International Group for Indigenous Health Measurement

Vancouver 2005

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better health and wellbeing for Australians through better health and welfare statistics and information.*

Please note that as with all statistical reports there is the potential for minor revisions of data in *International Group for Indigenous Health Measurement, Vancouver 2005* over its life. Please refer to the online version at <www.aihw.gov.au>.

A complete list of the Institute's publications is available from the Institute's website <www.aihw.gov.au>.

Suggested citation

Australian Institute of Health and Welfare (AIHW) 2006. International Group for Indigenous Health Measurement, Vancouver 2005. Cat. no. IHW 18. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair
Hon. Peter Collins, AM, QC

Director
Penny Allbon

Any enquiries about or comments on this publication should be directed to:

Dr Fadwa Al-Yaman
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1146

Published by Australian Institute of Health and Welfare

Printed by Union Offset Printers

Contents

Foreword

It is with great pleasure that I am able to present a report of the first meeting of the International Group for Indigenous Health Measurement. This report provides valuable historical context on the formation and early development of this initiative, which culminated in the gathering of dedicated participants from Australia, Canada, the United States and New Zealand in Vancouver during October 2005. The initiative represents a good example of how an international collaboration can be organised among geographically and culturally diverse Indigenous groups, governments and academic organisationsw, with the common goal of working together to better understand the issues that surround measuring Indigenous health.

We would like to acknowledge the valuable work of the participants who presented on a variety of issues throughout the meeting, including topics that explored the paradigms of colonialisation, issues of methodological development and the sharing of best practices, to name just a few. The material presented at the meeting resulting from the international collaboration on indicators for the measurement of Indigenous health in Australia, Canada, the United States and New Zealand illustrates the clear need for the development and implementation of culturally relevant indicators with the involvement of Indigenous community throughout the process.

This meeting also provided an opportunity to formally establish the International Group for Indigenous Health Measurement (Measurement Group). In addition, the meeting stimulated reflection on past and current work in the area of data and health measurement, while allowing for the long-term strategic planning of the Measurement Group. This included addressing issues surrounding the sustainability of the group, as well as the development and prioritisation of future key activities.

This report, and future endeavours of the Measurement Group, will not only serve to highlight existing health status issues amongst Indigenous groups, but it will also drive the need to improve data for the measurement and advancement of Indigenous health status internationally.

We would like to take the opportunity to thank all those who contributed to this report.

F. Sam Notzon, PhD, Convenor
Director, International Statistics Program
National Centre for Health Statistics
United States of America

Acknowledgments

Abbreviations

AI/AN	American Indians/Alaskan Natives
AIHW	Australian Institute of Health and Welfare
CDC	Centres for Disease Control and Prevention
INIHKD	International Network for Indigenous Health Knowledge and Development
NACCHO	National Aboriginal Community Controlled Health Organisation
WHO	World Health Organization

1 | Introduction

Second Forum of the International Network for Indigenous Health Knowledge and Development

The International Network for Indigenous Health Knowledge and Development (INIHKD) is an international assembly dedicated to improving the health of Indigenous peoples in Australia, New Zealand, Canada and the United States through Indigenous and community-led research, health services and workforce development.

Following the first inaugural Forum of the INIHKD held in Australia in October 2003, the second biennial meeting was held in Vancouver, Canada in October 2005. The meeting brought together people from many diverse backgrounds, such as researchers, community health providers and Aboriginal organisations, as well as from government.

The University of British Columbia's First Nations Longhouse was the setting for the forum. The Longhouse is a unique building that reflects the architectural traditions of the North-west Coast. The building, constructed of West Coast red cedar logs, was awarded the 1994 Canadian Governor-General's Award for Architecture. The Great Hall in the Longhouse is named 'Sty-Wet-Tan' in Hun'q'umin'um, meaning 'spirit of the west wind', which welcomes people from the four directions. Indeed, people did travel from all four directions to attend the INIHKD/ International Group for Indigenous Health Measurement assembly, with the goal of improving the health of Indigenous peoples in Australia, New Zealand, Canada and the United States.

Inaugural meeting of the International Group for Indigenous Health Measurement

The International Group for Indigenous Health Measurement (Measurement Group) grew out of discussions between health data professionals in the United States and Australia in 2004. The concept grew, and the circle of interested parties widened, during the following year through a series of conference calls. The inaugural meeting of the Measurement Group was attended by representatives of four countries—Australia, Canada, New Zealand and the United States. The Group's focus is on facilitating meaningful comparisons, exchange, mutual learning and collaborative projects in the area of Indigenous health measurement between countries, with the ultimate aim of improving Indigenous health and wellbeing.

The first meeting of the Measurement Group was held in conjunction with the 2005 INIHKD meeting. The Measurement Group organised three sessions within the INIHKD meeting, followed by a special purpose 2-day meeting of Measurement Group members. This 2-day meeting included a day of presentations and group discussion, followed by a day of discussion about the future functioning and organisation of the Group.

Participants in the Measurement Group meeting included representatives from government, university and Indigenous organisations, all with an interest in improving the collection, analysis, dissemination and use of health information for Indigenous populations.

This document summarises the first meeting of the Group, and the agreements regarding its future activities.

2 | Why an international meeting on measuring the health status of Indigenous populations?

This chapter consists of a concept document that was prepared prior to the Vancouver meeting by the Measurement Group Planning Committee. The Planning Committee used this document to generate interest in the Measurement Group among health researchers, academics, Indigenous organisations and health and statistical government agencies in Australia, Canada, New Zealand and the United States. The text of the original document has undergone some minor amendments for the purposes of this publication.

There are important and well-known health disparities between the Indigenous and non-Indigenous populations of the United States (Denney et al. 2005, Young 1997), but similar, or even greater, differences exist in other countries. Recent reports document significantly poorer health outcomes for Indigenous peoples in Australia (Ring & Brown 2002, ABS & AIHW 2005), New Zealand (Ajwani et al. 2003), and Canada (Health Canada 2003). In all of these countries, there is an urgent need to address differentials in health outcomes for Indigenous populations through a variety of programs addressing access to care, prevention programs and other approaches. An important part of any health improvement program will be the measurement of health disparities for these Indigenous groups, and tracking the progress of such programs over time in reducing disparities. The measurement of health status in Indigenous populations has been problematic in all countries, however, owing largely to problems in correctly identifying the Indigenous identity of individuals on administrative records, such as hospital registries and death registration forms. In order to improve the measurement of health status in Indigenous populations, an international conference was held on this topic to review existing health disparities across countries, consider improvements in measurement methodologies and establish an international interest group. This group was named the International Group for Indigenous Health Measurement, hereafter referred to as the Measurement Group.

2.1 Background

As noted above, the measurement of health disparities between Indigenous and non-Indigenous peoples is complicated by deficiencies in the data used. For mortality data, this reporting problem means that an unknown proportion of Indigenous deaths are incorrectly classified as non-Indigenous. Owing to the small size of the Indigenous population, the effect of this misclassification is a minor increase in the reported death rate of the non-Indigenous population, but a substantial reduction in the reported Indigenous death rate. This misclassification can vary over time and across areas, so that mortality comparisons over time or space—even comparisons limited to Indigenous populations— should be made with caution.

Notwithstanding these limitations, the magnitude of health disparities in Indigenous populations in certain countries is striking; perhaps equally important is the absence of reductions, or even increases in these disparities, in recent years. In Australia, Indigenous life expectancy is estimated to be 17 years lower than for the non-Indigenous population (ABS & AIHW 2005). Some reductions in Indigenous death rates have occurred in certain areas of Australia, but similar reductions in mortality for the non-Indigenous population have probably maintained the disparity in death rates. Major disparities in death rates exist for treatable and preventable conditions including diabetes, respiratory diseases, circulatory conditions and injury (ABS & AIHW 2005, Ring & Brown 2002). In New Zealand, recent improvements in the identification of Indigenous individuals have resulted in a major deterioration in the gap in life expectancy between the Maori and the non-Indigenous population (Young 1997). For males, this gap in life expectancy grew from 6.3 years in the early 1980s to 9.9 years by the late 1990s. The increasing disparity in life expectancy is largely due to stagnating or increasing death rates among the Maori for certain chronic diseases, including cardiovascular diseases and cancer. The US Indian Health Service (IHS) estimates that life expectancy for American Indians and Alaska Natives residing in the IHS service area was 5.4 years less than for the US white population in the mid-1990s (Paisano 2002). Major disparities in death rates for the Indigenous population were reported for diabetes, accidents, suicide, pneumonia and influenza, and homicide. In 2002, the life expectancy gap between First Nations and the general population in Canada was 6.4 years (Indian and Northern Affairs Canada 2002). Estimates for Canada's Inuit suggest that an even larger gap in life expectancy exists for this population. First Nations and Inuit in Canada bear a larger burden of disease than the general population, with significant disparities in health status and the prevalence of chronic diseases, such as circulatory disease, cancer and diabetes. Higher rates of suicide and injuries also exist in First Nation and Inuit communities and are the leading causes of death in these populations (Health Canada 2003).

