status**

Country	Size of indigenous population	Percentage of total population	Subgroups of indigenous population	Treaties
Australia	517,200 <sup>(a)</sup>	2.5%	Aboriginal (90%) Torres Strait Islander (6%) Aboriginal & Torres Strait Islander (4%)	None
Canada	1,172,790 people identified themselves as aboriginal <sup>(b)</sup>	3.8%	First Nations (60%) Métis (33%) Inuit (4%) Multiple and other responses (3%)	Treaty status is given to those of First Nations heritage who have registered with the federal government. Health Canada provides free health care to the First Nations and Inuit populations who live on reserves and/or Inuit communities. The Métis are not eligible for treaty status or free health care.
New Zealand (NZ)	565,329 (Maori ethnic group) <sup>(c)</sup> 643,977 (Maori descent) <sup>(c)</sup>	15%	Maori (100%)	The Treaty of Waitangi (1840) established British control while setting out Maori rights. The Treaty is integrated into health policy, with Maori people given the rights to partnership, participation and protection in health-related policies.
United States (US)	4.5 million <sup>(d)</sup>	1.5%	American Indian or Alaska Native (AI/AN) only (60%) AI/AN plus another race (40%)	562 federally recognised tribes exist as sovereign entities. The US government is obligated to provide free health care to federally recognised American Indians and Alaska Natives.

(a) Estimated resident population—30 June 2006 preliminary, based on the 2006 Census and post-enumeration survey (ABS 2007).

(b) 2006 Census count (Statistics Canada 2008a).

(c) 2006 New Zealand Census.

(d) US Census Bureau 2008.

Among the four countries, the United States has the largest indigenous population, with 4.5 million people, but is the smallest proportionally at 1.5% of the total US population. Canada has the second largest indigenous population, with approximately 1.2 million indigenous people who constitute nearly 4% of the population. Over half a million ethnic Maori make up almost 15% of the total New Zealand population and in Australia just over half a million Aboriginal and Torres Strait Islanders make up 2.5% of the total Australian population.

The size of the Australian Indigenous population shown in Table 1 is the estimated resident population on 30 June 2006. To derive this number, the 2006 Census count was adjusted for Australian Indigenous people missed or counted more than once by the Census, those temporarily overseas and those who did not respond to the question. A post-Census enumeration survey was undertaken to estimate the sizes of these adjustments.

The size of the Canadian aboriginal population shown in Table 1 is the adjusted count from the 2006 Census. Respondents self-identified as North American Indian (First Nations people), Métis or Inuit, or with more than one group. This count was adjusted by including Registered Indians or members of an Indian Band or First Nation who did not identify as aboriginal.

Two counts from the 2006 Census have been presented in Table 1 as representing the size of the Maori population: the self-identified Maori ethnic group and those who have Maori ancestry. The latter number is used for the purposes of Treaty of Waitangi claims and other rights and entitlements.

The size of the American Indian/Alaska Native population in the United States shown in Table 1 is the modified race count as at 1 July 2006, based on the 2000 Census. In the United States the census is conducted every 10 years, the most recent in 2000. The original race data from the 2000 Census has been modified to reallocate those in the 'some other race' category, and adjusted for births, deaths, net international migration and net movement of US Armed Forces overseas. Indigenous Hawaiians are included under the classification Native Hawaiian and other Pacific Islander.

## Key statistics

Significant health disparities exist between indigenous and non-indigenous populations in Australia, Canada, New Zealand and the United States. In all four countries indigenous people have lower life expectancies, higher rates of chronic and preventable illnesses, poorer self-reported health and higher likelihood of hospitalisation (Bramley et al. 2004; Freemantle et al. 2007; ABS & AIHW 2008). Relevant and accurate data are necessary to shape programs aimed at reducing health inequalities. Current data on indigenous health and wellbeing in the four countries have problems of coverage and quality and this undermines the usefulness of the data for good policy decision making.

Infant mortality rates and life expectancy at birth are two of the key measures of health status for which data are available on indigenous persons in Australia, Canada, the United States and New Zealand. A summary of this information is presented below.

### Infant mortality

The infant mortality rate is defined as the number of infant deaths in the first year of life expressed as a proportion of 1,000 live births. Table 2 presents the indigenous and non-indigenous infant mortality rates in the four countries. Indigenous infant mortality rates in all four countries are higher than infant mortality rates for the non-indigenous populations.

The coverage and quality of indigenous birth and death data determine the accuracy of infant mortality rates. The lack of a mandatory aboriginal identifier on Canadian birth and death registrations means that the aboriginal infant mortality rate cannot be accurately estimated. In Australia the coverage of Australian Indigenous birth data is higher than the coverage of

Australian Indigenous death data, so the Australian Indigenous infant mortality rate is likely to be underestimated. In both New Zealand and the United States, birth and death registrations are matched, so indigenous infant mortality rates can be estimated with greater accuracy.

**Table 2: Infant mortality**

Country	Indigenous and non-indigenous infant mortality	Coverage and data quality issues
Australia	The Australian Indigenous infant mortality rate for the period 2002 to 2004 is estimated to be 11.5 per 1,000 live births, using mortality data from the four states and territories that have adequate levels of Indigenous identification in their mortality data collections. This compares with a non-Indigenous rate of 4.1 per 1,000 live births for the same states/territories over the same period (AIHW 2007a:311).	Australian Indigenous infant deaths and births are both underestimated; however, Indigenous identification in birth data is higher than in death data, so the Indigenous infant mortality rate is likely to be an underestimate (AIHW 2007a:322). Australian estimates could be improved by linking birth and death data, as occurs in the United States and New Zealand, as well as by linking birth registrations with perinatal data.
Canada	The infant mortality rate for First Nations peoples in 2000 was estimated to be 6.4 per 1,000 live births, using vital registrations data from the four western provinces that collect ethnicity data, combined with data collected from nursing stations for the rest of the country. The comparable rate for all births in Canada is 5.2 per 1,000 live births (Treasury Board of Canada Secretariat 2005)  Analyses of mortality data for regions with high percentages of aboriginal inhabitants have estimated higher infant mortality rates. For example, First Nations infant mortality in 1999 is estimated to have been 8 per 1,000 live births, as compared with the Canadian average of 5.5 per 1,000 live births (Kermode-Scott 2005).	The lack of a mandatory question on birth and death registration forms relating to aboriginal status means that infant mortality rates cannot be accurately estimated for the First Nations, Inuit or Métis populations.
New Zealand	For the period 2000 to 2004, the Maori infant mortality rate was 8.1 deaths per 1,000 live births, as compared with the non-Maori rate of 5.0 deaths per 1,000 live births (Robson and Harris 2007:45)	Because infant mortality rates are calculated from matched birth and death registrations, the Maori rate is considered to be relatively accurate.
United States	Based on analysis of the linked birth and infant death data sets for the period 1995 to 2003, the AI/AN infant mortality rate was 8.7 per 1,000 live births, as compared with 6.8 for the whole of the United States (National Center for Health Statistics 2007:160; National Center for Health Statistics 2006:5).	The National Center for Health Statistics matches birth and death records and uses the race recorded on the birth certificate to calculate race-specific mortality rates (National Center for Health Statistics 2006:5). Once the 2003 amendments to the birth certificate are fully implemented in all states, the classification of race in birth data should be relatively accurate, which will result in relatively accurate estimates of AI/AN infant mortality, both alone and in combination with other races.

## Life expectancy at birth

Life expectancy estimates are an important aspect of assessing indigenous disadvantage. Indigenous life expectancy at birth in all four countries is reported as being lower than the life expectancy at birth for the non-indigenous population. The coverage and quality of death data and census data determine the accuracy of the calculation of life expectancy at birth and all four countries have data-quality issues which affect the accuracy of their estimates.

In Australia, a number of indirect methods have been used to estimate Australian Indigenous life expectancy at birth. All of these methods rely on assumptions and expert opinions. There have been significant uncertainties attached to the level of life expectancy estimates for Aboriginal and Torres Strait Islander peoples in the past, and although there has been significant progress in terms of using better methods to estimate life expectancy, there continues to be a level of uncertainty around the estimate of life expectancy for Indigenous Australians.

**Table 3: Life expectancy at birth**

Country	Indigenous and non-indigenous life expectancy at birth	Methodological issues
Australia	The latest available experimental estimates of Australian Indigenous life expectancy at birth are for the period 1996–2001 and are 59 years for males and 65 years for females (as compared with 77 years for all males and 82 years for all females for the period 1998–2000). The difference is approximately 17 years for both sexes.	Because of coverage and quality issues associated with Australian Indigenous births, deaths and population data that are summarised in Tables B2.1 and B2.2, a number of indirect methods have been used to estimate the life expectancy of Indigenous Australians. According to the ABS (2008), these indirect methods are no longer appropriate and direct methods are recommended for future calculations.
Canada	In 2001: First Nations men 70.4 years, all Canadian men 77.1 years; FN women 75.5 years, all Canadian women 82.2 years (Treasury Board of Canada Secretariat 2005).  Inuit-inhabited areas (using death data for the period 1999–2002): Men 64.4 years, women 69.8 years (Statistics Canada 2008b).	Because of lack of aboriginal identifiers on death registrations, standard data sources and methods cannot be used to estimate basic health indicators. Instead a geographic-based approach is often used to estimate life expectancy for the entire population of areas having a high percentage of aboriginal inhabitants.
New Zealand	For the period 2000–2002, females of Maori ethnicity 73.2 years, non-Maori females 81.9 years; males of Maori ethnicity 69.0 years, non-Maori males 77.2 years (Statistics New Zealand 2008b)	Every 5 years Statistics New Zealand produces complete period life tables using average mortality rates for three successive years centred on a census year. Before 2000, methods such as ‘ever Maori’ were used to resolve the undercount in Maori deaths. However, since 2000, the quality of Maori death data has improved, and no undercount is now apparent (Robson and Harris 2007).
United States	Life expectancy tables by race published by the US Government through the National Center for Health Statistics relate only to the white and black populations. No tables are available for the AI/AN population. The Indian Health Service has published estimates of life expectancy for the period 1999–2001, which state that life expectancy for the AI/AN population is 2.4 years less than for the all-race population of the United States (74.5 years, as compared with 76.9 years) (Indian Health Service 2006).	The undercounting of AI/AN deaths referred to in Table B2.2 means that AI/AN death rates are underestimated, hence life expectancy is overestimated for the AI/AN population. Despite the development of adjustment factors to correct the under-identification of AI/AN deaths, life expectancy estimates, which are based on age-specific death rates, should be interpreted with caution.

The Australian Bureau of Statistics (ABS) has recently published a discussion paper entitled *Assessment of methods for developing life tables for Aboriginal and Torres Strait Islander Australians, 2006* (ABS 2008), which presents an assessment of various methods for adjusting incomplete Aboriginal and Torres Strait Islander death registration data for use with the latest available estimates of the Australian Indigenous population so as to compile Australian Indigenous life expectancy estimates. The key findings of this paper were that the indirect methods previously used by the ABS to estimate Indigenous Australian life expectancy are no longer considered appropriate in the Australian context; and that currently the best option for adjusting under-coverage of Australian Indigenous deaths is to use more direct methods such as that used in the ABS Indigenous Mortality Quality Study (part of the Census Data Enhancement project) which linked 2006 death records to Census records. Findings from this study suggest that the coverage of Australian Indigenous deaths in death registration data is higher than previously estimated.

In New Zealand the quality of Maori death data has improved since 2000, with no undercount now apparent. In the United States, the number of indigenous deaths is underestimated, which means that indigenous life expectancy at birth is overestimated. The lack of a mandatory aboriginal identifier on Canadian death registrations and the lack of a question on aboriginality on the majority of census forms means that aboriginal life expectancy at birth cannot be accurately estimated.

### **Data governance**

An overview of the agencies and committees which have a strategic role in relation to indigenous data in the four countries is presented in Table 4.

**Table 4: National agencies and committees which provide strategic advice in relation to indigenous data and information**

Country	Agency/committee	Role
Australia	The National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID)	<p>NAGATSIHID was established to:</p> <ul style="list-style-type: none"> <li>• provide broad strategic advice to the Australian Health Ministers' Advisory Council and its National E-Health Information Principal Committee on ways of improving the quality and availability of data and information on Aboriginal and Torres Strait Islander health and health service delivery</li> <li>• draw together the range of Australian Indigenous health information activities into a coordinated and strategic process.</li> </ul> <p>Membership comprises the Australian Bureau of Statistics, Australian Institute of Health and Welfare, Department of Health and Ageing, Department of Families, Housing, Community Services and Indigenous Affairs, Australian Institute of Aboriginal and Torres Strait Islander Studies, Torres Strait Regional Authority, National Health Information Statistics and Standards Committee, National Aboriginal and Torres Strait Islander Health Officials Network, National Aboriginal Community Controlled Health Organisation, Indigenous advisors on Aboriginal and Torres Strait Islander health and welfare and an epidemiologist with expertise in Indigenous health issues. A key priority of NAGATSIHID is to maintain an Australian Indigenous majority at meetings.</p> <p>NAGATSIHID provides a forum for all key stakeholders involved in Indigenous Australians health policy and data to work together towards improving the data and reporting.</p>
Canada	First Nations Statistical Institute (FNSI)	The Institute was set up by the First Nations Fiscal and Statistical Management Act 2002 to provide statistical information and analysis of key issues related to members of First Nations and other aboriginal groups, ensure data quality and compatibility, work in cooperation with Statistics Canada, and build statistical capacity within First Nations governments. The Institute is still in the developmental phase and is not yet fully operational.
	First Nations Information Governance Committee (FNIGC)	FNIGC operates under the auspices of the Assembly of First Nations and is the responsible authority for the Regional Longitudinal Health Survey.
New Zealand	Maori Statistics Forum	The Forum provides Statistics New Zealand with expert external input into critical statistical issues in relation to Maori. A Maori statistics framework is currently being developed.
United States	American Indian and Alaska Native Advisory Committee	The Committee advises the US Census Bureau on ways to increase the participation of AI/AN people in the census, facilitates the Bureau's outreach to the AI/AN population during the planning and implementation of the census and the American Community Survey, and advises on ways census data can be disseminated for maximum usefulness to the AI/AN populations and other users. The nine-member Committee comprises representatives from the public and private sectors, community-based organisations, academic institutions and other individuals as appropriate from the public at large.
	Tribal Consultation Advisory Committee (TCAC)	In 2004 the Department of Health and Human Services (HHS) implemented a Tribal Consultation Policy that applies to all HHS divisions. In compliance with the Policy, the Centers for Disease Control and Prevention (CDC), which is a division of HHS, established the Tribal Consultation Advisory Committee. The Committee advises the CDC Director and the Administrator of the Agency for Toxic Substances and Disease Registry on policy issues and broad strategies that may affect AI/AN peoples.

## ■ Part A: Meeting proceedings

### **A1 International collaboration on indigenous health measurement— Canberra 2006 meeting**

The purpose of the second meeting of the International Group for Indigenous Health Measurement, held in Canberra, 2006, was to further international collaboration to tackle health measurement issues for indigenous populations, building on the work that began at the inaugural meeting in Vancouver, Canada, in 2005.

The second meeting was held on 28–30 November 2006 in Canberra, Australia. It was hosted and sponsored by the Australian Institute of Health and Welfare (AIHW), and co-sponsored by the Office for Aboriginal and Torres Strait Islander Health. The meeting was attended by approximately 65 participants from Australia, Canada, New Zealand and the United States. Participants came from indigenous organisations, national statistical agencies, departments of health and research organisations.

