

First Nations Regional Longitudinal
Health Survey (RHS) 2002/03



Report on Process and Methods



CONDENSED VERSION
Appendices are not Included

© First Nations Centre
ISBN: 0-9736623

For further information or to obtain additional copies, please contact:

First Nations Centre
220 Laurier Avenue West, Suite 1200
Ottawa, ON K1P 5Z9
Tel.: (613) 237-9462
Fax: (613) 237-1810

This report is available in English electronically at:

http://www.naho.ca/firstnations/english/regional_health.php

June 2006

Special thanks to Health Canada for its continued support for the RHS process.
Les versions françaises de cette publication sont disponibles sur demande.

TABLE OF CONTENTS

| | |
|---|----|
| 1. Background | 1 |
| 2. Origin of the Survey | 1 |
| 2.1 Project Management for the First Round (1996 to 1999) | 2 |
| 2.2 Methods: 1997 Survey | 3 |
| 2.3 The First and Second Rounds, Compared | 4 |
| 3. Overview of the Second Round | 5 |
| 3.1 Project Management for the Second Round (2000 to Present) | 5 |
| 3.1.1 First Nations Organizations Involved | 5 |
| 3.1.2 Governance | 5 |
| 3.1.3 Coordination and Implementation | 6 |
| 3.1.4 Guiding Principles and Values | 7 |
| 4. Methods for the Second Round | 8 |
| 4.1 Survey Development | 9 |
| 4.1.1 Pilot/Field Testing | 10 |
| 4.2 Survey Content | 10 |
| 4.3 Interviewing | 11 |
| 4.4 Sampling Design | 11 |
| 4.4.1 Design Overview | 11 |
| 4.4.2 Target Population and Coverage | 12 |
| 4.4.3 Overall Sampling Design | 13 |
| 4.4.4 Cross-Sectional Estimates | 13 |
| 4.4.5 Longitudinal Component | 14 |
| 4.4.5.1 Longitudinal Design Parameters | 15 |
| 4.4.5.2 Attrition Rates | 15 |
| 4.4.6 Combined Sampling Approach | 15 |
| 4.4.6.1 Selection of Communities | 16 |
| 4.4.6.2 Allocation of Sample to Communities | 16 |
| 4.4.6.3 Minimum Community Samples | 16 |
| 4.4.6.4 Sampling of Older Adults | 16 |
| 4.4.6.5 Replacement of Communities | 17 |
| 4.4.6.6 Community Sampling Frames and Selection of Individuals | 17 |
| 4.4.7 Other Sampling Considerations | 18 |
| 4.4.7.1 Overall Data Quality—Cross-Sectional Component | 18 |
| 4.4.7.2 Overall Data Quality: RHS—Longitudinal Component (to 2014) | 18 |
| 4.4.7.3 Overall Data Quality—Regional and Canada-Level Sample Sizes | 18 |
| 4.5 Long-Term Sampling Plans | 18 |
| 4.6 Data Collection | 19 |
| 4.6.1 Regional Coordination | 19 |
| 4.6.2 Fieldworker Training | 19 |
| 4.6.3 Computer Assisted Personal Interviewing | 20 |

| | | |
|----------|---|----|
| 4.6.3.1 | Rationale | 20 |
| 4.6.3.2 | Selection of Laptop Technology | 20 |
| 4.6.3.3 | Laptop-Server Design | 21 |
| 4.6.3.4 | Privacy/Security | 21 |
| 4.6.3.5 | Time | 21 |
| 4.6.3.6 | Connectivity Problems | 22 |
| 4.6.3.7 | Paper-Based Surveys | 22 |
| 4.6.3.8 | Changes to Software After Start of Data Collection | 23 |
| 4.6.3.9 | Survey Upload Reports | 24 |
| 4.6.3.10 | Overall Assessment of the CAPI Approach | 24 |
| 4.6.4 | Consent | 25 |
| 4.7 | Final Sample | 27 |
| 4.7.1 | Coverage | 27 |
| 4.7.2 | Final Sample in Relation to Design | 28 |
| 4.7.2.1 | Proportion of Target Samples Achieved | 28 |
| 4.7.2.2 | Community Participation and Replacement | 30 |
| 4.7.2.3 | Individual Participation (Participation Rate) | 30 |
| 4.7.2.4 | Use of Alternate Community Sampling Frames | 31 |
| 4.7.2.5 | Inclusion of Off-Reserve Sample | 32 |
| 4.7.2.6 | Changes to Community Sampling Targets | 32 |
| 4.7.2.7 | Individuals Completing the Wrong Survey Type | 32 |
| 4.8 | Data Processing | 33 |
| 4.8.1 | Data Capture (Data Entry) | 33 |
| 4.8.2 | Editing: In the Field | 34 |
| 4.8.3 | Removal of Records Deemed Not Valid | 34 |
| 4.8.3.1 | Removal of Duplicates | 34 |
| 4.8.3.2 | Removal of Incomplete Surveys | 35 |
| 4.8.3.3 | Removal of Records with Inadequately Documented Consent | 35 |
| 4.8.4 | Integration of Missing/Blank Responses | 37 |
| 4.8.5 | Editing: Validity and Outliers | 37 |
| 4.8.6 | Coding and Re-coding | 37 |
| 4.8.7 | Weighting | 38 |
| 4.8.8 | Analysis and Interpretation | 39 |
| 4.8.8.1 | Overview of Analysis, Interpretation and Dissemination Strategy | 39 |
| 4.8.8.2 | Overview of 34-Chapter Report | 40 |
| 4.8.8.3 | Writing and Statistical Standards for 34-Chapter Report | 41 |
| 4.8.8.4 | Review and Quality Control for 34-Chapter Report | 41 |
| 4.8.8.5 | Data Analysis for 34-Chapter Report | 42 |
| 4.8.9 | First Nations Interpretation | 42 |
| 4.9 | Data Quality | 43 |
| 4.9.1 | Sampling Errors | 43 |
| 4.9.2 | Non-Sampling Errors | 43 |
| 4.9.2.1 | Interview/Response Errors | 44 |
| 4.9.2.2 | Coverage | 44 |
| 4.9.2.3 | Total Non-Response | 44 |
| 4.9.2.4 | Partial Non-Response | 44 |
| 4.9.2.5 | Processing Errors | 45 |

LIST OF TABLES

| | | |
|----------|---|----|
| Table 1 | Overview of First and Second Rounds of the RHS | 4 |
| Table 2 | Topics Addressed in Each National Survey Component | 10 |
| Table 4 | Time to Complete Surveys, Median and 95th Percentile | 11 |
| Table 3 | 2002/03 Regional Modules by Survey Type | 11 |
| Table 5 | Estimated First Nations Population in First Nations Communities, by Region (Adjusted, Projected 2002 Indian Register Counts) | 12 |
| Table 6 | Attrition Rates by Age Group for Each Survey Year to 2014 | 15 |
| Table 7 | Target Sample Sizes by Region for the Combined Sample Design | 16 |
| Table 8 | Proportion of Target Sample Achieved, by Region | 29 |
| Table 9 | Proportion of Target Sample Achieved, by Age/Gender Group | 29 |
| Table 10 | Number and Proportion of First Selection and Replacement Communities, by Region | 30 |
| Table 11 | Number of Respondents Completing the “Right” and “Wrong” Surveys, by Age | 33 |
| Table 12 | Mean Weights by Region and Database | 38 |
| Table 13 | Weights at the 80th and 90th Percentile, by Database | 39 |
| Table 14 | Chapters in Technical Report | 40 |
| Table 15 | Mean Number of “Don’t Know” and “Refused” Responses: Paper-Based vs. Other Surveys | 45 |
| Table 16 | Summary of Available Data Estimates, by Level of Geography | 45 |

LIST OF FIGURES

| | | |
|----------|--|----|
| Figure 1 | First Nations “Sub-Regions” | 14 |
| Figure 2 | Data Collection Schedule, 1997-2014 | 15 |
| Figure 3 | Examples of Consent Form Elements Requiring a Mark | 26 |
| Figure 4 | Number of Sub-Regions and Communities and Proportion of On-Reserve Residents Sampled, by Region | 27 |
| Figure 5 | Percent of First Nations Community Population Sampled, by Age | 28 |
| Figure 6 | Overview of Individual Participation Based on Survey and Consent Form Records | 31 |
| Figure 7 | Data Processing Flowchart | 34 |
| Figure 8 | Proportion of Surveys According to Level of Item Non-Response | 36 |
| Figure 9 | Chapter Drafting and Review Process | 42 |



APPENDICES

| | |
|---|-----|
| Appendix 1: National Adult Survey | 47 |
| Appendix 2: National Youth Survey | 91 |
| Appendix 3: National Child Survey | 125 |
| Appendix 4: Themes of the 2002/03 RHS Regional Surveys | 151 |
| Appendix 5: Regional Surveys | 153 |
| Appendix 5.1: Yukon Surveys | 155 |
| Appendix 5.2: British Columbia Surveys | 171 |
| Appendix 5.3: Manitoba Surveys | 175 |
| Appendix 5.4: Ontario Surveys | 221 |
| Appendix 5.5: Quebec Surveys | 223 |
| Appendix 5.6: Dene (NT) Survey | 241 |
| Appendix 5.7: Nova Scotia/Newfoundland Surveys | 259 |
| Appendix 6: Estimated Community Populations By Sub-Region and Size Group (2002) | 267 |
| Appendix 7: Combined Community Population (On Reserve or Crown Land), by Sub-Region | 281 |
| Appendix 8: Cross-Sectional and Longitudinal Sampling Design Table | 283 |
| Appendix 9: Information and Consent Form Package | 287 |
| Appendix 10: Sample Regional Weekly Upload Report | 295 |
| Appendix 11: Proportion of Population Sampled, by Sub-Region | 303 |
| Appendix 12: Proportion of Target Sample Achieved, by Sub-Region | 305 |
| Appendix 13: Communities Initially Selected and Included in Final Sample | 307 |
| Appendix 14: Adult Data Dictionary | 325 |
| Appendix 15: Youth Data Dictionary | 423 |
| Appendix 16: Child Data Dictionary | 463 |
| Appendix 17: Adult Survey Database Weights by Region and Sub-Region | 497 |
| Appendix 18: Youth Survey Database Weights by Region and Sub-Region | 499 |
| Appendix 19: Child Survey Database Weights by Region and Sub-Region | 501 |
| Appendix 20: February 2005 Request for Authors (RFA) for Major National Report | 503 |
| Appendix 21: Tabulation Request Form for RHS Chapter Authors | 521 |
| Appendix 22: Notes to “First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Report on Process and Methods” | 533 |

1. Background

The First Nations Regional Longitudinal Health Survey (RHS) traces its origins back to 1995. Although initially proposed essentially to fill data gaps, the nature of the project has evolved considerably.

Ten years later, in keeping with its mandate from the Assembly of First Nations' Chiefs Committee on Health, the RHS has disseminated results from two rounds of data collection and has emerged as the only national research initiative under complete First Nations control.

Results from the 1997 round were released in 1999.¹ For the 2002/03 survey, a series of preliminary releases were followed by the launch of national reports² at a dedicated First Nations research conference in November 2005.³

After an overview of the project's development, including general information about the 1997 and 2002/03 surveys, this report focuses on methods used in the 2002/03 round.

2. Origin of the Survey

The need for a national longitudinal survey of Aboriginal people was identified in 1994, after the launch of three Canadian longitudinal surveys that specifically excluded First Nation reserves and Inuit communities in the provinces: *National Population Health Survey (NPHS)*, *National Longitudinal Survey of Children and Youth (NLSCY)* and *Survey of Labour and Income Dynamics (SLID)*. The sample sizes of the new surveys were also too small to describe the off-reserve First Nations or Aboriginal populations. The idea for an Aboriginal survey to fill the gaps created by the new surveys was vetted through a feasibility study based on a series of consultations conducted in the fall of 1994 with Aboriginal professionals in Aboriginal communities and organizations.

RHS Timeline

1994 Three Canadian longitudinal surveys launched, excluding First Nations and Inuit communities.

FIRST ROUND OF THE SURVEY

1995 Funding for first round by Health Canada. Indian Affairs and Human Resources Development Canada declined.

1996 Mandate from Assembly of First Nations.

1996 Direct First Nations and Inuit control established.

1996 Development of instruments and methods.

1997 Data collection in nine regions: 14,008 surveys (9,870 adults; 4,138 children).

1997 Code of Research Ethics adopted.

1998 "OCA" principles first articulated.

1999 Final report based on 1997 survey released.

SECOND ROUND OF THE SURVEY

2000/01 Proposals and long-term plans submitted for funding and potential Treasury Board submission.

2000/02 Development of instruments and methods for 1st wave of longitudinal survey.

2002 Coordination transferred to the First Nations Centre (NAHO).

2002/03 Data collection in 10 First Nations regions: 22,602 surveys (10,962 adults; 4,983 youth; 6,657 children).

2004 Data processing.

2004 Preliminary results released.

2005 Major reports released.

The guidelines and direction that emerged, particularly with respect to Aboriginal control, regional processes, and capacity development, provided the project's foundation when it was funded as *The First Nations and Inuit Regional Health Survey*⁴ by the Medical Services Branch

¹ <http://www.naho.ca/firstnations/english/initial_data1997.php>

² <http://www.naho.ca/firstnations/english/regional_health.php>

³ <<http://www.naho.ca/firstnations/english/FirstNationsResearchConference.php>>

⁴ The name was subsequently changed to *The First Nations Regional Longitudinal Health Survey (RHS)*, reflecting the longitudinal design of the second round and the decision of the Labrador Inuit not to participate.

(MSB) of Health Canada in 1996.^{5,6,7} The two other departments that had initially contributed to the feasibility study (Indian and Northern Affairs Canada and Human Resources Development Canada) subsequently declined to contribute.

2.1 PROJECT MANAGEMENT FOR THE FIRST ROUND (1996 TO 1999)

A total of eight First Nations authorities and one Inuit entity coordinated the initial round of data collection in their respective regions in 1997:

- Labrador Inuit Health Commission
- Union of Nova Scotia Indians
- Union of New Brunswick Indians (including PEI)
- First Nations of Quebec and Labrador Health and Social Services Commission
- Chiefs of Ontario
- Assembly of Manitoba Chiefs
- Federation of Saskatchewan Indian Nations
- Alberta Indian Health Care Commission
- First Nations Health Summit (BC).

First Nations in the Northwest Territories and the Yukon were excluded from MSB's funding allocations for the first round of the survey.

In 1996, the Assembly of First Nations' Chiefs Committee on Health provided a mandate for the survey to take place every four years. Gail McDonald, a Mohawk from Akwesasne, was hired as the national coordinator and the project was hosted at the Chiefs of Ontario. Widely respected for her vision of First Nations self-determination in health, McDonald worked diligently with the National Steering Committee (NSC) and

other collaborators, building trust and unity, as she guided the project through its first round and into its second.

In 1997, the NSC assumed complete (regional) First Nations and Inuit control of the project. The committee developed a *Letter of Understanding* and a *Code of Research Ethics* (subsequently updated⁸), outlining the respectful processes, roles and relationships that would guide the project.

The *Code of Research Ethics* policy statement clearly outlines the values and motivations that underpin the project to this day:

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.⁹

The original National Steering Committee, signatories to the *Code of Research Ethics*, included:

- Iris Allen, Labrador Inuit Health Committee
- Ceal Tournier, Federation of Saskatchewan Indian Nations
- Sharon Rudderham, Union of Nova Scotia Indians

⁵ O'Neil, J. D., et al. The First Nations and Inuit Longitudinal Health Survey: A Process Report. 1998.

⁶ O'Neil, J. D., and Commanda, L. Determining the Feasibility of the Canadian First Nations and Inuit Regional (Longitudinal) Health Surveys. Circumpolar Health, 1998.

⁷ First Nations of Quebec and Labrador Health and Social Services Commission. Regional Medical Survey on the Health of First Nations Members, Quebec region: Final Report. Information Codification, 1997.

⁸ <http://www.naho.ca/firstnations/english/pdf/code_ethics_RHS.pdf>

⁹ Ibid.

- Richard Saunders, Alberta Indian Health Care Commission
- Wendy Paul and Darren Graham, Union of New Brunswick Indians
- Phil Hall, B.C. First Nations Health Summit
- Gary Cole and Jane Gray, First Nations and Inuit of Quebec and Labrador Health and Social Services Commission
- Allen Deleary, Assembly of First Nations, Ex-officio
- Cathryn George, Association of Iroquois and Allied Indians, Ontario
- Roda Grey, Pauktuutit, Inuit Women's Health Association (Pauktuutit withdrew in January 1997)
- Audrey Leader, Assembly of Manitoba Chiefs
- Nichole Simond, Medical Services Branch, Ex-officio.

A critical factor in the success of the survey has been the ability of the steering committee members to stay connected and remain accountable to First Nations. The members' individual and collective abilities to bring regional First Nations issues, priorities and concerns to the national table have kept the project on solid footing. Committee members ensured that First Nations and Inuit processes and protocols were followed, communities remained actively engaged and community-level interests were reflected in design and implementation. The members' relationship with First Nations and Inuit leadership were also key to building and maintaining support for the project. Numerous regional and national First Nations Chiefs' resolutions serve as testament.¹⁰

There was also a "Co-Principal Investigators" group, made up mostly of university-based researchers who wrote the first report and

worked alongside the representatives of the First Nations and Inuit regional organizations on the technical aspects of the project. In addition to collaborating nationally, the researchers also supported implementation and undertook analysis in their respective regions.

