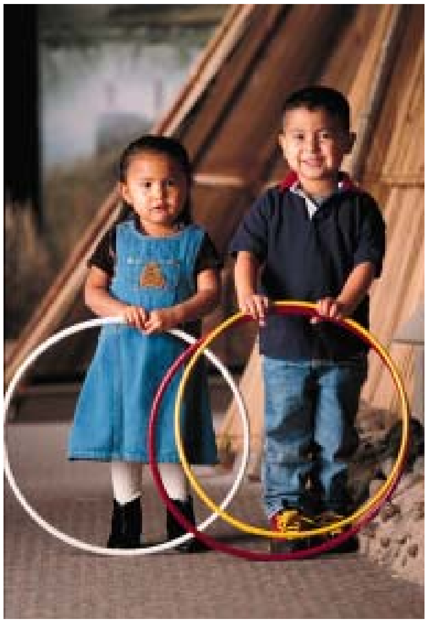
# United States & Canada
# HEALTH RESEARCH PRIORITIES

# Roundtable Briefing Book

September 19-20, 2004
Doubletree Hotel
Rockville, MD



Health Canada
Santé Canada
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

INDIAN HEALTH SERVICE · PHS · 1955

# Table of Contents

# Agenda

**Day One: SUNDAY, SEPTEMBER 19, 2004 (Doubletree Hotel)**

| | |
|---|---|
| 8:30 AM | Morning Refreshments |
| 9:00 AM | Welcome and Opening Ceremony |
| | Leo Nolan, Senior Policy Analyst - External Affairs, IHS<br>Clayton Old Elk, Native Cultural Advisor, Great Crow Nation<br>Dr. Charles Grim, Director, IHS |
| 9:15 AM | Introductions |
| 9:30 AM | Overview and Purpose of the Roundtable |
| 9:45 AM | Expectations (co-facilitators) |
| 10:00 AM | Break |
| 10:15 AM | Presentation and Discussion of Research Issues |
| | 1: *Native Health Status in US and Canada* |
| | 2: *Native Health Systems in US and Canada* |
| | 3: *Principles Guiding this Roundtable Effort and Ethics of Research* |
| 12:00 Noon | Catered Lunch |
| 1:30 PM | Exercise: "What is our vision for collaborative research?" |
| 2:30 PM | Exercise: "What are the overall challenges and opportunities?" |
| 3:30 PM | Break |

| | |
|---|---|
| 4:00 PM | Identification of Major Research Priorities<br>o Discussion of each issue<br>o Discussion of challenges and opportunities for each |
| 5:00 PM | Recess for the Evening |

**Day Two: MONDAY, SEPTEMBER 20, 2004 (NIH Stone House)**

| | |
|---|---|
| 8:00 AM | Morning Refreshments |
| 8:30 AM | Review Progress from Previous Day and Set Plan for Remainder of Time |
| 8:45 AM | Develop Recommendation Statements |
| 10:00 AM | Break |
| 10:30 AM | Finalize Recommendations |
| 12:00 Noon | Catered Lunch |
| 1:00 PM | Develop Next Steps<br>o Implementation Strategies<br>o Marketing Strategy<br>o Commitment to Follow-Up Assignments |
| 2:15 PM | Break |
| 2:30 PM | Report on Recommendations and Next Steps |
| 3:30 PM | Closing Remarks |
| 4:30 PM | Adjourn |

# Participant List

## United States

Tom Becker, MD
Professor
Department of Public Health and Preventive Medicine
Oregon Health Sciences University
Phone: (503) 494-1175
Email: beckert@ohsu.edu

Jay Butler
Program Director
Arctic Investigations
Centers for Disease Control
Phone: (907) 729-3404
Email: jay.butler@cdc.hhs.gov

Maxinne Cole
Board Member
Akwesasne Health Board
Phone: (613) 938-8300

Sarah Hicks
Director
National Center for American Indian Research and Policy Analysis
National Congress of American Indians
Phone: (314) 863-2652
Email: shicks@wustl.edu

Carl M. Hild, MS
Associate Director
Institute for Circumpolar Health Studies
University of Alaska Anchorage
Phone: (907) 786-6584
Email: ancmh@uaa.alaska.edu

Brenda LaFrance
Cultural Researcher
Haudenosaunee Environmental Task Force
Phone: (518) 358-3326

## Canada

Laura Arbour, MD
Assistant Professor
Medical Genetic Department
University of British Columbia
Phone: (604) 875-2827
Email: larbour@cw.bc.ca

Bernice Downey
Executive Director
National Aboriginal Health Organization
Phone: (877) 602-4445

Denise Henning, PhD
Academic Vice President
First Nations University
Phone: (306) 790-5950 ext. 2305
Email: dhenning@firstnationsuniversity.ca

Lucie Kalinda
Senior Policy Advisor
Inuit Tapiriit Kanatami
Phone: (613) 238-8181

Malcolm King, PhD, FCCP
Professor and AHFMR Senior Scholar
Department of Medicine
Pulmonary Research Group
University of Alberta
Phone: (780) 492-6703
Email: malcolm.king@ualberta.ca

Harriet Kuhnlein
Professor of Human Nutrition
Founding Director
Centre for Indigenous Peoples' Nutrition and Environment
Macdonald Campus of McGill University
Phone: (514) 398-7671
Email: harriet.kuhnlein@mcgill.ca

Julien Naylor, MD, MPH
Alaska Area Diabetes Consultant
Alaska Native Medical Center
Phone: (907) 729-1126
Email: jlnaylor@anmc.org

Kurt Schweigman, MPH
Project Coordinator
Black Hills Center for American Indian Health
Phone: (605) 348-6100
Email: kschweigman@bhcaih.org

W. Craig Vanderwagon, MD
Chief Medical Officer
Indian Health Service
Phone: (301) 443-1083
Email: wvanderw@hqe.ihs.gov

Clifton Poodry
Director of Minority Opportunities in Research Division
National Institutes of Health
Phone: (301) 594-3900
Email: clifton.poodry@nih.hhs.gov

Barbara Sina
Fogarty International Center
Phone:(301) 402-9467
Email: Barbara.sina@nih.hhs.gov

Margaret Terrance
Chief
St. Regis Mohawk Tribe
Phone: (518) 358-2272

## Observers

Leo Nolan
Senior Policy Analyst- External Affairs
Indian Health Service
Phone: (301) 443-7261
Email: leo.nolan@ihs.hhs.gov

Alan Trachtenberg, MD, MPH
Research Director
Indian Health Service
Phone: (301) 443-0578
Email: alan.trachtenberg@ihs.hhs.gov

Rod McCormick, PhD
Associate Professor
Counseling Psychology
University of British Columbia
Phone: (604) 822-6444
Email: rod.mccormick@ubc.ca

John O'Neil, PhD
Senior Investigator
Canadian Institutes of Health Research
Professor and Head
Department of Community Health Sciences
Director
Centre for Aboriginal Health Research
Faculty of Medicine
University of Manitoba
Phone: (204) 789-3434
Email: oneilj@ms.umanitoba.ca

Ian Potter
Assistant Deputy Minister
First Nations and Inuit Health Branch
Health Canada
Phone: (613) 957-7701
Email: ian_potter@hc-sc.gc.ca

Jeff Reading, MSc, PhD
Scientific Director
Institute of Aboriginal Peoples' Health
Canadian Institute of Health Research
Professor
Faculty of Human and Social Development
University of Victoria
Phone: (250) 472-5449
Email: jreading@uvic.ca

## Observers

Laura Commanda, MSW
Assistant Director - Ottawa
Institute of Aboriginal Peoples' Health
Canadian Institutes of Health Research
Phone: (613) 946-6495
Email: lcommanda@cihr-irsc.gc.ca

Jared Jobe, PhD
National Heart, Lung and Blood Institute
National Institues of Health
Phone: (301) 435-0407
Email: jobej@nhlbi.nih.gov

Richard Fabsitz, PhD
Leader, Genetic Epidemiology SRG
Division of Epidemiology and Clinical Applications
National Heart, Lung and Blood Institute
National Institute of Health
Phone: (301) 435-0458
Email: RRF@nih.gov

## Facilitators

Jo Ann Kauffman
President
Kauffman and Associates, Inc.
Phone: (509) 747-4994
Email: joann@kauffmaninc.com

Ara Walline
Research Assistant
Kauffman and Associates, Inc.
Phone: (509) 747-4994
Email: ara@kauffmaninc.com

Mohan Denetto
Senior Advisor
First Nations and Inuit Health Branch
Health Canada
Phone: (613) 957-3440
Email: mohan_denetto@hc-sc.gc.ca

Healther McCormack
Senior Policy Analyst
Research, Coordination and Special Projects
First Nations and Inuit Health Branch
Health Canada
Phone: (613) 957-1096
Email: heather_mccormack@hc-sc.gc.ca

Earl Nowgesic
Assistant Director
Institute of Aboriginal Peoples' Health
Canadian Institutes of Health Research
University of Victoria
Phone: (250) 472-5453
Email: Nowgesic@uvic.ca

Brian Schnarch
Research Analyst
National Aboriginal Health Organization
Phone:(877) 602-4445

Nicole Stevenson
Community Facilitator
Indigenous Peoples Health Research Centre
First Nations University

## Facilitator

Harold Tarbell
Senior Partner
Gaspe Tarbell Associates
Phone: (604) 990-4418
Email: htarbell@total.net

# Introduction

On May 14, 2002, Department of Health and Human Services Secretary, Tommy G. Thompson, signed a Memorandum of Understanding (MOU) with Canadian Minister of Health, A. Anne McLellan, to improve the health status of indigenous communities through enhanced international collaborations, identification and reinforcement of best practices, and innovative approaches to learning opportunities. The MOU focused on improving health care delivery and access to the American Indians and Alaska Natives (AI/AN) of the United States, and to the First Nations and Inuit (FN/I) people of Canada. This agreement allowed for a more efficient exchange of information and personnel between the US and Canada and called for establishing workshops, seminars, and meetings on indigenous health issues. Additionally, the MOU called for the development of a comprehensive work plan to address specific health management factors such as financial health management systems, tele-medicine and tele-health capabilities, chronic disease collaboration, indigenous health support mechanisms, coordination with outside agencies, and approaches to health care delivery.[1]

Liaisons were designated to carry out activities under the MOU in the US and in Canada. For the United States, that liaison was the Indian Health Service (IHS). The IHS is the principal federal health care provider and health advocate for AI/AN people. IHS works with tribal and urban programs to provide health services to approximately 1.6 million AI/ANs who belong to more than 560 federally recognized tribes in 35 states. IHS's Canadian counterpart, the First Nations and Inuit Health Branch (FNIHB) of Health Canada, was designated as the liaison for Canada. The FNIHB works with more than 600 First Nations and Inuit communities, other Health Canada branches, and other Canadian government departments to provide health programs and services to address health disparities.[2]

This Roundtable on Native Health Research Priorities is sponsored by the IHS and FNIHB as an activity under the MOU to assist these agencies in developing a plan of work that meets the common objectives of the two countries. By focusing on health research priorities, these agencies hope to identify ways to both raise the health status of FN/I people in Canada and AI/ANs in the United States and to improve approaches to health issues within these groups by identifying and reinforcing best practices. In addition to the IHS and FNIHB, the Canadian Institute of Health Research (CIHR) and the National Institutes of Health (NIH) have also been invited to take an active role in mobilizing the research communities in both countries.

Ten representatives from each country's health research community will gather for a two-day roundtable discussion on September 19-20, 2004 to share expertise, identify major health concerns, and develop a set of recommendations for the health research priorities that are shared between the US and Canadian indigenous populations. It is anticipated that bringing together such a group of interested and knowledgeable parties will result in innovative approaches to and understandings of health research needs in these communities. Specifically, the roundtable will serve three main objectives:

1. Provide a forum for leading researchers and experts on Indigenous health, including FN/I and AI/AN health representatives, to discuss the health research priorities that are shared between US and Canadian Native communities and to develop recommendations for how to partner to meet these priorities.

2. Identify and discuss current knowledge and understanding of US and Canadian health research priorities with respect to the following areas:
   - Native health status in the US and Canada,
   - Native health systems in the US and Canada, and
   - Principles guiding this roundtable effort and ethics of research.

3. Develop an action plan for collaborative research between the US and Canada that will benefit the indigenous communities of each country and identify opportunities for implementation.

The results of this roundtable will be summarized, published, and disseminated by the IHS and the FNIHB as a means to continue the dialogue among tribal communities, urban Indian health programs, and other key federal and non-federal partners.

It is also hoped that this roundtable will serve as a forum for partnership activities to grow between the CIHR and the NIH to improve health and research outcomes for indigenous populations.[3] Such a relationship has already been modeled by the liaison agencies of IHS and FNIHB under the US Canada MOU and by the 2002 tripartite memorandum of understanding on health research for indigenous health signed by Canada, Australia, and New Zealand.[4]

This briefing paper provides an overview of the health systems available to indigenous peoples in the US and Canada, a snapshot of the current health status of these native communities, an overview of the health issues and research priorities identified in interviews with tribal and area health directors, and a review of current research literature.

## References

1. Indian Health Service. (May 14, 2002). Secretary Thompson Signs Agreement with Canada on Indigenous Health during 55th World Health Assembly. HHS Press Office. Website: http://www.hhs.gov/news/press/2002pres/20020514.html

2. Memorandum of Understanding between the Department of Health and Human Services of the Government of the United States of American and Health Canada of the Government of Canada. (13 May 2002).

3. Cooperation Agreement between 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). (29 April 2002).

4. Cunningham, Chris, Jeff Reading and Sandra Eades. (23 August 2003). Health Research and Indigenous Health. *British Medical Journal*, 327, 445-447.

# The Indian Health Service and Native Health Systems in the United States

Federally recognized American Indian tribes and Alaska Native corporations enjoy a government-to-government relationship with the US government. This unique relationship has been given substance through numerous Supreme Court decisions, treaties, legislative acts, and Executive Orders.

The provision of health services grew out of this government-to-government relationship. The IHS is the principal federal health care provider and health advocate for Indian people. The principal legislation authorizing federal funds for health services to recognized Indian tribes is the Snyder Act of 1921. It authorized funds "for the relief of distress and conservation of health . . . [and] . . . for the employment of . . . physicians . . . for Indians tribes throughout the United States."

