

CANADA

Overview: Canadian Strategy for Cancer Control (CSCC)

The number of Canadians diagnosed with cancer each year is steadily rising. Population growth and aging are the primary factors driving this increase. 70% of new cases and 82% of deaths occur in those 60 years of age and older. By the year 2010 cancer will become the leading cause of death. Cancer prevalence is estimated to be almost three times higher than the annual incidence. In 1998, cancer ranked third accounting for 11.7% of the total economic burden.

Most provinces have provincial cancer agencies or equivalents, which provide specialized care for cancer patients. The lack of coordination among them has resulted in a human resource crisis in cancer care. The need was to develop coordinated strategies to maximize impact in the face of dramatic increases in demand for treatment and supportive care. Until now, no national strategy for the control of cancer has existed. The Canadian Strategy for Cancer Control (CSCC) collaboratively led and governed, brought together the public at large, and service providers and federal/provincial/territorial governments. A Canadian Cancer Control Council provided national leadership for advancing the vision of the CSCC, and established working groups to undertake or co-ordinate particular activities, guided by the 94 recommendations of the CSCC working group reports. The formation of a Stakeholder Caucus was encouraged to provide a conduit for information to and from Canadians concerned with cancer control. The Council also supported a special Caucus of Patients and Survivors to be constituted within the Stakeholder Caucus.

Goals of the CSCC are: reduced incidence of cancer, mortality, and morbidity; increased quality of life for those living with, or recovering from, cancer; equitable access to evidence-based cancer control interventions; improved integration of cancer health care, from primary to palliative care; rebalanced investments that sustain effective prevention, psychosocial/supportive and palliative care; empowered patients; and, harmonization with provincial, territorial and federal health plans.

In order to move towards these goals, 12 working groups examined the most pressing issues across the cancer control spectrum and decided six priority areas:

1. Standards and guidelines – establish mechanisms and improve capacity for collaborative guideline and standards development.
2. Primary prevention – establish integrated prevention system.
3. Rebalancing focus – improve resources and systems for delivery of supportive care/rehabilitation and palliative care.
4. Human resource planning – establish human resource planning database and coordinated approach to planning.
5. Research priorities – establish national priorities for strategic investments in cancer research.
6. A Pan-Canadian governance structure to oversee implementation of the CSCC.

Subsequently, separate action groups were established for ‘Standards of Practice’ and ‘Clinical Practice Guidelines’. More recently a ‘Surveillance’ action group was established and a working group on ‘Targets (Performance and Quality Assurance)’ was initiated. The ‘Research’ action group was subsequently integrated with existing cancer research funding bodies at the Federal and Provincial level to create a Canadian Cancer Research Alliance to link strategy, policy, implementation and funding into a coherent national plan.

Additional information on the Canadian Strategy for Cancer Control can be accessed at:
http://www.cancercontrol.org/home_csc.html

The following information was provided in a telephone interview (March 2006) by:

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1. The plan that you have in Canada is it a new plan or is it an updated plan?

The plan is called the Canadian Strategy for Cancer Control. It is a new plan in the sense that it was initiated in 1998 and we are working with that same plan. There has not been a previous national cancer control plan in Canada.

2. How often is the plan updated?

The plan is reviewed on continuous basis and is monitored by a governing council of the plan. We meet at a minimum of twice a year and review the actions of the plan.

3. What did you exactly have?

We did not have any national plan. That largely reflects that in Canada we have a number of provinces and territories which are the principle vehicles for delivery of population health care. And in essence each province was developing its own approach to cancer control without an over all national framework other than the Canada health act.

4. But you had initiatives anyway?

Yes. There were initiatives in each province, there was quite a variation in cancer incidence and cancer mortality across the country and quite a degree of variability in access to services, wait times for services, access to drugs. That variation and fragmentation was the reason for designing the new national plan.

5. Who were the main actors involved in the design of the plan? How did it start? Who decided?

It was initiated by three organizations:

1. Health Canada, who are the Federal Government's Health Management Branch.
2. The Canadian Cancer Society and the National Cancer Institute of Canada who would represent the principal Non governmental organization for Cancer.
3. The Canadian Association of Provincial Cancer Agencies who are the vehicles for cancer service delivery in each of the provinces or territories of Canada through government funding.

