CANADIAN PARTNERSHIP AGAINST CANCER CORPORATION (CPACC) EVALUATION

Final Report

Approved by

Senior Management Board
Finance, Evaluation and Accountability (SMB-FEA)
Health Canada

July 7, 2010





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Canadian Partnership Against Cancer Corporation (CPACC) – Evaluation MANAGEMENT ACTION PLAN

This Management Action Plan is a summary of CPACC's Action Plan. Please refer to Appendix C for the full Management Response.

	Recommendations	Actions	Responsible Manager	Time Frame
1	. CPACC should continue to facilitate the integration and coordination amongst the eight strategic priorities and two supporting activities wherever appropriate. Encouraging more integrated approaches to developing initiatives will facilitate coordination and impact.	Consultation on integration and coordination across strategies and supporting initiatives	CPACC management and Advisory Group Chairs	Current to October 2010
2	2. CPACC must continue in its recently increased efforts at addressing the perspectives and needs of First Nations, Inuit and Métis into all of its activities.	Caucus meeting between CPACC Board member and National Aboriginal Organizations	CPACC management and CPACC Aboriginal Board member	Twice per year
		Development of Action Plan for First Nations, Inuit and Métis (FN/I/M) Cancer Control	CPACC FN/I/M manager	By June 2010
		First Nations, Inuit and Métis portal pages	CPACC portal team, CPACC strategy team	By July 2010
3	 CPACC should develop formal mechanisms for assessing the usefulness of the data and information it is providing. Stakeholders and users of CPACC data and information 	Evaluation of Cancer View Canada	CPACC Senior Management, Knowledge Management	By September 2010
	should be consulted on a regular basis to gauge the usefulness, credibility and accessibility of CPACC data and information. The results of these consultations would be used to facilitate ongoing improvements to CPACC knowledge transfer/knowledge exchange.	Refined Cancer View Canada plan	CPACC Senior Management, Knowledge Management	By December 2010
4	CPACC should develop mechanisms for communicating with stakeholders who are not currently "in the loop"	Ambassador Program	CPACC Communications	By May 2010
	about CPACC. This could be done through attendance and presentations at conferences and other such events.	Impact Report Dissemination (Stakeholder meetings)	CPACC Board, Senior Management, Communications	From May to October 2010
		Media relations outreach	CPACC Communications	From May to October 2010

	Recommendations		Actions	Responsible Manager	Time Frame
5.	It is recommended that CPACC assess mechanisms for increasing its regional presence. This could include options such as affiliation with university-based partners. An increased regional presence would better enable CPACC staff to network and develop relationships with regional cancer control organizations. This is particularly critical in the context of the Canadian healthcare system and for CPACC to ensure needs are being met at the jurisdictional level.		Feasibility assessment of increased regional presence	CPACC Senior Management	By September 2010
6.	CPACC must ensure that the needs of jurisdictions are reflected in all of CPACC activities and initiatives, as their buy-in and active engagement are required for CPACC to fulfill its objectives.	•	Stakeholder outreach meetings Stakeholder consultation meeting	CPACC Board, Senior Management CPACC Board, Senior Management	May – September 2010 October 2010
7.	It is recommended that CPACC work to clarify the roles and responsibilities of CPACC and its stakeholders on an on-going basis, to ensure that all individuals affiliated with stakeholder organizations are aware of CPACC and their organization's relationship with CPACC.	•	Clarify and codify business models with key partners	CPACC Senior Management	Ongoing
8.	CPACC must develop and implement a performance monitoring system using both qualitative and quantitative measures appropriate to the current stage of CPACC's development, which should include measuring outcomes. As a new organization it is clear that early on the focus of performance monitoring will be on outputs (# of meetings, #of reports produced, etc.); however, as CPACC evolves the emphasis should move away from measuring outputs to measuring outcomes. This will require the full engagement of the federal government and jurisdictions.		Performance measurement framework linking initiative outcomes to logic model outcomes	CPACC Senior Management	Fall 2010
9.	It is recommended that CPACC put in place a transparent and clearly articulated mechanism for soliciting and selecting projects. There must also be a mechanism in place for communicating the results of decisions made.	•	Public posting and clarification of CPACC business models on website	CPACC Senior Management	June 2010

Recommendations	Actions	Responsible Manager	Time Frame
10. It is recommended that CPACC work to increase awareness of CPACC among the cancer control community as well as the Canadian public.	Monitor use of tools for Ambassador Program (including presentations, dissemination of Impact Report, and satisfaction survey on use of tools).	CPACC Communications	May – December 2010

Note:

The Chronic and Continuing Care Division, Health Care Policy Directorate, Strategic Policy Branch, Health Canada will monitor the response to the evaluation through the ongoing management of the funding agreement between Health Canada and CPACC and through Health Canada's annual review and approval of the CPACC Corporate Plan. A number of specific activities will be used to monitor CPACC's response to the recommendations, for example: review of CPACC's Performance Reporting and Communications Strategy (corporate plan); regular meetings of the Cancer Portfolio Working Group; and assessment of CPACC's content and communications on its on-line properties (website and Cancer View Canada portal).



CANADIAN PARTNERSHIP AGAINST CANCER CORPORATION EVALUATION

FINAL REPORT

May 6, 2010



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LIST OF ACRONYMS

AFN	Assembly of First Nations
AG	· · · · · · · · · · · · · · · · · · ·
	Appraisal of Guidelines Research and Evaluation
	Canadian Association of Medical Radiation Technologists
	Canadian Association of Provincial Cancer Agencies
	Canadian Guideline Adaptation Program
	Canadian Association of Pathologists
	Canadian Platform to Increase Usage of Real-World Evidence
	Canadian Association of Radiation Oncology
	Canadian Cancer Research Alliance
CCS	
CEO	
	Chief Financial Administrative Officer
CHA	
CHT	
	Canadian Institutes of Health Research
_	Coalitions Linking Action and Science for Prevention
	Canadian Organization of Medical Physicists
	Canadian Partnership Against Cancer
	Canadian Partnership Against Cancer Corporation
CPG	
	Canadian Partnership for Tomorrow Project
CRC	1
CRCNet	
CRM	
	Canadian Strategy for Cancer Control
	Canadian Strategy for Cancer ControlCancer Survival and Prevalence Analytic Network
	Departmental Performance Measurement and Evaluation Directorate
EOL	
	Food and Drug Administration (USA)
	First Nations and Inuit Health Branch
НС	
HHR	
HPV	
HR	
	Health Service Executive (Ireland)
	International Agency for Research on Cancer
IHC	· · · · · · · · · · · · · · · · · · ·
IT	
KM	
	Memorandum of Understanding
MP	
	National Aboriginal Organizations
NCI	
	Non-Governmental Organization
NHS	National Health Service (UK)

NIH	National Institute of Health (USA)
OECD	Organisation for Economic Co-operation and Development
PHAC	Public Health Agency of Canada
PLANET	Plan, Link, Act, Network, with Evidence-Based Tools
PMO	Project Management Office
PSA	Prostate-Specific Antigen
RFP	Request for Proposal
RSS	Really Simple Syndication or Rich Site Summary
SAGE	Standards and Guidelines Evidence
SMC	Senior Management Committee
TB	Treasury Board
TFRI	Terry Fox Research Institute
UICC	International Union Against Cancer
	Vice President
WHO	World Health Organization

EXECUTIVE SUMMARY

The Canadian Strategy for Cancer Control

Recognizing the increasing number of cancer cases and deaths, cancer stakeholders came together in 1999, under the leadership of the Canadian Cancer Society, the National Cancer Institute of Canada, the Canadian Association of Provincial Cancer Agencies and Health Canada, to develop an integrated, comprehensive and pan-Canadian approach to cancer control. During this planning and consultation stage, stakeholder engagement events were held and working groups were formed to assess opportunities and priorities in 11 areas of the cancer continuum¹, leading to the release of an Action Plan for the Canadian Strategy for Cancer Control (CSCC) and the appointment of the CSCC Council in 2002.

The work of the Council and cancer control stakeholders culminated in 2006 with the release of a Business Plan and the Government of Canada's commitment to implement the strategy announced in Budget 2006. The CSCC Business Plan outlined the vision, mission and purpose of the CSCC, and identified a list of priority areas for investment as well as a recommended governance model for implementation.

The Canadian Partnership Against Cancer Corporation

The Canadian Partnership Against Cancer Corporation (CPACC) was established in 2006 as an independent, not-for-profit corporation funded by the federal government through Health Canada. It seeks to accelerate action on cancer control for all Canadians by augmenting, building upon and implementing the multi-tiered CSCC. CPACC operates in a complex environment of stakeholder linkages and partnerships, many of which predate its existence.

While CPACC's governance model may differ in some ways to that outlined in the CSCC Business Plan, it is consistent with its key features: it is an independent legal entity established outside of the formal mandate of the federal government, it is financially accountable to the Minister of Health, and it is governed by a Board which holds the discretion to invest funds according to the mandate of CPACC.

CPACC is responsible for the translation, transfer and sharing of knowledge in eight strategic priority areas. These priorities had been identified in the development of the CSCC and CPACC inherited the CSCC Working/Action Groups that were previously assigned to these areas. The Strategic Priority Areas as defined in the CSCC Business Plan include: prevention, screening/early detection, standards, cancer guidelines, rebalance focus (cancer journey), health human resources, surveillance and research.

The eleven areas identified were: prevention, screening, diagnosis, treatment, supportive care, palliative care, paediatric cancer, human resources, informatics/technology, research and surveillance.

Expected outcomes relating to each of the eight Strategic Priorities (and two supporting activities) have been documented in CPACC's strategic plans, according to three relatively long-term timelines. The immediate outcomes expected within a few years from the establishment of CPACC are forecast to be most attributable to the influence of CPACC. The intermediate outcomes are expected to occur within seven to fifteen years of the start of the initiative, and the resulting final outcomes within twenty five to thirty years.

Immediate Outcomes (progress in first mandate)

- > Improved quality of screening
- Access to evidence-based knowledge and research on screening and prevention
- Improved access to integrated patient care
- > Improved coordination and enhanced population-based cancer research capacity
- Capacity to answer real time population-based questions about cancer risk factors and behaviours
- Improved accuracy and completeness of information on cancer control
- > Improved reporting on performance in cancer control domain
- > Improved coherence of HHR coordination in cancer control

Intermediate Outcomes (seven to 15 years)

- Enhanced population-based screening and prevention
- > Improved cancer experience for Canadians
- > Enhanced cancer control system
- Enhanced integration of knowledge and research

Final Outcomes (25 to 30 years)

- Lessen the likelihood of Canadians dying from cancer
- > Reduce the expected number of cases of cancer
- Enhance quality of life of those living with cancer

The Funding Agreement between Health Canada and CPACC earmarked up to \$250 million over five years in equal instalments of up to \$50 million per year. The original Funding Agreement was amended in year two of the agreement to better reflect variations in annual spending across multi-year and multi-stakeholder initiatives.

Evaluation Context

This evaluation is a provision within CPACC's Funding Agreement with Health Canada, and is intended to provide senior Health Canada managers with information on the early progress of CPACC. This evaluation will also inform decisions regarding Health Canada funding of CPACC. Specifically, the evaluation will assess:

- Whether CPACC has, in carrying out the Strategy, advanced the public health objectives for cancer control in Canada; and
- Whether this not-for-profit corporation is an effective tool for advancing the CSCC objectives.

In interpreting the evaluation findings a key contextual point must be borne in mind. As CPACC was only announced in late 2006 and implemented in January 2007², it is still early in the lifecycle of the Partnership. Therefore, this evaluation has focused largely on early results and outputs rather than the achievement of intermediate or long-term outcomes. The time period for the evaluation is from CPACC implementation in January 2007 to January 2010.

The evaluation issues addressed in the evaluation align with the standard Treasury Board evaluation requirements including relevance, design and delivery, success, governance and cost-effectiveness and alternatives.

Methodology

The evaluation methodology consisted of four key lines of evidence:

- > Interviews with 43 key informants;
- Survey of 100 CPACC stakeholders;
- > Document and file review; and
- On-line literature review.

Findings

Design and Delivery

Findings from the evaluation indicate that as an organization, CPACC is fully operational and has implemented a robust governance structure including an executive team, Board of Directors, and Advisory Groups that are consistent with an organization of this type. The organizational structure appears to strike an appropriate balance between the need for input from stakeholders (including patients/survivors) and experts and the day-to-day operations of the organization focused on moving the CSCC forward.

² CPACC's Board of Directors was established in April 2007, and the CEO was appointed in October 2007

Based on interviews, survey findings and a literature review examining approaches implemented in other countries, the organizational structure of CPACC (i.e. an NGO) is arguably the most appropriate model given the structure of the healthcare system in Canada. Cancer control stakeholders interviewed and surveyed for this evaluation are almost unanimously supportive of the NGO structure because it allows CPACC to maintain an arm's length relationship with government and it allows the organization to be more nimble than would be the case if CPACC was part of a federal department.

CPACC has made progress with respect to the integration of the eight strategic priorities and two supporting activities. However, in order for the activities within each of the eight strategic priorities and two supporting activities to be integrated more fully, individuals who work in the area of cancer control will need to be brought together and actively encouraged to work together on a continual basis. This will take time since the tendency to work in silos is entrenched in the cancer control community in Canada (and internationally), however CPACC is actively working at increasing collaboration and coordination across Canada.

CPACC management has made some modifications to the design and delivery of the organization. Evaluation findings indicate that the changes made to date have been well planned and in keeping with the mandate of CPACC and the spirit of the Strategy. Overall, the findings indicate a strong level of support among stakeholders for the changes implemented by CPACC to date.

Although CPACC was slow to incorporate working with First Nations, Inuit and Métis organizations, there has been recent progress with respect to addressing the needs and perspectives of these communities into CPACC activities. These efforts have only been recently implemented and much remains to be done before CPACC is able to meet the requirements to address First Nations, Inuit and Métis needs into its activities as required in the Health Canada funding agreement.

Success

Despite it being relatively early in its lifecycle, CPACC has made good progress with respect to most of its immediate outcomes. There is evidence that progress has been slower for outcomes where more active engagement or buy-in from practitioners and those responsible for delivering health services is required, specifically integrated patient care and health human resources. However, CPACC has made progress in putting in place the necessary mechanisms to engage jurisdictions.

Given that progress is evident with respect to achieving immediate outcomes, evidence suggests that CPACC is making progress towards achieving its intermediate and final outcomes. However, this result should be interpreted with caution given the long-term nature of the intermediate and final outcomes and that CPACC alone cannot achieve the identified intermediate and final outcomes – participation and active engagement from all parties involved in cancer control, particularly the jurisdictions will be required. The jurisdictions are responsible for the delivery of health care to the Canadian public and so CPACC activities must reflect the needs and priorities of jurisdictions.

The evidence indicates that CPACC has successfully developed partnerships and collaborations with other stakeholders in the cancer control domain in Canada. As well, CPACC has done much to bring together stakeholders and facilitated partnerships, collaborations and coordination. Insofar as CPACC was intended to increase coordination across cancer control stakeholders, CPACC has achieved this. However, there continues to be a lack of clarity and understanding among various stakeholders of the specific roles and responsibilities in their relationships with CPACC.

CPACC has demonstrated some progress in establishing relationships with Aboriginal communities, however this has not yet translated into the implementation of a broad range of activities that reflect their needs. It has developed relationships through the caucus and the advisory committee on First Nations, Inuit and Métis cancer control. CPACC has also recently implemented a First Nations, Inuit and Métis Portal Advisory Network.

Governance

Understanding of the Strategy on the part of CPACC's stakeholders is variable. Stakeholders who have the closest ties to CPACC through membership on the Board, Advisory Groups or collaborative relationships have the best understanding of the Strategy and the strategic direction of CPACC. Not surprisingly, those whose relationship with CPACC is further removed tend to be less clear in their understanding of CPACC's strategic direction. Although CPACC has ongoing communication with stakeholders through meetings, forums, e-bulletins and the cancerview.ca website, the evidence indicates that the communication is not penetrating or being further disseminated by all stakeholder groups, including the Canadian public.

The majority of stakeholders feel they have had sufficient opportunity for input into CPACC's strategic direction and decision-making. However, not all stakeholders have adapted to the existence of CPACC and its leadership role with respect to the CSCC. Despite the strong dissatisfaction on the part of a relatively small group of stakeholders, there is an overall sense that CPACC has struck an appropriate balance between moving ahead with implementation of the Strategy and stakeholder input into decision-making.

Although CPACC has put in place a robust process for monitoring progress being made by projects, CPACC has yet to develop and implement a robust process for measuring outcomes. The measurement of progress made by projects is sufficient for measuring outputs but does not provide sufficient information for measuring progress with respect to outcomes.

Similarly CPACC has implemented a well-defined process for approving and funding projects. However, the process for soliciting and selecting projects to be funded is not understood or seen as transparent by all stakeholders. No process has been put in place by CPACC to ensure there is First Nations, Inuit and Métis content included in projects funding. However, this is likely to change once the First Nations, Inuit and Métis Action Plan has been developed by CPACC and validated by these organizations.

A key role of CPACC is to disseminate knowledge and information. The evidence indicates a high level of satisfaction on the part of stakeholders with the credibility, accessibility, and timeliness of information provided by CPACC.

Relevance

There is strong evidence that the health burden of cancer will continue to be significant over the coming years, particularly as the Canadian population ages. Given the health burden of cancer and the variable and fragmented nature of cancer control in Canada, there is a need for an organization such as CPACC to act as a knowledge broker in the area of cancer control.

The funding of an organization such as CPACC fits within the mandate of the federal government without encroaching on provincial and territorial areas of responsibility. CPACC is intended to assist in the coordination of knowledge production and brokering activities and not in the delivery of healthcare or the development of healthcare policy.

At present there is little potential for transferring all or part of the responsibility for CPACC to the stakeholders. Beyond the question of capacity, there is also the need for neutrality that could be jeopardized if the responsibility for CPACC were transferred.

Cost-effectiveness and Alternatives

There is strong evidence of synergies and cost savings resulting from CPACC activities. However, despite the qualitative evidence of synergies there is no quantifiable data available on actual cost savings. The data required for measuring cost savings resulting from the knowledge and information made available to jurisdictions would need to be collected and shared by jurisdictions.

Although alternatives to the NGO model ultimately selected for CPACC exist, the current model is seen as the most appropriate. There is no evidence of a need to change or modify the current model. Other countries have implemented different models that reflect the structure of their healthcare models. CPACC has maintained contact with other jurisdictions, particularly Australia, in order to identify any best practices or lessons learned that could be transferred to the Canadian context.

Recommendations

Design and Delivery

- > CPACC should continue to facilitate the integration and coordination amongst the eight strategic priorities and two supporting activities wherever appropriate. Encouraging more integrated approaches to developing initiatives will facilitate coordination and impact.
- > CPACC must continue in its recently increased efforts to address the perspectives and needs of First Nations, Inuit and Métis in all of its activities.

Success

- CPACC should develop formal mechanisms for assessing the usefulness of the data and information it is providing. Stakeholders and users of CPACC data and information should be consulted on a regular basis to gauge the usefulness, credibility and accessibility of CPACC data and information. The results of these consultations would be used to facilitate ongoing improvements to CPACC knowledge transfer/knowledge exchange.
- ➤ CPACC should develop mechanisms for communicating with stakeholders who are not currently engaged with CPACC but who work in the area of cancer control. This could be done through attendance and presentations at conferences and other such events.
- It is recommended that CPACC assess mechanisms for increasing its regional presence. This could include options such as affiliation with university-based partners. An increased regional presence would better enable CPACC staff to network and develop relationships with regional cancer control organizations. This is particularly critical in the context of the Canadian healthcare system and for CPACC to ensure needs are being met at the jurisdictional level.
- ➤ CPACC must ensure that the needs of jurisdictions are reflected in all of CPACC activities and initiatives, as their buy-in and active engagement are required for CPACC to fulfill its objectives.
- ➤ It is recommended that CPACC work to clarify its roles and responsibilities and those of its stakeholders on an on-going basis, to ensure that all individuals affiliated with stakeholder organizations are aware of CPACC and their organization's relationship with CPACC.

Governance

- ➤ CPACC must develop and implement a performance monitoring system using both qualitative and quantitative measures appropriate to the current stage of its development, which should include measuring outcomes. As a new organization it is clear that early on the focus of performance monitoring will be on outputs (# of meetings, #of reports produced, etc.); however, as CPACC evolves the emphasis should move away from measuring outputs to measuring outcomes. This will require the full engagement of the federal government and jurisdictions.
- It is recommended that CPACC put in place a transparent and clearly articulated mechanism for soliciting and selecting projects. There must also be a mechanism in place for communicating the results of decisions made.
- It is recommended that CPACC work to increase awareness of itself among the cancer control community as well as the Canadian public.

1. Introduction

This chapter provides the context for this evaluation. The work of cancer stakeholders in developing a national cancer control strategy and the creation of a not-for-profit organization, the Canadian Partnership Against Cancer Corporation, as the mechanism to implement that strategy are described below.³

1.1 THE CANADIAN STRATEGY FOR CANCER CONTROL

Recognizing the increasing number of cancer cases and deaths, cancer stakeholders came together in 1999, under the leadership of the Canadian Cancer Society, the National Cancer Institute of Canada, the Canadian Association of Provincial Cancer Agencies and Health Canada, to develop an integrated, comprehensive and pan-Canadian approach to cancer control. During this planning and consultation stage, stakeholder engagement events were held and working groups were formed to assess opportunities and priorities in 11 areas of the cancer continuum⁴, leading to the release of an Action Plan for the Canadian Strategy for Cancer Control (CSCC) and the appointment of the CSCC Council in 2002.

The mandate of the Council, which included 30 members drawn from the Canadian Cancer Society, the National Cancer Institute of Canada, provincial/territorial cancer agencies, the Canadian Association of Provincial Cancer Agencies, the Canadian Cancer Advocacy Network, the Public Health Agency of Canada, the CSCC Action Group Leaders, the CSCC Working Group Leaders, and selected cancer experts, was to lead the development of a comprehensive, evidence-based, and sustainable cancer control strategy.⁵

The work of the Council and cancer control stakeholders culminated in 2006 with the release of a Business Plan and the Government of Canada's commitment to implement the strategy announced in Budget 2006. The CSCC Business Plan outlined the vision, mission and purpose of the CSCC, and identified a list of priority areas for investment as well as a recommended governance model for implementation.

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Please note that we have tried to the greatest extent possible to refer to the Canadian Partnership against Cancer Corporation as the Partnership. Acronyms are also used in various documents. The most common are CPAC and CPACC.

The eleven areas identified were: prevention, screening, diagnosis, treatment, supportive care, palliative care, paediatric cancer, human resources, informatics/technology, research and surveillance.

⁵ Canadian Strategy for Cancer Control: 2006-2010 Business Plan, April 2006.

1.2 THE CANADIAN PARTNERSHIP AGAINST CANCER

Established in 2006, the Canadian Partnership Against Cancer Corporation (CPACC) is an independent, not-for-profit corporation funded by the federal government through Health Canada. It seeks to accelerate action on cancer control for all Canadians by augmenting, building upon and implementing the multi-tiered Canadian Strategy for Cancer Control. CPACC operates in a complex environment of stakeholder linkages and partnerships, many of which predate its existence.

CPACC inherited many of the components outlined in the CSCC, including its purpose and objectives:

"The purpose of the CSCC is to maximize the translation, transfer and sharing of knowledge across Canada's cancer system to reduce fragmentation in cancer knowledge and service delivery, and make measurable improvements in the health of Canadians, including:

- Reducing the expected number of Canadians diagnosed with cancer;
- Enhancing the quality of life of those living with and through cancer; and
- Lessening the likelihood of dying from this disease. 6"

While CPACC's governance model may differ in some ways to that outlined in the CSCC Business Plan, it is consistent with its key features: it is an independent legal entity established outside of the formal mandate of the federal government, it is financially accountable to the Minister of Health, and it is governed by a Board which holds the discretion to invest funds according to the mandate of CPACC.

a) CPACC Strategic Priority Areas

CPACC is responsible for the translation, transfer and sharing of knowledge in eight strategic priority areas. These priorities had been identified in the development of the CSCC and CPACC inherited the CSCC Working/Action Groups that were previously assigned to these areas. The Strategic Priority Areas as defined in the CSCC Business Plan are introduced below and also summarized in Appendix A, along with the corresponding 5-year Action Plan activities.

Prevention

Some exposures are linked to cancer such as environmental and occupational carcinogens, sun exposure, and some infectious agents such as HPV. Others are modifiable behaviours such as tobacco and alcohol use, physical inactivity, poor nutrition, and obesity. The prevention strategy balances addressing these common risk factors by maximizing opportunities and avoiding duplication with partners in other areas of public health.

⁶ Canadian Strategy for Cancer Control: 2006-2010 Business Plan, April 2006, p.12.

Screening/Early Detection

Cancer screening is reported to have contributed significantly to cancer control in Canada; however, more can be done specifically in the areas of colorectal screening, breast, and cervical cancer. CPACC will focus on maximizing the impact of screening in cancer sites that are known, and use evidence-based analysis to have the potential to reduce incidence or mortality through screening.