Congress passed the Indian Self-Determination and Education Assistance Act (Public Law 93-638, as amended) to provide tribes the option of either assuming from the IHS the administration and operation of health services and programs in their communities, or to remain within the IHS administered direct health system. Congress subsequently passed the Indian Health Care Improvement Act (P.L. 94-437), which is a health-specific law that supports the options of P.L. 93-638. The goal of P.L. 94-437 is to provide the quantity and quality of health services necessary to elevate the health status of AI/ANs to the highest possible level and to encourage the maximum participation of tribes in the planning and management of those services.[2]

## MISSION, GOAL, AND FOUNDATION

The IHS provides a comprehensive health services delivery system for AI/ANs with opportunity for maximum tribal involvement in developing and managing programs to meet their health needs. The mission of the IHS, in partnership with AI/AN people, is to raise their physical, mental, social, and spiritual health to the highest level. The goal of the IHS is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to all AI/AN people. The foundation of the IHS is to uphold the federal government obligation to promote healthy AI/AN people, communities, and cultures and to honor and protect the inherent sovereign rights of tribes.

In order to carry out its mission, uphold its foundation, and attain its goal, the IHS:

1. Assists Indian tribes in developing their health programs through activities such as health management training, technical assistance, and human resource development;
2. Facilitates and assists Indian tribes in coordinating health planning, in obtaining and using health resources available through federal, state, and local programs, and in operating comprehensive health care services and health programs;
3. Provides comprehensive health care services, including hospital and ambulatory medical care, preventive and rehabilitative services, and development of community sanitation facilities; and
4. Serves as the principal federal advocate in the health field for Indians to ensure comprehensive health services for AI/AN people.[2]

## HEALTH CARE DELIVERY

Preventive measures involving environmental, educational, and outreach activities are combined with therapeutic measures into a single national health system. Within these broad categories are special initiatives in traditional medicine, elder care, women's health, children and adolescents, injury prevention, domestic violence and child abuse, health care financing, state health care, sanitation facilities, and oral health. Most IHS funds are appropriated for American Indians who live on or near reservations. Congress also has authorized programs that provide some access to care for Indians who live in urban areas.

IHS services are provided directly and through tribally contracted and operated health programs. Health services also include health care purchased from more than 9,000 private providers annually. The Federal system consists of 36 hospitals, 61 health centers, 49 health stations, and five residential treatment centers. In addition, 34 urban Indian health projects provide a variety of health and referral services.

The IHS clinical staff consists of approximately 2,700 nurses, 900 physicians, 350 engineers, 450 pharmacists, 300 dentists, 150 sanitarians, and 83 physician assistants. The IHS also employs various allied health professionals, such as nutritionists, health administrators, engineers, and medical records administrators. The IHS has a vacancy rate of about 12 percent for health professional positions, ranging from a vacancy rate of five percent for sanitarians to 23 percent for dentists.

Through P.L. 93-638 self-determination contracts, American Indian tribes and Alaska Native corporations administer 13 hospitals, 158 health centers, 28 residential treatment centers, 76 health stations, and 170 Alaska village clinics.

## RESEARCH CAPACITY AND ACTIVITIES

### Native American Research Centers for Health[3]

The IHS, with the National Institute of General Medical Sciences (NIGMS) of the NIH, and the Agency for Healthcare Research and Quality (AHRQ) sponsor an initiative to support the Native American Research Centers for Health (NARCH) grants. This funding mechanism develops opportunities for conducting research and research training to meet the needs of AI/AN communities.

The NARCH initiative supports partnerships between AI/AN Tribes or Tribally-based organizations such as the National Indian Health Board (NIHB) and Area Health Boards, and institutions that conduct intensive academic-level biomedical, behavioral, and health services research which form the NARCH partnerships. The purposes of the NARCH initiative are:

1. 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 NIH and AHRQ funding;

2. To 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

3. To 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.

The estimated funds (total costs) available for support for the entire initiative is over four million dollars per year. The grantees may request a project period of up to four years of support, and direct costs not to exceed $800,000 in the first year. Direct costs to the applicant include the entire cost of each subcontract—that is, each subcontract's direct cost plus the subcontract's appropriate Facilities and Administration (F&A) cost. A minimum of 30 percent of the grant funds must remain with the applicant (tribal) organization.

## Epidemiology Centers Program[4]

Although acquisition of medical data through development of information systems is critical, it is equally important to analyze and interpret the data. Because most medical data are complex, simple reports automatically generated by computer systems cannot answer many questions posed by health professionals and administrators. Trained epidemiologists are needed to complete the system of health information for tribes and communities. Epidemiology is critical in identifying diseases to target, suggesting strategies for successful interventions, and testing the effectiveness of health interventions that have been implemented. The innovative IHS Tribal Epidemiology Center program was authorized by Congress as a way to provide significant support to multiple tribes in each of the IHS areas. Beginning in FY 1996, four centers were funded up to $155,000 each. In FY 2000, the four original centers were funded for another five years, and two new centers were funded. Funding in FY 2003 allowed IHS to add one new epidemiology center in another region. The annual level of funding for FY 2003 is approximately $300,000 for each center.

There is continued consensus among tribes that the regional Epidemiology Centers provide support for a variety of public health activities. The one million dollar funding increase for FY 2003 enabled the six existing Epidemiology Centers to provide additional service to tribal communities in their regions.

Operating from within tribal organizations such as regional health boards, the Epidemiology Centers are uniquely positioned to be effective in disease surveillance and control programs and in assessing the effectiveness of public health programs. In addition, they can fill gaps in data needed for Government Performance and Results Act (GPRA) and Healthy People 2010. Some of the existing Epidemiology Centers have already developed innovative strategies to monitor the health status of tribes, including development of tribal health registries, and use of sophisticated record linkage computer software to correct existing state data sets for racial misclassification. These data may then be collected by the National Coordinating Center at the IHS Epidemiology Program to provide a more accurate national picture of Indian health.

**Existing Epidemiology Centers:**

Northwest Portland Epi Center
Inter-Tribal Council of ArizonaEpi Center
Alaska Native Epi Center
Great Lakes Inter-Tribal Epi Center
Seattle Indian Health Epi Center
United South & Eastern Tribes, Inc. Epi Center
Northern Plains Tribal Epi Center

The seven existing Epidemiology Centers provide critical support for tribal efforts at self-governing of health programs. Data generated locally and analyzed by Epidemiology Centers enable tribes to evaluate tribal and community specific health status data so that planning and decision-making can best meet the needs of their tribal membership. Because these data are used at the local level, immediate feedback is provided to the local data systems which will lead to improvements in Indian health data overall.

Epidemiology Centers assist tribes in looking at the cost of health care for Indian people in order to improve the use of resources. In the future, in the expanding environment of tribally operated health programs, Epidemiology Centers will ultimately provide additional public health services such as disease control and prevention programs. Some existing centers provide additional assistance to tribal-participants in such areas as sexually transmitted disease control, cancer prevention, and conducting Behavioral Risk Factor Surveys in order to establish baseline data for successfully evaluating intervention and prevention activities.

## Native Health History Database (NHHD)[5]

The IHS, the National Library of Medicine (NLM), and the University of New Mexico (UNM) Health Sciences Center (HSC) entered a partnership to develop the NHHD. The NHHD is a centralized, nationally accessible, computerized information resource containing complete bibliographic information and abstracts on historical AI/AN medical and health research reports. The database contains about 3,000 entries that cover a time period from 1652 to 1966.

## Native Health Research Database (NHRD)[5]

Developed by the UNM Health Sciences Library and Informatics Center with funds made available by a contract with the IHS, the NHRD provides access to bibliographic information pertaining to health and medical issues of the AI/AN and Canadian First Nations populations. The scope of the NHRD is limited to contemporary articles, studies, and reports focused on the medical (physical and psychological), anthropological, and administrative aspects of AI/AN health. The database entries cover a time period from approximately 1970 to the present. NHRD is updated on a regular basis, usually at least once a month.

NHRD provides information for the benefit, use, and education of organizations and individuals with an interest in AI/AN health-related issues, programs, and initiatives. The material available on this site has been summarized to allow the user an overview. Sources include:

- IHS - reports, studies, publications, memoranda;
- PubMed - a service of the National Library of Medicine, providing access to over 11 million MEDLINE citations back to the mid-1960's and additional life science journals;
- Government agencies (e.g., CDC, NIH) - reports, studies, publications; and
- Unpublished reports, studies, statistical information from tribal-sponsored projects/programs.

## References

1. Indian Health Service. (April 2003). Indian Health Service: A Quick Look.

2. Indian Health Service. (29 March 2004). Fact Sheet. Wesite Address: http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisFacts.asp

3. Indian Health Service. (24 February 2004). NARCH Announcement. *Federal Register*, 8460-8471. Website Address: http://www.ihs.gov/MedicalPrograms/Research/narch.cfm

4. Indian Health Service. (February 2004). FY 2005 Budget Justification: Epidemiology Centers. Website Address: http://www.ihs.gov/adminmngrresources/budget/downloads/FY_2005/Epidemiology%20Centers.doc

5. Native Health Database. (2003). Information. Website Address: http://hsc.unm.edu/library/nhd/info.cfm

# The Canadian Health Care System: Aboriginal Health

The basis for the federal role in FN/I health stems from section 91.24 of the *1867 Constitution Act*, (interpreted in 1939 to include Inuit), and the 1874 Indian Act. The 1874 Indian Act gave authority to the federal government to:

- make regulations, mitigate, and control the spread of diseases on reserves,
- provide medical treatment and health services for Indians,
- provide compulsory hospitalization and treatment for infectious diseases, and
- provide for sanitary conditions on reserves.

These services were designed to respond to the poor health conditions on reserves and the absence of health services from other sources. More formalized federal government involvement began in 1904 with the creation of a Chief Medical Officer for the Department of Indian Affairs, and the development over the next forty years of a series of health facilities directed at addressing the health needs of FN/I, with particular concern for the high incidence of tuberculosis on reserves. The first departmental hospital was constructed in 1917, with an additional 13 in operation by 1943, as well as a number of nursing stations to provide primary care on-reserve as well as in remote and isolated areas.

During the late 1950s and mid-1960s Canada began to move forward in the creation of a system of publicly funded health services for all residents. As medicare evolved, the federal government looked increasingly to the provinces to provide services to FN/I that are similar to those for other residents, that is coverage for necessary hospital and physician services.

The 1979 *Indian Health Policy* attempted to define more clearly the role of the federal government with respect to FN/I health services by recognizing the existence of an inter-jurisdictional health care system. This policy framework identified the following three pillars upon which improved health for FN/I could be built:

1. Socioeconomic community development, and cultural and spiritual development;

2. The traditional relationship of the Indian people to the federal government

in which the federal government advocates for the interests of Indian communities in the larger Canadian society; and

3. An interrelated Canadian health system, which may be the responsibility of federal, provincial/territorial, or municipal governments, Indian bands, or the private sector. The most significant federal roles are in public health activities on reserves and health promotion, and the detection and mitigation of hazards to health in the environment.

In 1988, the Cabinet approved the Health Transfer Policy which began the transfer of federal resources for First Nations health programs to First Nations control (south of the 60th parallel). Devolution of responsibility for the provision of health services to the territories also began at this time and was completed in 1999 when Nunavut assumed control of universal health programs and services, and through administrative agreement, federal health programs.

Recognizing the growing First Nations population off-reserve, in 1997, the federal Cabinet renewed the mandate of the Non-Insured Health Benefits (NIHB) program, providing health benefits to all eligible First Nations living both on or off-reserve. The NIHB program, as it is known today, is the culmination, over several decades, of early efforts during the twentieth century to provide basic public health care and essential treatment to Indian people, with limited federal funds.  Prior to provincial programs of hospital care and Medicare, the federal government developed a comprehensive set of programs of health care for FN/I. These programs included dental care, pharmaceutical benefits, and vision care. With the development of provincial programs supported by federal transfer payments, the hospital and physician services were transferred to the province.

After 1966, with the evolution of Medicare, the federal government retained a role in providing non-insured services to FN/I. A more systematic approach to non-insured health benefits emerged from the 1979 Indian Health Policy. This policy confirmed a commitment to provide non-insured health benefits to First Nations people both on and off the reserve.

Federal government involvement in health activities related to non-status Indians and Métis has developed in a targeted fashion, as it has with other vulnerable and at risk populations. For example, Health Canada’s Hepatitis C, HIV-AIDS, Fetal Alcohol Syndrome (FAS), and diabetes prevention programs have components that address the needs of all Aboriginal people.

## CURRENT SITUATION

In principle, the health needs of all Aboriginal people, as members of the Canadian population, are addressed by the federal government's overarching roles in health and by the provincial/territorial governments' role in providing universal insured health services to all citizens. Insofar as Aboriginal people in general face disproportionately high levels of various health problems, the federal government continues to provide health promotion and related programs to Aboriginal people in general, as a population with special health needs, without regard to status.

The federal government maintains that its role in the provision of health services is based on policy rather than legislation or rights. This role is based in the 1979 Indian Health Policy and includes the following responsibilities:

- delivering primary and supplementary health care services and programs to First Nations living on reserve and to Inuit living in Inuit communities;
- research, program evaluation, and policy development;
- targeted health promotion programs (regardless of residency);
- public health and community health programs on all reserves;
- insurance coverage of drug, dental, vision and medical transportation services for all Status FN and Inuit.

Current statistics relating to Aboriginal people in Canada provide the following demographics: First Nations. i.e. "Status Indians" as defined by the Indian Act, living on-reserve (pop. 380K) or off-reserve (pop. 301K)[1], Inuit (pop. 45K[2]), and Métis (pop. 292K).

## ACTIVITIES AND EXPENDITURES

Health Canada's budget for 2003-2004 is estimated at $3,157 million. Over half of that amount goes toward the programs and services of First Nations and Inuit Health Branch (FNIHB). Of the balance, a small proportion is targeted specifically to Aboriginal people (e.g. for the Aboriginal Head Start program), while most would be seen as targeted to the entire population, including Aboriginal people.

FNIHB provides Non-Insured Health Benefits (drug, dental, vision and medical transportation) to over 749,000 eligible FN/I. In addition, the FNIHB delivers public health, health promotion and disease prevention programming to approximately 640 FN/I communities, and primary care in remote and isolated communities through a network of 74 nursing stations. FNIHB also administers targeted programs for all Aboriginal people, regardless of residency, such as the

Aboriginal Diabetes Initiative, the Tobacco Control Strategy and the Indian Residential Schools counselling.