The meeting was opened by Matilda House, a Ngambri-Ngunnawal elder, who performed a traditional welcoming ceremony. Penny Allbon, the Director of AIHW, then welcomed participants and provided an overview of the meeting's purpose, a brief history of the Kambarri and Ngunnawal people (the traditional owners of the land in the Canberra region), discussions of partnership approaches in Australia and internationally, some data issues for Australia and the meeting's agenda, which is provided in Chapter A2. Representatives from New Zealand (the Hon. Mita Ririnui, Associate Minister of Health), Australia (Dea Delaney-Thiele, CEO of the National Aboriginal Community Controlled Health Organisation—NACCHO), Canada (Chief Thomas Bressette, Chairman, First Nations Statistical Institute Advisory Panel) and the United States (Leo Nolan, Senior Policy Analyst, Indian Health Service) then provided brief overviews of issues for their own countries and organisations.

The meeting was launched by the Australian Minister for Health, the Hon. Tony Abbott, MP, who stressed the government's commitment to improving the health of Aboriginal and Torres Strait Islander peoples and welcomed recent data that showed real improvements.

Participants were introduced to traditional Aboriginal dancing with local family dance group Wiradjuri Echoes. The meeting dinner was opened by a performance from the Palanu Dancers from Melbourne. The Australian Statistician, Dennis Trewin, shared strategies being adopted by the Australian Bureau of Statistics (ABS) in an effort to improve the quality of Australian Indigenous statistics. Ted Wilkes gave an Australian Indigenous perspective on growing up and living in Australia and also introduced participants to didgeridoo playing.

The agenda for the 3-day meeting is provided in Chapter A2. Seven sessions were held during the meeting, which encompassed 34 presentations covering the following areas:

- ▷ demand for data by researchers and policy makers
- ▷ supply of data

- ▷ innovative approaches to indigenous health information
- ▷ methods used to count indigenous populations
- ▷ linking statistical agencies and indigenous organisations in the four countries.

The themes from the sessions can be broadly organised into the following categories:

### Who counts whom?

A cluster of issues can be characterised as falling under the theme of indigenous involvement and leadership in health information:

- ▷ Indigenous people in all four countries are concerned with being over-researched; being 'research subjects'; wanting to have more control over what information is sought, whom it is sought from and how it is collected; being involved in the collection, analysis and management of information; ensuring the collection and analysis of information by local communities for their own use; ownership of data; access to data; and the right to self-manage population-based health information.
- ▷ Indigenous people in all four countries want information and research findings to be given back to communities in appropriate ways and their communities to have a say in information collection and reporting.
- ▷ A number of papers from all four countries discussed how to create partnerships between indigenous people and data collection and health research agencies, how to provide indigenous advice to specialists, and how to obtain advice from agencies that will enable indigenous communities to develop, manage and control their health information.
- ▷ Indigenous people want collaboration on interpretation, analysis and joint reporting of outcomes.

### Capacity building

- ▷ Arising from the concerns expressed above, indigenous people in all four countries want strategies put in place that will build capacity within their communities so that they can collect, manage and 'own' data.
- ▷ Community capacity to collect information is needed to allow communities to better manage local health needs. This includes the training of local people as data collectors.
- ▷ The need to increase the indigenous statistical workforce was also discussed.

### Information governance issues

- ▷ Governance of indigenous health data is different in each of the four countries and there are areas where they can learn from each other.
- ▷ It was argued that governance mechanisms need to support indigenous leadership and partnership structures. A major improvement in health information can be demonstrated when all major players cooperate and decide what will happen together. In Australia this is represented in the development of a national survey program (through ABS) and of national standards, analysis and reporting (with AIHW).

### Importance of collaborative efforts

- ▷ Good-quality data depend on good relationships between all parties.
- ▷ Good relationships require an appropriate governance framework that allows all parties to speak to each other and have their points of view heard and respected.
- ▷ The development of high-quality health information systems involves:
  - a priority-setting process
  - genuine collaborative structures
  - efficient and meaningful ways of communicating decisions and information between all parties.
- ▷ To achieve this level of collaboration between government and communities requires an improvement in the skills and knowledge possessed by people in communities.

### Data for us, not just about us: Importance of the community seeing benefits from the data

It was argued that for communities to have access to information and for information to be returned to communities:

- ▷ all health research on indigenous people must be clearly demonstrated to be for their direct benefit
- ▷ how data management systems can be developed to meet the needs of Indigenous health at all levels must be investigated
- ▷ Indigenous people need to see value and benefits from all the data collected.

### Importance of cultural factors/holistic approach to wellbeing

A number of papers argued that:

- ▷ it is important to capture information on cultural attributes (e.g. language group or tribe) and not just information about physical health, so that information about health can be disaggregated to a more local level
- ▷ cultural attributes influence physical health
- ▷ a better understanding is needed on how indigenous health concepts influence how indigenous people understand health issues; research must therefore take local concepts of health and wellbeing into account
- ▷ data frameworks should have indigenous-specific and universal indicators.

### Data

Many aspects of data were discussed—the following is a summary.

- ▷ **The balance between national and local data**
  - Aggregated data do not reflect differences by tribe or geographical area and critical information is lost when data is aggregated.
  - Local level information is needed to guide local development.
  - The balance between national priorities and local community issues needs to be sorted out.
  - There is a need to capture the diversity within indigenous populations.

### ▷ The usefulness of data

- High-quality data are essential to monitor trends in indigenous health.
- Sophisticated trend analyses that are now possible show significant improvements in infectious diseases and some chronic diseases.
- Better information is needed to support service delivery improvement.
- Good data can be used to 'bust' myths.
- Data are needed to guide policy and planning, as they are often based on poor knowledge or prejudicial myths.
- Data are important as a basis for arguing successfully for funding from national and state budgets. In New Zealand, for example, data on health inequalities have been influential in protecting programs aimed at the indigenous people from budget cuts.
- Good data can be used to show that investment in health services can work, e.g. declines in child mortality.
- More systematic processes are required to ensure that available data are used to monitor indigenous health.

### ▷ Data quality, classification and coverage

- Although the extent of problems with data varied across countries, most countries had issues around the extent of coverage of the indigenous populations. There are differences between the four countries in how ethnicity data are collected and the inclusiveness of ethnic identification.
- All countries have problems of identifying who is indigenous. This is a result of different historical attempts at racial classification.
- Apart from the problems of differentiating indigenous from non-indigenous, there are problems associated with the need to collect more specific information on indigenous people, such as 'tribe' or 'language group'.
- Examples of strategies to better capture the indigenous population included techniques such as the 'ever Maori' ethnicity classification method in New Zealand. This method links and compares Maori status across data sets. Linking data sets was also described by researchers from the United States and Australia.
- The New Zealand Ministry of Health has implemented ethnicity data protocols for the standardised collection, recording and output of ethnicity data.
- Incentives for reporting indigenous data have been used in Australia and New Zealand.
- The under-reporting of indigenous people in urban populations in different data sets and the lack of sampling frames for urban populations are issues for all countries.
- Another common problem is that rates are often calculated using numerators and denominators that come from different data sources, of which at least one is known to underestimate indigenous numbers.
- Adjustment factors for under-identification have been used in Australia, New Zealand and the United States. Participants agreed that an improvement in the quality of indigenous identification in health data sets needs a systematic and sustained effort at all levels, rather than a technical fix. This requires cultural change and strong leadership from indigenous communities and data collection and research organisations.

## International collaboration

The meeting reaffirmed the value of the International Group for Indigenous Health Measurement and highlighted the commitment of the agencies represented to improving health information on indigenous people, for the benefit of indigenous people.

The current role of the International Measurement Group is information sharing, capacity building and providing a forum to discuss issues and share ideas. It was agreed that the International Measurement Group should set itself the objective of going beyond information sharing to working together to improve data, perhaps through collaborative projects. Examples of potential collaborative projects are:

- ▷ training of indigenous people to collect data
- ▷ work to measure cultural diversity, cultural status, language and participation in traditional culture
- ▷ research on resilience and health and the development of a common set of indicators from hospital services, health status and health determinants
- ▷ comparative studies of health services performance across the collaborating countries and the development of a set of common indicators
- ▷ research into the influences of racism and discrimination on health.

## The way forward

The following actions for furthering the International Measurement Group were agreed on:

1. A subgroup will prepare a paper on the International Measurement Group's purpose and terms of reference. Endorsement from each country will then be sought.
2. A report will be prepared on how the population is counted in each country, and whether and how accurately ethnicity is collected in the census, vital statistics databases, administrative and surveillance systems and national surveys.
3. A letter of invitation for subsequent meetings will be sent from high-level officials within the hosting country. The United States agreed to host the next meeting in 2008 (which is now taking place in 2009).
4. The possibility of becoming a Collaborating Centre of the World Health Organization (WHO) will be investigated.
5. Representatives will request their Minister of Health to send his/her counterparts in the other countries three important documents relevant to the current status of indigenous health in their country. Copies of these documents will also be sent to the WHO and the United Nations.

The last day of the meeting covered organisational issues and plans for a 2008 meeting. Abstracts of the presentations and biographies of the presenters are provided in chapters A3 and A5.

## A2 Agenda

### Day 1: 28 November 2006

#### **Welcome**

Welcome to Country  
*Matilda House*

Welcome  
*Penny Allbon*

Welcome—Country representatives  
*The Hon. Mita Ririnui*  
*Dea Delaney-Thiele*  
*Chief Thomas Bressette*  
*Leo Nolan*

#### **Keynote address**

NACCHO's experiences and challenges: An overview  
*Dea Delaney-Thiele*

#### **Session 1: Setting the scene: Demand for data to support policy relevant analyses and research— Comments by data users**

Improving indigenous peoples' health: An opportunity for international collaboration  
*Jeff Reading*

Small numbers, big issues: Perspectives from a US data user  
*Michelle Chino*

Health Research Council presentation to the International Group for Indigenous Health  
Measurement Meeting  
*Aroha Haggie*

Australian Indigenous health measurement: Policy context and stocktake  
*Ian Anderson*

#### **Welcome—the Hon. Tony Abbott, MP, Australian Minister for Health and Ageing**

#### **Session 2: Setting the scene: Supply of data—Stocktake presentations**

Australian Indigenous health measurement: Policy context and stocktake  
*Ian Anderson*

Australia's stocktake of health information on the Aboriginal and Torres Strait Islander peoples  
*Fadwa Al-Yaman*

First Nations, Inuit and Métis health measurement in Canada: An overview  
*Janet Smylie*

United States stocktake regarding health information on the American Indian/Alaska Native population

*Howard Goldberg*

Setting the scene—Supply of data in New Zealand

*Paula Searle and Natalie Paki Paki*

### ***Dinner Speakers***

*Dennis Trewin and Ted Wilkes*

## **Day 2: 29 November 2006**

### ***Session 3: Innovations/recent developments***

Initiatives and technology integration with service policy

*Leo Nolan*

Unequal impact: Maori and non-Maori cancer statistics

*Donna Cormack*

Aboriginal and Torres Strait Islander Health Performance Framework

*Lesley Podesta and Debra Reid*

The First Nations Regional Longitudinal Health Survey (RHS)

*Jane Gray*

### ***Session 4: Linking indigenous groups, national statistical agencies, health ministries (examples of mechanisms for linking these groups in each country)***

Maori health, racism and inequalities in New Zealand: Results from the 2002–03 New Zealand Health Survey

*Ricci Harris*

Health data in context

*Shane Houston*

Making the right links to improve aboriginal data

*Valerie Whetung*

Linking indigenous groups, national statistical agencies, health ministries: Mechanisms for linking these groups in the United States of America

*Francine Romero*

### ***Session 5: Population session—How is the indigenous population counted? How is indigenous identification obtained?***

Counting the Aboriginal and Torres Strait Islander population: How is the Indigenous Australian population counted? How is identification obtained?

*Dan Black*

Aboriginal population statistics: Australia's statistical performance

*Richard Madden*

Aboriginal population data

*Valorie Whetung*

The challenges of collecting data from indigenous people in the United States

*Susan Lavin*

Counting Maori

*Whetu Wereta*

**Session 6: Population session—What does it mean for an indigenous person to be counted?**

Population session—Australia

*Shane Houston*

Assembly of First Nations population session—Canada

*Jane Gray*

The Métis: What does it mean to be counted?

*Kim Bulger*

Who counts? An indigenous response

*Leo Nolan*

The right to be counted

*Ralph Forquera*

What does it mean for an indigenous person to be counted?

*Fiona Pimm*

**Day 3: 30 November 2006**

**Session 7: Terms of reference, organisational issues**

Plans for 2008 International Group for Indigenous Health Measurement meeting

*Sam Notzon and Jacinta Elston*

Presentation of framework and Terms of Reference

*Michelle Chino*

## **A3 Presentation abstracts**

### **Session 1: Setting the scene: Demand for data to support policy relevant analyses and research—Comments by data users**

#### ***Improving indigenous peoples' health: An opportunity for international collaboration***

*Jeff Reading*

This presentation describes the progress of the Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health (CIHR-IAPH) over the past 5 years. Capacity building, networking, ethics, and knowledge translation highlight strategic opportunities for international partnership. The presentation concludes with a brief discussion of future challenges and opportunities.

#### ***Small numbers, big issues: Perspectives from a US data user***

*Michelle Chino*

The ability to access and use health data from AI/AN populations in the US poses a myriad of problems. Although data needs and usage are increasing, problems with how data are collected, by whom, and for what purpose impacts the ability to gain meaningful information both locally and nationally. Challenges for data users include data comparability and compatibility, tribal and regional variation, classification, and access limitations.

#### ***Health Research Council presentation to the International Group for indigenous Health Measurement Meeting***

*Aroha Haggie*

Extending the lifespan and increasing the quality of life, improving access to quality health services, improving service provision, and decreasing morbidity and mortality for the Maori population require high-quality research, collaboration between sectors, and Maori research methodologies. This presentation describes the roles that the Health Research Council and the Maori Health Framework play in achieving these goals.

#### ***Australian Indigenous health measurement: Policy context and stocktake***

*Ian Anderson*

Over the last decade Australia has seen significant progress in the development of health information systems that are fundamental to the broader policy agenda. This presentation covers some of the keys to these advances, such as a series of inter-governmental and inter-agency agreements, the National Strategic Framework and Health Information System, research, local service development, and governance from the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data.

## Session 2: Setting the scene: Supply of data—Stocktake presentations

### *Australian Indigenous health measurement: Policy context and stocktake*

*Ian Anderson*

This presentation highlights the ways in which Australian Indigenous health data are collected in Australia, including the Census, Indigenous-specific surveys, national-level surveys including Indigenous respondents, and administrative/service-activity reporting. Issues related to data quality, performance measurement, and key challenges including the development of the Indigenous workforce and local level planning systems are also discussed.

### *Australia's stocktake of health information on the Aboriginal and Torres Strait Islander peoples*

*Fadwa Al-Yaman*

Australia's Indigenous population still experiences considerable health and socioeconomic disadvantages compared with the general population. Recent data emphasising the levels of this inequality are presented, along with a critique of the current sources of Indigenous health-related data and the impact of these problems. The policy context and its influence on the improvement of data definitions, collections, and reporting mechanisms are underscored.