Standards

Standards are required to develop best practices for cancer diagnosis, treatment and care; and to establish performance indicators to evaluate service delivery and foster improved access and quality. Standards are also used as key measures within the other priority areas, such as benchmarks for cancer system performance.

Cancer Guidelines

Cooperation among provincial/territorial cancer guideline programs will be facilitated, common principles will be established, and a communication infrastructure and training opportunities will be developed. CPACC will guide the use of evidence-based clinical practice guidelines.

Rebalance Focus (Cancer Journey)

Develop and promote strategies, tools, and targets to address the urgent need for resources, including programs and staff, and ensure that health care professional receive education in psychosocial, supportive and end-of-life care in order to ensure that cancer patients' overall needs are better served by the health care system.

Health Human Resources

A lack of human resources has been identified as a potential threat to cancer control and chronic disease efforts in Canada and around the world. The focus of this strategy is to understand where CPACC can be most helpful in addressing the future needs of health human resources.

Research

Innovative research partnerships will be leveraged to address emerging issues under this strategy. In partnership with the Canadian Cancer Research Alliance (CCRA), CPACC will seek to capitalize on Canadian research strengths and focus them on the challenges in cancer control.

Surveillance

The objective of this priority is to provide better data on which to base prevention, screening, health care delivery, and policy decisions by bringing together cancer epidemiological data and cancer control information from the provinces and territories for use in planning, implementing, and evaluating Canadian cancer control efforts.

b) Expected Outcomes

Further to the objectives of CPACC overall, expected outcomes relating to each of the eight Strategic Priorities (and two supporting activities) have been documented in CPACC's strategic plans; these outcomes are also summarized in Appendix A.

In 2008, Government Consulting Services developed a logic model of CPACC as part of the framework for this evaluation. An updated logic model (revised in December 2009 to better reflect how CPACC is functioning) may be found in Appendix B.

Expected outcomes have been established for the overall CPACC Initiative according to three relatively long-term timelines. The immediate outcomes expected within a few years from the establishment of CPACC are forecast to be most attributable to the influence of CPACC. The intermediate outcomes are expected to occur within seven to fifteen years of the start of the initiative, and the resulting final outcomes within twenty five to thirty years.

Immediate Outcomes (progress in first mandate)

- > Improved quality of screening
- Access to evidence-based knowledge and research on screening and prevention
- Improved access to integrated patient care
- Improved coordination and enhanced population-based cancer research capacity
- Capacity to answer real time population-based questions about cancer risk factors and behaviours
- > Improved accuracy and completeness of information on cancer control
- > Improved reporting on performance in cancer control domain
- > Improved coherence of HHR coordination in cancer control

Intermediate Outcomes (seven to 15 years)

- Enhanced population-based screening and prevention
- > Improved cancer experience for Canadians
- > Enhanced cancer control system
- Enhanced integration of knowledge and research

Final Outcomes (25 to 30 years)

- Lessen the likelihood of Canadians dying from cancer
- Reduce the expected number of cases of cancer
- Enhance quality of life of those living with cancer

c) Financial Resources

The Funding Agreement between Health Canada and CPACC earmarked up to \$250 million over five years in equal instalments of up to \$50 million per year. The original Funding Agreement was amended in year two of the agreement to better reflect variations in annual spending across multi-year and multi-stakeholder initiatives. CPACC's actual and projected spending over the life of the Funding Agreement is summarized in the table below.

	2007-08	2008-09	2009-10	2010-11	2011-12	5 Year Total (\$M)
Strategic Initiatives	2.5	24.1	36.4	39.9	37.2	140.1
Advisory Groups	3.8	7.4	5.7	4.6	4.4	25.9
Central Activities	10.0	17.3	16.4	14.0	13.7	71.4
Reserves and Adjustments	3.4	0.0	(1.6)	0.6	0.6	3.0
Total (\$M)	19.7	48.8	56.9	59.1	55.9	240.4
Lapsed funding	9.6					9.6
Total (\$M)						250.0

Table 1.1: Proposed Five Year Spending for CPACC (as of January 2010)

1.3 EVALUATION CONTEXT

This evaluation is a provision within CPACC's Funding Agreement with Health Canada, and is intended to provide senior Health Canada managers with information on the early progress of CPACC. This evaluation will also inform decisions regarding Health Canada funding of CPACC. Specifically, the evaluation will assess:

- ➤ Whether CPACC has, in carrying out the Strategy, advanced the public health objectives for cancer control in Canada; and
- Whether this not-for-profit corporation is an effective tool for advancing the CSCC objectives.

In interpreting the evaluation findings a key contextual point must be borne in mind. As CPACC was only announced in late 2006 and implemented in January 2007⁷, it is still early in the lifecycle of the Partnership. Therefore, this evaluation has focused largely on early results and outputs rather than the achievement of intermediate or long-term outcomes. The time period for the evaluation is from CPACC implementation in January 2007 to January 2010.

The evaluation issues addressed in the evaluation align with the standard Treasury Board evaluation requirements including relevance, design and delivery, success, governance and cost-effectiveness and alternatives.

⁷ CPACC's Board of Directors was established in April 2007, and the CEO was appointed in October 2007.

2. Methodology

2.1 EVALUATION DESIGN

The issues and questions addressed in this evaluation were derived from the Evaluation Framework Developed by Government Consulting Services on behalf of Health Canada. The Evaluation Framework for CPACC was developed with input from Health Canada managers responsible for overseeing the CPACC Funding Agreement, as well as representatives from the Public Health Agency of Canada (PHAC), CPACC, DPMED at Health Canada, and CPACC stakeholder organizations. Early in the project, EKOS reviewed and refined the evaluation matrix under the guidance of the Evaluation Steering Committee which included representatives from Health Canada, PHAC, and CIHR. The refinements and changes implemented were largely focused on refining and defining indicators and data sources in order to ensure that the indicators were clear and that the evaluation questions could be responded to in a meaningful manner.

The evaluation matrix incorporates a multiple lines of evidence approach and includes both qualitative and quantitative data. An early challenge in developing the approach to the evaluation was the large number of evaluation questions and indicators relative to the number of data sources. This meant that the interview guides and survey questionnaire risked being too long, resulting in a substantial response burden on interviewees and survey respondents. Some changes were proposed to Health Canada to mitigate this and as a result the number of lines of evidence for some questions was decreased. However, in all cases there is more than one line of evidence for each evaluation question.

The nature and timing of the evaluation meant that there were no benchmarks or comparison groups against which to measure the progress of CPACC. It should be anticipated that the evaluation results presented in this report will serve as a benchmark with respect to many of the evaluation questions and success indicators for subsequent evaluations of CPACC. Given that CPACC is a new organization, much of its early efforts have been focused on implementation and relationship building and this is reflected in the findings.

2.2 Data Collection

This section describes the data collection methods for the four lines of evidence: key informant interviews; survey of CPACC stakeholders; document and file review; and on-line literature review.

a) Key Informant Interviews

In order to generate a list of CPACC stakeholders to be interviewed or surveyed, Health Canada consulted with their internal partners involved in the Cancer Portfolio Working Group (which includes members of various groups within Health Canada, PHAC, CIHR, and others who have an interest in cancer-related activities in general and specifically CPACC) and with CPACC. Health Canada requested a short list of individuals they felt could inform the evaluation with their input. EKOS was provided with a list of 264 stakeholders. Of these stakeholders, 55 were selected as interviewees and the remaining 209 were designated as survey participants. Key informant interviews were conducted with a total of 43 individuals. Interviewees were grouped into seven categories by Health Canada and CPACC. The number of interviews conducted under each of these categories is as follows:

- CPACC Management and Staff (n=6)
- CPACC Board Members and Cancer Control Experts (n=12)
- > Federal representatives (n=5)
- Provincial and territorial representatives, including provincial/territorial cancer agencies (n=5)
- Advocacy groups, NGOs (n=8)
- > Professional organizations (n=5); and
- Representatives from other jurisdictions (e.g. U.K., France, Australia, etc.) (n=3).

Interview guides were designed to address all of the pertinent issues and questions. A bilingual introduction letter and the appropriate interview guide were sent by EKOS to all prospective respondents in advance of the interviews. This letter introduced the evaluation, provided necessary background information, as well as making reference to privacy provisions. Health Canada alerted all stakeholders to the evaluation, and so most respondents anticipated being contacted for an interview. A short time after sending the initial email to potential interviewees (one to two days), the EKOS research team contacted potential interviewees to schedule the interview.

All interviews were conducted by phone, in the preferred official language of the interviewee. As well, interviewees were reminded that their comments would be kept strictly confidential. We note that in most circumstances the assurance of confidentiality elicits more honest and open responses; however we understand that we can only assure participants that their responses will remain confidential within the purview of the *Canada Privacy Act* and the *Access to Information Act*.

Interview questions were open-ended, to allow the interviewees to explain their responses in depth and detail. Interviews averaged 60 minutes in duration with many exceeding 90 minutes.

Analysis of interview data is qualitative. Our general approach to analysing interview data is to use an iterative content analysis approach whereby interview summaries are reviewed multiple times to identify and refine patterns and trends as well as to identify variations across interviewee categories. To ensure a common understanding of the terms used in our analysis, we have the following approximate guidelines in analysing and reporting on interview results for this report:

- > "A few interviewees" = less than 25 per cent;
- ➤ "A small minority of interviewees" = 25 to 39 per cent
- ➤ "A minority of interviewees" = 40 to 49 per cent;
- ➤ "A majority of interviewees" = 50 to 59 per cent;
- ➤ "A large majority" = 60 to 74 per cent;
- > "Most interviewees" = over 75 per cent; and
- > "Almost all interviewees" = 95 per cent or more.

b) Survey of CPACC Stakeholders

The survey of CPACC stakeholders was conducted using a *web-based* approach, with a telephone reminder to augment the response rate. Stakeholders to be surveyed include experts in the cancer control field and recipients of funding or other support from CPACC. The final results include 100 stakeholder cases of the 209 invited to participate, for an overall response rate of 48 per cent. This is considered a high response rate for this type of survey, and given the relatively short period of time for data collection.

Nearly half of the 100 stakeholders responding to the survey are closely affiliated with cancer agencies/centres/institutes (33) or charitable/voluntary/advocacy/survivor/support organizations (16). The remaining are more affiliated with either governments (10), provincial/territorial/regional health authorities (9), research organizations (9), universities or institutes (9), professional associations or societies (2), or other groups not mentioned (12).

Responding stakeholders in the survey sample reported that they are very familiar with CPACC and its initiatives, with 96 per cent who are either 'somewhat' (33 per cent) or 'highly' familiar (62 per cent) with the organization. By way of example, those familiar with CPACC were asked whether or not they are aware of CPACC's eight strategic priorities and two supporting activities. Overall, 92 per cent say they are.

c) Document and File Review

The major purpose of the document review was to provide a useful context for interpreting, confirming and supplementing information gathered through other data collection methodologies undertaken for the evaluation. Documents reviewed comprised materials describing the relevance, design and delivery, activities, achievements and governance of CPACC.

The document review methodology included a general review of CPACC, Health Canada and Government of Canada documentation provided to EKOS by CPACC and Health Canada. This was followed by a more detailed review of core program documentation and of program information posted on the CPACC Portal. Relevant extracts from the documentation were aligned to the evaluation issues addressed by the documentation review.

The breadth of the evaluation questions and issues covered by the documentation review, as well as the large number of CPACC strategic priorities and initiatives for which information needed to be reviewed, limited the scope of the document review. In order to meet the information requirements of the evaluation in an efficient way, emphasis was placed on the most recent reports and communications. Also, the number of information sources was limited, to a large extent, to a review of core program documentation (i.e., key areas of activity and results) produced by CPACC.

d) On-Line Literature Review

The focus of the literature review was on alternative models to CPACC. Encompassed within this were descriptions of international models, their effectiveness, their connections to a cancer control framework or plan, any information on the cost-effectiveness of these approaches, and any best practices identified.

The resources that informed the literature review component were largely gathered through our own efforts via an Internet search using the following terms: *Cancer control (country)*, *Cancer agency (country)*. Phone calls and interviews with national and international experts in the area of cancer control were also carried out. This included contact with cancer control agencies in the United Kingdom and Australia. A few documents from World Health Organization (WHO) and the Economist were provided to us by a key informant interviewee.

2.3 Limitations

As with any evaluation, there are a number of limitations to this study. The reader is encouraged to take these into account when reviewing the findings in this evaluation report. The main limitations associated with this evaluation are presented in the sections below.

a) Key Informant Interviews

The majority of key informants have a stake in CPACC. Individuals tend to bring their own biased views into an interview, which makes it very important to balance any evidence from interviews with more "objective" data (from the documentation and literature review, for example). Furthermore, few individuals interviewed or surveyed were expected to be able to comment in detail on all aspects of CPACC's activities. Reporting thus focuses only on those interviewees who were able to comment (excluding those who were unable to respond to a specific question from the analysis related to that question).

The interviews were, in most cases, longer than 60 minutes resulting in some respondent fatigue. In general the quality of responses tends to diminish (i.e. become less detailed) as the interview becomes longer. Our interviewers mitigated this by allowing interviewees to provide somewhat less detailed responses to questions in order to ensure that we were able to complete the interviews and obtain some information on all the interview questions. In other words, there was a need to balance the level of detail of responses against being able to obtain responses to all the interview questions.

We have completed interviews with 43 individuals representing seven categories of interviewee. Because of the relatively small number of interviewees in most of these categories and the need to maintain confidentiality of interviewee responses, the analysis of most interview results cannot be broken down by category of interviewee. However, to the extent possible, we have sought to identify areas where opinions meaningfully diverge across categories of interviewee and to explain these differences where possible.

b) Survey of Stakeholders

Although the response rate for the survey was very high for a survey of this nature, the sample and thus the number of completed surveys represents only a small proportion of the individuals involved in cancer control in Canada. The mechanism through which the sample of survey participants was drawn was a purposeful sample in that individuals were identified by the Evaluation Steering Committee and CPACC as those who would have the most insight into CPACC. This was deemed an appropriate approach by the evaluators given the stage that CPACC is at in its lifecycle. However, the findings from the survey should be interpreted with caution when viewed in isolation of other lines of evidence for this evaluation. In other words, the survey findings on their own do not provide a full assessment of CPACC with respect to the evaluation issues and questions.

Similarly to key informant interviews, few stakeholders were able to respond in detail to all survey questions. This was expected since stakeholders generally focus their involvement or awareness of CPACC on specific, relatively narrow areas. The analysis, unless otherwise stated, excludes those who were not able to respond to a specific question.

c) Document and File Review

The high reliance on CPACC documentation limits the validity and reliability of the document review in that it introduces a potential bias into the reported results. Much of the relevant documentation used in the evaluation was provided by CPACC. However, given the descriptive nature of the document review and its purpose of providing a useful context for interpreting, confirming and supplementing information gathered through the other data collection methodologies undertaken for the evaluation, this limitation is considered acceptable for the purposes of the evaluation. In addition, our study team actively sought documentation from other sources to supplement information provided by CPACC.

d) On-Line Literature Review

A specific concern with the literature review and the questions it seeks to address is that relevant information is not always available in the public domain. This is particularly the case in the context of questions about finances, such as cost-effectiveness questions. Other jurisdictions are rarely willing to make this information readily available.

e) General Limitations

This evaluation was undertaken very early in the program lifecycle and so there is only very limited potential for measurable results. Furthermore, the nature of the outcomes in a population-based cancer control strategy tends to be very long-term, in the case of CPACC the ultimate outcomes are expected to be achieved in 25 to 30 years.

Since the federally-funded disease-based NGO model used for CPACC is new, there is a lack of benchmarks or control group(s). In addition, it is early in the life of CPACC hence there is no previous evaluation against which to measure progress.

Input from the survey and key informant interviews was obtained from 143 individuals. Input for the evaluation was sought from individuals who were expected to be the most knowledgeable about CPACC rather than those who were knowledgeable about cancer control in Canada. The approach implemented was the most realistic given the evaluation budget and context (i.e. very early in the lifecycle of CPACC).

There is limited quantitative data on effectiveness (i.e. achievement of outcomes) and related costs making it impossible to quantitatively address cost-effectiveness. As a result, the evaluation could only address whether CPACC was the most cost-effective approach using a qualitative assessment based on the views of stakeholders and a comparison of approaches used in other jurisdictions.

Limitations such as those described in this chapter are not unusual for program evaluations of this type. However, the validity of the overall results was controlled by comparing the results of the various sources of evidence. This approach is based on the principle of multiple lines of evidence, which acknowledges that each methodology has strengths and weaknesses, and that in many instances, one method compensates for the weaknesses of the other.

3. Design and Delivery

This chapter addresses evaluation issues related to the design and delivery of CPACC, including whether it has been implemented as intended and the effectiveness of the CPACC mechanism.

3.1 CPACC GOVERNANCE STRUCTURE

Health Canada provided start-up funding for the period of January to March 2007. Over the transition period a permanent Board was established, the Funding Agreement approved, Action Groups brought into the Partnership (these existed under the CSCC to address priority areas), and a corporate structure established. The transition phase ended October 2007 with the appointment of the Chief Executive Officer and the subsequent staffing of the Senior Executive team, and their divisions.⁸

CPACC's governance is overseen by a Board of Directors. The Board's primary responsibility is to provide oversight and direction to the Executive as they implement the Strategy. The Board is also responsible for ensuring that there are effective accountability mechanisms in place that are in line with their fiduciary responsibilities. The Board monitors CPACC's organizational performance against established priorities and deliverables and takes corrective action as required.

The structure of the Board governance took into account the need for representation from different constituencies to ensure a pan-Canadian and knowledgeable membership. The Board is structured to include a federal representative, five provincial representatives, an observer from Quebec, five regional representatives with experience in cancer, a representative of CCS, a representative from CAPCA, an Aboriginal person and patient/survivors⁹. CPACC Board members are elected and appointed such that they are proven contributors at a Board or executive leadership level and provide a mix of skills including financial, management and operations. The Board has established by-laws and policies that are intended to facilitate effective governance. The Board has also established Board committees including Governance and Nominating, Finance and Audit, and Performance. The patient perspective is represented on the Board through patient or survivor representation on the Board and the Advisory Groups.

Early in its mandate, CPACC established an Advisory Council. The Advisory Council acted as a resource for the Board, the Executive and the Chairs of the Advisory Groups (previously called Action Groups) on the implementation of CPACC's strategy. The Advisory Council was co-Chaired by the Vice-Chair of the Board and the CEO. Other members included experts in cancer control and chairs of Advisory Groups. The Advisory Council has since been disbanded.

⁸ BBMD Consulting. Independent Evaluation of the Canadian Partnership Against Cancer, Final Report. April 2009.

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¹⁰ Canadian Partnership Against Cancer. Strategic Plan 2008-2012, February 2008.

Advisory Groups (previously called Action Groups) are collaborative networks of volunteer experts intended to bring together cancer control knowledge and expertise from across Canada's healthcare system. Each Advisory Group is headed by a Chair who is a recognized subject matter expert, and their host organization (e.g. university or NGO) is compensated for their time in this leadership role. The Chairs report to VPs for their leadership responsibilities. Members of the Advisory Groups are drawn from across Canada and include health practitioners and administrators, epidemiologists, researchers, patients and families. The make-up of each Advisory Group is flexible and changes as required. According to CPACC the Advisory Groups are currently undergoing a membership renewal process that is expected to be completed by April 1, 2010. There are currently seven Advisory Groups.

Evidence from the document review conducted for this evaluation indicates that as of September 2009 all positions of the CPACC senior management team were filled. CPACC's senior management team is comprised of the CEO, three Vice-Presidents, and the Chief Financial and Administrative Officer. In addition to the CPACC senior management team, there are seven Advisory Group Chairs (Cancer Guidelines, Health Human Resources, Surveillance, Primary Prevention, Research, Screening and Cancer Journey). There are seven directors who support the priority areas and advisory groups, and other directors who work on central activities (such as Knowledge Management, Finance).

Based on evidence in the review of CPACC documentation, CPACC has established a governance model and has filled all key positions at the senior management and director levels. The evidence suggests that CPACC governance model is effective in that it provides oversight for the Executive team and includes input from external experts and stakeholders in cancer control.

3.2 EXTENT TO WHICH DELIVERY SUPPORTS THE STRATEGIC PRIORITIES

As noted in previous sections, CPACC was established in order to implement the Strategic Priorities of the CSCC. The eight priority areas and two supporting activities continue to be the foundation of CPACC's activities. Each priority area addresses a key aspect of cancer control in Canada and are acknowledged by many international agencies as being key to the implementation of an integrated cancer control strategy. The table below provides an overview of current strategic initiatives as presented to stakeholders at the July 2009 Momentum: Cancer Control in Action forum, hosted by CPACC.

Table: Strategic Initiatives by Strategic Priority and Core Frameworks (July 2009)

Strategic Priority	Strategic Initiatives
Primary Prevention	 CLASP (Coalitions Linking Action and Science for Prevention) CAPTURE CAREX
Screening	- Colorectal Cancer Screening - Cervical Cancer Screening
Surveillance	 Staging Initiative (includes Synoptic Pathology project) Cancer Surveillance and Epidemiology Networks Cancer Control PLANET Canada
Cancer Guidelines	 Synoptic Surgery Reporting Can-ADAPTE (Guideline Adaptation project) Capacity Enhancement
Cancer Journey	 Survivorship Integrated Person-Centre Care (includes Screening for Distress, Patient Navigation and Palliative Care projects) Canadian Virtual Hospice
Health Human Resources	- HHR Service Delivery Models (includes e-Mentorship project)
Research	 Canadian Partnership for Tomorrow Project Translational Research: Early Detection of Lung Cancer Pan-Canadian Cancer Research Strategy
Quality Initiatives and Standards	 Standards Quality Assurance for Diagnostic Immunohistochemistry (IHC) Endoscopy Quality Radiation Quality
Communications and Public Engagement	 Canadian Cancer Action Network and Patient Voice First Nations/Inuit/Métis Action Plan
Knowledge Management	- Cancer View Canada (portal) - Cancer Risk Management

Source: Momentum: Cancer Control in Action July 7-8, 2009, Summary Report, Canadian Partnership Against Cancer, October 2009

CPACC management were asked to comment on the extent to which they feel the organizational structure supports the horizontal implementation and coordination of the eight strategic priorities and two supporting activities. All managers interviewed agreed that CPACC's organizational structure supports horizontal implementation and coordination, in fact this is illustrated in section 4.1 where a number of activities are identified as relevant to more than one strategic outcome. However, it was noted by about half of the managers interviewed that the process of integration across the eight priorities and two supporting activities is, despite some early progress, still evolving. As one interviewee explained, people that traditionally work in the area of cancer control are not used to working in a coordinated or horizontal fashion. There are very specific vertical domains within cancer control so someone who works in screening will tend to work only in screening, etc. This interviewee went on to explain that CPACC has been actively encouraging people to collaborate across the eight strategic priorities.

The evidence indicates that the eight Strategic Priorities and two supporting activities form the basis for all of CPACC's activities. All projects implemented by CPACC are directly linked to these Strategic Priorities and supporting activities. However, there is less evidence to support the view that there is full integration and coordination amongst the Strategic Priorities and supporting activities. There is evidence that CPACC is bringing together people involved in each of the Strategic Priorities and encouraging collaboration, however given pre-existing ways of working, this will take time to fully materialize.

3.3 Modifications to Design and Delivery to Date

The initial CPACC strategy was refined in February 2008. The refinements implemented are intended to reflect the evolution of the CSCC by focusing on areas where the Board felt CPACC would have the most measurable impact within the timeframe of their five-year mandate.

Based on information collected for this evaluation, some modifications to the design and delivery of CPACC were implemented. The key modifications are discussed below.

- Advisory Groups (previously called Action Groups): In 2009 CPACC undertook a renewal of its Advisory Groups by implementing a more formal process for recruitment and selection to ensure that the advisory base was kept sufficiently broad and to enhance accountability. Beginning in 2010 CPACC will be creating an on-line posting for membership as well as approaching partner organizations regarding coordinating their representative membership across the Advisory Groups.
- Advisory Council: With initiatives across priority areas fully implemented and supported by the evolution of their own advisory mechanisms, the Board decided to dissolve the Advisory Council in 2009-2010 in line with the findings of CPACC's independent evaluation. Members of the now defunct Advisory Council that are not Chairs continue to be involved in other advisory mechanisms across CPACC. The Advisory Council was co-Chaired by the Vice-Chair of the Board and the CEO; other members included experts in cancer control and Advisory Group Chairs. The role of the Advisory Council was initially modified in September 2008 to be more advisory to senior management of CPACC rather than to the Board. This has been replaced, in part, with independent advice to the Board (see below).
- ➤ Independent Advice to the Board: CPACC has implemented an informal process to draw on cancer control expertise within Canada and internationally by bringing independent advisors in to present to Board members on an as needed basis. 11

Canadian Partnership Against Cancer Corpo

Canadian Partnership Against Cancer. Briefing Note: 2010/11 Corporate Plan Development, Board of Directors, December 2009.

