

First Nations Regional Health Survey (RHS)

*Best Practice Tools for
OCAP Compliant Research*



“WE BELIEVE IN RHS!”



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

The First Nations Information Governance Centre
170 Laurier Avenue West, Suite 904
Ottawa, Ontario K1P 5V5
Tel: (613) 733-1916
Fax: (613) 231-7072
Toll Free: (866) 997-6248
www.fnigc.ca

This booklet is available in English and French electronically
at: www.fnigc.ca

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1. RHS BACKGROUND – ORIGINS

The First Nations Regional Health Survey (commonly abbreviated to RHS) is the only First Nations governed national health survey in Canada. It is a governed national health survey in Canada that collects information based on both Western and traditional understandings of health and well-being.

In 1996, the Assembly of First Nations Chiefs Committee on Health mandated that a First Nations health survey be implemented every four years across Canada. This mandate came as a result of the activities that began in 1994, when the federal government began three major national surveys. The national sampling frame for these surveys, however, specifically excluded First Nations people living on-reserve. Following a national consultative process in 1995 with First Nations, Inuit and Aboriginal communities and organizations, it was determined that in order to proceed collectively, the process must include a collaboration of distinct regional surveys with a national core content.

This decision began a First Nations and Inuit controlled process of research, identification of health status and health planning, and a new partnership with Medical Services Branch and national First Nations and Inuit organizations.

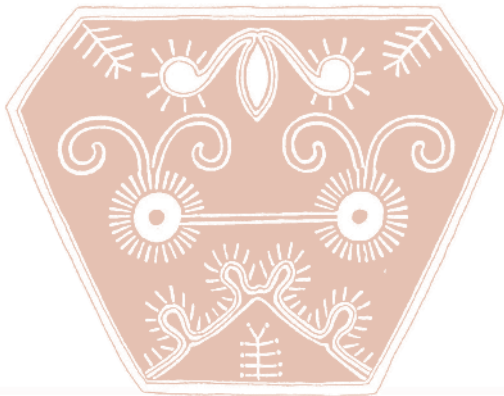
The first RHS took place in 1997 (RHS 1997) and involved First Nations and Inuit from across Canada. The survey was implemented to address the deficiencies in First Nations and Inuit health and well-being while acknowledging the need for First Nations and Inuit to control their own health information. RHS 1997 is commonly referred to as the pilot survey.

The RHS Phase 1 was implemented in 2002-03. Since the pilot study in 1997, two new regions joined the RHS

process, the Yukon and Northwest Territories. The Inuit withdrew from the RHS process in favor of an Inuit specific survey. Hence, the change from the First Nation and Inuit Regional Health Survey to the current First Nations Regional Longitudinal Health Survey.

Data collection for RHS Phase 1 (2002/03) began in the fall of 2002 and was completed in mid-2003. RHS Phase 1 was designed as the baseline study of a design. In total, 22,602 surveys were collected from 238 First Nations communities.

The RHS Phase 2 was initiated in 2008 and was completed in the fall of 2010. In RHS Phase 2, 72.5% of the target was achieved and in total, 21,757 surveys were collected in 216 First Nations communities.



2. RHS CODE OF RESEARCH ETHICS

The purpose of the Code of Ethics is to establish a framework of principles and procedures to guide the members of the First Nations Information Governance Centre (FNIGC) to accomplish the mandate and objectives of the RHS. This Code outlines the responsibilities of each member through all aspects and phases of the surveys and potential spin-off research to its conclusion.

FIRST NATION RESEARCH POLICY STATEMENT

It is acknowledged and respected that the right of self-determination of First Nations includes the jurisdiction and authority to make decisions about research in their communities. The benefits to the communities, to each region and the national effort should be strengthened by the research. Research should facilitate First Nations communities in learning more about the health and well being of their peoples, taking control and management of their health information and assist in the promotion of healthy lifestyles, practices and effective program planning. The FNIGC promotes making the most of the funding opportunity on behalf of First Nations. We will reclaim the original foundations of our health and healing.

