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Progress Report

Aboriginal Cancer Care Unit

January 2006

Aboriginal Cancer Care Unit (ACCU)
Progress Report

Cancer is the second leading cause of death in First Nations people living on reserve in Canada.[1] Cancer patterns among Aboriginal populations display significant differences from those observed in the general population. These patterns, including the increasing incidence of cancer, and the presentation of cases at much later stages of cancer development, underscore the need for targeted Aboriginal cancer control strategies.

Since the Aboriginal Cancer Care Unit was established in 2000, Cancer Care Ontario (CCO), has demonstrated its commitment to the Aboriginal Cancer Strategy (ACS) by making it one of four priorities of *Cancer 2020*, a plan for cancer prevention and screening in Ontario. In September 2002, both CCO and the Joint (Cancer Care) Ontario – Aboriginal Cancer Committee (JOACC) supported moving the Unit's strategic plan forward.

Messages and Acknowledgements

Mrs. Helen Cromarty, Co-Chair
Joint (Cancer Care) Ontario-Aboriginal Cancer Committee
Nishnawbe-Aski Nation

My involvement with the Aboriginal Cancer Care Unit (ACCU) stems from the very first meeting between Aboriginal and First Nation representatives and The Ontario Cancer Treatment and Research Foundation in September 1996, from which the JOACC evolved. Although I left my post briefly to assist in the development and implementation of another project, I felt the burden of cancer on Aboriginal and First Nations people was one that required immediate and ongoing address.

Since the inception of the Aboriginal Cancer Care Unit, its staff, JOACC members and Cancer Care Ontario have been working to lay the foundation for what is now the Aboriginal Cancer Strategy. Further direction was sought from The People through the *Needs Assessment*, completed in 2002.

The first phase of the strategy focused on research – to determine the burden of cancer in First Nations communities – and planning. The strategy is now ready to embark on the implementation phase as outlined in *Honouring the Aboriginal Path of Well-Being: 5-Year Plan* (henceforth referred to as the 5-Year Plan). The plan outlines the work and the resources required for ACCU to continue to forge ahead.

I look forward to working with my JOACC cohorts and CCO as we develop and implement an Aboriginal Cancer Strategy that is reflective of the needs identified by The People and respectful of our traditional ways in our communities.

Dr. Verna Mai, Co-Chair
Joint (Cancer Care) Ontario-Aboriginal Cancer Committee
Acting Vice-President, Division of Preventive Oncology
Cancer Care Ontario

In my role as acting vice-president, Division of Preventive Oncology, I have had the pleasure of being directly involved in the development of the Aboriginal Cancer Strategy initiative. Cancer Care Ontario (CCO), the Ontario Ministry of Health and Long-Term Care's principal adviser on cancer issues, acknowledges that Aboriginal people are the best equipped to speak on issues that affect their own. The work of the JOACC provides overall guidance and advice to CCO on the development and implementation of the Aboriginal Cancer Strategy (ACS). The ultimate aim is to reduce the incidence of cancer among Ontario's Aboriginal populations.

The ACCU has started to move ahead with the strategy as outlined in the Unit's 5-Year Plan, and there is much work to be done as we move ahead. Surveillance data in the First Nations population has shown certain preventable cancers to be on the rise. The JOACC will need to continue to develop its partnerships with the Integrated Cancer Programs (ICPs), government agencies and Aboriginal communities and organizations to help move the strategy forward.

Ms. Carmen Jones
Director, Aboriginal Cancer Care Unit
Cancer Care Ontario

In my time as the director of the Aboriginal Cancer Care Unit, the Aboriginal Cancer Strategy (ACS) has evolved tremendously. The *Needs Assessment* gave us the foundation to build a strategy that is informed by Aboriginal peoples. Important milestones have been reached as the Unit and the work accomplished thus far take us further along the path to Aboriginal health and wellness.

The developmental work of the Unit has given rise to a 5-Year Plan. In this document, the Unit's five strategy areas are identified: policy/planning, surveillance/research, health promotion, community liaison and regional Integrated Cancer Program (ICP) network support. The two immediate priority areas of the plan are health promotion and surveillance. In order to move the strategy forward, support has been given by the Chiefs of Ontario in the form of a resolution, and by the representatives of the JOACC. This plan is a tool to help Cancer Care Ontario move forward on implementing the Aboriginal Cancer Strategy. The next step will be to secure the commitment of all governments and develop partnerships to provide the proper and necessary resources to implement the plan.

