

**THE NEW BRUNSWICK
CANCER NETWORK
(NBCN)**

**A Cancer Control
Accountability
Framework**

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1.0 LETTER OF TRANSMITTAL

December 12, 2003

Dear Andrée Robichaud:

Re: Cancer Control Accountability Framework for New Brunswick

Please find enclosed the results of the external review of cancer control in New Brunswick with particular emphasis on a structure for the Provincial level. This review was conducted at the request of the Department of Health and Wellness and took place over a four month period from early June 2003 to late September 2003.

The review is largely concerned with a proposed cancer control accountability framework for New Brunswick. Several options were considered by the reviewers. The one chosen that is believed to best fit the New Brunswick context, as well as accepted principles of cancer control is a 'managed network'. It is suggested that it be called the New Brunswick Cancer Network (NBCN). The review also encompasses recommendations regarding linkages, performance measurement, performance contracts, priorities, a budget and a 2 year (3 fiscal periods) implementation plan.

The review identifies a number of issues and challenges that must be addressed in order to improve outcomes. Having said this, there are also significant opportunities for New Brunswick to move forward with improvements in cancer control and position itself better within the Canadian and International contexts. This includes, of course, addressing the burden of this disease being experienced by its people and the increasing burden for the future if appropriate steps are not taken.

The reviewers would like to express their thanks to the staff of the DHW for their cooperation and support. Thanks to Pam Mitchell and Deanna Stewart-McGarry for their guidance and editorial assistance. Also, a thank you to Michèle Michaud for transcription. We are also grateful to Pam, Deanna and Majella Dupuis for capably guiding the reviewers through several stakeholder meetings in various locations throughout New Brunswick. We would also like to express our gratitude for the cooperation and support received from all of those interviewed and those who provided written submissions. We were very impressed with the level of commitment and dedication on the part of so many people.

If the DHW or any stakeholders have questions or matters requiring clarification, the review team would be very happy to respond.



Donald R. Carlow MD
Chair – External Review Team

2.0 EXECUTIVE SUMMARY

2.1 The Review - Purpose Structure and Process

At the request of the Department of Health and Wellness, a review of New Brunswick's provincial approach to cancer control was undertaken. This review took place between June and September of 2003. The charge to the review team was to propose an organizational structure responsible for planning, funding and monitoring cancer services in New Brunswick with goals to improve access and coordinate cancer services across the province within an integrated cancer service delivery system. The review team was asked to propose an implementation plan which defined options, relationships, linkages, areas needing policy, standards, and guidelines. The team was also asked to define a budget, an implementation schedule and how the structure would be monitored and evaluated.

- A three person review team was struck, comprised of Dr. Donald R. Carlow, team leader, Dr. Susan O'Reilly – both from British Columbia and Dr. Denis Roy of Quebec. All reviewers have extensive experience in the design and leadership for comprehensive cancer systems and have played important roles at the provincial, Canada-wide and international levels.
- The review process was comprehensive. It involved 4 days on site with meetings being held with a wide variety of stakeholders (approximately 175) throughout New Brunswick. The team had the opportunity to review a number of documents about the New Brunswick health care and the cancer system. The team also reviewed written submissions and brought forward information about cancer systems in other provinces as well as at the Canada-wide and international levels. The team then identified and analyzed issues, proposed options for a cancer control framework, chose a preferred option and defined an implementation and budget plan. The team provided a verbal debriefing at the conclusion of the site visit and also briefed the Department of Health and Wellness senior staff in August and again in September 2003.

2.2 The Cancer Imperative – The Burden of the Disease

- Cancer is the leading cause of premature death in Canada and will become the leading cause of death within the next decade. The number of cases is increasing at a rate of 2-3% annually, while the prevalence of individuals on active treatment is increasing by 8-10% per year. In many instances not only is cancer a preventable disease, but organized systems of cancer control for defined populations have been shown to improve survival and quality of life. Such systems are in place in all but two provinces (NB and PEI) in Canada and they are being implemented at an increasing rate in many developed countries.
- Differences in lifestyle and in the organization of delivery systems accounts for variation in results across Canada. There are higher incidence and mortality rates in the Atlantic Provinces compared to the Western provinces where more organized systems of cancer control have been put in place.
- Specifically New Brunswick has the second highest rate of cancer incidence in Canada. There are more new cases and higher mortality in general, compared to the rest of Canada. In New Brunswick, the potential years of life lost due to all cancers exceeds the combination of coronary artery and other cardiovascular diseases. And it will get worse. Between 1996 and 2008, New Brunswick projects a 37% increase in new cancer cases and a 29% increase in the number of deaths and this is likely a conservative estimate since risk behaviours associated with cancer tend to be more prevalent in New Brunswick. And yet there is no provincially coordinated or organized system for Cancer Control. Each area of the province acts independently, there is considerable fragmentation, poor coordination amongst the care providers, variation in practice, inconsistent or absent standards, no 'game plan' and some safety issues that need attention.
- Failure on the part of New Brunswick to implement an organized system of cancer control will assure even worse results and will cause it to fall even further behind other provinces and countries. It will also not be in a position to take advantage of Canada-wide initiatives to control cancer which are being pursued by the Canadian Strategy for Cancer Control (CSSC) and the Canadian Association of Provincial Cancer Agencies

(CAPCA). The work of these two bodies is driving even further developments in provinces that already have systems in place.