RHS GUIDING PRINCIPLES

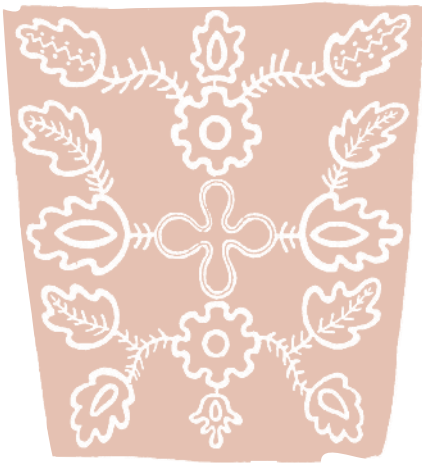
1. First Nations principles of Ownership, Control, Access, and Possession (OCAP) will be respected. OCAP is self-determination applied to research.
2. The FNIGC encourages and will facilitate research of the highest quality while striving to establish the conditions and skills for First Nations self-determination and responsibility for the total health of our communities.

3. The FNIGC recognizes the highest standards of research practice and will subject the RHS to review and/or evaluation to ensure data quality and integrity while respecting the First Nations principles of OCAP.
4. The FNIGC recognizes that participatory culturally-based research takes several years to develop. However, the RHS should demonstrably contribute information, skills and capacity building.
5. The FNIGC recommends that, as far as possible, fact finding and analysis should be participatory allowing communities to determine which aspects of health should be addressed and how.
6. The surveys should stimulate informed dialogue between communities, local authorities, federal and provincial governments and services.
7. The communities must be involved as full partners in all aspects of the research. Feedback, input, participation in analysis and interpretation and communications should always characterize the research relationship.
8. First Nations community authorities must approve data collection in their regions.
9. All data collected belongs to the communities and must be returned as grouped results.
10. First Nations local community and regional protocols must be respected.
11. The strengths, cultures, languages and traditional norms of the communities must be respected and utilized wherever possible.
12. Survey questionnaires will be developed for each of the regional surveys to give selected communities an

opportunity to include questions of a cultural nature as well as questions that specifically address pressing local concerns.

13. Informed consent from survey respondents will be obtained prior to collecting personal information.
14. Survey questionnaires of a personal nature are to be answered in the strictest confidentiality or to be completed anonymously.
15. Confidentiality of the respondents must be assured. The respondents will remain anonymous when the results are reported.
16. All research results, analyses and interpretations for the National Core Data must first be reported to the FNIGC to ensure accuracy and avoid misunderstanding. This same process must be respected in each region as it pertains to the regional data where the communities and the regional advisory committees would first be reported to.
17. All national core raw data will be stored at the FNIGC which assumes the responsibility for all First Nations health information. Raw data will be kept on a server in FNIGC. All data will be password protected and confidentiality of data is maintained as outlined in the Data Protection and Stewardship Protocol and Survival of Confidentiality Requirement of the regional contribution agreement.
18. Access to the national database will only be available to researchers as approved by the FNIGC as necessary for purposes of data analysis. This will be managed by the RHS National Team as directed by the FNIGC by resolution.

19. Long term research research requires a stable research environment for data storage.
20. The FNIGC members must approve the release of the national results and products directly or through the established protocols to such releases.



3. RHS CULTURAL FRAMEWORK

The FNIGC commissioned the development of the RHS Cultural Framework to assist in achieving a culturally informed interpretation process. That is, research should be presented back to communities in ways that are usable and reinforce their ways of seeing, relating, knowing and being. Simply stated, the RHS Cultural Framework encompasses the total health of the total person within the total environment.

From the beginning, First Nations peoples have been taught that we start with a focus on the people – by giving thanks for their caring, honesty, sharing, and strength. Therefore, in keeping with the RHS Cultural Framework, we wish to extend our appreciation to all the First Nations people that participated and shared in this process.