**Table 1: FNIHB Program Responsibilities**

| ALL ELIGIBLE FIRST NATIONS & INUIT PEOPLE | ON ALL FIRST NATIONS RESERVES | IN ISOLATED & REMOTE COMMUNITIES |
|---|---|---|
| · Visioncare<br>· Dental treatment<br>· Drugs<br>· Crisis mental health<br>· Provincial health premiums | · Prevention and promotion programs<br>· Public health<br>· Alcohol/drug addiction prevention<br>· Medical transportation program | · Nurse practitioners and physicians<br>· Emergency services<br>· Primary care (assessment, diagnosis, and referral to other health care services) |

## RESEARCH, HEALTH INFORMATION AND ANALYSIS

### *Health Information/Data Compilation and Analysis Capacity*

Federal departments routinely collect, analyze, and disseminate basic data on topics relevant to Aboriginal health such as specific diseases, demographics, social and economic conditions, housing, drinking water quality, education, and employment. For example, Indian and Northern Affairs Canada publishes an annual report on basic departmental data; monitors and reports on water quality, treatment facilities, and certification of facility employees in Aboriginal communities; and publishes periodic summaries of departmental research activities.

### *National Surveillance Information*

Various federal departments and their regional offices, as well as provincial and territorial governments, carry out surveillance activities using diverse sources of data, including compilation and analysis of health data on communicable diseases, immunization rates, as well as other health issues, such as injuries and diabetes.

The FNIHB recently released *A Statistical Profile on the Health of First Nations in Canada (*March 2003) which provides descriptions for on-reserve populations and certain Inuit communities concerning demographics, birth rates, infant mortality rates, leading causes of death, prevalence and incidence of leading communicable and chronic diseases, immunization data, dental health, hospital separations for a variety of chronic conditions, inpatient admissions for alcohol and drug abuse, education, employment, housing conditions, water quality, and sewage treatment. The profile also identifies important data limitations in an effort to reduce misuse of information.

### *The National Census and Population Surveys*

The Aboriginal Peoples Survey, a post-census survey of the national Census, was first conducted in 1991 and repeated in 2001 with increased consultation between Statistics Canada and Aboriginal organizations. Approximately 76,000 adults and 41,000 children, including both on- and off-reserve First Nations, Métis, and Inuit were selected to participate in the survey through a detailed "household" questionnaire covering topics such as language, labor, health, housing, education, technology, and mobility. While the survey contains much valuable information, health information is somewhat limited, and gaps remain in coverage of some communities. The first of a series of reports, *Aboriginal Peoples Survey 2001 Initial Findings: Well-Being of the Non-Reserve Aboriginal Population, 2001* was released in September 2003.

### *The First Nations Regional Health Survey*

Recognizing the need for comparable health information on First Nations on-reserve across Canada, Health Canada supported the development of the First Nations Regional Health Survey (RHS). The RHS was first implemented in 1996 and included core content reflective of national policy issues, including:

- measures of health status;
- accessibility and utilization of health services;
- availability of resources for FN/I health;
- dental health access issues and impacts of financial reductions to health services/benefits levels;
- prevalence of illness compared against the health of all Canadians;
- impacts of changes in national policy on FN/I health; and
- mental health, including residential schools, indicators of stress, utilization/access issues, and positive indicators.

The sample included close to 10,000 adults and over 4,000 children from 186 FN/I communities in all regions of Canada except the two northern territories.

The next wave of the survey is being undertaken in 2002/03 by the First Nations center at the National Aboriginal Health Organization. The survey will again collect information on the health and wellness of adults (18 years old and up), youth (12 - 17 years), and children (birth to 11 years), with a total sample size of 22,000. The survey's purpose is to facilitate community-based information gathering about the health status, concerns, and issues affecting First Nations across Canada. This research will assist First Nations in learning more about the health and well being of their communities, building their capacity to collect and analyze information on their own health status, and issues to support the promotion of healthy lifestyles and practices, and effective program and policy development.

## CURRENT RESEARCH ACTIVITIES AND CAPACITY

Developments in Aboriginal health research capacity in the last five years include the establishment of bodies for health research and knowledge transfer, significant increases in federal funding for Aboriginal health research, improvements in Aboriginal health information, advances in university-based research; possibilities for international collaboration, and progress towards the meaningful involvement of Aboriginal people in research affecting them.

### First Nations and Inuit Health Branch

FNIHB participates in many research related activities, encompassing a wide variety of health issues. An inventory of branch activities has been developed and FNIHB has aggregated its science/science-related activities into three key areas: public health, evaluative research, and research translation.

*Public Health Research: Risk Analysis, Management, and Environmental Health*

There are several key areas of current and recent research activity. First, collaborative research programs with First Nations encourage and support First Nations community-initiated research projects on environmental health contaminants and drinking water quality. Second, scientific review, risk assessment and risk management planning for the use of Bacille Calmette-Guérin (BCG) vaccine in FNIHB tuberculosis programs, with research components related to the prevalence of risk conditions of complications from the BCG vaccine is supported. Third,study protocols are developed to determine immunization coverage in First Nations communities and to estimate the incidence of Severe Combined Immune Deficiency Syndrome.

### *Environmental Health Research*

The National First Nations Environmental Contaminants Program (NFNECP) was launched in 1999 as a collaborative program between the Assembly of First Nations and Health Canada to assess the extent of environmental contaminant exposure and the potential health risks for First Nations. The NFNECP advances its mandate through the support of innovative community-based research initiatives designed to address both national and regional issues.

### *Traditional Healing/Medicine Research*

Health Canada and the CIHR are currently engaged in a research funding partnership on a study in northern Quebec on the use of traditional knowledge of medicinal plants in the management and prevention of Type 2 Diabetes. The community research aims to provide a novel way to integrate traditional and western approaches to medicine in a manner that is consistent with Aboriginal peoples' culture and lifestyle.

### *Water quality*

As part of Health Canada's implementation of the First Nations Water Management Strategy, $4.1 million over five years has been allocated to investigate waterborne diseases and emerging contaminants and facilitate the translation of research into policy and program development. This research will be carried out in partnership with other Health Canada branches, academic researchers ,and First Nations organizations. Research planning for 2004/2005 is underway, with input from FNIHB stakeholders as well as Health Canada branches, academic researchers, and First Nations organizations.

### *Evaluative research and Program effectiveness*

This research supports continued improvement of program design and guidelines, models for practice and evaluation, program performance information, and sustainable, effective and validated interventions. Areas of activity include program evaluation, quality assurance testing of management process, tracking trends in client population, benefit utilization and program expenditure patterns, and pilot programs to develop evidence-based guidelines that are culturally-appropriate, reflective of unique conditions ,and contribute to community capacity building. Research is conducted through pilot and demonstration projects, statistical analysis, literature reviews, key informant interviews, and focus-groups to validate interventions and identify gaps in service delivery and health promotion/prevention.

*Research Translation, Policy-related Research and Analysis*

Research translation is supported through collaborative work with Aboriginal organizations on the development of a service providers' network on early childhood development (ECD) and through contribution agreements with the National Aboriginal Health Organization. Policy development on ECD is supported through environmental scans and national dialogue on the possible scope of a single window approach to ECD; and, policy development, more generally, is supported through synthesis of research, data compilation, and analysis. In addition, demonstration projects are being used to support policy development on ECD and health service integration.

## Aboriginal Research Initiatives in the Federal Government

Many different departments across the federal government participate jointly in research related to the health of Canada's Aboriginal population. Examples include the Policy Research Initiative (PRI) and the Northern Contaminants Program (NCP). The PRI's core mandate is to advance research on emerging horizontal issues that are highly relevant to the federal government's medium-term policy agenda, and to ensure the effective transfer of this knowledge to policy-makers. Two key objectives are to contribute to the strengthening of the federal government's policy research capacity and to create an infrastructure that fosters collaboration on horizontal policy research. One of the recent examples is the Urban Aboriginal Strategy (UAS), led by the Privy Council Office and designed to cover a wide range of socioeconomic policy research issues.

The NCP at Indian and Northern Affairs Canada, funds a variety of policy, program, and research activities related to contaminants and traditional foods. The NCP is a collaboration between four federal departments, the territorial governments, Aboriginal organizations, and university researchers. Since its inception in 1991, a large portion of its annual $5.4 million budget has been dedicated to human health research. The research component of the NCP contributes to understanding the impacts of contaminants on human health and ecosystems;provides information to assist individuals and communities in decisions about food use; and studies the effectiveness of international controls of contaminants. Researchers are required to partner with community members in the design and conduct of studies under strict "Guidelines for Responsible Research," and to communicate research findings so that they are understandable and useful to communities.

## External Partnerships

### *Canadian Institutes of Health Research*

The CIHR is Canada's premier federal agency for health research. The CIHR-Institute of Aboriginal People's Health (IAPH) is leading a national advanced research agenda in the area of Aboriginal health and promoting innovative research that will serve to improve the health of Aboriginal people in Canada. With an annual budget of $5.32 million, CIHR-IAPH funds biomedical, clinical, health systems, social, cultural, and environmental research through grants competitions, both alone and in partnerships with other CIHR institutes. CIHR-IAPH also plays a lead role in supporting the development of research capacity in First Nations, Inuit and Métis communities, and supports partnerships and alliances between Aboriginal communities and non-Aboriginal health research bodies at the local, national and international levels.

CIHR-IAPH has identified four strategic research priorities for its five-year mandate:

1. To develop and nurture Aboriginal health research partnerships with Aboriginal and non-Aboriginal organizations in the public and private sectors at local, regional, national and international levels;

2. To maintain open communication with CIHR to influence policy development on ethical standards, peer review processes and knowledge translation systems that respect Aboriginal cultures;

3. To build Aboriginal health research capacity, especially among university graduate students studying Aboriginal health; and

4. To fund initiatives that address urgent or emerging health issues affecting Aboriginal people.

### *The ACADRE Program*

As one of its first initiatives, CIHR-IAPH established the Aboriginal Capacity and Development Research Environments (ACADRE) program to develop a network of supportive research environments across Canada. ACADRE centers aim to develop research in Aboriginal health in ways that respect the pursuit of scientific excellence as well as the need for community relevance in research.

The ACADRE initiative currently supports eight networks of Aboriginal health researchers affiliated with universities and research hospitals. This initiative is intended to provide support, experience, and skill development to Aboriginal health researchers, to increase the number of researchers working in Aboriginal health research, and to facilitate partnerships between researchers and communities. Combined funding for ACADRE from CIHR and IAPH is $24 million over six years.

Some of the activities that the ACADRE centers are involved in include training researchers, encouraging Aboriginal students to pursue health research careers, establishing a network of mentors, using a holistic approach to research on chronic diseases, indigenous and traditional healing methods, health service delivery and disease control and environmental health, and providing opportunities for participation in high profile indigenous research projects in Canada and internationally.

*CIHR: Other Aboriginal-related Activities*

In addition to CIHR's 13 institutes that focus on specific health problem areas, CIHR also offers a number of crosscutting strategic research priorities which have implications for Aboriginal health. In particular, the Strategic Initiative in Rural and Northern Health Research and the development of a National Agenda for the Environmental Influences on Health bear significantly on Aboriginal health research. Under these research themes, many of CIHR's institutes jointly support research programs to address health problems that disproportionately affect or are prevalent in Aboriginal populations in Canada.

## National Aboriginal Health Organization

The National Aboriginal Health Organization (NAHO) is an Aboriginal designed and controlled body, which strives to influence and advance the health and well being of Aboriginal peoples through carrying out knowledge-based strategies. With an annual budget of $5 million the organization carries out knowledge development and dissemination, policy research and analysis, and capacity development and information-sharing activities. The key objectives of NAHO are:

- to improve and promote health through knowledge-based activities;
- to promote understanding of health issues affecting Aboriginal Peoples;
- to facilitate and promote research and develop research partnerships;
- to foster participation of Aboriginal Peoples in delivery of health care;

and

- to affirm and protect Aboriginal traditional healing practices.

NAHO plays an important role as a knowledge broker and "translator" of health research into policy advice and program design. NAHO does not fund research directly, although co-funding with other organizations is used to cost share in knowledge development, utilize the mechanisms of established research bodies and gain access to high quality and experienced Aboriginal health researchers. NAHO also contributes to Aboriginal health research capacity through development of conceptual documents, resources, and tools.

## Canadian Population Health Initiative

The Canadian Population Health Initiative (CPHI) at the Canadian Institute for Health Information was established to generate new knowledge on the determinants of health, contribute to the development of population health information infrastructure, support policy analysis and synthesis of evidence, and transfer new knowledge to decision-makers and the public. One of its three policy priorities is Aboriginal peoples' health. CPHI began its work in this area by hosting a series of meetings with Aboriginal leaders and researchers to set a direction and determine priorities for research initiatives. CPHI remains in communication with key Aboriginal organizations such as the NAHO and the CIHR-IAPH. Through its research activities, CPHI is generating new knowledge, building capacity, enhancing infrastructure, and synthesizing and analyzing findings in population health research.

## Social Sciences and Humanities Research Council

The Social Sciences and Humanities Research Council (SSHRC) is an arms-length federal agency that promotes and supports university-based research and training in the social sciences and humanities. Research grants support projects in Aboriginal rights, health, and social issues, among others. In 2002, Aboriginal research was chosen as a priority area, and staff began a multistage public dialogue with stakeholders toward the creation of an Aboriginal research agenda.

Over 500 individuals have participated in the dialogue through briefs, a national round table, and four electronic discussion groups. SSHRC is considering new initiatives that support not only increased research on issues of concern to Aboriginal communities, but also new ways of working with Aboriginal communities and researchers.

## Aboriginal Healing Foundation

The Aboriginal Healing Foundation (AHF) was established to support healing activities for individuals and communities affected by residential schools. The AHF has an overall allocation of $350 million and a ten-year mandate that ends in 2008. It has the challenge of determining indicators for the long-term impact of community-based healing projects on individuals and social environments. In addition to short- and long-term evaluation of process and impact of the projects it funds, AHF also sponsors a wide range of strategic research that contributes to design, implementation, and evaluation of community projects including case studies and research on best practices. Also, AHF has funded studies on Métis and Inuit in residential schools, Aboriginal crime, the child welfare system, HIV/AIDS, and elder abuse. It also supports activities to synthesize knowledge on issues such as Aboriginal sexual offending, domestic violence, suicide, traditional healing, and resiliency.

## Canadian Health Services Research Foundation

The Canadian Health Services Research Foundation (CHSRF) was formed in 1997 to promote and facilitate evidence-based decision-making in Canada's health sector through the funding of researchers and policy makers who wish to investigate specific health system questions. The CHSRF funds management and policy research in health services and nursing, supports the synthesis and dissemination of research results, and supports the use of research results by managers and policy makers in the health system. An initial endowment of $66.5 million was complemented by an additional endowment of $60 million in 1999 which allows the CHSRF to leverage contributions for research projects from external partners including CIHR and regional health research foundations. The CHSRF sponsors a variety of health policy and health system governance research themes including a Special Program Initiative on health care access for rural and remote communities.