Refocusing efforts on measurable results: given the need to demonstrate measureable results by the end of its first mandate, CPACC set out to fund and implement initiatives that were most likely to produce measureable results within the five year mandate. This modification stemmed, in part, from the manner in which the Strategy was developed and evolved. As explained by a CPACC manager interviewed for this evaluation, the range of possible activities in the Strategy was developed by a broad range of stakeholders from across Canada and was intended to be inclusive of all possible activities. It was, in that sense, a list of all possible activities that could be implemented under the Strategy. CPACC in realizing that it was required to deliver tangible results by the end of its first mandate refined the list of activities so that measureable results could be demonstrated within the relatively short time frame of its funding agreement with Health Canada. This was a key element in the February 2008 version of the refined CPACC strategy.

Individuals interviewed for this evaluation almost unanimously agreed with the modifications made to the design and delivery of CPACC. A few Board members specifically noted that the focus of CPACC and priorities continue to be consistent with the Strategy and that the modifications made to date have been relatively minor.

As is often the case with new organizations, CPACC has evolved and has made modifications to its design and delivery. The evidence indicates that the modifications CPACC has implemented have been purposeful and thoughtful and reflect the evolving landscape in which it operates. There is no evidence of notable opposition to the modifications on the part of stakeholders or of a departure from the ideas and principles behind the CSCC. In fact the changes implemented are largely seen by the vast majority of stakeholders interviewed as part of the evolution of a new organization and part of the process of fine tuning the design and delivery.

3.4 Integration of Aboriginal Content and Issues

The Funding Agreement for CPACC specifically states that all priority areas would include activities to address Aboriginal considerations.

Early in the implementation of CPACC, Aboriginal organizations had hoped to have a representative from each of First Nations, Inuit and Métis organizations appointed to the Board. The rationale for including input/representation from each of these three groups related to their distinctiveness culturally, geographically as well as in terms of their needs and priorities with respect to cancer care. Ultimately it was determined that the overall constitution and framework for the Board appointments did not allow for three appointments to be made (one each from First Nations, Métis and Inuit representative organizations) and therefore a caucus approach was developed. The caucus approach has been generally well-received by the First Nations, Inuit and Métis communities and representative organizations. The caucus is implemented semi-annually with the three representative First Peoples organizations and CPACC's Aboriginal Board member. This provides each organization's governance body with the opportunity to meet face-to-face to discuss cancer control and to provide input into the strategy. The recognition on the

part of CPACC of the distinctiveness of these three First Peoples is reinforced by CPACC actively moving away from using the term "Aboriginal" but rather is using "First Nations, Métis and Inuit."

In addition to the caucus, a program manager was hired to work on First Nations, Inuit and Métis issues, a First Peoples' specific advisory committee was implemented (National Forum on First Nations, Inuit and Métis Cancer Control Planning Committee), and CPACC plans to launch portal pages with First Nations, Métis and Inuit specific content. The role of the manager is to find opportunities to leverage work across existing priority areas and seek input and validation from the advisory committee on opportunities that can be advanced by the communities. The advisory committee is expected to play a key role in developing an action plan that is culturally relevant and community driven. The Action Plan is expected to leverage the work across the priority areas yet recognize the need for culturally-relevant and specific initiatives. The Action Plan, once developed, will be presented to each organization representing First Nations, Inuit and Métis for validation. The development of a First Peoples specific section on the portal was the direct result of input from First Nations, Inuit and Métis representatives who indicated a need for a place where First Peoples could share and adapt culturally-relevant materials, and enhance their own work across their respective communities.

Given the CSCC did not include specific activities to address aboriginal considerations, the first step undertaken by CPACC was to engage each of these constituencies to plan a First Nations, Inuit and Métis forum. The forum participants confirmed that a culturally-based plan was the preferred approach. In addition, CPACC initiated a partnership with Saint Elizabeth Health Care in 2008 to build on their @YourSide Colleague program for First Nations community care providers to create a cancer course to address specific issues related to prevention, screening, treatment and care. The course was developed, validated and launched in December 2008.

Although CPACC has not yet made measurable progress in including Aboriginal considerations in its priority areas, a few individuals interviewed for this evaluation pointed to the complexities associated with integrating First Nations, Inuit and Métis content and issues. For example, the lack of Aboriginal identifier in the Canadian Cancer Registry as well as the variety of needs and priorities of First Nations, Inuit and Métis with respect to cancer control. However, as described above, CPACC has undertaken extensive consultation with First Nations, Inuit and Métis organizations which will ultimately lead to Aboriginal considerations being reflected in CPACC activities and priorities in ways that are culturally relevant and appropriate.

The evidence indicates that CPACC had a slow start in beginning work to reflect Aboriginal considerations into its activities and priority areas. Progress to date has been slow given the need to ensure input and engagement with First Peoples (First Nations, Inuit and Métis) in the planning of activities to ensure they are culturally relevant and appropriate. Although CPACC only recently began to put in place mechanisms for integrating First Peoples' perspectives into its activities, there is evidence that First Peoples' stakeholders are satisfied with the general direction of CPACC's efforts in this area. CPACC continues to work on an Action Plan for First Nations, Inuit and Métis which is expected to be completed within the coming fiscal year.

4. Success

This chapter addresses the success of CPACC in terms of its immediate outcomes, as well as the potential for achieving its intermediate and final outcomes.

4.1 Progress in Achieving Immediate Outcomes

The short-term outcomes identified in CPACC's logic model include:

- Improved quality of screening and access to evidence-based knowledge and research on screening and prevention;
- > Improved access to integrated patient care;
- > Improved coordination & enhanced population-based cancer research capacity;
- Capacity to answer real time population-based questions about cancer risk factors and behaviours;
- > Improved accuracy and completeness of information on cancer control;
- > Improved reporting on performance in the cancer control domain; and
- > Improved coherence of HHR coordination in cancer control.

Progress with respect to achieving each of these outcomes is addressed in sections (a) to (g) below. While specific examples of CPACC's progress with respect to each of the identified outcomes are provided in the sections below, we note however that this list is not intended to be exhaustive, but rather to provide the reader with a sense of the types of activities implemented by CPACC. In addition, knowledge management is a key supporting activity for CPACC's achievements, and this activity is discussed in Section 5.5. The sections below align with CPACC's logic model and reporting on outcomes to Health Canada.

a) Improved quality of screening & access to evidence-based knowledge and research on screening and prevention

Detecting the presence of cancer early can have significant impact on treatment and survival. CPACC supports organized delivery of screening through population-based programs, which offer high-quality tests to everyone in a specific demographic group. Screening programs are supported through the development of performance indicators, the sharing of effective strategies to improve access and participation, and fostering collaborative work across jurisdictions in Canada. Strategic initiatives for the screening priority area include the Colorectal Cancer Screening Initiative and Cervical Cancer Control.

Prevention is generally considered a cornerstone of cancer control worldwide and it is an important element within CPACC's overall strategy. CPACC's work includes helping to build a stronger evidence base to support prevention initiatives. As well, there is recognition of the role of common risk factors with other diseases, such as diabetes and heart disease, which are tied to cancer risk factors such as poor nutrition, smoking, alcohol consumption and lack of physical activity. Working relationships and partnerships with other disease groups are expected to maximize the impact of CPACC's work on the overall health of Canadians. Strategic initiatives for the prevention priority area include: Coalitions Linking Action and Science for Prevention (CLASP); the Canadian Platform to Increase Usage of Real-World Evidence (CAPTURE); and CAREX.

Overall, the majority of stakeholders interviewed are of the opinion that CPACC has made progress towards improving the quality of screening and access to evidence-based knowledge and research on screening and prevention. Results from the survey of stakeholders yielded a similar result with virtually every survey respondent indicating that CPACC has had at least some positive impact.

Survey respondents were invited to provide examples of progress made to date in improving the quality of screening and access to evidence-based knowledge and research on screening and prevention. Examples provided indicate good awareness among stakeholders of CPACC's efforts in this area. Several respondents noted that colorectal cancer screening has been the primary focus to date. Interviewees noted similar examples of progress made with respect to screening and prevention, with a few mentioning that CPACC's contribution via bringing all the key players together and facilitating the development of guidelines was invaluable. A few further noted that CPACC has helped the provinces and territories appreciate the benefits of working together.

A few survey respondents also noted that efforts have begun to address cervical cancer screening, through the development of indicators and guidelines, as well as the HPV vaccines, surveillance, and consistent messaging around HPV. A few underscored the value of research or analysis undertaken on the value of the PSA test for prostate cancer screening.

The following represents a sample of some of CPACC's key contributions in the area of screening and prevention:

The National Colorectal Cancer Screening Network membership includes provincial and territorial government representatives, screening program leads, representatives from major Canadian cancer organizations and medical associations. The Network was established and is Chaired by CPACC. Through the efforts of the Network, jurisdictions are working together to establish measures to indicate the quality of colorectal cancer screening. A forum sponsored by CPACC in May 2008 and a follow-up forum in 2009 led to the development of a set of quality indicators for colorectal cancer screening. 12

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² January 2010: http://ww.partnershipagainstcancer.ca/colorectal-screening

- **The HPV Senior Partnership Group** is developing a plan of action for integrating immunization, screening and diagnosis. The group provides a forum for discussion to limit overlap, maximize synergy, share progress and facilitate the alignment of strategies.
- ➤ The Pan-Canadian Cervical Screening Initiative provides a national forum for discussion and action to improve cervical cancer control. The initiative includes key stakeholders from the provinces and territories, professional health groups, Public Health Agency of Canada First Nations and Inuit Health Branch, and national cancer organizations. 13
- The Coalitions Linking Action and Science for Prevention (CLASP) is expected to contribute to broadening the reach and extending the impact of existing collaborative chronic disease prevention efforts at municipal, regional, provincial/territorial, and national levels by fostering collaboration among groups of researchers, practitioners and policy specialists already involved in the prevention of cancer and other chronic diseases. ¹⁴
- The CAPTURE project is intended to establish a platform for developing, validating and enabling the use of common indicators and tools to evaluate primary prevention policies and programs. Over the long-term, this is expected to result in a more evidence-based, coordinated approach to chronic disease prevention in Canada. 15
- The CAREX Canada project is working to integrate data sources on geographic variation in carcinogenic exposures and mapping the presence and prevalence of workplace and environmental carcinogens across the country. In the long term this project is expected to inform priorities for action to reduce carcinogens in the environment. ¹⁶
- PACC has created expert panels to make sense of new research findings in the area of screening referred to as "Anticipatory Science". In advance of publications on new evidence, panels of experts review and summarize existing evidence and prepare to incorporate new findings. Rapid reports are prepared for multiple stakeholders to create a shared understanding and make sense of new evidence. Experts can respond to questions raised by the media. Additionally, a consensus statement may be developed if applicable. This process facilitates consensus across the expert community in Canada. This information can assist with the integration of new evidence into policy. The first panel was in the area of prostate cancer and PSA testing.

Overall, the evidence collected from the survey, interviews and document review indicates that CPACC has been successful in making progress on improving the quality of screening and access to evidence-based knowledge and research on screening and prevention. Particular success is evident with respect to colorectal screening.

Canadian Partnership Against Cancer Corporation — Evaluation — Final Report Health Canada — May 2010

January 2010: http://www.partnershipagainstcancer.ca/hpv

January 2010: http://www.partnershipagainstcancer.ca/coalitions

January 2010: http://www.partnershipagainstcancer.ca/platform

January 2010: http://www.partnershipagainstcancer.ca/carex

b) Improved access to integrated patient care

One of the key challenges identified by cancer patients and their families is the lack of integrated, patient focused care. For many people, lack of access to information and supportive care services makes the cancer experience more difficult. There is also growing evidence that survivors may continue to have special needs after their cancer has been treated. For others, improvements are needed in end-of-life care. CPACC is working to provide and foster leadership to promote integrated, person-centred care throughout the cancer journey. Strategic initiatives include: Integrated Person-Centred Care; and Survivorship.

Of the stakeholders surveyed almost all of the responding stakeholders (80 per cent) said that there has been at least a moderate level of impact (with 49 per cent saying the extent of impact has been moderate and 31 per cent saying that CPACC has done very well in this area).

Responses from interviewees were more mixed with respect to what has been accomplished by CPACC in this area to date. While some interviewees pointed to groundwork being laid and certain initiatives being undertaken, such as the navigation program, screening for distress, and the survivorship initiative, there is a sense among respondents of the complexity of this issue. Patient care is the responsibility of the provinces and territories and therefore coordinating efforts is a challenging task that will take time to make progress on.

Survey respondents were invited to provide examples of progress made to date in improving access to integrated person-centred care. Examples cited by survey respondents included a broad range of activities and initiatives led by CPACC including work on psychosocial needs, practice guidelines, the survivorship program, work related to palliative care, screening for distress, and patient navigation tools.

The following represents a sample of some of CPACC's key contributions in the area of integrated person-centred care:

- ➤ The Integrated Person-Centred Care Initiative is working to bring together experts in screening for distress and navigation to bring action on these important elements of cancer care. The goal is to establish screening for distress and/or navigation programs in at least six new areas by 2012.¹⁷
- ➤ The Survivorship Initiative is seeking to address the needs of people living beyond their cancer treatment. The current focus is on plans for implementing care maps and models of care to guide survivors and their caregivers through the transition and long-term phases following treatment. 18

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January 2010: http://www.partnershipagainstcancer.ca/person-centred care

January 2010: http://www.partnershipagainstcancer.ca/survivorshipintro

Based on evaluation findings there are signs of early progress being made with respect to improved access to integrated person-centred care however there remains much to be done before cancer patients are directly impacted by the work being coordinated by CPACC. There is recognition among stakeholders interviewed that this is a particularly challenging objective because of the jurisdictional implications – patient care is a direct responsibility of jurisdictions and it will take on-going effort to encourage change.

c) Improved coordination and enhanced population-based cancer research capacity

With the provinces and territories each undertaking cancer research independently, a national standard for research data was unavailable. CPACC is working to enable the development of consistent, national research data in order to facilitate sharing of best practices across the cancer control system.

Based on survey results, CPACC has had an important impact on coordination and enhanced research, with virtually all survey respondents indicating that CPACC has made an impact. Results from key informant interviews are likewise positive with almost half of those interviewed noting that this is an area where progress has been particularly evident. A few interviewees specifically praised CPACC for bringing together so many varied stakeholders to collaborate in this area. These interviewees specifically cited the cohort study as an example, as well as the CLASP Initiative.

The following represents a sample of some of CPACC's key contributions with respect to improving coordination and enhancing research capacity:

- ➤ Canadian Cancer Research Alliance (CCRA) is the Advisory Group that coordinates a united research response for cancer control. The CCRA is a 24 member organization that brings together most of the major national funders of cancer research in Canada, and has its own by-laws. CPACC provides core funding for CCRA to enable its operations. CCRA (as the Research Advisory Group) identifies opportunities for CPACC to enable projects that are beyond the scope of individual members. Two large scale initiatives have been selected. The Canadian Partnership for Tomorrow Project (also known as the Cohort study) is a long-term population study. The second project is a translational research initiative in partnership with the Terry Fox Research Institute focusing on moving laboratory discoveries into practice.
- The main triggers for cancer are a mix of genetics, behaviour and environmental factors. Understanding all these factors and their long term impact on cancer risk is the goal of the Canadian **Partnership for Tomorrow Project** (also known as the Cohort study) the largest population study in Canada to date. Over the next several years, five main researchers and their host agencies in five regions will work together to recruit 300,000 Canadians in this "population laboratory". The project, with lead national funding and coordination provided by CPACC, will study a sample of Canadians over the next several

decades. The Canadian database is expected to provide policy-makers with information on how to target disease prevention efforts and provide a legacy for future research worldwide. In the long term, this project is expected to enhance Canada's ability to do population research into all chronic diseases, reduce cancer cases and ultimately lessen the likelihood of dying from cancer. 19

- CPACC is working closely with the **Terry Fox Research Institute** to strengthen translational research. Translational research is defined as research that puts discoveries into action. This initiative is committed to working with others on projects that will improve cancer screening and treatment. One project is a national study that will explore how new technologies can help detect lung cancer early in order to improve lung cancer detection rates (described below). One of its benefits is expected to be in training a group of professionals to use an X-ray technique called spiral CT or bronchoscopy (a possible way to screen for lung cancer). As well, the research will look at whether markers in the blood or other clinical information can be used to identify people who are most likely to benefit from screening. The research is expected to help identify more effective and efficient ways to screen at risk people for lung cancer.²⁰
- Launched in September 2008, the Pan-Canadian Early Lung Cancer Detection Study, which is to include 2,500 participants, will screen current and former smokers between the ages of 50 and 75. The study builds on current international initiatives. By evaluating the effectiveness of readily accessible and low cost detection techniques, the study will inform any eventual nationwide approach to the early detection of lung cancer.²¹

The evidence indicates that CPACC has been successful at implementing projects that are aimed at improving coordination and research capacity. The progress made on this CPACC objective is illustrative of the strength of CPACC in bringing together researchers, policy makers, and NGOs.

Capacity to answer real-time, population-based questions about d) cancer risk factors and behaviour

According to the RMAF for CPACC, this outcome will serve to streamline activity and improve efficiency around the development and dissemination of effective cancer control measures.

Surveillance is the collection and analysis of data to monitor changes in cancer patterns, such as the number of new cases, prevalence and survival rates. Establishing a coordinated cancer surveillance system, including connecting the many areas where information resides, will facilitate comparisons and enable accurate conclusions. A key area is enhancing the collection of staging data, an indicator of the severity of a patient's disease at diagnosis. This data will be used

January 2010: http://www.partnershipagainstcancer.ca/tomorrowprojectintro

January 2010: http://www.partnershipagainstcancer.ca/translationalintro

January 2010: http://www.partnershipagainstcancer.ca/lung nov

to help partners plan cohesive action in prevention, screening, health-care delivery and policy. Strategic initiatives of the Surveillance Advisory Group include the: Staging Initiative; and Surveillance and Epidemiology Networks.²²

Over 85 per cent of stakeholders surveyed said that CPACC has had at least a moderate impact (with 35 per cent saying that the impact was large) with respect to enhancing capacity to answer real time population-based questions about cancer risk factors and behaviours. Similarly, interviewees were almost all positive with respect to CPACC's contribution in this area. There was a sense from a minority of interviewees that most of what has been accomplished in this respect represents groundwork for future success.

The cohort initiative was cited by survey respondents as an initiative that over time will provide the capacity to answer real-time population-based questions about cancer risk factors and behaviour. In addition, respondents also identified the Cancer Risk Management Platform housed on cancerview.ca (the web portal) as a tool which would be supportive to this endeavour. Once again, stakeholders interviewed placed a lot of value on CPACC's ability to bring diverse partners together.

The following represents a sample of some of CPACC's key contributions with respect to enhancing capacity to answer real-time, population-based question about cancer risk factors and behaviour:

- The Cancer Risk Management Platform is expected to result in web-based tools that allow both CPACC and its stakeholders to evaluate strategies in terms of future disease burden over the next 20 to 30 years. The platform will also help assess the economic impact of strategies and will serve organizations and policy makers as they make decisions regarding investments in cancer control. The Cancer Risk Management platform will be available through Cancer View Canada.²³
- The staging initiative is developing a pan-Canadian approach to determining the extent of a person's cancer (or the cancer stage) and collecting this information in a standardized way. The project is working with every province and territory so that they can collect and store stage information electronically, focusing on the four most common cancers: colorectal, breast, prostate and lung. The main focus of this initiative will be on supporting provincial/territorial implementation across the country. Capturing the stage of a patient's cancer at diagnosis is critical to proper treatment and follow-up planning.²⁴
- The Surveillance and Epidemiology Networks initiative will improve the production and distribution of Canadian cancer surveillance products, which include short reports, peer-reviewed articles, fact sheets and monographs. Networks are also intended to develop additional analytic capacity through training and mentoring opportunities. The program addresses issues in coordination, data access and analytic capacity in national cancer surveillance.²⁵

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January 2010: http://www.partnershipagainstcancer.ca/surveillance

January 2010: http://www.partnershipagainstcancer.ca/cancer_risk_management

January 2010: http://www.partnershipagainstcancer.ca/staging

January 2010: http://www.partnershipagainstcancer.ca/networksintro

Four pan-Canadian analytic networks were selected to develop new tools and methods, generate analysis of existing data and hold knowledge transfer sessions with various stakeholders. The new networks, which are platforms for collaboration both within and among provinces and territories, are the: Cancer Survival and Prevalence Analytic Network (C-SPAN); Colorectal Cancer Network (CRCNet); Canadian Hospice Palliative End-of-Life (EOL) Care Surveillance Team Network; and Projections Network (which will predict the future cancer burden in Canada).

There is evidence that CPACC has made good progress on the objective of enhancing capacity to answer real-time population-based questions about cancer risk factors and behaviour. In particular, the evidence indicates that CPACC has done much to lay the groundwork for future success. The nature of this objective is such that the data and information required to provide the capacity will take time to develop.

e) Improved accuracy and completeness of information on cancer control

Standards are required to develop best practices for cancer diagnosis, treatment and care as well as to establish performance indicators to evaluate service delivery and foster improved access and quality. Standards will also be used as key measures within the other priority areas and as a benchmark for cancer system performance. CPACC-led, collaborative projects include: developing quality assurance for diagnostic immunohistochemistry; system performance indicators; working with partners to develop standards, for example, for chemotherapy delivery; and, endoscopy quality.²⁷

Ninety three per cent of stakeholders surveyed said that CPACC's impact in this area was at least moderate or higher. Similarly almost all interviewees who could comment had positive things to say. Some of these interviewees tied CPACC's success in this area to success in the area of knowledge management.

A small minority of key informant interviewees cited the portal as a specific example of CPACC's contribution, as well as praising CPACC for bringing together the necessary parties. Another example brought up by a few interviewees is the synoptic surgical reporting initiative. Another gap CPACC is seen by a few respondents to be filling is that of staging, which, as explained by one respondent, "is important because it will allow us to see some of the early benefits of screening – catching cancer at an earlier stage and so helping us monitor the cancer control environment." Survey respondents provided similar examples of CPACC activities in this area with the Cancer View Portal, synoptic surgical reporting, staging initiative, and surveillance networks.

Canadian Partnership Against Cancer Corporation — Evaluation — Final Report Health Canada — May 2010

January 2010: http://www.partnershipagainstcancer.ca/networksintro

January 2010: http://www.partnershipagainstcancer.ca/standards

CPACC's work on standards is spread throughout its work. The following represents a sample of some of CPACC's key contributions to date in the area of standards:

- A key example of CPACC's contribution in the area of standards and cancer system performance is CPACC's **collaboration with the Canadian Association of Pathologists (CAP)**. This project is expected to provide a framework for more accurate cancer diagnosis and better treatment planning across the country. Central to high quality patient care is standardization in diagnostic immunohistochemistry (IHC), a process of examining abnormal (possibly cancerous) cells. ²⁸
- > Standards and Guidelines Evidence (SAGE) is an online repository of evidence-based information for those interested in guidelines and standards and in sharing knowledge to improve cancer control. ²⁹
- The National Colorectal Cancer Screening Network membership includes CPACC staff, provincial and territorial government representatives, representatives from major Canadian cancer organizations and medical associations. Through the efforts of the Network, jurisdictions are working together to establish measures to indicate the quality of colorectal cancer screening. A forum sponsored by CPACC in May 2008 and a follow-up forum in 2009 led to the development of a set of quality indicators for colorectal cancer screening.
- The CAPTURE project is intended to establish a platform for developing, validating and enabling the use of common indicators and tools to evaluate primary prevention policies and programs. Over the long-term, this is expected to result in a more evidence-based, coordinated approach to chronic disease prevention in Canada. ³¹
- **The Synoptic Surgical Reporting Initiative** is developing standardized electronic templates for selected types of cancer surgery. These are being piloted at various centres across Canada in an effort to standardize data collection and enhance physician practice.

There is evidence that CPACC has made progress in this area. Much of the progress in this area is dependent on jurisdictions' participation – the evidence indicates that thus far all jurisdictions are involved.

f) Improved reporting on performance in the cancer control domain

Guidelines are statements, based on evidence, that steer clinical practice and policy decisions. Guidelines are tools that promote appropriate practice, inform investment in new technologies and enhance quality improvement programs. The cancer guidelines priority area's strategy is aimed at building capacity for evidence-informed decision making, using social networks and

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January 2010: http://www.partnershipagainstcancer.ca/standards

January 2010: http://www.partnershipagainstcancer.ca/sageintro

January 2010: http://www.partnershipagainstcancer.ca/colorectal_screening

January 2010: http://www.partnershipagainstcancer.ca/platform

technology platforms to transfer knowledge and skills across provincial/territorial jurisdictions. Strategic initiatives include: synoptic reporting (surgery); Guideline Adaptation Program (CAN-ADAPTE); capacity enhancement; and SAGE: standards and guidelines evidence. 32

The System Performance initiative measures and reports on the quality of cancer control and healthcare. The objective of the system performance initiative is to facilitate the exchange of this information throughout the reporting of cancer control indicators in Canada across provincial jurisdictions and throughout the cancer control continuum.³³

In terms of rating the impact of CPACC on reporting of performance, virtually everyone who responded to the survey agrees that the impact has been at least moderate. Survey respondents specifically noted CPACC's knowledge management framework, the development of system performance indicators, and the first pan-Canadian report on performance indicators, released in 2009.

