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## CALL FOR MEMBERSHIP FIRST NATION DATA GOVERNANCE COMMITTEE

The Chiefs of Ontario is looking for individuals, youth and Elders/First Nation Knowledge Keepers that have knowledge and experience in First Nation health research, research practices, community based research, experience with the Regional Health Survey (RHS), reviewing and writing research projects, knowledge of First Nation research ethics to sit on the First Nation Data Governance Committee.

Research and surveillance involving First Nations communities has become a sought after demographic. First Nation communities are becoming more involved and want to make sure that research conducted and information collected is benefiting their communities. Due to this rapid change in the environment involving First Nation research the leadership has mandated and continues to support the Chiefs of Ontario in its work with the First Nation Data Governance Committee.

### ROLE OF THE FIRST NATION DATA GOVERNANCE COMMITTEE

The First Nation Data Governance Committee will be guided by the principles of ownership, control, access and, possession (OCAP®) and will provide advice, guidance and recommendations on regional research and surveillance projects. The Committee's role will be to:

1. Review regional research/surveillance projects requesting First Nation data;
2. Provide advice and recommendations on the development of tools that will assist First Nation communities with research; and
3. Oversee the implementation of Phase IV, Regional Health Survey (RHS) and provide analysis and advice in the drafting of Phase IV, RHS Report.

Individuals who are successful will be selected by the Chiefs Committee on Health (CCOH) for a three (3) year term. Individuals will be compensated for travel expenses, meals and accommodations when attending the Data Governance Committee meetings.

### SUBMISSION PROCESS:

If you interested in this exciting opportunity, please review the Terms of Reference attached and submit your resume outlining your knowledge, experience, interest and any information that might help with selection, along with two references:

Roseanne Sutherland  
Research Manager, Health  
Chiefs of Ontario  
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Email: [FNDGC@coo.org](mailto:FNDGC@coo.org)

For more information, please contact Roseanne Sutherland at 416-986-9856 or email [Roseanne.sutherland@coo.org](mailto:Roseanne.sutherland@coo.org). First Nation Data Governance Committee - Terms of Reference attached for reference.



Chiefs of Ontario

First Nation Data Governance  
Committee

*Terms of Reference*

*Approved by:  
Ontario Chiefs Committee on Health 2014*

# CHIEFS OF ONTARIO FIRST NATION DATA GOVERNANCE COMMITTEE

## PREFACE

Research and surveillance involving First Nation communities is rapidly changing. There are a number of First Nations scholars who are contributing to research as academics and community researchers. Communities are becoming better informed about the risks and benefits of conducting research and surveillance. Technological developments allowing rapid distribution of information are presenting both opportunities and challenges regarding the governance of First Nation data.

It has been proven that First Nations through the Regional Health Survey have taken control of conducting their own research. The Regional Health Survey has been in operation for over 16 years and is a prime example of First Nation taking control of collecting their own data. The RHS has been praised by Harvard University as being “*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.*”<sup>1</sup> Through the RHS First Nations have developed protocols and the principles of Ownership, Control, Access, and Possession (OCAP<sup>TM</sup>), these principles are unique to First Nations. The RHS has received national acceptance from First Nations across the country. The First Nations Information Governance Centre, responsible for implementing and coordinating the Regional Health Survey is now moving beyond health and implementing the First Nation Regional Early Childhood, Education and Employment Survey based upon the RHS model.

Ontario First Nations people want to ensure that any research initiatives carefully consider all potential impacts upon First Nation communities, both positive and negative and that research not be conducted without the free, prior and informed consent of First Nations leadership.

Through resolution AOCC 09/33 First Nation Cancer Surveillance and AOCC 01/26 Support for First Nation and Inuit Regional Health Survey, (Appendix -1), Ontario First Nations are now assuming an important role in First Nations data governance which will include the RHS data and First Nations health data found within provincial health systems, identified through the Indian Registry System (IRS).

On September 1, 2010 the Political Confederacy of the Chiefs of Ontario passed a motion (Appendix - 2) to negotiate a Memorandum of Understanding on Data Governance with the Institute for Clinical Evaluative Sciences (ICES) to control and manage the collection, use and disclosure of the First Nations health data and to submit an application to access the Indian Registry System (IRS) data from Indian Affairs. The Data Governance Agreement was signed on April 5, 2012 between the Chief of Ontario and ICES. The Agreement sets out the development of Data Governance Committee (DGC) and that ICES will act as a data steward for the collection of First Nations data, until such time as First Nations build the

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<sup>1</sup> *Review of the First Nations Regional Longitudinal Health Survey (RHS) 2002/03.* Adams, Alyce, Courtney Andrews, and Miriam Jorgensen. 2006. Cambridge: Harvard University Project on American Indian Economic Development.



necessary capacity to act as their own data steward. A data sharing agreement has also been signed between Indian Affairs and ICES which permits the transfer of the IRS data file.