Simply put the gap between New Brunswick and the rest of Canada is widening. New Brunswick must act now or be substantially out of 'sync' with the rest of Canada, while its people suffer from the increasing burden of this disease.

2.3 Cancer Control Developments in Canada and Around the World

- Except for two provinces (NB and PEI), Canada continues to be a leader in the development and operation of provincial cancer control systems. Six provinces have provincial cancer agency systems with dedicated boards and budgets. Two have Ministry of Health led programs and two have no provincial structure.
- Those with organized systems offer a comprehensive approach from prevention through to palliation and have developed a number of networking arrangements in areas such as surgical oncology and palliative care. Some have also developed formal provincial program structures in areas such as radiation therapy and systemic therapy. All of these arrangements are to ensure the consistent application of standards, policies and clinical practice guidelines for both the formal cancer system and the rest of the health system. They also conduct research, operate registries, run cancer centres, operate screening programs and have organized systems for outreach. There is every indication that such systems deliver better results. There are, however, challenges such as integrating with the rest of the health system, human resource shortages and cost pressures. However, the presence of an organized system provides a very helpful vehicle to address these and other issues.
- Two Canada-wide important developments have occurred over the past 5-6 years which have relevance for New Brunswick. These are the formal development of CAPCA as an organization and the establishment of the CSCC. All provincial cancer agencies/programs have come together in CAPCA, an interprovincial structure, to systematically address in a coordinated way for Canada, several areas such as human resource planning, standards, clinical practice guidelines, surveillance, education and technology assessment. The CSCC as a partnership of CAPCA, Health Canada and CCS (Canadian Cancer Society) / NCI(C) (National Cancer Institute (Canada) has also addressed a number of priorities that are similar to CAPCA's but also include prevention and palliative/supportive care. The purpose of these two coordinated efforts is to create a Canada-wide framework for consistent implementation in the provinces. The absence of a provincial cancer structure will seriously compromise effective implementation of these Canadian wide priorities. It will be important for New Brunswick to effectively position itself to connect with these initiatives.
- Many countries faced with the same burden of cancer, have developed cancer control plans. These include New Zealand, Australia, Denmark, Italy, Germany, France, Israel and England and Wales. Most are challenged by effective implementation but there are some useful lessons that can be learned, particularly from the experience in England and Wales. These are:
 - cancer control planning should be government led;
 - plans should be comprehensive with a clear delineation of priorities;
 - plans should be based on reliable/consistent data and analysis;
 - there should be emphasis on standards, guidelines, performance targets and performance expectations;
 - there should be extensive coordination / integration with user group involvement;
 - there needs to be well defined leadership and action oriented teams for all elements of cancer control;
 - there needs to be an effective 'networking' mechanism for implementation which includes dedicated management support;
 - there should be effective monitoring at the local and system wide level.

It is interesting that these developments have occurred while maintaining cancer control within a broader health delivery model as opposed to a cancer agency model. In this regard, these ‘lessons’ may be particularly relevant for New Brunswick.

2.4 The New Brunswick Context

- It was important for the reviewers to understand the overall New Brunswick Health System in order to design a framework that would fit. The Health Authorities Act defines the regional structure which includes seven regions and eight regional health authorities with governing boards accountable to the minister and chief executive officers who are accountable to the Deputy Minister. There is a developing vision for the system and a draft provincial health plan that focuses on five priority areas including access, population health, human resources, best practices and accountability. The minister is responsible for planning, priorities, standards, defining services to be delivered, approving plans, providing funds and evaluating. The regions identify needs, define how resources are to be used, ensure citizen input and report on outcomes. There are levels or degrees of care defined for the system, some work has been done on primary health care, there is a provincial epidemiology service and some good work has been done on performance measurement for the system. It is clear that the current structure will stay in place for the foreseeable future and there is a desire to support the role and responsibilities of the regional health authorities.
- The New Brunswick Cancer System is decentralized, fragmented and uncoordinated with regional health authorities acting independently. Although good work was done by the Cancer Services Advisory Committee, little has been done to implement the priorities that were recommended and there is no ongoing provincial structure for purposes of planning, policy development, coordination or accountability. There are major radiation based cancer centres in Moncton and Saint John. Chemotherapy is delivered in the major centres and in twelve outreach centres. There is a provincial registry, a provincial breast cancer screening program, decentralized cervical screening, and a few palliative care units.
- Although many issues characterize the system, there are some strengths including committed people, the spontaneous development of some initiatives, reasonable capacity / facility infrastructure, a high rate of registry capture and the commitment of the minister to a cancer strategy. There are also opportunities, in that a coordinated cancer system can be developed based on best practices and the experience of others without having to modify an existing structure. The existence of the CSCC and CAPCA provides the opportunity to ‘tap’ into work that has already been done and adapt / apply it to the New Brunswick setting. Federal priorities in health care – particularly primary health care reform and palliative care – also provide opportunities.
- In moving forward, however, there are many threats and challenges that need to be confronted. These include human resource shortages in all major disciplines contributed to by major salary discrepancies; inequitable resource distribution; a widening gap between developments in New Brunswick and the rest of Canada; fragmentation and the potential for unsafe care; the burden of the disease with comparatively poor cancer control performance; more prevalent cancer risk behaviours; punitive drug costs; insufficient cancer epidemiology resources; incomplete development of evidence based cancer screening programs; poor coordination and variations in care and wait list management; no coordinated approach to standards and guidelines; no clear definition of roles, levels of care or responsibilities; problems for patients and physicians in attempting to navigate the system; support groups not uniformly available; and poorly developed cancer research, including clinical trials.