Figure 1: The RHS Cultural Framework



WHERE THE MODEL COMES FROM

The underlying science behind the RHS Cultural Framework has been handed down through generations of First Nations peoples as a cumulated body of knowledge and beliefs. While it is recognized that Indigenous Knowledge is not a uniform concept across all First Nations in Canada, for most First Nations peoples there is a common belief in a connection with the natural world. With this in mind, we represent the natural world with a circle.

We begin at the centre of the cultural model (see Figure 1) with a focus on First Nations people. It is reflective of the reasons, rules and rationale that are incorporated in the underlying science of the cultural model. In accordance with these rules, we will then move from the Centre to the East, South, West, North, and East again.

VISION (WAYS OF SEEING)

Within a First Nations cultural paradigm, vision is considered the most fundamental of principles. Visioning First Nations' well-being involves examining the complete picture of health including physical, mental, emotional and spiritual health issues. From an Indigenous Knowledge perspective, visioning will examine what is the ideal state of First Nations health and wellness (what was the standard in the past and what is the desirable/achievable in the future). In order to envision First Nations' health and wellness, it is imperative to establish a baseline of the extent and causes of the current situation. It is from that baseline that First Nation communities and stakeholders can move forward towards the ideal vision.

RELATIONSHIPS (TIME/WAYS OF RELATING)

Refers to the experiences that one encounters as a result of relationships built over time and examines how we relate to people. It provides an opportunity to gain an

understanding of the attitudes and awareness that exist at this particular point of time, regarding the individual, community and national wellness issues.

REASON (ANALYSIS/REASON)

Also referred to as learned knowledge. It is where we become reflective, meditative and self-evaluative. It is in this direction that the broader determinants of health are examined.

ACTION (BEHAVIORS)

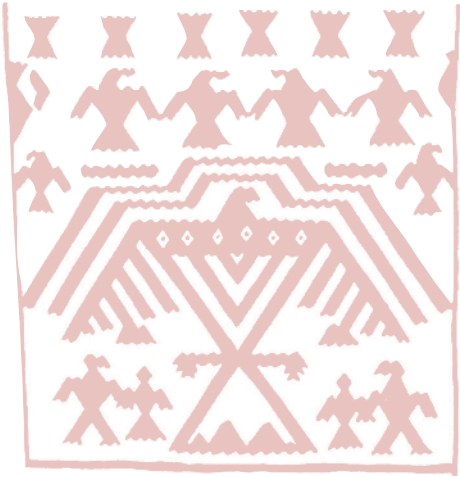
Also referred to as movement and represents strength. This direction explores what has been done about previously identified barriers and how to nurture us as First Nations. This component is important in that it activates positive change to improve the program so that it better achieves the vision (expectations) of First Nations resulting in the healthy development of their children, families and communities. It is important to note that the circular models presented in the RHS cultural framework are not medicine wheels.

While each First Nation has its own particular view of the world, some principles are held in common. Including: a view that the world is alive and all nature is connected and related; an appreciation for wholeness that cannot be reduced to the sum of its parts; and because all is alive, nature is in a constant state of renewal.

The RHS Cultural Framework guides both the development of the questions for the survey and the interpretation of the information received by First Nations. The implication of this holistic approach is the necessity to consider all the data from all areas prior to making decisions.

This acknowledges that decisions in any area will have implications for the other areas. "This approach to health and wellness is based on "BALANCE" of seeking balance,

of achieving balance and of maintaining balance". While it is beyond the scope of this document to describe the entire cultural framework, it is important to understand that the beliefs and values First Nations hold in common guide and shape the RHS.



4. FIRST NATIONS GOVERNANCE OVER RHS

The First Nations Information Governance Centre (FNIGC) has been mandated to coordinate and oversee the (RHS) and serve as the data stewards of the national data. The Regions have been mandated to coordinate the RHS within their respective regions and to serve as stewards of that data. As data stewards, the Regions and the FNIGC respect and uphold the sovereign rights of First Nations and the authority conferred or mandated to their representative bodies.

The RHS infrastructure and system for information governance has been uniquely and successfully designed by First Nations, for First Nations, to include three essential elements:

1. Protecting individual and collective privacy;
2. Recognizing and respecting the First Nations Principles of OCAP and ensuring that RHS results are disseminated and data are made available for research and study, by government and others, to advance knowledge that will improve First Nations health; and
3. Respect for national, regional and community information governance.