## University-based Research

In addition to the work of the CIHR-funded ACADRE centers, a number of Canadian universities support the work of affiliated bodies such as institutes, councils, or networks, which advance Aboriginal health research. Usually these bodies are multi-disciplinary and collaborate with the ACADRE centers and other universities, as well as community organizations. Examples include the Centre of Indigenous People's Nutrition and Environment, the National Network for Aboriginal Mental Health Research, the Manitoba First Nations Centre for Aboriginal Health Research, and the Nunavik Research Centre.

### International Network for Indigenous Health Knowledge and Development

The International Network for Indigenous Health Knowledge and Development (INIHDK) was established through cooperative agreements between health research councils in Canada, Australia, and New Zealand and aims to provide a network for people working to improve the health of indigenous peoples.

One of the key aims of the INIHDK is to provide a vehicle for indigenous communities and indigenous academics to collaborate on research on key indigenous health issues. The INIHDK is uniquely positioned to support and contribute to international efforts to accurately define health risks, trends, and emerging issues as well as to effectively design and deliver more targeted programs and services to assist indigenous populations in improving their health and well-being. The INIHDK provides a forum to encourage researchers to engage in indigenous health research, foster collaboration on research, promote dissemination of research protocols and ethics, and current research and findings, and share models for building indigenous health research infrastructure and capacity.

## References

1. Indian and Northern Affairs Canada. 2003. Registered Indian Population by Sex and Residence 2002. www.ainc-inac.gc.ca/pr/sts/index_e.html

2. Statistics Canada. 2001 Census of Population

# Native Health Status: United States & Canada

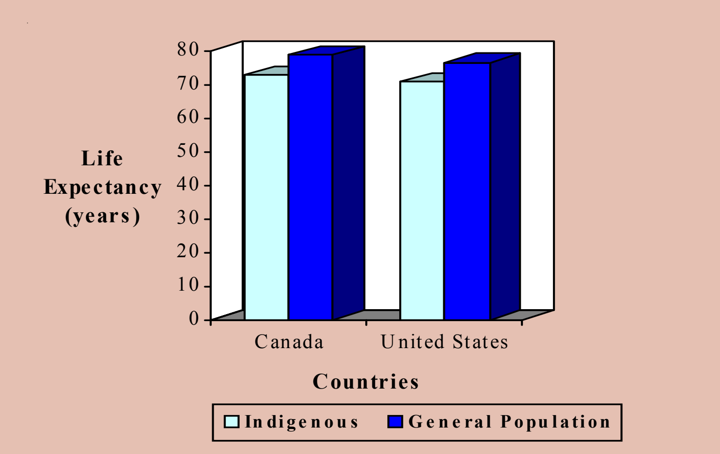
The continuing disparities between the health of indigenous people and the non-indigenous populations of Canada and the US is a matter of major concern. Remarkable similarities in health status, epidemiology, key health issues, trends in health and disease, and the causal systemic factors that underlie these findings are evident in Canadian Aboriginal and AI/AN peoples. There are also some striking differences relating to these factors.

This section presents an international comparison of the current health status of the indigenous peoples of Canada and the US. Throughout this document there has been an attempt to compare the health status of each country's indigenous population to the corresponding health status of the general, or non-indigenous, population.

## LIFE EXPECTANCY

In Canada, the life expectancy rate for First Nations is 72.8 years and the Inuit rate is 69 years. This is compared to the general Canadian life expectancy rate of 78.8 years.[1] The situation in the US is similar, as AI/ANs have a life expectancy rate of 70.8 years, which is considerably lower than the general American rate of 76.5 years.[2]

**Figure 1: Life Expectancy**



## POPULATION AGE

The indigenous populations in both Canada and the US are younger in their population distributions, compared to each country's general population. This is evident when comparing the median age. For indigenous populations, the median age is generally in the low to mid 20s, while the general populations have a median age in the mid to high 30s.[3]

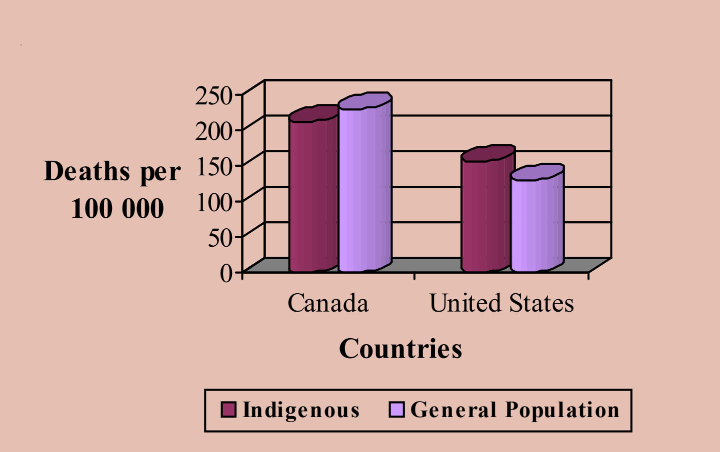
## MORTALITY RATES

Generally mortality and infant mortality rates are higher among indigenous populations compared to non-indigenous people. Even though the overall mortality rates for FN/I in Canada versus the general population are almost identical, the age standardized rate may be misleading because the majority of deaths occur in younger ages for First Nations and at older ages for all Canadians. Thus mortality rates are a significant concern for Canadian First Nations youth.[4] The AI/AN mortality rate is 1.5 times greater than the general American rate.[5] Both the Canadian and American indigenous infant mortality rates are 1.5 times greater than the rates for the general population.[6]

## CARDIOVASCULAR DISEASE

Cardiovascular disease is the leading cause of death for both indigenous populations. In the US, the indigenous cardiovascular mortality rate is 1.2 times higher than non-Indigenous rate.[7] Alternately, in Canada, the general population has a cardiovascular mortality rate that is 1/3 higher than the First Nations

**Figure 2: Cardiovascular Disease Mortality Rate**

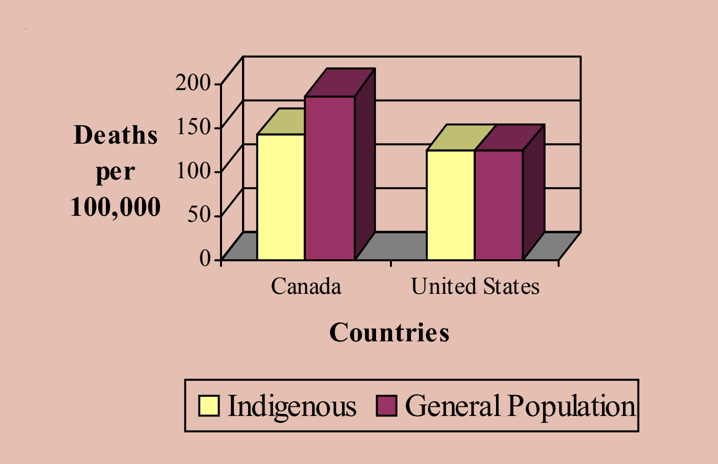


rate. However, because of the difference in median age between the First Nations and non-indigenous population these figures can be misleading since the majority of First Nations are younger and have a lower life expectancy. This trend is similar for many diseases that often set in in elderly ages.[8]

## CANCER

Cancer is the second leading cause of death among both Canadian and US indigenous populations. In the US, the indigenous and general population rates are equal; however, rapid increases in rates of tobacco related cancers, breast cancer, prostate, and colon cancer have been observed among AI/AN. AI/AN have the poorest survival rate from cancer of any ethnic group in the US due to lack of access to specialist care and negative socio-economic conditions.[9] One difference noted in the study is that in Canada the general population has a higher cancer mortality rate than First Nations. While cancer was lower among First Nations populations, cancer is still common with 141.5 deaths per 100,000.[10]

**Figure 3: Cancer Mortality Rates**



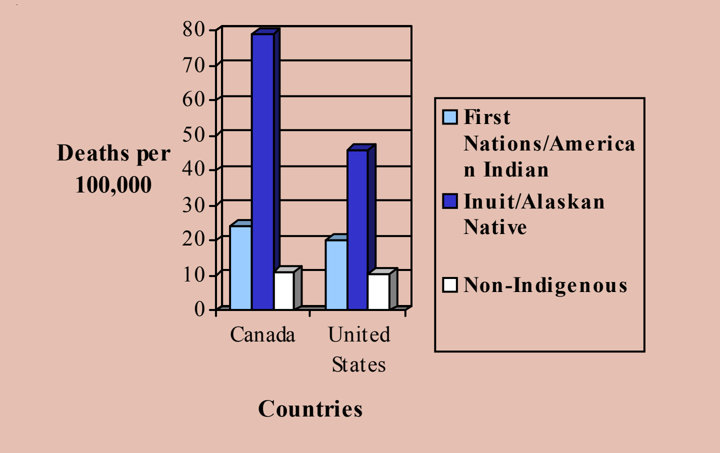
## DIABETES

Diabetes is a major health concern for indigenous peoples in both countries. In Canada, the First Nations diabetes prevalence rate is three to five times higher than Canadian rate.[11] In the US, AI/AN have the highest prevalence of Type 2 diabetes in the world. The AI/AN diabetes mortality rate is 3.9 times higher than general US rate.[12]

## SUICIDES

Suicide is primarily a youth phenomenon in Canada and the US; and is seen as a significant problem amongst indigenous people. In Canada, suicide is identified as the number one health priority as the First Nations youth suicide rate is eight times greater than the Canadian rate and accounts for 38 percent deaths among First Nations youth aged ten - 19.[13] In the US, the AI/AN youth suicide mortality rate is 2.4 times higher than the US youth rate.[14]

### Figure 4: Suicide Mortality Rates



## INJURIES

In both Canada and the US injuries are the third leading cause of death at approximately three times the rate of non-indigenous populations.[15] The most common cause of death for First Nations people aged one to 44 is injury and poisoning.[16]

## TUBERCULOSIS

The tuberculosis rate in First Nations was eight to ten times higher than that of the entire Canadian population in 1999. Overcrowded housing is associated with an increased risk of tuberculosis in a community. The 1999 First Nations tuberculosis rate of 61.5 cases per 100,000 population was due in part to large outbreaks in several regions—41 percent of total tuberculosis cases occurred in five communities.[16] In the US, the problem of tuberculosis among indigenous peoples is also apparent. For the years 1996-98, AI/AN in the IHS Service Area died from tuberculosis at rates 400 percent higher than US all-races in 1997.

Tuberculosis was responsible for 1.5 AI/AN deaths per 100,000 population for the years 1996-98. This is five times greater than the 1997 US all-races rate of 0.3 deaths per 100,000 population.[17]

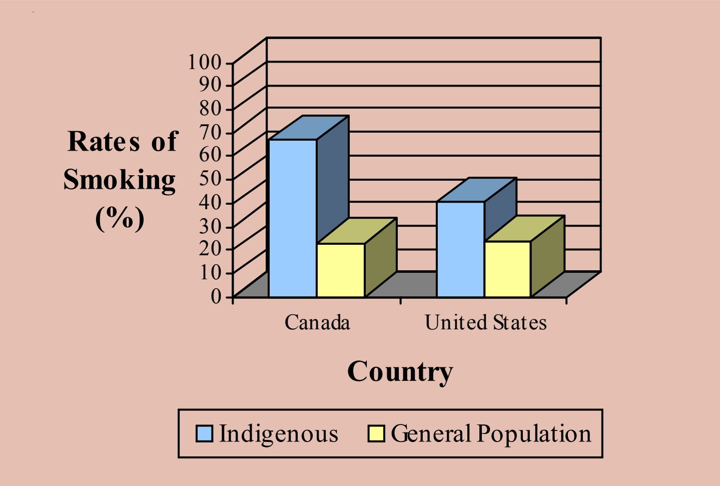
## OBESITY

Obesity is a concern for indigenous people in both countries. In Canada, obesity rates among off-reserve Aboriginal peoples are almost two times greater than the general Canadian population.[18] In the US, in addition to a prevalence rate of obesity of 30 percent, an additional 26-30 percent of American Indians are overweight.[19]

## SMOKING

In Canada, 63 percent of First nations and 72 percent of Inuit smoke. This is compared to only 23 percent for the general Canadian population. Of the FN/I who smoke, 60 percent started before the age of 16.[20] In the US, 40.8 percent of AI/AN are smokers, while only 24.1 percent of the general US population smokes. Of all ethnic/racial groups in the US, AI/AN have the highest rates of smoking.[21]

**Figure 5: Smoking Rates**



## CONCLUSION

It is evident that there are significant gaps between the health status of indigenous and non-indigenous populations in Canada and the US. Action must be taken by the international community in order to alleviate the disparity in health status of North America's indigenous populations. The international community must look to each other in order to compare "best practices" and policy approaches and to collaborate on research in health areas that pose challenges to both countries.

## References

1. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003. and, Indian Health Services. *Health and Heritage Brochure*. February 2001.

2. Health Canada. *A Statistical Profile on the Health of First Nations*. 2003.

3. Indian Health Services. *Regional Differences in Indian Health – Demographic Section (2000-2001)*. 2001.

4. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003.

5. Indian Health Services. *Regional Differences in Indian Health – Demographic Section (2000-2001)*. 2001.

6. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003. and, Indian Health Services. *Fact on Indian Health Disparities*. September 2002.

7. Indian Health Services. *Unpublished Data*. 2003.

8. Health Canada. *A Statistical Profile on the Health of First Nations*. 2003

9. Indian Health Services. *Health and Heritage Brochure*. February 2001.

10. Health Canada. *A Statistical Profile on the Health of First Nations*. 2003

11. Ibid.

12. Indian Health Services. *Unpublished Data*. 2003.

13. Health Canada. *A Statistical Profile on the Health of First Nations*. 200

14. Indian Health Services. *Trends in Indian Health 1998-99*. 1999

15. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003. and, Indian Health Services. *Unpublished Data*. 2003.

16. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003.

17. Indian Health Services. *Unpublished Data*. 2003.

18. Canadian Population Health Initiative. *Improving the Health of Canadians*. 2004.

19. American Heart Association. *Biostatistical Fact Sheet – American Indians/Alaska Natives and Cardiovascular Diseases*. 2001.

20. Health Canada. *A Statistical Profile on the Health of First Nations in Canada*. 2003.

21. American Lung Association. *Fact Sheet: American Indians and Alaska Natives and Tobacco*. June 2002.

# Interview Findings

In order to gain insight into what could constitute a shared perspective on tribal/ Aboriginal health and research priorities, the IHS and Health Canada solicited input from a diverse range of key experts and opinion leaders. For the US, these respondents included elected tribal leaders, tribal health directors, urban Indian health program directors, and IHS area health directors or chief medical officers. For Canada, the respondents were researchers particularly focused on Aboriginal health and representatives of Aboriginal organizations actively engaged in addressing health issues within the Aboriginal communities. Brief phone interviews and/or discussions were conducted with these community health, research, and opinion leaders and the findings were used to direct the research literature review.