Clearly, there is a need for New Brunswick to move forward and establish a provincial cancer control accountability framework.

2.5 The Solution - A Provincial Cancer Control Accountability Framework

- Considerable experience is now available regarding the principles that should characterize a cancer control system as applied to New Brunswick. These are:
 - clarity of purpose / mission and goals;
 - a single, unified coordinated and connected system;
 - a broad based approach to cancer control from prevention to palliation;
 - evidence based plans, strategies and practice;
 - clarity of roles and responsibilities;
 - an equitable system that recognizes cultural diversity and language preferences;
 - inclusivity;
 - accountable to the DHW (Deputy);
 - cost effectiveness;
 - respect for the roles of RHA's;
 - respects cancer advisory Committee recommendations;
 - has well established linkages to provincial and Canada wide initiatives.
- The review team examined four options. In addition, within some options, choices could also be made - options within options if you will. The options examined ranged from modest improvements to the status quo at one end to a full cancer agency model at the other. The advantages and disadvantage of each are examined. The review team recommends a managed network model. This model falls short of a full cancer agency but achieves the same ends and meets the previously described principles and the lessons learned from other jurisdictions. The model fits well with the current RHA system, does not compromise current governance responsibilities, and can be achieved at reasonable cost. A full cancer agency model would mean a “huge” change at substantial cost and would alter the current RHA governance responsibilities as they relate to cancer, and place cancer control at a distance from the DHW. Modest improvements to the current system were included as an option for completeness but are not recommended. Simply put it would not lead to significant improvement in N.B's cancer control performance.
- The proposed model – The New Brunswick Cancer Network – encompasses many of the features of a cancer agency and can be defined as a structural framework to develop and implement a cancer control plan with a goal to deliver evidence based consistent cancer control. It aspires to achieve a reduction in cancer incidence and mortality, improve survival and improve the quality of life of those living with cancer. It has the responsibility for plans, strategy, policy, priorities, standards, guidelines, evaluation / outcome analysis. It coordinates implementation and defines roles and responsibilities of all components of the system from primary care to tertiary and back. The scope is broad encompassing all elements of cancer control and a number of enabling functions. The structure creates the performance expectations to be fulfilled by the RHAs. It brings together a broad base of stakeholders and provides a unified linking central point of coordination and leadership. The term network could be suggestive of something that is “loose”, ill defined and that may not be effective. A key ingredient to assure effectiveness is the provision of dedicated management support. In essence it must be a “managed network”. It is structurally located within the DHW.
- The overall structure of the proposed network is depicted in figures 2, 3 and 4 in the main body of the report. The following are the essential elements of this structure:
 - **Provincial Cancer Network Leader**

This is a key position in the NBCN fulfilling the role of chief executive of the system and reporting directly to the Deputy Minister of Health. The position should be considered a peer of the RHA CEO's and should have a seat on their council. This position is responsible for the network strategy,

network staff and group's and is equivalent / comparable to CEO positions for cancer agencies throughout Canada. It must be compensated at a competitive level. This position would sit on the CSCC council and on the board of CAPCA representing N.B.

- **Network Secretariat**

The secretariat reports to and supports the work of the network leader. It fulfills the role of administrative support to the network and is comprised of a chief operating officer, coordinators and secretaries. The COO is responsible for operational aspects of the network. The five coordinators – acting as policy analysts- who support the cancer control functions / enablers report to the COO.

- **Provincial Cancer Advisory Council**

Reporting to the Minister of Health and Wellness, this key structure provides the vehicle for the coordinated involvement of a wide range of stakeholders. While it does not govern it serves to bring diverse perspectives to cancer control plans and results. It also serves to coordinate the input of an even broader base of stakeholders through regular forums.

- **Provincial Cancer Network Team**

This is a multidisciplinary group of 14-16 members reporting to the network leader. It is comprised of the leader of each of the cancer control functions, enablers and sub networks. It is the major policy advisory group to the leader. Each member in turn chairs a cancer control function / enabler group and brings forward policy recommendations to the network team. The results of the work of these groups contribute to the content of the performance contracts which define the responsibilities/deliverables of the regions in cancer control.