One of the fundamental principles underlying the RHS is that First Nations have the right and the responsibility to govern their information in a manner that respects their values, cultures and traditions. First Nations have always maintained an understanding and relationship to information and have recognized and respected certain protocols pertaining to the collection, use and passing on

of information. Information governance is multi-layered. It has implications for individual and collective privacy, data collection, storage and dissemination and national, regional and community information governance.

First Nations share and respect values of personal privacy with other Canadians. However, in addition to personal privacy, First Nations also value community and collective privacy. Recognition of collective privacy interests is based upon the principle that groupings of people, and not just individuals, have an interest in controlling access to information, particularly sensitive information, regarding that specific group or community.

It is acknowledged and respected that the right of self-determination of First Nations includes the jurisdiction and authority to make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate First Nations communities in learning more about the health and well being of their peoples, taking control and management of their health information and assist in the promotion of healthy lifestyles, practices and effective program planning.

During the data collection and roll-up phase of the RHS, the Regions delegate responsibility for the care of RHS survey data to the RHS National Office. The RHS National Office under the direction of the FNIGC, is responsible for managing and protecting national and, where applicable, regional RHS data. Specifically, the RHS National Office ensures that data meet the highest standards, and serves as data steward of regional and national data until final cleaned and weighted databases are prepared, containing all data from regional respondents. At that time, the regional data are transferred back to the respective First Nations regional organization, and the RHS National Office

continues to act as a steward of all survey data related to national 'core' questions, on behalf of and under the direction of the FNIGC.

The RHS National Office retains no record of regional modules thereafter, all research results, analyses and interpretations for the national core data must first be reviewed and approved by the FNIGC to ensure accuracy and avoid misunderstanding. Access to the national database is managed by the RHS National Office as directed by the FNIGC. General analysis of the national core data is conducted as per the direction of the FNIGC to include a detailed, comparative analysis of the national core data against other national surveys and relevant First Nations health data.

Requests for access to RHS national-level data – or for the generation of statistical reports based upon RHS national-level data – for research or study purposes must be made through the FNIGC and approved according to the RHS Code of Research Ethics. The FNIGC has entered into a License to Use Agreement with FNIHB, Health Canada regarding statistical reports from the RHS national core data, for national-level data only.

The RHS National Office is mandated and authorized to report on national level statistics and cannot share, provide or report on regional or community-level statistics. First Nation communities and regions can only be identified if the respective First Nation or region provides explicit consent. Each region is completely independent and responsible for its own databases, reports and dissemination.

The RHS National Office is governed by its policies and procedures, particularly the RHS Code of Research Ethics, the Data Stewardship and Protection Protocol, and the Personal Privacy Policy. It is accountable to the regions, through the FNIGC and through the contractual agreements.

5. FIRST NATIONS PRINCIPLES OF OCAP

In the 1990s, First Nations were increasingly dissatisfied with Canadian privacy and access to information laws that did not meet their needs and aspirations. First Nations believed they had been 'researched to death' with little or nothing to do with the information that was collected from them and taken out of their communities. The First Nations principles of OCAP (Ownership, Control, Access and Possession) were initially coined as 'OCA' in 1998 as a framework for asserting self-governance over information related to research at a RHS National Steering Committee meeting.

The 'P' for possession was later added to exert ownership, control and access over data that proved nearly impossible in the possession of governments and academia.

Ownership: The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information. It is distinct from stewardship or possession.

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research and information. The principle of 'control' asserts that First Nations, their communities and representative bodies are within their rights in seeking to control research and information management processes which impact them. This includes all stages of research projects, and more broadly, research policy, resources, review processes, formulation of conceptual frameworks, data management, and so on.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where these are currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.

