

RESEARCH ACTIVITIES OF THE FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION

Seminar on the Ethics of Research with Aboriginal Peoples
Val d'Or, September 21, 2011

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Presentation outline

- First Nations of Quebec and Labrador Health and Social Services Commission
- Assembly of First Nations of Quebec and Labrador
- Background
- Research Unit
- Tools
- Partners
- Publications
- Realizations in progress
- Challenges
- Conclusion

First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)

□ Creation

The FNQLHSSC was created in 1994 by way of resolution by the Chiefs' Assembly of the First Nations of Quebec and Labrador.

□ Mission

Improving the physical, mental, emotional and spiritual well-being of the First Nations communities, families and members while respecting their local autonomy and culture.

□ Structure

The FNQLHSSC is composed of several sectors: administration, health, social services, early childhood, social development and research.

First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)

□ 2007-2017 Blueprint

Chapter 6 – Human capital that is sufficient and supported by the research and development assets

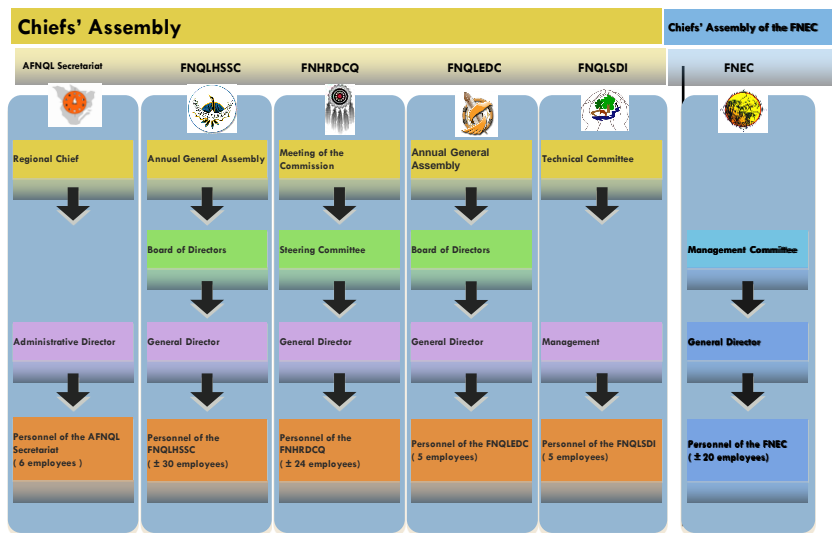
Problems identified:

- ❖ Exclusion of Aboriginals
- ❖ No identifiers for Aboriginal people – no distinction between the First Nations, Inuit and Métis
- ❖ Production of limited and sometimes biased data
- ❖ Ethical considerations
- ❖ Underfunding for the First Nations organizations
- ❖ Research agendas that are defined by the governmental authorities

First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)

- 2011-2014 Strategic Plan
 - ❖ Orientation 9- Reinforcing human capital in addition to research and development
 - 9.1 Focus areas:
 - To increase the analysis and planning skills
 - 9.2 Informed decision-making
 - To foster FN access to and repatriation of the information and data held by the governments
 - To increase the Research and Development efforts among the First Nations

Assembly of First Nations of Quebec and Labrador



Background

□ 1997: Creation of the First Nations Regional Longitudinal Health Survey

The origins of the FNRLHS are in line with two events:

1. The establishment of the Royal Commission on Aboriginal Peoples

"The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it and who should have access to it."

"The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters."

Derived from the Royal Commission on Aboriginal Peoples

Background

2. The exclusion of the Aboriginal people in the three national surveys carried out by Statistics Canada:

- ❖ National Population Health Survey (NPHS).
- ❖ National Longitudinal Survey of Children (NLSC).
- ❖ Survey of Labour and Income Dynamics (SLID).

Background

- **1998:** Creation of the Principles of Ownership, Control, Access and Possession (OCAP) regarding information and the management of information by Catherine Georges (AFN 2007);
- **2001, June:** Adoption of a resolution by the Chiefs of the AFNQL asserting their support for the boycotting of any survey or research endeavours not respecting the Principles of Ownership, Control, Access and Possession of data;
- **2003, June:** Resolution by the Chiefs of the AFNQL for the adoption of the First Nations of Quebec and Labrador Consultation Protocol;
- **2005, June:** Resolution by the Chiefs of the AFNQL for the adoption of the First Nations of Quebec and Labrador Research Protocol (Resolution 14/2005);
- **2006, October:** During the Socio-Economic Forum in Mashteuiatsh, a common commitment was presented by the RCO for the creation of a First Nations Research Institute;

Background

- **2007, May:** The Canadian Institutes of Health Research (CIHR) created the Guidelines for Health Research Involving Aboriginal People;
- **2008:** Adoption of a resolution through which the Chiefs of the AFNQL entrusted the FNQLHSSC with the power to receive upon request and directly from any federal or *Québécois* ministry or organization;
- **2010, February:** Adoption of a resolution by the Chiefs of the AFNQL ensuring regional support for the creation of the First Nations and Inuit Information Governance Centre (FNIGC);
- **2010:** The FNQLHSSC established a governance structure supported by the health/social services directors in the framework of the Infostructure project aiming, among other things, to foster the implementation of various information management systems in the area of health/social services;

Background

- **2010, October:** Revision of the First Nations of Quebec and Labrador Research Protocol. Work in progress for the two subsequent years;
- **2010, October:** Inauguration of the First Nations and Inuit Governance Centre (FNIGC) located in Ottawa;
- **2010, December:** Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Chapter 9: Research targeting the First Nations, Inuit or Métis in Canada.