So those three bodies initiated a process which was sponsored and supported by the federal government, supported by the provincial cancer agencies so the provinces were involved, and the principal cancer NGO. Twelve working groups were created that involved about 700 people across Canada representing the diversity of the public, patients inclusive of cancer survivors

group, advocacy groups, professionals, members of the governments to get a broad cross spectrum and an inclusive view point of what should be in the cancer control strategy.

6. Can you tell me some of the steps?

We initially structured a number of working groups who were assigned various tasks related to cancer control to examine and take an evidence based approach as to what constituted best practice and what the issues and challenges were. For example there were different groups for primary prevention, screening services, diagnostic services, treatment, palliative and end of life care, genetics, human resources, information technology, cancer research etc. Each of these groups constituted their membership with a broad constituency. They came back with a series of recommendations for how we would establish a satisfactory bench mark or a current state of appropriateness in each of those areas.

When all the reports were received back, which was a process of two years, a national stakeholder forum was convened and approximately 270 people were invited representing public advocates, patients, professionals. Over a two day period, they reviewed the plans, assessed the recommendations, narrowed the recommendations down and grouped them into a manageable number. Out of the first major stakeholder forum there were a number of recommendations about specific actions that would have priority and also a recommendation on the governance and on-going management of the strategy.

7. When was the plan launched?

It was launched in 2002.

8. What was the source for funding?

It was launched with a commitment of funding from the Federal government and a matching but smaller contribution from the Non-Governmental Organization, the CCS-NCIC. This, in total, was an annual budget of \$ 650,000, which as you will appreciate, is a very small number for a national cancer plan.

The rationale for that was that the money was believed to be sufficient to put in place the governance mechanism and to initiate the actions and the planning of 8 action groups. The primary prevention group, the clinical practice guidelines group, the standards of practice group etc. It was believed that as health care is primarily delivered in the provinces that they would be the ones who would be paying for implementation. That was not particularly well thought out. In reality you cannot run a national cancer strategy with \$650,000. The provinces did not agree to put additional money in. They agreed to use the existing money, in ways that would be supportive of the strategy and was that not enough.

9. So what has happened?

The strategy has now been alive for just over 3 years. It has continued to be managed and overseen by governing council that has a membership of 27 individuals who represent the major stakeholders in cancer control including public and advocacy movements. It has continued to be funded by the federal government and the contribution from the Canadian Cancer Society. It has

continued to promote the actions and the planning of the action groups such that continued planning and infrastructure work has been done.

10. So is it working out in your opinion?

Well, it has just come to a new point. During the last year 2005, the federal government through the Public Health Agency of Canada, has been pursuing an integrated strategy for healthy living and chronic disease management. It has done this in response to emerging issues in communicable diseases like SARS and because it is believed that most chronic illnesses affecting western societies share common determinants. However, that had tended to sideline the thinking and the investment in a cancer strategy. And so we have been trying to balance the wishes to move towards an all encompassing chronic disease management strategy, and to keep the focus of the cancer strategy. The government changed in January 2006. The in-coming government has expressed a very strong view point that it supports a national cancer plan and that it believes that it should be investing in the national cancer plan at the level that the Canadian Strategy identifies in its business plan, which is \$260 million over 5 years.

11. What lessons did you learn from the planning process?

The vast majority of the work to create the strategy was 'in kind' contributions. People donated time and travel. Money itself is not the key issue in designing the cancer control plan. The key learning experiences are firstly the realization that you have to have a national strategy if you want to change cancer control at population level. But we came from a long history of fragmentation where we were happy to deal 'with our own backyard' but we did not want to actually talk someone else's backyard. That is what had impeded us for the previous 20 years. So crossing that threshold of a fragmented approach and moving to collaborative approach was a key step.

The second key piece was inclusivity. Having everybody (patients, public, advocates, NGOs) in 'at the table' at the start of the planning process. There was a strong commitment and a recognition that the patients, public, advocates need to be paid to participate, because they have no other form of funding.

The third point is that one has to recognize the key elements in a strategy. For example is it directed to the whole population? Do you have interventions that you can deliver with quality and appropriate standards? Do you have measures to establish that the population will adopt and comply with the interventions that you want to do? Do you have ways of measuring the change in significant outcome measures that would indicate your plan is going to work? Have you got a mechanism for inclusivity of all the elements of the population i.e. First Nations, aboriginals, multi ethnic groups etc. All of these issues have to be conceptualised up front before you actually get into the details of the plan.

12. Please tell briefly about the evaluation and the results?

Yes it is. There are two types of evaluation.