Health authorities and others have used a variety of methods to highlight the health disparities of Indigenous populations. For example, in the United States the reduction of health disparities for the Native American population and other minority groups is one of the primary objectives of the Healthy People 2010 Program (US Department of Health and Human Services 2000).

National health research bodies in all four countries promote the development of research and knowledge on Indigenous health issues. Internationally, increasing levels of cooperation between the four countries and their institutions are beginning to address the similarities between each country's health outcomes. In 2002, the Canadian Institutes of Health Research (CIHR), the National Health and Medical Research Council of Australia (NHMRC) and the Health Research Council of New Zealand (HRC) agreed to undertake a trilateral collaboration to support research in the area of Indigenous peoples' health, with the goal of improving the health of Indigenous peoples in these three countries. Through this innovative agreement, Canada, Australia and New Zealand will use both existing knowledge and new research to address the disparities between the health of Indigenous peoples and the health of the general population. A memorandum of understanding between the Department of Health and Human Services in the United States and Health Canada signed in 2002 focuses on improving health-care delivery and access to the Indigenous populations of those two countries. Sharing knowledge and expertise between the two governments' departments enhances efforts to raise the health status of Indigenous peoples in Canada and the United States (US Department of Health and Human Services 2000).

2.2 Structure of the international meeting

In order to further document the poor health status of Indigenous populations, health authorities from Australia, Canada, New Zealand and the United States held an international conference on measuring the health status of Indigenous populations. A stated objective of the meeting was to establish the Measurement Group—an international group dedicated to the measurement of Indigenous health status. The precise measurement of Indigenous health status is important not only for the statistical community but also for the general health community, as accurate information on health status is required to identify the specific health needs of the Indigenous population and to determine the success of health improvement programs. The focus on measurement is timely because a number of methodological issues currently exist that make the measurement of Indigenous health outcomes in any country particularly challenging.

The 2-day Measurement Group meeting took place in Vancouver in October, 2005, in collaboration with the second biennial meeting of the INIHKD. Several sessions originally planned for the Measurement Group meeting were instead held within the INIHKD meeting, a sign of the importance of measurement issues for all Indigenous interest groups and the convergence of interests of the Measurement Group and the INIHKD. The Measurement Group meeting was divided into sessions on health status and measurement by country, data standards, useful and relevant health measures, and community capacity building. The last day of the meeting focused on plans for the creation of the Measurement Group. The meeting provided a useful forum for sharing information across the participating countries, as well as a discussion of important statistical issues such as improving the collection of Indigenous population and health information from sources including the census, vital statistics, hospital and clinic registries.

The establishment of the Measurement Group is particularly important to ensure that continued international attention is focused on improving data for the measurement of Indigenous health status. This group promotes the sharing across countries of new techniques for the measurement of health status for Indigenous populations; it also promotes the development of international partnerships for the development of new methodologies. Discussion of the Measurement Group at the Vancouver meeting included the identification of key members of the group, selection of initial research topics for the group, plans for regular meetings to share research findings and consideration of funding for future meetings of the group.

2.3 Participation

Because one of the central aims of the Measurement Group is to convince national statistical agencies to improve the quality and depth of health-data collection for Indigenous populations, it is important to include representatives of these statistical agencies within the Measurement Group. However, a crucial part of any activity involving Indigenous peoples is active participation by representatives of Indigenous groups. Such participation will be ensured by the active solicitation of Indigenous participants from key Indigenous groups in all four countries, including Indigenous experts from statistical agencies, universities and interest groups, and by the integration of the Measurement Group meeting with the INIHKD meeting.

In order to facilitate the development of the Measurement Group, the first meeting was limited to Australia, Canada, New Zealand and the USA—four countries with a common language, good statistical systems and a long history of collaboration. Now that the Measurement Group is established, however, it will be possible to consider adding other countries that have Indigenous populations and well-developed statistical systems.

2.4 Organisations involved in planning the meeting

The following organisations were involved in the planning for the first meeting of the International Group for Indigenous Health Measurement:

Australia

Australian Institute for Health and Welfare
Office of Aboriginal and Torres Strait Island Health, Department of Health and Ageing
Australian Bureau of Statistics
National Aboriginal Community Controlled Health Organisation

Canada

Health Canada
Canadian Institutes of Health Research–Institute of Aboriginal Peoples Health
Statistics Canada
National Aboriginal Health Organization

New Zealand

Ministry of Health
Statistics New Zealand

USA

Centers for Disease Control and Prevention
Indian Health Service

3 | Agenda for the first meeting

Saturday 1 October 2006

Session 1: Health information for health services

Aboriginal and Torres Strait Islander Health Information in Australia
Debra Reid

Counting Indigenous people – the Canadian context
Lorne Clearsky

Using data for Maori health services research in New Zealand
Linda Smith

Improving cancer incidence data through data linkages
David Espey and Tom Becker

Sunday 2 October 2006

Session 2: Health information for health services development

(Concurrent session with INIHKD)

Session 3: Health workforce information

Indigenous health workforce development in Canada
Bernice Downey

Developing the Māori health workforce—data issues
Paula Searle

Health information for the development of the American Indian and Alaskna Native health workforce
Cheryl Mason

Workforce issues in Aboriginal community controlled health services
Dea Delaney-Thiele

Session 4: Health information for Indigenous health workforce development

(Concurrent session with INIHKD)

Session 5: Health information and health research

Māori health research capacity development
Rachel Brown

'"Gimme" data and nobody gets hurt': native communities and the need for data
Jennie Joe

Western Australian Aboriginal Child Health Survey
Ted Wilkes

A national Canadian cohort study of Aboriginal children's health
Jeff Reading

Session 6: Health information and health research development

(Concurrent session with INIHKD)

Monday 3 October 2006

Session 7: International health comparisons of the Indigenous peoples

Ian Ring, Jacinta Elston

Session 8: Keynote address—International Indigenous health enumeration

Ian Anderson

Session 9: Panel discussion—International Indigenous health enumeration

Moderator: Jeff Reading
Panel Members: Michelle Chino, Jane Gray, Joanne Baxter

Tuesday 4 October 2006—Methods

Session 10: Data measurement

Disparities in Australian health: issues in measuring the health of Australia's Indigenous peoples
Fadwa Al-Yaman

Indigenous health measurement—Canada
Janet Smylie

Measurement issues—Maori health
Paula Searle

Health population data and its role as a mediating variable between race/ethnicity and health disparities: A case study examining off-island Native Hawaiians and off-reservation American Indians
Maile Taualii

Session 11: Data utility

Common standards in Canadian aboriginal health data?
Chris Penney

Setting the standards
Bridget Robson

Quality of race and Hispanic reporting on death certificates in the US: special focus on the American Indian population
Elizabeth Arias

Data standards for the Aboriginal population of Australia
Lisa Jackson-Pulver

Session 12: Health measures that are useful and relevant to Indigenous communities

Community level health measurement and Indigenous communities
Steve Larkin

Measures of particular relevance for Indigenous peoples—reflections
Joanne Baxter

The wellbeing of First Nation communities
Sacha Senécal

Historical trauma, microaggressions, and colonial trauma response: Indigenous concepts in search of a measure
Karina Walters

Session 13: Indigenous Community Capacity Building

Enabling tribal information and data sharing across systems
Ada Melton

Indigenous community capacity building: health information systems
Dea Delaney-Thiele

Action-oriented indicators of health systems development for Indigenous peoples in Canada, Australia, and New Zealand
Janet Smylie

Māori-driven health information systems
Cathrine Waetford

Wednesday 5 October 2006—Creating an international interest group

Session 14: Organisational Issues

Facilitators: Sam Notzon and Jacinta Elston

Purpose, goals and expectations: discussion groups

1. Organisation
   (a) Principles and governance issues—leadership
   (b) Formation of organising structure
   (c) Types of agencies to include in group
       (i) Government agencies
       (ii) Community groups

2. Identification of topics of interest
   Specify short list of topics relevant to measuring health of Indigenous populations arising from methodological session the previous day or ensuing discussions

3. Activities/communication
   (a) Frequency and location of meetings
   (b) Modes of communication: email, bulletin board
   (c) Publications: proceedings of meetings, others, who will publish

4. Knowledge transmission/translation
   Transferring information to other countries, Indigenous communities, etc.

5. Links with other groups
   (a) International Indigenous Network
   (b) World Health Organisation (WHO), International Statistics Institute, United Nations

6. Funding

Session 15: Summary and Conclusions

Facilitators: Sam Notzon and Jacinta Elston

Summary of group discussions and development of next steps—action plan

4 | Future organisation of the Measurement Group

In the final sessions of its first meeting, the Measurement Group considered a number of topics including the founding principles, governance issues, topics of interest for collaboration, an action plan, links with other groups, and other concerns. The following paragraphs summarise the discussion.