Respondents to the survey of stakeholders were invited to provide examples of progress made to date in improving reporting on performance in the cancer control domain. The primary example provided surrounds efforts at performance reporting. A small minority of survey respondents note that this is a work in progress and still in the early stages. However, a few noted that the first performance report has been released, with some describing this as "a remarkable endeavour" or "will add tremendous value". They note that collaborative work is ongoing to develop additional indicators. This particular outcome was seen by interviewees as another area in which progress is complicated considerably by provincial/territorial and jurisdictional issues.

The following represents a sample of some of CPACC's key contributions with respect to improving reporting on performance in the cancer control domain (including Guidelines and System Performance):

The Synoptic Surgical Reporting Project is creating tools to easily apply guidelines to cancer surgery reports. This project is an extension of work spearheaded by Alberta and funded by Canada Health Infoway. Synoptic surgical reporting is being piloted in five provinces across five cancer sites: colon, rectum, breast, ovary, and head and neck cancers. A national consensus process has brought together surgeons from across the country to create standardized templates so that this information can be collected systematically. By using technology to create an electronic system that embeds guidelines at the point of care, this project is expected to facilitate more detailed and complete reports. In addition, clinicians will get real-time information about how their practice compares with provincial/territorial and, eventually, national averages, thus providing an opportunity for quality improvement. Over the long term, this project is expected to improve treatment planning and follow-up, thus improving patient care. 34

January 2010: http://www.partnershipagainstcancer.ca/quidelines

The System Performance Initiative, A First Year Report, October 2009

January 2010: http://www.partnershipagainstcancer.ca/synopticsurgeryintro

- The Guidelines Adaptation Project (CAN-ADAPTE) is developing and evaluating a methodology to facilitate the work of guideline developers who are adapting guidelines. Building on existing guidelines will improve the quality and efficiency of the guideline development process and reduce the duplication of effort.³⁵
- The Guidelines Capacity Enhancement Program is facilitating the development of evidence-based guidelines and their use across Canada. Its core objectives include: an inventory of cancer guidelines; a training, education and skills acquisition program; and a cancer evidence casebook. ³⁶
- > Standards and Guidelines Evidence (SAGE) is an online repository of evidence-based information for those interested in guidelines and standards and in sharing knowledge to improve cancer control. ³⁷

The evidence indicates that progress with respect to guidelines has been positive. While there is to date no quantifiable evidence of the uptake of guidelines, early progress in developing the necessary tools and guidelines is well underway.

Although there is evidence that progress is being made in the area of reporting on performance, the evidence also suggests that progress has been slower than anticipated. Progress with respect to this objective and the strategic initiatives linked to it is complicated by the need for agreement by jurisdictions to collect and share data. To date most of the deliverables have involved the bringing together of people, which is important in the context of the Canadian healthcare system, and this represents, along with the first report released in 2009, the first step towards improving reporting on performance.

g) Improved coherence of Health Human Resources coordination in cancer control

Many factors, including a growing and aging population, are making demands on health human resources. The increased demands on HHR can be met with increased supply of HHR in Canada, or more efficient use of current HHR supply. The Service Delivery Models project is intended to facilitate the more efficient use of the current HHR supply. The Service Delivery Models project is working to identify innovative and promising models for delivering cancer control from within Canada and around the world.

A key venue for CPACC's contribution in the area of health human resources is the **Service Delivery Models Project**. The Service Delivery Models Project expects to develop a searchable database of at least 100 innovative leading models of service delivery that optimize the contribution of health professionals while striving to improve the patient's experience. It also

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January 2010: http://www.partnershipagainstcancer.ca/guidelineadaptationintro

January 2010: http://www.partnershipagainstcancer.ca/capacityenhancementintro

January 2010: http://www.partnershipagainstcancer.ca/sageintro

expects to forge links and help create communities among Canadian stakeholders involved in service delivery and human resources planning for the cancer workforce. By building capacity in the cancer control workforce, this project will strengthen the delivery of cancer control services for all Canadians.³⁸

As part of the process of revising its Strategic Plan and refocusing activities on areas where CPACC could have the most measurable impact in its first five-year mandate, it was agreed that CPACC would reallocate resources away from HHR. This is not to say that HHR has not been an area of focus for CPACC but rather the emphasis on HHR was decreased.

In terms of HHR coordination three in four (77 per cent) survey respondents said that there was at least a moderate impact on HHR coordination. That said, relatively few pointed to a strong impact. Likewise, this outcome attracted a lot of mixed opinions among interviewees. While awareness of the HHR group is generally good, most people were not able to comment on any actual progress.

By way of examples of progress made on this objective, most survey respondents acknowledge that the CPACC HHR Advisory Group is active, but suggest that there has been little visible progress to date. Some noted that this is a challenging area, and that the ability to affect change may be limited given the number of partners and jurisdictions that need to be engaged. This perspective was echoed by stakeholders interviewed. Even so, there were many encouraging words provided by a minority of interviewees, along the lines that there is a need for work to be done in this respect, so CPACC should persevere. There is perceived to be a need among stakeholders interviewed for this type of coordination, and the potential appears to be there for CPACC to take a significant role in it; however a few respondents raised concerns about this noting that CPACC cannot come up with a solution on its own. While initially this issue may have taken a back seat due to its complexity, there is the sense that CPACC can and should take on a leadership role in the future.

The evidence collected for this evaluation suggests that although some early progress has been made in this area, measurable progress has not been made. Much of the lack of progress can be attributed to jurisdictional responsibility – health human resources fall firmly within provincial/territorial jurisdiction making it more difficult for CPACC to have an immediate, measurable impact. That said there is a strong sense among CPACC stakeholders and partners that health human resources is an important issue in cancer control that must be addressed and that CPACC is likely in the best position to bring all the key players together. Thus although there is some evidence of disappointment on the part of stakeholders and partners at the lack of progress there is also a firm understanding of the complexities and challenges presented by this objective.

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January 2010: http://www.partnershipagainstcancer.ca/hhr_service

Overall, the evidence collected from key informant interviews, the survey of stakeholders and document review indicates that CPACC has made progress in achieving its immediate outcomes. In areas where progress has been more dependent on the buy-in and active engagement of practitioners and those responsible for delivering health services progress has been slower, specifically with respect to health human resources and integrated person-centred care.

4.2 Intermediate Outcomes

As noted previously, it is still early in the lifecycle of CPACC and realistically one cannot anticipate significant, measureable progress to be made on outcomes anticipated beyond five years. It is important to note that the achievement of CPACC's intermediate outcomes is expected in seven to 15 years after implementation and so assessing the extent to which these have been achieved in any tangible way is premature. However, this section addresses the extent to which progress has been made and the perceptions of stakeholders and partners of whether CPACC has the potential to achieve its intermediate outcomes. The intermediate outcomes identified for CPACC are:

- > Enhanced population-based screening and prevention;
- > Improved cancer experience for Canadians;
- > Enhanced cancer control system; and
- **Enhanced integration of knowledge and research.**

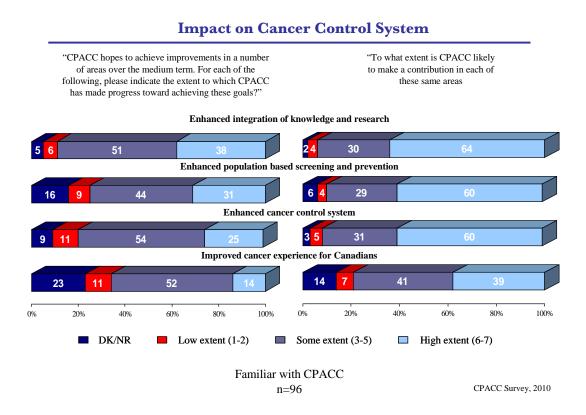
a) Progress Made

Most stakeholders interviewed feel that CPACC has been implementing initiatives that will ultimately contribute to the intermediate outcomes. A few interviewees noted that CPACC is only one player in the cancer control system, representing only about one per cent of annual funding to cancer control in Canada.

In particular, a small minority of interviewees pointed to progress on *enhanced population-based screening and prevention*, sometimes citing the achievements relating to colorectal screening as a concrete example. Another contributor to progress in this area noted by interviewees is knowledge around behavioural initiatives; the CAPTURE project was mentioned by a few respondents. With regards to *improved cancer experience*, a few respondents mentioned the work concerned with survivorship, while others mentioned activities related to access to services and palliative care. But once again, the differences in delivery across provinces and territories were cited as an obstacle for making measurable progress on these outcomes. This was also discussed in the context of progress towards an *enhanced cancer control system*; however CLASP, CAPTURE and work related to standardization were seen as contributors towards CPACC eventually achieving this medium term outcome. Finally, when asked about progress

towards *enhanced integration of knowledge and research*, some progress has again been perceived, through initiatives such as the portal, the Partnership for Tomorrow project and the ongoing collaboration with the Canadian Cancer Research Alliance (CCRA).

The perceptions of stakeholders surveyed largely mirror those of individuals interviewed for this evaluation. Results are largely positive in terms of the extent to which CPACC has made progress toward achieving its intermediate goals, according to majorities of stakeholders surveyed who indicated that progress has been made. Survey results are summarized in the graphic below.



b) Perceived Potential to Achieve Intermediate Outcomes

When asked whether they considered CPACC to be on track to achieve its medium-term outcomes and objectives, most individuals interviewed were generally positive in their opinions. Even so, when asked to suggest changes to help enable this achievement, many respondents had a variety of ideas. Most frequently, suggestions were made to the effect of more engagement with a broader range of stakeholders, especially the provinces and territories as they are integral to delivering cancer care across Canada.

The survey of stakeholders asked respondents to rate the extent to which CPACC is likely to make a contribution in each of CPACC's intermediate objectives. Overall, stakeholders feel that CPACC has an important contribution to make in each of the areas identified (3 in 5 or more providing top ratings (6-7)). The results are fairly consistent across all respondents, with a few

minor exceptions. Those less familiar with CPACC more often underestimate the contribution CPACC is likely to make in each of the areas. This may be an indication of a lack of familiarity with the full scope and potential of CPACC's work.

There is evidence that CPACC is making progress in the direction of achieving its intermediate outcomes. Given the evidence that progress is being made with respect to the immediate outcomes it is likely that progress will also be made on the intermediate outcomes.

4.3 FINAL OUTCOMES

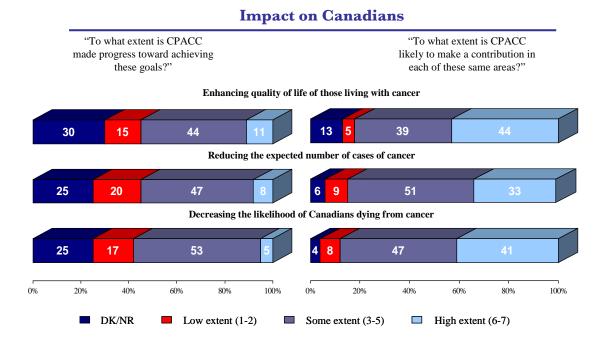
As was noted for the intermediate outcomes, it is still early in the lifecycle of CPACC and realistically one cannot anticipate significant, measureable progress to be made on outcomes anticipated beyond five years. It is critical to note that as one moves down the continuum of outcomes from immediate to intermediate and to final, the ability to attribute change to CPACC greatly decreases. In the case of an organization such as CPACC which is dependent on the active participation and buy-in on the part of its partners and stakeholders, this is even more true. As noted by a few interviewees, CPACC's funding represents only one per cent per year of total cancer spending in Canada – CPACC can have an impact but it cannot result in measureable change on its own. However, it is the role of CPACC to bring stakeholders together and to coordinate activities. This section addresses the extent to which progress has been made in the direction of CPACC's final outcomes and the perceptions of stakeholders and partners of whether CPACC has the potential to achieve its final outcomes. CPACC's final outcomes are:

- > Decreasing the likelihood of Canadians dying from Cancer;
- > Reducing the expected number of cases of cancer; and
- Enhancing quality of life of those living with cancer.

a) Progress Made

Interviewees tend in general to believe that progress is being made in the direction of CPACC's final outcomes. A few respondents pointed out that the final outcomes are very much tied to the medium-term. However, it stands to reason that at this point these outcomes are seen by many respondents as being a long way off in the future; timeframes quoted by respondents were as long as 20 to 30 years. Another point made a few times is that the final outcomes are shared by the entire cancer control community, and that CPACC plays only a small role. A few interviewees raised concerns about attribution of results to CPACC.

Stakeholders surveyed were asked to rate the progress CPACC has made towards achieving its final outcomes. Overall, progress in these three areas is not perceived to be as strong as the results for immediate and intermediate outcomes, although a sizeable portion indicated at least some degree of progress has been made.



b) Perceived Potential to Achieve Ultimate Outcomes

Interviewees generally agree that CPACC will ultimately contribute, in a significant manner, to cancer control in Canada; its role as a coordinator of knowledge activities across many different players in the field of cancer control was often cited as a key reason. Also, a large minority of interviewees again feel that it is quite early in CPACC's lifespan to tell for sure whether it will contribute to cancer control, but the potential is there.

Familiar with CPACC

Similarly, a majority of survey respondents believe that CPACC is likely to make at least a modest contribution in each area. In fact at least eight in ten stakeholders believe that CPACC has a moderate or stronger role to play in each of the three areas, which is again a testament to the fact that the organization is early in its mandate and stakeholders expect the level of longer-term impact to continue over time. Results are summarized in the graphic above.

Overall, the evidence suggests that CPACC is making progress in the direction of its final outcomes. However, due to issues of attribution and the short timelines since implementation, these results should be interpreted with caution. CPACC is only one of many players in cancer control in Canada, the nature of the anticipated final outcomes and the structure of the Canadian healthcare system will require concerted effort on the part of all key players. Based on the evidence, CPACC is well placed to play a coordinating and leadership role in achieving these outcomes.

CPACC Survey, 2010

4.4 ENABLING OF PARTNERSHIPS

a) Partnerships, Collaborations and Joint Initiatives

This section describes progress made by CPACC in developing partnerships, collaborations and joint initiatives since implementation.

Interviewees were asked the extent to which they feel that CPACC has successfully enabled partnerships within the cancer control community; key informants were for the most part at least somewhat positive, with just under half of responses being positive. Some interviewees praised CPACC for having a broad cross-section of partnerships, as identified in their corporate plan and as illustrated by advisory committee membership. In the research arena in particular partnerships enabled by CPACC are seen as successful.

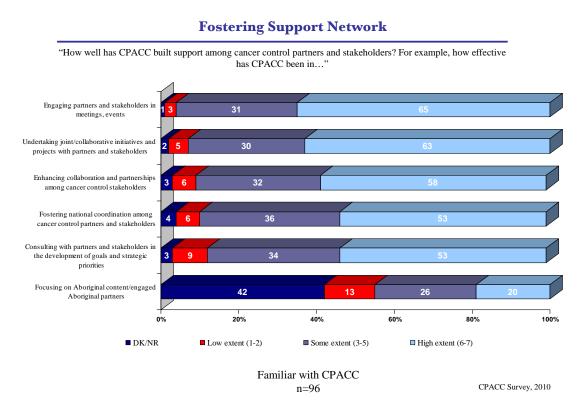
As to whether CPACC is encouraging and strengthening collaborative partnerships and creating new ways for enhancing the translation and transfer of knowledge, expertise and best practices, most responses were positive, citing examples such as the Survivorship Initiative, the Portal, and the synoptic reporting. Again, there is seen to be room for improvement, such as reaching out to a broader cross-section of stakeholders and being more direct in trying to engage them; there are concerns that not all the relevant potential partners have been involved yet, or CPACC was slow to involve them, and that CPACC needs to consider more carefully what different partnerships can contribute to the achievement of CPACC's objectives.

One problem raised by a few interviewees concerns the distinction between partner and stakeholder. It was suggested by one respondent that while both words are used, partners typically take more of an active decision-making role and therefore most of CPACC's relationships are more of a stakeholder type rather than a partner type. A few respondents suggested that roles and responsibilities are still very much in evolution at the moment. Further, CPACC has limited funding and is largely meant to be a coordinating organization and therefore, given the complexity of the task, clarifying relationships and roles will take a great deal of time.

Survey respondents were likewise asked to comment on various aspects of CPACC's efforts at fostering support among cancer control partners. As shown in the chart below, CPACC performs well in virtually all aspects of building support within the cancer control community (majorities indicate CPACC has been 'highly' effective).

Across the various subgroups of survey respondents, the broadly positive results are consistent, with some minor variations. Those very familiar with CPACC are more likely than those less familiar to rate the effectiveness of CPACC highly in the areas of engaging partners and stakeholders in meetings and events (74 versus 47 per cent, respectively); fostering national coordination among cancer control partners and stakeholders (61 versus 38 per cent); and consulting with partners and stakeholders in the development of goals and strategic priorities (61 versus 38 per cent).

Those who have been working in the cancer control area for less time are more likely than their more experienced counterparts to rate the effectiveness of CPACC's coordination efforts at the national level highly (70 per cent versus the overall average of 53 per cent).



Based on survey results, those who are very familiar with CPACC tend to be more engaged and are more likely to seek the opportunity to collaborate with CPACC. They are also more likely to have previously sought information from them. Respondents to the survey of stakeholders were asked whether they intend to seek an opportunity to collaborate with CPACC in the future. Nine in 10 respondents indicated that they did intend to try to collaborate with CPACC

As stated elsewhere in this report, CPACC's role is to act as a knowledge broker in advancing the Strategy and it is CPACC's partners and stakeholders who ultimately own its implementation and sustainability. As a result, CPACC has identified the building of greater relevance across the provinces and territories in the Strategy and current initiatives as a priority. To this end, as requested by its provincial/territorial partners, CPACC has developed a number of background documents targeting provincial/territorial cancer agencies and ministries of health/health promotion. These backgrounders will be used to inform engagement activities with provincial/territorial leads/stakeholders.³⁹

In the first year of its mandate, CPACC signed an MOU with the Canadian Cancer Action Network, providing multi-year funding to support a more formal coalition that brings together disease-site patient groups, advocacy organizations, the Canadian Cancer Society, and

³⁹ CPACC. Chief Executive Officer (CEO) Report to the Board of Directors, December 2009.

population organizations such as the Assembly of First Nations, ITK among others. The relationship between CPACC and CCAN is intended to ensure that the patient voice is engaged through their membership in the implementation of the strategy and that the multiple stakeholders in the patient community are informed and will participate in the initiatives underway. CCAN members are part of CPACC's Advisory Groups. Further a member of the CCAN Board sits on the CPACC Board, and a member of the CPACC senior management team sits on the CCAN Board.

Similarly, another relationship that CPACC has established is with the Canadian Association of Provincial Cancer Agencies (CAPCA). Cancer agencies and programs are a key constituent within provincial jurisdictions. Many of the initial initiatives that CPACC has supported are dependent on cancer agency leadership for their implementation. Some developments in this relationship-building include: co-location of CAPCA offices with CPACC; CPACC's membership on CAPCA's Board and a CAPCA representative on the CPACC Board; CAPCA Board and CPACC senior management meetings; and collaboration on development of standards around the delivery of intravenous chemotherapy. 40

In July 2009 CPACC hosted a stakeholder forum to provide stakeholders with the opportunity to discuss partner engagement in Canada's cancer control strategy and to strengthen collaboration on shared priorities. Among the 180 participants were clinicians, professional associations, patient and advocacy groups, cancer agencies, health ministries, federal agencies and other national organizations. Feedback from this forum will inform the process of planning beyond 2012. Further consultations are planned for 2010. 41

b) Understanding of Roles and Responsibilities

CPACC has sought to implement the strategy through multiple means. Throughout CPACC documents (Annual Reports, 2008-2012 Strategic Plan), it describes its role as a catalyst, a convenor and collaborator. In addition, CPACC funds strategic initiatives that are both delivered through third parties (e.g. provinces and universities), and also delivers central activities such as the portal. These roles (both leading and supporting initiatives) recognize the numerous stakeholders already engaged in cancer control activities and areas where there are gaps that CPACC can address through its own staff and resources.

Interviewees representing the provinces and territories, federal departments, professional groups, advocacy groups/NGOs and CPACC were asked whether they believed the roles and responsibilities of CPACC partners to be clearly defined, communicated and understood. Responses to this question suggest that this is an issue of significant concern. Responses were considerably varied regarding this issue, with almost half expressing negative opinions. A small minority presented a mixed picture, where some parties' roles are clear and understood, while others are not at all. More than once respondents from a variety of categories said that level of clarity varies from project to project.

Canadian Partnership Against Cancer Corporation — Evaluation — Final Report Health Canada — May 2010

⁴⁰ CPACC. Chief Executive Officer (CEO) Report to the Board of Directors, December 2009.

Canadian Partnership Against Cancer. Momentum: Cancer Control in Action July 7-8, 2009, Summary Report, October 2009.

There is also some evidence in the document review, and supported by comments made by one interviewee, that Health Canada (including FNIHB) and PHAC are developing a closer collaborative relationship with CPACC but some duplication of effort still existed in 2008, particularly with respect to PHAC and CPACC. 42

c) Collaboration with First Peoples

Based on the interviews, focusing on Aboriginal content seems to still be a work in progress for CPACC. Although there are some promising signs, such as development of Aboriginal partnerships and involving Aboriginal communities in meetings, regular communications are still being established with key partners in the area. Roles and responsibilities, once again, do not appear to be clearly understood at this point. As an action plan for Aboriginal populations is articulated it is hoped this will change. The hiring in 2008 of a program manager to focus on First Peoples' content will likely facilitate greater collaboration between CPACC and First Nations, Inuit and Métis organizations.

Many respondents are not aware of the work underway and the survey results do not seem as positive in the area of focusing on Aboriginal content and engagement/participation. Considering only those respondents who provided a rating in this area, eight in 10 (79 per cent) said that they believe that CPACC has made at least a moderate to large impact, with 34 per cent rating the impact as high.

CPACC has been successful at its roles as catalyst and has brought together stakeholders and enabled partnerships. The resulting partnerships can be expected to foster progress towards CPACC's objectives over the coming years.

There is some evidence of a continued lack of clarity with respect to the roles and responsibilities of CPACC and its partners and stakeholders. There is evidence to suggest that some CPACC stakeholders who are less involved with CPACC on a regular basis have a less positive view of CPACC's collaborative and partnering efforts. However, there is evidence of a strong desire to partner with CPACC among stakeholders.

Collaboration with First Peoples (First Nations, Inuit and Métis) has been relatively weak to date however there is evidence of momentum being built.

4.5 Unintended Impacts

The document review conducted as part of this evaluation did not uncover any unintended impacts (positive or negative) as a result of CPACC activities. However a minority of stakeholders interviewed (representing all categories of interviewee with the exception of international representatives) noted unintended impacts, both positive and negative, that have occurred as a result of CPACC. Of particular note was a negative impact mentioned by a few

⁴² Canadian Partnership Against Cancer. 2008-2009 Business Plan, Presentation to Board of Directors, June 2008.

interviewees representing the provinces and territories and advocacy groups: increased burden on partner organizations due to CPACC. For some this meant an increased workload, leading to the neglect of their other responsibilities. For others, this led to a need to find more money to contribute, sometimes at the expense of some of their other activities. Other impacts described by one or two respondents are summarized below.

Positive

- Funding opportunities that have arisen; for example, one province received funds to update their Tumour Registry software, for which they had been trying to obtain the money for years.
- The inventories of primary prevention activities from across Canada have been useful to the provinces and territories. Without CPACC the provinces and territories would have had to undertake this themselves and would likely not have done it collaboratively.
- > Broadening the number of people who can be engaged in policy discourse; for example the unexpected involvement of environmental groups in the context of exposure.
- Rapidity of getting colorectal screening in place resulted from getting provinces and territories together to talk about it; if some provinces and territories are implementing, others will feel more comfortable doing it as well.

Negative

When CPACC was founded, organizations representing other diseases such as cardiovascular were asking "what about us?" On the other hand, another key informant believes that this has led to partnerships with other chronic disease groups on the prevention level – a positive impact.

It is important to note that some of the positive impacts noted are not entirely unintended.

4.6 BARRIERS AND FACILITATORS TO SUCCESS

a) Facilitators to Success

Stakeholders, including those surveyed and interviewed were asked to comment on what they felt to be the key facilitators for CPACC's success. The following are the most frequently cited facilitators:

➤ **High calibre of staff.** The most frequently cited facilitator related to the excellent calibre of the staff, particularly at the senior level of CPACC. Many stakeholders identified CPACC staff as a strength and several said that it is because of this that CPACC has had as much success at engaging the stakeholder community.

