

MAKING OUR VOICES HEARD

Canadian Cancer Action Network Strategic Plan 2008-2012





Canadian Cancer Action Network (CCAN)

MEMBERS COUNCIL

Cancer-Site Patient Organizations

Brain Tumour Foundation of Canada
Canadian Breast Cancer Network
Canadian Liver Foundation
Canadian Lung Association
Canadian Prostate Cancer Network
Canadian Skin Patient Alliance
Canadian Thyroid Cancer Support Group (Thy'vors Inc.)
Carcinoid NeuroEndocrine Tumour Society Canada
Childhood Cancer Foundation Candlelighters Canada
Colorectal Cancer Association of Canada
Kidney Cancer Canada
Leukemia & Lymphoma Society of Canada
Lung Cancer Canada
Lymphoma Foundation Canada
Ovarian Cancer Canada

Population Organizations

Assembly of First Nations
Canadian Cancer Society
Canadian Partnership Against Cancer
Cancer Advocacy Coalition of Canada
Inuit Tapiriit Kanatami

Provincial CCAN Organizations

Manitoba
New Brunswick
Newfoundland & Labrador
Nova Scotia
Ontario
Saskatchewan (SCAN)
Coalition Priorité Cancer au Québec

Representatives on CPAC Action Groups

Cancer Guidelines
Cancer Journey
Health Human Resources
Primary Prevention
Research
Screening
Standards
Surveillance

CCAN MISSION STATEMENT

Empower the cancer patient voice across Canada to ensure a strong patient perspective in health policy making and access to care.

BACKGROUND

WHO ARE WE? The Canadian Cancer Action Network (CCAN) is a volunteer-driven, incorporated organization dedicated to ensuring patient interests remain a key priority on the national cancer agenda. CCAN was created in order to ensure that the patient perspective is (and remains) an integral part of the cancer control strategy.

CCAN unites all cancer-site patient support organizations from across Canada in support of the Canadian Partnership Against Cancer (CPAC) agenda. Functioning as a key voice, CCAN informs CPAC on issues pertaining to cancer from prevention, early detection, screening, education, control, research, treatment, care and the pursuit of a cure.

In 2004, over 850,000 Canadians were living with a diagnosis of cancer that had been made within the past 15 years. With this in mind, CCAN strives to empower the cancer patient voice nationwide, and to incorporate a strong patient perspective to the process of health policy making and access to care. Through the cultivation of linkages, partnerships and collaborative efforts at the local/provincial/regional/national levels, and through effective dialogue, CCAN works to ensure the inclusion of all Canadians with regard to communicating issues from a patient perspective. This requires that CCAN concentrate on identifying and pursuing avenues and platforms that foster the development of a healthy and viable collaborative network, or coalition culture.

Currently, CCAN receives funding from two sources: (1.) Fees collected from membership dues (2.) Funds from CPAC allocated toward operational costs, and to strategic initiatives and projects identified by CCAN.

HISTORY: In 2001, in an unprecedented show of unity, national volunteer-driven cancer organizations sent representatives to the initial meeting of CCAN. At that time, those present reached consensus that one voice representing patients and their families was imperative, lending support to the development of a national coalition structure.

In 2005, over 26 cancer patient groups and Provincial/Territorial and Regional cancer sites met to reaffirm their commitment to supporting CCAN as their key national voice in a joint effort to ensure that the Canadian Strategy on Cancer Control (CSCC) remains on track.

In 2008, CCAN received Affiliation Status with CPAC. This important partnership will contribute to the evolution of cultivating, broadening and strengthening the presence of patients, survivors and families and ensuring their active voice is heard. With the hiring of a new full-time Executive Director, CCAN will engage with stakeholders primarily through the work of active provincial committees and issue specific working groups.

STRATEGIC PRIORITIES (2008-2012)

1. PATIENT ISSUES

Goal	Action Plan	Measurable Outcomes
<p>To ensure all issues relevant to cancer patients and their families are appropriately addressed by the Canadian Partnership Against Cancer, and the emerging national strategy.</p>	<p>Develop and implement a defined process that allows for the identification and prioritization of relevant patient issues, or projects.</p> <p>For each issue identified, create and implement a comprehensive plan with accountability, leadership, actions and a budget.</p> <p>Develop a realistic / comprehensive approach directly relevant to the Pharma issues. Implement the approach, and evaluate the results.</p> <p>Work with CCAN network to ensure effective transfer of knowledge and identify collaborative opportunities.</p> <p>Present to CPAC (through Advisory Council representation) identified patient issues that require more focused attention.</p>	<p>A defined, inclusive process for identifying patient issues is in place culminating in a prioritized list of issues.</p> <p>A clearly defined strategy for addressing or acting upon patient issues (reached through dialogue and interaction) is place.</p>

2008–2009 Activities:

- Review and define issues of system access.
- Review cancer drug access (i.e. eligibility for drugs and patient awareness around the process.)
- Focus on Pharma issues.