2.2 METHODS: 1997 SURVEY

The 1997 survey was very regional in nature, with nine largely autonomous processes. A limited number of questions, representing about 20 minutes of interview time, were shared nationally. Those questions were the basis for the national results. The regional questionnaires, developed in eight of the nine regions, were typically longer and covered more topics. The final sample included 14,008 people (9,870 adults and 4,138 children) in 186 communities based on sampling strategies that varied greatly from region to region. The methods ranged from two-stage cluster sampling, to interviewing all the heads of households, to opportunistic (volunteer) sampling. In one region adults were defined as 15 years and over, elsewhere 18 and over. In some regions, household sampling was adopted; elsewhere, local band membership lists were used. Weighting made up for some of the variation when the diverse databases were rolled up into a national one.

In 1999, final regional and national reports¹¹ were released. The national report included eight thematic chapters: 1) Non-traditional use of tobacco; 2) Chronic Diseases; 3) Children's Health; 4) Disability; 5) Health Services; 6) Dental Health; 7) Residential Schools and the Health of the Elderly and, 8) Wellness. Subsequently, fact sheets and a synthesis of regional reports¹² were also released. As the only

¹⁰ Since 1996, there were six national support resolutions from the Assembly of First Nations (1998, 1999, 2000, 2001, 2001, 2004) as well as one in the Yukon (2004), one in the Northwest Territories (2005), two in British Columbia (2003, 2004), one in Saskatchewan (2001), one in Manitoba (1998), one in Ontario (2004), four in Quebec (1996, 2001, 2001, 2004) and one in the Atlantic provinces (2001).

¹¹ <http://naho.ca/firstnations/english/initial_data1997.php>

¹² <http://naho.ca/firstnations/english/initial_data1997.php>
<http://naho.ca/firstnations/english/pdf/RHS_synthesis_report.pdf>

national First Nations and Inuit health data of its kind at the time, results were widely cited in published literature¹³ and used by Government and others to set policy and support programs.¹⁴

More detail on the history from 1994 through completion of the survey's first round, including information about methodology, academic technical support and regional processes, is contained in an earlier process report.¹⁵ Additional historical information is also contained in the *RHS Code of Research Ethics*.

The 1997 round was successful as a first-ever national research initiative carried out under First Nations and Inuit governance. It created the conditions for trust in research and established the foundation and governance structures needed for a more harmonized survey in 2002/03.

2.3 THE FIRST AND SECOND ROUNDS, COMPARED

Although the second round of the survey is a continuation of the first, there are a variety of differences between the two, summarized in Table 1.

| | First Round (1997) | Second Round (2002-03) |
|---|--|---|
| Title | <i>First Nations and Inuit Regional Health Survey</i> | <i>First Nations Regional Longitudinal Health Survey</i> |
| Acronym | FNRLHS or RHS | FNRLHS or RHS |
| Mandate | Assembly of First Nations Chiefs Committee on Health | Assembly of First Nations Chiefs Committee on Health |
| National governance | RHS National Steering Committee | First Nations Information Governance Committee |
| Regional coordination | First Nations Regional Organizations | First Nations Regional Organizations |
| National coordination | Assembly of First Nations ¹⁶ Aboriginal Health Organization | First Nations Centre, National |
| Number of regions | 8 First Nations Regions (provinces) and 1 Inuit Region (Labrador) | 10 First Nations Regions (including all provinces and territories except Nunavut) |
| Target population | The Inuit of Labrador and First Nations communities in the provinces (not the territories) | First Nations communities across Canada ¹⁷ |
| Longitudinal cohort | First round for Nova Scotia only | First round for all other regions |
| Sample design | Varied by region | Largely standardized |
| Sample size | 14,008 surveys: 9,870 adults and 4,138 children | 22,602 surveys: 10,962 adults, 4,983 youth and 6,657 children |
| Communities | 186 included | 238 included |
| Length of national "core" components | Approximately 20 minutes of interview time (for adult and child components combined) | 84 minutes median interview time (for adult, youth and child surveys combined) |
| Region-specific questions | Detailed questionnaires in 8 of 9 regions. | Additional modules of varying length in 7 of 10 regions |

¹³ For example: Young T. K., et al. Type 2 diabetes mellitus in Canada's first nations: status of an epidemic in progress. *CMAJ* (163:561-566), 2000; <<http://www.diabetes.ca/cpg2003/chapters.aspx?references2.htm>>; <<http://dsp-psd.pwgsc.gc.ca/Collection/H35-4-6-2001E.pdf>>; <http://www.hc-sc.gc.ca/sr-sr/pubs/hpr-rps/bull/2003-5-aboriginal-autochtone/index_e.html>; <<http://www.hc-sc.gc.ca/iacob-dgiac/arad-draa/english/accountability/indicators.html>>; <http://www.hc-sc.gc.ca/fnih-spni/pubs/gen/2003_stat_profil/index_e.html>; Kirkland, S. A., Greaves, L., Devichand, P. "Gender differences in smoking and self-reported indicators of health." *Women's Health Surveillance Report: A multidimensional look at the health of Canadian women.* BMC Women's Health, 2004. (4:S7-19).

¹⁴ For example, it was used for planning and funding the federal First Nations and Inuit Home and Community Care program, the Aboriginal Diabetes Initiative and the First Nations and Inuit Tobacco strategy.
¹⁵ O'Neil, J. D., and Commanda, L. *Determining the Feasibility of the Canadian First Nations and Inuit Regional (Longitudinal) Health Surveys.* Circumpolar Health, 1998.
¹⁶ National coordination of the first round was initially through the Chiefs of Ontario.
¹⁷ Excluding the James Bay Cree of Northern Quebec and the Innu of Labrador (see 4.7.1 and 4.9.2.2).

3. Overview of the Second Round

The design phase of the second survey began in 2000. The instruments and methods were fine-tuned through an inclusive, iterative process that lasted over two years. Data collection took place between August 2002 and November 2003 in First Nations communities throughout Canada. Over 22,000 surveys were collected and the First Nations Centre released preliminary national results in September 2004.¹⁸

3.1 PROJECT MANAGEMENT FOR THE SECOND ROUND (2000 TO PRESENT)

In addition to important changes in methods and instruments described in section 4, the cast of players changed, decision-making processes evolved, the guiding principles were further focused and the beginnings of a First Nations health data/research infrastructure emerged.

3.1.1 First Nations Organizations Involved

Two regions were added and one opted not to participate. First Nations in the Northwest Territories and Yukon regions joined the process once funding was secured to include them. The Labrador Inuit, though, decided to pass on the second round (first wave of the longitudinal) and pursue Inuit-specific initiatives instead. As of 2005, survey partners were:

National

- Assembly of First Nations (Coordination of First Nations Information Governance Committee)
- First Nations Centre of the National Aboriginal Health Organization (National coordination and data stewardship)

Regional Coordination and Data Stewardship

- Union of Nova Scotia Indians
- Union of New Brunswick Indians

- First Nations of Quebec and Labrador Health and Social Services Commission
- Chiefs of Ontario
- Assembly of Manitoba Chiefs
- Federation of Saskatchewan Indian Nations
- First Nations Adult and Higher Education Consortium (Alberta)
- First Nations Chiefs' Health Committee (B.C.)
- Dene National Office
- Council of Yukon First Nations

3.1.2 Governance

The RHS National Steering Committee has been renamed the First Nations Information Governance Committee (FNIGC). It is made up of members of the partner organizations and is a standing committee of the national Chiefs Committee on Health (Assembly of First Nations). The name change reflects the broadened mandate and range of issues that years of work on the RHS had brought into focus. The group's initial (spring 2000) mandate and vision reflect this bigger vision:

Mandate

"... to ensure that accountability, respect, ethics, values and the principles of ownership, control, access and possession to First Nation data are protected and advanced in the development of the First Nation Health Info structure (regional and national) and within the various current national federal initiatives that are underway (and provincial and territorial) where applicable."

Vision

"First Nations will assume authority, control and responsibility for research, data gathering, information management systems to support First Nations self government and to build a distinct, autonomous info structure that will be strategically interconnected Regionally and Nationally to the Canada Health Infoway."¹⁹

¹⁸ <http://www.naho.ca/firstnations/english/pdf/RHS_prelim_results_nov8.pdf>

¹⁹ First Nations Information Governance Committee. Terms of Reference. Rev. 2000.

While continuing to devote a great deal of attention to guiding the RHS, the FNIGC increasingly addresses issues related to university research, government data collection processes, health information systems and initiatives, research ethics and development of First Nations research infrastructure. Within most regions a research advisory committee or similar entity parallels the work of the FNIGC, including oversight and direction of the survey.

3.1.3 Coordination and Implementation

The university-based “Co-Principal Investigators Group” was no longer active after the first round, as the emphasis focused increasingly on the development of expertise within First Nations organizations. With RHS funding from Health Canada, Regional Coordinator or Research and Information Coordinator (RC) positions were created in the 10 regional partner organizations. RCs are responsible for regional implementation of the survey through all phases and generally for managing health research and information issues. Creating these positions is seen as a step towards a First Nations health research infrastructure. Despite being housed in political (rather than research) organizations, and despite the uneven flow of RHS project funding, the group has remained effective thanks to the dedication of the individuals and First Nations organizations involved.

In addition to their regional roles, Regional Coordinators come together to provide technical guidance and mutual support as part of the “National RHS Team.”

Since 2002, the national process has been coordinated through the First Nations Centre at the National Aboriginal Health Organization (NAHO). Following extensive consultations with Aboriginal groups, NAHO²⁰ itself was incorporated in 2000 and the First Nations Centre (FNC) was established in 2001. With its recognized

role in research and knowledge-based activities in general, the FNC was considered an obvious choice for both coordination and data stewardship. In 2002, the FNIGC and the Chiefs Committee on Health adopted a formal motion

Steps taken to protect privacy and OCAP rights

- Sought and obtained First Nations political mandates.
- Conducted a Privacy Impact Assessment.
- Conducted a First Nations Ethics Review.
- Supported National and Regional First Nations Governance/Steering committees.
- Developed innovative “License to Use” statistics agreement with Health Canada.
- Developed detailed data protection protocols, including data release rules.
- Made lifetime commitments to protect data.
- Devised protocols for return of community results.
- Required oath of confidentiality for interviewers, coordinators and other staff.
- Required community consent prior to data collection.
- Required individual informed consent.
- Provided training on privacy and data protection.
- Incorporated data protection measures into all computer software.
- Ensured First Nations interpretation and developed cultural framework to guide analysis.

²⁰ NAHO was named the Aboriginal Health Institute during consultations and was incorporated as the Organization for the Advancement of Aboriginal Peoples’ Health.

to move the project's coordination from the AFN to the FNC. All significant decisions, though, continued to rest with the FNIGC.

In 2002, Jane Gray, a Miq'mak from Listiguj, assumed the role of National Coordinator responsible for leading the project nationally. Ms. Gray, the FNIGC, and all those involved, work to ensure that the collection, analysis, interpretation and dissemination phases are carried out in keeping with First Nations' processes and values.

3.1.4 Guiding Principles and Values

At the heart of the RHS are the First Nations principles of Ownership, Control, Access and Possession (OCAP). Sometimes referred to as "self-determination applied to research", OCAP was crystallized by the RHS National Steering Committee (now the FNIGC). Since the acronym was coined (initially as "OCA") in 1998, it is increasingly recognized as the emerging paradigm for research and the management of data involving First Nations peoples. The principles have been articulated this way:

Ownership: *Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].*

Control: *The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies, are within their rights in seeking to control all aspects of research and information management*

processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access: *First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.*

Possession: *While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor."*²¹

Another primary focus of the RHS is research capacity development. The emphasis is not only on individuals but also on building long-term research and data management capacity within First Nations communities and regional organizations.

Capacity development and OCAP are seen as closely related. Research capacity enhances the ability to assert OCAP while the assertion of OCAP creates new opportunities for capacity

²¹ Schnarch, B. "Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities." *Journal of Aboriginal Health*. Vol. 1, No. 1. Ottawa: National Aboriginal Health Organization, 2004.

National Data Release (excerpt from RHS 2004 Data Protection and Stewardship Protocol)

“The Regional Organizations and the First Nations Centre (FNC) seek to maximize benefits to First Nations that may be derived from the RHS survey process and the information that it produces. To that end, the FNC and Regional Organizations are committed to extensive and strategic use, analysis and dissemination of the RHS data. In order to maximize benefits and ensure the effective and appropriate use of RHS data, validation by First Nations authorities (FNIGC/CCOH) is required.

In respect of the privacy rights of individuals, the sovereign rights of First Nations and the authorities conferred or mandated to their representative bodies and in keeping with the principles of OCAP, the FNC and Regional Organizations are bound by the following:

The FNC will not release or disseminate any data or statistical information from the RHS except if:

- a. The FNC has thoroughly complied with statistics release protocols (or data release protocols) approved by the FNIGC or
- b. The FNC has received direct approval of the FNIGC...

...The FNC and the Regional Organizations will not release or disseminate any data or information from the RHS that identifies or could lead to the identification of a community without authorization from that community’s recognized leadership.

The FNC will not release or disseminate any data or information from the RHS that identifies or could lead to the identification of a First Nations Region or group of communities (e.g., tribal council, treaty area) without authorization from the appropriately mandated First Nations authority. “

development in First Nations organizations and communities. The development of a sustainable First Nations, community-driven health research infrastructure is seen as the long-term goal, developing capacity and implementing OCAP at the same time.

As noted, the 2002/03 RHS was more harmonized than the first round (e.g., standardized sampling methods, larger set of national “core” questions) while maintaining its regional emphasis. The RHS did not shift the balance from regional to national. Rather, the national process is strengthened because it is built on top of and supported by regional processes. The RHS emphasizes collaboration and mutual support among First Nations partners.

4. Methods for the Second Round

A set of broad objectives helped to focus the survey’s implementation:

- To offer scientifically and culturally validated information;
- To enhance First Nations capacity and control over research;
- To provide First Nations with key information for planning, policy and advocacy at the community, regional and national levels;
- To assist First Nations in assessing their communities’ progress in health;
- To serve as a model for community based research.

Specifically, the purpose of the survey was to provide detailed data on the health and well being of First Nations within in a holistic framework and, more specifically,

to provide information on topics considered priorities by First Nations.

The following sections detail the methodology for the 2002/03 survey following the chronology of its development and describe the design stage, data collection, data processing and finally, the analysis, interpretation and dissemination phases. Some issues may be addressed in more than one section. Participant consent, for example, is discussed in relation to survey design, data collection and data processing. The description of methods closes with an overview of data quality.

4.1 SURVEY DEVELOPMENT

In addition to the adult and children’s surveys, it was decided that a separate and distinct youth survey was needed to reflect the unique issues facing First Nations youth. A survey specific to older adults was considered but ultimately not developed. An over sampling of those 55 years and over was, though, built in to the sampling design (see 4.4.6.4).

Starting with the most common and useful questions and topics contained in the 1997 national and regional questionnaires, initial drafts of the child, youth and adult surveys were prepared. Each questionnaire subsequently went through dozens of revisions over a two-year period. A large number of people provided input, including:

- Regional Coordinators;
- First Nations Information Governance Committee members;
- Assembly of First Nations and First Nations Centre staff;
- Health workers in First Nations communities;
- Health Canada (First Nations and Inuit Health Branch) staff;

- Physicians and nurses;
- University-based researchers;
- Staff and consultants of First Nations regional and national organizations.

Most of the active survey development work was undertaken by the “National RHS Team”—ten First Nations Regional Coordinators plus the national staff. The team held meetings and teleconferences to fine-tune the instruments, while seven of ten regions simultaneously developed components focused on their regional priorities.

The requirement to produce instruments that were both scientifically and culturally valid guided the development phase. In formulating questions, a balance was sought between content comparable to questions used in other Canadian surveys²² and questions specifically appropriate to First Nations. Topics primarily of regional interest were excluded from the national surveys. Keeping the instruments to a manageable length while covering all topics deemed important by the group was challenging. Deciding how to address “sensitive” questions presented a further challenge.

A 1998 Chiefs Committee on Health resolution directed that the second iteration of the survey incorporate sensitive issues such as HIV/AIDS, suicide and mental health. Ultimately the adult and youth questionnaires addressed those issues as well as questions about residential school, alcohol, drug use and sexual activity. Inclusion of these topics raised ethical issues. Concern that the survey questions could cause painful memories to resurface and result in difficult and even potentially dangerous situations had to be balanced with the importance of addressing critical health and social issues. To mitigate the concerns, special efforts were made in recruitment and training. The fieldworker manual included a detailed chapter on handling sensitive issues and difficult situations; fieldworkers

²² Including the Canadian Community Health Survey (CCHS), the National Population Health Survey (NPHS), the National Longitudinal Survey of Children and Youth (NLSCY) and the 2001 Canadian Census.

were instructed on how to avoid and how to deal with various scenarios and were provided with ongoing support, referral lists and phone numbers (see 4.6.2).

4.1.1 Pilot/Field Testing

In addition to individual input and group reviews, each draft questionnaire was subject to at least two rounds of formal qualitative field testing based on standardized procedures and probes. The qualitative testing was led by

regional coordinators and resulted in substantial changes to the survey instruments.

