

**REVIEW OF THE
FIRST NATIONS REGIONAL LONGITUDINAL HEALTH
SURVEY (RHS) 2002/2003**

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**Review of the
First Nations Regional Longitudinal Health Survey (RHS)
2002/2003**

**Prepared by the Harvard Project on American Indian
Economic Development**

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Table of Contents

EXECUTIVE SUMMARY

I. INTRODUCTION

II. METHODS

FINDINGS

III. SAMPLING DESIGN

A. Overview

B. Technical Assessment

1. Identification and Selection of Target Population
2. Sampling Scheme
3. Achieved Sample Size
4. Respondent Selection
5. Response Rate
6. Summary

C. OCAP Assessment

1. Ownership
2. Control
3. Summary

D. Comparative Perspectives

IV. DATA COLLECTION

A. Overview

B. Technical Assessment

1. Informed Consent
2. Mode of Data Collection
3. Questionnaire Design
4. Data Quality
5. Summary

C. OCAP Assessment

1. Ownership
2. Control and Access
3. Possession
4. Summary

D. Comparative Perspectives

V. DATA ANALYSIS AND DISSEMINATION

A. Overview

B. Technical Assessment

1. Data Analysis Plan
2. Data Cleaning, Coding and Documentation
3. Data Analysis Training
4. Data Presentation
5. Data Dissemination and Interpretation
6. Summary

C. OCAP Assessment

1. Ownership

2. Control
3. Access
4. Possession
5. Summary

D. Comparative Perspectives

VI. CONCLUSIONS

APPENDICES

- Appendix 1) List of Supplemental Materials
- Appendix 2) Stakeholders & Advisory Groups
- Appendix 3) Regional Coordinator Interview Questions
- Appendix 4) FNIGC Staff/Members Interview Questions
- Appendix 5) Regional Health Director Interview Questions
- Appendix 6) Community Health Director Interview Questions
- Appendix 7) Comparative Analysis Methods
- Appendix 8) Copy of Internal Review Board Approvals

LIST OF FIGURES

- Figure 1) Logic Model for the FNRLHS
- Figure 2) Role of Review in the 2002/2003 RHS Implementation Process
- Figure 2) Process Model for the FNRLHS
- Figure 3) Activities of the Review

LIST OF TABLES

- Table 1) List of Contacts for In Depth Interviews
- Table 2) Sampling Design Quality Indicators
- Table 3) Proportion of Total Sample Achieved, by Region
- Table 4) Proportion of Total Sample Achieved, by Age/Gender Groups
- Table 5) Summary of Technical Quality of the Sampling Design
- Table 6) OCAP Principles and Sampling Design
- Table 7) Comparison of Sampling Design Factors Across Surveys
- Table 8) Comparison of Response Rates Across Surveys
- Table 9) Data Collection Quality Indicators
- Table 10) Summary of Technical Quality of Data Collection Phase
- Table 11) OCAP Principles and Data Collection
- Table 12) Data Analysis and Dissemination Quality Indicators
- Table 13) Summary of Technical Quality of Data Analysis and Dissemination
- Table 14) OCAP Principles and Data Analysis and Dissemination

Executive Summary

INTRODUCTION

This report summarizes the results of an independent review of the First Nations Regional Longitudinal Health Survey for 2002/2003 (2002/2003 RHS), undertaken for the First Nations Information Governance Committee (FNIGC), a standing committee of the Chiefs Committee on Health (CCOH), and the First Nations Centre (FNC) at the National Aboriginal Health Organization (NAHO). The FNC at NAHO was mandated by the Chief's Committee on Health and the First Nations Information Governance Committee to coordinate and act as data steward for the 2002/2003 RHS.

The purpose of this review was to assess the quality of the research design and the consistency of the research process with the principles of First Nations' ownership, control, access and possession of research (commonly known as the "OCAP¹ principles").

- Ownership refers to First Nations communities own information collectively in the same way that an individual owns their personal information.
- Control refers to the fact that First Nations are within their rights to seek to control all aspects of research and information management processes which impact them.
- Access is the right of First Nations communities to manage and make decisions on access to their collective information.
- Possession is the mechanism by which ownership can be asserted and protected.²

To accomplish this, the review addressed the following research questions:

1. Are the overall research design, data collection processes, and analytic plan consistent with well-established survey research principles?
2. Are the overall research design, data collection processes, analytic plan, reporting and dissemination of study findings consistent with the First Nations' principles of ownership, control, access, and possession (OCAP)?
3. What factors supported or hindered the execution of the RHS?

METHODS

The methodologies employed in this review of the 2002/2003 RHS included document and literature review, technical assessment of the RHS methodologies, a comparative analysis of the 2002/2003 RHS to other national surveys of Indigenous people, and in-depth interviews with key stakeholders. The review team had no involvement in the design, implementation or dissemination of data from the 2002/2003 RHS and, therefore, could provide an independent review of the 2002/2003 RHS process.

¹ Schnarch, B. "Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research." Journal of Aboriginal Health. January 2004.

² First Nations Regional Longitudinal Health Survey. "Code of Research Ethics." Adopted July 25, 1997, Revised January 27, 2004.

KEY FINDINGS

In summary, the review team was impressed with the overall quality of the 2002/2003 RHS, its consistency with previously validated survey research practices and its innovations with respect to the involvement of First Nations communities and their representatives in the research process. The 2002/2003 RHS used information gained from the first round of data collection (1997 RHS) to develop more refined methodology and protocols. Compared to other national surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process. All of this was accomplished under considerable resource constraints.

The following provides a brief synopsis of our findings with respect to sampling design, data collection, and data analysis and dissemination.

Sampling Design

- ⌘ High Technical Quality Marks
 - Standardization of sampling schemes across regions
 - Probability-based sampling design
 - Adequate sample size for cross sectional and longitudinal analysis
 - High response rate
 - High level of community representation

- ⌘ Consistency with OCAP
 - Use of community membership lists to identify respondents
 - Ongoing communication with community representatives regarding sampling design specifications
 - Stewardship of decision making at the regional and national level

- ⌘ Comparative Perspectives
 - One of two surveys to include Indigenous representatives in decision-making regarding the sampling design
 - Only survey to use Indigenous-owned data sources to identify sampling frame

- ⌘ Potential Limitations/Concerns
 - Exclusion of off-reserve First Nations communities and communities with less than 75 persons.
 - Insufficient sample size for data analysis among smaller communities
 - Variation in degree of representation of FN communities among regional organizations
 - Limited ability to assess selection due to lack of baseline data

Data Collection

- ⌘ High Technical Quality Marks
 - Intensive training offered to regional coordinators and fieldworkers
 - Oral and written consent
 - Accommodation in consent forms for longitudinal cycles
 - Use of a highly reliable mode of data collection (CAPI: Computer Assisted Personal Interviewing)
 - Inclusion of community representatives as interviewers
 - Pre-survey evaluation
 - Low rates of error for CAPI-based surveys

- ⌘ Consistency with OCAP
 - Community level ownership and regional stewardship
 - Regional participation in questionnaire design and selection
 - Regional modules
 - Explicit protocols for release of national, regional and community level data

- ⌘ Comparative Perspectives
 - One of two to use CAPI for data collection
 - Only survey to consistently employ and train Indigenous community interviewers
 - Most extensive coverage of cultural concepts in the questionnaire design

- ⌘ Potential Limitations/Concerns
 - Lack of funding to provide consent forms in First Nations languages
 - Use of household level consent
 - High turnover of regional coordinators and fieldworkers limited institutionalization of knowledge and infrastructure development at the regional and community level
 - High rates of non-response on paper-based surveys
 - Inadequate handling of partial non-response
 - More justification may be needed for wide scope of questions and sensitive questions

Data Analysis and Dissemination

- ⌘ High Technical Quality Marks
 - Intensive process of error correction, imputation, weighting and standardization to increase data quality
 - Training sessions at the regional and community level in data analysis, interpretation and use
 - Clear and simple presentation of national data
 - Standardization of statistical methods for comparison of subgroups
 - Acknowledgement of sampling error
 - Multi-level dissemination strategy

- ⌘ Consistency with OCAP

- Community level ownership and regional stewardship
- Collaborative process for national data release
- Explicit protocols for release of national, regional and community level data
- Analysis and data use training sessions at regional and community level

⌘ Comparative Perspectives

- Only survey where data release was clearly controlled by Indigenous organizations

⌘ Potential Limitations/Concerns

- Exclusion of surveys with 50% non-response
- Inadequate sample size for community level analysis for smaller communities
- High turnover of regional coordinators limited dissemination of information gained in training sessions

Themes from In Depth Interviews

⌘ Internal Constraints

- Lack of an Independent Infrastructure
Interviewees noted that the lack of an independent 2002/2003 RHS structure created greater dependency on existing regional organizations that may not be representative of all communities. Others cited a need for more than one individual in each region or sub-region who would be responsible for championing the project over the long term.
- High Rates of Staff Turnover
There was high turnover of both regional coordinators and fieldworkers, diverting resources from data collection and analysis to recruitment, hiring and training of new staff.
- Translation of Research Findings into Action
Community health directors described a need for community rather than “provincial” level data for documentation of need and development of indicators for program planning, program development and grant writing; others cited a need for a more widespread marketing campaign to increase visibility of the 2002/2003 RHS.

⌘ External Constraints

- Level and Timing of Funding
Funding emerged as a primary cause of limitations in sampling design, data collection and analysis. Examples of funding limitations described by those interviewed included lack of funding for community engagement, community-level data collection, and training needed to effectively carry out a survey of this magnitude.

- Small rural nature of many communities and wide geographic spread
Interviewees reported that larger communities had an advantage in using 2002/2003 RHS for community planning due to the inability to obtain community-level estimates for most medium and small communities. This was a common theme in the other Indigenous surveys we reviewed, suggesting that these challenges are not unique to the 2002/2003 RHS.

RECOMMENDATIONS

The following recommendations are directed to the First Nations Information Governance Committee and the First Nations Centre at NAHO, as well as to Health Canada, regarding future rounds of the RHS. The recommendations derive from the research team's analysis and from interviews conducted for this report.

Recommendations for the 2007/2008 RHS

- ⌘ Identify region and community specific barriers to use of CAPI.
- ⌘ Disseminate findings from the debriefing sessions via a toolkit for participating regions. Evaluate variation in regional community readiness for data collection and analysis and develop a targeted training approach to provide those in need with expanded training programs.
- ⌘ Explore the causes of regional coordinator and fieldworker turnover and possible retention mechanisms. Consider increasing salaries and/or payment of bonuses for exceeding specific data collection targets. Consider assisting fieldworkers in identifying research related positions upon completion of their roles as interviewers for the RHS.
- ⌘ Report don't know and refusal statistics separately and consider the exclusion of survey domains, rather than individuals, from analysis where non-response is great than 10-15%.
- ⌘ Gather demographic information from membership lists to assess possible bias in the selection of respondents within and across communities.

Recommendations to Health Canada

- ⌘ Increase the 2002/2003 RHS budget to reflect the intensive, ongoing collaborations needed with community representative and the need for human resource and infrastructure development at the regional and community levels.
- ⌘ Increase the flexibility of funding arrangements to allow for greater community involvement at all levels of the process.

I. INTRODUCTION

This report summarizes the results of an independent review of the First Nations Regional Longitudinal Health Survey for 2002/2003 (2002/2003 RHS), undertaken for the First Nations Information Governance Committee (FNIGC), a standing committee of the Chiefs Committee on Health (CCOH), and the First Nations Centre (FNC) at the National Aboriginal Health Organization (NAHO). The FNC at NAHO was mandated by the Chief's Committee on Health and the First Nations Information Governance Committee to coordinate and act as data steward for the 2002/2003 RHS.

The purpose of this Review was to assess the quality of the research design and the consistency of the research process with the principles of First Nations' ownership, control, access and possession of research (commonly known as the "OCAP³ principles").

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- Possession is the mechanism by which ownership can be asserted and protected.⁴

Key research questions, the review framework and review measures are described in the methods section below.

I.A. Motivation for the 2002/2003 RHS

The purpose of the RHS is to support First Nations research capacity and control and provide scientifically and culturally validated information to support decision-making, planning, programming and advocacy with the ultimate goal of improving First Nations health.
-The People's Report

Indigenous communities in Canada have disproportionately high rates of disease, disability, and premature mortality.^{5,6,7,8,9,10,11,12,13,14,15} The reasons for these disparities between First Nations

³ Schnarch, B. "Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research." Journal of Aboriginal Health, January 2004.

⁴ First Nations Regional Longitudinal Health Survey. Code of Research Ethics. Adopted July 25, 1997, Revised January 27, 2004.

⁵ Enarson DA, Gryzbowski S. "Incidence of active tuberculosis in the Native population of Canada." Canadian Medical Association Journal 134 (1986): 1149-1152.

⁶ Hammond GW, Rutherford BE, Malazdrewicz R, MacFarlane N.. "Haemophilus influenzae meningitis in Manitoba and the Keewatin District, NWT: Potential for mass vaccination." Canadian Medical Association Journal 139 (1988): 743-747.

⁷ Young TK. "Prevalence and correlates of hypertension in a Subarctic Indian population." Preventive Medicine 20 (1991): 474-485.

men and women and the overall Canadian population may be related to any number of factors, including (among others) access to care, a long history of oppression, abuse and neglect, genetics, quality of care, the legacy of residential school and other environmental, cultural, historical, and epidemiological risk factors.^{16,17,18,19}

The complex relationships among politics, history, culture and health has generated increasing interest in Indigenous views of health and in culturally based treatment approaches.²⁰ Similarly, disparities in Indigenous health in Canada and around the world have prompted calls for greater involvement of Indigenous peoples in health research.²¹ In Canada, control over the collection, analysis and dissemination of health statistics has remained primarily in the hands of the Canadian government and university based researchers, which in the past led to the exclusion of First Nations and Metis from three major national longitudinal surveys.²² A consequence of the exclusion of Indigenous peoples from the research process is the loss of an Indigenous

⁸ Canada. Ministry of Supply and Services. Looking Forward, Looking Back: Report of the Royal Commission on Aboriginal Peoples Volume 1. Ottawa: 1996.

⁹ Canada. Basic Departmental Data. Department of Indian Affairs and Northern Development. Ottawa: 1998).

¹⁰ Mao Y, Moloughney BW, Semenciw R, Morrison H. "Indian reserve and registered mortality in Canada." Canadian Journal of Public Health 83 (1992): 350-353.

¹¹ Evers S, McCracken E, Antone I, Deagle G. "The prevalence of diabetes in Indian and Caucasians living in southwestern Ontario." Canadian Journal of Public Health 78.4 (1987): 240-243.

¹² Young TK, McIntyre LL, Dooley J, Rodriguez J. "Epidemiologic features of diabetes mellitus among Indians in northwestern Ontario and northeastern Manitoba." Canadian Medical Association Journal 132.7 (1985): 793-797.

¹³ Ng E. "Disability among Canada's Aboriginal Peoples in 1991." Health Reports 8.1 (1996): 25-32.

¹⁴ Young TK, Reading J, Elias B, O'Neil JD. "Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress." Canadian Medical Association Journal 163.5 (2000): 561-566.

¹⁵ Marrett LD, Chaudhry M. "Cancer incidence and mortality in Ontario First Nations, 1968-1991". Cancer Causes and Control 14 (2003): 259-268.

¹⁶ Rock M. "Sweet blood and social suffering: Rethinking cause-effect relationships in diabetes, distress, and duress." Medical Anthropology 22 (2003): 131-174.

¹⁷ Waldram JB, Herring DA, Young TK. "Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives." Toronto: University of Toronto Press, 1995.

¹⁸ Young TK. "Sociocultural and behavioral determinants of obesity among Inuit in the central Canadian Arctic." Soc. Sci. Med. 43 (1996): 1665-1671.

¹⁹ MacMillan HL, MacMillan AB, Offord DR, Dingle JL. "Aboriginal health." Canadian Medical Association Journal 155 (1996): 1569-1578.

²⁰ Brady M. Culture in treatment, culture as treatment. "A critical appraisal of developments in addictions programs for indigenous North Americans and Australians." Soc. Sci. Med. (1995):1487-1498.

²¹ Cunningham C, Reading J, Eades S. "Health research and indigenous health." BMJ 327 (2003): 445-447.

²² O'Neil J, Commanda L. "Determining the feasibility of the Canadian First Nations and Inuit regional longitudinal health surveys." International Journal of Circumpolar Health 57.1 (1998): 611-616.

perspective on the health and well-being and lack of disaggregated, community-level data for health planning and assessment.²³

I.B. 2002/2003 RHS Mission and Organizational Structure²⁴

The first, RHS was created and implemented in 1997. While intended to be longitudinal, variations in data collection and sampling at the regional level limited the use of this survey for longitudinal purposes. The particular focus of the 2002/2003 RHS was to collect baseline data, enhance First Nations' research capacity and infrastructure, and generate community knowledge from First Nations' own perspective. Through subsequent rounds, goals of the 2002/2003 RHS include: improving knowledge of community needs; improving knowledge of services provided within First Nations communities; and improving overall individual and community well-being through the study of associated factors, underlying causal relationships, motivations for specific behaviors and how changes over time influence health and wellness. The 2002/2003 RHS is grounded in a First Nations cultural framework.²⁵

The 2002/2003 RHS organizational structure consists of multiple First Nations organizations that committed to facilitating the RHS process. The FNIGC was charged with oversight of the project including ensuring accountability for the process and its consistency with OCAP principles, ethics and respect for persons and communities. At the national level, the 2002/2003 RHS was coordinated through the FNC at NAHO. Additional oversight was provided by the 10 regional partners that also were in charge of implementing the survey at the community level with the help of designated regional coordinators.

The major responsibilities of the regional coordinators included coordinating the data collection of the RHS as well as any other regional level initiatives related to data collection. Specific tasks included recruiting, training and supervising fieldworkers, ensuring data quality and privacy protections, participating in national meetings with other regional coordinators, facilitating the flow of information from the national office to the region and the participating communities and participating in the final report among other tasks. The fieldworkers were community members, recruited by regional coordinators and/or other members of the community. Their tasks included recruiting individuals to participate in the RHS via consent forms and conducting the interviews. No recruitment of individual participants could take place without the expressed consent of the community leadership (i.e., based on Band or Council resolution).²⁶

²³ Casellano MB. "Updating Aboriginal traditions of knowledge." Indigenous Knowledges in Global Contexts: Multiple Readings of Our World. Ed. GJ Sefa, Hall B, Gosenberg DG. Toronto: University of Toronto Press, 2000: 21-36.

²⁴ Unless otherwise stated, all information on the structure, purpose and processes of the 2002/2003 RHS were obtained from information provided in the Report on Process and Methods provided by the First Nations Centre at the National Aboriginal Health Organization.