Beyond 2009:

- Explore understanding navigation of the cancer pathway (i.e. How to navigate with ease, the role of navigators, how to make the process effective and efficient.)
- Work toward the development of national guidelines.
- Work with population organizations such as AFN, and ITK.
- Conduct an environment scan. (i.e. encompassing survivor support issues.)
- Work toward enhancing access of patients to systematic therapy / screening / radiation.
- Proactively promote patient access to necessary care and support through education.

2. PATIENT VOICE

Goal	Action Plan	Measurable Outcomes
<p>To empower and encourage the cancer patient voice to be heard resulting in positive and quantifiable changes.</p>	<p>Ensure consistent, informed patient voices representation on all CPAC Action Groups/ other appropriate groups and, where available, at other forums or decision making levels.</p> <p>Develop and adopt an accepted and consistent process for concise reporting and active information sharing both within CCAN and externally.</p> <p>Create and disseminate resources and print materials in support of those representing Patient Voices, both CCAN and otherwise.</p> <p>Identify and implement an effective engagement process that (a) further promotes active dialogue between CCAN and CCAN member organizations and (b) encourages participation from those who represent (or speak on behalf of) a patient constituency; maintain communication and offer appropriate training.</p>	<p>The identification, cultivation and existence of an inclusive platform that allows cancer patients to be heard and to feel as though identified issues and concerns are being effectively addressed.</p> <p>The formation and implementation of an informed strategy based on contributions from various patient and stakeholder levels.</p> <p>The demonstrated existence of an interactive and healthy dialogue between CCAN and stakeholders including CPAC, member organizations and action groups representatives.</p> <p>A strong, unified cancer patient voice is in place representing the perspective of patients at all levels in the health care system.</p>

2008–2009 Activities

- Implement recommendations as per the Knuttila Report.
- Completion of a Patient “Bill of Rights.”
- Further website development directly relevant to Patient Voices.

Beyond 2009:

- Develop and introduce training materials to support the effectiveness of representatives who bring “Patient Voice” to groups, task forces and committees.
- Develop a training module for those representing Patient Voices. (i.e. print materials and a toolkit.)
- Deliver training workshops for new CCAN representatives.
- Complete a nationwide inventory.

3. REGIONAL INITIATIVES

Goal	Action Plan	Measurable Outcomes
<p>To establish a strong, active and recognized CCAN presence in each province and territory through provincial CCAN representation.</p>	<p>Enhance existing CCAN provincial / regional networks by creating and implementing a framework and process for facilitating dialogue and action.</p> <p>Establish collaborative relationships and expand CCAN network in order to broaden the patient collective.</p> <p>Create opportunities for exchange of knowledge and engagement of patients / families / survivors that will contribute to future CCAN planning and action.</p>	<p>To have appropriate documents in place defining the role and responsibility of provincial CCAN members.</p> <p>To have an established, functional provincial CCAN in each province or territory.</p> <p>To have a system in place that promotes collaboration and two-way communication between a provincial CCAN and respective community cancer groups and agencies.</p>

2008–2009 Activities

- Identify and introduce internal mechanisms (vehicles/avenues) that further support the development and growth of the provincial CCAN structure.
- Develop an active provincial CCAN in the provinces of British Columbia, Alberta and Prince Edward Island.
- Develop print materials (i.e. bulletins) in order to share information on best practices and activities in each of the active provinces.

Beyond 2009:

- Formulate a strategy to reach the Aboriginal and Inuit communities more effectively.
- Work with the Coalition Priorité Cancer au Québec to promote CCAN provincial goals.
- Work to affect change at the provincial government level.
- Where feasible, work with the provincial government in support of CCAN and CPAC goals.
- Work toward developing provincial capacity building for all provinces as a means of identifying who and what exists in support of CCAN and determining what needs to be done to build capacity further.