4.1 Purpose

There was considerable discussion about how best to express the purpose of the Measurement Group. A broad consensus was reached on the following statements:

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.

A key related purpose identified by the Measurement Group was to develop a statement about the roles to be played by stakeholders, especially statistical agencies, in enhancing information about Indigenous health. Such a statement will be developed in the lead-up to future meetings of the Group, with a view to achieving agreement among all participant countries.

It was agreed that the work of the Group could proceed on the basis of these consensus statements.

4.2 Principles

It was agreed that a number of principles should govern the development and operation of the Group. The most important of these are:

- The right of Indigenous people to be counted (Indigenous people should not be invisible in national health statistics)
- Indigenous leadership and participation
- Principled partnerships with communities and governments
- Government responsibility and accountability
- Activities should be transformative—data collection, analysis and dissemination should be linked to improvements in health
- Activities should build the capacity of Indigenous peoples to assemble, analyse and use health data.

4.3 Governance

It was agreed that the Measurement Group should serve as a facilitator, broker and information provider to its members and to others interested in improving the health of Indigenous peoples. The Group should ensure transparency in all its activities. Key aspects of governance include the following:

- There should be an International Steering Committee, with representatives from all four countries, drawn from the following groups:
  - statistical experts, Indigenous where possible
  - Indigenous communities
  - government agencies
- The link with INIHKD should be maintained.

4.4 Research topics

The participants discussed a number of possible research topics for the Measurement Group to pursue over the next two years. The purpose of these research activities was to provide insight to national policies and programs, both through research findings in each country and through international comparisons. The focus was on practical outcomes that would lead to improvements in the health and wellbeing of Indigenous communities.

Participants outlined a number of principles that the research program should follow, including:

- the need to involve community members as well as governments in these activities
- the need to build data skills within the communities
- the recognition that collaboration should be both across countries and within countries (national level, province/state level and community level)
- the need to share the results of these projects across countries
- the need to serve as a broker of research results that can inform national decision-making.

The list of research topics proposed by the Group included the following:

- **Stocktake**
  - What information is available regarding Indigenous health data in each country, what do we need, what will it take?
- **Historical analyses of Indigenous data in each country**
  - Issues of counting Indigenous people
  - History of counting
  - Role of Indigenous people and organisations in contributing to statistical agencies.
- **Indicator harmonisation**
  - Describe/create inventory of what is collected
  - Describe collection system that underlies indicators
  - Develop international standards for indicators of health and wellbeing.
- **Feasibility study for a national longitudinal survey of Indigenous children**

4.5 Communication

It was agreed that it was essential to continue monthly teleconferences, and, as has been the case, the teleconference should be attended by representatives of the International Steering Committee of INIHKD. This regular communication will be supplemented by email as needed, along with information posted on a bulletin board/website. Face-to-face meetings should be held once or twice a year, and the Measurement Group should be a regular part of future biennial meetings of the INIHKD.

4.5 Links with other groups

It was agreed that the Measurement Group should maintain strong links with the INIHKD. The Group should also explore the possibility of links to the UN working group on Indigenous data collection, and should invite a WHO representative to the next meeting of the Measurement Group. Links to other international groups should be considered as well.

4.6 Funding

The funding needs for the Measurement Group are small, at least for the present, as they need cover only the cost of monthly teleconferences, travel to meetings, and contributed staff time. It was agreed that each country should self-finance their participation in the Group. In the future, members will look for government/foundation funds to support the cost of a secretariat.

5 | Draft terms of reference for the Measurement Group

Following the Vancouver conference, members of the Group agreed that they should develop a draft set of terms of reference, with a view to their being endorsed at the meeting in late 2006. The latest version, at the time of writing, is as follows:

Vision

The right to count and be counted

Mission

To improve, internationally, the quality, depth and utility of health knowledge and data for Indigenous populations.

Goals

1. Collaborate across countries.
   (a) To work collaboratively with Indigenous and government agencies and groups to ensure that knowledge is useful and meaningful for Indigenous lives and communities
   (b) To facilitate dialogue on issues of Indigenous measurement across countries
   (c) To be sensitive to each country's perspectives.

2. Develop and promote improved methods.
   (a) To promote the use of improved methods for collection, analysis, interpretation, and dissemination of information useful for improving the health of Indigenous populations
   (b) To develop meaningful comparisons, meaningful exchanges, mutual learning, and collaborative projects that can inform policy development, locally and globally.

3. Inform policy.
   (a) To inform national statistical agencies on ways to improve the collection of Indigenous health data and transform current Indigenous health knowledge and data.

Membership

1. Countries with Indigenous populations and well developed statistical systems.

    Initial members are:

    (a) Australia

    (b) Canada

    (c) New Zealand

    (d) United States.

It is envisaged that additional countries may join the Measurement Group in the future.

2. Representation from each country should include:

    (a) Indigenous statistical and health experts, decision-makers, researchers, health professionals

    (b) representatives of national and world health and statistical agencies and statistical experts

    (c) other persons identified as contributing to Indigenous health measurement.

3. Maintain strong linkage to INIHKD.

6 | Forthcoming activities of the Measurement Group

It was agreed that the Measurement Group should undertake the following activities during the next couple of years:

- Publish a report of the first meeting of the Measurement Group, as a background document to a meeting in 2006.

- Hold a second meeting in the Southern Hemisphere during 2006. The goals of this meeting would be to:

  - review the four national stocktakes of information about Indigenous health and the four historical analyses

  - facilitate discussion between key stakeholders in information about Indigenous health—namely, Indigenous community leaders, policy agencies and statistical agencies—to work toward a common statement about what is needed to deliver better information and better health outcomes, and to define the roles that each stakeholder should play.

- Hold a third meeting in Hawaii during 2007.

Appendix 1 | Participants in the first meeting

Australia

Fadwa Al-Yaman
Head, Aboriginal and Torres Strait Islander Health and Welfare Unit,
Australian Institute of Health and Welfare

Ian Anderson
Director, Centre for the Study of Health and Society
Research Director, Cooperative Research Centre for Aboriginal Health
University of Melbourne

Jacinta Elston
Professor of Public Health, Faculty of Medicine, Health and Molecular Sciences,
James Cook University

Traven Lea
National Manager, Aboriginal and Torres Strait Islander Program,
National Heart Foundation

Lisa Jackson-Pulver
Senior Lecturer (Research and Development)
Muru Marri Indigenous Health Unit
School of Public Health and Community Medicine, Faculty of Medicine
University of New South Wales

Steve Larkin
Principal, Australian Institute of Aboriginal and Torres Strait Islander Studies

Richard Madden
Director, Australian Institute of Health and Welfare

Debra Reid
Director, Office for Aboriginal and Torres Strait Islander Health (Tasmania State Office)
Department of Health and Ageing

Ian Ring
Professorial Fellow, Centre for Health Services Development
University of Wollongong

Dea Delaney-Thiele
Chief Executive Officer
National Aboriginal Community Controlled Health Organisation

Andrew Webster
Assistant Director
National Centre for Aboriginal and Torres Strait Islander Statistics
Australian Bureau of Statistics

Ted Wilkes
Founding Chair, Kulunga Research Network,
Telethon Institute for Child Health Research
Professorial Fellow in Aboriginal Health,
Curtin University of Technology

Canada

Lorne Clearsky, MD
Deputy Medical Officer of Health
Calgary Health Region

Laura Commanda
Institute of Aboriginal Peoples' Health
Canadian Institutes of Health Research

Dr Rene Dion
Manager, Indicator Development
Health Information and Analysis
First Nations and Inuit Health Branch
Health Canada

Bernice Downey
Chief Executive Officer
National Aboriginal Health Organization

Jane Gray
FNRLHS National Coordinator
First Nations Centre

Andrew Kmetic
Faculty of Human and Social Development
University of Victoria

Malcolm King, PhD
Principal Investigator
Alberta ACADRE Network

Barry Lavallee, MD
Senior Physician
Aboriginal Health and Wellness Centre of Winnipeg