- ➤ Collaborative approach. Many stakeholders described a culture of collaboration with a wide variety of stakeholders that is a foundation of CPACC's success. This commitment to the development of knowledge networks and information sharing that has made the organization stand out. One stakeholder said that CPACC has engaged just about every key organization and researcher working in cancer control today.
- Nimbleness. CPACC is seen by many stakeholders as a nimble organization that can mobilize and move quickly. It has inherent "flexibility to respond to opportunities quickly".
- Sovernance structure. Another strength cited by several stakeholders is its governance structure. It is a national body that transcends the jurisdictions of federal and provincial/territorial boundaries. This enables it to collaborate at all levels and also to be able to put forward national standards in cancer control.

b) Barriers to Success

Stakeholders were also asked about what they felt could be barriers to CPACC's success. The following are perceived as barriers by stakeholders:

- Funding cycle. The five year cycle and related five year mandate are seen as too short and restrictive, making the future of CPACC uncertain. Not knowing the future of CPACC past 2012 ties its hands in many ways. It reduces its ability to plan for a long-term horizon or fund/be involved in long-term projects. This in turn makes it difficult to engage with the cancer control community in a meaningful way (when long term sustainability is seen as a key focus in the community). The short timelines within which to achieve results (five years, when it took between 12 and 18 months to get effectively up and running) are seen as far too short a period in which to realistically expect sizable measurable outcomes, according to some stakeholders.
- **Too many projects.** When CPACC was created it inherited 111 identified activities from the CSCC. Under the direction of the Board and leadership of senior management, focus and impact were sought across the portfolio. Projects have been integrated, refined or cancelled to approximately 34. Some of these were short term and completed. In addition, strategic initiatives were drawn from the priority areas where there would be impact within the five year mandate. For these, targets have been established and are publicly posted on the website. These targets can be directly linked to the immediate outcomes. Nonetheless, a few stakeholders believe that there are too many projects that have been taken on by CPACC to be able to credibly achieve results. It also results in a more diffuse focus, resulting in CPACC looking disorganized to the cancer control community.
- ➤ **High staff turnover.** The high turnover in staff at CPACC, particularly at the senior levels was noted by a few stakeholders. This has resulted in further disjointedness in the approach of CPACC.

- ➤ Clarity of mandate. Several stakeholders said that CPACC has not been able to clearly articulate its mandate in a way that distinguishes it from other national bodies involved in cancer control. A general lack of transparency around goals and objectives was cited by a handful of stakeholders in fact. A lack of visibility or publicity was also cited by two or three stakeholders as a weakness.
- **Bureaucratic and centralized.** A few stakeholders suggested that CPACC is overly bureaucratic, as well as Ontario centric. Several stakeholders said that the burdens of reporting requirements tie up resources, making it overly officious and hampering its ability to achieve actual progress and real results.
- Lack of ability to leverage. A lack of levers or authority with the other national agencies or bodies, or with the provinces and territories, was suggested by quite a number of stakeholders to be a fundamental weakness. Several pointed out that, without the power to compel others to work with CPACC in a coordinated way (and without a longer-term mandate) CPACC has no way to really maximize coordination of efforts. CPACC does not have direct control or responsibility for implementation of healthcare and so cannot directly influence what decisions are made at the provincial/territorial level. Healthcare delivery is largely a provincial/territorial responsibility.
- > Insufficient engagement of the cancer control community. Almost a dozen stakeholders who were interviewed suggested that CPACC does not engage the cancer community enough. It does not sufficiently rely on these organizations with the expertise in cancer control, nor does it consult sufficiently. Perhaps related to the turn over at senior levels, some stakeholders pointed to a shifting model of consulting and obtaining advice from the cancer control community over a relatively short period of time.

5. GOVERNANCE

This chapter presents evaluation results related to the governance of CPACC including: how well the strategy is understood by stakeholders; progress monitoring; and allocation of project funding.

5.1 Understanding of Strategy by Stakeholder Groups

Starting in fiscal year 2008-2009, quarterly status reports of the annual business plan were prepared by the CPACC Executive and submitted to the Board. Status reports include: summaries of strategic initiatives, action/working groups, and central projects; a quarterly financial forecast; and the enterprise performance and risk management scorecard. In addition to the summary report, each status report contains a risk and forecast summary of project status and an outlook for each strategic initiative, action group, central project and key central activities.

Quarterly one-page updates are prepared by the Chair of each of the Advisory Groups and are compiled into a quarterly report that is submitted to the Board. The updates include information on planning, implementation, achievements and impacts of the activities for the quarter.

However, given the ongoing membership renewal process for Advisory Groups to be completed in April 2010, it is unclear what the communications strategy will be moving forward. However, it should be noted that these reports pass information to stakeholders since stakeholders sit on these groups.

Survey respondents familiar with CPACC were asked whether or not CPACC's strategic priorities and supporting activities have been clearly communicated to them. Reflecting high levels of awareness of CPACC's strategic priorities and supporting activities among stakeholders, seven in 10 say these strategic directives have been clearly communicated to them. That said, one in six (17 per cent) said that this is not the case, and one in seven (14 per cent) were not sure.

Interview results indicate challenges with the degree of understanding of the overall Strategy and/or the strategic direction of CPACC. Close to half of respondents feel that the Strategy is not well understood at all, or have mixed opinions on the matter. In fact, most of those who feel that it *is* well understood are CPACC management and staff, and Board members (i.e. those most involved in the operation of CPACC).

A number of interviewees pinpointed the problem to the issue of communicating to a larger cross-section of stakeholders. Concerns were raised a few times that understanding of the Strategy tends to be limited to those immediate partner and stakeholder groups. Meanwhile, the broader community such as smaller agencies, NGOs, health professionals and staff and the Canadian public are still quite out of the loop.

A few interviewees suggested that the lack of understanding of CPACC's strategic direction is not entirely the fault of CPACC, that it is also "a local and regional issue". CPACC cannot be everywhere, they can only communicate with the key communicators.

There is evidence of a limited understanding of CPACC's strategic direction on the part of stakeholders. Although CPACC has communicated with its stakeholders at the level of the Board and the various advisory committees there continues to be a limited understanding of CPACC's strategic direction among the broader stakeholder population.

5.2 EFFECTIVENESS AND APPROPRIATENESS OF INPUT

Stakeholder input into CPACC strategic initiatives and projects is provided through direct advice, structured feedback, consultation and ongoing communications tools. These input mechanisms, include:

- Advisory mechanisms: The partnership receives input and perspectives from across Canada's cancer community through the Advisory Council (disbanded in June, 2009), Action Groups and the Action Council as well as through various working groups and steering committees;
- > Surveys and feedback forums: To guide the strategic direction of many of its initiatives and projects, CPACC gathers structured input from stakeholders, notably, in the areas of communications, research, primary prevention and screening activities;
- Consultative forums: The partnership also gathers input from stakeholder groups through in-person forums and strategy sessions, recent examples include: Knowledge Management in Cancer Control Focus, Impact and Sustainability (October 2008); National Forum on First Nations, Inuit and Métis Cancer Control (March 2009); and Momentum Cancer Control in Action (July 2009);
- Fools for ongoing communication and collaboration: Stakeholders also offer feedback on an ongoing basis using a variety of tools hosted on the Cancer View Canada portal, such as targeted feedback forms that invite stakeholders to suggest high-quality resources that should be included on the portal, and virtual workspaces (Collaborative Group Spaces) that anyone in Canada with an interest in advancing cancer control can access freely to set up a collaborative community (e.g., discussion forums, document sharing, wikis and blogs). In addition, stakeholders can email to make suggestions and recommendations through a link on the cancerview.ca site. This link enables visitors to contact a Canadian Cancer Society Information Specialist to ask specific questions about the online content offered and provide feedback on the site.

The Strategy was developed over a ten year period by a consortium of stakeholders concerned with cancer control who subsequently worked to have the Strategy implemented. Thus CPACC evolved from the advocacy efforts of a large number of stakeholders. Overall, most stakeholders interviewed for this evaluation feel that the implementation of CPACC has involved stakeholders; however, with the implementation of CPACC the responsibility for overseeing the Strategy has moved from the CSCC Council to CPACC, with some stakeholder groups having less control or decision making authority.

A few interviewees who are Board members noted that involvement of stakeholders has decreased somewhat as CPACC evolved into delivering on the Strategy. There is a sense from these interviewees that the implementation phase for CPACC is complete and thus there is no longer a need for extensive consultation on as frequent a basis. As indicated in interviews and survey responses, a very small number of stakeholders are very dissatisfied with this diminished role. These individuals would like more input into how CPACC implements the Strategy. We note that these stakeholders are a very small minority. The vast majority of stakeholders are relatively satisfied with their role with respect to CPACC and the Strategy.

At the July 2009 Stakeholders' Forum, participants identified a number of means through which CPACC could build more effective partnerships, notably: expand beyond current collaborations or networks to engage more people; more work across chronic disease groups; enhance clear pathways of communication in all mediums into, and out of, the Partnership; and challenge existing system barriers to pan-Canadians solutions.

Interviewees were asked whether they feel that stakeholder groups have effective and/or appropriate input into CPACC decision-making processes. Opinions were mixed, with about half indicating that the important stakeholder groups are included in CPACC decision-making and that CPACC consults with a broad range of stakeholders. A few significant concerns were nevertheless raised. For instance, it was mentioned by some respondents that the effectiveness and appropriateness of input depends both on the type of stakeholder and the issue at hand. More specifically, deficiencies in opportunities for patient input were noted by some respondents representing advocacy groups and the provinces/territories, whereas provincial/territorial cancer agencies and other key stakeholder groups had more opportunity. In particular, respondents from professional organizations raised concerns related to a lack of input, and a predominantly 'top-down' approach.

In an effort to make CPACC more accountable and transparent with respect to its Advisory Groups, CPACC has established a more formal process for recruitment, selection and term renewal of experts, representatives from partner organizations and patient/survivor members. Each of the seven Advisory Groups has been reassessing their membership. At the beginning of 2010, CPACC will be creating online postings for some members' position on each Advisory Group. CPACC will also be approaching some partner organizations for more formal arrangement of their representative members. Appointments will have fixed terms and renewal patterns, and final approval of membership will reside with the Senior Management Committee.

Some groups of interview respondents were asked to discuss the extent to which the provisions for input into the partnership promote stakeholder engagement. In general the sense is that if people's input is sought, they are more likely to be engaged. Those who feel that there is not enough input, therefore, feel that stakeholder engagement is not being cultivated as it should be.

Finally, in the context of this issue, interviewees were asked to make suggestions for improvements to the decision-making process and provisions for stakeholder input. A few respondents noted the movement to Advisory Groups from Action Groups as a step in the right direction. Another suggestion made more than once is to revise how the provinces and territories provide input into something more formal and systematic. Also, more generally, a few respondents suggested broadening engagement of stakeholders.

Survey respondents were invited to identify improvements which could be made to CPACC's engagement of the cancer control community. Several respondents noted that CPACC has done well in their engagement efforts in the time they have been in existence. In fact, some did not suggest any need for improvement, while others noted that ongoing improvements are evident. Suggestions provided by a few respondents can be summarized as follows:

➤ Clear focus: Several respondents suggested that it is important that CPACC maintain a clear vision and focus, and/or limit their focus to initiatives where national leadership can bring the greatest benefit. A priority setting exercise was suggested by some.

- **Stakeholder engagement:** Several respondents suggested a need to increasingly engage stakeholders so as to instill confidence that CPACC does represent all key stakeholder groups. Some suggested engaging stakeholders in the process of priority setting, while others suggested increasingly engaging stakeholders in projects or initiatives that touch their jurisdiction.
- Communications and awareness: Several pointed to a need for increasing exchange and dialogue amongst stakeholder groups engaged or represented by CPACC. As well, increasing awareness of CPACC outside the cancer community is suggested as a potential improvement.
- ➤ Increase transparency: A need for increased transparency, particularly in resource allocation, was also identified by some respondents.

The evidence is mixed with respect to stakeholders feeling they are being given sufficient opportunity to provide input into CPACC's decision-making. This reflects the breadth of stakeholders and diversity of expectations in the cancer control community. However, there is also evidence to suggest that CPACC is continuing to work on striking a balance between on-going stakeholder input into decision-making and being able to move ahead with current initiatives.

5.3 PROGRESS MONITORING AND REFINEMENTS

CPACC has implemented a number of processes to monitor progress on projects. As previously described, the quarterly status reports include risk and forecast summaries that are intended to provide senior management and the Board with key risk information on work and spending variances for each strategic initiative and action group as well as central projects and activities. As noted in the most recent report reviewed for the evaluation (Q2 2009-2010), budgets and forecasts had been provided on the financial plan, while forecast data was being collected for the development of project plan deliverables and milestones.

Annual Funding Requests include a Business Plan Deliverables report, which provides an overview of the status of all current and planned activities based on the enterprise performance scorecard. This deliverables report provides a description of the planned deliverable, the performance objective, the performance scorecard reference, annual or current fiscal year deliverables and the performance status of each activity.

At the level of each project, CPACC has implemented a quarterly project status review process. Before the quarter ends, directors and project managers complete Project Management Office (PMO)-generated status reports identifying current status on objectives, milestones and budget. Work and spending risk indicators (low, medium and high) are automatically generated based on entries. Based on the status reports and reviews, Finance and the PMO compile summary reports that are ultimately provided to the Board.

The small group of interviewees, namely CPACC staff, who were asked about the extent to which provisions for monitoring progress and changes in the cancer control environment have been implemented, responded positively. Among the provisions identified were the Enterprise Risk Management Program and the System Performance project. Relevance mapping and environmental scanning appears to be ongoing. A few respondents also said that provisions will increase over time.

As for whether these monitoring activities have led to any refinements to strategic priorities, organizational structure or activities, the respondents generally agree that they did. An example cited was the decision to become involved in the Joint Oncology Drug Review. Another was the decision to modify the Standards Action Group into a Quality and Performance Measurement Working Group. A few respondents also noted that these activities contribute to a larger picture than CPACC alone; that they are relevant to the cancer community as a whole.

Although CPACC has made some early progress on performance measurement through its work on targets and relevance mapping, no clear mechanisms for collecting performance measures related to the expected outcomes for CPACC were identified. The relevance mapping and targets work will provide a good basis for the development of a performance measurement plan. It must be noted that the collection of outcome data for CPACC will require the engagement of jurisdictions to collect and share the necessary data. As described in Chapter 4, CPACC has engaged jurisdictions in the identification and collection of data for a key set of indicators. This will provide some data to measure progress towards outcomes, however a clearly articulated performance measurement plan focused on outcomes has not yet been developed.

The evidence suggests that CPACC has put in place some processes for monitoring progress on specific projects. However, a performance measurement plan with measureable results has not yet been fully developed. Monitoring activities developed to date largely focus on project management and deliverables rather than the measurement of CPACC's progress towards the outcomes identified in the Funding Agreement with Health Canada. However, CPACC has implemented a number of initiatives such as relevance mapping and targets that are likely to contribute to quantifiable data on outcomes.

5.4 SELECTION OF PROJECTS AND ALLOCATION OF FUNDS

Based on established priorities and Board approved Strategic Initiatives, CPACC goes through three different stages of funding decisions for projects:

➤ Preliminary allocation: To bring the other partners to the table, CPACC must indicate its willingness to bear the costs of part of the Initiative. Based on a highly preliminary understanding of requirements and time path of spending, multi-year allocations are set aside to be made available to the projects involved (project conception phase);

- Firm commitment: As sponsors are identified, plans are worked through and detailed agreements are entered into for an overall multi-year funding commitment that specifies conditions to be met for each tranche of funds to be flowed (approval of project charters and plans). At that time, based on the expected flow for phases, determined by milestones and deliverables, the annual funding profile is re-estimated;
- **Payment for execution:** As the initiative proceeds, the funding flows are advanced for phases based on the progress achieved towards milestones and deliverables. 43

The process for approval of funding to specific projects has likewise been established by CPACC. CPACC's project approval process includes a two-step process. In the first step, projects are submitted for approval in principle. The VP's review and decision is required for projects under \$250,000; senior management review and decision is required for projects under \$1 million, and Board review and decision is required for project over \$1 million. In the second step once a project is approved in principle, Directors complete and submit detailed project plans and budgets for review and Project Management Office (PMO)/Finance/ VPs jointly review the submitted project plans. For projects valued under \$250,000 only VPs review and decision is required, for projects valued under \$1 million senior management review and decision is required, and for projects valued at over \$1 million Board review and decision on project plans is required. On an annual basis the Corporate Plan is updated to incorporate all projects and approved by the Board for submission to Health Canada.

Similarly CPACC has developed and implemented a process for approving changes to existing projects. When a change is known, the Director identifies changes in objectives, milestones, budget or project state and then consults with PMO and Finance to assess implications of proposed changes. If changes are required to the plan, the Director discusses implications of the change with the VP. Significant changes (greater than \$50,000) are presented to senior management for review and approval.⁴⁵

As of September 2009, CPACC had implemented a total of 15 active Strategic Initiatives with a total annual budget of \$35M. The seven Advisory Groups operating budget and the twelve small projects within had an annual budget of \$6.4 million. In addition, there were four central projects or core framework activities identified with an annual budget of \$4.9M. Central activities for the year were budgeted at \$13.7 for a total annual budget of \$60.7M.

Opinions of interviewees appear to be quite mixed on whether funding processes and criteria used to select projects are clear and transparent. Some interviewees believe that it is, due at least in part to the great deal of process associated with a large organization – RFPs and so on. On the other hand, a minority of stakeholders raised concerns including a lack of a clear decision-making body or vetting process, a sense that perhaps some funding had been predetermined, and comments/feedback indicating that CPACC had not truly read or understood the proposal put forward by the stakeholder. Nevertheless, still other respondents saw this process as another

⁴³ Canadian Partnership Against Cancer. Briefing Note for Health Canada on the Funding Agreement, November 2008.

⁴⁴ Canadian Partnership Against Cancer. Project Approval Process,– presentation slide.

⁴⁵ Canadian Partnership Against Cancer. Change Approval Process– presentation slide.

"work in progress", and anticipate improvements in the future. The mixed results indicate confusion among stakeholders as to CPACC's role with some stakeholders perceiving CPACC as a granting agency. There is also a tendency for those who do not have their funding proposal accepted to have a more negative view of the funding process overall; some of these negative feelings could be tempered by providing unsuccessful applicants with the opportunity to receive a debrief on their proposal from CPACC.

The evidence indicates that CPACC has put in place processes for the selection and funding of projects. However, there is evidence of a lack of understanding on the part of stakeholders of criteria for selecting projects once the proposals have been received. At present, CPACC does not yet have its First Nations, Inuit and Métis Action Plan in place and so no specific funding criteria for First Nations, Inuit and Métis projects are in place.

5.5 Knowledge and Information Dissemination

The cancer control landscape consists of a wide array of stakeholders from governments, cancer agencies and programs, patient advocacy groups and national health organizations. Each serves a wide constituency in terms of communication and dissemination of knowledge. Cancer stories receive widespread media coverage nationally, regionally and locally. CPACC's approach to the dissemination and communication of information and knowledge has been through identification of target audiences that recognizes the partners involved in the implementation of the strategy. The advisory mechanisms involved in the strategy represent most stakeholder groups across Canada and information is also made publicly available through a variety of vehicles; online through the CPACC website and Cancer View portal; through newsletters and electronic updates and through publications and reports. Media outreach has been proactive around strategic initiatives where there is significant public interest, such as the Canadian Partnership for Tomorrow Project, CLASP funded projects and colorectal screening and awareness.

Knowledge management is a core function of CPACC that supports progress toward all outcomes. CPACC aims to maximize the value of cancer control information that is constantly evolving, through the establishment of networks of collaboration, with the ultimate goal of using these resources to solve common challenges in cancer control. CPACC's communication goal is to provide their stakeholders, partners and interested members of the public with information about the implementation of the CSCC while engaging them in the Partnership's efforts. CPACC seeks to proactively communicate with its key audiences to: inform them of progress and outcomes of the strategy for cancer control; align with organizational priorities such as the portal, screening and prevention initiatives; encourage dissemination of efforts; support transparency; support knowledge transfer; and manage issues and mitigate risks.

To reach target audiences, CPACC has developed and employed a number of communications' vehicles: online presence (corporate website and portal); newsletters, monthly e-bulletins; media outreach; annual and progress reports. Key communications results achieved as of November 2009:

- Media impressions ⁴⁶: outreach has generated more than 50 million media impressions resulting from announcements, letters to the editors and expert commentary;
- Online traffic: since the launch of CPACC's online presence, monthly traffic has steadily grown to an average of 4,000 unique visitors per month in November 2009, up from 255 per month in June 2007;
- Newsletters: CPACC launched a monthly bilingual e-bulletin in December 2009 newsletter is issued twice a year to more than 1,400 people per month;
- RSS feed⁴⁷: the CPACC corporate website has an RSS feed which people can subscribe to providing updated stories in real time. In January 2010, this feed was viewed over 1,000 times.⁴⁸
- Corporate reports: the annual report and the winter 2009 progress report have, in total, reached 6,000 people, including MPs, provincial/territorial ministers of health and deputy ministers by mail and electronically, as well as approximately 2,000 downloads per document; and
- Other: on average 5 to 10 news features are added to the Partnership's website monthly and reports developed by the Partnership are posted online as they become available.

In addition, targeted knowledge dissemination mechanisms have also been used by the Partnership to support priority initiatives. For example, the anticipatory science panel weighed the state of current evidence in preparation for new research studies on the appropriateness of PSA testing. This review was distributed to key informants in the medical community across the country to assist them in responding to media inquiries regarding the newly published results. All of CPACC's tools, resources, publications and reports are housed on CPACC's website or portal and are publicly available.

Technology plays a crucial role in this work to foster the creation, exchange and application of accurate, timely information. The primary basis for this work is Cancer View Canada, a portal to comprehensive cancer control resources, launched in the summer of 2009. CPACC's portal, **cancerview.ca**, is an online community that offers the best available cancer knowledge. It is an initiative between CPACC and a network of regional and national partners.⁴⁹

The number of people who may have seen an article, heard something on the radio or in a podcast, watched something on television, or read something on a web page or blog. (January 2010: http://www.marketing-metrics-made-simple.com/media-impressions.html)

⁴⁷ An RSS feed is a type of web feed format used to publish frequently updated works on-line.

Email correspondence from CPACC management, February 2010.

⁴⁹ January 2010: http://ww.partnershipagainstcancer.ca/cancerview

The Cancer View Canada site was officially launched in July 2009, six months prior to the initiation of this evaluation, via a national press release and media outreach. The media response to date has been positive with 83 known media stories. This is helping to increase awareness of the portal across the country. The portal was honoured with a bronze award at the Public Sector Leadership Awards ceremony in Toronto on November 5, 2009. The awards recognize "organizations that have demonstrated outstanding leadership by taking bold steps to improve Canada, through advancements in public policy and management."

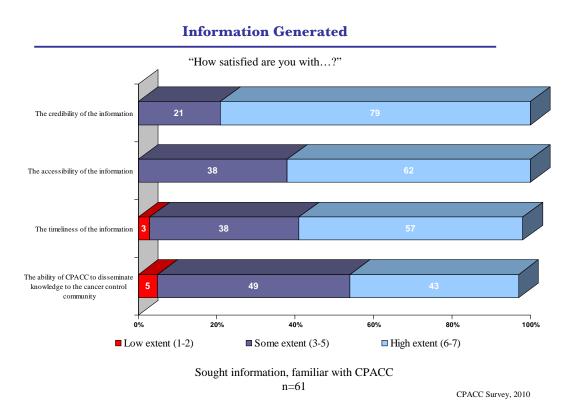
The overall mixed-to-positive opinions of interviewees on the extent to which CPACC is considered a key depository of credible, timely and relevant cancer related information, create a picture of an organization that has made some strides and is on the right path, but has a ways to go. On the positive side, a large minority praised CPACC for initiatives such as the portal and Cancer Control PLANET, and acknowledged that they have seen significant progress. On the other hand, though, there was a sense from a few interviewees that how CPACC is perceived in this context is largely dependent on who is doing the perceiving; that is to say, its visibility is better with people who have been directly involved with it, or in areas where the most work has been achieved. Not surprisingly, then, many of the criticisms levelled at CPACC in this respect pertain to obtaining and disseminating *more* information on a greater diversity of issues, and better publicizing the fact that it is there. There is an acknowledgement on the part of a few respondents that this may come in time.

Most interviewees feel that there is considerable room for improvement when it comes to the mechanisms for acquiring and disseminating information and knowledge with stakeholders, government partners and the Canadian public. A small minority of respondents in particular identified communications to the general public as an issue; although a few respondents considered the possibility that this is due, at least in part, to factors that they cannot yet control; for example, perhaps the nature of their available information makes it less interesting to the general public, and also Canadians may not want more information in general. A few other respondents suggested that there needs to be more focus on less direct stakeholders such as the Canadian public.

Survey respondents that have sought information on cancer control from CPACC have looked for cancer screening information, CPACC initiatives and clinical trial information. Information sought regarding cancer screening includes: tools and strategies for cancer control and screening, information related to screening and best practices in colorectal screening and synoptic reporting. Respondents have also sought information in a wide range of areas related to CPACC initiatives. Respondents have also sought information regarding clinical trials such as the Canadian clinical trial information, and availability of clinical trials across the country.

Engaged stakeholders (those who are very familiar with the organization and who have sought information from CPACC) were asked to rate their level of satisfaction with the credibility, accessibility and timeliness of the information they received from CPACC; and to rate CPACC on its ability to disseminate knowledge to the cancer control community.

Satisfaction runs highest in the area of credibility, where 79 per cent are highly satisfied and no one is dissatisfied. Majorities of stakeholders are also highly satisfied with the accessibility and timeliness of information (62 and 57 per cent indicating high levels of satisfaction). Satisfaction is marginally lower with CPACC's ability to disseminate knowledge, although 43 per cent still point to a strong level of satisfaction. In all cases, virtually no one is dissatisfied; also there is a strong indication of positive results with regard to information dissemination.