Another important milestone is the update of the First Nations cancer surveillance data to the year 2001. The data revealed that the overall cancer incidence rate in First

Nations people, while still below the rate for the general population, is rising more quickly. Education and awareness will be the key to addressing rising cancer rates. We have already begun to use these approaches through the ACS health promotion strategy, and the Aboriginal Tobacco Strategy, now in its third year of development. I want to thank Cancer Care Ontario and the JOACC for their support throughout this past year. I also want to thank the staff for their commitment and hard work in the development of the Aboriginal Cancer Strategy.

Meegwetch.

Dr. John McLaughlin
Interim Director, Aboriginal Cancer Care Unit
Cancer Care Ontario and
In-coming JOACC Co-Chair

I look forward to assuming the responsibilities of co-chair for the JOACC. Aboriginal cancer rates, although currently below the rates seen in the Ontario population, are on the rise. Cancer patterns in the Aboriginal population also differ from that of the general population. The ACCU is an important component of CCO in further developing and implementing the Aboriginal Cancer Startegy. The Unit's role of creating knowledge in a specialized field, acting as a knowledge broker and developing partnerships with key stakeholders and networks will be instrumental in moving the strategy forward.

Joint (Cancer Care) Ontario – Aboriginal Cancer Committee (JOACC)

The JOACC was established because CCO recognized that traditional western methods of delivering health care services did not reach the Aboriginal population to the same extent as the general population. The mandate of the Committee is to assist CCO to develop and promote cancer care services that will reach and support the Aboriginal communities. The Committee meets twice annually at rotating locations throughout Ontario.

At its June 2004 meeting in Thunder Bay, the Committee initiated planning for a retreat to deliberate about the plans and implications of shifting from the first phase of developing the Aboriginal Cancer Strategy – which focused on research and planning – to the implementation phase.

The retreat was held on September 13 and 14, 2004 at Neyaashiingaming, Chippewas of Nawash First Nation. Discussions and consensus emerged from the following themes:

- The need to continue to work on surveillance – including commencing discussions about surveillance of the Métis population – and research;
- The importance of the Aboriginal Tobacco Strategy;
- The need to understand and follow appropriate protocol when communicating with Aboriginal communities and organizations;
- The need to ensure that communities are central in the implementation of the strategy;
- The importance of taking a wholistic approach and focusing on the determinants of health.

Following the Aboriginal Path of Well-Being
ACCU 5-Year Plan 2004–2009[2]

ACCU's strategic planning document, The 5-Year Plan was completed in 2004.This tool was developed to guide and give shape to the Aboriginal Cancer Strategy (ACS). This document outlines a vision and mission, and a goal to be reached. The plan identifies the resources required to move the ACS forward. It is based on The People's direction as identified in the needs assessment.

The ACCU's 5-Year Plan supports the strategic initiatives of the Division of Preventive Oncology (DPO): planning, capacity building/support to regions, knowledge exchange, research, evaluation and surveillance.

The expected long-term (5–10 year) outcomes of the ACCU's proposed plan include:

- Development of an Aboriginal cancer surveillance system for Ontario;
- Increased capacity in the Aboriginal communities for cancer prevention and tobacco issues;
- Development and delivery of Aboriginal-specific smoking cessation programs;
- Improved survival for Aboriginal cancer patients;
- Development of cancer programming for communities;
- Decreased rates in cancers related to tobacco, nutrition/diet and physical activity;
- Relationship building with regions and Aboriginal communities;
- Establishment of a regional patient navigation system.

This tool will assist Cancer Care Ontario and the JOACC members to advance the strategy and build partnerships across health sectors to assist in its implementation.