### *First Nations, Inuit and Métis health measurement in Canada: An overview*

*Janet Smylie and Marcia Anderson*

Although multiple indicators of indigenous health are currently available, the use of these indicators has not effectively contributed to improved health outcomes for First Nations, Inuit, or Métis people in Canada. The failure of these indicators to translate into improved program planning and service delivery, and thus improved health outcomes, is not clearly understood by health researchers. This presentation gives an overview these issues, illustrating the underdevelopment of measurement systems that deliver culturally and geographically relevant health data at the community/multicommunity level and the barriers to effective measurement.

### *United States stocktake regarding health information on the American Indian/Alaska Native population*

*Howard Goldberg*

The prevalence of most major health conditions and many behaviors adversely related to health are much higher for the American Indian/Alaska Native (AI/AN) population than for the overall population of the US. In spite of these disparities, much less information exists about the health of AI/AN than any other major US subpopulation, and the data that do exist are often of questionable quality or completeness. The factors contributing to this lack of adequate health information are presented, including the absence of a comprehensive framework for the collection and provision of such information, misclassification and inconsistent classification of race in individuals; lack of sampling frames to identify AI/AN for surveys and studies, poor population accessibility and phone coverage of the population, the diversity within the AI/AN population which limits the ability to generalize about Indian health, and cultural factors. Recommendations are put forward with regard to improving the availability of health information.

### ***Setting the scene—Supply of data in New Zealand***

*Paula Searle and Natalie Paki Paki*

Quality data and information are essential for continually assessing the performance of the Ministry of Health and other key institutions concerned with improving Maori health outcomes and reducing inequalities. This presentation summarises the key Maori health strategies and initiatives undertaken by the Ministry of Health, including the completion of Tatau Kahukura: Maori Health Chartbook (which provides a picture of health by using key indicators for Maori compared with non-Maori), making these statistics available online on our Maori Health website, and promoting other Ministry products such as PHI online which has local-level data on a range of indicators for Maori.

### **Session 3: Innovations/recent developments**

#### ***Initiatives and technology integration with service policy***

*Leo Nolan*

The provision of health care for citizens of the 561 federally recognized American Indian and Alaska Native tribal nations is predicated on a special government-to-government relationship with the United States. The health status of American Indians and Alaska Natives has increased dramatically since the Indian Health Service (IHS) was transferred to the Department of Health and Human Services from the Department of the Interior 51 years ago. While much of the change was due to infectious disease control and the installation of water and sanitation facilities, challenges now center on chronic disease and behavioral health. Three initiatives from the Director of IHS for dealing with these challenges are highlighted: chronic disease management, behavioral health, and health promotion/disease prevention. In addition, the adoption of a system-wide electronic health record by 2008 will provide more accurate recording of patient outcomes and health status.

#### ***Unequal impact: Maori and non-Maori cancer statistics***

*Donna Cormack, Bridget Robson, Gordon Purdie, Shirley Simmonds*

Comprehensive and detailed information on cancer among Maori is vital to the development of policies and programs that will be effective in cancer control. This presentation gives an overview of a series of chartbooks of Maori and non-Maori cancer statistics designed to provide analyses of differences in cancer incidence, mortality, stage at diagnosis and survival in Aoteroa/New Zealand along with the methodological issues regarding the classification of Maori cancer registrations and deaths, and the choice of a standard population for the calculation of age-standardised rates.

#### ***Aboriginal and Torres Strait Islander Health Performance Framework***

*Lesley Podesta and Debra Reid*

The Aboriginal and Torres Strait Islander Health Performance Framework (HPF) is specifically designed to provide the basis for quantitative measurement of the impact of the National Strategic Framework for Aboriginal and Torres Strait Islander Health (NSFATSIH) 2003–2013. The goal of NSFATSIH is to ensure ‘that Aboriginal and Torres Strait Islander

peoples enjoy a healthy life equal to that of the general population that is enriched by a strong living culture, dignity and justice'. The HPF provides a comprehensive framework for performance measurement, including health outcomes, determinants of health, and health system performance. Regular reporting against the HPF will provide a structured account of current status and progress in relation to each of the three tiers and play an important role in documenting the impact of Government policies and strategies on the health of Aboriginal and Torres Strait Islander people. The presentation also discusses some of the findings from the first report of the HPF.

### ***The First Nations Regional Longitudinal Health Survey (RHS)***

*Jane Gray*

The RHS is recognized as the 'First Nations Survey of Choice in Canada' and has gained tremendous credibility among First Nations communities, leadership, governments and academic scholars. This survey represents a new paradigm in First Nations research in which the control and responsibility for the success of the survey rests with First Nations. The presentation provides a detailed look at this successful national health survey process that is First Nations controlled from start to finish and is guided by the First Nations Principles of OCAP (Ownership, Control, Access and Possession) as it relates to holistic health information.

### **Session 4: Linking indigenous groups, national statistical agencies, health ministries (examples of mechanisms for linking these groups in each country)**

#### ***Maori health, racism and inequalities in New Zealand: Results from the 2002–03 New Zealand Health Survey***

*Ricci Harris, Martin Tobias, Mona Jeffreys, Kiri Waldegrave, Saffron Karlsen, James Nazroo*

Ethnic inequalities in health in New Zealand are most pronounced between Maori and the majority European population. Accumulating research suggests that racism may be a major driver of such inequalities. This presentation describes a project examining the potential impact of experience of racial discrimination and deprivation on inequalities in health between Maori and European ethnic groups in New Zealand. This was a joint project between the Ministry of Health, Massey University and University College London. It used data from the 2002–03 New Zealand Health Survey to examine the relationship between experience of discrimination and health, and to assess the effect of adjustment for experience of racial discrimination and deprivation on ethnic inequalities for various health outcomes.

#### ***Health data in context***

*Shane Houston*

The development and role of the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) are described, along with the types and variations of indicators required of the Northern Territory Health and Community Sector in order to monitor its performance. These indicators relate primarily to service provision, and in the past have been linked primarily to financial assessments of performance. Suggestions for how to use performance indicators as measurements of real progress rather than financial management are also presented.

### ***Making the right links to improve aboriginal data***

*Valerie Whetung*

The Canadian Constitution recognizes three groups: Indians, Métis and Inuit. This presentation describes Canadian strategies for collecting data on these three groups, including the Census, the Aboriginal Peoples Survey, and the Aboriginal Children's Survey. To assist in the survey process an advisory committee was established to advise on questionnaire content, ensure relevance and usefulness of the data, provide aboriginal perspective on all aspects of survey development, and assist in dissemination strategy. In addition, the First Nations Statistical Institute was established to provide statistical information and analysis on the fiscal, economic and social conditions of First Nations, and other aboriginal groups and persons who live on reserve lands.

### ***Linking indigenous groups, national statistical agencies, health ministries: Mechanisms for linking these groups in the United States of America***

*Francine Romero*

Two programs supported by the Indian Health Service (IHS) are highlighted. In 1994, the IHS formed the Tribal Epidemiology Programs with the goal of providing tribal entities with timely and accurate health data. At present, there are 10 tribal-based epidemiology centers in the United States each focusing on regional health disparities, health priorities set by tribal leadership, and establishing specific health initiatives. The IHS has also collaborated with the US National Institutes of Health to establish the Native American Research Centers for Health (NARCH) designed to develop a cadre of AI/AN scientists and health professionals engaged in biomedical, clinical, behavioral and health services research who will be competitive in securing National Institutes of Health funding, increase the capacity of both research-intensive institutions and AI/AN organizations to work in partnership to reduce distrust by AI/AN communities and people toward research, and encourage competitive research linked to the health priorities of the AI/AN organizations and to reducing health disparities. These purposes will be achieved by supporting student development projects, faculty/researcher development projects, and research projects (including pilot projects) developed by each NARCH partnership.

### **Session 5: Population session—How is the indigenous population counted? How is indigenous identification obtained?**

#### ***Counting the Aboriginal and Torres Strait Islander population: How is the Indigenous Australian population counted? How is identification obtained?***

*Dan Black*

The count of Aboriginal and Torres Strait Islander peoples increased by 33% between the 1991 and 1996 Censuses, and by 16% between the 1996 and 2001 Censuses. These increases are greater than can be explained by demographic factors (births, deaths and migration) alone. The intercensal volatility in Australian Indigenous census counts and the quality of the data on births, deaths and migration do not support the standard approach to population estimation. This presentation discusses the factors that affect the quality of Indigenous identification data in the various sources used to develop population estimates—the Census, births and mortality

data. It also outlines the methods the ABS uses to account for these factors when producing intercensal and postcensal Indigenous population estimates, and the strategies currently being pursued by the ABS and other agencies within Australia to improve Indigenous identification and overall data quality.

### ***Aboriginal population statistics: Australia's statistical performance***

*Richard Madden*

A realistic estimate of population data and vital statistics such as births and deaths is essential to understanding the history and relative status of any population over time. Estimating the Aboriginal population of Australia has challenged statisticians for well over 100 years. Estimates of the 1788 population are reviewed, as well as estimates from colonial censuses and the early Yearbooks. The wide variation in contemporary estimates is discussed. More recent improvements in data and data quality are examined, and a scenario for the size of the Aboriginal population based on what we know today is presented.

### ***Aboriginal population data***

*Valorie Whetung*

The development of the First Nations Statistical Institute (FNSI) is described in this presentation. The FNSI is a collaboration between First Nations community leaders and technicians, along with government officials and will focus on becoming a data navigator and research center for First Nations information. The FNSI will identify key data holdings and work with government and First Nations to improve this information and to strengthen accessibility. First Nations will benefit by having an independent, recognized statistical organization that will provide information essential for community planning, encouraging economic development, negotiations with government, and to support self-governance.

### ***The challenges of collecting data from indigenous people in the United States***

*Susan Lavin*

As the central statistical agency of the United States, the US Census Bureau is responsible for collecting data on a variety of demographic and economic surveys, as well as the Economic Census (conducted every 5 years) and the Population and Housing Census (conducted every 10 years). This presentation discusses the unique relationship federally recognized tribes have with the US government and highlights some of the challenges of collecting accurate data on the 10-year Census of Population and Housing. In the process the presentation draws comparisons between working with the American Indian population and the Native Hawaiian population. It concludes with suggested ways to overcome some of the many challenges to collecting accurate data from these populations.

### ***Counting Maori***

*Whetu Wereta*

The official statistics system in New Zealand encompasses all statistics collected by government agencies and includes those collected by the Ministry of Health. Statistics New Zealand is the

main provider of population, demographic, social and economic statistics and coordinates and leads the official statistics system. The collection of ethnicity statistics is subject to the Statistical Standard for Ethnicity 2005, which emphasizes self-identification rather than ancestry. The various ways that have been used to count the Maori population are presented, along with ways that Maori statistical needs are met in New Zealand.

## **Session 6: Population session—What does it mean for an indigenous person to be counted?**

### ***Population Session—Australia***

*Shane Houston*

Good-quality data on Aboriginal and Torres Strait Islander peoples are needed to assess the effectiveness of programs and interventions, to evaluate policies aimed at improving service delivery and health status, and to inform policy and program development. To meet these needs, there is a growing demand for high-quality, regularly reported, Australian Indigenous information and data at a range of geographic levels. How the diversity in Aboriginal and Torres Strait Islander culture, conceptualisation of health and wellbeing, family structure, living arrangements and the relatively high proportion of people living in remote areas create practical and statistical challenges for the collection, interpretation and analysis of data on Indigenous peoples are covered in this presentation.

### ***Assembly of First Nations population session—Canada***

*Jane Gray*

This presentation provides a historical and political context to the definition and collection of data relating to the aboriginal population in Canada and highlights key current issues, such as data definitions and data collection strategies. New initiatives based on First Nations self-determination are described, including the First Nations Regional Longitudinal Health Survey, the First Nations Research and Information Centres—Epicentres, Client Registry Projects, and the First Nations—Federal Crown Political Accord.

### ***The Métis: What does it mean to be counted?***

*Kim Bulger*

Limited data collection processes and analysis have traditionally required the Métis to often use anecdotal information and proxy measures. This data scarcity is problematic when trying to secure resources to intervene in health areas for the Métis Nation. Often policy makers, decision makers and funders require ‘proof’ that a problem exists prior to allocating resources. As well, the use of proxy measures in lieu of Métis-specific information leads to questionable results. Current developments of inclusive, collaborative approaches will result in lending credence to data collection, analysis and dissemination strategies, ensuring that ‘being counted’ will not only produce authentic results but is in itself an act of social justice.

***Who counts? An indigenous response****Leo Nolan*

The historical and political setting for the development of the Indian Health Service, its current levels of service provision, and socioeconomic data highlighting continued inequalities for the American Indian/Alaska Native population are presented, emphasizing some of the key issues facing the counting of the indigenous population in the United States.

***The right to be counted****Ralph Forquera*

Urban American Indians and Alaska Natives have not been systematically or routinely recognized or counted as a population in the United States. As a result, our knowledge of the size of the population, location, basic demographics, and health status remains sketchy at best. Current data collection techniques show considerable problems that have prevented an accurate picture of the health disparities that challenge this group. In 2000, the Seattle Indian Health Board created the Urban Indian Health Institute as a focal point for addressing this problem. This presentation demonstrates how the failure to collect data on urban Indians has limited our development, describes the current limitations in today's data collection methods, and outlines the challenges we face in attracting the technical and financial resources needed to meet the growing call for measurement.

***What does it mean for an indigenous person to be counted?****Fiona Pimm*

There is evidence-based research highlighting the poor health outcomes for Maori and the lesser life expectancy for Maori. Until recently, there was a widespread assumption that this poorer health status was due to the behaviours of the Maori people—that they do not access available services, wait until their illness is well advanced before seeking health services, and do not comply with recommended health plans and treatment plans. This presentation presents evidence showing these assumptions are false and highlights key questions and types of data that need to be collected in order to address the current health inequalities in New Zealand. Counting indigenous people throughout the health system is not a solution in itself but will provide the evidence that will lead to us identifying effective solutions.

**Session 7: Terms of reference, organisational issues*****Plans for 2008 International Group for Indigenous Health Measurement meeting****Sam Notzon and Jacinta Elston*

This session provides an opportunity to discuss the plans for the next meeting of the International Group for Indigenous Health Measurement.

## **Presentation of framework and Terms of Reference**

*Michelle Chino*

This session presents the draft framework for the 'Terms of Reference' document for the International Group for Indigenous Health Measurement. Participants will discuss and clarify the purpose of the document, its target audience, and its role in the developing infrastructure of the group. As an important unifying construct, this document must reflect the issues for each participating country and provide a foundation for identifying terms and concepts for future work.