Ontario First Nations through the Chiefs in Assembly have determined that the development and implementation of a First Nation Data Governance Committee will also prove beneficial in advancing the Ontario First Nations' health care agenda and community development.

The Chiefs of Ontario will be the coordinating body for the Data Governance Committee. COO will provide administrative support to the DGC and will monitor authorized projects, together with regional data governance and data sharing agreements. Until such time as a separate regional First Nations information governance entity is created, COO may also assume the role of data steward for regional research and surveillance projects, as appropriate.

The following "Terms of Reference", sets out the mandate, purpose, roles, and membership of the First Nation Data Governance Committee.



**CHIEFS OF ONTARIO**  
**FIRST NATION DATA GOVERNANCE COMMITTEE**  
***TERMS OF REFERENCE***

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**MANDATE:**

The mandate of the First Nation Data Governance Committee (DGC) is to provide, the Chiefs of Ontario, Health Coordination Unit (HCU) and the Chiefs Committee on Health (CCOH), advice, views and recommendations on the collection, utilization and requests of First Nation data in regional research and surveillance projects. The DGC will remain accountable to the First Nations for data governance by ensuring that Ownership Control, Access, Possession (OCAP®) principles are respected. This mandate also affirms the United Nations Declaration on the Rights of Indigenous Peoples:

*[Ensure that any research initiatives do not adversely affect Ontario First Nations people, with particular reference to research impinging on First Nations' cultural, intellectual, religious and spiritual property taken] without their free, prior and informed consent or in violation of their laws, traditions and customs [UNDRIP, Article 11(2)].<sup>2</sup>*

**PURPOSE:**

The purpose of the DGC committee will be to provide advice, recommendations on regional projects that promote First Nations health research and surveillance. The DGC will review regional projects on the principles of OCAP®; and will provide advice, and guidance on the implementation and drafting of the Regional Health Survey.

**ROLE OF COMMITTEE:**

1. To review regional research and surveillance projects requesting First Nation data;
2. To assist in the development of tools that will help First Nations communities with research and surveillance projects in their communities; and
3. To guide, and provide input on the implementation of the Regional Health Survey, and to guide the drafting of Regional Health Survey Peoples' Report.

**WORK OF THE COMMITTEE:**

*Regional Health Research/Surveillance Projects and Data Access:*

- Evaluate regional research/surveillance projects for OCAP®; compliancy and certification;
- Make recommendations to the HCU on whether regional research/surveillance projects are OCAP® compliant;
- Provide recommendations on the application of regional research/surveillance proposals for OCAP® certification;
- To review requests for the use, access or creation of First Nations data maintained by ICES, RHS Data or other organizations holding First Nations data, and to provide recommendations to the HCU; and

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<sup>2</sup> *United Nations Declaration on the Right of Indigenous Peoples, Article 11(2), Published by the United Nations 07-58681—March 2008—4,000*



- To evaluate requests for access to regional First Nation data and ensuring that First Nation data access protocols are followed.

*Administrative:*

- To review and support the development of collaborative research projects, mentoring programs, and other capacity building projects;
- To review and provide advice the HCU regarding the administration and interpretation of First Nations data protocols; and
- Review and provide advice on procedures and criteria for evaluating applications for research and surveillance using the principles of OCAP®.
- Review completed research projects presented by research applicants to ensure OCAP® compliance.

*Communities:*

- When requested by communities, First Nation organizations, First Nation health authorities, etc. review active Data Governance Agreements, Data Sharing Agreements and other collaborative relationships for compliance, effectiveness, and whether First Nations needs are met; and
- From time to time the committee may be asked by a First Nation(s) community to provide advice and recommendations on a community research or surveillance projects that is being considered by a First Nation.

*Tools:*

- To provide advice and assist in the development of tools that will assist communities in making decisions before embarking on a research/surveillance projects for their community. Provide communities with:
  - examples of data sharing agreements
  - draft codes of research ethics,
  - privacy and security policies;
  - research principles ; and
  - list of questions will assist communities in making a decision on research/surveillance project being proposed by researchers.

*Other:*

- Provide advice, and expertise in the development of data sharing agreements, between COO and other parties as requested by the HCU.

**MEMBERSHIP:**

The members will be individuals who have acknowledge and respect for First Nations right to self-determination in health research. The membership will consist of interested individuals who have: community based health knowledge; are community-based health researchers; experience in qualitative and quantitative research; experience in research or surveillance projects; experience or who are interested in the implementation of health surveys, such as, the Regional Health Survey.

Membership will comprise of seven (7) members and two alternates, i.e. five (5) members from across the province, an Elder or Indigenous Knowledge Keeper, and a youth representative with an interest in research or surveillance. A data analyst from the COO and an epidemiologist from Institute of Clinical



Evaluative Sciences will provide technical advice and expertise to the committee and the Research Manager will chair the meetings. From time to time other experts will be recruited for specific agenda items as needed. All selections will be made by the Chiefs Committee on Health (CCOH). There will be no substitutes, except for those alternates that have been selected by CCOH for replacement. Membership on the committee will be for three (3) years. Committee members will sign a confidentiality agreement when appointed and be provided with training.

