

FIRST NATIONS AND INUIT REGIONAL HEALTH SURVEY

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First Nations and Inuit Regional Health Survey



TABLE OF CONTENTS

Acknowledgements	i
Preface	iv
Chapter 1 - Children's Health	1
Chapter 2 - An Examination of Residential Schools and Elder Health	27
Chapter 3 - Chronic Diseases	55
Chapter 4 - Tobacco Report	87
Chapter 5 - Activity Limitations and the Need for Continuing Care	137
Chapter 6 - The Search for Wellness	181
Chapter 7 - Health and Dental Services for Aboriginal People	
Appendices	

Appendices

Appendix 1 - Data Dictionary	A-1
Appendix 2 - Technical Report	A-34
Appendix 3 - Key Themes and Implementation Issues	A-45
Appendix 4 - Code of Research Ethics	A-54
Appendix 5 - Participating Communities	A-59

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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:

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- 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
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First Nations and Inuit Regional Health Surveys

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- Mr. Doug Kelly, British Columbia
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- Ms. Debbie Milne, Labrador

First Nations and Inuit Regional Health Surveys

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- 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

First Nations and Inuit Regional Health Surveys

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 Heath 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.

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Introduction

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.

Chapter 1

Children's Health

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Authors		4
Acknowl	edgements	4
Introduc	tion	4
Literatu	re	4
Mothods		1
Samula	Coloction	4
Missing	Selection	5
Missing Information		5 5
Findings		9 7
Damage	anhim Ann Condon and Ennilly Sing	- 7
Demogr	apnics: Age, Genaer and Family Size	/
Compar	ison with the NLSCI Sample	8
Infant E	lealth Factors	8
	Birth Weight	8
	Birth Weight NLSCY	9
	Breast-Feeding	9
	Breast-Feeding NLSCY	9
	Current Health	10
	Current Health NLSCY	10
Specifie	d Health Problems	11
-	Allergies	11
	Bronchitis	11
	Asthma	12
	Tuberculosis	12
	Heart Condition	12
	Kidney Problems	12
	Epilepsy	12
	Diabetes	12
	Weight Problems	12
	Psychological Difficulties	13
	Ear Problems	13
	Specified Health Problems	13
Injuries		14
-	Serious Head Injury	14
	Serious Burn	15
	Broken Bones or Fractures	15
	Near Drowning	15
	Frostbite and Hypothermia	15
	Loss of Limbs, Hearing or Vision	15
	Injuries NLSCY	15

Emotional and Social Health and Culture	16
Tobacco, Alcohol and Substance Abuse Problems	16
Behaviour and Emotional Problems	17
Behaviour and Emotional Problems NLSCY	18
Child Getting Along with Family	18
Knowledge of Native Culture	18
Discussion Conclusions	

List of Figures

Figure 1:	Children's health sample size	6
Figure 2:	Distribution of ages in sample unweighted numbers	7
Figure 3:	Number of children in the home for those aged 0 to 11 years	7
Figure 4:	Birth weight categories for males and females aged 0 to 3 years	8
Figure 5:	Percent breast-fed age 0 to 1 year, and months breast-fed for those who were breast-fed, age 0 to 2 years	9
Figure 6:	Respondents' rating of child health, age 0 to 11 years	9
Figure 7:	Prevalence of specified health problems	10
Figure 8:	Prevalence of specified medical conditions, various age grouping	12
Figure 9:	Lifetime prevalence of injury, age 0 to 17 years	13
Figure 10:	12 month prevalence of most serious injury age 0 to 11 years	14
Figure 11:	Lifetime prevalence of injury age 0 to 11 years	14
Figure 12	FNIRHS: Emotional or behavioural problems by age group	15
Figure 13:	Child getting along with family, parents, sibling, age 4 to 11 years only	16
Figure 14:	Respondent's satisfaction with child knowledge of	
	Native culture, by respondent's language	17

AUTHORS

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INTRODUCTION

LITERATURE

This report was prepared by Dr. Harriet MacMillan, Christine Walsh, Ellen Jamieson, Allison Crawford and Dr. Michael Boyle from the Centre for Studies of Children at Risk, affliliated with McMaster University and Hamilton Health Sciences Corporation,

The authors gratefully acknowledge the support of Gail McDonald and the National Steering Committee. We appreciate the work of John O'Neil, Brenda Elias and the Northern Health Research Unit in preparing the national roll-up. We would like to thank all those communities where information has been gathered. This report is dedicated to First Nations and Inuit children and youth, including those generations yet to be born.

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This report concerns the health of First Nations and Inuit children and youth in Canada. In this context, health is broadly considered with aspects related to physical, emotional, social, spiritual and cultural well-being. While the core component concerning children's health was limited to ten questions, many of the regional surveys had a more comprehensive section on the health of children and youth. In at least two regions, a separate questionnaire was completed by youth about their own health.

The report sections are presented in the same order as the child health questions in the survey, with relevant information available from other published sources preceding the section. The child health questions can be found in Appendix 1. Wherever possible, comparisons have been made between this survey, the First Nations and Inuit Regional Health Survey (FNIRHS), and the National Longitudinal Survey of Children and Youth (NLSCY).¹ The NLSCY is a longitudinal survey designed to measure child development and well-being. The sampling frame of the NLSCY excludes individuals living on Aboriginal reserves. Comparisons were based on data collected in the first cycle of the NLSCY (1994-95) involving equivalent age groupings in both surveys; in most cases this was the group aged 0 to 11 years.

Data from both the FNIRHS and the NLSCY were weighted so that each child in the sample represents a group of children in the population. All figures presented are based on weighted data, unless otherwise noted. Statistical testing used the 'child analytic weight' in the FNIRHS and the 'sample weight' in the NLSCY. Chi square tests were used for categorical data, and t-tests or one-way ANOVA for continuous data. Because of the number of tests done, a Bonferroni correction was applied resulting in an alpha set at .0008.

One of the authors previously carried out a review of Aboriginal health which included citations up until November 30, 1995 to determine what was known about the health of Canada's Aboriginal people including children, prior to the FNIRHS.² This review was updated to include articles published prior to January 31, 1998. The systematic review was carried out using the following methods. In the original literature review,

MEDLINE was searched with the use of MeSH headings "Eskimos" and "Indians, North American," excluding headings pertaining to genes, genetics and the history of medicine. The updated review included the databases HealthSTAR and CINAHL. The following criteria were used to determine whether the article was relevant; target population was Aboriginal children or youth (Canadian populations), the topic was health status or health determinants, and the type of article was a review or original research article. The terms "Native," "Aboriginal" and "people of the First Nations" will be used when referring to the literature, depending on the terms employed in the specific references. Many Aboriginal people object to the term "Indian." This term will be used only when it appears in the original source and is required to describe information accurately. The sections that follow include information from these literature reviews in addition to the data from the FNIRHS. While some reports discussing health concerns of subgroups of Canadian First Nations children and youth will be reviewed, it is important to underscore that health issues identified in one region may not be representative of Aboriginal young people as a whole. American studies are often quoted when discussing the health of Canada's Aboriginal children and youth, yet there may be important differences in health issues, making the applicability of such information to Canadian young people very limited. Therefore, literature which focuses exclusively on American Native people will not be included. Further information regarding areas of child health that could not be covered in the core questions may be forthcoming from reports on the findings of the individual provincial surveys, some of which included a broader range of questions about child health.

For the purposes of the survey, a child was defined as anyone under the age of 18 years. One child was randomly selected from each household using a two-stage random sampling procedure. Interviewers made a list of children living in the household in chronological order. A set of correspondingly numbered cards was put into a container and one was withdrawn. The numbered card chosen by chance identified the child selected for the sample.

Exceptions to this sample selection procedure occurred in the following regions. Alberta did not include the section on children's health in their regional survey and thus the following findings exclude representation from Alberta. In Ontario and Nova Scotia, children and youth were randomly selected for the sample based upon their population representation.

Of the 10085 (unweighted) adult respondents in the survey, 6878 (68.2%) indicated that they had children (under age 18) living in their household; in 833 (8.3%) cases, information on the number of children at home was missing. However, of these 833 cases, 314 adult respondents answered at least one question on children's health. Of the 6878 who indicated that they had children living at home, 2221 (32.3%) did not answer any questions on children's health; this number includes those sampled from Alberta who did not complete the section on children's health. Two persons who indicated that they did not have children living

METHODS

SAMPLE SELECTION

MISSING DATA

First Nations and Inuit Regional Health Surveys

in the household answered at least 1 child health question. Those records which contained a response to at least 1 of the 28 child items and indicated that there were children living in the household were included, giving 4149 proxy responses for children. Child records with no weights calculated were excluded (N=220). Records for youths 18 years old (N=124) and 19 years old (N=14) were excluded. The final sample consisted of 3791 (unweighted) child records. These responses when weighted represented 108270 children. Figure 1 shows how the sample was derived.

INFORMANTS

The individual identified as the person most knowledgeable about the child completed the section concerning children's health. Information about children was given most often (81% of the time) by female informants. The majority of informants were married (40%). About 27% were living common-law; 17% were single; 10% were separated; 3% and 2% were divorced and widowed respectively. There was no specific information on the relationship between the individual child and the informant.



Figure 1: Children's Health Sample Size









FINDINGS

Demographics

Age,Gender and Family Size

A ccording to the Aboriginal People's Survey (APS) the Aboriginal population has proportionally more young people than the Canadian population. In 1991, 38% of First Nations people were below the age of 15 compared with 21% for the total population.³

In the FNIRHS, the age of the child ranged from newborn to 17 years old, with a mean age of 8.7 years (standard deviation (sd) = 5.0) and median age of 8 years.

Overall, 51% of the sample was male. This percentage was consistent across all age groups, where males comprised 51% of the sample in each age group.

The number of children living at the respondent's home ranged from 1 to 18 (those respondents with no children at home did not answer the child health section), with a mean of 2.6 (sd = 1.5). The majority (52%) of children lived in families with fewer than three children living at home.



Figure 2: Distribution of ages in sample, unweighted numbers



Figure 3: Number of children in the home for those aged 0 to 11 years

Comparison with the NLSCY Sample

In the NLSCY, information was collected solely about children newborn to age 11 years. Figure 2 shows the sample age distribution for both surveys. The mean age in the NLSCY was 5.5 years (sd = 3.4), with a median of 5 years.

Fifty-one percent of the sample was male. This percentage was the same in both age categories; newborn through age 5 and age 6 through 11 years.

Two-thirds (67%) of children lived in families with one or two children under the age of 18 living in the household. No family size exceeded four children in this survey. Figure 3 shows the comparison data for family size from the NLSCY and those aged 0 to 11 years in the FNIRHS.



Figure 4: Birth weight categories for males and females aged 0 to 3 years

Infant Health Factors

Birth Weight

F etal growth and birth weight are important determinants of infant health, yet there is a lack of standardized information about such measures among Aboriginal infants.² It is difficult to assess the effect of factors on the growth of Aboriginal infants without data that are specific to Native people.

The average birth weight for female newborn infants was 3440 gm (sd = 572)[7 lbs, 9 oz] and median birth weight was 3430 gm [7 lbs, 9 oz] in the FNIRHS; for males the average birth weight was 3570 gm (sd = 660) [7 lbs, 14 oz] with a median of 3572 gm [7 lbs, 14 oz]; this difference between males and females was statistically significant.

Both low and high birth weights are of concern. Low birth weight was defined as a weight less than 2500 gm [5 lbs, 8 oz]; 5.4% of children fell into this category. This figure was consistent across age groups, at 5.5%, 4.8% and 6.0% in the three age groupings from youngest to oldest. Rates for male and female newborns were similar, with 5.2% of females and 5.7% of males having low birth weight. Low birth weight is associated with increased neonatal morbidity and mortality.⁴ The lower the birth weight the greater the likelihood of intellectual and neurological deficits. The highest risk of neonatal mortality occurs among infants who weigh less than 1000 gm [2 lbs, 3 oz] at birth; the lowest risk occurs among infants with birth weights of 3000 [6 lbs, 10 oz]to 4000 gm [8 lbs, 13 oz].⁴ High birth weights (above 4000 gm, 8lbs, 12 oz) are found significantly more often in male newborns (21.7%) than female newborns (14.0%). In addition, neonatal mortality rises significantly for infants whose gestational age.⁴

Birth Weight, NLSCY

Q uestions regarding birth weight in the NLSCY were asked only for those children aged newborn to 3 years. Mean birth weight for male newborns was 3457 gm (sd = 581) [7 lbs, 10 oz] and for female newborns was 3322 gm (sd = 545) [7 lbs, 5 oz].

In the NLSCY, 5.7% of children had low birth weight and 12.1% had high birth weight (Figure 4). Rates of low birth weights for males and females were similar between genders, with 5.1% of females and 6.3% of males having low birth weight. However, boys had higher rates of high birth weight (15.9%) than girls (8.1%).

Birth weight for males aged 0 to 3 years was significantly higher in the FNIRHS than in the NLSCY. This was also the case for females aged 0 to 3 years.

Small numbers of children in the low birth weight category precluded statistical testing of birth weight categories by gender. However, birth weight categories for males and females taken together were significantly different in the two surveys: although the proportions of children who had low birth weight were similar, more children fell into the high birth

weight category in the FNIRHS. The proportions of males and females in the 0 to 3 years age group were not significantly different in the two samples, so this difference in birth weight was not due to unequal representation of males in either sample.



Children's Health

Figure 5: Percent breast-fed age 0 to 1 year, and months breast-fed for those who were breast-fed, age 0 to 2 years



Figure 6: Respondents' ratings of child health, age 0 to 11 years

Breast-feeding

Reports from Health Canada provide some information about the extent of breast-feeding among Aboriginal mothers.⁵ Despite a shift toward bottle-feeding among the Native population in the 1950's,⁶ the rate of initiation of breast-feeding was 60.7% by 1988.⁵ Although many

N a tive mothers begin breast-feeding, the rates drop significantly by six months.^{5,7}

A study of Inuit women in Northern Quebec revealed that high levels of organic chlorine compounds such as polychlorinated biphenyls (PCBs) were present in the breast milk.⁸ This was attributed to the consumption of sea mammals and fish containing these components. Although this may have adverse effects on fetuses and breast-feeding women, the authors concluded that nutritional, economic and cultural benefits of traditional food far outweigh the risks.⁸



Figure 7: Prevalence of specified health problems

Based on information from the FNIRHS, half (50%) of respondents

reported that the child had been breast-fed. There appeared to be a trend toward greater proportions of younger children being breast-fed: 46% in the age group 12+, 52% in the 6 to 11 year-old age group and 53% in the 0 to 5 year-old group. However, these differences were not statistically significant.

Of the children who were breast- fed, more than half (55%) were breast-fed for more than seven months. No differences in the average number of months breast- fed were seen by age group or gender.

Breast-feeding, NLSCY

Q uestions about breast-feeding were asked only for those children up to two years of age. Published figures⁹ show that of these children, 75% were breast-fed. This figure is significantly higher than for those up to two years of age in the FNIRHS (54%).

About one quarter (24%) were breast-fed for more than 6 months, a significantly lower rate than the percentage for those aged 0 to 2 years in the FNIRHS (39%). Figure 5 shows the proportions of those who were breast-fed, as well as the distribution of months breast-fed for children up to two years of age.

Current Health

R espondents were asked to rate the child's health as "excellent," "very good," "fair" or "poor." About 84% of respondents rated their child's health as very good or excellent. Ratings for very good and poor health were similar across age groups and by gender.

Current Health, NLSCY

I n the NLSCY, respondents were asked to rate the child's health as "excellent," "very good," "good," "fair" or "poor." About 88% rated the child's health as excellent or very good.

The percentage of children with poor/fair health was significantly higher in the FNIRHS than the NLSCY (16% versus 2%). However, this may be due to the different categories offered to respondents in the two surveys. If a First Nations child's health was not "excellent" or "very good," the respondent may have answered "fair," since no "good" category was offered in the interview. Figure 6 shows the comparison of ratings from the FNIRHS and NLSCY.

Specified Health Problems

Native children appear to be at increased risk for infectious diseases compared to non-Native children.¹⁰⁻¹²Among Canadian Aboriginal children, there are increased rates of lower respiratory tract infections (bronchitis, pneumonia and croup),^{10,11} and otitis media.^{13,14} There is some suggestion that infections may also be more severe in First Nations people.^{11,15} In a national study of pediatric patients hospitalized for lower respiratory tract infections, Aboriginal children experienced increased morbidity compared to non-Native patients.¹² They were found to have prolonged periods of hospitalization and were more likely to be admitted to an intensive care unit.

Other infectious diseases for which there has been some report of increased risk among Canada's Native people or Aboriginal subgroups include tuberculosis,¹⁶⁻¹⁸hepatitis A and hepatitis B,^{19,20} gonorrhea,¹⁹⁻²¹ meningitis ¹⁹⁻²¹ and gastroenteritis.^{19,21} A recent study evaluated the incidence of shigellosis, a highly infectious diarrheal disease, among First Nations people compared with that of the rest of the population.²² The incidence in the Native population was 29 times greater than the rate for the rest of Manitoba. The Native patients were significantly younger compared to patients in the rest of the population. In addition, First Nations people were 12.2 times more likely to be hospitalized and were more likely to be antibiotic-resistant. This predominance of cases in the pediatric population was likened to the pattern reported in developing countries. Limitations in type of sewage system and waste disposal as well as presence of crowded living conditions were all found to be associated with this increased risk.22

It is not known why Aboriginal people are at increased risk for some infectious diseases, however some suggested risk factors include nutritional problems, poverty and crowding, and environmental factors such as tobacco smoke and wood fire smoke.²

Godel and colleagues compared the vitamin A status of mothers and infants in two Native groups and a non-Native group living in Northern Canada.²³ Based on their findings, the authors postulate that Northern Canadian Native infants are at higher risk for vitamin A deficiency compared to non-Native infants. Moffat proposes that subclinical vitamin A deficiency may lower resistance to infections, particularly respiratory illnesses and communicable diseases such as measles.²⁴

Higher rates of infectious disease are associated with increased rates of hospitalization among Native compared to non-Native children.¹⁵ Kashuba and colleagues referred to work demonstrating that in the first year of life, Native children are four times more likely to be admitted for respiratory infections, diarrhea and gastroenteritis.¹⁵ In one study examining acute care hospitalizations of a First Nation community living off-reserve, this pattern was maintained through the life cycle.

In the FNIRHS, the most frequently reported disorder for all ages and both genders was ear problems (15%), followed, in decreasing frequency, by allergies (13%), asthma (12%), bronchitis (7%) and overweight problems (7%). Psychological problems (3%), heart (2%) and kidney (2%) problems were relatively rare. Rates for tuberculosis, diabetes and epilepsy were not reportable, since the number of children with these disorders was too small to make a reliable estimate. About 5% of respondents said that their children had health problems other than those listed above (see Figure 7).

Allergies

T here was no difference in the prevalence of allergies across age groups; 13% of children in each age group were reported to have allergies. Similarly, 13% each of males and females were reported to have allergies.

Bronchitis

R ates of bronchitis in males and females were similar: 6% for females and 7% for males. Significantly higher rates of bronchitis in the youngest age group (newborn to age 5) were observed: 9% in the youngest group versus 5% and 6% in each of the older groups.

Asthma

As in bronchitis, there was a significant increase in rates of asthma in the younger age groups: 15%, 11% and 9% in the 0 to 5, 6 to 11 and 12+ age groups respectively. Rates were similar in males and females: 13% and 11% respectively.

Tuberculosis

The unweighted number of respondents reporting a child with tuberculosis was too small to report rates with any accuracy.



Figure 8: Prevalence of specified medical conditions, various age groupings

Heart Condition

The prevalence of heart problems was similar by gender, at about 2%. Age grouping produced numbers too small to report any trends based on age.

Kidney Problems

The number of respondents reporting children with kidney problems was too small to compare across age groups. Males and females showed similar rates at about 2%.

Epilepsy

As in tuberculosis, the total number of respondents reporting children with epilepsy was too small to report a reliable estimate of the prevalence of this condition.

Diabetes

N^(NIDDM), typically a disease with onset in middle adulthood, has been identified in an increasing number of children between 7 and 15 years of age in a First Nations group in the Sioux Lookout region.²⁵ The age-adjusted prevalence rate rose from 0.5/1000 in Native children in 1985 to 2.5/1000 in 1994. The prevalence rate in youth was found to be six times more common in females than males. Adolescents with diabetes were typically asymptomatic, obese and had a strong family history of NIDDM.²⁵

In the FNIRHS, the total number of children reported to have diabetes was too small to report accurately.

Weight Problems

Evaluation of growth patterns, including weight Consider the results of recent studies showing that Aboriginal children likely have a pattern of growth that differs from other children.²⁶ A high weight-for-height pattern appears to exist among Arctic children, including Canadian Inuit; this should not be misinterpreted as an indication of obesity. Two additional studies of Canadian Inuit youth have shown similar patterns of high weight for height.^{27,28}

The number of low weight-forheight children among certain subgroups of the Aboriginal population may be underestimated if standard growth charts for Canadian children are used.²⁹ At the same time, presence of obesity needs to be carefully evaluated among Aboriginal children and youth since obesity has been described as a major risk factor for the development of NIDDM.³⁰ A recent study of Mohawk preschool and



Figure 9: Lifetime prevalence of injury, age 0 to 17 years

school-aged children (4 to 9 years old) found diets which exceeded recommended intakes for energy, fat and saturated fats.³¹ The authors emphasized that energy intake needs to be balanced with energy expenditure.

The proportion of children in the FNIRHS with overweight problems was similar in boys and girls (6% and 7% respectively). However, there was a significant trend toward more weight problems with increasing age; rates for the 0 to 5, 6 to 11 and 12+ age groups were 3%, 6% and 10%.

Psychological Difficulties

S ample sizes in the youngest age group were too small to report a reliable estimate. If the two younger age categories are collapsed to compare 0 to 11 year- olds with those age 12 and over, rates of psychological problems are 2% in the younger group and 4% in the older age group. Rates were similar in females and males, at 3%. Neither difference was statistically significant.

Ear Problems

A significant trend toward higher rates of ear problems in the youngest age group was observed, with 20%, 17% and 11% in the youngest through oldest group. Similar rates (15% and 16%) were found in females and males.

Specified Health Problems, NLSCY

Participants in the NLSCY were asked specifically about the following long-term conditions: asthma, allergies, bronchitis, heart condition, epilepsy, cerebral palsy, kidney condition, mental handicap, learning disability, emotional or psychological difficulties, and whether the child has any other long-term condition. The NLSCY had information on "ear infections or otitis," the FNIRHS asked about "ear problems." In the NLSCY, a condition must have been diagnosed by a health professional; this was not the case in the FNIRHS. This could possibly result in lower reported rates of illness in the NLSCY.

All health conditions were asked in those children aged 0 to 11 years, with the exceptions of emotional difficulties (age 6 to 11 years) and ear infections (age newborn to 3 years).

NLSCY health condition variables were suppressed for confidentiality reasons on the public access version of the data, so no statistical comparisons of FNIRHS and NLSCY data could be run. However, weighted percentages for the entire NLSCY sample were available on paper; these are included here.

The most commonly reported health problem was ear infection, in 53% of children aged 0 to 3 years, followed by allergies (14%), asthma (11%) and bronchitis (3%) in those aged 0 to 11 years. Heart and kidney conditions and epilepsy were rare (under 1%). Psychological difficulties were reported in 2% of those aged 6 to 11 years.

Figure 8 shows the proportions of children reported to have the specified health problems common to both surveys. It should be noted that the FNIRHS sample has been modified to match the age range available in the NLSCY.

Injuries

C ompared to the total number of children in Canada, Native children have much higher death rates due to injuries.³² Comparing Indian children with the total Canadian population of children, for infants the rate of death from injuries is almost four times greater (63

versus 17 per 100,000 population) and for preschoolers the rate is five times greater (83 versus 15 per 100,000 population); teenagers experience death by injury at more than three times the Canadian rate (176 versus 48 per 100,000).

In the FNIRHS, broken bones or fractures were by far the most frequently reported injury (13% overall), followed by serious head injury (4%), serious burn (3%), near drowning (3%), and frostbite or hypothermia (2%). The total number of those



Figure 10: 12 month prevalence of most serious injury age 0 to 11 years



Figure 11: Lifetime prevalence of injury age 0 to 11 years

reporting loss of limbs, vision or hearing was too small to report a reliable estimate. Figure 9 shows the rate of specified injuries.

Serious Head Injuries

R ates for serious head injury were similar across age groups: 3% for the 0 to 5 year-old age group, 4% for those 6 to 11 year-old and 5% for those

12 years and over. Rates for females and males were comparable, at 4%.

Serious Burns

T he prevalence of serious burn injuries was similar across age groups, at 3%, 3% and 4% for the youngest through oldest age groups. Rates were similar by gender: 3% for females and 4% for males.

> Broken Bones or Fractures



Figure 12: FNIRHS: Emotional or behavioural problems by age group

Fractures showed a significant

 Γ pattern with increasing age; the rates were 4% in the youngest group, 14% in the group aged 6 to 11 years, and 20% in the 12+ age group. Rates for males and females were similar, at 14% and 12% respectively.

Near Drownings

W hen divided into three age groupings, the numbers reporting near drowning were too small to give a reliable estimate of the prevalence within age groups. When collapsed into 0 to 11 years and 12+ age groups, rates of near drowning were 3% and 5% for younger and older children, respectively. This difference is statistically significant. For males and females, rates were similar: 4% and 3% respectively.

Frostbite and Hypothermia

When grouped by age into 0 to 11 years and 12+ cohorts, 1% of the younger group had experienced frostbite or hypothermia, compared with 4% in the older group. This difference is statistically significant. Numbers within gender divisions were too small to provide a reliable estimate of the prevalence of frostbite/hypothermia by gender.

Loss of Limbs, Hearing or Vision

O have lost limbs, vision or hearing was large enough to report a reliable estimate (2%).

Injuries, NLSCY

lthough information about injuries was Collected in the NLSCY, the questions differed substantially from those in the FNIRHS. First, information was collected about injury within the last 12 months, not for lifetime prevalence of injuries as in the FNIRHS. Second, information on the type of injury was collected only for the most serious injury in the last 12 months. And third, a list of specified injuries was not given; respondents were asked to indicate the most serious injury. These factors will likely yield much lower rates of injury in the NLSCY than in the FNIRHS. The prevalence of some specific types of injuries in the NLSCY (poisoning, internal injury and multiple injury) was not large enough to yield a reliable estimate and therefore is not reported. Figures 10 and 11 show the injury comparison data for those aged 0 to 11 years.

Emotional and Social Health and Culture

Tobacco, Alcohol and Substance Abuse Problems

≺ igarette smoking appears to - be a significant health problem among Native youth.³⁴⁻³⁸ In a survey of Cree children residing in northern Quebec, 51.4% of children ages 11 through 18 years were classified as current smokers.³³ Two surveys which assessed the smoking behaviour of children and adults in the Canadian Arctic showed that among the youth, Inuit females between 15 and 19 years had the highest smoking rates, followed by the Dene and non-Native groups.34, 35 The use of smokeless tobacco by 100 90 80 70 60 50 40 30 20 10 0 **VERY / QUITE WELL** OCCASIONAL PROBLEMS NOT WELL FNIRHS family **NLSCY** avg NLSCY parent NLSCY sibling

Figure 13: Child getting along with family, parents, siblings, age 4 to 11 years only

Native youth in the Northwest Territories³⁶ and northern Saskatchewan poses a significant health problem³⁷ based on recent surveys. The health risks associated with the use of smokeless tobacco are similar to those associated with cigarette smoking. They include discolouration and abrasion of teeth, gingival recession, elevation of blood pressure, nicotine addiction, and increased risk of cancer (particularly of the oropharynx).³⁵⁻³⁸

There is significant concern about substance abuse, including drug and alcohol use, among Native youth.³⁹ Again there is very limited information about the extent and pattern of use among Canadian Aboriginal young people. Prevalence rates of substance use are difficult to obtain, particularly since most surveys of youth have focused on US Native populations.²

A 1985 survey carried out in rural Quebec explored the use of alcohol, tobacco, cannabis and other illicit drugs among Francophone and Native high school students.⁴⁰ There was a higher prevalence of amphetamine, hallucinogen and inhalant use among the Native adolescent group compared to the rural Francophone group. There was no difference in use of tobacco or occasional alcohol consumption, however rural Francophone students tended to be more regular users of alcohol. These results should be interpreted cautiously however, because there was a limited sample size (N=100) and only one of the two eligible Native schools agreed to participate. Among a study of First Nations people in Ontario, female youth in the 15 to 19 year age group had a significantly higher rate of non-prescription drug use compared to other ages.⁴¹

A recent Canadian survey examined rates of substance use between 1990 and 1993 among Native and white adolescents residing in a central Midwest city.⁴² Each year, the number of students participating exceeded a sample size of 2400, and the participation rate was 85%. A greater proportion of Native youth compared to non-Native youth reported use of substances (eg. LSD, marijuana, solvents, and other hallucinogens) except alcohol during each of the four years. The groups had similar rates of alcohol use.

Some Native communities have identified use of inhaled intoxicants as a major health problem but there is little data available about the extent of this problem.³⁹ There are reports that solvent use, including the inhalation of volatile substances such as gasoline, glue and cleaning products is increasing among isolated Native communities.³⁹ A survey carried out in 1985 among Native youth on 25 reserves in Manitoba reported that 20% of

respondents used solvents.³⁹ The median age of children using solvents was 12 years, although sniffing was reported for those as young as 4 years of age.

Although a few case studies suggest that Fetal Alcohol Syndrome (FAS) is more common among Canadian Native children than non-Native children, there is yet no good evidence to support this conclusion.⁴³ For example, researchers have studied FAS in Native communities without including a non-Native comparison group. When a comparison group has been included, it is not clear that criteria for FAS have been applied consistently to both groups. To date, a valid comparison of the

Figure 14: Respondent's satisfaction with child's knowledge of Native culture, by respondent's language

prevalence rates of FAS for Natives and non-Natives has not been carried out.

Due to limitations in the number of questions concerning children's health, no information about tobacco use, alcohol or substance abuse was collected. However, information regarding tobacco use was obtained in the adult core questions.

Behaviour and Emotional Problems

There are few scientifically rigorous epidemiologic studies that specifically address the mental health of Native youth. Most published literature comes from the U.S. One of the few studies to gather information about the emotional health of Canadian Aboriginal youth was the Flower of Two Soils Project.44 This study examined the relationship between academic performance and mental health in First Nations children at several sites across the U.S. and Canada. The Canadian areas included the Northern Woodlands (Manitoba) and the Coastal Region (British Columbia). At each site, a non-Native comparison sample was assembled. The investigators examined symptoms of depression and conduct disorder rather than the actual disorders. First Nations male children were more often classified in the conduct symptom groups by parents and teachers compared to

non-Native children. There was some question about whether this was due to bias of the raters; non-Native teachers tended to rate Native children as showing more behavioural problems in the classroom than did Native teachers rating Native children.

There are some data available about suicide which suggests that it is a significant problem among Aboriginal youth. In 1986 to 1990, the suicide rate among Indian youth was 37 per 100,000; five times greater than the rate for the total Canadian population.³² Wide variation in suicide rates for Native people within provinces has been found in two studies.^{45,46} In a study of young Native males in Alberta, Bagley⁴⁷ demonstrated that suicide rates were strongly correlated with northern latitude in Alberta. Reserves in the north had higher levels of poverty, while those in the southern region were more prosperous and had relatively low suicide rates.⁴⁷

In the FNIRHS, respondents reported that 17% of children have behavioural or emotional problems in the past six months that exceeded those of similar age. These problems increased significantly with age, with 9% in the youngest group, 18% in the age 6 to 11 year group and 23% in the 12+ age group reported as having behavioural or emotional problems. Rates for females and males were similar: 17% and 18% respectively. Figure 12 shows rates for emotional or behavioural problems by age group.

Behaviour and Emotional Problems, NLSCY

Information on emotional and behavioural problems was captured in several ways in the NLSCY. For 2 to 3 year-olds, scores on five factors were calculated: hyperactivity-inattention, prosocial behaviour, emotional disorder-anxiety, physical aggression-opposition, and separation anxiety. For 4 to 11 year-olds, six factors were computed: hyperactivity-inattention, prosocial behaviour, emotional disorder-anxiety, physical aggression-conduct disorder, indirect aggression, and property offences. Cut points which distinguish between those with and without disorder were not reported for any of the factors, so the data were not comparable to the yes/no responses in the FNIRHS data on emotional or behavioural problems.

Child Getting Along with Family

Overall, 76% of children were reported to get along with the family "very well" or "quite well," although the proportion of children who got along well decreased with increasing age: 2% in the youngest group got along "not too well" or "not well at all," compared with 3% in the 6 to 11 year- old age group and 8% in the oldest age group. This difference was statistically significant.

Boys and girls had similar rates, with 77% of girls, and 75% of boys getting along "very well" or "quite well" with their families.

Getting Along with Family, NLSCY

This information was collected only for those 4 to 11 years of age, in two questions: how has the child gotten along with (1) his/her parents, and (2) his/her brothers or sisters. In the NLSCY, rates of getting along well with parents were significantly higher (88%) than rates of getting along well with brothers or sisters (60%).

Rates of getting along well with the family in the First Nations sample were significantly higher than rates of getting along with siblings in the NLSCY, but significantly lower than rates of getting along with parents. Comparison of FNIRHS rates with the average of parent and brother/sister rates in the NLSCY showed slightly higher percentages of those who get along well, but also higher percentages of not getting along well; more NLSCY respondents described occasional problems (this fell between the categories of "quite well" to "not well at all"). Figure 13 compares the FNIRHS data on "getting along with the family" to the NLSCY data on (1) parents (2) brothers/sisters (3) the average of parents and brothers/sisters.

Knowledge of Native Culture

When respondents were asked to rate their satisfaction with the child's knowledge of Native culture, 69% were "very satisfied" or "satisfied." There were no significant differences by age group, with rates of 73%, 68% and 68% in the youngest through oldest group. Rates were similar for females and males, with 71% of respondents reporting satisfaction with the females' knowledge, and 67% for the males' knowledge of Native culture.

Significant differences were found when satisfaction was grouped according to the language which the respondent used every day. Those who spoke an Aboriginal language were much more satisfied with their child's knowledge of Native culture than those who spoke English, French or another non-Aboriginal language. Figure 14 shows satisfaction with child's knowledge of Native culture by language spoken.









DISCUSSION

The Child Health Section of the FNIRHS focuses in on some key aspects of child health, particularly injuries and certain chronic conditions such as asthma. Since only a limited number of questions could be included, the area of emotional

health was much harder to capture within a few questions. To ascertain the prevalence of such conditions as depression or antisocial behaviour, two of the most common conditions experienced by

non-Aboriginal youth, it would be necessary to ask several questions about symptoms related to each specific disorder.

The Child Health Section asked about two important correlates of infant health: birth weight and breast-feeding. A low birth weight infant is one who weighs less than 2500 gm at birth. These infants are at increased risk of morbidity and mortality.^{4,32} Native infants may be at particular risk for prematurity and

low birth weight,⁴⁸ according to some sources, but the rate of low birth weight in the FNIRHS did not differ significantly from that in the NLSCY. According to

these data, approximately 5% of infants had a birth weight less than 2500 gm in both the FNIRHS and the NLSCY. The rate of high birth weight which is associated with higher neonatal mortality was significantly higher for the FNIRHS than the NLSCY; 17.9% compared to 12.1% respectively. Information about birth weight in both surveys however was collected from the respondent by retrospective recall. While parents may well remember accurately the birth weight of their infants, it is important to obtain these data at the actual time of birth.

Unfortunately standards of growth for measurements such as weight and height have often been based on non-Native populations. There is some evidence to

Families with larger numbers of children and inadequate housing typically experience crowding. This is considered one of the factors that may be important in the spread of infectious diseases. There is some evidence to suggest that First Nations and Inuit infants may have growth patterns that differ from that of the majority culture. Although the use of 2500 gm as a standard for low birth weight is applied across different

ethnic populations, it would be important to collect information about patterns of growth within the First Nations and Inuit people so that standards more relevant to the specific culture may be developed. For example, if Aboriginal people do have a higher weight for height growth pattern compared to non- Aboriginal populations, then a weight of 2500 gm may be set too low for the First Nations population in capturing infants at increased risk of health problems. It is also

Injuries are a major cause of morbidity and mortality among children and youth generally.

of note that families of low socioeconomic status (SES) are at increased risk for having low birth weight infants. According to information from Statistics Canada, the

percentage of low birth weight infants by income level in 1986 was 1.4 times higher among those in the lowest SES neighbourhoods compared to the highest.³² Information from the literature review suggests that a significant proportion of Aboriginal people are exposed to the potentially devastating effects of poverty.^{49,51} Assessing the relationship between poverty and low birth weight in the Aboriginal

population requires growth charts standardized for First Nations and Inuit people.

Approximately half of mothers indicated that their child had been breast-fed. This is less than the proportion in the NLSCY who indicated that they breast-fed. Data from the FNIRHS indicate that a higher proportion of First Nations and Inuit women are breast-feeding their infants for longer than six months compared with respondents to the NLSCY.

Although slightly more than half of children described by respondents in this survey lived among families with fewer than three children residing at home, a large percentage of children lived in families with three or more children. Families with larger numbers of children and inadequate housing typically experience crowding. This is considered one of the factors that may be important in the spread of infectious diseases.⁵² According to the APS, Aboriginal people report poor housing as a major problem.⁵⁰

Although this survey did not inquire specifically about a range of infectious diseases, there is evidence that low SES and crowding are associated with increased rates of certain infectious diseases such as diarrhea and respiratory infections.^{2,22} Some communities also experience inadequate water supply and waste disposal;² these factors may also increase the prevalence of certain infectious diseases.⁵³ For example, inadequate water supply has also been related to gastrointestinal disease among young children on two First Nation reserves in North Central Saskatchewan.⁵³

Within a group of specified health conditions, ear problems were reported among 15% of the sample. While the term "ear problems" is very general, previous literature suggests that otitis media (middle ear infections) are experienced more frequently by Aboriginal children. Diseases of the respiratory system, including asthma and bronchitis, were also very common. Allergies were reported by 13% of the sample; this likely included a range of symptom patterns. In addition, it was not possible to ascertain whether the presence of an allergy had been confirmed by a health care professional.

Although it may be surprising that the number of children and youth reported to have diabetes was too small to even report accurately, in fact the type of diabetes commonly occurring among the Native population is NIDDM, a type of diabetes which mainly affects people beyond the age of 18. There does appear to be a link between obesity and NIDDM.³⁰ It is of note that the proportion of children with overweight problems was 6% in boys and 7% in girls. With increasing age, there was a rise in the prevalence rates of weight problems reported. It may be helpful to examine the pattern of obesity in relationship with NIDDM specifically within the First Nations population. As outlined above in the literature review, growth patterns including height and weight, should be examined with specific standardized information from the Aboriginal population.

Psychological problems were reported among 3% of individuals below the age of 18 years. If there had been the opportunity to include more questions in this area, it would have been useful to determine the major areas of concern within the broader category of psychological disturbance.

Injuries are a major cause of morbidity and mortality among children and youth generally. Although information about death due to injury was not inquired about in the FNIRHS, the rate of injuries reported was very high with 13% of children and youth described as having experienced broken bones or fractures. While reported at much lower rates, serious head injury, serious burns, near-drowning, and frostbite or hypothermia were all experienced by more than 1% of children and youths. Unfortunately, information about injuries experienced by Canada's young people generally focuses on rates of hospitalization due to injury.³² Since children and youth who experience injuries are not necessarily hospitalized, this precludes a useful comparison. It was not possible to examine correlates of injuries, such as alcohol use, within the limited number of questions in this survey. However, information about factors associated with the occurrence of injuries among Native children and youth would be important to examine and may provide essential knowledge about ways to prevent injury through identification of risk factors. Understanding why injuries were reported so commonly among Native children and youth represents an important area of investigation, but any decisions about further study arising from these data are to be determined by Aboriginal people themselves.

The majority of Native and Inuit children were not identified as having emotional or behavioural problems when respondents were asked a general question about this area of health. Children over 12 had the highest rate of emotional or behavioural problems. It would be useful to understand the specific nature of such difficulties. Data from large-scale community surveys measuring emotional and behavioural problems in non- Aboriginal children and youth suggest that the prevalence of psychiatric disorders varies between 17% and 22%.⁵⁴ The measurement of psychiatric disorder is generally guided by pre-existing scales. In this way it addresses a different concept from asking generally about the presence of any emotional or behavioural problem and precludes direct comparison of data from the FNIRHS with data about prevalence rates of psychiatric disorder.

It is important to highlight the positive finding that over three- quarters of children were described as getting along with the family "very well" or "quite well." Again the proportion of children who did not get along well with the family was the highest in the oldest age group. While only limited information is available from the core questions on child health, it suggests that adolescence may be a period of risk for First Nations and Inuit children. Before drawing such a conclusion, however, more detailed information would be needed with data collection from as many sources as possible. For example, information could be obtained from parents, youth themselves and school teachers.

In terms of the overall health of children and youth, it is of note that more than 80% of respondents rated their child's health as "very good" or "excellent." Unfortunately, a response category of "good" was not included in the FNIRHS so it is difficult to determine if this perception of children's health among respondents to the FNIRHS differs substantially from that of respondents to the NLSCY. Another key issue is ascertaining in detail what respondents mean when they report their child's health as "very good" or "excellent." A parent's assessment of a child's health is dependent on many issues including the parent's expectations of that child's health as well as the health of siblings and peers. It would be useful to obtain further information about how the perception of a child's or youth's health is correlated with certain objective measures such as number of injuries, number of hospitalizations and frequency of infections. Finally information from multiple informants, for example, both the mother and the child or youth, would be most useful in determining the overall health of this age group.









CONCLUSIONS

In summary, the majority of respondents to the FNIRHS rated their child's health as very good or excellent. At the same time, injuries, emotional and behavioural problems, respiratory conditions and ear problems were reported among many Aboriginal children. Since only ten core questions could be included on child health, there are many areas, particularly emotional and behavioural problems, about which adequate information could not be captured without further questions. Hopefully with the approval of the National Steering Committee, these data can be regarded as a first step to understanding the health and quality of life experienced by Aboriginal children. There were many issues such as substance abuse, exposure to violence including experiences of child maltreatment, and academic performance, which could not be covered within the limited number of questions possible. If further surveys examining child health are carried out, the inclusion of more topics would allow questions that matched those used in the NLSCY. This would ensure that direct comparisons with the general Canadian population could be done. Evaluation could also be carried out over the long-term, to determine any changes in child health. A longitudinal FNIRHS would provide a more comprehensive picture of the well-being of Aboriginal children.

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Chapter 2

An Examination of Residential Schools and Elder Health

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TABLE OF CONTENTS

 $\mathbf{52}$

	List of Figures
	List of Tables
	Introduction and Background
-	Methods
	Review of Literature
	Indian and Inuit Residential Schools in Canada
- Anne	Harms Caused by Residential Schooling
	Physical and consequent Emotional Harm to Children
	Educational Harm
	Loss of Culture and Language
	Harm to Family Structures
2	Health Conditions of Elders
301	Socio-cultural Factors
7	Family Support Net works
- and the	Health and Social Services
	Mental Health
(1917)	Elder Abuse
	Poverty
1111	Results
Silver	Discussion
	References

First Nations and Inuit Regional Health Survey
Figure 1.	Age by Gender	40
Figure 2	Aboriginal Language Used Daily by Age	40
Figure 3.	Highest level of Education	41
Figure 4.	Excellant / Good Self reported Health Status By Gender and Age	41
Figure 5.	Poor / Fair Self-reported Health Status by Smoking Behavior and Age	42
Figure 6.	Asthma by Pack-Years Smoking and Age Group	42
Figure 7.	Breathing Problems by Pack-Years Smoking and Age Group	42
Figure 8.	High Blood Pressure by Pack-Years Smoking and Age Group	43
Figure 9.	At Least One Chronic Health Problem by Gender and Age	43
Figure 10.	Diabetes Alone and Cardiovascular Co-Morbidity in the Presence of Diabetes	44
Figure 11.	Diabetes Alone and Cardiovascular Co-Morbidity in the Presence of Diabetes by Age	44
Figure 12.	Rank Order of Health Services in Need of Improvement	45
Figure 13.	Disability and Activity Limitation	45
Figure 14.	Community Progress Over the Last Two Years	46
Figure 15.	Community Progress and Wellness	46
Figure 16.	More Than One Year Since Last Received Dental Care by Gender and Age	47
Figure 17.	Dental Treatment Needed at the Time of Survey by Gender and Age	47
Figure 18.	Residential School Attendance by Gender and Age	47

Figure 19. Determinants of Health - Shaded Factors Theoretically Impacted by Residential School 50

LIST OF TABLES

Table 1.	Estimated life expectancy at birth, total population, Inuit and Registered Indian, 1991.	32
Table 2.	Life expectancy at birth, age 30 and age 60, Registered Indian and Total Populations, 1978-81, 1982-85 and 1990	33
Table 3.	First Nation and Inuit Elder Smoking Rates versus Canadian Population	41
Table 4.	Chronic Conditions, First Nations and Labrador Inuit compared to the Canadian Population: Age-gender-specific and age adjusted prevalence for self-reported heart problems, hypertension (high blood pressure), diabetes, arthritis and rheumatism	43

LIST OF FIGURES

INTRODUCTION AND BACKGROUND Ultimately, everyone has a vested interest in maintaining optimal health and wellness particularly with advancing age. Those fortunate enough to live to an old age will likely be personally confronted with some of the health and social issues that accompany aging. Population demographic trends show that the numbers of First Nations and Inuit elder peoples are increasing. Presently, and to a greater degree in the future, aboriginal society will increasingly encounter the aging of family, friends and community members. Thus, the broad health issues associated with aging need to be addressed.

For the purposes of this report people in older adult age groups (45 years +) were defined as 'elders' and not 'middle age adults' or 'seniors', since elders is an acceptable term used by Aboriginal peoples. The term elders was used here to signify age only, not the spiritual definition that is usually used in Aboriginal communities to define an Elder.

Whereas an expanding body of information exists concerning the impact of residential school experiences on Aboriginal peoples in Canada, relatively little information exists regarding the current health status of elders. This report was written to investigate the health of First Nations and Labrador Inuit elders living in their home communities. In addition, the report will explore the numbers of elders who attended residential schools.

The Assembly of First Nations recognized the importance of reconciling history to make sense of current health stating that:

"First Nations need to know their history. History provides a context for understanding individuals' present circumstances, and is an essential part of the healing process."

Assembly of First Nations (1994)

A comprehensive examination of elder's health status should begin by linking historical health determinants to social, political, environmental, economic and cultural influences. Thus, a study that proposes to examine the health status and social circumstances of elders living in their home communities in Canada cannot ignore the pervasive impact that residential schools have had on many individuals and the ripple effects felt throughout their families and communities. The reader is particularly encouraged to consider health survey indicators in a holistic context of past residential school experiences as a significant cohort-specific determinant of health.

The rationale for such an approach to understanding health is found in the 'determinant of health' conceptual framework that builds on the link between health status and income inequality (including poverty, lack of education and under-employment) but extends to include a shift away from 'material constraints' to 'social constraints' as the limiting condition on quality of life (Wilkinson, R., 1994). In other words, health may be viewed as a holistic balance and harmony involving body, mind, emotions and spirit. Theoretically, residential school experiences seem to have created fundamental inequalities that, in part, could have been manifest in the profound poor health of elders when compared to their non-aboriginal counterparts in Canadian society. The aim of this report is to describe the health of First Nations and Labrodor Inuit elders, explore the complex multiple causative factors in the etiology of ill health and to make recommendations that fundamentally improve health. Failure to acknowledge the potential impacts of the past events and current social, political, economic and cultural circumstances in the complex etiology of poor health will likely lead to an incomplete understanding of the root causes of ill health.

In January of 1996, a national steering committee (NSC) was struck to develop the FNIRHS. The NSC included membership from First Nations political organizations drawn from nine participating regions including Labrador, New Brunswick, Nova Scotia, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia. Two ex-officio members attended, one each from the Assembly of First Nations and Medical Services Branch of Health Canada.

All decisions were reached by consensus. The NSC managed the entire survey process including the development of national core questions, a detailed code of ethics, financial and community accountability, data security, ownership, control, analysis, interpretation and dissemination of results.

The national core questions were common concerns that were developed and mutually agreed upon by all members of the NSC. The survey examined chronic medical conditions including diabetes, residential schools and elders health issues, the 'non-traditional' or recreational use of tobacco, wellness, children's health, dental health, health services, disabilities and restrictions on activities. It should be noted that regions and communities had the flexibility to develop additional regional questions that aimed to address regional and local health issues.

The nine participating regions each submitted national core data reports and electronic copies of their databases. After a series of quality checks were performed, individual records were appropriately weighted to properly represent the national population of adults living in First Nations and Labrador Inuit communities. Comparable data responses from the National Population Health Survey (1994-95), the Aboriginal Peoples Survey (1991), and community-specific ecological variables (1997) were appended to the national database. Individual, community and regional identifiers were removed from the sample of 2,663 respondents ranging in age from 45 years and older.

METHODS









REVIEW OF LITERATURE

Indian and Inuit Residential Schools in Canada

T he following review draws heavily on the Royal Commission on Aboriginal Peoples' final report (1997), which contains extensive research on Indian and Inuit residential schools. Readers are encouraged to access this important source of information for further reading and recommendations made by the commission.

Education, administered by the church became an essential tool in the assimilation of Indians. In 1879 the federal government adopted the American model of Indian residential

schools with the added provision that these schools be operated by various Christian denominations. In 1920 the Indian Act was amended to make school attendance compulsory for all First Nations children between the ages of seven and fifteen.

By 1923, there were 72 Residential schools. That number grew to a high of 80 in 1931. There was then one school in Nova Scotia, 13 in Ontario, 10 in Manitoba, 14 in Saskatchewan, 20 in Alberta, 16 in British Columbia, four in the Northwest Territories, 2 in the Yukon and plans for 2 schools in Quebec. That number then gradually fell through school closures, many because of fires, to 75 in 1943. Indian and Inuit residential schools operated in Canada for nearly 150 years. The majority of them were in western Canada, and the ones in British Columbia operated until the 1970s.

	Male	Female
Total Population	75	81
Inuit	58	69
Registered Indians	62	70

Table 1: Estimated Life Expectancy at Birth, Total Population, Inuit and Registered Indian in 1991 (years)

Source: M.J. Norris et al., "Projections of the Aboriginal Identity Population in Canada, 1991-2016", research study prepared by Statistics Canada for RCAP (February 1995).

Note: Total Population' refers to all Canadian citizens including Aboriginal peoples.

> The stated policy of the Canadian government was to assimilate aboriginal people into the dominant society by educating children away from their parents' control and their community's culture. By financing and regulating these residential schools, the Crown bears ultimate responsibility for this action.

Milloy, (1996) clearly states that:

"Federal policy since Confederation, and what it would remain for many decades, was a policy of assimilation, a policy designed to move Aboriginal communities from their 'savage' state to that of 'civilization' and thus to make in Canada but one community; a non-Aboriginal one. At the core of the policy was education. In the education of the young lay the most potent power to effect cultural change a power to be channeled through schools and, in particular, through residential schools.....Aboriginal knowledge and skills, had enabled the newcomers to find their way, to survive and to prosper. But they were now merely historic;

they were not to be any part of the future as Canadians pictured it at the founding of their new nation in 1867. That future was one of settlement, agriculture, manufacturing, order, lawfulness and Christianity. In the view of politicians and civil servants in Ottawa whose gaze was fixed upon the horizon of national development, Aboriginal knowledge and skills were neither necessary or desirable in a land that was to be dominated by European industry and, therefore, by Europeans and their culture."

The long term consequences of these schools, designed to 'christianize and civilize', have been, in sum, disastrous. For as long as five generations in some areas of Canada, children were removed from their homes, families, culture and language to be immersed far away for long periods in what has been described as a 'cultural commando course'. At the schools children's long hair was cut off and school uniforms issued, they were forbidden to speak their own language and forced to live by strict rules which prevented any contact with siblings or children of the opposite sex, in short, many of these children endured long years of isolation and loneliness.

To give some idea of the impact of residential school it is important to examine the context of the residential

school experience. Children entered a strange new world in residential boarding schools that were run primarily by the Christian churches: Roman Catholic, Presbyterian, Anglican and what is now the United Church of Canada.

In many of the schools missionaries taught western culture to Indian children. Yet, in western society, priests, brothers and nuns were people who lived on the fringe of their own society. They deny sex, marriage and family, opting instead, to live their whole lives within a religious culture. Further, within the religious culture of priests and nuns, missionaries are a marginal group. They move away from their own cultural group and yet take their culturally-based and culturally-biased views with them. Many spent their

	At Birth		At Ag	je 30	At Age 60	
	Registered Indians	Total Population	Registered Indians	Total Population	Registered Indians	Total Population
Male						
1978-81	61.6	71	39.5	43.4	18.4	17.5
1982-85	64	72.4	40.8	44.4	17.9	18
1990	66.9	73.9	41.1	45.7	16.9	19
Female						
1978-81	69	79.2	44.1	50.7	21.4	23.4
1982-85	72.8	80.1	46.8	51.4	22.5	23.8
1990	74	80.5	46.7	51.6	20.5	23.7

Table 2: Life Expectancy at Birth, Age 30 and Age 60, Registered Indian and Total Populations, 1978 - 1981, 1982 - 85 and 1990

Notes:

- Total population is the total population of Canada, including Aboriginal peoples.
- Life expectancies at age 30 and 60 for registered Indians in 1990 are the average life expectancies for ages 30-34 and 60-64 respectively.

Source:

Health and Welfare Canada, "Health Indicators Derived from Vital Statistics for Status Indian and Canadian Populations, 1978-1986" (September 1988); DIAND, "Life Tables for Registered Indians, 1985 and 1990", Information Quality and Research Division, unpublished tables (May 1995); Statistics Canada, Report on the Demographic Situation in Canada, catalogue no. 91-209E (Ottawa: 1993)

lives isolated from any influence from their own culture and kind.

Scores of children died from disease; others were emotionally and spiritually destroyed by the harsh discipline and living conditions. Children were referred to as 'inmates'. Survivors report being hungry all the time. In some cases, children were separated from their siblings, tortured for speaking their mother tongue, forbidden to honor their traditions. Grievous sexual abuse also occurred in some schools, but other outstanding issues include physical abuse and poor quality of education. Very few students graduated until education passed into the control of First Nations communities. Some communities were completely de-populated of children from ages 5 to 20. Traditional means of educating and parenting children were lost. In many cases the extended family was destroyed.

In retrospect it seems that the effect of the Indian and Inuit residential schools could be described as an assimilation process that failed. Former students were often confused and frustrated, unable to fit back into their own families, communities and Nations, while not adequately prepared to join mainstream Canadian society.

The legacy of these schools is multi-generational, thought to be reflected in the unacceptably high rates of suicide among First Nation and Inuit peoples, as well as high incidence of substance abuse, family violence and alcoholism.

Harms Caused by Residential Schooling

Réaume, D.G. and P. Macklem (1994), identifying the harms caused by residential schooling including four possible types of harm and potential claimants as follows:

Physical and Consequent Emotional Harm to Children

Most readily recognizable by the legal system who were mistreated or abused within the system. These include, in addition to the obvious physical harm of physical or sexual abuse, the emotional harm consequent upon such abuse, and harm to dignity. The psychological effects of abuse, the full extent of which needs further study, have long outlasted their physical progenitors. In the category of physical harm we also include the under-nourishment suffered by some children, as well as general health problems and the exposure to disease due to unhealthy living conditions.

Educational Harm

Individual children within the system were given a radically inferior education, which may have had enormous consequences for the quality of their lives... No serious attempt seems ever to have been made by the Churches or the government to design an educational program for Aboriginal children that was consistent with their own cultures. Instead, Aboriginal children received a second class education that ill equipped them to live productive lives.

Loss of Culture and Language

Repeople the benefits of education in a way consistent with Aboriginal traditions, the residential school system was designed to do and did lasting damage to the culture, spiritual traditions, and languages of entire communities. This harm extended far beyond the individual children who attended; it encompassed their whole communities. Languages were nearly wiped out; traditions were lost. Generations of Aboriginal people were alienated from their past.

Harm to Family Structures

The last type of harm has both individual, family, and communal manifestations. In removing children from their parents for long periods of time, the system had a negative impact on the normal development of parent\child relationships.

Sivell-Ferri (1997) equates the residential schools to prisons and the educational process as a means to achieve social control:

"Prisons are one place today in which people are obviously watched and monitored in this way. The Indian residential school system, now abolished, certainly stemmed from this same history of thought. European educational systems still follow this logic when classrooms are arranged in rows and the teacher's desk is placed at the back or on a raised platform....European societies are based on a particular idea of order arising from the rule of reason and rationality. That which does not fit, whether an indigenous society in the Americas or the complex natural world, into a specific category within this system of order has traditionally been classified as disorder, irrational, and unreasonable and thus becomes a problem to be solved or a crisis to be averted.".

The Government of Canada acknowledged their role in development of residential schools recently in a speech given by the Hon. Jane Stewart (1998):

"Sadly, our history with respect to the treatment of Aboriginal people is not something in which we can take pride. Attitudes of racial and cultural superiority led to a suppression of Aboriginal culture and values. As a country,

we are burdened by past actions that resulted in weakening the identity of Aboriginal peoples, suppressing their languages and cultures, and outlawing spiritual practices. We must recognize the impact of these actions on the once self-sustaining nations that were disaggregated, disrupted, limited or even destroyed by the dispossession of traditional territory, by the relocation of Aboriginal people, and by some provisions of the Indian Act. We must acknowledge that the result of these actions was the erosion of the political, economic and social systems of Aboriginal people and nations....One aspect of our relationship with Aboriginal people over this period that requires particular attention is the Residential School System. This system separated many children from their families and communities and prevented them from speaking their own languages and from learning about their heritage and cultures. In the worst cases, it left legacies of personal pain and distress that continue to reverberate in Aboriginal communities to this day. Tragically, some children were the victims of physical and sexual abuse.

The Government of Canada acknowledges the role it played in the development and administration of these schools. Particularly to those individuals who experienced the tragedy of sexual and physical abuse at residential schools, and who have carried this burden believing that in some way they must be responsible, we wish to emphasize that what you experienced was not your fault and should never have happened. To those of you who suffered this tragedy at residential schools, we are deeply sorry.

In dealing with the legacies of the Residential School system, the Government of Canada proposes to work with First Nations, Inuit and Métis people, the Churches and other interested parties to resolve the long-standing issues that must be addressed. We need to work together on a healing strategy to assist individuals and communities in dealing with the consequences of this sad era of our history."

The Government of Canada recently allocated some \$350M to an Aboriginal Healing Strategy as part of "Gathering Strength Canada's Aboriginal Action Plan".









HEALTH CONDITIONS OF ELDERS

A growing body of research examines gerentologic health issues in the general public however serious gaps exist in the published literature concerning the health status of elders. Ruiz, (1995) concludes "Epidemiological data on mental disorders among older Asian and Native American populations are virtually non-existent."

Life expectancy rates of First Nations and Inuit peoples are profoundly lower than the rest of Canada. The Royal Commission on Aboriginal Peoples report prepared by Statistics Canada (tables 1 and 2) indicate that the life expectancy for Status Indian males and females were approximately 13 and 11 years less respectively, when compared to the Canadian population statistics. Inuit males and females were approximately 17 and 12 years less longevity respectively, when compared to the Canadian population rates. Females in all three populations lived over 6 years longer than their male counterparts. In general, life expectancy rates for the Status Indian and Inuit population resemble the rates seen in the Canadian population 40 or 50 years ago.

Table 2 estimates that the life expectancy gap is present at each 'life-stage'. These datum were published in 1988, thus 1990 data presented are based on a theoretical improving trend for longevity for Status Indians, however examination of table 1 shows that improvements in life expectancy at birth fell short of the prediction value depicted in table 2. Even given the inherent limitations of rosy predictions that apparently suggested a narrowing of the life expectancy gap, the predicted pattern for the gap in life expectancy still appears to be increasing for Status Indians in comparison to the general population. In other words, table 2 shows that the average years of life remaining for those who reach age 60 appears to be decreasing (1985 to 1990) while longevity appears to have plateaued for the rest of Canadians, thus

increasing the life expectancy gap between First Nations peoples and the rest of Canada.

The next section of this brief review will specifically focus on studies examining aboriginal elder's potential determinants of health and discuss a broad range of possible etiologic circumstances including social factors, family support networks, perceived advantages and disadvantages of old age, health and social services, mental health and coping with change, poverty and the potential impacts of residential schools.

Socio-cultural Factors

P erhaps due to lower life expectancy (see tables 1 and 2) a serious paucity of empirical data exists concerning the health of aboriginal elders living in Canada. Assembling comparative evidence from research in the United States may limit its interpretation in a Canadian context however, it seems likely that aboriginal elders in Canada and America are similar in many respects and quite different from their non-native counterparts. Clearly, much more investigative work needs to be done to obtain a better understanding of this rapidly growing and changing population.

Cultural traditions reflected in values, attitudes, and behaviors clearly differ in varying degrees among ethnic 'minority' elders. For example, studies of Native American elders have shown a belief that healing a sick person requires a restoration of harmony, especially with the use of super-natural forces (Yee, B., et al., 1994). M. Harris, et al., (1989) examined advantages and disadvantages of aging among 128 Native American, Hispanic, and Anglo adults aged 60-92 living in central New Mexico. Participants reported improved relationships with their

families since turning age 60. The most commonly mentioned advantage of old age was increased freedom and free time; other advantages mentioned included improved relationships with families, increased relaxation, not having to work, increased self-acceptance and self-respect, and the opportunity to engage in specific activities. Poor health and physical problems were viewed as a major disadvantage of growing old, as were limitations on activities, feelings of loneliness and isolation, and concerns about dependency.

Family Support Networks

n examination of social integration of 101 elderly Seneca Indians aged 55 or older from the Allegany reservation in New York State, (1984) show that the overwhelming majority (83 percent) of the elders were integrated within their familial and friendship networks as well as in informal social organizations. In this study health status was the most important determinant of social integration, followed by employment and marital status. Not one of the elders who worked was socially isolated. Elderly women were more likely to be employed in old age than the elderly men. The emergence of informal agespecific social groups on the Allegany reservation after relocation was seen as an adaptive measure following the tremendous social change experienced by the Senecas since the 1960s due to building of a dam and involuntary relocation off flooded land. This involuntary relocation was thought to have had a deteriorating effect on the traditional kinship networks of the Senecas and accelerated the assimilation process. (Randy, J. 1995).

Chipperfield and Havens, (1992) assessed serial changes in older Canadians' levels of perceived respect and found there was not a uniform increase across ethnic groups; while respondents of British, French, and German descent reported significant increases in perceived respect, those of North American, Native Canadian, or other descent did not. Other evidence suggests that this finding is not consistent with traditional aboriginal values.

Among Native American families, elders are considered an integral resource and play a central role in family life by providing assistance to younger members for discipline, spiritual guidance, and maintenance of cultural heritage. In return for meeting family responsibilities, Native American elders expect to be respected and cared for when they become too frail to care for themselves (Yee, B., 1990).

Family support networks are important in older age. Elders who live on or near the Prairie Band Potawatomi reservation in Kansas were questioned about their contact with each living child and sibling regarding nine common family activities. Results documented that the family support network functions better if it includes an adult child rather than a sibling. Females were somewhat more involved in family interactions than men, although this was not always the case when particular family activities or relationships were studied in detail. The presence of a spouse acted to insulate elders rather than increase contact within the family support network, (Robert, J., 1991).

In studies of inter-generational co-residence, pronounced differences were found in both the patterns and the trends according to race and ethnicity in both younger and older co-resident households. In 1984-1986, 30 percent of Asian American households with an older host generation were co-resident, compared with 24 percent of older African American households, 22 percent of the older Hispanic households, 21 percent of the older Native American households, and 12 percent of the older white households. The factors that determine intergenerational co-residence are consistent with the idea that economic situations, the available human resources, and housing situations act as constraints on meeting the independent living norms and the family care norms (Morris and Winter, 1995).

Health and Social Services

C uellar (1990), reviewed the literature on the health status and health and human service needs of elderly Native Americans, including American Indians, 'Eskimos', and Aleuts. Demographic profiles, ethnographic descriptions, needs assessments, research projects, policy analyses, and critical reassessments were reviewed. Native American elders generally lived in worse socioeconomic conditions than the majority of older persons in the United States and were more functionally dependent at a younger chronological age because of the earlier onset of "old-age" problems. Almost one of three older Native Americans lived below the poverty level. Death among Native Americans occurred an average of 9 years earlier than among the general population.