In the US, the IHS received input from thirteen individuals who are considered health leaders in communities that border Canada and those who are familiar with the health issues in Canada as well as the US. As six of the twelve IHS service areas border Canada (Alaska, Portland, Billings, Bemidji, Aberdeen and Nashville), the Area Directors or Chief Medical Officers (CMOs) were interviewed. In addition to these interviews, an additional six interviews were conducted with one tribal health director, tribal leader, or urban Indian health director in each area.

In Canada, five interviews were completed. Two individuals are responsible for health issues at National Aboriginal representative organizations (Assembly of First Nations – AFN and the Inuit Tapiriit Kanatami - ITK). One interview was conducted with the Executive Director of NAHO and supplemented by written responses from two of NAHO's centers of excellence (First Nations and Metis). One interview was conducted with a senior board member with the ACADRE center in Atlantic Canada and one interview was conducted with a prominent research specialist on Aboriginal health issues.

A formal, structured interview process was not used. Instead, a discussion guide was followed to allow for free flowing discussion about health and research priorities from the local perspective of each respondent. Two questions were used to initiate this discussion: 1) What are the three major health concerns that you believe are shared with tribal communities across the border? and 2) In your opinion, what are the highest priority areas for health research you think might be shared between AI/AN populations in the US and First Nations populations in Canada?

## MAJOR HEALTH CONCERNS

Four main areas of concern were identified by US respondents at both the federal and tribal levels.  Generally, these areas may be described as: 1) Mental and behavioral health issues; 2) Lifestyle behaviors and chronic disease; 3) Healthcare services, delivery and access; and 4) Environmental impacts.

In the US responses, some variations to the issues were area specific, such as the environmental impacts on subsistence foods in Alaska or the impact of PCB contamination on the Mohawk reservation.  Several respondents recommended a holistic approach to both understanding health needs and developing appropriate interventions.  They also described the interdependence of individuals and communities, noting the importance of addressing individual health within the context of community wellness practices.  In addition, two respondents expressed concern about emergency preparedness in response to potential terrorist activity at reservations on the border.

While the Canadian respondents had a general knowledge of the US/tribal situation, there was some reluctance to speak to ‘shared US/Canada concerns’ and as such they responded to the questions in terms of their own situations. The Canadian responses suggest two primary areas of concern which can be described as 1) suicide and mental health, and 2) diabetes. In terms of these two areas all five Canadian respondents mentioned suicide/suicide prevention, four of five mentioned mental health, and three of five mentioned diabetes.  These responses are consistent with the two top health concerns identified by the US respondents.

Other concerns mentioned by the Canadian respondents suggest potential themes related to addressing the social determinants of health/population health, behavioral health, reducing the disease burden (HIV/AIDs, TB), and addressing injuries and violence. Several respondents emphasized a preference for a prevention/resiliency focus. The Inuit respondent, whose population resides predominately in northern Canada mentioned the environmental impacts on health, access to culturally appropriate services, and the importance of ensuring specific relevance to isolated and remote communities.  NAHO’s Inuit and Metis center respondents noted the importance of addressing the current gap in health data relating to their populations and the AFN emphasized the importance of addressing the concerns already identified in the Joint US/Canada workplan (e.g. suicide prevention, Fetal Alcohol Syndrome/Fetal Alcohol Effect, and Behavioral health).

## Mental and behavioral health issues

The number one identified health concern among US and Canadian respondents was the spectrum of issues affecting mental and behavioral health. Depression, substance abuse, violence, and suicide were each identified as serious concerns for tribal communities. In addition, it was noted that these issues are linked, making it important to address them in context. A Tribal Health Director described this process, "High levels of trauma and abuse in families of origin lead to depression and anxiety that is then self-medicated by food or alcohol and drugs leading to obesity and metabolic syndrome and the resulting chronic health issues." A US Indian Health Board respondent, also identified mental health and the chain of events leading to disease and disability as a major health concern of urban Indian populations noting that, "Mental illness both of diagnosed forms such as schizophrenia and depression, as well as undiagnosed forms, such as feelings of social isolation, can prevent individuals from engaging in job training or other activities that would help improve the economic opportunities available to them."

## Lifestyle behaviors and chronic disease

Lifestyle behaviors leading to chronic disease were also identified as a major concern by respondents. Several respondents described obesity and smoking as major health concerns, identifying these behaviors as the roots of much of the chronic disease in tribal communities today. Diabetes, heart disease, and cancer, commonly associated with obesity, lack of exercise, and poor nutrition, were widely recognized as major contributors to the disease and disability burden of these communities. Asthma and other lung conditions related to smoking tobacco were also cited as health concerns.

## Healthcare services, delivery and access

Larger systems issues of poverty and limited economic infrastructure on reservations as well as health care systems concerns were boted as negatively affecting the health of tribal communities. In Alaska and some rural reservations in the lower 48, the costs of healthcare include a high price and burden of transportation which may contribute to lowered numbers of individuals accessing health care services or inability to benefit from preventive care. Across the board, the inadequacy of health care resources to meet health care needs was described as a major concern. Limited health care service availability can also support stereotypes that the American Indian community is not cared for and can reinforce emotional or social isolation and feed into the mental and behavioral health concerns identified above. Another tribal health representative noted that “there is always a struggle for funding and resources and tribes are seeking as much help as possible.” In this respondent’s community, after 15 years of waiting, a hospital has been built, but now the operational and staffing costs of the hospital are creating a new set of challenges.

### Environmental Impacts

Two communities in the US and the Inuit respondent in Canada specifically noted environmentally-related health concerns, particularly those associated with environmental contaminants. One Tribal Health Director identified environmental pollution as a primary concern, because the tribe is the site of a superfund cleanup project for polychlorinated biphenyls (PCB) contaminants. Pollution is also a major concern for Alaska Natives. Circulating heavy metal and air born pollutants deposited in the north and south poles and re-released into the food chain have influenced the subsistence foods for many Alaska villages. The link between such environmental pollution and cancer is the primary concern.

## RECOMMENDED HEALTH RESEARCH PRIORITIES

When asked what areas of research would best serve tribal and Aboriginal communities, the respondents had wide agreement and identified important considerations for the research process as well. Respondents noted the importance of involving the community in the research process and making sure that findings were presented to the community so that the community could benefit from its participation. In Canada this was described as going beyond ethics to include participation in the governance of the research process. Respondents also expressed interest in intervention and prevention strategies that are culturally specific. One US respondent described the need “to work with communities to conduct research and evaluation activities that reduce risks for disease and design education activities that help individuals take control of their own lives and impact behavior choices.” A Canadian respondent stated that resiliency research is needed to examine “how health is constructed by those who are resilient and how that can be shared.” It was recommended that research goals be "achievable within the context of the resources available" and have "practical outcomes."

The Canadian responses suggest that there is a need for a shift in the focus of existing research where necessary (e.g., current research on Aboriginal diabetes), and that gaps in current knowledge be filled (e.g., data, surveillance, indicators). The Canadian responses also suggest that research provide usable results (e.g. best practices, and improvements to service and access) and support Aboriginal participation in the research process (e.g. governance of the research process) and the provision of health services.

The US respondents also recommended that research be conducted looking at Indians as an "ethnic population," so that data could be compared to other populations or used when developing international studies. Included in such a broad description might be Native Hawaiians as well as urban Indians.

For both the US and Canada specific research areas followed the health concerns noted above and fall into the same four main categories. The Canadian research priorities were relatively consistent with the health concerns identified, and also continue to fit within the four major categories identified. As one Canadian respondent described, the research should be about "understanding the causes of those health problems...designing culturally appropriate prevention and impact reduction strategies...and training Aboriginal researchers/scientists to conduct the research."

## Mental and behavioral health issues

Behavioral health interventions focused on addressing substance abuse, violence, suicide, injury, and depression as important issues to communities across the board. One Tribal Health Director asked questions related to injury prevention that reflect suggestions made by other respondents and have application to other areas as well: What intervention strategies work? What best practices are most effective for injury prevention? What approaches have been effective in other communities and how might they be used effectively in Indian country?

Another issue that was raised was dual diagnosis of addiction and mental health needs. Determining to what extent they are separate concerns and to what extent they are interrelated would help communities learn to address each one most appropriately. In discussing mental health and suicide, Canadian respondents called for research on causes of suicide and the role of cultural factors in addressing it, as well as research on best practices and the use of community/nation based approaches. One respondent stated that there is a need for prevention and resiliency work including "large scale intervention work that goes beyond risk factors and genetics."

## Lifestyle behaviors and chronic disease

In the words of one IHS respondent, "there are thousands of ideas being circulated [about effective behavioral health interventions], but not a whole lot of data to determine what is effective or to compare effectiveness." Several respondents noted that a great deal of research and attention has been currently given to diabetes and suggested that the approach should be adjusted. This could include examining the 'stress hypothesis,' looking at groups with low/no incidence rates, and exploring alternatives to amputation as rates, largely due to complications of diabetes, remain high and create significant disability. The respondents also noted that other behavioral and chronic disease issues should be addressed as well. Suggestions for areas of research included chronic disease associated with obesity (heart disease, cancer, etc.) and tobacco smoking (asthma, cancer, etc.). Identifying trends in these chronic diseases and addressing the unique experiences of the communities that face them would be appreciated.

It was also mentioned that research on a holistic approach to individual and community health in combination would be beneficial. One respondent commented that "old ways of knowing and healing are lost." Recovering traditional knowledge of healing would benefit many tribal communities. Information that would help health care providers, lay people, spiritual or ministry people, and counselors work as a team to impact the cycle of disease would also be greatly appreciated. Several Canadian responses supported this holistic approach, including the comment about the usefulness of comparing how social, demographic, historic, and political diversity amongst native people contribute to/detract from health status.

## Healthcare services, delivery and access

Several respondents noted that it is common for individuals from Canada to access health care services in the US, especially in tribes such as the Mohawk that are divided by the US/Canada border, or in urban health care service centers. As a result, specific healthcare delivery and access issues emerge. When referral networks are not available, or there are limited services offered in one country, health care systems find it difficult to respond.

Determining and addressing barriers to health care was recommended by respondents as a priority. In Alaskan and Inuit communities research investigating health care access would also need to target the unique service delivery issues faced by communities located in geographically isolated areas and remote communities. Canadian respondents particularly supported this last comment relating to access noting several areas where research could support improved treatment access (e.g. mental health, HIV/AIDS, and diabetes) as well as Aboriginal participation in the provision of health services , such as capacity, resources, institution building, human resources, treaty basis/right to health, substandard levels, and assessing affirmative action policies.

### Environmental Impacts

For communities who know or suspect that the incidence of cancer or other chronic diseases may be related to environmental pollution, this is a major research priority. In the Billings, Nashville, and Alaska areas, research in this area was requested to determine the extent of the impact on the tribal populations. In Alaska, the Institute of Circumpolar Health is taking the lead in this area. As noted, this was both a major health concern and a priority for research for the Inuit respondents. Further study is needed.

## CONCLUSION

These summary results of the interviews are being shared only with the US and Canadian participants on the planning group for the September forum on research and with the invited participants. They are designed to assist in the development of the agenda and to inform the discussion at that session.

# Review of Literature

Based on the findings of the interviews described in the previous section and the input of the experts on the planning committee, a brief review of the health research literature in the US and Canada was conducted. The first part of this review includes an overview of indigenous health research activities in the US and Canada as well as Australia and New Zealand in the past five years. In this way, larger research trends were identified as well as research gaps. The second part of the review consists of a summary of research articles conducted in the US and Canada that reflect the research that has been published in the research priority areas identified by interview respondents and planning committee members. Those research priorities include: 1) Lifestyle related health conditions and wellness interventions; 2) Environmental impact on subsistence food, lifestyle, and wellness of Northern peoples; 3) Healthcare systems issues; 4) Mental health, behavioral health and historical trauma; and 5) Population health determinants. This second part of the review also seeks to describe the research gaps that currently exist in these priority areas.

## PUBLISHED RESEARCH ON INDIGENOUS HEALTH

Scans of the Medline database, for research pertaining to Aboriginal health, were conducted for the periods of 1990 to 2001, and 2001 to 2003. The searches encompassed Canada, Australia, New Zealand, and the US and population characteristics included Aborigines, Indians (North American), Eskimos, Inuit, and Indigenous peoples. A combination of population with country search criteria produced approximately 360 results for the time period of 2001 to 2003. For the time period spanning from 1990 to 2001, 4161 records were produced (Mexico was also included in the countries category for the 1990 to 2001 time period). The individual research pieces were assigned to different categories of research, ranging from addictions to infectious diseases to women's health.

Across all four countries throughout the 1990 to 2001 time period, a search of the Medline database revealed that the most research pertaining to Aboriginal health issues was conducted in the categories of diabetes (315 articles), child health (303 articles), and infectious diseases (279 articles). The next most commonly researched indigenous health issues were genetics (208 articles), addictions (184 articles), mental health (174 articles), health care issues (163 articles), and infant and fetal health (152 articles). Research categories that

| Country | | CANADA | UNITED STATES | AUSTRALIA | NEW ZEALAND |
|---|---|---|---|---|---|
| **Key Health Issues** | Circulatory Disease | * Leading cause of death<br>* 213.6 deaths per 100,000 | * Leading cause of death<br>* 157.1 deaths per 100,000<br>* AI/AN rate 1.2x general US rate | * Leading cause of death<br>* 154.1 deaths per 100,000 | * Leading cause of death<br>* 217.6 deaths per 100,000<br>* Maori rate 2.2x non-Maori |
| | Cancer | * 2nd leading cause of death<br>* 141.5 deaths per 100,000 | * 2nd leading cause of death<br>* 124 deaths per 100,000 | * 3rd leading cause of death<br>* 85.2 deaths per 100,000<br>* 1.3x rate of general population | * 2nd leading cause of death<br>* 201.6 deaths per 100,000<br>* Maori rate 1.6x non-Maori |
| | Injuries | * 3rd leading cause of death<br>* 123.9 deaths per 100,000<br>* FN rate 3x Canadian rate | *3rd leading cause of death<br>* 94.7 deaths per 100,000<br>* AI/AN rate 3.1x general US rate | * 2nd leading cause of death<br>* 88.9 deaths per 100,000<br>* 2.2x rate of general population | * 4th leading cause of death<br>* 58.8 deaths per 100,000 |
| | Respiratory Disease | * 4th leading cause of death<br>* 63.6 deaths per 100,000 | * Leading cause of hospitalization for AI/AN under 15 years of age | * Some communities have the highest incidence of invasive pneumococcal disease in the world | * 3rd leading cause of death<br>* 65.5 deaths per 100,000 |
| | Suicide | * 27.9 deaths per 100,000<br>* FN suicide rate 2.1x Canadian rate | * 20.2 deaths per 100,000<br>* AI/AN rate 1.9x general US rate | * Suicide accounted for 2x as many deaths as expected for females and 2.6x for males | * 12.1 deaths per 100,000<br>* Maori and non-Maori rates almost identical |
| | Diabetes | * Aboriginal diabete rate 3-5x Canadian rate | * 4th leading cause of death<br>* AI/AN rate 1.9x general US rate | * 5th leading cause of death<br>* 6x rate of general population | * 55.8 deaths per 100,000<br>* Maori rate 6.3x non-Maori |
| **Focus of Current Research** (# of articles in Medline Database, 2001-2003) | | Health Care - 6 articles<br>Women's Health - 6 articles<br>Diabetes - 5 articles<br>General Health - 5 articles | Diabetes - 16 articles<br>Addictions - 13 articles<br>Cardiovascular Health - 11 articles<br>Cancer - 9 articles | Health Care - 14 articles<br>Children's Health - 11 articles<br>Diabetes - 9 articles<br>Addictions - 8 articles | Nursing Care - 12 articles<br>Health Care - 9 articles<br>Addictions - 5 articles |
| **Gap Analysis** | | * No Canadian research has been conducted on cancer, addictions, adolescent health, or chronic diseases<br>* 2 articles on injuries and 1 on suicide | * Minimal research has been produced regarding children's health, chronic diseases and injuries | * No research on injuries, cancer, or elderly care<br>* 1 article addressing the issue of suicide among Australian Aboriginals | * No research on chronic diseases, injuries, mental health (including suicide), or traditional medicine<br>* 3 articles on cardiovascular health and 3 on cancer<br>* 1 article on respiratory disease |

received significantly lower amounts of research throughout this time period included cardiovascular health (81 articles), traditional medicine and healing (48 articles), injuries (40 articles), and preventative medicine and behavior modification (26 articles).