After three years, 2 members will continue on for an additional year so that there is consistency on the committee.

### **MEETINGS:**

- The meetings will be chaired by the Research Manager, Health, Chiefs of Ontario;
- Meetings will occur four times a year in person;
- Additional meetings may occur in person or by teleconference or videoconference depending on other factors such as research/surveillance projects, implementation of projects or reviewing of documents for recommendation or for the Regional Health Survey;
- Dates and locations will be determined as much in advance as possible.
- All reasonable attempts will be made to gain consensus, if a consensus cannot be made reached then a vote will be taken and the majority of votes will carry. The Chair shall exercise no vote except in the event of a tie, in which case the Chair shall exercise the casting vote.
- A quorum for the committee will be four 4 members out of the seven (7).

### **CONFLICT OF INTEREST:**

- Committee members must declare a conflict of interest or perceived conflict of interest before any project is reviewed.
- A conflict must be declared two weeks in advance of the proposal review.
- When a conflict of interest is declared an alternate will be appointed to replace that member to review the project.

### **ROLE OF THE RESEARCH MANAGER:**

The role of the Manager will be to provide administrative functions such as:

- Setting up meetings and notifying the DGC members
- Setting the agenda
- Drafting summary of record for the meetings
- Receiving research and surveillance proposals, requests and presenting them to the DGC
- Recording decisions on proposals, projects and requests
- Providing necessary templates for reviewing proposals, projects and requests
- Arranging and providing travel and accommodations

### **EVALUATION:**

The Data Governance Committee will be evaluated after one year of operation, i.e., from the date of the first Committee meeting to determine if the process needs to be changed or improved. The evaluation will be a formative (process) evaluation. The final evaluation report will be presented to the OCCOH with recommendations.





## CODE OF CONDUCT

### First Nation Data Governance Committee Members

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The First Nation Data Governance Committee (DGC) is committed to supporting First Nation(s) research and surveillance projects that promote, address, contribute and recognize the diversity, uniqueness and the rights of First Nation peoples towards self-determination.

**The following is the Code of Conduct and principles to guide the First Nation Data Governance Committee members:**

1. Respect the wisdom of those on the committee.
  - Respect demands that you listen intently to the ideas of others on the Committee and that you do not insist that your idea (s) prevail.
  - Indeed you should freely support the ideas of others if they are true and good, even if those ideas are quite different from the ones you contributed. The clash of ideas as we work towards consensus brings for the spark of truth.
  - Be respectful of others.
  - Respect the decisions made by the committee
2. Listen to and follow the guidance given to your heart. Expect guidance to come in many forms in prayer, in dreams, in times of quiet solitude and in the work and deeds of wise elders and friends.
3. Be honest in describing professional skills, abilities, and background.
4. Ensure that we do not force our personal beliefs or values on others to influence an outcome.
5. Be professional in our decisions and maintain a high standard of behaviour in reviewing research/surveillance and project proposals.
6. Always treat your guests with honour, consideration, and respect.
7. Be honest and truthful in your deliberations in reviewing project proposals and requests.
8. Treat every project proposal in a fair manner.
9. Be truthful at all times and under all conditions.
10. Committee members are not above or below others in the circle of life every committee member brings their gifts to the table that the creator has given them.
11. Take into consideration the impact of the recommendations being made on the Seventh Generation and to consider those who are not yet born but who will inherit those decisions.

#### **12. Confidentiality:**





- All members must sign a Oath of Confidentiality
- All proceedings of the committee are kept confidential, meaning that no committee member can speak about a proposal or project outside the committee meetings.
- Information about discussions will be made available only to members of the DGC.
- If confidentiality is broken then the member is asked to remove themselves off the DGC or be asked to remove themselves off the committee.

### **13. Conflict of Interest:**

Although it is not possible to avoid all sources of conflict, it is in the best interests of the DGC to recognize conflicts of interest and to take steps to nullify or mitigate those conflicts.

- When reviewing research proposals, members of the DGC shall disclose real, potential or perceived conflicts of interest to the Chair.
- If a member of the Committee has a personal or financial conflict of interest; the member must disclose the nature of the conflict and absent themselves from the discussions and decision regarding that project.
- A member of the DGC must declare a conflict of interest if the member has been involved in consulting, preparing or writing of the proposal that has been submitted to the DGC and withdraw from reviewing the proposal.
- Potential conflicts or perceived conflicts must be declared two weeks in advance of a project being reviewed by the Committee.
- An alternate will then asked to attend the meeting for the purpose of reviewing the project.

#### *References:*

1. Understanding Haudenosaunee Culture - <http://www.peacecouncil.net/NOON/articles/culture1.html>
2. Seven Grandfather Teachings, Ojibway People - Love-Respect-Honesty-Truth-Humility-Wisdom-Courage, <http://ronniebeaver.myknet.org/>