The sources of dissatisfaction with information identified by those who are not entirely satisfied with CPACC information relate to timeliness of access to information, the relevancy or credibility of the information, and poor reporting of CPACC's activities. Information that respondents have obtained is described by a few as not relevant or inaccurate. In addition to these factors, CPACC's reporting of their activities is perceived to be poor.

The evidence collected indicates that CPACC has been successful at disseminating information and knowledge to many, but not all stakeholders. Not surprisingly, those most involved with CPACC believe the information and knowledge have been well conveyed by CPACC. It should be acknowledged that Cancerview.ca which is a key vehicle for information dissemination was only six months old at the time of the evaluation.

6. Relevance

This chapter addresses the relevance of the Canadian Partnership Against Cancer Corporation. Questions related to the extent to which CPACC serves the public interest and the federal government's role in funding a national NGO for cancer control are addressed in this chapter.

6.1 EXTENT TO WHICH CPACC SERVES THE PUBLIC'S INTEREST

According to the most recent data available, cancer continues to be an important public health issue. Based on Statistics Canada data, cancer was the leading cause of death for Canadians aged 35 to 64 in 2007 with cancer accounting for more deaths in this age group (43 per cent) than heart disease (17 per cent), injury (six per cent), suicide (five per cent), stroke (three per cent) or infection (two per cent) combined. According to the Canadian Cancer Society, an estimated 171,000 new cases of cancer (excluding about 75,100 non-melanoma skin cancers) and 75,300 deaths were expected to occur in Canada in 2009. On average, 3,300 Canadians were expected to be diagnosed with cancer every week in 2009. On average, 1,450 Canadians will die of cancer ever week. Based on current incidence rates, 40 per cent of all Canadians and 45 per cent of men will develop cancer in their lifetimes. An estimated one out of four Canadians is expected to die from cancer.

Canadian average incidence and mortality rates for lung, prostate, breast and colorectal cancers (the most common cancers), per 100,000 population, is summarized in the table below.

Canadian average cancer rates	Incidence Rates		Mortality Rates	
(per 100,000 population)	2000	2004	2000	2004
Lung cancer (males & females)	59.1	57.6	47.1	46.6
Prostate cancer (males)	125.3	122.7	26.7	23.4
Breast cancer (females)	101.9	97.2	25.0	23.1
Colorectal cancer (males & females)	52.7	50.8	19.0	18.7

Source: Healthy Canadians: A Federal Report on Comparable Health Indicators 2008, Health Canada. 2008

The key purpose behind the implementation of CPACC was to provide the Canadian cancer control community with an organization to coordinate knowledge and activities related to cancer control. CPACC is intended to respond to a need for a national body to coordinate the many facets of cancer control knowledge. This need was articulated in the 2006 CSCC *Cancer Plan for Canada*. There was seen to be a clear need for a mechanism for coordinating activities, sharing learning and distributing best practices to policy-makers, health professionals, patients and Canadians in general. This view was reinforced by the experience of other countries such as Australia, New Zealand, Ireland, France, and the United Kingdom, all of which had put in place national cancer control programs that were seen as successful.⁵⁰

⁵⁰ The Canadian Strategy for Cancer Control: A Cancer Plan for Canada, Discussion Paper, July 2006.

Stakeholders surveyed as part of this evaluation almost universally support the view that there is a need for a national body that can act as a catalyst for a coordinated approach to cancer control with nine in ten survey respondents indicating that the need for such an organization is "high". In elaborating on their response, over half of survey respondents focused on the importance of coordination of knowledge-related activities as the main reason why such an organization was needed. These respondents noted that coordination provides the opportunity to share information, best practices, play a catalyst role in developing standards and creating a unified approach to cancer control. They also noted that a more coordinated approach will reduce duplication across Canada.

There is similarly evidence of a need for a national organization to facilitate the sharing of knowledge and information on cancer. Prior to the implementation of CPACC there was a sense that cancer control knowledge and expertise were dispersed throughout Canada's healthcare system and that sharing of information and knowledge was not sufficient. Stakeholders responding to the survey undertaken for the evaluation of CPACC indicated a very high level of support for the view that there is a need for an organization to ensure readily accessible and available knowledge on cancer control.

Overall the evidence supports the need for an organization such as CPACC to coordinate knowledge and information on cancer control, cultivate relationships and generally act as a catalyst for cancer control in Canada. There is strong evidence that cancer is, and will continue to be, a public health issue over the coming years.

6.2 NEED FOR FEDERAL INVOLVEMENT IN CANCER CONTROL

a) Alignment with Federal Government Priorities

The Government of Canada administers the *Canada Health Act (CHA)*. The *Act* articulates the main objective of Canadian health care policy, which is "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers." It specifies the criteria and conditions provinces and territories must adhere to – universality, accessibility, portability, comprehensiveness and public administration – in order to receive their full share of the federal cash contribution under the *Canada Health Transfer (CHT)*. The Government of Canada funds independent, third-party organizations that support the development and transfer of knowledge related to health care issues including CPACC.⁵¹

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Health Canada. Healthy Canadians: A Federal Report on Comparable Health Indicators 2008.

Health Canada is the federal department responsible for helping Canadians maintain and improve their health. One of the five key roles and responsibilities of Health Canada in fulfilling its mandate is as an information provider through the generation and sharing of knowledge and information on which decision making, regulations and standards and innovation in health rely. One of Health Canada's four Strategic Priorities is, "Contribute to the improvement of the health of Canadians." CPACC fits within these Health Canada Strategic Priorities though its eight Strategic Priorities and two supporting activities that are focused on the development and transfer of knowledge related to cancer control. Supporting CPACC is consistent with one of Health Canada's core roles, which is to provide funds via grants and contributions to various organizations that reinforce the Department's health objectives. 53

In the 2006 Budget, the federal government identified cancer as a major health issue for Canadians and announced the funding of the CSCC to help improve screening, prevention and research activities, and enhance coordination of knowledge-related activities among the federal government, cancer advocacy groups, and the provinces and territories. Although the federal government is the sole funder of CPACC, the federal government has been careful to note that the delivery of healthcare falls within provincial/territorial jurisdiction; this was explicitly noted by the Prime Minister at the 2006 launch of CPACC.⁵⁴ The funding allocation provided to CPACC for coordinating a pan-Canadian effort is about one per cent of the total estimated expenditure on cancer programs made by all stakeholders, including federal government programs, provinces, territories and other cancer organizations, etc. ⁵⁵

Overall, there is support for federal involvement in a cancer control NGO such as CPACC on the part of stakeholders interviewed for this evaluation (including provincial and territorial representatives, federal representatives, CPACC Board and Advisory Group members and NGOs), with most indicating that the funding of a national catalyst or NGO for the coordination of knowledge-related activities in cancer control is an appropriate role for the federal government. A key rationale provided for federal involvement was the need to ensure that knowledge was consistently available in all jurisdictions across Canada. The NGO structure is seen by stakeholders as providing a neutral (non-government) body for key players in cancer control to come together.

Some of the concerns about federal involvement in funding a cancer control NGO such as CPACC pertained to whether a holistic, less disease-specific approach was more appropriate, and that perhaps the provinces and territories could ultimately take on the responsibility for funding CPACC depending on what CPACC delivers at the end of its first five year mandate.

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⁵² Health Canada, 2008-2009 Report on Plans and Priorities.

http://www.hc-sc.gc.ca/ahc-asc/activit/about-apropos/index-eng.php

News release – Prime Minister Harper launches Canadian Partnership Against Cancer, November 24, 2006.

Breakaway: The global burden of cancer – challenges and opportunities, Economist Intelligence Unit, The Economist

As the key funding source for CPACC, there is a need for the mandate of CPACC to align with the strategic policy and priorities of Health Canada. Although cancer control is not explicitly stated as an objective of the Federal Government, as evidenced in Health Canada priorities, the evidence collected suggests a good alignment between CPACC and those of the federal government. In general stakeholders in the cancer control area interviewed for this evaluation are supportive of federal funding of cancer control and CPACC.

b) Capacity of Stakeholders to Fund Cancer Control

When presented with the possibility of sharing the funding of an arms'-length NGO for cancer control among key stakeholders, stakeholders interviewed for this evaluation did not unanimously dismiss the idea; in fact a few support it. A few asserted that a truly national strategy needs to be funded by various players at the national level, including the provinces and territories since all are benefiting from the work of the organization. Of those who felt that sharing the funding was not a realistic option, the majority noted the difficulty in getting provinces and territories to provide money, and difficulty coordinating efforts across the provinces/territories and other key players in cancer control.

Stakeholders interviewed were generally not in favour of transferring the cancer control agency role to the private or voluntary sector. A small minority of those interviewed expressed concern that voluntary and private organizations are already stretched too thin in terms of human and financial resources; additionally it was suggested by a similar proportion of interviewees that such organizations would raise questions about the agenda and objectivity of a cancer care organization operated by the private or voluntary sectors.

Overall, findings from interviews with CPACC stakeholders indicate there is little capacity or interest in sharing the funding for an NGO such as CPACC focused on cancer control at this time. Beyond the question of funding and capacity, there are also concerns over objectivity and the perceived neutrality of organization that is funded by CPACC stakeholders (including provinces and territories and NGOs). However, despite the overall rejection of shared funding of a cancer control NGO, there was recognition of the merits of shared funding for the organization as a measure of such an organization's value to its stakeholders.

7. Cost-Effectiveness/Alternatives

This chapter addresses evaluation issues related to the cost effectiveness and alternatives to CPACC.

7.1 Cost-Effectiveness

Respondents from federal, CPACC, and provincial/territorial groups were asked to comment on whether they viewed CPACC as the most cost-effective mechanism through which to support the CSCC. Opinions overall were positive, but with some qualification. For example, importance was placed on the buy-in of provinces and territories and stakeholders such that CPACC can leverage a lot of work from others. However, another concern raised is that CPACC may have initially taken on too many projects.

a) Synergies and efficiencies

The review of documentation uncovered a wide range of synergies and time and/or money efficiencies directly resulting from CPACC. The examples presented below contribute to synergies and efficiencies by way of helping to reduce duplication, enhance collaboration, and accelerate action on cancer control:

- Public Health Agency of Canada and the provincial and territorial cancer registries to support and co-ordinate provincial/territorial implementation of stage data collection.
- The Colorectal Screening Initiative, led by the colorectal cancer screening network, is developing a shared approach to colorectal cancer screening quality determinants and surveillance across the country.
- The Partnership united over 100 experts in epidemiology, gynaecology, infectious disease surveillance, oncology and public health with other cancer control experts, in an effort to coordinate the improvement of cervical cancer control.
- ➤ CAREX Canada, based at the University of British Columbia, aims to identify and map the presence and prevalence of workplace and environmental carcinogens across the country. A Canadian workplace database is being developed that will contain data on exposure to these carcinogens in the workplace. Similarly, a population-based database will develop estimates on our exposure to carcinogens through the environment, food, beverages and consumer products.
- The Canadian Platform to Increase Usage of Real-World Evidence (CAPTURE) project involves integrating science with practice and establishing a platform for developing common indicators and tools for the evaluation of prevention programs.

- ➤ The CAN-ADAPTE project will help reduce duplication of guideline development efforts by better coordination across the country.
- Approximately 1,000 cancer control guidelines are being compiled and reviewed for inclusion in an online searchable repository publicly available through the Partnership portal. A component of the review uses the AGREE tool to assess and score the quality of the guideline.
- > Synoptic reporting (surgery) this project focuses on improving the collection and use of information on surgery details through standardized electronic operative reports for cancer surgeries.
- Palliative and end of life care is an important part of the cancer journey for many patients and a working group of experts in this field is exploring the potential of investment through the completion with Health Canada to ensure alignment of program priorities and avoid duplication of resources.
- The partnership portal is a web-based tool that provides a focused view into the cancer control system for people working in the system or providing support to someone experiencing cancer, and those experiencing the system as a patient or family member.
- The cancer workforce scoping study undertaken in 2007-08 indicated that new models of service delivery were emerging within the system driven both by evolving practice with new drugs and technologies, as well as by necessity to retain professionals and address HR gaps.
- Provincial/territorial and national members of the cancer surveillance community (such as PHAC, Statistics Canada, and CIHI) are working together to ensure the quality of reported data.
- Cancer control knowledge and expertise are dispersed throughout Canada's health care system. To make this information and expertise readily accessible to all stakeholders, in 2006, the CSCC Council established pan-Canadian, collaborative networks of experts in priority areas.

Interviewees, when asked if they were aware of any synergies or efficiencies that have resulted from CPACC activities, cited a few key examples, with only two respondents saying that they could not think of any synergies or efficiencies at all. Firstly, the initiatives that were introduced by one province or territory and then picked up on by others were seen as a great example of synergy and efficiency because they eliminated the need for every province/territory to do all the work themselves. Some specific examples of this are the colorectal screening initiative, the virtual hospice, and synoptic reporting. Some of the research that has just begun was seen as having the potential to create great synergy in the future, such as CLASP and CAPTURE. Another specific example brought up by an interviewee is the use of webinars and other electronic meetings in order to save travel costs for stakeholders.

b) Barriers to cost-effectiveness

Interviewees were not able to think of much in terms of barriers that are negatively influencing CPACC's cost-effectiveness. A key issue raised by a few interviewees concerns again the five-year mandate. This is best illustrated in the following quote: "the thought that pops into my mind is 'Canada is a nation of pilot projects'. We have a terrible experience with starting things and not finishing them. We don't learn anything. CPACC is working well enough that it shouldn't die after five years...The biggest threat to its cost-effectiveness would be to let it die."

The evaluation evidence indicates that CPACC has directly resulted in improved synergies and cost savings within the Canadian healthcare system. However, this result is strictly qualitative in nature – no measures of the value of these costs savings are available.

7.2 ALTERNATIVES

During the entry phases of developing CPACC, consideration was given to several alternatives; the federally-funded NGO model was considered to be most appropriate.

a) Satisfaction with NGO Model

All interviewees, including representatives of cancer organizations in other jurisdictions, were asked whether they believe CPACC to be the best or most appropriate model for supporting a comprehensive cancer control program for Canada. The response was mostly positive; more than half of the interviewees answered in the affirmative.

A few interviewees asserted that the current approach is what is 'realistic' under the circumstances of the Canadian healthcare system. A few interviewees also praised the creation of an organization outside of government, saying that there is more perceived neutrality because CPACC is not embedded within a federal department. Others said that this makes CPACC more nimble and able to act across jurisdictions. It was suggested by yet another few respondents that while this might not be the least expensive approach, it is more effective in the long run.

Concerns raised by interviewees about the CPACC approach pertained to a handful of issues. One point raised by a few respondents relates to how cancer, as well as other chronic diseases for which there have been federal strategies such as heart disease and diabetes, are all very much influenced by healthy living and therefore perhaps it would make more sense to focus less on individual diseases and more on a broader healthy lifestyle strategy. A few other respondents feel that there should have been more provincial and territorial collaboration in establishing CPACC.

Interviewees were asked whether they considered there to be any alternative approaches to CPACC for supporting a national framework on cancer control. On this issue, opinions were somewhat mixed. While a minority feel that there are no viable alternatives, or that there may be alternatives, but they are not sure how well they would work, a small minority of interviewees did have some thoughts on other directions the federal government could have taken, as described below:

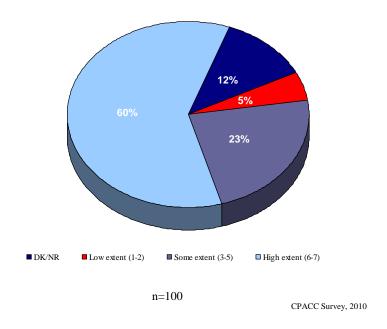
- In the US, there are comprehensive cancer control frameworks at the State level; there is no template for them and each State creates their own individual model. State programs are then complemented by the National Cancer Institute that coordinates best practices, along with independent Centres of Excellence.
- If the provincial/territorial governments could have set it up on their own (as is the case for Canadian Blood Services, for example), it would be much more dynamic.
- Mixed model GOC and provincial/territorial funding with increased accountability of CPACC to provinces and territories; CPACC could increase its impact if it reported directly to provinces and territories.

Interviewees from jurisdictions outside Canada were asked about alternative approaches to CPACC for supporting a national framework on cancer control. A few of these interviewees compared CPACC with their experiences in a multijurisdictional context. For example, they noted that some form of coordinating role is almost essential, or that existing provincial/territorial structures would be a challenge. Still another interviewee pointed out that while it is important to make decisions at the local level, without a national view many people could potentially fall through holes in the system. In order to engage so many NGOs, and consumers whose needs might otherwise be lost at the local level such as those with rare cancers, minorities and Aboriginal groups, CPACC "needs to look very close to the way it does."

Stakeholders responding to the survey were asked to comment on whether the current structure of CPACC (i.e. a not-for-profit corporation) is the best way to achieve the goals set out for the Strategy. Overall, nearly two thirds (60 per cent) of respondents provided a rating of 6-7 (high).

Conducive Structure

"Given the overall objectives and mandate, to what extent do you feel the current structure of CPACC – a not-for-profit corporation - is the best way to achieve these goals?"



In terms of reasons for the support of the current structure by survey respondents, the independence of CPACC topped the list. This was seen as critical because it enables CPACC to engage governments directly, while also addressing the needs, gaps and opportunities of the cancer control community directly. The NGO structure allows CPACC to act quickly in a way that is very responsible and proactive to the cancer control community. CPACC's structure makes it a more nimble and action-oriented organization than it would otherwise have been if it were a government agency. A small minority also pointed out that they see it as a neutral body that has no competing mandate or conflicts of interest. This makes it more credible (i.e., the honest knowledge broker) when coordinating cancer control activities.

A few stakeholders responding to the survey pointed to the short-term funding, suggesting that a permanent mandate and funding is required to remove barriers to progress that CPACC can make.

Evaluation findings indicate a high level of satisfaction with the organizational structure (i.e. NGO) of CPACC. As an NGO, CPACC is seen as effective in engaging with various levels of government and stakeholders. The NGO structure is also seen as allowing CPACC to be more nimble and neutral than would be possible for a government agency. Although alternatives to the NGO model exist, stakeholders and external experts generally believe that the CPACC model is sound and should be maintained.

7.3 OTHER NATIONAL AND/OR INTERNATIONAL MODELS

A number of other nations have implemented national cancer control strategies. The literature review focused on cancer control strategies taking place in the following nations:

- > The United Kingdom;
- > France:
- New Zealand; and
- Australia.

Brief descriptions of these countries' cancer control strategies follow. While reviewing approaches taken by other countries, it is important to bear in mind some key points of comparison between these countries' strategies and CPACC:

- Like CPACC, all of these strategies were developed in response to national cancer plan documents.
- While the UK does place considerable focus on networking in order to improve cancer control and better share knowledge regarding cancer control, it is worth mentioning that the UK's cancer control activities are more immediately connected with service delivery. This may be due in part to a lack of provincial/territorial jurisdictional issues. Furthermore, the UK relies on networks connecting various stakeholders, including providers, rather than a central body.
- France's approach shares many commonalities with CPAAC, even though it also does not have to contend with jurisdictional concerns. Like CPACC, it is research-focused, putting much of its energies into connecting those involved with cancer research and cancer care, in order to improve the broader cancer experience. It also has a strong focus on prevention and screening, and, like CPACC, is a central national organization.
- New Zealand's cancer control mechanism has a broad scope like that of CPACC. However, it is not a central agency but rather a larger plan, and furthermore it deals more directly with service delivery, identifying priorities such as a workforce plan and capital expenditure on equipment, drugs and new initiatives.
- Australia is the only other nation included in this literature review that has to navigate jurisdictional divides in a manner similar to Canada. Like CPACC, Cancer Australia is an agency separate from government, with an area of focus similar to that of CPACC. Rather than being involved with ground-level service delivery, Cancer Australia takes on more of a knowledge broker role, advising and providing information and training.

a) United Kingdom

Cancer Networks are key to implementing cancer care in the UK. Cancer Networks are the organisational model for cancer services to implement the Cancer Plan with responsibility to develop an annual Strategic Service Delivery Plan, which is underpinned by workforce, education & training and facilities strategies. Networks base much of their work around the patient pathway, which is the route patients take through the healthcare system from first contact with the National Health Service through referral, diagnoses and completion of their treatment⁵⁶. There are more than 30 cancer networks across England.

2007 saw the development of the Cancer Reform Strategy, designed to set a clear direction for cancer services until 2012. It sets out a program of action across ten areas, six of which focus on improving cancer outcomes and four of which aim to ensure service delivery.⁵⁷

b) France

The French National Cancer Institute is a health and science agency dedicated to cancerology. It operates on an interdisciplinary basis, with the aim of federating, uniting and mobilizing players and resources around joint projects. It provides relevant information to the population, patients and healthcare professionals, and ensures that there is a continuum between care and research.

To meet those objectives, the National Cancer Institute produces expert reports at the request of its supervisory authorities. It foresees issues, related for instance to new screening or treatment techniques. It disseminates recommendations on best practices, in particular by drawing up guidelines for medicines. It tracks and assesses the initiatives funded. The Institute takes action through the stakeholders involved in care and research. It launches calls for projects to support structures and fund innovative initiatives in the fields of research, care, prevention, screening and patient support. It supports, for instance, multidisciplinary research programmes around a cancerous pathology, such as the integrated colorectal cancer programme launched in 2007. It develops partnerships with other institutions to bring together skills (methodology and expertise) around shared projects, such as the publication of guides for primary physicians and patients, or support for technological and organisational progress intended to improve the quality of care and information. The National Cancer Institute is involved in all aspects of the fight against cancer in France. It coordinates and instigates progress in cancerology.

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North West London Cancer Network. (2009). What We Do. Online: http://www.nwlcn.nhs.uk/what-we-do.htm

National Health Service (2007). *Cancer Reform Strategy*. Online: http://www.cancer.nhs.uk/documents/cancer_reform_strategy/cancer_reform_strategy.pdf

c) New Zealand

The New Zealand Cancer Control Strategy Action Plan was launched in 2005, and covers a five-year time period. The Plan identified actions which extend across the cancer control continuum, which includes primary prevention, screening, early detection, diagnosis and treatment, rehabilitation and support, and palliative care. They also include workforce development, research, data collection and analysis. The Action Plan incorporates and builds upon existing activities that contribute to cancer control.

d) Australia

Cancer Australia, a statutory agency responsible to the Minister for Health and Aging, was established by the Australian government in 2006. It advises the Australian Government on all cancers and all aspects of cancer control, including research, prevention, early detection, diagnosis, treatment, supportive care, rehabilitation, assistance in living with cancer, and palliative care. Cancer Australia's work is divided into four areas of focus: research and clinical trials; the National Centre for Gynaecological Cancers; education and service development, which includes improving cancer services, improving cancer data and supporting and improving professional development resources for cancer professionals; and consumer support, information and participation⁵⁸.

Much like CPACC, approaches in other jurisdictions are based in federal government frameworks and plans, with some having roots in recommendations made in the 1990s. Nevertheless, efforts have been made to make sure these strategies remain current.

7.4 BEST PRACTICES FROM OTHER JURISDICTIONS

While best practices were not explicitly identified in the literature on specific nations' cancer control strategies, the broader literature provides some direction. The World Health Organization (WHO) identifies four key components of cancer control: prevention, early detection, treatment and palliative care. It also outlines several basic principles of cancer control:

- ➤ **Leadership** to create clarity and unity of purpose, and to encourage team building, broad participation, ownership of the process, continuous learning and mutual recognition of efforts made.
- Involvement of stakeholders of all related sectors, and at all levels of the decision-making process, to enable active participation and commitment of key players for the benefit of the program.

Cancer Australia (2007). Roles and Functions. Online: http://www.canceraustralia.gov.au/about-us/roles-and-functions.aspx

- ➤ Creation of partnerships to enhance effectiveness through mutually beneficial relationships, and build upon trust and complementary capacities of partners from different disciplines and sectors.
- Responding to the needs of people at risk of developing cancer or already presenting with the disease, in order to meet their physical, psychosocial and spiritual needs across the full continuum of care.
- **Decision-making** based on evidence, social values and efficient and cost-effective use of resources that benefit the target population in a sustainable and equitable way.
- Application of a systemic approach by implementing a comprehensive programme with interrelated components sharing the same goals and integrated with other related programmes and to the health system.
- **Seeking continuous improvement**, innovation and creativity to maximize performance and to address social and cultural diversity, as well as the needs and challenges presented by a changing environment.
- Adoption of a stepwise approach to planning and implementing interventions, based on local considerations and needs (see next page for WHO stepwise framework for chronic diseases prevention and control, as applied to cancer control)⁵⁹.