For the time period of 2001 to 2003 there has been a shift in research priorities. In the last three years, the international community has focused indigenous health research on health care issues (36 articles), diabetes (27 articles), addictions (26 articles), nursing issues (23 articles) and cardiovascular health (22 articles). Eighteen articles addressed the issue of child health throughout this time frame, which is still a significantly larger amount of research than has been awarded to issues such as cancer (12 articles), mental health (10 articles), infectious diseases (ten articles) and injuries (four articles).

The table on the preceeding page provides a summary of the key health issues for the indigenous populations in Canada, the United States, Australia and New Zealand. Also included is a brief look at the most predominant research areas found in the Medline Database for the last three years for each country. Often there is a discrepancy between key health issues and the research that has been conducted.

## OVERVIEW OF INDIGENOUS HEALTH RESEARCH PRIORITIES

Based on the findings of the US and Canada health research interviews, five health research priority areas were identified. These areas were used to guide the literature review that follows. Representative articles from the US and Canadian indigenous health research communities were selected in each priority area. A general description of these five area follows.

### Lifestyle-related health conditions and wellness interventions

This topic includes disease and disability related to lifestyle such as obesity, diabetes, heart disease,and cancer. It also includes the successful and culturally appropriate wellness interventions that have been developed to address these conditions in tribal communities.

### Environmental impact on subsistence food, lifestyle, and wellness of Northern peoples

Due to the circulation of global pollutants to the North and South poles where they are reintroduced into the food chain, native peoples who rely on subsistence foods for survival may have elevated levels of toxins in their bodies. This topic includes health issues associated with climate change.

### Healthcare systems issues

Access to healthcare in tribal communities, remoteness of tribal populations, workforce capacity, service delivery, telemedicine, alternative care, transportation, and funding are all issues that would be included in this topic.

### Mental Health/ Behavioral Health and Historical Trauma

This topic would include the chain of issues influencing native communities such as alcohol and substance abuse, depression, social isolation, mental illness, and behaviors related to these conditions such as suicide, domestic violence, and accidents. These topics may also be included in the first category.

### Population Health Determinants

Included in this category is the infrastructure that supports health, including adequate employment opportunity, housing, and water, as well as the support network available to those who are not currently experiencing health and that is accessible to help them recover. This area includes the sociocultural context in which tribal communities exist, the political environment, the role of tribal communities in research, and the ways in which health is linked to the amount of community involvement in the research process.

## RESEARCH SUMMARY: CANADA

Fourteen articles were reviewed on the status and type of research available in Canada on the research priorities described above. Summaries of these descriptions are provided by category. The authors name and title of the research article is used to identify the article. Bibliographic information can be found in the references section of this briefing book. Articles were selected as representative of the type of research currently available on these topics. Summaries are not meant to provide comprehensive or critical review of the study data quality or methods.

## Health Research Ethics

*Castellano, M.B. "Ethics of Aboriginal Research"*

All Aboriginal research must be grounded in the context of the particular cultural world view and the struggle for self-determination shared by Aboriginal peoples. Aboriginal peoples have a right to participate as partners in research that generates knowledge which affects their culture, identity, and well-being.

There are a number of shortcomings with current Canadian ethical guidelines and their administration, as defined by the Tri-Council Policy Statement:

- Ethical guidelines are administered on a voluntary basis through a mix of different procedures and institutions;
- Once a research proposal has been approved by a university ethics committee, there is no provision for monitoring how the research is actually conducted;
- Ethics committees appear to focus on the procedure to be used to obtain informed consent from participants, the ethical character of the project itself is generally not examined;
- There are few sanctions to discipline researchers who violate existing ethical guidelines; and
- Research funded by individuals or corporations independent of a university or research institute is not subject to publicly approved ethical guidelines.

Aboriginal academics, professionals, service providers, and political leaders are rediscovering and updating traditional ethics, challenging the assumptions of research that is rooted in a scientific world view that clashes with Aboriginal values. For example, the ethics of non-interference found in Iroquoian, Cree, and Ojibway peoples inhibits argument and advice-giving as normal means of communication. This type of information about cultural norms has particular relevance for researchers and professionals offering services to Aboriginal peoples.

Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable. Applied research is demonstrating that when learning, healing, or rehabilitating is aligned with traditional ethics and values, it achieves greater positive outcomes.

## Northern Environment

*Jenkins, A.L. et al. "An Overview of Factors Influencing the Health of Canadian Inuit Infants"*

Inuit infants in the Arctic experience higher mortality and poorer health than their non-Inuit counterparts. Despite significant advances in standards of living and health care delivery, Inuit infants suffer disproportionately from bacterial and viral infections, which account for much of the excess morbidity and mortality compared to other Canadian infants. A range of inter-related factors may influence the susceptibility of Inuit infants to infection:

- Poverty, low educational attainment, and unemployment can all adversely affect health outcomes, which in turn influence personal health practices such as smoking, alcohol dependence, and breast-feeding;

- Inuit people are more at risk of exposure to environmental contaminants through their traditional diet of fish and marine mammals, where contaminants tend to accumulate;

- Inadequate housing, over-crowding, and inadequate water supply and sewage disposal systems are major problems which could contribute to the overall higher rates of infectious diseases among the Inuit living in the north; and

- Geographic remoteness, communication problems, differences in values, attitudes and beliefs, and the existence of racism and prejudice all act as barriers to Inuit access to high quality, culturally appropriate health care.

Locally-driven, focused, and methodologically sound epidemiological research that addresses key gaps in knowledge could lead to more appropriate and effective preventive strategies to improve health in Northern communities. Suggested areas for future research include:

- Assessing the potential relationship between iron deficiency anemia and/or vitamin A deficiency and immune function in Inuit infants;
- Evaluating the potential role of environmental contaminants in increasing susceptibility to infection;
- Measuring the contribution of household crowding to rates of infection;
- Clarifying the role of tobacco smoke as a risk factor for infections and SIDS in Inuit communities;
- Determining the impact of infant adoption, and the subsequent lack of breast feeding, on infection rates in Inuit infants; and
- Exploring whether early acquisition of viral infections predisposes Inuit infants to secondary infections.

*Webster, Paul. "For Precarious Populations, Pollutants Present New Perils"*

The largest study of Arctic pollutants revealed that northern populations may be at risk of serious health hazards. For the first time, pesticides, PCBs and mercury have been linked to weakened immune systems and developmental deficits in Inuit children. The study also identifies many other compounds that could pose a long-term threat to humans and wildlife. These findings were presented in March 2003 and were the result of Canada's ten-year, $38 million Northern Contaminants Program.

## Health Care System

*Lemchuk-Favel, L. "Aboriginal Health Systems in Canada: Nine Case Studies"*

Existing Aboriginal-specific health systems in urban and rural First Nations communities must address the following challenges to be effective: the health needs of Aboriginal peoples and their cultural uniqueness, federal and provincial roles in health service delivery, and the physical geography of many Aboriginal communities.

The strengths of Aboriginal-controlled health systems include holism, synergy of western and traditional health philosophies, focus on primary care, collaboration with provincial services, integrated service delivery, and administrative reform.

Aboriginal health systems must contend with the challenges of low population health status, small community size, remoteness, lack of human resources including Aboriginal health professionals, a growing and aging population, inadequacy of funding coupled with non-sustainability of the system, and jurisdictional barriers.

The paper presents nine case studies showing successful approaches to Aboriginal health systems that provide effective, responsive, and culturally-appropriate health services. Examples of successful approaches to Aboriginal health systems include:

- Development of a single entry point into the mental health and social services system;
- Processes to obtain community input, which also reduces community resistance to change;
- Flexible program structure that is respectful of community needs and is subject to regular reviews, which may result in the closure of programs no longer deemed necessary for the community;
- Development of community-based midwifery education and with it the return of community expertise in birthing practices;
- Adjustment from a physician-centred primary care model to one that includes nurses in expanded roles in response to significant shortages of physicians;
- Building of partnerships with post-secondary education associations to aid the recruitment of Aboriginal people into health careers, such as nursing; and
- Inclusion of culturally-specific training tailored to the community (i.e. Inuit-specific health care training) as a component of new programs, such as community crisis response teams.

Aboriginal health systems in Canada must accommodate vast differences in cultural expectations, jurisdictional complexity and geographic diversity.

**Research gaps**: Development of effective recruitment and retention strategies for Aboriginal health careers.

*Minore, B. et al. "Facilitating the Continuity of Care for First Nation Clients within a Regional Context"*

There is evidence of many disruptions in the continuity of health care in remote First Nations communities. These disruptions are often the result of a combination of geographic isolation, staffing instabilities, and focus on acute rather than preventive care.

The small size and remote location of these communities results in reliance on a "fly in-fly out" model of care where access may be dictated by weather conditions. Isolation also makes it difficult to recruit health professionals who are willing to serve remote communities for a reasonable period of time. As a result, staffing instability limits services to providing treatment, rather than prevention, detection, or client education.

Challenges in continuity of health care include:

- Staff instability and turnover;
- Access to client information;
- Delays in the flow of information due to clients moving between community-based primary care and tertiary care in larger regional centres;
- Expenses associated with constant staff recruitment; and
- Lack of attention given to chronic and public health care.

Despite these challenges, comparably good continuity of care is achievable in First Nations communities. However, the treatment of mental health is generally poor. The incidence of suicidal behaviour among youth is so high that the mental health care system functions in crisis mode only. Emergency interventions occur, but there is little capacity for prevention or follow-up.

Continuity of care depends on having adequate, appropriate, and well-prepared staff at the local level and effective communication between primary and tertiary care centers. The ideal is to recruit and retain staff who are knowledgeable about the unique requirements of highly independent northern practice. Even those hired to provide short-term coverage must use holistic approaches to care. Continuity depends on local paraprofessionals being recognized, accepted, and supported by professionals, both inside and outside the community. Given the problems associated with attracting health professionals, appropriate use must be made of health caregivers from the community.

**Research gaps**: Health human resource issues must be researched as they are an underlying source of gaps and an overarching area of policy concern. The chronic nature of staffing shortages, the consequences of short-term staffing and continuous turnover among providers must be addressed. Two studies are suggested: 1) most effective mechanisms to introduce content relevant to practice in northern communities into the curriculum of undergraduate programs in the health sciences and medicine, and 2) identify core knowledge that all practitioners must have procedural, cultural, and clinical essentials.

## Mental Health

*Kirmayer, L. et al. "The Mental Health of Aboriginal Peoples: Transformations of Identity and Community"*

Aboriginal peoples suffer from a range of health problems at higher rates than occur in the general Canadian population. Cultural discontinuity, a history of social dislocations, and the disruption of historical subsistence patterns and connection to the land have been linked to high rates of depression, alcoholism, suicide, and violence in many communities, with the most profound impact on youth. Despite these challenges, many communities have done well and research is needed to identify the factors that promote wellness. Cultural psychiatry can contribute to rethinking mental health services and health promotion for Indigenous populations and communities.

Most estimates of the prevalence of psychiatric disorders are based on rates of service use, but since many Aboriginal people never seek treatment, service utilization is, at best, a low estimate of the true prevalence of distress in Aboriginal communities. The wide variation in suicide rates and other indices across Aboriginal communities makes it important to consider the nature of communities and the different ways in which groups have responded to the ongoing stresses of colonization, sedentarization, bureaucratic surveillance, and technocratic control.

An important aspect of the recent history of most Aboriginal communities is the rapidity with which social and cultural change has occurred, introducing the forces of globalization to even the most remote communities. These changes affect the whole population; therefore, mental health services and promotion must be directed at both individual and community levels. However, conventional models of service and health promotion require rethinking in order to be consonant with Aboriginal values and aspirations. For example, in most urban areas mental health services have not been adapted to the needs of Aboriginal clients; this is reflected in low rates of use.

There is evidence that local control of community institutions and cultural continuity may contribute to better mental health in Aboriginal communities.

**Research gaps**: What is the effect of "community-level factors" on mental health generally, and more specifically, on suicide rates (i.e. Quebec: Inuit, Attikamekw and several other Nations have very high rates of suicide while the Cree have rates no higher than the rest of the province)? Differences between communities need to be studied through "systematic comparisons of the communities." The different ways in which groups have responded to the ongoing stress of colonization, sedentarization, bureaucratic surveillance, and technocratic control need to be studied.

*Six articles were reviewed in this section*

Despite the fact that suicide is one of the leading causes of death amongst Aboriginal people in Canada, research concerning Aboriginal suicide prevention is very limited in this country. There are only a few significant reports that have been produced on this health issue over the last few years.

