



This past year has been marked with impressive growth in the First Nations Centre's (FNC) team and activities. The FNC has embraced new opportunities and met these with energy and success. The Centre doubled its staff as well as its core activity budget, produced 70 publications, took part in/sponsored 51 events, and visited 9 provinces and territories. Perhaps more rewarding than the state of its productivity, the Centre has remained

true to its vision, mission, principles, and work plan.

The FNC developed a FNC Communications Plan at the beginning of 2003 to help it develop information materials and promote its activities. The Centre now has an approved two-year work plan and operations budget. The FNC Governing Committee committed to a calendar of meetings and a series of reporting mechanisms. The FNC staff also produced protocols for their own team-building and for building relations with other First Nations organizations.

More than 12,000 tool kits on privacy, surveillance, research, and research ethics have been sent to people across Canada. Reaching out to communities, health providers, and leaders has helped us improve our communications approach and refine our products. With the FNC "on the map," invitations for presentations and information products have been received from First Nations across Canada. Thanks to all of those who thought of the FNC as a credible source of information.

The FNC continues to benefit greatly from the mandate it received from the Chiefs Committee on Health to act as the national co-ordinator and data steward of the First Nations Regional Longitudinal Health Survey (RHS) under the guidance of the First Nations Information Governance Committee (FNIGC). The RHS completed data collection of its second phase with a high participation rate and anticipation is building for the release of its findings in 2004. The success of the RHS as the only First Nations-controlled research project of national scope has laid the foundation for expanding the FNC's research capacity and activities. The FNC has co-ordinated a pilot survey on using insect repellents in First Nations communities and a feasibility study of a survey on First Nations immunization coverage, attitudes, and practices in collaboration with the 10 First Nations regional partners of the RHS.

The FNC is dedicated to promoting the principles of ownership, control, access, and possession (OCAP) of First Nations information



in all its activities; principles set by the RHS process. The FNC has secured a grant from the Canadian Institutes of Health Research, in collaboration with Dr James Sa'kej Henderson of the Native Law Centre, to develop conceptual and applied models of First Nations ethics and privacy based on OCAP principles. First Nations information governance is at the core of health infostructure projects, public health surveillance, non-insured health benefits, and other health programs and services. These principles became even more apparent in the FNC's work in co-ordinating the development and approval of long-awaited First Nations health infostructure recommendations, a First Nations Multi-Purpose Smart Card Discussion Paper, and a national roundtable and legal analysis on the new health protection legislative renewal.

Research, policy, and legal analysis is a vital part of the FNC's contribution to the health and well-being of First Nations peoples and their communities. It is an invaluable service that First Nations might not be able to do on their own. However, this contribution would not be complete without offering First Nations health providers and youth opportunities to improve their understanding and skills in research and information processes. FNC held two workshops with health providers, and three more workshops with youth, to introduce basic concepts of health information and research, to conduct an OCAP simulation exercise, and to develop customized community health information and research planning. Participant evaluations have been enthusiastic and the demand for more workshops is high. For this reason, the youth workshops will follow a "Train The Trainer" model.

While many more accomplishments could be highlighted, I wish to end by congratulating the FNC staff and Governing Committee for their teamwork and dedication to First Nations rights and issues of interest. In our travels, we have listened to the needs and priorities of First Nations living across Canada and know how closely health is tied to our traditions and values, as well as our strength and well-being as communities and Nations. The FNC will continue to foster a collaborative service approach to its activities with the aim of helping First Nations peoples achieve their aspirations.

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Le CPN se consacre à la promotion des principes de propriété, de contrôle, d'accès et de possession (PCAP) de l'information par les Premières Nations dans toutes leurs activités; ces principes ont été définis par le processus de l'ERS. Le CPN a reçu une subvention des Instituts de recherche en santé du Canada, en collaboration avec le Dr James Sa'kej Henderson du *Native Law Centre*, pour élaborer des modèles conceptuels et appliqués de l'éthique et de la confidentialité des Premières Nations sur la base des principes de PCAP. La gouvernance de la part des Premières Nations en matière d'information est au cœur des projets infostructure sanitaire, de surveillance médicale publique, de services de santé non assurés et d'autres programmes et services de santé. Ces principes sont devenus encore plus apparents avec les efforts du CPN pour coordonner l'élaboration et l'approbation des recommandations longtemps attendues sur l'infostructure de santé des Premières Nations, un article de discussion sur une carte à puce polyvalente à l'usage des Premières Nations, et une table ronde nationale comportant une analyse juridique du renouveau législatif en matière de protection de santé.