In their report entitled Breakaway: The Global Burden of Cancer — Challenges and Opportunities, the Economist articulates a number of next steps for cancer control around the world. Some highlights are:

- ➤ Effective cancer control strategies require monitoring: Epidemiologists, cancer control researchers and policymakers have made great use of the limited data in existence. The best way to plan effective cancer control strategies is to base them on accurate measures of trends and patterns, and on detailed and rigorous understandings of the determinants and consequences of different cancers. The need for greater resources for cancer surveillance is widely accepted, to increase the share of the world's population that is covered by such measures.
- Successful cancer control programs are built upon effective strategies and evidence: Integrated healthcare systems create opportunities to effectively manage and leverage scarce resources. Cancer surveillance and control has an important role to play in defining healthcare policies. There are opportunities to contain the spread of cancer and manage the disease across for regions with all levels of resource availability. Implementing effective cancer control programs is likely to pay dividends in other areas of healthcare, and may also help advance economic development.

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World Health Organization. (2008). Cancer Control: Knowledge Into Action – WHO Guide for Effective Programmes.

- Cancer is a costly disease, but effective resource allocation yields positive outcomes: Cancer surveillance and control programs should consider target outcomes and priorities according to the level of resources available. In this way, the effectiveness of programs can be improved. Not every program will yield similar outcomes wherever implemented for a variety of reasons. Proper planning and priority setting is essential.
- The developed world offers many lessons relating to the burden of cancer and cancer control strategies: Cancer prevention is an important and effective strategy for attacking the growing burden of diseases in the developing world. Programs should be implemented today to lessen the adverse impacts of cancer for generations into the future. In the developed world, effective cancer control programs have shown great success—however only after cancer incidence rates and death rates grew without being challenged for many decades. There is no reason to replicate such mistakes today ⁶⁰.

Key informants were asked whether they were aware of best practices from other jurisdictions that could improve or enhance the effectiveness of the CPACC model. Suggestions included:

- There are some models that came out of the NIH FDA model, where there is integration of consumers at different levels of the structures Lay participants, but not lay subcommittees.
- The House of Commons Committee on Health is just in the process of doing their own HHR study, and they are taking submissions and inviting witnesses. An overarching HHR observatory could help.
- Although people looked to the UK approach as a success on which to base CPACC, in the UK there is a single payer system that enables coordinated accountability.
- A key lesson from other jurisdictions is the need to focus on evidence.

Interviewees representing cancer control in other jurisdictions were also asked to provide any relevant best practices that they were aware of. The following were identified:

- The key challenge for any coordinating arrangement is identifying where they can get the most value, and when they are better off letting jurisdictions deal with it themselves. This point could be taken into consideration when CPACC is negotiating relationships with the provinces and territories.
- The key success factors are defining the areas where one can make the most difference growth in access across whole communities, screening participation, ready access to therapy when cancer is diagnosed, good follow up with survivors, and good palliation when needed. This appears to be a central tenet of CPACC as well.
- The issue of where policy advice sits is always difficult between federal government and CPACC. That tension will not go away, but the strength is where there is collaboration and multi-level contact on a daily basis. This also applies, in the Canadian context, to relations with the provinces and territories.

Economist Intelligence Unit . (2009). Breakaway: The global burden of cancer — challenges and opportunities.

- In terms of our program, the jewels in our crown are specifically around direct engagement with states and territories through contracts. To contract them to get the information and report on it has really ensured that we have formal mechanisms to engage the states and territories. CPACC appears to be headed in this direction, and this best practice underscores the importance of continuing on this path.
- ➤ Going out and getting funding partners for research and research providers through NGOs has almost doubled our research money and has been incredibly effective for engaging the sector. This approach is something CPACC may consider in the future.
- The UK has a centre for reviews and assessment of new developments, technologies and approaches, and while CPACC has that on a smaller scale, they should consider expanding it.
- It would be logical to have a national centre to produce guidelines that could be worked on at a provincial/territorial level. A more explicit connection between CPACC and the provinces and territories could be conducive to implementing such an approach.

8. Overall Conclusions and Recommendations

8.1 Conclusions

a) Design and Delivery

As an organization, CPACC is fully operational and has implemented a robust governance structure including an executive team, Board of Directors, and Advisory Groups that are consistent with an organization of this type. The organizational structure appears to strike an appropriate balance between the need for input from stakeholders and experts and the day-to-day operations of the organization focused on moving the CSCC forward.

The organizational structure of CPACC (i.e. an NGO) is arguably the most appropriate model given the structure of the healthcare system in Canada. Cancer control stakeholders interviewed and surveyed for this evaluation are almost unanimously supportive of the NGO structure because it allows CPACC to maintain an arm's length relationship with government and it allows the organization to be more nimble than would be the case if CPACC was part of a federal department.

CPACC has made progress with respect to the integration of the eight strategic priorities and two supporting activities. However, in order for the activities within each of the eight strategic priorities and two supporting activities to be integrated more fully, individuals who work in the area of cancer control will need to be brought together and actively encouraged to work together on a continual basis. This will take time, since ways of working are entrenched, however CPACC is actively working at increasing collaboration and coordination across Canada.

CPACC management have made some modifications to the design and delivery of the organization, and evidence indicates that the changes made to date have been well planned and in keeping with the mandate of CPACC and the spirit of the Strategy.

There has been recent progress with respect to addressing the needs and perspectives of First Nations, Inuit and Métis in CPACC activities. These efforts have only been recently implemented and much remains to be done before CPACC is able to meet the requirements to address First Nations, Inuit and Métis needs into its activities as required in the Health Canada funding agreement.

b) Success

Despite it being relatively early in its lifecycle, CPACC has made good progress with respect to most of its immediate outcomes. There is evidence that progress has been slower for outcomes where more active engagement or buy-in from jurisdictions is required, specifically integrated patient care and health human resources. However, CPACC has made progress in putting in place the necessary mechanisms to engage jurisdictions.

Given that progress is evident with respect to achieving immediate outcomes, evidence suggests that CPACC is making progress towards achieving its intermediate and final outcomes. However, this result should be interpreted with caution given the long-term nature of the intermediate and final outcomes and that CPACC alone cannot achieve the identified intermediate and final outcomes – participation and active engagement from all parties involved in cancer control, especially the jurisdictions, will be required. Active engagement with the jurisdictions will be required in order for CPACC to achieve its objectives. The jurisdictions are responsible for the delivery of health care to the Canadian public and so CPACC activities must reflect the needs and priorities of jurisdictions.

The evidence indicates that CPACC has successfully developed partnerships and collaborations with other stakeholders in the cancer control domain in Canada. As well, CPACC has done much to bring together stakeholders and facilitated partnerships and collaborations and coordination. Insofar as CPACC was intended to increase coordination across cancer control stakeholders, CPACC has achieved this. However, there continues to be a lack of clarity and understanding among various stakeholders of the specific roles and responsibilities in their relationship with CPACC.

CPACC has demonstrated some progress in establishing relationships with First Nations, Inuit, and Métis communities, however this has not yet translated into the implementation of a broad range of activities that reflect their needs. It has developed relationships through the caucus and the advisory committee on First Nations, Inuit and Métis cancer control. CPACC has also recently implemented a First Nations, Inuit, and Métis Portal Advisory Network.

c) Governance

Understanding of the Strategy on the part of CPACC's stakeholders is variable. Stakeholders who have the closest ties to CPACC through membership of the Board, Advisory Groups or collaborative relationships have the best understanding of the Strategy and the strategic direction of CPACC. Not surprisingly, those whose relationship with CPACC is further removed tend to be less clear in their understanding of CPACC's strategic direction. Although CPACC has ongoing communication with stakeholders through meetings, forums, e-bulletins and the cancerview.ca website, the evidence indicates that the communication is not penetrating or being further disseminated by all stakeholder groups, including the Canadian public.

The majority of stakeholders feel they have had sufficient opportunity for input into CPACC's strategic direction and decision-making. However, not all stakeholders have adapted to the existence of CPACC and its leadership role with respect to the CSCC. Despite the strong dissatisfaction on the part of a relatively small group of stakeholders, there is an overall sense that CPACC has struck an appropriate balance between moving ahead with implementation of the Strategy and stakeholder input into decision-making.

Although CPACC has put in place a robust process for monitoring progress being made by projects, CPACC has yet to develop and implement a robust process for measuring outcomes. The measurement of progress made by projects is sufficient for measuring outputs but does not provide sufficient information for measuring progress with respect to outcomes.

Similarly CPACC has implemented a well-defined process for approving and funding projects. However, the process for soliciting and selecting projects to be funded is not understood or seen as transparent by all stakeholders. No process has been put in place by CPACC to ensure there is First Nations, Inuit and Métis content included in projects funding. However, this is likely to change once the First Nations, Inuit and Métis Action Plan has been developed by CPACC and validated by First Nations, Inuit, and Métis organizations.

A key role of CPACC is to disseminate knowledge and information. The evidence indicates a high level of satisfaction on the part of stakeholders with the credibility, accessibility, and timeliness of information provided by CPACC.

d) Relevance

There is strong evidence that the health burden of cancer will continue to be significant over the coming years, particularly as the Canadian population ages. Given the health burden of cancer and the variable and fragmented nature of cancer control in Canada, there is a need for an organization such as CPACC to act as a knowledge broker in the area of cancer control.

The funding of an organization such as CPACC fits within the mandate of the federal government without encroaching on provincial and territorial areas of responsibility. CPACC is intended to assist in the coordination of knowledge production and brokering activities and not in the delivery of healthcare or the development of healthcare policy.

At present there is little potential for transferring all or part of the responsibility for CPACC to the stakeholders. Beyond the question of capacity there is also the need for neutrality that could be jeopardized if the responsibility for CPACC were transferred.

e) Cost-effectiveness and Alternatives

There is strong evidence of synergies and cost savings resulting from CPACC activities. However, despite the qualitative evidence of synergies there is no quantifiable data available on actual cost savings. The data required for measuring cost savings resulting from the knowledge and information made available to jurisdictions would need to be collected and shared by jurisdictions.

Although alternatives to the NGO model ultimately selected for CPACC exist, the current model is seen as the most appropriate. There is no evidence of a need to change or modify the current model. Other jurisdictions have implemented different models that reflect the structure of their healthcare models. CPACC has maintained contact with other jurisdictions, particularly Australia, in order to identify any best practices or lessons learned that could be transferred to the Canadian context.

8.2 RECOMMENDATIONS

a) Design and Delivery

- ➤ CPACC should continue to facilitate the integration and coordination amongst the eight strategic priorities and two supporting activities wherever appropriate. Encouraging more integrated approaches to developing initiatives will facilitate coordination and impact.
- > CPACC must continue in its recently increased efforts at addressing the perspectives and needs of First Nations, Inuit and Métis into all of its activities.

b) Success

➤ CPACC should develop formal mechanisms for assessing the usefulness of the data and information it is providing. Stakeholders and users of CPACC data and information should be consulted on a regular basis to gauge the usefulness, credibility and accessibility of CPACC data and information. The results of these consultations would be used to facilitate ongoing improvements to CPACC knowledge transfer/knowledge exchange.

- ➤ CPACC should develop mechanisms for communicating with stakeholders who are not currently engaged with CPACC but who work in the area of cancer control. This could be done through attendance and presentations at conferences and other such events.
- It is recommended that CPACC assess mechanisms for increasing its regional presence. This could include options such as affiliation with university-based partners. An increased regional presence would better enable CPACC staff to network and develop relationships with regional cancer control organizations. This is particularly critical in the context of the Canadian healthcare system and for CPACC to ensure needs are being met at the jurisdictional level.
- CPACC must ensure that the needs of jurisdictions are reflected in all of CPACC activities and initiatives, as their buy-in and active engagement are required for CPACC to fulfill its objectives.
- ➤ It is recommended that CPACC work to clarify its roles and responsibilities and those of its stakeholders on an on-going basis, to ensure that all individuals affiliated with stakeholder organizations are aware of CPACC and their organization's relationship with CPACC.

c) Governance

- ➤ CPACC must develop and implement a performance monitoring system using both qualitative and quantitative measures appropriate to the current stage of its development, which should include measuring outcomes. As a new organization it is clear that early on the focus of performance monitoring will be on outputs (# of meetings, #of reports produced, etc.); however, as CPACC evolves the emphasis should move away from measuring outputs to measuring outcomes. This will require the full engagement of the federal government and jurisdictions.
- ➤ It is recommended that CPACC put in place a transparent and clearly articulated mechanism for soliciting and selecting projects. There must also be a mechanism in place for communicating the results of decisions made.
- It is recommended that CPACC work to increase awareness of itself among the cancer control community as well as the Canadian public.

APPENDIX A

CPACC's Eight Strategic Priority Areas and Corresponding 5-Year Action Plan Activities and Expected Outcomes The eight Priority Areas identified in the most recent (February 2008) strategic plan are summarized in this Appendix. Each Strategic Priority Area has a corresponding 5-Year Action Plan. Further to the objectives of CPACC overall, expected outcomes have been identified for each of the eight Strategic Priorities for the period 2008-2012. These are summarized below.

Prevention

Some exposures are linked to cancer such as environmental and occupational carcinogens, sun exposure, and some infectious agents such as HPV. Others are modifiable behaviours such as tobacco and alcohol use, physical inactivity, poor nutrition, and obesity. The prevention strategy balances addressing these common risk factors by maximizing opportunities and avoiding duplication with partners in other areas of public health.

5-year Action Plan for Prevention includes:

- Develop and execute a national prevention surveillance initiative that will provide new information in the prevalence of environmental and occupational exposure to carcinogens.
- Collaboratively develop a strategy to address obesity and dietary risk factors for cancer, aligned with best available knowledge.
- Working with stakeholders, develop and execute a sun exposure approach that minimizes the risk of skin cancer, but recognizes the recent information on the potentially positive effects of Vitamin D.
- Review the role of infectious agents and the development of cancer and identify related approaches to prevention.
- Work with partners in screening and early detection to develop an integrated approach to HPV prevention and to cervical cancer screening during this era of new opportunities, and some concomitant risks, in cervical cancer control.

Expected Outcomes for Prevention are:

- Canadians will better understand their modifiable cancer risks and will be enabled to make informed choices—reducing the number of cancer diagnoses and deaths over the long term.
- > Targeting specific high-risk populations will reduce the health inequalities between advantaged and disadvantaged populations.
- Cutting-edge, reliable and rigorously derived information will be provided to governments, cancer professionals, and cancer support groups, patients, their families and individual Canadians.

Screening/Early Detection

Cancer screening is reported to have contributed significantly to cancer control in Canada; however, more can be done specifically in the areas of colorectal screening, breast, and cervical cancer. CPACC will focus on maximizing the impact of screening in cancer sites that are known, and use evidence based analysis to have the potential to reduce incidence or mortality through screening.

5-year Action Plan items for Screening/Early Detection include:

- Working collaboratively with key stakeholders, the achievement of participation targets for breast, cervical and colorectal screening.
- ➤ Champion the concept of programmatic screening (vs. opportunistic screening) where appropriate with key partners and stakeholders to promote better understanding of the population health approach and facilitate better integration and linkages with other health care system strategies.
- Develop outcome and process objectives for cancer screening in Canada, including a set of national screening performance indicators and benchmarks, building on previous work and accomplishments of the national breast and cervical screening committees, cancer care agencies and internationally recognized approaches.
- ➤ Identify gaps and key areas for improvement in the delivery of organized screening programs in Canada and develop strategies, working collaboratively, to address these gaps.

Expected Outcomes for Screening/Early Detection are:

- Appropriate use of screening will contribute over time to improved quality of life through earlier identification and reduction of the expected number of Canadians dying from cancer.
- > Improved patient understanding, supporting informed decision making about screening.
- > Improved policy-maker knowledge regarding screening.
- > Improved quality of screening provided through performance tools and professional adoption of standards.
- Provision of a national perspective built on comparability, transparency, consistency, and portability of knowledge across Canada.
- Creation of a participative and evidence-based platform for communication and joint action of all stakeholders to enable efficient alignment of screening/early detection cancer control resources.

Standards

Standards are required to develop best practices for cancer diagnosis, treatment and care; and to establish performance indicators to evaluate service delivery and foster improved access and quality. Standards are also used as key measures within the other priority areas, such as benchmarks for cancer system performance.

5-year Action Plan items related to Standards include:

- Identify and develop through collaboration, a core set of evidence-based cancer control standards, indicators and benchmarks for use by cancer agencies and programs.
- Establish an inter-provincial/territorial mechanism to promote and facilitate the development, dissemination, uptake and evaluation of pan-Canadian standards and performance indicators and benchmarks.
- Establish and recommend rigorous methodologies, including tools and templates for the development, implementation and monitoring of standards, indicators, and benchmarks for use within Canada, developed in consultation with key stakeholders.
- Develop and execute a common data and technology system for storing and accessing performance indictors and best-practice standards information.
- Improve access to standards and performance indicator information by professionals, patients, and the community at large.

Expected outcomes for Standards are:

- Widely accepted standards and indicators that enable performance assessment of the cancer control system.
- Provision of a national perspective by enabling comparability, transparency, consistency of standards and indicators across Canada.
- Engagement of cancer control community experts, leveraging critical experience and expertise for use by all (capacity building).
- Support for target setting and system performance measurement.

Cancer Guidelines

Cooperation among provincial/territorial cancer guideline programs will be facilitated, common principles will be established, and a communication infrastructure and training opportunities will be developed. CPACC will guide the use of evidence-based clinical practice guidelines.

5-year Action Plan items for Cancer Guidelines include:

Champion through national collaboration a pan-Canadian strategy to facilitate the optimal use of evidence through clinical practice-guidelines for cancer control.

- ➤ Develop a quality Canadian-based online resource designed to provide the optimal use of evidence for clinical practice. This comprehensive cancer knowledge resource will include links to high quality Canadian and international sources.
- Collaboratively develop and implement resources and tools to help provinces and territories develop, adapt, appraise, disseminate, implement, evaluate and maintain high quality evidence-based clinical practice guidelines that are relevant to their circumstances.
- Design a core curriculum to assist in the training of information and specialists to facilitate the optimal use, evaluation, and utilization of evidence-based guidelines and products related to informed decision making.
- Working with key stakeholders, develop and implement reporting tools that enable better clinical decisions.
- Develop tools for government decision-makers that facilitate greater consistency in clinical practices across the country.
- Build on participation of key leaders in guideline and knowledge management to foster consistent information sharing, collaborative action and efficiency across organizations, clinical communities, and national and international researchers.

Expected outcomes for Cancer Guidelines are:

- Provision of a national perspective by enabling comparability, transparency, consistency and portability of knowledge across Canada.
- Timely access to optimal evidence-based information for health professionals, government decision-makers, patients, and the community.
- Tools and guidance for jurisdictions and other stakeholders to develop better clinical practice guidelines and adapt existing guidelines.
- Tools to enable consistent decision-making by governments.
- Increased public awareness, involvement, and understanding of issues that have a major impact on patient care.
- Canada seen as a world leader in clinical practice guidelines through participation in international projects.
- > Capacity building through leveraging cancer control experts for use by all practitioners.

Rebalance Focus (Patient Centred Support)

Develop and promote strategies, tools, and targets to address the urgent need for resources, including programs and staff, and ensure that health care professional receive education in psychosocial, supportive and end-of-life care in order to ensure that cancer patients' overall needs are better served by the health care system.

5-year Action Plan items related to Patient Centred Support include:

- Define deliverables for a patient-focused system, and validate with patients and their families.
- Establish best-practice standards and performance indicators in the areas of psychosocial, supportive and palliative care.
- Increase and enable patient access to knowledge about supportive and palliative care.

Expected outcomes for Rebalance Focus (Patient Centred Support) are:

- Improved patient experience for those currently being treated for cancer, and for those living with cancer.
- Enhanced availability of reliable, current information and supports for patients and their families, cancer support groups, cancer professionals, and governments.

Health Human Resources

A lack of human resources has been identified as a potential threat to cancer control and chronic disease efforts in Canada and around the world. The focus of this strategy is to understand where CPACC can be most helpful in addressing the future needs of health human resources.

5-year Action Plan items related to Health Human Resources include:

- Promote information exchange on health human resource issues across the country and on innovative practices being used to mitigate them.
- Link into existing human resources planning processes at the federal and provincial/territorial level to provide input from the perspective of the cancer workforce.

Expected Outcomes for Health Human Resources are:

- > Improved planning information regarding health human resources.
- Rapid dissemination of effective innovative practices to cancer care agencies and governments.
- > Support to activities within other priority areas.

Research

Innovative research partnerships will be leveraged to address emerging issues under this strategy. In working with the Canadian Cancer Research Alliance (CCRA), CPACC will seek to capitalize on Canadian research strengths and focus them on the challenges in cancer control.

5-year Action Plan items related to Research include:

- Establish and maintain pan-Canadian cancer research network promoting integration of research across Canada.
- With CCRA, coordinate funding for cancer translational clinical research to foster the rapid transfer of new knowledge between the scientific community, health professionals, policy makers and the community at large.
- As part of CCRA, coordinate funding for a groundbreaking cancer cohort study to better understand risk factors for cancer, and to create a legacy "population laboratory" to enhance the understanding of many population-based health issues.

Expected outcomes for Research are:

- Cost-effective cancer research agenda that avoids unnecessary duplication and overlap.
- More rapid translation of research into clinical practice and government decision-making.
- The initiation of a true legacy, in the creation of a large (300,000 people) population cohort, which would not be possible under other funding mechanisms currently in place in Canada.

Surveillance

The objective of this priority is to provide better data on which to base prevention, screening, health care delivery, and policy decisions by brining together cancer epidemiological data and cancer control information from the provinces and territories for use in planning, implementing, and evaluating Canadian cancer control efforts.

5-year Action Plan items for Surveillance include:

- Working collaboratively, expand and standardize core set of epidemiological data collected by cancer registries, to ensure high quality staging information is available.
- Development of more frequent, timely, and relevant cancer surveillance data, which will result in greater application of the information to inform policy and interventions.
- Enhanced capacity for meaningful analysis through training and development of team reporting of critical information.
- > Improve record link between existing databases.

Expected outcomes for Surveillance are:

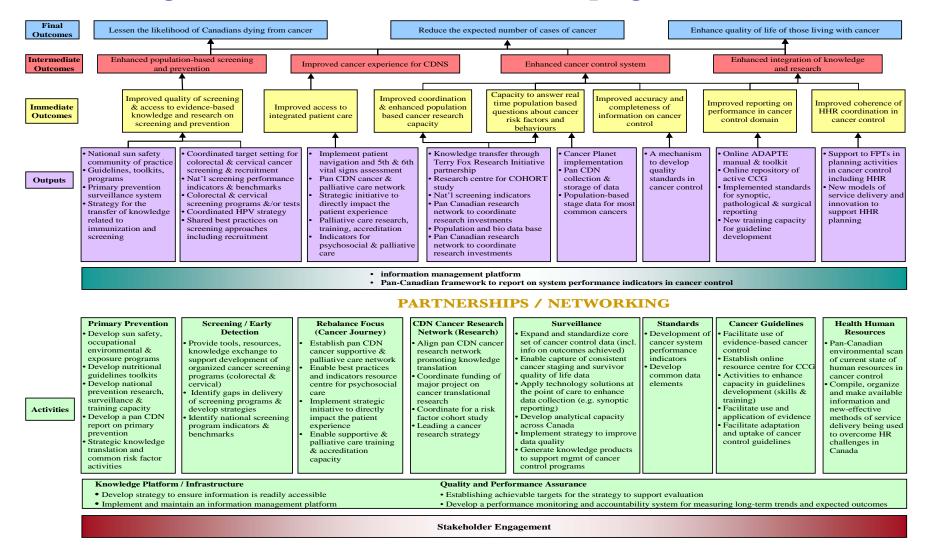
- Required support for CPACC's knowledge and evidence-based strategy.
- Improved information for basing actions to prevent, screen, provide care and decide policy.

- > Support for a national perspective by enabling comparability, transparency, consistency, and portability of cancer data across Canada.
- **>** Basis for Action Groups to analyze gathered cancer information and knowledge across the cancer control continuum.
- > Improved capacity for evidence-based policy and programs to meet population needs.
- Capacity building through leveraging critical expertise and providing to cancer community.

APPENDIX B

CPACC LOGIC MODEL – UPDATED DECEMBER 2009

Logic Model — Canadian Partnership Against Cancer



APPENDIX C

CPACC MANAGEMENT RESPONSE TO HEALTH CANADA EVALUATION



MANAGEMENT RESPONSE TO HEALTH CANADA EVALUATION CONDUCTED BY EKOS RESEARCH ASSOCIATES, MAY 2010

INTRODUCTION

The Canadian Partnership Against Cancer (CPACC) welcomes the findings of the Health Canada evaluation conducted by EKOS, and overall agrees with the recommendations.

Mid-way through the initial mandate is a crucial time to assess CPACC's progress, to examine what is working well and what might need modification to ensure ongoing success. Work is already underway to address these recommendations and our next steps are described in the management response. Two key conclusions of the evaluation are as follows:

- "Overall the evidence supports the need for an organization such as CPACC to coordinate knowledge and
 information on cancer control, cultivate relationships and generally act as a catalyst for cancer control in Canada.
 There is strong evidence that cancer is, and will continue to be, a public health issue over the coming years." 61
- "Evaluation findings indicate a high level of satisfaction with the organizational structure (i.e. NGO) of CPACC. As an NGO, CPACC is seen as effective in engaging with various levels of government and stakeholders. The NGO structure is also seen as allowing CPACC to be more nimble and neutral than would be possible for a government agency. Although alternatives to the NGO model exist, stakeholders and external experts generally believe that the CPACC model is sound and should be maintained."⁶²

CPACC was established by the federal government with a five-year mandate to shape and implement the Canadian Strategy for Cancer Control (CSCC), with the goal of significantly reducing the impact of the disease on all Canadians. The terms of the CSCC were defined by the collective vision, expertise and firsthand experience of more than 700 cancer practitioners, patients and survivors from coast to coast. The CSCC embraces the full spectrum of cancer control, including prevention, screening, research, surveillance and the cancer journey. It recognizes that all are essential if incidence, mortality, quality of life, safety and affordability of care are to be controlled.

