



# First Nations Regional Longitudinal Health Survey (RHS)

## Code of Research Ethics

*Revised January 27, 2005*

*Originally adopted July 25, 1997*

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### Introduction

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 resulted in the creation of the First Nations and Inuit Regional Longitudinal Health Survey (RHS)<sup>1</sup> a stepping stone in First Nations control over research process. This mandate came as a result of the activities that began in 1994, Statistics Canada began three major national longitudinal surveys however, the national sampling frame for these three longitudinal surveys specifically excluded First Nations people living on-reserve, and Inuit communities.

Following a national consultative process in 1995 with First Nation, Inuit and Aboriginal communities and organizations, it was finally determined that in order to proceed collectively, the process must include a collaboration of distinct regional surveys with a national core content. This decision began a First 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.

From November 1995 to January 1996, the Indian and Inuit Health Programs Unit of the Medical Services Branch coordinated, with the assistance of the Assembly of First Nations, a National Steering Committee comprised of the First Nations and Inuit organizations from each participating region. The National Steering Committee members at the time were:

- Phil Hall, B.C. First Nations Health Summit
- Richard Saunders, Alberta Indian Health Care Commission
- Ceal Tournier, Federation of Saskatchewan Indian Nations Health and Social Development Commission
- Audrey Leader, Assembly of Manitoba Chiefs
- Cathryn George, Association of Iroquois and Allied Indians, Ontario
- Gary Cole and Jane Gray, First Nations and Inuit of Quebec and Labrador Health and Social Services Commission
- Wendy Paul and Darren Graham, Union of New Brunswick Indians
- Sharon Rudderham, Union of Nova Scotia Indians
- Iris Allen, Labrador Inuit Health Committee
- Allen Deleary, Assembly of First Nations, Ex-officio
- Nichole Simond, Medical Services Branch, Ex-officio

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<sup>1</sup> The initial RHS included the Inuit of Labrador and was titled the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS). The RHS 2002/03 survey includes First Nations on-reserve/communities only and is called the First Nations Regional Longitudinal Health Survey (FNL RHS). The Inuit have opted for Inuit specific research initiatives. The two acronyms are used interchangeably in this document.



- Lori Meckelborg/Jay Lambert First Nations Chief's Health Committee (BC)
- Jordan Head Alberta Treaty 7 Tribal Council
- Ceal Tournier (Co-chair) Health and Social Development, Saskatoon Tribal Council
- Darren Stevenson Assembly of Manitoba Chiefs
- Tracy Antone Chiefs of Ontario
- Nadine Gros Louis First Nations of Quebec and Labrador Health and Social Services Commission
- Wendy Paul Union of New Brunswick Indians
- Sally Johnson Union of Nova Scotia Indians
- Dr. Valerie Gideon (Co-chair) Assembly of First Nations
- Jane Gray (Ex-officio) RHS National Coordinator, First Nations Centre, National Aboriginal Health Organization

The second wave of the RHS was implemented in 2002-03. Since the first study in 1997, two new regions have joined the RHS process, the Yukon and Northwest Territories. The Inuit have since withdrawn from the RHS 2002-03 in favor of an Inuit specific process. (Hence, the change from the First Nation and Inuit Regional Longitudinal Health Survey to the First Nations Regional Longitudinal Health Survey).

#### I. Purpose of the Code of Ethics

The purpose of this Code of Ethics is to establish a framework of principles and procedures to guide the members of the First Nations Information Governance Committee to accomplish the mandate and objectives of the First Nations Regional Longitudinal Health Survey. This Code outlines the responsibilities of each member through all aspects and phases of the surveys and potential spin-off research to its conclusion.

#### II. First Nation Research Policy Statement

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

#### III. Regional Health Survey Guiding Principles

1. First Nation principles of **Ownership, Control, Assessed, and Possession (OCAP)**<sup>2</sup> will be respected. **OCAP** is self-determination applied to research.

It is a response to being “researched to death” and offers a way forward for First Nations research and information management. Originally “Ownership, Control and Access,” the principles were named during a 1998 brainstorming session of the National Steering

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<sup>2</sup> Adapted from First Nations Information Governance Committee and B. Schnarch, “Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research,” *Journal of Aboriginal Health*, Vol. 1, No. 1 (2004) p. 80-95.

Committee for the First Nations and Inuit Regional Health Survey (RHS). Cathryn George of the Association of Iroquois and Allied Indians is credited with the original acronym: “OCA.”