- **Provincial Cancer Control Functions / Enablers / Programs.**

The various elements of cancer control are served by policy advisory groups in the following areas:

- Prevention
- Screening
- Diagnosis
- Treatment
 - Systemic
 - Radiation
 - Surgical
- Clinical Practice Guidelines
- Provincial Programs
- Palliative / Supportive Care
- Research
- Surveillance
- Primary and Community Care
- Facilities / Equipment / Technology planning
- Professional Practice Council
 - Human Resources
 - Education
 - Professional standards

The composition of each of these groups is interdisciplinary, networked throughout the province and connected to DHW portfolios. In addition, the leaders of these groups should be connected to CSCC and CAPCA structure. The full text of the report details the roles of each of these groups. It should be noted however that certain areas may need to

have a provincial program rather than a network approach. The best example is the need for a dedicated provincial chemotherapy budget with at least one pharmacist position to support its activities. There was a suggestion that gynecology should develop as a provincial program, however it should be part of the provincial surgical oncology network. Surveillance needs better support, research needs a strategic plan and the structure of screening will depend on provincial policy decisions re: cervical and colorectal screening.

Human resource planning needs special attention but it along with education and professional practice standards should be undertaken by the Professional Practice Council. Special attention should also be given to primary health care through the appointment of a primary care 'lead'. Prevention should be part of cancer chronic disease prevention but the component concerned with cancer should link to the network structure and to regional initiatives, to ensure a coordinated approach to risk behavior reduction. Insufficient professional resources are available to support individual tumor site specific groups. A CPG group however can 'tap' into the work of the CPG initiative of CSSC and CAPCA and adapt guidelines developed elsewhere for application in New Brunswick.

- **Cancer Network Executive**

This group is comprised of the NBCN leader and COO along with the two leaders of the area wide networks and a senior ministry staff person. Its major purpose is to act on behalf of the network team between meetings and be the vehicle for coordinating implementation.

- **Regional Health Authority CEO Council**

The NBC Network leader should be part of this group to receive feedback on plans and be made aware of issues at the regional level requiring resolution.

- **Role of the Department of Health and Wellness**

DHW should accept responsibility for the NBCN and should review and approve plans, strategies, priorities, policies performance contracts and performance measures.

- **Area - wide Subnetworks**

Two area wide sub networks are proposed with one serving Regions 2 and 3 and the other serve Regions 1, 4, 5, 6 and 7. This enables connection to the two 'lead' cancer centers. These sub networks are served by cancer advisory committees who identify needs, develop a multiyear plan, ensure coordination of care, monitor performance and act as a forum for patients, advocates and NGOs. The chairs sit on the Provincial Cancer advisory Council. A sub network management team comprised of a lead clinician, lead nurse and administrator support and are responsible for day to day management. Some regions may establish local cancer care teams at the management level.

- **Levels of service delivery**

It is important to clearly define roles and responsibilities in a structured system of levels of care for the entire province. Levels of service locations should be determined by volume, complexity and by ability to deliver accepted standards with a critical mass of expertise. This levels approach should be used for all elements of cancer control but priority should be given to chemotherapy and surgical oncology.

2.6 Linkages

A great deal has already been said about linkages throughout the province. There should, at some point, be definition of cooperative activity within the Atlantic Region and there should be early and strong connections built to the CSCC and CAPCA.

2.7 Performance contracts

An important process that helps to unify and bind the NBCN is the development of performance contracts that clearly specify expected deliverables and performance measures. In fact performance contracts are key to ensuring an

effectively functioning accountability framework. The principles that should characterize these contracts along with the components relevant to cancer are described in the full report.

2.8 Priorities

The reviewers were asked to provide an opinion on the priorities for cancer control. Principles, opportunities and specific priorities are described in the full text. Suffice to say here that safety of care is a concern to be addressed and that priorities should align with those of the cancer services advisory committee, CSCC and CAPCA. It will be important to proceed to immediately implement the network and address not only safety but human resources, clinical practice guidelines, standards, surveillance needs, primary and community care, levels of care within the system and cancer risk behaviors through a coordinated approach to cancer prevention.

2.9 Cancer Control performance measurement

An integrated model for cancer control performance measurement is proposed. A performance measurement matrix integrating the functions of cancer control with the Canadian Institutes for Health Information (CIHI) and the Canadian Council on Health Services accreditation framework is described. The model is consistent with the work of PIRC (performance indicators reporting committee) and the balanced score card system described in the report of the Premier's Health Quality Council. Goals, types of measures and responsibility for determining indicators and targets are also described.

2.10 Budget for cancer control accountability framework

An annualized operating budget to support the recommended cancer control accountability framework is described. The budget is based on certain assumptions and on compensation policies of the DHW. The report proposes a phased two year implementation plan carried out over three fiscal periods from October 2003 to September 2005. The total annualized budget ranges from \$2,513,044.00 to \$2,570,544.00 During fiscal 2003/04 less than \$0.5 million will be required. During fiscal 2004/05 this would increase to approximately \$1.5 million with full costs being realized in fiscal 2005/06. As experience is gained with this new structure and depending on provincial policy decisions, further assessment of resource needs for the effective operation of the network will be required.