4.2 SURVEY CONTENT

The three national survey instruments address a comprehensive range of health status, wellness and health determinant measures. Table 2 provides an overview of the subjects addressed. For purposes of comparability across age groups, where possible, the same questions were used in all three surveys.

| Adult Survey (18+ years) | Youth Survey (12-17 years) | Child Survey (0-12 years) |
|---|--|--|
| <ul style="list-style-type: none"> • Age, gender, marital status, community • Languages—comprehension, use • Education • Employment • Income and sources • Household— composition, income • Housing—condition, crowding, mold • Water quality • Services (phone, water, smoke detector, internet etc.) • Height, weight • 28 health conditions—duration, treatment, effects • Diabetes—type, treatment, effects • Physical injuries • Dental care • Disabilities, limitations • Physical activity • Food and nutrition • Home care—use, need • Health services—use, access, NIHB • Traditional medicines, healers • Smoking, alcohol, drugs—use, cessation, treatment • HIV/AIDS, STD's and sexuality • Pregnancy, fertility • Preventative health practices • Wellness, supports & mental health • Suicidal ideation and attempts • Residential schools—impacts • Community wellness • Culture, spirituality, religion • Community development | <ul style="list-style-type: none"> • Age, gender, household/family composition • Education—level, performance, personal goals • Language—comprehension, use • Food and nutrition • Activities—physical, social • Height, weight, satisfaction with • Diabetes—type, treatment • 19 health conditions—duration, treatment, effects • Injuries • Dental care • Smoking, alcohol, drugs • Sexuality • Preventative health practices • Personal wellness, supports & mental health • Suicidal ideation, attempts • After school activities • Traditional culture—importance, learning • Residential school (parents, grandparents) | <ul style="list-style-type: none"> • Age, gender, household/family composition • Parental education • Education—level, performance, Head Start • Height, weight—at birth, current • Breastfeeding history • Smoking, second hand smoke exposure—pre & post natal • Language—comprehension, use, interest • Food and nutrition • Activities—physical, social, after school • 19 health conditions—duration, treatment, effects • Injuries • Disabilities, limitations • Health service access—NIHB • Dental, baby bottle tooth decay • Traditional culture—importance, learning • Emotional & social well-being • Childcare –babysitting • Residential school (parents, grandparents) |

The complete national questionnaires are contained in Appendix 1, Appendix 2 and Appendix 3. Regional modules were administered immediately following the national component. Table 3 identifies which regions developed and administered regional modules. A summary of the primary themes of each regional questionnaire is presented in Appendix 4. The regional modules themselves are included in Appendix 5.

| | Regional Survey Components | | |
|-----------------------|----------------------------|----------|----------|
| | Children | Youth | Adults |
| Yukon | ✓ | ✓ | |
| Northwest Territories | | | ✓ |
| British Columbia | | | ✓ |
| Alberta | | | |
| Saskatchewan | | | |
| Manitoba | ✓ | ✓ | ✓ |
| Ontario | | ✓ | ✓ |
| Quebec | | ✓ | ✓ |
| Nova Scotia/NFLD | ✓ | ✓ | ✓ |
| New Brunswick/PEI | | | |
| Number | 3 | 5 | 6 |

4.3 INTERVIEWING

Surveys were completed using laptop computers in the respondent's home with a few exceptions discussed in section 4.6.3.7. The adults were interviewed directly. The children were surveyed by proxy with a person who knew them well, generally the mother (81.7%²³), father (12.5%²⁴) or grandmother (3.1%). Youth completed the survey themselves, with interviewer assistance when required or requested.

The decision to have the youth questions self-administered was intended to diminish non-response and increase honest disclosure, especially on sensitive or private topics, such as sexuality and drug use. The fieldworker remained in the room positioned where she/he could not see the screen, and offered help as needed.

²³ Including those who identified themselves as birth mothers (79.0%), adoptive mothers (1.2%), foster mothers (1.43%) and stepmothers (0.2%).

²⁴ Including those who identified themselves as birth fathers (12.0%), adoptive fathers (0.2%), foster fathers (0.1%) and stepfathers (0.2%).

If required or requested, the fieldworker would conduct an interview. Likewise, although adults were generally interviewed, some preferred to complete the survey themselves. No record was kept of how often this occurred.

Survey questionnaires were in English or French only. Each of the regions decided not to translate the survey into local First Nations languages, largely due to funding limitations. Recruitment and training of interviewers, though, ensured that interpretation would be provided to respondents who wished or required it.

The laptops recorded how long each individual survey was "open" on the screen. Not including introductory discussions and consent administration, which preceded administration of the questionnaire, the median times varied from 20 minutes for child surveys to 36 minutes for adults. Nineteen out of twenty adult surveys (95%) were completed in less than 88 minutes. In other words, one in twenty took longer than that. Table 4 shows the median times and 95th percentiles for each survey type.

Table 4 Time to Complete Surveys, Median and 95th Percentile

| Survey type | Median time | 95% of surveys completed in less than: |
|-------------|-------------|--|
| Adult | 36 minutes | 88 minutes |
| Youth | 28 minutes | 62 minutes |
| Child | 20 minutes | 51 minutes |

4.4 SAMPLING DESIGN

4.4.1 Design Overview

As with the questionnaires, the sample design was built on lessons from 1997 and was developed through an iterative grass-roots process. A

consultant provided specialized expertise and drafted several versions of the sampling plan.²⁵

The design was tailored to meet specific coverage needs for each region longitudinally and for each sub-region for cross-sectional purposes, as well as to produce a nationally representative sample. Key design elements and methods were harmonized as much as possible while respecting regional differences. The sample was designed to be methodologically sound, efficient and feasible within limited budgets.

The final plan set a total target of 28,178 surveys in 273 First Nations communities. The details of the design are described in sections 4.4.2 through 4.4.7, below. The size and nature of the final sample and how it differs from the design is described subsequently, in section 4.7.

4.4.2 Target Population and Coverage

The RHS covers First Nations in private dwellings within First Nations communities in 10 provinces and two territories. Excluded were Nunavut, which has no First Nations communities, and residents of collective dwellings (e.g., group homes).

The initial frame consisted of 624 communities, later revised to 607 communities to reflect the non-participation of two First Nations sub-regions: the Quebec James Bay Cree and the Innu of Labrador. The final population covered totalled 384,638 nationally across all age/gender groups. Table 5 shows the overall community population by region. Appendix 6 shows the estimated

community populations for each age/gender group and Appendix 7 shows the total community population by sub-region.

Table 5 Estimated First Nations Population in First Nations Communities, by Region (Adjusted, Projected 2002 Indian Register Counts)

| Region | First Nations Community Population (2002) |
|--------------|---|
| NB/PEI | 8525 |
| NS | 8377 |
| NF | 767 |
| QC | 34528 |
| ON | 80942 |
| MB | 71659 |
| SK | 54673 |
| AB | 57723 |
| BC | 53382 |
| YK | 3436 |
| NT | 10626 |
| Total | 384638 |

All sampling was based on Indian Register²⁶ counts of those living on-reserve or on Crown land.²⁷ The population estimates used for the design was based on projecting 1999 counts to 2001, using age/gender-specific birth and death rates, to estimate age/gender totals within each community. The 2002 estimates used for weighting (see section 4.8.7) were based on 2002 counts but were further adjusted for late reporting and underreporting,²⁸ although not for inaccuracies in place of residence.²⁹ Local sampling frames were based on more up-to-date, locally validated counts (see section 4.4.6.6).

²⁵ Sampling plan for The First Nations Regional Longitudinal Health Survey (RHS). 2002.

²⁶ The Indian Register, maintained by Indian and Northern Affairs Canada (INAC), is the official record of Status Indians in Canada. Sole authority for determining who will be registered is vested in the post of Registrar in keeping with the Indian Act. First Nations authorities may recognize members that are not Registered Indians but they are not entitled to Indian rights and benefits under Canadian law.

²⁷ Under the Indian Act, reserves are tracts of land set aside for the use of Indian bands. Crown land can also be specifically identified for use of a specific Indian band or can be "no-band" Crown land. See

<http://sdiprod2.inac.gc.ca/FNProfiles/fnprofiles_definitions.asp> for definitions.

²⁸ Counts were adjusted for late reporting and underreporting at the community level for each age/gender group based on region-specific ratios (adjusted/unadjusted), according to methods described in Description of Population Projections of Registered Indians for Canada and Regions, 2001-2021. Statistics Canada, Development and Demographic Methods Section, Demography Division, 2002.

²⁹ Although the Indian Register is believed to overestimate the proportion of people living on-reserve (vs. off), no validated quantification was available with which to attempt a correction.

The accuracy and update frequency of the Indian Register— which is based on local registrations of births, deaths and moves—varies from place to place. Despite the adjustments, community population estimates were higher in some places and lower in others when compared with field counts in many communities. Specific age/gender group counts at the community level were sometimes widely discrepant. Unfortunately, no other more reliable source of population data was available for all communities and regions.³⁰

4.4.3 Overall Sampling Design

Design targets were adopted to provide reliable estimates for specified age/gender groups at the regional level for longitudinal estimates and the sub-regional level for cross-sectional estimates. Due to budget constraints, the initial design developed to produce community level estimates for all communities could not be carried through.

The overall sample design used to meet the survey targets called for a stratified two-stage sample³¹ with strata defined as community size classes within sub-regions, and the two stages of sampling as communities within strata and individuals within selected communities. A sample of communities was selected with equal probability within each size class within each sub-region. Selected communities were substratified by age/gender classification and an equal probability sample of individuals selected within each size class within each selected community. As was inevitable in a budget-constrained survey, some adjustments were necessary between the sample as designed and what could actually be achieved in practice. These modifications are described in detail in the following sections.

Based on the design parameters described in the following sections, region-by-region instructions were provided, identifying:

- Which communities to sample and which to use as replacements, if needed;
- Sample objectives for each age/gender group for each community.

Unlike in 1997, and with a few exceptions noted in section 4.7, procedures were standardized for the development of community sampling frames, random selection of individuals within age/gender groups and their replacements, as required. The sampling directions contained in the Sampling Plan³² were key components of field-worker training and the Fieldworker Manual.³³

4.4.4 Cross-Sectional Estimates

Cross sectional estimates were to be provided for six gender/age groups (0 to 11, 12 to 17 and 18+ years old males and females) for each sub-region. Regional partners identified sub-regions based on geographical areas and political groupings, such as Nations in Quebec (e.g., Abenakis, Algonquins, Hurons), Tribal Councils in Saskatchewan and Manitoba, and Treaty areas in Alberta (see Figure 1).

After due consideration of the budget constraints and numerous iterations, the design target adopted for each age/gender group in each sub-region was that an attribute having a true incidence of 20% ($p=0.2$) would be estimated as being in the range 20% +/- 8% (coefficient of variation=40%) with 95% confidence.

Once established, initial cross-sectional sample targets for each age/gender group were totalled within each sub-region and then allocated to groups of communities according to the size of the local population:³⁴ small (<300) medium (300-1499) and large (1500+). Within each sub-region, allocations were set in proportion to the total population within that size/sub-region grouping. An example will help to clarify: Nishnawbe-Aski Nation (NAN) in Ontario required 556 surveys to meet its cross-sectional

³⁰ The census excludes a number of First Nations communities that have refused to participate.

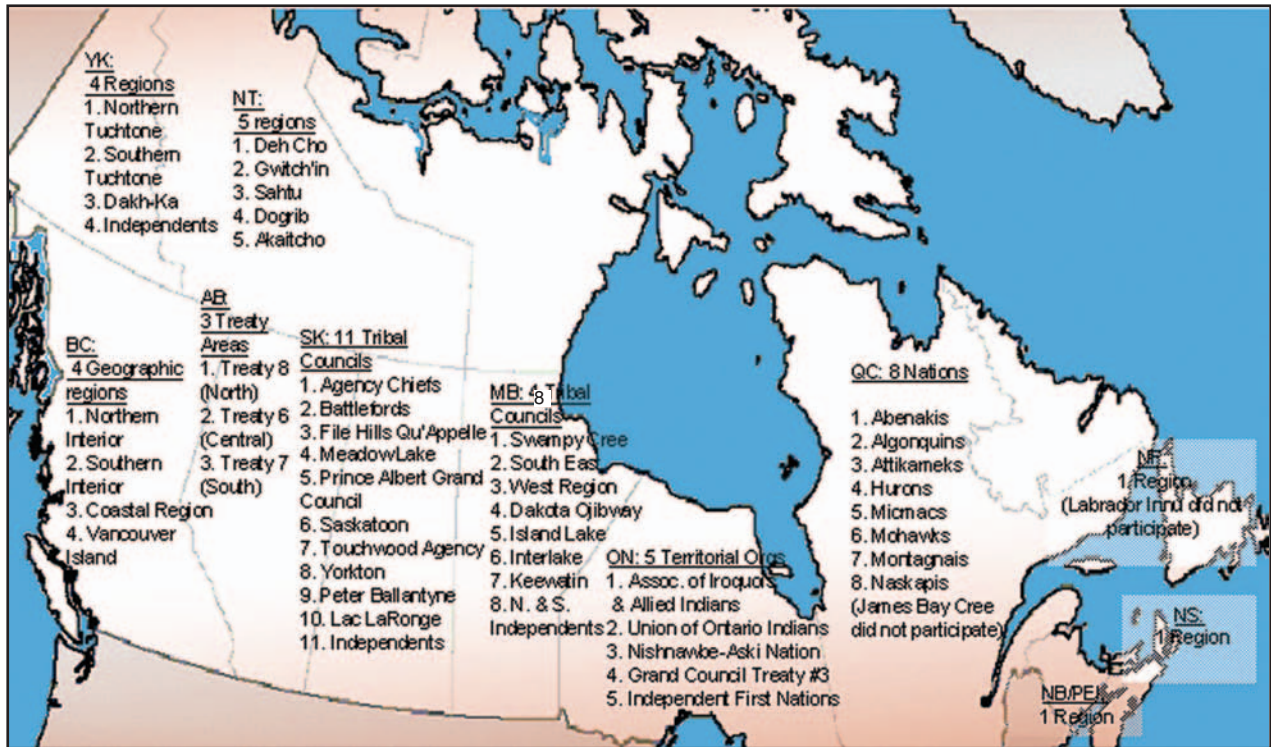
³¹ A two-stage sample here refers to the fact that communities were selected first, then individuals within those communities. The sample is considered stratified because communities were selected from groups or strata, as were individuals (by age/sex).

³² Sampling plan for The First Nations Regional Longitudinal Health Survey (RHS). 2002.

³³ <http://www.naho.ca/firstnations/english/pdf/key_docs_manual.pdf>

³⁴ Including on-reserve and on Crown land.

Figure 1 First Nations “Sub-Regions”



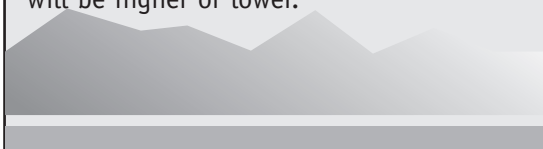
design parameters. The population of NAN’s four large communities represents 34% of NAN’s on-reserve population. The 20 medium-sized communities represent 57% and the 17 small ones

account for 9%. NAN’s sample target of 556 was distributed according to those proportions: 190 (34%), 316 (57%) and 50 (9%), respectively.

Sampling Math in Plain Language

Assuming target samples were met, the results for that group would have a level of precision that can be summarized this way:

If something is true for 20% of the group, our estimate will range from 12% and 28% (20±8%), for 95 out of every 100 samples we select. The other five times it will be higher or lower.



For each sub-region/size group, Appendix 8 lists the population, number of communities, number of communities selected and the cross-sectional and longitudinal sample objectives.

4.4.5 Longitudinal Component

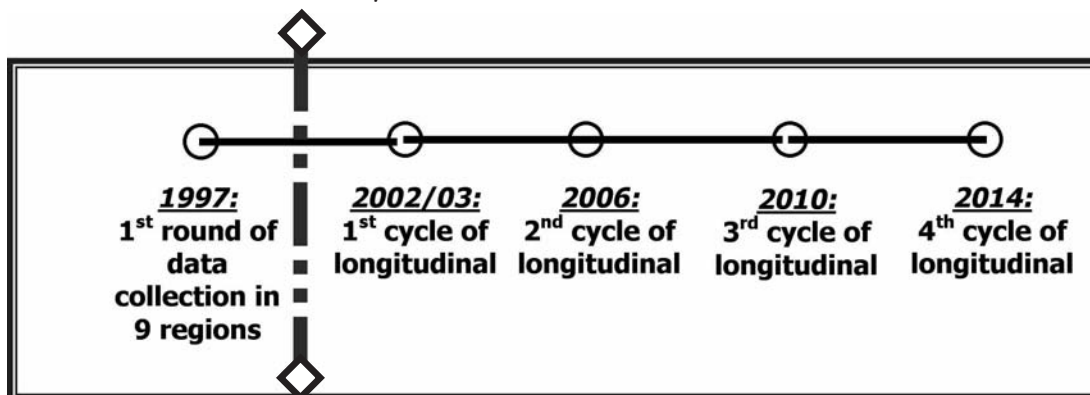
The cross-sectional sample of the RHS identifies the number of interviews required to achieve the desired level of analysis for 2002/03. For the longitudinal component, a sample size was established to obtain the desired level of analysis through four waves to 2014, for a cohort first interviewed in 2002.³⁵ For a variety of reasons,³⁶ except in Nova Scotia, respondents from the 1997 survey were not followed up in

³⁵ The longitudinal survey was initially planned for 2001 through 2013 but was delayed due to late receipt of funding for data collection. Subsequent references refer to 2002 through 2016 to avoid confusion and simplify the text.

³⁶ Reasons for starting the longitudinal survey in 2002/03 and not following the 1997 respondents include (1) improper consent in some regions to ethically return to respondents; (2)

inadequate or missing documentation of personal information in some regions; (3) inadequate sample size in some regions for a statistically healthy cohort; (4) lack of continuity in the survey instruments; (5) addition of new regions in 2002/03; and (6) non-standardized and, in some regions, sub-optimal samples in 1997.

Figure 2 Data Collection Schedule, 1997-2014



2002/03. The 2002/03 survey marks the first wave of the longitudinal survey.

Projections³⁷ were used to estimate populations for each region at the time of the final wave. Sample sizes were calculated on these projections using confidence level, incidence and sampling errors that would give statistically reliable results through the final wave. Estimated attrition rates were used to augment the regional samples in order to reach the desired samples in 2014.