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

The principles of OCAP mean that First Nations control data collection processes in their communities. First Nations own protect and control how their information is used. Access to First Nations data is important and First Nations determine, under appropriate mandates and protocols, how access by external researchers is facilitated and respected. The right of First Nations communities to own, control, access, and possess information about their peoples is fundamentally tied to self-determination and to the preservation and development of their culture. OCAP allows a community to govern how information is collected, used or shared.

6. RHS SURVEY DESIGN & SAMPLING FRAME

The RHS systematically seeks to improve upon its research methods and processes. While the RHS 1997 relied mostly on university-based researchers who worked alongside First Nations and Inuit representatives from regional organizations, RHS Phase 1 (2002/03) enhanced the capacity of First Nations in a number of areas including: survey design; data collection; and analysis, and interpretation and dissemination of information. This section offers an overview of each area.

SURVEY DESIGN

Building on the strengths and lessons learned from RHS 1997, three national survey instruments were developed for the RHS Phase 1 (2002-03) data collection. In addition to the adult and children's survey, a youth survey was added to reflect the unique issues this population faces. Consideration was also given to older adults (55 and older) with over-sampling built into the adult sampling design.

The RHS Phase 1 (2002/03) questionnaires were developed and refined over two years with participation from a large number of people including health workers in First Nations communities; physicians and nurses; staff and consultants of First Nations regional and national organizations; Health Canada, FNIHB staff; university-based researchers; Assembly of First Nations; RHS Regional Coordinators; and FNIGC members.

The survey design phase sought to balance First Nations content with comparable Canadian surveys while remaining culturally and scientifically valid. A 1998 AFN Chiefs Committee on Health resolution also called for incorporating sensitive issues such as HIV/AIDS, suicide and mental health. The adult and youth questionnaires

included these topics as well as questions on residential school, alcohol and drug use and sexual activity.

Participants in the design phases discussed the ethical issues raised by the addition of these sensitive topics and identified ways (e.g., training for fieldworkers, referral lists, etc.) for addressing the emergence of painful memories with participants. In addition, the survey design allowed for a region-specific survey modules.

The RHS Regional Coordinators subsequently led two rounds of qualitative field testing based on standardized procedures and probes with each questionnaire. This process led to further refinements of the survey instruments.

The participatory research process was inclusive of all regions and was characterized by repeated collaborative cycles of deliberation and decision making, organized by the RHS national office, with FNIGC and the RHS Regional 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.

Further, the RHS survey design includes an opportunity for a range of spin-off surveys that build on the RHS infrastructure using the RHS Phase 1 (2002/03) sample as a frame. Potential spin-offs could include, for example, surveys on nutrition, disability, diabetes, smoking, mental health, nutrition, and children's issues that can be conducted at a community, regional or national level. Two small pilot surveys – the West Nile Virus, the RHS Community Ecological Survey and the First Nations Oral Health Survey – were completed by leveraging the RHS process.

Finally, the RHS Phase 2 (2008/10) builds on previous strengths and lessons learned to further understand the factors that influence individual and community well-being. The questionnaire content underwent extensive

reviews and revisions, assessed comparability, non-response, redundancies; and new themes have been added to the RHS 2008/10 core components based on extensive feedback. The adult survey includes questions about migration, food security, violence, care giving, depression, the health utilities index and gambling. The youth survey includes questions on community wellness and children's survey has added questions on immunization.

SAMPLING FRAME

The sampling design requires cross-sectional and coverage in each region, as well as a nationally representative sample. The RHS 1997 sample included First Nations living on-reserve and Inuit in Labrador communities, and it consisted of an original cohort of 14,008 individuals (9,870 adults, 4,138 children) in 186 First Nations communities and five Inuit communities. Sample designs for this survey varied from region to region.

The FNIGC improved upon the sampling plan of 1997 by using one consistent sampling frame. The sampling frame used a two-stage stratified sampling design to obtain a representative sample. While the Indian and Northern Affairs Canada registry files were used to structure the sampling design, community membership lists were used to identify potential individual respondents thereby allowing communities to define their own membership. In RHS Phase 1 (2002/03) the response rate was 80% or a total of 22,602 survey responses from 238 different First Nations communities. Although the sample size was adequate for cross sectional and analyses. The sample was stratified by age/sex and by geopolitical groupings identified as relevant by the First Nation regional organizations. Communities were randomly selected within strata and according to their population.