2.11 Implementation

Implementation has already been touched on in the section concerned with the budget. Again a two-year phased approach over three fiscal periods is proposed. Implementation is largely concerned with establishing the NBCN structure. It is recommended that a 'transition' implementation team under the cancer care steering committee be established and through that group a detailed work plan be developed. The first phase of implementation involves the recruitment of the NBCN leader and quickly thereafter the members of the NBCN executive including the COO and the sub network leaders. This group, as the executive, can now take on the rest of the implementation under the steering committee until the NBCN team is formed. The second phase includes improved staffing for surveillance, and defining terms of reference for the NBCN team and sub network advisory committees. Also included is appointing the first chair of the Provincial advisory council and putting in place the first wave of cancer control functions / enabler chairs groups and coordinators. During this phase levels of service delivery and short term performance expectations can be determined. Phase 3 brings the establishment of the second wave of cancer control functions / enablers chairs and groups, convening the first meeting of the provincial advisory council and recruiting the remaining secretariat staff positions. During the latter part of this period the NBCB team can develop multiyear plans, priorities and performance expectations for the regions and invite the regions to develop their three year plans.

3.0 THE REVIEW – PURPOSE AND PROCESS

At the request of the Department of Health and Wellness a review of New Brunswick's overall approach to cancer control was undertaken with particular emphasis on the provincial level. The following is the charge to the review team, the structure and the process.

3.1 The Charge to the Review Team

- a) A proposed organizational structure responsible for planning, funding, distributing and monitoring of cancer care services in New Brunswick aimed at improving access to and coordinating cancer services across the province within an integrated cancer care services delivery system.

This structure will give consideration to:

- Existing resources and capabilities (strengths/limitations/gaps) within health regions.
- Trends and activities across other jurisdictions.
- Recommendations of the cancer services action plan.
- Alignment with the Canadian Strategy for Cancer Control.
- Provision of services in both official languages.

The project will describe linkages between the various stakeholders and between providers and levels of care that may include acute and long term care, home care, hospices, volunteer networks, palliative and pastoral care and the Canadian Cancer Society – NB Division.

- b) A proposed Implementation Plan which:

- Defines approaches, options, key involvement, roles, relationships, linkages and review points.
- Identifies areas needing policies, standards and service guidelines.
- Defines timelines and associated costs.
- Defines monitoring and evaluation criteria.

3.2 The Structure of the Review Team

A three person external review team was struck to undertake this assignment. The team was comprised of:

Dr. Donald Carlow - Team leader. He is a Health Care Consultant, CEO of the Canadian Association of Provincial Cancer Agencies (CAPCA) past president/CEO of the Ontario Cancer Institute/Princess, Margaret Hospital and the BC Cancer Agency and a member of the Canadian Strategy of Cancer Control Council.

Dr. Susan O'Reilly - Leader of the provincial systemic therapy program for BC, Academic Head of Medical Oncology at the UBC medical school and Chair of CAPCA's systemic therapy policy advisory committee.

Dr. Denis Roy - Director of the Quebec Centre for Cancer Control, a member of the Canadian Strategy for Cancer Control Council, a board member of CAPCA and possessing qualifications in population health and epidemiology.

3.3 The Review Process

The review process involved four days on site with visits to most regions and meetings with a wide variety of stakeholders. The schedule of meetings, locations and those attending is attached as Appendix I. In preparation for the review a number of questions were posed to stakeholders to stimulate discussions and help the reviewers better understand various aspects of cancer control in New Brunswick. These questions are identified in Appendix II. The

reviewers also invited and received a number of written submissions, the titles and authors for which are listed in Appendix III.

The steps in the review itself involved the following:

1. Internal/External Environmental Analysis

- *Current Cancer Control System in NB*
Through meetings with stakeholders, a review of written submissions and the analysis of various other documents on Cancer Control in New Brunswick, the team became familiar with the strengths, weaknesses, opportunities and threats regarding cancer control in NB.
- *The New Brunswick Health Care Context*
The review team undertook to thoroughly understand the current and future directions in health care for New Brunswick to ensure that a proposed framework would fit well within the overall system. Through interviews with DHW staff and the regions as well as reviewing various documents this perspective was gained.
- *The Canadian Context*
Members of the review team brought thorough knowledge of the current state and some of the future plans for cancer control in Canada and the various provinces. This included the priorities of the Canadian Strategy for Cancer Control and the developments in various provinces towards improved cancer control. Awareness of the various provincial “models” with their strengths and weaknesses enabled “best practices” to be identified to enrich the proposed framework.
- *International Context*
Members of the review team brought an understanding of the status and successes in developing and implementing cancer control plans in other countries. While health care systems may differ in other countries, multi-jurisdictional systems of cancer control (within National Strategies) have been developed with lessons learned that could be useful in the NB context.