Cuellar (1990) stated:

"Health and human service systems have failed to address the needs of older Indians because they do not integrate family generations; are not based on adequate information of older Indians; and do not include assessment of family lifestyle, institutional arrangements, cultural factors, and native languages in their service plans."

Gaps in the existing research literature indicated the need for much more information about aging and health among Indian, Eskimo, and Aleut populations.

Review of the extent of current knowledge about drug use among older minority women led to the conclusion that the particular problem facing Native Americans is distance from the health care system both culturally and physically. It was suggested that policy makers should consider providing adequate funding for drug regimens, make efforts to bridge the distance between minority elderly and the health care system, and encourage more extensive use of informal sources of support. (Kail, B., 1989)

Mental Health

Tarduzzi, (1994) investigated the mental health Nstatus of Native American elderly using a research model that evaluated stress and coping among a sample of Native American and Alaskan Natives. Data were used from the National Indian Council on Aging's study of older American Indians and Alaskan Natives conducted in 1978-1980. A subsample of 682 persons, aged 44 to101 years (mean age 62), was used in this study, with 75 percent reservation Native Americans and 14 percent Alaskan Natives. The median income ranged from \$4,000 to \$4,999 per year. Of the total, only 29 percent were employed either full- or part-time at the time the survey was administered. A research model was developed that equated mental health status with a combination of stressors including: physical health, income, education, social support, and coping. Social support networks and coping behavior were believed to

mediate the impact of the other variables on individual mental health. Regression analysis and analyses of variance showed that physical health and coping were consistent predictors of mental health; coping mediated the impact of physical health on mental health; and important male-female and urbanreservation differences existed within the Native American population in terms of mental health.

Elder Abuse

Elder abuse was examined among 37 elderly Navajos aged 59-90+ from the Oljato Chapter, and from a close relative of each elderly person. Results show that neglect was the most prevalent form of abuse. Three dependency-related factors made the elderly vulnerable to abuse: suddenness of becoming dependent, mental problems, and lack of income (Brown, S., 1989).

While few studies have examined the extent of elder abuse in Australia, existing research has identified older women as the most likely victims of neglect, abuse, and exploitation. Widows, aged migrants, disabled or frail persons, the Aboriginal and Torres Strait Islander aged populations, isolates, medication users, rural and remote dwellers, and poor persons were thought to be most vulnerable to abusive situations. (Dunn, P. 1995)

Poverty

Schiefelbusch, R., and John, R. examined urban and rural/reservation American Indian elders, (1991). Their study revealed a mixed portrait of American Indian elders' status and characteristics. Compared with their urban counterparts, rural and reservation elders experienced greater problems with social and economic resources, mental and physical health, ability to perform routine activities of daily living, and need for and use of social services. A majority of both urban and reservation elders lacked more than a grade school education.

Schiefelbusch, R., and John, R. (1991) also examined social service needs of reservation Elders living New Mexico including the Nambe, Picuris, Pojoaque, Tesuque, Isleta, Laguna, San Felipe, San Juan, Santa Clara, Taos, and Zuni; the Ponca Tribe and Sac and Fox Nation of Oklahoma; and the Warm Springs Confederation of Oregon. The results indicated high levels of social service needs with the greatest needs reported in the areas of financial assistance (8), food assistance (6), social/recreational services (6), information and referral (5), transportation (2), housekeeping assistance (2), and regular monitoring (2). Ponca elders were the notable exception to other tribes studied; they appear to have adequate social support, with 100 percent reporting having both a confidant and a person who would care for them if they became sick or disabled. Ponca elders enjoyed substantially higher median annual income, employment-related education, medical services, housekeeping assistance, and access to health information and referral.

Earlier work conducted almost twenty years ago by John (1980), concluded that the problems of the Native American community concern the mechanics of program implementation and result from basic uncertainties of the government-native American Indian relationship including uncertainty that the Federal Government would make a positive commitment to honor past agreements and confusion over areas of Federal-State jurisdiction. In the United States, Indians stressed the need for direct Federal funding of programs in order to eliminate intervening State government units. They also addressed the problem of conflicting regulations that Natives encounter when seeking benefits from various Federal programs. Other concerns focused on Indian problems in confronting the diverse bureaucratic structures that administer programs for the elderly. Because Indians view life holistically, comprehensive programs that reflect an understanding of Indian cultures needed to be designed. The most important service needs of the Indian elderly were thought to fall into the categories of communication and information dissemination, income maintenance, interventions that respect Indian values, and the entire spectrum of health services. Services to the Indian elderly also needed to be sensitive to the diversity of Native American cultures (John, 1980).









RESULTS

The survey sample results include 2,663 respondents ranging in age from 45 years and older, living in 183 First Nations and 5 Labrador Inuit communities. The sample results were weighted to reflect the actual age and gender distributions in the population according to the department of Indian Affairs data appended to the national core database in electronic format. Thus, datum presented are representative of a population of 51,755 elders (45 years and older) living in First Nations and Labrador Inuit communities.

Selection of age 45 years as a starting point in analysis was based on two main criteria; first, it was necessary to group respondents into categories that would span several decades to demonstrate age and genderspecific trends, if present within the cohort, and secondly, it was postulated that First Nations and Labrador Inuit peoples were more functionally dependent at a younger chronological age due to an earlier onset of chronic 'old age' health problems when compared to their Canadian counterparts.

Papers in this series deal with specific health concerns such as chronic conditions including diabetes, tobacco use, activity limitation, wellness etc. Rather



Figure 1 : Age by Gender



Figure 2: Aboriginal Language Used Daily by Age

than replicate all elder age group findings from other papers, data from other relevant papers will be discussed and presented with reference to the source documents. It is envisioned that the research reports will be published and bound as a series thus the reference to other papers in the series seems an appropriate approach that aims to direct the reader toward a more in-depth treatment of a specific area of interest.

Concerning residential schools, the scope of questions were quite limited and when crosstabulated to specific health concerns the results did not show significant between group differences when controlled for age. Attempting to quantify the specific effects of residential schools on long-term health outcomes was not feasible since the entire community of elders experiences would have been severely confounded over time by the experience of other pressing health determinants such as inadequate education, employment and income. In other words, the residential school experience is but one early life influence along a continuum of social, economic and cultural influences that, in sum, determined health status for the entire community.

Figure 1 shows the age and gender distribution of the weighted sample. Females exceed males above age 65.

Fifty-nine percent of elders were married (legal or commonlaw partner), the remaining 41% were separated, divorced, widow or single. Comparing language used most often in daily life indicates that Aboriginal language is used by 39 percent of First Nations and Labrador Inuit over age 45 years. As Figure 2 shows, Aboriginal language increases in direct proportion with increasing age, with some 30% speaking their Aboriginal language daily for 45-55 years. This increases to 60% above age 75.



Figure 3: Highest level of Education by Age



Figure 4: Excellent / Good Self-reported Health Status by Gender and Age

Age	FNIRHS*	NPHS**
45-49	59	32
50-54	54	29
55-59	48	27
60-64	37	25
65-74	35	17
75+	23	10

Table 3: First Nation and Inuit Elder Smoking Rates versus Canadian population

* = FNIRHS weighted proportion 1997;

** = National Population Health Survey, 1994

Examining the highest level of education completed shows that many First Nations and Inuit elders did not complete high school. In the youngest age group (45-54), fourteen percent completed high school and began some post-secondary education, a substantial increase over the older age groups.

Excellent/good health status self reports decrease with increasing age. Females were consistently less likely to report excellent/good health than their male counterparts.

Cigarette smoking rates were compared and reported in a companion paper of this series (Reading, 1998). The following chart compares cigarette prevalence rates and shows that First Nations and Labrador Iunit consume tobacco at a rate that is roughly twice that of their agematched counterparts in Canada.

Smokers and former or 'exsmokers' are also more likely to report poor/fair health than never smokers (Figure 5). Above age 75 years never smokers report poorer health status than ex-smokers and smokers which likely reflects a well known 'survivor effect' that suggests a selection or screen out of those who have succumbed to the ill effects of tobacco or those who may have moved away from the community to receive medical care.

Examination of tobacco and specific chronic health problems (Figures 6 to 11) shows that asthma rates increase with increasing total amount of tobacco smoked in all age groups studied, suggesting that tobacco smoking contributes to asthma.



Figure 5: Poor / Fair Self reported Health Status by Smoking Behavior and Age



Figure 6: Asthma by Pack - Years Smoking and Age Group



Figure 7 : Breathing Problems by Pack - Years Smoking and Age Group

Breathing problems also increased with the total amount of tobacco smoked in all age groups.

High blood pressure (hypertension) increases with increasing total amount of tobacco smoked in all elder age groups studied.

Respondents were also asked to recall whether a health professional had ever diagnosed a chronic health problem. As figure 9 shows, chronic health problems are widespread among First Nations and Inuit elders. Such problems are more prevalent among women than men and increase with age.

Chronic conditions included heart problems, hypertension, diabetes, cancer, arthritis and rheumatism. Comparative results were obtained from a companion paper in this series (Young, et. al., 1998) show that the First Nations/Inuit to Canadian rate ratio for age-adjusted prevalence for diabetes is 3.3 (M) and 5.3 (F), for heart problems is 3.0 (M) and 2.9 (F), for cancer is 2.0 (M) and 1.6 (F), for hypertension is 2.8 (M) and 2.5 (F); and for arthritis/rheumatism is 1.7 (M) and 1.6 (F).

Comparison of chronic condition rates between the Canadian population and the First Nations and Labrador Inuit population (table 4) clearly show that chronic conditions are present at profoundly higher rates for First Nations and Labrador Inuit. Chronic conditions are linked to lifestyle risk factors (exercise patterns, diet, smoking habits, etc.) and changing these factors may impact the future course of these diseases or conditions. Smoking



Figure 8 : High Blood Pressure by Pack - Years Smoking and Age Group



Figure 9: At Least One Chronic Health Problem by Age and Gender

Chronic Conditions	Gender	Age Adjusted		45-54 YRS		55-64 YRS		65+ YRS	
		FN/I	CDN	FN/I	CDN	FN/I	CDN	FN/I	CDN
Heart	Male	13	4	14	4	24	8	44	18
Problems	Female	10	4	10	2	24	5	30	15
Hypertension	Male	22	8	29	9	36	5	49	23
	Female	25	10	29	10	37	22	59	32
Diabetes	Male	11	3	18	3	18	7	28	11
	Female	16	3	22	3	34	5	32	9
Arthritis/ Rheumtism	Male	18	10	21	10	32	21	49	33
	Female	27	18	32	18	47	33	57	47

Table 4 : Chronic conditions, First Nations and Labrador Inuuit compared to the CanadianPopulation: Age - gender - specific and age adjusted prevalence (%) for Self-reported heart problems, hypertension (high blood pressure), diabetes, arthritis and rheumatism

is related to respiratory conditions and lung cancer. Diabetes is also associated with higher risk for hypertension and heart disease. The following data clearly indicated that multiple interventions are needed.

Diabetes affects one in five elders from 45 to 55 years and increases to affect more than one in three elders above age 65; affecting one in three women above age 55 and one in five men above age 55. Diabetes cases include other associated illnesses or conditions known as comorbidity in two out of three cases. Cardiovascular conditions associated with diabetes include high blood pressure and heart problems.

The pattern of diabetes related cardiovascular co-morbidity changes with increasing age. Diabetes appears to precede cardiovascular problems. As age increases, it appears that cardiovascular co-morbidity for diabetes also increases.

When respondents aged 45 years. and over were asked "do First Nations and Inuit have the same level of services as other Canadians", 48% said no while 18% didn't know. In other words, only 34% answered that First Nations and Inuit had the same level of health services. Figure 12 shows that a great number of health services are needed urgently. Prevention, education and long-term health care services for the elderly and pediatric health services for children were identified as most in need of improvement.

Activity limitation is widespread among elders. One in



Figure 10: Diabetes Alone and Cardiovascular Co-morbidity in the Presences of Diabetes



Figure 11: Diabetes Alone and Cardiovascular Co-morbidity in the Presence of Diabetes, by Age

three elders experienced problems with hearing. One in four elders experience activity limitations within the home. Elders require help leaving home for short trips. One in eight elders is unable to leave home and is in need of personal care in the home. These data suggest that activity is limited by specific health problems but questions on specific disabilities and their causes were not included in the survey questionsdue to survey time constraints.

Eighty percent of respondents answered yes to the question "Do you think a return to traditional ways is a good idea for promoting community wellness?" The 80% that answered yes were asked to respond to a list of specific areas where there has been progress as depicted in Figure 14.

Figure 15 shows where respondents believe community progress has been made.

Concerning dental care, more than half of all respondents said that it has been more than one year since they last received dental care. Some 3 out of 4 elders above age 65 years had not received dental care over the past year.

Examining dental treatment needed shows that younger groups require treatment with males slightly higher than females.

Figure 18 shows that thirty-nine percent of elders attended residential schools. The mean duration was 6

years (range = 1 to 15 years).

Sixty-five percent of those who attended residential school reported fair or poor health. When the group of former residential school students were sorted into two groups according to duration of stay at residential school (less than 6 years and greater than 6 years), both groups indicated that a return to traditional ways was a good idea for promoting community wellness (< 6 years = 83%, > 6 years = 86%); and both groups responded that mental health services were in need of improvement (< 6 years = 89%, > 6 years = 87%).



Figure12: Rank Order of Health Services in Need of Improvement



Figure 13 : Disability and Activity Limitation



Figure14: Community Progress over the Last Two years



Figure 15 : Community Progress and Wellness



Figure16: More than One Year Since Last Received Dental Care by Age and Gender



70 60 50 40 30 20 10 0 45-54 55-64 65-74 75+ I Female Male

Figure 17 : Dental Treatment Needed at the time of Survey, by Age and Gender

Figure18: Residential School Attendance by Age and Gender









DISCUSSION

I nvestigating the health status of First Nations and Inuit elders was a primary concern for the First Nations and Inuit Regional Health survey national steering committee. This study did not attempt to review the entire body of aging or gerentological literature but to review data sources that have relevance to the aboriginal elder community.

Thirty-nine percent of First Nations and Labrador Inuit over age 45 years said Aboriginal language was the most often language used in daily life. Aboriginal language is used most often as age increase; 30% spoke Aboriginal language daily in the 40-45 year olds age group compared with 60 % for age 75+. Clearly language services will continue to be an important part of medical services to the elder client group.

The large majority of First Nations and Inuit elders did not complete high school which likely had a profound impact on income and employment thereby indirectly influencing health status.

As age increases excellent/good health status self reports decrease. Women were consistently less likely to report excellent/good health than their male counterparts. Chronic health problems are widespread among First Nations and Inuit Elders. Such problems are more prevalent among women than men and increase with age.

Diabetes affects one in five elders from 45 to 55 years and increases to affect more than one in three elders above age 65; affecting one in three women above age 55 and one in five men above age 55. Diabetes cases include cardiovascular co-morbidity in two out of three cases. Cardiovascular conditions associated with diabetes include high blood pressure and other heart problems. The pattern of diabetes related cardiovascular co-morbidity changes with increasing age. Diabetes appears to precede cardiovascular problems. As age increases, it appears that cardiovascular co-morbidity for diabetes also increases. Women experience higher rates of diagnosed diabetes.

Asthma rates, breathing problems, and high blood pressure increase with increasing total amount of tobacco smoked in all elder age groups studied. Smokers and former or 'ex-smokers' are more likely to report poor/fair health than never smokers. There were no questions concerning alcohol consumption, diet and nutrition, exercise or other behavioral factors which should be considered in a follow-up survey.

Elders identified prevention, education and longterm health care services for the elderly and pediatric health services for children as most in need of improvement in their communities. Activity limitation is widespread among elders and is likely due to disability. One in three elders experienced problems with hearing. One in four elders activity within the home is limited. Elders require help leaving home for short trips and one in eight elders is unable to leave home and is in need of personal care within the home.

Eighty percent of respondents answered yes to the question "Do you think a return to traditional ways is a good idea for promoting community wellness?" When the group of former residential school students were sorted into two groups according to duration of stay at residential school (less than 6 years and greater than 6 years), both groups indicated that a return to traditional ways was a good idea for promoting community wellness (< 6 years = 83%, > 6 years = 86%).

Concerning dental care, more than half of all respondents said that it has been more than one year since they last received dental care. Some 3 out of 4 elders above age 65 years had not received dental care over the past year. Examining dental treatment needed

shows that younger groups require treatment with males slightly higher than females. Thirty-nine percent of elders attended residential schools. The mean duration was 6 years (range = 1 to 15 years). Sixtyfive percent of those who attended residential school reported fair or poor health. Almost 9 out of 10 former residential school students responded that mental health services were in need of improvement.

Residential schools were the most overt instrument used to assimilate aboriginal children and youth into mainstream Canadian culture. Removal of children from community and family to an institutional setting can create a 'cultural vacuum' whereby people may be unable to 'fit in' either in their home community of out side the community. A great number of elders experienced residential schools and the health impacts will likely never be fully understood.

Examining the link between health status and psycho-social dislocation in areas such as resilience, parenting skill, social factors, family support networks, perceived advantages and disadvantages of old age, health and social services, mental health and coping with change, poverty and other potential impacts of residential schools would seem appropriate.

Little has been done to investigate the complex context of health determinants for First Nations and Labrador Inuit elders. The following chart attempts to model the various determinants of health factors that may be linked indirectly to present health status via early residential school experiences. The model is meant as a starting point to explore various associations within the elder cohort to better understand the etiology of ill health.

Inadequate education is an independent determinant of health and this factor was shown to be very prevalent in the elder population. Education and other factors are inter-related thus early education experiences, if negative, would likely have a negative impact on future education, employment, social status, working and living conditions in the community, health practices and coping skills.

Residential schools were an ubiquitous feature of community life for the First Nations and Labrador Inuit elder cohort examined in this study. In other words, the effects of the residential school experience were so widespread within this group as to be unavoidable - essentially everyone was affected either via their peer group or passed on through family generations impacting on fundamental family values such as child rearing (Ing, 1990).

The following theoretical model (Figure 19, Page 50) identifies sub-components that link residential schools as a predisposing factor that may determine current health status.

Economic circumstances, availability of resources and housing situations are potential additional constraints on meeting independent living and family care. Poverty among elders appears to be widespread. Overall, the poor health status and profound gaps in life expectancy must no longer be tolerated.

The health concerns uncovered in this report are limited by three major factors. First, the national core content of the survey contained too few questions to adequately address the broad range of health concerns of elders. An important aspect of the study was to reserve the majority of the survey for regional concerns as regional autonomy was an important fundamental principle for the study (O'Neil et. al., 1998) The findings presented here are an introduction to elders health concerns. Unfortunately, these data lack a context due to a paucity of literature available concerning the health of elders and the factors that affect their health. Secondly, survey data is based on self-reports of illnesses, conditions, behaviors etc., and are recognized as an under-estimate of true prevalence due to under-reporting. The reader is instructed to interpret prevalence data with caution as true prevalence is likely higher than reported here. Third, the residential school question instructed respondents to skip the question if they believed it was sensitive issue that they did not wish to discuss. Thus, the residential school attendance rate was likely underestimated and represents a conservative estimate of the true prevalence rate for attendance.

Clearly, the study raises more questions than it answers and the following are potential areas that could to be addressed:

Much more detailed research in the form or ongoing longitudinal studies need to be undertaken to obtain a comprehensive understanding of the health concerns for the elder population that will continue to grow and change in the future.



Figure 19;

Determinants of Health - Shaded Factors Theoretically Impacted by Residential School

Reports state that residential schools were a state sanctioned instrument of oppression linked to the political economy of Canada (Chrisjohn, R., et al., 1997) and suggest the European doctrine of manifest destiny (RCAP, 1997) made operational by the eager cooperation of church and state. It seems reasonable that residential schools would have profound and far-reaching impact that potentially influences almost every aspect of community life and likely contributes to ill health either directly of indirectly.

Health, marital and employment status are important factors in social integration. Elders need opportunities for social interaction, exercise, recreation and leisure time activities. Gender specific health concerns, on- and off-reserve differences in health status and security issues need immediate attention.

It is critical that elders health and social service concerns be given the attention of communities, health professionals, governmental and non-governmental organizations, and leadership.

Concerning elders health status, an epidemic of chronic disease conditions indicates that elders now require intensive secondary and tertiary prevention programs and improved access to specialized acute and chronic medical care.

Elders also need home support to continue living in the community. The provision of home care services are urgently needed since a great number of elders experience severe activity limitations in their homes and community.

Community level care management, prevention, rehabilitation services and specialized services specifically targeted to the special needs of elders is an urgent need that will only become more pressing in the future. There is a need to conduct more detailed longitudinal surveys on the health and social service needs of First Nations and Inuit elders. This survey contained no questions concerning alcohol consumption, drug use and abuse, diet and nutrition, exercise or other behavioral factors which should be considered in a follow-up survey.

Adequate and appropriate medical transportation and access to medical escort and language services are an important and critical health service needs for elders.

In conclusion, findings from the First Nations and Labrador Inuit Regional Health Survey support the notion that elders are more functionally limited at a younger chronological age due to earlier onset of so called 'old-age' or chronic health problems. Functional limitations are manifest as profoundly higher rates for chonic medical conditions compared to age and gender matched Canadian citizens.

Failure to address the legitimate health concerns of elders by tolerating inadequate social and economic circumstances (determinants of health) will likely be reflected higher costs for medical interventions. Factors that determine and improve the health and well-being of elders need urgent careful investigation and detailed longitudinal follow-up study with the aim to develop, plan and implement integrated community based interventions.

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Chapter 3

Chronic Diseases

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Chronic Diseases



List of Figures	57
List of Tables	57
Background	58
Results	58
Conclusions	58
Introduction	59
Methods	59
Cardiovascular Diseases	62
Burden of Disease	62
Risk Factors	62
Hypertension	64
Serum Lipids	64
Prevention and Control	65
Diabetes	66
Burden of Disease	66
Complications of Diabetes	67
Obesity and Other Risk Factors	68
Prevention and Control	69
Cancer	71
Burden of Disease	71
Risk Factors	72
Prevention and Control	72
Arthritis and Rheumatism	74
Burden of Disease	74
Risk Factors	74
Prevention and Control	74
Significance and Implications	75
Health and Social Impact	75
Coexisting Diseases and Health Determinants	75
Temporal Trends	76
Health Care Needs	76
Appendix Tables	79
Bibliography	81



List of Figures

Figure.1:	Crude prevalence of self-reported chronic conditions based on the	
	First Nations and Inuit Regional Health Survey %	60
Figure 2:	Age-sex-specific and age-adjusted prevalence of self -reported "heart problem" $\%$	63
Figure 3:	Age-sex-specific and age-adjusted prevalence of self-reported hpertension $\%$	64
Figure 4:	Age-sex-specific and age-adjusted prevalence of self -reported diabetes $\%$	66
Figure 5:	Proportion of First Nations people with diabetes attending diabetes clinics or receiving diabetes education. %	70
Figure 6:	Age-sex-specific and age-adjusted prevalence of self-reported arthritis and rheumatism $\%$	73
Figure 7:	Prevalence of disability among First Nations People with and without selected chronic diseases %	75
Figure 8:	Comparison of self-rated health status between individuals with and without chronic diseases. $\%$	77
Figure 9:	Prevalence of smoking individuals with and without chronic diseases $\%$	77
Figure 10:	Association between education and history of chronic disease $\%$	78
Figure 11:	Comparison of prevalence estimates of chronic diseases by the FNIRHS and APS $\%$	78

List of Tables

Table 1:	Comparison of self-rated health status between individuals with and	
	without chronic diseases	79
Table 2:	$Prevalence\ of\ smoking\ among\ individuals\ with\ and\ without\ chronic\ diseases$	79
Table 3:	Age-specific prevalence and age adjusted relative risk of chronic diseases according to history of attending residential school, marital status and education	80

BACKGROUND

RESULTS

Five chronic conditions (diabetes, cancer, heart disease, hypertension and arthritis / rheumatism) are selected for the literature review with regard to the burden of illness, the health and social impact, co-morbidity, and health care needs. Data from the recently completed First Nations and Inuit Regional Health Survey (FNIRHS) are compared with the 1994 National Population Health Survey (NPHS) for the non-Aboriginal population and the 1991 Aboriginal Peoples Survey (APS) to detect temporal changes.

Using the NPHS as comparison, the prevalence of all five conditions among First Nations exceeds that of all Canadians in all major agesex groups. The First Nation /Canada ratio of age-adjusted prevalence for diabetes is 3.3 (M) and 5.3 (F); for heart problem is 3.0 (M) and 2.9 (F); for cancer is 2.0 (M) and 1.6 (F); for hypertension is 2.8 (M) and 2.5 (F); and arthritis/rheumatism is 1.7 (M) and 1.6 (F). The FNIRHS tends to yield higher estimates than the APS of 1991. There is also some discrepancy from studies reported in the literature which tends to show a lower risk for cancer and heart disease among First Nation people. The limitations of self-reports in assessing disease burden must be recognized. Of particular interest is diabetes, which is extremely prevalent. Above the age of 45, a quarter of the First Nation population reports having diabetes.

Chronic diseases are associated with considerable disability in terms of activity limitation, needing help with personal care, and being housebound. Individuals with chronic diseases are also more likely to report being in "poor" health and less likely to report "excellent'. There is a higher prevalence of all 5 chronic diseases among individuals with less education, who are widowed or having a past history of attending residential school. However, when age has been controlled for, the association disappears. In terms of concurrent health risk behaviours, those with chronic diseases are less likely to be current smokers; while this is encouraging, the prevalence of smoking is still too high (in the 50%+ range).

While a high proportion of respondents want more health care staff, chronic care facilities, home care, education on medications, prevention education, and mental health services, among individuals with chronic diseases, the proportion tend to be even higher (80%+).

The prevalence of chronic diseases in Aboriginal communities appears to be increasing and substantially higher than in the Canadian population. Diabetes continues to be a serious problem with respect to burden of disease, impact on quality of life, and utilization of health services. Providing services to address this "epidemic" will pose a significant challenge to the health care system. Failure to prevent it will result in substantial increase in health care costs.

CONCLUSION

INTRODUCTION

Over the past several decades Aboriginal people in Canada have Oundergone a health transition marked by a decline of infectious diseases and an increasing burden of chronic diseases and injuries in the population (Young 1988). There is no generally agreed definition of "chronic" diseases, apart from the fact that they are of insidious onset, long duration and not caused by microorganisms. However, some infectious diseases are also of insidious onset and long duration (e.g. tuberculosis) while the clinical presentation of some chronic diseases may be acute (e.g. myocardial infarction). Furthermore, some cancers and peptic ulcer have now been shown to be caused by viruses and bacteria. The division of diseases into "infectious" and "chronic" is therefore arbitrary but it does serve a purpose in that some chronic diseases, and they are useful as indicators of the health transition of specific populations.

Since it is impossible to cover all chronic diseases, many important conditions such as digestive (eg. peptic ulcer, gallbladder disease), neurological (e.g. dementia), respiratory (e.g. chronic obstructive lung disease), and psychiatric (e.g. schizophrenia) illnesses have been excluded from this review. Five conditions are selected: heart diseases, hypertension, diabetes, cancer, and arthritis. The first three are considered to be relatively "new" diseases in Aboriginal communities but of public health concern because of the rapidly increasing burden of disease and adverse social impact. Cancer is rare, but many communities perceive themselves to be at high risk. Arthritis is very common, and there is some historical evidence to indicate that it is an "old" disease in the Aboriginal population.

The source of data in this review includes the published literature as well as various mortality and morbidity databases. Only Canadian data are reviewed - the US Native American literature is vast, substantive reviews of which are already available (see, for example, Young 1994). The just completed First Nations and Inuit Regional Health Survey (FNIRHS) is analysed with regard to questions on past history of various chronic diseases. Comparison data from the non-Aboriginal population are obtained from the 1994 National Population Health Survey (NPHS). The Aboriginal People Survey (APS), conducted some 6 years earlier than the FNIRHS, provide a perspective on temporal changes. The questions on past health history are generally comparable.

This report is organized by disease category. Within each category, the discussion is divided into (1) Burden of Disease, providing estimates of incidence, prevalence and mortality, and the sources of Aboriginal data on which such estimates are based; (2) Risk Factors, reviewing data on the distribution of known risk factors for the disease in the Aboriginal population; and (3) Prevention and Control, discussing strategies for interventions (preventive, curative and rehabilitative) that have been attempted in the Aboriginal population. A final chapter considers the health and social impact of these diseases, comorbidity, temporal trends, and the implications for health care policy.

METHODS

In addition to heart problems, hypertension, diabetes, cancer and arthritis/rheumatism, the FNIRHS also contains questions on asthma, tuberculosis, and "breathing problems". These are not discussed in this review. Fig.1 ranks the crude prevalence of all self-reported conditions in the FNIRHS to indicate their relative importance.

The FNIRHS is a First Nation and Inuit controlled health interview survey conducted during 1997 in 9 regions (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec Nova- Scotia, New Brunswick, and Labrador). While each region designed its own survey questions, a set of national core questions were included in each regional survey. The present analysis focuses on these national core questions by merging the datasets from the 9 regional surveys. Individual, community and regional identifiers were removed from the total sample of 9,870 respondents. All individual records were appropriately weighted to represent the national population of on-reserve First Nation people and Labrador Inuit. [Note the Inuit in the Northwest Territories and northern Quebec are not part of the FNIRHS]. Two types of weights are used expansion (or population) weights and analytic weights. The former consists of the record weights used to generate prevalence estimates for the national target population. An individual's analytic weight is obtained



Figure 1: Crude prevalence of self-reported chronic conditions based on the First Nations and Inuit Regional Health Survey %

60

by dividing his or her expansion weight by the average expansion weight of all respondents in the sample. Analytic weights are used in various statistical procedures (e.g. cross-tabulations) within the sample. Separate sets of weights are calculated for the adults and children.

The presence of chronic diseases is derived from responses to the question: "Have you ever been told by a health care professional that you have high blood pressure, arthritis/ rheumatism, heart problems, cancer, diabetes? It should be noted that such self-reports may be diagnostically imprecise. For example, "heart problems" may represent a diversity of disease entities ranging from acute myocardial infarction to chest pains of musculoskeletal origin. The use of self reports to indicate the presence of a specific disease has been the subject of much research [see the review by Harlow and Linet (1989)]. Traditionally the validity of such measures is established by comparison with medical record reviews and/or clinical and laboratory tests. Such methods are not feasible in large population surveys such as the FNIRHS and the APS. However, in a study comparing self-reports of diabetes, heart disease, stroke, hypertension and high cholesterol in the Manitoba Heart Health Survey with hospital and physician diagnoses as reported in claims submitted to the provincial health insurance plan for payment, a high degree of agreement was found for diabetes (kappa=0.72) and hypertension (0.59), but less so for the other conditions (0.4)









Cardiovascular Diseases

Burden of Disease

Diseases of the circulatory system or Cardiovascular diseases (CVD) comprise a heterogeneous group of diseases of the heart and blood vessels. Within the context of "diseases of modernization", it is primarily ischemic heart disease (IHD) that is of particular interest. However, data are often only available for the broader category of CVD as a whole or "diseases of the heart". In populations undergoing the health transition, it is well recognized that rheumatic heart disease, which has an infectious etiology, tends to decline, while IHD increases as a result of socioeconomic and lifestyle changes.

Among residents of First Nation communities in 7 provinces during 1976-83 and 1984-88, the female IHD and stroke mortality rate was higher than all Canadians, while among males, the stroke rate but not the IHD rate was higher (Mao et al 1986, Mao et al 1992). Regional studies in the 1970s and 1980s generally showed a deficit in cardiovascular diseases among Aboriginal people (Young 1983, Robinson 1988, Abu-Zeid et al 1978). The age-standardized hospitalization rate for all CVD among the James Bay Cree was 60% of the provincial rate for men, but 1.3 times higher for women (Robinson 1988). More recent data on mortality and hospital morbidity are not available.

The low incidence of IHD among the Inuit has been recognized for some time. Autopsies during the 1950s (Lederman et al 1962) indicate that cases of atherosclerosis, while not an important cause of death, were by no means absent. The age-standardized mortality rate for IHD in the Northwest Territories has remained consistently lower than the national rate, although the rate among Dene women approached that of all Canadians and exceeded that among the Inuit and non-Aboriginal people. Among residents of the Keewatin region, who are 90% Inuit, the hospitalization rate for all CVD during 1985-90 was only 54% and 73% of that of Canadian men and women respectively. The difference was especially pronounced among the elderly (Young, Moffatt et al. 1993). ECG surveys conducted in two NWT communities showed low rates of abnormalities, particularly ischemic changes. (Schaefer, Eaton et al 1980).

Analysis of the FNIRHS shows that 8% of respondents report having been told by a health professional to have "heart problem". Men over the age of 65 are more likely to report heart problems; at other ages, the prevalence is about the same in men and women. The proportion of Aboriginal people reporting heart problems exceed the Canadian national population in all age-sex groups (Fig.2). When adjusted to the Canadian population age structure, the prevalence among Aboriginal people (13% in M and 11% in F) was three times that among the national population.

Risk Factors

Many large-scale epidemiological studies have concluded that cigarette smoking, hypertension and elevated serum cholesterol levels are major independent risk factors for ischemic heart disease. Other risk factors include diabetes, physical inactivity, obesity, stress and personality characteristics. As the major risk factors are



Figure 2: Age-sex-specific and age-adjusted prevalence of self-reported "heart problem" % Source: FN refers to First NAtions and Labrador Inuit data from the FNIRHS (1997); Canadian Data are from the NPHS (1994)

potentially modifiable, - IHD is largely a preventable disease. Hypertension, hypercholesterolemia, diabetes and obesity can also be considered as diseases in their own right with their own risk factors and complications. Because of the importance of diabetes among Aboriginal people, it is reviewed separately in Section 3.

Certain fatty acids in the diet referred to as the longchain omega-3 fatty acids, such eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), have been found to be protective of IHD. Innis and Kuhnlein (1987) found substantial quantities of both EPA and DHA in land-based caribou in the Arctic. A study of the Tsimshian on Vancouver Island found that 50% of calories in the "traditional" diet were derived from salmon, rich in EPA and DHA (Bates et al 1985). They also had low levels of arachidonic acid (AA, an omega-6 fatty acid), which remained unchanged among those who had abandoned the traditional diet. Horrobin (1987) suggested that the low AA levels among Inuit and Tsimshian may be due to a genetically determined enzymatic deficiency or reduced activity. As AA promotes thrombosis, its low level should reduce the risk of IHD.

Various genetic markers have been found to be associated with an atherogenic plasma lipid profile and increased risk of ischemic heart disease in some populations. Using plasma samples from the Keewatin survey, Hegele, Young and Connelly (1997) found that the frequency of several genes [AGT T235, FABP2 T54, PON R192, and APOE B4] was higher among the Keewatin Inuit than in non-Inuit, whereas that of others [eg. ACE D] was lower. These data suggest that the Inuit may well be genetically predisposed to be at high risk for ischemic heart disease. That their rate of IHD has actually been quite low could be the result of the protective effect of the traditional Inuit diet and lifestyle. The implications of the Inuit's increasing adoption of the "western" pattern of physical activity and diet are thus obvious. An alternative explanation is that these genetic markers have no association with ischemic heart disease in the Inuit and that other, as yet unmeasured, genomic variants may well determine disease susceptibility in this population.

Another study among the Keewatin Inuit which illustrates gene-environment interaction in disease susceptibility shows that they have a low prevalence of the V677 mutation in the enzyme methylenetetrahydrofolate reductase (MTHFR). Individuals homozygous for V677 have been shown to be at risk for IHD especially if the diet is deficient in folate. V677 occurs in only 6% of Keewatin Inuit, compared to 35% of whites; only 1.2% of Inuit are



Figure 3: Age-sex-specific and age-adjusted prevalence of self-reported hypertension % Source: FN refers to First Nations and Labrador Inuit data from the FNIRHS (1997); Canadian Data are from the NPHS (1994)

homozygous for V677, compared to 12% among white Canadians (Hegele, Tully, Young & Connelly 1997). The low frequency of this particular gene may be partially responsible for the lower risk of RID among Inuit.

Among the Dogrib in the NWT where IHD is still very rare, genotype-associated quantitative lipoprotein variation can still be demonstrated in the absence of disease. Fasting triglyceride levels in women varied significantly with the XnmI locus of the apolipoprotein A-I/C-III/A-IV gene cluster (Cole et al 1989). The extent to which observed lipoprotein gene frequency differences between Aboriginal and non-Aboriginal populations contributes to the differences in CVD frequency remains to be further investigated.

Hypertension

Data on self-reported history of hypertension are available from both the APS and the FNIRHS. The APS shows that Aboriginal people have a slightly lower crude prevalence of hypertension than all Canadians, and among Aboriginal people, on-reserve Indians have the highest, and Inuit the lowest, prevalence (Statistics Canada 1993). According to the FNIRHS, 18% of respondents reported having been diagnosed with high blood pressure. At each age-sex group, the prevalence is higher among FN than among all Canadians. When age-adjusted, the FN prevalence is 2.8 and 2.5 times higher than among Canadian men and women respectively (Fig. 3).

The APS, FNIRHS and NPHS are based on selfreports. Surveys involving actual blood pressure measurement have been conducted in several regional groups, e.g. in northwestern Ontario (McIntyre and Shah 1986) and northern Quebec (Thouez et al 1990). A survey of over 700 Ojibwa and Cree in northern Ontario and Manitoba in the 1980s showed higher mean diastolic blood pressure (BP) in all age-sex groups compared to Canadians nationally, while for systolic BP, the level was lower above the age of 45. Age, male sex, unemployment, body mass index, total cholesterol, positive family history, and single marital status were independent predictors of hypertensive status on multivariate analysis (Young 1991). In the Keewatin region of the NWT, the prevalence of hypertension (defined as diastolic BP(90 or on treatment) among the Inuit was lower than among Manitobans in all age-sex groups except men aged 25-44 (Young, Moffatt et al 1993). In Igloolik, NWT, a
survey of 400 subjects in 1969-70 showed a low mean BP but no rise with age (Hildes and Schaefer 1973). Later surveys showed an age-dependent increase in BP in both sexes in Inuvik, a large town, but not among males in remote Arctic Bay (Schaefer, Eaton et al 1980).

Serum Lipids

The level of various lipids (such as cholesterol **L** and triglycerides) in the serum, which reflects dietary intake and genetic regulation of metabolic processes, has been identified as a strong risk factor for IHD. The Nutrition Canada Survey during the early 1970s (DNHW 1975) provided some data on serum cholesterol and triglycerides for 29 First Nations across the country and 4 Inuit communities in the NWT. Using the age-dependent criteria from the Framingham Study, which linked serum cholesterol level with long term disease risk, the proportion of people at "high" risk was lower among First Nations and Inuit than among Canadians in general, except for First Nation men aged 55 and above. More recent data on a national level are not available. With the exception of Manitoba, the series of provincial heart health surveys conducted during the early 1990s, which analysed serum samples for lipids, excluded Indian reserves from the sampling.

Regional studies have also been conducted among the Nootka and Chilcotin in BC (Desai and Lee 1971), Yukon Dene (Desai and Lee 1974), Cree-Ojibwa (Reeder et al 1988) and the James Bay Cree (Thouez et al 1989). Among the Inuit in the Keewatin region, the mean total cholesterol was not different from Manitobans, although the level of triglycerides was lower and that of high-density-lipoprotein cholesterol (which has a protective effect) was higher than in Manitoba, except for women aged 25-44 (Young, Nikitin et al 1995). There is some evidence that cholesterol levels have increased over the years. In Arctic Bay, NWT, cholesterol levels were tracked over three surveys in 1976, 1978 and 1980 during which time an increasing prevalence of high risk status was observed (Verdier et al. 1987).

Prevention and Control

Primary prevention of CVD involves reducing the prevalence of risk factors through smoking cessation, cholesterol reduction, the detection and treatment of hypertension, maintenance of an ideal body weight, and regular physical activity. Few community trials have been attempted in Canadian Aboriginal communities (those with a diabetes focus are discussed in Section 3).

Health promotion programs must recognize the importance of cultural factors. Ethnographic studies of cultural knowledge of hypertension in some communities have provided important data on Aboriginal concepts of disease causation, manifestation and treatment. In an Ojibwa community in southern Manitoba, Garro (1988) found that the cultural model can be at odds with the prevalent biomedical view on the chronicity of the illness and the importance of "compliance" with treatment. Hypertension is conceived by the Ojibwa as episodic in nature, accompanied by perceptible symptoms, and treatment is only needed when symptoms are present.









Diabetes

Burden of Disease

Since the 1970s diabetes has been recognized as an emerging, serious health problem among many Aboriginal communities in North America (Young 1993). In Canada, Schaefer conducted studies on carbohydrate metabolism on Inuit patients in Edmonton during the 1960s and 1970s (Schaefer 1968, Schaefer, Crockford et al 1972). Population-based studies, however, began later.

While mortality does not accurately reflect the incidence of the disease, an increased risk of death from diabetes among residents

of First Nations compared to Canadians nationally (2fold among men and 4-fold among women) has been demonstrated (Mao et al 1986).

Various regionally based studies on the prevalence of diabetes in Canada has been conducted since the 1980s, among the Dogrib in the NWT (Szathmary and Holt 1983), the Cree-Ojibwa in northwestern Ontario (Young, McIntyre et al 1985, Young and Krahn 1988, Fox et al 1994, Harris et al 1997), the Mohawks in Kahnawake, Quebec (Montour and Macaulay 1985), the Oneida, Chippewa and Delaware in southwestern Ontario (Evers et al 1987), the Algonquins in Quebec (Delisle and Ekoe 1993, Delisle et al. 1995), the James Bay Cree (Brassard et al 1993), Okanagan in BC (Daniel et al 1995), and First Nations in Saskatchewan (Pioro et al 1996). It should be emphasized that the





Source: FN refers to First Nations and Labrador Inuit data from the FNIRHS (1997); Canadian Data are from the NPHS (1994)

methodologies used in these studies varied widely, and that no single set of diagnostic criteria was uniformly adhered to. Some studies involved registries of diagnosed cases while others surveyed blood glucose levels. There are as yet no national diabetes registries, although a few regional, population-based registries have been established in some zones (e.g. the Sioux Lookout Zone).

The prevalence of diabetes is not uniform across the country - it varies according to language family, culture area, geographical location, and also degree of isolation (Young, Szathmary et al 1990). Such variation has also been demonstrated within regions, e.g. Saskatchewan (Pioro et al 1996).

Diabetes among Aboriginal people is predominantly non-insulin-dependent (NIDDM), or type 2, as distinct from the insulin-dependent type (IDDM) or type 1. While many type-2 patients are treated with insulin, few are truly insulin-dependent. However, a trend toward earlier onset of type-2 diabetes during the young teen years has been observed (Dean et al 1992, Dean 1998). While the FNIRHS contains a children's sample, the small number of cases makes the prevalence data unreliable.

Statistical data indicating time trends in diabetes prevalence are limited since few groups have been continuously monitored longitudinally for any length of time. The observation that diabetes was probably unknown or extremely rare among Aboriginal people prior to World War II seems to be correct, even allowing for changes in the availability of, and accessibility to, health services. In one report from Saskatchewan in the 1930s, no case of diabetes was detected in over 1,500 clinical examinations conducted as part of a tuberculosis survey (Chase 1937). A physician in Aklavik, NWT, noted the absence of glycosuria among the Dene (Urquhart 1935). Since the 1980s, an increase in prevalence has been documented in some regions, such as Saskatchewan (Pioro et al 1996) and northwestern Ontario (Fox et al 1994), where comparable surveys of cases were conducted a decade apart. In any community, the majority of existing cases have been diagnosed in the recent past, an indication that diabetes as a health problem is of relatively recent origin (Montour, Macaulay and Adelson 1989, Young, McIntyre et al 1985).

Health interview surveys, by asking respondents to report if they had ever been told by a health professional to have diabetes, provide another source of prevalence data. Both the Aboriginal Peoples Survey and the FNIRHSs contain questions on diabetes and its treatment (Fig.4).

According to the FNIRHS, about 30% of women with diabetes reported that their diabetes was first diagnosed during pregnancy. The definition of gestational diabetes requires that the diabetes has its onset during pregnancy but disappears after the pregnancy. It is not possible to determine how many of the 30% of cases represent gestational diabetes and how many are cases that happen to be detected during pregnancy who will continue to be diabetic after the pregnancy. Accurate assessment of the extent of gestational diabetes requires all pregnancies to be screened with oral glucose tolerance tests.

Complications of Diabetes

Diabetes is associated with acute complications such as ketoacidosis which may be lifethreatening. Such metabolic events, however, are generally associated with type 1 rather that type 2 diabetes. It is its association with various chronic, long-term complications which makes both types of diabetes an important public health problem. Such complications affect the circulatory system, eyes, kidneys, and nervous system and may result in premature mortality, disability and compromised quality of life. The development of complications actually proceeds even though the diabetes itself may not be clinically recognized, and indeed diabetes is often detected when a patient presents with a complication as an initial complaint.

Among Mohawks with diabetes, over 60% had at least one major complication. The risk of having such complications was 6 times that experienced by individuals without diabetes, even after adjusting for differences in age, sex, and the level of smoking, hypertension and obesity (Macaulay, Montour and Adelson 1988). Among the Cree-Ojibwa, the duration of illness and coexisting hypertension were associated with the presence of complications, whereas the initial glucose level and weight status were not (Young, McIntyre et al 1985). Among the James Bay Cree (Brassard and Robinson 1995), factors associated with the presence of renal or retinal microvascular complications include: poor glycemic control reflected by a need of insulin therapy (odds ratio [OR] 2.7), elevated triglycerides (OR 4.5), duration of illness>5 years (OR 3.0).

Diabetes affects the structure and function of the kidneys which may eventually culminate in end stage renal disease (ESRD), requiring dialysis and renal transplantation. Aboriginal people are at an increased risk for ESRD, a substantial proportion of cases of which can be attributed to diabetes. Using data from the Canadian Renal Failure Registry, the overall risk of ESRD from all causes among Aboriginal people was 2.5 to 4 times higher, and the risk of ESRD due to diabetes specifically was at least 3 times higher than Canadians nationally (Young, Kaufert, McKenzie et al 1989). Similar excess risk of ESRD has been found among the Cree in Moose Factory Zone (Wilson et al 1992) and in Saskatchewan (Dyck and Tan 1994).

Disorders of the eyes associated with diabetes include retinopathy, cataract and glaucoma, all of which can lead to visual impairment and ultimately blindness. The major risk factor for diabetic retinopathy is hyperglycemia, and glycemic control can reduce the incidence and progression of retinopathy. Ross and Fick (1991) identified a high prevalence of serious and untreated diabetic retinopathy in both insulin-using and non-insulinusing Aboriginal diabetes patients in southern Alberta. They also have a high prevalence of both microalbuminuria and macroalbuminuria, indicative of eventual serious hypertension and renal failure.

Diabetes increases the susceptibility to infection. A study in Manitoba (Nicolle et al 1996) showed that Aboriginal women were hospitalized 5-20 times more frequently for acute pyelonephritis than non-aboriginal women, partially attributable to the greater frequency of pregnancy and diabetes. It also increases the risk of reactivation of tuberculosis (TB).

Obesity and Other Risk Factors

Diabetes is a chronic disease with a multifactorial etiology. To date, epidemiological evidence of varying consistency has implicated heredity, obesity, physical activity, diet, and metabolic factors as risk factors. The current wisdom is that genetic susceptibility is unmasked by rapid and unfavourable changes of environmental/lifestyle factors. There is increasing evidence to suggest that insulin resistance may be the key metabolic defect that leads to such related disorders as obesity, hypertension, diabetes, dyslipidemia and atherosclerosis.

The mode of inheritance of diabetes is complex. and has been likened to a "nightmare" by geneticists. Despite advances in molecular genetics, to date a diabetes gene has not been discovered, although a variety of mutations have been found to be associated with a minority (<5%) of cases of NIDDM. Maternal diabetes has been shown to be an important determinant of subsequent diabetes and obesity in the offspring. Among Algonquins in two Quebec communities, maternal history of diabetes is associated with higher serum triglyceride, BMI, SC skinfold, and fasting insulin, risk factors for diabetes, though not in plasma glucose level itself (Ekoe et al 1996), an indication of the important role of the intrauterine environment during fetal development.

Among the potentially modifiable risk factors for diabetes established from various large scale epidemiological studies, obesity is considered the strongest. It is now recognized that the distribution of fat is as important as, or more important than, overall obesity as a risk factor of diabetes. Limited data do indicate that obesity among Aboriginal people is predominantly of the central type, characterized by a high waist-to-hip ratio (WHR). Among the Cree-Ojibwa, overall 38% of men had WHR greater than 0.99, compared to only 11 % among women. If this were taken as the cut-off point for "central" obesity, then among men with BMI of over 30, 75% were of the central type, while among men with BMI between 26 and 30, 46% were of the central type. Central obesity was much less evident among women, where only 18% of those with BMI over 30 and 13% of those with BMI between 26 and 30 could be considered as centrally obese (Young and Sevenhuysen 1989). The independent role of central fat. distribution in predicting diabetes or glucose intolerance has been demonstrated in the Dogribs in the NWT (Szathmary and Holt 1983) and the Oneida and Ojibwa in southwestern Ontario (Evers et al 1989). In Sandy Lake, ON, among adults under age 50, BMI, WHR and percent body fat (determined by bioelectrical impedance) are all associated with diabetes (Harris et al 1997). The FNIRHS did not involve anthropometry but asked respondents about their heights and weights. Self-reported data on heights and weights tend to be biased and they have not been used in this review.

The role of dietary factors such as total energy intake, specific nutrients, and the lack of fibre in diabetes has not been consistently demonstrated. Patterns of dietary change, particularly the substitution of modem for traditional food items, have been observed in many Aboriginal communities. Nationally, Aboriginal people who still obtain most of their meat and fish from hunting and fishing are in the minority (about 15%), according to the APS, although the proportion is considerably higher among the Inuit (Statistics Canada 1993). Among the Cree-Ojibwa, energy intake per unit body weight was lower among individuals with diabetes, reflecting their lower physical activity level (Young, Sevenhuysen, Ling and Moffatt 1990). Among the Dogribs, dietary differences between villages at different levels of acculturation were demonstrated but they had little influence on the plasma glucose levels (Szathmary et al 1987).

Lack of physical activity is an important risk factor for diabetes. Many Aboriginal People, particularly elders, recall times when most activities of daily living involved vigorous physical exertion. The decline in physical activity often accompanies the transition to a more sedentary lifestyle. The APS shows that 54% of Aboriginal adults nationally participate in leisure-time activity (Statistics Canada 1993). In the NWT, the 1985 Health Promotion Survey reported that Inuit and Indians were less likely than non-aboriginal people to exercise more than 15 minutes per day at least three times per week, the respective proportions being 43%, 38% and 51 % (Imrie and Warren 1988). However, the need to exercise may not be obvious to northerners who spend a significant portion of their time living "on the land".

Why is diabetes so prevalent in many Aboriginal populations and why has there been an increase compared to half a century ago? It was Neel who first proposed the "thrifty genotype" hypothesis in 1962 and subsequently revised it in 1982. There are critics of the thrifty gene theory, e.g. Szathmary (1990), who note that it assumes a nutritional environment in which carbohydrate intake exceeds daily energy requirements. This was not the situation when the ancestors of modem Aboriginal people first occupied the continent, where the diet was one based predominantly on meat and fat. Survival advantage in a low carbohydrate, arctic/subarctic environment was provided by having an efficient formation of endogenous glucose through gluconeogenesis, efficient use of free fatty acids to provide for the energy needs of nonglucose dependent tissues, and the efficient use of ketone bodies as fuel. Under such conditions, selection should have favoured individuals in whom gluconeogenesis and free fatty acid release 69

and use were enhanced. Ritenbaugh and Gooby (1989) also emphasized the physiologic consequences of the northern hunting lifestyle: low carbohydrate availability, intermittent lipid storage, protein sufficiency, and high energy demands for activity and body warmth. With the transition to agriculturallybased subsistence systems and modem industrial societies, genetically controlled modifications could have occurred in several enzymatically mediated pathways in lipid and glucose metabolism to "spare" glucose.

Prevention and Control

As the consequences of diabetes to the individual and the community are so serious, it is clear that the prevention of diabetes is the key to reducing the magnitude and extent of the problem. A variety of community-based diabetes prevention/health promotion projects have begun in a few locations across Canada, for example, in Kahnawake, QC (Macaulay et al 1997) and Sandy Lake, ON (Gittelsohn et al 1995). These projects, with intervention sites in schools, stores, and the community-at-large, demonstrated a high degree of community support and awareness, and preliminary data do indicate that they have resulted in measurable behavioural change.

With regard to blood glucose screening for diabetes in well individuals, national expert committees such as the Canadian Task Force on the Periodic Health Examination and the US Preventive Services Task Force do not recommend it in the general population, as there is insufficient evidence that such procedures improve the health outcomes of those screened, although it may be justified in high risk populations such as some Aboriginal communities. On the other hand, screening for diabetic complications in individuals with diagnosed diabetes, which involves periodic examination and tests of the eyes, renal, cardiovascular and peripheral nervous system, is a well established and important aspect of continuing care for diabetes.

The Clinical Practice Guidelines for the Treatment of Diabetes proposed by the Canadian Diabetes Advisory Board in 1992 (and currently being revised) contains a



Figure 5: Proportion of First Nations people with diabetes attending diabetes clinics or receiving diabetes education. % Source: FNIRHS (1997)

section on Aboriginal people. It emphasizes the need to view diabetes in the context of the profound social changes experienced by Aboriginal communities. It recognizes the importance of community involvement in developing and implementing treatment and education programs, programs which are compatible with and indeed incorporate traditional values and customs. It sees the Aboriginal diabetes worker, who may be a community health representative (CHR), as the foundation of community care.

Recent clinical practice appears to favour intensive pharmacologic therapy to maintain tight glycemic control in order to prevent microvascular complications. This often involved moving quickly towards the use of oral hypoglycemic agents and then insulin to achieve control. Such practices will have enormous implications for Aboriginal people with diabetes. Data from the southern Alberta study indicate that over 80% of Aboriginal insulin-users have adequate endogenous production of insulin, compaired to 40% of non-aboriginal insulin users. The data further suggest that insulin may be a prominent risk factor for vascular complications in NIDDM patients who take insulin (Ross and Fick 1991).

Data from Australia and Hawaii indicate that reversion to traditional lifestyles can have beneficial effects on metabolic control in diabetes patients. This approach merits investigation in the Canadian setting, especially in northern, remote communities. Robinson et al (1995) compared Cree diabetes patients who spent 3 months in the bush and those who stayed in the village. Bush living was found to have only limited effects on a variety of indices (body weight, plasma glucose, glycated hemoglobin and blood pressure). While bush dwellers became more active, they also brought along large quantities of store-bought foods for sustenance.

Education is the cornerstone of diabetes treatment. Innovative education programs do exist and they can be found in scattered localities across the country, e.g. Kahnawake (Macaulay and Hanasaik 1988). Such programs have produced manuals, videos, posters, and board games, use the local media (community radio, TV, newspapers) extensively, and organize community events such as feasts, school visits, elder's teas, etc. According to the FNIRHSs, not all individuals with diabetes are benefitting from educational resources available in diabetes clinics or education centres. Young women with diabetes is the group with the lowest participation rate (Fig. 5). It is not known, however, if such women have received care at prenatal clinics if their diabetes is associated with pregnancy.









Cancer

Burden of Disease

While all Canadian provinces have had population-based cancer registries for some time, the number of cancer cases among Aboriginal people is not readily available. Statistics Canada does not report or collect cancer statistics by ethnic status. It is possible to determine cancer incidence/mortality for members of First Nations from some provincial registries through data linkage with the MSB or INAC population registry or based on residence on-reserve. A Canadian Inuit cancer registry, comprising cases from the NWT, Nunavik and Labrador, was established as part of an international, circumpolar review of cancer among Inuit (Gaudette et al 1996). This registry is not being maintained or updated, although the NWT registry is ongoing.

A survey of all Indian Health Service facilities during 1948-52 found an overall lower risk of cancer among First Nation people, with the exception of cancer of the cervix, compared to Canadians nationally (Warwick and Phillips 1954). In the 1970s, data from British Columbia (Gallagher and Elwood 1979), northwestern Ontario (Young and Frank 1983), and Manitoba (Young and Choi 1985) all showed a lower incidence when all cancer sites are combined. There are, however, a few sites in which Aboriginal people are at an increased risk: kidney in men and gallbladder and cervix in women. The risks of cancer of the breast, colon, lungs, and prostate are lower in the Aboriginal relative to the non-Aboriginal population, although they are still among the commonest cancers within the Aboriginal population. Geographical variation in overall cancer mortality is also evident.

The Inuit pattern has generally been different from that of First Nation people. Of particular interest is the extremely high risk of several cancers which are relatively rare in other populations: nasopharyngeal, salivary gland, and esophageal cancer (Gaudette et al, 1991,1993). These have been called "traditional" Inuit cancers. According to Schaefer and Hildes, between 1950-66 and 1974-80 in the central and western Arctic, there was a decline in the proportion of these traditional cancers relative to those cancers more commonly found in "modem" society such as lung, cervix, colon, and breast (Schaefer, Hildes et al 1975, Hildes and Schaefer 1984).

According to the FNIRHS, 1.5% of men and 2.8% of women reportedly suffer from some kind of cancer. It should be recognized that the burden of rare and highly lethal conditions such as cancer is not adequately conveyed by a one-time cross-sectional survey.

Time trend data are available only for a few groups. An overall increase in cancer from all sites combined was observed among the Inuit of both sexes in the Northwest Territories between 1970 and 1984 (Gaudette et al 1991) and Saskatchewan First Nations between 1967 and 1986 (Gillis et al 1991). Much of the increase in cancer incidence among these groups is accounted for by lung cancer, particularly among women. Since the early 1970s the lung cancer incidence has increased at least twofold in these populations.

An increasing trend in cancer of the cervix has also been reported. In Saskatchewan, the age-standardized mortality rate in First Nations rose by 52% between 1967-71 and 1982-86, while in the province there was a 43% decline. The relative risk increased from 2.3 in the first period to 6.2 in the second period (Irvine et al 1991). In British Columbia, the relative risk of death from cervical cancer increased from 3.6 during 1953-62 to 4.7 during 1973-84 (Band et al 1992).

Cancer is an important health problem because of its impact on the quantity and quality of life of those who suffer from it and also of their families and communities. Only limited data on survival are available for Canadian Aboriginal people. In Saskatchewan, First Nations cancer patients experience an overall lower survival compared to the province as a whole. Survival was better among women than men, but decreased with age (Gillis et al 1991). The reasons for the lower survival are unclear. but may be related to differences in the stage of disease at diagnosis and access and use of available health services. For certain specific sites, for example, cervix, the survival experience of First Nations women is not significantly different from the provincial norm (Irvine et al 1991).

Risk Factors

Despite the large number of cancers, the recognized "causes" of cancer are limited. Tobacco, dietary factors, infectious agents, reproductive and sexual factors, occupation, alcohol, radiation, pollution, and drugs are all considered to be risk factors for various types of cancer. Some individuals may also be genetically predisposed to developing certain cancers. Smoking is clearly the most important risk factor. The high prevalence of smoking among Aboriginal people is well recognized (Longclaws et al 1980, Millar 1992, McIntyre and Shah 1986, Reading 1996).

Among dietary factors which have been implicated in the causation of cancer is animal fat for colorectal and breast cancer. On the other hand, vitamin A and its precursor the beta-carotenoids are protective for lung cancer, while fibre reduces the risk of colorectal cancer. The Aboriginal diet in the Arctic and Subarctic traditionally contains little leafy green vegetables rich in vitamin A. Unfortunately, the modem store-bought diet which has replaced the Aboriginal diet in many locations tends to be high in saturated fat but low in vitamin A and fibre content. The link between the human papillomavirus (HPV) and cervical cancer is well established. Data on the prevalence of HPV among Canadian Aboriginal women are limited. One study from the inner city of Winnipeg found that the prevalence of HPV infection was not significantly different between Aboriginal and non-Aboriginal women, despite the high risk for cervical cancer and other behavioural risk factors among Aboriginal women (Young, McNicol et al 1997).

Prevention and Control

Ccreening plays an important role in the Deprevention and control of some types of cancer, for example cancer of the cervix and breast. Several studies from British Columbia have shown a lower coverage for Pap smear among Aboriginal women (Hislop et al 1992, 1996, Calam et al 1992). The Santé Québec surveys among the Inuit in Nunavik (Jetté 1994) and James Bay Cree (Davelluy et al 1994) found that the Inuit had higher Pap smear participation rate than Quebec women, whereas the Cree had a lower rate. The higher rate among the Inuit can be attributed to the existence of an organized program of tracking and recall. Among Cree women who stated that they had never had a pap test, 83% said that no one had ever suggested the test. With regard to breast self-examination and examination by a health professional, both Aboriginal groups fared worse than the provincial population.

In interviews with BC Cancer Agency researchers (Deschamps et al 1992, Hislop et al 1996), Aboriginal women mentioned that they were not comfortable talking about Pap smears, even among family and friends. Many women reported having been screened because of pregnancy, and some confused the test with testing for sexually transmitted diseases, while others thought it was necessary for obtaining oral contraceptives. On the whole, they were embarrassed and uncomfortable both psychologically and physically, particularly with male physicians. Clearly, cultural factors must be taken into account in any program to promote cancer screening among Aboriginal people.

Various clinical procedures such as colposcopy and cervicography are used to improve the sensitivity of Pap smear screening. In the small hospital in Churchill in northern Manitoba, a colposcopy program staffed by visiting gynecologists and assisted by local family physicians was found to reduce travel costs and social dislocation of Inuit women from the Keewatin Region, NWT, who would have gone to Winnipeg for further investigations (Smith et al 1995)



Figure 6: Age-sex-specific and age-adjusted prevalence of self-reported arthritis and rheumatism % Source: FN refers to First Nations and Labrador Inuit data from the FNIRHS (1997); Canadian data are from the NPHS (1994)









Arthritis and Rheumatism

Burden of Disease

A mong musculoskeletal disorders, the arthritides are of particular importance because of their contribution to long-term disability and pain and suffering, especially among the elderly. Only limited data are available for Canadian Aboriginal people, primarily from British Columbia (Gofton et al 1975, Hill 1977), Alberta (Russell et al 1977) and Inuit in the central Arctic (Oen et al 1986). Survey data need to be interpreted with caution due to the variability of clinical manifestations and the diagnostic criteria and laboratory tests used. In a comprehensive survey of chronic arthritis among children, Oen and Cheang (1996) found that ethnicity has little effect on the prevalence and incidence of the disease.

The Inuit have been found to suffer from osteoarthritis (the "wear-and-tear' variety especially common among the elderly) and rheumatoid arthritis to an extent not much different from the general North American population. On the other hand, they are at a much increased risk for the spondyloarthropathies (SPA), a group of related rheumatic disorders including ankylosing spondylitis, Reiter's syndrome, and a variety of other poorly classified and understood diseases (Oen et al 1986).

Surveys such as the FNIRHS do ask about "arthritis and rheumatism" but cannot distinguish the various diagnostic varieties. Most respondents who report having arthritis most likely suffer from osteoarthritis. As Fig.6 shows, First Nations people suffer from arthritis more than Canadians at all age/sex groups. The problem is more prevalent among women, and, as expected, increases with age.

Risk Factors

I nterest in arthritis among Aboriginal people in North America is sparked by the known association between certain genetic markers and specific types of arthritis. A strong association between SPA and the histocompatibility antigen HLA-B27 is well established in a variety of populations. The prevalence of the HLA-B27 marker has been shown to be much higher among the Inuit than in European populations. Unlike diabetes and heart disease, the significance of arthritis as a marker of lifestyle change is unclear.

Prevention and Control

Intervention in arthritis and rheumatism is available mainly in the tertiary type or rehabilitation, the restoration of functional capacity and the reduction in disabilities. Rehabilitation requires more than individual treatment, but also environmental change, such as physically restructuring the home, public buildings and transportation to facilitate access, mobility and the performance of daily activities. The health care system must also ensure the proper design and distribution of prosthetic devices and physical aids. For most First Nations communities, rehabilitative services tend to be poorly developed.









Significance and Implications

C hronic diseases have assumed increasing importance as causes of mortality and morbidity among Canadian Aboriginal people. The FNIRHS provide useful self-reported data on the prevalence of chronic diseases. For all 5 diseases selected for analysis, the First Nation prevalence exceeds the Canadian one in all age-sex groups. For some diseases such as diabetes, it can be considered as being out of control.