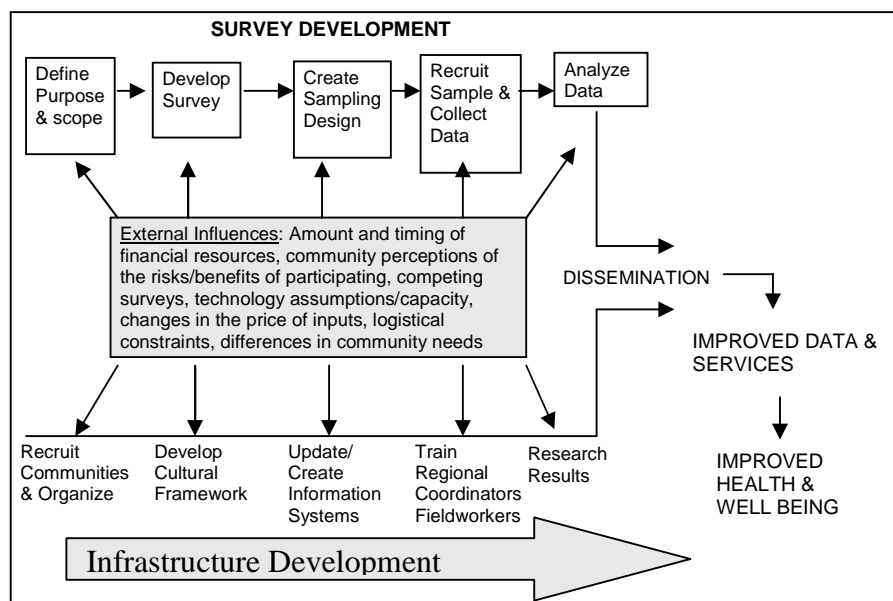
²⁵ First Nations Centre at the National Aboriginal Health Organization. First Nations Regional Longitudinal Health Survey (RHS) 2002/03: The People's Report. Pgs. 7-12.

²⁶ First Nations Centre at the National Aboriginal Health Organization. Data Protection and Stewardship Protocol (Schedule C).

I.C. 2002/2003 RHS Process

Figure 1 describes the logic model for the 2002/2003 RHS.²⁷ The logic model presents the simultaneous development of the survey and the infrastructure for the 2002/2003 RHS. It emphasizes the wide variety of external factors that influenced these development processes. Resulting outcomes of the process include improved data, community-level infrastructure, services, and health and well-being.

Figure 1: Logic Model



In addition to the tasks related to survey implementation (e.g., design, recruitment, data collection, data analysis), the survey process included evaluation activities at various stages of development that were facilitated by outside consultants. One example is the Privacy Impact Assessment, an external review designed to identify risks to participants prior to data collection.²⁸ Another example is the “Lessons Learned” exercise that took place in Ottawa on March 2nd and 3rd of 2004. Participants included past and present regional coordinators, data collectors and analysts among others.²⁹ Regional coordinators were also asked to evaluate their training opportunities in relation to the RHS.^{30,31,32} This report presents the findings of an

²⁷ The People’s Report, page 12.

²⁸ Flaherty DH. A Privacy Impact Assessment of the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS). Prepared for the First Nations Centre, National Aboriginal Health Organization (NAHO), September 3, 2002.

²⁹ Powless RC. First Nations Regional Longitudinal Health Survey: Lessons Learned Report. Prepared for Jane Gray, National Coordinator, First Nations Regional Longitudinal Health Survey, March 2004.

³⁰ First Nation Centre at the National Aboriginal Health Organization. Overview and Evaluation of the National Training Sessions for the FNLRHS, 2002-03, May 9, 2003.

independent review of the 2002/2003 RHS process with respect to methods and the consistency of the process with First Nations principles of OCAP.

³¹ First Nations Centre at the National Aboriginal Health Organization. RHS Data Analysis Training: Evaluation Report. Aylmer, Quebec. January 24-26, 2003.

³² First Nations Centre at the National Aboriginal Health Organization. RHS Data Analysis and Media Training: Evaluation Report. Ottawa, Ontario. November 16-18, 2004.

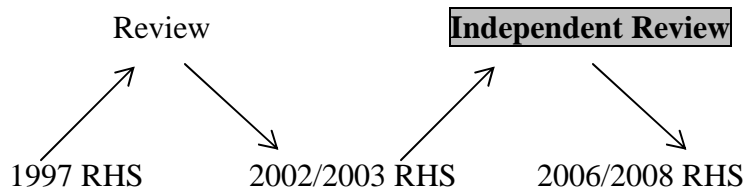
II. METHODS

The purpose of this review was to examine the effectiveness of the processes and methodologies put in place to collect, analyze and disseminate data from the 2002/2003 RHS, and to identify areas for improvement. The project addressed the following research questions:

1. Are the overall research design, data collection processes, and analytic plan consistent with established survey research principles?
2. Are the overall research design, data collection processes, analytic plan, reporting and dissemination of study findings consistent with the principles of self-determination?
3. What factors supported or hindered the execution of the 2002/2003 RHS?

This independent review of the 2002/2003 RHS aims to contribute to the ongoing RHS process by identifying factors that influenced (positively or negatively) the implementation of the survey, so that future cycles can be further improved and the benefits of the survey maximized for the communities involved. This review provides an external lens through which to assess progress, identify strengths and areas of future consideration. The figure below describes the role of the review in the 2002/2003 RHS life cycle.

Figure 2: Role of the Review in the 2002/2003 RHS Implementation Process



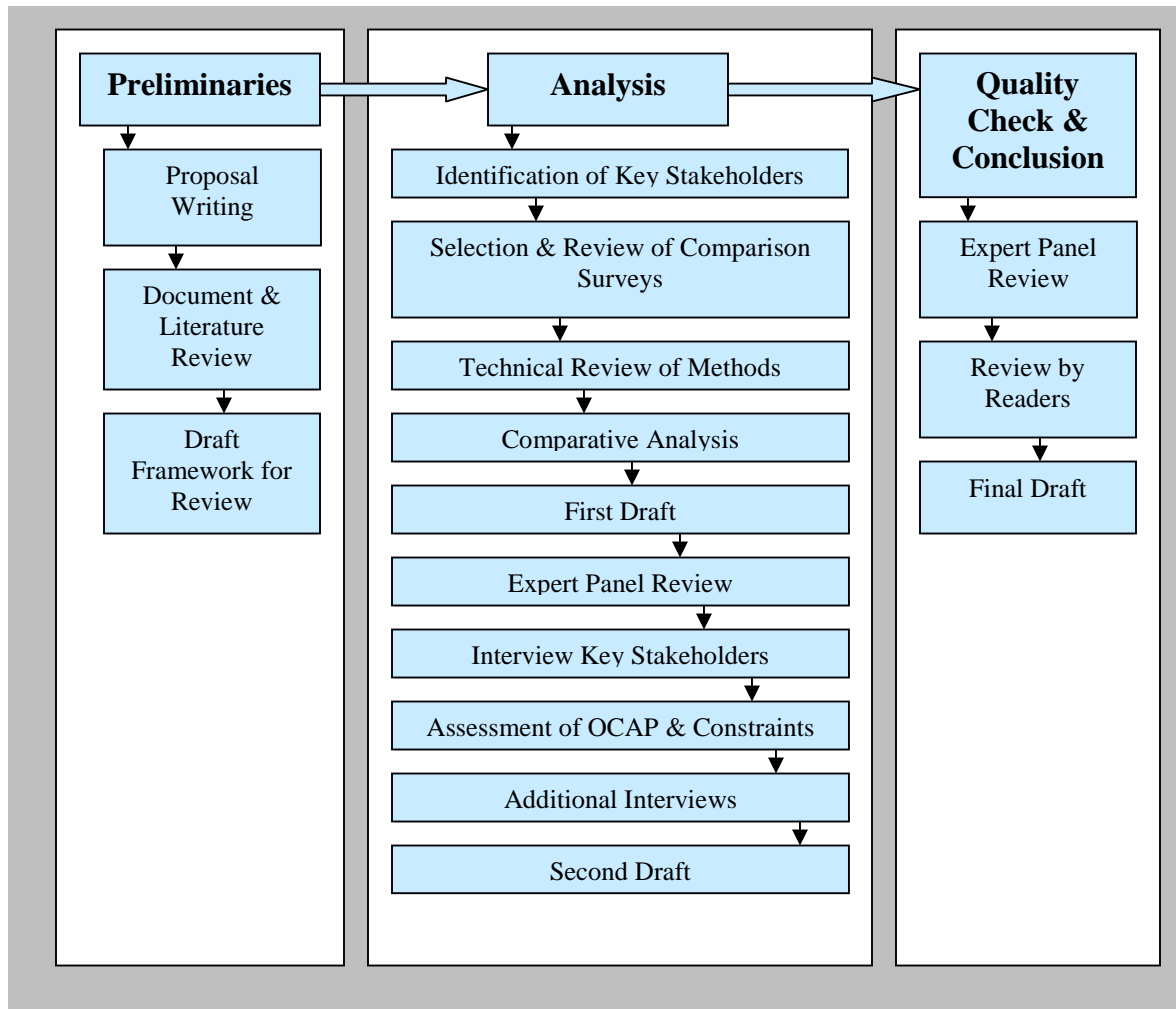
The specific activities of the review are described in Figure 3; they include document and literature reviews, a technical review of the 2002/2003 RHS methodology, and in-depth interviews with key stakeholders. A list of documents reviewed is included in Appendix 1. Appendix 7 provides a detailed description of the search terms, criteria and data collected from the comparison surveys. Copious and extensive documentation relevant to the implementation process were provided to the Review Team by the RHS national team at First Nations Centre at NAHO.

The RHS was examined for both technical validity and consistency with First Nations' principles of OCAP. Technical validity, defined as the level of consistency with previously validated survey research practices, given resource and other constraints, was assessed through a document review, including the Process and Methods Report,³³ interviews with 2002/2003 RHS Regional Coordinators and FNIGC staff, personal communications with Jane Gray and Brian Schnarch, and a comparison of the 2002/2003 RHS to other national surveys of Indigenous populations. Regional Coordinators and FNIGC staff were asked to complete an online survey. Several respondents also participated in telephone interviews with research staff about their experience with the 2002/2003 RHS.

³³ Report on Process and Methods (Draft 7). November 4, 2005.

Consistency of the 2002/2003 RHS process with OCAP principles was assessed through community interviews (i.e., regional and community health directors) and a review of documents. Finally, the research team assessed the presence of external factors that positively or negatively influenced the 2002/2003 RHS process. Sources of information for this analysis included in-depth interviews with key stakeholders and document review. It is important to note the commitment to full disclosure of the FNIGC and the First Nations Centre at NAHO their willingness to provide extensive internal documentation for the 2002/2003 RHS to the review team.

Figure 3: Activities of the Review



The goal of the comparative component of the review was to examine the 2002/2003 RHS in relation to previously identified similar surveys to compare strategies to address common challenges such as identification of Indigenous populations, interviewing, and the collection of data for both national and regional analysis. Where possible, we used several quantitative

measures (e.g., response rate) to assess survey quality. We also examined the specific questions included in the surveys where information was available.

It is important to note that the purpose, scope, resources and population of these surveys varied considerably. Therefore, a head to head comparison to determine which methods were best was not appropriate. Instead, we used the comparison surveys as a way to identify common challenges, commonalities and variations in how these challenges were addressed and opportunities for mutual learning.

We conducted a review of both published and unpublished sources to identify relevant surveys for comparison. Details of this process are included in Appendix 7. The following surveys were identified for inclusion in the comparative review: the 2001 Aboriginal Peoples Survey (APS) in Canada, the 1987 Survey of American Indians and Alaska Natives (NMES) in the United States, and the 2004/2005 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) in Australia. In addition, we also examined national surveys with sufficient Indigenous participation for analysis including the 2003 US National Health Insurance Survey and the 2003 Behavior Risk Factor Surveillance Survey, as well as the 2002/2003 New Zealand Health Survey. Other surveys were identified (e.g., Canadian Incidence Study on Reported Child Abuse and Neglect) but were excluded based on the range of topics covered or because they were regional rather than national in scope. Their exclusion from this analysis is in no way a reflection of their importance to First Nations or Indigenous communities more generally.

The following describes the number of people from different stakeholder groups who were contacted and, among those, the number who agreed to participate.

Table 1: List of Contacts for In-Depth Interviews

Stakeholder Group	Number Contacted	Number Interviewed
Community Health Directors	2	2
Regional Health Directors	6	3
Regional Coordinators	13	7
FNIGC/RHS Staff	15	8
Statistics Canada	3	3
Health Canada	2	2

As a check on the quality of the Review process and our interpretation of key findings, we convened a sounding board of experts in First Nations issues on the national, regional and local level to help us understand the contexts within which the 2002/2003 RHS was implemented. In addition, we convened an expert panel, composed of survey research methodologists to provide feedback on our methods and presentation of the technical aspects of the report. We presented our methods and preliminary findings to a variety of audiences to gain additional insight and feedback into our review process and interpretation of the findings. A full list of individuals and group who provided feedback on this review is included in Appendix 2.

There are limitations of this review that deserve consideration. Due to the timing of the review, the analytic, dissemination and report writing phases of the 2002/2003 RHS were ongoing during the review process. As a result, intermediate and long term outcomes of the 2002/2003 RHS

could not be fully assessed. However, the review focuses on project activities that are likely to affect outcomes in the future, including information infrastructure development and community capacity building. Based on an agreement between the funders and the research team, this report will not include a financial assessment of the 2002/2003 RHS. Nonetheless, some discussion of funding and the timing of funding will be included, as it is relevant to issues of survey development and implementation, and as reported in the qualitative responses from key stakeholders.

Ideally, the Review team would have examined differences between respondents and non-respondents to assess whether participants in the 2002/2003 RHS were representative of FN community members. Unfortunately, baseline data on non-respondents were not collected by fieldworkers due to lack of resources. While comparisons of the respondent sample to Census data were conducted by Brian Schnarch at the request of the Review team, the expert panel advised us against the inclusion of these analyses because differences in the way these two samples were selected made them inherently incomparable.

We did not reach our goals for in depth interviews with a number of key stakeholder groups. In some cases, people may have been unclear about the role of the review team. In addition, we were unable to conduct interviews in-person due to the vast geographic spread of the target population, as well as limited time and resources. We suspect that some of the interviews may have been more fruitful had in-person visits been feasible. Where possible, the research team called particular individuals or made in-person visits to enhance our understanding of key issues identified through the review process.

Individuals who chose to participate in the in-depth interviews (whether via the web, phone or in-person) obviously do not represent all First Nations voices and they tend to reflect a select group of highly interested individuals. Therefore, the voices of important constituents or future users of the 2002/2003 RHS may not be adequately represented in this report. Further, we restricted our community survey to individuals directly involved in health care services or planning. However, other providers (e.g., educators) may also have a direct interest in the 2002/2003 RHS and data produced by the survey. Their important perspective is not captured.

FINDINGS

REVIEW OF THE 2002/2003 RHS

This portion of the report has been divided into three key sections: A) Sampling Design, B) Data Collection, and C) Data Analysis and Dissemination. For each section, we provide a brief overview of the topics to be discussed, a technical assessment, a discussion of the consistency of the activities with OCAP, and comparative perspectives in Indigenous health survey research. We approached the technical assessment through a review previously validated and accepted indicators of survey quality (e.g., as response rates). Our assessment of OCAP relied on in depth interviews and a review of documentation provided by the 2002/2003 RHS national team at the First Nations Centre at NAHO. While the assessment of technical validity and OCAP are presented separately in this analysis, it is important to note that they are interdependent. For example, the technical validity of a survey would be threatened by the failure of the questionnaire design to reflect culturally relevant experiences and to use accessible and appropriate language, both of which are enhanced when the community being studied is in control of the questionnaire design process.

In summary, the Review team was impressed with the overall quality of the 2002/2003 RHS, its consistency with previously validated survey research practices, and its innovativeness with respect to the involvement of First Nations communities and their representatives in the research process. The 2002/2003 RHS used information gained from the first round of data collection (1997 RHS) to develop more refined methodology and protocols. Compared to comparable surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process. All of this was accomplished under considerable budget constraints.

The following provides a brief synopsis of our findings with respects to sampling design, data collection, and data analysis and dissemination. We begin our review with an assessment of the 2002/2003 RHS sampling design.

III. SAMPLING DESIGN

III.A. Overview

The 2002/2003 RHS is designed as a longitudinal survey, with cycles every four years. The sampling design reflects the need for cross-sectional and longitudinal coverage in each region, as well as the need for a nationally representative sample. The validity and reliability of the sampling methods chosen by FNIGC for the 2002/2003 RHS affect the strength of survey findings and the interpretation of results. They also affect the comparability of findings between First Nations and other Indigenous (First Nations, Inuit, and Métis) and non-Indigenous communities across Canada and beyond. While there is no uniform quality standard that must be reached by every sample, sample quality is particularly important for large-scale continuing studies that may be used to gather new information on special populations (such as Indigenous peoples) and for policy formulation. Table 1 describes the sampling design quality indicators that were both applicable to and available for the assessment of 2002/2003 RHS processes, as well as the comparative analysis.

Table 2 Sampling Design Quality Indicators

Quality Indicators	Available Information	
	2002/2003 RHS	Comparative Analysis
Technical Validity		
Selection of the Target Population	✓	✓
Target vs. Achieved Sample Size	✓	✓
General Sampling Scheme	✓	✓
Selection of Respondents	✓	✓
Identification of Indigenous Populations (where applicable)	✓	✓
Participation Rate	✓	✓
Sampling Error	✓	NA ³⁴
Cultural Validity		
Ownership	✓	✓
Control	✓	✓
Access	NA	NA
Possession	NA	NA

III.B. Technical Assessment

The 2002/2003 RHS was designed to provide estimates of individual behavior, health status, access to care, health services utilization and other indicators of health and well-being for First Nations communities. The degree of sampling error^{35,36,37} in the 2002/2003 RHS was influenced by the following factors:

³⁴ NA indicates that the measure is either not applicable to the particular section or that there was insufficient information for assessment.

³⁵ Frankel MR, Frankel LR. "Fifty Years of Survey Sampling in the United States." *The Public Opinion Quarterly* 51.2 Supplement:S127-S138 (1987).

- Identification and selection of a target population
- Differences between target sample size and achieved sample size
- Sampling scheme
- Respondent selection

III.B.1. Identification and Selection of Target Population

The 2002/2003 RHS target population was defined as First Nations (excluding Métis and Inuit) people living on-reserve within First Nations communities in 10 provinces and 2 territories. Labrador Inuit withdrew in favor of an Inuit process of data collection. Sampling targets were based on information contained in the 1999 (projected to 2001) Indian Register of First Nations people living on-reserve or on Crown land. A large number of First Nations people were excluded from the survey because they live off-reserve. A few (15) communities included people living off-reserve temporarily or who lived nearby and used on-reserve services. Lack of funding is cited as the primary barrier to inclusion of off-reserve communities in the 2002/2003 RHS.³⁸

Data in the Indian Register came directly from local vital statistics information and was used to project 2001 estimates for the populations of interest. The reliability of the Indian Register varied by locality, field surveys revealed wide discrepancies in the estimates of age and gender subgroups.