The Canadian Partnership Against Cancer has made significant progress since the organization began operations in 2007. In this short timeframe, CPACC has established the organization and its accountability and management frameworks to oversee the implementation of the national strategy, and is driving – with our partners – the successful implementation of activities across all priority areas identified in the strategy.

This evaluation of CPACC was undertaken in year three of its five year mandate to assess:

- Whether CPACC has, in carrying out the Strategy, advanced the public health objectives for cancer control in Canada; and
- Whether this not-for-profit corporation is an effective tool for advancing the CSCC objectives.

⁶¹ Evaluation of the Canadian Partnership Against Cancer Corporation, EKOS Research Associates Inc., p60, May 6, 2010. 62 Evaluation of the Canadian Partnership Against Cancer Corporation, EKOS Research Associates Inc.,p67, May 6, 2010.

RECOMMENDATIONS AND MANAGEMENT RESPONSES

Overall, the evaluation suggests that CPACC is on the right track, successfully implementing the cancer strategy with partners in the cancer control community, and should continue its outreach and engagement efforts to successfully achieve its intermediate and long-term outcomes for the benefit of all Canadians.

The recommendations that CPACC is responding to fall into three areas: design and delivery; success; and governance. These can be summarized as improving stakeholder relations and communications, enhancing performance monitoring and continuing to address First Nations, Inuit and Métis considerations. In addition to the specific actions described below, continued activities responding to the recommendations, will be captured in our annual Corporate Plan submissions.

a) Design and Delivery

Recommendation: CPACC should continue to facilitate the integration and coordination amongst the eight strategic priorities and two supporting activities wherever appropriate. Encouraging more integrated approaches to developing initiatives will facilitate coordination and impact.

Management response:

Management agrees with this recommendation. Prior to the period of the evaluation, CPACC had re-aligned some of the priority areas in order to integrate work to achieve more tangible results. The need to drive focus and impact was early direction from the Board of Directors and continues to be reinforced as work progresses.

In order to successfully implement the work across the eight priority areas, CPACC has engaged experts across the country with dedicated knowledge in specific domains to advance the work. All work across the priority areas of the strategy is inter-connected and we continue to focus on improved coordination of effort to ensure we achieve significant impact within the current five year mandate. Many of the new advisory structures cut across the entire strategy, such as the System Performance working group, the Cancer Risk Management advisory group and the advisory committee on First Nations, Inuit and Métis cancer control.

As an example of integration, the early work of the Standards priority area is now fully integrated with System Performance and Quality Initiatives. The initial pan-Canadian indicators for performance were informed by the Standards working group. These indicators for performance were then validated by provinces to confirm their use in measuring performance across the cancer control domain in Canada. Identifying areas where there are gaps in performance will inform the development of quality initiatives. This in turn can be measured by indicators of performance to drive improvements in cancer control.

The Action Council, created in 2008, includes the Chairs of priority areas and is chaired by the VP, Cancer Control. It initially met monthly, and as integration has progressed, has been meeting six times per year to discuss opportunities for enhanced coordination and better integration of effort across the portfolio of work. Further integration across the portfolio is occurring now as we begin to consider a new strategic plan beyond 2012. We will be looking at synergies between primary prevention and screening and early detection; system performance and quality initiatives; and the potential integration of initiatives within the cancer strategy and alignment to chronic disease management. These

synergies will be further explored through consultations with our advisory mechanisms over the summer, at our stakeholder consultation in October 2010, and incorporated into the next strategic plan. We will continue to refine the implementation of work to ensure the cancer strategy is integrate and aligned to the cancer and health systems in the country.

Key activities	Responsibility	Stakeholders engaged	Timeline
Ü		Advisory mechanisms Stakeholder Forum October	Current to October 2010

Recommendation: CPACC must continue in its recently increased efforts at addressing the perspectives and needs of First Nations, Inuit and Métis into all of its activities.

Management response:

Management agrees with this recommendation and is committed to furthering early work with First Nations, Inuit and Métis communities and organizations.

At this point in our initial mandate, CPACC is encouraged by the relationships it has established with First Nations, Inuit and Métis organizations through its caucus meetings with national aboriginal organizations and the recently formed First Nations, Inuit and Métis (FN/I/M) advisory committee on cancer control. CPACC's work in this area has been informed directly by FN/I/M organizations and it was their expressed desire to ensure a cancer control strategy that recognized the distinct needs of each population and ensured cultural relevance. The approach taken by CPACC supports the self determination and engagement in priority setting required by each distinct population.

In the early years of the mandate, CPACC leveraged an existing program through Saint Elizabeth Health Care – the @YourSide Colleague online program. This had significant credibility and use among First Nations community health workers in Manitoba, Saskatchewan and British Columbia yet there was no course about cancer prevention, early detection, or treatment and management. Together CPACC and Saint Elizabeth created a cancer care module to fill this identified gap in the existing @YourSide modules.

While the curriculum was being developed for this course, CPACC initiated plans to host a FN/I/M forum whereby the work of the cancer strategy could be informed by FN/I/M needs and perspectives, build on existing programs where they were successful, and develop a plan for moving forward. The forum resulted in several concrete recommendations: to create a "clearinghouse" on cancerview.ca – CPACC's portal – specific to First Nations, Inuit and Métis cancer control; to focus on surveillance to better understand the cancer burden; to address remote and rural cancer control education issues; and the establishment of a separate advisory committee for First Nations, Inuit and Métis cancer control to develop and implement a population-specific cancer control plan.

Work is also well underway to launch culturally relevant pages on the portal. A First Nations, Inuit and Métis portal advisory network was struck to source and validate appropriate cancer control content across Canada. In surveillance, an opportunity was identified with Cancer Care Ontario to evaluate a pilot project on aboriginal identifiers collected through regional cancer centres to improve data in the cancer registry. The initial results of the

evaluation have been shared through a PHAC workshop and the final evaluation will be shared with interested provinces, and is anticipated to be complete in summer 2010. To enhance access to continuing education on cancer control in remote and rural communities, CPACC and Saint Elizabeth Health Care are exploring the potential expansion of the course to other provinces. Additionally, the FN/I/M advisory committee will be meeting in May to develop the action plan. The FN/I/M manager at CPACC works with each priority area director to determine where there are opportunities to address FN/I/M considerations. Through this work, several proposals were submitted for CLASP funding that would specifically address prevention efforts with First Nations and Inuit populations. Three projects including First Nations and Inuit populations have been funded and are currently underway. We expect significant progress will continue to be made now that relationships have been established and there is full participation and engagement of First Nations, Inuit and Métis partners to develop an Action Plan by June 2010. CPACC will also continue with ongoing caucus meetings with CPACC's Board member and National Aboriginal Organizations (AFN, ITK and MNC).

Key activities	Responsibility	Stakeholders Engaged	Timeline
Caucus meeting between CPACC Board member and National Aboriginal Organizations	CPACC management, CPACC Aboriginal Board member	National Aboriginal Organizations	Twice per year
Development of Action Plan for First Nations, Inuit and Métis Cancer Control	CPACC FN/I/M manager	CPACC FN/I/M Advisory Committee	By June 2010
First Nations, Inuit and Métis portal pages	CPACC portal team, CPACC strategy team	FN/I/M portal advisory team	By July 2010

b) Success

Recommendation: CPACC should develop formal mechanisms for assessing the usefulness of the data and information it is providing. Stakeholders and users of CPACC data and information should be consulted on a regular basis to gauge the usefulness, credibility and accessibility of CPACC data and information. The results of these consultations would be used to facilitate ongoing improvements to CPACC knowledge transfer/knowledge exchange.

Management response:

Management supports this recommendation. CPACC views evaluation (both formal and informal) as a key strategy to ensure that its activities, including information dissemination, are relevant and useful.

Evaluation is already integrated into the vast majority of CPACC's projects and initiatives. This is done through assessment of milestone achievement, and through soliciting feedback from partners on the value of information in ongoing projects. We have also piloted the use of an External Review Panel, which gives independent feedback on current and planned written material, including that on our corporate website and cancerview.ca. Reviewers are drawn from a range of backgrounds, and have provided insightful comments of value to our materials. Finally, we regularly collect evaluations on meetings and workshops hosted by CPACC as part of ongoing quality assurance.

CPACC is in the process of conducting an initial (in-depth) evaluation of the cancerview.ca portal, including a review of the tools, resources and information developed through the advisory mechanisms. By understanding the usefulness of the tools, and how they are being disseminated and adopted, we can further refine the products being developed and shared. Feedback will be formally solicited from cancerview.ca users. This exercise will be supplemented with utilization statistics and assist CPACC in refining the relevance and usefulness of the cancerview.ca tool. Initial results of the evaluation will be available in September 2010. The current portal plan will be refined to incorporate feedback from the evaluation.

Key activities	Responsibility	Stakeholders Engaged	Timeline
Evaluation of Cancer View Canada	l	Sample Cancer View users Key partners	By September 2010
Refined Cancer View Canada plan	CPACC Senior Management, Knowledge Management		By December 2010

Recommendation: CPACC should develop mechanisms for communicating with stakeholders who are not currently "in the loop" about CPACC. This could be done through attendance and presentations at conferences and other such events.

Management response:

Management supports continuing to ensure that stakeholders are kept 'in the loop', and also expanding our communications to a broader audience.

The Communications team recently completed an audit of its communication efforts, including assessing the tools and vehicles developed and whether outreach (whether through media, online or e-mail) is reaching the intended audiences. Overall, the tools and resources are valued by those surveyed, and they reported information is easy to find on the corporate website. Media efforts in particular, have been very successful in reaching broad public audiences with good penetration of key messages. Additional effort is required to reach beyond our existing stakeholder list, and to continue to leverage the breadth of individuals on our advisory networks and have them in turn disseminate information through their respective organizations.

To support better dissemination of information, CPACC has recently struck an Information Dissemination Committee comprised of a cross-divisional group to better plan, coordinate, leverage and target appropriate audiences with tools, resources, information and publications being developed. CPACC is launching an "Ambassador Program" in May 2010 that will provide communications tools to the Board, staff and advisory leads about progress made across the strategy so that they can further disseminate information about CPACC to other stakeholders. CPACC relies on its advisory networks to inform and implement the work, and also recognizes that its 400+ advisors work for other organizations. By providing resources to support their communications efforts, we can ensure messages and information reaches others not currently working directly on the implementation of the strategy. While cancerview.ca was only recently launched, both online properties (the corporate website and cancerview.ca) continue to attract more traffic. Further marketing efforts will be implemented to drive visits to the sites and to encourage registration to receive CPACC's online newsletters.

The Board of Directors and senior management also travel across the country and meet with local stakeholders to hear about their cancer control landscape and efforts. This represents an opportunity to update local jurisdictions about progress and ensure the strategy is relevant to their priorities. In the last three years, the Board has met across the country. Upcoming meetings will be held in Iqaluit, Winnipeg and Regina.

While many stakeholders were involved in the development of the CSCC, and continue to work on the implementation of the strategy, CPACC recently launched a formal and transparent advisory group renewal process to attract new experts to its advisory groups. Information about each group and roles being sought were posted online to reach a broader audience in a more transparent manner. This has resulted in many new experts joining the advisory mechanisms of CPACC. Ongoing efforts across CPACC through communications, stakeholder outreach, dissemination and adoption of tools and resources, will continue in order to create greater awareness across the cancer control community.

CPACC concurs that it is important to share the impact of the work to a wide audience. Upcoming media announcements over the next six months include the release of the pan-Canadian Cancer Research Strategy; a public service announcement through social media for colorectal cancer screening; staging and system performance; and ongoing media efforts to support the regional recruitment efforts of the Canadian Partnership for Tomorrow Project. The Communications team also considers opportunistic media efforts related to the priority areas of the strategy.

Many of the leads of CPACC's advisory groups and strategic initiatives make presentations at national and international conferences about the work in their priority areas, and have published in peer-reviewed journals. We have also produced several documents and resources targeted to key partner audiences. CPACC has been working closely with the International Union on Cancer Control (UICC) on its prevention stream at their upcoming conference in August 2010, and several abstracts have been accepted for presentations and posters.

Key activities	Responsibility	Stakeholders Engaged	Timeline
Ambassador Program	CPACC Communications	CPACC Board, Senior management, AG Chairs, CPACC staff	By May 2010
Impact Report Dissemination Stakeholder meetings	CPACC Board, Senior Management, Communications		From May- October 2010
Media relations outreach (list of announcements on the previous page)		Federal Minister of Health and Health Canada, National and regional media, general public	From May-October 2010

Recommendation: It is recommended that CPACC assess mechanisms for increasing its regional presence. This could include options such as affiliation with university-based partners. An increased regional presence would better enable CPACC staff to network and develop relationships with regional cancer control organizations. This is particularly critical in the context of the Canadian healthcare system and for CPACC to ensure needs are being met at the jurisdictional level.

Management response:

Management agrees with the recommendation to increase its regional presence. Currently, AG Chairs are seconded from host organizations across the country, including cancer agencies, hospitals, universities and national organizations. All of CPACC's priority areas and initiatives include strong regional presence, whether through organizational appointees, individual experts or patients and survivors. Management will explore and consider options to increase its regional presence (including the feasibility of co-location of staff or regional pilots) that can strengthen liaison with the multiple levels within jurisdictions and to facilitate integration/synergies between CPACC initiatives and regional priorities.

Key activities	Responsibility	Stakeholders engaged	Timeline
.		CPACC senior management, cancer agency CEOs, CPACC Board	

Recommendation: CPACC must ensure that the needs of jurisdictions are reflected in all of CPACC activities and initiatives, as their buy-in and active engagement are required for CPACC to fulfill its objectives.

Management response:

Management supports the need for engagement at various levels within jurisdictions, including F/P/T Deputy Ministers, ADMs, and cancer agency leadership and has been active in its outreach to these important stakeholders. We will continue to work with and through these partners as an essential component of how we can successfully implement the strategy. The provincial cancer agencies or equivalent organization or program in provinces and territories without formal agencies are the lead agents for cancer in their jurisdictions. CPACC has actively worked to establish robust relationships with the cancer agencies/programs through joint leadership team meetings, joint Board appointments and co-location of the Canadian Association of Provincial Cancer Agencies with the CPACC office to ensure greater collaboration and coordination. Through the recent advisory group renewal process, CPACC has broadened the depth of its geographic representation, and encouraged all jurisdictions to suggest nominees. We have also, through this process, ensured a depth of subject matter expertise and representation from key strategic partners at the national level. Further engagement and outreach is being undertaken with Deputy Ministers, national and federal health partners, health authorities and advocacy organizations leading up to the stakeholder forum in October 2010.

CPACC's role is to work as an accelerator and catalyst and thus CPACC has not restricted itself to initiatives where every jurisdiction is ready to move forward. CPACC has elected to move forward on initiatives/activities where there is a critical mass of three or more provinces interested in moving forward, thus helping to build evidence and demonstrate progress. The Synoptic Surgery and Synoptic Pathology initiatives are two examples of CPACC working with jurisdictions that are "interested early adopters".

For other CPACC driven initiatives such as Systems Performance Reporting, the National Colorectal Cancer Screening Network, the staging initiative and the pan-Canadian cervical screening network, CPACC has engaged representatives from jurisdictions across Canada through direct recruitment via cancer agencies (or equivalents) and/or letters of invitation to each responsible Deputy Minister of Health in provincial/territorial jurisdictions. These partnerships include the development of indicators, as well as the sharing and analysis of data and results. CPACC is committed to continued engagement of jurisdictional representatives at various levels to ensure its activities and initiatives are reflective of provincial and territorial priorities in Canada.

Key activities	Responsibility	Stakeholders engaged	Timeline
	Management	DMs of health and health promotion, federal MPs and key bureaucrats, cancer agency leadership (CAPCA), CCS National and Divisions	May – September 2010
	Management	ADMs of health, cancer agency leadership, national and federal health organizations, CCS, CCAN, chronic disease partners, CPACC advisory leads, FN/I/M partners, clinicians	October 2010

Recommendation: It is recommended that CPACC work to clarify the roles and responsibilities of CPACC and its stakeholders on an on-going basis, to ensure that all individuals affiliated with stakeholder organizations are aware of CPACC and their organization's relationship with CPACC.

Management response:

Management supports this recommendation.

With CPACC advancing all its work with and through others, and the annual funding representing less than 1% of total cancer control spending in Canada, the need to work with partners is essential. CPACC's business models mean that in some cases we lead efforts, in other cases we support the work of others and leverage what is working in one part of the country and transfer that knowledge more consistently across Canada. Roles and responsibilities are typically negotiated depending on the nature of the work being advanced and whether CPACC is leading or supporting the initiative. For example, when CPACC was developing and preparing to launch "Colonversation", a great deal of stakeholder work took place to clearly identify where CPACC could add value to current screening programs in provinces/territories and avoid duplication of effort or message confusion. The successful launch of the program was March 2010, done with support from Canadian Cancer Society and screening programs across the country.

Another key effort in is the mapping of all strategic initiatives across the priority areas of the strategy. This was provided to cancer agency leadership to ensure there was greater awareness of current engagement (and which individuals were involved) and to validate that the initiatives were aligned to P/T cancer priorities. CPACC will continue to work with cancer control stakeholders and national and federal partners where there is need for greater

role clarity (to avoid potential for duplication of effort) to codify our business models. This includes the Public Health Agency of Canada, the Canadian Cancer Society (national and divisional offices), Canadian Association of Provincial Cancer Agencies and others), and will require ongoing attention. While many individuals are involved across the priority areas from these organizations, CPACC agrees that more work needs to be done to ensure their colleagues are aware of their organizational support and involvement in the implementation of the strategy.

Key activities	Responsibility	Stakeholders engaged	Timeline
Clarify and codify business models with key partners	CPACC Senior Management	PHAC, CAPCA and cancer agencies, CCS, etc	Ongoing

c) Governance

Recommendation: CPACC must develop and implement a performance monitoring system using both qualitative and quantitative measures appropriate to the current stage of CPACC's development, which should include measuring outcomes. As a new organization it is clear that early on the focus of performance monitoring will be on outputs (# of meetings, #of reports produced, etc.); however, as CPACC evolves the emphasis should move away from measuring outputs to measuring outcomes. This will require the full engagement of the federal government and jurisdictions.

Management response:

Management agrees with this recommendation and will continue to adjust its existing performance measurement framework appropriate to the stage of CPACC's development. Once strategic initiatives from across the priority areas were established, targets for each initiative were set in 2009, and expected outcomes defined. Depending on the phase of implementation, the targets were both qualitative and quantitative. As initiatives are further defined, the measures of performance are expected to become more quantitative in nature.

A key way of driving performance has been by engaging program leaders across jurisdictions using evidence and data to establish benchmarks to measure progress. CPACC is committed to advancing performance in areas where there is clear consensus on achieving milestones that will contribute to reducing the burden of cancer. Over the next two years, CPACC will be undertaking planning on gap analyses with jurisdictions. Based on these gaps, a priority setting exercise will be undertaken with jurisdictions to address new indicators for system performance.

CPACC has already demonstrated where data can be used by provinces and territories to evaluate their own progress. Continuing to promote the use of data for performance monitoring and system change will support the process of performance improvements. This will in turn contribute to reduction in incidence, mortality and improving quality of life for Canadians.

Another key CPACC data initiative has been the development of the Cancer Risk Management Platform. This platform will assist CPACC and its stakeholders in projecting the impact of various cancer control interventions over time on a variety of indicators including incidence, mortality as well as the micro and macro-economic perspectives.

In addition, CPACC is in the process of developing a measurement framework that will tie the targets and outcomes of each initiative to immediate and intermediate outcomes as described in the logic model for the organization. This work will be completed by the fall of 2010.

Key activities	Responsibility	Stakeholders engaged	Timeline
Performance measurement framework linking initiative outcomes to logic model outcomes	3	CPACC Board, CPACC Advisory mechanisms	Fall 2010

Recommendation: It is recommended that CPACC put in place a transparent and clearly articulated mechanism for soliciting and selecting projects. There must also be a mechanism in place for communicating the results of decisions made.

Management response:

Management supports this recommendation. First and foremost, CPACC is not a granting organization and this needs to be reinforced continually with many stakeholders. CPACC inherited a number of projects through the CSCC, shaped by 10 years of planning to identify the most important initiatives to address population-health outcomes in cancer control. Further initiatives were drawn from existing priority areas, and CPACC funding was allocated in areas where the best advice (through advisory mechanisms and stakeholder consultation) told us we could achieve the best outcomes. Many of the early investments required significant engagement with many stakeholders since these investments were multi-year in scope and included several partners.

CPACC's funding beyond the previously established initiatives has been allocated based on existing (or priority specific) envelopes that were established using planning advice. Contracts are negotiated with partners to identify important milestones and deliverables. Funding has been awarded through a number of mechanisms including RFPs posted on CPACC's website, with larger projects also posted on MERX (examples include developing the Cancer Risk Management Platform and Cancer View Canada); through calls for proposals that include an open and adjudicated process (examples include CLASP, survivorship care plans, and surveillance and epidemiology networks), and to third parties with unique expertise and where their existing work supports the implementation of the cancer strategy (such as CAREX, CAPTURE, Canadian Virtual Hospice).

A full project management process has been established to establish, monitor and track progress against milestones and budget. This allows CPACC to monitor project delivery and to work with partners to remediate where required. CPACC also agrees that the business models and processes for making investments needs to be more clearly communicated. The business models and processes will be posted on our website by June 2010.

Key activities	Responsibility	Stakeholders engaged	Timeline
Public posting and clarification of CPACC business models on website		Partners, stakeholders and general public through website	June 2010

Recommendation: It is recommended that CPACC work to increase awareness of CPACC among the cancer control community as well as the Canadian public.

Management response:

Management supports this recommendation. In the first years of the CPACC mandate, communications efforts focused primarily on raising awareness of strategic initiatives where work was underway. These efforts needed to not only convey information about the initiative, but also establish CPACC as a new entity in the cancer control community. CPACC consciously chose not to brand the organization or the strategy but rather to focus on the work – which is of greatest importance. CPACC has also been respectful of ensuring attribution is given to partners who are implementing efforts, such as the regional partners of the Canadian Partnership for Tomorrow Project and Canadian Virtual Hospice. There are a myriad of organizations that communicate directly with the public about cancer (including at least 200 registered cancer charities). Many of these organizations have key relationships and accountabilities to communicate with the public. We will work with and through them on areas of alignment to ensure consistent messaging and increased profile for the cancer strategy. We will also continue to make our work publicly available through our online properties.

CPACC has continued to enhance communications outreach efforts through bi-weekly updates to CPACC staff, Board and advisory group members, monthly e-bulletins to a wide audience of stakeholders, newsletters and targeted dissemination of resources, tools and publications. Ongoing efforts are made to increase subscriptions to online distribution at CPACC meetings, conferences and presentations.

The media is typically used as a vehicle to inform the broader public about CPACC's initiatives. To date, many initiatives have been launched through the media and have received widespread coverage (90 million impressions to date) in national and regional newspapers, online and through television and radio. These include, among others, the launch of the Canadian Partnership for Tomorrow Project, the translational lung study, the launch of Cancer View Canada and the clinical trials database, the colorectal cancer screening public awareness survey and recent launch of "Colonversation", CLASP funding announcement, the Adolescent and Young Adult initiative and the public opinion survey on prevention. The two key vehicles for providing access to CPACC's information products are the Cancer View Canada portal and CPACC's corporate website.

In May and June 2010, CPACC will launch an Impact Report to stakeholders in cancer control, governments, advisory networks and to the public on the website. The Impact Report describes the progress made across the cancer strategy, told through the lens of those working in or affected by cancer. This will be a key communications tool for expanded outreach efforts over the spring and summer.

Key activities	Responsibility	Stakeholder engaged	Timeline
		CPACC AG Chairs, staff, Board, key partners	May- December 2010

CONCLUSION

By consciously organizing CPACC to be a nimble, responsive organization, we are able to leverage existing investments, share knowledge more efficiently and accelerate the adoption of innovative best practices in jurisdictions across the country. By methodically defining, planning, implementing, monitoring and celebrating success, we are able to bring coherence, meaning and credibility to big, complex system changes. This work means Canada's cancer control community can progress faster, with more facts and insights, to marshal our resources intelligently.

While it will take decades to achieve the full scope of this national cancer control strategy, the work underway, and its positive impact – regionally, nationally and worldwide – only three years into the first mandate, are compelling evidence of its importance. This evaluation is a critical moment for reflection and adjustment to ensure that we reach our goal: fewer people diagnosed with or dying of cancer and improved quality of life for those affected by the disease.