CANADIAN PARTNERSHIP AGAINST CANCER CORPORATION EVALUATION

FINAL REPORT EXECUTIVE SUMMARY

May 6, 2010



Prepared by:

EKOS RESEARCH ASSOCIATES

Ottawa Office

359 Kent Street, Suite 300 Ottawa, Ontario K2P 0R6

Tel: (613) 235 7215 Fax: (613) 235 8498 E-mail: pobox@ekos.com

Toronto Office

181 Harbord Avenue Toronto, Ontario M5S 1H5

Tel: (416) 598 8002 Fax: (416) 598 2543 E-mail: toronto@ekos.com

www.ekos.com

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.