Recent Aboriginal suicide prevention research in Canada includes:

- a study of the history of the community approach to suicide prevention in Canada;[7]
- a study on healing through occupation in Canadian Inuit;[8]
- a study of attempted suicide among Inuit youth, with implications for prevention;[9] and
- a study that looks that the healing experiences of British Columbian First Nations women.[10]

In March 2003, experts from around the circumpolar world gathered in Iqaluit for the "Best Practices Suicide Prevention and Evaluation of Arctic Suicide Prevention Programs" workshop. The workshop report[11] presents 19 actionable recommendations that fall into two main themes, culturally appropriate prevention and cooperation around the Arctic. Research specific recommendations include: the need to conduct culturally sensitive and culturally appropriate research into the causes of suicide; and, the need to examine how having spiritual life can be preventative and enriching.

## Lifestyle Related

*Green, C. et al. "The Epidemiology of Diabetes in the Manitoba-Registered First Nation Population"*

A recent article on diabetes among First Nations in Manitoba highlights key issues around diabetes among First Nations in Canada. Although the prevalence of diabetes rose steadily in both the First Nations and the non-First Nations populations between 1989 and 1998, the epidemiological pattern of diabetes in these two populations differed significantly. The prevalence rates of diabetes for the First Nations population was up to four and one half times higher than those found in the non-First Nation population. The sex ratio and the geographic patterning of diabetes incidence and prevalence in the First Nations and non-First Nation study populations were reversed. In the First Nations population, both incidence and prevalence of diabetes were higher among women than in men. The opposite trend was observed in the non-First Nations population.

The results of the study suggest that diabetes prevalence will likely continue to rise in the Manitoba First Nations population into the foreseeable future. As a result, the health burden due to all types of diabetic complications will likely continue to rise in First Nations populations. The negative impact of this rising diabetes prevalence can only be effectively managed through a population-based public health approach which focuses on primary and secondary prevention.

Recommendations for health care and social service systems presented by the authors include:

- Preparations to provide secondary prevention and support systems to maintain quality of life for those with diabetes, including diabetes-screening programs, foot-care programs, accessible dialysis services, dietary counselling services, and enhanced infrastructure at the community level to facilitate independent living by adults with limited mobility and eyesight; and

- "Upstream" population-based primary prevention programs implemented aggressively to ensure that diabetes incidence among First Nation populations begins to decrease in the future. Prevention programs that draw on Aboriginal customs and ways of life and focus particularly on Aboriginal youth need to be implemented.

The dramatically higher rates of diabetes in Manitoba First Nations population as compared with the non-First Nations population highlight the urgency of this problem.

**Research gaps**: Community and individual-level factors that appear to alter some First Nations population groups risk for developing diabetes need to be analyzed. First, lower prevalence of diabetes in northern and remote areas suggests that living in these areas has a protective effect on diabetes. Research is needed to determine whether this is due to a greater adherence to traditional lifestyle practices (such as hunting, fishing, and consumption of wild game) or whether it is due to broader community level factors or alternatively to genetics. Second, the higher prevalence of diabetes in First Nation women needs to be understood. The relationship to earlier episodes of gestational diabetes should be investigated as one possible pathway that increases susceptibility of First Nations women to diabetes.

## Population Health

*Wilson, K. and Rosenberg, M.W. "Exploring the determinants of health for First Nations peoples in Canada: can existing frameworks accommodate traditional activities?*

While much research has examined First Nations peoples' health in Canada, few studies have explored the role of traditional activities in enhancing health. Research on the determinants of health helps to identify and explain health inequalities but few studies have incorporated culture into analyses of health. Individuals who are involved in traditional activities have been shown to be less likely to report their health as unhealthy compared to those who are not involved in traditional activities.

Attachments to traditional activities vary by gender. Men tend to spend more time living on the land, hunting, fishing, and trapping relative to women, regardless of age. Attachments to traditional activities also vary by geography. A much higher percentage of individuals living on-reserve report spending time undertaking traditional activities compared to those in urban and off-reserve communities. Visiting a physician has been found to be significantly related to health status, but only on-reserve. Overall, determinants of health are better predictors of 'unhealthy' health status on-reserve, rather than in urban and off-reserve communities.

The majority of variables that are statistically related to First Nations peoples' health (i.e., age, income, education, employment, utilization of health care, and place of residence) are similar to variables that are commonly shown to be determinants of health for the general Canadian population. This implies that the health of First Nations peoples is dependant on similar determinants of health as those found for the Canadian population in general. It follows that the same policies and programs used to improve the health of Canadians in general should be sufficient to improve the health of First Nations peoples. However, a comparison of the evidence on morbidity and mortality between the two populations does not support this.

**Research gaps:** If the analysis of First Nations peoples' health is to move from a focus on traditional activities to cultural attachment, future population health surveys will need to take into account other potentially important cultural determinants of health (i.e., participation in sweat lodges, use of traditional medicines, offering of tobacco).

*Mignone, J. "Measuring Social Capital: A Guide for First Nations Communities"*

Social capital emphasizes the social dimension of life and they way that people interact. In general, the more social capital there is in a community, the better that community is for its population's health. A community with high levels of social capital would be expected to have a culture of trust, participation, collective action, and norms of reciprocity. There is evidence that these aspects of social capital influence health positively, while low levels of social capital can have a negative impact on health. There are five elements that compose a community's social capital: social relationships, social networks, social norms, trust, and resources.

Policy decisions can intentionally or unintentionally strengthen or weaken community levels of social capital. The ability to measure social capital has the potential to be useful for understanding why some communities are healthier than others.

A research tool to measure social capital within First Nations communities has been developed by researchers at the Centre for Aboriginal Health at the

University of Manitoba. The measurement tool can help communities to:

- Identify the relative strengths and weaknesses of communities;
- View the social effects of policies;
- Guide and prioritize action within and between communities;
- Clarify decisions in the path towards self-governance;
- Analyze an entire territory using a standardized approach;
- Establish baseline measures for social capital and improving health; and
- Get a better understanding of how to implement policies and programs to improve social capital and health.

**Research gaps:** Understanding of social capital and the tools for its measurement need continual improvement, ongoing evaluation, measurement refinement, and validation.

## RESEARCH SUMMARY: UNITED STATES

Nine articles were reviewed on the status and type of research available in the US on the research priorities described above. Summaries of these descriptions are provided by category. The author's name and title of the research article is used to identify the article. Bibliographic information can be found in the reference section of this briefing book. Articles were selected as representative of the type of research currently available on these topics. Summaries are not meant to provide comprehensive or critical review of the study data quality or methods.

### Lifestyle Related

*Howard, Barbara. et al. "Rising Tide of Cardiovascular Disease in American Indians: The Strong Heart Study"*

*The Strong Heart Study*, undertaken in 1988, provides significant weight to the current understanding of heart disease within the AI/AN population. The study was designed to investigate cardiovascular disease (CVD) and its risk factors, to identify differences in CVD among the four study centers, and to determine if the differences in known risk factors explained well-established variation in incidence. For study purposes, the definition of CVD was broad and included heart attack, congestive heart failure, and stroke. For event measurement purposes, it included all survivors as well as those who died during the examination period. The largest of its kind, the *Strong Heart Study* included data gathered from three time-separated physical examinations given to 4,549 American Indian men and women between the ages of 45-74. These participants were from 13 American Indian tribes in three distinct geographic regions that also acted as study centers: Arizona, Oklahoma, and South Dakota/ North Dakota. Among its most important conclusions, the *Strong Heart Study* showed the dramatically increased incidence rates of CVD among American Indians compared to other populations and confirmed that diabetes is a significant risk factor for CVD in this population, with diabetes contributing substantially to this rising incidence of CVD.

The expanded scope of the *Strong Heart Study* has provided a rich data set from which to make reliable assessments and conclusions about CVD, its risk factors, and related conditions in American Indian and Alaska Native populations. In addition to examining conditions of the heart, the *Strong Heart Study* examined self-reported rates of emphysema, arthritis, cancer, and gallstones. The study also looked at knowledge of CVD and its risk factors. While it found a high level of knowledge regarding these risk factors, including high blood pressure, diabetes, high blood cholesterol, stress, inactivity, and smoking, the study concluded that "changing high-risk behaviors is very difficult at both the individual and community level." In areas of measured data, the study looked at total cholesterol levels, low density lipoproteins (bad cholesterol) and high density lipoproteins (good cholesterol), triglyceride levels, and the prevalence of overweight and obesity. Other risk factors examined within the study included environmental and lifestyle risk factors. Tobacco and alcohol use, nutritional intake including level of saturated fats, cholesterol, calcium, sodium, salt, zinc, potassium, vitamins, and physical activity were all measured as part of the *Strong Heart Study*. In nearly all instances, the studied populations experienced standards of nutritional performance that were far below the recommended daily allowances.

There were few comparisons within the *Strong Heart Study* to the larger US population. One such comparison, however, found that mild ventricular dysfunction, that is a reduced ability to pump blood with each heart beat, among the American Indian men studied was 50 percent higher (Arizona) to 350 percent higher (Dakotas) compared with a similarly-aged New York City population. Similarly, the prevalence of mild to severe ventricular dysfunction was significantly higher among American Indian men compared to American Indian women.

Although very difficult and expensive to achieve, the *Strong Heart Study's* impact would be greatly strengthened through regular comparison in each of these data sets to the US population overall; what is indisputable, however, is the rapidly increasing incidence of the metabolic syndrome diabetes, and CVD within this population. Chapter five of the *Strong Heart Study* Data book is devoted to "diabetes prevalence and diabetes-related variables." Diabetes rates varied widely from nearly 65 percent in the Arizona group to 32 percent in the Dakotas's population among men, and 71 percent and 43 percent respectively among the women studied. The Strong Heart Study confirms that the emergence of CVD as the major health threat to Native American populations is closely related to the rapid increase in the incidence of diabetes among these populations.

Perhaps the most valuable contribution of the *Strong Heart Study* has been the nearly 70 peer-reviewed journal articles that drew upon the study's data. Among the most important of these is Howard, et al.'s article examining the basis for what it characterizes as a "rising tide" of CVD mortality rates among American Indian communities. The clinical literature long held that American Indian populations had an inherent protection against cardiovascular disease and early data from the IHS and other studies indicates very low rates. Current analysis from the *Strong Heart Study*, however, suggests that contrary to other populations in the US, cardiovascular disease is rapidly increasing within American Indian populations and the incidence rates are almost double that of the general US population. In addition, there is a significant contribution of diabetes to this rapidly increasing trend. Indeed, 56 percent of all CVD events in men and 70 percent in women in the *Strong Heart Study* occurred in individuals with diabetes.

Howard et al's *The Rising Tide* hypothesizes that hyperglycemia, that is abnormally high concentrations of glucose in the blood, may contribute to atherosclerosis (build-up of deposits on the walls of the arteries) by interfering with normal endothelial function that is the function of the cells lining the walls of the heart and the lymph and blood vessels. Howard, et al., also hypothesize that albuminuria, which is the abnormal leakage of albumin (a protein) from the kidneys into the urine, and is an indicator of microvascular disease in the kidneys, may also be an indicator for vascular disease in other organs such as the heart. This study notes, "The consistent finding of albuminuria as a major risk factor further emphasizes the importance of measuring urinary albumin in clinical assessments of individuals with diabetes and applying aggressive measures to attempt to retard the progression of microvascular disease as a strategy to control coronary disease." *Rising Tide* concludes that "even in those populations that may have had an innate protection" against CVD, that protection may be "overridden by diabetes."

*Gilliland, Susan et al. "Strong in Bodyand Spirit: lifestyle intervention for Native American adults with diabetes in New Mexico"*

Few studies specific to AI/AN communities have been conducted with the objective of determining the impact of behavioral interventions on chronic disease or risk factors for disease. While interventions that emphasize a combination of diet, physical activity, and clinical treatment may offer the greatest potential for reducing risk factors for diabetes related complications, they are often viewed as impossible to achieve. Nevertheless, this study demonstrates that lifestyle intervention has the potential to substantially reduce microvascular complications, mortality, and health care utilization and costs if change is sustained over time.

This study shows that positive effects on health are achieved through lifestyle intervention and suggests that the planning and preparation process is important to achieving these results. This intervention was designed as a communit- based model focusing on small changes over time. The eight communities participating in the study had all expressed interest in participating in the testing of this model and the intervention materials were designed and developed with input from focus group sessions of community members to determine preferences. Traditional native storytelling was used to present information. Traditional foods and physical activities were integrated into the curriculum and videos were used that showed Native American individuals engaging in healthy behaviors. In these ways the intervention proved culturally relevant and of value to participants. Culturally appropriate interventions need to consider the specific tribal community in order to have the best results.

**Research gaps:** Culturally appropriate and clinically comprehensive interventions designed for subset populations that may have greater treatment resistance such as men or younger people.

## Mental Health/ Historic Trauma

*Yellow Horse Brave Heart, Maria and Lemyra DeBruyn "The American Indian Holocaust: Healing Historical Unresolved Grief"*

A long legacy of chronic trauma and unresolved grief across generations resulted from the losses of lives, land, and culture experienced by American Indians. Viewing the current health status of AI/ANs through this lens of loss and unresolved grief shows that healing must be holistic in nature addressing not only the physical symptoms of disease but also its mental, emotional and spiritual roots. This article explores the extent of loss and trauma experienced by American Indian communities as well as acknowledging the "disenfranchised grief" that resulted from the inability to openly acknowledge and publicly mourn these losses through ritual, mourning, and ceremony. Such historic losses are compounded by the traumatic losses of relatives and community members through alcohol-related accidents, homicide, and suicide.

In response to this pervasive experience of grief, models have been developed to bring resolution to grief using clinical and traditional American Indian interventions as a catalyst for healing. Healing processes at the community, family, and individual spheres must be engaged. By healing past trauma, it becomes possible to provide the positive and healthy community activism necessary to transform the health of the community in the present time.

**Research gaps:** Considering addiction, violence, and other chronic disease through the lens of historic trauma and grief offers an important perspective to inform interventions developed to address these health issues in the present time. Research studying interventions using appropriate healing response to these issues may be useful to communities who are attempting to move forward and encourage community members to adopt healthy lifestyle patterns.

*Frank, John, Roland Moore and Genevieve Ames "Historial and Cultural Roots of Drinking Among American Indians"*

While extensive research has been conducted on the topic of alcohol and substance abuse in AI/AN communities, the issue remains a significant concern and cause of poor health for individuals and communities. Treating addiction within the larger conceptual framework of the physical and social environmental factors influencing health and acknowledging the role of historic trauma and grief is an approach that has had the best response in community and warrants further study. In particular, efforts to resist substance abuse through identification with traditional spirituality has shown promise. Understanding the regional variations in culture, economy, and history may help to understand the variations in addiction that are charted across service areas.