First Nations people with a possibility of being selected for inclusion in the 2002/2003 RHS (i.e., the sampling frame) were identified through First Nation Membership Lists of those living on-reserve or on Crown land.³⁹ The “membership list approach” was used by some regions in the 1997 RHS.^{40,41} After much consideration, the FNIGC selected this approach as a national strategy for 2002/2003. Strengths of this approach are that it produces a sampling frame that is statistically sound and, if the data come from the local or First Nation level, they are community-validated and respect the community’s right to control and define its own membership.⁴² In addition to community-level information, data sources for community membership lists may include national, regional, province/territory, or First Nation level registration systems. Other

³⁶ Korn EL, Graubard BI. “Analysis of Large Health Surveys: Accounting for Sampling Design.” Journal of the Royal Statistical Society 158.2 (1995): 263-295.

³⁷ Groves RM. “Research on Survey Data Quality.” The Public Opinion Quarterly 51.2 Supplement:S156-S172. (1987).

³⁸ Resources permitting, an off-reserve component of the survey is planned and pilot programs for off-reserve data collection have been conducted in the Quebec region.

³⁹ Some membership lists may have included ‘non-status’ First Nations people, but many used inclusion and exclusion criterion similar to those in the Indian Register and excluded persons designated as non-status.

⁴⁰ O’Neil JD, et al. FNIRHS Technical Report. September 1998.

⁴¹ O’Neil JD. Process Report. August 1998.

⁴² Norton IM, Manson SM. “Research in American Indian and Alaska Native Communities: Navigating the Cultural Universe of Values and Process.” Journal of Consulting Clinical Psychology 64.5 (1996): 856-60.

sources of data may include benefits systems that employ registry or membership list data to generate eligibility lists.

These lists included the name, current residence status (on-reserve or off-reserve) and the age and sex of each member of the community. The use of membership lists was a deliberate attempt to allow communities to define their members. The 2002/2003 RHS Fieldworker Manual included explicit training for fieldworkers on maintaining the confidentiality of these lists.⁴³ Fieldworkers collaborated with the communities to update the accuracy of the information.

In some areas, membership lists were unavailable, sometimes due to privacy concerns. As an alternative avenue for identifying respondents, the Manitoba region used a household sampling frame. Twelve communities outside Manitoba also adopted household sampling frames.

III.B.2. Sampling Scheme

In the 2002/2003 RHS, procedures were standardized for the development of community sampling frames and random selection of individuals within age/gender groups, where individuals were identified via First Nations membership lists. The sampling plan was a key unifying component across regions and was overseen by the FNIGC and implemented by the 2002/2003 RHS Regional Coordinators and community fieldworkers. This sampling scheme was in direct response to problems that arose in the 1997 RHS when regional differences in sampling schemes resulted in variation in data quality at the local, regional and national levels.⁴⁴

The sampling scheme was a stratified, two-stage sample with strata defined as community groups within sub-regions, and the two stages of sampling as communities within strata and individuals within selected communities. To increase the likelihood that the sample would be representative of the communities of interest, strata were defined for each sub-region by population size (communities with population less than 300 were designated as “small,” communities of 300-1499 as “medium,” and communities of 1500 or more as “large”). All communities with populations greater than 1500 were invited to participate (“take all” stratum). “Small” and “medium” sized communities were sorted by sub-region and a predetermined number of communities from each of these strata were selected for individual-level sampling. A minimum of 25 people from each community was established for efficiency reasons.

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 to maximize community representation. Communities with populations less than 75 (11% of communities) were excluded from participation both because of cost (benefits relative to the cost of implementation would be low) and privacy concerns (in small communities there is the risk that individuals could be linked to their responses).

⁴³ First Nations Centre. National Aboriginal Health Organization (NAHO). RHS Fieldworker Manual. July 2002.

⁴⁴ First Nations and Inuit Regional Health Survey. First Nations and Inuit Regional Health Survey National Steering Committee, 1999, Appendix 2-Technical Report, pp. A34-A44.

Community perspectives:

*“RHS is a prime example of First Nations taking control of their own data.”
(Community Health Director)*

To increase the likelihood that individuals within each community were representative of their communities in terms of age and gender, people were randomly selected within strata. Adults older than age 55 were over-sampled because 2002/2003 RHS implementers were interested in learning about the experiences of Elders in these

communities.

III.B.3. Achieved Sample Size

The 2002/2003 RHS sampling plan set a target sample size of 28,178 responses from First Nations individuals within 273 communities. After 15 months of data collection and processing, a total of 22,178 survey responses from 238 different First Nations communities were available for analysis. 14,008 respondents were included in the 1997 RHS, representing 186 First Nations and 5 Inuit communities.

The final sample represented 80% of the sampling plan’s target sample. There was significant variation in percent-of-target figures by region, community and by age/gender group (see Tables 2 and 3). Also, some communities did not have the required a minimum of 25 respondents (see Report on Process and Methods, Appendix 6).

Table 3: Proportion of Total Sample Achieved, by Region

Region	2002/2003 RHS Proportion of Target Achieved
New Brunswick & Prince Edward Island	40%
Nova Scotia	81%
Newfoundland	60%
Quebec and Labrador	81%
Ontario	64%
Manitoba ⁴⁵	85%
Saskatchewan	98%
Alberta	80%
British Columbia	90%
Yukon	84%
Northwest Territories	66%
Total	80%

Table 4: Proportion of Total Sample Achieved, by Age/Gender Group

⁴⁵ Additional surveys, not reflected in this figure, were collected in the Manitoba region following the end of data collection for the 2002/2003 RHS.

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%

2002/2003 RHS Regional Coordinators from those regions with high recruitment rates attribute their success to consistent communication with both fieldworkers and the participating communities:

Community Perspectives:

“...I picked the most motivated and effective interviewers and worked with them very hard to” meet the region’s data collection goals

“...good communications via e-mail and phone daily and a visit weekly” with fieldworkers

Factors that may have contributed to low proportions of target samples achieved in some regions included fieldworker turnover, which reduced the amount of time fieldworkers could spend in the field and did not allow time for fieldworkers to increase their effectiveness through experience. In addition, some target sample sizes, especially among children and adolescents, may have been unachievable due to the limited number of potential respondents in some communities. These challenges were exacerbated by overestimates of population figures from the Indian Register relative to the membership lists (see further discussion in subsection IV.D, below, “Comparative Perspectives”).

III.B.4. Respondent Selection

The 2002/2003 RHS relied heavily on randomized selection of respondents to reduce the possibility of biased responses due to a highly selected sample of respondents. Respondents were selected randomly within age and sex subgroups. Substitutions for non-respondents were allowed for up to half of the people who failed to respond. These substitutions were selected from the ordered listing, which was randomly generated.

III.B.5. Response Rate

The response rate, the proportion of the selected sample who participated in the survey, is commonly used to assess the quality of survey data. A low response rate increases the likelihood that the survey sample is not representative. The actual amount of bias can be conceptualized as a function of two factors—the amount of non-response, which is measured by a response rate, and the differences between the respondents and the non-respondents.

The 2002/2003 RHS generated 22,602 usable survey responses. A target sample of 28,178 was identified, and the response rate for those potential participants who were approached was 84%. Responses were excluded from analysis based on lack of a corresponding consent form, inadequate consent documentation, or more than 50% non-response. In addition, some respondents began a survey and then later completed a full survey. These “false starts” were excluded from analysis (N=2658). Two regions (Alberta and the Yukon) were not included in the calculation of the response rate because they did not document non-participation and to exclude them would have artificially inflated the overall response rate.

III.B.6. Summary of Technical Quality of the Sampling Design

The 2002/2003 RHS sampling design exhibited several strengths. First, it utilized a two stage stratified sampling design to obtain representative samples and random sampling within age and gender strata to reduce the possibility of selection (i.e., systematic differences in those who were chosen to participate relative to those not chosen). While a federal data source was used to structure the sampling design, community membership lists were used to identify potential individual respondents thereby allowing communities to define their own members. The response rate was 84%, representing 238 First Nations communities.

Limitations of the sampling design included the exclusion of off-reserve communities due to budget constraints and the inability to obtain sufficient samples for community level data. According to the 2001 Canadian Census, this meant that more than 300,000 off-reserve FN people were excluded from participation in the survey. Also, the response rate is calculated as a participation rate (i.e., the number who completed a survey divided by the number who agreed to complete a survey). Response rates are traditionally calculated including all those approached about the survey in the denominator. The following table summarizes our key findings with respect to the technical quality of the sampling design of the 2002/2003 RHS.

Table 5: Summary of Technical Quality of the Sampling Design

Indicators	Strengths	Potential Limitations/Concerns
Target Population	<ul style="list-style-type: none"> • On-reserve • Crown lands 	<ul style="list-style-type: none"> • Exclusion of off-reserve FN⁴⁶ • Communities <75
Sampling	<ul style="list-style-type: none"> • Probability based • Standardization across regions 	
Sample Size	<ul style="list-style-type: none"> • 80% of target • Cross sectional & longitudinal 	<ul style="list-style-type: none"> • Insufficient for some community analysis
Response Rate	<ul style="list-style-type: none"> • 84% 	
Selection	<ul style="list-style-type: none"> • 238 FN communities (30% of all FN communities) 	<ul style="list-style-type: none"> • James Bay Cree & Labrador declined (3%)

⁴⁶ It should be noted that the Quebec regional partner included an off-reserve component in 97 and 2002/2003.

III.C. OCAP Assessment

The long, complex process of collaborative decision making that characterized the 2002/2003 RHS process is the greatest testament to its consistency with the FN principles of ownership and control. While access and possession are equally important aspects of OCAP, they were less applicable to issues of the sampling design because of their focus on data. The participatory research process was inclusive of all regions and was characterized by repeated collaborative cycles of deliberation and decision making, organized by the national and regional 2002/2003 RHS coordinators. The process was designed to maximize opportunities for individual community input into the design of the survey despite the geographic vastness of Canada and limited funds. Several aspects of the sampling design are reflective of this process. We describe a few specific examples of Indigenous ownership and control over sampling design and describe challenges in balancing these principles against the need for consistency in sampling design across communities and regions to facilitate regional and national level data analysis.

III.C.1. Ownership

The principle of collective ownership of data is reflected in the explicit participation of First Nations representatives in the sampling design of the 2002/2003 RHS. Ownership can be exercised by individual communities or by their representatives. Representatives of the communities at the regional and national level were mandated to make decisions that took into account the needs of FN communities. First, the sampling strata (regions, sub-regions) were based on geopolitical groupings of relevance to First Nations communities. In addition, the use of local membership/citizenship lists for the identification of potential respondents valued local definitions of community membership.

Community perspectives:

“RHS has taken a new path, adopting a holistic approach, based on a framework that is inclusive of Aboriginal culture and governance. It signifies a transformative change in the way research has been conducted on and among Aboriginal peoples.”

(RHS Regional Coordinator)

III.C.2. Control

Feedback from the regions on the 1997 RHS implementation process provided a strong foundation for the 2002/2003 sampling design. Regional coordinators, FNIGC and others further developed a universal sampling design to obtain reliable regional and national estimates of First Nations people. In 1997, RHS tried to achieve consistency with the OCAP principles by giving each region control over the design and implementation of sampling scheme. However, this process precluded the creation of a reliable participation rate (estimated to be 80%). Based on this important limitation, the FNIGC, with input from local and regional levels, decided to standardize methods across all regions for the 2002/2003 RHS. Therefore, while communities

did not have control over the specific sampling design used in their region, they were active participants in the process of determining the sampling scheme for the survey overall because of the collaborative development process. Further, some regions added to their sampling targets to increase the potential for community level data analysis. Other regions (e.g., Saskatchewan) included all communities and others included their 1997 RHS samples to assess longitudinal trends in health statistics. However, these designs were created to be supplementary rather than in conflict with to the national sampling design strategy. Additional regional modifications to the sampling plan are reported in the Process and Methods Report (sections 4.7.2.5, 4.7.2.4, and 4.7.2.6).

Other aspects of the sampling scheme were also reflective of Indigenous control. For example, over-sampling of the population over the age of 55 was consistent with Indigenous understanding of the traditional, empirical and revealed knowledge that is transferred to present and future generations by Elders.⁴⁷ Incorporating their voice in 2002/2003 RHS data was a key goal of the sampling scheme.

Control over the sampling design process was facilitated by active, ongoing communications through the regional organizations and workshops conducted at national health conferences. The use of existing infrastructure was an efficient means of including First Nations communities in the development of the sampling design. While some small communities were excluded from the final target sample, most communities had a known chance of being selected. However, if the affected communities did not perceive the regional organization as representative of their views and experiences, there is the potential for some communities to feel alienated from the decision making process. Further, the FNIGC had final determination of the sampling scheme.

III.C.3. Summary of OCAP Principles and Sampling Design

Features of the sampling design that best highlighted the OCAP principles were the use of community membership lists to identify respondents and the ongoing communications with communities regarding the specifications of the sampling design. Interviews with key informants suggest that the budget for the 2002/2003 RHS did not support the intensive ongoing exchanges with community representatives, meaning that some communities were not reached. Further, the reliance on regional and national organizations for decision making enhances the importance that these organizations represent all First Nations communities to ensure accountability of those organizations to the collective.

The following table summarizes our key findings with respect to the cultural validity of the sampling design.

⁴⁷ Brant Catellano M. "Updating Aboriginal Traditions of Knowledge. In: Indigenous Knowledges" *Global Contexts: Multiple Readings of Our World*. Ed. GJ Sefa Dei, BL Hall, Goldin Rosenberg D. Toronto: University of Toronto Press: 2002. 21-36.

Table 6: OCAP Principles and Sampling Design

Indicators	Strengths	Potential Limitations/Concerns
Ownership	Use of community membership lists to identify respondents	
Control	Ongoing communications regarding sampling design specifications Final decisions made at the national level by regional representatives	Standardization may be required to ensure valid response rates and national estimates Regional organizations may not be representative of all communities Final decisions made at the national level by 10 regional representatives

III.D. Comparative Perspectives

Sampling design information was available from all of the selected comparison studies. Due to differences in how sampling error is estimated and reported, we did not compare sampling errors across surveys. All but two of the comparison surveys, NHIS and BRFSS, limited their target populations to Indigenous peoples.

The comparison surveys used two primary methods for identifying Indigenous people for participation in a survey: self-identification (i.e., self-reported identity, membership, origin) and membership lists (i.e., national, regional, or local registries). The NMES used the Indian Health Service user population, which consists of federally recognized tribe members. The APS, New Zealand Health Survey, NATSIHS, NHIS, and BRFSS all used various forms of self-report to identify Indigenous respondents. Data sources for self-identification included household surveys, labor surveys, census data, and other self-reported documentation. While self-reports are more likely to capture off-reserve Indigenous people, they are also prone to error, particularly in large national surveys.⁴⁸

Only one survey, the NATSIHS, achieved 100% of its target sample goal of 11,000 Indigenous people living in private dwellings throughout Australia. Like the 2002/2003 RHS, the APS and NZ Health surveys all had greater than 80% ascertainment of their target sample goals. All of the surveys used multistage, stratified sampling designs and some type of probability sampling to identify possible respondents.

Table 7: Comparison of sampling design factors across surveys

Survey	Target population	Target sample	Actual sample	Sampling scheme	Respondent Selection	Respondent Identification
2002/2003 RHS	FNs living on-reserve or on Crown lands	28,178	22,602	Stratified, 2 stage	Random w/in sex/age strata	Local FN membership lists

⁴⁸ National Research Council. Changing Numbers, Changing Needs: American Indian Demographic and Public Health. Ed. GD Sandefur, RR Rindfuss, B Cohen. Washington, DC.: National Academy Press, 1996.

2001 APS	Aboriginal Canadians: on/off-reserve	117,241	98,649	3 groups, 2 stage stratified	Varied by phase	Self-report on 2001 Census
1987 NMES	IHS user population	13,700	6,500	Multi-stage area probability sample	Probability sample	IHS
2004/2005 NATSHIS	Indigenous Australians	11,000	Approx. 11,000	4 stage	Random, up 2 adults, 2 children per hh	Census, remoteness benchmarks?
2002/2003 NZ Health	NZ adult pop (15+)	12,000 (4000 Maori; 1000 PI)	12,929 (4369 Maori; 910 PI)	Stratified, 2 stage	Random selection	HH Labor Force Survey
2003 NHIS	US civilian population	75,515 hh	35,921 hh 92,148 p	Stratified, 2 stage	Random selection	Self-identification
2003 BRFSS	US adult population	Varies by state	264,684	Phone calls to hh ID by CDC	Probability sample	Self-identification

Table 8: Comparison of Response Rates across Surveys

Survey	Response Rate*	Percent/Number of Indigenous Respondents
2002/2003 RHS	84%	100% of all respondents
2001 APS	84%	100% of all respondents
1987 NMES	73%	NA
2002/2003 NZ Health	72% (~70% for Maori) (~60% for PI)	41% of all respondents 105% of target sample for Maori and PI
2004/2005 NATSHIS	85% (remote areas) 90% (non-remote areas)	100% of all respondents
2003 NHIS	89% of households	1% of all respondents
2003 BRFSS	Median 53% (varies by state)	2% of all respondents

*Because of differences in the calculation of response rates across surveys, response rates for the selected surveys are not directly comparable.

The lowest overall response rate in surveys targeted at Indigenous populations was 73% for the NMES/AIAN, conducted in the U.S. in 1987 (for non-Indigenous targeted populations it was the BRFSS with 53%). The highest response rate was for the Australian survey, which achieved a response rate of 90% in non-remote Aboriginal populations and 85% for remote populations. However, comparison of response rates across surveys was hindered by differences in how these rates were calculated. For example, the reported response rate for the 2001 APS was 84%.

However, the 21 FN reserves and 1 Inuit community (5,455 individuals) that were originally selected but who were not surveyed were not included in this calculation.⁴⁹

Only one of the comparison surveys (2001 APS) provided information about the participation of Indigenous people in the development of the survey. The methods report of the APS states that through a consultative process, several Indigenous organizations (the Native Women's Association of Canada, the National Association of Friendship Centres, the Inuit Tapiriit Kanatami, the Congress of Aboriginal Peoples, and the Metis National Council) were involved in the development of the survey. Specific activities included the creation of a committee with an Indigenous representative majority that made decisions regarding the process of survey content and dissemination for the APS. However, it is important to note that only 123 First Nations communities participated in the APS and many communities represented by the Assembly of First Nations refused to participate in this process. After a long process of negotiation between Statistics Canada and the Assembly of First Nations, AFN passed a resolution reaffirming its commitment to support data collection that is consistent with the principles of OCAP and highlighting the limitations of the APS in this respect.^{50,51,52}

While the identified surveys served quite diverse populations, they shared similar goals in collecting information from often exploited and underserved populations. Further, they faced similar challenges in obtaining community level data in a national survey. The 2002/2003 RHS stands out among these surveys for its direct, explicit and documented involvement of First Nations communities in the development of the sampling design. It was also the only survey which used community membership lists to define the sampling frame. However, the exceptionally high response rate for the Australian survey suggests an opportunity for mutual learning between the Australian Bureau of Statistics and the staff of the 2002/2003 RHS. Still, reports of high (>95%) from other surveys of Indigenous communities suggests that there may be cultural differences in the acceptance of research in Australian Indigenous communities, making them somewhat less comparable to First Nations.⁵³

⁴⁹ Statistics Canada. Aboriginal Peoples Survey 2001: Concepts and methods guide. September 2003.

