FIRST NATIONS AND INUIT REGIONAL HEALTH SURVEY

Published by the First Nations and Inuit Regional Health Survey National Steering Committee
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>i</td>
</tr>
<tr>
<td>Preface</td>
<td>iv</td>
</tr>
<tr>
<td>Chapter 1 - Children’s Health</td>
<td>1</td>
</tr>
<tr>
<td>Chapter 2 - An Examination of Residential Schools and Elder Health</td>
<td>27</td>
</tr>
<tr>
<td>Chapter 3 - Chronic Diseases</td>
<td>55</td>
</tr>
<tr>
<td>Chapter 4 - Tobacco Report</td>
<td>87</td>
</tr>
<tr>
<td>Chapter 5 - Activity Limitations and the Need for Continuing Care</td>
<td>137</td>
</tr>
<tr>
<td>Chapter 6 - The Search for Wellness</td>
<td>181</td>
</tr>
<tr>
<td>Chapter 7 - Health and Dental Services for Aboriginal People</td>
<td>217</td>
</tr>
</tbody>
</table>

## Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1 - Data Dictionary</td>
<td>A-1</td>
</tr>
<tr>
<td>Appendix 2 - Technical Report</td>
<td>A-34</td>
</tr>
<tr>
<td>Appendix 3 - Key Themes and Implementation Issues</td>
<td>A-45</td>
</tr>
<tr>
<td>Appendix 4 - Code of Research Ethics</td>
<td>A-54</td>
</tr>
<tr>
<td>Appendix 5 - Participating Communities</td>
<td>A-59</td>
</tr>
</tbody>
</table>
The First Nations and Inuit Regional Longitudinal Health Survey National Steering Committee is pleased to present the First Nations and Inuit Regional Health Survey Report. These reports were developed from the National Core Data derived from the historical 1997 national health survey. They represent the most current, validated health information on the First Nations in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and the Inuit Peoples of Labrador.

This document was written, under the direction of the National Steering Committee, by the technical advisors and Principal Investigators to the Projects within the participating Regions. These Reports represent the work of many, many individuals who dedicated their expertise and commitment to see this Report to its successful conclusion. Some of those people include:

- Dr. Jeff Reading, Principal Investigator to the British Columbia and Manitoba Regional Surveys and Technical Advisor to the National Steering Committee
- Ken Svenson and Christopher Lafontaine, Principal Investigators and Advisors to the Federation of Saskatchewan Indian Nations Regional Survey
- Dr. John O’Neil, Principal Investigator and Advisor to the Assembly of Manitoba Chiefs Regional Survey, Advisor to the National Steering Committee
- Dr. Kue Young, Principal Writer, University of Manitoba, Northern Health Research Unit
- Brenda Elias, Ph D. Candidate, Principal Writer and Technical Advisor, University of Manitoba, Northern Health Research Unit
- Dr. Harriet MacMillan and Christine Walsh, Phd. candidate, Centre for Studies of Children at Risk, Affiliated with McMaster University and Hamilton Health Sciences Corporation, Principal Investigator and Advisor respectively to the Chiefs of Ontario Regional Survey
- Dr. Jacques Thibault, Principal Investigator and Advisor to the First Nations of Quebec and Labrador Health and Social Services Commission
- Darren Graham, Principal Investigator and Advisor to the Union of New Brunswick Indians Regional Survey
- Dr. Fred Wein and Dr. Lynn MacIntyre, Principal Investigators and Advisors to the Nova Scotia Regional Survey and Technical Advisors to the National Steering Committee
- Dr. Rolland Chrisjohn, Principal Investigator, Advisor to the Alberta Regional Health Survey

This project was funded by Health Canada under the Tobacco Demand Strategy, Health Canada
Special Acknowledgements to individuals who shared the Vision for this Survey and contributed their motivation, ideas, values, support, time and resources to the success of the Project; they are:

- Ms. Laura Commanda, Medical Services Branch, Health Canada
- Ms. Kathleen McGovern, Medical Services Branch, Health Canada
- Ms. Ellen Bobet, Medical Services Branch, Health Canada
- Ms. Nichole Simond, Medical Services Branch, Health Canada
- Ms. Debra Gillis, Medical Services Branch, Health Canada
- Mr. Paul Glover, Medical Services Branch, Health Canada
- Mr. Chris Green, Medical Services Branch, Health Canada
- Mr. Yvon Allard, University of Manitoba, Northern Health Research Unit
- Mr. Allen Deleary, Director, Assembly of First Nations Health Secretariat, Ex-Officio Member and Chairperson
- Ms. Lisa Tabobadung, former Analyst, Assembly of First Nations Health Secretariat
- Ms. Roda Gray, Pauktuutit, Inuit Women’s Health Organization, former Ex-officio National Steering Committee member
- Ms. Andrea Chrisjohn, former Executive Director, Chiefs of Ontario
- Ms. Alice Longboat, Chiefs of Ontario
- Mr. Michael Sherry, Legal Advisor, Chiefs of Ontario
- Mary Whitlow, Cynthia Martin, Victoria Sandy, Chiefs of Ontario Finance

Acknowledgement must also be made to the Regional Advisory Committees established and mandated in each participating Region who oversaw the regional projects and contributed to the development of the national direction. A special acknowledgement to the 183 First Nations and 5 Inuit communities in Labrador for their participation and belief in the Project; may your data serve your community health planning needs for years to come.