Earl Nowgesic, BScN, RN, MHSc
Assistant Director
Institute of Aboriginal Peoples' Health
Canadian Institutes of Health Research
University of Victoria

Chris Penney
Policy Analyst
Health Information and Analysis Division
First Nations and Inuit Health Branch
Health Canada

Jeff Reading, MSc, PhD
Scientific Director
Institute of Aboriginal Peoples' Health
Canadian Institutes of Health Research
University of Victoria

Dr Janet Smylie, MD MPH CCFP
Director, Indigenous Peoples Health Research Centre
Associate Professor, Department of Community Health and Epidemiology
University of Saskatchewan

Sacha Senécal, PhD
Research Manager
Strategic Research and Analysis Directorate
Indian and Northern Affairs Canada

Dr Chandrani Wijayasinghe
Regional Epidemiologist, Alberta Region
Data Analysis Unit, First Nations and Inuit Health Branch
Health Canada

New Zealand

Joanne Baxter
Senior Lecturer
Department of Preventive and Social Medicine
University of Otago

Dale Bramley, MD
Manager, Greenlane Hospital
Auckland District Health Board

Rachel Brown
Māori Health Research Centre
Auckland University of Technology

Fiona Cram, MD
Katoa Limited

Sue Crengle, MD
Head of Discipline
Department of Maori and Pacific Health
University of Auckland

Bridget Robson
Eru Pōmare Research Centre
Wellington School of Medicine and Health Sciences

Paula Searle
Manager, Strategic Projects
Māori Health Directorate
Ministry of Health

Linda Tuhiwai Smith, MD
Joint Director, Nga Pae o te Maramatanga (Horizons of Insight)
National Institute of Research Excellence in Maori Development and Advancement
University of Auckland

Cathrine Waetford
Māori Health Research Centre
Auckland University of Technology

USA

Elizabeth Arias, PhD
Mortality Statistics Branch, Division of Vital Statistics
National Center for Health Statistics

Ralph Bryan, MD
Senior Tribal Liaison for Science
Office of Minority Health, Office of the Director, CDC

Michelle Chino, PhD
Associate Professor/Director
Center for Health Disparities Research
American Indian Research and Education Center
University of Nevada Las Vegas School of Public Health

David Espy, MD
Epidemiologist, CDC Division of Cancer Prevention and Control

Howard Goldberg, PhD
Assistant Director for Global Health
Division of Reproductive Health, NCCDPHP

Jennie Joe, PhD, MPH
Professor of Family and Community Medicine
Director, Native American Research and Training Center
University of Arizona USA

Dr Zeenat Mahal
Director, Epidemiology Center
Inter Tribal Council of Arizona, Inc.

Cheryl L. Mason, MPH
Epidemiologist and Acting Director
Navajo Division of Health

Ada Melton
President, American Indian Development Associates

Leo Nolan
Senior Policy Analyst
Indian Health Service

F. Sam Notzon, PhD
Director, International Statistics Program
National Center for Health Statistics

Edna Paisano
Director, Division of Program Statistics/OPHS
Indian Health Service

Maile Taualii, MPH
Seattle Indian Health Board

Teshia G. Arambula Solomon, PhD
Director, Epidemiology Center
Oklahoma City Area Inter-Tribal Health Board

Mark A. Veazie, DrPH, MPH
Epidemiologist
Native American Cardiology Program
Indian Health Service
US Department of Health and Human Services
Adjunct Professor, College of Health Professions, Northern Arizona University
Adjunct Professor, College of Public Health, University of Arizona

Karina Walters, MSW, PhD
Associate Professor
School of Social Work
University of Washington

Appendix 2 | Abstracts

Session 1: Health information for health services

Aboriginal and Torres Strait Islander health information in Australia

Ms Debra Reid

This paper seeks to provide an overview of information relating to Aboriginal and Torres Strait Islander health information.

While Australians in general are one of the healthiest populations of any developed country, Indigenous Australians are generally the least healthy of all Indigenous populations within comparable developed countries (NATSIHC 2003). The life expectancy of Indigenous Australians is around 17 years less than for non-Indigenous Australians, and all-causes death rates 2.7 times as high. The leading causes of death for both Indigenous and non-Indigenous Australians are similar; however, deaths occur at much higher rates for Indigenous Australians for nearly all causes. This includes higher death rates for Indigenous Australians due to circulatory diseases, diseases of the respiratory system, endocrine diseases and injury (ABS & AIHW 2005).

The aim of the National Strategic Framework for Aboriginal and Torres Strait Islander Health (NSFATSIH), endorsed by all Australian Health Ministers in July 2003 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 NSFATSIH recognises that health system interventions are only one lever in a whole-of-government approach that is needed to address Indigenous health disadvantage. The NSFATSIH acknowledges that 'concerted action both across and beyond the health sector to address the complex and interrelated factors that contribute to the causes and persistence of health problems amongst Aboriginal and Torres Strait Islander people' is needed.

The data for measuring improvements against our new national policy for Aboriginal and Torres Strait Islander people will come from national administrative datasets and the Australian Bureau of Statistics national survey program. A key to gaining sound information is ensuring that people are asked if they are of Aboriginal and Torres Strait Islander origin. There are problems with Aboriginal and Torres Strait Islander identification processes; however, these issues are known and Australia is working at national, state/territory and local level to resolve these issues.

Counting Indigenous people—the Canadian context

Dr Lorne Clearsky

(abstract not available)

Using data for Maori health services research in New Zealand

Linda Smith

(abstract not available)

Data linkages to improve cancer surveillance for American Indians and Alaskan Natives

David Espey

Past linkages between the Indian Health Service (IHS) data and a subset of central registries supported by the National Cancer Institutes (NCI) and the Centers for Disease Control and Prevention (CDC) revealed substantial racial misclassification in American Indians and Alaska Natives (AI/AN). The objectives are: 1. to expand linkages to all central cancer registries in the US and 2. to include AI/AN data for the first time in United States Cancer Statistics. We used LinkPlus, a probabilistic linkage software developed by CDC, to link records from 55 central cancer registries with IHS administrative records dating from 1985 through 2004. Linkages for NCI registries included cases from 1988–2002 and those for CDC from 1995–2002. To date, 55 registries have been linked and we have identified 7,220 AI/AN that had been misclassified as non-Native in 44 CDC-supported registries and 2,872 AI/AN that had been misclassified as non-Native in 15 NCI-supported registries. We increased the total number of AI/AN in 59 central cancer registries by 23% (range 1.3% to 72.0%). Through data linkages, we have identified substantial racial misclassification in AI/ANS in central cancer registries allowing the most accurate description of the AI/AN cancer incidence to date. Such linkages should be performed routinely in central cancer registries to maintain optimal data quality for AI/ANs.

Session 3: Health workforce information

Indigenous health workforce development in Canada

Bernice Downey

(abstract not available)

Developing the Māori health workforce—data issues

Paula Searle

Challenges exist in monitoring the Māori health workforce in New Zealand, particularly around methods, data collection, analysis and reporting. Monitoring the current Māori health workforce is recognised as an important component of He Korowai Oranga, the Māori Health Strategy (Ministry of Health 2002). The topic workforce development is vast so this paper focuses on the Māori health workforce in registered health occupations. The Ministry of Health is the lead agency for monitoring the number of Māori in registered health occupations and the

New Zealand Health Information Service (NZHIS) within the Ministry undertakes this activity. An overview will be provided on Māori numbers in the registered health occupations. The development of Raranga Tupuake, the Māori Health Workforce Plan led by the Ministry will be briefly described. The plan provides the platform for Māori health workforce development over the next 10–15 years. Lastly, key issues for monitoring the Māori health workforce will be examined around utilising the data available to a greater extent and the large gaps in information about Māori working in unregistered health occupations.

Health information for the development of the American Indian and Alaskan Native health workforce

Cheryl Mason

The objective of this paper is to identify the role of health information in the development of the American Indian and Alaska Native (AI/AN) health workforce and, in future, assessments of health workforce needs and health services planning for AI/AN communities. A review of existing data on the AI/AN health workforce was conducted. Data included information from the Indian Health Service, the National Center for Health Workforce, the Association of Schools of Public Health, and a tribal health program. Anecdotal data were collected from a tribal health program director who oversees a community health representative program.

During the last 20 years, the number of AI/AN members of the medical and public health workforce serving the AI/AN population has grown. Both formally trained and informally trained health-care workers meet at the frontlines to address health disparities in areas such as diabetes, cardiovascular disease, injuries, violence, and drug and alcohol-related problems. Despite the increase in this workforce, two challenges exist: 1. how can we better equip AI/AN medical and public health workers already on the frontlines, which tend to be rural and lack adequate funding and 2. how do we encourage young AI/AN people to enter the health workforce? One way to better equip the existing AI/AN workforce is to establish a steady stream of easily comprehensible information regarding risk and protective factors in their communities, which encompasses cultural, linguistic and socioeconomic factors unique to their communities. On a greater scale, local and routine assessments on the quality and the quantity of the AI/AN health workforce would enable health planners to identify needs and priorities for health career promotion and recruitment to ensure a greater proportion of AI/AN health professionals.