Appendix 8 lists the longitudinal sample targets for each sub-region/size group, as well as other coverage and design elements as noted above.

4.4.5.1 Longitudinal Design Parameters

The design target adopted for the final cycle of the longitudinal (2014) applies to each age/gender group within each region. An attribute having a true incidence of 20% ($p=0.2$) in 2014 would be estimated as being in the range 20% +/- 6% (coefficient of variation=30%) with 95% confidence.

4.4.5.2 Attrition Rates

To compensate for the anticipated loss of sample due to death, refusal, inability to trace, etc., samples sizes were enhanced. The following age-specific attrition rates were applied:

Table 6 Attrition Rates by Age Group for Each Survey Year to 2014

| Age Group | 2006 | 2010 | 2014 |
|-----------|-------|-------|-------|
| 0-11 | 10.1% | 13.3% | 14.8% |
| 12-17 | 16.5% | 16.3% | 16.2% |
| 18+ | 16.0% | 16.0% | 16.0% |

The rates were derived from the first three cycles of Statistics Canada's National Population Health Survey (1994-95, 1996-96, and 1998-99). Attrition rates for 2006 (second column, Table 6) were based directly on the rates from the first to third NPHS cycles (4 years). For 2010 and 2014 the attrition rates for children and youth were calculated by averaging the 2006 rates for the (starting) age group and the next one, to reflect the aging of the cohort. The adults were not averaged in this way as they stay in the adult group for all cycles.

4.4.6 Combined Sampling Approach

The final sample size targets, at the regional level, were established by using the larger of those calculated separately for cross-sectional and longitudinal requirements. The resulting regional sample size was then allocated to strata within the region by stage within strata, and by age/gender group within selected communities.

³⁷ Based on estimates from Indian and Northern Affairs Canada (<http://www.ainc-inac.gc.ca/pr/sts/ipp_e.html>).

The final sample size goals for each component and the combined (final) targets are listed by region in Table 7.

Regional samples were allocated to strata within regions in proportion to their populations.

4.4.6.1 Selection of Communities

All communities were listed in strata, defined by their sub-region and population size (Appendix 6). Of the 624 communities in the initial frame, 43% were “small” (under 300 people in the community), 48% were “medium” (300 to

In Nova Scotia and Saskatchewan, all communities were included, respecting regional preferences. Outside of Nova Scotia and Saskatchewan, small and medium communities were randomly selected, with a randomized replacement strategy employed for those that declined participation.

4.4.6.2 Allocation of Sample to Communities

The sub-region/community size group sample allocations were split equally among the predetermined number of communities within that group. All samples were broken out for each age/gender group to ensure that the desired level of analysis would be met.

Before the target numbers were finalized, minor adjustments were made to the community samples to address communities with small samples and to enhance the sample of older adults as described in the next two sections.

4.4.6.3 Minimum Community Samples

In some instances, the allocation methods resulted in very small samples for certain communities. To make efficient use of resources, particularly given the remoteness of some communities, any community sample target of 24 or less was automatically increased to 25.

4.4.6.4 Sampling of Older Adults

Adults over 55 were not treated as a separate group in defining the initial sample targets as they make up only a very small percentage of the population (i.e., about 5 percent). Nevertheless, an over sampling of this population was incorporated to generally enhance precision for the group. Within the sample sizes allocated to the over 18 group, 10% was allocated to those 55 and over—twice their representation in the population. Fieldworkers thus received quotas for males and females in each of

Table 7 Target Sample Sizes by Region for the Combined Sample Design

| Region | Cross-Sectional Sample Requirement | Longitudinal Sample Requirement | Final Target Sample |
|--------------------------------------|------------------------------------|---------------------------------|---------------------|
| New Brunswick & Prince Edward Island | 523 | 1459 | 1459 |
| Nova Scotia | 523 | 1459 | 1459 |
| Newfoundland | 280 | 684 | 684 |
| Quebec and Labrador | 4687 | 1634 | 4687 |
| Ontario | 2665 | 1648 | 2665 |
| Manitoba | 4695 | 1651 | 4695 |
| Saskatchewan | 5370 | 1645 | 5370 |
| Alberta | 1659 | 1645 | 1659 |
| British Columbia | 2167 | 1640 | 2167 |
| Yukon | 1214 | 1177 | 1214 |
| Northwest Territories | 2118 | 1493 | 2118 |
| Total | 25903 | 16135 | 28178 |

1,499) and 9% were large (1,500+), with the largest a little over 11,000.

All communities with populations over 1,500 were invited to participate (“take all” stratum) since they represent the majority of the population. Within each sub-region, representative numbers of small- and medium-sized communities were picked keeping the number as small as feasible to lower costs without compromising the overall design. For reasons of cost-efficiency, communities with populations of less than 75 persons were not included (approximately 11% of all communities).

four age groups (0-11, 12-17, 18-54, 55+) instead of three.

4.4.6.5 Replacement of Communities

Communities were selected within sub-region/size groups, as described above. All large communities and a random sample of small- and medium-sized communities were included. In keeping with First Nations protocols and OCAP, communities were invited to participate. Surveys were collected only after local authorities, normally the Band Council, approved. In some regions, a band council resolution, or formal “community consent,” form was required.

When a community became “non-participating” due to refusal or for other reasons, it was replaced randomly with another community in the same sub-region and size grouping. When no other community existed in the same size category, a community could be substituted with one in a “neighbouring” size group. In such exceptions, though, the substitute community had to be close in size to the other group (e.g., almost 300 for a small community replacing a medium-sized one). Large communities could not replace medium-sized ones because all large communities were already included by design. Communities could not be substituted from a different sub-region.

Also, where a selected community did not have sufficient population to achieve the target sample (e.g., because of non-response), the balance could be obtained in another already participating or additional community in keeping with the same substitution rules.

4.4.6.6 Community Sampling Frames and Selection of Individuals

Local sampling frames, with exceptions as noted in section 4.7.2.4, were derived from First Nations community/band membership lists. The approach was adopted by the First Nations

Information Governance Committee, as it (a) was effective in 1997 in several regions; (b) provides locally validated information not available elsewhere; (c) provides an opportunity for local capacity development in survey methods; and (d) respects community definitions and control of their own membership lists.

To develop the local frame, Regional Coordinators or fieldworkers used the sampling kit and instructions contained in the *Fieldworker Manual*.³⁸ Typically, working with the local membership clerk (or other person delegated by council), a list of First Nations living in the community was drawn up based on (a copy of) the most recent band or membership list. Recent changes due to births, deaths or moves were incorporated prior to drawing the sample.

Membership lists were defined locally and, as such, may have differed from the lists of Registered Indians defined by Indian and Northern Affairs Canada (INAC) used to establish the target population (4.4.2) and for statistical weighting (4.8.7). The membership lists used for sample selection were generally more up-to-date and may have included individuals recognized as members by the band but not recognized as Registered Indians by INAC.

The membership lists were divided into eight lists based on the age/gender groups, and names were numbered consecutively. The selection of respondents, and substitutions for non-response, within each age/gender group was made by taking the first x members, where x is the sample size requirement, in a randomly ordered list of the members of the group. Substitutions for non-respondents among the first x members were allowed from, but not beyond, the following $x/2$ members (i.e., up to an additional 50%) in the ordered listing. Random number generators on the laptop were used to facilitate randomization.

³⁸ <http://www.naho.ca/firstnations/english/pdf/key_docs_manual.pdf>

Respecting local authority and privacy concerns, membership clerks generally supervised every step of the process and copies of membership lists were not supposed to be taken out of the community/band office. The sample and backup lists were stored securely in keeping with RHS data protection protocols. Actual membership lists were in no way modified by this exercise, although some communities may have taken advantage of the process to update their own lists.

4.4.7 Other Sampling Considerations

4.4.7.1 Overall Data Quality—Cross-Sectional Component

As noted, the cross-sectional design component focused on sub-regional strata, based on a 95% confidence level, with an incidence of 20% and a sampling error of +/- 8%. The final sample targets, however, also took the longitudinal requirements into account. As shown in the last column of Table 7, some regions required more samples to fulfill their longitudinal requirements than they needed for the cross-sectional component, thus increasing the samples available for 2002/03 and hence the anticipated precision for cross-sectional analysis. These regions are New Brunswick/Prince Edward Island, Nova Scotia and Newfoundland.³⁹

4.4.7.2 Overall Data Quality: RHS—Longitudinal Component (to 2014)

As noted, the RHS longitudinal design component was designed around region-level results for 2014. The final sample targets, however, also incorporated the cross-sectional requirements. As a result, as shown in Table 7, seven regions' cross-sectional component requirements were larger than their longitudinal requirements. Of those, three had cross-sectional target samples more than double their longitudinal targets (Quebec, Manitoba and Saskatchewan). These regions will have the luxury of extra sample

³⁹ The Union of Nova Scotia Indians coordinates the survey for Nova Scotia and Newfoundland; the Union of New Brunswick Indians was responsible for New Brunswick and Prince Edward Island.

⁴⁰ The Information and Consent Form (Appendix 9) foresees this possibility.

going forward longitudinally and the potential for higher precision in future waves.

4.4.7.3 Overall Data Quality—Regional and Canada-Level Sample Sizes

When rolled up from the regional or sub-regional level of the design to the national level, overall sampling precision increases substantially, cross-sectionally and for future waves.

4.5 LONG-TERM SAMPLING PLANS

In addition to the longitudinal plan, there is also potential for a range of spin-off surveys, building on the RHS infrastructure and, potentially utilizing the 2002/03 sample as a frame.⁴⁰ Potential spin-offs could include, for example, surveys on nutrition, disability, diabetes, smoking, mental health, nutrition, and children's issues. To date, one small pilot survey—on West Nile Virus and protection from mosquitoes—was completed in four communities by leveraging the RHS process.⁴¹ Other surveys are being considered.

There is keen interest to pursue a much larger cross-sectional sample, as initially proposed, in order to provide communities with much needed community level data. Finally, although the 2002/03 survey is restricted to First Nations communities, there have been plans (but no funding) since 1996 to include an off-reserve component—something that was piloted in the Quebec region in both 1997 and 2002.⁴²

In a broader perspective, the RHS is now widely seen as the model to build upon for First Nations research and data stewardship. Many view the governance structure, principles, processes and capacity developed through implementation of the RHS, as a potential foundation for future First Nations surveys, surveillance and data-related initiatives.

⁴¹ <http://www.naho.ca/firstnations/english/pdf/WNV_report_04.pdf>

⁴² The Quebec off-reserve samples included one city in 1997 and three cities in 2002/03. The urban sample is not included in the national database.

4.6 DATA COLLECTION

4.6.1 Regional Coordination

Each of the ten First Nations partner organizations hired a Regional Coordinator (RC) who was responsible for overseeing the planning and regional implementation of all phases of the survey, as well as related activities. The Regional Coordinators played key roles in the:

- Development of national questionnaires, tools and methods;
- Development of regional questionnaires and tools;
- Development and implementation of communications strategies with communities, regional organizations and other stakeholders;
- Recruitment, training, supervision and support of fieldworkers and, sometimes, field coordinators and assistants;
- Development and implementation of data protection protocols for survey data and personal information from consent forms;
- Data entry of consent form information;
- Management of contracts with technical consultants;
- Data processing (cleaning) of regional questionnaire components;
- Production of regional reports and other data products;
- Overall project and budget management;
- Development of a new community-level (ecological) survey on factors influencing health.

Regional Coordinators received support from the staff at the First Nations Centre by phone, email and in person, and through regular conference calls and meetings. Many new Regional Coordinators received an orientation session at the First Nations Centre office in Ottawa. Formal training was provided on several occasions, including two train-the-trainer sessions prior to

the commencement of fieldwork, and two sessions on data analysis upon its completion.

Generally speaking, the development of research and survey capacity in First Nations organizations, regionally, has occurred through the RHS Regional Coordinators. Many have broader roles in First Nations health research in their respective provinces and territories.

4.6.2 Fieldworker Training

A fieldworker manual and training tools were developed collaboratively to support standardized data collection processes. The training was provided in two steps: training the trainers, and training the fieldworkers.

Following train-the-trainer sessions, the Regional Coordinators returned home to deliver training to fieldworkers recruited from participating communities.⁴³ In some cases, the sub-regional or field coordinators helped provide the training. Sessions typically lasted two to three days and were based on standardized materials and the 150+ page *Fieldworker Manual*.⁴⁴

The manual includes everything fieldworkers need to prepare for and do their job, including answers to frequently asked questions, copies of forms and training exercises. Trainers reported that topics needing special attention were sampling, laptop use/interviewing practice, administration of the (complex) consent form, and dealing with sensitive situations.

In addition to the manual (viewable in PDF⁴⁵ format on the laptops), the more portable “fieldworker kits” that could be taken from house to house were provided. The kits contained everything needed in the field,⁴⁶ and were organized into folders and placed with the laptops in RHS-branded laptop bags.

⁴³ In one instance only, a team was hired to travel and interview in several communities.

⁴⁴ <http://www.naho.ca/firstnations/english/pdf/key_docs_manual.pdf>

⁴⁵ Adobe Acrobat Portable Document Format.

⁴⁶ Fieldworker kits included charged laptop and power cord, mouse and mouse pad, confidential personal information/consent forms, envelopes for confidential forms, information brochures, agenda books for scheduling, pens, paper surveys (if needed), tape measure (for height), survey response cue cards to show respondents, list of community services/contacts for referrals, participation gifts, the “Field Worker Review Sheet,” and the “Questions and Answers” sheet.

The rate of fieldworker turnover was considerably higher than initially anticipated. The need to re-recruit and retrain, sometimes several times within a community, contributed to fieldwork delays and increased field costs.

4.6.3 Computer Assisted Personal Interviewing

4.6.3.1 Rationale

A customized Computer Assisted Personal Interviewing (CAPI) package was developed for computers deployed directly to the field. The decision to adopt this technology was supported by the following considerations:

- Improved data quality related to:
 - Automated management of skip patterns—respondents answer only those questions that apply to them;
 - Integrated “checks” flagging impossibilities (e.g., a 3-year-old widow);
 - Elimination of missing responses by forcing either a regular response option or “don’t know” or “refused”;
- Ability to hyperlink explanations (glossary function);
- Expectation of increased respondent interest and, thus, participation rates;
- Fieldworker exposure to and training on new technology;
- Elimination of post-interview paper-to-computer data entry costs and errors;
- Reduced time between collection and analysis by eliminating paper-to-computer data entry and reducing post-collection “cleaning”;
- Ability to manage and monitor survey progress and to flag and correct problems quickly via uploads (transfer from the laptop to the server) and downloads (transfer from the server to the laptop);
- Decreasing hardware prices and increasingly available and sophisticated software and expertise.

The RHS’s longitudinal design and potential for spin-off surveys in the mid-term, as well as a range of other anticipated post-collection uses (e.g., computer-based training), also influenced the decision. The investment was expected to produce important cost-savings over the long term while developing First Nations’ health information infrastructure and capacity.

4.6.3.2 Selection of Laptop Technology

Despite a generally positive pilot of hand-held devices (PocketPC’s), it was decided that laptop computers would be preferable.

The decision was made considering a contrast of the technologies in terms of price, screen size, software choices, availability of qualified developers, relative technical complexity and the potential for post-survey re-deployment. Laptops offered a more standard and well-known platform, implying less risk and potential complication. A one-time infusion of capital funds from First Nations and Inuit Health Branch in 2002 made it possible to buy laptop computers. Servers and software were also purchased and a developer was hired on contract.

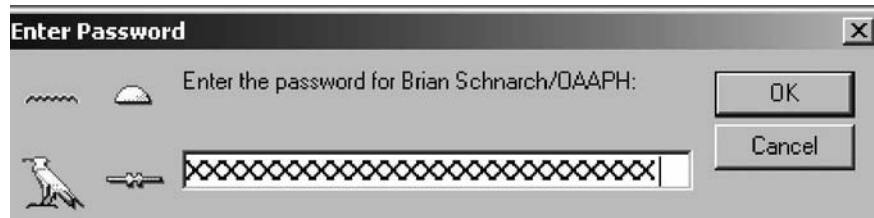
4.6.3.3 Laptop-Server Design

The CAPI system incorporated:

- 265 laptop computers and three servers (one each in Quebec, Saskatchewan and at the First Nations Centre for other regions);
- A customized client-server software package programmed within Lotus Notes®/Lotus Domino that supported secure data transfer from any phone line to dedicated toll-free lines;
- A locked down, user friendly primarily point-and-click interface incorporating:
 - questionnaires in English and French;
 - the Fieldworker Manual (PDF), a random number generator, a glossary and message window for updates;

- Automated report generation to support quality control and fieldworker management. Interviewers were paid according to the number of surveys completed. The reports (Appendix 10) were used to track progress and catch potential problems early (e.g., excessive numbers of refusals, surveys completed too quickly);
- Two-way server-laptop communications allowing not only for the transfer of survey data, but also the receipt (download) of software/database updates and “fieldworker news” items.

Transfer of encrypted survey-response data was one-way only (from the workstation in the field to the server) and only RHS-configured laptops with proper passwords were able to exchange data with the servers. Any other attempt to connect was rejected. The national server was stored at GT Telecom’s state-of-the-art collocation facility in Ottawa, Ontario. Remote access to the server for maintenance and quality control was available to the technical support group



4.6.3.4 Privacy/Security

The move away from paper-based surveys, by itself, eliminated the security risk associated with volumes of potentially visible personal information in fieldworkers’ bags and homes/offices. However, the switch to computer-based records posed potential security and data loss risks that had to be carefully addressed through procedures, training and software design, as outlined below.

The self-administration for youth and the opportunity for other respondents to hide their responses by turning the laptop screen were praised in the RHS Privacy Impact Assessment.⁴⁷ As a further protection, fieldworkers could not access (re-open or view) surveys once they were complete.