## **A4 Meeting participants**

### **Australia**

*Penny Allbon*

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Australian Institute of Health and Welfare

*Fadwa Al-Yaman*

Head, Aboriginal and Torres Strait Islander Health and Welfare Unit

Australian Institute of Health and Welfare

*Ian Anderson*

Research Director, Cooperative Research Centre for Aboriginal Health

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*Dan Black*

Director, National Centre for Aboriginal and Torres Strait Islander Statistics

Australian Bureau of Statistics

*Dea Delaney-Thiele*

Chief Executive Officer

National Aboriginal Community Controlled Health Organisation

*Barbara Dunlop*

First Assistant Statistician

Australian Bureau of Statistics

*Jacinta Elston*

Associate Professor/Associate Dean, Indigenous Health Unit

James Cook University

*Sally Goodspeed*

Assistant Statistician, Indigenous and Health Statistics Branch

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Assistant Director, Analysis and Reporting Section, Office for Aboriginal and Torres Strait Islander Health

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*Shane Houston*

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*Lisa Jackson-Pulver*

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*Steve Larkin*

Principal  
Australian Institute of Aboriginal and Torres Strait Islander Studies

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*Paul Magnus*

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*Julie Tongs*

CEO  
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*Dennis Trewin*

Australian Statistician  
Australian Bureau of Statistics

*Ted Wilkes*

Associate Professor, Aboriginal Research Programs, National Drug Research Institute  
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## **New Zealand**

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University of Otago

*Elana Curtis*

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University of Auckland

*Aroha Haggie*

Group Manager, Maori Health Research and Health Sector Relationships  
Health Research Council of New Zealand

*Ricci Harris*

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*Peti Murray*

Representative  
Te Runanga O Te Rarawa

*Natalie Paki Paki*

Maori Health Directorate  
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*Hon Mita Rinui*

Associate Minister of Health  
New Zealand

*Paula Searle*

Manager, Strategic Projects, Maori Health Directorate  
Ministry of Health

*Brendan Stevenson*

Research Centre for Maori Health and Development  
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*Whetu Wereta*

General Manager, Maori Statistics Unit  
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## Canada

*Chief Thomas Bressette*  
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Health Director  
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Assistant Professor, Department of Community Health Sciences and Co-Director of the Centre  
for Aboriginal Health Research  
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*Jane Gray*  
National Project Manager for First Nations Regional Longitudinal Health Survey  
Assembly of First Nations

*Jeff Reading*  
Scientific Director, Canadian Institutes of Health Research  
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*Janet Smylie*  
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Associate Professor, Department of Community Health and Epidemiology  
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*Valorie Whetung*  
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Statistics Canada

## United States

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Disparities, Office of Strategy and Innovation, Office of the Director  
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*Michelle Chino*  
Associate Professor/Director, Center for Health Disparities Research, American Indian Research  
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University of Nevada Las Vegas School of Public Health

*Ralph Forquera*  
Executive Director  
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*Howard Goldberg*  
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*Susan Lavin*  
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Senior Policy Analyst, External Affairs for the Office of the Director  
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*Sam Notzon*  
Director, International Statistics Program  
National Center for Health Statistics

*Francine C Romero*  
Director  
Jemez Health and Human Services

## **A5 Biographies of presenters**

**Penny Allbon** was appointed as Director of the Australian Institute of Health and Welfare, in February 2006. Born in New Zealand, Dr Allbon (or Dr Gregory as she was previously known) completed an Honours Degree in History at Massey University in New Zealand and then a PhD in Tongan History at the Australian National University. She has over 20 years of experience in government, at both federal and Territory levels and within the financial, health and welfare arenas. She has held a number of senior government appointments in the field of health and welfare, including the position of Chief Executive of ACT Health and ACT Commissioner for Housing. She has also run her own consultancy, working with clients such as AusAID, the Commonwealth Department of Health and Ageing, the Statistical Information Management Committee and the Solomon Islands Government.

**Fadwa Al-Yaman** is currently the head of the Social and Indigenous Group at the Australian Institute of Health and Welfare. Fadwa has BSc in Zoology (First Class Honours), PhD in Immunology, John Curtin School of Medical Research, Australian National University, and a Master of Population Studies from Research School of Social Sciences at the Australian National University. Fadwa used to be the head of the Aboriginal and Torres Strait Islander Health and Welfare Unit at the Australian Institute of Health and Welfare, whose major focus is to monitor and report on progress in the health and welfare of Aboriginal and Torres Strait Islander peoples. Before joining the AIHW in 2000, she worked as an immunologist at the Australian National University and before that was a Research Fellow at the Papua New Guinea Institute of Medical Research where she spent 4 years setting up the immunological side of the first major trial of a blood-stage malaria vaccine for children.

**Ian Anderson** currently holds the Chair in Indigenous Health at the University of Melbourne. He has worked in Aboriginal health for 20 years in a number of clinical/health care and administrative/policy roles and has been a full-time research academic since 1998 when he established the Onemda VicHealth Koori Health Unit with external funding from the Victorian Health Promotion Foundation and the Australian Government Department of Health and Ageing. He is also currently the Research Director for the Cooperative Research Centre (CRC) for Aboriginal Health. He chaired the working party that developed the first National Aboriginal and Torres Strait Islander Sexual Health Strategy in 1997 and is currently a member of the National Health and Medical Research Council.

**Dan Black** has been Director of the National Centre for Aboriginal and Torres Strait Islander Statistics in the Australian Bureau of Statistics since 2002, and has had direct involvement in the development of ABS Indigenous statistics since 1985.

**Chief Thomas Bressette** has been Chief of the Chippewas of Kettle and Stony Point First Nation in Southwestern Ontario, Canada since 2000, and was Chief from 1990 to 1997. He is a Regional Chief and an Executive Board Member for the Union of Ontario Indians and has served as Chairman of the First Nations Statistical Institute Advisory Panel since 2002. Chief Bressette has been in politics for 20 years, before which he held other positions including construction worker and drug and alcohol counsellor. He also served with the US Military for 3 years in West Germany.

**Kim Bulgar** has a Master of Public Administration and Master of Social Work, and is currently the Health Director for the Métis National Council (MNC)—a national aboriginal organisation in Canada. She has a background in community health and has worked at the municipal, provincial and national level. Within the MNC, she has worked on a number of projects, including contributing to the Aboriginal Health Blueprint—a process that identified priorities for aboriginal health in Canada for the next decade, diabetes, suicide prevention, capacity building, health and human resource initiatives and international health.

**Michelle Chino** completed her graduate training at the University of New Mexico (UNM) with a PhD in Evolutionary Ecology and formerly served as the Director of the Center for Injury Prevention at the UNM School of Medicine. She is currently an Associate Professor at the University of Nevada Las Vegas (UNLV) School of Public Health, and Director of the UNLV Center for Health Disparities Research. She is an American Indian researcher (Laguna Pueblo) with more than two decades of experience spanning the broad fields of public health and social justice. Areas of inquiry include injury and chronic disease prevention and health disparities. She has expertise in community-based participatory research methods, quantitative and qualitative methods, and program design and evaluation.

**Donna Cormack** (Waitaha, Kati Mamoe, Kai Tahu) is Research Fellow at Te Ropu Rangahau Hauora a Eru Pomare, Wellington School of Medicine and Health Sciences, University of Otago. She has been involved in research on ethnicity data collection and classification and disparities in Aotearoa/New Zealand. She has a particular interest in the discourses of 'race', ethnicity and health, and the ways in which these discourses work to maintain or challenge taken-for-granted knowledge in Aotearoa/New Zealand.

**Dea Delaney-Thiele** was born at the Burnt Bridge Mission at Kempsey, New South Wales and holds a postgraduate qualification in health management from the University of New England, Armidale. She was appointed Chief Executive Officer of the National Aboriginal Community

Controlled Health Organisation (NACCHO) in February 2003, has worked in the Aboriginal Community Controlled Health Sector for much of her adult life, and has served on a number of boards at the local, state and national levels. These include Chairperson of the Murawina Mt Druitt Aboriginal Childcare Centre in Sydney; CEO of the Daruk Aboriginal Medical Service in New South Wales; membership of the NSW Aboriginal Health and Medical Research Council and NACCHO Board (including a period as Treasurer) and Chairperson of Kamuka Building Enterprises Aboriginal Corporation.

**Rene Dion** completed his doctoral work at York University in Toronto and is currently the manager of Knowledge Development and Translation at the Health Information and Analysis Division of the First Nations and Inuit Health Branch, Health Canada. His primary role is to provide strategic direction in data development and analysis as well as to advise senior management in strategic planning and policy development. Before joining Health Canada, Rene worked at the Clarke Institute of Psychiatry and University of Toronto researching the cross-cultural applicability of population-based mental health measures such as depression in First Nations and majority culture children. His current professional interests include the interface between health surveillance and policy.

**Ralph Forquera** is a member of the Juaneno Band of California Indians, Acjachmen Nation (a state-recognised Indian tribe from the San Juan Capistrano region of Southern California) and has a Masters in Public Health from California State University, Northridge, and a Bachelor of Science in Health Science & Safety from San Diego State College. He is currently Executive Director for the Seattle Indian Health Board, one of the largest and most comprehensive urban Indian community health centers in the nation and holds a faculty appointment as a Clinical Assistant Professor with the School of Public Health and Community Medicine, Department of Health Sciences at the University of Washington. He is past-president of the Community Health Council of Seattle/King County, and a past-chair of the American Indian, Alaska Native, and Native Hawaiian caucus of the American Public Health Association. He is the urban representative to the American Indian Health Commission for Washington State and serves as the at-large member of the Executive Committee. He also serves on a number of local and national groups promoting better health care for low-income/uninsured Americans as well as for American Indians and Alaskan Natives.

**Howard Goldberg** received his PhD in Sociology/Demography at Princeton University, an MA in demography from Georgetown University, and a BS in psychology from Union College (NY). He has been at the Centers for Disease Control and Prevention (CDC) since 1980 where he has been the Associate Director for Global Health in the Division of Reproductive Health since 2000 and also serves as coordinator for Native American health activities in the Division of Reproductive Health. His major areas of professional interest are international reproductive health issues and the health of Native American populations. He has provided consultation on the design, planning, implementation and analysis of surveys of reproductive health, family planning and related topics in many countries, and has been involved in designing and carrying out survey research, demographic analysis, and program evaluation among Native Americans since 1988, particularly in the areas of maternal and infant health and health risk behaviours.

**Jane Gray** is a Mi'gmaq from the community of Listuguj, Quebec, Canada and is currently the National Project Manager for the First Nations Regional Longitudinal Health Survey currently housed at the Assembly of First Nations. She has held positions at the community, regional and national level in an active health career spanning 20 years advocating for improvements in First

Nations health where she upholds the First Nations Principles of Ownership, Control, Access and Possession (OCAP).

**Ricci Harris** (Ngati Kahungunu, Ngati Raukawa, Kai Tahu) is in her final year as a public health medicine registrar and currently works at Te Ropu Rangahau Hauora a Eru Pomare and Hutt Valley District Health Board. She has an interest in epidemiology and has been involved in Maori health research and investigating ethnic inequalities in Aotearoa/New Zealand., including research into sleep disorders, ethnic disparities in caesarean sections and cardiovascular procedures, the impact of socioeconomic position on ethnic inequalities in mortality, and the impact of racism on health and ethnic inequalities.

**Shane Houston** is a Gangulu man from Central Queensland who completed his PhD at Curtin University, graduating with a Chancellor's Commendation. He is currently the Assistant Secretary, Office of System Performance and Aboriginal Policy, Territory Health Services, and is also Adjunct Professor of Health Sciences at Curtin University. He has worked in Aboriginal affairs for more than 30 years and has held many positions at local, state, national and international levels including a stint with the World Council of Indigenous Peoples in Canada and as an Aboriginal community representative at various UN Forums. He has worked intensively in the community sector including as a CEO of an Aboriginal Medical Service and National Coordinator of the National Aboriginal and Torres Strait Islander Health Organisation and has held senior positions in the public sector for more than 12 years.

**Susan Lavin** has over 32 years of management and supervisory experience at the US Census Bureau and has been the Regional Director of the Denver region since January 1997. She was recently the first recipient of the Census Bureau's Outstanding Mentor Award. The Denver region covers ten states and stretches from the Canadian to the Mexican border and it contains 92 federally recognised tribal governments, including all 10 of the largest American Indian Reservations. Approximately 76% of all American Indians who live on reservation lands live in the Denver Region.

**Richard Madden** received his doctorate from Princeton University, and is Professor and Director of the National Centre for Classification in Health at the University of Sydney. A statistician and an actuary, he was named Australian Actuary of the Year in 2002. From 1996–2006 he was Director of the Australian Institute of Health and Welfare, prior to which he was Deputy Australian Statistician for 3 years. In earlier roles, he worked in government health and disability agencies, and headed the ACT and the Northern Territory Treasuries. He plays an active role in World Health Organisation (WHO) work on health and related classifications.

**Leo J. Nolan III, MEd**, is from the Onondaga Nation and is an enrolled member of the Akwesasne Mohawk Nation. He has degrees from Syracuse University and Pennsylvania State University. He serves as Senior Policy Analyst—External Affairs for the Office of the Director, Indian Health Service (IHS), Department of Health and Human Services, and has been with the IHS in various capacities since 1986. He began his federal government career with the Indian Education Program in the Department of Health, Education, and Welfare, and has also worked at the Bureau of Indian Affairs' Indian Education Program, the Senate Committee on Indian Affairs and in the State University of New York system. He is a member of the Iroquois Nationals Lacrosse Board and Interim Executive Director, member and Chairperson of American University's Washington Interns for Native Students Program, and adviser to the Tewaaronon Lacrosse Award Foundation.

**Sam Notzon** holds MS degrees in demography and economics from the University of Wisconsin and a PhD in Population Dynamics from Johns Hopkins University. He is currently Director of the International Statistics Program at the US National Center for Health Statistics (NCHS), CDC. He has worked in the area of international health statistics for more than 25 years, dealing with both developed and developing countries as well as multinational organisations. He is currently a member of the Statistical Advisory Commission of the Pan American Health Organization, WHO. He has also participated in several international collaborations sponsored by NCHS, on topics such as infant mortality, health data for the elderly, injury morbidity and mortality, and the use of automation in mortality data. His main area of interest is in international comparisons of health data, and in recent years he has focused on the US–Mexico border, the Russian Federation, and Central and Eastern Europe.

**Natalie Paki Paki** is of Taranaki descent. She is a Senior Advisor in the Strategic Projects team in the Maori Health Directorate at the Ministry of Health. Before joining the Maori Health Directorate in 2003, she worked for Te Puni Kokiri. Before that she completed a Masters of Social Sciences in Demography at Waikato University.

**Fiona Pimm** is the CEO for He Oranga Pounamu, Ngai Tahu's Maori Development Organisation based in Christchurch. She is also a Director of the Public Trust Board, and member of the South Canterbury District Health Board. Previously she was Business Development Manager for the Ngai Tahu Development Corporation and General Manager with Pegasus Medical Group. She is a qualified Nuclear Medicine Technologist and completed her MBA through Massey University, and holds a Diploma in Public Health as well.

**Lesley Podesta** has a Bachelor of Arts from Deakin University and a Master of Arts from University of Melbourne in Political Science, and is currently the First Assistant Secretary in charge of the Australian Office for Aboriginal and Torres Strait Islander Health (OATSIH) which is responsible for funding primary health care and intervention services for Indigenous people across Australia. She has worked in the health portfolio for nearly 10 years. Some of her previous positions include the Assistant Secretary, Residential Programs Branch in Aged Care and Assistant Secretary, Biosecurity and Disease Control in Population Health Division. As a senior manager in the Department of Labour and Ethnic, Municipal and Community Affairs with the Victorian state government, she managed Indigenous employment and Indigenous vocational education and training. She was a Foundation Board Member of the Youth Research Centre, University of Melbourne, a member of the Council of Victoria University and a board member of the National Centre for Epidemiology and Population Health, Australian National University.

**Jeff Reading** earned his PhD in Public Health Sciences in the Faculty of Medicine at the University of Toronto and is the inaugural Scientific Director of the Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health, based at the University of Victoria. He is a full professor in the Faculty of Human and Social Development and a faculty associate with the Indigenous Governance Program and was elected as a Fellow into the Canadian Academy of Health Sciences. As an epidemiologist, his research has brought attention to such critical issues as disease prevention, tobacco use and misuse, healthy living, accessibility to health care, and diabetes among aboriginal people in Canada. As an aboriginal person, he encourages the meaningful involvement of community people working alongside multidisciplinary teams of health researchers, each contributing their own perspectives and expertise.