And a very special acknowledgement and thank you to the First Nations and Inuit Regional Longitudinal Health Survey National Steering Committee; both present and former members who have dedicated so much to this Project; both at their regional levels and the national level. They have taken their responsibility and mandate seriously and dedicated their invaluable expertise to this Project. The efforts of the National Steering Committee in advancing First Nations and Inuit control in research, data collection, ethics and information sharing are to be commended and honoured. It has been a pleasure working with this exceptional team of professionals. Niawen.

Current National Steering Committee Members:

- Mr. Doug Kelly, British Columbia
- Ms. Marlene Poitras, Alberta
- Ms. Ceal Tournier, Saskatchewan
- Ms. Audrey Leader, Manitoba
- Ms. Cathryn George, Ontario
- Ms. Jane Gray, Quebec
- Ms. Wendy Paul, New Brunswick
- Ms. Sharon Rudderham, Nova Scotia
- Ms. Debbie Milne, Labrador
Past participants on the National Steering Committee who have also made contributions to this project, particularly in its formative development, include:

- Mr. Wendall Nicholas, New Brunswick
- Ms. Francine Vincent and Mr. Gary Cole, Quebec
- Ms. Sharon Wabegijig, Ontario
- Ms. Marilyn Tanner-Spence, Manitoba (Alternate)
- Ms. Maureen Lerat, Saskatchewan
- Mr. Phil Hall, British Columbia
- Mr. Richard Saunders, Alberta
- Ms. Shirley Montague and Ms. Iris Allen, Labrador

As this National Survey moves toward the continued longitudinal development, we will see further development and enhancement of First Nations and Inuit capacity in health research and evidence-based decision making to contribute to the improved health status in our communities. As our evidence has demonstrated, the need is great and we have our responsibilities clearly identified.

Respectfully submitted:

Ms. Gail Mc Donald,
National Coordinator
First Nations and Inuit Regional Longitudinal Health Survey
January 1999
Longitudinal studies are designed to follow a group of people over a long time period in an attempt to understand how changes in peoples’ well-being are linked to changes in their lifestyles and social environments. In the case of children, changes in growth and development can be linked to changes in home, school, and community environment. The results of these kinds of studies have more powerful policy implications than cross-sectional studies, which merely describe the presence of problems at one point in time.

In 1994, Statistics Canada began three major national longitudinal surveys, the National Population Health Survey (NPHS), National Longitudinal Survey of Children and Youth (NLSCY), and the Survey of Labour and Income Dynamics (SLID). The NPHS and NLSCY are collecting data on a two-year cycle on samples of approximately 22,000 and 25,000 Canadian households respectively. The SLID collects data annually on a sample of 15,000 households. The general objectives of each of the three surveys are to assist federal and provincial governments, researchers and non-governmental organizations to develop public policy by providing information as summarized below:

1. National Population Health Survey:
   - Comprehensive information on the health status of the Canadian population
   - Information on trends and changes in health status
   - Examination of the social determinants of health status including economic, social, demographic, occupational, and environmental correlates
   - Better understanding of the relationship between health status and use of health services

2. National Longitudinal Survey of Children and Youth:
   - Determine the prevalence of various biological, social and economic characteristics and risk factors of Canadian children and youth.
   - Monitor the impact of such factors, life events and protective factors on the development of these children.
   - Provide information to policy and program officials for use in developing effective policies and strategies to help children live healthy, active and rewarding lives.

3. Survey of Labour and Income Dynamics:
   - Improve an understanding of links between demographics, labour market events and changes in family circumstances and income

First Nations and Inuit Excluded

The national sampling frame for these three longitudinal surveys specifically excludes First Nations people living on reserves, and Inuit communities in the provinces. Aboriginal peoples living off-reserve may be selected randomly in the national surveys, but this Aboriginal sub-sample will not be large enough to produce reliable information for First Nations people living off-reserve, or Métis people. Aboriginal peoples in the Yukon and Northwest Territories were to be included in an integrated NPHS/NLSCY survey conducted on behalf of Statistics Canada by the Departments of Statistics within each Territorial government, also beginning in 1994.

Recognising the need for comparable information on the Aboriginal population outside the Territories, Health Canada, Human Resources Development Canada and the Department of Indian and Northern Affairs contracted the Northern Health Research Unit at the University of Manitoba Unit in January 1994 to conduct a Feasibility Study into the possibility of developing a National Longitudinal Aboriginal Survey. Although the funds originally
identified by the federal departments for the development of a longitudinal survey were specifically for First Nations people on-reserve and Inuit in northern Quebec and Labrador as determined by federal policy, the terms of reference for the Feasibility Study included an assessment of the interest in, and feasibility of, extending the survey to include First Nations people living off-reserve and Métis.