Each survey required two passwords (bios/start-up and interviewer identification) as well as redundant consent form number entries. Laptops were “locked down” such that non-survey applications or functions were inaccessible and there was no way to inappropriately access, copy or transfer data.

and the FNC through a modern, secure virtual private network (VPN).

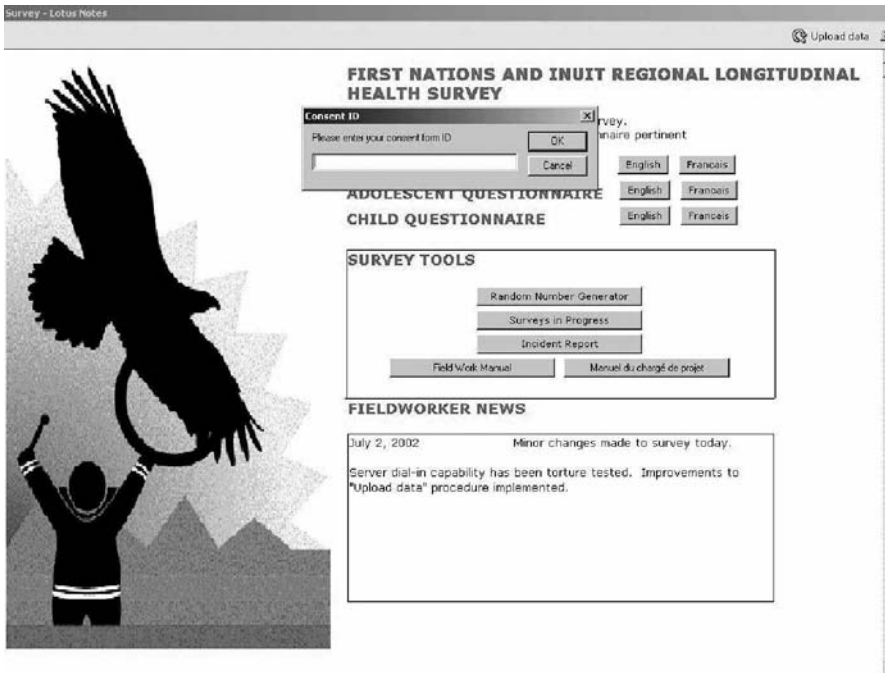
4.6.3.5 Time

According to field tests, individual surveys were completed more quickly on laptops than on paper. The elimination of the data entry phase also resulted in a significant time savings. The number of laptops, though, emerged as a crucial bottleneck limiting the pace of data collection.

Regional Coordinators frequently had to recall and re-deploy laptops once community target samples were met or when laptops were unproductive or under-utilized. The process of recalling, re-deploying and the associated re-training represented a significant amount of down time. One region sought to maximize productivity by instituting laptop sharing among several interviewers in a community.

As noted, data collection lasted 15 months from start to finish. Although a paper-based survey could likely have been collected more quickly, a larger cadre of interviewers, as well as a time-

⁴⁷ Flaherty, D. A Privacy Impact Assessment of the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS), 2002.



Connectivity problems of this nature had not been anticipated. During the design phase, telecommunications experts had indicated that any phone line that could successfully transmit a fax would be adequate. It turned out that this was not the case in some First Nations communities.

4.6.3.7 Paper-Based Surveys

In Manitoba, a decision was made to switch to paper-based surveys in communities with telecommunications difficulties

consuming data entry phase, would have been required.

Preliminary results, based on partial data were made public in January 2003, just a few months into data collection. With a conventional paper-based survey, this would not have been practical until after all data edits and corrections were complete.

4.6.3.6 Connectivity Problems

In some remote communities, largely concentrated in Manitoba and to a lesser extent the Northwest Territories, “noisy” phone lines or poor connectivity made data transfer and remote software updates difficult or impossible. In some cases, laptops with completed surveys had to be shipped to other places for data transfer. This increased costs, delayed fieldwork (while the laptop was unavailable for collection) and raised concerns about the potential risk of losing surveys if the laptop was damaged or stolen.

rather than have to ship laptops. In British Columbia, some surveys were also collected on paper. In that case, the decision was intended to increase the pace of data collection, given the limited number of laptops.

Altogether, 2205 surveys were paper-based. The vast majority of those (1947) were collected in Manitoba and the rest (258) in British Columbia. Thus, about one in 10 (9.8%) surveys nationally were collected on paper. In Manitoba, the proportion was nearly half (49.0%) and for British Columbia, about one in seven (13.3%).

Paper surveys were mailed back and data entered into dedicated laptop computers at the regional office using the standard CAPI programs. Without the benefit of the software validation and skip management procedures, the surveys were subject to the same limitations as other paper surveys—most notably, skipped questions.

ADULT QUESTIONNAIRE – Lotus Notes

First Nations and Inuit Regional Longitudinal Health Survey

B. PERSONAL BACKGROUND INFORMATION

NOTES MENU GLOSSARY NEXT

1. Date of Birth
 Date of birth Age
 Day Month Year

2. Gender
 Male Female

3. Name of First Nation or Inuit community where you currently live

4. Present marital status
 Married Common Law Separated
 Divorced Widowed Single

NEXT

Since blanks were not possible with the final CAPI software instruments (exceptions are discussed in section 4.6.3.8), the Manitoba team decided to enter them as “refused” responses. Unfortunately, this both increased the rate of item non-response (see section 4.9.2.4) and may have resulted in an underestimation of negative (i.e., “no”) responses (see section 4.8.4) typical of paper surveys.

4.6.3.8 Changes to Software After Start of Data Collection

Minor errors and missing response validations for certain questions were identified within the survey instrument software after deployment of most of the laptop computers. Fortunately, the built-in update/download functionality allowed for remote updating. Unfortunately, this same functionality contributed to significant harmonization problems. Put simply, not all surveys were collected with identical instruments.

Before reaching a final version, two major updates comprising numerous small changes were made to the software during the first three months of the 15-month data collection period. Surveys collected early and surveys collected using software that had not been updated—by the regional office, national office or fieldworker—were based on less refined CAPI instruments.

The fact that there were three independently managed servers contributed further to the lack of standardization. While the laptops automatically downloaded revisions when they dialed in, the three servers did not communicate directly with each other. National software updates had to be deliberately integrated by the regional server manager. Although the Quebec server software was kept up-to-date, not all changes were incorporated in Saskatchewan. Surveys collected using Saskatchewan laptops were collected using essentially the same instruments as those used for early surveys elsewhere.

Although interview date and laptop number and region were automatically documented, the inability to track which version of the software was being used complicated the process of identifying which survey records were collected with less refined software. It is estimated that approximately one-quarter of all surveys, mostly from Saskatchewan, were collected using software that was not in its final version.

The important differences between the earlier and later instruments were:

- Correction of approximately one dozen typos/spelling mistakes, mostly in the French versions of the surveys;
- Correction of problems resulting in technical software error messages;
- Incorrect skip pattern (e.g., current smokers being asked when they quit smoking);
- Implementation of response validation for questions that could previously be skipped and left blank. Requirement of some kind of response, even if only “don’t know” or “refused”, was added in November 2002, for:
 - 20 of 117 adult questions (17%)
 - 13 of 82 youth questions (16%)
 - 8 of 65 child questions (12%)

The corrections implemented to harmonize those surveys containing questions that could be left blank with those that could not are described in section 4.8.4

4.6.3.9 Survey Upload Reports

Automated weekly reports (sample in Appendix 10) provided details on all survey records uploaded (transferred) to the server. The reports included details on the previous week’s surveys as well as cumulative totals.

Regional Coordinators matched the consent numbers of the uploaded surveys with consent

forms sent in from the field and then released payment to interviewers accordingly. The weekly reports provided basic information about each completed survey (e.g., interviewer comments if entered, time to complete survey, number of “don’t know” and “refused” responses) that facilitated quality control. Interviewers were contacted if something appeared to need attention or if surveys were not coming in.

Nationally, the automated reports were used to monitor, analyze and report progress towards sample targets. In addition to the automated weekly reports, 24 national data collection progress reports were prepared. The reports provided everyone involved with various measures of progress (e.g., percent of target sample achieved to date by region/age/gender), productivity (e.g., surveys per laptop per month over time), and survey quality (e.g., mean number of “don’t know” and “refused” responses, mean time to complete surveys).

4.6.3.10 Overall Assessment of the CAPI Approach

Although most were positive, a few respondents did indicate a distrust of the technology, expressing concerns about putting their information “into that box.” Initial concerns that some older respondents would be particularly uncomfortable with the technology were not substantiated.

Regional Coordinators provided feedback on the CAPI system based on their experience in the development/testing phase, fieldworker training, “front line” technical support and the overall management and deployment of the technology. Although some were initially sceptical about fieldworker uptake and respondent comfort with the technology, the concerns dissipated with time and exposure.

Primary complaints about the technology included:

- The number of software problems, particularly those that required correction after the data collection had begun;
- The difficulties with software harmonization;
- Inability to transfer (upload/download) data in several remote communities (with poor connectivity/noisy phone lines), which resulted in frustration, logistical complications, lost time and increased costs;
- The limited number of laptops slowing data collection. A number of lost, stolen and damaged computers exacerbated the problem;
- Although providing excellent user interface and data transfer, the output data was in a format that required extensive manipulation prior to analysis. An alternate choice in software and a design team more experienced in data analysis applications would have decreased the time needed to prepare data for analysis.

Regional Coordinators—including those that were less technically inclined— were satisfied with the experience overall, citing among other features data quality, capacity, privacy, speed and the management/tracking benefits. The upload reports and data collection progress reports were appreciated for providing timely, relevant information in useful formats.

There was general consensus that computers would be chosen again over paper, but with improved quality control prior to deployment, and with alternative data transfer and backup procedures (e.g., via diskette), primarily for communities with inadequate connectivity. More laptops would also be preferable.

4.6.4 Consent

Like the questionnaires and sample design, consent forms were developed through an iterative process with regional partners. Following expert advice, an early shorter and “friendlier” version was dropped in favour of a more detailed form (Appendix 9).⁴⁸ The information and consent form package included a participant log sheet that helped fieldworkers remain organized, a two-page consent form in two copies (one for the study, one for the respondent) and a page with contact information for longitudinal follow-up.

In response to privacy concerns from some regions, it was decided that the consent form package would be paper-based (not on the laptops) and that all personally identifying information⁴⁹ required for longitudinal follow-up would be collected through this instrument. Although more complicated, separate storage of consent records increased privacy protection and permitted regional offices to be the exclusive custodians of identifying information. The RHS data protection schedules laid out the requirements for proper storage and protection of this information, needed for subsequent cycles of the survey.

Consent form packages were consecutively numbered for unique identification. The numbers had to be double entered into the laptop in order to begin a survey and verify that the consent process had been completed and the forms signed. The tear-out “study copies” of the forms were sealed in envelopes and returned to the Regional Coordinator, who matched the numbers with those on the automated weekly upload report from the server before paying interviewers. The “participant copies” of the forms were left with the respondents.

The information on the information and consent form packages was entered into a stand-alone

⁴⁸ Manitoba region used its own (similar) consent form.

⁴⁹ The consent form package included sections for the name and contact information of respondents (or proxies for children) and contact people who could help to find them, if needed, in the future.

data entry program regionally and was later matched by the FNC to the survey response records to ensure that consent had been properly documented. Once all regional consent form databases were received (excluding personal information fields) the first linkage was completed, revealing some unanticipated problems:

- Surveys with no matching consent forms;
- Consents with no matching surveys;
- Consent forms with unmarked elements (see Figure 3);
- Consent forms not (initially) entered into the data entry module;
- Consent forms incorrectly entered into the data entry module (typos, etc);
- Consent forms used for more than one member of a household;
- Verbal consent not formally documented.

Although they received an “A+” in the RHS Privacy Impact Assessment,⁵⁰ the forms were lengthy and complex to administer. Ten separate elements

required a mark, signature or initials. In addition, proper documentation entailed different

things for children, youth and adults. Some of the elements are illustrated in Figure 3.

Complex consent administration, fieldworker turnover, a consent form data entry template that required multiple updates, and the coincidental timing of First Nations’ information cam-

Figure 3 Examples of Consent Form Elements Requiring a Mark

paigns about Health Canada’s Non-Insured Health Benefit (NIHB) consent form were among the underlying factors behind uneven practices.

⁵⁰ Flaherty, D. A *Privacy Impact Assessment of the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS)*, 2002.

The lack of complete consent documentation for some surveys raised an ethical dilemma. After due consideration, the FNIGC decided that some surveys would have to be discarded rather than run the risk of using personal information without certainty of consent. Section 4.8.3.3 discusses the specific consent documentation requirements adopted and the number of survey records impacted.

4.7 FINAL SAMPLE

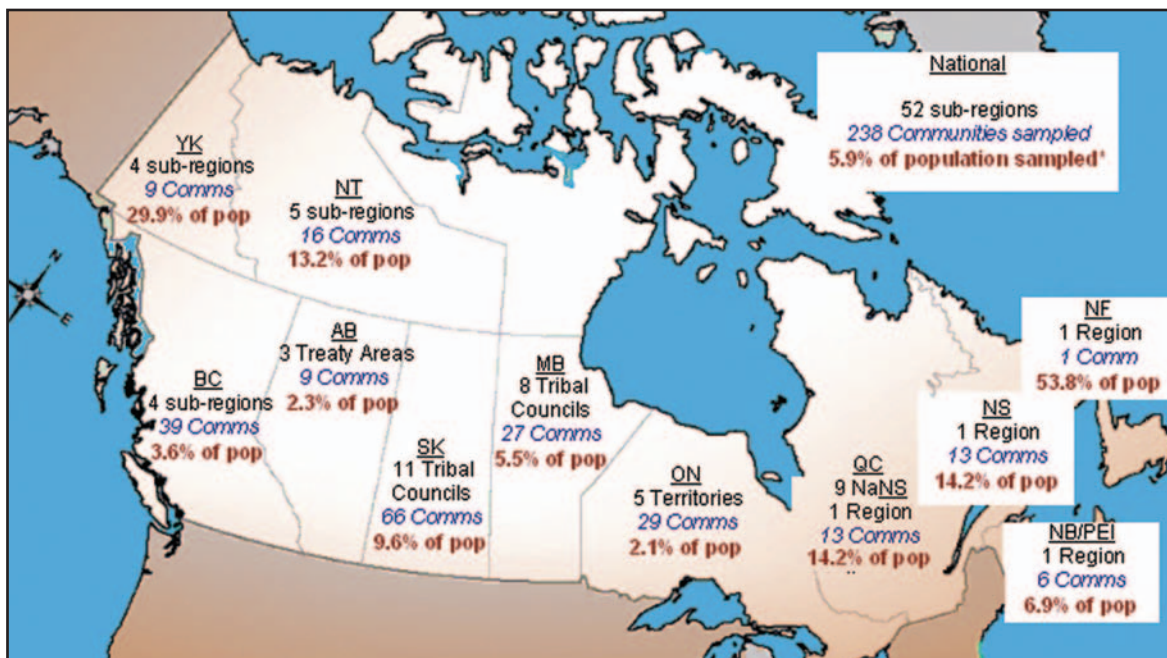
4.7.1 Coverage

The final sample of 22,602 includes 10,962 adults, 4,983 youth and 6,657 children living in 238 communities within 52 sub-regions in 10 regions.⁵¹ This is the final number available for analysis after removing duplicate records,

records with more than 50% item non-response and those with inadequate consent documentation (as described in section 4.8.3).

With the exception of the James Bay Cree of Northern Quebec and the Innu of Labrador, all First Nations sub-regions were represented. Overall, the national sample represents 5.9% of First Nations living in First Nations communities (mostly reserves) in Canada. As shown in Figure 4, coverage rates ranged from 2.1% in Ontario to 53.8% in Newfoundland. These variations are primarily a reflection of the sub-regional design.⁵² The level of “success” in reaching targets described in section 4.7.2.1 only contributes marginally to the variation. Sub-regional coverage rates are shown in Appendix 7.

Figure 4 Number of Sub-Regions and Communities and Proportion of On-Reserve* Residents Sampled, by Region



*Figures show the proportion of all First Nations living in First Nations communities that were included in the sample.

⁵¹ Note that Manitoba region collected additional surveys after the national collection period was over and the RHS database was closed. The additional sample will be available for Manitoba regional analysis but will not be integrated into the national database.

By survey type, the final available sample represents 6.0% of First Nations children living in First Nations communities, 10.0% of youth and 4.9% of adults. Figure 5 displays the percent of population sampled by gender/age group, separating out those 55 and over. As shown in Figure 5, the sampling rates range from 4.1% for 18-34 year old males to 10.8% for 12-17 year old females. The higher rates for youth and children reflect the design's intent to provide equivalent statistical precision across all three survey types.