⁵⁰ Assembly of First Nations. Resolution No. 9: Aboriginal People's Survey II and First Nations and Inuit Longitudinal Health Survey Process, Confederacy of Nations, April 12-14, 1999, Ottawa, ON.

⁵¹ Assembly of First Nations. Resolution No. 72: First Nations and the Aboriginal People's Survey II, Confederacy of Nations, December 13-14, 2000, Ottawa, ON.

⁵² Assembly of First Nations. Resolution No. 32: Support for the First Nations Regional Longitudinal Health Survey (RHS) and First Nations Jurisdiction in Information and Research, Annual General Assembly, July 20-22, 2004, Charlottetown, PEI.

⁵³ Valery PC, Chang AB, Shibasaki S, Gibson O, Purdie DM, Shannon C, Masters IB. "High prevalence of asthma in five remote indigenous communities in Australia." European Respiratory Journal 17 (2001): 1089-1096.

IV. DATA COLLECTION

IV.A. Overview

The selection and implementation of the data collection strategy had direct impacts on the quality of the data collected and the capacity of the 2002/2003 RHS to meet OCAP standards. Assessment of the data collection process for the 2002/2003 RHS provides one of the first opportunities to assess the applicability of computer assisted personal interviewing (CAPI) in First Nations communities on a large scale. In the following paragraphs, we will describe various aspects of the data collection process and examine their likely impact on data quality and OCAP. The following paragraph describes the specific quality indicators we considered for the review of the data collection phase of 2002/2003 RHS.

Community perspectives:

*“I think success in this survey was the trust
between the respondents and the fieldworkers.”*

(FNIGC Member)

Table 9: Data Collection Quality Indicators

Quality Indicators	Available Information	
	2002/2003 RHS	Comparative Analysis
Technical		
Informed Consent	✓	✓
Mode of Data Collection	✓	✓
Questionnaire Design	✓	✓
Data Quality	✓	NA
OCAP		
Ownership	✓	✓
Control	✓	✓
Access	✓	✓
Possession	✓	✓

IV.B. Technical Assessment

IV.B.1. Informed Consent

The process of recruiting participants to the 2002/2003 RHS occurred in two stages: community recruitment and recruitment of respondents. The process of selecting communities for inclusion in the 2002/2003 RHS is described in the sampling scheme section above. Individuals were recruited to participate in the survey by community interviewers (i.e., fieldworkers), all of whom signed an Oath of Secrecy to protect individual privacy and personal information and who completed training sessions provided by the regional coordinators or other community representatives. The fieldworkers training manual⁵⁴ included explicit instructions on how to recruit respondents for the 2002/2003 RHS. The process of clarifying and correcting consent documentation occurred through ongoing communication between the national office, regional coordinators and community representatives.

Several steps were taken within the 2002/2003 RHS to maximize participation, while protecting the respondents' confidentiality, privacy and rights. First, due to community concerns about privacy and confidentiality, consent was obtained using paper forms rather than computer-based (electronic) forms. The consent form identified the organizations involved in the 2002/2003 RHS and described the purpose of the study including topics to be covered, how the data would be used, measures taken to ensure confidentiality of responses, and the voluntary nature of the 2002/2003 RHS. The consent forms also provided assurances that refusal to participate would not affect an individual's health care or other services and that the individual could withdraw from the study at any time.

The information contained in the consent form was read to participants and provided to them in paper format. As assurance that the participant read the document, the participant was asked to initial each page of information. The form then provided opportunities for the respondent to indicate 1) consent to participate, 2) willingness to be contacted for future rounds of the survey, and 3) willingness to provide contact information for someone who could locate the participant in case of a future move or change telephone numbers. The documentation was less clear on the

⁵⁴ Fieldworker Manual, July 2002.

process of renewing consent over time. As consent is an active and ongoing process, reaffirmation of the respondent's right to disengage from the survey process or not to answer any question must be reviewed throughout the data collection process. Further, such rights must be reaffirmed during subsequent rounds of data collection.

Copies of all forms in English or French were provided to the participant, and the interviewer completed the participant log, which records information on the individuals' personal information and contact information forms. Surveys were not translated into FN languages due to funding limitations.⁵⁵ To ensure quality of the consent process and to allow for past respondents to be contacted for future rounds of the 2002/2003 RHS, consent forms were linkable to individual respondents.⁵⁶ This linkage allowed the 2002/2003 RHS team to identify problems in the consent form process including surveys with no consent forms (624 surveys were discarded for this reason), no written record of consent and other problems. The 2002/2003 RHS staff attributed these problems to the length and complexity of the consent form, as well as confusion with an unrelated consent form concerning changes in a Health Canada policy that affected First Nations. This was particularly true in Quebec, where recruitment of the 2002/2003 RHS and discussion of the related Health Canada policy overlapped.

In accordance with the 2002/2003 RHS Code of Research Ethics, the 2002/2003 RHS staff deemed some unsigned consent forms analyzable if there was adequate documentation by the fieldworker of verbal consent. Most institutional review boards would find this an acceptable standard of practice as long as participants can drop out of the survey process at any time⁵⁷ and the method is clearly stated in the consent information for the 2002/2003 RHS. This decision affected approximately 400 surveys, which were primarily from Quebec. In about 30 cases, the 2002/2003 RHS also allowed consent from one family member to apply to the entire household, which primarily affected respondents in Saskatchewan. While this practice may be consistent with cultural norms in Saskatchewan, the implications for individual confidentiality and rights is unclear. Because the information packet assures that the respondent can refuse to answer any question, these concerns may be reduced.

Through the consent process, the fieldworkers acted as guides through which community members could be introduced to the 2002/2003 process. Specifically, they began building relationships and trust with these communities, an arduous task given years of exploitation of these communities by outside researchers. The value of hiring of community members to conduct interviews is becoming clear to researchers around the world as they embark on community-based participatory research.⁵⁸ The uniqueness of the 2002/2003 RHS is in the integration of community perspectives at the survey design, implementation, analysis and dissemination processes.

⁵⁵ Brian Schnarch, Personal communication, March 16, 2006.

⁵⁶ This process may have left data vulnerable to disclosure through subpoena by a court of law. More information is needed on the implications of this decision.

⁵⁷ Fowler, Jr., FJ. Survey Research Methods, 3rd ed. Applied Social Research Methods Series, V 1. Thousand Oaks: Sage Publications, 2002.

⁵⁸ RTI International. Community-based participatory research: Assessing the Evidence. Agency for Healthcare Quality and Research, US Department of Health and Human Services, Pub. No. 04-E022-2, July 2004.

IV.B.2. Mode of Data Collection

The 2002/2003 RHS was administered using computer assisted personal interviewing (CAPI) in which information from the respondent is entered directly into a computer by the interviewer and/or the respondent,⁵⁹ Adults responded directly to the interviewer and youth surveys were self-administered. Proxies, usually their mothers, were used for the child survey. CAPI was conducted using a laptop computer and an interactive software program designed to guide the interview process. Data entered on the laptop were then transferred electronically via telephone to a central data storage unit, eliminating the need for the time consuming (and often error ridden) task of post interview data entry.

CAPI is especially appropriate for complex, longitudinal surveys like the 2002/2003 RHS and has become the data collection method of choice in comparable domains. Therefore, use of CAPI in the 2002/2003 RHS improved the quality of data collection compared to the 1997 RHS through automation of the data collection, entry and editing processes, all of which led to greater consistency across regions in the reliability and validity of data. While adults generally responded to questions asked by the fieldworker, who would then record the responses using the laptop, sometimes adults would choose to complete the survey themselves with the fieldworker observing from a distance. At times, this procedure was undertaken for specific, sensitive questions while others the entire interview was conducted in this way. In cases where a laptop was either unavailable or not working, paper surveys were used.

The success of CAPI was enhanced by the intense training sessions offered to the regional coordinators. Among those we interviewed, three reported having had prior experience with health related programs. Those who attended the train the trainer sessions provided by the 2002/2003 RHS national office said they were very satisfied with the quality of the training sessions and written materials, as well as with the explanation of the design of the 2002/2003 RHS. Two of the seven regional coordinators who participated in depth interviews reported that they did not attend the training sessions at the national office, indicating that they were hired later in the data collection process. Only one reported that they were not in charge of hiring fieldworkers and did not receive manuals pertinent to fieldworker training. Training and recruitment strategies sometimes included members of the Regional Advisory committees and other community representatives.

Information we received from in depth interviews confirmed findings of high rates of turnover of regional coordinators and fieldworkers reported in the 2002/2003 RHS Process and Methods Report and in the Lessons Learned exercise. Reasons for high fieldworker turnover included the temporary and part time nature of the positions, low pay rates, not tying payment to performance, and the length of the data collection process.⁶⁰

⁵⁹ Bradburn NM, Frankel MR, Baker RP, Pergamit MR. "A comparison of computer-assisted personal interviews (CAPI) with paper-and-pencil (PAPI) interviews in the National Longitudinal Study of Youth." Prepared for presentation at the annual meeting of the American Association for Public Opinion research, Phoenix, Arizona, May 16-19, 1991.

⁶⁰ Powless RC. Lessons Learned Report. March 2004.

The limitations of having only one regional coordinator with limited resources in each region were also noted by the regional coordinators. In spite of these challenges, regional coordinators reported that intensive, ongoing communications with the fieldworkers resulted in higher response rates. In addition, regional coordinators demonstrated innovation and autonomy in the field in order to increase their response rates. For example, regional coordinators and fieldworkers considered the comfort level of respondents with CAPI in determining whether paper-based or CAPI-based surveys should be administered. Further, interviewers sometimes offered to interview respondents in a public, prearranged place to ensure their comfort level and confidentiality. Specific strategies for recruiting interviewers and participants were shared among the regional coordinators to promote the use of effective and culturally appropriate practices.

IV.B.3. Questionnaire Design

The following sections analyze the process of pre-survey evaluation for the 2002/2003 RHS and the final survey instrument for consistency with accepted standards of question construction.⁶¹ For most of this section, we will use examples from the adult survey. However, where appropriate, we will discuss question items included on the youth and child surveys.

IV.B.3.a. Pre-Survey Evaluation

Questions developed for the 1997 RHS provided a foundation for the creation of the 2002/2003 RHS questionnaire. As was consistent with standard research practices, the adult, youth and children's surveys were developed through discussions with diverse stakeholders, including Regional Coordinators, FNIGC staff, AFN and FNC staff, health workers in First Nations communities, Health Canada staff, physicians and nurses, university-based researchers and staff and consultants of First Nations regional and national organizations. While large groups can be difficult to organize and facilitate, the variety of interests and perceptions was likely a crucial step in garnering support for the 2002/2003 RHS and for development quality instruments.

The 2002/2003 RHS Regional Coordinators and 2002/2003 RHS national staff members, acting within their roles as data stewards, took responsibility for final survey development. Guiding principles included comparability with other Canadian surveys and cultural validity to First Nations peoples. Because each region was encouraged to develop its own module to supplement the core survey, the decision was made to exclude region-specific questions from the national survey. National health concerns also influenced 2002/2003 RHS question development. Specifically, the Chiefs Committee on Health passed a resolution in 1998 directing survey designers to include the topics of HIV/AIDS, suicide, and mental health.

Each of the three 2002/2003 RHS questionnaires was subject to two rounds of formal field testing.⁶¹ Recommendations for changes to the survey instrument were made based on the results of field testing.⁶² However, the lessons learned exercise revealed concerns that the

⁶¹ Fowler FJ, Jr. "Improving Survey Questions." *Applied Social Research methods Series, Volume 38*. Thousand Oaks: Sage Publications Inc, 1995.

⁶² RHS Adolescent Survey, Field Testing-June 2001 and Qualitative Testing Adolescent Questionnaire, June 2001. Provided to the Review research team by the First Nations Centre.

company contracted to implement the survey did not have sufficient experience in conducting health surveys and therefore did not provide ample time for field testing.⁶³ There is no standard for how many times or for how long field testing should occur. However, the number of participants in the field testing was lower than that recommended (15-35) in survey research texts. Whether a longer field testing process or additional participants would have improved the quality of the final survey instrument is unclear. However, findings from a review of the final survey instrument revealed more strengths than weaknesses (see IV.B.3.b).

IV.B.3.b. Final Survey Instrument

In most cases, questionnaire wording in the 2002/2003 RHS was highly consistent with standard practices to increase the rate and accuracy of responses. For example, ranges were used to obtain information on estimates of the frequency of health behaviors (e.g., smoking) and personal information (e.g., income) that may have been sensitive for some respondents. However, in one case, this technique may not have been culturally appropriate. Specifically, the question regarding number of sexual partners required respondents who wished to answer 1 to answer in the range 1-2. For those in long term relationships, the differences between one partner and two was quite significant. Information on this and other experiences with the questionnaires have been recorded for consideration in the 2007-2008 RHS through a series of debriefings conducted with the regional coordinators by the national office. Additional information on the final survey instrument is provided in Appendix 9.

A key concern raised by the interviewees was the length of the adult survey. The median interview time was 36 minutes, with 95% of surveys being conducted in less than 88 minutes in length. Information from the lessons learned exercise suggested that the length and complexity of the consent form added five minutes to the length of the survey. Other factors that may have contributed to survey length included having to repeat household level questions for each interviewee in the household, difficulties in translating some concepts into the interviewee's language and lack of clarity with some survey questions.⁶⁴ However, there is no gold standard for how long a survey questionnaire can be. The length is a compromise between gathering needed information and recruiting and retaining respondents.⁶⁵ One possible consequence of the survey length is respondents dropping out of the survey or partial non-response. The following section addresses partial non-response and other indicators of data quality in the 2002/2003 RHS.

IV.B.4. Data Quality

Based on the available literature, we would expect CAPI to reduce the incidence of interviewer mistakes, reduce the frequency of missing data, and lower rates of social desirability bias within the 2002/2003 RHS.⁶⁶ However, the lack of interpreters and high turnover of interviewers may have reduced the impact of transitioning to CAPI for 2002/2003 RHS data collection. While, the

⁶³ Powless RC. Lessons Learned Report. March 2004.

⁶⁴ Powless RC. Lessons Learned Report. March 2004.

⁶⁵ Fowler, Jr., FJ. Survey Research Methods, 2002.

⁶⁶ Karwait N, Meyers, Jr. ED. "Computers in Survey Research." Handbook of Survey Research, Chapter 11. Ed. Rossi PH, Wright JD, Anderson AB. Sand Diego: Academic Press. 379-414.

acceptability of CAPI in First Nations communities is unknown, results from the debriefing processes conducted by FNIGC and FNC suggested a high level of acceptance among community respondents of CAPI.

IV.B.4.a. Acceptability of CAPI and Biased Responses

Little information is available on the acceptability of CAPI-based surveys in Indigenous communities, and no prior studies have assessed its feasibility in First Nations communities.⁶⁶ We note that in the implementation of the 2002/2003 RHS, some regions opted to use paper-based survey as well. In a few instances, the fieldworkers expressed discomfort with the laptop and may have preferred the paper-based method.

In addition, the 2002/2003 RHS administrators incorporated processes to encourage honest reporting and increase overall acceptance of the CAPI technology. First, the surveys could be self-administered and locked such that the interviewer was unable to access an individual's responses once the survey was complete. Evidence from other studies suggests that this may be a particularly useful method for gathering sensitive health information.⁶⁷ The employment of community members as interviewers may have further strengthened the acceptance of CAPI and of the survey more generally. Previous studies have shown the use of community members as interviewers to be successful in establishing trust and rapport between the interviewer and interviewees. This relatively new method of interviewing may have been facilitated by its introduction by community members.

Despite the benefits of CAPI in this regard, the presence of community members in the role of interviewer may have caused some respondents to be reluctant to provide honest responses to sensitive questions. One interviewee noted that this was a problem for youth in particular. Where CAPI was used, the youth survey was self-administered to avoid respondent discomfort. However, evidence from the lessons learned exercise suggested that sensitive questions were a bigger concern from interviewers when gathering data from elders and concerns among the interviewers about being disrespectful by asking sensitive questions.⁶⁸

To encourage honest responses, some fieldworkers traded respondents when appropriate to decrease the likelihood of conflict between the interviewer and the respondent. Also, fieldworkers were not always from the communities in which they conducted interviews. Further, the Oath of Secrecy taken by the interviewers reinforced their commitment to the privacy of individual respondents.

⁶⁷ Hewett PC, Erulkar AS, Mensch BS. "The feasibility of computer-assisted survey interviewing in Africa: experience from two rural districts in Kenya." Working Paper No. 168, Policy Research Division of the Population Council, 2003.

⁶⁸ Powless RC. Lessons Learned Report. March 2004.

IV.B.4.b. Technology and Telecommunications

Hardware (250 laptops, 3 servers) and software (Lotus Notes[®]/Lotus Domino[®]) were purchased with funding from the First Nations and Inuit Health Branch in 2002. While the use of CAPI via the laptops reportedly accelerated the process of data collection relative to face-to-face interviewing, some interviewers did not use the technology. 2002/2003 RHS staff attribute this omission to problems with phone lines (e.g., Manitoba), an insufficient number of laptops, technical problems with some laptops and, in a few cases, possible resistance to the use of this technology. In addition, the high turnover of fieldworkers and continual retraining meant that even working laptops sat idle for period of time. Because of the problems with recalling and re-deploying laptops, as well as high staff turnover, 2002/2003 RHS staff estimated that the survey could have been deployed on paper in fewer than 15 months. However, this was not a failing of the CAPI technology. In fact, the use of the CAPI technology allowed for the release of preliminary data even before data collection was complete and for higher quality data than that obtained from the paper-based surveys.

Another problem reported by communities was delays in data transfer due to poor connectivity. This was especially problematic in rural areas of Manitoba. The inability to transfer data meant that laptops were unavailable for data collection and increased the possibility that the data would be lost due to damage or theft. These difficulties led to reversion to paper among communities in Manitoba, thereby obviating the advantages offered by CAPI and introducing additional variation in data entry, resulting in unanticipated errors.

Finally, while the data collection technology allowed for automatic updates of the survey instrument, these changes were not automatic for the Quebec and Saskatchewan and were instead provided to them on CD. This technological limitation resulted in some inconsistencies in implementation of the necessary changes.

IV.B.4.c. Specific Data Quality Measures

IV.B.4.c.1. Interviewer Error

One type of interviewer error is discussed in detail in the 2002/2003 RHS methods – the proportion of each type of survey completed by respondents of the wrong age. Specifically, 3% of children surveys, 3% of youth surveys and 0.2% of adult surveys were completed by members of the wrong age group (e.g., youth completing adult survey). While it is impossible to determine whether these numbers were lower than they would have been had CAPI not been used, the FNC national office believes that some of these errors may have occurred when paper surveys were used instead of CAPI.

IV.B.4.c.2. Total Non-Response

87% of those selected and who completed paperwork completed the survey. Fieldworkers collected data on reasons for non participation. Problems in variation in the documentation of consent across regions made it difficult to discern actual refusals from errors in documentation. Information on the characteristics of the non-responders beyond age and gender was not collected by the fieldworkers.