La recherche, les politiques et l'analyse juridique sont des éléments essentiels de la contribution du CPN à la santé et au bien-être des peuples des Premières Nations et de leurs communautés. C'est un précieux service, que les Premières Nations ne seraient pas en mesure d'assurer par elles-mêmes. Cependant, cette contribution serait incomplète si l'on ne donnait pas aux prestataires de services de santé des Premières Nations et aux jeunes des Premières Nations des occasions d'améliorer leur compréhension et leurs compétences concernant les processus de recherche et d'information. Le CPN a organisé deux ateliers avec des prestataires de services de santé, et trois autres avec des jeunes, pour présenter les concepts de base de l'information de santé et de la recherche sur la santé, et pour réaliser un exercice de simulation selon les principes de PCAP et élaborer des documents d'informations communautaires personnalisés sur la planification de la santé et de la recherche. Les évaluations de la part des participants ont été enthousiastes. Il existe une forte demande pour d'autres ateliers, et un cours pour les futurs formateurs est en cours de planification.

Je pourrais illustrer beaucoup d'autres réalisations. Je tiens à remercier en concluant le personnel et le Comité directeur du CPN pour leur sens du travail d'équipe et pour leur dévouement envers les droits des Premières Nations et les questions les concernant. Au cours de nos déplacements, nous avons prêté l'oreille à l'expression des besoins et des priorités des Premières Nations qui résident dans tout le Canada, et nous avons perçu combien la santé est liée à nos traditions

et à nos valeurs. C'est pourquoi nous sommes fiers de collaborer avec les Instituts de recherche en santé du Canada (Canadian Institutes of Health Research), Dr James Sa'kej Henderson et le Dr James Sa'kej Henderson du *Native Law Centre*, pour élaborer des modèles conceptuels et appliqués de l'éthique et de la confidentialité des Premières Nations sur la base des principes de PCAP. La gouvernance de la part des Premières Nations en matière d'information est au cœur des projets infostructure sanitaire, de surveillance médicale publique, de services de santé non assurés et d'autres programmes et services de santé. Ces principes sont devenus encore plus apparents avec les efforts du CPN pour coordonner l'élaboration et l'approbation des recommandations longtemps attendues sur l'infostructure de santé des Premières Nations, un article de discussion sur une carte à puce polyvalente à l'usage des Premières Nations, et une table ronde nationale comportant une analyse juridique du renouveau législatif en matière de protection de santé.

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Achievements for 2003-04 Improving and promoting health through knowledge-based activities

- Developed and submitted a discussion paper on the First Nations Multi-Purpose Smart Card to regional and national leadership for consideration.
- Completed an extensive review of money the federal government spent on First Nations between 1998/99 and 2002/03.
- Distributed widely, including posting on the Internet, a report synthesizing national and regional reports of the 1997 First Nations Regional Health Survey.
- Co-ordinated the development and distribution of recommendations on the First Nations Health Infrastructure with the approval of First Nations leaders.
- Completed 42 briefing notes and nine information sheets on various health issues.

Promoting an understanding of health issues affecting First Nations

- Conducted an environmental scan of existing health research and projects targeting urban First Nations peoples to further the development of an Urban First Nations Outreach Strategy.
- Developed a Community Planning Tool Kit for Suicide Prevention as a follow-up to the final report of the Suicide Prevention Advisory Group.
- Developed the methodology for a preliminary needs assessment called Exploring Models for Quality Maternity Care in First Nations and Inuit Communities, in collaboration with the Ajunnginiq Centre and with support from the FNIHB.
- Collected ecological variables data and began preliminary analysis of the First Nations Regional Longitudinal Health Survey (RHS) 2002/03. This, along with the federal expenditures analysis, will complete the First Nations Health Report Card.



et à nos valeurs, notre force et notre bien-être en tant que communautés et que Nations. Le CPN continuera à promouvoir dans ses activités une approche collaborative du service, afin d'aider les peuples des Premières Nations à réaliser leurs aspirations.

Personnel

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- Received a call for participation/nominations and developed terms of reference for the National First Nations Youth Health Network.
- Participated in the youth working group for NAHO's National Aboriginal Role Model Program.
- Created a process for launching a "best practices" program with broad use and drafted a Knowledge Translation/Best Practices Tool Kit.