Health and Social Impact

S urveys such as the FNIRHS provide a means to assess the health and social impact of chronic diseases. As shown in Fig.7, all the chronic diseases are associated with substantial disability as reflected in

activity limitation and other indicators such as needing help with personal care, inability to take short trips, and being house-bound. Activity limitation is reported by 24% of individuals with hypertension, 28% among those with diabetes, 33% for arthritis, 36% for heart problem, and 38% for cancer. Individuals who suffer from a chronic disease also tend to view their health status as inferior. Fig.8 (and Appendix Table 1) shows that such individuals are more likely to report their overall health as "poor" and less likely to rate it as "excellent" compared to individuals without chronic diseases.



Figure 7: Prevalence of disability among First Nations People with and without selected chronic diseases % Source: FNIRHS (1997)

First Nations and Inuit Regional Health Surveys

Coexisting Diseases and Health Determinants

C hronic diseases have a tendency to co-occur or cluster in the same individuals. According to the FNIRHS, 26% of persons with diabetes also report having heart problem, and 50% report hypertension, a prevalence that is 3.9 and 3.3 times that of individuals without diabetes.

The co-occurrence of diabetes with other risk factors such as smoking compound the risk for cardiovascular complications. The FNIRHS indicates that those with chronic diseases are less likely to be current smokers than those without such diseases. There is thus some indication that health education regarding lifestyle changes is succeeding among Aboriginal people, at least among those who are afflicted with chronic diseases. Even so, the prevalence of smoking among Aboriginal people with chronic diseases is still too high (Fig. 9 and Appendix Table 2).

There is a higher prevalence of chronic diseases among individuals with less education, those who are widowed, and those who have attended residential schools in the past. However, it is unlikely that these health determinants are causally related to chronic diseases. The observed association (Fig.10) can be accounted for by confounding with age, as older people are more likely to have less education, to be widowed, and have gone to residential school. When age has been controlled for, the association of these health determinants with chronic diseases disappears. Appendix Table 3 shows that the age-adjusted relative risks (i.e. number of times a person who had gone to residential school, is not married, or have received secondary education is more likely to have hypertension, diabetes, etc) do not differ significantly from unity, indicating no excess risk.

Temporal Trends

A comparison of the FNIRHS with the APS provides a temporal perspective on the increase in the prevalence of chronic diseases among Aboriginal people, as the two surveys were conducted

Chronic Diseases

some 6 years apart and fix questions on self-reported disease are comparable. Fig. 11 shows that FNIRHS estimates are all higher than the APS ones. Note that the APS population has been adjusted to include only on-reserve First Nations people in 8 provinces and Labrador Inuit to correspond to the FNIRHS target population.

Such data indicate the importance and potential value of longitudinal surveys in tracking the growth in the burden of specific diseases over time.

Health Care Needs

I ndividuals with chronic diseases obviously have more health care needs than those without. Most respondents to the FNIRHS consider that their health care needs improvements, for example, more health care staff, chronic care facilities, home care, education on medications, prevention education and mental health services. For individuals with chronic diseases, the proportion reporting need for improvements in these areas is even higher, exceeding 80% in most cases. Clearly, the health care system needs to accommodate the increasing burden of illness in the population attributable to chronic diseases.

In terms of actual use of health services, according to the APS, over 90% of diabetic individuals report having seen a health professional in the past year, compared to only 75% among those without diabetes (Bobet 1997).

Health professionals who serve Aboriginal people with chronic diseases are confronted with the need to adapt their treatment plans and education programs to the culture and social environment of their patients. Furthermore, many Aboriginal communities are located in geographically remote areas with little or no access to specialized services often required for the optimal treatment of chronic diseases. It is difficult for many health professionals to appreciate fully the impact of these diseases and their treatment on individual patients and their families. The patients are expected to modify their lifestyle drastically and follow a complex regimen of rules relating to diet, physical activity, medications, self-monitoring and

self-care, on a daily basis for the rest of their lives. It is no wonder that compliance with prescribed treatment plans is generally low. Research on cultural factors associated with chronic diseases in Aboriginal people (Garro 1988, 1995, Hagey 1984) has provided important data that could be used by health care providers in understanding Aboriginal concepts of disease causation and attitude towards treatment.

Surveys such as the FNIRHS play a useful role in identifying diseases of public health significance in the Aboriginal population, estimating their magnitude and extent, and investigating potential causes, associated factors, and health and social impact. Such data are critical to the rational planning of programs and services to prevent and control chronic diseases, and provide a baseline upon which future evaluation of such programs and services can be based.



Figure 8: Comparison of self-rated health status between individuals with and without chronic diseases. % Source: FNIRHS (1997)



Figure 9: Prevalence of smoking individuals with and without chronic diseases % Source : FNIRHS



Fig.10 : Association between education and history of chronic disease %



Fig.11: Comparison of prevalence estimates of chronic diseases by the FNIRHS and APS %

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	No	Yes	No	Yes	No	Yes	No	Yes	No
	14.80	6.10	15.60	5.00	15.50	3.30	14.80	5.10	13.90
	14-15.6	4.9-7.2	14.7-16.4	3.8-6.1	14.7-16.4	2.1-4.8	14.0-15.6	2.4-9.1	13.2-14.7
	Q	17.50	5.10	20.40	5.00	24.10	6.00	23.20	7.10
	5.4-6.5	15.7-19.4	4.6-5.6	18.3-22.5	4.5-5.5	21-27.2	17.1-65.5	6.6-7.7	6.6-7.7

TABLE 2: PREVALENCE OF SMOKING AMONG INDIVIDUALS WITH AND WITHOUT CHRONIC DISEASES

65.40 52.80 64.60	50.60	4.10
3-66.5 50.3-55.4 63.5-65.7	5	48.3-53.0 64.

	F	Resid	ential	School		Martial St	atus			Educatio	on	
	No	Yes	RR	RR-Adj	Married	Not Married	RR	RR-Adj	Primary	Secondary	RR	RR-Adj
Hypertension												
15-24	7.3	3.8	0.5		8.2	6.2	0.8		4.9	7	1.4	
25-44	14.5	15.3	1.1	1.00	14.2	14.3	1	0.97	14.1	14.5	1	0.89
45-64	31.9	33.6	1.1	0.87 - 1.15	31.6	32	1	0.86 - 1.09	36.3	30.9	0.9	0.75 - 1.0
65+	57	53.9	0.9		59.4	55.7	0.9		56.1	55.2	1	
All Ages	18	40.3	2.2		19.5	17	0.9		34.7	16	0.5	
Arthritis												
15-24	3.6	6.9	1.9		5.5	3.2	0.6		1.6	4.1	2.5	
25-44	11.7	10.6	0.9	1.06	12.1	10.9	0.9	0.94	10.6	11.7	1.1	1.09
45-64	29.9	33.6	1.1	0.92 - 1.22	30.5	31.9	1	0.82 - 1.06	34.7	29.8	0.9	0.92 - 1.3
65+	55.3	50.5	0.9		51.8	55.1	1.1		49.6	59.2	1.2	
All Ages	15	23.6	1.6		17.5	14.4	0.8		31	13.7	0.4	
Heart Problem												
15-24	2.5	1.4	0.6		2.9	1.9	0.7		0.8	2.2	2.7	
25-44	3.7	5.8	1.6	1.07	4.2	4.2	1	0.99	4.3	4.2	1	0.80
45-64	17.6	15.3	0.9	0.89 - 1.29	16.1	17.6	1.1	0.73 - 1.34	21	15.8	0.8	0.67 - 0.9
65+	35.2	39.4	1.1		39.5	33.9	0.9		37.4	35	0.9	
All Ages	7.6	13.4	1.8		8.8	7.6	0.9		20.7	6.4	0.3	
Cancer												
15-24	0.3	1	3.3		0.4	0.3	0.8		0	0.4	0	
25-44	1.5	0.9	0.6	1.12	1.6	1.4	0.9	0.88	0.4	1.5	3.9	0.99
45-64	4.6	5.8	1.3	0.81 - 1.55	4.6	5.3	1.1	0.77 - 1.01	4.9	4.6	0.9	0.67 - 1.4
65+	6.1	6.9	1.1		6.8	6.1	0.9		7.2	5.8	0.8	
All Ages	1.9	3.5	1.8		2.4	1.9	0.8		4.3	1.8	0.4	
Diabetes												
15-24	2.6	6.6	2.5		2.9	3	1		4.9	3	0.6	
25-44	7	7.1	1	1.05	7.6	5.8	0.8		7.1	6.9	1	0.89
45-64	23.3	22.4	1	0.89 - 1.23	22.8	21.6	0.9		25.8	21.1	0.8	0.73 - 1.0
65+	30.3	29.6	1		27.3	32.7	1.2		28.7	32.8	1.1	
All Ages	4.5	33.6	7.5		11.4	9.2	0.8		20.7	8.7	0.4	

Table 3: Age-specific prevalence and age-adjusted relative risk of chronic diseases according to history of attending residential school, martial status and education

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Chapter 4

The Tobacco Report

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The Tobacco Report: First Nations and Inuit Regional Health Surveys

"Grade 7, that was the year I started smoking. I was 10 years old at the time. I remember when I first started...I don't know why but that day I felt that I had to impress that girl so I said that I should try puffing. After that incident, I started smoking — I smoked a lot that year, when I was ten....Mona, she must have been 8 or 9 when she really started smoking...Not that long ago, maybe a year or something, I read this article in a newspaper that said that 77% of women in the NWT smoke."



Source: Royal Commission on Aboriginal Peoples. UNIKAAVUT - Our lives stories from the lives of three generations on Igluluk Inuit. 1997

The Tobacco Report

TABLE OF CONTENTS

Abbreviation and Glossary	90
List of Tables and Figures	91
Introduction and Background	92
Methods	94
Review of Literature	96
Historic and Cultural Context	96
Harmful Effects of Tobacco Smoke	100
Chronic Lung Disease and Smoking	101
Lung Cancer and Smoking	102
Cardio-vascular Disease (CVD) and Smoking	103
Non-traditional Use of Tobacco Among Aboriginal Peoples	104
Results	107
Cigarette Smoking Prevalence	108
Cigarette Smoking Initiation	110
Environmental Tobacco Smoke	110
Smokeless Tobacco Use	111
Chronic Conditions including Diabetes	11
Social and Economic Determinants of Smoking - Education	112
Wellness	112
Dental Health	113
Community Health Services	113
Discussion	115
Appendix	118
Bibliography	128





Abbreviations

- APS: Aboriginal Peoples Survey
- CVD: Cardio-vascular Disease
- COPD: Chronic Obstructive Pulmonary Disease
- ETS: Environmental Tobacco Smoke
- FNIRHS: First Nations and Inuit Regional Health Surveys
- LC: Lung Cancer
- MSB: Medical Services Branch of Health Canada
- NLSCY: National Longitudinal Survey of Children and Youth
- NPHS: National Population Health Survey
- NSC : National Steering Committee
- RCAP: Royal Commission on Aboriginal Peoples
- SLID: National Survey of Labour and Income Dynamics
- TDRS: Tobacco Demand Reduction Strategy

GLOSSARY

Angina Pectoris:

Pain in the chest due to insufficient blood supply to the heart muscle.

Atherosclerosis:

Build-up of fatty deposits on the interior walls of arteries.

Carcinogenesis:

The development of cancers.

Endothelium:

A layer of cells forming the inside of blood vessels.

Epidemic:

The occurence in a community or region of cases of an illness, specific health-related behavior, or other health related events clearly in excess of normal expectancy.

Hypertrophy:

Tissue growth due to cell enlargement.

First Nations and Inuit Regional Health Surveys

The Tobacco Report

Hyperplasia:

Tissue growth due to an increase in the number of cells.

Lipid:

Fatty substances in blood and tissues.

Myocardial Infarction;

Heart attack.

Pandemic:

An epidemic occurring over a wide area, crossing international boundaries and usually affecting a large number of people.

Thrombus:

A blood clot.

At-Risk Behaviors:

Activities done by persons, who are healthy, but see themselves at greater risk of developing a particular disease, condition, or disorder. For example, the fact that most smokers know that they are at risk of disease but continue to smoke.

Pre-disposing Factors:

Those circumstances existing which influence behavior by providing a motivation for the behavior to happen. For example, the fact that a school-age child's parents smoke is a pre-disposing factor influencing the possibility of the child also smoking. Conversely, circumstances can pre-dispose toward healthy habits and behavior.

LIST OF TABLES AND FIGURES

Table 1: Respondent Characteristics	107
Figure 1: Smoking Rates for First Nations / Inuit vs Canadian	107
Figure 2: First Nations/Inuit Smoking Rates versus Canadian Smoking Rates by Age Group	108
Figure 3: Persons Reporting Excellent or Very Good Health by Pack-Years and Age Group	108
Figure 4: Ever Smoked versus Current Smoking Rates by Age	109
Figure 5: Age of Initiation to Smoking	109
Figure 6: Nunber of Cigarettes Smoked Daily by Age and Gender	110
Figure 7: Environmental Tobacco Smoke	110
Figure 8: Smoking Controls in Community	111
Figure 9: Chewing Tobacco by Age and Gender	111
Figure 10: Snuff Tobacco Use by Age and Gender	112
Figure 11: Sum of 7 Chronic Health Conditions	112
Figure 12: Current Smoking and Educational Attainment	113
Figure 13: Smokers: Health Services in Need of Improvement	114

First Nations and Inuit Regional Health Surveys

INTRODUCTION AND BACKGROUND

The main purpose of this paper is to highlight results concerning the non-traditional use of tobacco from the First Nations and Inuit Regional Health Survey (FNIRHS, 1997). The non-traditional use of tobacco among Aboriginal peoples living in Canada is a serious and growing health concern, thus tobacco misuse is an appropriate target for health promotion and disease prevention efforts.

Whereas the general Canadian population has significantly reduced habitual tobacco consumption over the last 30 years, the current tobacco use prevalence for First Nations and Labrador Inuit who participated in this national survey is still remarkably high, with some two thirds of all adults smoking. Consequently, this paper will examine, in some detail, the unique historic and cultural contexts of tobacco for Aboriginal peoples, and provide a description of the health effects of tobacco misuse including the current tobacco use prevalence rates and some of the health consequences of habitual recreational smoking, to investigate certain associations between tobacco misuse and various health status measures and to provide literature sources on programs designed to educate about, prevent or promote the cessation of smoking.

The developmental process for collaborative research relationships between Aboriginal political organizations and health researchers at national and regional levels, combined with extensive networking and capacity building within the Aboriginal community, is a second major objective of this study and a particularly strong aspect of the FNIRHS research process.

Briefly, the past experience of many First Nations and Inuit communities with researchers has left them wary and uncomfortable. In many cases, First Nations and Inuit communities have had little control over survey design, community ownership of the process or free access to the research data generated by health and social surveys. Frequently, communities do not receive the results until they appear in the media or research reports often in a negative and stigmatizing form and in a manner that is often prejudicial to community interests and self-governing aspirations. There is a growing sense that research knowledge can be a powerful tool and that shaping the research agenda to meet community needs can be made explicit in a detailed code of research ethics to avoiding negative research outcomes.

Aboriginal peoples in Canada are culturally and linguistically diverse, geographically dispersed and undergoing rapid social change. In the health programs and services sector three significant changes are driving the need for timely health intelligence information. First, the administration for health services is being transferred from Medical Services Branch of Health Canada to community control; secondly, the pattern of disease is rapidly changing with increasing prevalence rates for chronic disease including diabetes, respiratory, bone and cardiovascular conditions (Young, T.K., 1990); and third, the population demographic profile of First Nations and Inuit living in their home communities is young and growing. Given these changes, gaps in programs and services have occurred and are likely to occur more often in the future. First

Nations and Inuit communities need to have full access to all relevant health information to respond to a legitimate need to highlight changing aboriginal health issues and concerns. The key is to engage communities in on-going health surveillance for evidence-based community health services planning, health promotion campaigns, disease prevention, health policy development and overall health service management.

In 1992, Health Canada acknowledged the important need for comprehensive longitudinal health surveys by committing funds to several detailed longitudinal Canadian population health and determinants of health studies including; the National Population Health Survey (NPHS), the National Longitudinal Survey of Children and Youth (NLSCY) and the National Survey of Labour and Income Dynamics (SLID). First Nations and Inuit living in their home communities were specifically excluded from these three longitudinal investigations. Such an omission is inappropriate since the health status of Aboriginal peoples has been consistently documented as below that of their non-aboriginal counterparts in Canada and the epidemiological picture is rapidly changing according to the Royal Commission on Aboriginal Peoples, (RCAP, Young, K. 1997).

In partial response to the need for some level of Aboriginal comparability with these surveys, a consultation process was undertaken to gauge the feasibility of a national Aboriginal population health survey (Health Canada. O'Neil, J. 1993). Briefly, the results of the feasibility consultation indicated the following:

- Aboriginal peoples clearly indicated they want to have control and ownership of the research process and access to results,
- Surveys should be geographically multi-layered addressing national, regional and community specific health concerns,
- Specific questions need to reflect Aboriginal perspectives while also including questions that have comparability to other Canadian population surveys in progress,
- Ownership and control of community-based research needed to be made explicit by Aboriginal peoples through development of a detailed code of research ethics,
- Community, regional and national level capacity building for research and evaluation was to be an integral part of the survey process, and
- Surveys were to be longitudinal in scope after the initial crosssectional baseline study was completed.

In 1991, the British Columbia Royal Commission on Health Care and Costs suggested that a need exists to improve on Aboriginal specific health intelligence systems:

"Lack of access to properly integrated health and social services is an additional contributor to poor health. However, the current information on Native health and the conditions which affect it are not adequate for planning and policy purposes." In Canada, there has never been a comprehensive national level health survey performed under First Nations and Inuit control. The Aboriginal Peoples Survey (APS) was the first post-census health survey of Aboriginal peoples performed by Statistics Canada in 1991. Despite significant gaps in regional coverage the APS provided the first comprehensive national picture of Aboriginal health concerns and health determinants. The need to take control of the research agenda was restated by the Royal Commission on Aboriginal Peoples in 1997:

"Control over Aboriginal health research and over special health education campaigns is still denied to Aboriginal people..." and, "The (Royal) Commission (on Aboriginal Peoples) believes it is important to develop a national research and development capacity in economic development, as part of an overall policy capability encompassing this and related fields, such as education, health and social policy."

In 1994, Medical Services Branch (MSB) headquarters successfully obtained a one-time allocation of funds from the tobacco demand reduction strategy (TDRS) to undertake a national level survey of tobacco use among First Nations and Inuit peoples. The FNIRHS took advantage of this opportunity to demonstrate that a national-level health survey could be accomplished with a high degree of scientific validity, community credibility and political support.

This paper is one of a series from the national core content of the FNIRHS (1997) and is concerned with the 'non-traditional' or recreational use of tobacco among First Nations and Labrador Inuit. The on-going funding for a national longitudinal health survey is the key to monitoring the epidemic of tobacco misuse, and for developing, targeting and evaluating community based interventions that may succeed in reducing the prevalence of tobacco consumption in the future. Such a commitment to follow-up for health research and surveillance would add value to the FNIRHS and consolidate efforts toward development of a national Aboriginal tobacco reduction strategy.

For a detailed discussion on technical aspects and sample methodology please refer to Appendix 2. The following is a brief review of the FNIRHS process. In January of 1996, a national steering committee (NSC) was struck to develop the FNIRHS. The NSC included membership from First Nations political organizations drawn from nine participating regions including Labrador, New Brunswick, Nova Scotia, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia. Two ex-officio members attended, one from the Assembly of First Nations and Medical Services Branch of Health Canada. Technical expertise was provided by a team of 'co-principle investigators' contracted to undertake the study in their specific regions and agreeing to participate on the national technical committee.

Since funding was provided by the Tobacco Demand Reduction Strategy of Health Canada, tobacco related questions were required content in the survey. The author was directed by the NSC to obtain

METHODS

tobacco related questions that were comparable to other Canadian health surveys. Final content decisions for the tobacco related questions and all other parts of the survey were reached by NSC consensus. The NSC directed the entire survey process including the development of national core questions, a detailed code of ethics, financial and community accountability, data security, ownership, control, analysis, interpretation and dissemination of results.

Tobacco specific national core questions were common concerns that were developed and mutually agreed upon by all members of the NSC. The national core questions examined chronic medical conditions including the 'non-traditional' or recreational use of tobacco, diabetes, residential schools and gerontological issues, wellness, children's health, dental health, health services, disabilities and restrictions on activities. It should be noted that regions and communities were encouraged to develop unique region-specific tobacco related questions that aimed to address regional and local community health issues. Many regions did look at creative ways to enhance the national core content by adding both quantitative and qualitative tobacco related research at the local and community levels.

Following the regional data collection, the nine participating regions each submitted their tobacco related responses included with national core data reports and electronic copies of their national level databases. After a series of quality checks were performed, individual records were appropriately weighted to properly represent the national population of adults living in First Nations and Labrador Inuit communities.

Comparable tobacco-related questions and data responses from other national level surveys including the NPHS and APS, and communityspecific ecological variables (obtained from Indian Affairs) were appended to the national database. Individual, community and regional identifiers were removed from the sample of 9,870 adult respondents and 3,791 children and youth that were surveyed by proxy interviews provided by their primary caregivers. The final data was stored on a high capacity disk and analyzed using the Statistical Analysis Software (SAS) pc-version.

The Tobacco Report









REVIEW OF LITERATURE

Historic and Cultural Context

T obacco has been used in the Americas in rituals, ceremonies and prayer for millennia. The first written references to tobacco smoking are found in the accounts of New World explorers during the sixteenth century (US DHHS 1992).

Tobacco as "the primary sacred plant..throughout the Americas save for the Arctic" (Paper, J., 1988). During the 'pre-European contact' period the ceremonial use of tobacco had deep spiritual meanings because it established a direct communication link between the person giving and the spiritual world receiving (Reading, 1996). Such communication was accomplished by the burning and/or smoking of tobacco leaves, planting tobacco around medicinal plants to encourage their continued growth, or placing tobacco leaves on bodies of water to ensure safe passage for travelers. In a traditional spiritual context tobacco was a sacred gift given by the Creator (McGuire, J., 1897; Linton, R., 1924; West, G., 1934; Keppler, J., 1941; Ritzenthaler, R.E., 1955; Rutsch, Edward S. 1973; Beauchamp, W.1988; Kearsley, 1998).

Glenn Kearsley (1998) theorizes that intense spiritual meanings of tobacco based rituals were pervasive in times of health crisis and social turmoil. Some four hundred Iroquoian smoking pipes were produced from 1620 to 1650 and have been collected as artifacts (almost one hundred in a Royal Ontario Museum collection). The pipes were carved with hunch-backed, pinched-faced figures. Kearsley suggests that these pipes were associated with a spiritual war waged by Iroquoian-speaking peoples against the French explorers and Jesuit missionaries who threatened traditional established native social institutions with Christianity in order to open their societies to trade with France.

Disease such as smallpox had reduced the Iroquoian population by as much as half prompting Iroquoians to openly denounce the Christian faith as the sole cause of their misfortune. One of the most powerful and influential shaman/healers named Tonneraouanont was physically disfigured with a hunchback who spent his time healing the sick with traditional remedies while denouncing the Christian faith. Kearsley proposed that the figure depicted in the pipe was Tonneraouanont and that communication between the shaman and owner of the pipe took place through the act of smoking thus facilitating healing.

The symbolic pinched-faced pipe depicts the shaman in the act of sucking (part of the 17th century Iroquoian healing ritual in which the shaman sucked the disease out of the patient). Furthermore, research on the pipe designs indicate that the pipe figures held tremendous knowledge and the ability to transverse the Iroquoian cosmos to communicate with spirits on behalf of the smoker. Smoking sacred tobacco in these pipes were thought to allow the smoker to make direct communication with the spirit world, as smokers of the pinched faced pipes would have blown the smoke back at the pipe with the sucking gesture depicted on the pipe symbolizing the spirit world receiving the smoke (Kearsley, 1998).

Throughout the eighteenth century post-contact fur trade era, when the Hudson's Bay Company and the Northwest Company competed intensely for trade with Aboriginal peoples, tobacco and alcohol were employed in elaborate "gift-giving" ceremonies (Ray, A.J., 1980; Hudson's Bay Company: Archives of Canada; Ray,A.J.,1980). European fur traders used these 'ceremonies' to induce Natives to trade with one company or the other because tobacco was a highly

The Tobacco Report

valued commodity, cherished by many First Peoples. Thus, early fur traders were shrewd to capitalize on the important ceremonial gift-giving role of tobacco and to recognize the deeply spiritual and culturally significant meanings that prevailed even in an economic context.

During the seventeenth and eighteenth centuries, tobacco was a major cash crop in the American colonies, setting the stage for rapid expansion of tobacco product use and high speed cigarette manufacturing in North America, and indeed worldwide, through to the end of the nineteenth and twentieth centuries.

It should be noted that the 'industrial revolution' or 'machine age' that produced the manufactured tobacco cigarette is a relatively recent phenomenon, first introduced by factories during the 1880s. Throughout the early part of the twentieth century to the present, manufactured cigarettes became the predominant form of tobacco consumed in the World.

Cigarette use increased in parallel with the largescale industrial production of tobacco products (factory made cigarettes) beginning in earnest at the turn of the century. The excess production capacity provided by manufacturing, at the turn of the century, gave the impetus needed for tobacco firms to engage in massive advertising efforts that have successfully changed world-wide cultural mores and personal behaviors toward habitual tobacco consumption. (Warner, K.E., 1985; Bartecchi, C., et.al. 1994; Bartecchi, C., et.al. 1995; Reading, 1996).

Science-based agricultural practices also combined with industry-based product research produced cigarettes and other tobacco products that are high in nicotine but less 'harsh' or irritating to the throat. Nicotine is a highly addictive drug. Intense marketing aimed to link smoking with high social status while the health risks were portrayed as either non-existent or inconsequential. In short, the consumption of cigarettes rose rapidly (along with tobacco firm profits) during this century with the greatest increase noted during World War II (US DHHS 1989). By 1963, annual per capita cigarette consumption reached its peak at 4,300 per adult but has steadily declined since that period.

Dr. Kue Young comments on smoking prevalence

in the general North American population, the health benefits of smoking cessation and the link to societal change (RCAP report, Young, K., 1997):

"the prevalence of smoking in adult males has dropped from a high of 50.2 per cent in 1965 (two years after the first official warnings from the Surgeon General) to 31.5 per cent in 1987 with a concomitant drop in death from lung cancer and emphysema. This shift reflects the gradual changes in attitudes toward smoking, societal values and laws that came about as a result of both formal and informal changes in society" (May, 1992).

It is important to emphasize that during the 1960's the 50% estimated smoking prevalence in America was the peak estimated prevalence before the harmful effects of tobacco were widely recognized. Once the harmful effects were proven and accepted, the prevalence rates continued to drop. For the general population, the significant health risk associated with half of the population smoking was still very much lower that the current estimation of smoking prevalence for First Nations and Inuit peoples (62%) in Canada - after more than three decades since publication of the landmark 1964 Surgeon General's report! (Advisory Report to U.S. Surgeon General Luther L. Terry, U.S. Public Health Service, 1964).

The recreational or habitual use of tobacco products in contemporary Aboriginal society is now a serious health threat due to widespread acceptance and availability since the turn of the century.

In the general Canadian population the trend toward declining prevalence of smoking has been accompanied by a slight decline in overall smokingattributable mortality through the 1970s and 1980s (Peto et al. 1992) In spite of this, smoking attributable mortality and years of potential life lost remain substantial. Cigarette smoking remains a major chronic disease risk factor that is a specific risk factor in lung cancer, cardiovascular disease, chronic lung disease (bronchitis, emphysema) (Samet and Lange 1996, Van de Mheen and Gunning-Schepers 1996).

In the United States the prevalence of smoking among youth has remained unchanged since 1985. Since more than 90% of smokers begin smoking before age 21, tobacco companies have targeted the young in their advertising. Media reports also allege that tobacco companies add nicotine to tobacco to increase its addictive appeal.

The tobacco industry is very lucrative, operates world-wide and continues to expand. In Canada, Imperial Tobacco is living up to its name by strengthening a multi-national tobacco empire. Imperial Tobacco, for example, earned \$462 million from 1993 annual sales of 31 billion cigarettes that brought in gross total sales of \$2.8 billion. The company currently claims two-thirds of the Canadian market. In 1994 the firm announced plans to overhaul their Canadian production capacity by modernizing its manufacturing, packaging and handling capability. This includes installation of the latest in high speed cigarette making equipment at a cost of \$118 million over two years. (Gibbon, A., Globe and Mail, 1994)

After four years of delays the state of Florida recently received \$57 million in tobacco money, the first cash to reach the state's coffers since an \$11.3 billion class action settlement was reached with cigarette makers. The state sued cigarette makers in 1994, seeking to recover public money spent treating the poor for diseases, such as emphysema, that are linked to smoking. The money will be used to launch an anti-smoking campaign aimed largely at curbing teen smoking (Gold, S., 1998). In British Columbia the Ministry of Health is planning to launch a class action suit against tobacco firms for tobacco related health care costs (Berger, Thomas R., 1998).

While profits may be down and legal costs are rising in the U.S., tobacco firms are rapidly expanding world-wide markets, with draconian trade measures sanctioned by Washington, to offset dropping domestic demand for tobacco products (Washington Post, 1996). The following Washington Post excerpt from a four-part series published in 1996 is unequivocal:

"Despite the 15-year decline in U.S. cigarette consumption, American tobacco companies are making larger profits than ever before, thanks to foreign sales in Asia and the former Soviet Bloc.... The U.S. "big three" cigarette companies had targeted Thailand and enlisted Washington's help in prying it open for their products. Following a carefully planned strategy, they started by softening the Thai market with advertisements and sponsorships, then applied U.S. government pressure and the threat of trade retaliation..."

The final tobacco frontier may be China where multi-national tobacco firms are deeply involved in capturing the rapidly expanding market for western made cigarettes. One strategy seems to predominate tobacco marketing efforts. Tobacco firms introduce their product as a luxury that few could afford in order to initially capitalize on the prestige of smoking. The marketers concentrate on impressionable youth, minimize health consequences and lower the price.

North American smoking rates are highest among lower-income groups (Chen, 1993) and minority populations including Blacks, Native Americans and Alaska Natives (Bartecchi, C., et. al., 1994). In Canada, smoking rates are extraordinarily high among Aboriginal peoples compared to the general population. (Longclaws et al 1980, Young 1982, McIntyre and Shah 1986, Imrie and Warren 1988, Millar 1990, Stevens 1991, Rode and Shephard 1992, Clarkson et al 1992, Young et al 1993, Mills et. al., 1993, Erickson 1996; Health Canada: Advisory Committee on Aboriginals and Tobacco Use, 1993, the Tobacco Demand Reduction Program, 1994, Stephens, 1994, Reading 1996, Wunska 1997).

The tobacco industry targets American Indians and Alaska Natives by funding cultural events such as powwows and rodeos to build its image and credibility in the community, (Freeman, H., et al., 1993). Recently, American Indian youth have become proactive recognizing that ceremonial and cultural meanings for tobacco are actively being manipulated by tobacco companies. Using their own internet home page the young people in California issue a public health warning:

"American Indians across this country have used tobacco in their ceremonies and in prayer for centuries. It was smoked or burned in a fire; some people offered a pinch in each of the four directions; and yet others wore it in a pouch around their necks. The use of this gift varied from tribe to tribe, but one common bond that was shared by all tribes was the respect shown to this powerful plant...

The Tobacco Report

"A tobacco marketing campaign is currently being waged, one that capitalizes on a rising 'Native American' empathy, and the role of tobacco in its culture. The Santa Fe Tobacco Company is advertising a cigarette called "Natural American Spirit Tobacco." The company also produces a blend of pouch tobacco called the "Pow Wow Blend," a mixture of botanicals that is not completely composed of tobacco, but rather other herbs that American Indians have used in ceremonies and even drank as tea...

'American Spirit' has found a successful market in Humboldt County, due largely to the student population of both Humboldt State University and College of the Redwoods. It is a good thing that people want to learn the true history and know the plight of the American Indian. This type of empathy is the exact same kind of interest that the tobacco companies look at when they decide on a campaign slogan. "American Spirit" is also portrayed as a type of 'micro-smoke', a form of cigarette that is modeled after a successful marketing campaign called 'microbreweries', another success in Humboldt County. These factors have boosted sales for the Santa Fe Tobacco Company, all at the expense of Native tradition and culture."

(American Indian Youth Against Tobacco Exploitation, 1998. Internet site, http://www.shastaco.k12.ca.us/life/spirit.html).

The Santa Fe Natural Tobacco Company recently launched 'Natural American Spirit Menthol Lights' to compliment its other cigarette brands including regular filter, medium filter, light filter and regular menthol cigarette product lines. (Santa Fe Natural Tobacco Company, 1998)

For First Nations peoples tobacco has historically been used in a variety of ways. Tobacco has been used in a legal context during ceremonies and treaty deliberations:

"The initial rite of all religious and ceremonial occasions was the smoking of tobacco, accompanied by a prayer to the waiting spirits. And tobacco smoking by both parties was an essential part of the making of a treaty.

(RCAP: The Robinson Treaty of 1860: A Case Study).

"Looked at from a purely common-sense perspective, for the Indian parties who did not have the ability to read and write the English language, the real Treaty must have been the oral agreement. The paper document may have been perceived as having equal importance to the Crown's representatives as the ceremonial exchanges of wampum or the smoking of tobacco to signify the solemnity and finality of the agreement;"

(RCAP: Treaties and Aboriginal Lands, The Numbered Treaties and Extinguishment: A Legal Analysis 1997).

Traditional use of tobacco by Aboriginal people is recognized in Ontario law. The Aboriginal Health Policy in Ontario makes a clear exemption in law concerning traditional tobacco use. The Tobacco Control Act, 1994 acknowledges the use of tobacco as part of Aboriginal culture and spirituality, permits Aboriginal youth under 19 to use tobacco for ceremonial purposes, allows the ceremonial use of tobacco in otherwise smoke-free areas, and requires health facilities to provide space where traditional uses of tobacco are possible (Tobacco Control Act, 1994. S.O. (1994), c.10, s.13).

American Indian and Alaska Native lands are treated as sovereign nations and are not subject to state laws prohibiting the sale and promotion of tobacco products to minors. As a result, American Indian and Alaska Native youth have easier access to tobacco products at a young age. (Schinke SP, et al., 1989). In Canada, Federal legal exemption from gst, provincial retail sales taxes, and tobacco taxes means on-reserve First Nation businesses have a significant pricing advantage for their customers who are registered Indian status according to the provisions of the Federal Indian Act. Enforcement of tobacco policies on Indian reserves by provincial authorities conflicts with federal taxation rules governing Federal Indian lands and is seen as an encroachment by provinces on Indian rights thus many First Nations refuse to comply with the provincial tax. (Seguin, R., Globe and Mail, June 12, 1998)

Harmful Effects of Tobacco Smoke

How are chemical compounds taken up by the body from tobacco smoke? Fundamentally, the lungs transfer gases (oxygen) from the atmosphere to the bloodstream where they are distributed, along with nutrients, to body tissues to sustain life. When a person smokes, harmful substances along with oxygen are mixed with the blood in the lungs. Once these substances enter the bloodstream, they can be distributed to all body tissues including organs and muscles. Most smoking related disease can be explained, in part, by the direct effects of smoke on the lungs and the "downstream" effects of harmful substances transported to body organs and tissues by the blood (Reading, 1996).

Bartecchi, C., et.al., (1995) discuss in detail the harmful effects of tobacco smoke. The main points are discussed as follows, however, the reader is encouraged to obtain the original review article for an in-depth discussion. Nicotine is the main active ingredient in tobacco, but it is only a small component of tobacco smoke. The smoke contains more than 4,700 chemical compounds, including 43 cancercausing substances. Many conditions not formerly associated with tobacco use are now found to be higher in smokers. Smoking tobacco has been associated with seemingly unrelated ailments such as cataracts, delayed healing of broken bones, periodontal problems, ulcers, high blood pressure and brain hemorrhage. It is estimated that cigarette smoking causes 85% of lung cancers and is associated with cancers of the mouth, pharynx, larynx, esophagus, stomach, pancreas, kidney, ureter, bladder and colon. For non-smokers breathing side-stream smoke from burning tobacco and inhaling secondhand smoke also poses health risks (Bartecchi, C., et.al., 1995).

While many First Nations in Canada and the United States consider tobacco a sacred gift and use it during religious ceremonies, the tobacco-related health that stem from the non-traditional uses of tobacco lead to health problems caused by chronic cigarette smoking and smokeless tobacco use.

Cigarette smoking has been recognized as a risk factor for the development of chronic diseases such

lung cancer, cardiovascular disease and chronic lung diseases for approximately 40-50 years. The first studies to link smoking and lung cancer were published by Laurence (1949), Wynder and Graham (1950), Levin and colleagues (1950) and Doll and Hill (1950). The first studies to link smoking and cardiovascular disease were published by Doll and Hill (1956) in Great Britain and by Hammond and Horn (1958) in the United States. Further studies in the 1950s (Wynder 1997) and the 1964 Surgeon General's Report (USPHS 1964) expanded this epidemiologic link. By the 1980s the Surgeon General's Reports (US DHHS 1983, 1986, 1988, 1989) concluded that cigarette smoking was the most important of the known modifiable risk factors for lung cancer and cardiovascular disease. Although the epidemiologic evidence correlating smoking and chronic diseases is convincing, there are many possible confounding variables such as obesity, dietary habits, exercise level, and others that might obscure the link between smoking and the mechanisms of pathophysiology of chronic disease (chronic lung diseases, lung cancer, and cardiovascular disease).

It is useful to examine, in some detail, risk factors that associate tobacco use and health status. Risk factors are those experiences, behaviors, acts or aspects of lifestyle, that increase the chances of acquiring or developing a disease, condition, injury, disorder, disability, or death. For example, the United States Surgeon General established in 1964 that cigarette smoking increased risk for the development of lung cancer (USPHS 1964).

To understand the impact of risk factors the first step is to examine the risk factors for chronic diseases and then to examine their interaction. Increased single risk factor exposure increases the probability of disease occurrence, and an epidemiological association of getting the disease (Van de Mheen and Gunning-Schepers 1996). The presence of several risk factor exposures multiplies the risk of disease occurrence. For example, combining two independent risk factors such as untreated high blood pressure and a heavy smoking habit produces a higher combined risk for cardiovascular disease than either factor would exert by itself.

One way to determine risk factors is by reducing or modifying the exposure to a specific risk in a
population and observe the results over a sufficient period of time. Studies show that when exposure to smoking is reduced, the rates for chronic diseases also decrease (chronic lung disease, lung cancer, cardiovascular disease) (CDC 1998, NCI 1992, USPHS 1964, US DHHS 1983, 1989).

Risk factors have subtle but important differences and are referred to as 'at-risk behavior', also as 'predisposing conditions or factors'. At-risk behaviors are those activities done by persons, who are healthy, but see themselves at greater risk of developing a particular disease, condition, or disorder. For example, most current smokers likely know that they are at higher risk of lung cancer, respiratory disease and cardiovascular disease by smoking, but continue to smoke. Pre-disposing factors are those factors or circumstances existing which influence behavior by providing a motivation for the behavior to happen. For example, the fact that a school-age child's parents smoke is a pre-disposing factor influencing the possibility of the child also smoking (CDC 1998, NCI 1992). Whether one smokes or not and whether one aquires a chronic disease like cancer is the result of a complex and still poorly understood and multi-faceted interaction between behavioral, environmental, physiological, genetic, and lifestyle choices which can all contribute to causation risk factors for chronic diseases. The important point is that smoking is one causative factor that could be altered by the individual. Tobacco use is a risk factor for heart disease, cancer, and stroke-all leading causes of death among American Indians and Alaska Natives. (Shelton DM, et al., 1993)

CHRONIC LUNG DISEASE AND SMOKING

I tis important to examine in some detail the link between tobacco smoke and disease. Cigarette smoking may result in chronic bronchitis and/or emphysema, otherwise known as chronic obstructive pulmonary disease (COPD). Cigarette smoking is the pre-dominant cause of COPD, with 10-15% of current smokers eventually developing clinically significant cough, labored breathing with light exercise (exertional dyspnea) and severely reduced lung function. Chronic ventilatory impairment, as quantified by lung function (spirometric) measurements, has been shown to be both an

Tobacco smoking is undoubtedly the most important risk factor for chronic respiratory disease (Kryger 1990, West 1992). The symptom prevalence of this disease including chronic cough, chronic phlegm, wheeze and breathlessness were found to be more frequent in current smokers than in non-smokers. In ex-smokers, the prevalence rates of the symptoms were lower than in the people continuing to smoke. An analysis of the cross-sectional Scottish Heart Health Study confirmed the beneficial effect of stopping smoking and indicated that the reduction in the symptom prevalence rates in ex-smokers was related to the number of cigarettes smoked daily before cessation (Brown et al. 1991). These data suggest that a disease risk gradient exists which correlates the amount of tobacco smoked to COPD symptoms suggesting that cause (smoking) is related to effect (COPD symptoms).

Cigarette smoke affects both the airway and the lung tissue. Hence, chronic smokers usually develop some degree of both chronic bronchitis and emphysema, although the contribution by each differ among individual smokers. Passive smoking (breathing environmental tobacco smoke; ETS) has also been found to be associated with COPD (Robbins et al. 1995, Lebowitz 1996, US DHHS 1986).

It is unclear why certain cigarette smokers develop significant pulmonary dysfunction but others smokers do not. Cohen and colleagues (1980) studied COPD extensively. They found that more of the first-degree relatives of lung cancer patients and COPD patients had impaired ventilatory function than neighborhood control subjects or the relatives of non-pulmonary patients. This difference could not be accounted for by the following adjustment factors: age, sex, ethnic group, socio-economic status, smoking, coffee, tea, alcohol, or any of the tested genetic markers. Furthermore, the observed difference was present among those who never smoked cigarettes. These findings suggest that non-smokers who are exposed to environmental tobacco smoke or 'second-hand smoke' and may be pre-disposed genetically to COPD may succumb to the condition even more readily than a smoker without a genetic pre-disposition. In other words, it is a complex interplay of factors that play a role in chronic lung disease. Those who are nonsmokers may be particularly sensitive to the harmful effects of the smoke and avoid exposure. Clearly, smokers should respect the wishes of non-smokers, particular attention should be paid to pregnant women, infants, children and the elderly who have diminished function relative to adults and less opportunity to adapt their surroundings.

Lung Cancer and Smoking

ung cancer (LC) rates and mortality have risen → to epidemic proportions in Canada, United States and other industrialized nations during the 20th century (Beckett 1993, Samet 1993). Population studies performed in the 1950s and 1960s firmly established cigarette smoking as the single most important risk factor for lung cancer (Wynder 1997). It has been estimated that between 80 and 85% of all lung cancer deaths can be attributed to tobacco use (Beckett 1993, Samet 1993). The average annual risk of developing lung cancer in Canadian males in 1988, as estimated by incidence rates standardized to the 1981 Canadian population, was 74.26/100,000 (Villeneuve and Mao 1994). Lifetime risk estimates of developing lung cancer suggest that almost one out of ten (9.6%) Canadian men will eventually develop lung cancer (Villeneuve and Mao 1994). Cancer of the bronchus and lung was the fourth leading cause of premature death in 1988 for both Canadian males and females in terms of potential years of life lost (Wilkins and Mark 1991).

Early work that examined cancer rates in the central and western Arctic between 1950-66 and 1974-80 demonstrated a rise in those cancers more commonly found in most "modern" society e.g.. lung, cervix, colon, and breast. (Schaefer et al 1975, Hildes and Schaefer 1984, Young, RCAP report, 1997).

There is now considerable evidence at the biological level that lung cancer is associated with genetic change (Davila and Williams 1993, Hirschowitz and Crystal 1997, Richardson and Johnson 1993). The four main types of lung cancer – adenocarcinoma, squamous cell, large cell, and small cell carcinoma – are responsible for 95% of diagnosed cases (Davila and Williams 1993, Hirschowitz and Crystal 1997, Richardson and Johnson 1993).

Carcinogenesis, or the development of cancers, is

a now viewed as a multi-step sequence in which cells accumulate multiple genetic changes. A growing body of data is beginning to describe the nature of this genetic damage (Davila and Williams 1993, Hirschowitz and Crystal 1997, Richardson and Johnson 1993). One hypothesis states that a balance exists between activated (switched on) tumor genes and/or inactivated (switched off) tumor-suppessor genes as the competitive forces driving a normal cell to become a malignant one (Slebos et al. 1991). Progression of lung cancer can be viewed as a process of environmental selection that yields highly adapted and aggressive sub-populations, some of which have the capacity of metastasis (Davila and Williams 1993, Hirschowitz and Crystal 1997, Richardson and Johnson 1993).

The known risk factors for lung cancer are cigarette smoking (both active and passive smoking), radon gas and occupational carcinogens (Beckett 1993, Samet 1993, Takkouche and Gestal-Otero 1996). Environmental agents found in the home and workplace, including radon and asbestos, have also been shown to increase lung cancer risk in both smokers and non-smokers (Samet 1993). Diet is a factor in that several epidemiologic studies have convincingly shown that a greater dietary intake of vegetables modestly lower risks for lung and other cancers. Non-modifiable risk factors are age, gender, race and inherited or genetic pre-disposition (Beckett 1993, Samet 1993, Takkouche and Gestal-Otero 1996).

Well-established risk criteria, based on observational evidence, have been used for the attribution of causality. These criteria are based on five factors including consistency, strength of association, specificity, temporal relationship, association between a disease and risk factor (Altman 1991, Kelsey et al. 1996).

The major evidence linking cigarette smoking to human lung cancer has been primarily based on an enormous body of prospective (forward over time) and retrospective (backward over time) epidemiologic research (Beckett 1993, Samet 1993, Takkouche and Gestal-Otero 1996). The relative risk for lung cancer in long-term cigarette smokers is dramatically increased versus that of lifetime non-smokers, with estimates varying from 10- to 30-fold (Beckett 1993, Samet 1993, Takkouche and Gestal-Otero 1996). The lifetime risk for development of lung cancer in a nonsmoker is approximately 1% or less. In dramatic contrast, the cumulative lung cancer risk may be as high as 30% in heavy smokers. Passive smoking (environmental tobacco smoke or second hand smoke) also increases the risk of developing lung cancer (US DHHS 1986).

It has been demonstrated that the risk for development of lung cancer is substantially increased by previous asbestos exposure. Further the risk of lung cancer in those exposed to asbestos and cigarette smoking is multiplicative. Asbestos workers' risk for dying of lung cancer is increased 16-fold if they have smoked more than 20 cigarettes per day and 9-fold if they have smoked less than 20 cigarettes per day, compared to asbestos workers who have never smoked regularly. When cigarette smokers are considered as a group, a history of asbestos exposure increases the risk for dying of lung cancer about five-fold (Beckett 1993, Samet 1993). In recent years, the risks of lung cancer caused by radon gas in uranium mines and in common households have been examined (Samet 1993). An interaction between radon exposure and cigarette smoking has been demonstrated (Samet 1993).

CARDIO-VASCULAR DISEASE (CVD) AND SMOKING

CVD and the clinical syndromes of heart disease are not simply the result of coronary disease, but are due to a complex interplay of several processes over time, which can be exacerbated or caused by smoking. The earliest coronary artery lesions (buildup of fatty deposits on the interior arterial walls) results from injury to the artery wall and progresses via fatty accumulation and several stages that lead to coronary artery blockage (Fuster et al. 1992).

Nicotine from cigarette smoke has a direct damaging effect on the blood vessel walls (US DHHS 1983, 1988). Acute coronary syndromes, such as heart attack, are thought to be a result of blood clot formation at the site of artery wall disruption (Fuster et al. 1992). The processes of blood clot formation and build-up of fatty deposits in arteries are thought to be, in part, effects of smoking and are the major mechanisms involved in CVD found in smokers. The acute and chronic effects of smoking are complex, mediated not only by nicotine, but also by carbon monoxide and over 4,000 other constituents of tobacco smoke (US DHHS 1989).

Observational studies of the possible association of cardiovascular disease and cigarette smoking have consistently shown that smoking increases the risk for cardio-vascular disease (CVD) illness and death (US DHHS 1983, 1989, Samet and Lange 1996, Van de Mheen and Gunning-Schepers 1996). Early information on this association was reported by Hammond and Horn (1958). They noted a 52% excess mortality from CVD in smokers and a definite doseresponse relationship between the number of cigarettes smoked per day and CVD mortality in a cohort of 18,783 men. Mortality data from a British study involving over 34,000 men also showed a marked excess mortality among smokers from CVD mortality (Doll and Peto 1976).

The population-based cohort in the Framingham Heart Study has exhibited similar rates of excess CVD mortality in smokers (Gordon et al. 1974). CVD mortality has also been shown to be consistently higher in smokers versus non-smokers among various ethnic groups and among international cohorts (USPHS 1964). Prospective studies have also found strong correlation between smoking and non-fatal CVD events (Samet and Lange 1996, PHS 1983).

The Pooling Project Research Group (1978) reported a 3.2 times greater risk of a first CVD event in smokers versus non-smokers for a follow-up group of over 8,000 men. The absolute risk of an event increased progressively with age and with increasing cigarette consumption. Similar conclusions have come from studies comparing relative risk in various ethnic groups and among women (US DHHS 1983, Van de Mheen and Gunning-Schepers 1996).

Smoking appears to interact with other CVD disease risk factors by multiplying risk (Brophy 1997). In a follow-up group of over 300,00 men, elevated blood pressure (systolic and diastolic) and serum cholesterol interacted with smoking to increase risk of CVD mortality significantly (Neaton and Wentworth 1992). The relative risk for smokers at the highest levels of systolic pressure and cholesterol was over 20 times that in non-smokers who were at the lowest

levels for systolic blood pressure and cholesterol. The Pooling Project Research Group (1978) showed similar interactions between blood pressure, cholesterol, and smoking.

The association between smoking and increased risk for CVD is strong and consistent across studies and groups of subjects. There is a consistent smoking dose-dependent relationship between cigarettes consumed and risk for disease. The association is also biologically plausible, with multiple links between smoking and proposed mechanisms of CVD. The temporal element is the weakest link in this chain of causality. However, one recent study showed that length of time exposed to cigarettes was an important factor in determining CVD risk (Kawachi et al. 1994). Thus, a relatively long latent period between smoking initiation and evidence of significant CVD events is to be expected.

NON-TRADITIONAL USE OF TOBACCO AMONG ABORIGINAL PEOPLES

Tobacco consumption rates are higher for Aboriginal peoples but significant variation exists (Gilliland, et al., 1998). The following epidemiological statistics are derived from the United States and Canada.

Aboriginal women who smoke during pregnancy increase their chance of miscarriage, fetal and neonatal death, premature delivery and sudden infant death syndrome (SIDS). Since the fetus is completely dependent on the mother, harmful substances from tobacco smoke can cross the placenta directly from the mother to the unborn child. Maternal smoking has been associated with low birthweight babies Godel, et al., 1992) and SIDS. In British Columbia, between 1987 and 1992, the status Indian SIDS death rate (5.97 per 1,000 live births) was over three times the SIDS death rate for all of British Columbia (1.57 per 1,000 live births), (Amershi and MacDonald, 1994). These data were similar for Indians living in Washington state from 1984 to 1988. Similarly, infants with mothers identified as Indian were more than three times likely to die of SIDS than infants whose mothers were identified as white (relative risk = 3.25; 95% confidence interval = 2.41 to 4.38). However, the relative risk of SIDS diminished after adjusting for differences in smoking status, (Irwin et al., 1992). SIDS rates among Indian people in the United States vary according to geographic location. In the northern United States, there were 4.6 deaths per 1,000 live births, while the incidence among Southwestern Indians was 1.4 per 1,000 live births (risk ratio = 3.4; 95% confidence interval - 2.4 to 4.8). Differences in socio-economic status, maternal age, birth weight and prenatal care did not appear to explain the higher incidence of SIDS. However, cigarette smoking during pregnancy was exceptionally high among northern Indians and low among southwestern Indians. The rate of smoking could explain, in part, the excess risk of SIDS among Indians in the Northern regions. It further reveals that effective smoking cessation programs are needed for Aboriginal women of reproductive age (Buterys, 1990).

Comparing smoking to maternal age, race, marital status and social class indicate that higher smoking rates are found in unmarried women, women aged 25 through 29, Native Americans and women in low socio-economic classes, (Milham and Davis, 1991). A Washington state investigation examining maternal teenage smoking trends revealed a small but significant increase between 1984 (32%) and 1988 (37%). In this study, First Nations Americans showed the greatest increase in smoking prevalence over time, (Davis et al., 1990).

Aggregated high school senior data from 1990-1994 show that smoking prevalence was 41.1% among male American Indians and Alaska Natives and 39.4% for female American Indians and Alaska Natives. Smoking prevalence was 33.4% for white males and 33.1% for white females, 28.5% for Hispanic males and 19.2% for Hispanic females, 20.6% for Asian American and Pacific Islander males and 13.8% for Asian American and Pacific Islander females, and 11.6% for African American males and 8.6% for African American females, (U.S. Department of Health and Human Services, 1997).

Evidence suggests that the non-traditional use of tobacco may lead to drug and alcohol experimentation, gambling and other unhealthy behaviors. The Nechi Institute reports that graduates of their alcohol and drug treatment programs began smoking at an early age with some 80% of Aboriginal female adult smokers and 60% of Aboriginal male smokers

beginning to smoke between the ages of 11 and 15 (Nechi Institute, 1992). The Nechi Institute published Spirit of Bingoland (Hewitt, 1994) a report concerning problem gambling among Native people in Alberta. Seventy-three percent of respondents in the report were smokers. On average participants began to smoke at 20 years (18 and 21 years for women and men, respectively). Thirty-six percent (more than one third of smokers) began before the age of 16 years and 55 percent before age 19.

Comparing Alaskan non-natives, Alaskan First Nations, American Indians and a sample of the general population shows there are high prevalence rates for tobacco, alcohol and drug use and that prevalence rates among the American Indian, Alaskan First Nation and non-native Alaskan groups were statistically higher than the national comparison sample, (Leukefeld et al., 1992). (Breakdown by gender showed no differences among First Nations males or females.) The study also suggests an overlap between tobacco use and drug and alcohol experimentation for all youth examined. This study shows high prevalence of teenage tobacco use, alcohol and marijuana, but it does not describe the pattern of use over time. Identifying the sequence of events would lead to identification of "gateway" behaviors in the progression of drug use.

Such a progression was described in a 10-year longitudinal study of 1,325 grade 10 and 11 students living in New York State, (Kandel and Logan, 1984). The investigation began in two waves, starting in 1971 and ending in 1981. Notably in this study special effort was made to survey "chronic absentees" who had missed the first waves of the study. These absentees or non-participants were more likely to be enrolled in New York City schools; to be male and Black or Hispanic; to reside in "mother-headed" families; to be less successful academically and to be more heavily involved in drugs, except alcohol. In the study alcohol and cigarette use increased at the same rate from age 7 to 14. Then alcohol use increased faster than cigarette smoking. The peak of the initiation to cigarettes was 16 years, which preceded the peak in alcohol at 18 years (coinciding with the legal drinking age of 18 years in New York State). The study further reveals that tobacco use and alcohol seem to be the triggers or gateway drugs that lead to other drug use. The study related initiation, stabilization and decline to changes in maturity within the student population. Adolescents were also unlikely to experiment with marijuana without first experimenting with alcohol or cigarettes; very few youths tried illicit drugs without first trying marijuana, (Kandel, 1975; Kandel, 1975).

Statistical models of progression into adulthood were applied to the New York data and this revealed striking gender differences. Cigarettes played a greater role among women then men in the sequence of drug involvement. Cigarettes could precede marijuana in the absence of alcohol use in women; for men, alcohol preceded marijuana use in the absence of cigarettes. Cigarettes preceded other illicit drug use among women, but not among men. Furthermore, men placed greater importance on alcohol as an experience prior to marijuana use (Yamaguchi, K. and D. Kandel, 1990).

Combined 1994 and 1995 United States national survey data show that, among the five major racial and ethnic groups, adult smoking prevalence was 39.2% for American Indians and Alaska Natives, compared with 26.5% for African Americans, 25.9% for whites, 18.9% for Hispanic, and 15.3% for Asian Americans and Pacific Islanders. (United States Department of Commerce, 1997). Smoking rates and consumption among American Indians and Alaska Natives vary by region and state. Smoking rates are highest in Alaska (45.1%) and the North Plains (44.2%) and lowest in the southwest (17.0%). The prevalence of heavy smoking (25+ cigarettes per day) is also highest in the North Plains (U.S. Department of Health and Human Services, 1998.) Since 1978, the prevalence of cigarette smoking has declined for African American, Asian American and Pacific Islander, Hispanic, and white women of reproductive age (18-44 years), but not for American Indian and Alaska Native women. In 1994-1995, the rate of smoking among American Indian and Alaska Native women of reproductive age was 44.3% as compared with white (29.4%), African American (23.4%), Hispanic (16.4%), and Asian American and Pacific Islander (5.7%) women of reproductive age (U.S. Department of Health and Human Services, 1997 and 1998).

The health and well-being of a population are influenced by several key factors. These include income and social status, social support networks, education, employment and working conditions, biology and genetic make-up, personal health practices and coping skills, childhood development and available health services. Each are important in their own right but the factors are also interrelated (Advisory Committee on Population Health, 1994). Since the Lalonde Report (1974), growing evidence suggests that the health care industry has had a relatively small impact on the people's health because the root causes of illness, disability and premature death have not been addressed. Narrowing the gap between rich and poor by eliminating poverty, providing better education, improving working and living conditions (including housing and diet) and providing access to preventative health information are now seen as important factors in improving health.

Smoking has been related to lack of education, low socio-economic status and alcohol consumption. All of these factors are higher for Aboriginal peoples living both on and off reserve. (Stephens, 1991; Yukon Health promotion Survey, 1994). A comparison of socio-economic factors for smokers surveyed from the general population in the Yukon Territory examined ethnicity, employment pattern, income level and educational attainment. The study shows that tobacco users are more likely to be Aboriginal however, socioeconomic status is likely the primary determinant of tobacco use (Andrews, 1994).

In this brief review it is clear that tobacco use among Aboriginal peoples is complex involving an array of inter-related factors. It seems appropriate to conclude that tobacco has traditionally been highly valued and has spiritual significance for Aboriginal peoples that continues into contemporary society. Given the current high cigarette smoking rates and clear health risks associated with the non-traditional use of tobacco, it is likely that tobacco related illness and death rates will increase in the future.

The next chapter will examine tobacco use patterns in First Nations and Labrador Inuit communities.









RESULTS

The results of this study aim to provide an accurate and reliable cross-sectional picture of First Nations and Inuit tobacco use in 1997. These data will be compared to other sources where possible and the association to various health conditions will be explored. The following data presented will attempt to contribute to earlier work and provide new evidence, from First Nations and Labrador Inuit communities, to answer an old question concerning tobacco consumption and health impacts associated with habitual nontraditional tobacco use. The new evidence has been described as efficiently and clearly as possible.

Table 1 depicts the sample and population characteristics with 9,870 respondents representing a population of 199,782 adults living in First Nations and Labrador Inuit communities. The survey sample results were weighted to reflect the age and gender distribution of the reference population according to the department of Indian Affairs data provided in electronic format (see appendix for detailed sample weighting protocol). The survey acknowledges a discrepancy in sampling among regions for age 15 to 20, with some regions sampled 18 and over whereas others began the adult sample

	Survey Sample	Population Expansion Weight
Total	9,870	199,782
Female	5,742 (59%)	98,269 (49%)
Male	4,040 (41%)	101,513 (51%)
dult mean age = 36.5 years		Range = 15 to 97 years

Table 1: Respondent Characteristics



Figure 1: Smoking Rates for First Nations / Inuit vs Canadian %

controlling for age (by showing smoking rates by each age group).

behaviour is similar with rate decreasing as age increases however, the prevalence rate is double for First Nations and Labrador Inuit in many age categories.

Examining the pattern of First Nations and Inuit smoking prevalence depicted in Figure 2 shows a very strong negative

and Age Group %

The general Canadian

population differs from the First

Nations and Inuit population in

age structure, and age structure has

an important bearing on smoking

rates. Figure 2 compares smoking

rates for the two populations

The overall pattern of smoking

above age 15. Since data was presented without regional identifiers it was decided to present age 20 and older in groups.

Cigarette Smoking Prevalence

Seventy-eight percent of respondents said they have ever used tobacco in nontraditional ways (Yes=78%, No=21%). At the time of the survey 62% smoked cigarettes, 4% used snuff and 1% used chewing tobacco.

Figure 1 compares cigarette smoking rates from the First Nation and Inuit regional health survey (FNIRHS, 1997) to the Canadian population from the national population health survey (NPHS, 1994), and to an onreserve cohort from the Statistics Canada post-census Aboriginal Peoples Survey of Health (APS, 1991). First Nations and Labrador Inuit are smoking daily at a rate that is twice compared to their non-aboriginal counterparts in Canada. Furthermore, cigarette smoking rates do not appear to be decreasing for First Nations and Labrador Inuit peoples because smoking prevalence data reported here as 62%, from the FNIRHS collected in 1997 is unchanged from the Statistics Canada estimate of 62%, APS collected in 1991.

The exceedingly high and stable smoking rates would not be expected in a population that is so culturally diverse and geographically dispersed. Such a result could suggest a strong cultural identification with tobacco, a reluctance to view it as harmful to health and an association to social and economic health determinants.

Figure 2: First Nations/Inuit Smoking vs Canadian Smoking by Age Groups %





Tobacco

correlation between age and current smoking (r = -0.97). The majority of the population are under age 40 years (some 60 percent) and the smoking rates are up to 72 percent for the youngest adult age group (20-24 yrs.). Clearly, tobacco smoking is a growing health concern popular most among young adults. The rapid demographic changes characteristic of a growing population, combined with smoking rates that appear to be increasing will likely result in smoking related health problems for smokers and those exposed to smoke in the household and public areas. Pregnant women, infants, young children and elders will be the most affected by the secondhand smoke of others.

Overall, 52% of all survey respondents rated their health as 'excellent or very good'. Current smokers health ratings of 'excellent or very good' decreased with increasing age; 58% rated themselves as 'excellent or very good' for age group 20-29 years, while 51% of those aged 30-44 years and one third (34%) of respondents in the 45+ age category rated their health as 'excellent or very good'.

Figure 3 differentiates among current smokers by 'Pack-Years' and age group. The pack-years of smoking variable is a "dosage" measurement, similar to those used in toxicology. The formula included intensity of exposure (of cigarettes smoked per day) times the duration of exposure. The number of cigarettes smoked per day is multiplied by the number of years smoked, and then divide by the "pack" unit (20). For example,



Figure 4: Ever Smoked vs Current Smoking Rates by Age%



Figure 5: Age of Initiation to Smoking %

10 cigarettes per day x 20 years smoking = 200 cigarette-years of smoking then 200 / 20 (20 cigarettes per pack unit) = 15 pack-years of total smoking dosage. While age reduces the percent of persons reporting 'excellent or very good' health, there is a substantial decrease above 10 pack-years for those under age 45 indicating a 'dose response' between the amount smoked and self reported health status.

Figure 4 compares respondents who have ever smoked to the current smokers. The strong negative correlation trend indicate that the likelihood of 'ever smoking' and 'currently smoking' is reduced as age increases. The two lines of best fit depicted in Figure 4 compare those who have ever used tobacco in non-traditional ways ('ever smoked', r=-0.91) and those who presently smoke ('current smokers', r=-0.94). Since the vast majority of tobacco users are cigarette smokers the difference between the two lines likely represents those who have quit smoking. Thus the older an individual the less likely to have ever smoked and the less likely to smoke at the time of the survey. Comparing the differences in trend between the two lines shows a remarkable consistence (r=-0.99). The gap between 'ever smoked' and 'current smoking' categories could indicate that older age cohorts were also more likely to also have quit smoking, or that some older smokers were occasional puffers and never really addicted.

Cigarette Smoking Initiation

Figure 5 shows that smoking L 'begins as early as 6 to 8 years but rapidly increases at age 11 to 12 with a peak initiation at about age 16 years. These data indicate that prevention needs to begin earlier at grades from 1 to 3, and that prevention should be mixed with smoking prevention. cessation curriculum and health promotion together from 9 years (grade 4) to age 16. Remaining smoke free by age 18-19 indicates a low probability of ever starting a tobacco addiction.