IV.B.4.c.3. Partial Non-Response

While refused and don't know are conceptually different indicators, average partial non-response was defined in the 2002/2003 RHS as the percentage of responses to a given question represented by the sum of refusals to answer and "don't know" responses. Partial non-response was highest among adults (21% of questions), followed by adolescents (17%) and children (9%). The higher rate of item non-response on the adult survey was likely due to the greater length of the survey and increased probability of non-response. In general, item non-response was dramatically lower among respondents who completed the CAPI version of the survey rather than the paper based method (2205 paper-based surveys, 1947 from Manitoba). More than 85% of the paper surveys had high rates of item non-response (4, 5 and 6 times higher than that for the CAPI surveys) compared to CAPI-based surveys.⁶⁹

Other characteristics associated with high rates of item-non-response included region (i.e., Manitoba, Northwest Territory, Ontario, and Yukon), community size (1500+ persons), age (55+), unemployment, low-income, lower education (<high school), First Nations language fluency, and fair to poor health. These findings indicate the possibility of lower data quality among especially vulnerable subgroups of First Nations communities.

IV.B.4.c.4. Duplication

In some cases, surveys with identical respondent identifiers (i.e.. duplicates) were collected. 12% of surveys (3,228/26,130) were identified as possible duplicates representing 1,397 unique IDs were identified in the survey. However, the majority of these surveys were identified as test surveys or 'false starts'. After their resolution, only 2% of surveys were identified as true duplicates, where the most complete survey was included for analysis.

IV.B.5. Data Storage, Protection and Individual Privacy

Design of the 2002/2003 RHS included the development of detailed protocols for data storage, release and dissemination. Prior to data collection, a Privacy Impact Assessment (PIA) was conducted of the data collection and storage plan for the 2002/2003 RHS.⁷⁰ An outside consultant, Dr. David Flaherty, was hired by the FNC at NAHO to assess the protection of community and individual data. Strengths identified by the PIA included the authority for RHS data collection come from a council or band resolution, the explicit chain of decision making and accountability among the data stewards, and regional control of data protection. The PIA also applauded the use of explicit informed consent and CAPI to minimize errors in reporting. Other strengths included the extensive advertising of the survey at the community level.

Risks identified in the PIA included the scope of questions asked without obvious research goals and the collection of sensitive personal information. The concerns about sensitive questions were somewhat addressed by the ability of the individual to self-administer sensitive questions.

⁶⁹ Schnarch, B. Personal Communication, February 24, 2006.

⁷⁰ Flaherty DH. A Privacy Impact Assessment of the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS). Prepared for the First Nations Centre at the National Aboriginal Health Organization. September 3, 2002.

However, as was revealed in the Lessons Learned Report, concerns about the sensitive nature of some questions continued to be an issue. Further, the length of the survey indicated that limiting the questions asked may not only minimize risk to the participants, but increase the number of completed surveys. Other issues relating to data security and individual privacy are addressed in the OCAP assessment below (IV.C.).

IV.B.6. Summary of Technical Quality of the Data Collection Phase

Strengths of the RHS data collection process included the detailed training sessions for regional coordinators and fieldworkers, the use of CAPI, the use of pre-survey evaluation techniques to improve the quality of the survey questions, the inclusion of community members as interviewers, flexibility in the application of CAPI at the regional and community level to accommodate cultural differences and respondent preferences, and low error rates for surveys collected using the CAPI method.

Limitations of the data collection phase were few, but deserve consideration. First, it was not clear whether respondent identification could be revealed through a court process. In the U.S., this can be prevented through a Certification of Confidentiality. Further, lack of infrastructure development, high rates of fieldworker turnover and malfunctioning laptops among other factors contributed to the use of paper survey in some communities. Because the use of paper surveys was associated with much higher error rates, barriers to CAPI implementation deserve further investigation.

The key findings from our technical review of the data collection phase of the 2002/2003 RHS are summarized in the table below.

Table 10: Summary of Technical Quality of Data Collection Phase

Indicators	Strengths	Potential Limitations/Concerns
Informed Consent	Fieldwork training Oral and written consent Longitudinal cycles	Lack of funding to provide consent forms in First Nations languages Impact of translation on consent unclear Reaffirmation of consent over time unclear Use of household level consent
Mode	CAPI-highly reliable for complex surveys Community representatives as interviewers	High turnover of regional coordinators and fieldworkers
Questionnaire Design	Pre-survey evaluation Reliable and valid	
Data Quality	Low rates of error on CAPI-based surveys	Higher non-response on paper-based surveys
Data Storage, Protection and Individual Privacy	Explicit protocols for data protection	Additional justification may be needed for wide scope of questions and sensitive questions

IV.C. OCAP Assessment

IV.C.1. Ownership

A key goal of the 2002/2003 RHS is community ownership with regional level stewardship of data. Stewardship was accomplished through the involvement of communities in the development of the data collection tools (e.g., consent forms, questionnaires) and through the creation of a local data collection infrastructure headed by the regional coordinator and fieldworkers as interviewers. CAPI is particularly sensitive to interviewer training and works best when the interviewers are both highly skilled in interview techniques and receptive to the new technology. Interviewers need to understand the process of recruiting respondents, be able to explain the survey's purpose and methods to participants, extract honest responses in a reliable way and report those data back using consistent, approved processes.

Training for Regional Coordinators was conducted by RHS staff and hired consultants.⁷¹ A train-the-trainer session was offered in April of 2002, followed by a Regional Coordinator's meeting and training in May of 2002. The goal of the sessions was to prepare the Regional Coordinators to recruit and train community members to act as fieldworkers or interviewers.

Community perspectives:

"We hired and trained community interviewers for the data collection. We made a strong attempt to ensure interviewers spoke the language and had an understanding of the traditions and unique situations of each of the First Nations communities."

(Community Health Director)

Fieldworkers were recruited by regional coordinators and/or community representatives from the participating communities and received intensive training that included a discussion of the sampling frame, information about consent and data security, interviewing techniques and data collection using the laptops. Each fieldworker was provided with a 150-page manual covering all of these topics. Community members were chosen as fieldworkers in order to increase Indigenous control over the process, develop survey research capacity at the local level and increase the level of rapport between interviewers and respondents. These activities enabled the regional coordinators and fieldworkers to become effective stewards of the community-owned resource.

2002/2003 RHS staff report that most fieldworkers were comfortable with the CAPI technology, though there were problems worth noting. In particular, lack of familiarity with the technology may have prevented some fieldworkers from identifying problems in data collection and correcting them. Specific concerns about the technology included technical problems slowing

⁷¹ First Nations Centre at the National Aboriginal Health Organization, Overview and Evaluation of the National Training Sessions for the FNL RHS, 2002-03. May 9, 2003.

down the data collection process, connectivity issues, and insufficient number of laptops. Insufficient funds and high turnover of regional coordinators and field workers appear to have been significant contributing factors.⁷²

IV.C.2. Control and Access

Due to the structure of the 2002/2003 RHS, the issues of control over research and information and the right of communities and organizations to manage and make decision on access to their collective information are inextricably intertwined. A primary goal of the 2002/2003 RHS was to develop the capacity of communities to collect, manage and analyze data on their communities.

Explicit protocols for the storage, management and release of data were created to facilitate regional and community access to data, while maintaining individual privacy. There are explicit protocols for data requests. Requests for national level data are processed through the national office. Requests for regional level data are processed through the regional office. Requests for community data are process through the regional office when the community is requesting the data and through the community and region when someone outside the community wishes to use community level data.

FNIGC cites protection of individual privacy per the consent form process as reasons for requiring communities to formally request community level data. Once a request for data has been made, the data steward de-identifies the data such that individuals cannot be identified at the community level. To further protect individual data, survey results are presented to communities as statistical tables rather than individual response when the community does not have adequate data storage capacity or when the number of respondents is less than 50. The explicit protocols created for data storage, release and use creates a standard to which all regions and communities are held enables monitoring of equity and fairness in access over time.

IV.C.3. Possession

The above described data stewardship strategy is efficient in that it uses existing infrastructure and decentralizes data storage, protection and decision making at the regional level. Funding limitations did not permit the collection of community level data for analysis for smaller communities. Therefore, the available data are most valuable to these communities when aggregated at the regional or sub-regional level. However, if the regional or sub-regional data stewards are not seen as representative by all participating communities, the data steward approach could hinder the ability of communities to exercise and protect their ownership of the data.

⁷² Powless RC. Lessons Learned Report. March 2004.

IV.C.4. Summary of OCAP and Data Collection

This high level of community representative participation in the data collection process and the use of regional questionnaires were highly consistent with the principles of community control. The process strikes a delicate balance between protecting individual data and community ownership of the data. Due to funding limitations, data were unreliable for many smaller communities, limiting the use of these data for health planning purposes. This tension between the efficiencies created by regional level data stewardship and the need for community level data and control will require continued collaboration and negotiation among the national, regional and community representatives.

A summary of our key findings with respect to the cultural validity of the 2002/2003 RHS data collection process is provided in the table below.

Table 11: OCAP Principles and Data Collection

Indicators	Strengths	Potential Limitations/Concerns
Ownership	Community level data ownership with regional stewardship ⁷³	Community representatives (chief and council) have to request data
Control	Community participation in questionnaire design & selection Regional modules	Reliability/availability of laptops in some regions
Access	Explicit protocols for release of data and at what level (table vs. raw data)	Community representatives (chief and council) have to request data
Possession	Provision of data back to communities except in cases of small sample size or inadequate data storage capacity	Lack reliable community level data for analysis among smaller communities Inability of some communities to store data safely

IV.D. Comparative Perspectives

Among the comparison surveys, administrators used a number of different strategies for data collection, including in-person and telephone-based interviewing. However, the Australian survey was the only one to use the same CAPI technology employed in the 2002/2003 RHS. Yet, due to small sample size and the remoteness of many Indigenous communities, all of the surveys reported difficulty in establishing analyzable data estimates at the local level.

Most interviews were conducted in English or French and made interpreters available where necessary. However, details on the process of translation were not provided in any of the comparison surveys or the 2002/2003 RHS. However, the 2002/2003 RHS did record which respondents required assistance or translation.

⁷³ There was some reported regional variation in whether the individual communities or the regional organization was the owner of the data.

Little information is provided in the surveys regarding the recruitment and retention of interviewers and their relationship to the communities being interviewed. The Australian survey did employ Indigenous ‘facilitators’ of both genders where possible to assist the Australian Bureau of Statistics interviewers in the “conduct and completion of the interviews’ and may have provided some assistance with translation of the survey. However, no data were provided in the methods report on how frequently these Indigenous assistants were employed.

All of the surveys covered similar topics related to health and well-being: health care utilization, health status, disability status, health behavior. Further, several of the surveys we examined (e.g., New Zealand, APS, U.S., Australia) asked the respondents about knowledge of Indigenous language and the use of traditional or Indigenous healers. In addition, the 2001APS asked about cultural activities, residential schools, and educational experiences with Indigenous teachers or teaching materials and specific traditional activities. The 2001 APS survey of “Aboriginal” adults was limited to one question about involvement or engagement in cultural activities. However, more detailed questions about specific activities (e.g., hunting, fishing) were included in surveys created for specific subgroups of the population (e.g., Metis, Nunavut). Questions about well being and community engagement in the 2001 APS focused on issues such as housing quality, safety and satisfaction with government services.

Relative to the comparison surveys, the 2002/2003 RHS stands out for its use of CAPI, the inclusion of community members as interviewers and the facilitation of community level decision making regarding data collection. Further, the 2002/2003 RHS included the most extensive questions regarding participation in community cultural activities, revitalization of traditional practices, and the impact of residential schooling. The 2002/2003 RHS was also the only survey to create a separate component for youth to address the specific challenges of this vulnerable subgroup. There are opportunities for mutual learning between the 2002/2003 RHS staff and the other survey administrators on the integration of community perspectives into data collection. For all the surveys, the impact of the process of translation on the reliability of the data obtained and strategies for increasing community level sample size estimates deserve further exploration.

V. DATA ANALYSIS AND DISSEMINATION

V.A. Overview

The focus of analyses stemming from the 2002/2003 RHS was to create baseline data for future rounds of the RHS and to explore aspects of health and well-being, among other topics. Analysis of the national data was standardized for the first major reporting of data from the three surveys and took into account the sampling design. While the national results have been presented in several mediums and regional analyses are underway, this sections of the Review focuses on the national data presented to date by the FNIGC and FNC at NAHO.

Table 11: Quality Indicators: Data Analysis and Dissemination

Quality Indicators	Availability	
	2002/2003 RHS	Comparative Analysis
Technical		
Data Analysis Plan	✓	NA
Data quality, coding and documentation	✓	NA
Analysis training	✓	NA
Data presentation	✓	NA
Data dissemination	✓	✓
OCAP		
Ownership	✓	✓
Control	✓	✓
Access	✓	✓
Possession	✓	✓

V.B. Technical Assessment

V.B.1. Data Analysis Plan

The 2002/2003 RHS analytic plan included the calculation of weighted estimates at the national level using univariate statistics as well as two, three and four way comparison tables. Cells containing fewer than 30 observations were suppressed. Significance was determined by calculation of 95% confidence intervals (using Bonferroni adjustment to account for multiple comparisons). Confidence intervals were calculated for all comparisons, but suppressed in the report where the estimated coefficient of variation was greater than 33%. Only statistically significant data were reported in comparisons between groups. Significance of group differences was determined by examining overlap between 95% confidence intervals. No multivariate analyses were conducted, though some are planned for more focused reports.

The FNC put out a call for organizations and individuals to conduct analyses for the final report and serve as contributors to the report. These individuals were provided with the above parameters for the analysis and specifications regarding presentation. Analysis at the national

office was conducted using SPSS[®] Version 13 software⁷⁴ and the Complex Samples Module, with specifications for analysis provided by the investigators.

V.B.2. Data Cleaning, Coding and Documentation

Several procedures for data cleaning and analysis were standardized across regions for the 2002/2003 RHS. Examples of these protocols include the following:

- 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”);
- “Other (specify)” responses 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;
- Detailed data dictionaries (Appendix 14, Appendix 15 and Appendix 16) were prepared.

Analysis of regional data was decentralized to the regional and sub-regional level in direct response to concerns about centralization of data analysis at the national level expressed in the feasibility assessment report on the 1997 RHS:

Participants were also concerned that if the survey used Aboriginal researchers to collect data but analysis and interpretation remained in the hands of non-Aboriginal researchers, results of the study might be harmful to the communities. However, some participants also acknowledged that Aboriginal expertise in survey research may not be as developed as necessary to manage a longitudinal survey on the scale proposed.⁷⁵

Because there was no baseline data on the sampling frame (i.e., baseline characteristics of people on the membership lists), a comparison of respondents to non-respondents was not possible. While an analysis comparing non-responders to characteristics of individuals from the Census data were conducted at our request by the 2002/2003 RHS staff, the expert panel advised against presenting these data due to differences in the sampling frame.

Sampling weights were used in the analysis of 2002/2003 RHS to control for respondents selection. Specifically, weights were used to control for the probability of an individual being

⁷⁴ SPSS for Windows, Rel. 13.0 2004. Chicago: SPSS Inc.

⁷⁵ O’Neil JD. Process Report. August 1998.

selected for inclusion. If baseline demographic data were available from the sampling frame, additional weights could be created to control for non-response and possible bias resulting from selected response to the survey.

Partial non-response, missing data on particular questions within a survey, was highest for the paper-based surveys and included people who responded either ‘don’t know’ or who refused to answer the question. As these are different concepts, the combination of don’t knows and refusals as partial non-response is not advised. In addition, reported non-response would be most useful if reported as the proportion of the total number of questions that were missing. (See section V.B.4.c.3 above)

Surveys were excluded when partial non-response exceeded 50%. However, sample size could be maximized by excluding items representing specific domains based on a pre-determined non-response cut off (e.g., 10%), rather than excluding individuals from analysis. For example, if a respondent completed the survey, but did not answer 1 out of ten questions relating to chronic medical conditions, it would be appropriate to drop all questions for that individual relating to chronic medical conditions (i.e., the domain), but to keep their remaining data for analysis. Typical cut off’s for exclusion range between 5-15%. As an alternative, imputation of missing items may be considered using methods described by Little and Rubin among others.⁷⁶

These and other decisions, justification for methods and implications of these decisions for the quality of the data produced were provided in detail in the Report on Process and Methods, as well as in several other documents we cite in this report. The level of disclosure in these reports and efforts to provide transparency in the process were commendable.

V.B.3. Data Analysis Training

Regional Coordinators were offered two opportunities for data analysis training from the national office. The first session, was held in January of 2003 in Quebec and trained twenty individuals. The second session was held in November of 2004 in Ottawa. Both sessions focused on data management and analysis using the SPSS software package. The second session also included discussion of media and the application of the First Nations cultural framework. Overall, both trainings received favorable evaluations from those who responded to our questionnaire:

“The training was of great quality, just not long enough to go into inferential analysis depth.” (2002/2003 RHS Regional Coordinator Interview)

“The sessions helped greatly in understanding the information and conveying the importance of how the information could be used.” (Regional Health Director Interview)

The FNC at NAHO also conducted evaluations of these trainings and found similar results. In particular, lessons learned from the January training were applied at the November session. For both our assessment and that conducted by the FNC, small numbers limited the value of asking

⁷⁶ Little RJA, Rubin DB. Statistical Analysis with Missing Data. John Wiley and Sons: New York. 2002.

closed or scaling questions. For example, the January 2004 Evaluation Report provided pie charts showing the distribution of responses regarding the value of the training. However, when there were a limited number of respondents (e.g., 7), the distribution was less meaningful. We found this to be the case in our interviews as well. Discussions with participants about their experiences, such as those detailed in the Lessons Learned report,⁷⁷ may prove more valuable for both assessing the overall quality and identifying areas for improvement.

Specifically, participants in the Lessons Learned exercise noted that more computer training sessions were needed. They also suggested that community health representatives be invited to attend and that a technical committee be established to “share analysis” methods among the regions. Such a step would help to institutionalize knowledge and reduce the impact of high turnover of regional coordinators. Participants also called for more training in the application of research information. This may be a particular challenge for smaller communities who do not have reliable data due to inadequate sample size.

V.B.4. Data Presentation

While several reports, fact sheets, press releases and presentations of the national data have been produced, this section will focus on the presentation of national level data in the First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities, a 34 chapter volume. Authors of the report were recruited from across Canada and were selected based on their expertise in the subject matter of their assigned chapter. Each chapter contained an introductory section, results and conclusions and/or recommendations.

The introductory section generally included a review of the literature on a particular topic (e.g., chronic disease and disability) as it related to First Nations and also provides political, historical and cultural contexts for the data. We examined the chapter for both display of the information and interpretation of the findings. Specific factors considered in judging the display of data in the report were: standardization across chapters, clarity, objectivity of presentation appropriateness of comparison data (i.e., comparisons to other data sources), and robustness of findings (i.e., efforts were made to control for confounding factors in order to assess the robustness of findings/correlations). Indicators of appropriate interpretation were whether the author put the findings in context with the published literature and other environmental factors and/or spoke beyond the data regarding the implications of the findings. We summarize our key findings below.