DATA COLLECTION

To improve the data collection process for the RHS Phase 1 (2002-03), a customized Computer Assisted Personal Interviewing (CAPI) package was developed and deployed in laptops to fieldworkers. RHS Regional Coordinators and fieldworkers receive intensive training on the use of the system. The CAPI system incorporates 'client-server' architecture and a telecommunication infrastructure that allows two-way communication for the secure upload of data from the field as well as the receipt (download) of software/database updates and 'fieldworker news'. The data are uploaded on servers maintained nationally and in two regions by First Nations organizations (Saskatchewan and Quebec).

This technology allowed survey participants further control over the interview process. For instance, the protocol for interviewing provided for: adults to be interviewed directly; children to be interviewed by their primary caregiver (i.e., mother, father or grandfather); and youth to complete the survey themselves. The technology enabled all participants the opportunity to self-administer the questionnaire thus ensuring privacy and confidentiality of data. Where participants chose self-administration, the interviewer remained in the room to offer assistance as needed.

This technology also improved data quality, decreased interview time, increased participation rates, offered fieldworkers exposure to new technologies and resulted in a dramatic reduction in the delay between collection and analysis. Moreover, the system provided RHS staff with real-time remote access for purposes of quality assurance, reporting, analysis and monitoring.

Improvements for the RHS Phase 2 (2008/10) continue with the use of Techneos Entryware™ system. This off-the-shelf system consists of an Entryware Server™ program for the national or regional servers, and Entryware Mobile™

program for the mobile data collection laptops. The use of this system enables further efficiencies and effectiveness in prototyping, development, testing, piloting, and quality control. The system also allows for more flexibility to undertake other surveys.



7. RHS ETHICS AND PRIVACY

FIRST NATION ETHICS

FNIGC commissioned two independent ethical reviews. The first review was held in 2002 with the second occurring in 2007. Each review included an open call for First Nations experts with recognized experience and knowledge in the area of First Nations research.

This panel of experts was to assess the RHS and its methods for compliance with ethical codes of research. For instance, the 2002 review included: the Code of Research Ethics, First Nations and Inuit Regional Health Survey (1997); Ethical Guidelines for Research, Royal Commission on Aboriginal Peoples (1996); and the Ethical Conduct for Research Involving Humans, Tri-Council Policy Statement of the Medical Research Council of Canada, Natural Science and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council (1999).

The second review conducted in 2007 applied the revised RHS Code of Research Ethics (2007), the recent Canadian Institutes of Health Research (2007) guidelines, the results and recommendations from the first review, and the RHS Lessons Learned Report from RHS Phase 1. Following the assessment, the panels were to make recommendations for changes or modifications to the RHS and its methods.

Each review resulted in high marks concerning compliance and an acknowledgement for efforts toward continuously strengthening the work. For instance, Dr. David Flaherty, a privacy expert noted that a “culture of review and transparency of RHS processes has been demonstrated and established”. These improvements were also noted by the Research Ethics Board of Health Canada who reviewed the RHS Phase 2 (2008/10) and subsequently approved the research for funding.

RHS PRIVACY IMPACT ASSESSMENTS

At an individual level, the RHS exists because First Nations community members consent to share their personal information with RHS fieldworkers. This trust is taken very seriously and the RHS has developed and utilized detailed policies, procedures and technologies to protect personal privacy and to ensure the security of RHS data.