Although the AI/AN health workforce in the US has grown in the last 20 years, consideration of the current and future workforce may contribute to the overall quality of the AI/AN health workforce and, thus, the vital role of health information in meeting the challenges in AI/AN health.

Workforce issues in Aboriginal community controlled health services

Dea Delaney-Thiele

This presentation will discuss the role of the national peak body in Aboriginal health (NACCHO) in influencing and directing national policy decisions regarding workforce development in Aboriginal Community Controlled Health Services (ACCHS).

The presentation will begin with an overview of the Aboriginal and Torres Strait Islander Health Workforce Strategic Framework (May 2002). This will be compared with the priorities set by the NACCHO Board in the NACCHO Business Plan 2003–2005.

The role of the state and territory Workforce Implementation Policy Officers (WIPO) will be explored in conjunction with the implementation strategies for the Aboriginal and Torres Strait Islander Health Workforce Strategic Framework.

NACCHO has been closely involved in the review and development of national Aboriginal Health Worker (AHW) competencies. These competencies will be close to completion at the time of the conference and the presenter will be able to give an overview of the structure and key changes of the new competencies. The professionalisation of the role of the AHW will also be explored.

The recent development of a support network for ACCHS who are Registered Training Organisations (RTO) delivering AHW training will be explained. The role of these RTOs as an integral part of the training and professional development for AHWs will be explored with a specific focus on rural and remote locations. The future potential for these organisations to broaden their scope of training delivery to encompass management and administration training will also be examined.

The role of governments with respect to capacity building in Aboriginal communities to ensure that ACCHS have the resources and skills to effectively manage their organisations will be explored. The Australian Government has traditionally focused on the governance needs of ACCHS once they are in some level of operational or financial difficulty. NACCHO has advocated for a proactive approach that builds the capacity within ACCHS to monitor and regulate their own business effectively. It is a multifaceted inter-sectoral approach that requires commitment from governments to ensure sustainability. This approach will be outlined.

Session 5: Health information and health research

Māori health research capacity development

Rachel Brown

In recent years there have been major gains in Māori health research capacity in New Zealand as measured by Māori-specific methodological development, the size and quality of the Māori health research workforce, the number of Māori health research centres, the level of resources directed to Māori-specific research, and the standard of Māori health research evidence available to inform strategies and activities to improve Māori health. Despite these gains, there is, however, some way to go in terms of achieving optimal Māori health research capacity. This paper reviews factors that have contributed to capacity gains, as well as barriers, and identifies key characteristics of Māori health research capacity building in Aotearoa.

'"Gimme" data and nobody gets hurt': native communities and the need for data

Jennie Joe

Today, increasing number of native communities manage their own health program and, in this role, some are having to make decisions about how best to collect data and how to encourage their communities to become more data friendly. These efforts are not without compromise or conflict, as many native communities have had a long history of mistrust of researchers and/or data collectors.

This presentation will discuss some of the reasons for the reluctance of native communities to serve not only as research 'subjects', but also as data gatherers. Some of the resistance is politically motivated, but much of it is also due to the lessons learned from various historical encounters with researchers and/or government agents who collected and reported data without making an effort to use the data to help those in need.

Western Australian Aboriginal Child Health Survey

Ted Wilkes

The aim of the Western Australian Aboriginal Child Health Survey (WAACHS) was to establish the prevalence and risk and protective factors associated with: chronic medical conditions and disabilities; emotional and behavioural problems; health risk behaviours (smoking, alcohol, drug and volatile substance misuse); success in school learning and achievement; and resiliency in Aboriginal children and young people. The key to its success lay with the close links with Aboriginal people, organisations and communities. This was achieved through a governance structure, overseen by a steering committee, which linked the project team with community controlled health services, the Australian Bureau of Statistics and a schools reference group. The role of the steering committee, which consisted of senior representatives of key Aboriginal organisations and services, was to oversee all aspects of the project and to ensure: the cultural integrity of survey methods and processes; employment opportunities for Aboriginal people; data access issues and communication of the findings to the Aboriginal community and the general community; and to maintain appropriate and respectful relations within the study team, with participants and communities, with stakeholders and funders and with the governments of the day.

The survey included 5,300 Aboriginal and Torres Strait Islander children under the age of 18 in Western Australia. Over 60% of the interviewers were Aboriginal. There will be five volumes of findings covering: the health of Aboriginal children and young people; social and emotional wellbeing; education, health and wellbeing; family and community wellbeing; and health, education and the justice system. A multilevel communication and dissemination strategy has been devised to: empower Aboriginal communities and service providers with locally relevant information; give information back to families who participated in the survey; provide information for state and national policy development; provide information for the scientific community; and to inform the general Australian population.

Session 7: International health comparisons of Indigenous peoples

Ian Ring, Jacinta Elston and David Firman

Substantial reductions in mortality occurred in the Indigenous populations of the United States, New Zealand and Canada up until the 1980s. However, what is not widely appreciated is that there has been comparatively little reduction in mortality in these Indigenous populations since the mid 1980s, despite continuing sizeable reductions in overall mortality for the population as a whole in each of these countries. Mortality in the Australian Indigenous population was much higher than for the other Indigenous populations and had shown little or no change until the late 1990s. Mortality differentials between Indigenous and non-Indigenous populations, which for the Canadian, US and NZ populations were narrowing until the mid-1980s, increased until the mid 1990s and since then have continued to increase in the US and do not appear to have narrowed appreciably in NZ or Canada. Circulatory, respiratory and endocrine conditions, injury and poisoning and neoplasms were responsible for most of the total deaths in the Indigenous populations of these four countries. There are both commonalities and differences in the trends and patterns of mortality for these conditions in the four populations. The major causes of mortality gain in both the US and Canadian Indigenous populations were from injuries; in New Zealand Maoris and in the Australian Indigenous population the main gain was from circulatory conditions. However, mortality from endocrine conditions has increased rapidly in all four Indigenous populations since the mid-1980s, and, together with variable increases in neoplasms and a surprising lack of progress with circulatory conditions, has been a dominant factor in widening disparities between the Indigenous and non-Indigenous populations. Equitable access to prevention and health-care services, along with the continuing need to deal adequately with the underlying causes of health disparities, requires far more vigorous and effective action in all four countries.

A national Canadian cohort study of Aboriginal children's health

Jeff Reading

(abstract not available)

Session 10: Data measurement

Disparities in Australian health: issues in measuring the health of Australia's Indigenous people

Fadwa Al-Yaman

The Indigenous population of Australia has a younger age profile than the non-Indigenous population—with higher fertility and mortality levels. The majority of Aboriginal and Torres Strait Islander peoples live in capital cities and regional areas of Australia. Indigenous Australians live in all states and territories, but their proportion to the total population of these states and territories is small (less than 5%) with the exception of the Northern Territory where they represent 30% of the population.

Significant health disparities exist between Indigenous and non-Indigenous Australians. Life expectancy at birth is around 17 years lower for Indigenous people, disability rates are higher (57% compared with 40%), and the infant mortality rate is three times as high. In addition, a greater proportion of Indigenous Australians die or are hospitalised at younger ages than non-Indigenous Australians. Significant social and economic disparities are also apparent. Indigenous Australians have lower high school completion rates, lower average weekly incomes, higher unemployment rates and lower rates of home ownership.

A number of issues and challenges exist in the collection of health and welfare information about Aboriginal and Torres Strait Islander peoples. Fundamental to these is the way in which Indigenous people are identified in the various data collections. Identification in Australia is based on self reporting to a question 'are you of Aboriginal or Torres Strait Islander Origin?' The person being asked the question may wish to identify for one purpose of reporting, but not another. The reason why Indigenous people may choose to identify may depend on how the question is being asked, who is asking the question, the purpose for asking and the overall social environment in the country at the time.

In addition, some data providers may not ask a question at all and assume an identity, or may ask in an inconsistent way, without using the standard question. As a result, the completeness and quality of Indigenous identification in the different data collections is variable and Indigenous people are under-identified in many administrative data collections, such as birth and death registers and hospitalisation data. The degree of under-identification varies by state/territory, by remoteness and over time. This makes it extremely difficult to assess trends over time in order to distinguish changes in identification from changes in health status.