Figure 6 depicts the number of cigarettes smoked daily sorted by



Figure 6: Number of Cigarettes Smoked Daily by Age and Gender %



Figure 7: Environmental Tobacco Smoke %

age and gender. Males report smoking consistently more than females. The amount smoked increases steadily until age 40 years. The average amount smoked is less than one 20 pack per day.

Enviromental Tobacco Smoke

Figure 7 shows that more than half (57%) of the respondents said that smoking occurred in their households. Both non-smokers (73%) and smokers (39%) said they feel the unpleasant effects of other's tobacco smoke. These data indicate that, for a great number of

Tobacco

people, the smoke of other's is unpleasant suggesting that there could likely be support for public area tobacco smoking restrictions.

Only one third of respondents interviewed were aware of smoking controls within their community. Asked if these controls were effective, Figure 8 shows that only 1 in 8 respondents thought respondents the smoking controls were effective. Thus there is a need to establish smoking controls for public areas in the community and to develop regulations for enforcement of the smoking controls.

Smokeless Tobacco

Fewer than 5% of respondents Fused chew and snuff tobacco. Young males were the principle users of snuff. Males age 20 to 24 years account for one third of chew and snuff consumed. The target for prevention and cessation of smokeless tobacco use should be males up to age 40 years.

Chronic Conditions Including Diabetes

Figure 11 shows the sum of seven chronic conditions present in smokers and nonsmokers. Smokers report more prevalence for chronic conditions compared to non-smokers in early and middle ages (20 to 55 years). In other words, non-smokers appear to be less likely to have a chronic health condition than smokers. These data suggest that avoiding smoking is associated with better health (less chronic illness) from age 20 to 55 years. Never smokers above age 65 years



Figure 8: Smoking Controls in Community %



Figure 9: Chewing Tobacco Use by Age and Gender %

are more likely to report a chronic condition than smokers. This is likely due to screening out those with ill health, smokers who may have died prematurely or those who may have quit when a chronic conditions were diagnosed. It seems likely that since many First Nations and Inuit are in under-served rural or remote regions, potential respondents who are chronically ill may have already moved away from their home community to access health programs and services. In other words, even for older age smokers,

the more healthy are more likely to

'survive' and continue to live in their home community.

Social and Economic Determinants of Smoking - Education

 ${\rm E}$ ducation is used here as a proxy measure for social and economic factors. Comparing current smokers to education attainment indicates that those with incomplete secondary school education smoke more than respondents who completed secondary school. As Figure 12 shows, respondents who have completed secondary school and had some post-secondary education smoked less than the other two groups. Figure 12 also depicts that an inverse trend exists between smoking and educational attainment; as education increases smoking decreases. However, a smoking rate of 53% in the group with highest educational attainment is still almost double the Canadian smoking rate.

Wellness

Overall, 14% of adults rated their health as excellent, 38% as very good, 41% as fair and 7% as poor. Those who never smoked were more likely to report excellent health (17%) compared to current smokers (12%).

Eighty percent of those who 'ever used' tobacco in nontraditional ways and eighty percent of 'current smokers' both answered "yes" when asked the question "Do you think a return to traditional ways is a good idea for promoting community wellness?"



Figure10: Snuff Tobacco Use by Age and Gender %



Figure 11: Sum of 7 Chronic Health Conditions %

This response could suggest that framing tobacco use as 'nontraditional' may be a useful starting point for changing smoking behaviour.

Dental Health

Comparing dental treatments indicates that there were no differences between smokers and non-smokers for the last time they received dental care, whether dental treatment was needed at the time of the survey, or whether the respondent experienced dental problems in the last month.



Figure 12: Current Smoking and Educational Attainment %

Community Health Services

Forty-seven percent of smokers believe that health services for First Nations and Inuit peoples are not at the same level as other Canadians, another 19% didn't know. Figure 13 depicts the rank order of services in need of improvement as described by smokers. There was little difference between smokers and non-smokers concerning the rank order of health services in need of improvement.

Concerning community level ecological variables, seventy-two percent of all respondents lived in communities that were involved in the health transfer process. Communities that had signed health transfer agreements comprised 38%, while another 34% of communities were actively involved in pre-transfer activities. However, there was no pattern for the distribution of smokers according to health transfer status.

Comparing smoking controls in the community, those who signed community health transfer agreements were more likely to have implemented smoking controls (41% vs 36%) and those involved in pre-transfer were also more likely to have implemented smoking controls in the community (37% vs 30%). Isolated communities (no scheduled flights, minimal telephone or radio services, no road access) were more likely to have smoking controls in the community than non-isolated communities (38% vs 26%). Twenty-seven percent of communities had either inadequate, or no fire protection services (20% and 7%, respectively). Comparing fire protection services to smoking controls in the community shows that community smoking controls were not present in one third (32%) of communities with inadequate or no fire protection services indicating a serious potential fire safety risk due to smoking. Community size shows no significant relationship to smoking status.



Figure 13: Smokers - Health Services in Need of Improvement









DISCUSSION

This study confirms that the profile of Aboriginal smokers is very different from other ethnocultural groups in Canada. The present study shows that 62% of adult First Nation peoples living onreserve and in Labrador Inuit communities are smokers and that over 70% of all respondents age 20-29 were smokers (see figure 2). Clearly, this is a major public health concern and needs to be addressed.

A comprehensive national strategy to address tobacco use in aboriginal communities would identify prevention, cessation and protection measures. Given the profound smoking prevalence rate identified in this study, tobacco smoking must be seen as a high public health priority and a call to action for the community, leadership, health professionals and government.

Historically, tobacco is a sacred plant that has an important role in traditional ceremonies and gift giving. However, the prevalence of non-traditional smoking of tobacco is very high and appears to be increasing among First Nations and Labrador Inuit peoples in Canada. Preventative action is needed in schools, communities, public spaces and workplaces.

Health promotion research identifies the following stages of behavioral change that can be applied to smoking cessation:

- 1. Pre-contemplation (not thinking about quitting)
- 2. Contemplation (thinking about quitting but not ready to quit)
- 3. Preparation (getting ready to quit)
- 4. Action (quitting)
- 5. Maintenance (remaining a non-smoker)

Protection measures are urgently required. There is a need for basic public education within Aboriginal communities about the effects of smoking, secondhand smoke and also smokeless tobacco. While more immediate community challenges such as diabetes and substance abuse can sometimes overshadow or minimize concern about smoking, the truth is that smoking is a major health concern that is not fully appreciated. As a result, many smokers are likely to be in the pre-contemplation stage of change with respect to smoking. In other words, most smokers are probably not yet thinking about quitting or reducing the amount smoked. As the multi-stage model suggests one has to think about quitting, prepare to quit, make a decision and stick to it.

Community based health promotion and disease prevention research needs to examine the stages of change in an Aboriginal context to elucidate those factors most associated with success.

A first and necessary step to help these smokers move to the next stage of change is to increase community awareness about the health effects of tobacco abuse versus traditional tobacco use. However, almost all of the smoking education and cessation programs that are currently available in Canada are not readily accessible to Aboriginal groups. Access is limited by the language used and, in some cases, by the literacy level of materials used in many of these programs. Furthermore, these programs are not culturally appropriate for First Nations and Inuit Peoples.

Too few resources make smoking prevention, cessation and protection messages either personally and culturally relevant. For many Aboriginal communities, being 'culturally sensitive' also includes respecting tobacco's sacred role and clearly distinguishing between smoking and ceremonial tobacco use. As well, the vast majority of these programs and materials focus exclusively on the individual in contrast to the Aboriginal holistic approach of involving the family, the community and the environment. The NASAWIN smoking education program, which is described in appendix 1, along with other resources, provides one of the few examples of a culturally appropriate smoking intervention for Aboriginal Peoples.

Whereas cultural values with respect to tobacco vary for different Aboriginal groups, the health toll of smoking related illness will not. The extensive literature review clearly shows that habitual tobacco consumption is toxic and dangerous. However, some of the health risks can be lowered as soon as one quits, assuming that a disease has not yet had time to become established.

Greater collaboration within and amongst Aboriginal organizations, health associations and program providers is central to incorporating smoking cessation interventions into an effective health promotion strategy for Aboriginal communities. Federal, Provincial and Territorial governments need to provide financial support and expertise directly to First Nations and Inuit communities to enable the healing process to begin.

This study did not specifically examine smoking in youth. However, in a 1990 to 1993 comparison of the use of alcohol and other drugs among Aboriginal and non-Aboriginal youth in one American city, a progressive increase across Grades 7-8, 9-10, and 11-12 in rates of use of alcohol, marijuana and cigarettes was found among both groups. However, the 1993 rates of cigarette use for Aboriginal youth across the three grade levels were 45%, 69% and 80% - much higher than the corresponding rates of 13%, 32%, and 42% among non-Aboriginal youth.

In Canada, the First Nations Youth Inquiry into Tobacco Use (Wunska, 1997) confirms that tobacco smoking is a serious public health problem and suggest that cessation and prevention should begin at 10 years in recognition of the increasing incidence of 'occasional smoking'. Reasons that First Nations youth begin smoking are 'to be cool or cooler' (41%), peer pressure (19%), parental or family influence (4%). The question seems to be, how can not smoking be portrayed as 'cool' for youth. Youth smokers were asked to rank resilience or protective factors for not smoking. These include; not drinking alcohol, attending school, having few friends that smoke, age under 12 years, parental disapproval, find it easy to say no and see smoking as dangerous. These data show that for youth smokers health concerns are not as important as the link to alcohol and social status. Conversely, for youth non-smokers, reasons for not smoking sorted by rank included; want to stay healthy, personal choice, uncool, don't know and family pressure. Clearly parents can also have an important impact as role models for both smoking and nonsmoking youth.

In comparison to the overwhelming body of literature on smoking there are few studies that address the problem of smoking by First Nations peoples. In a study of smoking prevalence among adult Aboriginal people in northern California (Hodge et al., 1995), the most popular method of quitting was cold turkey (78% of former smokers and 60% of current smokers.) Fifty per cent of current smokers and 32% of former smokers had tried decreasing their intake of cigarettes. The least popular method was following instructions in a book or pamphlet.

Using the higher prevalence rates as evidence, Reading (1996) notes that existing cessation strategies have not been as successful in the Aboriginal population as with other populations in Canada. He concludes that cessation programs need to include cultural values and be designed and delivered from within the Aboriginal community. A key consideration is the historical role tobacco has played in Aboriginal traditions and rituals.

Prior to contact with Europeans, tobacco was the most important plant in the spiritual lives of Aboriginal North Americans (Reading, 1996). Sacred tobacco was burned to encourage favorable environmental events, spread on the ground around medicinal plants to support their growth, thrown on fires before trying to communicate with the spirit world, and thrown on water before travel to ensure safe passage. Smoking a Sacred Pipe was common among many tribes to cement political and economic agreements. Tobacco has traditionally held a legitimate place in many Aboriginal ceremonies, rituals, spirituality and trading patterns. Reading suggests that placing tobacco within the context of Aboriginal traditional uses may be a powerful means of reducing its current misuse. This concept needs to be evaluated.

It is important to evaluate tobacco use cessation programs to determine which methods are most successful among Aboriginal people (Bulterys et al., 1990). Programs that fail to acknowledge the spiritual value of tobacco, focusing instead on its negative uses, may not work with Aboriginal people. It has also been suggested that placing tobacco in its historical and spiritual context may be an important way of preventing smoking among Aboriginal youth (Reading, 1996).

The Circumpolar Conference on Tobacco and Health (1990) recommended that health promotion and education on all forms of tobacco use was needed and it should consist of mainly visual material, material of local relevance, and use of local languages, simple terms and Aboriginal role models.

Some of the themes evident in planning Aboriginal health services in general (Pekeles, 1988) might also apply to tobacco cessation programs for Aboriginal people. These include:

- Aboriginal participation in the development and implementation of cessation programs;
- Training of Aboriginal personnel to deliver the programs;
- Taking a socio-environmental approach and improving living conditions as part of a tobacco reduction strategy.

Considerations in developing tobacco use cessation resources for Aboriginal Canadians are:

- evaluate existing cessation approaches including group therapy, self-help and nicotine replacement therapy to ascertain which have the greatest potential for working in Aboriginal communities;
- incorporate an understanding of the traditional uses of tobacco into cessation programs, and
- promote traditional respect for tobacco;
- recognize that First Nations and Inuit peoples are a heterogeneous multi-cultural group.

Health promotion and disease prevention models must be developed by people from Aboriginal communities. Research information needs to be meaningfully disseminated so First Nations and Inuit peoples can make informed choices about lifestyle behaviors that have health risks. Tobacco use seems to be a marker for the disadvantaged in society. It is critical that Aboriginal people design, develop, implement and evaluate their own tobacco prevention, cessation and protection initiatives.

The process for health promotion and disease prevention efforts needs to be designed by the community at the community or grass-roots level. Failure to do so will likely result in failure of the program since the community will not feel it has any say in how the program develops, who owns the process and who has responsibility for its success.

Following are brief descriptions of three programs that are models for addressing the growing problem of non-traditional use of tobacco. Additional programs are described in the appendix. However, more programs need to be shared and more programs need to be developed. Readers are encouraged to explore the following:

- NASAWIN is a community approach to tobacco education for Aboriginal peoples. It is best suited to smokers who are in the earlier stages of change rather than smokers in the action stage. The program combines posters, pamphlets, a program manual and a 15-minute video, and can be delivered as either a group or self-help program. The role of tobacco in traditional ceremonies and gift giving is incorporated in the program.
- Sacred Plants, Sacred Ways has been developed with the input of Elders to raise awareness of the sacred uses of tobacco in traditional ceremonies, in spiritual communication and as a gift symbolising appreciation and respect. It is intended for Aboriginal Peoples living in urban settings, and combines information on prevention, cessation and protection.
- Integrated Tobacco Recovery for Urban Aboriginal Adults and Adolescents is an adaptation of the Smoker's Treatment Centre's New Tools for Survival. The Nechi Institute has re-worked the original document to make it culturally suitable for Aboriginal youth and adults living in urban communities. The adaptation includes acknowledging the traditional use of tobacco's spiritual and healing role for Aboriginal Peoples.

The appendix gives more detailed information on several other programs and provides information on contacts, materials and cost.

Aniqsaattiarniq - Breathing Easy - Community Resource Kit

Information Source: Pauktuutit Inuit Women's Association of Canada

Ms. Catherine Carry, Project Coordinator

192 Bank Street

Ottawa, ON K2P 1W8

Tel: (613) 238-3977 Fax: (613) 238-1787

The goals of this project are to reduce and prevent tobacco use in Inuit communities and to work towards a tobacco-free culture. Pauktuutit Inuit Women's Association has developed the Aniqsaattiarniq-Breathing Easy Community Resource Kit that includes a video on the health effects of tobacco use and cessation methods with supporting leaflets, posters, and resource manual. These resources are culturally and linguistically appropriate for Inuit youth, pregnant women, adults and elders. Anticipated distribution date is May, 1997. Also, the Aniqsaattiarniq-Breathing Easy School Kit has been produced to help prevent tobacco use. It contains a video, teacher's manual, storybook and poster for use with elementary school children in Inuit communities.

Developed by: Pauktuutit

Date Developed: Program, 1994; Resource, 1997

Language: English; Inuktitut

Target: Aboriginal groups

Program Type: Community development; Group support; Individual counselling; Mutual support; Self-help

Program Approach: Addiction model; Behaviour modification; Community-based leadership model; Reduction as a legitimate outcome

Resource Descriptors: Facilitator guide/manual; Kit; Low reading level; Video

Site: Community-at-large; Health care settings

Duration: On-going - dependent on the counsellor/facilitator as to how they choose to utilize the materials.

Cost: Initial distribution to Inuit communities is free (2-3 copies each). Limited subsequent general distribution - approx. \$140/kit within Canada.

Availability/Locations: National

Evaluation: Resources yet to be distributed and implemented.

A Pregnant Woman's Guide to Quit Smoking

Information Source: The Health Promotion Group Dr. Richard Windsor P.O. Box 59687 Homewood, AL, USA 35259

First Nations and Inuit Regional Health Surveys

Tel: (205) 969-3717 Fax: (205) 975-5432

This 40 page self-help guide provides a ten day cessation program for pregnant women. Leading up to quit day on day seven, participants are helped to prepare mentally, emotionally and physically for stopping smoking. A contract to read and use the guide is signed on the first day. Participants identify why they want to quit and their level of motivation, keep a diary of when and where they smoke, learn about their own triggers to smoke, relaxation techniques, getting support from others, and how to cope with urges to smoke and withdrawal symptoms. A 'smoke-tasting' exercise, where the tobacco smoke is held in the mouth rather than inhaled, is used to reinforce a negative association with tobacco use. The last three days of the program following quit day focus on dealing with relapses and maintaining the decision to quit.

Developed by: Richard A. Windsor, PhD

Language: English

Target: Pregnant women

Program Type: Individual counselling; Self-help

Additional Descriptors: Physician interview/Assessment; Prenatal period

Site: Community-at-Large; Health Care Settings

Cost: 1- 20 copies \$5 each (US funds; include \$1.00 postage and handling per book); 50 - 400 copies \$4.00 each (US funds; units of 50 only); 500 - 1,500 copies \$3.50 each (US funds; units of 100 only); 2,000 - 4,000 copies \$3.00 each (US funds); 5,000 or more \$2.50 each (US funds); bulk price does not include shipping and handling - allow 4 weeks for delivery.

Availability/Locations: International

Evaluation: A 1985 randomized controlled trial of this program in the United States showed a 14% success rate. This evaluation is published as: Windsor, R.A., et al. 'The effectiveness of smoking cessation methods for smokers in public health maternity clinics: A randomized trial', American Journal of Public Health, 1985, Vol. 75, pp. 1389-1392. A Canadian evaluation which used this guide as part of an intervention program for pregnant women showed comparable results. This study is published as O'Connor, A.M., et al. 'Effectiveness of a Pregnancy Smoking Cessation Program', JOGNN, October 1992, Vol. 21, No. 5, pp. 385-392.

Catching Our Breath - A Guide for Facilitators

Information Source: Women's Health Clinic Resource Coordinator

419 Graham Avenue, 3rd Floor

Winnipeg, MB R3C 0M3

Tel: (204) 947-1517 Fax: (204) 947-3844

This guide presents an alternative model to smoking and smoking cessation for women, one that is women-centred, flexible, and embodies a feminist view of women in society. The guide is intended to assist anyone who wants to facilitate a women's smoking cessation group. Areas addressed include guidelines for facilitating a group, how to create a group, communication and empowering skills. There are detailed outlines for twelve group sessions beginning with an introductory meeting, and continuing with sessions on why women smoke, body image, health consequences of smoking, how to quit smoking, withdrawal/recovery symptoms, and maintaining the decision to quit. There is special emphasis on creating a non-judgemental, supportive environment as well as placing quitting smoking in the wider context of making changes. Participants in this group program use Catching Our Breath - A Journal about Change for Women Who Smoke which is also used on a self-help basis. Group programs are currently running in some cities such as Winnipeg. Women's Health Clinic is adapting this program for women with lower literacy skills and women in workplaces.

Developed by: Women's Health Clinic, Winnipeg, Manitoba

Date Developed: Resource, 1st Edition 1990, latest edition 1997

Language: English

Target: Community leaders; Counsellors; Women; Health educators

Program Type: Group support; Mutual support

Program Approach: Addiction model; Adult learning principles; Community-based leadership model; Feminist; Holistic; Reduction as a legitimate outcome; Stages of change

Resource Descriptors: Correspondence; CD-ROM; Facilitator guide/manual

Additional Descriptors: Facilitator training

Site: Community-at-large; Health care settings; Workplace

Duration: 6 - 12 weeks

Cost: Facilitator's manuals cost \$12 each, plus \$1 shipping. Costs for participants vary with location. The new manual in production will cost \$35.00 each, plus \$2.00 shipping (journal included).

Availability/Locations: National / The new edition of Catching Our Breath will be made available in bookstores across Canada or may be ordered through the Women's Health Clinic.

Evaluation: A qualitative and quantitative evaluation of Catching Our Breath was conducted during the project that applied this approach to workplaces and to priority women. Preliminary results indicate a 25% cessation rate and a 61.3% reduction in amount smoked as well as increased confidence and coping skills. Final evaluation results will include the pros and cons of using COB in the workplace and with priority women.

Notes: The program will be made available on CD ROM in the future.

Catching Our Breath - A Journal about Change for Women who Smoke

Information Source: Women's Health Clinic

Resource Coordinator

419 Graham Avenue, 3rd Floor

Winnipeg, MB R3C 0M3

Tel: (204) 947-1517 Fax: (204) 943-3844

This innovative self-help manual explores issues relating to why women smoke. An alternative model of smoking and smoking cessation for women is presented, one that is women-centred, flexible, and embodies a feminist view of women in society. It is designed to be used intensely over a short period of time or slowly over many weeks, depending on the individual's needs. Each of its 13 chapters discusses an aspect of the process of quitting smoking. The areas covered include understanding the physical and psychological addiction to smoking, motivation, the cultural context of smoking for women, triggers to smoke, dealing with feelings and situations, relaxation techniques, stress management, how to handle quit day, and strategies for remaining smoke-free. The program also addresses weight and body image and emphasizes the need for women to establish personal space and reward time. The journal format gives women an opportunity to practice alternative ways of coping with stresses and behaviours that sustain smoking.

Developed by: Women's Health Clinic, Winnipeg, Manitoba

Date Developed: Resource publication, 1990 and 1997

Language: English

Target: Aboriginal groups; Community leaders; Counsellors; Lower socioeconomic status; Seniors; Women; Young single parents; Young adults

Program Type: Group support; Mutual support; Self-help

Program Approach: Adult learning principles; Feminist; Holistic; Reduction as a legitimate outcome

Resource Descriptors: Facilitator guide/manual

Additional Descriptors: Body image; Low literacy; Women-centred approach to healing and change.

Site: Community-at-large; Health care settings; Workplace

Duration: 6 - 12 weeks; On-going / drop-in sessions

Cost: Manuals: \$13.90 plus \$1.05 GST plus \$2.00 shipping

Availability/Locations: Local; National in the future The 1997 edition should soon be available in bookstores across Canada. The 1997 edition should soon be available in bookstores across Canada.

Evaluation: A qualitative and quantitative evaluation of Catching Our Breath (COB) was

conducted during the project that applied this approach to workplaces and to priority women. Preliminary results indicate a 25% cessation rate and a 61.3% reduction in amount smoked as well as increased confidence and coping skills. Final evaluation results will include the pros and cons of using COB in the workplace and with priority women.

Freedom from Smoking for You and Your Baby

Information Source: Canadian Lung Association

Blair Business Park

1900 City Park Drive, Suite 508

Gloucester, ON K1J 1A3

Tel: (613) 747-6776 Fax: (613) 747-7430

This 10 day self-help program includes a 32 page guide, a poster-size progress calendar, a special exercise chart designed for expectant mothers and an audio cassette featuring exercise and relaxation techniques. The guide uses quizzes, activities and information to help participants discover why they smoke, why they want to quit and how to prepare for quit day. Topics discussed include breaking smoking patterns, weight control, how to be assertive and coping strategies for dealing with urges to smoke. The last section of the guide is about maintaining the decision to quit before and after the baby is born.

Developed by: American Lung Association Language: English Target: Pregnant women Program Type: Self-help Program Approach: Behaviour modification Site: Community-at-large Duration: 10 days Cost: Approximately \$7 to \$10 (varies with province) Availability/Locations: This program is offered by the Lung Association in British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Prince Edward Island and Newfoundland.

Freedom from Smoking for You and Your Family

Information Source: Canadian Lung Association Blair Business Park 1900 City Park Drive, Suite 508 Gloucester, ON K1J 1A3 Tel: (613) 747-6776 Fax: (613) 747-7430

Evaluation: Status unknown

This 54 page guide to smoking cessation discusses how to overcome roadblocks to quitting, leads the participant through a nicotine 'fading' program, and provides tips on remaining smoke-free. Emphasis is placed on participants understanding their day to day smoking behaviour, learning how to replace cigarettes with healthy activities, coping with

the first few weeks after quitting and what to do if they start to smoke again. New nonsmokers are encouraged to remember their reasons for becoming smoke-free, reward themselves and help others to quit smoking.

Developed by: American Lung Association Language: English Target: General Population Program Type: Self-help Program Approach: Behaviour modification Site: Community-at-large Cost: Approximately \$5 to \$10 (varies with province) Availability/Locations: This program if offered by the Lung Association in Alberta, Saskatchewan, Manitoba and New Brunswick. Evaluation: A 1990 evaluation of this program by researchers at the Fox Chase Cancer Centre and the University of

North Carolina showed an 11% cessation rate at the six month follow-up interval. This was felt to compare favourably with current studies of self-help programs. About three-quarters of participants in the evaluation had high school education or less and on average smoked one pack of cigarettes a day. Cessation rates were determined using mailed questionnaires and telephone interviews.

Freedom from Smoking Group Course

Non-fumeur en 5 jours Information Source: Canadian Lung Association

Blair Business Park

1900 City Park Drive, Suite 508

Gloucester, ON K1J 1A3

Tel: (613) 747-6776 Fax: (613) 747-7430

The format, length, and group size for this course varies with each province. These are

multi-component behavioural-based group courses for the community or the workplace. The programs generally include self-monitoring, relaxation training, developing a cessation strategy, weight management, problem-solving, dealing with recovery symptoms, and maintaining the decision to quit. In addition to a program for adults, New Brunswick Lung Association offers an adaptation of this program for teens. The Alberta Lung Association offers a comprehensive facilitator training course for their program. In New Brunswick, this program is called Freedom from Smoking in 5 Days and has a 'train the trainer' component. As well, the program is aired on cable television throughout New Brunswick annually in mid February.

Developed by: Individual Lung Associations

Language: English; French (New Brunswick only)

English/French Translation: Literal translation

Target: Adolescents; General Population

Program Type: Group support

Program Approach: Behaviour modification

Site: Community-at-large; Health Care Settings; Workplace

Cost: Price varies with province.

Availability/Locations: This program is offered by the Lung Association in Alberta,

Saskatchewan, Manitoba, New Brunswick, Prince Edward Island and Newfoundland. For address information please refer to the Appendix.

Evaluation: The American Lung Association studied 494 smokers attending 42 Freedom from Smoking Clinics in western New York State. While the clinics studied are not necessarily the same as the programs in this entry, the results of the evaluation may be representative. A cessation rate of 29% was reported one year after completion of the clinics. The evaluation was based on telephone interviews and is published as: Rosenbaum, P. and R. O'Shea, Large-Scale Study of Freedom from Smoking Clinics—Factors in Quitting, Public Health Reports, Vol. 107, No. 2, April, 1992.

Freedom from Smoking in 20 Days and A Lifetime of Freedom from Smoking

Non-fumeur en 20 jours et Je ne fume plus

Information Source: Canadian Lung Association

Blair Business Park

1900 City Park Drive, Suite 508

Gloucester, ON K1J 1A3

Tel: (613) 747-6776 Fax: (613) 747-7430

Freedom from Smoking in 20 Days is a 64 page manual with supplementary materials. Participants analyse personal smoking patterns (days 1 - 7), break this pattern and reduce consumption (days 8 - 15), quit smoking (day 16), and learn how to maintain a smoke-free lifestyle (days 17 - 20). A Lifetime of Freedom from Smoking is a 28 page guide that helps recent ex-smokers to remain smoke-free. It includes tips for dealing with nicotine withdrawal and for handling social situations in which cravings for a cigarette arise. This guide is accompanied by a pocket reminder that can be referred to if a former smoker is tempted to have a cigarette.

Developed by: American Lung Association

Language: English; French

Target: General Population

Program Type: Self-help

Program Approach: Behaviour Modification

Site: Community-at-large

Cost: \$7 to \$16 (varies with province) for Freedom from Smoking in 20 Days and A Lifetime of Freedom from Smoking as a set.

Availability/Locations: This program is offered by the Lung Association in British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland. For address information please refer to the Appendix. Manitoba Lung Association offers only the Lifetime of Freedom From Smoking booklet from this set, at a cost of \$4.00.

Evaluation: A 1984 U.S. study of 308 participants indicated a 15% cessation rate one year after receiving the program. In this evaluation, non-responders were counted as having remained smokers.

Integrated Tobacco Recovery for Urban Aboriginal Adults and Adolescents

Information Source: Nechi Institute Ms. Ruth Morin, Chief Executive Officer P.O. Box 34007 Kingsway Mall Edmonton, AB T5G 3G4 Tel: (403) 458-1884; 1-800-459-1884 Fax: (403) 458-1883 nechi@Nechi.com

124

Nechi Institute has adapted the Smokers Treatment Centre's New Tools for Survival, A Guide to Building Your Own Recovery to be culturally appropriate for Aboriginal adults and adolescents living in urban settings. The guide, Tobacco Addiction and Recovery: A Spiritual Journey, includes sections on the traditional uses of tobacco and its spiritual and healing role in the Aboriginal community. The emphasis on recognizing non-traditional tobacco use as a survival tool is retained in the adapted guide. There is also an emphasis on community training. Developed by: Nechi Institute and Smokers Treatment Centre Date Developed: 1996/97 Language: English Target: Aboriginal groups Program Type: Group support; Mutual support; Self-help Program Approach: Addiction model; Holistic; Reduction as a legitimate outcome; Stages of change.

Resource Descriptors: Interactive workbook; Participant guide/manual; Training module

Site: Community-at-large; Health care settings; Schools; Workplace

Duration: On-going / drop-in sessions

Cost: Varies

Availability/Locations: National

Evaluation: No evaluation to date

Kichi Chistemaw Pimatisiwin (Tobacco is the Way of Life)

Information Source: Native Women's Transition Centre

Ms. Lucille Bruce, Executive Director

105 Aikins Street

Winnipeg, MB R2W 4E4

Tel: (204) 989-8240 Fax: (204) 586-1101

This approach is designed as an educational program to help participants learn about tobacco addiction, how conditioning towards the non-traditional use of tobacco occurs and the effects of smoking on self and others. It acknowledges that recovering from tobacco addiction is more than the act of giving up cigarettes. The decision to stop smoking is left to the individual and is not a requirement for participation. Individuals take responsibility for their recovery process and are supported by a facilitator who provides information so the participants can make informed decisions; guide the sessions to ensure the group stays focused; support participants in developing alternatives to their addictive behaviour patterns and to utilize community resource people for further support.

Developed by: Native Women's Transition Centre

Date Developed: Program, March 1997; Resource, June 1997

Language: English

Target: Aboriginal groups; Women

Program Type: Group support

Program Approach: Adult learning principles; Holistic; Reduction as a legitimate outcome.

Resource Descriptors: Facilitator guide/manual

Site: Community-at-large; Schools; Transition Centres

Duration: 6 - 12 weeks

Cost: To be determined

Availability/Locations: Facilitator guide can be ordered nationally; Groups are only offered locally.

NASAWIN

Information Source: Union of Ontario Indians Health Office a/s Curve Lake First Nation Curve Lake Post Office Curve Lake, ON K0K 1R0 Tel: (705) 657-9383 Fax: (705) 657-2341

NASAWIN (the Cree word for 'breathing' or 'to breathe') is a 10 week smoking education program designed for Aboriginal Peoples. While the focus of this program is not directly on smoking cessation, the topics covered raise awareness about the harmful effects of smoking in contrast to traditional use of tobacco with the intention of helping participants move towards quitting. The program consists of six posters, three pamphlets, a program manual organized into 10 sections and a 15 minute video that compliments the manual. The subjects addressed in the program manual cover the health effects of smoking including smoking during pregnancy, issues concerning smoking and children, secondhand smoke in the home and workplace, traditional use of tobacco, smoking and diseases, and information about quitting smoking. Each section in the manual contains an activity and game in addition to written information. All of the materials in the kit are culturally appropriate and recognize the important role of tobacco in traditional ceremonies and gift giving. The philosophy of the program is to involve the whole community rather than just those members who smoke and to take a holistic approach to reducing smoking based on respect and community support. This program is very flexible in its format and does not require specific training for facilitators. The resources can also be used as a self-help kit.

Developed by: Union of Ontario Indians

Date Developed: Program, 1991; Resource, 1992

Language: English

Target: Aboriginal groups

Program Type: Community development; Group support; Mutual support; Self-help

Program Approach: Behaviour modification; Community-based leadership model; Holistic

Resource Descriptors: Facilitator guide/manual; Video

Additional Descriptors: Prenatal period; Youth led/Assisted; Community led

Site: Community-at-large

Duration: 6 - 12 weeks; plus on-going/drop-in sessions

Cost: \$35.00 per kit, as well as posters for \$6.00 and pamphlets for \$0.25

Availability/Locations: National Aboriginal communities and organizations can obtain the NASAWIN manual and video without cost by sending a blank video with a request for the program to:

Health Programs Support Division,

Medical Services Branch, 11th Floor, Jeanne Mance Building, Postal Locator 1911C, Tunney's Pasture, Ottawa, Ontario, K1A 0L3, Tel: (613) 952-2117, Fax: (613) 954-8107. All First Nations communities, as well as other Native organizations, were sent a copy of the manual and video in 1993.

Aboriginal communities and organizations can obtain the NASAWIN manual and video without cost by sending a blank video with a request for the program to:

Health Programs Support Division,

Medical Services Branch, 11th Floor, Jeanne Mance Building, Postal Locator 1911C, Tunney's Pasture, Ottawa, Ontario, K1A 0L3, Tel: (613) 952-2117, Fax: (613) 954-8107. All First Nations communities, as well as other Native organizations, were sent a copy of the manual and video in 1993.

Evaluation: A program evaluation by the Union of Ontario Indians is in progress. There are indications that this type of program can have a dramatic effect on awareness, attitudes and smoking rates: there was a 50% drop in smoking in one year in one community using NASAWIN.

Sacred Plant, Sacred Ways

Plante sacrée, Usages sacrés

Information Source: National Association of Friendship Centres

Ms. Tanya King, National Facilitator

275 Maclaren Street

Ottawa, ON K2P 0L9

Tel: (613) 563-4844 Fax: (613) 594-3428

This guide is a culturally appropriate tobacco prevention, cessation and protection program for Aboriginal Peoples living in urban centres. The cultural component of the program will be developed using the knowledge and wisdom of Elders to rediscover the traditional sacred uses of tobacco in ceremonies, in spiritual communication and as a valuable gift to show appreciation and respect. The concept and approach used in the program is based on an analysis of the reasons why existing cessation and prevention programs have not been effective for urban Aboriginal Peoples.

Developed by: Louise Lahache

Date Developed: Program, 1995; Resource, 1997

Language: English; French

English/French Translation: Literal translation

Target: Aboriginal groups

Program Type: Community development; Group support

Program Approach: Community-based leadership model; Holistic

Resource Descriptors: Facilitator guide/manual

Additional Descriptors: Cultural awareness

Site: Community-at-large; Schools; Workplace

Duration: 6 - 12 weeks

Cost: To be determined

Availability/Locations: National

Evaluation: The participant-focused evaluation was conducted in March 1997. It was previously reviewed in June, 1996, also participant-focused through questionnaires and interviews. The results were very positive and the community members were very receptive to the cultural components of the program.

TeenNet: Using Information Technology to Engage Teens in Smoking Prevention and Cessation

Information Source: Department of Behavioural Science, University of Toronto Ms. Meg Morrison, Project Manager McMurrich Building Toronto, ON M5S 1A8 Tel: (416) 978-7543 Fax: (416) 978-2087 Meg.Morrison@uoft.ca

TeenNet will use a 'teens in action' approach and the INTERNET interactive technology to engage more teens in smoking prevention and cessation activities. This program is being designed for use in the classroom, in the home and in other community settings. TeenNet will be housed in a World Wide Web site that uses the metaphor of a 'teens only' island called CyberIsle. The CyberIsle Home Page will provide access to all components of the program as well as an electronic magazine composed by teens. The program will also include: interactive, multimedia information on smoking and related health issues using simulations and games; lifestyle assessment, individualized feedback and guided self-change strategies; and 'HotTalk' an ongoing peer-led discussion group and special topics forum using electronic networks. Members of the target group are involved in helping to design the concepts and presentation of this program. Anticipated completion date: March, 1997.

Developed by: Department of Behavioural Science - University of Toronto; Commit to a Healthier Brant Organization

Date Developed: Program, June 1995; Resource, February 1997

Language: English

Target: Adolescents; Young adults

Program Type: Community development; Group support; Mutual support; Self-help

Program Approach: Behaviour modification; Community-based leadership model; Holistic; Stagesof change

Resource Descriptors: Internet/Electronic magazine; Internet/Electronic peer-led discussion

Additional Descriptors: Body image; Facilitator training; Low literacy; Youth led/Assisted

Site: Community-at-large; Schools

Duration: Ongoing/drop-in sessions

Cost: Free; Internet

Availability/Locations: International

Evaluation: No evaluation to date; Notes: Internet: www.cyberisle.OG

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First Nations and Inuit Regional Health Surveys

Chapter 5

Activity Limitation and the Need for Continuing Care

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Activity Limitations and the Need for Continuing Care **TABLE OF CONTENTS Table of Figures** 139 List of Tables 139 Introduction 140 Adult Care and Disability Policy at the Federal level 144 Provincial barriers to continuing care services 146 Disparity, programs, and needs 147 Criticism of federal initiatives and programs 149 Measuring Functional Status, Resource Needs & disability 150 Prevalence of disability and adult care needs 151 Burden of Illness and its link to limitations 153 **Subjects and Methods** 156 **Participants** 156 Measures 156 Statistical Analysis 158 **Population at Risk** 159 159 Social demographics Health status 160 Limitations, Health Status, and Environment 164 Social demographics and limitations 164 Limitations and health status 164 General health 164 Chronic conditions 166 Limitations and Perceptions of health service delivery 177 **Discussion and Recommendations** 172 Discussion 172 174 **Recommendations** Measurement Issues 174 Health Service Needs 174 References 175

First Nations and Inuit Regional Health Surveys



139

TABLE OF FIGURES

Figure 1 -	Continuing Care System in Canada, 1995	141
Figure 2 -	Disability Rates, Comparing All Aboriginal Peoples	
	to the All-Canadian Population (Statistics Canada 1994)	152
Figure 3 -	Types of Functional Limitations experienced	
	by Aboriginal Peoples (Statistics Canada, 1994) %	152
Figure 4 -	Gender and living arrangements %	159
Figure 5 -	Living Arrangements by Age and Gender %	160
Figure 6 -	Diabetes, Arthritis, and Respiratory Co-morbidity %	162
Figure 7 -	Hearing Problems and Gender Differences, Controlling	
	for Age %	163
Figure 8 -	Proportion of People Reporting Limitations by Age $\%$	164
Figure 9 -	Limitations by age and gender %	165
Figure 10	Limitations by living arrangements and Gender %	165
Figure 11 -	Poor Health Status by Age, Comparing People with Activity Limitations and	
	People without Limitations %	166
$Figure \ 12 \ -$	Poor Health Status by Living Arrangements, Comparing People with	
	Activity Limitations and People without Limitations %	167
Figure 13 -	Chronic Condition Prevalence, Comparing People with Activity Limitations	
	and People without Limitations %	168
Figure 14 -	Chronic Condition Prevalence and Gender, Comparing People with	
	Activity Limitations and People without Limitations %	168
Figure 15 -	Hearing Problems and Age, Comparing People with Activity Limitations	
	and People without Limitations %	169
Figure 16 -	Hearing Problems and Poor Health Status, Comparing People	
	with Activity Limitations and People without Limitations %	169
Figure 17 -	Perception of Same Level of Health Services, Comparing People	
	with Activity Limitations and People without Limitations %	170
Figure 18 -	Health Service Areas in Need of Improvement, comparing	
	People with Activity Limitations and People without Limitations $~\%$	170
Figure 19 -	Lack of Progress in Areas Important For Community Wellness,	
	Comparing People with Activity Limitations and People without Limitations $\%$	171

LIST OF TABLES

Table 1 -	Housing Conditions and Health Problem	149
Table 2 -	Support Needs and Sources of Support	153
Table 3 -	Leading Cause of Short Disability, Santé Québec Survey %	154
Table 4 -	Leading Cause of Long Term Disability, Santé Québec Survey %	154
Table 5 -	Health Status by Age and Gender %	161
Table 6 -	Chronic Conditions by Age %	162
Table 7 -	Chronic Conditions by Age and Gender %	163
Table 8 -	Chronic Conditions and Age, Comparing People with Activity Limitations	
	and People Without Limitations %	169
Table 9 -	People With Activity Limitation By Complex Co-Morbidity and Gender %	169

First Nations and Inuit Regional Health Surveys

INTRODUCTION AND BACKGROUND

F irst Nations and the Inuit face a disproportionate number of serious health problems, and they are more likely than other Canadians to have a disability (Ng 1996). They are further disadvantaged because of geographic isolation and many reside in communities far from large urban centers, which provide continuing care services for people with a disability or a chronic condition (Ng et al. 1997). Although services provided by Medical Services Branch have resulted in many health improvements, health and social services for people with a disability or a chronic condition have not been forthcoming in a systematic or effective way because of intra-and inter-governmental jurisdiction problems. These problems are persistent even though a major objective of a publicly funded health care system is to provide comparable access to health services for everyone.

Health service delivery, in general, is a part of provincial/territorial programs, and it should be consistent with the Canada Health Act (1984) in that it should be accessible, comprehensive, portable, publicly administered and universal (Government of Canada 1984). Services available under this system include fee-for-service and salaried practitioners, hospital beds, and diagnostic facilities. These facilities are generally located in larger urban or rural centers. Continuing care services are provided at a provincial level, and these services vary from province to province. Two components of continuing care are that care is to continue over a long period of time and that it is an integrated program of care that continues across service components (Angus et al 1995). Continuing care services, in many ways, are an emerging system of the health sector, and as Hollender (1996) contends, in time, they will become a distinct, separate and major product line in the overall health care system.

The shape that continuing care will take for First Nation and Inuit people will be a major challenge, given the complexity of the continuing care system, which varies from one provincial jurisdiction to another. For instance, continuing care services are provided to the elderly, but also serve people of all ages, including people who are mentally and physically disabled, emotionally disturbed children (e.g. FAS/FES), people with alcohol/drug problems, street youth, homeless people, single mothers/fathers, and families in crisis (Angus et al 1995).

Community-based and residential care services are an integral part of this system. Community-based services include home care, which depending on the model, targets people with health and/or functional deficits in the home setting in order to foster independent living and to prevent health and functional breakdown and even institutionalization. This care can also be long term care for people who would otherwise require institutionalization or it can be acute care for people who would otherwise have to reside in acute care facilities. Figure 1 illustrates the core elements of the existing continuing care system in Canada as of 1995 (Angus et al 1995, Hollender 1996).

Continuing care is multi-faceted in that it combines aspects of health and social services into a system of service delivery (Angus et al 1995,



Figure 1: Continuing Care System in Canada 1995

Activity Limitations

Health and Welfare Canada 1992). The effectiveness of this system, however, largely depends on the variety of services available, the departments that deliver these services, and on the structural features of the service delivery system. Effectiveness also depends on the inter-and-intra-governmental jurisdictions involved in this system of service delivery.

For First Nation and Inuit communities, there are inter-and-intra-governmental jurisdictions, which complicate the provision of continuing care. Initially, the federal Department of Indian Affairs (DIAND) provided health services by employing part-time physicians as early as 1880 in recognition that a need for such services existed and were not being met from other sources (Department of National Health and Welfare, 1969). Health services, including health education, diagnosis, treatment, and rehabilitation, were transferred to the Department of National Health and Welfare in 1945. Indian Affairs restricted their activities to programs related to housing, education, social assistance, child welfare, policing, water, sanitation and other aspects of community health. These jurisdictions are not legislated. The Federal government interprets its provision of services and infrastructures to First Nation and Inuit people through a 1984 Memorandum of Understanding (MOU), which delineates responsibility between Medical Services Branch (MSB) of the Department of National Health and Welfare and the Department of Indian and Northern Development (DIAND). By way of this memorandum, all health programs are under the control of Medical Services Branch of Health Canada and most, if not all, social, education, economic and housing programs are under the jurisdiction of Indian Affairs.

Medical Services Branch (MSB) finances all community health services and environmental health and surveillance programs on-reserve, and in some areas, hospitals have been supported on a negotiated per diem by the provinces (Postl et al 1993). Community health services have ranged from disease and injury prevention, health promotion, health education, immunization, nutrition counseling, dental health, non-insured health benefits (e.g. drugs, eyeglasses, hearing aids, patient transportation), and emergency treatment where not otherwise available. MSB, for the longest time, coordinated the availability of health professionals to communities, ranging from community health representatives (CHRs) to specialist care. Community Health Representatives are front line health workers who work in the community full-time, and they have been mandated to provide disease and injury prevention programs, health promotion, health education, nutrition counseling, and interpretation. Community health nursing is also available in communities without primary care nursing stations. In communities that have nursing stations, nurses provide primary and emergency treatment, and the vast majority of on-site clinical services in northern and remote areas are provided by nurses, with physicians and specialists (psychologists, physiotherapists, etc.) providing services during scheduled visits. Larger communities have general physician services available on-site, but these communities are few. The environmental health and surveillance provided in communities involves environmental inspections, water sampling and contaminant testing. Isolated communities rely on air transport to support health services, and air ambulance support is available to these communities. Medical transportation is also available in non-isolated communities because of their distance from larger urban centers.

Federal transfer policy for First Nation and Inuit communities involves the transfer of control over these services, which adds another jurisdiction into a continuing care system of delivery. Health transfer first began in 1986, when Medical Services Branch announced the Indian Health Transfer Policy. The assumption of transfer is that community control over services will overcome some of the jurisdictional issues around health and social services.

In 1991, Medical Services Branch reviewed the health transfer process and found conflicting results. As a community development process, health transfer initiatives had helped communities establish and control health programs according to cultural, social and health needs. However, the transfer process was plagued with problems that further complicated health service delivery. Postl et al (1993) summarized some of the problems experienced. The transfer process occurred as the Federal government moved out of the administration of health and decreased its funding base for health programs. As government downsized, there was no "enrichment" policy, which meant that communities had little choice but to work within an existing but decreasing resource base. Another problem area was the lack of assurances given by the Federal government that it would not off load its fiduciary responsibility onto provincial governments. Communities had a reason to be concerned. In 1969, the federal government had considered the idea of transferring "Indian" health services to provincial governments, while maintaining programs to contend with unmet health needs. Provincial governments, however, rejected this idea, and many continue to exclude on-reserve First Nation peoples from health and social programs because they are considered a federal responsibility.

The transfer process, which began in 1986 as a pilot project, continues with little regard for the potential impact of disabilities and chronic conditions. The limited scope of health transfer is what mainly delimits any attention to this area. The health transfer process, at the outset, excluded noninsured health benefits (NIHB - MSB), social services (DIAND), and mental health services, which are critical services for people with a disability or chronic conditions. At this time, these services are under negotiation. However, the health transfer process overall may not adequately lead to the development of an effective continuing care system, which involves both aspects of health and social services. Because the potential impact of disabilities and chronic conditions on health transfer is unknown, there is no way to gauge whether the financial envelope will be adequate. There is also concern over past jurisdictional problems and their continuation. These problems create barriers to selfgovernment, equity, and quality of life for First Nation and Inuit peoples. These barriers are further obstacles that limit the life chances of people who require the services of a continuing care system.

Health information is critical to get a sense of the continuing care needs of First Nation and Inuit peoples and the impairments that influence their need for continuing care services. To date, there is no coherent or national database on the provision of continuing care services in Canada. British Columbia, which keeps data on the major elements of its continuing care sector, have reported that the elderly are the heaviest users but younger groups also make notable use of long term facilities and community-base programs. The first wave of the First Nation and Inuit Regional Health survey provides critical and timely information, although somewhat limited, on activity limitation problems and unmet needs, which fall in the community-based area of continuing care services.

This survey is the first step towards assessing community and residential needs, including needs for additional services, of First Nation peoples and the Inuit. This paper summarizes the data from this survey and provides a profile of activity limitations and service needs. The analysis describes the population at risk and characterizes people who have limitations and unmet needs. Age, gender, living arrangements, and self-perceived health status measures distinguish people within and across these groups.

A review of the literature provides a discussion of First Nation and Inuit disability service provision issues, as well as measurement issues critical to assessing limitations. National and regional studies are also reviewed (e.g. National Health and Activity Limitations Survey 1986, Aboriginal Peoples Survey 1991, Santé Québec Survey of the Inuit and Cree 1991-92, National Population Health Survey 1994-95). These surveys, although not exhaustively examined, provide a sense of what is known about the prevalence of activity limitations and service needs and the leading causes of disability. Literature on specific chronic conditions is also reviewed to identify the activity limitations and unmet needs associated with those conditions.

The overall intent of this paper is to provide First Nations and Inuit peoples with information that can help shape the development and assessment of an equitable and effective continuing care system.









Adult Care and Disability Policy at the Federal Level

T nitiatives improving accessibility and the participation of people with disabilities have been largely due to the successful lobbying by people with disabilities themselves (DeJong 1979; Driedger 1989; Enns 1981; French 1994). National and international governing bodies have advanced several initiatives. International strategies by the United Nations have focused on disability prevention, rehabilitation, and the equalization of opportunities (United Nations 1983). The Standard Rules on the Equalization of Opportunities for Persons with Disabilities emphasize the rights of persons with disabilities, freedom of choice, and equal opportunities (United Nations 1983). The rules underscore the importance of adapting the environment to the individual by focusing on their abilities, not disabilities.

In Canada, several attempts have been made to develop initiatives to improve accessibility and participation of people with disabilities. However, First Nation and Inuit peoples have not had equitable access to these initiatives. The Royal Commission on Aboriginal Peoples (1995) and other national bodies have succinctly described this history of inequity.

In 1981, the Special Parliamentary Committee on the Disabled and Handicapped released its report, Obstacles, which called for a change in policy affecting Canadians with disabilities (Fricke 1998). In this report, the committee concluded that Aboriginal people live in poverty and suffer from living conditions that greatly increase the probability of being disabled at some point in their lifetime (RCAP 1995). They urged all governments in Canada to develop programs for Aboriginal people with disabilities. They also called for an amendment of the Human Rights Act of Canada to protect all Canadians with disabilities from discrimination, specifically in employment, architecture, communication systems, public transportation, and public housing areas (Enns 1981). In April 1982, the Canadian Charter of Rights and Freedoms was expanded to include the rights of persons with disabilities. This legislation guaranteed equal benefits and protection under the law and prohibited discrimination based on physical or mental disability (Council of Canadians with Disabilities). Provisions for enforcement or implementation guidelines, however, were not provided.

Several initiatives followed the constitutional amendment with the intent of improving the quality of life of people with disabilities. Two national surveys, which will be discussed later, were conducted by Statistics Canada to estimate the prevalence of disability. The Health and Activity Limitation Survey (1986) targeted Canadians, including Aboriginal people. The Aboriginal Peoples Survey (1991) targeted all Aboriginal people and included several questions on limitations experienced by people with disabilities.

In 1986, the Department of Health and Welfare released its report Achieving Health for All: A Framework for Health Promotion (Epp 1986). This report had an expanded view of health. It identified health promotion as the means to enable all people, including people with disabilities, to increase control over, and to improve their health. In 1991, the Federal government announced its first national strategy that specifically targeted people with disabilities. The national strategy called for the integration of persons with disabilities into mainstream society. This strategy applied in a limited way to First Nation peoples and the Inuit (NWT). The national program funded to a maximum of \$158 million over five years had a long list of commendable objectives to achieve. Both Indian Affairs and Medical Services Branch contributed to development of this agreement. The Federal government interpreted this provision of services and infrastructure according to the 1984

Memorandum of Understanding (MOU).

Indian Affairs allocated \$5 million to improve coordination and accessibility and to promote sensitive design and delivery of existing social programs and services to people with disabilities living on-reserve (RCAP 1995). Health Canada responded by holding consultations to identify a number of issues regarding health care for elderly people and First Nation peoples with disabilities on-reserve, with the promise of action to come. Medical Services Branch allocated \$2 million over five years to retrofit existing health facilities, despite an estimate of \$7.5 million for a complete retrofit of health facilities. Other initiatives occurred, which incorporated people with disabilities into adult care services. As early as 1980, Indian Affairs established basic standards to be applied to adult care programs (DIAND 1982). However, these standards applied to basic auxiliary family services and essential home care programs. The Federal government interpreted any provision of adult care services through the 1984 Memorandum of Understanding. In Annex A of the standards document a definition of adult care was advanced:

Adult care comprises a range of health and social services for adults which have, as their goal, the maximization of individual self-sufficiency through the maintenance of individual functioning and, as necessary, through encouraging the disabled and elderly to receive care within the context of the family and community. These health and social services are designed to provide assessment, treatment, rehabilitation and supportive care as well as to prevent or minimize disability of adults suffering from chronic physical, development, or emotional impairments. These services are provided to individuals, their families and their communities in a variety of health and social care settings and management.

Annex A also listed the principal components of Adult Care and identified the responsibility of departments, Indian Affairs or Medical Services Branch, over funding and management. A qualifying statement was added which set limits on funding:

The list of components is not to be considered as either exhaustive or obligatory. The availability of these components will vary depending on the resources of the individual, the Band, and the responsible Department.

The adult care services provided by Indian Affairs included the Home Care and Personal Care Program and funding for personal care homes (some of which are jointly funded by the province). The management and administration of the Home Care and Personal Care Program fell under the "Social Services" area of Indian Affairs. This program provided homemaker services, which involved the following support services for daily living: 1) cleaning and cooking, 2) assistance with personal hygiene, 3) shopping and delivery of groceries or other goods, 4) cutting and hauling fire wood for Elders, and 5) hauling water where required. Excluded from the list were services that involved nursing care such as administration of medication or providing injections or other services requiring medical knowledge or skill. The Home Care and Personal Care Services were made available to the disabled, people with a chronic condition or who are ill, and the elderly. Access to these services could only be obtained by contacting the health office in the community or by referral from NNADAP (National Native Alcohol Drug and Addiction Program), Child Family Services, hospital, doctor, welfare and social services, or Chief and Council.

The state of these and other continuing care services have been a national concern for some time (Health and Welfare Canada 1992). In 1989, a joint working group, comprised of MSB and DIAND staff, initially gave its support for continuing care, only to conclude that there were significant gaps in the availability of community support programs in most areas of continuing care. In 1991, Medical Services Branch recommended that a complete system for continuing care services be set up, one that would include evaluation of clients' needs, case management, and an evaluation strategy. It was hoped that these programs would have a mandate and the resources needed to provide home care services (Health Canada - MSB, 1991). By 1993, provincial governments were reforming their health systems, and Medical Services Branch was concerned how reductions in hospital stays would create a demand for continuing care services (Health Canada - MSB 1993). They were concerned with: 1) the shift to out patient services; 2) increased waiting periods for surgery; 3) increased deinstitutionalization; 4) growth in non-insured health benefits; 5) increased demand for home nursing care; 6) the unavailability of some programs to First Nations; and 7) the lack of coordination between hospital personnel and service providers at the community level.

In August 1994, Indian Affairs and Medical Services Branch jointly funded (50-50 cost funding) an adult care needs and services assessment project in Manitoba for the elderly and disabled First Nation peoples. Medical Services Branch also received \$2.5 million to support a Home Care Nursing Program. The program, like others, could only meet service needs that fell under MSB jurisdiction. The Memorandum of Understanding was used to delineate MSB jurisdiction from Indian Affairs, as illustrated in a correspondence from W.D. Rutherford, Regional Nursing Officer (MSB) to Assembly of Manitoba Chiefs (January 11, 1995 reported in the First Nations of Manitoba - Adult Care Initiative 1997):

The funding must be used to develop a program that delivers "nursing care" and cannot be used for support of programs that are under the Indian Affairs mandate ... That is, homemakers services, attendant services and personal care are not considered to be programs to be funded from this resources base.

This program initiative illustrates the jurisdictional ambiguity in which a continuing care system operates. It also illustrates the problems of initiatives that are developed outside of First Nations and Inuit selfgoverning structures. For instance, a Joint Working Group (DIAND-MSB, 1997) developed a federal strategy for the delivery of continuing care to First Nations. Its objective was to improve access to, and the effectiveness of, home care programs to bring them into line with those delivered to the Canadian population. The working group projected that the demand for home nursing care would rise, due to the reduction in the number of hospital beds available, the shift to ambulatory care, and the early discharge of patients. The working group contended that the lack of harmonization in the availability of continuing care services offered by different departments had considerably hindered efforts to include the program in transfer, funding, and self-government agreements.

Such jurisdictional ambiguity continues, and it is a barrier to quality of care and the very essence of the Canada Health Act. The conclusion reached by a Special House of Commons committee in March 1993 still stands. There was no comprehensive plan of action then covering all Aboriginal peoples with disabilities or chronic conditions and no single agency had been charged with developing one (RCAP 1995). Today, fragmented efforts within the federal government and jurisdictional murkiness between federal and provincial/territorial governments continue to be the two main barriers to relieving unacceptable human suffering.

The federal government is now paying specific attention to a National Home Care Strategy for all Canadians in order to universalize access to these services (Wilkins and Park 1998). First Nations and the Inuit, however, require a national strategy formulated under Self-Government. Another Federal strategy that does not involve negotiations with First Nations and Inuit peoples, however, will complicate the development of an effective system. Provincial governments may also ignore such strategies because of federal fiduciary responsibilities. The position taken by provincial governments in delivering and financing of health and social services to First Nations people is an example of another barrier to an effective system of continuing care services.

Provincial Barriers to Continuing Care Services

high degree of fragmentation occurs when A provincial governments refuse to provide services because of jurisdictional issues. For purposes of illustration, the Manitoba approach is described here. The Manitoba Home Care program first emerged to contend with the poliomyelitis epidemics of 1952 and 1953 (Desmarais et al. 1956; Alcock et al. 1984), and expanded to cover other chronic conditions and disabilities. The Manitoba Home Care Program attempts to keep individuals with severe physical and mental health impairments in the community, especially when they do not require permanent institutionalization. It provides support and continuing care services to enable people with a disability or chronic conditions to remain in their home environment at a lower cost than institutionalization (Manitoba Health, 1992). Services provided range from nursing care (VON), orderly care for personal hygiene, homemaker services, respite care for family caregivers, meal on wheels, to rehabilitation services.

The intent of this program was to supplement family and community networks of care in that families have to continue providing care where possible. Although considered a model for other

provincial programs, it was not available to Manitoba First Nation communities because this government considered such care a federal responsibility. The 1996 policy on First Nation Government produced by the Manitoba Northern Affairs Secretariat, illustrates the division over responsibility and the inaccessibility caused when federal-provincial arrangements for providing health are not in place (First Nations of Manitoba 1997):

Under Section 91.24 of Canada's Constitution, only Parliament may exact laws in relation to First Nation peoples. Provincial legislatures have no power to enact legislation to implement special rights for First Nation people or special powers for First Nation governments (for example, child welfare on reserves)...

The rights of First Nation people under Treaties are constitutional rights. There are two types of Treaty rights. One is rights that First Nation people can exercise without government involvement, such as hunting and fishing. The second is other rights involving Crown promises to provide certain benefits, including reserves, schools and health care. Clearly it is the federal government that must fulfill these treaty promises...

Because only the federal government has special powers over the assets and affairs of First Nation people, only the federal government has the fiduciary obligations over these matters. To the extent that implementation for First Nation government will reduce these powers, it will change the relationship...

Manitoba will ensure that the shift of federal programs and services to First Nations does not result in further shifts of costs to the province, or pressure to fill funding gaps in services on reserves to meet provincial standards...

Statistics indicate that Status Indian use of health and social services is higher than that of the average Manitoban. The extraordinary costs of these services must be addressed in the federal-provincial arrangements for providing health...

Jurisdictional posturing does little to alleviate the burden of illness experienced by First Nations and the Inuit. Instead, it contributes to the disparity that already exists. Ambiguity in the provision and funding of continuing care services consequently avoids the future development of continuing care services and creates further disparity.

Disparity, Programs, and Needs

High levels of poverty experienced by First Nations and the Labrador Inuit have strongly influenced levels of certain chronic and acute conditions over time and have limited their life chances (Young 1994a, 1994b). The following discussion illustrates that programs currently available are not funded in accordance with levels of disparity or need, which is problematic given the high rates of disabilities and chronic conditions experienced by this population. As impairment advances, it can be hypothesized that more extensive use of services will be required such as rehabilitative services, assistive devices (helping aids), and barrier free and healthy environments (private dwellings and public buildings).

For instance, a rehabilitation team, in an ideal sense, is composed of physiotherapists, occupational therapists and speech language pathologists, working in conjunction with physicians, nurses, psychologists, social workers, dieticians and other health care providers as required. Together, they are to work with the client to pursue interventions that assist the individual's return to as active and independent lifestyle as possible. However, there is much disparity in how these resources are distribute. When rehabilitative services are available, they are limited in quantity and in the type of service offered. Eligibility for vocational rehabilitative services requires that individuals must leave their communities and establish a permanent residence where services are available. Similiar displacement is required for extensive rehabilitation after a stroke, limb amputation, or joint replacement. Individuals, requiring these services, are referred to urban settings, resulting in relocation away from the support provided by family, friends, and community. When they return, they must depend on the support of their family, friends, and nursing personnel who may have inadequate resources to provide support.

Continuing care services available through the Non-Insured Health Benefits Program (NIHB) provide supplementary health benefits to over 650,000 registered Indians, Inuit and Innu peoples to meet medical or dental needs which cannot be met by provincial services or other health plans. The purpose of this program theoretically is to provide benefits that are appropriate to "unique health needs" and to contribute to an overall health status that is comparable to the Canadian population. The program has to sustain a fiscal and benefit management perspective, yet facilitate First Nations and Inuit control at a time and pace of their choosing (Health Canada 1997). Under this program, assistive devices for people with disabilities and chronic conditions are made available to enhance independence. They may be used for functional activities, such as mobility or agility; pain management, such as resting splints for inflamed joints or prescription drugs; or prevention of further deterioration. Other items include eyeglasses and hearing aids, limb braces, wheel chairs, crutches, or augmentative communication devices. Historically, this program has been plagued by administrative inconsistencies, which resulted in the inconsistent availability of services (Waldram et al 1995).

To access specialist services that provide devices and other medically required services, many First Nation and Inuit people have to depend on the medical transportation system currently available under NIHB program. However, if a community has a fixed transportation budget and high service needs, some individuals may have to wait until their condition becomes so chronic that they have to be sent out resulting in a cost over run in the transportation budget and a more complicated condition to treat. Transportation funding is not the only barrier experienced. For some people, it can be a barrier if attendants (DIAND) are not provided or if the transportation system itself does not meet accessibility standards. For instance, public transportation to remote northern communities is often possible only by airplane. The accessibility guidelines for people with disabilities in the Air Transportation Regulations (Transportation Canada 1991; National Transportation Agency of Canada 1994) apply only to carriers with more than 30 seats. The aircraft generally used to provide scheduled service to many remote communities have less than 30 seats, which means that these transportation companies are not required to meet the same accessibility standards. Other transportation limitations can occur. In many communities, local governments or private companies that provide taxi service do not offer accessible transportation for medically required services as found in urban settings, such as wheelchair accessible vans.

Other problem areas involve environmental

barriers, such as housing or public buildings that prevent someone with a disability or chronic condition from using these environments to their full capacity. In most cases, Indian Affairs has jurisdiction over public infrastructures except for public health buildings, which fall under the jurisdiction of Medical Services Branch. Public buildings, in general, can vary in terms of their universal accessibility. Communities have been encouraged to consider access issues in the construction of any new public buildings by the federal government. Many buildings, however, remain accessible to only a selected portion of the population because funding is limited and there is no enforcement of accessibility regulations (Fricke 1998).

Housing conditions are another potential barrier, which is under the jurisdiction of Indian Affairs. Limited housing resources in First Nation and Inuit communities have been an ongoing concern and may contribute to high rates of disability and chronic conditions. In Table 1, some probable relationships between housing conditions and health are identified (adapted from the Canadian Medical Association 1994).

Overcrowding and safety issues are major concerns reported by First Nation peoples living onreserve (Statistics Canada 1994). Historically, household crowding had characterized the poverty of First Nations and the Inuit. It continues to be a major problem as the supply of housing fails to accommodate a fast growing population. Although the average Canadian home had 0.4 persons per room (Statistics Canada, 1994), overcrowding was twice the national rate for Inuit and on-reserve dwellings in 1991, with an average of 0.8 persons per room. While significant efforts have been made to rectify this situation, the demand for adequate housing is still high. Because of this demand, decision-makers are forced to consider the housing needs of not only the individual with impairments but of all community members. For instance, special housing for a disabled person in a wheelchair may conflict with community development priorities that are limited by funding. As a result, individuals with a disability have to rely upon the good will and intentions of their elected officials, as long as accessibility policies regarding adequate housing are not funded or enforced adequately.