**Debra Reid** is the State Director of the Australian Office for Aboriginal and Torres Strait Islander Health in the Tasmanian State Office of Department of Health and Ageing, and co-

developer of the Aboriginal and Torres Strait Islander Health Performance Framework . She has worked for over 21 years in Aboriginal and Torres Strait Islander Health in Australia, with 10 years experience in the Aboriginal Community Controlled Health Sector, 8 years with a State Health Department as an Aboriginal Health Policy Officer and 4 years with the Australian Government Department of Health and Ageing, Office for Aboriginal and Torres Strait Islander Health.

**Ian Ring** is a Professorial Fellow at the Centre for Health Service Development at Wollongong University, and was previously Head of the School of Public Health and Tropical Medicine at James Cook University, Principal Medical Epidemiologist at Queensland Health, and Foundation Director of the Australian Primary Health Care Research Institute at the Australian National University. He has been a Member of the Board of the Australian Institute of Health, and Member of the Council of the Public Health Association (PHA) and the Australian Epidemiological Association. He was the Elkington Orator for the Queensland Branch of PHA in 1992, and was awarded the Sidney Sax medal by James Cook University in 2001. His current interests include public health aspects of cardiovascular disease and Aboriginal and Torres Strait Islander Health.

**Hon. Mita Ririnui** is the Associate Minister of Health, New Zealand. He is a member of the Labour Maori Caucus and member of the Maori Affairs Select Committee. Previously he has also been the Associate Minister of Corrections, Associate Minister in Charge of Treaty of Waitangi Negotiations, Associate Minister of Forestry, Cultural Advisor for the Special Education Services, and Maori Education Resources Advisor to the School Board of Trustees Association. He is a Maori Tertiary Education Advisor and Academic Board Member, and is involved with Bay of Plenty Polytechnic and Tauranga University College. Other involvements include Board Member, Tauranga Moana Māori Trust Board; Chairperson, Ngati He Hapu Committee; Chairperson, Ngai Te Ahi/Ngati He Hou Ora; Registered Minister, Ratana Established Church of New Zealand; Private Secretary to Raniera Te Aohou Ratana, Ratana President; Chairman of the Maugatapu School Board of Trustees; Cultural Advisor for the Special Education Services and Māori Education Resources Advisor to the School Board of Trustees.

**Francine C Romero**, PhD, MPH, is Director of the Jemez Health and Human Services Department for the Pueblo of Jemez (New Mexico) and Principal Investigator to the Northern Plains NARCH Program. She is the former Director of the Northern Plains Tribal Epidemiology Center, Aberdeen Area Tribal Chairmen's Health Board (AATCHB), Rapid City, South Dakota. She received her Doctor of Philosophy from the University of New Mexico and her Master of Public Health in Epidemiology from the University of Washington. Her doctoral dissertation focused on the genetic variation in American Indian populations of the American Southwest and Alaska. She is also a former Chair of the Portland Area Indian Health Service (IHS) Institutional Review Board (IRB), and co-Chair of the National IHS IRB.

**Paula Searle** is of Ngati Mutunga ki Wharekauri descent and has a Master of Arts in Geography from the University of Auckland. Experienced in research, evaluation and monitoring at a central government level, she is currently the Manager of the Strategic Projects team in the Maori Health Directorate at the Ministry of Health. Before joining the Maori Health Directorate in 2002, she worked for Te Puni Kokiri where she managed a unit that monitored outcomes and undertook research and evaluation, prior to which she was a senior analyst specialising in evaluation in the Monitoring and Evaluation Branch.

**Janet Smylie** is an Associate Professor in the Department of Community Health and Epidemiology at the University of Saskatchewan and the outgoing Director of the Indigenous Peoples Health Research Centre. In January 2007 she joined the Centre for Research on Inner City Health at St Michael's Hospital in Toronto as a research scientist. Dr Smylie completed her Masters of Public Health Degree at Johns Hopkins University. She has practised and taught family medicine in a variety of urban and rural aboriginal communities. She is a member of the Métis Nation of Ontario, with Métis roots in Saskatchewan. She is the vice-president of the Indigenous Physicians Association in Canada. Her current research interests are focused in the area of aboriginal health and include health indicators of relevance to aboriginal communities, interfacing Indigenous knowledge and Western science, and the health of young aboriginal families. She holds a senior research fellowship from the Canadian Institutes of Health Research.

**Brendan Stevenson** completed an MA in Psychology from Massey University and has been with Best Outcomes for Maori: Te Hoe Nuku Roa (THNR) for 6 years where he has gained experience in cross-sectional and longitudinal data analysis, survey design, questionnaire design, data entry and storage, and fieldwork management. He has also researched and written in the areas of health, Maori culture, older Maori (60+) and Maori workers. He is currently part of a study of the health of older adults in the transition from work to retirement (Massey University) and is a member of the reference group for the NZ government-produced 'The Social Report'.

**Dennis Trewin** joined the Australian Bureau of Statistics in 1966 as a statistics cadet and has been Australian Statistician since 2000. Prior to that he was Deputy Australian Statistician responsible for economic statistics and a Deputy Government Statistician in New Zealand. Other appointments he holds are Australian Electoral Commissioner, Chairman of the World Bank Board on the International Comparison Program, and a member of the committee responsible for preparing the 2006 report on the State of the Environment and Adjunct Professor at Swinburne University. He is a past president of the International Statistical Institute, International Association of Survey Statisticians and the Statistical Society of Australia.

**Whetu Wereta** began working for Statistics New Zealand after completing postgraduate studies in the 1970s. She has continued to work for the department periodically for the last 30 years. She is currently a member of the senior management team, holding the position of General Manager, Maori Statistics. She has also worked as a policy researcher and/or a manager in the Ministry of Maori Development (and its predecessors) as well as in the Department of Internal Affairs. She has also been a consultant, advising a number of other government departments on a range of issues.

**Valorie Whetung** is the Chief of Aboriginal Liaison and Training of the Social and Aboriginal Statistics Division of Statistics Canada, and is an Ojibwas member of the Curve Lake First Nation. As the chair of the Implementation Committee for the Aboriginal Peoples' Survey and the Technical Advisory Group for the Aboriginal Children's Survey, she has worked directly with aboriginal groups and government departments to tackle issues of data management. Before her work at Statistics Canada, she spent 15 years working in the health field both clinically and as a manager of Health and Social Service at two First Nations, and as the manager of the Aboriginal Tobacco Strategy in Cancer Care Ontario. In addition, she helped establish the Health Commission with the Union of Ontario Indians, and was a representative on the Health Advisory Board for the Association of Iroquois and Allied Indians.

## A6 Media Release by the AIHW

### AIHW hosts International Group for Indigenous Health Measurement

The challenge of understanding the differences in health status between indigenous and non-indigenous populations is being addressed by four nations at a three day conference in Canberra starting today.

The meeting, hosted by the Australian Institute of Health and Welfare (AIHW) in partnership with the National Advisory Group Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID), will focus on improving data and look for shared projects, such as a common set of indicators, to highlight progress.

Representatives from New Zealand, Canada, the United States and Australia have come together as the International Group for Indigenous Health Measurement to exchange experiences and work towards improving indigenous health in these colonised countries.

Members of the group will also discuss ways to formalise working relationships and maintain the momentum towards improving indigenous health data.

Speakers include the Associate Minister for Health in New Zealand, the Hon Mita Ririnui, Chief Tom Bressette, Chairman of the First Nations Statistical Institute Advisory Panel, Canada, Leo Nolan, from the Office of the Director of the Indian Health Service in the United States and Dea Delaney-Thiele, Chief Executive Officer of the National Aboriginal Community Controlled Health Organisation in Australia (NACCHO).

'The Hon Mita Ririnui said, 'We know that the health status of the indigenous people in our four countries is significantly poorer than the non indigenous populations, and this meeting is a chance for us to build on improving health outcomes and reducing inequalities by sharing what we have learned from indigenous researchers, officials and community based providers.'

Dea Delaney-Thiele said, 'Measuring what is important to indigenous communities and to government is a priority to ensure we are doing the rights things in the right way.'

The Hon Tony Abbott, Australian Minister for Health, addressed representatives and delegates to Canberra today. He welcomed recent data that shows real improvements in Aboriginal and Torres Strait Islander health and stressed the Government's commitment to improving the health of Aboriginal and Torres Strait Islander people.

The Canberra meeting is the second meeting of the International Indigenous Health Measurement Group following the first meeting in Vancouver last year.

**Canberra, 28 November 2005**

Further information: Fadwa Al-Yaman, AIHW tel. 0417 024 275.

## ■ Part B: Data on indigenous health

### B1 Census

Table B1.1 presents a summary of the definitions of indigenous status in the censuses of the four countries. The extent of coverage of the indigenous population and whether trends in the size of the population over time can be accurately estimated are also summarised.

As shown in Table B1.1 the conceptualisation of indigenous identity is somewhat different in each country, which hampers cross-country comparisons. Canada and New Zealand collect multiple indicators of indigenous status, because of legal and electoral requirements and the link to entitlements. In each country there have been changes over time in the questions that are asked about indigenous identity in the censuses. There have also been changes in the propensity to self-identify, which are related to broader social, cultural and legal issues within each country.

In the 2006 Australian and Canadian censuses and in the 2000 United States census the person designated as Person 1 filled in the census questionnaire, which included information on every person in the household. In the 2006 New Zealand census there were both a Dwelling Form, which asked questions about the dwelling and the household, and a separate Individual Form for each person in the household.

The 2006 Canadian census and the 2000 United States census included both short- and long-form questionnaires. In Canada the long-form questionnaire was administered to almost the entire population in northern areas and reserves and 20% of other households. The long-form questionnaires asked the questions that are listed in Table B1.1 in relation to every person in the household. The remaining 80% of households were mailed the short-form questionnaire, which did not include any questions on aboriginal status.

In the 2000 Census in the United States, approximately five in six households were sent the short-form questionnaire, which contained one household question and six questions relating to each individual in the household. One in six households was sent the long-form questionnaire. Both the short- and long-form questionnaires asked the question on race that is shown in Table B1.1 in relation to every person in the household.

The willingness of people to answer the indigenous status question relates to their social and cultural values, the role of the person asking the question and whether the reasons for asking the question are considered to be legitimate or not. Strategies have been implemented in all four countries to promote the value to indigenous people of collecting accurate census data. Specific strategies have included culturally appropriate local promotion, personal visits and direct enumeration by trained indigenous enumerators.

**Table B1.1: How indigenous people are identified and counted in the census**

Agency/ (Frequency)	Indigenous identity	Ancestry/descent	Registration/tribe	Coverage and data quality issues	Can trends be measured?
Australian Bureau of Statistics (ABS) (5 yearly, last conducted in 2006)	<p><b>Is the person of Aboriginal or Torres Strait Islander origin?</b></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• No</li> <li>• Yes, Aboriginal</li> <li>• Yes, Torres Strait Islander</li> </ul> <p>(both yes boxes can be checked)</p>	Torres Strait	None	<p>The increase in the Australian Indigenous census count between 1996 and 2001 was far greater than can be explained by demographic factors alone (births, deaths and migration). This increase highlights the volatile and social nature of identification practices. The increase in Indigenous status reporting between the 2001 and 2006 Census counts reflects a more stable demographic population increase but the components of growth have not yet been analysed by the ABS (ABS 2004:3, 2006a:4).</p> <p>The ABS implements an Indigenous enumeration strategy to improve Indigenous census coverage in both remote and urban areas. It also conducts a post-census enumeration survey to estimate the net undercount of people and dwellings in the census. The Indigenous resident population is estimated by adjusting the census count to take account of unknown Indigenous status and net undercount (ABS 2006a:10).</p>	<p><b>Not yet</b></p> <p>Between 1986 and 2006 the census count of Indigenous people doubled. This high growth is the result of both natural increase and non-demographic factors, such as people identifying as Indigenous for the first time in the census. The ABS has not yet completed the analysis of the components of growth between 2001 and 2006 (ABS 2006a:5).</p>

(continued)

**Table B1.1 (cont'd): How indigenous people are identified and counted in the census**

Agency/ (Frequency)	Indigenous identity	Ancestry/descent	Registration/tribe	Coverage and data quality issues	Can trends be measured?
Statistics Canada (5 yearly, last conducted in 2006)	<p><b>Is this person an aboriginal person, that is, North American Indian, Métis or Inuit (Eskimo)?</b></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• No</li> <li>• Yes, North American Indian</li> <li>• Yes, Métis</li> <li>• Yes, Inuit (Eskimo)</li> </ul>	<p><b>What were the ethnic or cultural origins of this person's ancestors?</b></p> <p>An ancestor is usually more distant than a grandparent</p> <p>Examples include Cree, Mi'kmaq (Micmac), Métis and Inuit (Eskimo). Space is provided to write in the response</p>	<p><b>Is this person a member of an Indian Band/First Nation?</b></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• No</li> <li>• Yes, Indian Band/ First Nation</li> </ul> <p>Specify Indian Band/ First Nation (for example, Musqueam)</p> <p><b>Is this person a Treaty Indian or a Registered Indian as defined by the Indian Act of Canada?</b></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• No</li> <li>• Yes, Treaty Indian or Registered Indian</li> </ul>	<p>It is estimated that the majority of the aboriginal population lives in urban areas outside the territories and reserves (Statistics Canada 2008a:12). However, only approximately 20% of urban households were asked the questions relating to aboriginality, cultural origin and registration/tribe in the 2006 census. The following three census forms were used:</p> <p>2A (short form—7 questions, administered to 80% of households) did not contain questions to identify aboriginal peoples;</p> <p>2B (long form—59 questions, administered to 20% of households);</p> <p>2D (Northern and Reserves questionnaire)—same as 2B, except for adaptation of the examples. Form 2D was administered to every household in northern areas (with the exception of Whitehorse and Yellowknife) and almost all Indian reserves, settlements, Government districts and terres réservées.</p>	<p><b>No</b></p> <p>Despite the questions relating to aboriginality, cultural origin and registration/tribe being asked identically in 1996, 2001 and 2006, coverage issues (such as fewer incompletely enumerated reserves) and the increased tendency to report as aboriginal since 1986 mean that population trends cannot be accurately estimated (Statistics Canada 2003:6)</p>

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**Table B1.1 (cont'd): How indigenous people are identified and counted in the census**

Agency/ (Frequency)	Indigenous identity	Ancestry/descent	Registration/tribe	Coverage and data quality issues	Can trends be measured?
Statistics NZ (5 yearly, last conducted in 2006)	<p><b>Which ethnic group do you belong to?</b> <i>Mark the space or spaces which apply to you</i></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• NZ European</li> <li>• Maori</li> <li>• Samoan</li> <li>• Cook Island Maori</li> <li>• Tongan</li> <li>• Niuean</li> <li>• Chinese</li> <li>• Indian</li> <li>• Other such as DUTCH, JAPANESE, TOKELAUAN. Please state</li> </ul>	<p><b>Are you descended from a Maori (that is, did you have a Maori birth parent, grandparent or great-grandparent etc.)?</b></p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know</li> </ul>	<p>If yes to Maori descent:</p> <p><b>Do you know the name(s) of your iwi (tribe or tribes)?</b></p> <p>A list of iwi can be found on the back of the Guide Notes.</p> <p>Responses:</p> <ul style="list-style-type: none"> <li>• Yes. Mark your answer and print the name and home area, rohe or region of your iwi below</li> <li>• No</li> </ul>	<p>A post-enumeration survey following the 2006 Census estimated the Maori undercount to be 3.1%. In 2001 the estimated undercount was 4.4% (Statistics New Zealand 2007:1,14).</p>	<p><b>Some limitations</b></p> <p>The 1996 census question on ethnicity differed from that used in the 2001 and 2006 censuses. Hence population estimates for the years before 2001 are based on the 2001 and 2006 censuses. Limitations are inherent in the data (Statistics New Zealand 2008a).</p>