In Australia, Indigenous health information is coordinated through the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID). NAGATSIHID provides a national forum for the development of Indigenous health data and information priorities. NAGATSIHID oversees the improvement of information through the implementation of the National Indigenous Health Information Plan and the Group's data development efforts and activities are linked to the National Strategic Framework for Aboriginal and Torres Strait Islander Health. The National Health Performance Framework for Indigenous Health provides the basis for quantitative measurement of the impact of policy on health outcomes for Indigenous people.

Indigenous health measurement—Canada

Janet Smylie

(abstract not available)

Measurement issues—Māori health

Paula Searle

(abstract not available)

Health population data and its role as a mediating variable between race/ethnicity and health disparities: a case study examining off-island Native Hawaiians and off-reservation American Indians

Maile Taualii

The objectives of this paper are: to describe the plight of urban Indigenous Americans; to describe the causal relationship between health population data and health disparities of Indigenous Americans; and to outline the necessary methodology for conducting a study to address the problem of limited and inaccurate population data.

This presentation will describe the role population data plays as an advocacy tool for urban Indigenous Americans and how, without the tool of accurate health information, Indigenous Americans are unable to effectively advocate on behalf of their communities.

In contrast to commonly held beliefs, 43% of Native Hawaiians no longer reside in Hawaii and 61% of American Indians and Alaska Natives no longer reside on reservations. For many American Indians and Alaska Natives this migration to urban areas is a result of the federal government 'relocation' policies. For Native Hawaiians, migration has occurred due to employment, education and housing opportunities. Regardless of the cause of migration, the lack of awareness on the presence of Indigenous Americans in urban areas has played a significant role in the misclassification of health records. This misclassification underestimates the disease burden of urban Indigenous Americans. For example, significant discrepancies between age-adjusted American Indians and Alaska Natives and total mortality rates exist in some urban areas. In areas such as New York, NY, where American Indians and Alaska Natives make up a small fraction of the population (1%), misclassification is extensive. This can be seen in the low mortality rate of 120 per 100,000. While in an urban area, such as Helena, Montana, the mortality rate for American Indians and Alaska Natives is 1,388 per 100,000. However, even with misclassification errors, urban AI/AN have higher infant mortality rates and mortality rates attributed to accidents, chronic liver disease, diabetes and alcohol when compared with the general population in the same urban areas.

For Native Hawaiians off island there is relatively little information. This is a result of racial-aggregate categories. Native Hawaiians and Pacific Islanders are grouped into the Asian/Pacific Islander category. Pacific Islanders only make up 5% of the Asian/Pacific Islander category. This aggregation of population groups makes it almost impossible to identify and address the particular health needs of Native Hawaiians and Pacific Islanders, who, in many cases, experience a greater burden of health disparities than those in the larger Asian population category. For example, the age-adjusted death rate for Asian/Pacific Islanders is 350 per 100,000 (compared with 524 for the total American population), but for Native Hawaiians, the rate is 901 per 100,000.

Session 11: Data utility

Common standards in Canadian aboriginal health data?

Chris Penney

(abstract not available)

Setting the standards

Bridget Robson

Indigenous peoples have the right to determine their own health futures and to monitor the disparate impact of Crown policy. Differences in the age-structure of the Māori population (relatively young) and the non-Māori population (relatively old) make it necessary to adjust for age when comparing health outcomes. The choice of population age-standard can result in different rates, ratios, rankings, trends and confidence limits. This study examined the impact of three standard populations (Segi's, WHO, Māori) on age-standardised mortality, hospital admissions and cancer registrations. Rates standardised to the Māori population reflect Māori realities more closely than those adjusted to the older standards. An Indigenous population standard could reduce some colonising aspects of future epidemiological work.

Quality of race and Hispanic reporting on death certificates in the US: special focus on the American Indian population

Elizabeth Arias

The death certificate is the primary source of mortality data in the United States. Death certificates provide the numerator for death rates, while census population estimates provide the denominator. In turn, death rates serve as the primary measure of mortality status. Race- and Hispanic-origin-specific death rates are the foundation of our knowledge about disease burden and life expectancy across the various race and Hispanic origin populations in the United States. Incongruence between race and Hispanic origin identification in the numerator and denominator of a rate leads to biased estimates of mortality status. This study assesses the quality of race and Hispanic origin reporting on the death certificate, based on an analysis of the latest version of the National Longitudinal Mortality Study. 'Quality' is gauged by comparing race reporting on Current Population Surveys (CPS) with that reported on the death certificates of a sample of decedents whose CPS records were linked to their death certificates.

Data standards for the Aboriginal population of Australia

Lisa Jackson-Pulver

The first step in improving the health of Indigenous people is to ensure that Indigenous people are systematically identified within health-related administrative databases. This is essential to support and inform effective monitoring and evaluation of the impact and outcomes of public health or clinical interventions for Indigenous people. A number of case studies are presented that show how improvements can be made in this important area through a systematic review of health data and how they contribute to improved enumeration of Indigenous people.

The first case study shows, for the first time, meaningful cancer incidence and mortality for Aboriginal people in New South Wales; the second uses obstetrics and perinatal data to enumerate more accurately the number of Aboriginal babies born in one Area Health Service; and the third involves researching publications on Aboriginal and Torres Strait Islander health.

Session 12: Health measures that are useful and relevant to Indigenous communities

Community-level health measurement and Indigenous communities

Steve Larkin

This paper briefly discusses the proposition that existing Indigenous health measurement collection systems ought to extend data catchment to the Indigenous community level. Whilst generally supportive of the concept, it is argued that such activities do not occur without complication. In particular, attention is drawn to the potential sociopolitical impact on communities and government, where inscriptive and calculative technologies of government, as manifested in vast and sophisticated statistical regimes, form the basis for the quantification of complex social realities. Quantification assists the formation of problematisations by government of social phenomena so that it may act on these phenomena through an array of programs. Through numbers, governments can control how data contributes to problematisations, or what problematisations are constructed from the data. The paper concludes by emphasising the importance of ensuring expanded statistical activity does not act to limit community contestation in theorised problematisations developed by bureaucrats, nor compromise opportunities for transformation by circumventing socio-political debate centred on principles of equity and justice.

Measures of particular relevance for Indigenous peoples—reflections

Joanne Baxter

Māori researchers have an imperative to undertake research that is useful, relevant and safe for Māori and should contribute knowledge that leads to improved outcomes for Māori. This talk will explore the concepts of relevance and usefulness within the context of emerging measures used in health research. In particular, challenges and issues associated with the use of measures of culture and identity, and measures of perceived racism will be discussed.

The wellbeing of First Nation communities

Sacha Senécal

The Community Well-Being (CWB) index was developed by the Strategic Research and Analysis Directorate of INAC to measure the wellbeing of First Nations and non-First Nations communities. The CWB index provides a powerful tool for researchers, policy makers and First Nations organisations and communities. The ability to measure the wellbeing of communities and examine the determinants of wellbeing over time will prove invaluable to the development of effective policies.

The CWB Index is a means of examining the wellbeing of individual Canadian communities. Various indicators of socioeconomic wellbeing, including education, income, housing and labour force activity, were derived from the Census of Canada and combined to give each community a wellbeing 'score'. This presentation will provide an overview analysis of the CWB scores of First Nations communities relative to those of other Canadian communities and describe how the gap in wellbeing between First Nations communities and other Canadian communities has changed between 1991 and 2001.

This CWB index serves four principal purposes. First, it identifies prosperous First Nations communities that could serve as role models and sources of best practice for less-developed communities. Second, it identifies those communities whose particularly serious socioeconomic difficulties demand immediate attention. Third, the system of scores can be used in other research projects to expeditiously and cost-effectively assess the determinants and correlates of wellbeing in First Nations communities. Finally, the index allows us to examine wellbeing in First Nations communities relative to other Canadian communities.

Historical trauma, microaggressions and colonial trauma response: Indigenous concepts in search of a measure

Karina Walters

American Indians and Alaska Natives have endured a succession of historically traumatic assaults on their communities and families over time. Historical trauma combined with contemporary microaggressions and other discriminatory events can lead to a soul wound or colonial trauma response. This presentation will describe how intergenerational historical trauma, microaggressions and colonial trauma response were conceptualised and measured in a community-driven and led HIV prevention study of urban American Indians living in the north-eastern part of the United States. Preliminary results indicate that these traumatic stressors are associated with mental health and health-risk outcomes among American Indian individuals, families and communities.