The principles crystallize themes advocated by First Nations for years. Although not understood and applied the same everywhere, some tentative definitions were prepared at the request of the RHS 2002 Steering Committee, also known as the First Nations Information Governance Committee:

**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 (see below).

**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.

2. The First Nations Information Governance Committee encourages and will facilitate the research at the highest possible professional level while striving to establish the conditions and skills for First Nations self determination and responsibility for the total health of our communities.
3. The First Nations Information Governance Committee recognizes the highest standards of research practice and will subject the RHS to a review and/or evaluation to ensure data quality and integrity while respecting the First Nations principles of OCAP.
4. The First Nations Information Governance Committee recognizes that a fully participatory, evidence based planning culture takes several years to develop. However, the First Nations Regional Longitudinal Health Survey should contribute demonstrably in information, skills and capacity building.
5. The First Nations Information Governance Committee recommends that, as far as possible, fact finding and analysis should be participatory allowing communities to determine which aspects of health should be addressed and how.
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 territories.
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 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, analysis and interpretations for the National Core Data must first be reported to the First Nations Information Governance Committee to ensure accuracy and avoid misunderstanding. This same process must be respected in each region as it pertains to the regional data where the communities and the regional advisory committees would first be reported to.
17. All national core raw data will be stored at the First Nations Centre at the National Aboriginal Health Organization office until such time as a First Nations organization is mandated or authorized to assume responsibility for all First Nations health information. Raw data will be kept on a computer in the First Nations Centre office. All data will be password protected and that confidentiality of data is maintained as outlined in the Schedules C Data Protection and Stewardship Protocol and Schedule D Survival of Confidentiality Requirement of the regional contribution agreement. The schedules shall survive and be binding upon the parties involved for as long as they are in control or possession of the 2002-03 FNIRLHS survey data.
18. Access to this data will only be available to research technicians in the FNC Statistical Unit approved by the First Nations Information Governance Committee as necessary for purposes of data analysis. This will be managed by the surveys National and Technical Coordinator as directed by the First Nations Information Governance Committee by resolution.
19. Longitudinal research requires a stable research environment for data storage.
20. The First Nations Information Governance Committee members must approve the release of the national results and products directly or through the established protocols to such releases.

#### **IV. Obligations of the First Nations Information Governance Committee Members**

1. To involve the First Nation community in active participation in this process and promote the knowledge that this is a First Nation owned research process.
2. To ensure the design, implementation, analysis, interpretation, reporting, publication and distribution of the research are culturally relevant and in compliance with the standards of competent research.
3. To undertake research that will contribute something of value to First Nations nationally and in the regions in which the research is being conducted.
4. To enhance the capacity and skills of First Nations in research i.e. survey development, data collection, analysis, computer skills, health planning.
5. To assist in advocating and addressing health and social issues that may emerge as a result of the research.
6. To provide expertise to respond to questions that emerge from First Nations communities.
7. To promote knowledge of the First Nations Regional Longitudinal Health Survey and its outcomes through publication and presentations.
8. To be responsible for longitudinal data until the end of the survey process.
9. To be involved in any future analysis of the data consistent with the general principle of the sovereignty of First Nations peoples, and with the particular research ethics of this Code.

#### **V. National Steering Committee Communication Guidelines**

As the First Nations Regional Longitudinal Health Survey is a first time ever national initiative which will scientifically collect health status data from First Nations communities in a process controlled by and for First Nations, it will be appropriate to share the experiences of this Project with as many interested parties as possible to enable others to benefit from our experiences.

#### **VI. Communication Strategy**

Communication with regard to the First Nations Regional Longitudinal Health Survey will be directed at the following interested parties:

1. National and Regional First Nation Political Organizations
2. First Nation communities.
3. Federal, Provincial, Local and International Health and Social officials
4. Academics, Scientists and Researchers (National, International)

The interest in the Project will include:

- Knowing how the FNRLHS and process functioned under direct First Nations control.

- Knowing how the FNRLHS was developed and implemented as well as the outcomes, barriers, innovations.
- Knowing what methods were used, the process, the impacts measured, and the answers as a result of the research questions.
- How the results can be used for political advocacy and strategic health planning.

#### **VII. Communication Principles**

All the research undertaken in the First Nations Regional Longitudinal Health Survey will be of the highest quality and relevant to First Nations communities.

All communication pertaining to the FNRLHS will follow generally accepted ethical standards.

Those standards include:

1. **Confidentiality:** All personal information will be made anonymous and remain confidential.
2. **First Nation Principles of OCAP will be respected.** The communities participating will be the first to receive results and the first invited to provide input and feedback on the results.
3. **No Prejudice.** All communication efforts shall be calculated to benefit First Nation communities, and not harm them in any way.

#### **VIII. Access Protocol to National Core Data**

A protocol outlining access to the aggregated national data will be clearly outlined and agreed upon prior to the completion of the project. This protocol will define issues such as access and confidentiality of the national core data.

The Protocol will address at least the following considerations:

- ownership and control of the data collected will remain with the First Nations Information Governance Committee and those communities involved, as outlined in Section III, sub-section 9.
- access to the national data will be controlled by the First Nations Information Governance Committee as outlined in Section III, sub-section 18.
- regional data can only be accessed after permission has been granted by the appropriate regional steering committee or similar group.
- community level data (if available) can only be accessed after permission has been granted by the appropriate community authorities.