Facilitating and promoting research and developing research partnerships

- Working with 10 First Nations regional partners, the FNC co-ordinated the following activities throughout Canada for the RHS 2002/03 with support from FNIHB's Health Information and Analysis Division



and overseen by the First Nations Information Governance Committee:

- Completed collection of data.
- Began the analysis, interpretation, and dissemination plan.
- Completed a Discussion Paper for an RHS Communications Strategy and drafted a new logo.
- Completed a License to Use the Data Agreement with the FNIHB and the First Nations Information Governance Committee.
- Completed a Pilot Survey on the Use of Insect Repellents in First Nations Communities in four regions (250 sample) with support from FNIHB's Environmental Health Division.
- Presented progress to First Nations leadership and to a United Nations Workshop on Data Collection and Disaggregation on Indigenous Peoples.
- Created the FNC's Statistical Services Unit.
- Commissioned a business plan for a sustainable First Nations Health Research and Information Infrastructure.
- Co-ordinated a national roundtable on the new health protection legislative renewal and commissioned a legal opinion.
- Visited and completed a report on the United States Indian Health Service's Tribal Epicentres.
- Produced the Final Report of the First Nations Youth Survey.
- Produced a report called What First Nations Think of Their Health and Health Care: Final First Nations Results of the 2002 NAHO Public Opinion Poll.
- Secured a grant from the Canadian Institutes of Health Research (CIHR) to develop First Nations conceptual frameworks and applied models on ethics and privacy on health research and information.
- Published an article on the principles of OCAP in the first issue of NAHO's *Journal on Aboriginal Health* and a paper for a CIHR Workshop on Ethics and Privacy.
- Participated in the Tri-Council Policy Statement revisions on Aboriginal research on behalf of NAHO and presented to Health Canada's Research Ethics Board on First Nations research ethics and principles of OCAP.

Fostering participation of First Nations people in the delivery of health care

- Distributed more than 3000 each of four tool kits on privacy, surveillance, research, and research ethics.
- Piloted an online training program for First Nations community public health workers on basic techniques of epidemiological research.



- Developed a curriculum and held two regional workshops for First Nations community health workers called “How to Use Data More Effectively in Your Community.”
- Developed a curriculum and held three workshops for First Nations youth, introducing them to the basics of health information and research, and asset mapping.
- Led the development of a proposal called “Assessing the Needs of the Nursing Workforce in First Nations and Inuit Communities” in collaboration with the Aboriginal Nurses Association of Canada, the Assembly of First Nations, NAHO’s Ajunnginiq Centre, Policy Research Unit, and Inuit Tapiriit Kanatami.

Affirming and protecting First Nations traditional healing practices

- Drafted a Traditional Knowledge Tool Kit led by First Nations youth.
- Participated in NAHO’s Policy Research Unit activities.
- Participated in the Unity Ride and Run 2003.



Priorities for 2004-05

- Ensure ongoing liaison with First Nations leadership and health-care workers regionally and nationally through partnership agreements.
- Participate in/sponsor events to share information on FNC activities.
- Assist national and regional First Nations organizations pursue the implementation of First Nations Health Infostructure recommendations.
- Producing and distributing briefing notes and information sheets on policy and key developments affecting First Nations.
- Produce a visioning document and outline an Urban First Nations Outreach Strategy.
- Pilot, revise, and produce/distribute a Community Planning Tool Kit for Suicide Prevention.
- Produce and distribute a final report of the preliminary needs assessment on maternity care in First Nations communities.
- Complete the First Nations Health Report Card.
- Obtain approval for the terms of reference and work plan and create ongoing network mechanisms for the National First Nations Youth Health Network.
- Complete and distribute a Knowledge Translation/Best Practices Tool Kit and a Partnership Building Tool Kit.
- Co-ordinate at a national level the implementation of the Analysis, Interpretation, Dissemination Phase of the RHS 2002-2003 process in collaboration with 10 First Nations regional partners and overseen by the First Nations Information Governance Committee.



- Distribute and seek support for the implementation of the Business Plan for a sustainable First Nations Health Research and Information Infrastructure.
- Produce a discussion paper on a possible FNC Ethics Office and disseminate a Template for Building Ethical Guidelines in First Nations Communities.
- Pursue opportunities to develop a framework for a First Nations public health action plan in collaboration with the Assembly of First Nations.
- Seek support for First Nations consultations on information governance.
- Continue to participate in the Tri-Council Policy Statement revisions relating to Aboriginal research on behalf of NAHO.
- Distribute tool kits on infostructure, indicators, determinants, and health careers.
- Conduct regional workshops for First Nations community health workers on How to Use Data More Effectively in Your Community.
- Conduct more workshops for First Nations youth to introduce them to the basics of health information and research, and asset mapping and planning using a “Train The Trainer” model.