4.7.2 Final Sample in Relation to Design

The following sections contrast the sampling design described in section 4.4 with the final sample and sampling methods actually used on the ground. The nature and extent of all significant deviations from the plan and methods are outlined in the following areas:

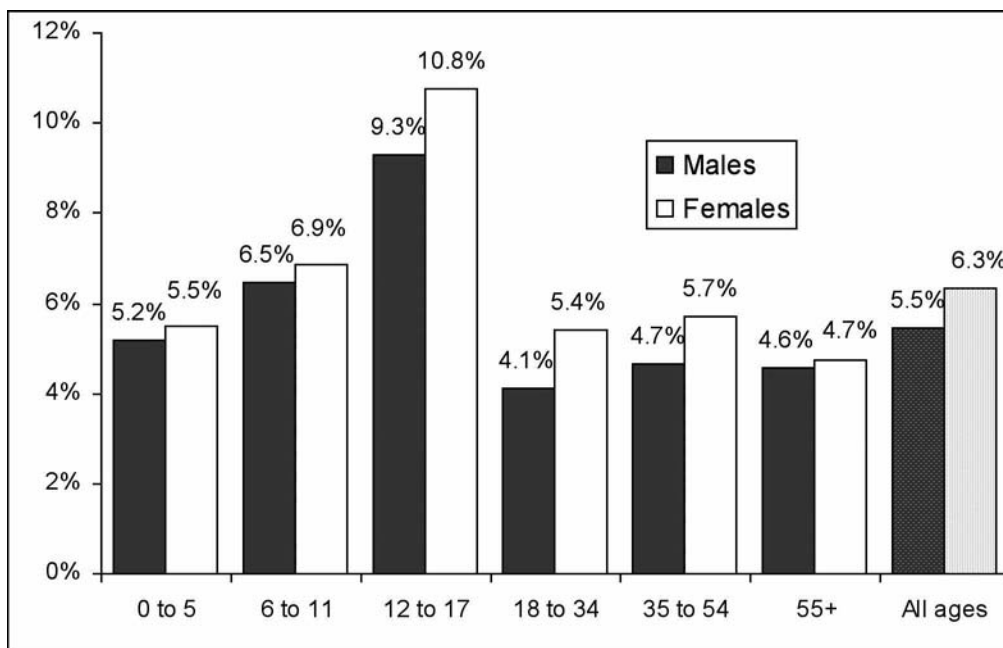
- Proportion of target samples achieved (4.7.2.1)

- Community participation and replacement (4.7.2.2)
- Individual participation (participation rate) (4.7.2.3)
- Use of alternate community sampling frames (4.7.2.4)
- Inclusion of off-reserve sample (4.7.2.5)
- Changes to community sampling targets (4.7.2.6)
- Individuals completing the wrong survey type (4.7.2.7)
- Proportion of Sampling Design Targets Achieved.

4.7.2.1 Proportion of Target Samples Achieved

The final sample represents 80% of the sampling plan's target sample of 28,178. The percent-of-target available varies by region and by age/gender group, as shown in Tables 8 and 9. The breakdown by sub-region is provided in Appendix 12.

Figure 5 Percent of First Nations Community Population Sampled, by Age



⁵² To be more precise, the regional sampling proportions are predominantly driven by the ratio of sub-regions to population within that region.

Table 8 Proportion of Target Sample Achieved, by Region

| Region | Proportion of Target Achieved |
|--------------------------------------|-------------------------------|
| New Brunswick & Prince Edward Island | 40% |
| Nova Scotia | 81% |
| Newfoundland | 60% |
| Quebec and Labrador | 81% |
| Ontario | 64% |
| Manitoba* | 85% |
| Saskatchewan | 98% |
| Alberta | 80% |
| British Columbia | 90% |
| Yukon | 84% |
| Northwest Territories | 66% |
| Total | 80% |

*Surveys collected by Manitoba after the national database was closed are not counted here.

Table 9 Proportion of Target Sample Achieved, by Age/Gender Group

| AGE/GENDER | % of Target Achieved |
|---------------|----------------------|
| 0-11 Males | 70% |
| 0-11 Females | 70% |
| 12-17 Males | 58% |
| 12-17 Females | 62% |
| 18-54 Males | 88% |
| 18-54 Females | 106% |
| 55+ Males | 141% |
| 55+ Females | 160% |

A number of factors help to explain the difference between the final sample and the initial targets:

- 3,528 surveys initially counted towards the targets were subsequently removed because they were duplicates, had greater than 50% item non-response or were lacking adequate consent documentation (see 4.8.3);

- The number of laptop computers, fieldworker turnover, financial and human resources were limited;
- High sampling rates, especially among youth, made it difficult or impossible to reach targets within some smaller communities;
- The challenge of high sampling rates in certain communities was exacerbated by inflated population estimates (based on the Indian Register). Sometimes the actual community population was too small to meet sampling requirements, particularly for youth;
- There were issues of timing when soliciting participation of certain replacement communities.

4.7.2.2 Community Participation and Replacement

A total of 238 communities are represented in the final sample. Of those, 197 (83%) were “first selections” in the sampling plan and the other 41 (17%) were replacements. Table 10 provides a breakdown by region. Appendix 13 provides a complete listing of all communities identifying “first selections” and those in the final sample.

Seven regions met a rigorous standard with:

- At least 70% of their sampled communities being “first selections”;
- At least 70% of their “first selection” communities being in their final sample.

These seven regions—Nova Scotia, Newfoundland, Saskatchewan, Quebec, Yukon, New Brunswick/PEI, and the Northwest Territories—came closest to the initial design in terms of community selection.

Given that all sub-regions and community sizes are represented, and given the number of communities involved, the impact on representativity nationally is considered minor. The impact at

the regional level may be addressed in regional reports.

Following a decision by the First Nations regional authorities, two communities that had expressed an interest in participating were added as replacement communities in British Columbia although they had not been randomly selected (see 4.4.6.5).

Of those who were sampled and for whom a form was completed (27,094), 87% filled out surveys, either partially or completely. After excluding surveys that could not be used because they were either too incomplete or lacked proper consent documentation (see 4.8.3.2 and 4.8.3.3), the proportion of those documented as eligible to be interviewed that were retained for analysis dropped to 84% (see Figure 6.)

Table 10 Number and Proportion of First Selection and Replacement Communities, by Region

| | 1st selection communities in final sample | Replacement communities in final sample | Total communities in final sample | 1st selections sampled/all communities sampled | First selection communities in design | 1st selections sampled/1st selections in design |
|----------|---|---|-----------------------------------|--|---------------------------------------|---|
| AB | 5 | 4 | 9 | (5/9) 56% | 16 | (5/16) 31% |
| BC | 24 | 15 | 39 | 62% | 38 | 63% |
| MB | 17 | 10 | 27 | 63% | 35 | 49% |
| NB/PEI | 5 | 1 | 6 | 83% | 7 | 71% |
| NF | 1 | 0 | 1 | 100% | 1 | 100% |
| NS | 13 | 0 | 13 | 100% | 13 | 100% |
| NT | 12 | 4 | 16 | 75% | 14 | 86% |
| ON | 29 | 0 | 29 | 100% | 44 | 66% |
| QC | 18 | 5 | 23 | 78% | 18 | 100% |
| SK | 66 | 0 | 66 | 100% | 70 | 94% |
| YK | 7 | 2 | 9 | 78% | 8 | 88% |
| National | 197 | 41 | 238 | 83% | 264 | 75% |

4.7.2.3 Individual Participation (Participation Rate)

A separate consent form package was to be used for each individual drawn from the sampling frame regardless of whether they ended up participating. Each name from the randomly drawn community samples (see 4.4.6.6) was transferred to the tracking sheet at the front of the consent package. Names from the backup sample lists were also transferred over to the tracking sheets, but one-by-one, as needed, in seeking to reach quota. The forms were then either administered (to document consent) or marked with the reason for non-participation (e.g., refused, absent, deceased).

The figures exclude two regions (Alberta and Yukon) that did not document non-participation. Their inclusion would have artificially inflated the participation rates. In other regions, despite training and written guidelines, it is likely that some non-participation also went unrecorded as fieldworkers were compensated only for completed surveys. The extent of undercounting and thus overestimation of participation rates can, unfortunately, not be quantified.

Among the 13% with consent form records but no survey, exactly half provided a reason for non-participation. And, of those, 41% were excluded because they were deceased and 36%

were documented as refusing to participate. Overall, of the 27,094 forms completed, 555 (2.0%) were specifically identified as refusals. The actual number of refusals was likely higher. Uneven administration and documentation of consent (see 4.6.4) make more precise estimates impossible.

4.7.2.4 Use of Alternate Community Sampling Frames

Although standardized procedures called for the use of local membership lists as sampling frames, this was not always feasible. In some communities, the lists could or would not be shared, primarily due to confidentiality/privacy concerns, in spite of safeguards that had been put in place. In total, a household-based frame was adopted in 39 of the 238 (17%) participating communities instead. Manitoba decided to standardize regionally with a household-frame approach for all of its 27 communities because frames based on membership lists were not uni-

versally accessible. Alternate local frames were also used in eight Saskatchewan communities and in one community in each of the following: Alberta, Quebec, Ontario and Nova Scotia.

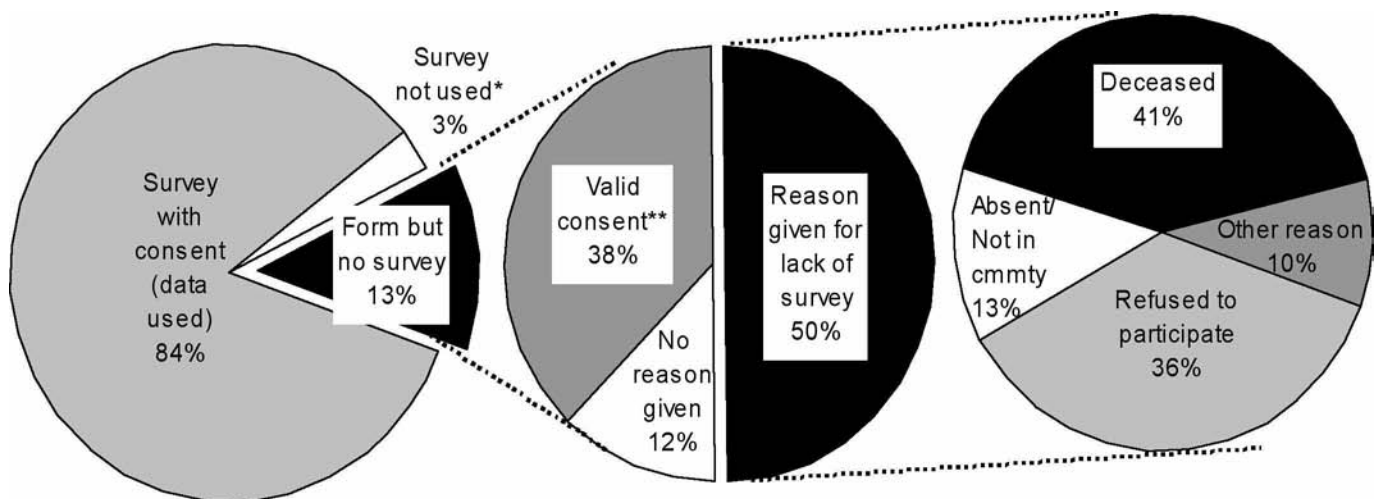
In all cases, sampling was randomized, with backup lists to ensure the attainment of established quotas.

4.7.2.5 Inclusion of Off-Reserve Sample

In 15 of the 238 communities sampled (6%), individuals living off-reserve (or outside the community) were included in the national sample.⁵³ Based on Regional Coordinator reports, the total number of people represented is estimated at 200—less than 1% of the total sample.⁵⁴ The two primary reasons for including people from off-reserve areas were:

- People were living off-reserve temporarily (examples included people living out of their community for seasonal work, those

Figure 6 Overview of Individual Participation Based on Survey and Consent Form Records



* Surveys were removed if consent documentation was inadequate or item non-response exceeded 50% (see 4.8.3.2 and 4.8.3.3).

** Valid consent was documented but no survey was completed (or successfully uploaded).

⁵³ Quebec region's urban sample in three cities is excluded from the national sample and is not considered here.

⁵⁴ Each region provided a report detailing any deviations from the sample design and sampling procedures.

waiting for band housing and those waiting while mold was being cleaned from their houses);

- People living close to the reserve boundaries who made use of reserve-based services.

4.7.2.6 *Changes to Community Sampling Targets*

Regional Coordinators reported all changes to sample targets relative to the initial design described in section 4.4. In 58 communities, at least one age/gender group's target sample was **increased**. The increased community targets were intended to do one of the following:

- Provide community-level statistics where not provided by the design;
- Include all community members—complete census—to provide rich community-level statistics (communities in Saskatoon Tribal Council, Saskatchewan);
- Meet sub-regional targets when sample in other communities was not adequate for whatever reason;
- Decrease sampling error (improve confidence).

Meanwhile, in 13 communities,⁵⁵ at least one age/gender group's target sample was **decreased** relative to the initial design. In every case, this was the result of populations too small to meet the initial target, usually due to an initial over-estimation of the population (based on projected adjusted Indian Register estimates). In almost all cases, only youth and children—with their higher sampling rates—were affected.

The deliberate increases and decreases to community targets are generally distinct from the actual level of success in meeting targets described in section 4.7.2.1.

4.7.2.7 *Individuals Completing the Wrong Survey Type*

A few children and a few adults completed youth surveys while some youth completed adult or child surveys. The reasons for this were not documented but the following are likely scenarios:

- Errors may have been made in age calculation during sample selection;
- Some respondents may have had their 12th or 18th birthdays between the time they were selected and the time they were interviewed;
- Errors may have been made in recording birth date or age within the CAPI system;
- Children and youth may have felt that they “belonged” in the younger or older age group (e.g., 11-year-olds considering themselves to be youth);
- The age of some respondents who completed paper surveys (see 4.6.3.7) may have been artificially inflated by one year. This is because the age-at-time-of-survey calculation was based on the data entry date (into the CAPI system) and not the actual (on-paper) survey administration date. Thus, those who had their 12th or 18th birthdays between completing the paper survey and its recording in the CAPI system would appear to be misclassified.

Table 11 provides a breakdown of those who completed the “wrong” surveys.

In all cases, individuals of the “wrong” age were kept within the database for the survey they completed. They were assigned weights corresponding to the closest “legitimate” age in the group. For example, 17-year-old “adults” were treated as 18-year-olds in the weighting (see 4.8.7). For the purposes of reporting, unless otherwise noted, analyses include those who completed the “wrong” survey.

⁵⁵ Three of these were also among the 58 with increased samples for other age/gender groups.

Table 11 Number of Respondents Completing the “Right” and “Wrong” Surveys, by Age

| | Right age | Wrong age for survey | | | | |
|-----------|------------------|-----------------------------|----|----|---------------|-----------------|
| Child age | 0 to 11 | 12 | 13 | 14 | Total “wrong” | Total, all ages |
| Number | 6458 | 187 | 10 | 2 | 201 (3%) | 6657 |
| | | | | | | |
| | Right age | Wrong age for survey | | | | |
| Youth age | 12 to 17 | 11 | 18 | 19 | Total “wrong” | Total, all ages |
| Number | 6458 | 40 | 55 | 9 | 104 (2%) | 4983 |
| | | | | | | |
| | Right age | Wrong age for survey | | | | |
| Adult age | 18 and up | 17 | | | Total “wrong” | Total, all ages |
| Number | 10941 | 21 | | | 21 (0.2%) | 10962 |

4.8 DATA PROCESSING

Figure 7 provides a simplified view of the main steps in the data processing phase. Survey data was uploaded from laptops in the field to two regional servers and one national server as described in section 4.6.3. The data was combined nationally and exported from Lotus Notes/Lotus Domino via Microsoft Excel and then translated into SAS format for data cleaning and re-coding. Data from the separate consent form databases were then merged with the survey data. After removing records deemed to be lacking adequate consent documentation (see 4.6.4) or that were otherwise unusable (see 4.8.3.2 and 4.8.3, below), the final list of valid records was established. Statistical weights were then developed, based on adjusted Indian Register counts (see 4.4.2). The data was translated into SPSS format.⁵⁶ Databases were standardized for a large number of users by applying labels and developing detailed data dictionaries.

4.8.1 Data Capture (Data Entry)

Survey capture took place directly on the laptops in the field using a customized laptop-based tool (see 4.6.3) Data from check boxes (choose many), radio buttons (choose one), pull-down lists and write-in text boxes were all captured. As noted above, some surveys were com-

pleted on paper and the data was captured later using the standard laptop interface.

Data from the consent form packages was captured regionally into a Microsoft Excel-based database template developed by the national office. A portion of the resulting data was subsequently merged using unique identifiers with the survey response records to validate consent (see 4.6.4).

4.8.2 Editing: In the Field

Until each survey was marked as complete and became inaccessible (see 4.6.3.4), the fieldworker could return to any question in order to correct mistakes. Fieldworkers were trained to verify that responses were correctly entered during the interview. They did not need to be concerned about missed questions or skip patterns as the laptop-based CAPI system managed those.

4.8.3 Removal of Records Deemed Not Valid

At the close of data collection, there were 26,130 records. As part of the validation process, a series of filters was applied reducing the number of records available for analysis. A total of 3,528 records were removed through application of the following steps, applied in order:

⁵⁶ SPSS and SAS are advanced statistical analysis software packages. Although some initial data manipulations were completed using SAS, final databases were prepared in SPSS format after considering the pros and cons of various options.

1. Removal of duplicate records—2,658 cases (primarily test/practice surveys and surveys with matching useable records).
2. Removal of records within excess of 50% item non-response—246 cases.
3. Removal of records with improperly documented consent—624 cases.

- Record was a “false start,” later started again as a new survey (rather than continuing the original). These were usually blank or almost blank;
- Data entry mistake (e.g., typo);
- One consent identification number was used for everyone in a household (see 4.6.4).

Each step is detailed further in the sections that follow.