The Home Care and Personal Care Program (DIAND) and the Home Care Nursing Program

(MSB) continue to be offered. Most First Nation communities provide housekeeping and home help services through their band or tribal councils, and trained medical staff will make home visits but often these visits are not a priority when there is a large clinical workload. Supplementary services are rarely available such as personal care services, meals on wheels programs, and volunteer services. Almost all regions have acknowledged major delays in case management, as well as problems regarding the evaluation of clients' needs. Current alternatives to institutional care, like residential homes for the elderly, adult day care, family home care, and integrated home and institutional care services, are not offered or are inaccessible to the vast majority of First Nations and the Inuit. In addition, existing funding levels are inadequate and generate further inequalities and much criticism.

Housing Conditions	Health Problems
Crowded Condition	Infections (e.g. Respiratory, skin, and eyes, tuberculosis, meningitis, measles) Injuries Mental Health Homicides and Domestic / Non-Domestic Violence
Inadequate housing stock (e.g. House in disrepair)	Injuries
Water Sewage Systems	Gastroenteritis, Skin infections
Indoor Air Quality (e.g. Wood stoves, High humidity levels and mold, cigarette smoke)	Respiratory symptoms (e.g. Asthma)
Cleanliness (Dust)	Respiratory (e.g. Asthma)
Structure: 1) Steps and Hand rails 2) Cupboard and closets 3) Washrooms 4) Exterior Doors 5) Interior Doors	Barriers for people with mobility, agility, sensory or physical disability
 Safety: 1) No electricity or appliances resulting candle, kerosene lamp, or camp stove use in the home 2) Faulty wiring 3) Faulty installation of wood stoves 4) No inspection or cleaning of chimneys in houses with wood stoves 	Fires

Table 1: Housing Conditions and Health problems

Criticism of Federal Initiatives and Programs

O verall, Federal initiatives and programs have not addressed the major problems experienced by First Nations and the Inuit. Inadequate programs continue to create frustration and to foster much criticism. The following reports provide a sense of the frustration experienced by First Nation people.

The Obstacles and the Follow - Up Report: Native Population (Special Committee on the Disabled and the Handicapped 1981 and 1982) first identified the major problems experienced by Aboriginal people in general. Completing the Circle (Standing Committee on Human Rights and the Status of Disabled Persons 1993) and The Path to Healing (Sinclair 1993) illustrated the continuing history of inequity, as did other reports. Each report consistently identified the major determinants to poor health 1) jurisdictional problems in health and social service delivery, 2) unemployment, 3) poverty, 4) social-geographic isolation, and 5) inadequate living conditions. They also addressed such issues as disability prevention, coordinated service delivery, accountability, and accessible/culturally sensitive health care. Similar issues were identified by the Council of Canadians with Disabilities (Demas - Native Consumers Speak Out 1987; Access to the Sweet Grass Trail 1993).

The Report on B.C. Aboriginal People with Disabilities (1993) also identified a need for equal recognition by all governments, including First Nations. This report also identified poor economic conditions, high unemployment, attitudinal barriers, and inaccessible, culturally inappropriate service delivery issues. They also identified inadequate living conditions, and emphasized as their first priority the need for affordable and appropriate housing. In the National Strategy for the Integration of Persons with Disabilities Report: National Consultation on Continuing Care Needs in First Nation Communities (Health Canada, 1994), continuing care services on-reserve were compared to their provincial off-reserve counterparts. Existing services on-reserve were criticized for under funding, and an overall lack of integrated programming. The discontinuity in care was magnified by an absence of formally trained personal care attendants, case coordinators, dedicated Home Care nursing staff, and standardized measurement tools to assess the support required.

In summary, these reports illustrate that program and special funding initiatives have not fully addressed poverty, inadequate housing, poor education, inadequate social support, mobility limitations, and fragmented health service delivery that were first identified in 1981.

Measuring Functional Status, Resource Needs & Disability

I deally, population based estimates should provide comprehensive measures that document activity limitations and resource needs by measures that differentiate impairment, disability, and handicap. These dimensions have evolved from initiatives to standardize the measurement of disability by the World Health Organization (WHO). In 1980, the WHO published the International Classification of Impairments, Disabilities and Handicaps, which added a functional component to the condition specific morbidity categories of the International Classification of Diseases (World Health Organization 1980).

Impairments represent mobility, sensory and intellectual "deficits" or abnormalities of psychological, physiological or anatomical structure or function. In much of the literature impairments are actually measured as consequences of specific diseases or less specific dysfunction or anomalies of organ systems. In the epidemiological and clinical literature, impairments are measured as observed signs of pathology, injury or congenital malformations (Verbrugge 1990). Disability is a measure of difficulty in performing an activity in a manner or within the range considered normal for human beings. The concept thus refers to the consequences that impairment or "health problems" present for a person doing activities at home or in a community environment. In this context, disability is disability experienced by the person as a whole (Verbrugge 1990). Handicap refers to disadvantages experienced by a given individual, resulting from an impairment or disability that limits or prevents the performance of a social role or that creates barriers in the physical or social environment. Social role performance is defined in terms of the age, gender, social and cultural context within which the individual functions.

These dimensions have been proposed as a mechanism for making distinctions between the physical, sensory measures of impairment, social role performance (reflected in activity limitations), and handicapping effects of physical and social barriers which become obstacles to participation in home and community environments (Wood 1987). These dimensions have undergone continuing re-examination at both the conceptual and operational level. There has been much discussion as to how activity limitations and the need for compensating resources has been approached in the published data on functional status and in the estimates of disability-related service needs of First Nations and the Labrador Inuit.

Measures of the prevalence of disability among Aboriginal peoples in Canada have applied some elements of this more comprehensive approach by including questions that document impairments or losses/deficits in physiological, psychological or anatomical losses or deficits in function or structure. In 1986, the National Health and Activity Limitation Survey (HALS) and the Aboriginal Peoples Survey (1991) included questions that documented morbidity associated with the incidence of specific chronic illnesses. Impairment related to specific chronic conditions has already been described in Young's et al (1998) report on chronic illness. Young's analysis of the Regional Health Survey data shows that individuals who report significant chronic illnesses include disproportional numbers of individuals who also report activity limitations.

Most surveys include questions that measure disability in terms of the effects of impairment on functional status. The HALS and APS also included questions that measured a selected inventory of activities of daily living and "instrumental activities" reflecting peoples functional independence at home and in the community. These surveys also included partial measures of handicap or disadvantage resulting from environmental, social, or psychological barriers limiting the function of persons with disabilities. Other questions included in the HALS and APS involved housing quality, mobility within the home and community, and transportation access, which all indirectly document barriers to functional performance.

Prevalence of Disability and Adult Care Needs

In 1986, the Canadian Health and Activity Limitation Survey (HALS) had estimated that 10% of First Nation peoples living on-reserve and 13% living off-reserve experienced some type of disability. The National Aboriginal Network on Disability (1990) criticized these findings as an underestimate of the true rate of disability among Canada's Aboriginal peoples. They outlined the following reasons for the underestimation: 1) the survey excluded Aboriginal peoples living in institutions; 2) some communities refused to participate in the survey; 3) survey questions were inconsistent with cultural interpretations of "disability;" and finally 4) the length and complexity of the research tool limited participation.

In 1991, the Aboriginal Peoples Survey (APS) was the first attempt at a national post census survey, which targeted persons in the 1991 Census who reported Aboriginal origins or registration under the Indian Act of Canada. From this population, individuals were randomly selected and interviewed. The overall response rate was 78.5% (Statistics Canada, 1993b). The survey included a number of questions on functional limitations. From this survey, it was estimated that nearly a third of all-Aboriginal peoples (31%) aged 15 years and older had a disability (Figure 2). This rate was more than double the national rate for that time period (Statistics Canada, 1994). For the age group 15 to 34, the disability rate was three times higher for all-Aboriginal peoples than for all-Canadians, 23% and 8% respectively. There was little difference between the Aboriginal groups. However, the disability rate of all-First Nations People living on-reserve (33%) and all-Inuit peoples (29%) was high.

According to the APS, mobility was the most common type of disability reported by Aboriginal peoples with disabilities (45%), which was comparative to all-Canadians (Figure 3). Agility was the second most commonly reported disability (35%), followed by hearing (35%), and seeing (24%)(Statistics Canada, 1994). Differences in the nature of disability also existed between Aboriginal groups. Mobility was the most common type of limitation reported by First Nations and Métis, followed by agility. In comparison, hearing impairments were the most frequently reported type of disability by the Inuit (44%), while ranking only third (35%) among First Nation Peoples (Statistics Canada 1994). These rates are almost double those reported by the rest of Canadians. The higher incidence of hearing loss among Aboriginal peoples had often been attributed to a higher incidence of repeated middle ear infections (otitis media), environmental factors such as increased noise exposure, and a lack of readily available health services in remote northern communities.

Nearly a quarter (24%) of Aboriginal peoples reporting a disability indicated that they used specialized technical aids or services (Statistics Canada, 1994). Technical aids were used for the management of visual impairments (74%), followed by mobility or agility impairments (33%), and hearing impairments (16%).

The proportion of individuals who reported a need for assistance in completing their activities of daily living are presented in Table 2 (Statistics Canada, 1994). Reported activities include personal care, light housekeeping, and meal preparation. These activities are normally included in the services provided by a provincial continuing care program. Of note is the high reliance on family members for assistance. The survey did not explore the impact, if any, that these dependency relationships had upon either the individual or on family members.

The need for assistance when travelling was also high. Almost 10% of people reported difficulty taking short trips, of which 29% were unable to leave their residence, and 13% needed a companion or attendant on short trips (Statistics Canada, 1994).

The Santé Québec Health Survey (Québecers 1987; Cree 1991; and Inuit 1992) assessed disability as short-and-long-term by leading cause. In this

survey, short-term disability was defined as generally affecting people who were usually in good health and involved younger age groups forced to reduce or curtail activities for a certain period of time. Long-term disability was defined as exerting a limiting affect on overall activities and hampered individuals mobility and capacity to function independently. This form of disability characterized the elderly population. Tables 3 and 4 illustrates the leading causes of short-and-long-term disability among the Inuit, the Cree and Québecers. Short-term disability for the Inuit and Cree is primarily associated with respiratory and other illnesses, whereas a larger proportion of short-term disability for Quebecers is associated with osteo-articular problems and accidents. Long-term disability for all groups is primarily associated with osteo-articular problems, but Cree and Quebecers have a larger proportion associated with circulatory disease.

Limitations have been associated with having at least one chronic condition in the Canadian population. In the National Population Health Survey (1994-95), the majority (75%) of people aged 55 and over who live in the community, as opposed to living in long-term health care institutions, reported that they have at least one chronic condition (Wilkins and Park 1996). Overall, about one in six people over 55 reported some physical limitations. Gender differences were apparent. One in six men and one in four women needed help with everyday activities such as housework or meal preparation. With advancing







Mobility: Limited in the ability to walk, move from room to room, carry an object for 10 meters, or stand for long periods.

Agility: Limited in the ability to bend, dress or undress oneself, get in and out of bed, cut toe-nails, use fingers to grasp or handle objects, reach or cut one's own food.

Seeing: Limited in the ability to see a printed page or to see someone from four meters, even when wearing corrective glasses.

Hearing: Limited in the ability to hear what is being said in a conversation with one or more people, even when wearing a hearing aid.

Speaking: Limited in the ability to be understood when talking.

Other: Limited because of a learning disability or because of a mental health condition.

Figure 3 - Types of Functional Limitations experienced by Aboriginal people with disabilities (Statistics Canada, 1994) %

age, it was found that the prevalence of most chronic conditions increased, as did the prevalence of physical problems and dependency. The conditions most strongly related to physical limitations and the need for help were epilepsy and the effects of stroke. In the 55 and older age group, arthritis/rheumatism, nonarthritic back problems and cataracts were all associated with physical limitations and dependency.

Successful prevention and postponement of functional disabilities depends on early diagnosis of illness and on identifying even minor signs and symptoms of disease and functional limitations (Laukkanen et al. 1997). As a result, there is a need to focus health care interventions accordingly. In general, functional status measures of the individual are not linked to the presence or absence of specific diseases and their

	Personal Care	Light house keeping	Meal preparation
% People needing Help	5 %	17 %	7 %
% People getting Help	91 %	88 %	95 %
% Receiving Help from their family	75 %	84 %	84 %
% Receiving Help from external sources (excluding help from friends & neighbors)	35%	25%	27%

Table 2: Support Needs and Sources of Support

diagnostic labels, which is critical to understand impairment and functional status (Young 1998). Although the relation between poverty and poor health is well established, there are also limited studies that link the cumulative impact of social-economic conditions to chronic conditions and functional limitations (Lynch et al. 1997).

Burden of Illness and its Link to Limitations

T he disparity in rates of injury, accidents, violence, self-destructive/suicidal behavior, and chronic illnesses all correspond with the disparity between First Nation/Inuit rates of disability and that of the Canadian population (RCAP 1995). The magnitude of illness experienced by First Nation and Inuit peoples has been well documented (Mao et al. 1986, Morrison et al. 1986, Young 1988, 1990, 1994a, 1994b, 1998, O'Neil 1995).

Although disease rates are higher than they are for Canadians, there are some noteworthy differences between Inuit and First Nation peoples (Bjerregaard and Young 1998). Circulatory diseases are more prevalent in the First Nation population than the Inuit population. The apparent low risk of heart disease (e.g., ischemia) in Inuit people is associated with their country food (fish and sea mammals) dietary habits, which includes fatty acids (high HDL and low LDL) that are heart healthy. Other diseases, such as respiratory conditions and diabetes, also distinguish First Nation peoples from the Inuit. The Inuit, historically, have had higher rates of respiratory morbidities (e.g., T.B. and chronic lung diseases) than First Nation people, but smoking has contributed to higher rates in both populations. However, First Nation people continue to have higher rates of diabetes and diabetes co-morbidity than the Inuit, but the rates for the Inuit are rising with the shift to low quality store bought foods.

First Nation and Inuit people also have higher hospital admission rates and increased morbidity patterns overall. For instance, hospitalization data for the provinces of Saskatchewan, Manitoba and British Columbia reveal that hospitalization rates are higher among on-reserve First Nation people for most causes than the provincial population, with the exception of neoplasms. In Manitoba, the age-standardized hospitalization rate for infectious diseases, circulatory diseases, respiratory diseases, and injuries were 6.3, 1.8, 3.0, and 3.3 times higher among First Nation people than other Manitoba residents (Young 1994b). They also tended to visit physicians more often for respiratory and endocrine-nutritional-metabolic diseases.

The evidence suggests that a number of specific chronic conditions have had a significant influence on the high disability rate amongst First Nation and Inuit peoples. Poverty and loss of culture have been driving the burden of illness experienced by Aboriginal peoples (Bjerragaard and Young 1998). Older people generally have more chronic health conditions such as diabetes (Type II), cardiovascular problems and arthritis (i.e., rheumatoid and/or osteo-arthritis). They

153

also report respiratory problems, but as a single morbidity, this problem is more prevalent in younger populations.

Diabetes, which is at epidemic levels in First Nation communities, is a major illness that causes medical complications and activity limitations due to disability (Young 1994a; also see Mueller et al. 1997). Kidney disease, heart and circulatory disease, blindness, amputations, nervous system disease, and birth defects among infants born to diabetic mothers are complications and disabilities experienced by diabetic First Nation peoples and to a less extent by Inuit peoples. The development of non-insulin diabetes is not a condition that only characterizes adults but occurs in adolescents and it can be a debilitating condition, which requires support to deal with the disease (Burroughs et al. 1997).

Activity limitations can also occur from a number of cardiovascular diseases. Shortness of breath (angina), leg pain (peripheral vascular disease), tiredness/weakness (murmurs), and dizziness/fainting (arrhythmias) can affect mobility in the home and force some individuals to be house bound or unable to travel long distance. Cardiovascular disease is also associated with sleep disturbances that limit activities of daily living (Newman et al. 1997).

Arthritis is another major health condition experienced by First Nation and Inuit peoples, and this disease results in lifelong disability from joint deterioration regardless of age resulting in the need for support around the home

Short-Term Disability	Population				
Leading Causes	Inuit	Cree	Québecers		
Respiratory	41	30	27		
Other	20	22	18		
Digestive	15	4	11		
Discomfort / Headache	7	13	7		
Osteo-articular	7	9	12		
Lesions / Accidents	6	8	10		
Skin infection	5	1	1		
Circulatory problems	1	3	6		
Sense-organ problems	-	10	3		
Pregnancy & Genitial Problems	-	1	2		
Mental Problems		-	3		

Table 3: - Leading Cause of Short-term Disability, Santé Québec Survey %

Long-term Disability Leading Causes	Population					
-	Inuit	Cree	Québecers			
Osteo-articular	36	25	27			
Discomfort / Headache	9	-	-			
Sense-organ Problems	9	1	3			
Digestive	4	2	2			
Circulatory	4	13	16			
Skin infection	4	-	-			
Metabolic & Endocrinal Disease	4	1	2			
Mental Problem	4	7	5			
Lesion / Accidents	Not Asked	10	11			
Respiratory	-	13	5			
Other	26	28	25			

Table 4 - Leading Cause of Long-term Disability, Santé Québec Survey %

or with personal care. Most cases of arthritis are osteo-arthritis, and prevalence rates do increase with age. It is the leading chronic condition in mid and late life, and women's rates exceed men's at all ages (Vergrugge 1995). Higher rates in later life for women are associated with menopause. It is the leading cause of disability and limitation in activities of daily

living, and its economic, psychological and social impact are enormous (Callahan et al. 1996). Women with this condition are more likely to report poor to fair health, as well as a physician diagnosis of angina, myocardial infarction, hypertension, diabetes, stroke, lung disease, and hearing and vision problems (Hochberg 1995). For all age groups and

155

across gender, arthritis and other musculoskeletal disorders are the leading chronic condition, resulting in long-term disability, restricted activity days, and high health care utilization (Bradley et al. 1994).

Respiratory conditions, such as chronic obstructive pulmonary diseases (COPD), can result in activity limitations (Miles-Tapping 1994). COPD is a group of diseases (emphysema, chronic bronchitis, bronchial asthma, cystic fibrosis and bronchiectasis) characterized by increased resistance to flow in the airways of the lungs, usually resulting in variable degrees of dyspena, rapid tiring, wheezing and cough productive of sputum. Decreased lung function can disturb night rest, limit home activity and stop people from going outdoors (especially during cold weather). It can restrict their ability to leave home, go on trips, personal care (feeding and dressing), or walking and talking due to shortness of breath. Such conditions are often associated with cardiovascular conditions (e.g. right heart failure), which create further impairment.

Co-morbidities can also increase the degree of functional limitations and the support required, especially in specific cultural groups characterized by low social-economic status (Haan and Weldon 1996). Diabetes and some cardiovascular conditions (hypertension and myocardial infarction heart disease) can result in blurred vision, which can affect functioning and wellbeing (Lee 1997). Difficulties escalate for people with arthritis when they have other concurrent conditions (Verbrugge et al. 1991). Arthritis and cardiovascular diseases are associated with functional limitations (Boult et al. 1994). When individuals have complex co-morbidity, the likelihood that they will require intensive support or will experience activity limitations (Brod 1998; Perkowski et al. 1998) or institutionalization may increase (Culler et al. 1998; Wolinsky 1997, 1998; Miller et al. 1996). For young people, the development of chronic conditions early results in restricted activity days and greater need of support, much like the experiences of childhood disability that have a profound impact on them, the education system, and the health care system (Newacheck and Halfon 1998).

People with mental health problems (e.g. depression) also have substantial and long-lasting functional limitations that are equal or exceed people with chronic medical illnesses (Hays et al. 1995). Hearing impairment is another type of disability. Along with excessive noise (Moffatt et al. 1994), otitis media has resulted in a lifelong hearing disability among First Nation and Inuit people (Duval et al. 1994). Otitis media is an acute or chronic inflammation of the middle ear due to an infection caused by a cold or flu and often results in premature hearing loss in children and life long hearing loss (Woods et al. 1994). This condition consequently requires the need of specialist care (audiologist and ear, nose and throat specialist) and of hearing aids early or later in life if medical and surgical management (tympanoplasty) is not successful.

Overall, the high prevalence of chronic morbidities are a cause for concern for First Nations and the Inuit, especially if the continuing care system and funding environment does not adequately meet their needs.









Subjects and Methods

Participants

The First Nations and Inuit Regional Health Survey was conducted in 1997 in nine regions of Canada: British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec (excluding James Bay Cree and Inuit), New Brunswick, Nova Scotia, and the Inuit communities of Labrador. Each region designed their own survey questions. In addition, a limited set of national core questions were replicated in each regional survey. The final sample population was 9870, of which 5782 were women and 4040 were men aged 15 and over. The sample was weighted to represent the national population of on-reserve people and Labrador Inuit. A population expansion weight, derived from the age and sex strata of each regional target population, was calculated to provide prevalence estimates for the national target population. The survey represents approximately 199,782 people, of whom 98,269 are women and 101,513 are men.

Measures

Activity limitation questions used in the First Nation and Inuit Regional Health Survey did not measure comprehensive functional status, differentiating impairment, disability and handicap. The questions also do not facilitate more specific determination of whether activity limitations reflect the direct effect of physical, sensory or developmental impairments. In addition, it is not possible to determine directly whether activity limitations reflect the presence of physical or mental impairments or the impact of "handicapping" factors in the social environment (e.g. caring responsibilities for children or elders limiting mobility and role performance). It is also not possible to determine whether they are the impact of physical environmental barriers (uneven terrain, inaccessible buildings) or the need for services or resources facilitating rehabilitation, mobility, and functional independence. The limitations in the range of functional indices and the lack of questions probing sensory impairment, means that data from the First Nations and Inuit Regional Health Survey cannot generate estimates of the incidence of all dimensions of disability. The analysis also cannot generate comparable estimates generated in major epidemiological studies of prevalence within defined populations.

The decision was made to include only a limited number of questions dealing with individual functional limitations and need for compensating services. The intent of these questions was to provide policy relevant indicators of unmet need. The strength of this approach is that it provides basic information on the impact of impairment on mobility and self-care capacity. It also provides information on the perceived needs for assistance for activities of daily living and mobility. In general, questions reflected community requirements for pragmatic measures of individual, community and regional estimates of the incidence of functional limitations influencing self-care and mobility. Questions asked also provided immediate measures of the need for compensating services, environmental adaptations and mobility assistance. Overall, data was required that had immediate relevance to ongoing initiatives, which require an estimate of a generalized need for services especially for negotiations around health transfer service agreements and for the estimation of home care.

Several questions were adopted from the Aboriginal Peoples Survey, which documented activity limitations and perceived need for compensating services. These questions probed whether in the home environment a person experienced limitations because of a long-term physical condition or health problem, which continued over a 6 months period. Need for compensating care for functional limitations to enhance performance of key self-care activities was measured by asking: Because of your condition or health problem, do you need help with your personal care, such as washing, grooming, dressing and feeding yourself? A follow-up question probed the extent to which a limited array of self-care functions were provided and asked if the individual needed more help. This question, however, was not included in the analysis because of the differences in way the question was administered in different regions.

Three questions addressed mobility limitations. One question probed mobility limitations over distances: Have difficulty leaving your residence to take short trips, that is trips to work, shopping, or any other local trips under 80km or 50 miles? Another question probed the extent to which individuals were unable to leave their homes: Consider yourself housebound, that is unable to leave your home? The third question asked whether people "Require an attendant or companion to accompany you on short trips." There was also a single question dealing with sensory impairment and asked: Do you have any difficulty hearing what is said when you are having a conversation with one other person? A more complete set of items documenting other sensory and intellectual impairments was not included in this survey.

A dichotomous "limitation" variable was created from the activity limitation and need for support questions. An index was created by summing the responses of the questions and then collapsed to identify people with limitations and people with no limitations. The sensory impairment question was not included in this calculation because it represents a limitation that is uniquely attributable to a medical device intervention, which needed to be assessed independently. To characterize the population experiencing limitations and the population at risk, several measures were derived: age, living arrangements, self-reported health status, and chronic condition measures.

Age was grouped according to time frames along a life cycle, which also represent the cumulative history of life experiences and morbidity development (Arber and Ginn 1993). The age group 15 to 29 years of age represents a group that is less likely to experience chronic conditions and should be largely free of limitations, with the following exceptions. Some young people have a disabling condition from birth. Some develop a condition early, or may have an injury disability. The experience of poverty may not be as great in this group, but for some it may be more apparent. The age group '30 and 54 years' is a period when chronic conditions and co-morbidity appear early, resulting in a need for support or restricted activities. The greatest need for adult care and the most activity limitations generally occur in the 55 years and older group (Wilkins and Park, 1996). It is a period in which the cumulative history of living in poverty manifests itself as complex co-morbidity.

Education (less than high school and high school +) was used in a descriptive way. It is intricately tied to age (Young et al. 1998). It also reflects the socialeconomic mobility of people. People with low education, especially in the middle and older age groups, are far more likely to have experienced poor social-economic status for most of their lives and are more likely to continue experiencing poor social-economic status. As a consequence, this variable was used to reflect the extent of poverty experienced by First Nations and the Labrador Inuit. Since the age and education variables were intricately intertwined however, age was used for more in depth analysis.

If living arrangements play a major role, one would expect to find that people who live with a partner would have lower morbidity and activity limitations/need for support than people who would live alone (Joung et al. 1994). This measure is a proxy measure of the social support in the household. It is also a measure of the stress in a household if the household is dependent upon limited resources, is overcrowded, or the house itself is in need of repair. These measures illustrate the persistent link between poor social-economic position and physical demands to which persons of lower social-economic position are explosed (Kaplan et al. 1986). However, no information was collected at the level of the individual on these dimensions and the community level data on crowding and housing stock may not adequately reflect all the dimensions of these potential stresses. The living arrangement measure was derived from the marital status of respondents and whether children under eighteen were living in the house. The dimensions of this variable covered single people without children, single people with children residing in the household, respondents with a partner and no children living at home, and respondents with a partner and children residing in the household. Although this variable has potential as a proxy measure of social support, caution has to be exercised in its interpretation as support. The survey only asked questions on the respondent's marital status and whether children under the age of 18 years were currently residing in the household. This variable, consequently, does not include other adults living in the house or their relationship to the respondent. The interpretation of this variable in relation to the support or stress that living arrangements can create is therefore limited to a nuclear family composition opposed to an extended family system. The extended family system, which characterizes many First Nation and Labrador Inuit communities, may reflect support available but a shortage of housing often results in extended family members residing in family member's homes which may contribute to further stress in the household.

An overall measure of health conditions was constructed to distinguish people with no chronic conditions from people with at least one chronic condition. Several co-morbidity variables were constructed. A diabetes co-morbidity variable was derived to identify people with only diabetes, people with diabetes and high blood pressure, people with diabetes and heart problems and people with diabetes, high blood pressure, and heart problems. A comorbidity variable for arthritis was also constructed. It identified people with arthritis only, arthritis and cardiovascular problems, and arthritis, diabetes and a cardiovascular condition. A respiratory co-morbidity variable was constructed. It identified people with respiratory conditions only, respiratory and cardiovascular conditions, and respiratory, cardiovascular and arthritis conditions. Another measure of health was self-perceived health status, and it identified people with poor to fair health and very good to excellent health.

In the analysis, several ecological variables were used, and they identified respondents who shared a particular group characteristic. The variable "isolation from health services" and the variable "health transfer status" describe shared group characteristics, and they were derived from Medical Services Branch community level data. The measure "isolation" describes if people come from a community isolated from health services or not isolated from health services. The "health transfer measure" represents individuals who live in communities that have entered pre-transfer agreements, signed health transfer agreements, or have not entered into health transfer negotiations. These ecological characteristics were attached to each individual in the First Nation and Inuit Regional Health Survey through their community of residence. Previous studies have used similar types of ecological measures, and consider them valid measures of group characteristic that can be associated with various outcomes (Haan et al. 1986; Dougherty et al. 1990; Krieger 1992; Kaplan 1996; Kaplan et al. 1996). These measures are sometimes used as proxy measure when individual measures are not available.

Other proxy measures were used to describe the level of disadvantage experienced at the community level. Infrastructure measures, such as housing adequacy, crowding, and adequacy of water and sewer services are associated with poverty experienced by First Nations and the Labrador Inuit. Similar measures have been used in recent population health studies that have examined the social-economic determinants of health (Kaplan 1996, Kaplan et al. 1996, and Krieger 1992). For descriptive purposes, these ecological measures and others characterize disadvantages in the social environment. They are population size, crowded housing (<4 people or 4 or more people), housing stock (less than 50% are inadequate or 50% plus are inadequate), water and sewer services (adequate or inadequate), and road access (yes or no).

Statistical Analysis

T he analysis first describes the population at risk. A more in depth analysis compares individuals who experience some support and activity limitations with individuals who do not experience activity limitations. Health status differences are analyzed within and between the two groups, controlling for social-demographic characteristics. Ecological variables and perception of health services are also compared.

Data analysis was descriptive (percentages) and involved chi-square tests of significance. Significance was reported at 0.05 and 0.001 levels of probability. Caution must be exercised in the interpretation of significance. For instance, small differences in large samples can be very important but not significant or small differences may be significant, but not informative (Grosof and Sardy 1985).









159

Population at Risk

he survey describes a population of 199,782 First Nation and Inuit adults (15 and over) who may be at risk for developing a need for support or an activity limitation. Poor socialeconomic environment is associated with the increased risk of developing limitations. In First Nation and Inuit communities, previous surveys confirm that social-economic conditions are poor (APS 1991). Low education attainment reflects the potential of poverty persisting. Of First Nations and Inuit people, nearly 80% had not attained a high school education.

Most First Nation and Inuit adults (66%) live in small communities (<1000 people). Although 78% live in communities that have year around road access, 33% live in communities isolated from health services. A large number of people (67%) live in non-isolated communities located in rural areas that are some distance from large urban centers. Overall, 74% of people reside in communities where there is no special purpose housing facilities designed to provide for physical, social and emotional conditions, or disability. Approximately 55% live in communities where 50% of the houses are inadequate. A large number of people (70%) live in



Figure 4: Gender and Living Arrangements %

communities where overcrowding is persistent in that on average four or more people live in a household. However, 80% of people live in communities that have adequate water and sewer systems.

Social Demographics

F orty-nine percent of the population are women and 51% are men. Forty-two percent of adults were 15 and 29 years, 44% were 30 and 54 years, and 14% were 55 years or older. A little over half (54%) stated that they

have a partner while 46% are single, divorced or widowed, with few differences by gender.

Forty-three percent indicated that they have a partner and children under eighteen living at home, 12% have a partner and no children at home, 20% are single and have children under eighteen living at home, and 25% are single and have no children living at home. More women (65%) reported that they were single parents with children living at home, whereas more men (66%) indicated that they are single without children (Figure 4). Of

those that have a partner, slightly more women (53%) stated that they have children at home, whereas more men (56%) have no children living at home. Most women, aged 15-29 years, were either single (33%) or in a partnership with children living at home (44%) (Figure 5). Most men in this age group were single with no children (43%) or had a partner and children at home (30%). Most women aged 30-54 years were either single with children at home (25%) or had a partner and children at home (57%). Most men in this age group were single without children (22%) or had a partner and children at home (54%). Most women, aged 55 years and older, were more often single with no children at home (40%) or with a partner and no children at home (33%). Older men were living more often with partners (40%) than single (32%).

Health Status

early half of all First Nations and Labrador Inuit people (48%) reported that they have poor to fair health, and 46% reported that they had been told by a health care professional that they have at least one health problem. Health status decreased with age. The majority of people aged 15-29 years reported very good to excellent health (62%). Only half of the people aged 30-54 years reported very good to excellent health and 73% of people aged 55 years and older reported poor to fair health. The same was true for health problems. More younger people reported no health problems (72%), while the



Figure 5: Living Arrangements by Age and Gender %

majority of the oldest group reported having at least one health problem (84%). In general, men (55%) reported very good to excellent health and no health problems (60%), while half of all women reported having at least one health problem (52%) and poor to fair health (52%). Younger men reported better health than did younger women (Table 5). There were little differences between men and women in terms of selfperceived health status in the middle aged group. However, slightly more women reported having at least one health problem. In the 55 years and older group, a larger number of both women and men had reported poor health status, but again more women ranked their health as poor and reported a greater burden of disease than did men.

The prevalence of specific chronic conditions are: diabetes (11%); respiratory problems (i.e., breathing problems or asthma) (14%); muscular skeletal condition (arthritis) (16%); and cardiovascular problems (high blood pressure or heart problems) (23%). A number of people who reported diabetes, arthritis, or respiratory problems also reported having another chronic condition.

Of people reporting diabetes (Figure 6), 44% indicated that they had diabetes only, 31% also have high blood pressure, 8% also have heart problems, and 17% also have high blood pressure and heart problems. Of people reporting arthritis, 47% have arthritis only, 35% also have cardiovascular problems, and 18% also have diabetes and a cardiovascular problem. Of people reporting a respiratory problem, 52% have a respiratory problem only, 21% also have a cardiovascular problem, and over a quarter (27%) also have arthritis and a cardiovascular problem.

In Table 6, although fewer young people reported a chronic disease problem, the level of morbidity is relatively high and illustrates the potential of comorbidity and activity limitations in the future. Morbidity and comorbidity increased significantly with age.

There were some differences between men and women. Younger women reported higher rates of respiratory, cardiovascular, and arthritis problems, whereas younger men reported higher rates of diabetes. Morbidity increased for both men and women in the middle-aged and older age group, with a general trend towards higher levels of morbidity and comorbidity among women.

Hearing impairments were also high. Fifteen percent of all First Nations and Inuit people have difficulty hearing a conversation. Hearing problems increased for both men and women as they got older (Figure 7). Approximately 20% of people with hearing problems reported poor health status.

Health Status	15 - Male	29 Years Female	30 - 5 Male	4 Years Female	55 an Male	d Over Female
Very Good - Excellant	67	57	51	49	31	24
Poor - Fair	33	43	49	51	69	76
No Chronic Conditions	77	66	56	44	20	13
At Least One Chronic Condition	24	34	44	56	80	87

Table F. Haakk	Ctatura	her Anna		Canalan 0/
Table 5 : Health	Status	by Age	ana	Gender %



Figure 6: Diabetes, Arthritis and Respiratory Co-morbidity %

Table 6 : Chr	onic Conditior	is by Age %
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Chronic Conditions	15 - 29 Years	30 - 54 Years	55 and ove
Arthritis	5	18	48
Respiratory	21	14	30
Cardiovascular	11	24	59
Diabetes	4	12	30
Diabetes Only and Co-Morbidity	15 - 29 Years	30 - 54 Years	55 and Ove
Diabetes Only	3	6	8
Diabetes & High Blood Pressure	1	4	10
Diabetes & Heart Problems	-	1	3
Diabetes, High Blood Pressure & Heart	-	1	9
Arthritis Only & Co-Morbidity	15 - 29 Years	30 - 54 Years	55 and Ove
Arthritis Only	3	10	13
Arthritis & Cardiovascular	2	5	19
Arthritis, Diabetes, Cardiovascular	-	3	16
Respiratory Only & Co-Morbidity	15 - 29 Years	30 - 54 Years	55 and Ove
Respiratory Only	8	7	8
Respiratory & Cardiovascular Problems	4	4	8
Respiratory & Cardiovascular	-	3	14

Chronic Conditions	15	20 Voars	20	54 Voars	55 0	ad over
Chrome Conditions	Male	Female	Male	Female	Male	Female
Arthritis	3	7	14	21	43	54
Respiratory	9	14	12	17	27	32
Cardiovascular	8	13	24	23	57	60
Diabetes	5	2	10	14	24	35
Diabetes Only and Co-Morbidity	15 - 2	9 Years	30 -	54 Years	55 ar	nd Over
Diabetes Only	3	1	4	8	7	10
Diabetes & High Blood Pressure	2	1	4	4	6	13
Diabetes & Heart Problems	-	-	1	1	3	3
Diabetes, High Blood Pressure & Heart	-	-	1	1	8	9
Arthritis Only & Co-Morbidity	15 - 2	9 Years	30 -	54 Years	. 55 ar	nd Over
Arthritis Only	2	4	8	13	12	14
Arthritis & Cardiovascular	1	3	4	5	18	20
Arthritis, Diabetes, Cardiovascular	-	-	2	3	13	20
Respiratory Only & Co-Morbidity	15 - 2	9 Years	30 -	54 Years	. 55 ar	nd Over
Respiratory Only	6	11	6	10	7	8
Respiratory & Cardiovascular Problems	3	3	3	4	7	9
Respiratory & Cardiovascular Problems & Arthritis	-	-	3	3	13	15

Table 7: Chronic Conditions by Age and Gender %



Figure 7: Hearing Problems and Gender Differences, Controlling for Age %









Limitations, Health Status, and Environment

Social Demographics and Limitations

M ost First Nation and Inuit people (85%) reported that they did not require help with personal care or require an attendant for short trips. In addition, they were not house bound and did not have difficulties going on short trips. Nevertheless, 15% experienced at least one limitation (activity or support). This experience increased for older people (Figure 8).

Few gender differences were apparent (Figure 9). Older men and women reported similar activity limitations, whereas slightly more women than men reported limitations in the younger and middle-aged groups.

A ctivity limitations experienced by men and women in different living arrangements revealed some interesting differences (Figure 10). Single women with no children reported the most limitations, followed by women with a partner and no children living at home. Only Men with a partner and no children at home reported a similar level of limitations.



Figure 8 : Proportion of People Reporting Limitations by Age %

Limitation and Health Status

General Health

O f people who experienced no limitations, 41% reported that they had a health problem diagnosed by a health professional, and a similar proportion (45%) reported poor to fair health. People with an activity limitation reported much poorer health. Nearly three-quarters (74%) had a health problem, and a

similar proportion (75%) reported poor to fair health. The vast majority (84%) who had a health problem also reported poor to fair Women health. reporting limitations had poorer health status women reporting than no limitations. The same was true for men. Women also reported slightly poorer health status than did men who reported activity limitations. Health status also decreased with age in both groups, which perhaps indicates not only the impact of disease, but the experience of

164



Figure 9: Limitations by Age and Gender %



Figure 10: Limitations by Living arrangements and Gender %

poverty over a lifetime (Figure 11).

"Having a partner and/or children at home" suggests that some form of support is available within the household and that support may improve health status. However, people with limitations, regardless of living arrangements, continued to report poor health status (Figure 12).

Chronic Conditions

lthough the First Nation A and Inuit Regional Health Survey did not directly link impairment with functional limitations, a profile of people who report activity limitations and specific chronic conditions can be reported (Figure 13). People reporting activity limitations reported a much higher burden of cardiovascular disease (47%), arthritis (45%), respiratory problems (31%), and diabetes (27%). Women with activity limitations reported slightly higher prevalence of arthritis, respiratory illness, and diabetes than did men with limitations (Figure 14).

Age differences were apparent (Table 8). People, aged 15-29 years, who reported activity limitations reported a higher proportion of cardiovascular, arthritis, respiratory and diabetes conditions than did people without limitations. People aged 55 and older who reported activity limitations had a higher burden of disease than did people without limitations.

People with more complex comorbidity reported more activity limitations, and this was especially





Figure 11: Poor Health Status by Age, Comparing People with Activity Limitation and People without Limitations %

true for men (Table 9). In general, men who reported complex comorbidity were unable to leave home or had difficulty leaving home to go on short trips. They also needed help with personal care. Women who reported complex co-morbidity were more likely to need help on short trips.

People who reported activity limitations (36%) also had more

hearing problems, and men (38%) did so more than women (35%). Age differences were apparent (Figure 15). People, aged 55 years and older, who reported activity limitations had more hearing problems (57%). However, a large number of people under 55 had hearing problems as well. People who reported activity limitations and hearing problems (Figure 16)

also reported poor health status (40%).

Limitations and Perceptions of Health Service Delivery

Over a third of people with activity limitations reside in communities that have already signed health transfer agreements (34%) or live in communities that are in health transfer negotiations (39%). Twenty-seven percent reside in communities that have not entered in to health transfer negotiations.

Geographic proximity to health care services for people with limitations will be a major health care challenge facing First Nations and the Labrador Inuit. Thirty percent of people who experience limitations live in isolated communities, and 13% reside in communities that have no year round road access. Nonisolated communities may also experience problems providing accessible medical transportation for a growing number of people who have complex co-morbidity and activity limitations.

A vast majority of First Nation and Labrador Inuit people had stated that they do not have the same level of health services as the rest of Canadians. There are some differences in perception between people with activity limitations and people with no limitations on the availability of health services (Figure 17). Only 29% of people with activity limitations, compared to 35% of people with no limitations, agreed that they have the same level of health services.





Figure 12 : Poor Health Status by Living Arrangements, Comparing People with Activity Limitations and People without Limitations %

Partner and

children

Single with

no children

There are many health service areas in need of improving according to First Nation and Labrador Inuit people (Figure 18). Again, there were significant differences between people with activity limitations and people with no limitations. The differences were greatest for continuing care services. The group reporting limitations identified senior homes, home care

Single with

children

Significant at P = 0.001

40

30

20

10

0

services, medication awareness programs, chronic care facilities, kidney dialysis services and translation services as the areas in need of greatest improvement.

Partner and

no children

More people with limitations (81%) favored a return to traditional ways in order to promote community wellness than did people without activity limitations (79%). There were also



Figure 13: Chronic Condition Prevalence, Comparing People with Activity Limitations and People without Limitations %



Figure 14 : Chronic Condition Prevalence and Gender, Comparing People with Activity Limitations and People without Limitations %

differences in the perception of progress made in factors important for community wellness (Figure 19). People with activity limitations were generally less optimistic, regardless of area: infrastructure development (housing, water, sewer), socio-economic opportunities (education and employment), traditionality (language use, land use, healing, networking, and traditional ways), and selfgovernment developments (First Nations/Inuit health professionals, training in health field, cultural awareness programs, reduction in alcohol/drug use).

	15-29	Years	30 - 54	Years	55 and	Over
Chronic Condition	Not Limited	Limited	Not Limited	Limited	Not Limited	Limited
Cardiovascular	10	15	21	39	50	74
Arthritis	4	18	14	39	38	68
Resipiratory	11	19	12	30	23	42
Diabetes	3	11	11	21	22	44

Table 8: Chronic Condition and Age, Comparing People with Activity Limitations and People without Limitations %

Complex Morbidity	Home Activity Limited by a Health Problem		Unable to Leave Home		Diffficulty leaving home on short trips		Need help on short trips		Need help with personal care	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Diabetes & Cardiovascular	44	42	21	17	31	28	29	32	19	20
Arthritis, Diabetes & Cardiovascular	58	60	32	21	44	39	44	43	34	29
Respiratory, Cardiovascular & Arthritis	52	50	24	17	34	37	37	43	32	27

Table 9: People with Activity Limitations by Complex Co-Morbidity and Gender %



Figure 15: Hearing Problems and Age, Comparing People with Activity Limitations and People without Limitations %



Figure 16: Hearing Problems and Poor Health Status, Comparing People with Activity Limitations and People without Limitations %



Figure 17 :

Perception of Same Level of Health Services, Comparing People with Activity Limitations and People without Limitations %



Figure 18 :

Health Services Areas in Need of Improvement, Comparing People with Activity Limitations and People without Limitations %

First Nations and Inuit Regional Health Surveys



Figure 19 : Lack of Progress in Areas Important for Community Wellness, Comparing People with Activity Limitations and People without Limitations %

First Nations and Inuit Regional Health Surveys

171









Discussion and Recommendations

Discussion

The First Nations and Labrador Inuit Regional Health Survey clearly suggests that First Nations and Labrador Inuit people are at high risk of developing activity limitations and a need for support. Morbidity rates for cardiovascular conditions, arthritis, respiratory conditions, and diabetes are high. A substantial number of people who report diabetes, arthritis, or respiratory problems have also reported that they have another chronic condition. Complex comorbidity such as arthritis, diabetes, and cardiovascular problems are particularly high. People 55 years and older have the most complex comorbidity, but a good proportion of people who are middle-aged also report co-morbidity. Younger people are also reporting co-morbidity, particularly diabetes and high blood pressure and respiratory and cardiovascular problems. Together these findings indicate that disabilities associated with chronic illness are going to become major concern as the First Nation and Inuit population age.

People with current activity limitations represent a particular group in First Nation and Labrador Inuit communities. The data suggests that people who are middle-aged or older experience activity limitations, but a large proportion of young people also reported limitations. Few gender differences were apparent. Although the family is the first line of support in a continuing care system, the living arrangements of First Nations and Labrador Inuit people suggest that people, regardless of age, may not have the necessary support in the household. For instance, single women who have no children living at home reported the most activity limitations. Although the survey did not directly link impairment with functional limitations, a distinct profile of people with and without activity limitations emerged. People with limitations reported higher morbidity, regardless of gender. Younger people reporting activity limitations had a higher burden of disease than did younger people without limitations. The burden of disease was higher for the older age group reporting activity limitations. People with complex co-morbidity reported more activity limitations.

Disability and disabling co-morbidity will place a disproportionately large burden on the heath care system. For instance, the burden of diabetes and associated complications is large and will increase, as the population grows older. Effective primary, secondary, and tertiary prevention strategies are needed on top of the programs already in place. Programs are needed that prevent blindness, lowerextremity amputations, cardiovascular disease, and adverse outcomes of pregnancy among persons with diabetes. Young people who develop this condition early will experience activity limitations, which may impact both the education system and the health care system. Older adults are reporting very high rates of diabetes co-morbidities and the functional limitations associated with complex co-morbidities. The same applies for people experiencing respiratory co-morbidity and arthritis co-morbidity. Early development of complex co-morbidity, high rates of morbidity in middle-aged and older people, and a relatively high prevalence of chronic conditions in younger people are a cause for concern.

The data indicate that people perceive improvements are necessary. People with activity limitations were more likely to recognize that they did not have the same level of health services as other Canadians. They were also more inclined to see a

greater need for improving access to senior residential homes, medication awareness programs, chronic care facilities, kidney dialysis services, and translation services. They were also less optimistic than other people in terms of the progress made in factors important for community wellness.

These findings have important implications for the development of a continuing care system for First Nations people on-reserve and the Inuit. Barriers to continuing care services are due to jurisdictional problems between federal departments, between provincial governments and the federal government, and between provincial governments and First Nation and Inuit governments. Isolation and non-isolation from health services will complicate the development of this system. People with activity limitations living in isolated regions may have to travel great distances to access continuing care services. The demand for home care and other continuing care services will increase due to the reduction in the number of hospital beds available, the shift of ambulatory care, and the early discharge of patients. The demand will also increase with the escalating burden of chronic illness.

The data points to an escalating burden of chronic illness related disabilities and activity limitations. Since current programs are inadequate to current needs, planning for future needs is urgently required. The down-stream costs of not providing adequate home care and continuing care services will be huge. Needless to say, the deterioration in the quality of life of people with disabilities and activity limitations will also be enormous.
Recommendations

Measurement Issues

- Future surveys should adopt more comprehensive and internationally recognized measures of disability, handicap, and impairment and rethink these measures to reflect the cultural-social-geographic-health-and-economic context of First Nations and the Inuit.
- Include functional and activity limitations questions using item formats comparable to those used in the Aboriginal Peoples, HALS, and National Population Health Surveys to facilitate comparative analysis with other populations.

Health Service Needs

- Continuing care services need to be effective and integrated, and provide health care that is in accordance with the Canada Health Act.
- Resolution of jurisdictional problems related to continuing care services must be achieved with active First Nations and Inuit participation.
- Development of on-reserve/community home care services is urgently required to meet the expanding burden of chronic illness and disability-related activity limitations.
- Training programs for home care services must be developed, which provide in-depth training in how to effectively provide care to people with chronic illness and disability-related activity limitations in particular social-cultural-and-geographic contexts.
- Failure to develop these services and programs will result in rapidly escalating health service costs at a tertiary level as First Nations and Inuit people with disabilities and chronic conditions are either hospitalized or relocated to urban centers.
- Provincial and regional health authorities must recognize the downstream costs associated with poor home care and continuing care services and must advocate on behalf of First Nations and Inuit communities for improvements in these services.
- First Nations and Inuit leadership must continue to press for changes in funding formulas for non-insured health benefits and community services, particularly in transferred communities. Without substantial increases in funding, First Nations and Inuit people with chronic illnesses and disabilities will suffer increasing limitations in their daily activities.

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Chapter 6

THE SEARCH FOR WELLNESS

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Published by the First Nations and Inuit Regional Health Survey National Steering Committee



"The wellness of our people, including their social, economic and spiritual well-being, crosses the boundaries of the separate terms [of reference of the Royal Commission]. Wellness is a community issue, a national issue, a women's issue. It touches youth concerns, family considerations, even self-government and historical concerns. I firmly believe that no other [issue] so fundamentally relates to the survival of our people as that of health."

Tom Iron, Fourth Vice-Chief, Federation of Saskatchewan Indian Nations Wahpeton, Saskatchewan, 26 May 1992 Government of Canada (1996) Royal Commission on Aboriginal People - Final Report volume 3, Chapter 3. Ottawa, Canada: Minister of Supply and Services.

"We are different. We have a different perspective on life and all creation. We have many wonderful things to share. We have different and wonderful teachings to share that are simple to live by, reasonable, sensible, for the good of all within the community, full of respect. These have remained a mystery to mankind until now."

Government of Canada (1996) Royal Commission on Aboriginal People - Final Report volume 4. Ottawa, Canada: Minister of Supply and Services. Page 2

"Five hundred years ago Europeans arrived on the American continent but did not listen. They did not understand the land and the people they sought to conquer. Today, in the light of so much that has taken place in world history, we (the Europeans) can no longer feel such confidence in the rightness and inevitability of our position. Perhaps the time has come when we can simply sit down, listen, and come-to-knowing. Maybe, as the millennium reaches its close, we can all engage in a ceremony of renewal that will cleanse earth and sky. Maybe the time is right."

Peat, F. D. (1994) Lighting the Seventh Fire – the Spiritual Ways, Healing and Science of the Native American, New York, New York: Birch Lane Press, Carol Publishing Group. Page 312

IABLE OF CONTENTS	104
List of Figures and Tables	184
Abstract	185
Introduction	186
The Context/Review of Literature	188
The Survey Results - Returning to	
Traditional Ways	193
The Survey Results - Who Answered "Yes"?	195
The Survey Results - Where is Progress?	197
Interpretation	201
Conclusion	203
Recommendations	205
APPENDIX 1 Statistical Tables	207
References	215



First Nations and Inuit Regional Health Surveys

	List of Tables	_
Figure 1:	The Medicine Wheel	190
Figure 2:	Harmony Wheel	191
Figure 3:	Harmony Wheel in Disarray	192
Figure 4:	% Desiring to Return to Traditional Ways	194
Figure 5:	% Return to Traditional Ways by Age Group	195
Figure 6:	% Return to Traditional Ways by Language	195
Figure 7:	% Return to Traditional Ways by Health Transfer	197
Figure 8:	Community Wellness Factors Showing No Progress (%)	197
Figure 9:	Community Wellness Factors Showing Good Progress (%)	198
Figure 10:	Community Wellness Factors Showing Some Progress (%)	198
Figure 11:	Community Wellness Factors Showing Any Progress %	199
Figure 12:	Progress in Returning to Traditional Way by Desire to Return	199
Figure 13:	% Respondents Involved in Control by Health Transfer	200
Figure 14:	Perceived Progress in Control by Health Transfer	200

List of Tables

Table 1:	Respondents in Communities Involved in Health Transfer	207
Table 2:	Returning to Traditional Ways Promotes Community Wellness	207
Table 3:	Return to Traditional Ways by Sex	208
Table 4:	Return to traditional Ways by Age Group	208
Table 5:	Return to Traditional Ways by Language of Daily Life	209
Table 6:	Return to Traditional by Post Secondary Education	209
Table 7:	Return to Traditional Ways by Martial Status	210
Table 8:	Return to Traditional Ways by Attendance at Residential School	210
Table 9:	Return to Traditional Ways by Perception of Same Level Health Care	211
Table 10:	Return to Traditional Ways by Rating of Own Health	211
Table 11:	Return to Traditional Ways by Isolation of Community	212
Table 12:	Return to Traditional Ways by State of Health Transfer	212
Table 13:	Progress in Returning to Traditional Ways	213
Table 14:	Progress in Other Community Wellness Factors	213
Table 15:	Perceived Progress in First Nation / Inuit Control by State of Health Transfer	214
Table 16:	Desire to Return to Traditional Ways by Perception of Progress in Returning to Traditional Ways	214

First Nations and Inuit Regional Health Surveys

ABSTRACT

A health survey of First Nations and Inuit people was conducted during 1997 in response to the reality that First Nations and Inuit people had been left out of the three major national surveys related to health – the National Population Health Survey (NPHS), the National Longitudinal Survey of Children and Youth (NLSCY), and the Survey of Income and Labour Dynamics (SLID). The survey was conducted in each region of Canada under the umbrella of the regional First Nation or Inuit political organization but each survey contained a set of core questions that were common in every region. These questions became known as the national core questions. Several of the national core questions were listed under the heading of "wellness".

Nine regional data sets were merged to create a national database¹. After a series of data quality checks, individual records were appropriately weighted to properly represent the national population of on-reserve First Nations adults and Labrador Inuit communities. Individual, community, and regional identifiers were removed from the sample of 9,870 adult First Nations and Inuit respondents.

The wellness questions are significant because they directly address the question of "what kind of health care system do First Nations and Inuit people want?" This is of great importance to First Nations and Inuit people at this time because there is a growing concern that present health systems are not meeting their need, scarce resources are forcing all agencies to make program priority choices and many First Nations and Inuit governments are involved in health transfer agreements with the Federal government.

Approximately 71 percent of the respondents to the survey nationally live in jurisdictions that are involved in the transfer of health care responsibilities from the Medical Services Branch of the Government of Canada to the local jurisdiction (i.e. they live in a jurisdiction which has either signed a Health Transfer Agreement – 42 percent, or they are actively involved in pre-transfer negotiations – another 29 percent). As local jurisdictions take over responsibilities for health care they must ask questions like, "what kind of health care system are we taking over?", and "what kind of health care systems do the agreements allow the local jurisdiction to create in response to local desires and needs?" They must also ask, "what are the local desires for an effective health care system?"

Over 80 percent of respondents answered "yes" to the question "Do you think a return to traditional ways is a good idea for promoting community wellness?" This result indicates that a very large majority of respondents see the solution to their wellness issues in a very different kind of system than that being delivered to the rest of Canadians and a very different system than the one that is being transferred under health transfer agreements – a system based upon "wellness" and "traditional ways".

Questions regarding the adequacy of present health care approaches are also seen in the responses to questions about progress (or lack of progress) in some basic wellness indicators. Thirty percent or more of the respondents see "no progress" in the following factors assumed to be related to wellness - "a reduction in alcohol and drug abuse", "a return to more traditional roles of women and men", the "number of First Nations and Inuit health professionals", "increased personal healing", "employment opportunities", a "renewed relationship with the land", and "networking among communities". Fewer than 30 percent of respondents see "good progress" in "water and sewage facilities", "quality of housing", "the use of Elders", "traditional ceremonies", the "use of a First Nations or Inuit language", and "First Nations and Inuit controlled programs".

In 1994, a national Aboriginal Inuit Steering Committee consisting of First Nation, Inuit and Metis health and social development professionals was formed to explore the lack of statistical information to support health planning in communities. This lack of information was largely due to the exclusion of First Nation, Inuit and Metis communities from the current three major national longitudinal surveys – the National Population Health Survey (NPHS), the National Longitudinal Survey of Children and Youth (NLSCY), and the Survey of Income and Labour Dynamics (SLID). Under the direction of this steering committee a series of consultations was conducted across Canada with First Nations and Inuit professionals and technical staff to determine the feasibility and nature of conducting a longitudinal study in First Nations, Inuit and Metis communities. The consultations and feasibility study were conducted by the Northern Health Research Unit at the University of Manitoba, and it was decided to proceed with the development of such a study.

The Steering Committee decided that the survey should take the form of a group of regional surveys with some national core content. The regional surveys were to be controlled and implemented by regional organizations and 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 these people became known as Co-principle Investigators. Each region also created a Regional Steering Committee to ensure that the survey met regional and local needs.

Data from each of the regional surveys was compiled into a common data base by staff at the University of Manitoba under contract to The National Steering Committee. Since the sampling approach was a little different in each region, each individual record in the data file received a weighting which was designed to relate the samples to age and sex data obtained from Indian Affairs. For a more detailed explanation of the history, process, and statistical methods of this survey see appendix 2 and the paper in this series on methodology.

INTRODUCTION

In the National First Nation & Inuit Health Survey, several questions were asked under the heading of "wellness". These questions are:

- Do you think a return to traditional ways is a good idea for promoting community wellness?
- Thinking about the past two years, in which of the following areas has there been progress in your community?
 - 1. Traditional approaches to healing
 - 2. Renewal of native spirituality
 - 3. Revival of traditional roles of women
 - 4. Revival of traditional roles of men
 - 5. Traditional ceremonial activity
- Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
 - 1. First Nations and Inuit controlled programs
 - 2. Return to traditional ways
 - 3. Use of Elders
 - 4. Personal commitment to healing
 - 5. Renewed relationship with the land
 - 6. Networking among communities
 - 7. Use of First Nations or Inuit language
 - 8. Training in the health field
 - 9. Reduction in alcohol and drug abuse
 - 10. Availability of First Nations and Inuit health professionals
 - 11. Cultural awareness programs in schools
 - 12. Education and training opportunities
 - 13. Employment opportunities
 - 14. Housing quality
 - 15. Water and sewage facilities

These questions will form the core of the discussions in this paper. The questions do not provide all of the information required by the topic of the paper because the questionnaire was designed before the topics of the papers to be produced from the data were decided. This limits the conclusions that can be drawn from the data.

188 Search for Wellness Image: Search for Wellness Image: Search for Wellness

The Context/Review of Literature:

T he main argument of this paper is that:

- 1. Traditional Aboriginal (First Nations and Inuit) people and non-Aboriginal people have differing world views.
- 2. These different world views lead to different views as to the nature of a desirable health care system. The health care system that is presently being delivered to First Nations and Inuit people is based upon a non-Aboriginal world view.
- 3. The present health system lacks a First Nations and Inuit perspective.
- 4. The First Nations and Inuit people of Canada, by a large majority, want a health care system based more on "traditional ways". This does not necessarily mean a total abandonment of the existing system because the existing system can fit as a part of the more holistic system permitted by a First Nations and Inuit world view. A major problem with the existing system is that it has little tolerance for alternative approaches.
- 5. Respondents who see a lack of progress in factors assumed to be linked to a more traditional approach to health care outnumber those respondents who see significant progress although perceptions (as would be expected) vary from factor to factor.
- 6. There is some question about whether the existing health transfer arrangements (the transfer of the program responsibility from Health Canada to First Nations and Inuit control) are actually allowing the development of a health care system based upon a more traditional world view.

A "world view" is the set of beliefs through which we view and interpret the world around us. Our world

view defines those elements of the world which are important and worthy of our attention. Our world view defines our relationship to the world around us. Capra (1982) is one of the writers with the most indepth discussions of the world view concept as it relates to health care. Other writers, especially writers in education (Souers, 1992), business (Hansen, 1995) and time management (Covey, 1994) have popularized the world view concept but on a smaller scale and have referred to the world view concept as a "paradigm" and referred to the need to have a "paradigm shift" in our approach to business and personal life management.² Capra (1982) traces the foundations of modern science back to the 17th century thinker Descartes. He begins with a discussion of physics where the influence of Descartes' thinking (sometimes he uses the term "Cartesian" thinking) led to a view of the universe as a mechanical system that could best be understood by breaking it into its constituent parts. He then traces the influence of this type of thinking into the other areas of science. One of his conclusions is:

"Throughout the history of Western science the development of biology has gone hand in hand with that of medicine. Naturally then, the mechanistic view of life, once firmly established in biology, has also dominated the attitudes of physicians toward health and illness. The influence of the Cartesian paradigm on medical thought resulted in the so-called biomedical model, which constitutes the conceptual foundation of modern scientific medicine. The human body is regarded as a machine that can be analysed in terms of its parts; disease is seen as the malfunctioning of biological mechanisms which are studied from the point of view of cellular and molecular biology; the doctor's role is to intervene, either physically or chemically, to correct the malfunctioning of a specific mechanism. Three centuries after Descartes, The science of medicine is still based, as George Engel writes, on 'the notion of the body as a machine, of disease as the consequence of breakdown of the machine, and of the doctor's task as repair of the machine.'

"By concentrating on smaller and smaller fragments of the body, modern medicine often loses sight of the patient as a human being, and by reducing health to mechanical functioning, it is no longer able to deal with the phenomenon of healing. This is perhaps the most serious shortcoming of the biomedical approach. Although every practising physician knows that healing is an essential aspect of all medicine, the phenomenon is considered outside the scientific framework; the term "healer" is viewed with suspicion, and the concepts of health and healing are generally not discussed in medical schools." (p. 123-124)

"The Cartesian division has influenced the practice of health care in several important ways. First, it has split the profession into two separate camps with very little communication between them. Physicians are concerned with the treatment of the body, psychiatrists and psychologists with the healing of the mind. The gap between the two groups has been a severe handicap in the understanding of most major diseases, because it has prevented medical researchers from studying the roles of stress and of emotional states in the development of illness. Stress has only very recently been recognized as a significant source of a wide range of diseases and disorders, and the link between emotional states and illness, although known through the ages, still receives little attention from the medical profession.

"As a result of the Cartesian split, there are now two distinct bodies of literature in health research. In the psychological literature the relevance of emotional states to illness is widely discussed and well documented. This research is carried out by experimental psychologists and reported in psychology journals that biomedical scientists rarely read. For its part, the medical literature is well grounded in physiology but hardly ever deals with the psychological aspects of illness. Cancer studies are typical. The connection between emotional states and cancer has been well known since the late nineteenth century, and the evidence reported in the psychological literature is substantial. But very few physicians are aware of this work, and medical scientists have not integrated the psychological data into their research."(p. 143)

Has this Western approach to health care been as successful as we sometimes believe it is? Capra (1982), after a number of examples, concludes:

"The conclusion to be drawn from these studies of the relation between medicine and health seems to be that biomedical interventions, although extremely helpful in individual emergencies, have very little effect on the health of entire populations. The health of human beings is predominantly determined not by medical intervention but by their behavior, their food, and the nature of their environment. Since these variables differ from culture to culture, each culture has its own characteristic illnesses, and as food, behavior, and environmental situations gradually change, so do the patterns of disease. Thus the acute infectious diseases that plagued Europe and North America in the nineteenth century, and that are still the major killers in the Third World today, have been replaced in the industrialized countries by illnesses no longer associated with poverty and deficient living conditions but, on the contrary, with affluence and technological complexity. These are the chronic and degenerative diseases - heart disease, cancer, diabetes - that have aptly been called "diseases of civilization," since they are closely related to the stressful attitudes, rich diet, drug abuse, sedentary living, and environmental pollution characteristic of modern societies."(p. 138-139)

Capra (1982) further argues that a new "world view" is needed in medicine and in all other scientific fields. He says that physics was forced to make changes from its Cartesian view of the world when it studied the behavior of sub-atomic particles and those studies led to what we now know as "quantum physics". Quantum physics presents us with a view of the world in which matter is interpreted in terms of its relationships and interactions.

"The conception of the universe as an interconnected web of relations is one of two major themes that recur throughout modern physics. The other theme is the realization that the cosmic web is intrinsically dynamic. The dynamic aspect of matter arises in quantum theory as a consequence of the wave nature of subatomic particles, and is even more central in relativity theory, which has shown us that the being of matter cannot be separated from its activity. The properties of its basic patterns, the subatomic particles, can be understood only in a dynamic context, in terms of movement, interaction, and transformation." (p. 87)

Capra goes on to suggest that now, since a world view change has occurred in physics, such a change is both required and inevitable in all other areas of science. A more holistic world view is required in which we see the inter-relationships of all things – that everything is related to everything else.