Session 13: Indigenous community capacity building

Enabling tribal information and data sharing across systems

Ada Melton

Information about Indian people is gathered by local, tribal, state and federal governments and by non-governmental groups for various purposes. Often information about individual Indians and aggregate data are needed by multiple agencies for different purposes. Tribes need to have mechanisms that allow them to collect program data for various purposes, such as evaluation and research. These multiple agencies often need to share and exchange the information they have with one another, but often lack the policy and technology infrastructure needed to support data collection and storage, integrated information systems or systems that simply provide information to another system. As governments, Indian nations must address these issues at the intra-tribal, inter-tribal, tribal-state and national levels. Towards that end, Indian nations need to have sound governance policies and procedures, the right technology infrastructure, as well as policies for privacy and strategies to ensure data quality and integrity.

This presentation outlines some of the issues related to culturally relevant data collection and analysis, data sharing and exchange across health, social services, education and justice systems, and some strategies that support tribal capacity and capability to determine how this all occurs.

Indigenous community capacity building: health information systems

Dea Delaney-Thiele

(abstract not available)

Action-oriented indicators of health systems development for Indigenous peoples in Canada, Australia and New Zealand

Janet Smylie

(abstract not available)

Māori-driven health information systems

Cathrine Waetford

Māori have expressed concern that New Zealand health information systems are biased towards regional and national level information requirements, and fail to provide information necessary for optimal local planning and decision-making. Specific concerns relate to the capacity of conventional indicators to measure health as defined by Māori, the feedback of relevant data to communities, and opportunities for meaningful Māori input into monitoring frameworks and indicator development and selection. This presentation discusses Māori health information issues, which provide a rationale for the development of Māori-driven health information systems, and identifies prerequisites to strengthening the capacity of Māori communities to use and contribute to health information systems that lead to health gains.

Cardiovascular disease and diabetes mortality among American Indians and Alaska Natives (AI/AN): a multiple cause analysis

Mark Veazie

Using the National Center for Health Statistics multiple cause (MC) of death file and census data, the authors estimated the number of deaths, the co-occurrence of different causes of death, and mortality rates specific to diabetes and standard categories of cardiovascular disease among AI/AN (1999–2001) in Indian Health Service areas and the US population (2000). Rates were calculated using 1. the occurrence of a particular cause of death one or more times in the death record and 2. the traditional underlying cause of death (UC). Compared with UC data, MC data changed the relative importance of conditions such as diabetes and heart failure among AI/AN. The ratio of heart failure deaths identified anywhere on the death certificate to deaths where heart failure was selected as the underlying cause was 5.5 among AI/AN vs 2.3 among US all races. This ratio varied substantially by cause and race (AI/AN vs US all races). MC or UC analysis affected the differences between age- and cause-specific mortality rates by race. The co-occurrence of different causes of death also varied by race. For example, when diabetes is the UC, renal disease is the leading accompanying cause of death among AI/AN, while coronary heart disease is the leading accompanying cause among US all races.

There were also substantial differences in the distribution of deaths across each combination of the following conditions: diseases of the heart, diabetes, renal disease, hypertension and cerebrovascular disease, suggesting the possibility of documenting disparities in a new way. Since many chronic diseases occur together to cause death, the use of MC along with UC, may provide a more complete picture of chronic disease mortality. Consensus is needed on the strengths and limitations of MC analysis as well as standards for analysis and presentation to permit inter-tribal, regional and international comparisons.

Appendix 3 | Biographies of presenters

Fadwa Al-Yaman has a BSc, Zoology (First Class Honours, Kuwait University), PhD in Immunology, John Curtin School of Medical Research, The Australian National University (ANU) and a Master of Population Studies from Research School of Social Sciences at the ANU. Fadwa currently heads the Aboriginal and Torres Strait Islander Health and Welfare Unit at the Australian Institute of Health and Welfare (AIHW). Before joining the AIHW in 2000, Fadwa worked as an Immunologist at the ANU and before that she worked as a Research Fellow at the Papua New Guinea Institute of Medical Research, where she spent four years setting up the immunological side of the first major trial of a blood-stage malaria vaccine for children.

The major focus of the Aboriginal and Torres Strait Islander Health and Welfare Unit is to monitor and report on progress in the health and welfare of Aboriginal and Torres Strait Islander peoples. The Unit uses relevant current strategic information plans and agreements to guide its work program and set its priorities in the health, housing and community services areas. In addition, relevant policy and reporting frameworks are used to guide priorities. Since the Unit's inception, the relevance to government policy of the information produced on Aboriginal and Torres Strait Islander peoples has been a major driver of the work program.

Jo Baxter is of Ngai Tahu, Ngati Mamoe and Waitaha iwi and is a public health medicine physician. She lives and works in Dunedin and currently works as a senior lecturer in Māori health and a senior research fellow in the Ngai Tahu Māori health research unit in the University of Otago, Dunedin School of Medicine. She has a previous background in psychiatry and has particular research interests in Māori mental health, suicide and Māori, and access to, and outcomes from, health services for Māori. In addition, she has an interest in methodological issues associated with the safe use of epidemiological designs and methods to inform Māori health.

Rachel Brown is a Research Officer in the Māori Health Research Centre, Auckland University of Technology. She is a member of a research team member working on various projects aimed at improving health for Māori, and a member of the advisory group for the Cancer Society Operational Group. Her previous employment includes the Ministry of Health—Cervical Cancer Audit Team; Counties Manukau District Health Board; and a background in social work with experience in both government and community agencies. She also has experience in working alongside Māori on social issues that affect their health.

Michelle Chino 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 research 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. Dr Chino is nationally recognised for her work with Native communities and for her contributions at state and national levels. Dr Chino completed her graduate training at the University of New Mexico (UNM) with a PhD in Human 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 two UNLV research centers—the American Indian Research and Education Center and the Center for Health Disparities Research.

David Espey, MD graduated from medical school at Wake Forest University in Winston–Salem, NC, in 1986 and completed training in internal medicine at the University of New Mexico Health Sciences Center in 1989. He worked with Doctors without Borders in West Africa from 1990 to 1991 and worked as a staff internist at Gallup Indian Medical Center from 1991 to 1993. He joined the Centers for Disease Control and Prevention in 1993 as an Epidemic Intelligence Officer. From 1995 to 2000 he was assigned to the New Mexico Department of Health to support chronic disease prevention and control programs by strengthening the state chronic disease epidemiologic capacity. He was active during that time in cancer, tobacco and diabetes control programs and in developing a statewide clinical prevention initiative. Since July 2000 he has been working with the Indian Health Service National Epidemiology Program supporting cancer control programs in American Indian/Alaska Native communities.

Jennie R. Joe, PhD, MPH is a professor in the Department of Family and Community Medicine and directs the Native American Research and Training Center at the University of Arizona. In addition to this position in the College of Medicine, she is also among a number of other affiliated faculty members from other disciplines who are teaching and mentoring students in the American Indian Studies program. Her research and teaching interests include Indian health, health policy, chronic diseases, spirituality and health, and sociocultural aspect of health for American Indians and Alaska Natives. Prior to coming to the University of Arizona, she held a number of other positions with the federal Indian Health Service, California State Department of Health, and was on faculty in the Department of Anthropology and Indian studies at the University of California, Los Angeles.

Lisa Rae Jackson-Pulver was appointed to her current position as Senior Lecturer Indigenous Health (Development and Research) in 2003, following a career that has progressed through public and community health. Dr Jackson Pulver is committed to identifying the causes of health issues in order to develop solutions to improve population health outcomes for disadvantaged groups and communities. Being an Aboriginal woman, Lisa's particular, although by no means exclusive, area of interest is Indigenous health. Over the last three years, Dr Jackson Pulver has been a full and participating member of a number of important committees, including the National Health and Medical Research Council (NHMRC), Committee of Deans of Australian Medical Schools (CDAMS), and an invitee to the Australian Vice-Chancellors' Committee (AVCC) and the Australian Health Ethics Committees' recent review of ethical guidelines, the CDAMS Medical Education forum and represented the University at a recent briefing to the House of Commons in London. She has also secured a number of residential scholarships for Aboriginal medical students and continues to attract new scholarships for postgraduate students in Aboriginal Health. Dr Jackson Pulver's health background includes positions as epidemiologist, public health officer, postgraduate health and medical student, registered nurse and counsellor.

Cheryl L. Mason is an epidemiologist and a member of the Diné Nation (Navajo) of New Mexico, Arizona and Utah. She completed a Masters in Public Health with a focus on epidemiology in 2001 from the University of New Mexico, Masters in Public Health Program. She is currently assigned from the Indian Health Service Division of Epidemiology as the Acting Director to the Navajo Epidemiology Center at the Navajo Division of Health in Window Rock, Arizona.