2. Issue Identification/Issue Analysis

Through the aforementioned process issues were identified and analyzed to set the stage for the development of framework options and priorities.

3. Options for a Cancer Control Framework

Options for a framework were developed by the team in response to the foregoing. This included an analysis of the advantages/disadvantage of each, along with the identification of priorities which will guide decision making and the implementation plan.

4. Preferred Option

A detailed description of the preferred option is provided, with full rationale, and with full elucidation of a coordinated/integrated system that responds to the mandate set out for the team.

5. Implementation and Budget Plan

A multi-year, step-wise implementation and budget plan was proposed as set out in the mandate.

At the conclusion of the on site review, the team provided an overview of its findings to some members of the Department of Health and Wellness staff. In July, the chair of the review team briefed the Deputy Minister and other senior Department of Health and Wellness staff on key issues and recommendations. Based on a draft report the review team held a teleconference meeting in late August 2003 and came to its final conclusions. Prior to finalization, a penultimate report was submitted to DHW for further input and the identification of any factual errors. The final report was submitted December 2003.

4.0 THE CANCER IMPERATIVE – THE BURDEN OF THE DISEASE

4.1 Canada Wide

Cancer is the leading cause of premature death in Canada, with over 30% of potential years of life lost to age 70 being due to cancer. While it is currently the second leading cause of death, it will become the leading cause of death within the next decade. It is expected that despite a levelling off or a decrease in rates, the total burden of the disease will at least double over the next twenty years.

Age standardized incidence rates are constant or declining, however the number of cases is increasing because of population growth, aging and earlier detection. Breast, lung and prostate cancer account for the large increase in new cases. The overall incidence in males peaked in 1993 while incidence in females continues to rise. For example in women lung cancer incidence is now four times greater than it was in the early 1970s. For women there has been an increase in the incidence of breast cancer in the 50-69 age group due to the introduction of breast screening programs. The introduction of uncontrolled Prostate Specific Antigen (PSA) testing in Canada along with aging accounts for an increase in the incidence of prostate cancer.

To better understand the increasing burden for the future a glimpse at the past may be in order. Between 1987 and 1997 the number of new cases for males increased by 39% and for females 32%. During the same time period the number of deaths in males increased by 22% and for females by 29%. But when you consider prevalence, the challenge for the future is even greater. Better treatment has led to an increasing number of people surviving with cancer. The prevalence of individuals on active treatment is estimated to be increasing by 8-10% per year, bringing with it the serious impact on current systems of interventional treatment and the increasing needs of cancer patients for support, pain and symptom control and palliative care. It is interesting to note, for example, that for palliative care, while progress is being made, current capacity enables only 20-25% of those in need to have access to palliative care services, with only 5% of patients getting access to the professional expertise they need.

Recently, the province of Manitoba projected the increasing burden of cancer from the year 1999 to 2025. They project that by 2025, incident cases will increase by 45-54% and prevalence by 75-84%. Their conclusion is – an urgent need for a strategy.

It is also worth noting that cancer in many instances is a preventable disease. It has been estimated that cessation of smoking would reduce the incidence of smoking related cancers by 30% and that a combination of improved diet and increased physical activity would lead to a further reduction of certain cancers by 30%. And yet the majority of dollars are spent on treatment.

While some progress has been made, in Canada, this has not been uniform due to a combination of differences in lifestyle and variations in practice/fragmented approaches to cancer control in some Canadian provinces. For example, variation in the incidence and mortality occur throughout Canada. There are higher incidence and mortality rates in the Atlantic Provinces compared to the national average and compared to several of the more western provinces such as Alberta, British Columbia, Saskatchewan and Ontario. Simply put, organized systems of cancer control that are broad based should exist to assure the consistent application of evidence based strategies with more emphasis on seeking causes and addressing prevention. It has been estimated that the cancer burden as measured by mortality could be reduced by as much as 10% if such a strategy is pursued.

But there are other challenges. There are significant disparities in access and in results between the rich and the poor. There are significant variations that are a result of geography alone – the so called ‘postal code lottery’. There are examples of inequitable resource distribution and significant shortages in health human resources for the cancer field. The latter is leading to significant access problems and poses if unchecked, a major threat to the integrity of the current system let alone the threat to implementing improvements to the system for the future.

The foregoing is why many Canadian provinces are moving forward to develop and implement better systems of cancer control. This is why through a cooperative approach amongst major partners that Canada has developed a

cancer strategy. This is why other countries, which have lagged behind are developing strategies and organized systems to deploy them.

4.2 New Brunswick

While there is a need for improvements in cancer control throughout Canada, there is even a greater need within the province of New Brunswick. New Brunswick has the second highest rate of cancer incidence in Canada. There are more new cases and higher mortality in general than the rest of Canada. This gap is even greater in comparison to the more western provinces. Survival rates for lung and colorectal cancer are 10% below the national rate and even further below the western provinces.