4. EDUCATION & AWARENESS (Communications Internal / External Outreach)

Goal	Action Plan	Measurable Outcomes
<p>To ensure effective internal and external vehicles for communication and interaction with all relevant stakeholders are cultivated and maintained.</p>	<p>Develop and implement a comprehensive external communications strategy (i.e. consistent messaging) supported by a strong educational and awareness platform. Actively engage patient constituency in member organizations.</p> <p>Develop and implement a comprehensive internal communications strategy promoting educational outreach efforts, and initiatives. Improve communication flow with member organizations.</p> <p>Develop and implement an effective internal communications strategy with CPAC that allows for sharing of information, and opportunity for insight, input or comment.</p> <p>Develop and introduce an “Implementation and Monitoring Matrix” as a blueprint (or landscape) charting CCAN activities, timelines and deliverables.</p>	<p>To have in place an elevated awareness resulting in transparency of issues.</p> <p>As leader of a coalition, recognition of CCAN in a leadership capacity in at least (3) issues directly relevant to patient perspective on cancer care in Canada.</p> <p>The presence of an informed, supportive and active CCAN membership on both a national and provincial level.</p> <p><i>Education & Awareness (or communications) refers primarily to: (a) education, awareness, communication and dialogue within both the membership and the organizational structure (b) external educational outreach or engagement of the Canadian public (c) development and strategic dissemination of marketing and promotional materials (d) website development and/or maintenance.</i></p>

2008–2009 Activities

- Following the development of CCAN print materials – identify methods for distribution that support translation of promotional materials in both official languages.
- Work with community partners / stakeholders to raise awareness; further engage and open interactive dialogue and communication channels.
- Further develop website.

Beyond 2009:

- Work to affect change at the federal government level with non-CPAC funds.
- Following the development of toolkits (i.e. training materials) – identify and pursue options that allow for extended sharing of materials nationwide.

5. GROWTH & SUSTAINABILITY (Governance)

Goal	Action Plan	Measurable Outcomes
<p>To establish and implement a strong, effective governance model for CCAN.</p>	<p>Establish governance policies and procedures to effectively oversee all CCAN operational issues.</p> <p>Conduct an annual, in-house analysis in order to chart areas of growth and development. Incorporate those results into an Annual Report.</p> <p>Formalize and implement a membership development model addressing such issues as membership expectations and engagement.</p>	<p>An accountable, transparent and viable governance model is developed, adopted and implemented.</p> <p>An Annual Report is developed and released charting activities, results and impacts.</p>

2008–2009 Activities

- Identify and articulate (a) the expectations CCAN has of member organizations and (b) the expectations member organizations have of CCAN.
- Complete an Annual Report for sharing amongst member organizations and stakeholders.
- Host an Annual General Meeting.

Beyond 2009:

- Review and continue to develop/implement core operational controls.

PATIENT ISSUES

GOAL: *To ensure all issues relevant to cancer patients and their families are appropriately addressed by the Canadian Partnership Against Cancer, and the emerging national strategy.*

Introduces patient focused research and patient projects focused on access and education. Emphasizes issue identification as key to putting forward relevant issues and concerns that might positively change the health care system. Promotes mobilization of member organizations with a focus on achieving active consensus. Allows for the creation and maintenance of partnerships or collaborative efforts in an attempt to move forward.

PATIENT VOICE

GOAL: *To empower and encourage the cancer patient voice to be heard resulting in positive and quantifiable changes.*

Ensures strong representation and informed patient voices on CPAC action groups, and in other forums. Provides opportunity to engage in transparent, accountable and direct representation relevant to patient perspective without engaging in advocacy addressed to the public. Provides a strong voice in the deliberations of each CPAC Action Group, and other appropriate cancer-related initiatives and works with allied groups for optimum access to quality care for cancer patients in Canada. Offers opportunity to press for public policies with an emphasis on cancer prevention and persuades and informs government at all levels of the necessity to sustain and increase funding for cancer control.

REGIONAL INITIATIVES

GOAL: *To establish a strong, active and recognized CCAN presence in each province and territory through provincial CCAN representation.*

Promotes the ability to build capacity and sustain CCAN relationships within all provinces and territories while concurrently establishing a support structure of CCAN representation in provinces and territories. Promotes the sharing of information through representation at provincial levels. Where feasible, works with the provincial government in support of CCAN and CPAC goals.

**EDUCATION & AWARENESS
(Communication)**

GOAL: *To ensure effective internal and external vehicles for communication and interaction with all relevant stakeholders are cultivated and maintained.*

Allows for increased outreach through the development and sharing of promotional print and website materials. Offers opportunity to utilize website as an interactive communications tool. Encourages stronger, more effective marketing of the organization externally, as well as effective messaging of related CCAN issues. Supports an improved, more productive communication.

**GROWTH & SUSTAINABILITY
(Governance)**

GOAL: *To establish and implement a strong, effective governance model for CCAN.*

Provides organizational structure with accountability and transparency. Provides a critical framework for continued growth and development, as well as key ingredients to ensure both short and long-term viability.

CANADIAN CANCER ACTION NETWORK (CCAN)
1 University Avenue, Suite 300
Toronto, Ontario
M5J 2P1

Tel: 416.619.5784

Marjorie Morrison, Executive Director
mmorrison@canceraction.ca

www.ccanceraction.ca