## Enironmental Impact

*Health Research in Alaska: A Report in Response to SJR 44*

Over the last50 years, Alaskan citizens have enjoyed dramatic gains in health status, yet retain high rates of violence, injury, and substance abuse. In addition, chronic health conditions are emerging in previously healthy populations, and some infectious diseases threaten to re-emerge. While NIH has helped to fund research activities in the state, research needs remain in the areas of bio-medical, injury surveillance and prevention, behavioral health, health services, disability, gerontology, and maternal and child health. Health disparities between Alaska Native and white populations exist, particularly for the indicators of malignant neoplasms, heart disease, unintentional injury, suicide, and alcoholism.

Impacts of pollution of subsistence foods and the resulting contaminant exposure is a topic of current concern. Proposed research projects address the traditional foods of communities and estimate the contaminant level of these foods. Contaminants in air and wildlife are another source of concern. Research determining the comparative risks and benefits of eating specific wild foods may be valuable.

The large impact of global climate change is another candidate for research which affects health disparities in Alaska. The influence of arctic climate change on the ecosystem may in turn affect human health if traditional food supplies are changed and dietary patterns and cultural practices are influenced.

*Peter Stenlund "The Arctic Council and Health Issues"*

The interdependence of environment and the health of Alaska Natives is recognized by the Arctic Council, a forum for cooperation between national governments and indigenous peoples in the Arctic. The US and Canada are two of the eight member nations and share the mandate to tackle the health problems that affect the residents of the Arctic. With the development of sensitive and specific biomarkers, however, rates of exposure in some parts have been found to be at higher concentrations than in the lower latitudes. With some contaminants acting as endocrine disrupters, it is possible that these contaminants act as co-factors in the development of hormone related cancers, altered immune status, and reduced fertility.

**Research gaps:** Details and knowledge about the connection between mortality and morbidity rates and risk factors specific to the Arctic. Clinical evidence linking health effects in children and adults to levels of exposure to contaminants.

## Healthcare Systems

*Dixon, Mim and Yvette Roubideaux "Promises to Keep: Public Health Policy for American Indians and Alaska Natives in the 21st Century"*

Dixon and Robideaux's seminal study of the health care system for AI/ANs traces the evolution of the current system from its early days under the Bureau of Indian Affairs (BIA) to its more recent emergence as a largely tribally-managed health system. Comprehensive in scope, in 12 highly readable chapters it covers the historical development of and legal basis for Indian health care; examines the unique systems challenges facing native peoples in the US; describes the cultural, financial and geographic barriers to access; explores the impact of specific disease states on Indian people; inspects specific population subsets including urban Indians and Elders; and studies in-depth the changing nature of health care delivery in Indian Country that is resulting from fuller implementation of the Indian Self-Determination and Education Assistance Act (PL 93-638).

Tribal sovereignty, the federal trust responsibility and the unique government-to-government relationship are the foundations of the health care system for AI/AN peoples. These principles underscore understanding of all issues explored within *Promises to Keep* while providing the framework for the policy recommendations that follow each chapter. For example, in exploring "The Unique Role of Tribes in the Delivery of Health Services" (Chapter 2), Dixon suggests that only by truly understanding the unique role of tribes and federal and state agencies, can policies be developed that "enhance the Indian health system." Similarly, the chapter on behavioral health (Chapter 7) ascribes the shortcomings in mental health services for Indians to the failure of the relationship between states, the federal government, and tribes while holding out hope for the future of behavioral health services in the seeds of self-determination.

Amidst all the depressing statistics that too frequently encompass the research and dialogue around the status of health and health care for AI/ANs, *Promises to Keep* is unequivocal in its findings that self-determination is a positive good for health care delivery: Contracting or compacting tribes offered more new programs, more new facilities and were perceived by users to provide superior services than those directly managed by the IHS (Chapter 4).

As the comprehensive primer on health policy forAI/ANs, *Promises to Keep* is unique and is thus the starting point for any in-depth study of the health and health care issues facing AI/AN peoples. Building on 25 years of experience with tribally-operated health care systems, *Promises to Keep* charts a course for public policy that would reduce the disparities in funding and health status among AI/ANs and the general population.

*U.S. Commission on Civil Rights "Broken Promises: Evaluating the Native American Health Care System"*

*Broken Promises* is the sequel to the excellent study, *Quiet Crisis*, also by the US Commission on Civil Rights. *Quiet Crisis* examined the across the board failure of the federal government to meet the needs and to address its treaty obligations to the 556 federally recognized tribes in the US. While *Quiet Crisis* looks at all federal funding including the Departments Of Interior, Health and Human Service, Housing and Urban Development, Justice, Education, and Agriculture,[3] *Broken Promises* confines itself to the federal government's responsibility for Indian health and health care. The US Commission on Civil Rights is a bi-partisan body, appointed by the President and the Congress whose mission includes "To study and collect information relating to discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice." Taken together, these two studies are a damning indictment of the federal government's commitment to meet its treaty obligations.

Chapters 1 through 4 regurgitate the familiar litany of depressing statistics regarding the status of AI/AN health and health care delivery. Chapter 1 looks at specific disease states and the federal responsibility for health care in Indian Country while Chapter 2 looks at specific social and cultural barriers to access that also contribute to the disparities in health status between AI/AN and the remainder of the US population. Chapter 3 examines structural barriers to health care including the shortage of and geographic remoteness of health facilities, and the lack of adequate funding for the IHS which contributes to waiting times, lack of access to specialist care and dilapidated facilities. Chapter 4 explores the financial barriers to adequate health care services, noting that the Level of Need Funded (now referred to as the Federal Disparity Index or FDI) is currently running at 52 percent of need while revealing in sharp detail specific areas of severe want including funding for most hospital and specialty care services (Contract Health Services), Contract Support Costs (which have not been funded in several years) and most spectacularly for urban Indian programs.

Chapter 5 makes distinct proposals for legislative changes “with the potential to significantly affect the delivery of health services to Native Americans.” The most significant recommendation is the reauthorization of the Indian Health Care Improvement Act including provisions to strengthen scholarship programs for health professionals, institutionalizing the national diabetes program and decentralizing the Catastrophic Health Emergency Fund, institutionalizing tribal consultation for health facilities expenditures, eliminating barriers that prevent AI/AN from accessing public health insurance programs, expanding funding for urban Indian health centers, elevating the director of the IHS to an assistant secretary position within HHS, and establishing a continuum of care model for behavioral health.

**Research gaps**: Of the several hundred programs funded by the DHHS, AI/ANs are eligible for 123. However, AI/AN communities accessed only 76 of these discretionary grant programs.  Of these 76, 24 only awarded one or two grants to AI/AN communities. Funding for the IHS alone is unlikely to ever address the unmet needs of AI/AN peoples. The disparity in funding for other programs for which these populations are eligible is an urgent issue for research and correction.

# References

## US RESEARCH ARTICLES

U.S. Commission on Civil Rights. (2 July, 2004). Broken Promises: Evaluating the Native American Health Care System.

US Commission on Civil Rights. (July 2003). A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country.

Howard, Barbara V., Lee, Elisa T, Cowan, Linda D, Devereaux, Richard B, Galloway, James M., Go, Oscar, Howard, William James, Rhoades, Everett, Robbins, David, Sievers, Maurice, Welty, Thomas. (1999). Rising Tide of Cardiovascular Disease in American Indians: The Strong Heart Study. *Circulation*, 99, 2389-2395. Website: http://circ.ahajournals.org/cgi/content/full/99/18/2389

Indian Health Service. (May 14, 2002). Secretary Thompson Signs Agreement with Canada on Indigenous Health during 55th World Health Assembly. HHS Press Office. Website: http://www.hhs.gov/news/press/2002pres/20020514.html

Memorandum of Understanding between the Department of Health and Human Services of the Government of the United States of American and Health Canada of the Government of Canada.

Gilliland, Susan, Georgia Perez, Stanley Azen and Janette Carter. (January 2002). Strong in Body and Spirit: Lifestyle intervention for Native American adults with diabetes in New Mexico. Diabetes Care, 25 (1), 78-83.

Yellow Horse Brave Heart, Maria and Lemyra DeBruyn. (1998). The American Indian Holocaust: Healing Historical Unresolved Grief. American Indian and Alaska Native Mental Health Research, 8 (2), 60-82.

Frank, John, Roland Moore and Genevieve Ames. (March 2000). Historical and Cultural Roots of Drinking Among American Indians. American Journal of Public Health, 90 (3), 344-351.

Stenlund, Peter. (2002). The Arctic Council and Health. International Journal of Circumpolar Health, 61, 88-91.

Dixon, Mim and Yvette Roubideaux. (2001). Promises to Keep: Public Health Policy for American Indians and Alaska Natives in the 21st Century. American Public Health Association: Washington, D.C.

Indian Health Service. (April 2003). Indian Health Service: A Quick Look.

## CANADA RESEARCH ARTICLES

Cooperation Agreement between 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).

Reading, Jeff and Earl Nowgesic. (September 2002). Improving the Health of Future Generations: The Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health. *American Journal of Public Health,* 92 (9), 1396-1400.

Reading, Jeff. (May-June 2003). A Global Model and National Network for Aboriginal Health Research Excellence. *Canadian Journal of Public Health,* 94 (3), 185-189.

Ring, Ian & Ngiare Brown. (23 August, 2003). The health status of indigenous peoples and others. *British Medical Journal*, 327, 404-405.

Young, T Kue. (23 August, 2003). Review of research on aboriginal populations in Canada: relevance to their health needs. *British Medical Journal*, 327, 419-422.

Cunningham, Chris, Jeff Reading & Sandra Eades. (23 August, 2003). Health research and indigenous health. *British Medical Journal*, 327, 445-447.
Fabsitz, Richard. (28-29 July, 2004). Research with Arctic Peoples: Unique Research Opportunities in Health, Lung, Blood and Sleep Disorders Workshop.
Jenkins, A.L. et al. "An Overview of Factors Influencing the Health of Canadian Inuit Infants," *International Journal of Circumpolar Health*, 62:1, 2003, 17-39.

Webster, Paul. “For Precarious Populations, Pollutants Present New Perils”. Science Magazine, Vol 299: March 2003, 1642-1643.

Lemchuk-Favel, L. “Aboriginal Health Systems in Canada: Nine Case Studies,” *Journal of Aboriginal Health*, January 2004, 28-50.

Kirmayer, L. Et al. “The Mental Health of Aboriginal Peoples: Transformations of Identity and Community,” *Canadian Journal of Psychiatry*, 2000, 45:607-61.

Henderson, Ailsa. “Report of the Workshop on Best Practices for Suicide Prevention and Evaluation of Arctic Suicide Prevention Programs”. Government of Nunavut (2003).

Paproski, D.L. “Healing Experiences of British Columbia First Nations Women: moving beyond suicidal ideation and intention”. Canadian Journal of Community Mental Health, 16(2): Fall, 1997, 69-89.

Thibeault, R. “Fostering Healing through Occupation: the case of the Canadian Inuit”. Journal of Occupational Science, 9(3):November, 2002, 153-158.

Leenaars, A. “Suicide Prevention in Canada: a history of a community approach”. Canadian Journal of Community Mental Health, 19(2): Fall, 2000, 57-73.

Green, C. et al. “The Epidemiology of Diabetes in the Manitoba-Registered First Nation Population,” *Diabetes Care*, 26:7, 2003, 1993-1998.

Wilson, K. and Rosenberg, M.W. “Exploring the determinants of health for First Nations peoples in Canada: can existing frameworks accommodate traditional activities?,” *Social Science and Medicine*, 55, 2002, 2017-2031.

Mignone, J. “Measuring Social Capital: A Guide for First Nations Communities,” Canadian Population Health Initiative, December 2003.

Kirmayer LJ, Boothroyd LJ, Hodgins S. “Attempted suicide among Inuit youth: psycho social correlates and implications for prevention”. Canadian Journal of Psychiatry, 43(8): October, 1998, 816-822.

Minore, B. et al. “Facilitating the Continuity of Care for First Nation Clients within a Regional Context," *Canadian Health Services Research Foundation*, September 2001.

Castellano, M.B. "Ethics of Aboriginal Research," *Journal of Aboriginal Health*, January 2004, 98-114.

# Planning Committee

## US Planning Committee:

### Leo Nolan

Senior Policy Analyst- External Affairs
Indian Health Service
801 Thompson Ave, Suite
Rockville, MD 20852
Telephone: (301) 443-7261
Internet: leo.nolan@ihs.hhs.gov

### Jon Perez

Director
Indian Health Service, Behavioral Health
12300 Twinbrook Parkway
Rockville, MD 20852
Telephone: (301) 443-2038
Internet: jon.perez@ihs.hhs.gov

### Clifton Poodry

Director of Minority Opportunities in Research Division
National Institutes of Health
NIH Building 45, Suite 2
Telephone: (301) 594-3900
Fax: (301) 480-2753
Internet: clifton.poodry@nih.hhs.gov

### Barbara Sina

National Institutes of Health
NIH Center Drive BE
Telephone: (301) 402-9467
Fax: (301) 402-0779
Internet: Barbara.sina@nih.hhs.gov

### Natalie Tomitch

National Institutes of Health
Telephone: (301) 496-4784
Internet: tomitch@nih.gov

## Canada Planning Committee:

### Laura Commanda

AD, Partnerships, KT and Int'l Relations
Institute of Aboriginal People's Health
Canadian Institutes of Health Research
410 Laurier Avenue West
Ottawa, Ontario
Canada
Telephone: (613) 946-6495
Internet: lcommanda@cihr-irsc.gc.ca

### Mohan Denetto
Senior Advisor
Health Canada
Tunney's Pasture
Ottawa, Ontario
Canada
Telephone: (613) 957-3440
Internet: mohan_denetto@hs-sc.gc.ca

### Heather McCormack
Senior Policy Analyst
Research, Coordination and Special Projects
First Nations and Inuit Health Branch
Health Canada
Tunney's Pasture
Ottawa, Ontario
Canada
Telephone: (613) 957-1096
Fax: (613) 957-1118
Internet: heather_mccormack@hc-sc.gc.ca

### Jeff Reading
SD, Aboriginal People's Health
Canadian Institutes of Health Research
Institute of Aboriginal Peoples' Health
University of Victoria
PO Box 1700 STN CSC
Victoria, BC
Canada
V8W 2Y2
Telephone: (250) 472-5451
Internet: jreading@uvic.ca

**Alan Trachtenberg**

Research Director
Indian Health Service
12300 Twinbrook Parkway
Rockville, MD 20852
Telephone: (301) 443-0578Internet:
alan.trachtenberg@ihs.hhs.gov

**Denice Turk**
Staff Assistant
801 Thompson Ave, Suite
Rockville, MD 20852
Telephone: (301) 443-7261
Internet: denise.turk@ihs.hhs.gov