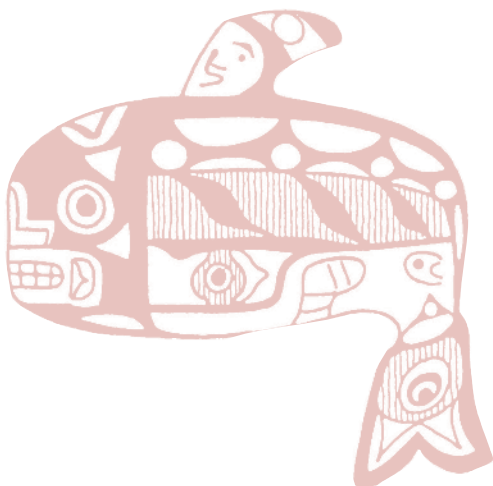
In RHS Phase 1 (2002/2003), consultant Dr. David Flaherty was retained to conduct a Privacy Impact Assessment (PIA) of the data collection and storage plan for the RHS. A PIA is a tool used for data protection and to raise privacy alarms at an early stage in an organization's planning process for the collection of personal information. The PIA is a risk-assessment tool for decision makers to address not only the legal but also the moral and ethical issues around privacy. Conducting a PIA is an effective method of engaging a team within an organization to work together to identify and resolve data protection problems. Dr. Flaherty's review was based on the ten privacy principles contained within the Canadian Standards Association (CSA) Model Code for the Protection of Personal Information, which is found in Schedule 1 of the Personal Information Protection and Electronic Documents Act, S.C. 2005, c. 5.

The RHS received an Overall Grade of B to B+ on its 'Privacy Report Card' from Dr. Flaherty, with the RHS consent process being noted as particularly excellent. Since 2003, the RHS has further enhanced personal privacy protection with practical innovations, including:

- development of a Privacy Breach Protocol;
- development of a Personal Privacy Policy for use nationally and regionally;
- development of a Criminal Records Check Policy for RHS fieldworkers; and

- development of a Protocol for the Return of RHS statistical reports to the participating First Nation.

Moreover, personal privacy protection is continually considered and evaluated by the RHS National Team and the First Nations Information Governance Centre in an effort to maintain the highest possible level of personal privacy. This is necessary to honor the trust of the interviewees, as well as to protect the integrity and reputation of the RHS.



8. RHS INDEPENDENT REVIEW

In 2005, an independent review was conducted by the Harvard Project on American Indian Economic Development, Harvard University (Cambridge, Massachusetts) to examine the effectiveness of the processes and methodologies used in data collection, analysis, interpretation and dissemination of the RHS Phase 1 2002-2003 (Adams et al. 2006). This review included a document and literature review; a technical assessment of RHS methodologies; a comparative analysis of the survey to other surveys concerning Indigenous peoples in Australia, New Zealand, Canada and the United States; in-depth interviews with several key stakeholders; and a sounding board of key informants in First Nations issues on the national, regional and local level.

The review identified notable improvements over the RHS 1997, gave the survey high marks for technical quality, and noted a number of advantages over other national surveys. The Review team referred to RHS as a landmark survey and gave the survey high technical quality marks, and also noted a number of advantages over other national surveys.

In summary, the Harvard 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.”

9. ACCESS TO RHS DATA – RETURNING OF COMMUNITY DATA

USE AND DISSEMINATION OF RHS DATA

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

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

1. The FNIGC will not release or disseminate any data or statistical information from the RHS except if:
 - (a) The RHS National Team has thoroughly complied with statistics release protocols (or data release protocols) approved by The FNIGC; or
 - (b) The RHS National Team has received direct approval of The FNIGC.
2. While collaborating with the RHS National Team, the Region staff and representatives may receive draft and internal copies of national tables, statistics, reports and other national RHS-related information. The Region will not release or disseminate the information except if:

- (a) The Region has thoroughly complied with statistics release protocols (or data release protocols) approved by The FNIGC; or
- (b) The Region has received direct approval of The FNIGC.
3. The FNIGC and the Region will not release or disseminate any data or information from the RHS that identifies or could lead to the identification of a community without authorization from that community's recognized leadership.
 4. The FNIGC will not release or disseminate any data or information from the RHS that identifies or could lead to the identification of a First Nations Region or group of communities (e.g. tribal council, treaty area) without authorization from the appropriately mandated First Nations authority.
 5. The FNIGC and the Region will not release or disseminate any data or information from the RHS that identifies or could lead to the identification of an individual except under circumstances described under the following section "Other First Nations Authorities and Third Parties."