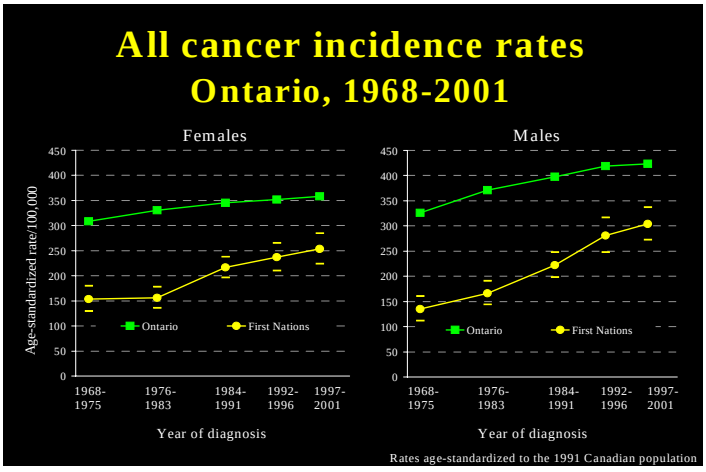
Aboriginal Cancer Care Unit Staff

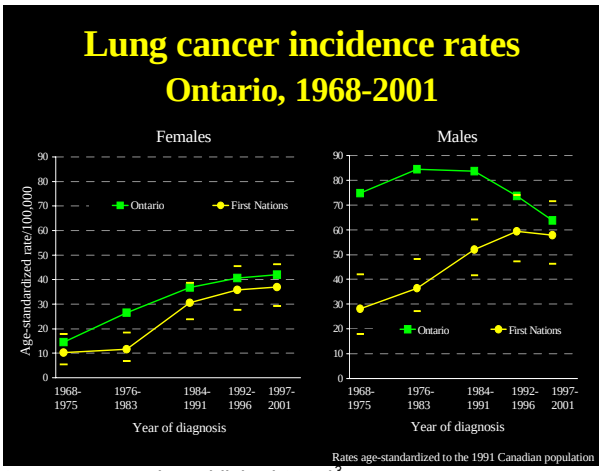
L to R (front row): Pam Johnson, Elisa Levi, Carmen Jones, Rina Chua-Alamag, Christine Smillie-Adjarkwa (Back row): Joey Fox, Sally Hare

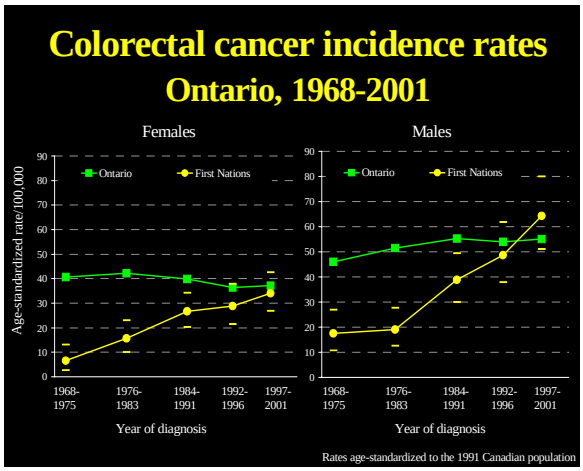
Strengthening the Aboriginal Cancer Strategy

This past year marked a period of continued evolution and forward movement for ACCU. New staff members joined the Unit and contributed to developing the Aboriginal Cancer Strategy. ACCU continued to develop and deploy its mandate to facilitate Aboriginal research, knowledge exchange, monitoring and evaluation of tobacco-wise pilot projects, and strategies for prevention and health promotion activities.

First Nations cancer trends data was strengthened with the update of Dr. Loraine Marrett's surveillance research on cancer incidence and mortality in First Nations up to 2001. The overall incidence, while still well below the rate for the general population, is rising more quickly in Aboriginal populations. Much of this increase is due to a rise in colorectal cancer rates, and rapidly rising lung cancer rates. Smoking, the most important risk factor for lung cancer, is now also established as a risk factor for colorectal cancer.







Source: Marrett (unpublished 2004)[3]

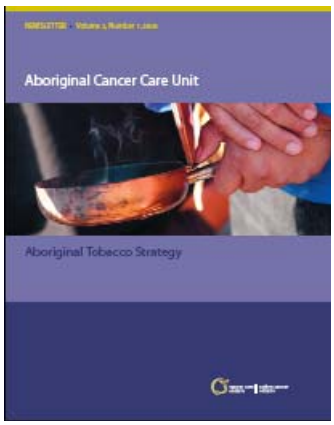
Research work is forging ahead with the start of the Breast Cancer Pilot Project. The intent of this study is to identify reasons for the poorer survival observed among First Nations women in Ontario, as compared with women in the general population, after a breast cancer diagnosis. This work is expected to inform health care decision-makers about barriers to cancer screening, treatment and surveillance for First Nations women compared with non-Aboriginal women in Ontario.