4.8.3.1 Removal of Duplicates

The first filter applied to available records was the removal of duplicates.⁵⁷ Duplicate records were defined as those with the same consent identification number. Although consent identification numbers on the consent forms were unique (see 4.6.4), many duplicates were nonetheless entered into laptop computers, generally for the following reasons:

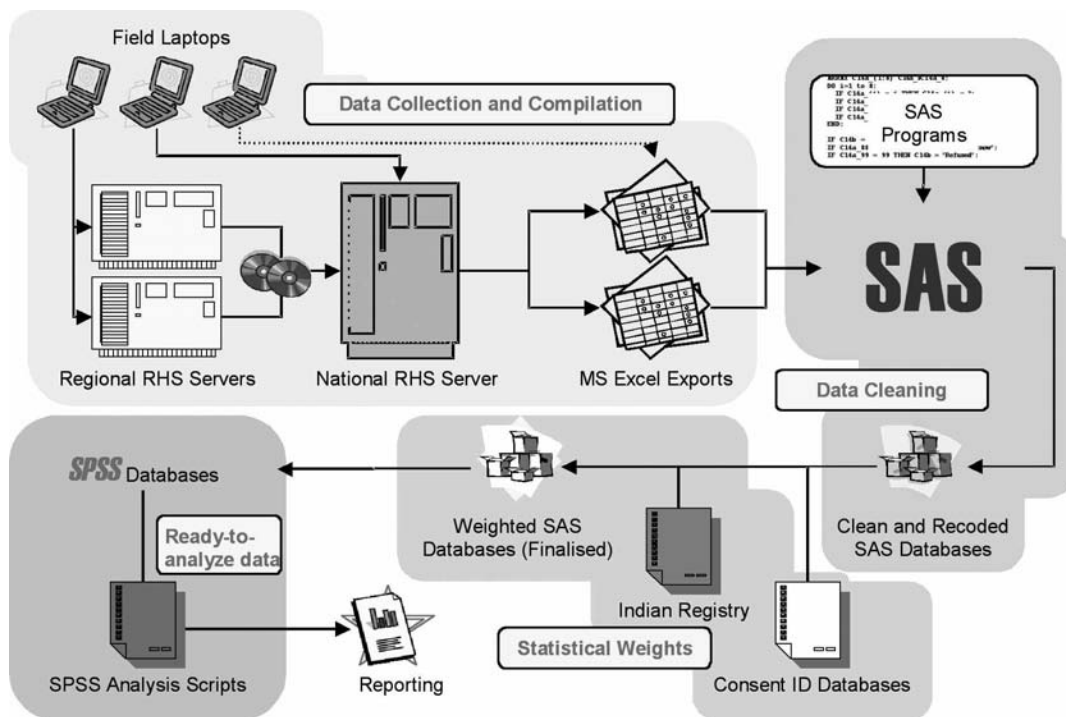
- Record was created as a test or during practice/training;

The status of duplicates was resolved by reviewing and comparing them on a case-by-case basis. Where required, Regional Coordinators’ verified the original (paper) consent form information and updated the database records. In some cases fieldworkers were also contacted.

Typos were corrected, individuals with “household consents” were given new unique numbers, and the more complete survey was retained when more than one was available for an individual.

Of the initial 3,228 duplicate records representing 1,397 unique identification numbers, 570

Figure 7 Data Processing Flowchart



⁵⁷ “Duplicates” here includes triplicates, quadruplicates and so on. One consent form identification number was entered 45 times—perhaps during a training session simulation.

were retained and 2,658 were removed. The majority of those removed were simply test/practice surveys and “false starts” that could have been removed by fieldworkers prior to uploading.

4.8.3.2 Removal of Incomplete Surveys

After unusable duplicates were filtered out, incomplete surveys were removed from the analysis databases by applying a “maximum 50% missing rule.”

There were 756 data elements in the adult survey that could be identified as missing. For youth, the count was 534 and for children, 450. If more than half (50%) were missing (blank, “don’t know” or “refused”), the record was removed from the analysis database.⁵⁸

As shown in Figure 8, the vast majority (86.1%) of available records had an item non-response rate of less than 10%. 246 records met the 50% threshold for removal from the analysis databases. Of those removed, though, about half were empty records with no valid responses. Although the reason was not recorded or quantified, the most common explanations for non-duplicate incomplete records were identified:

- Some represented respondents who changed their minds about participation during the interview;
- The vast majority was likely either practice surveys or “false starts” (as described above) and was subsequently completed as new records with new numbers.

The level of item non-response in surveys that were kept for analysis is discussed in section 4.9.2.4.

Surveys missing the respondent’s community, gender or age (or age group) were also excluded from analyses, as they could not be weighted (see 4.8.7.) There were 28 such cases.

4.8.3.3 Removal of Records with Inadequately Documented Consent

As described in section 4.6.4, consent forms were not always completed correctly or fully, in large part thanks to the complexity of the forms. Although extensive verification and updating decreased the number of surveys with incomplete consent documentation, the total remained substantial.

In keeping with the RHS Code of Research Ethics,⁵⁹ it was imperative to be certain that each respondent provided informed consent. At the same time, it was important not to lose or delete valuable data as a result of errors or misunderstandings related to complex forms and procedures. A series of meetings and briefings led to the following decisions by the First Nations Information Governance Committee:

- Verbal consent was deemed acceptable, in keeping with First Nations protocols, but only if properly documented. More than 400 surveys would have otherwise been lost. Most of these were in Quebec where a First Nations campaign against an entirely different consent form resulted in some confusion.
- A single consent was acceptable for more than one member of a family/household if documented as such by the fieldworker or Regional Coordinator. About 30 survey pairs (for a total of 60) were thus added, primarily from Saskatchewan.
- All other consents were valid only if the following were documented:
 - At least one consent validation mark or signature in a section reserved for the fieldworker, **and**
 - At least one consent validation mark or signature in a section reserved for the respondent.

⁵⁸ The 50% threshold was established as a conservative standard relative to other surveys, according to Tom Goss (Goss Gilroy Inc.).

⁵⁹ <http://www.naho.ca/firstnations/english/pdf/code_ethics_RHS.pdf>

Surveys with less complete or no consent documentation whatsoever were rejected despite the fact that respondents completed whole surveys (apparently implying consent) and despite a legal opinion obtained indicating they could be used. The requirement for unambiguous, documented consent was upheld as a matter of principle. As a result of these difficult decisions, 624 surveys were removed from the analytical databases. For longitudinal follow-up, a further filter will be applied later based on responses to the check box that asked respondents' permission to contact them in the future.

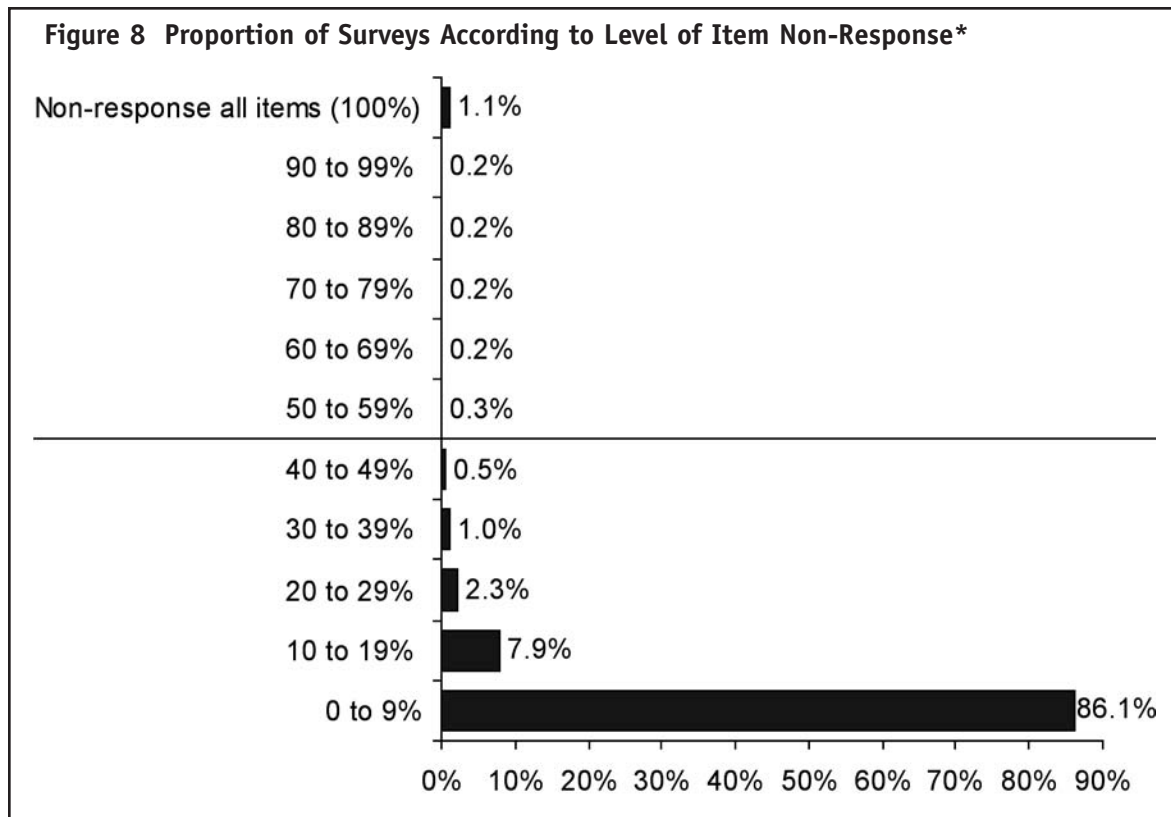
In future cycles, consent forms, their administration procedures and the related training will need to be reviewed.

4.8.4 Integration of Missing/Blank Responses

As discussed in section 4.6.3.8, it was possible to leave certain questions blank on surveys collected with early versions of the CAPI software. Those blanks were normally re-coded as "refused." For most analyses, they are treated as missing values, and excluded.

Blanks on paper-based surveys in Manitoba (see 4.6.3.7) were also entered as "refused" into the central laptop computers and not otherwise identified. (There was, of course, no "blank/skipped" flag available in the CAPI survey instruments.)

For paper-based surveys and those from the early CAPI software, it is impossible to know the



*Includes records later removed because of inadequately documented consent.

proportion of skipped questions that actually might have represented negative responses (i.e., a “no”). As a result, there may be an undercounting of negative responses and thus a relative overestimation of the proportion of responses that were positive. For the surveys based on non-final software versions, only the questions initially lacking “forced” replies are affected.⁶⁰ For the paper-based surveys, all questions are impacted. Thus, data-quality benefits anticipated from a CAPI-based system were not fully realized.

The level of item non-response for paper-based surveys is compared with CAPI-based surveys in section 4.9.2.4.

4.8.5 Editing: Validity and Outliers

Although validation procedures in the Computer Assisted Personal Interviewing (CAPI) tool avoided most potentially invalid or illogical responses (e.g., pregnant men, non-smokers smoking 10 cigarettes a day), some were still possible. Most derived from type-in responses and some were due to validations that had not been incorporated into the CAPI tool.

Using pre-specified edit rules, responses that were either internally contradictory or beyond normal human ranges (for type-in values) were generally changed to missing. Corrections were mostly automated, but case-by-case review occurred where necessary.

A running count of “offences” was used to try to identify potentially fictitious or fraudulent surveys. The counts were low and no survey records were removed as a result.

Verifications were also undertaken at the macro-level. Frequency distributions for all variables were reviewed to identify potential anomalies, such as unexpected frequencies/values or missing categories.

4.8.6 Coding and Re-coding

In order to prepare the three databases for analysis:

- Global variables were developed for individual questions and fields were packed more efficiently;
- Coding was standardized (e.g., 0 for “no” and 1 for “yes”, 88 for “don’t know”, 99 for “refused”);
- Blanks were re-coded as “refused” (as described in section 4.8.4);
- Open text responses (e.g., “other, specify”) were standardized and recoded into new or, where possible, existing categories;
- Numerous summary and derived variables were created to facilitate analysis (e.g., any grandparent attended residential school, body mass index from height and weight, crowding index from number of people and number of rooms);
- Some ecological (community-level) values were appended from other data sources based on the respondents’ residence;
- Descriptive SPSS variable and field labels were applied for all levels;
- Variables were identified as numeric or string;
- Data dictionaries (Appendix 14, Appendix 15 and Appendix 16) were prepared.

Given that the databases were prepared on behalf of and for ten different regions, and

⁶⁰ As noted in section 4.6.3.8, 17% of adult questions, 16% of youth questions and 12% of children’s questions had validations added to later survey instruments.

given that a large number of analysts with various levels of knowledge and expertise would be involved, databases were made as user-friendly as possible.

4.8.7 Weighting⁶¹

Sample weights were derived in three steps, the first two of which correspond to the second and first stages of sampling, while the third enhances the precision of resulting estimates:

- Individuals were weighted to the predetermined population for their age/gender group within their community;
- They were further weighted by the ratio of the number of communities within their stratum (i.e., sub-region and size class) to the number of communities sampled in the stratum—in other words, the inverse of the community sampling rate within the stratum.
- Finally, they were further weighted by the ratio of the stratum population for their age/gender group to the stratum population of their age/gender group in the selected communities only.

The final overall weight for an individual is the product of the three weights.⁶²

The mean weights are 20.4 for adults, 10.0 for youth and 16.7 for children, reflecting the different sampling rates in each. As shown below, the highest average weights are in Ontario and Alberta. The lowest are in Newfoundland and the Yukon. Sub-regional weights, including ranges, are provided in Appendix 17 (adult), Appendix 18 (youth) and Appendix 19 (child).

The weights at specific percentiles within the databases are one measure of sampling variability. As shown in Table 13, 80% of the weights in

the adult databases were below a value of 26.7. The values at that level in the youth and children's databases were 12.8 and 22.5, respectively.

Table 12 Mean Weights by Region and Database

| Region | Adults | Youth | Children |
|----------|--------|-------|----------|
| NB/PEI | 20.4 | 7.6 | 11.3 |
| NS | 10.0 | 3.7 | 6.0 |
| NF | 2.0 | 3.0 | 1.3 |
| QC | 11.3 | 4.9 | 8.3 |
| ON | 73.8 | 23.3 | 34.7 |
| MB | 16.4 | 11.4 | 30.4 |
| SK | 12.5 | 6.0 | 10.9 |
| AB | 42.2 | 36.0 | 51.6 |
| BC | 47.3 | 11.9 | 18.9 |
| YK | 3.5 | 3.3 | 2.9 |
| NT | 11.2 | 4.8 | 4.8 |
| National | 20.4 | 10.0 | 16.7 |

Table 13 Weights at the 80th and 90th Percentile, by Database

| | Adult | Youth | Child |
|--------------------------|-------|-------|-------|
| 80% of weights are below | 26.7 | 12.8 | 22.5 |
| 90% of weights are below | 46.1 | 17.7 | 34.6 |

4.8.8 Analysis and Interpretation

4.8.8.1 Overview of Analysis, Interpretation and Dissemination Strategy

National RHS analysis is undertaken under the guidance of the First Nations Information Governance Committee. In keeping with RHS protocols, regional, sub-regional and community level analyses are the exclusive responsibility of the First Nations regional authorities. All results released by the First Nations Centre, therefore,

⁶¹ Statistical weights are used to provide better estimates when a sample is not a perfect reflection of the target population it is intended to represent. Weights are used to mathematically expand the sample to the actual (target) population.

⁶² Note that preliminary results released prior to June 2005 were based on earlier statistical weights that did not incorporate the third stage (ratio-to-size adjustment factor). There will, therefore, be minor discrepancies with newer estimates.

are aggregated at the national level and no region-by-region comparisons are provided.⁶³

RHS analyses and releases are guided by the following general goals and priorities:

- Statistical results should be contextualized by First Nations understandings and frameworks and be consistent with the standards of competent mainstream research;
- Information products should be community-friendly and easy to understand;
- Results should help raise awareness of First Nations health issues and of the survey itself;
- Results should first and foremost be reported back to First Nations communities;
- Results should also be accessible to as many interested parties as possible;
- Releases should provide information to support policy development, decision-making and advocacy;
- The dissemination strategy and choices should contribute something of value to First Nations nationally, regionally and at the community level;
- Ultimately, data should be used for information that leads to positive change and improvements in the health and well being of First Nations.

Following the initial dissemination of three preliminary releases between September 2004 and October 2005,⁶⁴ two reports were launched at a conference held November 13-15 in Ottawa, Ontario, Canada:⁶⁵

1. A 322+ page report organized into 34 separate thematic chapters,⁶⁶ titled *First Nations Regional Longitudinal Health Survey 2002/03: Results for Adults, Youth and*

Children Living in First Nations Communities.

2. A shorter more community-friendly report titled *First Nations Regional Longitudinal Health Survey (RHS) 2002/03: The Peoples' Report*, incorporating results from the larger report within a four-direction cultural model.

Other “products” planned for the mid-term include:

- Fact sheets and “top 10” lists;
- “RHS at a glance” summary in handbook format;
- Brochures with key findings and recommendations;
- Thematic posters;
- Interactive CD-ROM;
- Poster presentations;
- Presentations at scientific colloquia, government meetings, conferences and First Nations venues;
- Radio messages/public service announcements;
- New thematic chapters on priority themes (e.g., women’s health);
- Media releases – highlighting key findings.

4.8.8.2 Overview of 36-Chapter Report

The framework and procedures for the largest report are described in detail here, as it is the primary reference for statistical information. Several of the other information products source their material from this report.

The report was designed to provide a high-level overview of national results for all subject areas from the three surveys. A competition was held (Appendix 20) to solicit contributors to develop the chapters listed in Table 14.

The competition’s review panel selected contributors, usually with supporting teams, to draft between one and three chapters each. The

⁶³ Certain types of geographical breakdowns (e.g., by remoteness or isolation status) are provided, however.

⁶⁴ <http://www.naho.ca/firstnations/english/regional_health.php>

⁶⁵ <<http://www.naho.ca/firstnations/english/FirstNationsResearchConference.php>>

⁶⁶ Initially 36, the total was reduced to 34 when the Chronic Conditions and Disabilities/Activity Limitation chapters were combined for both adults and children.

authors were a diverse group in terms of experience and expertise, including university-based researchers, postgraduate students, Aboriginal consultants and staff from non-governmental organizations, First

Nations/Aboriginal organizations and the First Nations and Inuit Health Branch (Health Canada). The majority of those selected were First Nations individuals.