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**Table B1.1 (cont'd): How indigenous people are identified and counted in the census**

Agency/ (Frequency)	Indigenous identity	Ancestry/descent	Registration/tribe	Coverage and data quality issues	Can trends be measured?
US Bureau of the Census (10 yearly, last conducted in 2000)	<p><b>What is this person's race?</b> <i>Mark one or more races to indicate what this person considers himself/herself to be</i></p> <ul style="list-style-type: none"> <li>• White</li> <li>• Black, African Am., or Negro</li> <li>• American Indian or Alaska Native</li> <li>– <i>Print name of enrolled or principal tribe</i></li> <li>• Asian Indian</li> <li>• Chinese</li> <li>• Filipino</li> <li>• Japanese</li> <li>• Korean</li> <li>• Vietnamese</li> <li>• Other Asian—<i>Print race</i></li> <li>• Native Hawaiian</li> <li>• Guamanian or Chamorro</li> <li>• Samoan</li> <li>• Other Pacific Islander—<i>Print race</i></li> <li>• Some other race—<i>Print race</i></li> </ul>	None	None	The classification of race in the 2000 Census was based on the 1997 Office of Management and Budget (OMB) Standard. The 1997 standard allows for observer or proxy identification of race, but states a preference for self-identification of one or multiple races.	<p><b>Some limitations</b></p> <p>The 1990 Census used OMD 1977, which had four race categories: AI/AN, Asian or Pacific Islander, Black and White. Based on self-classification or observation by interviewer or other person filling out the questionnaire. The Bureau has developed methods to estimate the trend from 1990 to 2000.</p>

In Australia, New Zealand and the United States the definition of an indigenous household is one that includes one or more members who self-identify as indigenous. However, US publications on numbers of AI/AN households include those for which one or more members identify as American Indian or Alaska Native only. The number of households where one or more members identify as AI/AN in conjunction with another race are not published.

Canada does not have a national definition of aboriginal household. The only definitions found through an Internet search are from the Yukon Bureau of Statistics and the Canadian Mortgage and Housing Corporation. These two definitions are identical and require either at least one spouse to self-identify as aboriginal or at least half the members to self-identify as aboriginal.

**Table B1.2: Criteria used to define an indigenous household**

Country	Definition of indigenous household
Australia <sup>(a)</sup>	A household which includes one or more members who identify as Aboriginal and/or Torres Strait Islander.
Canada <sup>(b)</sup>	A household which is either a non-family household in which 50% of household members identify as aboriginal or a family household that has at least one spouse, common law partner or lone parent who self-identifies as aboriginal or where at least 50% of household members self identify as aboriginal.
New Zealand <sup>(c)</sup>	Households with one or more people of Maori ethnicity.
United States <sup>(d)</sup>	A household which includes one or more members who identify as AI/AN.

(a) AIHW 2006 National Housing Data Dictionary, version 3:121.

(b) Yukon Bureau of Statistics; Canada Mortgage and Housing Corporation.

(c) Maori ethnicity in households. Statistics NZ 2004.

(d) Household income:1999 Census 2000 Brief.

## B2 Vital statistics

### Birth data

Table B2.1 provides an overview of the collection of birth data in the four countries, including a summary of indigenous coverage and data-quality issues.

Parents are required to register births in Australia, New Zealand and Canada. In New Zealand, hospitals must also notify births to the Registrar and the data from the parents and the hospital is cross-matched. In Australia, hospitals also collect birth data (called perinatal data), but this is not provided to the Registrar. Therefore birth data in Australia is processed by two different organisations: the Australian Bureau of Statistics which processes birth registrations and the Australian Institute of Health and Welfare which processes the perinatal data. In the United States birth data is collected mainly by hospitals (with a few exceptions, such as home births and babies born overseas).

All countries except Canada collect data on the indigenous status of at least one parent. New Zealand collects information on the ethnic group and Maori descent of both parents and the baby, the United States collects race data for both parents, and Australia collects the Australian Indigenous status of both parents on birth registrations, but only the Australian Indigenous status of the mother in the perinatal data collection. In Canada, First Nations-specific birth rates have been generated by cross-linking birth data from four provinces with the Indian Register. These birth data do not include non-registered First Nations, Inuit or Métis births.



Several countries have improved the coverage and quality of their indigenous birth data. The coverage of Maori births in New Zealand improved significantly after the inclusion on the birth registration form of the census question on ethnicity. Data on ethnicity is collected for both parents as well as for the baby. The United States has also improved its birth data collection forms, to enable multiple races to be identified for each parent. In Australia there has been progressive improvement in the coverage and quality of Australian Indigenous birth registration and perinatal data.

**Table B2.1: How indigenous births are identified and counted**

Country	The collection and publication of birth data	Coverage and data quality issues	Can trends be measured?
Australia	<p>Data on Australian Indigenous births in Australia is obtained from two sources:</p> <ul style="list-style-type: none"> <li>• Registrars of Births, Deaths and Marriages</li> <li>• the National Perinatal Data Collection (NPDC)</li> </ul> <p><i>Birth registrations</i></p> <p>Parents are jointly responsible for registering a birth within 60 days with the Registrar of Births, Deaths and Marriages in their state or territory. The registration form is supplied by the hospital or midwife, or can be obtained from the registry or downloaded from its website. In some states/territories, health professionals are also required to notify the Registrar. All states and territories include questions on the Indigenous status of both parents on their registration forms.</p> <p>States and territories provide their birth registration data to the Australian Bureau of Statistics (ABS) on a monthly basis and the ABS uses these to publish preliminary estimates of the resident population approximately 6 months after the end of each quarter. The publication of a report on births in a particular year occurs towards the end of the following year.</p> <p><i>National Perinatal Data Collection (NPDC)</i></p> <p>Midwives and other staff, using information obtained from mothers and from hospital and other records, complete notification forms for all births of at least 400 grams birthweight or at least 20 weeks gestation. The collection records the Indigenous status of the mother only.</p> <p>Data are held in state/territory perinatal databases and provided to the National Perinatal Statistics Unit yearly. There is a time lag of almost 2 years between the collection and publication of the data. For example, <i>Australia's mothers and babies 2005</i> was published in November 2007.</p>	<p>Birth registrations record the Australian Indigenous status of both parents, but the NPDC records the Indigenous status of the mother only. Hence, the total number of Indigenous birth registrations is higher than the number of births to Indigenous mothers in the NPDC. However, if only Indigenous mothers are considered, the number of birth registrations is substantially lower than the number in the NPDC (13% for the period 2001–03).</p> <p>The difference is due to late registration of some Indigenous births or failure to register altogether (AIHW 2007b:21)</p> <p>The ABS estimates the coverage of Indigenous birth registrations for the period 2002–06 to be 95%. However, almost one-quarter of Indigenous births actually occurred in the year prior to the year of registration or in an earlier year (ABS 2006b:25, 33).</p> <p>The number of Australian Indigenous births in both data collections is likely to be an underestimate, as the Indigenous status of the parents is not always recorded, or recorded correctly (ABS and AIHW 2008:82).</p> <p>Aboriginal status is not a required data item on birth registrations.</p> <p>First Nations-specific birth rates have been generated by cross-linking birth data from four provinces with the Indian Register. These birth data do not include non-registered First Nations, Inuit or Métis births.</p>	<p><b>Not accurately</b></p> <p><i>Birth registrations</i></p> <p>The ABS discourages over precise analysis of annual numbers, because of their inherent volatility and data limitations (ABS 2007b:28).</p> <p>NPDC</p> <p>Caution should be used when interpreting trends because changes in the accuracy of Australian Indigenous identification over time may influence the numbers (AIHW 2007b:60).</p>
Canada	<p>The form for the registration of a birth is completed by the parents, who are responsible for filling it in with the local registrar. Most provinces also require physicians (or other birth attendants) to report all births.</p> <p>All province/territory registrars must collect a specified set of data elements, but may collect additional information. Aboriginal status is not a required item.</p> <p>Vital Statistics registries in each province/territory provide the data to Statistics Canada, which publishes it annually.</p> <p>There is a time lag of almost 2 years between the collection and publication of the data. For example, the Vital Statistics—Birth Database for 2005 was released by Statistics Canada in September 2007.</p>	<p>Aboriginal status is not a required data item on birth registrations.</p> <p>First Nations-specific birth rates have been generated by cross-linking birth data from four provinces with the Indian Register. These birth data do not include non-registered First Nations, Inuit or Métis births.</p>	<p><b>No</b></p> <p>The coverage and data-quality issues previously identified mean that trends cannot be accurately estimated.</p>

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**Table B2.1 (cont'd): How indigenous births are identified and counted**

Country	The collection and publication of birth data	Coverage and data quality issues	Can trends be measured?
New Zealand	<p>Every birth must be notified to a registrar by the hospital, doctor or midwife within 5 working days. In addition, every guardian of a child born in New Zealand must notify Births, Deaths and Marriages as soon as practicable after the birth. The information from these data sources is then matched.</p> <p>Statistics New Zealand is sent a monthly electronic file of birth registrations by Births, Deaths and Marriages. Birth data are published quarterly by date of registration (not date of birth). Data are published shortly after the end of the quarter. For example, data on births registered in the March quarter 2008 were published in May 2008.</p> <p>Questions on the current birth registration form include the ethnic group and Maori descent of the child, mother and father.</p>	<p>In September 1995 new birth registration forms were introduced, including a revised question on ethnicity that was consistent with the 1996 Census. The data now relate to self-identification with one or more ethnic groups. The ethnicity of the child is now also collected separately from the ethnicities of the parents.</p> <p>Following implementation of the new forms the number of Maori birth registrations increased significantly (from under 15,000 in 1995 to almost 16,000 in 1996) (Statistics New Zealand 2008b).</p>	<p><b>Some limitations</b></p> <p>Birth data after 1 September 1995 are not comparable with earlier data.</p>
United States	<p>Birth certificates are generally completed in hospitals. The race of both parents is recorded, based on information provided by the mother. The 2003 revision of the US Standard Certificate of Live Birth allows the reporting of more than one race for each parent.</p> <p>Vital Statistics in each state are reported to the National Center for Health Statistics (NCHS). There is a time lag of approximately a year between the collection and publication of preliminary data and approximately two years before the publication of final data.</p>	<p>The various states in the United States are progressively implementing the 2003 revision. To provide comparable data across states during the transition period, the responses of those who reported multiple races are 'bridged' to a single race.</p>	<p><b>Limitations</b></p> <p>The 2003 revisions to the birth certificate are providing more accurate data, but 'technical fixes' are required in order to estimate trends.</p>

## Death data

Table B2.2 provides an overview of the collection of death data in the four countries, including a summary of indigenous coverage and data-quality issues.

In all four countries funeral directors fill in the death registration form. The Australian, New Zealand and United States forms include information on the indigenous status of the deceased, which is usually provided by the family. In Canada, aboriginal identity is not a mandatory item on death registrations, but First Nations-specific mortality rates are generated by cross-linking death data for four provinces with the Indian Register. These cross-linked mortality data do not include non-registered First Nations, Inuit or Métis deaths.

Australia and the United States also have some issues with the coverage of their indigenous death data registrations. In Australia the implied coverage of Australian Indigenous death registrations is currently being revised and estimates vary between 55% and 89% (ABS 2008); however, in the United States the National Longitudinal Mortality Study found that almost 30% more persons were identified as American Indian in the Current Population Survey files than on the corresponding death certificates.

Since 1996 death registration forms in New Zealand have included the census question on ethnicity, which has resulted in improved coverage of Maori deaths. Various methods have also been developed to improve the accuracy of mortality data, including adjusters and the 'ever Maori' method, which has been shown to increase the number of deaths classified as Maori for the period 2000–2002 by 6% (Ministry of Health 2006).

**Table B2.2: How indigenous deaths are identified and counted**

Country	The collection and publication of death data	Coverage and data quality issues	Can trends be measured?
Australia	<p>The attending doctor completes and signs the medical certificate of the cause of death within 48 hours of the death. This certificate includes a question on Indigenous status. The certificate is then sent to the Registrar of Births, Deaths and Marriages. If a death is referred to the coroner, there may be a delay in establishing the cause of death.</p> <p>Funeral directors fill in the death registration forms and are required to send them to the Registrar within 7 days of burial/cremation in most states/territories, or within 14 days of the death in others. The death registration form includes a question on Indigenous status. The funeral director fills in this information by asking the family, from personal knowledge, or by observation of the body.</p> <p>States and territories provide their death registration data to the Australian Bureau of Statistics (ABS) on a monthly basis and the ABS uses these to publish preliminary estimates of the estimated resident population approximately six months after the end of each quarter. The publication of a report on deaths in a particular year occurs towards the end of the following year.</p>	<p>Although it is considered likely that most deaths of Indigenous Australians are registered, a proportion of these deaths are not identified as Indigenous by the family, health worker or the funeral director. That is, although data are provided to the ABS for the Indigenous status question for 99% of all deaths, there are concerns regarding the accuracy of the data. The Indigenous status question is not always directly asked of relatives and friends of the deceased by the funeral director or not completed by the certifier on the medical certificate of cause of death.</p> <p>Both the medical cause of death certificate and death registration form include a question on Indigenous status. These sources have been combined by the ABS to estimate Indigenous mortality. However, the medical certificate cause of death is not currently supplied for New South Wales, Queensland and Victoria.</p>	<p><b>Not accurately</b></p> <p>Longer term mortality trends are estimated using data from the three states/territories that have 15 years of reasonable coverage of Indigenous death registrations (ABS &amp; AIHW 2008:152).</p>

*(continued)*

**Table B2.2 (cont'd): How indigenous deaths are identified and counted**

Country	The collection and publication of death data	Coverage and data quality issues	Can trends be measured?
Canada	<p>Funeral directors usually complete the Statement of Death, with the family providing information about the deceased. The medical Office or Coroner completes the Medical Certificate of Death, which contains information on the cause of death. Both forms are forwarded to the Registrar.</p> <p>Aboriginal identity is not a mandatory data item on death registrations. In British Columbia and Manitoba, vital statistics are linked to status verification files of Indian and Northern Affairs Canada.</p> <p>There is no way of determining aboriginal identity for Canada as a whole from Statistics Canada's Vital Statistics Database. Indigenous mortality data are available only for on-reserve First Nations people.</p> <p>There is a time lag of approximately 2 years between the collection and publication of the data. For example, the Vital Statistics—Death Database for 2005 was released by Statistics Canada in January 2008.</p>	<p>First Nations-specific mortality rates have been generated by cross-linking death data from four provinces with the Indian Register.</p> <p>These death data do not include non-registered First Nations, Inuit or Métis births.</p>	Only for the on-reserve First Nations population.
New Zealand	<p>Funeral directors fill in ethnicity and Maori ancestry on the Notification of Death for Registration form, based on information provided by the family or by observation. Multiple ethnicities can be recorded. The form is then forwarded to the registrars at Births, Deaths and Marriages within 3 days of disposal of the body.</p> <p>Statistics New Zealand is sent a monthly electronic file by Births, Deaths and Marriages. Death data (including ethnic group and Maori ancestry) are published quarterly and refer to the date of registration not the date of death. Data are published shortly after the end of each quarter, for example data on deaths registered during the March quarter 2008 were published in May 2008.</p>	<p>In September 1995 new death registration forms were introduced, including a revised question on ethnicity that was consistent with the 1996 Census. The data now relate to self-identification with one or more ethnic groups able to be identified.</p> <p>One approach that was implemented for a period is a statistical technique called 'ever Maori', which resulted in an increase in the number of deaths classified as Maori of 6% over the period 2000–02 (Ministry of Health 2006:78).</p>	<p><b>Some limitations</b></p> <p>Death data after 1 September 1995 is not comparable with earlier data.</p>