The Feasibility Study was undertaken by John O’Neil, a professor of community health at the University of Manitoba. The project was directed by a national Aboriginal Steering Committee consisting of First Nation and Métis health and social development professionals: Professor Madeleine Dion Stout, the Director of the Centre for Aboriginal Education, Research and Culture at Carleton University; Ms. Kim Scott (Kishk Anaquot), Health Policy Analyst, Royal Commission on Aboriginal Peoples and Lecturer, Institute of Women’s Studies at Carleton University; and Dr. Jay Wortman, Family Physician and Medical Consultant on STD’s and AIDS to the B.C. Ministry of Health.

The Feasibility Study consisted of consultations with Aboriginal technical staff working with Aboriginal organizations and communities. “Technical staff” included Aboriginal health, social service, child development, education and socio-economic development professionals active in service delivery, research and policy development with Aboriginal communities and organizations. Workshops were held in Ottawa, Halifax, Montreal, Toronto, Winnipeg, Saskatoon, Edmonton and Vancouver through the fall of 1994, where approximately 150 Aboriginal health technicians participated in discussions about the possibility of developing an Aboriginal longitudinal survey of health, children and social conditions.

Essentially, the feasibility study asked the question “What kind of national longitudinal study would be acceptable to First Nations, Inuit and Métis people at the community level, while at the same time meeting the information needs of First Nations, Inuit and Métis organizations at the community, regional and national levels, and other levels of government?”

The Steering Committee decided that the survey should take the form of a group of regional surveys. The regional surveys were to be controlled and implemented by regional organizations. Late in 1995 the First Nation/Inuit political organization in each region was invited to make a regional survey proposal. Each region found an organization or person to provide technical support to the survey and serve as Co-principal Investigators. In each region a Regional Steering Committee was created to ensure that regional and local needs were met. Data from each of the regional surveys were compiled into a common data base by staff at the University of Manitoba.

The Final Report

The Final Report of the First Nations and Inuit Regional Health Survey (FNIRHS), the finding which are presented in this document, consists of eight thematic volumes plus a process report. The thematic volumes correspond to the topical areas in the Core Questions and are: 1) Children Health, 2) An Examination of Residential Schools and Elder Health, 3) Chronic Diseases, 4) Tobacco Report, 5) Activity Limitations and the need for Continuing, 6) The Search for Wellness, 7) Health and Dental Services for Aboriginal People. Members of the Principal Investigators Group (lead Investigators from each region) were asked to select one or more thematic areas for analysis of core data. Each thematic volume includes a literature review as well as an analysis of core data results. Comparison of core data results with other databases such as NPHS, NLSCY, and APS is also included wherever possible.

Preminary reports of all thematic areas were first presented to the National Steering Committee and then were presented to the general public at the National Aboriginal Information and Research Conference in Ottawa, March 28 – 31, 1998.
Members of the National Steering Committee have further reviewed all volumes of the Final Report for overall content and direction. A second review was undertaken by anonymous scientists commissioned by the National Steering Committee. This second review focused on scientific considerations.

Although the production of Final Reports has gone smoothly in terms of co-operation among Investigators and the National Steering Committee, timeframes have once again created considerable difficulty. Because funding for the first wave terminates with the Final Report, and no further funding for either ongoing analysis or development of a second wave for the Survey has yet been secured, pressure to complete a full analysis of all results has been considerable. In comparison, in other national longitudinal surveys, analysis is ongoing and is usually conducted within more reasonable timeframes. That this report has been produced under such circumstances is a tribute to the willingness of participating communities, that readily recognized the importance of the FNIRHS initiative and the professionalism of contributing writers and researchers.

The extraordinary success of the first wave of surveys has laid the foundation for further institutional development and capacity-building of First Nations and Inuit authorities to develop and control the health information systems necessary to manage health care systems across the country. However at the time of publication, funding has not yet been secured for further longitudinal survey activity. The initial FNIRHS represents an historic opportunity for First Nations and Inuit communities and organizations across Canada, to overcome many challenges in the field of Aboriginal health research.

This is a challenge that First Nations and Inuit welcome. It is an opportunity that must not be allowed to pass unanswered. Aboriginal self-government and the advent of new information technologies in the health field make essential the need for consistently reliable and current health information for policy development, program planning and resource management. The capacity to generate core health data for the benefit of health workers and managers, at the community, regional and national levels is not a luxury or an afterthought. It is an integral element of effective health care management. The historically poorer health status of First Nations and Inuit communities has meant that Aboriginal communities and government often react to health situations. Aboriginal health authorities and other levels of government can be proactive and more effective if they have the ability to generate comprehensive information on the health status of the Canadian population and if they have the capacity to assess current health status and identify trends and changes in health status. In order to do so, initiatives like the First Nations and Inuit Regional Health Survey (FNIRHS) must be maintained as a continuing initiative of Aboriginal health planning.