Toronto Sunnybrook Regional Cancer Centre will be the host site for the pilot. The study will be led by Dr. Lorraine Marrett, with co-investigators Carmen Jones, Kue Young (professor, University of Toronto), Maureen Trudeau (oncologist, Sunnybrook), Diane Nishri (biostatistician, Cancer Care Ontario) and Amanda Ritchie (PhD candidate, University of Toronto).

Aboriginal Tobacco Strategy

The Aboriginal Tobacco Strategy (ATS) is a main priority area of ACCU. Its focus is on smoking cessation, public education, capacity building, promising practices and leadership engagement. In the past year, ATS has been active in administration and programming, adding three new staff members to the team. Twelve new capacity building projects were funded to promote tobacco-wise communities. These projects build upon a community's existing strengths to enhance its capacity to promote the health of their members and protect them from the harmful effects of tobacco misuse.

An integral part of the strategy is the ATS Working Group, which comprises staff and community members with experience in and commitment to the tobacco issue. Through this group, ATS consults with communities, engages in mutual capacity building, and disseminates information.



2004 Accomplishments:

- The production of the second ACCU newsletter, with a focus on traditional use of tobacco. The issue contains knowledge shared by elders and stories about community-based projects funded by ATS.
- In partnership with the First Nations and Inuit Health Branch of Health Canada, ATS sponsored the Native American Tobacco Intervention Skills Training, which offered skill building focusing on tobacco cessation. Thirty-six health care professionals and workers throughout Ontario completed the training.
- A proposal for a youth-centered media campaign was submitted to Health Canada for funding. The proposal was successful and work has begun to launch the PSA campaign.
- Funding was provided for a culture-based cancer prevention pilot project. The **Ononhkwas'shon:a** program teaches proper use of tobacco, good food, exercise and humour to awaken individuals in the Aboriginal community to a powerful cancer prevention lifestyle.

Prevention, Screening and Health Promotion

The health promotion strategy focuses on improving nutrition, achieving a healthy body weight, increasing physical activity and decreasing the use of commercial tobacco. Efforts have focused on networking and gathering resources to plan further development of the health promotion strategy. A partnership with the Canadian Cancer Society was developed for information sharing and collaboration on selected prevention and health promotion initiatives.

This partnership resulted in an awareness campaign with a goal of developing toolkits consisting of evidence-based cancer information fact sheets for the Aboriginal population. Dissemination of the awareness toolkits will be geared to health professionals working with Aboriginal clients/patients.

On going work will focus on disseminating the Cancer Awareness Campaign toolkits and campaign evaluation. The Health Promotion Officer will also be responsible for the development of the next ACCU newsletter, which will focus on colorectal cancer prevention.

Building Relationships and Knowledge Transfer

ACCU provides support and specialized expertise to regional partners and networks through work in knowledge exchange and development. Examples include the following:

- Development of a poster presentation for the 6th National Summit on Northern and Rural Community Cancer Control;
- Participation on the planning committee for the 4th World Conference on Breast Cancer, for which a day was dedicated to Aboriginal women's health;
- Presentation on "Development of a culturally competent cancer control strategy for Aboriginal peoples in Ontario" at the 1st International Cancer Control Congress.

I. Aboriginal Relationship and Development Training

Health service providers identified a need for cultural awareness in *"It's Our Responsibility… ."* They acknowledged a lack of understanding between the service provider, the patient and family.[4] In addition, the report identified the need to enhance outreach and networking with the Aboriginal community in order to improve referrals for Aboriginal patients.

Out of this feedback was born the Aboriginal Relationship and Development Training (ARDT) program. Key outcomes include:

- Creating linkages between local Aboriginal community members, and resource people and champions within each cancer centre;
- Changing hospital environments and cancer care practice for Aboriginal patients;
- Emphasizing the role history had in shaping current Aboriginal worldviews, health perceptions and behaviors related to cancer care and prevention.

North/wind Consultants was the successful contractor to develop a resource manual and provide two-day training sessions to eight selected cancer centres between December 2004 and May 2005. Reporting to a Technical Working Group, the consultants undertook an environmental scan of the regions before completing the resource manual.