V.B.4. a. Standardization

There was standardization of both the presentation of statistical significance and weighted data. Statistical significance for subgroup comparisons using 2002/2003 RHS are determined by comparison of 95% confidence intervals. Non-significant differences are identified using ‘NS’, while all other presented comparisons are significant at the 95% level. Data were weighted according to standardized weights based on the probability of being sampled and the distribution

⁷⁷ Powless RC. Lessons Learned Report. March 2004.

of age/gender strata. Contributors to the individual chapters were able to use two, three and four way comparisons, but no multivariate analyses in order to provide a high level, simple view of the data for the first national report. Multivariate analyses are planned for future reports.

V.B.4.b. Simplicity and Clarity

Data in the report were presented as text as well as in tabular and graphical form and were often presented alongside data from other key sources (e.g., Indian Register, Canadian Census). Across the chapters, the presentation of the graphical and tabular data was easy to understand and footnotes were provided regarding specific details of interest. While some tables were somewhat difficult to read due to misalignment of the columns, the overall presentation highlighted the key findings while not distracting the reader with extraneous information. The language was also simply stated, though there was some assumed knowledge regarding specific legislation and other contextual factors. For example, several references are made to Bill C-31, but a formal description of the legislation is provided. References, however, are provided throughout the document.

V.B.4. c. Objectivity

Several techniques for display of data protect the authors from accusations of biased or sensationalistic presentation of findings. These include the inclusion of data from other sources for comparison purposes (see below) and the use of previously validated measures such as the health rating scale. In addition, when sampling error threatened the validity of survey findings, the results are flagged with a cautionary note that the data should be used 'with caution'. Further, when the sampling data exceeded levels predetermined to be problematic, the data were not presented in the final report and the reason was noted in a footnote. A clear example of this method is found on pages 64-68 in Chapter 4, Tables 5, 8, 9, 10, and 11.⁷⁸ This addresses some of the concerns expressed the Privacy Impact Assessment regarding the sensitive nature of the questions and the small number of people surveyed.

V.B.4. d. Comparability

For comparative purposes, the 2002/2003 RHS included both references to published literature on related topics and data from other sources. For example, Chapter 1 included data from the Indian Register and the Canadian Census to ease comparison of the RHS estimates of population statistics to those from other data sources. Appropriately, no statistical comparisons are made between 2002/2003 RHS and data from other sources. Also, Chapter 3 includes data from other sources to assess whether findings from the 2002/2003 RHS are consistent with other published findings.⁷⁹

⁷⁸ :Disability and Chronic Diseases." Ch 4 In: First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities. First Nations Centre at the National Aboriginal Health Organization, November 2005. pgs. 64-68.

⁷⁹ "First Nations Housing and Living Conditions." Ch 3 In: First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities. First Nations Centre at the National Aboriginal Health Organization, November 2005, pgs. 41-50.

V.B.4. e. Robustness of Findings

Specific methods used to assess meaningful differences between subgroups (e.g., age/sex adjustment, multivariate analysis) were allowed to vary by chapter and sometimes within chapters where appropriate. The use of two, three and four way comparisons provided further evidence of the robustness of the findings. For example, in Chapter 2, the author(s) note that differences by language/culture with respect to risk factors and health status were not significant after age adjustment. Further, uniform standards for calculation of the results (e.g., age/gender adjustment) and their presentation (e.g., standard footnote for adjusted estimates) would provide clarification of the data and allow the reader to assess the robustness of the correlations presented.

V.B.5. Data Dissemination and Interpretation

The 2002/2003 RHS included a nation-wide dissemination plan using the internet, national and international meetings, to disseminate the 34 chapter report, the methods report, The People's Report, select findings, fact sheets and presentation slides. The decentralization of the data analysis and dissemination at the regional levels created an opportunity for interpretation of the data in local contexts. All regions developed plans to analyze the data to benefit their communities. In addition, some regions are developing community level infrastructure for data analysis or planning collaborations with academic centers for additional analyses and dissemination of results.⁸⁰

Two of those interviewed felt more could be done to disseminate the findings to First Nations communities including additional press releases and more community level meetings. In addition, some community representatives may have been dissatisfied with their ability to review the national findings before they were released publicly. However, these were not central themes in the in depth interviews.

⁸⁰ Brian Schnarch, Personal communication, March 16, 2006.

V.B.6. Summary of the Technical Quality of Data Analysis and Dissemination

The process of ensuring data quality in the 2002/2003 RHS was intensive and reasonable. In particular, decisions regarding error correction, imputation and standardization were consistent with standard practice. Further the data were weighted to account for the sampling design and training sessions were provided to facilitate the use of the data by regional and community representatives. The data were presented in a clear, objective manner in the final report and special efforts were made to avoid over-interpretation of the results.

Unfortunately, high turnover of the regional coordinators limited the institutionalization of the analysis training methods at the regional level. Further, the lack of community level data limited the value of the data for community health planning. The following table summarizes these findings.

Table 12: Summary of Technical Quality of Data Analysis and Dissemination

Indicators	Strengths	Potential Limitations/Concerns
Data quality, coding and documentation	Error Correction Imputation Standardization	Use of 50% rule for exclusion of surveys due to non-response
Analysis training	Weighted Analysis Training Sessions	Inadequate sample size at community level High turnover of regional coordinators
Data presentation and interpretation	Clear and simple presentation Inclusion of other data sources for comparison/ Standardized statistical testing for comparison of subgroups Sampling error acknowledgement Inclusion of contextual factors	
Data dissemination	Multi-pronged dissemination strategy	

V.C. OCAP Assessment

V.C.1. Ownership

The principle of ownership was reflected in the process of data stewardship and development of protocols for returning data to communities. The “Protocol for the Return of First Nations Regional Longitudinal Health Survey Results to Participating First Nations Communities” stipulates that data may only be returned to First Nations with a Band Council Resolution and to a designated representative (Chief or Council).⁸¹ This protocol prohibits individuals, even government employees from accessing community owned data. Specific protections of

⁸¹ Results to Participating Communities (Appendix G).

individual privacy through this process are discussed in the Data Collection section of this review.

V.C.2. Control

Data stewardship at the regional level and the availability of training sessions for 2002/2003 RHS data analysis were two strategies that reflected the FN principal of control. These strategies were an advance over the 1997 RHS in which some concern was expressed about resources being devoted to a national survey instead of community research initiatives.^{82,83}

In addition, in the 1997 RHS, there was also a “Co-Principal Investigators” group made up mostly of university-based researchers who 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.

In contrast, the 2002/2003 RHS did not rely on co-principal investigators. Instead, the chapters were written by various contributors (enlisted via a call for authors), who are listed at the end of the document. While not including authorship for each chapter ran counter to standard research dissemination practices, the exclusion of authorship attribution was an intentional decision to emphasize the principle that responsibility for the data rests with those involved in its collection and the community participants.

V.C.3. Access

To facilitate community understanding and use of the 2002/2003 RHS data, the FNC at NAHO has hosted three training sessions aimed at the effective use of 2002/2003 RHS data and plan more for the future. The audiences for these training are diverse, including community health professionals, youth, and other community members.⁸⁴ This also addressed a common concern regarding the need for Indigenous research to include not only the implementation of the survey but also the analysis and interpretation of results. Finally, RHS reporting functions were structured in order to meet the “knowledge production and program planning” needs of the community through the cultural framework developed by the First Nations Information Governance Committee (FNIGC). While this training proved beneficial to some, it is clear that others, particularly at the community level, would also benefit.

⁸² O’Neil JD. A Process Report. Aug 1998.

⁸³ O’Neil JD, et al. FNIRHS Technical Report. Sep 1998.

⁸⁴ National Aboriginal Health Organization (NAHO), First Nations Centre, Training and Education <http://www.naho.ca/firstnations/english/training.php>

Community Perspectives:

“It has been a great experience, especially regarding doing research from within a First Nations cultural framework. I already felt proficient in the field of health survey research, now I feel proficient in the field of Aboriginal health survey research, which I hope you understand is different.”
(RHS Regional Coordinator Interview)

“Training on how to read and use the data would be helpful at the community level.”
(Regional Health Director)

Training in data storage and security will be crucial for communities who have limited access to raw community-level data due to inadequate infrastructure. Further, those communities who have insufficient sample size for community level data analysis will require assistance in the use of regional or sub-regional data for community planning purposes.

V.C.4. Possession

Finally, possession was addressed through ability of regions to house data and elaborated on in the “Data Stewardship and Protection Protocol,”⁸⁵ which outlines possession and access. This protocol places control of the data in the hands of the appropriate regional organization and FNC. This protocol also stipulates the requirements for storing and providing access to the confidential 2002/2003 RHS data, which are discussed in the Data Collection section above. As stated previously, to the extent that regional organizations are not seen as representative of all participating communities, the principle of possession may be threatened by the housing of data at the regional level.

V.C.5. Summary of OCAP and Data Analysis and Dissemination

As summarized in Table 14 below, community data ownership, regional stewardship and analysis training were all consistent with the principles of OCAP. However, the lack of the community level estimates and high fieldworker turnover remain considerable barriers to true community access and possession. These issues are reflective of the limitations of survey design methods for conducting large scale surveys with community level benefit.

Table 14: OCAP Principles and Data Analysis and Dissemination

Indicators	Strengths	Potential Limitations/Concerns
Ownership	Community ownership or regional stewardship	
Control	Collaborative national release process Training to increase regional analytic	High turnover limits utility of training sessions

⁸⁵ Data Protection and Stewardship Protocols (Schedule C).

	capacity	Regional data stewards may not be seen as representative by all communities
Access	Protocols for data access Analysis training sessions for community members	Limitations of data for smaller communities Variations in security of data storage
Possession		Regional level representation

V.D. Comparative Perspectives

Among the comparison surveys we reviewed, a national statistics branch was usually in charge of data storage and dissemination. All had written policies regarding the protection of individual respondents and only de-identified aggregated data were available on the web. However, we found no evidence that Indigenous community approval was required to access data on Indigenous communities. We did not have sufficient information to assess whether communities were consulted on the release of national data or the dissemination of community-level findings. The 2002/2003 RHS was unique in its explicit protocols for release of data at all levels.

Because the limitations of national surveys for community level use are universal, there may be opportunities for learning among nations. In particular, the development of new methods for this purpose may be overdue. In addition to providing innovations in technical quality, the 2002/2003 RHS staff may be in a unique position to provide guidance on the development of cultural frameworks for future survey research.

VI. CONCLUSIONS

In summary, the review team was impressed with the overall quality of the 2002/2003 RHS, its consistency with previously validated survey research practices and its innovations with respect to the involvement of First Nations communities and their representatives in the research process. The 2002/2003 RHS used information gained from the first round of data collection (1997 RHS) to develop more refined methodology and protocols. Compared to other national surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in First Nations ownership of the research process and in its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process. All of this was accomplished under considerable resource constraints.

The following provides a brief synopsis of our findings with respects to sampling design, data collection, and data analysis and dissemination.

Sampling Design

⌘ High Technical Quality Marks

- Standardization of sampling schemes across regions
- Probability-based sampling design
- Adequate sample size for cross sectional and longitudinal analysis
- High response rate
- High level of community representation

- ⌘ Consistency with OCAP
 - Use of community membership lists to identify respondents
 - Ongoing communication with community representatives regarding sampling design specifications
 - Stewardship of decision making at the regional and national level
- ⌘ Comparative Perspectives
 - One of two surveys to include Indigenous representatives in decision-making regarding the sampling design
 - Only survey to use Indigenous-owned data sources to identify sampling frame
- ⌘ Potential Limitations/Concerns
 - Exclusion of off-reserve First Nations communities and small communities
 - Insufficient sample size for data analysis among smaller communities
 - Variation in degree of representation of FN communities among regional organizations
 - Limited ability to assess selection due to lack of baseline data

Data Collection

- ⌘ High Technical Quality Marks
 - Intensive training offered to regional coordinators and fieldworkers
 - Oral and written consent
 - Accommodation in consent forms for longitudinal cycles
 - Use of a highly reliable mode of data collection (CAPI)
 - Inclusion of community representatives as interviewers
 - Pre-survey evaluation
 - Low rates of error for CAPI-based surveys
- ⌘ Consistency with OCAP
 - Community level ownership and regional stewardship
 - Regional participation in questionnaire design and selection
 - Regional modules
 - Explicit protocols for release of national, regional and community level data
- ⌘ Comparative Perspectives
 - One of two to use CAPI for data collection
 - Only survey to consistently employ and train Indigenous community interviewers
 - Most extensive coverage of cultural concepts in the questionnaire design
- ⌘ Potential Limitations/Concerns
 - Lack of funding to provide consent forms in First Nations languages
 - Use of household level consent

- High turnover of regional coordinators and fieldworkers limited institutionalization of knowledge and infrastructure development at the regional and community level
- High rates of non-response on paper-based surveys
- Inadequate handling of partial non-response
- More justification may be needed for wide scope of questions and sensitive questions

Data Analysis and Dissemination

⌘ High Technical Quality Marks

- Intensive process of error correction, imputation, weighting and standardization to increase data quality
- Training sessions at the regional and community level in data analysis, interpretation and use
- Clear and simple presentation of national data
- Standardization of statistical methods for comparison of subgroups
- Acknowledgement of sampling error
- Multi-level dissemination strategy

⌘ Consistency with OCAP

- Community level ownership and regional stewardship
- Collaborative process for national data release
- Explicit protocols for release of national, regional and community level data
- Analysis and data use training sessions at regional and community level

⌘ Comparative Perspectives

- Only survey where data release was clearly controlled by Indigenous organizations

⌘ Potential Limitations/Concerns

- Exclusion of surveys with 50% non-response
- Inadequate sample size for community level analysis for smaller communities
- High turnover of regional coordinators limited dissemination of information gained in training sessions

Themes from In Depth Interviews

⌘ Internal Constraints

- Lack of an Independent Infrastructure
Interviewees noted that the lack of an independent 2002/2003 RHS structure created greater dependency on existing regional organizations that may not be representative of all communities. Others cited a need for more than one individual in each region or sub-region who would be responsible for championing the project over the long term.

- High Rates of Staff Turnover
There was high turnover of both regional coordinators and fieldworkers, diverting resources from data collection and analysis to recruitment, hiring and training of new staff.
- Translation of Research Findings into Action
Community health directors described a need for community rather than “provincial” level data for documentation of need and development of indicators for program planning, program development and grant writing; others cited a need for a more widespread marketing campaign to increase visibility of the 2002/2003 RHS.

⌘ External Constraints

- Level and Timing of Funding
Several of those interviewed noted that funding was inadequate for the level of community participation, community-level data collection, and training needed to effectively carry out a survey of this magnitude.
- Small rural nature of many communities and wide geographic spread
Funding emerged as a primary cause of limitations in sampling design, data collection and analysis. Examples of funding limitations described by those interviewed included lack of funding for community engagement, community-level data collection, and training needed to effectively carry out a survey of this magnitude.

Appendix 1: List of Reviewed Documents and Supplemental Materials

Technical Reports and Protocols

- First Nations Longitudinal Regional Health Survey (RHS) 2002, First Nations Ethical and Technical Review, May 22 and 23, 2002, Ottawa, ON
- FNIRHS Technical Report, John D. O'Neil, Brenda Elias, Jeff Reading and Robert Tate, September, 1998
- Comparison of respondents with high item non-response vs. those with low item non-response (RHS 2002/03 unweighted data)
- A Privacy Impact Assessment of the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS), May 2003 (final)
- Sampling Plan for the First Nations and Inuit Regional Longitudinal Health Survey (RHS), May 22, 2002 (with accompanying appendices)
- First Nations Regional Longitudinal Health Survey 2002-03: A Process Report. John D. O'Neil, August, 1998
- Sample Adolescent Survey Field Test Report July 01
- Sample Adolescent survey qualitative testing probes June 2001
- First Nations and Inuit Regional Longitudinal Health Survey, Report on Process and Methods November 4, 2005 Draft (Also received Jan, July and Oct 2005 drafts)
- Data Protection and Stewardship Protocol (Schedule C)
- Survival of Confidentiality Requirements (Schedule D)
- Oath of Secrecy (Schedule E)
- Fictitious Example of an Oath of Secrecy Log (Schedule F)
- Protocol for the Return of First Nations Regional Longitudinal Health Survey Results to Participating First Nations Communities (Schedule G)

Presentations

- The First Nations Regional Longitudinal Health Survey: The Survey of Choice. Brian Schnarch, May 6, 2003 (power point presentation)
- The First Nations Regional Longitudinal Health Survey: A Model Survey. Jane Gray, Brian Schnarch, NAHO Annual Conference. Jan 23, 2003, Ottawa (power point presentation)
- FN Survey of Choice: The First Nations Regional Longitudinal Health Survey for Children, Youth and Adults (RHS) 2002-2003. Jane Gray, Chief Shirley Clarke, Ceal Tournier, Brian Schnarch, Martin Paul, United Nations Meeting. May 19, 2004, New York (power point presentation)

Training Manuals and Materials

- RHS Data Analysis Training: Evaluation Report, Jan 24-26, 2003, Aylmer, Quebec
- First Nations and Inuit Regional Longitudinal Health Survey Training, April 3-5, 2002, Centre for Aboriginal Health Research, National Aboriginal Health Organization
- First Nations Longitudinal Regional Health Survey (RHS) 2002-2003, Fieldworker Manual, July 2002
- Draft Agenda, RHS Data Analysis Training, January 24-26, 2003. Aylmer, Quebec
- NAHO RHS Data Analysis Training: DAY 1 (power point presentation)
- NAHO RHS Data Analysis Training: DAY 2 (power point presentation)
- NAHO RHS Data Analysis Training: DAY 3 (power point presentation)

- First Nations and Inuit Regional Longitudinal Health Survey 2002, Regional Coordinator's Meeting/Training Session, Best Western Parkway Inn and Conference Centre, Cornwall, ON May 26-28, 2002
- First Nation's and Inuit Regional Longitudinal Health Survey Training, April 3-5, 2002 Loews Le Concorde, Quebec City
- Overview and Evaluation of National Training Sessions for the FNRLHS, 2002-03
- SPSS, Analysis, Cultural Framework, Media Training Nov 16-18 04
- RHS Data Analysis Training: Participant Evaluation, January 24-26, 2003. Aylmer, Quebec
- RHS Job Description for Regional Health Survey Coordinator - Template

Internal Memos and Background Material

- Possible Independent Review of the First Nations Longitudinal Regional Health Survey (RHS), Internal Use-Briefing Note, First Nations Centre, National Aboriginal Health Organization, Briefing #: FNC03-026
- First Nations Information Governance Committee Final Terms of Reference, As presented to the CCOH, June 2000, Revised July 3, 2000
- Agreement between the Organization for the Advancement of Aboriginal Peoples (represented by FNC) and Regional Office – template , Nov 7, 2002
- Backgrounder: First Nations Regional Longitudinal Health Survey (RHS), Sept 9, 2004
- First Nation and Inuit Regional Health Survey Project: Code of Research Ethics, January 25, 1997
- First Nations and Inuit Regional Health Survey, First Nations and Inuit Health Survey National Steering Committee.
- First Nations Regional Longitudinal Health Survey 2002-03: RHS First Nations Survey of Choice (short summary)
- First Nations Regional Longitudinal Health Survey 2002-03: Code of Research Ethics (revised January 27, 2004; Adopted July 25, 1997)
- RHS 2002-2003: Questionnaire Themes (Sept 9, 2004)
- More than Just a Survey: Questionnaire Themes for 2002-2003 (Revised January 2003)
- Events and Milestones: First Nations Regional Longitudinal Health Survey 2002-03
- Bringing Information to Life: First Nations Regional Longitudinal Survey 2002-03 Proposal (Draft)

Results

- Manitoba First Nations Regional Longitudinal Health Survey: Preliminary Results from the Manitoba Youth Resiliency Survey, November 11, 2005
- Preliminary Findings of the First Nations Regional Longitudinal Health Survey (RHS) 2002-2003: Adult Survey, 09/2004
- As First Ministers prepare to meet on health, First Nations Regional Health Survey (RHS) finds that the health and living conditions of First Nations are worse than those of Canadians. Press Release, September 9, 2004.
- Yukon RHS Summary
- First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities. First Nations Centre, November 2005.