*(continued)*

**Table B2.2 (cont'd): How indigenous deaths are identified and counted**

Country	The collection and publication of death data	Coverage and data quality issues	Can trends be measured?
United States	<p>Demographic information on the certificate, such as race, is recorded by the funeral director, based on information provided by an informant (usually a family member) or in the absence of an informant, by observation. Since the 2003 revision of the death certificate entry of multiple races is possible, however not all states have yet adopted the new certificate.</p> <p>Vital Statistics in each state are reported to the National Center for Health Statistics (NCHS). There is a time lag of approximately a year between the collection and publication of preliminary data and approximately two years before the publication of final data.</p>	<p>The National Center for Health Statistics cautions that the number of AI/AN deaths may be inaccurate because of problems in the correct identification of race on death certificates (National Center for Health Statistics 2008:4).</p> <p>The National Longitudinal Mortality Study found that almost 30% more persons were identified as AI in the Current Population Survey files than on the corresponding death certificates. Adjustment factors have been developed.</p>	<p><b>Not accurately</b></p> <p>Despite the development of adjustment factors to correct the under-identification of AI/AN deaths, the CDC advises that death rates should be interpreted with caution.</p>

### B3 Administrative data collections

Table B3.1 provides an overview of health and related services data collected by mainstream and indigenous health providers in the four countries. Although all four countries have issues with coverage and quality of indigenous identifiers, New Zealand has improved its data by linking data sets and using adjusters when required. The United States is also improving its indigenous administrative data by requiring all collections to progressively implement the 1997 Office of Management and Budget Standards, as used in the 2000 Census. There has also been some improvement in the coverage and quality of indigenous identifiers in Australian administrative data systems. In Canada, aboriginal status is not usually captured in administrative systems, although some analysis can be undertaken by linking data to the Indian Register or by using geography as an indicator of aboriginality in regions which have high percentages of aboriginal inhabitants.

**Table B3.1: Health and related services administrative data**

Country	Health and related services data collections	Indigenous coverage and data quality issues
Australia	<p><b>The National Hospital Morbidity Data Collection</b> (NHMD) comprises de-identified hospital separation records. <b>The Non-admitted Patient Emergency Care National Minimum Data Set</b> is a national collection of de-identified data on emergency department episodes.</p> <p><b>AIHW National Community Mental Health Care Database &amp; AIHW National Residential Mental Health Care Database</b></p> <p><b>Supported Accommodation and Assistance Program</b> (SAAP) national data collection on the provision of assistance and crisis accommodation to homeless people.</p> <p><b>National Perinatal Data Collection</b></p> <p><b>The Healthy For Life Data Collection</b> is an ongoing program which aims to improve the capacity and performance of primary health care services that deliver care to Australian Indigenous people.</p> <p><b>Medicare database</b> contains information recorded on Medicare enrolment application forms.</p>	<p>Australian Indigenous patients are undercounted in hospital morbidity data collections and are also likely to be undercounted in community mental health databases and in the information systems of other community services, such as disability services and aged care (ABS &amp; AIHW 2008:208, 219).</p> <p><b>SAAP:</b> The number of Indigenous clients is adjusted for SAAP agency non-participation and clients not giving consent for their data to be collected.</p> <p><b>Perinatal data:</b> This collection collects information on the Indigenous status of the mother only, and not that of the father or baby. Not all states and territories use the standard wording for the Indigenous status question on their forms, which affects the quality and comparability of the data collected.</p> <p><b>Healthy For Life (HFL) data:</b> Currently not all of the services involved in HFL are able to provide data on all of the essential indicators.</p> <p><b>Medicare:</b> The coverage of Indigenous Australians in this data set is not complete because the introduction of the Indigenous identifier is only recent.</p>
Canada	<p><b>The Indian Register</b> is the official record of status of Indians in Canada, who have rights and benefits not granted to unregistered Indians, Inuit or Métis, including the granting of reserves.</p> <p><b>Administrative health data</b>, such as the Hospital Morbidity Database, the Hospital Mental Health Database, The National Ambulatory Care Reporting System, The National Rehabilitation Reporting System and the National Trauma Registry.</p>	<p>Aboriginal status is not usually captured in administrative systems. Some analysis can be undertaken via linkage to the Indian Register, or by using geography as an indicator for regions that have high proportions of indigenous people. First Nations people can also be identified by their health card numbers in some provinces.</p>
New Zealand	<p><b>Public hospital discharges</b></p> <p>The <b>Mental Health Information National collection</b> includes data on inpatient and outpatient treatment, alcohol and drug services, early intervention services, child and youth specialty services and Maori services.</p>	<p>In order to assess the extent of the undercount of Maori hospital discharges, administrative data have been linked to other data sets, such as death registrations. This has confirmed that Maori hospitalisations are undercounted and that the size of the undercount appears to increase with age (Robson and Harris 2007:66).</p>
United States	<p><b>Health administrative data</b>, such as the Hospital Mental Health Database, The National Ambulatory Care Reporting System, The National Rehabilitation Reporting System and the National Trauma Registry. Hospital morbidity data is collected via the National Hospital Discharge Survey, which samples hospital records and is conducted annually.</p> <p><b>Indian Health Service data</b> on patient care, community health, use of services and health needs.</p>	<p>Health administrative data collections are required to progressively implement the 1997 Office of Management and Budget Standards, as used in the 2000 Census. The 1997 Standard allows for observer or other identification of race, but states a preference for self identification of one or multiple races.</p>

## **B4 Health surveillance**

All four countries have issues with the coverage and quality of indigenous identifiers in their health surveillance databases. New Zealand is improving Maori identification in health surveillance data collections by implementing Ethnicity Data Protocols. The United States is also improving its indigenous data by requiring all collections to progressively implement the 1997 Office of Management and Budget Standards. There has also been improvement in the coverage and quality of Australian Indigenous identifiers in Australian cancer registries. In Canada aboriginal status is not usually captured in surveillance systems, although some analysis can be undertaken by linking data to the Indian Register or by using geography as an indicator of aboriginality in regions which have high percentages of aboriginal inhabitants.

**Table B4.1: National and indigenous-specific surveillance systems**

Country	Surveillance	Indigenous coverage and data-quality issues
Australia	<p><b>National Notifiable Diseases Surveillance System (NNDSS)</b>, under which more than 60 diseases and conditions are notified by doctors and laboratories to state/territory health authorities.</p> <p><b>National AIDS Registry and National HIV Database</b></p> <p><b>Australian Childhood Immunisation Register (ACIR)</b></p> <p><b>Cancer registries</b> are administered by all states and territories, with data being sourced from pathology forms and hospital inpatient data.</p> <p><b>The National Diabetes Register</b> is administered by the AIHW and draws together data from national and state databases.</p> <p><b>Cancer screening registries</b> such as BreastScreen Australia and National Bowel Cancer Screening Register</p> <p><b>Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)</b></p>	<p><b>NNDSS:</b> Notifications represent a variable proportion of the actual cases. Australian Indigenous status data for five of the eight states/territories are incomplete, with less than 60% of notifications recording Indigenous status.</p> <p><b>AIDS/HIV Registry:</b> Indigenous status data for HIV/AIDS notifications are more reliable than NNDSS data. All states and territories have adequate Indigenous data for reporting.</p> <p><b>ACIR:</b> Indigenous status data for three of the eight states/territories are incomplete.</p> <p><b>Cancer registries:</b> Indigenous identification is good in three states/territories and improving in two further states.</p> <p><b>Diabetes Register:</b> The number of Indigenous people who are registered is lower than would be expected based on the prevalence of diabetes in the Indigenous population.</p> <p><b>Cancer screening registries:</b> It is not known how many women participating in Breastscreen Australia do not report their Indigenous status.</p> <p><b>ANZDATA:</b> Indigenous identification in the Registry is based on self-identification in hospital records. Indigenous identification in the Registry is more complete than in general hospital data.</p>
Canada	<p><b>Disease surveillance systems</b>, e.g. modifiable diseases and the National Diabetes Surveillance System</p> <p><b>Canadian Perinatal surveillance system</b></p>	<p>Data linkage to the Indian Register or geography is used as an indicator for regions with high proportions of indigenous people. First Nations individuals can be identified by their health card numbers in some provinces.</p>
New Zealand	<p><b>The NZ notifiable disease surveillance system</b> covers approximately 50 diseases for which reporting by medical practitioners is mandatory.</p> <p><b>Registers</b>, including the New Zealand Cancer Registry, the Cervical screening register, the National immunisation register and the Australia and NZ Dialysis and Transplant Registry</p>	<p>In 2004 the Ministry of Health released the Ethnicity Data Protocols, which specify procedures for the standardised collection, recording and output of ethnicity data for the health and disability sectors. Until improvements in ethnicity data collection are fully implemented, the use of the 'ever Maori' method and adjusters are being used. Implementation of the 'ever Maori' method resulted in a 16.6% increase in the number of Maori cancer registrations (Robson et al 2005).</p>
United States	<p><b>CDC disease surveillance systems</b>, e.g. notifiable diseases, HIV/AIDS, STD, abortions, National Program of Cancer Registries, the Pregnancy Risk Assessment Monitoring System (PRAMS).</p> <p><b>National Institutes of Health (NIH):</b> The Surveillance, Epidemiology and End Results (SEER) program sponsored by NIH is the most authoritative source of information on cancer incidence and survival in the United States.</p> <p><b>Indian Health Service surveillance systems</b>, e.g. immunisation register, diabetes register, women's health, Resource and Patient Management System.</p>	<p>Reporting of race varies by disease and state, with approximately 70% of records reported to the National Notifiable Diseases Surveillance System in 1990 having information on race (MMWR 1992:653). Health surveillance data collections are now required to progressively implement the 1997 Office of Management and Budget Standards, as used in the 2000 Census.</p> <p>States with high AI/AN populations have established data-oriented collaborations to meet the need for AI/AN-specific information, e.g. Council of State and Territorial Epidemiologists with tribal-based epidemiology centres. American Indian-specific data reports have been produced.</p>

## **B5 Health surveys**

Indigenous sample sizes in national surveys are generally too small to enable accurate indigenous rates to be estimated. In Canada, Australia and the United States, indigenous-specific surveys have been used, which include similar questions, so that indigenous rates can be estimated and compared with corresponding rates derived from mainstream surveys. However, the sampling frames for indigenous-specific surveys in the United States and Canada have not included the whole indigenous population, as they have been based on Indian Health Services data, or on Canadian census data. In New Zealand, mainstream surveys generally oversample the Maori population, so that rates for Maori can be estimated accurately.

**Table B5.1: Major national and indigenous-specific surveys**

Country	National health-related surveys	Coverage and data-quality issues
Australia	<p><b>Mainstream surveys</b>, e.g. National Health Survey, General Social Survey, Child Dental Health Survey, National Drug Strategy Household Survey</p> <p><b>Australian Indigenous-specific surveys</b>, e.g. National Aboriginal and Torres Strait Islander Health Survey, National Aboriginal and Torres Strait Islander Social Survey, Community Housing and Infrastructure Needs Survey, Western Australia Aboriginal Child Health Survey</p> <p><b>Bettering the Evaluation and Care of Health (BEACH) Survey</b>, which collects information on consultations with general practitioners</p> <p><b>Other, e.g. longitudinal surveys</b> such as the Longitudinal Survey of Indigenous Children (LSIC)</p>	<p>Australian Indigenous estimates from national surveys tend to have large sampling errors because of small sample sizes. However, a comprehensive program of Indigenous-specific surveys enables comparison of Indigenous and national results.</p> <p><b>BEACH</b> is thought to underestimate the number of Indigenous consultations.</p>
Canada	<p><b>The Aboriginal Peoples Survey (APS)</b> has been undertaken after the last three censuses. It surveys off-reserve First Nations people, Métis and Inuit living in urban, rural and northern locations across Canada.</p> <p><b>The Aboriginal Children's Survey (ACS)</b> is a national survey of First Nation, Inuit and Métis children under the age of 6 years. It was conducted for the first time in 2006. The survey is by personal interviews with parents/guardians in Nunavut, the Northwest Territories (except for Yellowknife) and remote areas, and elsewhere by phone interview.</p> <p><b>The First Nations Regional Longitudinal Health Survey (FNRLHS)</b> is a national survey of registered First Nations adults, youth and children living on reserves and some non-reserve communities, excluding Nunavut. The James Bay Cree and the Innu of Labrador did not participate.</p> <p><b>Canadian Community Health Survey (CCHS)</b>, the <b>Health Services Access Survey (HSAS)</b> and the <b>National Population Health Survey (NPHS)</b></p> <p><b>The National Longitudinal Survey of Children and Youth (NLSCY)</b></p>	<p>The sample frames for both the <b>APS</b> and <b>ACS</b> are derived from the Census, so have the same coverage issues as the Census.</p> <p><b>FNRLHS</b>: Sampling is based on the Indian Register, the accuracy of which varies from region to region. The survey excludes the majority of the aboriginal population.</p> <p>The <b>CCHS</b>, <b>HSAS</b> and the <b>NPHS</b> exclude people living on First Nations reserves and Crown lands and residents of certain remote regions.</p> <p>The <b>NPHS</b> is a longitudinal survey, with respondents followed up every 2 years. The general survey does not ask questions on ethnicity, although the options for language spoken do include Cree. A Yukon and Northwest Territories-specific NPHS includes ethnicity and race.</p> <p>The <b>HSAS</b> does not include a question on aboriginality. It is compiled by geographic region, so regions with high percentages of aboriginal inhabitants are used to estimate aboriginal results.</p> <p>The <b>NLSCY</b> does not include a representative sample of aboriginal children.</p>
New Zealand	<p>New Zealand conducts a comprehensive program of <b>national surveys</b>, including the Health Survey, the Disability Survey, the Mental Health Survey, the Mental Health and General Practice Investigation Study, the General Social Survey, the Tobacco Use Survey and the Child Nutrition Survey.</p>	<p>A number of national surveys, such as the New Zealand Health Survey and the New Zealand Mental Health Survey oversample the Maori population to ensure that rates for Maori can be estimated accurately (Baxter et al. 2006:141).</p>
United States	<p><b>CDC surveys</b>, e.g. National Health Interview Survey, National Health and Nutrition Examination Survey (NHANES), National Survey of Drug Use and Health, National Survey of Family Growth, Youth Risk Behaviour Survey, National Immunization Survey</p> <p><b>AI/AN-specific surveys conducted by the Bureau of Indian Affairs</b></p>	<p>Despite surveys generally including a question on race, sample sizes are often too small to provide accurate AI/AN estimates.</p> <p>Samples for AI/AN-specific surveys are generally drawn from service data, so non-users are excluded. The Indian Health Service provides services to 60% of the AI/AN population.</p>

## B6 Comparisons of indigenous health data

Table B6.1 provides a summary of the current status of indigenous data coverage and quality in Australia, Canada, New Zealand and the United States. Strategies which have been implemented in some countries and have resulted in improvements to the data may be able to be trialled in other countries.