Ninety-seven percent of participants of the pilot training session – held at Juravinksi Cancer Centre in Hamilton – indicated that they would change the way they approach Aboriginal clients after attending the training. Other changes that have occurred as a direct result of this cultural awareness training are:

- Placing Aboriginal art and cultural images in patient-care areas;
- Introducing sacred plants to healing gardens;
- Changing orientation programs to include Aboriginal specific information;
- Changing hospital admission practices to facilitate self-identification of Aboriginal clients.[5]

An evaluation of the training will encompass the following: (1) evaluation of the trainers and materials by the champions and cancer care staff, (2) follow-up with sites to determine what training or Aboriginal-specific initiatives had occurred over the months following the two-day session and (3) pre and post testing for people the champions will train, to determine if changes in attitudes, perceptions and practice patterns occur.

After the evaluation piece is completed, further development of a plan to seek financial and human resources will be required in order to continue to provide this training.

II. Aboriginal Patient Navigator Pilot Program

The ACCU Needs Assessment report *"It's Our Responsibility…"* strongly recommended that Aboriginal Patient Navigator (APN) positions be established at cancer centres in Ontario. The role would include:

- Providing support and advocacy for Aboriginal patients and their family members;
- Promoting awareness of the cultural needs of Aboriginal clients;
- Networking with Aboriginal and non-Aboriginal health groups and organizations.

Northwestern Ontario Regional Cancer Centre (NWORCC), due to its large Aboriginal clientele, was selected as the site for the APN pilot. The pilot started in December 2003 and was slated to last for one year. ACCU Director Carmen Jones established a design committee to develop the foundational framework for the project. ACCU provided the financial resources to NWORCC to conduct the pilot test, assist in the evaluation of the project, and keep the JOACC and CCO's Division of Preventive Oncology Management Committee apprised of developments.

An Aboriginal candidate fluent in three local languages was selected for the APN position, and worked as a staff member of NWORCC following the parameters established by the cancer centre.

ACCU contracted the services of Dr. Emily Faries to conduct a qualitative evaluation report of the pilot and to provide recommendations. The evaluation report provides a

point for moving forward, and for identifying and addressing barriers to successful implementation of an APN program. For this to occur, the following recommendations were tabled in the report:[6]

- Explore options for the continuation of the APN pilot project;
- Develop a support system for the APN;
- Have a design team involved throughout implementation of the program;
- Develop policies and procedures to address the cultural needs of Aboriginal clients.

ACCU could only sustain financial support for a pilot. Seeking resources for long-term maintenance of this program will require collaborative efforts from ACCU, JOACC and the regional cancer centres.

Provincial Cancer Plan

Cancer Care Ontario has undergone system-wide restructuring to improve accountability, administration, efficiency and streamlined clinical services. One of the most important changes is the integration of regional cancer centres with their host hospitals to create Integrated Cancer Programs, each of which has entered into a new performance management relationship with CCO. Cancer Care Ontario is now a knowledge-driven, evidence-based organization that uses data to plan, fund and report on performance on key issues in the cancer system.[7]

The Ontario Cancer Plan outlines a provincial strategy for improving the quality of cancer services throughout Ontario. It outlines a number of priorities, targeted investment and action plans with defined timelines and outcomes.

The provincial plan outlines six priorities for action, one of which is to close the gap by reducing demand and increasing capacity for cancer services. To help close the gap and increase capacity for Ontario's Aboriginal population, there is an urgent need to implement the Aboriginal Cancer Strategy, which will lead to reduction of preventable cancers.

The Path Ahead…

The key to success in the delivery of Aboriginal knowledge and the transfer of this knowledge is for communities to have the capacity to be involved and participate actively. There is a need to explore opportunities for improved coordination with provincial Aboriginal health program delivery infrastructures, such as First Nations Health Centres or Aboriginal Health Access Centres. It is the vision of the Aboriginal Cancer Care Unit that over the next 5 to 10 years there will be cancer prevention programming in the regions to implement the strategies being developed.

The report uses the term "wholistic" instead of "holistic," as wholistic represents wholeness. This has been adopted by the *Aboriginal Health Policy*, 1994, Government of Ontario.

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