An analysis of age-standardized incidence shows a rate of 534 new cancer cases per 100,000 per year among males in New Brunswick, the highest rate in Canada and almost 20% higher than the average Canadian rate. Cancer incidence rates among females (368 new cases /100,000 per year) are also 10 % higher in New Brunswick, ranking second among all provinces, just after Nova Scotia. Similar observations can be made for most common cancers among males, including prostate, lung, colo-rectal and bladder as well as for colorectal among females. As expected, mortality rates follow the same general trend, although the gaps tend to be less pronounced among females. In addition, New Brunswick experiences a greater number of potential years of life lost (PYLL) to lung cancer. On the other hand, PYLL are lower for prostate, breast and colo-rectal cancers compared to the rest of Canada, which is likely due to a later age of occurrence of the disease among affected individuals. Nevertheless, cancers of all sites constitute the first cause of premature mortality and the burden of cancer by far exceeds that of any other disease, including cardiovascular disease.

Risk behaviours associated with cancer also tend to be more prevalent in New Brunswick. Although smoking rates are comparable with the rest of Canada, second-hand smoking is significantly more common. In addition, data on dietary practices, leisure-time physical activity and frequency of heavy drinking suggest that cancer risk is more significant in New Brunswick than in most other Canadian provinces. Moreover, health officials at the provincial and regional levels repeatedly expressed concerns about current health behaviors trends among youth. Based on these observations, it is likely that cancer burden in New Brunswick will remain substantial in the future.

New Brunswick has projected its future new cancer cases and cancer mortality. Between 1996 and 2008 New Brunswick projects a 37% increase in new cancer cases (3% per year). During the same period the number of deaths from cancer is projected to increase by 29%.

And yet there is no provincially coordinated/organized system for cancer control in New Brunswick. Each area of the province acts independently and while there have been some good initiatives the absence of a provincial approach has generated a significant number of issues/challenges which are described elsewhere in this report.

Having said this, there are some encouraging developments. In 1998 a cancer services action plan was tabled promoting significant improvements and identifying several priority areas for action. It is also encouraging that the minister in a speech to the house in April of 2003 committed to the development and implementation of a cancer strategy.

The statement also included a commitment to improve access, improve safety, evaluate performance, improve community/primary health care, and introduce a new health workforce unit, including a recruitment and retention strategy for pharmacists and radiation therapists. A commitment was also made to evidence based decision making in clinical, management and policy setting areas. There was also a commitment made to improved accountability and population health.

This is a very powerful statement which addresses many issues in cancer control and which is very consistent with the development of a cancer control accountability framework for New Brunswick.

Quite apart from the challenging burden of cancer that New Brunswickers face, they also must face all of the issues that Canada as a whole is facing but at an order of magnitude that is greater.

5.0 CANCER CONTROL DEVELOPMENTS IN CANADA AND AROUND THE WORLD

It is important to understand cancer control developments across Canada and around the world as part of proposing a solution for New Brunswick. The absence of a provincial structure in New Brunswick could be viewed as “bad news” but on the other hand, it could be seen as an opportunity. Since many countries have developed cancer strategies and approaches to deploying them, there is the opportunity to take advantage of “lessons learned” and propose what might be a “best practice” model. It would, of course, have to fit within the overall New Brunswick health care context – but we will come to that later in the report.

5.1 Provincial Cancer Agencies/Programs

Canada continues to be a leader in the development of organized systems of cancer control at the provincial level. Eight out of ten of Canada’s provinces have provincial cancer agencies or other comparable programs whose overall mandate is to provide leadership to a comprehensive and integrated population based system of cancer control. These systems in general are directed towards ends such as:

- reducing the incidence of cancer;
- reducing mortality from cancer;
- improving the quality of life of those living with cancer.

While there is some variation in structure, processes and progress towards fully developed systems, there is in general, a common direction.

5.1.1 Classification

Provincial cancer agencies/programs in Canada could be broadly classified as follows:

- Provincial Cancer Agency structure
 - British Columbia
 - Alberta
 - Saskatchewan
 - Manitoba
 - Ontario
 - Newfoundland
- Provincial Program – Ministry of Health led
 - Quebec
 - Nova Scotia
- No Provincial Structure
 - New Brunswick
 - Prince Edward Island

5.1.2 Scope of Services

Provincial cancer agencies/programs have developed their approach to cancer control based on the notion of research to policy to practice as illustrated in the model outlined in figure 1 developed by the NCI(C) in the 1990s.

This model is generally applied to a spectrum of cancer control activities including prevention, screening, diagnosis, treatment, supportive care and palliative care. Broad based research and cancer surveillance programs enable policy and program development as well as evaluation in these areas. Deployment generally

occurs through a multilevel system involving major cancer centers, community cancer programs/ chemotherapy units and primary health care. Efforts are being undertaken to better integrate surgical oncology which has for the most part not been included in the formal cancer system as has been the case with radiation and systemic therapy.