Table 14 Chapters in Technical Report*

Adult survey topic areas

1. Demographics, education, employment, income
2. Language and culture
3. Housing and living conditions
4. Health conditions and chronic diseases (excluding diabetes)*
5. Diabetes
6. Injuries
7. Disability and activity limitation*
8. Dental health and care
9. Nutrition, physical activity, body mass index
10. Non-traditional use of tobacco (smoking)
11. Alcohol and drug use
12. Sexual activity
13. Health care access and use of preventative health care
14. Residential schools and impacts
15. Mental health, personal wellness and support

Children's survey topic areas

17. Household structure and income, parental education, childcare
18. Language, culture, Head Start and school
19. Birth weight, smoking during pregnancy, breastfeeding history
20. Nutrition, physical activity, body mass index
21. Health conditions, chronic diseases and activity limitation*
22. Injuries
23. Disability and activity limitation*
24. Dental health and care
25. Parent/grand-parent residential school attendance and child's well-being
26. Emotional and Social well-being

Youth survey topic areas

27. Household/family structure, language and culture
28. School education
29. Nutrition, physical activity, body mass index
30. Health conditions, chronic diseases and activity limitation
31. Injuries
32. Dental health and care
33. Non-traditional use of tobacco (smoking), alcohol, drug use
34. Sexual activity
35. Parent/grand-parent residential school attendance and youth's well-being
36. Mental health, personal wellness and support

*Note: The number of chapters was reduced to 34 after Chapters 4 and 7 and Chapters 21 and 23 were combined.

4.8.8.3 *Writing and Statistical Standards for 34-Chapter Report*

An orientation session, detailed writing guidelines and on-going communication helped to ensure standardization of chapters in terms of type of content, organization/sections, length, format, integration of the cultural framework, reporting of statistics, presentation of graphs and tables, and so on. The following statistical specifications/standards were established:

- To protect confidentiality and decrease the risk of misinterpretation, statistics based on cell sizes with less than 30 records were suppressed (and sometimes identified with a dash within tables);
- Confidence intervals were reported for figures with a coefficient of variation greater than 33%;
- No statement indicating or implying a difference between groups or categories was included unless the difference was statistically significant. Non-significant differences were identified, usually with “NS.” Differences were considered significant if the confidence intervals of the results for the groups/categories compared did not overlap at the 95% confidence level (after bonferroni adjustment).⁶⁷

In five of the 34 chapters, different thresholds for significance were used. The standards adopted are noted within each of these chapters.

Initial plans to include confidence intervals with all reported figures (in order to facilitate interpretation and comparison with results from other sources) were dropped because of the resulting text that was difficult to read. The original statistical tables, though, containing confidence intervals, and additional details are maintained on file at the First Nations Centre.

Non-overlap in confidence intervals was adopted instead of other methods of assessing statistical difference (e.g., chi square test) because it permits specific group-by-group comparisons. For example, this makes it possible to report that adults under 30 years old are more likely to have a certain characteristic but that the other age groups (30-39, 40-49, 50-59 and 60+) were not statistically different from each other in terms of that characteristic.

After signing a non-disclosure agreement, authors were provided with a “starter pack” containing tabulations for all the main variables considered to belong in that chapter. The “starter pack” statistics were, by default, broken down for a series of standard categories (e.g., age, gender, income, education, community isolation status). Subsequently, with data dictionaries and mock datasets on-hand, authors submitted request forms to access tabulations (Appendix 21). The FNC analyst received requests and returned tabulations to authors via email. Most analyses were based on two-way and three-way cross-tabulations. Age-adjustment and some other complex analyses and modeling were also used, but multivariate analyses were not developed as the report aimed to disseminate only high level statistics.⁶⁸

A collection of comparable statistics for Canadians overall and Aboriginal people living off-reserve, based on various Statistics Canada surveys,⁶⁹ was also provided to supplement authors’ background research.

4.8.8.4 *Review and Quality Control for 34-Chapter Report*

First drafts of chapters were peer reviewed by two other authors. Second drafts were reviewed/updated from a technical perspective and copy edited. In a few cases, chapters were changed quite substantially or redrafted alto-

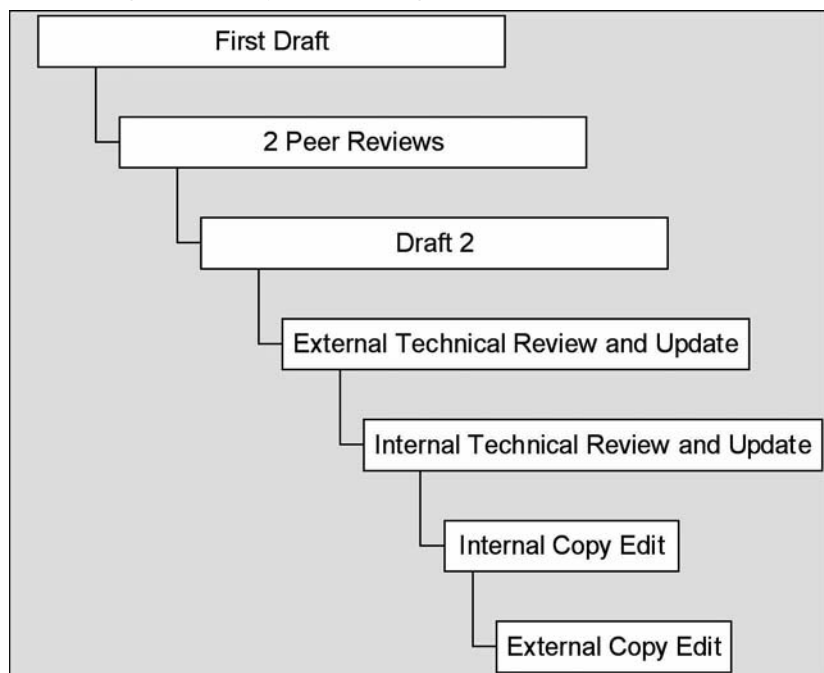
⁶⁷ The bonferroni adjustment or correction is a more conservative method of assessing statistical significance, particularly for analyses with many cells/groups.

⁶⁸ In future, more focused reports will include multivariate analyses.

⁶⁹ Comparable statistics were derived from in-house analyses of the Statistics Canada Canadian Community Health Survey: Public Use Microdata File (2003), custom tabulation requests from the Aboriginal Peoples Survey and the 2001 Census, as well as publicly available statistics compiled from the Internet.

gether. The stages of the review/revision process are shown in Figure 9.

Figure 9 Chapter Drafting and Review Process



The technical review/update:

- Verified that essential peer review comments were integrated;
- Validated and, where necessary, corrected all RHS-derived statistics;
- Removed statistics that fell below the established threshold for suppression;
- Added confidence intervals next to figures that fell below the established threshold for coefficient of variation;
- Validated, removed or revised statements that indicated or referenced differences between groups or categories, as needed, based on the established thresholds for statistical difference;
- Revised text to improve precision and clarity of statistical reporting and interpretation.

It was the responsibility of individual authors to verify results and statements based on sources other than the RHS (e.g., from the medical literature or other surveys). Additional verification by the First Nations Centre was not practical given the range and number of references, including some that would not have been accessible in a timely manner.

Relative to the technical review, copy editing focused more on standardization of language and style between chapters, grammar, formatting, plain language and overall readability.

4.8.8.5 Data Analysis for 34-Chapter Report

SPSS version 13 was used for most of the analysis. Estimates were weighted (see 4.8.7) and confidence intervals were calculated using the SPSS Complex Samples module.⁷⁰ The module goes beyond the simple-random-sampling assumptions of standard statistical analyses, producing estimates based on the relevant details of the sample's design. The weights and specifications of the RHS's complex stratified sample were programmed into the module to enhance the validity of results.

4.8.9 First Nations Interpretation

In addition to statistical conventions for reporting and interpreting data, a First Nations cultural framework was developed to help guide the interpretation of statistical results and organize the findings. The framework, described in the introduction, is applied more consistently within the "Peoples' Report." Finally, a First Nations review and the guidance of the First Nations Information Governance Committee helped to ensure that the meaning brought to the numbers was based on community-based knowledge and expertise.

⁷⁰ <http://www.spss.com/complex_samples/brochures.htm>

4.9 DATA QUALITY

Estimates of population values (e.g., the number of individuals with a certain attribute) are subject to both “sampling errors” and “non-sampling errors.” The former term refers to the difference between the value estimated from the sample and the value that would be calculated if questionnaires had been completed for the whole population. The latter term refers to the difference between the value that would be derived from the sample extended to the whole population, but subject to the same data collection, transcription, and calculation procedures as those used for the sample, on the one hand, and the underlying true value for the population, on the other.

The total error in the estimates is the combination of sampling and non-sampling errors.

4.9.1 Sampling Errors

In a “probability sample,” every member of the population has a known non-zero probability of selection. It is possible to obtain not only unbiased estimates of population values but also the distribution of sampling errors associated with the estimates. This distribution is usually summarized, as it is in this report, by providing the 95% “confidence interval” associated with the estimate.⁷¹

With a simple random sample (SRS),⁷² sampling error depends only on the sample size and on the variation in the value assigned to the variable itself (e.g., 1 if the individual has a certain attribute, 0 otherwise). However, with complex designs such as the one in this survey, the estimation of sampling error is similarly complex. The estimation calculations must take into

account such design features as stratification, multistage sampling, and unequal selection probabilities. Data analysis for the RHS incorporates suitable formulae through application of the Complex Samples modules of SPSS.⁷³

4.9.2 Non-Sampling Errors

Non-sampling errors include errors arising from departures from the sample design and in collecting and processing survey data including:

(1) Non-response bias: In this survey non-response arose both at the community level and at the individual level. Communities and individuals were randomly chosen as substitutes when those originally selected were unavailable. Nevertheless, there remains the possibility that the sampled population differs in some systematic way from the target population.

(2) Response bias: The value actually obtained and recorded for a particular respondent on a particular variable may differ from the true value, either because the respondent did not give the true value (possibly as a result of misunderstanding the question or simply not knowing the answer, the latter possibility being more prevalent in “proxy responses” given by adults for children), because the interviewer did not record the value correctly, or because the data was incorrectly captured and/or coded from the questionnaire.

These errors do not arise because this is a sample survey; in fact they tend to be less significant in a well-designed and managed sample survey than in a census. This is because of the tighter control possible for a sample under time and budget constraints.

⁷¹ For example, it is now usual for the results of polls to be given with some such statement as “this value is considered to be accurate to within +/- 4% 19 times out of 20.” This is, in effect, the 95% confidence interval for the estimate and is based on the distribution of sampling errors, as estimated from the sample itself.

⁷² While SRS is hardly, if ever, used for surveys of human populations, it provides a useful standard by which to measure the relative efficiency of a more practical design. The ratio of the variance of an estimate derived from a survey using a complex design to that of an SRS with the same overall sample size is referred to as the “design effect” (for the particular parameter estimated). Generally speaking, stratification tends to reduce the design effect while multistage sampling tends to increase it. Multistage sampling is justified, however, by its lower per-unit cost. The lower cost in turn allows for a larger overall sample size. For practical and efficient designs of samples of human populations, design effects are generally in the range of 1 to 3. The low end of this range corresponds to variables whose distribution is fairly uniform across the population surveyed, while the high end corresponds to distributions that are highly concentrated in certain sub-populations.

⁷³ <http://www.spss.com/complex_samples/brochures.htm>.

It is in the nature of non-sampling error that it is generally not possible to provide a measure of its magnitude. Allocating a sufficient portion of survey resources to its control can help to minimize the effect. This is reflected in the selection and training of interviewers, the Fieldworker Manual, the pre-testing of survey instruments and procedures and quality control during data collection editing of survey data. The protocols for this survey have been described in relevant sections of this report.

More specific information on the nature and scale of the response and non-response bias in the 2002/03 RHS are outlined in the next sections.

4.9.2.1 Interview/Response Errors

Interviewers may have misunderstood directions, misread questions or click the wrong response option. Respondents likewise may have made errors or misrepresented themselves in their responses. Although not quantifiable, these types of errors are expected to be few in total and non-systematic in nature. The removal of extreme values (outliers) and impossible combinations during the data-processing phase corrected some of these errors (see 4.8.4, 4.8.5 and 4.8.6).

4.9.2.2 Coverage

Because the 2002/03 RHS is a survey of "First Nations living in First Nations communities," the exclusion of Inuit communities in Quebec does not actually impact coverage. Removal of two First Nations sub-regions from the target population, however, diminishes representativity nationally. The two regions, James Bay Cree of Northern Quebec and the Labrador Innu, together represent two of 54 sub-regions, 10 out of 607 target communities and 3.3% of the First Nations community population.

The coverage limitations, though, are minor relative to the 1997 RHS (which excluded the Northwest Territories and the Yukon)⁷⁴ the 2001 Aboriginal peoples survey (which does not provide a nationally representative on-reserve sample).⁷⁵

4.9.2.3 Total Non-Response

Interviewers were trained to make repeated efforts to contact potential respondents and solicit their participation. They were instructed to not pressure respondents in any way and to respond to all questions.

As noted in section 4.7.2.3, 87% of those selected (and for whom paperwork was started) completed a survey. Of the 13% that did not complete a survey,⁷⁶ a reason was indicated for precisely half. Of those with a documented reason, 41% were excluded because they were deceased and 36% identified as refusing to participate. Overall, 555 of the 27,094 forms completed (2.0%) were specifically identified as refusals.

It is important to note, though, that problems with administration and documentation of consent resulted in an unquantified underestimation of both the non-response and refusal rates, as discussed in section 4.7.2.3.

4.9.2.4 Partial Non-Response

Partial non-response includes questions that were either answered with "refused" or with "don't know." Blank or skipped questions were recorded as "refused." As noted in section 4.8.3.2, records with 50% or more non-response were discarded. Considering only those kept for analysis, the mean number of non-response replies for each questionnaire is shown in bold on the last column of Table 15. On average, there were 24.9 missing items on an adult survey, 14.0 for youth and 5.9 for children.

⁷⁴ O'Neil, J. D., et al. *The First Nations and Inuit Longitudinal Health Survey: A Process Report*. 1998.

⁷⁵ Statistics Canada. *Aboriginal Peoples Survey 2001: Concepts and Methods Guide*. Housing Family and Social Statistics Division. 2003.

⁷⁶ After excluding two regions with incomplete records.

Without software-based validation, missing responses were more likely (and more possible) on paper-based surveys (see 4.6.3.7 and 4.8.4.) The average number of missing responses recorded on adult surveys completed on paper was 4.3 times that for the laptop-based survey (72.4 vs. 16.7). For youth, the mean number of missing responses was 4.9 times higher, and for children, 6.1 times higher.

Table 15 Mean Number of “Don’t Know” and “Refused” Responses: Paper-Based vs. Other Surveys*

| | | Paper-Based | CAPI-Based* | All |
|----------|--------------------|-------------|-------------|-------------|
| Adult | Don’t know | 19.3 | 11.2 | 12.4 |
| | Refused | 53.4 | 5.5 | 12.5 |
| | All missing | 72.4 | 16.7 | 24.9 |
| Youth | Don’t know | 11.6 | 6.8 | 7.4 |
| | Refused | 36.4 | 2.9 | 6.6 |
| | All missing | 48.0 | 9.8 | 14.0 |
| Children | Don’t know | 8.0 | 3.7 | 4.0 |
| | Refused | 19.3 | 0.8 | 1.9 |
| | All missing | 27.3 | 4.5 | 5.9 |

*Missing/blank responses were recoded as “refused”. Saskatchewan records were excluded because of differences related to software versions (see 4.6.3.8).

4.9.2.5 Processing Errors

Processing errors could occur during the data capture (i.e., in the field on the laptops), coding, editing, weighting and analysis phases. Quality control measures, including verification of expected outputs and reviews of edits and program syntax, were implemented at all stages. Quality control at the First Nations Centre was also supplemented by review and validation undertaken by staff at each regional office.⁷⁷

4.10 LEVELS OF ANALYSIS AVAILABLE

As determined by the First Nations Information Governance Committee, the First Nations Centre will not release regional, sub-regional level or community level results without approvals from respective mandated authorities. Regional offices, in keeping with their respective protocols, may release results “below” the national level.

Based on the sample achieved, Table 16 presents a summary of the levels of geography for which estimates can be produced on a cross-sectional basis.

Table 16 Summary of Available Data Estimates, by Level of Geography

| Level | Availability of estimates | | |
|--------------|---|---|--|
| | Children | Youth | Adults |
| National | ✓ with various breakdowns | ✓ with various breakdowns | ✓ with various breakdowns |
| Regional | ✓ with some breakdowns | ✓ with some breakdowns | ✓ with some breakdowns |
| Sub-regional | ✓ (most) | ✓ (most) | ✓ (most) |
| Community | 55 communities with some estimates* and, of those, 7 with detailed estimates.** | 53 communities with some estimates* and, of those, 4 with detailed estimates.** | 83 communities with some estimates* and, of those, 18 with detailed estimates.** |

*“Some estimates” refers to communities with coefficients of variation under 40% for an incidence (p) of 0.5 at the 95% confidence level.

**“Detailed estimates” refers to communities with coefficients of variation under 40% for an incidence (p) of 0.2 at the 95% confidence level.

⁷⁷ An analyst at the First Nations of Quebec and Labrador Health and Social Services Commission was an invaluable resource, identifying errors that affected all regions.

First Nations Regional Longitudinal
Health Survey (RHS) 2002/03



*Our Voice
Our Survey
Our Future*



Prepared by the First Nations Centre @ NAHO on behalf of the
First Nations Information Governance Committee