#### **IX. Procedures for Data Analysis and Publication of Results**

*A. The following procedure will be followed for purposes of data analysis and publication of results:*

1. General analysis of the national core data will be conducted as per the direction of the First Nations Information Governance Committee to include a detailed, comparative analysis of the national core data against other national surveys and relevant First Nations health data. The topics are comprehensive and cover a wide range of health issues, based on the FNLRHS survey instruments for adults, adolescents and children.

2. All resulting analysis will be reviewed by the First Nations Information Governance Committee for input into interpretation of the results.
3. All resulting draft reports or publications will be reviewed by the First Nations Information Governance Committee.
4. Best efforts will be made to reach consensus regarding the interpretation of results prior to any publication. In the event that a reasonable measure of consensus cannot be reached, no publication will be released.
5. Regional processes will be respected in their participation in the analysis and interpretation of the national reports prior to publication and release.
6. Dissemination of analytical results will be done under First Nation national and regional authority.
7. Analytical results should be validated through regional/community and technical review.
8. Detailed national results as well as data analysis and reporting tools will be provided to each region by the FNC to facilitate regional analysis and comparison.
9. Wide dissemination of the results will ensure First Nations perspectives and influence health research literature.
10. Publication of results must reflect the contributions of the First National Information Governance Committee representatives and appropriate references must be cited as follows:

Source: First Nations Regional Longitudinal Health Survey 2002-03; First Nations Information Governance Committee—Assembly of First Nations, First Nations Centre at the National Aboriginal Health Organization.

11. The original national core dataset must be maintained in an approved, secure facility to ensure that future data linkage in a longitudinal study is possible, and that confidentiality of data is maintained as outlined in the Schedules C Data Protection and Stewardship Protocol and Schedule D Survival of Confidentiality Requirement of the regional contribution agreement. The schedules shall survive and be binding upon the parties involved for as long as they are in control or possession of the 2002-03 FNRLHS survey data.

*B. Publication of results shall occur according to the following protocol:*

The appropriate Regional authority must approve regional publications prior to the release

One copy of each regional publication shall be sent to:

- 1) The regional office of each member of the First Nations Information Governance Committee.
- 2) The First Nations Centre at the National Aboriginal Health Organization.

Authors/writers involved in the writing of chapters for the 2002-03 shall receive credit for their role.

All publications resulting from analysis of the national core data shall include as AUTHORS the members of the First Nations Information Governance Committee in an appendix as follows:

- Charlie Gaudet Dene National Office
- Lori Duncan Council of Yukon First Nations
- Lori Meckelborg/Jay Lambert First Nations Chief's Health Committee (BC)
- Jordan Head Alberta Treaty 7 Tribal Council
- Ceal Tournier (Co-Chair) Health and Social Development, Saskatoon Tribal Council
- Darren Stevenson Assembly of Manitoba Chiefs
- Tracy Antone Chiefs of Ontario
- Nadine Gros Louis First Nations of Quebec and Labrador Health and Social Services Commission
- Wendy Paul Union of New Brunswick Indians
- Sally Johnson Union of Nova Scotia Indians
- Valerie Gideon (Co-chair) Assembly of First Nations
- Jane Gray (Ex-officio) RHS National Coordinator , First Nations Centre, National Aboriginal Health Organization

Other authors shall be included as deemed appropriate by the First Nations Information Governance Committee.

The First Nation Regional Longitudinal Health Survey Code of Research Ethics was duly approved by the First Nations Information Governance Committee on January 27, 2005.

Charlie Gaudet, Dene National Office

Lori Duncan, Council of Yukon First Nations

Lori Meckelborg/Jay Lambert, First Nations Chief's Health Committee (BC)

Jordan Head , Alberta Treaty 7 Tribal Council

Ceal Tournier, Health and Social Development, Saskatoon Tribal Council

Darren Stevenson, Assembly of Manitoba Chiefs

Tracy Antone, Chiefs of Ontario

Nadine Gros-Louis, First Nations and Inuit of Quebec and Labrador Health and Social Services Commission

Wendy Paul, Union of New Brunswick Indians

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Dr. Valerie Gideon, Assembly of First Nations

*Acknowledgments:*

In the preparation of this Code of Ethics, other research Code of Ethics were used as a guide; they included: *Kahnawake Schools Diabetes Prevention Project*, March 1996 and the *Manitoba First Nations Regional Health Survey Protocol for Data Sharing*. Permission has been granted to use these Codes of Ethics as a guide in the development of the First Nations Regional Longitudinal Health Survey Code of Research Ethics.

Other documents utilized to develop this Code include: First Nation and Inuit Regional Health Survey Project National Steering Committee - Letter of Understanding, November, 1996 and the National Steering Committee - Co-Principle Investigator's Group - Guiding Objectives for the First Nation and Inuit Regional Health Survey Project, September, 1996.

The First Nations Information Governance Committee gratefully acknowledges the contributions of the above mentioned Code of Ethics which have served as a guide and inspiration to this First Nations Regional Longitudinal Health Survey Code of Research Ethics document. They are true pioneers in the development of First Nations controlled research processes.