RETURNING OF RHS COMMUNITY DATA

Consistent with the principles of OCAP, the Regions are mandated to return survey results to participating First Nation communities, provided that the respondents' individual privacy rights are protected as required by this Agreement and the respondents' consent forms.

If any Region decides to adopt other procedures or protocols or varies the recommended protocol, the Region hereby agrees to save harmless and fully indemnify, The

FNIGC, including all its officers, employees, servants and agents, successors and assigns, from and against all claims, liabilities, demands and costs whatsoever arising directly or indirectly from the return of First Nation community data, in any way.

The FNIGC and the Region recognize that:

- First Nations communities own their respective communities' data, consistent with the principles of OCAP.
- That communities may wish to possess community level data and/or statistical results.
- Consultants and other third parties may require access to RHS data in order to carry out work for the Region or The FNIGC.
- Data related to a specific community or group of communities are, in most but not all cases, of very limited use from a statistical perspective (due to funding limitations). In many cases, at the community level in particular, the sample size will allow for either limited or no analysis whatsoever.
- Explicit commitments were made to survey respondents via the "Information and Consent Form" including the following:
 - Respondent names or other personal identifying information will not be used or revealed (except for quality inspection purposes and— if the respondent agreed—to contact them for subsequent surveys.
 - No one will have access to personal information other than research investigators and research associates.

PROTOCOL FOR THE RETURN OF RHS RESULTS TO PARTICIPATING FIRST NATIONS COMMUNITIES

Statistical tables containing RHS community-level results will be returned to communities according to the following procedures:

1. The First Nation will submit a request addressed to the applicable region for return of community-level statistical tables.
2. Upon receipt of the request, the RHS will begin preparing the statistical tables for return to the First Nation. The RHS will only return de-identified information.
3. Once the statistical tables for that First Nation are prepared, notice will be given and the First Nation will provide the applicable region with evidence of a duly executed First Nation Resolution (Band Council Resolution/BCR). The BCR will contain undertakings and conditions regarding confidentiality of the information, as required by the respondents' consent.
4. The statistical tables will be returned to the community, to the attention of the individual indicated in the BCR.

10. FNIGC CONTACT INFORMATION

THE FIRST NATION INFORMATION GOVERNANCE CENTRE
BOARD OF DIRECTORS

CONTACT LIST

CEAL TOURNIER – CHAIR
Saskatoon Tribal Council Health and
Family Services Inc.
ctournier@sktc.sk.ca

JON THOMPSON – CO-CHAIR
Assembly of First Nations
JonThompson@afn.ca

KATHI AVERY KINEW - SECRETARY
Assembly of Manitoba Chiefs
kathiaverykinew@manitobachiefs.com

NANCY GROS LOUIS McHUGH - TREASURER
First Nations of Quebec and Labrador
Health and Social Service Commission
Nancy.Gros-LouisMcHugh@cssspnql.com

CHIEF BILL TRAVERSE
Assembly of First Nations – Rep
RTraverse@afn.ca

IALEEN JONES
Dene Nation, Denendeh National Office
ijones@denenation.com

LORI DUNCAN
Council of Yukon First Nations (CYFN)
lduncan@cyfn.net

CHIEF CHARLES WEASELHEAD
Treaty 7 Management Corporation
cweaselhead@treaty7.org

TRACY ANTONE
Chiefs of Ontario
tracy@coo.org

PETER BIRNEY
Union of New Brunswick Indians
peter@unbi.org

SALLY (SARAH) JOHNSON
Union of Nova Scotia Indians
mha@unsi.ns.ca

BC - vacant
For RHS inquiries in BC contact Haike Muller
hmuller@fnhc.ca

RHS NATIONAL TEAM:

FNIGC Main Office:
170 Laurier Ave W Suite 904
Ottawa, ON K1P 5V5
Phone: (613) 733-1916
Fax: (613) 231-7072
Toll Free: (866) 997-6248
www.fnigc.ca



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First Nations Information
Governance Centre

Le Centre de Gouvernance de
L'information des Premières Nations