**Table B6.1: Comparative overview of indigenous data**

Country	Developments in improving indigenous coverage and data quality
Australia	<p><b>Census and post-census surveys</b></p> <p>All Australian households are asked the Australian Indigenous status of every person in the household in the census. The ABS implements an Australian Indigenous enumeration strategy to improve Indigenous census coverage in both remote and urban areas. It also conducts a post-census enumeration survey to estimate the net undercount of people and dwellings in the census. The Australian Indigenous resident population is estimated by adjusting the census count to take into account unknown Indigenous status and net undercount.</p> <p>Estimates and projections of the size of the Australian Indigenous population produced by the ABS are experimental, as the significant intercensal volatility in Indigenous counts and the quality of births, deaths and migration data do not support standard direct methods to estimate the growth of the Indigenous population. Experimental projections of the size of the Australian Indigenous population will be released by the ABS in August 2009.</p> <p><b>Birth and death registrations</b></p> <p>Australia maintains two separate collections of birth data: birth registrations, which record the Australian Indigenous status of both parents and are completed by parents, and the perinatal data collection, which records only the Indigenous status of the mother and is completed by the hospital. These data collections are not linked. The ABS has estimated that the coverage of Australian Indigenous birth registrations over the period 2002–06 was approximately 95%. The remaining births were either not registered, or were registered in a subsequent year.</p> <p>Almost all deaths in Australia are registered, but not all Australian Indigenous deaths are registered as Indigenous. The ABS has estimated that only 55% of Australian Indigenous deaths were registered over the period 2002–06 (ABS 2007a:69).</p> <p><b>Administration and surveillance systems</b></p> <p>Australian Indigenous patients are currently undercounted. The ABS and the AIHW are working with states, territories and service providers to ensure that the Australian Indigenous identification question is asked and the answer is recorded correctly.</p> <p><b>Health surveys</b></p> <p>Australian Indigenous estimates from national surveys tend to have large sampling errors because of small sample sizes. There is a comprehensive program of Australian Indigenous-specific surveys, the results of which are used to compare Indigenous and national results.</p> <p><b>Recent developments</b></p> <p>Strategies to improve data quality include the following:</p> <ul style="list-style-type: none"> <li>• ensuring that questions that ask Australian Indigenous status across data collections are consistent</li> <li>• working with Indigenous communities to encourage their involvement in the data definition and collection process</li> <li>• working with health providers and others (such as funeral directors) to ensure that Indigenous identification questions are asked.</li> </ul>

(continued)

**Table B6.1 (cont'd): Comparative overview of indigenous data**

Country	Developments in improving indigenous coverage and data quality
Canada	<p data-bbox="316 324 635 347"><b>Census and post-census surveys</b></p> <p data-bbox="316 367 1342 472">Almost every household in northern areas and on Indian reserves was asked questions relating to aboriginality, cultural origin and registration/tribe in the 2006 census, but only approximately 20% of urban households were asked these questions. This under-identification of aboriginal people in the census affects the accuracy of all health indicators that use census counts as the denominator.</p> <p data-bbox="316 492 836 515">Two aboriginal post-census surveys are also undertaken:</p> <ul data-bbox="316 533 1342 651" style="list-style-type: none"> <li>• the Aboriginal Peoples Survey, which has been undertaken after the last three censuses, surveys off-reserve First Nations people, Métis and Inuit</li> <li>• the Aboriginal Children's survey of First Nation, Inuit and Métis children under the age of 6 years was conducted for the first time in 2006.</li> </ul> <p data-bbox="316 672 1342 694">The sample frames for both post-census surveys are derived from the census, so have the same coverage issues.</p> <p data-bbox="316 714 608 736"><b>Birth and death registrations</b></p> <p data-bbox="316 757 1342 837">Aboriginal status is not a required data item on birth or death registrations in Canada. First Nations-specific birth rates have been generated by cross linking birth data from four provinces with the Indian Register. These birth data do not include non-registered First Nations, Inuit or Métis births.</p> <p data-bbox="316 857 719 880"><b>Administration and surveillance systems</b></p> <p data-bbox="316 900 1342 949">Indigenous status is not usually captured in national health administration or surveillance systems, which means that morbidity rates cannot be accurately estimated.</p> <p data-bbox="316 969 464 992"><b>Health surveys</b></p> <p data-bbox="316 1012 1342 1144">Although some national health-related surveys, such as the Canadian Community Health Survey, ask questions on aboriginality, others do not. Such surveys generally also exclude people living on First Nations reserves and Crown lands and residents of certain remote regions. Some surveys, such as the National Population Health Survey include an aboriginal-specific component, which is administered in regions with high aboriginal populations.</p> <p data-bbox="316 1164 533 1187"><b>Recent developments</b></p> <p data-bbox="316 1207 1342 1283">Linkages between Statistics Canada and aboriginal groups are being developed to promote an aboriginal perspective in the development of census material. The formation of the First Nations Statistical Institute may also assist in ensuring that national information systems meet the needs of First Nations peoples.</p>

*(continued)*

**Table B6.1 (cont'd): Comparative overview of indigenous data**

Country	Developments in improving indigenous coverage and data quality
New Zealand	<p><b>Census and post-census surveys</b></p> <p>All households are asked to identify the ethnicity and Maori ancestry of every household member. Multiple ethnicities can be recorded. Strategies have been implemented to improve Maori acceptance and participation in the census. The enumeration of the Maori population in the census is improving. A post-enumeration survey following the 2006 Census estimated the Maori undercount to be 3.1%, whereas in 2001 it was estimated to be 4.4%.</p> <p><b>Birth and death registrations</b></p> <p>All births must be notified to the registrar by both the hospital and the parents. The coverage of Maori births improved significantly after the introduction of new birth registration forms in 1995 that collected self-identified ethnicity for both parents as well as the baby.</p> <p>Funeral directors fill in ethnicity and Maori ancestry on the Notification of Death for Registration form, based on information provided by the family or by observation. Multiple ethnicities can be recorded. The form is then forwarded to the registrars at Births, Deaths and Marriages.</p> <p>When calculating infant mortality, the birth and death records are linked and Maori status is assigned if either record has Maori status.</p> <p><b>Administration and surveillance systems</b></p> <p>In 2004 the Ministry of Health released the Ethnicity Data Protocols which specify procedures for the standardised collection, recording and output of ethnicity data for the health and disability sectors. Until improvements in ethnicity data collection are fully implemented the use of the 'ever Maori' method of ethnicity classification and adjusters are being used. The 'ever Maori' method involves linking all available data files, and if a person was ever recorded as Maori in any file, they are designated as Maori.</p> <p><b>Health surveys</b></p> <p>National surveys oversample the Maori population to ensure that rates for Maori can be accurately estimated.</p> <p><b>Recent developments</b></p> <p>Strategies to improve data quality include the following:</p> <ul style="list-style-type: none"><li>• provision of grants and scholarships to build Maori capacity</li><li>• standardising rates to the age distribution of the Maori population.</li></ul>

*(continued)*

**Table B6.1 (cont'd): Comparative overview of indigenous data**

Country	Developments in improving indigenous coverage and data quality
United States	<p data-bbox="316 327 635 353"><b>Census and post-census surveys</b></p> <p data-bbox="316 367 1347 416">All households were asked the race of every member of the household in the 2000 Census. Multiple races can be recorded.</p> <p data-bbox="316 439 608 465"><b>Birth and death registrations</b></p> <p data-bbox="316 479 1353 560">Birth certificates are generally completed in hospitals. The race of both parents is recorded, based on information provided by the mother. The United States has improved its birth data collection forms, to enable multiple races to be recorded for each parent.</p> <p data-bbox="316 573 1353 654">The death certificate is usually filled in by the funeral director, based on information provided by the family. Entry of multiple races is possible using the 2003 revision of the death certificate, but not all states have adopted the new certificate yet.</p> <p data-bbox="316 676 1358 779">The US Centers for Disease Control and Prevention (CDC) caution that the number of AI/AN deaths may be inaccurate because of problems in the correct identification of race on death certificates. The National Longitudinal Mortality Study found that almost 30% more persons were identified as AI in the Current Population Survey files than on the corresponding death certificates. Adjustment factors have been developed</p> <p data-bbox="316 792 1337 851">Infant mortality is calculated by linking birth and death certificates and assigning the race if it is missing on one of the certificates.</p> <p data-bbox="316 864 719 891"><b>Administration and surveillance systems</b></p> <p data-bbox="316 904 1342 963">Health administration and surveillance data collections are being required to progressively implement the same race classifications as used for the 2000 Census.</p> <p data-bbox="316 976 464 1003"><b>Health surveys</b></p> <p data-bbox="316 1016 1342 1075">National health-related surveys generally include a question on race, but sample sizes are generally too small to allow accurate estimates for AI/AN people.</p> <p data-bbox="316 1088 533 1115"><b>Recent developments</b></p> <p data-bbox="316 1128 1353 1267">Native American Research Centers for Health (NARCH) have been established. Their mission is to reduce the mistrust of research by tribal communities by conducting culturally appropriate research, increasing the capacity of American Indian/Alaska Native health researchers and students, and forming partnerships with academic institutions. The Indian Health Service's Tribal Epidemiology Program has been created in response to tribal requests to have timely and accurate data at a tribe-specific level.</p> <p data-bbox="316 1281 1358 1420">In response to the lack of data on the urban AI/AN populations, the Urban Indian Health Institute (UIHI) has been established. The UIHI provides centralised nationwide management of health surveillance and research regarding the health status deficiencies affecting urban American Indians and Alaska Natives. The UIHI works with the 34 Urban Indian Health Organisations funded by the Indian Health Service to help provide technical assistance, manage data, produce reports and raise awareness of the issues.</p> <p data-bbox="316 1433 464 1460"><b>Health surveys</b></p> <p data-bbox="316 1473 1321 1500">National surveys oversample the Maori population to ensure that rates for Maori can be accurately estimated.</p> <p data-bbox="316 1514 533 1541"><b>Recent developments</b></p> <p data-bbox="316 1554 831 1581">Strategies to improve data quality include the following:</p> <ul data-bbox="316 1594 954 1675" style="list-style-type: none"> <li>• provision of grants and scholarships to build Maori capacity</li> <li>• standardising rates to the age distribution of the Maori population.</li> </ul> <p data-bbox="316 1688 635 1715"><b>Census and post-census surveys</b></p> <p data-bbox="316 1729 1347 1787">All households were asked the race of every member of the household in the 2000 Census. Multiple races can be recorded.</p>

*(continued)*

**Table B6.1 (cont'd): Comparative overview of indigenous data**

Country	Developments in improving indigenous coverage and data quality
United States (cont'd)	<p><b>Birth and death registrations</b></p> <p>Birth certificates are generally completed in hospitals. The race of both parents is recorded, based on information provided by the mother. The United States has improved its birth data collection forms, to enable multiple races to be recorded for each parent.</p> <p>The death certificate is usually filled in by the funeral director, based on information provided by the family. Entry of multiple races is possible using the 2003 revision of the death certificate, but not all states have adopted the new certificate yet.</p> <p>The US Centers for Disease Control and Prevention (CDC) caution that the number of AI/AN deaths may be inaccurate because of problems in the correct identification of race on death certificates. The National Longitudinal Mortality Study found that almost 30% more persons were identified as AI in the Current Population Survey files than on the corresponding death certificates. Adjustment factors have been developed</p> <p>Infant mortality is calculated by linking birth and death certificates and assigning the race if it is missing on one of the certificates.</p> <p><b>Administration and surveillance systems</b></p> <p>Health administration and surveillance data collections are being required to progressively implement the same race classifications as used for the 2000 Census.</p> <p><b>Health surveys</b></p> <p>National health-related surveys generally include a question on race, but sample sizes are generally too small to allow accurate estimates for AI/AN people.</p> <p><b>Recent developments</b></p> <p>Native American Research Centers for Health (NARCH) have been established. Their mission is to reduce the mistrust of research by tribal communities by conducting culturally appropriate research, increasing the capacity of American Indian/Alaska Native health researchers and students, and forming partnerships with academic institutions. The Indian Health Service's Tribal Epidemiology Program has been created in response to tribal requests to have timely and accurate data at a tribe-specific level.</p> <p>In response to the lack of data on the urban AI/AN populations, the Urban Indian Health Institute (UIHI) has been established. The UIHI provides centralised nationwide management of health surveillance and research regarding the health status deficiencies affecting urban American Indians and Alaska Natives. The UIHI works with the 34 Urban Indian Health Organisations funded by the Indian Health Service to help provide technical assistance, manage data, produce reports and raise awareness of the issues.</p>

## Appendix 1: List of AIHW publications provided to meeting participants

### Publications released by the AIHW

The following is a list of publications released by the AIHW. These publications, along with other publications, can be purchased online. They can also be viewed online for free; see <<http://www.aihw.gov.au/publications/index.cfm>>.

- ▷ *Aboriginal and Torres Strait Islander people with coronary heart disease: further perspectives on health status and treatment* (full report)—(RRP \$30.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10266>>.
- ▷ *Aboriginal and Torres Strait Islander people with coronary heart disease: further perspectives on health status and treatment* (summary booklet)—(RRP \$13.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10364>>.
- ▷ *Australia's health 2006*—(RRP \$60.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10321>>.
- ▷ *Australia's welfare 2005*—(RRP \$55.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10186>>.
- ▷ *Diabetes hospitalisation in Australia 2003–04*—(RRP \$10.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10236>>.
- ▷ *Drug use among Aboriginal and Torres Strait Islander peoples*—(FREE)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10360>>.
- ▷ *Expenditures on health for Aboriginal and Torres Strait Islander peoples, 2001–02*—(RRP \$27.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10147>>.
- ▷ *Family violence among Aboriginal and Torres Strait Islander peoples*—(RRP \$28.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10372>>.
- ▷ *Improving the quality of Indigenous identification in hospital separations data*—(RRP \$28.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10222>>.
- ▷ *Indigenous housing indicators report 2003–04*—(RRP \$25.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10134>>.
- ▷ *International Group for Indigenous Health Measurement Vancouver 2005*—(FREE)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10391>>.
- ▷ *Indigenous housing needs 2005—a multi-measure needs report*—(RRP \$30.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10166>>.
- ▷ *National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data Strategic Plan 2006–8*—(FREE)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10373>>.

- ▷ *Recent developments in the collection of Aboriginal and Torres Strait Islander health and welfare statistics 2005* — (RRP \$25.00)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10251>>.
- ▷ *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2005* — (RRP \$65.00) <<http://www.aihw.gov.au/publications/index.cfm/title/10172>>.
- ▷ *Towards a national prisoner health information system* — (FREE)  
<<http://www.aihw.gov.au/publications/index.cfm/title/10367>>.

## ■ Abbreviations

ABS	Australian Bureau of Statistics
AI	American Indian
AIHW	Australian Institute of Health and Welfare
AN	Alaska Native
CDC	Centers for Disease Control and Prevention
NACCHO	National Aboriginal Community Controlled Health Organisation
NARCH	Native American Research Centers for Health
NZ	New Zealand
US	United States of America

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