He is not alone in this view. Dr. David Eisenberg (as quoted by Covey, 1994) observes:

"We [in the Western world] invented the notion that 'biology' and 'physics' and 'psychology' and 'psychiatry' are separate. If we want to deal with health, and we're looking only at the chemistry or the emotional state, we have an imperfect glimpse. The patient sitting before me brings with him or her not only chemistry, but also family, relationships, emotions, and character. The distinctions we bring to a hospital in terms of mind and body are abstractions that we make. The patient is still a whole person, and to help him or her get better, ideally we would deal with all of these aspects – the balance of a person's life." (p. 121)

The concept of everything being related to everything else, is illustrated again in quotations from

the presentation of Jeanette Costello at the hearings of the Royal Commission on Aboriginal People (Government of Canada, 1996):

"With the healing in place we can have self-government, but without that healing we will have dysfunctional selfgovernment." (3 (3))

The implication of this statement is that unless there is a healing (an overcoming of dysfunction) of people, families and communities, that selfgovernment will not work.

The traditional First Nation and Inuit people of Canada, although culturally diverse, share a more holistic world view than is evident in the biomedical model. As Coggins (1990) says:

"Within the medicine wheel recovery way, four basic realms of human existence are addressed:

- 1. The physical realm
- 2. The realm of knowledge and enlightenment
- 3. The spiritual realm

4. The realm of introspective thought." (p. ix)

Each of the diverse First Nation and Inuit cultures has its own way of presenting the ideas of the "Medicine Wheel" but each contains the basic fundamentals (that everything is related to everything else, that things cannot be understood outside of their context and interactions, and that there are four aspects to the human condition — the physical, the emotional, the mental and the spiritual). These fundamentals make this First Nation and Inuit world view far more holistic than the bio-medical model. The following description is taken largely from the plains First Nations but the major elements, although they may be expressed differently by other First Nation and Inuit people, are basic concepts similar to all.

In societies with an oral tradition, like First Nations societies, the fundamental teachings (the "world view") are preserved in sacred stories, ceremonies and symbols. Just like the "words on a page" are symbols of the ideas, concepts and beliefs of a literate society, stories, ceremonies, and symbols are the symbols of the ideas, concepts, and beliefs of a society which has an oral tradition.

One of the basic symbols of the world view of First Nations is what is known among many prairie First Nations as the "medicine wheel. The medicine wheel illustrates that First Nations people believe that a person is not just a body. A person has a physical



Figure 1: The Medicine Wheel

part (the body), a spiritual part (the spirit) each with mental and emotional capacities. This is illustrated in Figure 1. (FSIN, 1994 and Bopp, 1984)

If a person is to be "healthy" or achieve "wellness" then each of the four aspects of their lives must be in balance. Appropriate attention must be given to each of the four aspects of a person – the physical, mental, spiritual and emotional.

Not only must a person keep themselves in balance, they must also achieve harmony. The concept of harmony is explained through another diagram. Traditional First Nations people see the individual in the context of the family, the community, nature, and the Creator. Each of these environmental elements has "laws" or rules of behaviour which should govern the actions of the people. A person must not only balance the four aspects of their lives but must carry out the balancing within the context of family, community, natural and Creator's laws. This is illustrated in Figure 2.³

Another concept from a First Nations world view is not as easily diagrammed, it is the concept that an individual not only acts in the context of the living family, the community, nature, and the Creator, but an individual is also the link between the ancestors and the children (to the seventh generation). Harmony, as a result, is a very complex concept. It involves achieving a harmony among all of these aspects of life, the individual, the living family, the community, nature (mother earth), and the Creator. It involves

harmony between the ancestors and generations yet unborn. But, as illustrated in Figure 3, what does an individual do if the family and the community are not in harmony with nature and the Creator? Does the individual then seek harmony with the family, the community or with nature and the Creator? This is part of today's dilemma for First Nations.

The community that is out of harmony is not only First Nations community. The lack of harmony is evident also in the wider society and the wider society controls many of the resources needed to restore harmony. (Peat, 1994)⁴

The "out-of-harmony" elements of society place individuals in a situation of high stress. Where should the individual seek harmony? When those responsible for health care do not see the individual within the context of her or his interactions and relationships with external and internal environments then the solutions to health problems will be misplaced. Health costs will rise without a corresponding improvement in health status. The problems in today's health can be seen mirrored in the concepts illustrated in the above diagrams.

Capra (1982) appears to be discussing a similar idea when he says:

"In the long rise of scientific medicine, physicians have gained fascinating insights into the intimate mechanisms of the human body and have developed their technologies to an impressive degree of complexity and sophistication. Yet in spite of these great advances of medical science we are now witnessing a profound crisis in health care in Europe and North America. Many reasons are given for the widespread dissatisfaction with medical institutions inaccessibility of services, lack of sympathy and care, malpractice - but the central theme of all criticism is the striking disproportion between the cost and effectiveness of modern medicine. Despite a staggering increase in health costs over the past three decades, and amid continuing claims of scientific and technological excellence by the medical profession, the health of the population does not seem to have improved significantly.

"The relation between medicine and health is difficult to assess because most health statistics use the narrow, biomedical concept of health, defined as the absence of disease. A meaningful assessment would deal with both the health of the individual and the health of the society; it would have to include mental illnesses and social pathologies. Such a comprehensive view would show that, although medicine has contributed to the elimination of certain diseases, this has not necessarily restored health. In the holistic view of illness physical disease is only one of several manifestations of a basic imbalance of the organism. Other manifestations may take the form of psychological and social pathologies, and when the



Figure 2 : Harmony Wheel

symptoms of a physical disease are effectively suppressed by medical intervention, an illness may well express itself through some the other modes." (p. 134-135)

Healing and wellness, in the context of a First Nations world view, is the process of achieving balance and harmony. It is an active process in which the individual, the family and the community is involved. Healing involves all four aspects of an individual – the spiritual, the physical, the mental, and the emotional. Healing is internal and external to the individual. Healing is something that individuals do themselves, families do and communities do. Healing includes concern for the past and for the future. It is an active process. Healing is a process that is sometimes referred to as a "healing journey".

The word "healing" when used in the medical model framework means something very different. It usually refers to the physical body only. It is something that is "done" by a medical practitioner in a healing centre (a hospital or clinic). It is an "event" (done in a specific place and at a specific time). The individual to be healed plays a passive role – required only to respond to the administrations (e.g. the surgery or medication) of the practitioner. Healing is external to the individual and has little to do with the family or the community.

Even when world view differences are not as clear as between Aboriginal and Western approaches, the question of the adequacy of the existing health care system is being discussed. Increasingly, Canadians in



Figure 3 : Harmony Wheel in Disarray

general are questioning the effectiveness of the existing system. In every part of Canada, people conclude that the existing system is not meeting the needs of Canadians in general. The government suggests that the system is too expensive. As a result hospitals are being closed. The burden of the care of those who are ill is being shifted from health professionals to the home. It has long been seen by some persons that the system has focussed on repairing illness rather than facilitating health.

Our general societal search for alternatives was discussed at length before the Royal Commission on Aboriginal people by Rosemary Proctor, Deputy Minister of Community and Social Services, Ontario. She said: (Government of Canada, 1993):

"Our society is really actively engaged right now, and has been for some years, in changing the way we think about health, illness, curing and caring. What we are doing is changing the paradigm that defines health and disease, how we think about health and what we do about illness." (p. 49)

"A really important aspect of the causation paradigm (medical model) is the way it defines disease. In this framework, disease has tended to be defined as a dysfunction or inability to function, the cause of which originates outside the individual. In short, it's not your fault that you are sick. The sickness comes from outside you. Health is then defined as the absence of disease, a relatively neutral state." (p. 51)

"Over time, these definitions have also resulted in the tendency to identify everything that is not health as disease. Addictions have become illness, bizarre behaviour has become illness, disability and aging have become illnesses. All these conditions are then supposed to be treated by the medicine or intervention prescribed by the dominant paradigm."

"Gradually, a new or modified paradigm is emerging to challenge the firm premises of specific causation. I tend to think of this emerging body of work as an environmental paradigm, because it explains illness and disease in terms of all aspects of our world environment and of our bodies themselves. In this environmental paradigm, health and illness are no longer opposites, but more like points along a continuum." (p. 52)

The questioning of the existing medical care system is more than just a reconsideration of how to deliver the existing services better, it is a reconsideration of the fundamental assumptions that have given rise to the existing system.

Dr. David Skinner, of the Yukon Medical Association, in his presentation to the Royal Commission on Aboriginal People said (Government of Canada, 1993):

"What we have to remember here is, we have a white ethnocentric health care system which we have brought to the native people, and we are asking them to see it and do it our way It is our belief, though, that because our white man's medicine is very technicaloriented, very drugs and surgeryoriented, it lacks something that native medicine has and which we desperately need but don't practise: spirituality, or a spiritual component." (p. 43)

Dr. John D. O'Neil, in his presentation to the Royal Commission on Aboriginal People said (Government of Canada, 1993):

"Gregory et al. . . . argue that the transfer policy reinforces the dominance of a medical model of health, which by definition maintains relations of power over Aboriginal people" (p. 43)

If the current health care system is not satisfactory, and it appears that it is not, then what kind of health care system do First Nations and Inuit people want? What would a system based on a traditional First Nation and Inuit world view be? This critical policy issue facing First Nations and Inuit policy makers (and similar questions are facing Canadians in general) is the focus of the questions on wellness in the First Nations and Inuit Regional Health Survey and is the primary focus of this paper. Answers to these questions will be attempted within the limitations of the data from the survey.









The Survey Results -Returning to Traditional Ways

T he survey asked, "do you believe that First Nations/Inuit people have the same level of health service as the rest of Canada?" Approximately 47 percent of respondents to this survey indicated that they felt that First Nations/Inuit health services were not at the same level as the rest of Canada. This leaves at least two policy options:

- improve eurocentric health services delivered to First Nations and Inuit people until the services are comparable to services to the rest of Canadians, or,
- change the direction of health services so that these services more adequately meet the needs of First Nations and Inuit people as perceived by them.

The survey did not go on to ask questions about how people felt about the desirability of improving existing services until services reach the same level as the "rest of Canada" (the first policy option) so the survey does not provide direct information on the desire for "comparable services". However, the question "Do you think a return to traditional ways is a good idea for promoting community wellness? in the First Nations and Inuit Regional Health Survey provides a partial answer to the questions posed by these policy alternatives.

The question ("Do you think a return to traditional ways is a good idea for promoting community wellness?") was answered by 8,860 respondents (adults living in First Nation and Inuit communities). Of these almost 9,000 respondents, over 80⁵ percent

answered "yes" (See Figure 4). This result indicates that a very large majority of respondents see the solution to their wellness issues in a return to "traditional ways". The specific meaning of "traditional ways" is not explored in the survey so, at this point, the results can only be interpreted broadly in the context of a very general view of First Nation and Inuit world view. This would likely result in a very different kind of system than that being delivered to the rest of Canadians – a system based upon "wellness" and "traditional ways" (Table 2). (Note: Tables containing additional information on all statistical areas are located in Appendix 1)

Eighty-five percent of those who say that the level of health care for First Nations and Inuit people is not the same as the rest of Canada also say that a return to traditional ways is a good way to promote wellness, compared with 77 percent for those who feel that First Nations and Inuit people have the same level of health care. (See Table 9).

This does not necessarily mean that all of the existing health care system should be abandoned. A more holistic approach to health care allows a place for elements of the bio-medical model (e.g. much of the bio-medical model practice could be retained if viewed in the broader context of the concepts of balance and harmony).



Figure 4 : % Desiring to Return to Traditional Ways









The Survey Results - Who Answered "Yes"

A lmost 82 percent of females and over 79 percent of the males included in the survey said that a return to traditional ways was the way to promote community wellness. Although both rates are high, females are more likely to respond with a "yes" than males (Table 3, page 211)

Respondents between the ages of 25 and 54 are more likely to want a return to traditional ways than people 55 and over or people under 25 years of age. Again all age groups have relatively high percentages of "yes" answers with the age group 15 to 24 having the lowest rate at just over 77 percent (Table 4, page 211 and Figure 5).

Respondents who use English as their language of daily life are more likely to desire a return to traditional ways than respondents who use a First Nations and Inuit language (82 percent and 78 percent respectively). At 69 percent, respondents who use French as their language of daily life are least likely to desire a return to traditional ways (See Figure 6 and Table 5, page 212).

Respondents with some postsecondary education are more likely to answer "yes" to this question than respondents with no post-secondary education (over 84 percent for the former and



Figure 5: % Return to Traditional Ways by Age Group



Figure 6: % Return to Traditional Ways by Language



Figure 7 : % Return to Traditional Ways by Health Transfer

78 percent for the latter) (See Table 6, page 212).

People who are "married", "common-law", or "separated" are more likely to want a return to traditional ways than people who are "single", "divorced", or "widowed" (See Table 7, page 213).

Eighty-six percent of respondents who attended residential schools want a return to traditional ways compared with 78 percent who did not attend residential schools (See Table 8, page 213).

Respondents with "very good" or "fair" health are more likely to advocate a return to traditional ways (81 and 82 percent respectively) than those in "fair" or "poor" health (77 percent), or "excellent health" — 78 percent (See Table 10, page 214).

Relative isolation is not associated with a desire to return to traditional ways. Eighty-one percent of respondents from isolated communities said returning to traditional ways was a good idea and so did almost 81 percent of respondents from communities that are not isolated (See Table 11, page 216).

The people living in communities that have a signed Health Transfer agreement are the most likely to advocate a return to traditional ways (almost 83 percent). Next comes those communities that are not engaged in the transfer process. Almost 82 percent of respondents in these communities said yes. Only 77 percent of respondents involved in pre-transfer

discussions said a return to traditional ways was important for community wellness (See Table 12, page 216 and Figure 7).

In summary, in all the respondent characteristics considered, a high percentage of all respondents are supporters of a return to traditional ways. Although some factors show some level of statistical significance between categories, the differences tend to be in the three to four percent range. The policy implications of these differences are unclear at this time but policy and program implementation staff should be aware of the potential of distinct groups that may feel excluded if not carefully worked with in the implementation of a traditional First Nation and Inuit approach to health care.

There is no geographic variable available in the data. This leaves a gap in the analysis because the desire to return to traditional ways is likely to vary from community to community. There is no way to examine this issue from the data in this survey because the geographic identifiers have been removed.









The Survey Results - Where is Progress

R espondents were asked two questions that required them to make a judgement as to whether there had been progress in factors assumed, by the National Steering Committee, to be related to community wellness. The first question included factors that are assumed to relate to "traditional ways" while the second included a broader list of items that would be assumed to have implications for a holistic view of community wellness. The individual items in these two questions were selected by the National Steering Committee from a list of issues considered important by people from First Nations communities in

Saskatchewan for maintaining individual and community ability to respond to crisis (e.g. suicide, sexual abuse, death). (FSIN, 1994) These items fit within measures related to a more holistic view of health than the view represented by the bio-medical model. For purposes of this analysis the answers to both questions are summarized together since the same range of responses was available in both questions. The answers are summarized in the following three charts.

Figure 8 shows the 8 variables in which the highest number of people saw "no progress".

Over 50% of respondents saw no progress in reducing alcohol and drug abuse despite a very significant number of resources being devoted to this area.

Other wellness areas where over 35% of respondents saw "no progress include a return to more



Figure 8 : Community Wellness Factors Showing No Progress (%)

traditional roles of women and men, more First Nations and Inuit health professionals, increased personal healing, more employment opportunities, a renewed relationship with the land, and more networking among communities.

Figure 9 shows the eight areas in which the highest number of respondents saw "good progress". It should be noted that the percentages are much lower in this chart than in the "no progress" chart. The highest percentage on this "good progress" chart is lower than the lowest percentage on the "no progress" chart.

There is a perception among respondents that good progress has been shown in the past two years (about mid-1995 to mid-1997) in water and sewage facilities (30 percent) and housing (20 percent) which are widely perceived as having a direct impact on physical health. There is also a perception of progress in the use of Elders (23 percent), traditional ceremonies (23 percent) and the use of a First Nations

197

or Inuit language (23 percent), all of which are more traditional ways. Finally there is a perception of good progress by about 15 percent of respondents in First Nations and Inuit controlled programs. The control of programs by First Nations and Inuit people is likely to be important if there is to be a return to more traditional ways to promote community wellness.

Figure 10 shows the items in which people see some progress. The percentages in this chart are higher than the percentages for either the "no progress" chart or the "good progress" chart (all over 53 percent). Some progress is seen in "return to traditional ways (60 percent), native spirituality (56 percent), traditional healing (56 percent) and the use of elders (53 percent) all of which are directly related to a return to traditional ways. Some progress is also seen in the mental factors of "training in the health field" (54 percent), "cultural programs in schools" (56 percent), and "education and training opportunities" (56 percent). Again, some progress is seen in "First Nation/Inuit Controlled Programs" (58 percent) (See Tables 13 and 14, page 216).

When responses indicating any perception of progress ("some progress" and "good progress") are tabulated together, then the items in Figure 11 received the highest percentage of "progress" responses.

At least 72 percent of respondents indicate some level of progress in Cultural Programs in Schools, Education/Training Opportunities, Water/Sewage Facilities, Use of Elders, First Nation/Inuit Controlled Programs, Traditional Ceremonial Activities, a Return to Traditional Ways, and the Use of First Nation/Inuit Language. Over 50 percent of all respondents saw progress in all rated factors except reduction in alcohol and drug abuse.

These questions of progress, although showing some significant levels of progress, do not show that



Figure 9: Community Wellness Factors Showing Good Progress (%)



Figure 10: Community Wellness Factors Showing Some Progress (%)

progress in these items is considered desirable or undesirable by respondents. There is no way of assessing, from this survey, if respondents want to see progress in any of these areas. There is one exception - the question of progress in returning to traditional ways is directly related to the central question of this paper, "do you think a return to traditional ways is a good idea for promoting community wellness?" The data show that people who desire a return to traditional ways to promote community wellness are more likely to see progress in returning to traditional ways than people who don't want a return to traditional ways. Over 76 percent of the respondents who want a return to traditional ways see at least some progress in returning to traditional ways while only 50 percent of those who don't want a return to traditional ways see progress in that area. This is shown in the

198

Figure 12 and in Table 16 on page 217.

Approximately 71 percent of the respondents to the national survey live in jurisdictions that are involved in the transfer of health care responsibilities from the Medical Services Branch of the Government of Canada to the local jurisdiction (i.e. they live in a jurisdiction which has either signed a Health Transfer Agreement -42 percent, or they are actively involved in pretransfer negotiations - another 29 percent, as noted in Figure 13 and Table 1, page 210). The Medical Services Branch is proceeding with the negotiation of agreements with the remaining jurisdictions as rapidly as the local jurisdiction is willing to proceed. The general approach is to transfer what the Medical Services Branch is doing to the administration of the local jurisdiction along with a budget to fund the activities under the agreement.

Some of the most important challenges for First Nation and Inuit jurisdictions that take over health care services are summarized in these three questions:

- Do we want to just take over the existing health care system and administer it in the same way, or in similar ways to the way that Medical Services Branch has administered it?
- If the answer to this first question is no, then what kind of health care system is desired by First Nations and Inuit people?
- If First Nations and Inuit people want a different kind of health care system then do the health transfer agreements



Figure 11: Community Wellness Factors Showing Any Progress %



Figure 12: Progress in Returning to Traditional Ways by Desire to Return

provide First Nations and Inuit people with the opportunity to design their own health services in accordance with the kind of health care system they desire?

The third question is critical to implementing any desired changes in the health care system. John McKnight has said (Canadian Broadcasting Corporation, 1994) that to be empowered an individual or community must be able to define its own problems, explore alternatives and select its own solutions, and then be able to implement the selected solutions. Implied in this empowerment is also the right of the individual or community to live with the consequences of these choices.

Are these three powers being transferred under the health transfer agreements? The answer to this question is not in the results of the survey but can be inferred from the nature of the agreements themselves. The agreements basically transfer program responsibility and budgets attached 200

to those programs. There is some flexibility for implementation decisions but the money attached to the programs generally must be spent within the program guidelines - guidelines designed from a non-Aboriginal world view. If there were to be a significant transfer of McKnight's three powers under the health transfer agreements, then it could be expected that those respondents that live in communities that have completed health transfer agreements should see significant progress in First Nations and Inuit control of programs. A transfer of power over health care is one of the objectives of participating in the health transfer process and it is part of the push for self-government. Also, if McKnight's three powers are being transferred, then, over time, there should be a change in the nature of health programs and services that show the influence of a tradtional First Nation and Inuit world view. Tracing this influence is not possible from this survey because the questions were not asked.

However, if health transfer is working appropriately, people living in communities that have completed health transfer should perceive more progress in First Nation/Inuit control of programs than people living in communities that have not completed health transfer. The data show that there is a small but statistically significant difference in

the perception of First Nations/Inuit control in communities where health transfer is complete over communities where there is no transfer. This is shown in Figure 14 and in Table 15, page 217. The data show that about 25 percent of respondents in communities that have completed transfer say that there is "no progress" in First Nation/Inuit control of programs compared with 27 percent in pre-transfer communities and 28 percent in communities that are not involved in health transfer. Although 75 percent





Figure 13: % Respondents Involved in Health Transfer



of the respondents in communities that have

completed health transfer indicate progress in gaining

control of programs, the perception of progress is

relatively shallow. Seventy-five percent of those

seeing progress report only "some progress". It seems

likely that the perception of progress could shift to "no

progress" relatively rapidly if experience in

implementing the transfer agreements does not result

Figure 14: Perceived Progress in Control by Health Transfer

progress" if implementation experience brought the desired result.

Interpretation

I t is evident from the responses to the "return to traditional ways" question that a very large majority of First Nation and Inuit people across Canada want a different "paradigm" or "model" of health care from the predominant model. They want health care based upon "traditional ways". They want a more holistic perception of "wellness", based upon a very different "world view" from the Eurocentric biomedical one.

The questions in the survey do not allow a complete definition of either what is meant by "traditional ways" or what is meant by "community wellness". This is a problem which should be addressed in future studies.

The items from both "progress" questions that obviously relate to "traditional ways are:

- traditional approaches to healing,
- a renewal of Indian spirituality,
- a revival of the traditional roles of women,
- a revival of the traditional roles of men,
- traditional ceremonial activity,
- the use of Elders,
- a personal commitment to healing⁶,
- a renewed relationship with the land, and,
- the use of First Nations/Inuit language.

The items "a revival of the traditional roles of women", "a revival of the traditional roles of men", "a personal commitment to healing", and "a renewed relationship with the land" all appear on the "no progress" list. This is four of the nine obviously traditional items. All of these traditional items on the "no progress" list are identified by 37 percent or more of the respondents as having "no progress". Since a large majority of respondents want a return to traditional ways and over a third of all respondents see "no progress" in at least four of the specifically traditional items measured, the question arises as to why there is no progress arise because the interest is not there in communities? Does the perception arise because of a lack of opportunity for progress in these items? Does the perception arise because there has not been sufficient time since attention has been given to a return to traditional ways for significant progress to occur in these items. The data do not allow a definitive answer but in the context of an understanding of differences in world views, the lack of opportunity for progress to occur may be a highly probable reason.

There are a several traditional items on the "good progress" list. These include "use of Elders", "traditional ceremonial activities", and "use of First Nation/Inuit language". These three items are rated as showing "good progress" by 23 percent or more of all respondents. The other two items "renewal of native spirituality" and "traditional approaches to healing" appear on the "some progress" list with 55 percent or more of respondents indicating "some progress". Again, the study does not allow a clear interpretation as to the reasons for a perception of progress for these items. Several possible explanations are:

- In the past, laws have prevented the exercise of some of these practices. Many people still carried on these traditions but did not do so openly. Even though, laws no longer restrict these activities they are still not done openly. In this case progress would be more perceived than real.
- These items have received a high-profile emphasis by First Nation and Inuit organizations (e.g. the use of Elders and ceremonies in public meetings and events). Because of self-government efforts among First Nations and Inuit people, there are now financial and other resources being devoted to these activities.
- These items can easily be "added on" to existing programs and services with the appearance of "enhancing" the service without disrupting or making major changes in the way services are delivered.

All of these represent reasonable interpretations that cannot be either supported or refuted by the data. Perhaps progress is perceived due to a mix of all these alternatives. Additional research will be required to answer the question.

People not only want a return to traditional ways but they see at least "some progress" in 5 of the nine traditional items. The items of "teaching culture in schools" and "First Nation and Inuit Control of programs" were not included in the "traditional ways" list because they are methods of achieving a return to traditional ways not inherently traditional ways. Twenty-two percent of respondents also see "good progress" in the teaching of culture in schools. To speculate, one of the reasons for progress in this area might be that the education system (also based in the same world view as the bio-medical model) finds it relatively easy to include First Nation and Inuit culture as an item to study, although the study is still from the Eurocentric viewpoint. This item was not included in the "traditional" list since it is a method or technique of returning to traditional ways and not a traditional way itself. This same reasoning also applies to "First Nations and Inuit controlled programs" in which 15 percent of respondents saw "good progress".

The most frequently mentioned "no progress" item (50 percent) is "reduction in alcohol and drug abuse". Respondents perceive "no progress" in spite of the relatively large amounts of money that have been devoted to treatment of alcohol and drug addictions. Some may argue that these amounts of money are justified because they have been successful in holding addictions at current levels in spite of "worsening social and economic conditions."⁷ This alternate perception is exactly the point of examining health issues from a more holistic world view. A world view based upon a return to traditional ways. An examination of the issue of addictions from an holistic world view may conclude that, even with significant increases in funding for addictions treatment that progress will not occur until there are significant changes in the conditions that lead to the creation of addictions. The lack of perceived progress in this area alone is a major justification for investigating a different model - a model based upon "traditional ways" and "community wellness".

Although the 9 items listed above are considered to be in the "traditional" category, they do not make clear what a model based on "traditional ways" and "community wellness" concepts would be like. Further clarification was sought from the participants in the "wellness" workshop at the National Aboriginal Information and Research Conference held in Ottawa from March 29 to 31, 1998. The participants added the following concepts:

- traditional ways include a holistic view of a person (e.g. includes spiritual, emotional, and mental elements as well as the physical element that is central to the regular medical model of health care).
- traditional ways include persons taking a major responsibility for their own healing – a person is an active participant in the healing process not just the recipient of a "treatment". This concept is further reinforced in the name of one of the workshops at the conference – it was titled "Taking the Responsibility to Heal Ourselves".
- traditional ways include seeing the individual in the context of the family and the community, in contrast to the medical model which treats individuals as if they were isolated from their family and community environments.
- the ceremonial activities associated with traditional ways are sacred and may vary from community to community. This means that the approach to wellness cannot be a standardized program across all First Nations and Inuit communities in Canada. Each community may have its own particular interpretation of "traditional ways" and "community wellness".

This understanding of different world views also has implications for the health transfer process. If the transfer process is to meet the expectations of these varied communities then it cannot simply be a transfer of existing programs and aproaches because the existing programs are designed to be "universal'— to apply equally to all people across Canada.









Conclusion

 \mathbf{C} eventy percent of respondents to this survey live **J** in communities that are at some stage in the transfer of responsibility for the delivery of health care services from the federal government to First Nations or Inuit control. As this transfer proceeds the question of the nature of health care services to be delivered is becoming the most important question. The results of this survey show that an overwhelming majority of First Nations and Inuit people want a very different kind of health system than that being delivered at the present time. This mean that they do not desire the system that is being transferred. Eighty percent of respondents indicate that a return to traditional ways is a good way to promote community wellness. Ouestions of the nature of the services and the model of health care are paramount questions.

It seems that there may also be an opportunity to introduce the ideas that arise from the more holistic models of First Nations and Inuit people into the wider society. This search for a different model of health care is not restricted to First Nations and Inuit people. There is an increasing awareness among the general population of Canada that the existing system is not working effectively and that an alternative model should be sought. This provides an opportunity to introduce the ideas that arise from a traditional First Nation and Inuit world view into the ongoing discussion of alternative health care models.

Although it is clear from the survey that a different model of health care is desired by a large majority of First Nations and Inuit people, it is not clear from the survey what that model will be. There are some indications of the outline of the model that can be derived from the results of the questions in the survey on perceptions of progress in assumed traditional and community wellness factors. These general parameters include:

- a holistic model that includes spiritual, emotional, and mental factors in addition to the physical factors of the current medical model (inferred from the "return to traditional ways).
- a family context that includes more traditional roles for men and women rather than the medical model approach that views each individual as an isolated element (again inferred from a "return to traditional ways).
- a greater emphasis on personal, family and community responsibility for healing and maintaining health rather than the more passive role of "receiver of treatment" that is prevalent in the medical model.
- a very diverse system where every community defines the specific services and the way in which they are delivered in a way that meets their own perceptions of their needs rather than the "standardized programs" that are the basis of the current system.

This new system will take time to emerge. It will require a cooperative effort by First Nations and Inuit people across Canada. The desire to build a First Nations and Inuit approach to health care based upon "traditional ways" and "community wellness" concepts is likely to find opposition from within the First Nation and Inuit community as well as from outside. All First Nation and Inuit people have been educated in a non-Aboriginal school system and as a result many have absorbed the non-traditional world view. Opposition will arise simply because there is a resistance to change (an inertia), there will be a resistance to change because some will be unable or unwilling to see a different world view, and there will be resistance to change by those who lack confidence in First Nations and Inuit communities' ability to

design and manage their own change. As Capra says:

"To adopt such a holistic and ecological concept of health. in theory and in practice, will require not only a radical conceptual shift in medical science but also a major public reeducation. Many people obstinately adhere to the biomedical model because they are afraid to have their life styles examined and to be confronted with their unhealthy behavior. Rather than face such an embarrassing and often painful situation, they insist on delegating all responsibility for their health to the doctor and the drugs. Furthermore, as a society we tend to use medical diagnosis as a cover-up of social problems. We prefer to talk about our children's "hyperactivity" or "learning disability," rather than examine the inadequacy of our schools; we prefer to be told that we suffer from "hypertension" rather than change our overcompetitive business world; we accept ever increasing rates of cancer rather than investigate how the chemical industry poisons our food to increase its profits. These health problems go far beyond the concerns of the medical profession, but they are brought into focus, inevitably, as soon as we seriously try to go beyond current medical care. Transcending the biomedical model will be possible only if we are willing to change other things as well; it will be linked, ultimately, to the entire social and cultural transformation." (Page 162)

The foundation of the opposition to changes in the health care system will most likely be a basic difference in "world view". The ideas and directions of First Nations and Inuit people are innovative in today's society because these ideas arise out of a very different world view than the view that is the foundation of the current health care system.

First Nations and Inuit people will have to take into account this anticipated opposition as the model based on "traditional ways" and "community wellness" is developed and enunciated. It should also be recognized that the definitions of the new models will not come from researchers. The definitions will emerge from the First Nations and Inuit communities in their struggle to meet the challenges of their own health care needs.









Recommendations

The momentum created by the First Nations and Inuit Regional Health Survey Project and the National Aboriginal Information and Research Conference toward defining a health care model based on "traditional ways" and "community wellness" as expressed by the large majority of respondents to the survey should be maintained and enhanced. The following suggestions could become part of this continuing effort.

- Under the health transfer agreements and other funding arrangements such as the new federal "healing fund" announced in response to the report of the Royal Commission on Aboriginal people there should be sufficient flexibility to develop a new health delivery system based upon a more traditional world view. Under existing agreements, federal and provincial governments have seen "culture" as being an "add on". Standard programs are transferred with the possibility of "adding on" some "extras" to accommodate a different culture. The assumption is ethnocentric in that there is only one legitimate world view – the one held by the Federal government and its staff - and First Nations and Inuit culture is simply an additional frill - an addon. Agreements, and the people negotiating, them must come to understand that a different culture has more to do with a different world view than the colour of the skin or the ceremonies of the people. This would mean that under the new healing funds and under other agreements there should be significant opportunities for communities to develop community and family oriented healing programs rather than simply the institutional approaches embodied in "healing centres".⁸ For example, community and family healing approaches recognize that healing is a process not just an event. An example of a community and family healing process as it applies to diabetes is the Kahnawake Schools Diabetes Prevention Project. The significance of a healing process that includes the individual, the family, and the community is almost unmeasurable. The self-government impact, for example, has been mentioned already in this paper.
- First Nations and Inuit people involved in education and training must give more emphasis to world view differences and to their implications for all aspects of our lives with particular attention to health and healing. World view differences are not well understood. Since medical practitioners, government officials, and academics exert so much influence over program design and development, funding, other views are seldom considered.
- Federal government politicians and officials should be prepared to listen, learn, and "come-to-knowing" about the significance of world view differences and the alternatives that a First Nations or Inuit world view presents for solving existing societal problems related to wellness especially in the area of health but also in the areas of education, justice, and the environment.

- First Nations and Inuit political organizations should increase the tenacity with which they pursue solutions suggested by a First Nations and Inuit world view. Since Canadians are questioning of all approaches to government services, now may be the time when First Nations and Inuit people will find a more receptive audience. Opposition will still occur but many people in the wider society are dissatisfied and are looking for alternative approaches. This presents a clear opportunity for First Nation and Inuit people to implement models based on a more traditional First Nation and Inuit world view.
- Funds should be sought for continuing research both of the survey kind (like this First Nations and Inuit Regional Health Survey) but also research that will elaborate, explain, and support the wellness concepts that are sought by 80 percent of the respondents in the survey.
- Funds should also be sought for community innovation projects that will support community definition and experimentation (like the Kahnawake Schools Diabetes Prevention Project). The definition of a modern health care model based in a traditional First Nation and Inuit world view will not emerge from researchers. It will be defined by the community and documented by researchers.

These are suggested as the "next steps" in defining, explaining, and establishing an alternative model of health care – a model based on "traditional ways" and "community wellness".

APPENDIX 1

STATISTICAL TABLES

APPENDIX 1-STATISTICAL TABLES Unadjusted

(Note: The original data from the survey has been made available in a couple of "weighted" forms – sample analytic weight and population analytic weight. The data for this paper was analysed using both of these weighting approaches but the statistical differences in the results appeared to be relatively minor and did not result in any differences in the conclusions. This paper has reported the unadjusted data only in order to maintain simplicity of reporting.)

Regional H National Dat 1	lealth Survey a - Unadjusted 997	
	Number	Percent
Transferred	3,291	42.70
Pre-transfer	2,179	28.27
No Agreement	2,237	29.03
Totals	7,707	100.00

Region National	al Health Survey Data - Unadjuste 1997	d
	Number	Percent
Yes	7,112	80.27
Νο	1,681	18.97
Don't Know	67	0.76
Totals	8,860	100.00

First Nations and Inuit Regional Health Surveys

		National D	a nealth Sur)ata - Unadju 1997	vey isted		
	Fen	nale	Ма	ale	Тс	otal
	Number	Percent	Number	Percent	Number	Percen
Yes	4,220	81.80	2,861	79.47	7,081	80.84
No	939	18.20	739	20.53	1678	19.16
Total	5,159	100.00	3,600	100.00	8,759	100.00

	1	Regional H National Data	lealth Surve a - Unadjust 1997	y ed			
	Ye	S	N	No		Totals	
	Number	Percent	Number	Percent	Number	Percent	
15 -24 Yrs	1,138	77.10	338	22.90	1,476	100.00	
25-34 Yrs	2,065	81.85	458	18.15	2523	100.00	
35-54 Yrs	2,700	82.27	582	18.00	1,255	100.00	
55 +	966	79.36	259	20.64	1,255	100.00	
Totals	6,899	80.62	1637	19.18	8,536	100.00	
Chi square Degrees of p value = 0.	= 41.18 Freedom = 3 .00 01030	3	1	<u> </u>	<u> </u>	1	

		Na	Regional F ational Dat 19	Health Surv a - Unadju: 997	ey sted			
	Abor	iginal	Eng	lish	Frei	nch	Tota	als
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Yes	1,838	78.75	4,342	82.30	248	69.86	6,428	80.70
No	496	21.25	934	17.70	107	30.14	1,537	19.30
Total	2,334	100.00	5,276	100.00	355	100.00	7,965	100.00
Iotal Cł	2,334	1.14	5,276	100.00	355	100.00	7,905	100.0

		F Na	Regional H tional Data 199	lealth Surv a - Unadjus 97	ey ted				
	No Post -	Sec	Inc. S Some	ec. / Post	Comp.Sec/ Some post		Totals		
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
Yes	3,485	78.65	1,401	84.40	1,083	84.54	5,969	80.97	
No	946	21.35	259	15.60	198	15.46	1,403	19.03	
Total	4,431	100.00	1,660	100.00	1,281	100.00	7,372	100.00	

Degrees of Freedom = 2 p value = 0.000000

		Regional He National Data ۱۹	ealth Survey - Unadjuste 997	d		
	Y	es	1	No	Тс	otals
	Number	Percent	Number	Percent	Number	Percent
Single	2,635	80.04	657	19.96	3,292	100.0
Married	1,360	84.89	242	15.11	1602	100.0
Common Law	436	86.85	66	13.00	502	100.0
Separated	266	84.98	47	15.00	313	100.0
Divorced	309	79.64	79	20.36	388	100.0
Widowed	2.06	78.11	578	21.89	2,640	100.0
Total	7,068	80.90	1,669	19.10	8,737	100.0

		National Dat	ta - Unadjus 1997	ted		
	Attended		Not At	tended	Total	
	Number	Percent	Number	Percent	Number	Percent
Yes	1,714	86.87	4,926	78.66	6,640	80.63
No	259	13.13	1336	21.34	1595	19.37
Total	1,973	100.00	6,262	100.00	8,235	100.00
		Regional National Da	Health Surve ta - Unadjus	ey ted		
-------	--------	----------------------	------------------------------	-----------	--------	---------
			1997			
	Same	Level	Not Sa	me Level	To	tal
	Number	Percent	Number	Percent	Number	Percent
Yes	2,279	77.99	3,467	85.73	5,746	82.49
No	643	22.01	577	14.27	1220	17.51
Total	2,922	100.00	4,044	100.00	6,966	100.00

		National Dat	a - Unadjuste 1997	ed		
	Y	′es	Ν	10	Тс	otas
	Number	Percent	Number	Percent	Number	Percent
Excellent	995	78.41	274	21.59	1,269	100.00
Very Good	2,598	81.47	591	18.53	3189	100.00
Fair	2,853	82.50	605	17.50	3,458	100.00
Poor	430	77.48	125	22.52	555	100.00
Totals	6,867	81.17	1,595	18.83	8,471	100.00

		National [Data - Unadj 1997	usted		
	Isol	ated	Not Is	solated	То	ot s l
	Number	Percent	Number	Percent	Number	Percent
Yes	2,542	81.01	4,570	80.81	7,112	80.88
No	596	18.99	1,085	19.19	1,681	19.12
Total	3,138	100.00	5,655	100.00	8,793	100.00
	05	100100	0,000	100100	0,700	10010

		٢	National D	ata - Una 1997	djusted			
	Agre Siç	ement gned	Pre-ti	ransfer	No Ag	reement	Тс	otsal
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Yes	3,095	82.91	1,955	77.12	2,032	81.74	7,112	80.88
No	638	17.09	589	22.88	454	18.26	1,681	19.12
Total	3,733	100.00	2,574	100.00	2,486	100.00	8,793	100.00

Regional Health Survey National Data - Unadjusted 1997								
	No Pro	ogress	Some P	rogress	Good F	rogress	Tota	als
	Number	Percent	Number	Percent	Number	Percent	Number	Percen
Traditional Healing	2,080	31.63	3,669	55.79	827	12.58	6,576	100.0
Native Spirituality	1,910	29.60	3610	55.94	933	14.46	6,453	100.0
Traditional Roles of Women	3,024	47.62	2,675	42.13	651	10.25	6,350	100.0
Traditional Roles of Men	2,813	44.26	2799	44.04	744	11.71	6,356	100.0
Traditional Ceremonial Activity	1,741	26.85	3223	49.71	1519	23.43	6,483	100.0

Table 14: Progress in Other Community Wellness Factors

Regional Health Survey National Data - Unadjusted 1997

	No Pr	ogress	Some P	rogress	Good P	rogress	То	tals
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
First Nation / Inuit Controlled Programs	2055	26.66	4474	58.05	1178	15.28	7707	100.00
Return to Traditional Ways	2158	27.23	4748	59.91	1019	12.86	7925	100.00
Use of Elders	1881	22.96	4348	53.08	1936	23.96	8192	100.00
Personal Commitment to Healing	2955	38.59	3766	49.18	937	12.24	7658	100.00
Renewed Relationship with Land	2929	37.89	3652	47.24	1149	14.86	7730	100.00
Networking Among Communities	2691	35.10	3833	50.00	1142	14.90	7666	100.00
Use of First Nations / Inuit Language	2219	27.31	4040	49.72	1867	22.96	8126	100.00
Training in Health Field	2532	32.37	4196	53.64	1094	13.99	7822	100.00
Reduction in Alcohol / Drug Abuse	4077	50.70	3313	41.20	652	8.11	8042	100.00
First Nation / Inuit Health Professionals	3347	42.66	3618	46.12	880	11.22	7845	100.00
Cultural Programs in School	1665	21.15	4421	56.16	1786	22.69	7872	100.00
Education / Training Opportunities	1738	21.28	4573	55.98	1858	22.74	8169	100.00
Employment Opportunities	3169	38.47	4129	50.13	939	11.40	8237	100.00
Housing Quality	2517	30.35	4073	49.11	1703	20.54	8293	100.00
Water / Sewage Facilities	1801	22.15	3837	47.20	2492	30.65	8130	100.00

Table 15: Perceived Progress in First Nation / Inuit Control
by State of Health Transfer

Regional Health Survey National Data - Unadjusted

1997

	Transfe	r Comp.	Pre-tra	ansfer	No T	ransfer	То	tal
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
No Progress	823	26.01	596	27.35	636	28.43	2,055	26.66
Some Progress	1,841	55.94	1,340	61.50	1,293	57.80	4,474	58.05
Good Progress	627	19.05	243	11.15	308	13.77	1,178	15.28
Total	3,291	100.00	2,179	100.00	2,237	100.00	7,707	100.00

Chi square = 71.67 Degrees of Freedom = 4 p value = 0.00000000

Table 16: Desire to return to Traditional Ways By Perception of Progress in Returning to Traditional Ways Regional Health Survey National Data - Unadjusted 1907										
	No Pro	gress	Some Progress		Good Progress		Total			
	Number	Percent	Number	Percent	Number	Percent	Number	Percent		
Yes	1,560	23.47	4,150	62.42	938	14.11	6,648	100.00		
No	457	49.67	416	45.22	47	5.11	920	100.00		
			+	-		1				

214

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ENDNOTES:

- The merging of the regional datasets into the national database was done by the Northern Health Research Unit, Department of Community Health Sciences, University of Manitoba. A separate report has been created that includes more details on the methodology.
- 2. Covey uses the concept of paradigm throughout the book beginning with his discussion of the "efficiency paradigm" in the introduction on page 13 and continuing through the "urgency paradigm" and "importance paradigm" in the body of the book.
- 3. Diagram adapted from presention by Colin Rope, Indian Child & Family Services, Health & Social Development Commission, Federation of Saskatchewan Indian Nations.
- 4. For a more extensive review of some of the world view differences between western European society and First Nations people.
- 5. This item is included in the "traditional" list because it is not part of the standard "medical model" of health care. In the "medical model" there is little perceived need for a "personal commitment to healing" because the disease comes from outside the individual and so does the solution. The only "personal commitment" needed is a trust in the expertise of the medical practitioner.
- 6. Technical review of "The Search for Wellness" July 29, 1998. Page 4
- 7. For examples of more community and family approaches see "Expanding the Circle of Healing A Report on Strengthening Individual and Community Capacity to Respond to Crisis", "Freeing the Next Generation – A Report on Addictions Options in First Nations Communities", and "Reclaiming Our Three Powers - A Community Orientation Project" all published by the Health & Social Development Commission of the Federation of Saskatchewan Indian Nations. An example already implemented is the Kahnawake Schools Diabetes Prevention Project – See Alex McCumber

Chapter 7

HEALTH AND DENTAL SERVICES FOR ABORIGINAL PEOPLE

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Table of Contents

List of Figures	219
Introduction	220
Review of the Literature	221
The Historical Development of Health Services	221
Contemporary Issues	224
A Sample of Recent Specific Studies	227
Utilization of Health Services	227
Studies that Identify Gaps in Service	228
The Preventive Aspect of Health Services	228
Occupational Roles	228
Dental Care	229
Summary	230
Methodology	231
Results	233
Health Services: Equal or Not?	233
Services in Need of Improvement	236
Dental Health	238
Conclusion	241
References	243



List of Figures and Tables

Figure 1: Contact with Health Professionals in the Past 12 Months	227
Figure 2: Gender of the Adult Population %	231
Figure 3: Age Distribution of the Adult Population $\%$	232
Figure 4: Belief in the Level of Health Services %	233
Figure 5: Belief Health Services Not Equal by Gender	233
Figure 6: Belief Health Services Not Equal, By Age %	234
Figure 7: Belief Health Services Not Equal By Education %	234
Figure 8: Belief Health Services Not Equal By Language %	234
Figure 9: Belief Health Services Not Equal, By Community Isolation $\%$	235
Figure 10: Belief Health Services Not Equal By Community Size%	235
Figure 11: Belief Health Services Not Equal By Health Transfer Status	235
Figure 12: Belief HealthServicesNotEqual, BySelf-ReportedHealthStatus%	236
Figure 13: Health Services in Need of Improvement %	236
Figure 14: Improvement in Medication Awareness Programs, By Level of Education $\%$	236
Figure 15: Improvement in Mental Health Services By Age Group $\%$	237
Figure 16: Improvement in Kidney Dialysis By Self-Reported Health Status $\%$	237
Figure 17: Last Time Received Dental Care by Gender %	237
Figure 18:Received Dental Care in Past Year By Age Group $\%$	238
Figure 19: Need Dental Treatment at this Time By Gender %	238
Figure 20: Need Dental Treatment at this Time By Age Group $\%$	238
Figure 21: Need Dental Treatment at this Time By Educational Level $\%$	239
Figure 22: Need Dental Treatment at this Time By Language Use $\%$	239
Figure 23: Type of Dental Treatment Needed	239
Figure 24: Number of Dental Problem Requiring Treatment $\%$	240
Figure 25: Dental Problems or Pain in Past Month By Gender $\%$	240
Figure 26: Dental Problems or Pain in Past Month By Community Size $\%$	240
Figure 27: Dental Problems or Pain in Past Month By Community Transfer Status $\%$	240

INTRODUCTION¹

The health of a population is not measured by its use of health services, but health services are an important contributor to the overall health of a population. Health services are also one measure of response to a population's health care needs. The First Nation and Inuit Regional Health Survey (FNIRHS) contains a number of questions that address the perception of quality of health services and the need and use of dental care.

The purpose of this paper is to summarize the results of questions asked on the survey about health services and dental health services and needs. We begin with a brief review of the literature, followed by a discussion of the methodology and results pertinent to this assignment. The paper concludes with some thoughts on policy and future research with respect to Aboriginal health and dental services.



Review of the Literature

The Historical Development of Health Services²

Pre-European contact Aboriginal peoples in the Americas lived under a variety of environmental conditions, consumed widely varying foods, experienced different levels of population densities, engaged in varying degrees of cooperation and conflict, and faced times of food scarcity as well as surplus. All of these factors, and more, could be expected to affect their health and therefore the need for health services. Among the Iroquois, for example, diets rich in carbohydrates based on the maize horticulture are being linked to dental problems. In the Arctic, there is evidence of respiratory diseases such as pneumonia as well as the potential for poisoning from toxic plants or shellfish. Along the Northwest Coast peoples, the examination of skeletal remains provides an indication that the high percentage of fractured limbs discovered was most likely caused by inter-tribal warfare. Young (1988:32-35) draws on the accounts of early European explorers to describe a native population in the Central Subarctic that is on the whole quite healthy but there is mention of conditions such as consumption, scrofula, and venereal disease.

Thus, while the concept of providing "health services" dates from more recent times and from Western culture, nevertheless Aboriginal people had their own forms of preventing illness or looking after or seeking to cure those who became ill. As with other functions such as education, health care was not, by and large, carried out by highly differentiated roles and institutions. Rather, traditional medicine could be described as being comprised of "sets of coherent beliefs and practices which were well integrated within Aboriginal societies and which served important social and religious as well as medical functions" (Waldram et. al., 1995: 99-100). While it is important to recognize variation among different cultural groupings, the available records indicate adherence to the belief that disease could be caused by both natural and supernatural causes. Health practices included those that are not far removed from Western medicine, such as the use of plant and herbal medicines, the recognition that open wounds needed to be dressed in order to avoid or reduce infection, the use of bandages and tourniquets, and the practice of surgery. But the spiritual element was also important, arising from a world view that included the existence of spiritual beings that were human but also those that were other than human. Among the Ojibwa, for example:

"Within this world view, minor illnesses such as colds, headaches and digestive disorders were not likely to arouse anxiety, and were treated with herbal remedies. Serious illnesses, in contrast, were viewed as a penalty for a prior transgression of the moral order, and therefore required the assistance of a specialized healer. Such transgressions could involve only human beings, or they could involve a breach in the relationship between human beings and otherthan-human beings. The cause of illness was sought within the web of interpersonal relations involving both sets of beings; hence both the occurrence of disease and its treatment served to reinforce both the social and moral order of Ojibwa society, an important function in a society where informal mechanisms of maintaining the moral order were the norm. Indeed, confession by individuals, detailing breaches of the order that they had committed in the past. was an essential ingredient of treatment.

In general, then, the Ojibwa case underscores a principle common to Aboriginal healing systems: the world is seen as a place in which harmony and balance exist between and among human beings or spiritual or 'other-than-human' entities, and serious illness is indicative of a disruption in this balance. Furthermore, it is apparent that these healing traditions encompassed a holistic view of manifestations of illness in the individual; there is little evidence of a clear distinction between what science would call somatic disorders and disorders of the psyche..." (Waldram et. al., 1995:101-102).

Then, as now, the first recourse in times of illness besides symptomatic care and nurturing in the household would be for adults to use knowledge passed on from their parents, about plant and herbal medicines and other first aid techniques. As the above quotation implies, however, more serious illnesses might well involve calling in additional resources such as healers of various kinds. Some might have more extensive knowledge of herbal and plant medicines while others might be known for their strengths in being able to contact spiritual entities to assist in diagnosis and treatment. As part of the healing process, the healers might play tricks on the demons within their patients, or attempt to suck poisons out of the body. More elaborate ceremonies involving spiritual assistance might also be organized, such as the shaking tent ceremony or the sweat lodge.

With the beginning of sustained contact with Europeans in the 1500's, Aboriginal peoples were faced with major intrusions in their way of life. Initial contacts with visiting fishing boats were temporary and usually benign. However, the arrival of fur traders, whalers, missionaries, settlers, soldiers and governmental officials had increasingly profound and far-reaching effects on Aboriginal lands, resources, and social structures.

In the early years of contact, it was perhaps more the Europeans who were in need of Aboriginal health services than vice versa. Indeed, there are many accounts of new arrivals suffering from scurvy and other illnesses, or lacking the means to survive the initial winters, who benefited from Aboriginal foods and medicines.

As is well known, however, Europeans also brought with them other, infectious diseases whose devastating effects quickly spread among Aboriginal populations. Diseases such as smallpox, measles, diphtheria, tuberculosis, and influenza decimated Aboriginal communities. In addition, the disruption of Aboriginal ways of making a living, which intensified as land hungry settlers flooded to the colonies, led to widespread malnutrition and starvation.

While Aboriginal health services continued to be provided within Aboriginal communities, Aboriginal people also looked to European medicines and technologies for relief. In the years prior to Confederation, the delivery of health services to Aboriginal peoples was largely sporadic and ad hoc. Fur traders, whalers and missionaries, who might have first aid supplies, vaccines or rudimentary medical instruments available, delivered it. Such health services as were on hand were also provided with motives that went beyond humanitarian ones – for example, to keep alive those who would supply a fur trading post with pelts or fresh meat, or as part of an agenda that included conversion to Christianity.

What is clear from the available accounts is that European health services were very limited in their reach as far as the Aboriginal population was concerned. The supply of medicines was limited, and those most likely to benefit were those who were employed by, settled near, or did business with, the trading post or whaling station. Clearly the health services that were available were no match for the disruptions and diseases that decimated Aboriginal populations. Indeed, the Royal Commission on Aboriginal Peoples reports a decline in the Aboriginal population from an estimated 500,000 persons around the year 1500 (a figure that many would regard as conservative) to a low of just over 100,000 in 1871. The population subsequently stabilized and began to grow in small increments until the 1950s when major population increases began to take place (RCAP, Vol. 1, 1996:13).

These patterns of ad hoc care provided by traders, missionaries and government agents continued even after Confederation in 1867, and the assumption of federal responsibility for "Indians and lands reserved for Indians" as specified by the British North America Act (Hawley, 1993: 151). The nature of the "government agents" changed, however, first with the establishment of the Northwest Mounted Police in 1873. Apart from their role in controlling the alcohol trade, there are accounts of individual police constables assisting Indian bands suffering from outbreaks of smallpox and diphtheria, enforcing quarantines, and providing relief to the starving. Police doctors also provided health services. After 1871, Indian agents were appointed and deployed across the country. Their wide-ranging powers included providing medical assistance and food rations to those in need. Some Indian agents were medically qualified, and in other cases a physician might be part of the staff attached to an Indian agent's office (Young, 1988:85). The Canadian military also played a role in the provision of health services, especially as their role expanded in the Canadian Arctic with the construction of the distance early warning (DEW) lines and other facilities after the

The period immediately after Confederation was also a time when major treaties were signed between representatives of the Crown and western and northern Aboriginal nations. The issue of Canada's legal responsibility to provide health care services became an issue. One of the so-called numbered treaties, Treaty 6, contains two clauses pertaining to health care. The first promised assistance in the event of any pestilence or general famine, at the discretion of the Chief Superintendant of Indian Affairs. The second pledged that a "medicine chest" would be kept at the house of each Indian Agent for the use and benefit of the Indians, at the discretion of the agent. Records of discussions in at least three other treaties indicate that the need for health services such as medicines and health personnel were raised, but no written provision appears in the text of these treaties. Aboriginal organizations have taken the position that a full reading of the treaties, including their spirit and intent, was such as to establish a treaty right and therefore a legal obligation, to health care. The federal government, however, has taken the position that it provides health care as a matter of policy governed by humanitarian considerations, and this perspective has by and large prevailed in the courts (Young, 1988:83).

The treaties notwithstanding, the predominant impression that emerges of the decades of the late 1800s and early 1900s is that health services available to the Aboriginal population were very meagre and grudgingly provided, constantly constrained by budgets and government officials who refused to make them a priority. Among the worst health conditions were found in the residential schools where conditions were almost ideal for the contracting and spreading of diseases such as tuberculosis. Indeed, the Royal Commission's account of residential schools indicates that "overcrowding, the most critical dynamic in the spread of tuberculosis, was systemic, a predictable outcome of underfunding and of the per capita grant arrangement that put a premium on each student taken from a community" (RCAP, Volume 1, 1996:357). One estimate of the early 1900s, prepared by the first medical officer to be appointed by the federal government with responsibility for Indian health, estimated that 25 to 35 per cent of children who had been attending residential schools had died, primarily because of diseases such as tuberculosis and measles (Waldram et. al, 1995:156).

Beginning with the post-World War I era, however, and accelerating after the Second World War, the investment of the federal government in Aboriginal health services increased significantly. Even though the budget was reduced in the early years of the Depression:

"In 1935, there were eleven medical officers in the Medical Branch who were employed full time, and eight Indian agents with medical training. Another 250 physicians were employed part time, or as needed, including urban-based specialists; and still others saw Indian patients privately. There was little in the way of dental services, outside of basic services such as extractions. A total of eleven field nurses were employed by the branch, supplemented by others employed by missionary or provincial organizations." (Waldram et. al., 1995:160).

The account goes on to describe the opening of nursing stations and the availability of a network of hospitals, including tuberculosis sanitaria. Located mostly in southern regions of Canada, the latter would be used extensively to care for Inuit flown in from the North as well as Metis and First Nation populations. Despite these gains, a 1934 estimate reveals that per capita spending on Indian health was only about onethird of the amount spent for the non-Aboriginal population, and this despite the manifestly poorer health situation of the Indian population (cited in Waldram et. al, 1995:161). Nevertheless, each subsequent decade showed continued expansion in the availability of health personnel and facilities.

As the health and welfare state expanded in Canada, especially in the post-World War II period, Aboriginal populations were included, although there are examples of programs where coverage for Aboriginal populations lagged behind the mainstream. In 1944, National Health and Welfare became the newest federal department and a year later the programs of the Indian and Northern Health Service which until then had been lodged in the Department of Indian Affairs, was transferred to it. A major step in improving the availability and accessibility of health services was taken on behalf of all Canadians in the 1960s when the national universal medical insurance program was established.

Contemporary Issues

t the present time, health services for registered AFirst Nation and Inuit persons are funded and in many cases administered by the Medical Services Branch (MSB) of Health Canada. This Branch has regional directorates, one per province with the exception of the Atlantic Region which encompasses the four Maritime provinces and includes services to the First Nations and Inuit of Labrador. Working with an Indian and Inuit Health Program budget in the order of \$1.064 billion in 1998-99, the Branch is responsible for a large number of health centres or nursing stations across the country, and a small and declining number of hospitals (MSB, 1999). In addition, MSB funds programs such as the National Native Alcohol and Drug Addiction Program (NNADAP), the Indian and Inuit Health Careers Program, and the Community Health Representatives Program. About half the budget is paid out in the form of non-insured health benefits, by which is meant a whole host of health-related items that are not covered by universal medical insurance programs. Included are the cost of health insurance premiums, drugs, medical supplies such as eyeglasses and prosthetic devices, dental care and patient transportation. Various cost-sharing and reimbursement provisions are in place to compensate for First Nation and Inuit clients' use of provincial health service programs.

Responsibility for the design and delivery of health services is changing rapidly. In the late 1980s, the Government of the Northwest Territories took over responsibility for health services for all residents of the Territory, and even this fairly recent arrangement will be superseded in the eastern Arctic by the creation of the new Nunavut Territory in April 1999. The Inuit in Labrador are on the threshold of a major land claim agreement that will contain provisions for selfgovernment, including the resumption of responsibility for health services. Treaty negotiations in British Columbia are also changing the shape of the legislative and administrative landscape. In addition, some other modern comprehensive land claim negotiations have resulted in agreements that included provision for selfgovernment in the health area. The James Bay and Northern Quebec Agreement (1975), which resulted in the establishment of a Cree Board of Health and Social Services (1978), is a case in point.

Apart from comprehensive land claim negotiations, since 1986 the federal government has also been pursuing a policy of negotiating the transfer of responsibilities for existing health services with those First Nations who wish to proceed in this direction. The transfer process involves a three step sequence, beginning with pre-transfer planning and moving on to a negotiation stage and finally to the signing of a transfer agreement. By late 1997, 30 per cent of First Nations had signed a health transfer agreement and a similar percentage was involved in pre-transfer planning. In addition, 12 per cent had concluded what are known as integrated agreements³. (DIAND, 1997:25).

While some examples of regaining control in the health area are now one or two decades old, it is still too early to see clearly what the impact of these changes have been on the health of the populations affected. Waldram et. al. (1995) give some initial indication based on a small number of case studies, and conclude that the preliminary results are promising. In particular, when control over health services passes to Aboriginal communities there is the prospect that priorities can change, for example toward more preventive kinds of approaches, or toward a more holistic conception. Health staff are more likely to be based in the community and to be able to deal with situations that might previously have required the patient to be removed to an urban area. Members of the community are also more likely to feel at home at the health centre, to be served in their own language and in a fashion that is consistent with the local culture. As has been the case with the assumption of control over family and children's services, so it is in the health area where community members such as elders are more likely to avail themselves of a service if they feel it is their own.

In its Final Report, the Royal Commission on Aboriginal Peoples was positive about the transfer process, but with some qualifications:

"The research we commissioned and the briefs and submissions we received leave us singularly impressed with the extent to which health programs in communities that have participated in transfer initiatives increasingly reflect Aboriginal priorities. First Nation and Inuit authorities at the community and regional levels have responded creatively to a limited opportunity and have begun to transform health facilities and programs along the lines we envision.....Creativity in Aboriginal services is dampened, nevertheless, by policy and funding constraints imposed from outside Aboriginal communities." (RCAP, Volume 3, 1996:250, 251).

More specifically, what is being transferred is authority over existing programs and services, and existing budgets. The transfer process stops well short of full self-government in the health area supported by appropriately negotiated fiscal relations and programs to build capacity in Aboriginal communities. It does not, for example, take into account a full assessment of the health needs of the population but rather is restricted to programs and services already developed. Even for existing programs, Aboriginal leaders are very concerned about the adequacy of funding arrangements. There is no provision to prevent unilateral cutbacks from the federal level, or to make secure provision for increases to meet rising demand for health services. There is also concern that, as First Nation and Inuit communities take over programs, the federal government's fiduciary responsibility for Aboriginal people will be eroded.

The Royal Commission and its report were a major event in the history of the relationship between Aboriginal and non-Aboriginal peoples in Canada. In its discussion of health and healing, the Commission took the broadest possible view of the determinants of health in Aboriginal communities. In the process it placed the preoccupation of many health professionals with the narrow parameters of health services into context⁴. It took the position that basic medical care and public health services (such as sanitation, attention to the quality of food and water, and housing) must exist at a minimum standard in order to ensure health. It stated that, beyond the public illness care system and private lifestyle choices, several other determinants were exceedingly important. These included economic factors such as poverty, unemployment and income distribution; social factors such as the degree of control that individuals and communities have over their life circumstances, and the quality of early childhood experiences; and emotional and spiritual factors that link elements such as stress, trauma, and the availability of social supports to physical health.

Commissioners were struck by the congruence between Aboriginal philosophies of health and wellbeing on the one hand, and the emerging paradigm shift in the approach to health arising from the findings of bio-medical researchers on the other. Areas of convergence included the belief that "true health comes from the connectedness of human systems, not their separate dynamics" and that "the essence of good health is balance and harmony within the self and within the social and natural environments we inhabit" (RCAP, Volume 3, 1996: 221, 222).

"A third converging theme is that of personal responsibility. In the health determinant field, this theme has taken two forms. One is the idea that personal health choices matter, and that we can all make a difference to our future health status by stopping smoking, reducing alcohol intake, eating properly, exercising regularly and so on. Added to this is the idea that medically trained experts are not the only ones with insight into health and wellness – that, in fact, the final judge of our well-being can only be ourselves. In the Aboriginal view, collective responsibility is also significant. Many speakers told us that solving health and social problems must become the responsibility of Aboriginal people taking action together, and that individual self-care must be matched by community self-care." (RCAP, Volume 3, 1996:221, 222).

The Commission dealt extensively with subject areas such as governance, economic development, and residential schools in its Final Report. With regard to health services more specifically, the Commission's strategy focused on four areas:

- "the reorganization of health and social service delivery through a system of healing centres and lodges under Aboriginal control
- an Aboriginal human resources development strategy
- adaptation of mainstream service, training and professional systems to affirm the participation of Aboriginal people as individuals and collectives in Canadian life and to collaborate with Aboriginal institutions, and
- initiation of an Aboriginal infrastructure program to address the most pressing problems related to clean water, safe waste management, and adequate housing." (RCAP, Volume 3, 1996:231).

The Commission recommended that "new Aboriginal health and healing systems should embody four essential characteristics:

- pursuit of equity in access to health and healing services and in health status outcomes
- holism in approaches to problems and their treatment and prevention
- Aboriginal authority over health systems and, where feasible, community control over services, and

• diversity in the design of systems and services to accommodate differences in culture and community realities" (RCAP, Volume 3, 1996: 223,224).

It took the federal government more than a year to come to grips with the Commission's final report and its recommendations. In February, 1998, the Minister of Indian Affairs and Northern Development released the Government of Canada's response. The main elements of the Gathering Strength document were a statement of reconciliation and the announcement of a fund to promote healing resulting from the damage caused by residential schools. However, the response also spoke about renewing the partnership, strengthening Aboriginal governance, developing a new fiscal relationship, and supporting strong communities, people and economies. Under the latter heading, the document made commitments to improve community infrastructure such as housing and clean water. It reviewed the major thrusts of the 1994 Building Healthy Communities Strategy, which emphasizes the transfer approach to facilitating community control and sought to address priority service gaps in mental health, solvent abuse and homecare nursing. It also made commitments in the area of the training of Aboriginal health professionals, and on the prevention, care and research related to diabetes. Finally, it supported the establishment of an Aboriginal Health Institute for purposes of research, training and information dissemination. (DIAND, 1998, 23-25).