Sam Notzon is Director of the International Statistics Program at the US National Center for Health Statistics, CDC. He holds Master of Science degrees in demography and economics from the University of Wisconsin (1973), and a PhD in Population Dynamics from Johns Hopkins University (1989). 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 multi-national organisations. He served as part of the Health Committee of the Gore-Chernomyrdin Commission, a US–Russia group dedicated to promoting collaboration between government scientists of the two countries. 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.

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 AIHW, 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.

Bridget Robson (Ngāti Raukawa) is a Māori health researcher with Te Rōpū Rangahau Hauora a Eru Pōmare (Eru Pōmare Māori Health Research Centre) at the Wellington School of Medicine and Health Sciences, University of Otago. Bridget is interested in how disparities between Māori and non-Māori are created and maintained, and in ways to intervene and eliminate them. Bridget's main experience is as a quantitative researcher, involved in the Hauora series of statistics on Māori health, the classification of ethnicity in health data, social determinants of health, the Whakatu Cohort study of the health effects of redundancy, and studies of unequal treatment in health care.

Paula Searle is of Ngāti Mutunga ki Wharekauri descent. She is experienced in research, evaluation and monitoring, as well as working at a central government level. Before joining the Māori Health Directorate in the Ministry of Health in 2002, she worked for Te Puni Kōkiri, the Ministry of Māori Development. Paula's research includes ethnicity data collection, Māori workforce development, Māori consumers research and evaluation projects, monitoring Māori health outcomes and, more recently, the development of the next Māori health action plan, Whakatātaka 2006–2011. She has a Master of Arts in Geography from the University of Auckland. Paula currently manages the Strategic Projects team who aim to improve advice on Māori health and disability issues through effective information and analysis.

Sacha Senécal was born in the Mohawk community of Kahnawake on the south shore of Montreal. He holds a PhD in social psychology from Université du Québec à Montréal (UQAM) as well as an undergraduate degree in psychology. During his graduate studies, he has specialised in the areas of statistics and research methods. Over the past 5 years, Sacha has been very active in the field of Aboriginal social statistics, holding analyst positions at Statistics Canada, where he was involved in the development and implementation of the Aboriginal Peoples Survey, and in the First Nations and Inuit Health Branch (FNIHB) of Health Canada,

where he played a role in the establishment of a national reporting structure of the Health of First Nations in Canada. He is currently a Strategic Research Manager within the Strategic Research and Analysis Directorate at Indian and Northern Affairs Canada in Ottawa. His main research interests involve social issues within Aboriginal populations of Canada with a particular interest in the topics of wellbeing, health, education and labour.

Maile Taualii, MPH is the Program Manager for the Urban Indian Health Institute (UIHI). The UIHI is an Indigenous epidemiology and research center designed with a national focus to provide leadership in health information and to increase recognition of the health status deficiencies affecting urban American Indians and Alaska Natives through a central point of focus for health surveillance, research and policy considerations. Ms Taualii is pursuing a PhD in Health Services at the University of Washington, School of Public Health and Community Medicine. She is a National Library of Medicine, Public Health Informatics Fellow. Ms Taualii is also actively involved in the Pacific Islander community. Her community activities include reporting the health and wellness of Pacific Islanders, coordinating conferences to gather the health concerns of the Pacific Northwest Native Hawaiian community, and working with the American Indian/Alaska Native/Native Hawaiian American Public Health Association caucus.

Dea Delaney-Thiele was born at the Burnt Bridge Mission at Kempsey, NSW. She was appointed Chief Executive Office of NACCHO in February, 2003. She holds a postgraduate qualification in health management from the University of New England, Armidale. She is married with three children and moved to the national capital in 1998 to take up a policy analyst position with NACCHO. She has, however, 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 NSW; membership of the NSW Aboriginal Health and Medical Research Council (AH&MRC) and NACCHO Board (including a period as Treasurer) and Chairperson of Kamuka Building Enterprises Aboriginal Corporation. Ms Delaney-Thiele has also served as a board member of the Children's Hospital at Westmead and the Western Sydney Area Health Service.

Mark A. Veazie is an epidemiologist with the Indian Health Service. He completed a Doctor of Public Health from the Johns Hopkins University in 1995 and a Master of Public Health from the University of Washington in 1990. Over the past two decades, he has worked as an environmental health specialist in state and local health departments, an epidemiologist with the Centers for Disease Control and Prevention, and a faculty member with the University of Arizona for 8 years, which included many collaborations with tribes and tribal organisations. He is now specialising in cardiovascular disease epidemiology and prevention with the Native American Cardiology Program of the Indian Health Service.

Cathrine Waetford is a physiotherapist and registered hand therapist. She is a hand therapy lecturer and Māori health researcher. She is a member of the Allied Health Services Sector Standard and Physiotherapy Committee, and is leading the review of the Ministry of Health Māori Health Scholarship Program.

Karina L. Walters, MSW, PhD is an enrolled citizen of the Choctaw Nation of Oklahoma and is an Associate Professor at the University of Washington's School of Social Work. Dr Walters is the William B. and Ruth Gerberding Endowed Professor at the University of Washington where she founded, and currently directs, the university-wide, multidisciplinary Indigenous Wellness Research Center. Dr Walters' research focuses on historical, social and cultural determinants of physical and mental health among urban American Indians and Alaska Natives. In particular, her research focuses on identifying cultural factors that buffer the effects of traumatic stressors on wellness outcomes, including HIV risk behavior, substance use, as well as physical and mental health. Dr Walters also is co-founder of the Native Wellness Research Center and the newly formed Institute for International Indigenous Health and Child Welfare Research at the School of Social Work. Currently Dr Walters is the principal investigator of a NIMH-funded seven-site national study on the relationships between traumatic stress, substance use, mental health, cultural resilience, and HIV risk behaviours among high-risk American Indians and Alaska Natives. Additionally, Dr Walters is principal investigator on a NIAAA-funded alcohol use and HIV risk study among urban American Indians and is a co-investigator on a NIMH-funded traumatic life events measurement study among American Indian Vietnam Veterans. In addition to her research responsibilities, Dr Walters serves as a grant reviewer for the NIH—in particular, as a member of the Behavioral and Social Science Approaches to Preventing HIV/AIDS Study Section for the Center for Scientific Review at NIH. Additionally, Dr Walters serves on the Ad Hoc Committee on Racial and Ethnic Diversity for the Office of AIDS Research and serves on the Native American Research Advisory Council for the National Institute of Drug and Alcohol Abuse.

References

ABS (Australian Bureau of Statistics) & AIHW (Australian Institute of Health and Welfare) 2005. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2005. ABS cat. no. 4704.0. AIHW cat. no. IHW 14. Canberra: ABS.

Ajwani S, Blakely T, Robson B, Tobias M & Bonne M 2003. Decades of disparity: ethnic mortality trends in New Zealand 1980–1999. Wellington: Ministry of Health & University of Otago. Viewed <www.moh.govt.nz/moh.nsf/49ba80c00757b8804c256673001d47d0/febdcf2d4baae173cc256d5c00137cae/$FILE/EthnicMortalityTrends.pdf>.

Denny CH, Holtzman D, Goins RT & Croft JB 2005. Disparities in chronic disease risk factors and health status between American Indian/Alaska Native and White Elders: findings from a telephone survey, 2001 and 2002. American Journal of Public Health, 95(5):825–827.

Health Canada 2003. A statistical profile on the health of First Nations in Canada. Viewed <www.hc-sc.gc.ca/fnih-spni/pubs/gen/2003_stat_profil/index_e.html>.

Indian and Northern Affairs Canada 2002. Basic departmental data, 2002. Ottawa: Minister of Public Works and Government Services Canada.

Ministry of Health 2002. He Korowai Oranga—Māori health strategy. Wellington: Ministry of Health.

NATSIHC (National Aboriginal and Torres Strait Islander Health Council) 2003. National Strategic Framework for Aboriginal and Torres Strait Islander Health: framework for action by governments. Canberra: NATSIHC.

Paisano E 2002. Trends in Indian health, 1998–99. Rockville, Maryland: Indian Health Service. Viewed <www.ihs.gov/PublicInfo/Publications/trends98/trends98.asp>.

Ring IT & Brown N 2002. Indigenous health: chronically inadequate responses to damning statistics. Medical Journal of Australia, 177:629–631. Viewed <www.mja.com.au/public/issues/177_11_021202/rin10435_fm.pdf>.

US Department of Health and Human Services 2000. Healthy people 2010. 2nd edn. Understanding and improving health and objectives for improving health. 2 vols. Washington, DC: US Government Printing Office. Viewed <www.healthypeople.gov/document/>.

Young TK 1997. Recent health trends in the Native American population. Population Research and Policy Review, 16:147–167.