- One third of First Nations households consider water unsafe to drink, according to the RHS report. Press Release, October 25, 2005.
- First Nations children face grim health conditions. Press Release, July 7, 2005.
- RHS report reveals both the progress and major concerns in First Nations youth health and living conditions. Press Release, October 25, 2005.
- First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Lessons Learned Report. Prepared by Richard C. Powless for Jane Gray, National Coordinator, First Nations Regional Longitudinal Health Survey. March 2004, Ottawa, Ontario.
- RHS at a Glance. Selected Findings from the First Nations Regional Longitudinal Health Survey (RHS) 2002/03.
- First Nations Regional Longitudinal Health Survey (RHS) 2002/03: The People's Report.
- RHS 2002/03 Youth Survey Highlights: The Good, the Bad and the Ugly.
- RHS 2002/03 Adult Survey Highlights: The Good, the Bad and the Ugly.
- RHS 2002/03 Children's Survey Highlights: The Good, the Bad and the Ugly.

Supplemental Materials

Battiste, M. (ed) 2000, *Reclaiming Indigenous Voice and Vision*, UBC Press, Vancouver.

Boldt, M. and Long J.A. (eds) 1985, *The Quest for Justice: Aboriginal Peoples and Aboriginal Rights*, University of Toronto Press, Toronto.

Davidson, E.J. 2005, *Evaluation Methodology Basics: The Nuts and Bolts of Sound Evaluation*, Sage Publications, Inc., Thousand Oaks.

Fowler, F.J. 1995, *Improving Survey Questions: Design and Evaluation*, Applied Social Research Methods Series, V. 38, Sage Publications, Inc., Thousand Oaks.

Little Bear, L., Boldt, M. and Long, J.A. 1984, *Pathways to Self-Determination: Canadian Indians and the Canadian State*, University of Toronto Press, Toronto.

Sefa Dei, G.J., Hall, B.L., and Goldin Rosenberg, D. 2000. *Indigenous Knowledges in Global Contexts: Multiple Readings of Our World*, University of Toronto Press, Toronto.

Thomas, D.P. 2004, *Reading Doctor's Writing: Race, Politics and Power in Indigenous Health Research 1870-1969*, Aboriginal Studies Press, Canberra.

Appendix 2: Stakeholders & Advisory Groups

Expert Panel Members

Virginia Casey

Kelly McShane

Janet Smylie

Sounding Board Members

Rene Dion

Alma Favel-King

Gail McDonald

Michael Mitchell

Barbara Oke

Sharon Rudderham

Ceal Tournier

External Readers

Kathy Absolon

Cindy Blackstock

Gary Carbonnell

Margo Greenwood

Michael Monture

Helen Stappers

Fred Wien

Appendix 3: Regional Coordinator Interview Questions

Thank you for agreeing to participate in this voluntary questionnaire about your experiences as a regional coordinator for the 2002/2003 RHS. We are particularly interested in learning about data collection, management, and analysis in your region and how you addressed any issues that arose. Your observations will aid us in assessing the overall success of this round of the 2002/2003 RHS and in making recommendations for the next round. Out of respect for your privacy, your observations will be summarized with those of other regional coordinators and will not be attributed to you in our report.

Please enter the survey number you were provided in the request e-mail: _____

A. Becoming a Regional Coordinator

We would like to begin this interview by learning about your employment as a regional coordinator for the First Nations Regional Longitudinal Health Survey (2002/2003 RHS).

A.1. What month and year did you begin working as a regional coordinator for the 2002/2003 RHS?

(e.g., Jan 2000)

- Don't Know/Not Sure
- Do Not Remember

A.2. Were you employed by a First Nations organization at that time?

- Yes
- No, SKIP to A.3.

A.2.a. What is the name of that organization, and which First Nation(s) does it represent?

A.3. Are you currently employed as a regional coordinator?

- Yes, SKIP to A.4.
- No

A.3.a. What was your last date (month and year) of employment as a regional coordinator? (e.g., Jan 2000)

- Don't Know/Not Sure
- Do Not Remember

A.4. What are/were your key responsibilities/tasks as a regional coordinator?

B. Train-the-Trainer Sessions

This next group of questions addresses the training you received in order to carry out your tasks as a regional coordinator for the 2002/2003 RHS.

B.1. Did you participate in a train-the-trainer session provided by the RHS national office?

- Yes
- No, SKIP to B.2.

B.1.a. Were you provided with written training materials?

- Yes
- No

B.2. Did you receive additional training from anyone other than the FNIGC (e.g., former regional coordinator)?

- Yes
- No, Skip to B.3.

B.2.a. If so, who provided that training? _____

B.2.b. Were you provided with written training materials by (Answer from B.2.a. above)?

- Yes
- No

B.3. At the end of your training, how prepared did you feel to help fieldworkers and others to understand the following:

Purpose of the RHS

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Sampling Design/Approach Used in the RHS

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Purposes of the Specific Questions Asked in the RHS Questionnaires

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Consent Process and Confidentiality Rules

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Recruitment of Survey Participants

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Fieldworker Duties and Training Process

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Data Collection Process (including use of Laptop computers)

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Process for Downloading Data from Laptop to Central Data Collection Unit

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Process of Finding Data Errors and Editing Data Them

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

Process of Returning Data Back to Analysts for Processing

- Very
- Somewhat
- Not at All
- Unsure/Don't Know

B.4. Is there any aspect of the train-the-trainers process that you found especially useful for implementation of the RHS? What and why?

B.5. Is there any aspect of the train-the-trainers process that you feel could be changed to increase its usefulness to regional coordinators in training? What and why?

C. Data Collection

This next group of questions addresses the data collection process, including training you provided to fieldworkers enlisted to collect data from community members and challenges your region faced in collecting survey data.

C.1. Did you receive the fieldworker manuals and kits you needed to train fieldworkers in your region?

- Yes
- No (explain)

C.2. Were you the person in your area responsible for recruiting fieldworkers?

- Yes, SKIP to C.3.
- No

C.2.a. Who in your region or sub-region was responsible for recruiting fieldworkers?
SKIP to C.4

C.3. How often did you communicate with the fieldworkers, and how effective do you feel that communication was?

C.4. Were fieldworkers provided monetary compensation for their participation?

- Yes
- If Yes, Please Describe
- No

C.5. How often were you called upon to provide additional training to fieldworkers or to solve specific problems (with, for example, the processes of respondent recruitment or data collection?)

- Very Often
- Often
- Not very Often
- Rarely
- Never

C.6. Please indicate how useful you think the training materials were for the fieldworkers with respect to the following tasks:

Recruiting of Respondents

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Explaining Consent and Obtaining Consent

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Collecting the Data

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Operating the Laptops

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Providing Answers to Respondents' Questions/Concerns

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Downloading Data from Laptop to Central Data Collection Unit

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

Finding Data Errors and Editing Data

- Very useful
- Somewhat useful
- Not very useful
- Unsure/Don't Know

C.7. Did you face any special challenges to data collection? [PROMPT: For example, some regions reported that fieldworkers sometimes gave out the wrong survey or miscoded the respondents' personal information, others reported difficulty in finding enough lap tops for the fieldworkers.]

- Yes

If Yes, Please Describe and Continue with C.8.

- No, Skip to Section D

C.8. Were you able to overcome these challenges?

- Yes

If Yes, Please explain how you addressed these challenges and whether there were parts of the training process you feel prepared you for these challenges

- No, Skip to Section D

D. Cultural Factors

We are now half way through the interview. This next section is about whether the data collection process respects community norms (e.g., ways of communicating), beliefs, and ethics.

D.1. Which of the three surveys (e.g., adult, child, adolescent) did your region use? [check all that apply]

- Adult

- Child
- Adolescent

D.2. What was the process for making this decision, and who was involved in that process at the regional or sub-regional or community level?

D.3. Were any changes made to the interview questions or the interview process at the regional or sub-regional or community level? (prompt: who conducts the interview, length of interview, etc.

- Yes

If Yes, Please describe how these decisions were made and by whom

- No, Skip to D.4.

D.4. Were interpreters available to translate the survey into the respondents' preferred language?

- Yes

If Yes, Please describe how this was achieved

- No, Skip to D.4.a.

D.4.a. Were people who could not communicate with the data collector excluded from the survey?

- Yes, SKIP to D.5.

- No

If No, Please explain

D.5. We understand that the regional coordinators and local fieldworkers attempted to incorporate cultural and local/regional considerations into the implementation of the RHS. With regard to that process, what worked well – and what did not?

E. Local Capacity

We are nearing the end of the survey. The last few questions are about the ability of local governments and organizations to store RHS data, ensure data quality and security, analyze information from the RHS, and use it for health planning purposes.

E.1. Is there one organization at the regional or sub-regional level that is responsible for storing and analyzing RHS data collected in your region?

- Yes

If Yes, please describe the organization and their relationship to you and the FNIGC:

- No

If No, please indicate where these data are stored and by whom:

E.2. Can participating communities access RHS data collected on their communities?

- Yes

If Yes, please explain the process for obtaining these data:

- No, SKIP to E.2.a.

E.2.a. Is there a plan for providing community access to RHS data?

E.3. What procedures are currently in place to ensure that only people authorized to use the data can access it? Please describe:

E.4. Do the communities in your region have the ability to store RHS data in a secure location?

- Yes, all or most can safely store RHS data from their communities.
- Some have the ability to safely store RHS data from their communities.
- No, most do not have that ability.

E.5. CURRENT REGIONAL COORDINATORS ONLY, all others proceed to section F, “Wrap Up”:

As the regional coordinator, will you be involved in conducting analysis with the RHS data?

- Yes, Go to E.5.a.
- No

E.5.a. Do you have the ability to conduct these analyses now?

- Yes, Go to Section F, Wrap Up
- No _____

E.5.b. Are there specific skills, software, equipment, funding, or other resources you need to conduct analyses using the RHS data?

F. Wrap-Up Reflections

In closing, we note that a key goal of the RHS was to First Nations’ control over and access to important data regarding their health. Could you reflect on the RHS’ success given these intentions? Has it, for example, supported First Nations rights, improved health information about First Nation people, aided appropriate program development, etc.?

At this time, are there any additional issues or lessons learned that you would like to share with us regarding your experience as a regional coordinator for the RHS?

Thank you, we have now completed the interview. We are interested in interviewing other regional coordinators from your area or elsewhere in Canada. Do you have anyone you would like to recommend to us?

Thank you again for your time and participation. We will send you a summary of our findings from this questionnaire.

Appendix 4: FNIGC Staff/Members Interview Questions

Thank you for agreeing to participate in this voluntary questionnaire about your experiences with the RHS as a First Nations Information Governance Committee (FNIGC) member or staff person. We are particularly interested in learning about your role in guiding the RHS process. The information you provide will assist us in assessing the overall success of this round of the RHS and in making recommendations for the next round. Out of respect for your privacy, your observations will be summarized with those of other regional coordinators and will not be attributed to you in our report.

1. Please enter the survey number you were provided in the request e-mail: _____
2. Please indicate which community you represent:
3. What was your role with regards to FNIGC?
 - Member
 - Staff Person
4. We understand that the role of FNIGC members in the implementation of the RHS was to guide the RHS process, could you briefly describe what specific tasks you had in carrying out the RHS?
5. Can you describe the process by which RHS findings or reports are approved for national release?
6. Do you feel that review of the core data by FNIGC improved the quality of the RHS data and analysis?
7. Did any conflicts arise among decision makers over the RHS survey design, data collection, analysis or dissemination process? If so, how were these resolved and what was your role in the resolution?
8. Could you describe the role of Health Canada and Statistics Canada with regard to the RHS and elaborate on any collaboration processes with these groups including any best practices or challenges with regards to this collaboration?
9. Finally, in your role as an FNIGC member/staff, please explain how your activities contribute to the goals of First Nations OCAP over health statistics and research?

Appendix 5: Regional Health Director Interview Questions

Thank you for agreeing to participate in this voluntary interview about the First Nations Longitudinal Regional Health Survey (RHS). We want to learn community experiences with the RHS. Out of respect for your privacy, your observations will be summarized with those of other respondents and will not be attributed to you in our report. The interview should last no more than 30 minutes.

Please enter the survey number you were provided in the request e-mail: _____

We would like to begin this interview by learning about your role as a regional health director.

I. Your Role

1. We have you listed as the Regional Health Director for [RHS Region]. Is this correct?

Yes No

2. Which First Nation(s) do you represent (in this interview, we will refer to these nations as “your communities”)?

3. What are your main duties as a regional health director?

II. RHS Activities

4. What was your role in the RHS? Please describe.

5. Overall, among the communities in your region, would you say the RHS was implemented unsuccessfully?

(Example: Did your communities feel included, heard, and were their needs addressed?)

Yes No

a. If YES, please provide specific examples of what worked well (e.g., data collection, interviewer training, etc.)

b. If NO, please provide specific examples of barriers to RHS implementation (e.g., preparation, resources, time, technical assistance, community resistance).

III. Use of RHS Data

6. Have you and members of your communities been involved in the analysis of RHS data?

Yes No

a. If YES:

i. How have you used it?

ii. How useful was it for your needs
(Example: for example community health planning)?

b. If NO:

i. What prevents you from using the data?
(Example: lack of time, lack of expertise, etc.)

ii. How would you use the data if you had access to it?

IV. Control Over Data

7. Have findings from the RHS data been made available to you and your communities?

Yes No

a. If YES, do your communities find the language, format and presentation of the data to be useful/understandable?

b. If NO, have you received information from the RHS national office about when findings will be available?

8. Are your communities able to store data in a way that protects the identity of participants and protects the data from harm?

Yes No

a. If YES, can you provide examples of things communities do to protect their data (i.e., best practices)?

b. If NO, what are the barriers to data storage in your communities?

V. Other Factors

9. Were there other factors that affected which of your communities participated in the RHS? (Examples might include lack of funding and other resources, concerns of local leaders about the RHS, relationships with Assembly of First Nations, Health Canada, or Statistics Canada.)

We have reached the end of our interview. Are there any additional thoughts or experiences you would like to share with us about your work with the RHS or the experiences of your communities?

Thank you for your time. We are interested in interviewing other regional and community health directors. Can you recommend other individuals for us to interview for this review?

Thank you again for your time and participation. We would be happy to send you a copy of our final report. Where would you like us to send the report?

Appendix 6: Community Health Director Interview Questions

Thank you for agreeing to participate in this voluntary interview about the First Nations Longitudinal Regional Health Survey (RHS). We want to learn community experiences with the RHS. Out of respect for your privacy, your observations will be summarized with those of other respondents and will not be attributed to you in our report. The interview should last no more than 30 minutes.

Please enter the survey number you were provided in the request e-mail: _____

We would like to begin this interview by learning about your role as a community health director.

I. Your Role

1. Which First Nation or community do you represent (in this interview, we will refer to this nation as “your community”)?

2. What are your main duties as a health director?

II. RHS Activities

3. Were you involved in the development, implementation or analysis of the RHS?

Yes No

a.) If YES, Please describe.

5. Overall, within your community, would you say the RHS was implemented successfully? (Example: Did your community feel included, heard, and were your needs addressed?)

Yes No

a. If YES, Please provide specific examples of what worked well (e.g., data collection, interviewer training, etc.)

b. If NO, please provide specific examples of barriers to RHS implementation (e.g., preparation, resources, time, technical assistance, community resistance).

III. Use of RHS Data

6. Have you and members of your community been involved in the analysis of RHS data?

Yes No

- a. If YES, how useful was it for your needs
(Example: for community health planning)?
- b. If NO:
 - i. What prevents you from using the data?
(Example: lack of time, lack of expertise, etc.)
 - ii. How would you use the data if you had access to it?

IV. Control Over Data

7. Have findings from the RHS data been made available to you and your community?

Yes No

- a. If YES, Did your community find the language, format and presentation of the data to be useful/understandable?
- b. If NO, Have you received information from the RHS national office about when findings will be available?

8. Is your community able to store data in a way that protects the identity of participants and protects the data from harm?

Yes No

- a. If YES, Can you provide examples of things your community does to protect their RHS data (i.e., best practices)?
- b. If NO, What are the barriers to data storage in your community?

V. Other Factors

9. Were there other factors that affected participation in the RHS in your community?
(Examples might include lack of funding and other resources, concerns of local leaders about the RHS, relationships with Assembly of First Nations, Health Canada, or Statistics Canada.)

We have reached the end of our interview. Are there any additional thoughts or experiences you would like to share with us about your work with the RHS or the experience of your community with the RHS?

Thank you for your time. We are interested in interviewing other community health directors. Can you recommend other individuals for us to interview for this review?

Thank you again for your time and participation. We would be happy to send you a copy of our final report. Where would you like us to send the report?

Appendix 7: Comparative Perspective Methods

Search Criteria

The first step in gaining a comparative perspective was to identify surveys that were similar in purpose and scope to the RHS. We conducted a search of the PubMed literature, the Native Health Databases (<http://hsc.unm.edu/library/nhd/>) and Native Web (<http://www.nativeweb.org/resources/health/>) to identify studies using surveys that included health information on Indigenous populations. Search terms included: First Nations; health survey and Indigenous; health survey and Indigenous and (Mexico, Latin America, South America, Central America, Maya, Garifuna, Quechua); health survey and Indigenous and Africa; health survey and aboriginal; health survey and Aboriginal and (Australia, New Zealand); health survey and Maori; health survey and rural Africa. We then conducted a targeted online search of the Ministries of Health and related agencies of Australia, New Zealand, and the U.S. as these countries have well known Indigenous communities living within them whose populations are relatively small. Because we anticipated that some surveys may not be cited in the published medical literature, we also conducted a search of international organizations such as the World Health Organization. The findings of the search are summarized in the results section and presented in Appendix A.

Inclusion and Exclusion Rules

In order to be included in the comparative analysis, surveys had to meet the following criteria:

- Respondents to the survey were community members answering questions regarding their health (e.g., health status, health care utilization, risk behavior, health care quality, satisfaction with services, awareness or knowledge of specific health conditions, quality of life, etc) or that of a dependent (e.g., child);
- Surveys were conducted at the national or regional level;
- The technical documentation was available in the English language; and
- The surveys did not intentionally exclude Indigenous people.