In this literature review, we have so far accessed some of the major, general studies and reports that pertain to the provision of health services to Aboriginal populations in Canada, both historically and at the

Health & Dental Services

present time. In the process, we have identified some of the major issues that are current in the field. These include the transition process, which might be labeled a process of decolonization, whereby Aboriginal governments are reconstituted and regain responsibility for the provision of health services to their populations. Related to this are issues of capacity building and financing. A second issue is that of making room for a respected place in the design and delivery of programs for Aboriginal perspectives on health which are complementary to, and at times in conflict with, the Western biomedical model. Thirdly, the Royal Commission Report and other sources have underlined the importance of coming to grips with the determinants of health in the broadest sense, in the context of which improvements of health services can make only a modest contribution. These and other issues, such as the need to shift services in a more preventive direction, and to improve the cross-cultural sensitivity of mainstream health service providers, are cited frequently in the literature.

In addition to these general studies, which are Canada-wide in their scope or encompass entire regions, there are many other studies that are specific to particular locales, projects, illnesses or interventions. Perhaps the most numerous are those that are medical in nature, describing particular chronic and other conditions and the effectiveness of medical interventions. These are relevant to health services in the sense that they document the kinds of health conditions to which health services need to respond. Specific studies on health services per se are less numerous, and can be classified into five groupings. We refer to several in each category by way of example, and limit our review to those that are quite recent.









A Sample of Recent Specific Studies

	Northwest Territories Aboriginal (%)	Northwest Territories Non-Aboriginal	Residents of the Provinces
General Practitioner	36.00	60	77
Dentist	46.00	54	56
Eye Specialist	34.00	33	35
Nurse	41.00	18	7
Other Medical Doctor	14.00	18	26
Social Worker	16.00	6	5

Figure 1: Contact with Health Professionals in the Past 12 Months

Source: 1994/95 National Population Health Survey as reported in Diverty and Perez (1998). The population analyzed is aged 12 years and older.

The Utilization of Health Services

number of studies are available that examine the Aextent to which Aboriginal people use particular kinds of health services. Dalrymple et. al. (1995), for example, presented data on admission rates for Native and non-Native clients to a psychiatric hospital in Thunder Bay, Ontario. The results showed that Native patients are admitted at a rate 33 per cent higher than would be expected on the basis of the size of the population, and that the length of stay is also longer. The authors explained that the hospital was providing services to Native populations that result from economic, social and cultural dislocation, more so than from other types of psychiatric illnesses. Admissions were also linked to atypical depressions, which could better be addressed through community mental health services.

Data on the utilization of a broader range of health

services are found in Diverty and Perez (1998), who present the data shown in Figure 1.

The results show much higher use of nursing and social work services for the Aboriginal population, reflecting in part how health services are organized in the Northwest Territories, and much lower use of general practitioners, other medical specialists except for eye specialists, and dentists. These results are broadly consistent with those reported by Waldram et. al., (1995).

Other studies in this vein include that by Newbold (1997) who examined factors that influence the use of physician services by Aboriginal people:

"The results demonstrate that Aboriginals were much less likely to use physician services even though Aboriginals rank their health similarly to the Canadian population. Location becomes an important aspect of both physician use and health status, with Aboriginals residing on-reserve generally having lower levels of self-assessed health and less likely to have seen a physician. While Aboriginals with the poorest health status were more likely to have seen a physician, other

factors including education were found to be barriers to use of health care. Aboriginal identity and cultural orientation produced mixed results."

Studies That Identify Gaps in Services

Waldram et. al (1995) point out that utilization rates reflect the interaction of at least three variables: the need for particular kinds of services; the availability of those services; and the barriers that may prevent access even if the service is available. There are many studies that identify particular health problems in Aboriginal communities, such as disability, mental health and chronic diseases requiring home care, and make the point that appropriate services are not available.

Ng (1996), for example, compared rates of disability among Aboriginal and non-Aboriginal people. She found that the majority of Aboriginal people with disabilities neither required nor received help with their disabilities, but at least 13 per cent did not receive help when they needed it or did not receive sufficient help. Kruk and Vryheid (1993) concurred, finding that the availability of services and programs for the disabled living on-reserve, and access to rehabilitation services off-reserve, were low. Much of the problem stems from the fact that rehabilitation services are not provided under federal jurisdiction, although provincially-run services look to the federal level when it comes to providing services to reservebased residents. Hence, a gap in service provision occurs.

Peters and Desmarais (1997), and MacMillan et. al. (1996), are among those who identified the inadequacy of mental health services for Aboriginal people, while Feather and Irvine (1990) addressed the need for home care services as a cost-effective alternative to institutional care.

Finally, we note the article by Wilson et. al.(1994) who address a recurring problem in the provision of health services, specifically the problems faced by Aboriginal patients from northern regions who are brought to health care settings in southern Canada for specialized care.

The Preventive Aspect of Health Services

It is encouraging to see that some studies are appearing that document preventive approaches to health care. Macauley et. al. (1997), for example, describe in some detail a 3-year community-based project that seeks to improve healthy eating and physical activity among elementary school children in a Mohawk community near Montreal. The authors stress the need for primary prevention in view of the high incidence of diabetes in Aboriginal populations, and they describe one of the first such programs to be evaluated in Canada. Along similar lines, Grams et. al. (1996) report how qualitative research was used to develop a culturally-sensitive community-based approach to managing non-insulin dependent diabetes, based on how Haida people experience the disease.

Many other health service interventions have a preventive aspect, whether it is to improve home care services to prevent unnecessary hospitalizations (Beirne, 1990) or to improve dental services to reduce the incidence of dental caries or the proportion of tooth extractions (Mayhill, 1990).

Occupational Roles

nother class of study includes those that discuss The roles of particular occupational groups in the provision of health care services, whether these be physicians, nurses, dental therapists, or interpreters. O'Neil (1989), for example, examined the role played by interpreters. He argued that a high level of patient dissatisfaction with medical services in the Keewatin could be attributed to poor communication between patient and doctor. These communication problems can best be understood if they are linked to wider issues of political economy, racism and exploitation in a colonial medical system. The development of Inuit-controlled health organizations has been severely constrained by this colonial structure, and a profound separation of knowledge and power between Inuit and non-Inuit care providers has resulted. The author suggests that one way of improving the medical system is to enhance the capacity of Inuit interpreters to act as advocates. Although some health care workers conceive interpreters to have a neutral role in patient-doctor

interaction, advocacy is argued to be a necessary strategy given the power differentials between Aboriginal people and health care professionals.

Dental Care

We mentioned at the outset that one of the health services in which we had a particular interest was that of dental care, because we will be reporting in the next section on some results on this topic from the First Nation and Inuit Regional Health Survey. The literature on dental services is not extensive and seems to deal primarily with dental problems and services in the more northern and remote regions.

The prevalence of dental problems historically has varied regionally and over time, depending on the diet and nutritional habits that Aboriginal people were accustomed to. Bjerregaard and Young (1998), for example, mention that dental caries among the Inuit around the turn of the last century were almost unknown due to the absence of sugar (as well as refined carbohydrates and fat) in the traditional diet. This changed in the latter half of the century. Rea et. al. (1993) write about the "epidemiologic transition":

"Surveys conducted in Alaska and Greenland in the early 1900s showed the Inuit, along with other aboriginal peoples living a traditional lifestyle, had excellent dental health minimal caries, and little tooth loss even in old age. Studies conducted during the period when Southern, highly cariogenic foods were first becoming available in the North found marked differences within Inuit communities along dietary lines. In several studies, a marked age differential was apparent. Parents and grandparents, still eating a more traditional diet, had better teeth or a slower decline in oral health than children raised on store-bought foods. In the third phase, residents of communities such as those in Keewatin, where Southern foods have been available for some time and are widely used, have a uniformly poor level of oral health. Whether a fourth stage will appear, in which preventive measures in diet, oral hygiene, and dental care will reduce the burden of illness, remains to be seen. Reductions in the caries burden of children in Greenland may be an early indication of this." (Rea et. al., 1993:123)

The current situation is not good. The most systematic, national, study is that undertaken by the Department of Community Health at the University of Toronto (Leake, 1992). This is a study that examines the dental health of Aboriginal children aged 6 and 12 years. The results show that, while nearly 75 per cent of the children surveyed had received dental care in the year preceding the survey, still 91 per cent of them suffered from tooth decay. However, children who had access to fluoridated water supplies suffered less from tooth decay than those who did not. Approximately 25 per cent of Aboriginal children regularly suffered from toothache or bleeding gums, and only half the children could be said to have healthy gums.

This national survey was repeated in 1996 with similar results. To take just two indicators, in 1996, 89 per cent of 12 year-olds and 95 per cent of six year-olds had at least one decayed, missing or filled tooth. As in 1991, two-thirds of the children examined required urgent treatment, restoration work, or extractions (Saskatchewan Indian Federated College, 1998).

For Inuit children in the North, Bjerregaard and Young (1998) draw from Leake (1992), and Zammit et. al. (1994) in coming to the following conclusions about dental problems affecting Aboriginal youth:

"A survey of the oral health of aboriginal children in Canada in 1990-91 shows that, in the NWT where the majority of the children surveyed are Inuit. 95% of children at ages 6 and 12 have at least one decayed, missing, or filled tooth. The mean DMFT score (the decayed-missing-filled-teeth index) is 8.2 and 8.7 in the two age groups. These figures are similar to those for other aboriginal children and considerably higher than figures for southern Canada. In Ontario, which has the best dental health indicators, 48% of 13 year old children are caries-free and the mean DMFT is 1.7. Baby bottle tooth decay is a very prevalent condition. The investigators were surprised by the high caries levels in the most remote communities and by the low level of care evident, as well as by the high level of reported use of sugar-snacks....In Labrador Inuit children and youth aged 5-22, only 3% were found to be caries free, and 88% of those with caries had untreated dental decay. The mean DFMT was 6.9...." (Bjerregaard and Young, 1998:96,97).

These and other studies, such as Rea et. al. (1993) who report on the Keewatin region, clearly establish the high level of need for dental services that exist, whether among children or adults. Indeed, speaking of adults, the Keewatin study concluded that:

"Sixty per cent of adults needed at least one restorative procedure, 68 per cent needed prophylaxis, and 45 per cent needed periodontal treatment. Men required treatment of all types more than women. The results of this study confirm the clinical impression that dental disease is rampant among the Inuit population. There are major needs for both preventive and treatment services." (Rea et. al., 1993:117).

Bedford and Davey (1993) report that, as little as

25 years ago, there were hardly any formal dental delivery services available for remote locations. They say it was not uncommon for nurses or priests to extract teeth, or for children to be flown into larger centers such as Iqaluit (then Frobisher Bay) to have a decayed tooth extracted. A major change in the situation began in the early 1970s when the University of Toronto was contracted to develop and operate a national school of dental therapy, whose graduates went on to serve in remote locations (McDermott et. al., 1990). The University of Manitoba also stands out in its service to communities in northern Manitoba and the Keewatin region (Odlum, 1995).

Dental services are now provided under the Non-Insured Health Benefits Program of the Medical Services Branch of Health Canada. First Nation and Inuit clients of MSB can access private practitioners across the country, as well as resident dental therapists in more remote locations. Blue Cross provides payment services to the private practitioners, under contract with MSB, and the national claims processing service is now able to capture national data and individual client histories and provider profiles for the first time. Annual negotiations take place between MSB and provincial dental associations to establish appropriate fee schedules (Bedford and Davey, 1993).

The federal government reports that expenditures for dental services increased steadily in the 1990s, at least up until 1996, when some limits were placed on the frequency of certain dental services (Canada, 1997). While there is some regional variation, the rate of use of dental services (that is, the number of beneficiaries having received at least one dental service during a given period, as a percentage of the eligible clientele) stood at 38 per cent in 1996-97. Restorative work such as crowns and fillings cost more than \$34 million that year and was the most costly form of dental care. Next came orthodontic services such as braces, followed by preventive work such as scaling or polishing, and diagnostic services (Canada 1997).

Summary

While there are still many gaps in our knowledge about the provision of health services to Aboriginal people in Canada, this brief literature review has demonstrated that quite a number of sources exist. The literature has addressed quite a variety of topics, although it will not escape the reader's attention that empirical studies providing data that go beyond particular localities are infrequently found.

The First Nation and Inuit Regional Health Survey, conducted in 1996, makes a contribution to filling some of the data gaps. In the following section, we briefly discuss the methodology of the survey as it pertains to questions about health and dental services, before proceeding to a discussion of the results.









Methodology

A s with the other papers in this Volume, the data we will be presenting on health services and dental care are taken from the First Nation and Inuit Regional Health Survey, conducted in 1996. Data were collected from nine regions of Canada – British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Labrador, Nova Scotia and New Brunswick. The sample includes First Nation persons living on reserve as well as Inuit living in Labrador communities.

Details about the FNIRHS, including sampling, questionnaire construction, interviews and the weighting of sample results are described in a technical appendix to this Volume.

While some data pertaining to

children and youth were collected, the questions in which we have a particular interest were asked only of adults – that is, persons 18 years of age and over. The final sample includes 9,870 adults who, with proper weighting, can be taken to represent a population of just under 200,000 individuals living on reserve or in Labrador Inuit communities. In keeping with the practice of the other papers in this volume, we will present the population-weighted results.

The questions asked about health services and dental care can be summarized as follows:

- The respondent is asked whether he/she believes that First Nations/Inuit people have the same level of health services as the rest of Canada
- If the answer to the first question is no, the respondent is asked what aspect of health services are in need of improvement. More than a dozen areas of health service are listed and a yes/no



Figure 2: Gender of the Adult Population %

response is sought for each one. There is also an opportunity to volunteer additional options

- On dental care, the respondent is first asked when he/she last had any dental care. Response options are less than a year, more than a year, and can't remember
- The interviewee is also asked whether he/she needs dental treatment at this time
- If yes, there is an opportunity to identify what type of treatment is needed. A wide range of responses were given to this question, but the responses were grouped into the following categories: maintenance (i.e., checkup or teeth cleaning); extraction (i.e., teeth pulled); restorations (such as fillings and crowns); periodontal (gum) problems; prostheses (meaning problems related to dentures); immediate (acute, painful) problems; and other. In addition, the number of dental problems that required

treatment for each respondent was also calculated.

• Finally, interviewees are asked whether they have experienced problems with their teeth, or any dental pain, in the past month.

The survey also includes a number of other questions that provide background information about the respondent, which can be used in crosstabulations. These include information about gender, age, level of education, marital status, and selfreported health status. Variables that describe the community in which the individual lives, such as size, geographic isolation, and where the community is in the transfer process, have also been added to the database. Data is presented in percentage form, and chisquare tests of significance are reported where appropriate. Almost all the reported relationships are statistically significant at the 0.001 level.

We begin the presentation of data by reporting the gender and age characteristics of the population. Figure 2 shows that the population in question is almost equally split between males and females.

The size of the age groups of the adult population are given in Figure 3 below, showing the relatively large size of the younger age groups which is characteristic of the adult Aboriginal population.



Figure 3: Age Distribution of the Adult Population %









233

Results

Health Services: Equal or Not?

The first question inquiring about health services asked respondents whether they believed that First Nations/Inuit persons have the same level of health services as the rest of Canada. Figure 4 reveals that almost half the respondents were of the opinion that services were not equal to the rest of Canada. However, a third believed that they were equal, and the remainder was unsure. Further analyses will consider only those who expressed an opinion about health services, leaving aside those who said they were unsure. Leaving aside the "don't know" responses, almost 60 per cent of those with an opinion believed services were not equal.

Figure 5 examines differences in belief that health services are not equal by gender. In fact, these differences are modest and are not statistically significant at the p = 0.05 level.

There is some difference in the response of different age groups to the question about equal health services. The pattern represents an inverse Ushaped curve (Figure 6). Those in both the youngest and the oldest age categories are somewhat more positive about the health services provided than are those in the middle age groups.

A somewhat similar pattern is found with level of education; this time as a regular U-shaped curve. Those with the least education are among those most likely to think that health services are unequal, as are those with the highest levels of education (Figure 7). These differences might be a function of frequency of health encounters related to illness. For example, one might speculate that those with low levels of education are also more likely to be low income and to have more health problems. It is possible that they



Figure 4: Belief in the Level of Health Services %



Figure 5: Belief Health Services Not Equal by Gender



Figure 6: Belief Health Services Not Equal, By Age %



Figure 7: Belief Health Services Not Equal By Education %



Figure 8: Belief Health Services Not Equal By Language %

have had more experience with the health system and have formed a more negative opinion of it, a hypothesis that is somewhat borne out by Figure 12, which appears later on. Those with high levels of education may also have more of an intellectual understanding of the differences between the two health systems.

There is little difference between those who most often use an Aboriginal language in daily life and those who use English. However, French-speaking Aboriginal persons are much more likely to believe that health services are equal (Figure 8 below⁵). This pattern of French-language differences runs through most of the results concerning health services.

Figure 9 suggests that individuals living in more isolated communities are more likely to believe that health services are unequal, a finding which is understandable given the difficulty of delivering services to remote locations⁶.

From Figure 10 we learn that the same is true for small communities, although the differences are not large.

It is interesting to learn from Figure 11 that persons living in communities that have engaged in the health transfer process, whether by concluding negotiations and signing an agreement or still engaged in the pre-transfer process, are more likely to believe that health services are equal than persons living in communities that have not taken part in the transfer process. This could be interpreted to mean that the transfer process is having a positive impact on people's perception of the quality of health care they are receiving, in relation to that received by the Canadian population. However, the differences are not large, perhaps less than one might expect, thereby giving support to the argument that the resources being made available in the transfer process are insufficient substantially to improve service delivery. A third explanation is also, possible, however. It may be that the communities engaged in transfer are those that already had better developed health systems and more qualified human resources, even before they undertook the steps that would give them more control over their health services. In other words, their residents might have been more likely to believe that services were equal even before the transfer process.

Perhaps the most interesting result in this sequence is shown in Figure 12, which reveals a



Figure 9: Belief Health Services Not Equal, By Community Isolation %



Figure 10: Belief Health Services Not Equal By Community Size%



Figure 11: Belief Health Services Not Equal By Health Transfer Status

positive linear trend relationship between selfreported health status and belief that health services are unequal. That is, the worse a person's health, the more likely it is that one would perceive shortcomings in the health services available, compared to what is believed to be available for others in Canada. The tempting conclusion to be drawn from this chart is that those with the most experience with health services are those who are the most dissatisfied.

Services in Need of Improvement

Those who believed that services were not equal had the option of indicating which health services were in need of improvement. They were asked to respond yes or no to a list of a dozen items, and could also choose "other" and write in their choice. Figure 13 summarizes the results, which on the one hand are rather uniform. That is, around three quarters of the respondents replied "yes" to all of the items, indicating a clear desire for better services on the whole.

The rank order is also interesting, however. The largest group of interviewees felt that pediatric services were in need of improvement. Looking at the six items that attracted at least 80 per cent of the respondents, at least three of them reflect a preventive thrust, having to do with such services as disease prevention, diabetes education, and medication awareness sessions. Concern for services to the elderly is also prominent (homes for the elderly and home care), and known gaps in mental health services are evident to many respondents.

In looking at sub-group variation on this question, there was little difference in the responses by gender. Both males and females had the same priorities with only minor variations in their rank ordering.

With respect to level of education, again the priorities and the rank ordering of items deemed to be in need of improvement were similar for the different levels of education. However, the typical pattern was one where the opinion that a particular health service was in need of improvement would increase with level of education until the highest level was reached, and then would decline. Figure 14 illustrates this pattern with respect to the need for improvement in





Type of Service	Percent	Type of Service	Percent
Pediatrician Services	85.90	Mental Health Services	81.30
Disease Prevention	84.20	More Health Staff	77.60
Medication Awareness	82.90	Chronic Care Facilities	77.30
Diabetes Awareness	82.00	Dental Services	76.70
Home for the Elderly	81.90	Translation Services	72.50
Home Care	81.30	Kidney Dialysis	72.30

Figure 13: Health Services in Need of Improvement %



Figure 14: Improvement in Medication Awareness Programs, By Level of Education %

medication awareness programs.

With respect to age group, the differences in priorities are not large but there is a tendency for the youngest age group to place pediatric services at the top of the list for improvement. Pediatric services are important for the other age groups as well, but in the older age groups other concerns such as medication,

disease and diabetes awareness, and mental health services, are picked by as many or more persons. Figure 15 illustrates how responses typically vary by age group, using mental health services as the example.

Some variation also occurs according to the language used in daily life by the respondent. For all language groups, the need for improvement in pediatric services is clearly evident as a priority at or near the top for all groups. Those who speak an Aboriginal language then prioritize preventive services and homes for the elderly. Those who speak English also favour preventive services, adding to these the importance of improvement in home care and mental health services. For French-speaking persons, homes for the elderly are mentioned by the most persons, followed by pediatric, preventive and mental health services. It is not surprising to see that the need for improved translation services is picked by the fewest respondents among English and French-speakers, but is a more important priority for those who usually speak an Aboriginal language.

Language use to some extent correlates with community isolation, with Aboriginal language use likely to be higher in the communities more remote from urban centres. Thus the findings that we have just described for Aboriginal and English language use hold true when measured against community isolation as well.

When we look at the results by community size, it is clear that persons living in small communities are most likely to mention the need for improvements in home care and homes for the elderly, along with education about diabetes. Those who come from medium and larger size communities are most inclined to mention the need for pediatric resources and preventive educational services.

There are no clear differences in response patterns by the transfer status of the community – that is, according to whether the community has signed an agreement to take over various health services or is engaged in pre-transfer projects or not. However, there is a pattern to the results for self-reported health status. In almost all cases, as self-reported health status deteriorates, we find larger proportions of persons stating that they would like to see improvements in particular kinds of health services. The biggest difference occurs between those who see themselves as having excellent health on the one



Figure 15: Improvement in Mental Health Services By Age Group %



Figure 16: Improvement in Kidney Dialysis By Self-Reported Health Status %



Figure 17: Last Time Received Dental Care by Gender %

hand and those with less positive health evaluations on the other. Figure 16, which reports results for the need for improvements in kidney dialysis, is fairly typical of this pattern.

The four health status groups have similar priorities in that large proportions in each group seek improvements in pediatric and preventive measures. Those in the fair and poor categories are especially likely, however, to mention the need for improvements in areas such as homes for the elderly and home care. This could reflect the possibility that these groups have a larger proportion of older respondents in them.

In addition to the list of health services described in Figure 13 above, respondents named a wide variety of other health service areas in need of improvement. These included AIDS awareness programs, education and treatment concerning alcohol and drugs, addressing the problem of lupus, and providing the services of speech pathologists. Other items mentioned were the need to improve services for victims of abuse, making increased use of traditional healers, and having better qualified doctors available, preferably in the community. A large number of persons mentioned that they would like to see improvements in physical fitness and nutrition programs.

Dental Health

This section presents results from the questions on dental health that inquired about the last time treatment was received, whether the respondent needed dental treatment at the time of the survey and if so what kind of treatment, and whether he/she had experienced any dental problems or pain in the past month. In presenting the data for these questions, we again use the population-weighted results.

Figure 17 reveals that females were much more likely to have received dental care in the past year than males. Of course this could mean either that they have had more dental problems or that they have been more diligent in seeking out the services of professionals in the dental field. Rea et. al. (1993), referring to women in the Keewatin region, suggests that both are true:

"We speculate that this gender difference relates to the fact that children are usually brought for dental treatment by their mothers, who can thus access treatment for themselves more easily than men can. It is worth emphasizing that despite their apparently greater access to dental treatment, women still have evidence of a greater total burden of dental disease. In isolation from preventive services, treatment alone has been insufficient to control ongoing dental decay" (Rea et. al., 1993:124).



Figure 18:Received Dental Care in Past Year By Age Group %



Figure 19: Need Dental Treatment at this Time By Gender %



Figure 20: Need Dental Treatment at this Time By Age Group %

Our results tend to support this interpretation, as Figures 17 and 25 indicate.

When the results for the same question are analyzed by age group, the pattern that emerges is that those in the younger age categories are more likely to have received dental care in the past year. As with women, younger adults may now be in the habit of seeking dental care on a regular basis, but it may be that they need it more because of their poorer dental health status.

In Figure 19, we see that females are slightly less likely than males to have needed treatment at the time of the survey although the difference is not large.

When it comes to the need for dental treatment by different age groups, we see from Figure 20 that the need for dental treatment is fairly high for the younger adult age groupings, but the need falls off markedly for the older age categories. It is possible that the latter include a higher proportion of persons who have enjoyed a traditional lifestyle such as living off the land and thereby have better dental health. It may also be the case that dentures have addressed dental problems that occurred in earlier years.

Figure 21 shows that the need for dental treatment at the time of the survey is directly related to the level of education of the respondent. While the relationship is not perfectly linear, there is a tendency for those with higher levels of education to be more in need of dental treatment. Some of the same factors that were discussed with regard to the age variable may be operative here as well, in the sense that those with little education are likely to be older. Those with higher education levels may also be more aware of the need for dental care.

Figure 22 shows a relationship between need for dental treatment and language use, with those who speak Aboriginal languages less likely to need dental treatment than English or French speakers. It may be that those who speak aboriginal languages actually have better access to dental services or are less in need of them.

Other variables, such as degree of community isolation, the size of the community, and health transfer status do not appear to be strongly related to the need for dental treatment.

Those who needed dental treatment were asked to specify the kind of dental care that was required. The results are shown in Figure 23, which reveals that the



Figure 21: Need Dental Treatment at this Time By Educational Level %



Figure 22: Need Dental Treatment at this Time By Language Use %

	Percent of Respondents
Dental Restoration	15.40
Dental Maintenance	8.50
Prosthetic Work (Dentures)	5.40
Dental Extractions	5.20
Periodontal Work	0.40
Immediate Dental Work (Pain)	0.20

Figure 23: Type of Dental Treatment Needed

most common treatment required was restorative work such as fillings. This was followed by maintenance work (check-ups or teeth cleaning), prosthesis work (i.e., dentures), and tooth extractions. Relatively few persons mentioned periodontal (gum) work.

Figure 24 shows that, among those who reported at least one problem in need of fixing, the vast majority specified only one problem. There was, however, a sizeable group that had more that one condition needing treatment.

The final question in the dental series asked respondents whether they experienced any dental problems or pain in the past month. Figure 25 shows that the answer was in the affirmative for 22 per cent of the cases, with females somewhat higher than males.

The sub-group differences on this question, however, are not strong and indeed little relationship is found by background variables such as level of education, language use or community isolation. There are small differences by community size, however, with persons in larger communities more likely to report dental problems or pain in the past month (Figure 26).

A modest relationship is also found with the transfer status of the community, as the final chart in our report reveals (Figure 27). This chart is again subject to the varying interpretations of the transfer process already discussed with respect to Figure 12 above.



Figure 24: Number of Dental Problem Requiring Treatment %



Figure 25: Dental Problems or Pain in Past Month By Gender %

Figure 26: Dental Problems or Pain in Past Month By Community Size %



Figure 27: Dental Problems or Pain in Past Month By Community Transfer Status %









Conclusion

Health services for Aboriginal people in Canada are clearly in transition in a number of respects. Perhaps the most fundamental transition concerns who provides the services and the manner in which they are provided. Within the broader context of self-determination and self-government, there is the very real prospect that Aboriginal governments and their agencies will once again have the primary responsibility for the design and delivery of health services to their own populations even though some utilization of mainstream services will no doubt continue.

In comparison with the situation even a century ago, it must be concluded from the evidence that the availability and quality of health services for Aboriginal people has improved greatly. Our literature review and data indicate, however, that there are still significant problems. Indeed, according to the FNIRHS, almost 60 per cent of the Aboriginal population believe that health services are still not equal to those that are offered to Canadians generally. We also learned from the survey that those who are likely to have had the most experience with available health services (that is, those who judge themselves to have less than excellent health) are the people who are most likely to believe that health services are unequal. They are also most likely to feel that particular health services are in need of improvement.

The survey has also helped us to identify some of the specific areas that are in need of improvement. Pediatric services head the list, followed by improved awareness concerning disease prevention, medication, and diabetes. Other items cited by more that 80 per cent of those who felt that health services were unequal included homes for the elderly, home care, and mental health services.

The effects of changes in Aboriginal life style in recent decades are evident in the many so-called "modern" health problems that now afflict Aboriginal people, including chronic conditions such as diabetes and heart disease, and cancer. Health services need to catch up with this transition. This is perhaps most clearly evident in the case of dental health, an area where problems have rapidly escalated due to the change in diet that people have undergone. Certainly the data presented in this report demonstrate the extent of the problem and the urgency of coming to grips with it.

The survey results also suggest that there is interest and support for further developing the preventive aspect of health services. This message came through when people were asked what services were in need of improvement, as we noted above. Preventive strategies are also the logical direction to be taken in addressing the dental health problems that have been documented in this paper. The means exist to greatly reduce or eliminate the problem of dental decay and dental disease. Clinical prevention measures such as dental screening, treatment services, the fluoridation of water supplies (or in some situations giving persons fluoride supplements directly), and community education and other programs that would lead to behavioural and lifestyle changes (such as diet and personal oral health activities) are important. These are the kinds of measures that will greatly reduce the dental health problems that Aboriginal people currently face.

We conclude this chapter with a few remarks about the First Nation and Inuit Regional Health Survey itself. We have reported on the results of the FNIRHS for a handful of questions about health and dental services. They have yielded some useful information but they can also be improved in their formulation if this survey is repeated. It would be useful to know, for example, not only that services are unequal but also to understand in what way this is

so. Is it because they are not accessible? Is it because their quality is inferior? If so, in what way? Secondly, the answers to some of the questions do not lend themselves to a clear interpretation, suggesting that more precise questions are required. Thirdly, the list of services in need of improvement should be revised to take into account some of the important items that at present are only captured under the "other" category.

Even in their present formulation, however, the questions are useful and they will be even more so if the survey becomes longitudinal in nature. It is only in this way that we can determine whether the health of Aboriginal people is improving, and the effects of positive health interventions.

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Endnotes

- 1. The authors are grateful to Jacques Thibault for his contribution to the development of this paper. We also extend our appreciation to Justin Jagosh, Linda MacLeod and James Warren at Dalhousie University.
- 2. Several good accounts of the evolution of Aboriginal health conditions and services are available. We have drawn especially on Waldram et al., (1995); Young, (1988); and the Royal Commission on Aboriginal Peoples, Volume 1 and 3, (1996)
- 3. Integrated agreements refer to those signed with communities that are prepared to take over some of the available health services, but not all. They may be seen as steps toward the signing of a complete agreement, or they may be all that is feasible due to the small size of the community.
- Apart from the Commission's Final Report in which Chapter 3 of Volume 3 deals most directly with health and healing issues, the Commission also published the proceeding of a National Round Table on Aboriginal Health and Social Issues. See RCAP, 1993.
- 5. A very small number of respondents, in order of 1 per cent, reported use of another European language. These have excluded from the analysis.
- 6. An isolated community is defined as one that is 90 kilometres or more from physician services. Such a community may also be handicapped by lack of scheduled flights or minimal telephone or radio services.

Appendices

- Appendix 1- Data Dictionary
- Appendix 2- Technical Report
- Appendix 3- Key Themes and Implementation Issues
- Appendix 4- Code of Ethics
- Appendix 5- Participating Communities


Appendix 1 First Nations and Inuit Regional Health Survey Data Dictionary

National Core Questions/Variables • Derived Variables • Ecological Variables January 22, 1998

SAMPLE VARIABLES

Variable Name:

Description: Adult variable was created for ease of data analysis to identify records in the database containing responses from adults.

Coding: 0 = Adult, record contains no response from an adult.

1 = Adult, record contains a response obtained from an adult.

Variable Name:

Description: Child variable was created for ease of data analysis to identify records in the database containing responses for a child.

Coding: 0 = Child, record contains no response for a child (proxy)

1 = Child, record contains a response obtained for a child.

Variable Name:

Description: Adult population expansion weight is the number of adults represented by this respondent at the population level (i.e., combined regions that participated in the national survey only)

Variable Name:

Description: Child population expansion weight is the number of children represented by the child (obtained by proxy) at the population level (i.e., combined regions that participated in the national survey only)

Variable Name:

Description: Adult sample analytic weight

Adult population expansion weight

Average population expansion weight of all adult respondents

Variable Name:

Description: Child sample analytic weight

Formula:

Formula:

Child population expansion weight

Average population expansion weight of all child (proxy interviews)

First Nations and Inuit Regional Health Surveys

WT PA

WT PC

WT AA

WT_AC

ADULT

CHILD

RESPONDENT INFORMATION

Variable Name:

Question: Sex Description: Sex of the Adult Respondent Coding: F = Female M = Male . = Not Stated

Variable Name:

Question:	Present Marital Status
Description:	Present Marital Status of the Respondent
Coding:	1 = Married
	2 = Common Law
	3 = Separated
	4 = Divorced
	5 = Widow
	6 = Single
	. = Not Stated

Variable Name:

B7

B4

B6

Number of Children
Total number of children that the respondent has ever had, including all biological (live births), adopted,
fostered, and extended family.
00 = no children
. = Not Stated

Variable Name:

B8

Question: How many of your children (under 18 years old) are currently living in your household?

Description: Total number of children, including all biological, adopted, fostered, and extended family, currently living in the respondent's household.

Coding: 00 =No children in the household

. = Not Stated for Adults responding for a child on the survey or missed entirely by an adult who did not answer questions on children's health

The National Core Questions B9A-B9D, B10A-B10D, and B11 have been recoded into the following variables.

 Variable Name:

 Question:
 Languages Spoken

 Description:
 Formerly B9A B9B B9C B9D

 The following new categories were created

 Coding:
 Aboriginal

 English

 French

 Other European

 . = Not stated

Variable Name:

Question:Languages WrittenDescription:Formerly B10A B10B B10C B10DThe followingnew categories were createdCoding:AboriginalEnglishFrenchOther European. = Not stated

Variable Name:

Question:	Languages most often used in daily life.		
Description:	Formerly B11: The following new categories were created		
Coding:	Aboriginal		
	English		
	French		
	Other European		
	. = Not stated		

Variable Name:

Question:What is the highest grade that you completed in elementary and secondary school?Description:The following new categories were created for the variable B12

Coding: 0 = Never Attended

- 1 =Grades 1-5
- 2 =Grade 6

3 =Grade 7

LANGB9A LANGB9B LANGB9C LANGB9D

LANGB10A LANGB10B LANGB10C LANGB10D

LANGB11

First Nations and Inuit Regional Health Surveys

B12

- 4 = Grade 8
- 5 = Grade 9
- 6 =Grade 10
- 7 =Grade 11
- 8 = Grade 12
- 9 = Grade 13
- . = Not Stated

Question: How many years of full-time study (or its equivalent if part-time) have you completed in a vocational or technical school?

Description: Same

Coding:	0 (Never Attended)	1	2	3	4	5	6 Years
	. = Not Stated						

Variable Name:

Question: How many years of full-time study (or its equivalent if part-time) have you completed in college or university? Description: As above Coding: 0 (Never Attended) 1 2 3 4 5 6 7 8 9 10 Years . = Not Stated

Three new education variables were created from the National Core Questions - B12, B13, and B14. The variables are:

Variable Name:

Description: B12 collapsed into the following categories

Code: 0 = None

1 = Elementary (Grades 1 - 6)

2 = Incomplete Secondary Education

3 = Completed Secondary Education

Variable Name:

Description: Created from the EDUC variable to show how many respondents who completed their secondary education had received some post-secondary education.

Code: 0 = None

1 = Elementary (Grades 1 - 6)

2 = Incomplete Secondary Education

3 = Completed Secondary Education but did not have any Post-Secondary Educational training

4 = Completed Secondary Education and received some Post-Secondary Educational training

A-4

First Nations and Inuit Regional Health Surveys

R_EDUC

EDUC

B14

B13

POST_SEC

Description: Created from the R_EDUC variable to show how many respondents who completed their secondary education had received some post-secondary education.

Code: 0 = None

1 = Incomplete Education (Grades 1 to 11 or 12 depending on region) and some post secondary training

2 = Completed Secondary Education (Grade 12 or 13 depending on region) and some post secondary training

CHILDREN'S HEALTH

Variable Name: **C2** Question: What is the sex of your child? Description: As above Coding: F = Female M = Male. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question:	What was the birth weight of your child?
Description:	Birth weight calculated as grams
Coding:	Grams

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question: What was the birth weight of your child? Description: As above Coding: D = Don't know= Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question: Was your child breast-fed? Description: As above Coding: Y = YesN = NoD = Don't know. = Not stated and Not applicable (no children's health questions answered)

C4

C3a

C3

A-6		Data Dictio	nary
Variable	e Name:	C4a	
Question:	If Yes to C4a, for how many months?		
Description:	## of month's child breast-fed		
Coding:	## of months		
	. = Not stated and Not applicable (no children	s health questions answered)	
Note:	Respondents who have answered $C4a = Y$		
Variable	e Name:	C5	
Question:	In general, how would you rate your child's he	ealth?	
Description:	As above		
Coding:	1 = Excellent		
	2 = Very Good		
	3 = Fair		
	4 = Poor		
	. = Not stated and Not applicable (no children	s health questions answered)	
Variable	e Name:	C6a	

 Question:
 Allergies

 Description:
 Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.

 Coding:
 Y = Yes No

. = Not stated and Not applicable (no children's health questions answered)

Question: Bronchitis

Description: Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.

C6b

C6c

Coding: Y = Yes

N = No

. = Not stated and Not applicable (no children's health questions answered)

Question:	Asthma
Description:	Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.
Coding:	Y = Yes
	N = No

. = Not stated and Not applicable (no children's health questions answered)

A-7

Variable	le Name:	C6d		
Question:	Tuberculosis			
Description:	Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.			
Coding:	ding: $Y = Yes$			
	N = No			
	. = Not stated and Not applicable (no children's health	questions answered)		
Variable	le Name:	C6e		
Question:	Heart condition or problem			
Description:	Which if any of the following long-term conditions or condition means a condition that has lasted at least 6 n	health problems does your child have. A long-term nonths.		
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{s}$			
	N = No			
	. = Not stated and Not applicable (no children's health	questions answered)		
Variable	le Name:	C6f		
Question:	Kidney problems			
Description:	Which if any of the following long-term conditions or condition means a condition that has lasted at least 6 n	health problems does your child have. A long-term nonths.		
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{s}$			
	N = No			
	. = Not stated and Not applicable (no children's health	questions answered)		
Variable	le Name:	C6g		

Question:	Epilepsy
Description:	Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.
Coding:	Y = Yes
	N = No

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question:DiabetesDescription:Which if any of the following long-term conditions or health problems does your child have. A long-term
condition means a condition that has lasted at least 6 months.Coding:Y = Yes
N = No
. = Not stated and Not applicable (no children's health questions answered)

C6h

A-0		Data Dictional y
Variable	le Name:	C6i
Question:	Overweight or obese	
Description:	: Which if any of the following long-term conditions or healt condition means a condition that has lasted at least 6 month	h problems does your child have. A long-term s.
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable (no children's health quest	tions answered)

Question: Psychological or nervous difficulties Description: Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months. Coding: Y = YesN = No

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Coding:

Coding:

Question: Ear infection and ear problems

Description: Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.

Y= Yes N = No

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Ouestion: Other long-term conditions

Description: Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months.

Y = Yes

N = No

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question: List of other long-term problems Description: Which if any of the following long-term conditions or health problems does your child have. A long-term condition means a condition that has lasted at least 6 months. Coding: Qualitative comments made by Respondents

First Nations and Inuit Regional Health Surveys

C₆la

C61

C6k

C6j

Disting

A-9

Variable	e Name:	C7a	
Question:	Has your child ever had a serious head	1 injury?	
Description:	As above		
Coding:	Y = Yes		
	$\mathbf{N} = \mathbf{N}\mathbf{o}$		
	. = Not stated and Not applicable (no	children's health questions answered)	
Variable	e Name:	C7b	
Question:	Has your child ever had a serious burn	1?	
Description:	As above		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable (no	children's health questions answered)	
Variable	e Name:	C7c	
Question:	Has your child ever had an accident/in	ijury causing broken bones or fractures?	
Description:	ription: As above		
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{s}$		
	N = No		
	. = Not stated and Not applicable (no	children's health questions answered)	
Variable	e Name:	C7d	
Question:	Has your child ever had an accident w	where he/she almost drowned or needed to be rescued?	
Description:	As above		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable (no	children's health questions answered)	
Variable	e Name:	C7e	
Question:	Has your child ever had a serious cold	weather injury such as frostbite, hypothermia?	
Description:	As above		
Coding:	Y = Yes		
	N = No		

. = Not stated and Not applicable (no children's health questions answered)

A-10		Data Dictionary
Variable	e Name:	C7f
Question:	Has your child ever had as accident/injury causing	g loss of limb(s), vision or hearing?
Description:	As above	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable (no children's he	ealth questions answered)
Variable	e Name:	C8
Question:	During the past 6 months, do you think that your o	child has had more emotional or behavioral problems than
	other boys/girls of his/her age?	
Description:	As above	
Description: Coding:	other boys/girls of his/her age? As above Y = Yes	
Description: Coding:	other boys/girls of his/her age? As above Y = Yes N = No	
Description: Coding:	other boys/girls of his/her age? As above Y = Yes N = No D = Don't Know	

Question: During the past 6 months, how well has he/she gotten along with the family?

Description: As above

Coding: 1 =Very well, no problems

2 = Quite well, hardly any problems

3 = Pretty well, occasional problems

4 = Not too well, frequent problems

5 = Not well at all, constant problems

. = Not stated and Not applicable (no children's health questions answered)

Variable Name:

Question: How satisfied are you with your child's knowledge of Native culture?

Description: As above

Coding: 1 =Very satisfied

2 = Satisfied

3 = Unsatisfied

4 = Very unsatisfied

. = Not stated and Not applicable (no children's health questions answered)

C10

HEALTH SERVICES

Variable	e Name: D1		
Question:	Do you believe that First Nations/Inuit people have the same level of health services as the rest of Canad		
Description:	As above		
Coding:	Y = Yes		
	N = No		
	D = Don't Know		
	. = Not stated		
Variable	e Name: D2a		
Question:	Kidney dialysis		

Question	
Description:	If yes, what aspect of health services is in need of improvement?
Coding:	Y = Yes
	N = No
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $D1 = No$

Variable Name:

D2b

Question:	Translation Services	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered $D1 = No$	

Variable Name:

D2c

Question:	Pediatricians, medical specialists for children	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered $D1 = No$	

A-12			Data Dictionary
Variable	Name:	D2d	
Question:	Dental services		
Description:	What aspect of health services is in need of improvement?		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered $D1 = \frac{1}{2}$	No	
Variable	e Name:	D2e	
Question:	More staff at clinics and local hospitals		
Description:	What aspect of health services is in need of improvement?		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered $D1 = \frac{1}{2}$	No	
Variable	e Name:	D2f	
Question:	Chronic care facilities		
Description:	What aspect of health services is in need of improvement?		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered $D1 = 2$	No	
Variable	e Name:	D2g	
Question:	Elderly homes		
Description:	What aspect of health services is in need of improvement?		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered $D1 = \frac{1}{2}$	No	
Variable	e Name:	D2h	
Question:	Home care		
Description:	What aspect of health services is in need of improvement?		
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered $D1 = 2$	No	

Data Dic	tionary	A-13
Variable	Name:	D2i
Question:	Awareness sessions for patients on medications	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered D1 =	No
Variable	Name:	D2j
Question:	Awareness sessions for patients on diseases, prevention	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered D1 =	No
Variable	Name:	D2k
Question:	Diabetes education/awareness programs	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered D1 =	= No
Variable	Name:	D2l
Question:	Eye specialists	
Description:	What aspect of health services is in need of improvement?	
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{s}$	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered D1 =	No
Variable	Name:	D2m
Question:	Mental health services	
Description:	What aspect of health services is in need of improvement?	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered D1 =	= No

A-14		Data Di	ctionary
Variable	e Name:	D2n	
Question:	Other services in need of improvement		
Description:	What aspect of health services is in need of improvement	nt?	
Coding:	Y = Yes		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who answered	d D1 = No	
Variable	e Name:	D2na	

Question:	Other health services (List)
Description:	List of other health services in need of improvement
Coding:	Qualitative comments made by Respondents
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $D1 = No$

TOBACCO AND ENVIRONMENTAL TOBACCO SMOKE

Variable Name:

Question: Have you ever used tobacco in non-traditional ways including smoking cigarettes, cigars, a pipe, or used smokeless tobacco (such as snuff or chewing tobacco)?

Description: As above Y = YesCoding: N = No

. = Not stated

Variable Name:

Question:	Smoke cigarettes
Description:	At the present time do you use tobacco in the following ways?
Coding:	Y = Yes
	N = No
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $E1 = Y$

Variable Name:

Question: If Yes, How many cigarettes per day? Description: I # of cigarettes per day by respondents who currently smoke Coding: # of cigarettes . = Not stated and Not applicable Question only applicable for respondents who answered E1 = Y and E2a = YNote:

E1

E2ab

E2a

Data Die	tionary		Δ-15
Variable	Nome	Elha	
	Smalleles tobacco (anuff	E2Da	
Question:	Smokeless tobacco / snull	11	
Description:	At the present time do you use tobacco in the fo	nowing ways?	
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{S}$		
	N = No		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who a	nswered $EI = Y$	
Variable	e Name:	E2bb	
Question:	If Yes, How much per day?		
Description:	Amount of snuff per day		
Coding:	Qualitative comments made by Respondents		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who a	nswered $E1 = Y$ and $E2ba = Y$	
Variable	Name:	E2ca	
Ouestion:	Chewing tobacco		
Description:	At the present time do you use tobacco in the fo	llowing ways?	
Coding:	Y = Yes		
C	$\mathbf{N} = \mathbf{N}\mathbf{o}$		
	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who a	nswered $E1 = Y$	
Variable	Name:	E2cb	
Ouestion:	If Yes, How much per day?		
Description:	Amount of chewing tobacco per day		
Coding:	Oualitative comments made by Respondents		
6	. = Not stated and Not applicable		
Note:	Question only applicable for respondents who a	nswered $E1 = Y$ and $E2cb = Y$	
Variable	Name:	E3	
Ouestion:	Are there any controls or restrictions on smokin	g in your community?	
Description:	As above	<u> </u>	
Coding:	Y = Yes		
C	$\mathbf{N} = \mathbf{N}\mathbf{o}$		
	D = Don't Know		
	. = Not stated and Not applicable		

Note: Question only applicable for respondents who answered E1 = Y

A-16	Data Dictionary
Variable	e Name: E4
Question:	Have any controls or restrictions affected how much you smoke each day?
Description:	As above
Coding:	Y = Yes
	N = No
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $E1 = Y$
Variable	e Name: E5
Question:	At what age did you begin to smoke cigarettes daily?
Description:	As above
Coding:	Age in years
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $E1 = Y$
Variable	e Name: E6
Question:	If you presently do not smoke at what age did you quit smoking cigarettes daily?
Description:	As above
Coding:	Age in years
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $E1 = Y$
Variable	e Name: F1
Question:	Does anyone in your household smoke regularly inside the house?
Description:	As above
Coding:	Y = Yes
	N = No
	. = Not stated
Variable	e Name: F2

Question:	How many people in your household, excluding yourself smoke daily?
Description:	As above
Coding:	## of people
	. = Not stated

Question: Do you ever feel unpleasant effects from cigarette smoke of others?

Description: As above

Coding: Y = Yes

N = No

. = Not stated

MEDICAL CONDITIONS, INCLUDING DIABETES

Variable Name:

 Question:
 High blood pressure

 Description:
 Have you been told by a health care professional that you have?

 Coding:
 Y = Yes

 N = No
 . = Not stated

Variable Name:

Question:High blood pressure - If yes, what age?Description:Have you been told by a health care professional that you have?Coding:Age in years. = Not stated and Not applicable

Variable Name:

 Question:
 Arthritis or rheumatism

 Description:
 Have you been told by a health care professional that you have?

 Coding:
 Y = Yes

 N = No
 . = Not stated

Variable Name:

G1ba

Question:Arthritis or rheumatism - If yes, what age?Description:Have you been told by a health care professional that you have?Coding:Age in years. = Not stated and Not applicable

First Nations and Inuit Regional Health Surveys

G1a

F3

G1aa

G1b

A-18		Data Dictionary
Variable	Name:	G1c
Question:	Heart problems	
Description:	Have you been told by a health care professional that you have	ve?
Coding:	Y = Yes	
	N = No	
	. = Not stated	
Variable	Name:	G1ca
Question:	Heart Problems - If yes, what age?	
Description:	Have you been told by a health care professional that you have	ve?
Coding:	Age in years	
	. = Not stated and Not applicable	
Variable	Name:	G1d
Question:	Breathing Problems	
Description:	Have you been told by a health care professional that you have	/e?
Coding:	Y = Yes	
	N = No	
	. = Not stated	
Variable	Name:	G1da
Question:	Breathing Problems - If yes, what age?	
Description:	Have you been told by a health care professional that you have	ve?
Coding:	Age in years	
	. = Not stated and Not applicable	
Variable	Name:	G1e
Question:	Asthma	
Description:	Have you been told by a health care professional that you have	/e?
Coding:	Y = Yes	
	N = No	
	. = Not stated	
Variable	Name:	G1ea
Question:	Asthma - If yes, what age?	
Description:	Have you been told by a health care professional that you have	/e?
Coding:	Age in years	

. = Not stated and Not applicable

Data Dic	tionary		A-19
Variable	e Name:	G1f	
Question:	Tuberculosis (TB)		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Y = Yes		
	N = No		
	. = Not stated		
Variable	e Name:	G1fa	
Question:	Tuberculosis (TB) - If yes, what age?		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Age in years		
	. = Not stated and Not applicable		
Variable	e Name:	G1g	
Question:	Cancer		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Y = Yes		
	N = No		
	. = Not stated		
Variable	e Name:	G1ga	
Question:	Cancer - If yes, what age?		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Age in years		
	. = Not stated and Not applicable		
Variable	e Name:	G1h	
Question:	Diabetes		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Y = Yes		
	N = No		
	. = Not stated		
Variable	e Name:	G1ha	
Question:	Diabetes - If yes, what age?		
Description:	Have you been told by a health care professional that you h	ave?	
Coding:	Age in years		

. = Not stated and Not applicable

A-20		Data Dictionary
Variable	e Name:	G1i
Question:	Other conditions	
Description:	Have you been told by a health care pro	fessional that you have?
Coding:	Y = Yes	
	N = No	
	. = Not stated	
Variable	e Name:	G1ib
Question:	Other conditions listed	
Description:	Have you been told by a health care pro	fessional that you have?
Coding:	Qualitative comments made by Respond	lents
	. = Not stated and Not applicable	
Variable	e Name:	G2
Question:	Are you currently attending a diabetes c	linic or seeing someone for diabetes education?
Description:	As above	
Coding:	$\mathbf{Y} = \mathbf{Y}\mathbf{e}\mathbf{s}$	
	$\mathbf{N} = \mathbf{N}\mathbf{o}$	
	. = Not stated and Not applicable	
Notes:	Question only applicable for respondent	s who answered $G1H = Y$
Variable	e Name:	G3
Question:	If female, were you diagnosed with diab	etes during pregnancy?
Description:	Gestational diabetes	
Coding:	Y = Yes	
	N = No	
	. = Not stated and Not applicable	
Notes:	Question only applicable for respondent	s who answered $B4 = F$ and $G1H = Y$
DISABI	LITY AND ACTIVITY LIMITAT	TION
Variable	e Name:	H1

Question: At your home, are you limited in the kinds and amount of activity you can do because of a long-term physi cal condition or health problem - one that has lasted or is expected to last 6 months or more?

Description: As above Coding: Y = Yes

N = No

. = Not stated

Variable Name:

Question: Because of your condition or health problem, do you need help with your personal care, such as washing, grooming, dressing and feeding yourself?

Description: As above Coding: Y = Yes

N = No . = Not stated

Variable Name:

Question: Are you getting the help you need with your personal care, such as washing, grooming, dressing and feeding yourself?
Description: As above

Coding: 1 = Yes, g

1 = Yes, get all the help needed

2 =Yes, sometime, but need help more

3 = No

. = Not stated

Variable Name:

Question: Have difficulty leaving your residence to take short trips, that is trips to work, shopping, or any other local trips under 80 km or 50 miles?

Description: As above

Coding:

Y = YesN = No

. = Not stated

Variable Name:

Question: Consider yourself house-bound, that is unable to leave your home? Description: As above Coding: Y = Yes N = No . = Not stated

Variable Name:

Question: Require an attendant or companion to accompany you on short trips?

Description: As above

Coding: Y = Yes

N = No

. = Not stated

H4

H6

H5

First Nations and Inuit Regional Health Surveys

A-21

H3

A-22	Data Dictionary
Variable	e Name: H7
Question:	Do you have difficulty hearing what is said when you are having a conversation with one other person?
Description:	As above
Coding:	Y = Yes, have difficulty
	N = No
	. = Not stated
RESIDE	ENTIAL SCHOOLS
Variable	e Name: I1
Question:	Did you attend residential school?
Description:	As above
Coding:	Y = Yes
	N = No
	. = Not stated
Variable	e Name: I2
Question:	If yes, at what age did you start to attend residential school?
Description:	As above
Coding:	Age in years
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $I1 = Y$
Variable	e Name: I3
Question:	If yes, at what age did you leave residential school?
Description:	As above
Coding:	Age in years
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $I1 = Y$
WELLN	VESS
Variable	e Name: J1
Question:	Do you think a return a traditional ways is a good idea for promoting community wellness?
Description:	As above
Coding:	Y = Yes
-	$\mathbf{N} = \mathbf{N}$

. = Not stated

Data Dictionary		A-23
Variable	e Name: J2a	
Question:	Traditional approaches to healing	
Description:	If yes, thinking about the past two years, in which of the following areas has there be community?	been progress in your
Coding:	1 = No progress	
	2 = Some progress	
	3 = Good progress	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered $J1 = N$	

Variable	Name: J2b
Question:	Renewal of native spirituality
Description:	If yes, thinking about the past two years, in which of the following areas has there been progress in your community?
Coding:	1 = No progress
	2 = Some progress
	3 = Good progress
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $J1 = N$
Variable	Name: J2c

Question:	Revival of traditional roles of women
Description:	If yes, thinking about the past two years, in which of the following areas has there been progress in your community?
Coding:	1 = No progress
	2 = Some progress
	3 = Good progress
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $J1 = N$

Variable Name:

J2d

Question:	Revival of traditional roles of men
Description:	If yes, thinking about the past two years, in which of the following areas has there been progress in your community?
Coding:	1 = No progress
	2 = Some progress
	3 = Good progress
	. = Not stated and Not applicable
Note:	Question only applicable for respondents who answered $J1 = N$

A-24		Data Dictionary
Variable	e Name:	J2e
Question:	Traditional ceremonial activity	
Description:	If yes, thinking about the past two years, in which of the f community?	ollowing areas has there been progress in your
Coding:	1 = No progress	
	2 = Some progress	
	3 = Good progress	
	. = Not stated and Not applicable	
Note:	Question only applicable for respondents who answered J	1 = N

Question: First Nations and Inuit controlled programs Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress

2 = Some progress

3 = Good progress

. = Not stated

Variable Name:

J3b

J3a

Question:	Return to traditional ways
Description:	Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
Coding:	1 = No progress 2 = Some progress 3 = Good progress . = Not stated
Variable	e Name: J3c

Use of Elders Question: Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress

- 2 =Some progress
- 3 = Good progress
- . = Not stated

Variable Name:

Question:	Personal	commitment t	o healing

Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress

2 = Some progress

- 3 = Good progress
- . = Not stated

Variable Name:

J3e

J3d

Question: Renewed relationship with the land

- Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
- Coding: 1 = No progress
 - 2 =Some progress
 - 3 = Good progress
 - . = Not stated

Variable Name:

J3f

Question: Networking among communities

- Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
- Coding: 1 = No progress
 - 2 = Some progress
 - 3 = Good progress
 - . = Not stated

Variable Name:

J3g

 Question: Use of First Nations or Inuit language
 Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
 Coding: 1 = No progress 2 = Some progress

- 3 = Good progress
- . = Not stated

A-26	Data Dictionary
Variable	Name: J3h
Question:	Training in the health field
Description:	Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
Coding:	1 = No progress
	2 = Some progress

Ouestion: Reduction in alcohol and drug abuse

3 = Good progress. = Not stated

- Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
- Coding: 1 = No progress
 - 2 =Some progress
 - 3 = Good progress
 - . = Not stated

Variable Name:

Question: Availability of First Nations and Inuit health professionals

- Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
- Coding: 1 = No progress
 - 2 =Some progress
 - 3 = Good progress
 - . = Not stated

Variable Name:

J3k

Question: Cultural awareness programs in schools Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community? Coding: 1 = No progress

- 2 =Some progress
- 3 = Good progress
- . = Not stated

First Nations and Inuit Regional Health Surveys

J3i

J3j

Variable Name:

Question:	Education	and training	opportunities

Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress

2 =Some progress

3 = Good progress

. = Not stated

Variable Name:

Question: Employment opportunities

Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress

2 =Some progress

3 = Good progress

. = Not stated

Variable Name:

 Question:
 Housing quality

 Description:
 Other factors have been identified by First Nations and Inuit people as important for community wellness.

 Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: 1 = No progress 2 = Some progress

3 = Good progress

. = Not stated

Variable Name:

J30

Question: Water and Sewage facilities

- Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?
- Coding: 1 = No progress
 - 2 =Some progress
 - 3 = Good progress
 - . = Not stated

J3m

J3I

J3n

130

Δ.	-28	

Question: Other factors listed

Description: Other factors have been identified by First Nations and Inuit people as important for community wellness. Thinking about the past two years, do you feel that there has been any progress in any of the following areas in your community?

Coding: Qualitative comments made by Respondents . = Not stated

Variable Name:

Question:In general, how would you rate your health?Description:As aboveCoding:1 = Excellent2 = Very Good3 = Fair4 = Poor

5 = Don't Know . = Not stated **J4**

J3p

DENTAL HEALTH

Variable Name:

Question: When was the last time you had any dental care? Description: As above Coding: 1 = Less than 1 year 2 = More than 1 year 3 = Can't remember . = Not stated

Variable Name:

Question: Do you need dental treatment at this time? Description: As above Coding: Y = Yes N = No D = Don't know . = Not stated **K1**

K2

Variable Name:		Χ3
Question:	If Yes, what type of dental treatment do you need?	
Description:	As above	
Coding:	Qualitative comments made by Respondents	
	. = Not stated and Not applicable	
Notes:	Question only applicable for respondents who answered $K2 = Y$	

Variable Name(s): MAINT EXT REST PERIOD PROSTH MMED OTHER

Description: These variables were created from the qualitative information provided by those respondents who indicated the type of dental treatment they need. Each variable represents a count for the number of people who said they need the following:

MAINT = Maintenance (ie., check-up or teeth cleaning)

EXT = Extractions (ie., teeth pulled)

REST = Restorations (ie., fillings, crowns, etc.)

PERIOD = Peridontal problems

PROSTH = Problems related to the need or maintenance/repair of dentures

IMMED = Dental problems requiring immediate attention

OTHER = Other dental problems

TSCORE = A score of the number of dental problems that require treatment by each respondent

Variable Name:

Question: Have you experienced problems with your teeth or experienced any dental pain in the last month?

Description: As above Coding: Y = Yes

N = No

D = Don't know

. = Not stated

ECOLOGICAL VARIABLES

The following variables describe each community that participated in the survey. The frequency distribution reflects the number of people who live in communities with those characteristics.

Variable	Name: H_TRANS
Description:	Health Transfer Agreement Status (involving agreements or projects with MSB - Medical Services Branch) of each community that participated in the survey
Code:	1 = Signed Health Transfer Agreement or signed Integrated Community Based Health Services Contribution Agreements, indicating that respondents (adults or children) live in a community that has signed such agreements
	2 = Active Pre-Transfer Projects, indicating that respondents (adults or children) live in a community that is involved in an active pre-transfer project

First Nations and Inuit Regional Health Surveys

K4

3 = No signed agreement or not involved in pre-transfer projects, indicating that respondents (adults or children) live in a community that is not involved in the MSB health transfer process at the community or tribal council level

Variable	Name: S_ISOL
Description:	Community's isolation from Health Services as defined by MSB - Medical Services Branch.
Code:	1 = Isolated, indicating the respondents (adults or children) who live in isolated communities
	2 = Non-Isolated, indicating the respondents (adults or children) who live in non-isolated communities
Note:	Isolated represents remote isolated communities (no scheduled flights, minimal telephone or radio services, no road access), isolated communities (scheduled flights, good telephone services, no road access), and semi isolated communities (road access greater than 90 km to physician services) Non-Isolated represents communities with road access less than 90 km to physician services.

Variable Name:

H_ADEQ

- Description: Percentage of the total number of adequate housing units in the community (as defined by DIAND) that do not require any minor or major renovations or replacement by the total number of housing units in the community located in the community. Housing unit is defined as any self-contained dwelling unit in a commu nity with at least one bedroom and considered to be the main residence (as opposed to a seasonal or vaca tion home) irrespective of occupancy (i.e., vacant or not), need for renovation or repair. It could be a detached or semi-detached house, a mobile home, a row house or a multi-unit residence such as an apart ment, condominium, duplex, triplex, etc., where each unit is to be counted separately.
 Code: Percentage of Adequate Housing available in the community derived from the formula
- Formula: H_adeq = <u>Total number of adequate housing units</u> X 100 Total number of housing units in the community

Percentage rounded to 1 integer.

Variable Name:

ADEQ H

Description: Percentage of the variable H_Adeq recoded into the following categories.

Code: 1 = Less than 25%, indicating that respondents (adults or children) live in a community where less than 25% of the housing units are adequate

2 = 25-49%, indicating that respondents (adults or children) live in a community where 25 to 49% of the housing units are adequate

3 = 50-74%, indicating that respondents (adults or children) live in a community where 50 to 74% of the housing units are adequate

4 = 75% or more, indicating that respondents (adults or children) live in a community where 75% of the housing units are adequate

Variable Name:

Description: House Crowding Index was calculated using the total number of housing units in the community and the population of the community that reflects Total Status Indian Population (by Band) less the Total Off-Reserve Population (DIAND).

Code: Index of crowding

 $H_Crowd =$

Formula:

wd = <u>Population</u> Total Number of Housing Units

Index rounded to one integer

Variable Name:

Description: Crowding index of the variable H_Crowd recoded into the following categories.

Code: 1 = 3 or Less, indicating respondents (adults or children) who live in a community with housing units that have a crowding index of 3 Individuals or less residing in the housing unit

2 = 4, indicating respondents (adults or children) who live in a community with housing units that have a crowding index of 4 individuals residing in the housing unit

X 100

3 = 5 or more, indicating respondents (adults or children) who live in a community with housing units that have a crowding index of 5 or more individuals residing in the housing unit

Variable Name:

Description:	Percentage of the total number of housing units in the community that require basic facilities (i.e., they do
	not have an indoor toilet, an assured supply of hot and cold running water, a bath or shower) by the total number of housing units in the community located in the community.
Code:	Percentage derived from the following formula
Formula:	$H_Plumb = $ <u>Total number of housing units with no indoor plumbing</u> X100
	Total number of housing units in the community

Percentage rounded to 1 integer.

Variable Name:

Code:

Description: Percentage of the variable H_Plumb recoded into the following categories.

1 = 0, indicating that respondents (adults or children) live in a community where all housing units have indoor plumbing

2 = 19% or Less (Fair), indicating that respondents (adults or children) live in a community where 19% or less of the housing units require basic indoor plumbing facilities

3 = 20% or More (Poor), indicating that respondents (adults or children) come from communities where 20% or more of the housing units require basic indoor plumbing facilities.

A-31

CROWD_H

H_CROWD

H_PLUMB

N_PLUM

minition. House Crowd

Variable	e Name: H_SPEC
Description:	Special purpose housing which refers to self-contained housing (as defined by DIAND), used as a principal residence, which includes on-site care services and facilities, related to residents' common physical, social and emotional condition or disability. Examples include Children's Aid Home, homes for ex-prisoners (halfway house), homeless persons shelter, unwed mothers home, victims of family violence home, alcohol and drug abusers home, physically or mentally disabled adults or children home, families of hospital patients residence and senior citizens' nursing home.
Code:	0 = None, indicating respondents (adults or children) live in a community that has no special purpose hous ing available
	1 = 9 or less, indicating respondents (adults or children) live in a community that has 9 or less special pur pose housing available
	2 = 10 or more, indicating respondents (adults or children) live in a community that has 10 or more special purpose housing

WATER_Q

- Description: The number of housing units with an adequate domestic water supply that meets health, hygiene, and safety purposes
- Code: 1 = Adequate domestic water supply, indicating that respondents (adults or children) live in a community where the majority of the housing units have a domestic water supply that meets health, hygiene and safety purposes.