FNQLHSSC Research Unit

- **2004:** A multidisciplinary team
 - Three focus areas:
 1. Social research
 2. Evaluations of programs/initiatives
 3. Public health surveillance

Social research

- Mandates stemming from the operations sector of the FNQLHSSC
- First Nations of Quebec Regional Research Committee
- The participatory approach is favoured
- Applies and respects the protocols and principles of the First Nations

Evaluations of programs/initiatives

- Mandates stemming from the operations sector of the FNQLHSSC
- The participatory approach is favoured
- Applies and respects the protocols and principles of the First Nations
- Promoting the evaluation culture in support of local capacity-building

Public health surveillance

- Surveillance plan for the state of health and its determinants for the First Nations of Quebec
- Definition of surveillance: Continuous appreciation for the state of health of the population and its determinants, focused on the entire First Nations population, based on permanent and recurring data collection systems, including surveys.
- Establishment of a warehouse storing all of the data on the state of health and its determinants for each of the communities
- Tool for the communities
- Reliable data sources for planning

First Nations of Quebec and Labrador Research Protocol



First Nations of Quebec and Labrador Research Protocol

- Based on recommendations stemming from many First Nations as well as various requests that have been forwarded to the FNQLHSSC and the FNQLSDI in addition to other organizations of the AFNQL.
- Negotiations between the FNQLSDI, the FNQLHSSC and the FNHRDCQ.
- Adoption of a resolution by the AFNQL Chiefs' Table in June 2004.
- Document presented and adopted at the Chiefs' Table in May 2005.

First Nations of Quebec and Labrador Research Protocol

- This document is a tool for reflection aiming to assemble all of the criteria that are essential to the development of a research policy reflecting the position of the AFNQL.
- This reference guide enables the communities to better govern the activities and requests related to research that is unfolding on their respective territories.
- It also aims to promote ethical, precise and well-informed research that unfolds while respecting the desires of the First Nations involved.
- It proposes tools: glossary, research license model, consent form, etc.
- Revision of the Protocol

First Nations of Quebec and Labrador Consultation Protocol



Partners

Regional level

- ❖ First Nations communities
- ❖ First Nations regional organizations (FNEC, FNQLEDC, FNHRDCQ, FNQLSDI, RCAAQ)
- ❖ AFNQL
- ❖ Cree Board of Health and Social Services
- ❖ MSSS
- ❖ Health Canada - FNIH
- ❖ INSPQ- Infocentre
- ❖ INAC
- ❖ *Université Laval*
- ❖ *Université Montréal*
- ❖ *Université Trois- Rivières*
- ❖ McGill University
- ❖ Ste-Justine Hospital
- ❖ Montreal Jewish General Hospital

National level

- ❖ First Nations Information Governance Centre
- ❖ Secretariat of the Assembly of First Nations
- ❖ Public Health Agency of Canada

Publications

- First Nations of Quebec and Labrador Research Protocol* (2005)
- First Nations Regional Longitudinal Health Survey (1999, 2006)
- An Assessment of Continuing Care Requirements in First Nations and Inuit Communities (2006)
- Alcohol, drugs and inhalants: Portrait of the users and consumption habits among the First Nations in the Quebec region (2008)
- Portrait of the accidental and intentional physical injuries that occur within the First Nations of Quebec communities (2008)

Publications

- Research on the Health of Quebec First Nations and Inuit: An Overview – 1986 to 2006 (2009)
- Community Characteristics, Birth Outcomes and Infant Mortality among First Nations in Quebec (2010)
- Evaluation of the implementation of the first-line social services in four communities of the First Nations of Quebec (2011)
- Study on the sexual behaviours, attitudes and knowledge related to STBBI among the youth and adults of the communities of the First Nations of Quebec (2011)
- The Diabetes situation among the First Nations and Inuit in the Quebec region (2011)

Realizations in progress

- 2008 RHS
- Surveillance Plan for the State of Health and its Determinants for the First Nations of Quebec
- Family Mediation and Aboriginal Peoples: The State of the Knowledge and Settings
- Research on the trajectory of the First Nations children in the youth protection system

Realizations in progress

- Evaluation of the implementation of the diabetic retinopathy distance screening project among the First Nations of Quebec
- Evaluation of the implementation of the mental wellness pilot project in two communities of Quebec
- Evaluation of the implementation of the Prevention of Violence and Aggression in the Communities (PVAC) Project among the First Nations
- Evaluation of the training project for the early childhood programs and services of the First Nations of Quebec

Anticipated for 2012

- ❖ Development of a research-specific strategic plan
- ❖ Revision of the First Nations of Quebec and Labrador Research Protocol

Challenges

- Recurring funding ensuring the maintenance of the infrastructure and activities
- The hiring of Aboriginal human resources

Conclusion

- It is imperative for the First Nations authorities to endow themselves with infrastructures in the area of research and development;
- Establishment of relationships of mutual trust between the First Nations communities and organizations, the scientific community and the governments, and initiation of a healthy and respectful discussion related to the field of research and governance;
- Development and repatriation of statistics and databases;

Conclusion

- Systematic respect for the First Nations protocols and compliance among the research priorities, objectives and processes with their realities;
- Improved knowledge of the situation among the First Nations decision-makers and support in their decision-making and planning processes as well as the management of the programs and services intended for their members;
- Strengthening of the local autonomy.

Questions?

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