We excluded surveys that involved the collection of specimens or clinical evaluations only without gauging the respondent’s assessment of their own health or health care. We excluded community level surveys due to their lack of comparability in terms of the complexity of the sampling design.

Domains of the Comparative Analysis

We identified numerous characteristics to describe all of surveys (Table 1).

Table 3 Survey Characteristics Used to Guide the Comparative Analysis

CHARACTERISTICS	DEFINITION/DESCRIPTION
Administrative	

Sponsor	Group/agency/organization responsible for the survey development and content
Date Mandated/Requested	If the survey was mandated by the government, the date on which the mandate went into effect?
Date Funded	Date funds were made available for the conduct of the survey
Funding Agency/Org	Name of the organization or group that funded the survey; Also described the nature of the relationship between the funder and the target Indigenous population
Administrator	Name of the organization or group that developed and fielded the survey; Includes information on the nature of the relationship between the administrator of the survey to the Indigenous population of interest and whether services were being provided to the community as part of an ongoing relationship to this agency
Purpose	Purpose or Aim of the survey, including specific goals for inclusion of indigenous peoples
Target Population	Target Indigenous population(s)
Data Collection Period	Specific dates of data collection including all waves
Data Release Date	Date on which the data were published or available for use?
General Sampling Frame	
Selection of Respondents	Method of selecting respondents (e.g., random selection from the phone book)?; Description of any extenuating circumstances with respect to identifying patients as Indigenous/Aboriginal and how they were resolved (e.g., patient preference, blood quantum, vital records)
Number of Strata	If the respondents were selected within strata (e.g., geographic areas), provides a detailed explanation of that process.
Probability of Selection	If sufficient information is available, gives the estimated probability that a member/citizen of an Indigenous population would have been selected given the chosen sampling frame.
Sampling Error	If provided, gives the estimated sampling errors and appropriate weighting schemes.
Human Subjects	
IRB Approvals	Describes the process of obtaining approval to conduct interview and the specific organizations/agencies from which this permission was obtained
Nation/Community Involvement	
Nation/Community Involvement in Survey	Specific nature of Indigenous involvement with the development, testing, fielding, and analysis of the survey. This may range from no involvement -- to consultation with the survey administrator -- to community control of entire process; How was information about the survey communicated to the community period to data collection?
Data Access/Ownership	Detailed description of who has access to and ownership of the raw data and findings from the survey
Questionnaire Design	
Comprehensiveness of Questions	Describes the type of questions (e.g., health status, health care utilization, risk behavior, health care quality, satisfaction with services, awareness or knowledge of specific health conditions, quality of life, etc) covered by the survey
Types of Questions	Describes the types of questions asked (e.g. open/closed; scales, etc.)
Validation of Questionnaire	Were the interview questions validated prior to data collection? If so, how were they validated and were they validated in the Indigenous community?
Linguistic/Cultural appropriateness	If the questions were from a pre-existing survey, were they adapted for this population (e.g., language)? Provide detail

Inter Rater Reliability/Construct Validity Testing	Includes IRR and other methods for testing the reliability and validity of survey questions and in what subpopulations validity testing (i.e., field testing) occurred
Verification of Self-Report	Includes any efforts to reinforce the respondents memory through the use of records, receipts, prescriptions, pill bottles, etc.
Data Collection	
Selection of Interviewers	To assess whether the interviewers were community members, government employees, researchers, etc. and how were they selected
Method of Data Collection	How was the survey conducted (e.g., by phone, face to face, by mail)?
Setting	Setting in which the data was collected (e.g., respondents home, community building, clinic)
Collection of Specimens	If specimens were taken, how were they stored?; If specimens were taken, how were they disposed/returned after the data were analyzed?
Length of Interview	How much time, on average, did it take respondents to answer the questions?; Did this vary by patient or interviewer characteristics?
Proxy Respondents	Were proxy respondents used? If so, how was their information recorded and was the identification of the proxy responder provided?
Interviewer Consistency	What was the consistency in coding between interviewers?
Method of Data Entry	How and when data were recorded
Results	
Response Rate(s)	Percent of the target population that actually completed the survey; If the survey was conducted in waves, what percent of patients completed each of the waves?
Post Stratification	Record of any post stratification prior to analysis of the data
Design Effect	Comparing of the sampling variance of the sample compared to a simple random sample of the same size
Dissemination of Findings	
Methods for Communicating Results	Assessment of how the results were communicated to Indigenous communities
Availability of Data to Indigenous Communities	Assessment of whether, when and to what extent the raw data elements and the analytic files were available to Indigenous communities

Where possible, information on the above characteristics was obtained from published documents. However, we also contacted the administrators directly to obtain information that was not available from the published reports. While all of the above characteristics were assessed as part of the comparative analysis, some characteristics (e.g., funding, Indigenous community involvement) were collected to inform the analysis of the consistency of the RHS with self-determination and barriers to its implementation.

Once we had sufficient information (80% of the key indicators identified) on all of the selected studies, we compared them with respect to the validity of the methods employed and their success in engaging Indigenous participation. Specifically, we ranked the RHS relative to other surveys along the following dimensions: (1) Response Rates and Sampling Error, (2) Question Validity/Reliability, (3) Comprehensiveness of Survey Questionnaires; (4) Validity/Reliability of Data Collection Methods, (5) Maximal Dissemination of Information back to Indigenous

Communities, and (6) overall agreement of the survey methodology with established standards of Research Ethics (e.g., Helsinki, Belmont).

We categorized the comparison surveys into two groups: those that targeted Indigenous populations and those that did not. The first group was most comparable to the RHS and, therefore, provided a comparison for the methodology and results employed. These surveys will provide examples of whether the RHS may be more or less reliable or more or less comprehensive. The second group provided a contrasting approach. For example, if the RHS obtained similar sample sizes and response rates as those obtained from surveys that did not target Indigenous populations, we might conclude that a separate survey was unnecessary to maximize Indigenous participation.

The comparative analysis was primarily qualitative, though we did compare the surveys using several quantitative measures (e.g., response rate) that have been identified in the literature as having an impact on overall survey quality. Our goal was not to assess which survey was best, but rather to assess whether the strategies employed in the RHS were reasonable and appropriate. The comparison was also used to identify whether there are opportunities to improve the methods in future rounds of data collection.

Appendix 8: Copy of Internal Review Board Approvals



Harvard Pilgrim
Health Care

May 24, 2004

Alyce Adams, PhD
DACP
133 Brookline Ave
Boston MA 02215

Dear Dr. Adams:

RE: " Mid-Term Review of the First Nations Longitudinal Regional Survey,"

Your proposed research, cited above, has been appraised and granted an exemption from review under 45 CFR 46, b (2) Research involving the use of educational tests, (cognitive, diagnostic aptitude, achievement) survey procedures.

Should anything change during the course of research, it is your responsibility to report changes to the Harvard Pilgrim Health Care Human Studies Committee.

Sincerely,

Laureen Kunches, NP, MPH, MS
Chair
Human Studies Committee

Harvard Pilgrim Health Care
Research Administration
133 Brookline Avenue, 6th Floor
Boston, Massachusetts 02215
Telephone: 617-509-9894 • Fax: 617-509-9859



**Harvard Pilgrim
Health Care**

March 28, 2005


Alyce Adams, PHD
DACP
133 Brookline Ave
Boston MA 02215

Dear Dr. Adams:

The proposed change (revised proposal to conduct a review of the First Nations Longitudinal Region Health Survey, (RHS).in your **exempt** status research, "Mid Term Review of the First National Longitudinal Regional Survey.", as requested in your correspondence dated March 24, 2005, is approved under the expedited review procedures of the Harvard Pilgrim Health Care Human Studies Committee.

Approval under the expedited review procedures is reviewed by the full HSC at its next meeting; your study will be on the agenda for April 21, 2005, at that meeting, the HSC may approve, modify or withdraw approval that is made today under the expedited review. If the HSC takes any action other than approval, we shall let you know.

Sincerely,


Laureen Kunches, NP, MS, MPH
Chair
Human Studies Committee

Harvard Pilgrim Health Care
Research Administration
133 Brookline Avenue, 6th Floor
Boston, Massachusetts 02215
Telephone: 617-509-9894 • Fax: 617-509-9859



**Harvard Pilgrim
Health Care**

January 10, 2006

Alyce S. Adams, MD, MPP
Department Ambulatory Care and Prevention
133 Brookline Ave, 6th Floor
Boston, MA 02215

Dear Dr. Adams:

Re: "Mid Term Review of the First Nations Longitudinal Regional Health Survey"

This letter confirms the continued exemption of your research, as cited above, and described in your letter of November 16, 2005, this is based upon: **45 CFR 46.101 (b) (2), Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:**

(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

We acknowledge the additions described in your letter to include the following:

- ◆ Increase in sample size for interviews
- ◆ Inclusion of community representatives

Thank you for continuing to notify the Harvard Pilgrim Health Care Human Studies Committee of any significant matters related to your study.

Sincerely,

A handwritten signature in cursive script that reads "Laureen Kunches".

Laureen Kunches, PhD
Chair, Human Studies Committee

**Harvard Pilgrim Health Care
Office of Sponsored Programs**
133 Brookline Avenue, 5th Floor
Boston, MA 02215
Telephone (617) 509-9843 • Fax (617) 509-9859

Appendix 9: Review of the 2002/2003 RHS Final Survey Instrument

Measures of Common Covariates

There are several questions that are asked on most surveys to assess common characteristics of respondents including age, gender, marital status, employment status, socioeconomic status, income, religion, and race or ethnicity. To assess age, the 2002/2003 RHS asks for date of birth or, for respondents who do not know their birth date, age as of December 31st of the previous year. This method is recommended over asking the individual's current age. It is unclear how gender is asked by the interviewers based on the questionnaire alone. Marital status is asked in a way that is consistent with recommended practice. While the questionnaire does not ask about whether the married couples live together, a subsequent question asks how many adults are living in the household. The CAPI system also included hyperlinks to definitions for any potentially confusing terms.

The adult 2002/2003 RHS also includes questions related to income, work and education level. Occupation is not included. To avoid the common problem of respondents providing the household income instead of their individual income, the 2002/2003 RHS asks for both individual and household income levels. In addition, income is specified as being for the preceding year, which is consistent with best practices. Income is also asked in ranges (e.g., \$10,000-\$14,999) rather than an exact number to increase response. The adult 2002/2003 RHS includes few questions on education and does not distinguish between high school graduation and an equivalency degree (GED). However, the youth survey contains several detailed questions about education, including whether the individual received a GED, whether they left school and their feelings about their education.

Respondents are not asked to provide information about their religious beliefs. They are, however, asked whether religion is important to them. Race and ethnicity are not obtained as part of the survey. We presume this is because the individuals included in the sample are those included on community lists. However, in areas where some household or other sampling frames were used in lieu of membership lists, some verification of race or ethnicity may be warranted. The consent form process may be ideal for obtaining additional information on First Nations identity.

Measures of Frequency

Measures of frequency attempt to assess how often the respondent carries out a particular activity (e.g., how often do you smoke) or feels a certain way (e.g., how often do you feel sad). In general, it is better to quantify the frequency (i.e., 1-2 times, 3-4 times) during a period of time than to ask in a qualitative way (e.g., very, often, never). However, the disadvantages of qualitative options are reduced when they are asked in a proportional way. For example, asking all of the time, most of the time, some of the time, almost none of the time, is better than asking always, sometimes, never.

The 2002/2003 RHS asks respondents to quantify the frequency of particular activities, while relying on qualitative assessments for questions relating to feelings. For example, in the adult survey, respondents are asked to report, "In the past two weeks, how often have you checked

your blood sugar levels?” and offers several quantitative options (e.g., more than once a day, between 10-13 time in the past 2 weeks). When asking respondents about how they feel, the survey provides respondents with proportion of time options. Both of these strategies are consistent with expert advice.

Measuring Quantity

The literature on survey design recommends the use of numerical scales rather than adjectives such as “very small” or “almost none” to measure quantities. The 2002/2003 RHS follows this guideline as well. For example, respondents are asked to report the number of people with whom they have had sexual intercourse and the number of cigarettes they smoke in a day. Respondents are asked to report a range for the number of sexual partners question (e.g., none, 1-2, 3-4, 5-6, 7-10), the intervals for which grow wider as the number of partners increases. This is in contrast to the cigarette question in which respondents are asked to report the exact number of cigarettes. Providing a range of responses for the more sensitive question regarding sexual behavior likely increased the response to this question.

Measuring Feelings

Differences in psychology and culture can cause people to describe their feelings in very different ways. As a result, asking people how they feel in a way that allows for comparison can be difficult. Use of pictures or diagrams can sometimes be more useful than words such as positive or negative or happy or sad. Examples may include the use of a temperature gauge or faces expressing various stages of emotion.

The 2002/2003 RHS uses more culturally specific imagery to achieve the same result. Namely, they ask about balance in four dimensions of well being: physical, emotional, mental and spiritual. The conceptualization of well being divisible into four distinct spheres is common among North American Indigenous groups and is often referred to as the medicine wheel concept. It is likely that many of the respondents to the 2002/2003 RHS will be familiar with this concept. However, the question may be further strengthened by invoking the visual display of a medicine wheel in the same way that health surveys use thermometers or faces.

Measuring Health Status

A key function of health surveys is to gauge the respondents’ view of their own health status. This can be accomplished by asking general questions, assessing the presence of specific diseases and asking the respondent to report limitations in activities stemming from health related issues (e.g., limitations in activities of daily living, missing work). The 2002/2003 RHS uses a subset of one of the most commonly used instruments to assess health status, the SF-36 Health Survey, developed for the Medical Outcomes Study.⁸⁶ The SF-36 includes questions regarding limitation in physical, social, and usual role activities due to physical, mental or emotional illness, presence of physical pain, general mental health, vitality, and general health

⁸⁶ Ware JE, Kosinski MO, Keller SD. SF-36 physical and mental health summary scales: A user’s manual. Boston, MA: The Health Institute, 1994.

perceptions. The instrument, both in full form or as a subset of questions, has been validated in several countries and found to be reliable method for assessing respondent health.⁸⁷

However, studies of the SF-36 in non-European and non-US contexts have brought into questions the universal applicability of the instrument. For example, studies in Japan showed the SF-36 to be more variable than in the US.⁸⁸ Others have questioned its applicability to sub-populations in US and European countries. The applicability of the SF-36 to Indigenous populations was explored in an earlier version of one of the comparison surveys highlighted in this review, the New Zealand Health Survey (1999).⁸⁹ Using principle components analysis, the authors found that Maori and Pacific respondents had higher average standard deviations across several scales (e.g., physical functioning, role physical, mental health) and had higher rates of missing data. Yet, the components of the SF-36 explained a similarly high proportion of the variance for all three groups.

In comparing the factors structure suggested by the factor loadings, the authors found that the Pacific Islander group did not load along the same lines as the European and Maori respondents. Further, there were age-related differences in the stability of the structural model among the Maori; data for those under age 45 suggested a two factor structure (physical and mental) similar to the model for Europeans, but this was not the case for Maori over age 44. This finding may suggest that older Maori do not distinguish mental and physical well being as separate constructs, which is more consistent with traditional Maori culture. The fact that the 2002/2003 RHS includes both a general health status and activities of daily living measures found in the SF-36 and questions about traditional culture and balance in the four dimensions suggests that a similar assessment of the validity of the SF-36 in First Nations may be possible among First Nations citizens.

In addition to general health status, the 2002/2003 RHS asks about specific health conditions, where the diseases of interest vary by the age of the respondent. For example, the adult survey does not ask about chronic ear infections and the adolescent survey does not ask about rheumatoid arthritis. The 2002/2003 RHS asks the respondent whether they have ever been told they have the disease, at what age they were first told, whether they are undergoing treatment or taking medication for the condition, and whether it has limited their activities. Interestingly, the survey uses the medical terms for these conditions. Given that research suggests that there may be cultural differences in how people refer to a particular disease (e.g., sugar vs. diabetes), additional investigation regarding whether the respondents recognized these conditions is warranted.

⁸⁷ Ware JE, Kosinski M, Gandek B, et al. The factor structure of the SF-36 health survey in 10 countries: Results from the IQOLA project. *J Clin Epidemiol* 1998;51:1159-1165.

⁸⁸ Fukuhara S, Ware JE, Kosinski M, et al. Psychometric and clinical tests of validity in the Japanese SF-36 health survey. *J Clin Epidemiol* 1998;51:1045-1053.

⁸⁹ Scott KM, Sarfati D, Tobias MI, Haslett SJ. A challenge to the cross-cultural validity of the SF-36 health survey: factor structure in Maori, Pacific and New Zealand European ethnic groups. *Soc Sci Med* 2000;51:1655-1664.

Measuring Priorities

In assessing how respondents prioritize items, it is harder for respondents to compare and rank items (see Option 1 in the text box below) than to evaluate each item separately (Option 2).

<p><u>Option 1:</u> Is physical or mental well being more important to you?</p>
<p><u>Option 2:</u> On a scale of 1 to 10 where 10 is extremely important, how important is physical well being to you? On a scale of 1 to 10 where 10 is extremely important, how important is emotional well being to you?</p>

Some questions in the 2002/2003 RHS ask respondents to describe the importance of Indigenous language, traditional cultural events, traditional spirituality and religion. In accordance with accepted practices, these questions are asked as separate items. Further, they provide examples of traditional cultural events to aid respondents in their answers.

However, this question may be prone to social desirability bias in particular communities or among respondents with specific characteristics. Because the respondents are not asked about whether they participate in these activities, those who respond that the activities are important may include those who do not participate in these activities routinely, but who sense that participation in them is socially desirable. Interestingly, the possibility of social desirability bias in response to this question may vary according to whether or not the interviewer is also from a First Nations community. Still, the impact of this possible bias on the analysis is unclear. Specifically, if the interviewer is interesting in learning about actual behavior, social desirability bias would be of concern. However, if the interest is in knowledge of or affinity toward cultural traditions, social desirability bias may not be a true threat to the validity of the findings.

Don't Knows

As a general rule, “don’t know” should be provided as an option when the respondent is being asked a factual question. As an alternative, the interviewer may include a screening question to assess the respondent’s knowledge about a particular topic before asking additional questions about it. An example would be to ask someone if they are aware of a particular legislative action before asking for an opinion on whether it should be passed. Due to the length of the survey, screening questions were removed from the 2002/2003 RHS. Instead, fieldworkers were trained to assess respondent knowledge or comfort with a topic and manage the interaction appropriately.

In the 2002/2003 RHS, screening questions are not used. However, “don’t know” answers are used primarily in conjunction with factual questions. An example is question 100 on the adult survey, in which the respondent is asked whether a parent attended residential school.

“Don’t know” is also provided as a response on questions about personal wellness. For these questions, it is unclear whether “don’t know” reflects genuine confusion about how the respondent feels or discomfort with the question (see social desirability bias discussion above). Given the low rate of “don’t know” responses in the 2002/2003 RHS (see data quality discussion that follows), however, it is unlikely that inappropriate responses posed a serious threat to the validity of the findings.