2 = Inadequate domestic water supply, indicating that respondents (adults or children) live in a community where the majority of the housing units have a domestic water supply that does not meet health, hygiene and safety purposes.

Variable Name:

Description: Sewage disposal system in the community

Code: 1 = Adequate sewage disposal system, indicating that respondents (adults or children) live in a community where the sewage is discharged from the housing unit to a collection and/or treatment system that is consistent with standards and does not constitute an environmental threat

2 = Inadequate sewage disposal system, indicating that respondents (adults or children) live in a communi ty where the sewage is discharged from the housing unit to a collection and/or treatment system that is inconsistent with standards and poses an environmental threat

3 = No service that meets sewage disposal requirements

Variable Name:

Description: Electrification Service provided to the community and which are considered by DIAND as adequate.

Code: 1 = Grid Service, indicating that respondents (adults or children) live in a community where the electrifica tion service is provided through a grid system linked to hydro generated power stations

2 = Diesel Generated Service, indicating that respondents (adults or children) live in a community where the electrification service is provided by diesel generated service.

3 =No Service

Variable Name:

Description: Road access refers to year round access to the community

C_ELEC

CROAD

SEWAGEQ

Code: 0 =Unavailable

1 = Available

Variable Name: **CWASTE** Description: Adequacy of solid waste disposal available in the community. Code: 1 = Adequate, indicating that respondents (adult or children) live in a community where household solid waste disposal is adequate in that the solid waste from the housing unit is disposed to a facility that is con sistent with standardized practices and does not constitute a health or environmental threat 2 = Inadequate, indicating that respondents (adult or children) live in a community where household solid waste disposal is inadequate in that the solid waste from the housing unit is disposed to a facility that is inconsistent with standardized practices and poses a health or environmental threat 3 = No service provided Note: DIAND indicates that a solid waste facility should not be deemed inadequate due to poor operator tech nique, neglect or improper operation. Variable Name: **CFIRE** Description: Fire protection available in the community that is rated on whether the service in the community is approved according to standards of fire protection or whether the community has access to outside agency support (e.g. Municipal Type Agreement) that provides required materials and staff. Code: 1 = Adequate, indicating that respondents (adults or children) live in a community where the fire protection provided has been approved by a fire specialist, does meet equipment and Fire Hall standards, or has an agreement with an outside agency that has the required materials and staff 2 = Inadequate, indicating that respondents (adults of children) live in a community where the fire protec tion provided has not been approved by a fire specialist, does not meet equipment and Fire Hall standards, or has no agreement with an outside agency that has the required materials and staff

3 = No service provided

Variable Name:

Code:

Description: Population of Community, indicating that respondents (adults or children) live in a community of that size. Population has been collapsed into the following categories.

251 - 500
501 - 750
751 - 1000
1001 - 1250
1251 - 1500
1501 - 1750
1751 - 2000
2001 - 2500
2501 - 3000
3001 +

C SIZE

Appendix 2 First Nations and Inuit Regional Health Survey Technical Report

INTRODUCTION

The purpose of this Report is to provide an overview of methodological aspects of the First Nations and Inuit Regional Health Survey (FNIRHS). The FNIRHS was undertaken in 1996 under the stewardship of national steering committee consisting of health technicians representing each of the regional First Nations and Inuit populations who expressed interest in participating in the Survey. The National Steering Committee established a technical advisory committee, known as the Co-Principal Investigators Group (CPIG), consisting of the primary technical consultants from each region, to provide advice and training related to methodological aspects of the Survey. Each Region was required to submit a proposal outlining survey design issues such as sampling, questionnaire design, data collection and analysis plans. These proposals were submitted for external review to an independent academic consultant, and methodological concerns were submitted to the CPIG group for purposes of developing an acceptable overall methodological plan for a national survey.

DEVELOPMENT OF THE SURVEY DESIGN

The Co-Principal Investigator's Group (CPIG) consisting of the primary technical consultants from each region developed a common perspective on the Survey objectives. These objectives were:

The National core content of the surveys must reflect national policy issues which will need to be impacted, including such areas as:

- Measure of First Nation and Inuit health status
- Accessibility of health services
- Availability of resources for First Nation and Inuit Health
- Dental Health Access Issues and Impacts of financial reductions to health service/benefit levels
- Prevalence of illness compared against health of all Canadians.
- Impacts of changes in national policy to First Nation and Inuit health.
- Mental Health
- Residential Schools
- Utilization /Access issues
- Stress Indicators
- Positive Indicators

The Regional Health Survey must also ensure:

- Sound research methods
- Comparability to other national surveys

• Questions be framed and interpreted to reflect First Nation and Inuit community realities.

The structure of the Survey reflected these principles in two key areas. First, each Region was provided the flexibility to develop their own sampling methodology to reflect political and cultural realities in each region. This contributed to the sampling variation that is described later in this report. Second, the questionnaire for the Survey was structured to include a small section for national "core" questions that would be included in all regional questionnaires. However, the majority of questions in each regional questionnaire were developed by regional steering committees and technical advisors. The "core" question" segment of the questionnaire was limited to twenty minutes for administration, and was finalized after piloting proposed questions in each region.

DEVELOPMENT OF THE NATIONAL "CORE QUESTIONS"

The CPIG group also undertook the development of core questions for the Questionnaire, assisted by Dr. Reading who was on contract to the National Steering Committee. All drafts of questions were reviewed extensively by the National Steering Committee. Achieving consensus in this area was influenced by several factors:

- Funding for the project was obtained from the federal government's "Tobacco Demand Reduction Strategy" (TDRS). The federal government created the TDRS in 1994 after reducing cigarette taxes in Ontario. TDRS funding has supported a variety of research and intervention projects directed towards reducing youth smoking rates in Aboriginal communities. Since funding for the national survey was from TDRS, a substantial number of core questions had to be about smoking behaviour.
- Some of the regions were particularly resistant to including "core content" questions which they perceived to be imposed by federal agencies. The NSC determined that no more than 20 minutes of questions would be provided for core content.
- Most of the regions felt that the "core questions" should be comparable to the national population surveys, and hence of standard format taken directly from the national survey questionnaires. Indeed one regional political organization passed an official resolution that required their regional survey to maximise comparability in questionnaire design in order to provide comparable data needed to negotiate for additional resources. However, in other regions, the priority focus was on developing a questionnaire that was grounded in community perceptions, with a particular focus on healing activities occurring in the communities.
- The time frame, imposed by Health Canada for pre-testing core questions was impossibly short. As a result, pre-testing of core content questions with respondents at the community level was very difficult.
- The "core question" segment of the questionnaire had to be completed before further development of regional questions. However, Regional organizations were under tight deadlines as well to complete Survey development and implementation within funding cycles. As a result, integration of core questions with regional questions became technically very difficult, and produced considerable redundancy in some areas.
- Core questions derived from other national surveys such as the NPHS were sometimes subjected to wording changes by National Steering Committee members who worried that some question response categories or wording might not be understood at the community level. For example, the question about self-rated health had one response category removed. Although this change was considered culturally appropriate, it created analytical difficulties later on when comparisons were made between FNIRHS results and national survey results.
• In the final development of the National Core Questions, seven (7) drafts were prepared and reviewed prior to final approval, by consensus, by the National Steering Committee on November 6, 1996. The National Core Questions focused on the following topics: Children's Health, Health Services, Tobacco, Environmental Tobacco Smoke, Medical Conditions including Diabetes, Disability and Activity Limitation, Residential Schools, Wellness, and Dental Health.

CREATION OF THE NATIONAL DATABASE

The national database is composed of records from 9,870 adult and 4,138 children from 186 First Nation and Inuit communities in all regions of Canada except the two northern Territories (other sampling exclusions are discussed below). Participation rates approximated 80% across all regions but are impossible to calculate since one region selected respondents opportunistically and other regions used households (interviewing all adults residing in a sampled household) rather than individuals as the sampling frame. No comparative analysis was undertaken of non-respondents since most regions did not record this information, but the database includes analytic and expansion weights as described below. Sample characteristics are summarized later in this section in Tables 1 and 2.

The creation of a national dataset from the regional surveys was undertaken by the Assembly of Manitoba Chiefs and the Northern Health Research Unit at the University of Manitoba on contract to the Chiefs of Ontario. Specialists in large dataset management and statistical consultants assisted with the process. This work involved the following steps: 1) assessment of how each region collected its data to account for sampling and data quality issues, 2) data capture, 3) submission of regional files for central processing, 4) editing the database at the level of each question to create a clean database, 5) creating new variables to better summarize national core question responses; 6) appending ecological variables to each respondent which describe community infrastructure and health service information; 7) weighting the data to best reflect the sample and the target population; 8) suppression of confidential information; 9) abstracting comparable variables from the NPHS, NLSCY and APS and appending these variables to the FNIRHS; and 10) disseminating the National Core Database to investigators and participating regions.

Regional Sampling Strategies:

In keeping with the principle of local control over the Survey process, each region independently identified its target population and developed its own sampling design. Different designs were used across the nine regions to meet local objectives. The following discussion summarizes the sampling design implemented by each region:

British Columbia

The target population was all First Nations people age 15 years and over, enumerated on reserve (36,219). The 197 communities were stratified by region; A) North (58), B) South (63) and C) Coast (76). Within these regions, communities were further stratified by size; A) under 350, B) 350-700, and C) over 700. Of those communities who agreed to participate, two communities from each of the nine strata were randomly selected (two communities later dropped out of the Survey). Five percent of individuals over 15 were then randomly selected from community band lists. The primary caregiver in each participating household randomly selected one child for proxy interview.

Alberta

The target population was all First Nation peoples over the age of 18 living on reserve in the Treaty areas of 6, 7 and 8. Thirteen communities from these Treaty areas volunteered to participate in the regional survey. Sampling of individuals was opportunistic; all individuals over 18 in participating communities were invited to participate. The Alberta Steering Committee decided that no proxy interviews could be conducted on children for cultural reasons; children were not included in the Alberta survey.

Saskatchewan

The target population was all First Nation on-reserve households in the 71 First Nation communities. In total, there are 7,986 households representing 44,510 First Nation peoples. All communities participated on a voluntary basis. Interviewers randomly selected 10% of all households in the community and interviewed the primary caregiver in households with children. One child in each household was randomly selected for proxy interview. In communities with less than 50 households, a random selection of five household heads was set as the minimum.

Manitoba

The target population was all First Nation communities, representing a population of approximately 36,000. Eight geo-political clusters of communities (Tribal Council regions) formed the sampling frame for community selection. In each cluster, investigators randomly selected two communities (one small and one large), plus alternates for a sample of 17 communities. In one cluster, three communities were selected because of the large number of communities in that region. The population targeted was adults 18 years and older. In each community, interviewers randomly selected 20% of households and all adults in the household were eligible to participate in the survey for a target sample of 2400 adults. In small communities a minimum sample of 100 persons was targeted. One child in each household was randomly selected for proxy interview.

Ontario

The target population was all First Nation on-reserve communities in Ontario. A two stage stratified cluster sample design was used. Stratification occurred according to: 1) Remote rural, 2) Rural, 3) Special Access, and 4) Urban. Sampling was proportional to the number of communities in those strata. Further stratification occurred at the community level. Community lists were sorted by sex and age (Children - under 12, Youth - 12 to 17, and Adults - 18 and older), and a systematic random strategy was used to select individuals from each age-sex strata. The person most knowledgeable (usually the mother) of the children selected answered the adult and child section of the survey.

Quebec

Three Nations (Cree, Mohawk and Inuit) did not participate in the Regional Health Survey in Quebec due to recent participation in other health surveys. The primary target population of the remaining eight Nations was 13,884 on-reserve adults representing 14 participating communities (from a total target population of 30,282 on and off reserve adults). A random sample of 2,452 people was generated which included an additional off-reserve sample of 200 people from the Montreal area (although this sample was excluded from the national database).

New Brunswick

A random sample of 150 households was drawn from all First Nations communities in New Brunswick and all adults in each selected household were interviewed.

Nova Scotia

A random sample of all individuals listed on the Band membership lists in all 13 Mi'kmaq communities in Nova Scotia was generated. In larger communities, the sample was 10% and in smaller communities the sample was 15%. The sample was stratified by age and gender.

Labrador

The sampling frame for Labrador was all LIA members in the 5 coastal communities (2,909 people). All household heads in each of the five coastal communities were interviewed and one child in each household was randomly selected for proxy interview.

Data Capture

EPI-Info was determined by the National Steering Committee as the most accessible program for data entry and analysis. The EPI-Info program is a freeware microcomputer program developed by the Centres for Disease Control in Atlanta, Georgia. It is designed to provide a user-friendly environment for non-specialists to organize epidemiological investigations and community health surveys. It includes features for basic statistical analysis and the ability to export data for use with such software programs as SAS or SPSS.

An EPI-Info data entry program was designed for the core content of the Regional Health Survey. All regions received a copy of it, along with a free-ware version of EPI-Info, a database/analysis-training manual, and a data dictionary. In January 1997, a training workshop in Ottawa provided regional representatives with the opportunity to learn how to enter their survey data and then analyze it using EPI-Info.

Data collection required interviewers to complete questionnaires by hand for the respondents. The regions then used various data entry approaches. In some regions, data entry occurred at the community level (e.g. Alberta), or the Tribal Council level (e.g., Saskatchewan), whereas in most others, a central office collected and entered survey data. Altogether, six out of the nine regions used EPI-Info as their data entry program (British Columbia, Saskatchewan, Ontario, New Brunswick, Nova Scotia, and Labrador), whereas the

remaining regions adopted other programs already in use within their organizations. Manitoba, for example, used an ASCII data management program. Alberta opted for Microsoft Excel, and Quebec used Lotus. Ontario used both Epi-Info and SPSS.

Each region asked regional specific questions, which resulted in different database configurations. The database created within each region extended beyond the National Core Content, with the exception of Alberta. For regions that opted to use EPI-Info, the National Core data-entry file was amended to accommodate regional questions. British Columbia and Labrador, for instance, added questions to the database. A patch program added the regional questions to the data entry program, and abstracted the National Core Content from the combined database for the National Roll-Up.

Nova Scotia required a different EPI-Info database configuration. Their regional survey involved three distinct surveys targeted at specific groups, which resulted in three distinct databases. Each record, consequently, was unique to the survey it represented. This design created some difficulty when the data set was prepared for data analysis. Data capture in Manitoba and Quebec was straightforward in that they designed the database to reflect their regional survey structure. Their databases captured both national and regional data, and then the national core content was abstracted for the national roll-up. Alberta's survey simplified their data entry requirements in that they only asked Adult National Core Content questions. However, they did experience inconsistency at the data capture stage and had to re-enter their data, which resulted in a late submission.

Submission of Files

Deadlines for the submission of regional datasets were extended several times to try to accommodate difficulties some regions were experiencing in completing their surveys. The regions that completed interviewing and data entry early, were the first to submit their databases (e.g., Quebec). Most of the databases arrived by late October, 1997. Some regions submitted partial datasets in order to meet the deadline for the national roll-up (Saskatchewan and Ontario). Late additions to these databases followed a few weeks later. Regions that started their surveys late (e.g. Nova Scotia) or experienced technical difficulties (Alberta) submitted their databases much later, with the last arriving in mid-December.

Merging

Overall, the EPI-Info abstraction program, after some minor technical modifications, worked quite well. Abstraction problems, however, sometimes occurred with databases developed by different data management programs. Nova Scotia originally captured their data in EPI-Info and then exported it into a SAS Software environment for data editing (cleaning). Nova Scotia and Manitoba submitted core data in SAS format. All SAS and Excel databases (Alberta) had to be converted to dBASE files because of the import feature of EPI-Info. EPI-Info imports both dBASE and Lotus databases, and transforms these into an EPI-Info format, which required merging. Some minor problems occurred with both exporting and importing. After some troubleshooting, the Manitoba, Alberta, Quebec, and Nova Scotia databases were finally in a format for merging.

Overall, the databases produced in EPI-Info merged quite easily. Problems did occur, however, with databases that arrived in an updated form after the initial submission or with databases produced by other programs. Regions that added records to their existing database after the first submission created technical merging problems in that the technician had to redo the merge process. On the other hand, regions that submitted community level databases (Saskatchewan) that arrived late to their offices and were then forwarded for merging, posed no problem. For databases produced by other programs, the importing feature of EPI-Info

First Nations and Inuit Regional Health Surveys

FNIRHS Technical Report

added decimal places to some numeric variables. After recognizing this problem, programming reconfigured the data to read as intended. Raw frequency distributions produced in SAS confirmed if the programming corrected the problem.

After merging the databases, we discovered that EPI-Info could not handle the size of the data set. Hardware problems were not the issue. The problem was software related. The program would stop running a few minutes after initiating data processing and all programming developed during that run disappeared. Because these problems wasted valuable time, the merged data set was imported into SAS, which is far more suitable for managing large databases, for data editing, and for high-level programming and statistical analysis. The export feature of EPI-Info cleanly exported the database into a SAS program/database.

Data Editing

Some regions (e.g., Quebec, Manitoba, Ontario and Nova Scotia) had the technical resources and/or the time to perform data edits (i.e., data cleaning) on their databases before submitting them for the national roll-up. Other regions, however, did not have the resources or the time to perform these checks. Consequently, data quality checks at the level of each question assessed range values and question skip patterns, and if an inconsistency appeared, the usual corrective action involved setting the inconsistency to "not stated." For questions with missing values, there was no way to determine if they were actually missed or not applicable since no coding system was in place for those responses at the data entry level in seven out of nine regions. We could not investigate why the values were missing, or determine whether missing data had any bearing on the questions themselves. Imputation on missing responses normally corrects an unbalanced database due to missing values. This was not possible, however. Consequently, missing values submitted to us in regional datasets were left as "missing" which may have affected some percentage calculations on some variables.

Derived and Ecological Variables

Several National Core Content questions allowed for write-in responses, requiring the creation of new unique categories or variables. Before importing the database into SAS, we summarized the responses in the nine language variables into the categories of Aboriginal, English, French, and Other European. The word identification feature of EPI-Info helped identify categorical patterns in the language questions, and it was most useful for identifying dental treatment requirements. For the question "What type of dental treatment do you need?" seven distinct patterns emerged through keyword identification, and they were maintenance, extractions, restorations, periodontal problems, prosthetic problems, problems requiring immediate attention, and other dental problems. A total score reflecting the number of dental problems required by each respondent was also developed.

New variables for children and adults were created which reported age groups at five-year intervals. Three new education variables were created to describe the extent of primary and secondary education achievement and exposure to post secondary education. To extend data analysis, an ecological (social environment) database providing community specific data was created and then appended to the national core database. Medical Services Branch provided 1997 community level information on health transfer-agreement status and isolation from health services. DIAND supplied community level information on adequate housing, household crowding, housing units requiring basic facilities, availability of special purpose housing, and the adequacy of community services (water, sewer, electricity, fire, garbage disposal, and road access). The information source provided was the 1996 Housing and Infrastructure Assets Summary Report. This report is a compilation of data submitted by First Nation Regions. The report consequently did not include the Labrador Inuit. The

First Nations and Inuit Regional Health Surveys

Labrador Inuit Association provided comparable 1996 information for the communities they surveyed.

The Nova Scotia database created a unique problem in that some records described children only. A variable had to be created that coded this particular problem. This variable served two purposes; for ease of data analysis and for calculating and then attaching the adult and children weights to the appropriate records. The Codebook for the National Core Database is appended.

Sampling Weighting

Responses from individuals interviewed in the Regional Health Survey are intended to represent the views and opinions of First Nations and Inuit people in participating regions across Canada. If a random sample of all eligible individuals across the nine regions had been obtained such that each person had an equal chance of selection, a "simple random sample" would have resulted. From such a random sample, statistically unbiased estimates of the frequency of responses to questions and valid statistical comparisons of sub-groups of individuals could be readily made. However, as in virtually all large surveys, due to considerations of convenience and reduced cost of field interviews, simple random samples are rarely obtained. This Survey was no exception. Sampling of individuals was conducted within Regions, referred to as strata. Sampling approaches within Regions varied from simple random sampling in some Atlantic areas to cluster samples in others. Further, within age and gender categories, individuals were not always included within each regional sample in the same proportion as the regional population distributions. Survey administration in First Nations communities has particular difficulties; youth, elders and men are sometimes resistant to answering questionnaires. Consequently, statistical adjustment is necessary during analysis to compensate for the unequal representation across the country in some regions, age categories and genders.

A sample probability is defined as the chance that an individual has to be included in the sample. The inverse of this probability is called a population expansion weight and is the number of individuals in the target population that each respondent represents. Hence, the sum of the expansion weights for all interviewed individuals in a Region equals the population size of that Region. Further, the weighted frequency or weighted prevalence of a characteristic using expansion weights, provides an unbiased estimate of the characteristic in the population. These weights can be scaled to reflect the size of the sample obtained, without affecting the unbiased nature of point estimates obtained. The scaled weights are called analytic weights.

To calculate these weights, each region provided information on their target population, sample population, and sampling frames. With the target populations identified regionally, it was then possible to construct the actual age-sex composition by region from the DIAND Indian Registry (1996) and the Labrador Inuit Association Membership (1996) database. Regional data on the distribution of males and females across age groups (children and adults) was entered into an Excel spreadsheet and then imported into SAS. A cross tabulation of the merged database was run to determine the age and sex sampling distribution by region.

Both expansion weights and analytic weights were calculated for the Regional Health Survey, thus properly providing adjustment for the variation in Regional sampling designs, and for differences in representation frequencies in five year age categories for males and females. The average population expansion weight as well as the minimum and maximum expansion weight across age categories for males and females within each Region is shown in the following Tables for children and adults. Low average expansion weights are seen for the Atlantic Regions, reflecting the greater sample size in these regions relative to their Regional population sizes. Larger expansion weights are indicative of proportionately fewer individuals sampled in a Region. Variation in the range of expansion weights within a Region is shown in the Tables as the minimum and maximum and is indicative of varying sampling fractions across age groupings in each Region. Interviews were typically more difficult to obtain from both the elderly and youth in some regions and this is reflected in

Table 1: Sample Characteristics - Adult

			Adult Population Expansion Weight				t	
First Nation & Inuit	Adult Target	Adult Sample on Size (M:F)	Male			Female		
Regional Participation	Population (M:F)		Mean	Min	Max	Mean	Min	Max
British Columbia	32,869 (52:48)	1,984 (45:55)	20.11	9.04	62.0	15.12	7.76	40.25
Alberta	27,782 (50:50)	709 (44:56)	18.25	115	23	35.75	23.12	83.91
Saskatchewan	26,298 (53:47)	869 (37:63)	45.38	16.41	247.89	23.86	13.91	89.28
Manitoba	32,813 (52:48)	1,948 (41:59)	22.16	5.14	98.71	14.19	4.83	120.0
Ontario	45,714 (50:50)	1,088 (30:70)	72.17	38.72	166.5	30.62	17.62	73.25
Quebec	25,285 (47:53)	1,875 (44:56)	14.46	11.52	27.69	12.88	9.34	39.43
Nova Scotia	4,067 (49:51	523 (47:53)	8.90	5.55	11.94	7.95	5.21	19.6
New Brunswick	3,252 (51:49)	357 (47:53)	11.09	7.83	31.0	9.29	6.87	23.0
Labrador	1,920 (54:46)	517 (34:66)	6.0	3.28	31.63	2.65	1.48	8.62
National	200,000 (51:49)	9,870 (41:59)	25.99	3.28	247.89	17.55	1.48	120.0

Table 2: Sample Characteristics - Children

			C	hildren F	Populatio	n Expans	sion We	ight
First Nation & Inuit Regional Participation	Children Target Population (M:F)	Children Sample Size (M:F)	Male			Female		
			Mean	Min	Max	Mean	Min	Max
British Columbia	19,161 (52:48)	924 (52:48)	23.55	14.58	32.93	22.89	10.05	36.05
Alberta	_	_	-	_	_	-	_	-
Saskatchewan	22,711 (51:49)	575 (55:45)	39.9	33.01	57.82	46.86	34.8	68.42
Manitoba	26,625 (51:49)	870 (53:47)	30.81	14.31	70.71	33.20	13.11	137.00
Ontario	25,679 (51:49)	492 (52:48)	51.43	40.86	81.31	53.92	46.41	72.51
Quebec	12.493 (51:49)	648 (54:46)	18.64	14.58	30.86	21.10	19.26	24.05
Nova Scotia	2,937 (51:49)	215 (50:50)	11.29	8.64	23.53	13.53	8.29	312.00
New Brunswick	2,044 (53:47)	84 (52:48)	26.44	23.15	36.14	25.26	19.31	66.00
Labrador	1,237 (50:50)	330 (50:50)	3.76	3.24	3.95	3.97	3.10	5.05
National	112,887 (51:49)	4,138 (53:47)	27.89	3.24	81.31	29.67	3.10	312.00

higher maximum expansion weights. Respondents from the lowest two adult age categories, 15-19 and 20-24, were combined and assigned one common weight for both age categories because some regions did not interview adults under 18 years old. Similarly, weights for the two oldest age categories were also calculated this way.

Suppression of Confidential Information

The National Steering Committee determined that since community and regional level datasets belonged respectively to participating communities and regions, no comparative regional or community analysis of the national database should be possible unless regions or communities agreed to undertake such an analysis. Once ecological variable records were attached to each file, unique identifiers for each respondent were suppressed, along with community and regional identifiers. However, two copies of the original database containing these identifiers have been kept in secure conditions under the stewardship of the Assembly of First Nations and the Assembly of Manitoba Chiefs (who were contracted to manage the national database development) in order to facilitate database linkage with subsequent waves of a longitudinal survey.

National Database Comparison

For comparison purposes, each region received the national databases for the National Population Health Survey, National Longitudinal Study of Children and Youth, and the Aboriginal People's Survey. The National Population Health Survey was packaged as a micro-data file that could only be accessed through the IVISION software, which limited any form of in-depth analysis. The IVISION software only permitted cross tabulations using at most two variables. The micro-data file did not permit the abstraction of variables into another database or more in-depth analysis with other types of statistical software (SAS or SPSS). The Northern Health Research Unit obtained another version, which was readable by SAS and SPSS statistical software. The National Longitudinal Study of Children and Youth and the Aboriginal Peoples Survey came in a format that was readable by SAS or SPSS. Unfortunately, health data for the first or second wave of the NLSCY was not available for public release at the time the national FNIRHS database was distributed. Comparable variables were identified and then the national database was reset to include only those variables. For the Aboriginal Peoples Survey, the database was limited to the regions that participated in the FNIRHS for further comparability.

Appendix 3

SUMMARY OF KEY THEMES FROM THE FEASIBILITY STUDY:

Excerpted from The First Nations and Inuit Longitudinal Health Survey – A Process Report, By John D. O'Neil, Ph.D., Northern Health Research Unit, University of Manitoba (With input from Gail McDonald, Brenda Elias and Jeff Reading Ph.D.) August, 1998

Power and Knowledge

First Nations researchers expressed the view that external inquiries into First Nations communities help to maintain the "hegemony" (meaning dominance or superiority of one social group over another) of Canadian society over Aboriginal people. Participants in the workshops, held during the National Feasibility consultations, considered the relationship of research to the process of self-government and argued that externally controlled research inhibits the self-government process. Others questioned the cultural values that support scientific activity, suggesting that "science" is embedded in a Eurocentric worldview.

Participants in the Workshops discussed the implications of the trend over the past decade, where an increasing number of Aboriginal communities have refused to participate in any externally derived research activity, from census data collection to medical research. Aboriginal people have become highly critical of government or university interests in conducting research on their communities. One concern expressed is the perception that despite decades of research on social problems in Aboriginal communities, these problems appear not to have not been improved as a result of this research. Another concern expressed was that the research seems to solely benefit non-Aboriginal researchers in terms of career advancement, employment, etc. Concerns were also expressed that much of the research on Aboriginal people over the last several decades has asked questions that seem inappropriate in the community context.

Participants at the Workshops had a variety of views about what these concerns might mean for the possibility of developing a Longitudinal Aboriginal Survey. Some felt that research should be rejected completely. In many instances, Aboriginal people and communities have embraced this option as a way of resisting the externally determined images that are potentially so destructive at the community level. From this perspective, research is seen as a waste of scarce resources and as a technical intrusion into the day to day experience of resolving problems at the community level.

However, other participants in the Workshops felt that the rejection of systematic collection of information on Aboriginal communities by any external agency with or without a collaborative alliance, does not necessarily meet the ideal objective of controlling the production of knowledge about Aboriginal communities. In such a vacuum, external institutions and agencies would continue to produce information about Aboriginal communities that will continue to be considered legitimate by government interests. Participants argued that this knowledge could be biased and consistent with the external societies' images of the Aboriginal community but would nonetheless be deployed in negotiations over resources between Aboriginal authorities and other governments.

Community Participation, Information Systems and Research Models

Another important theme raised in the consultations is that Aboriginal communities must have a major role in the development of longitudinal surveys. Participants felt that unless the surveys are seen as relevant to the needs and concerns of each First Nations reserve, Métis or Inuit community, they could not be supported.

Participants argued that the Western approach to survey research assumes that "communities" are merely the sum of individual actions and perceptions. It further assumes that individuals are "representative" of their communities in a statistical sense. Survey research makes further assumptions about diversity in any community population, and assumes that the effects of community influence can be determined through measurement of individual perceptions. Further, survey research assumes that all communities are essentially the same. Sampling strategies are based on these premises. Because of these assumptions, many Aboriginal communities are resistant to survey research and argue that if "health" or "children's development" is to be properly understood, more "participatory" or "qualitative" methodologies are necessary to fully understand the relationship of these issues to community context.

Much of the discussion in the workshops centred on the issue of whether alternatives to a longitudinal survey were possible. Survey research in particular was seen by many participants as inappropriate in Aboriginal communities. Alternatives suggested ranged from more qualitative approaches using Aboriginal methodology such as Sharing Circles, to needs oriented participatory action studies linked to program development and evaluation. Much of the criticism of survey research was based on experience with cross-sectional surveys like the Aboriginal Peoples Survey.

Participants to the workshops were also concerned that research just for the sake of collecting information would be unacceptable to Aboriginal communities. Many participants were of the view that this initiative should only go forward if commitments are made to fund programs identified as needed through the research.

Participants in the Workshops described community-based research activities. Some felt these activities are more useful to communities for policy and planning purposes than the development of large national information systems. Some felt that national databases are usually too technical, inaccessible, and removed from community experience to be of any use to communities. Community-based research programs, on the other hand, are often conducted without any involvement by external agencies or "experts", and are well-suited to the needs of knowledge production and program planning at the community level. Other participants commented on the possibility that the development of a longitudinal survey might draw resources away from community-based research.

Research Capacity Development

Participants in the Workshops were concerned that a longitudinal survey must contribute to the development of Aboriginal research capacity at the individual, community, and organizational level. Participants further articulated that since the longitudinal survey would continue into the next decade, it must also contribute in an important way to the development of Aboriginal research institutions which are consistent with other selfgovernment initiatives.

Some participants voiced concerns about the appropriateness of a Longitudinal Survey conducted by Statistics Canada. Although the Aboriginal Peoples Survey was developed in consultation with Aboriginal organizations and employed many Aboriginal people in the collection and analysis of data, some participants did not feel that this institutional model was successful in meeting the objective of increasing Aboriginal control over the research process.

Participants were also concerned that if the survey used Aboriginal researchers to collect data but analysis and interpretation remained in the hands of non-Aboriginal researchers, results of the study might be harmful to communities. However, some participants also acknowledged that Aboriginal expertise in survey research may not be as developed as necessary to manage a longitudinal survey on the scale proposed. Some felt that in some instances, non-Aboriginal researchers or research groups who have demonstrated their ability to work in partnership with Aboriginal researchers and organizations could be involved. All participants felt, however, that the decision as to which researchers or research groups to involve should remain with regional and/or national Aboriginal organizations.

Self-Government and Control over Research

The general consensus that emerged was that a longitudinal survey might be feasible if Aboriginal ownership of the study at all levels was a basic condition. Essentially the view of participants was that all aspects of the study including administration of funds, the design of questions, utilising and training Aboriginal people as research administrators, analysts and interviewers, and interpretation and dissemination of information from the survey, must be controlled by Aboriginal peoples. Throughout the workshops, participants were unanimous in their concern that decision-making at the highest levels regarding the expenditure of research dollars should be directed by Aboriginal people. There was little support for advisory committees within federal agencies.

Participants indicated that in the context of self-government, they could see the advantages of a longitudinal survey (over a cross-sectional) in producing information at a community, regional and national level useful for setting priorities, planning, and negotiating with other governments for resources and services. Some participants were particularly concerned that Aboriginal communities need longitudinal information to monitor the impact of social policy changes on their communities.

A frequent concern expressed during the workshops was whether the federal government had a "hidden agenda" for the longitudinal surveys. Participants were concerned that if the federal government maintained control over the surveys, the information could be either suppressed, misinterpreted, or used against Aboriginal communities.

Participants to the regional workshops were nearly unanimous in their insistence that this research initiative be controlled at the community and regional level. Equally important, a ten year longitudinal study must be considered in the context of the evolution of Aboriginal self-government over the next decade. Provincial First Nations and Inuit political organizations were identified by participants as the appropriate administrative authority for the surveys.

Participants also indicated that Aboriginal researchers or research groups must be accountable at the regional level and able to work in close collaboration with regional organizations. Most participants indicated that many Aboriginal communities and organizations already have established relationships with Aboriginal and non-Aboriginal researchers, and that these relationships should be nurtured.

Recommendations of the Feasibility Study

The general framework for a longitudinal Aboriginal survey proposed by the Feasibility Study is summarized below:

 Health Canada, Human Resources Development Canada, and the Department of Indian and Northern Affairs should commit funding to develop a framework of Regional Cohort Studies for First Nations and Inuit people in the ten provinces to generate information on community health, the well-being of children, and the documentation of socio-economic conditions associated with community health and the well-being of children. Representatives of these departments should work together with Métis representatives to secure funding for a similar initiative for Métis people in the provinces.

First Nations and Inuit Regional Health Surveys

Key Themes and Implementation Issues

- 2. National First Nations and Inuit organizations, and the major funding departments should be invited to appoint members to First Nations and Inuit National Steering Committees. These Committees will be responsible for the general supervision of the development of the regional cohort studies for their respective communities.
- 3. Regional First Nation and Inuit political organizations should be invited to submit letters of intent indicating their interest in developing the longitudinal survey on behalf of all communities in their respective regions.
- 4. Regional organizations should be asked to propose a Research Group with whom they wish to collaborate in the development of the survey. Research groups should be approved by the National Steering Committees.
- 5. National Steering Committees should appoint a Core Questions Research Group who will be responsible for the development of comparative "core questions" for the longitudinal surveys.
- 6. A National Aboriginal Technical committee should be established consisting of members of the "core question" Research Group and one member from all other Research Groups involved in the longitudinal surveys.
- 7. National Steering Committees should approve grants to each regional organization/research group to develop and implement the survey.
- 8. This initiative should be developed at a pace that is suitable to Aboriginal organizations and communities. It is likely that the first wave of the survey in 1996 will be restricted to several pilot projects in different parts of the country. Other regions and communities may not be ready to participate until 1998.

Implementation of the First Nations and Inuit Regional Health Survey

A lthough three federal departments were involved in the Feasibility Study, only one (Medical Services Branch of Health Canada) accepted the recommendations and proceeded with their implementation. A National First Nations and Inuit Steering Committee was established consisting of representatives from each province-based First Nation or Inuit political organization. Funding for the initiative was provided through the Tobacco Demand Reduction Strategy. Each regional (or provincial) political organization was invited to submit a research proposal identifying technical expertise and outlining a research design and methodology.

The Development of the National Steering Committee

Immediately, a range of problems emerged that threatened to derail the process. First, Medical Services Branch established impossible deadlines and timeframes, dictated by federal funding procedures. The proposals that emerged ranged from very preliminary two or three page outlines, to fully developed proposals suitable for peer review. Although the National First Nations and Inuit Steering Committee was mandated to review these proposals, decisions and directions continued to flow from the Medical Services Branch office responsible for managing the implementation of the Survey. Frustration with this process escalated until several representatives on the National Steering Committee threatened to withdraw from the process. Demands were made to fund the Steering Committee to manage the implementation of the survey and some competition emerged among regions as to where this co-ordination for the survey. Although initially resisted by MSB representatives, who expressed concern that administrative and political problems might compromise the integrity of the Survey, this move resulted in significant and rapid improvements in the quality of survey development in all regions. Significantly, although the MSB Co-ordinator and the Co-ordinator appointed by the Chiefs of Ontario were both Aboriginal women with similar educational backgrounds, the location of the Co-ordinator's office at Chiefs of Ontario rather than MSB, resulted in a dramatic improvement in levels of trust from the regions.

The National Steering Committee process has continued very productively under direct First Nation and Inuit control since July 3,1996. During this time National Steering Committee membership has remained remarkably stable.

As the National First Nation and Inuit Regional Health Survey Project evolved, there were a number of work plan objectives achieved and documents developed which defined the "understandings" among the National Steering Committee members. These understandings identified and delineated the way in which the Committee would work together to achieve success.

For example, the terms of Reference of the National Steering Committee were originally designed by Medical Services Branch and provided to the National Steering Committee at the onset of the Project. These Terms of Reference underwent considerable review and revision by the National Steering Committee before being approved by the AFN Chiefs Committee on Health.

The National Steering Committee developed a Letter of Understanding, signed in unity and respect among the National Steering Committee members, which outlined how the Committee would facilitate research delivery at the highest possible professional level and establish conditions and skills for First Nation and Inuit self determination and responsibility for the total health of the communities. The Letter further defined issues of governance, ownership of the process, and provided guidance on the dissemination of the final report and development of a strategy for utilization of the results. The Letter of Understanding was passed, by resolution on November 6, 1996 and signed by the National Steering Committee on July 25, 1997.

The National Steering Committee also undertook the development of a Code of Research Ethics as a means to establish a framework of principles and procedures to guide the Project. The Code outlines the responsibilities of all participants through all aspects and phases of the Project to its conclusion. In the preparation of this Code, other research code of ethics were used with permission as a guide including the Kahnawake Schools Diabetes Prevention Project Code of Ethics and the Manitoba First Nations Regional Health Survey Protocol for Data Sharing. This code is included in this report as Appendix 4.

Funding for the Initiative

The funding made available for this Project over the two fiscal years provided for one cohort study per region. Funding was initially distributed through Medical Services Branch Regional Offices based on a formula allocation according to population and minimum funding requirements. There was a \$10,000 base per annum provided for development and management of each separate survey. The Atlantic received two additional \$10,000 bases per annum to include the Inuit and separate survey for Nova Scotia and New Brunswick. A per capita amount was calculated by dividing the funding available by the sum of the total on-reserve population and the population of Inuit communities in Labrador. The population figures compiled for the Brighter Futures funding were used.

Funds for the National Steering Committee/National Coordination were based on 15% of the funding available in a given fiscal year. A maximum 15% was allowed out of each regional allocation to be utilized by a First Nation/Inuit Organization for the purpose of consultation and management of the survey.

Regional funding was managed by a representative regional First Nation/Inuit Organization. Funding provided for the technical components of the Regional Health Survey development including proposal development, training, internal communications and promotion of the project, software, questionnaire printing, regional coordination, and professional consultation.

The National Coordination funding provided for travel allocations for the National Steering Committee through contribution agreements with each National Steering Committee Member organization, salary, benefits and travel expenses of the National Coordinator, and technical consulting, meeting and organizational expenses.

Of notable significance, the National Coordination funding was efficiently managed by the National Steering Committee and a surplus of \$24,213 was produced by early January, 1996. This surplus supported additional interpretation meetings of the National Steering Committee and Co-Principal Investigator's Group.

Following a significant lobby effort with Medical Services Branch, the First Nation and Inuit Regional

Regional Allocation FY 1995-96	Regional Allocation FY 1996-97		
Pacific 77,794 Alberta 70,540 Sakatchewan 70,640 Manitob 85,643 Ontario 98,664 Quebec F.N. 61,057 Atlantic 50,360 Total Regional 514.698* Totals reflect a tone-third roll over into	Pacific 281,815 Alberta 254,430 Sakatchewan 254,811 Manitob 311,440 Ontario 360,591 Quebec F.N. 218,637 Atlantic 154,596 Total Regional 1,836,320 *		
fiscal year 1996-97 due to the late start up of the Project and distribution of funding to the regions from Medical Services Branch	Totals reflect a one-third roll over from fiscal year 1995-96		
National Committee/Coordination Allocation	National Committee/Coordination Allocation		
94,333 Managed by MSB	\$333,667 * * Out of this amount \$296,023 was transferred to First Nation and Inuit Control under the National Steering Committee by contribution agreement with the Chiefs of Ontario effective July 3, 1996.		
\$ 609,031 Total Allocation	\$ 2,169,987 Total Allocation		

Health Survey Project was granted in March, 1997 a further allocation of \$1,040,000 to assist in the Analysis, Interpretation and Dissemination activities which were to follow the Data Collection Phase of the Project.

This budget, as determined by the National Steering Committee, was equally distributed among the nine participating regional projects. This amounted to \$83,000.00 per regional survey project and a national coordination budget of \$293,000. These funds were administered entirely under First Nations and Inuit control through the offices of the Chiefs of Ontario, rather than through regional MSB offices as had been the case formerly.

The National Steering Committee stated, very strongly, that funding for the analysis, interpretation and dissemination of the Regional Health Survey Project should come from outside the Medical Services Branch envelope so that funds for this effort did not affect current community based programming. The Committee was advised that funding became available for Phase II activities via a second round of Tobacco Demand Reduction Strategy (TDRS).

For comparison purposes, the following is an illustration of the total approximate funding allocations provided by the Federal Government (through various departments) for the other national health surveys that have been undertaken which exclude First Nation and Inuit peoples and the Aboriginal Peoples Survey.

National Population Health Survey	National Longitudinal Survey of Children and Youth	Aboriginal Peoples Survey	First Nation and Inuit Regional Health Survey Project
\$3.2 Million annually on average.	First 5 years - \$10 Million and \$3 Million every year thereafter.	\$14 Million over 3 years.	\$3,819,018 over three years.
Does not include pre-test, new content development, and NHRDP funds for analysis.	Does not include additional analysis, survey coordination and expert advisory, and revenue generated from results.	Does not include revenue generated from results and additional funds for analysis.	Does not include the feasibility funding – 1995
22,000 sample	25,000 sample	135,000 sample	9,870 adult's sample 4,138 children's sample

An additional \$100,000 was provided by Medical Services Branch to support the coordination of the National Aboriginal Information and Research Conference in Ottawa in March, 1998. Although this conference was intended primarily to provide an opportunity for the National Steering Committee to present preliminary results from the analysis of national core data, the conference also included presentations of research results from many other projects throughout the country.

Technical Support

The Co-Principal Investigator's Group (CPIG) consisting of the primary technical consultants from each region (see Appendix) were also required to develop a common perspective on the Survey objectives. At their meeting of September 11 1996, Guiding Objectives for the Survey were developed:

- 1. The National core content of the surveys must reflect national policy issues which will need to be impacted, including such areas as:
 - Measure of First Nation and Inuit health status
 - Accessibility of health services
 - Availability of resources for First Nation and Inuit Health
 - Dental Health Access Issues and Impacts of financial reductions to health service/benefit levels
 - Prevalence of illness compared against First Nation and Inuit health.
 - Impacts of changes in national policy to First Nation and Inuit health.
 - Mental Health
 - Residential Schools Utilization /Access issues Stress Indicators Positive Indicators

- sound research methods
- comparability to other national surveys
- questions be framed and interpreted to reflect First Nation and Inuit community realities.

The structure of the Survey reflected these principles in two key areas. First, each Region was provided the flexibility to develop their own sampling methodology to reflect political and cultural realities in each region. This contributed to the sampling variation that is described later in this report. Second, the questionnaire for the Survey was structured to include a small section for national "core" questions that would be included in all regional questionnaires. However, the majority of questions in each regional questionnaire were developed by regional steering committees and technical advisors. The "core" question" segment of the questionnaire was limited to twenty minutes for administration, and was finalized after piloting proposed questions in each region.

Development of the National "Core Questions".

Dr. Jeff Reading, an assistant professor of epidemiology at the University of Manitoba, was under contract to provide technical support directly to the National Steering Committee. Reading's responsibilities were focused on drafting a "core content" component of the questionnaire that would be acceptable to all the regions represented on the National Steering Committee. Achieving consensus in this area was influenced by several factors:

- 1. Funding for the project was obtained from the federal government's "Tobacco Demand Reduction Strategy" (TDRS). The federal government created the TDRS in 1994 after reducing cigarette taxes in Ontario. TDRS funding has supported a variety of research and intervention projects directed towards reducing youth smoking rates in Aboriginal communities. Since funding for the national survey was from TDRS, a substantial number of core questions had to be about smoking behaviour.
- 3. Some of the regions were particularly resistant to including "core content" questions which they perceived to be imposed by federal agencies. The NSC determined that no more than 20 minutes of questions would be provided for core content.
- 4. Most of the regions felt that the "core questions" should be comparable to the national population surveys, and hence of standard format taken directly from the national survey questionnaires. Indeed one regional political organization passed an official resolution that required their regional survey to maximize comparability in questionnaire design in order to provide comparable data needed to negotiate for additional resources. However, in other regions, the priority focus was on developing a questionnaire that was grounded in community perceptions, with a particular focus on healing activities occurring in the communities.
- 5. The time frame, imposed by Health Canada for pre-testing core questions was impossibly short. As a result, pre-testing of core content questions with respondents at the community level was very difficult.
- 6. The "core question" segment of the questionnaire should have been completed before further development of regional questions. However, Regional organizations were under tight deadlines as well to complete Survey development and implementation within funding cycles. As a result, integration of core questions with regional questions became technically very difficult, and produced considerable redundancy in some areas.
- 7. Core questions derived from other national surveys such as the NPHS were sometimes subjected to wording changes by National Steering Committee members who worried that some question response categories or wording might not be understood at the community level. For example, the question about self-rated health had one response category removed. Although this change was considered culturally appropriate, it created analytical difficulties later on when comparisons were made between FNIRHS results and national survey results.

In the final development of the National Core Questions, seven (7) drafts were prepared and reviewed prior to final approval, by consensus, by the National Steering Committee on November 6, 1996. The National Core Questions focused on the following topics: Children's Health, Health Services, Tobacco, Environmental Tobacco Smoke, Medical Conditions including Diabetes, Disability and Activity Limitation, Residential Schools, Wellness and Dental Health.

Data Ownership and Control

The First Nation and Inuit Regional Health Survey Project has proven to be an evolutionary undertaking by First Nations and Inuit people as it relates to the control and ownership of a national process that will address many issues related to First Nations and Inuit health.

This process has seen the National Steering Committee address issues of data ownership and control with the goal of empowering First Nations, Inuit communities and regions to:

- Take control of the health information and statistics that will be forthcoming from the surveys by participating in the interpretation and analysis of that data to ensure it reflects the realities of First Nations and Inuit peoples.
- Maintain integrity and respect for First Nation and Inuit traditions, customs, languages, values and community norms.
- Effectively utilize the information to advocate their health needs based on scientific evidence.
- Build upon this process to continue the development of First Nation and Inuit capabilities and capacity in health research, analysis, information management, technology and management.

The National Steering Committee has ensured the ownership and the protection of data collected in this Process by incorporating legal safeguards in both the National and Regional Contribution Agreements with Medical Services Branch, Health Canada. Those legal clauses clearly state:

- The full ownership of and copyright in the data in all forms.
- The requirements for Health Canada to request access and utilization of the aggregate data that it will receive under a time limited license.
- Health Canada will not receive any raw data, only national aggregate data.

The National Steering Committee has also ensured protection of data ownership and control as stated in the First Nation and Inuit Regional Health Survey Project Code of Ethics, Letter of Understanding and Co-Principal Investigator's Group Guiding Research Objectives.

First Nation and Inuit Regional Health Survey Code of Research Ethics

INTRODUCTION

The First Nation and Inuit Regional Health Survey is a project which has evolved over a two year period. It began with the exclusion of First Nation and Inuit peoples from three national longitudinal health surveys. Following a national consultative process in 1995 with First Nation, Inuit and aboriginal communities and organizations, it was finally determined that in order to proceed collectively, the process must include a collaboration of distinct regional surveys with a national core content. This decision began a First Nation and Inuit controlled process of research, identification of health status and health planning and a new partnership with Medical Services Branch and national First Nation and Inuit organizations.

From November, 1995 - January, 1996, Medical Services Branch's Indian and Inuit Health Programs Unit coordinated, with the assistance of the Assembly of First Nations, a National Steering Committee comprised of the First Nation and Inuit Organizations from each participating region. The present National Steering Committee members are:

- Phil Hall, B.C. First Nations Health Summit
- Richard Saunders, Alberta Indian Health Care Commission
- Ceal Tournier, Federation of Saskatchewan Indian Nations Health and Social Development Commission
- Audrey Leader, Assembly of Manitoba Chiefs
- Cathryn George, Association of Iroquois and Allied Indians, Ontario
- Gary Cole and Jane Gray, First Nations and Inuit of Quebec and Labrador Health and Social Service Commission
- Wendy Paul and Darren Graham, Union of New Brunswick Indians
- Sharon Rudderham, Union of Nova Scotia Indians
- Iris Allen, Labrador Inuit Health Committee

- Allen Deleary, Assembly of First Nations, Ex-officio
- Nichole Simond, Medical Services Branch, Ex-officio
- Roda Grey, Pauktuutit, Inuit Women's Health Association (Pauktuutit withdrew from the National Steering Committee in January, 1997).

In July, 1996, a National Coordinator, Gail Mc Donald, was hired under contract, through the Chiefs of Ontario Office, to coordinate and support the work of the National Steering Committee in meeting its objectives.

The National Steering Committee Funding Guidelines and National Steering Committee Terms of Reference were passed by consensus in August, 1996 and a Letter of Understanding was passed in November, 1996 which all serve as guiding components of this initiative.

As a National Steering Committee, the members and their technical advisors have worked cooperatively and collaboratively in the design of the National Common Core Questions which are included in each regional survey. The National Content was approved, by consensus, on November 6, 1996 at the National Steering Committee meeting held in Quebec City. The National Questions will address issues such as Children's Health, Health Services, Tobacco, Environmental Tobacco Smoke, Medical Conditions including Diabetes, Disability and Activity Limitation, Residential Schools, Wellness and Dental Health. The questions were developed to collect national data on issues which require national impact for First Nation health planning and advocacy for policy decisions.

The National Core Questions will be rolled together for analysis in fiscal year 1997 and will continue to be under the direction and guidance of the National Steering Committee to oversee the analysis, review and prepare the final report for publication and communications.

Each National Steering Committee member and their technical advisors have provided their knowledge,

Code of Research Ethics

experience and ideas toward the success of this Project; both nationally and regionally. Together, through mutual respect for each other and their respective political and accountability processes, they have significantly strengthened the Project and its outcomes.

All members of the Project share an understanding that First Nation and Inuit community based research is a powerful tool for learning about health and wellness while contributing to the health of the communities in which research is being conducted and impacts on regional and national policy and planning. These factors contribute to First Nation and Inuit control of health information and surveillance as tools for effective health planning and advocacy.

Collaborative research acknowledges that there must be respect for the scientific and social integrity of the Project. Each member has obligations toward the other members.

PURPOSE OF THE CODE OF ETHICS

The purpose of this Code of Ethics is to establish a framework of principles and procedures to guide the members of the National Steering Committee to accomplish the mandate and objectives of the National Regional Health Survey Project. This Code outlines the responsibilities of each member through all aspects and phases of the Project to its conclusion.

FIRST NATION/INUIT RESEARCH POLICY STATEMENT

It is acknowledged and respected that the right of self determination of the First Nation and Inuit peoples includes the jurisdiction to make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate the First Nation and Inuit communities in learning more about the health and well being of their peoples, taking control and management of their health information and to assist in the promotion of healthy lifestyles, practices and effective program planning.

The National Steering Committee promotes making the most of the funding opportunity on behalf of First Nations and Inuit. We will reclaim the original foundations of our health and healing; while still meeting the requirements of the contractual requirements of the Project..

REGIONAL HEALTH SURVEY GUIDING PRINCIPLES

- 1. The National Steering Committee encourages and will facilitate the research delivery at the highest possible professional level while striving to establish the conditions and skills for First Nations and Inuit self determination and responsibility for the total health of our communities.
- 2. The National Steering Committee recognizes that a fully participatory, evidence based planning culture takes several years to develop. However, the Regional Health Survey Project should contribute demonstrably in information, skills and capacity building.
- 3. The National Steering Committee recommends that, as far as possible, fact finding and analysis should be participatory allowing communities to determine which aspects of health should be addressed and how.
- 4. The surveys should stimulate informed dialogue between communities, local authorities, federal and provincial governments and services.
- 5. The communities must be involved as full partners in all aspects of the research. Feedback, input, participation in analysis and interpretation and communications should always characterize the research relationship.
- 6. The strengths, culture, language and traditional norms of the communities must be respected and utilized wherever possible.
- 7. Survey questionnaires will be developed for each of the regional surveys to give the communities selected an opportunity to include questions of a cultural nature as well as questions that specifically address pressing local concerns.
- 8. Permission from survey respondents will be obtained prior to collecting personal information.

- 9. Survey questionnaires of a personal nature to be answered in the strictest confidentiality or to be completed anonymously.
- 10.Confidentiality of the respondents must be assured. The respondents will remain anonymous when the results are reported.
- 11.All research results, analysis and interpretations for the National Core Data must first be reported to the National Steering Committee to ensure accuracy and avoid misunderstanding. This same process must be respected in each region as it pertains to the regional data where the communities and the regional advisory committees would first be reported to.
- 12.All data collected belongs to the communities and must be returned as grouped results.
- 13.All national core raw data will be stored at the Chiefs of Ontario office until such time as a First Nations and/ or Inuit Organization is mandated or authorized to assume responsibility for all First Nations and/or Inuit health information. Raw data will be kept on a computer in the Chiefs of Ontario offices. All data will be password protected. Access to this data will only be available to research technicians approved by the National Steering Committee as necessary for purposes of data analysis. This will be managed by the National Coordinator as directed by the National Steering Committee by resolution.
- 14.Longitudinal research requires a stable research environment for data storage.
- 15. The National Steering Committee members must be involved in making decisions about the publication and distribution of all or parts of the research results.

OBLIGATIONS OF THE NATIONAL STEERING COMMITTEE MEMBERS, CO-PRINCIPAL INVESTIGATOR'S GROUP AND ACADEMIC RESEARCHERS.

1. To involve the First Nation and Inuit community in active participation in this process and promote the knowledge that this is a First Nation and Inuit owned research process.

- 2. To ensure the design, imple-mentation, analysis, interpretation, reporting, publication and distribution of the research are culturally relevant and in compliance with the standards of competent research.
- 3. To undertake research that will contribute something of value to the First Nation and Inuit peoples nationally and in the regions in which the research is being conducted.
- 4. To enhance the capacity and skills of First Nation and Inuit peoples in research i.e. survey development, data collection, analysis, computer skills, health planning.
- 5. To assist in advocating and addressing health and social issues that may emerge as a result of the research.
- 6. To provide expertise to respond to questions that emerge from the First Nations and Inuit community.
- 7. To promote the knowledge of the Project and its outcomes through publication and presentations.
- 8. To be responsible for the data until the end of the Project.
- 9. To be involved in any future analysis of the data consistent with the general principle of the sovereignty of the Inuit and First Nation peoples, and with the particular research ethics of this Code.

NATIONAL STEERING COMMITTEE COMMUNICATIONS GUIDELINES

As the National Regional Health Survey Project is an initiative which is a first time ever national initiative which will scientifically collect health status data from the First Nation and Inuit community in a process controlled by and for First Nation and Inuit peoples, it will be appropriate to share the experiences of this Project with as many interested parties as possible to enable others to benefit from our experiences.

COMMUNICATION STRATEGY

Communication with regard to the First Nation and Inuit Regional Health Survey Project will be directed at the following interested parties:

- 1. National and Regional First Nation and Inuit Political Organizations
- 2. First Nation and Inuit communities.
- 3. Federal, Provincial, Local and International Health and Social officials
- 4. Academics, Scientists and Researchers (National, International)
- The interest in the Project will include:
- knowing how the Project and process functioned under direct First Nation/Inuit control.
- knowing how the Project was developed and implemented as well as the outcomes, barriers, innovations.
- knowing what methods were used, the process, the impacts measured, and the answers as a result of the research questions.
- how the results can be used for political advocacy and strategic health planning.

A communication strategy will be developed and agreed upon prior to the completion of the Project which will outline a detailed strategy to disseminate a report with the detailed analytical outcomes as approved by the National Steering Committee.

COMMUNICATIONS PRINCIPLES

All the research undertaken in the Regional Health Survey Project will be defensible and of reproducible technical content relevant to First Nations and Inuit Communities.

All communication pertaining to the Project will follow generally accepted ethical standards. Those standards include:

- 1. Confidentiality: All personal information will be made anonymous and remain confidential.
- 2. First Nation and Inuit Ownership to the data will be respected. The communities participating will be the first to receive results

and the first invited to provide input and feedback on the results.

3. No Prejudice. All communication efforts shall be calculated to benefit First Nation and Inuit Communities, and not harm them in any way.

ACCESS PROTOCOL TO NATIONAL CORE DATA

A protocol outlining access to the aggregated or raw national data will be clearly outlined and agreed upon prior to the completion of the project. This protocol will define issues such as access and confidentiality of the national core data.

The Protocol will address at least the following considerations:

- ownership and control of the data collected will remain with the National Steering Committee and those communities involved, as outlined in Section III, sub-section 12.
- access to the national data will be controlled by the National Steering Committee as outlined in Section III, sub-section 13.
- regional data can only be accessed after permission has been granted by the appropriate regional steering committee or similar group.
- community data can only be accessed after permission has been granted by the appropriate community authorities.

PROCEDURES FOR DATA ANALYSIS AND PUBLICATION OF RESULTS

The following procedure will be followed for purposes of data analysis and publication of results:

1. General analysis of the national core data will be conducted as per the direction of the National Steering Committee to include a detailed, comparative analysis of the national core data against other national surveys and relevant First Nation and Inuit health data and to also conduct eight (8) separate reports, including specific literature reviews, on the topics within the national core data which include: children health, health services, tobacco and environmental tobacco smoke, medical conditions including diabetes, disabilities and activity limitation, residential schools, wellness and dental health.

- 2. All resulting analysis will be reviewed by the National Steering Committee and the Co-Principal Investigator's Group for input into interpretation of the results.
- 3. All resulting draft reports or publications will be reviewed by the National Steering Committee
- 4. Best efforts will be made to reach consensus regarding the interpretation of results prior to any publication. In the event that a reasonable measure of consensus cannot be reached, no publication will be released.
- 5. Regional Processes will be respected in their participation in the analysis and interpretation of the national reports prior to publication and release.

Acknowledgement : In preparation of the Code of Ethics, other research code of ethics were used as a guide ; they included : Kahnawake Schools Diabetes Prevention Project, March 1996 and the Manitoba First Nations Regional Health Survey Protocol for Data Sharing. Permission has been granted to use these Code of Ethics as a guide in the development of the First Nation and Inuit Regional Health Survey Project Code of Ethics.

Other documents utilized to develop this Code include : First Nation and Inuit Regional Health Survey Project National Steering Committee - Letter of Understanding, November, 1996 and the National Steering Committee- Co-Principal Investigators's Group - Guiding Objectives for the First Nation and Inuit Regional Health Survey Project, September, 1996

The National Steering Committee gratefully acknowledges the contributions of the above mentioned Code of Ethics which have served as a guide and inspiration to this First Nation and Inuit Regional Health Survey Project Code of Ethics document. They are true pioneers in the development of the First Nation and Inuit controlled research processes. The First Nations and Inuit Regional Health Survey Project Code of Ethics was duly approved and signed by the National Steering Committee on July 25, 1997

- Phil Hall, B.C. First Nations Health Summit
- Richard Saunders, Alberta Treaty Nations Health Secretariat
- Ceal Tournier, Federation of Saskatchewn Indian Nations Health and Social Development Commission
- Audrey Leader, Assembly of Manitoba Chiefs
- Cathryn George, Association of Iroquois and Allied Indians
- Jane Gray, First Nations and Inuit of Quebec and Labrador Health and Social Services Commission
- Wendy Paul, Union of New Brunswick Indians
- Sharon Rudderham, Union of Nova Scotia Indians
- Iris Allen, Labrador Inuit Health Commissions

Duly passed by the National Steering Committee, July 25,1997, Sidney Nova Scotia

Participating First Nation and Inuit Communities

A special acknowledgement and thanks go to all participating First Nations and Inuit communities who contributed to the FNIRHS. The concept and practice of First Nations and Inuit communities generating, controlling, using and ultimately benefiting from their own health data has been firmly established by their participation in the FNIRHS

Labrador		Ontario			
Nain Hopedate Makkovik	Postville Rigolet	Beausoleil Bearskin Lake Big Grassy Big Trout Lake	Credit Mohawks of Akwesasne Moose Cree		
Nova Scotia		Nawash	Pays Plat		
Acadia Annapolis Valley Afton Bear River Chapel Island Eskasoni Horton	Millbrook Membertou Pictou Landing Shubenacadie Wagmatcook Waycobah	Chippewas of the Thames Eagle Lake Fort William Henvey Inlet Chippewas of Kettle & Stony Point Kingfisher Magnetawan	Red Rock Six Nations of the Grand River Wasauksing Washagamis Bay Wikwemikong Shawanaga (Reliability Study)		
New Brunswick & PEI		Mishkeegogamang Mississaugas of New			
Big Cove Burnt Church Buctouche Indian Island Pabineau Fort Folly Red Bank Eel River Bar	Eel Ground Madawaska Tobique Woodstock Kingsclear St. Mary's Oromocto Lennox Island, PEI	Manitoba Little Grand Rapids Little Black River Waywayseecappo Wasaagamack Garden Hill Sioux Valley	Norway House Lac Brochet Split Lake God's Lake Narrows Opaskwayak Chemawawin		
Quebec		Sandy Bay Fairford	Pine Creek Ebb & Flow		
Betsiamites Kawawachikamach Kitigan Zibi Listiguj Mingan Natashquan Odanak	Timiskaming Uashat & Maliotenam Wendake Wemotaci Winneway Withworth Montreal (Urban)	Little Saskatchewan			

Obedjiwan

Saskatchewan

Birch Narrows Buffalo River Dene Nation Clearwater Lake Dene Canoe lake **English River** Flying Dust Island Lake First Nation Makwa Sahgaiehcan Waterhen Lake Kinistin Mistawasis Muskeg Lake John Smith One Arrow Whitecap Dakota Sioux Yellow Quill Carry The Kettle Day Star **Fishing Lake** Gordon Kawacatoose Little Black Bear Muscowpetung Muskowekwan Nekaneet Okanese Pasqua Peekpeekisis Piapot Standing Buffalo Star Blanket Wood Mountain Cote Cowesses Kahkewistehaw Keeseekoose Key

Sakimay Ocean Man Moosomin Mosquito-Grizzly Bear's Head Poundmaker Red Pheasant Sweet Grass **Big River** Pelican Lake Witchekan Lake Ahtahkakoop Beardy's & Okemasis Pheasant Rump **Onion Lake** (Onion Lake, Makoo, Seekaskootch) Saulteaux Thunderchild Ochapowace Joseph Bighead Lac La Ronge (Grandmother's Bay, Kitsakie, Lac La Ronge, Little Red River, Morin lake, Neheiben River, Stanley Mission) Peter Ballantyne (Denare Beach, Deschambeault Lake, Pelican Narrows, Sandy Bay, Sounthend, Sturgeon Weir, Kinesao) Black Lake Fond Du Lac Hatchet Lake James Smith Montreal Lake Red Earthx Shoal Lake of the Cree Nation Sturgeon Lake Wahpeton Dakota Nation **Cumberland House**

Alberta

Swan River Athabasca Chipewyan First Nations (Fort Chip Chipewyan) Chipewyan Prairie First Nation (Janvier) Ft. Mc Kay Ft. Mc Murray #468 Mikisew Cree First Nation (Ft. Chip Cree) Kehewin Cree Nation Enoch Cree Paul Little Red River Cree Nation Siksika Blood Peigan

British Columbia

Kispiox Nazko Gilanyow # 1 Gitsegukla Nak'zadli Adam's Lake Lower Nicola Osoyoos Sea Bird Little Shuswap Kitkatla Ahoushat Sliammon Namgis Malahat Songhees



For more Information on the First Nations and Inuit Regional Health Survey contact :

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