1. An evaluation of the plan in terms of: are the elements of putting the plan in place and delivering it being monitored and are they measurable. Can you demonstrate progress is being measured to implement your plan? 2. What are the actual measures of cancer control or the key

indicators that you are measuring? Have you got in place a mechanism to survey those measures across the population? Are you using standard and constant definitions of what you are measuring across the population? So key to that is having in place cancer registries being able to measure population mortality, stage of disease, 5 year survivals, etc. So the product of a national cancer plan is a change in population outcome. And clearly one has to decide the outcomes you are going to measure. And at the very minimum it has to be incidence and mortality as age-standardized rates

13. Whatever you intended to implement in the beginning, has it been implemented?

Partially, for example, one of the priority actions was to establish clinical practice guidelines that would be nationally available and accessible for use. We have worked on clinical practice guidelines, we have acceptance across all provinces of the process of clinical guidelines. We have tool kits for developing them. We have websites for the development and posting of clinical practice guidelines and workshops across the nation to essentially adapt the guidelines to the culture of the population that would have to comply with the guidelines. So we have implemented process measures that would get us to the outcomes we want to see. But we probably are not yet in a position to be able to say what proportion of the total population is being managed according to guidelines and what are the regional variations and how would we remedy that situation.

14. What else did you want to implement?

There are 8 priority action groups. The action groups include a primary prevention action group for a national primary prevention plan, and clinical practice guidelines in oncology for standards of practice for oncology. The Rebalance the Focus action group involves taking a holistic view to the management of the patient with cancer and recognizing that palliative care and end of life care and symptom control are as important as any other aspect. The development of the 5th and 6th vital signs for cancer which relate to assessment of pain and measures to address symptom control was part of this plan. The action group for the human resource plan is about various professional groups in cancer control. Developing a work force inventory, doing forward planning of the number of people training and the number of people practicing and the number expected to retire etc. This is trying to balance the work force to the national need for services. We have a group working on targets who are trying to define the indicators and the degree of change that is possible and represents the target. A working group addressing screening and early detection and the accrual for screening process has been established. We have a working group on surveillance and have outcomes measurement. A cancer research action group which has been broadened into a forum of major cancer research funders in Canada to bring alignment between the research funders and the people doing research towards a coordinated cancer plan.

15. Out of what you have mentioned, what has been partially implemented or what has been fully implemented?

Work is in progress in every area. Action plans have been developed. The human resource plan for example, has developed a detailed database for 5 professional groups representing radiation oncologists, clinical physicists, radiation therapists, medical oncologists, and pharmacists. Each of these databases is characterizing exactly who and how many people are there, where are they, how many people are in the training programmes. A model has been built about assumptions on how many will graduate, how many will stay. The model incorporates how many are expected to

retire on the basis of current age. This is essentially a dynamic model for human resource planning which is intended to be the blue print for working with universities and colleges involved in the training programmes. We are not yet at the point of influencing the intake into universities and colleges. We are still in the process of developing the data and ensuring that the models are accurate and can be used for planning purposes.

16. Any difficulties or obstacles you have encountered or are facing right now?

There are no specific obstacles. A country that has a federal government, with a national Health Act, but delivers health in provincial manner, poses issues. The issues between governments in terms of what they accept as their responsibility and what they share as their responsibilities, what they agree to fund etc. That is a challenge.

A second challenge is of course is the ideological challenge. The previous federal government moved strongly towards an integrated healthy strategy in the course of this plan and was less inclined to invest in disease specific strategies. We believe it should be an integrated strategy across all chronic diseases and should be based in determinants of health. We would not necessarily disagree that from a theoretical perspective, this is attractive. At this point in time it is also necessary to have disease specific strategies irrespective of whether you have integrated strategies. Ideological shifts of government pose barriers to the speed of what we can do and the level of support we have.

An area of challenge is actually keeping harmony across all the various groups who have a view point of what a cancer strategy should be. Historically, this was most difficult in the area of healthcare professionals, who actually disagreed and were fragmented. What we are seeing now is the potential for fragmentation in the patient/public engagement and advocacy area, rather than in the professional area. Advocates have very strong views, often about a single type of cancer. Having them step back and take a view that this is all about cancer control at the population level challenges the 'single disease' focus. .

17. New Zealand could be another example as well with different populations and different priorities?

I would say Australia, New Zealand and Canada are at relatively similar sort of level in their national planning.

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