Some agencies have made significant progress towards establishing provincial programs in areas such as radiation therapy and systemic therapy. Several have had long standing provincial structures for breast and cervical cancer screening. These provincial programs are characterized by common standards and processes, a single budget and unified provincial leadership. There have also been good examples of provincial network development for areas such as palliative care and surgical oncology where the bulk of service provision lies outside of the formal cancer system. Provincial Cancer pathology networks are at an early stage of consideration. Excellent examples of community cancer networks characterize provinces such as British Columbia, Alberta and Manitoba. Significant development in evidence based guidelines for oncology practice have been developed in British Columbia and Ontario where consistent application is believed to have had a beneficial impact on cancer mortality. While there are a few exceptions most provincial cancer agencies are also organizationally responsible for a provincial cancer registry.

5.1.3 Governance

While there are some variations in application, in general provincial cancer agencies are governed by a provincial and regionally appointed Board of Trustees, the responsibilities of which is defined in a cancer act or other enabling legislation. Exceptions would be Quebec, Nova Scotia and of course Prince Edward Island and New Brunswick. Each provincial cancer agency/program is led by a president/chief executive officer or equivalent who either reports directly to the board (BC, Alberta, Saskatchewan, Manitoba, Ontario, Newfoundland) or directly to a senior ministry of health official (Quebec, Nova Scotia). Those with boards have established linkages to regional health authorities where in many instances regional trustees are cross appointed to the Cancer Agency Board. In most models the chief executive works closely with other regional chief executive officers. In the case of Saskatchewan and Manitoba each of the Agency Boards are considered a distinct region at the provincial level, while in BC the cancer agency is a subset of the Provincial Health Services Authority which governs other provincial programs such as mental health, women and children's health and transplantation. Ontario continues with a dual system with the Ontario Cancer Institute/Princess Margaret Hospital being governed by the University Health Network and Cancer Care Ontario (CCO) by a provincially structured board. Recently, the government of Ontario has devolved the responsibility for the operation of the regional cancer centre to the host hospital although funding support for operations continues to flow through CCO.

Some provinces are in the early stages of developing Provincial Cancer Advisory Councils. These structures involve a number of stakeholders who by coming together will have unified input into the provincial cancer strategy and the opportunity to monitor progress. In some cases they may serve as the vehicle for coordinating the provincial response to the priorities of the Canadian Strategy for cancer control.

5.1.4 Budgetary Responsibility

Formal provincial cancer agencies have distinct global budgets for the components of the program that they govern and manage. These budgets include all provincial programs and services as operated through cancer centers, screening centers and community cancer programs except of course for those services which are delivered in the main through regional health authorities such as surgical oncology, palliative care, cancer pathology etc. In some cases cancer agencies have small coordinating budgets to provide for leadership in these areas. Those without a formal agency have smaller budgets for the operation of a provincial coordinating structure with funds for cancer service delivery flowing directly from a ministry of health to a regional health authority. In this model the 'cancer units' are governed by the regional health authority but with some expectation that they will do so within performance expectations defined by a ministry of health and based on the advice of the provincial coordinating structure.

5.1.5 Issues for Provincial Cancer Agencies/Programs

As previously stated, significant progress is being made in developing cancer systems throughout Canada. There are however issues that continue as challenges including:

- effectively integrating with other elements of the health care system including surgical oncology, diagnostic areas, palliative care and primary health care;
- playing a more significant role in cancer prevention;
- integrating various databases to allow for improved surveillance, monitoring and outcome evaluation;
- human resource shortages;
- standardization;
- significant cost pressures due to the increasing burden of the disease and new cancer control/therapeutic developments.

Effectively integrating with the rest of the health system to facilitate the consistent application of cancer control standards of practice probably remains as the biggest challenge. In the late 1930s and early 40s as a consequence of the Cody Commission some cancer agencies were established in parts of Canada to assure safety and effectiveness of radiation therapy. For the most part this model has continued and has developed in other provinces. One would have to ask, in light of the issues being faced today including the development of regionalization, whether the cancer agency model is the best direction for those provinces that have not yet established a formal cancer system. New Brunswick is an example. This question will be answered in the section entitled 'The Solution'.

5.2 The Canadian Association of Provincial Cancer Agencies (CAPCA)

This review would not be complete without reference to CAPCA – an interprovincial organization involving all provincial cancer agencies/programs across Canada. It exists to support the reduction of the burden of cancer through effective leadership, collaboration, communication and advocacy. It strives to promote the best practices of the provinces and their consistent application across the country. It was established under the Canada Corporations Act in the late 90s and is governed by a 16 member board, drawn from all provinces and other national partners and has established six priorities. These are human resources, standards and guidelines, information/surveillance, communication/education, technology assessment and research. It should be noted that,

- CAPCA co-chairs the Canadian cancer surveillance alliance along with Health Canada.
- CAPCA was a member of the research strategic alliance (now the Research action group of the CSCC) along with NCI(c) and ICR (CIHR) through which 6 research priorities were established for Canada.
- CAPCA is one of the three founding members of the Canadian Strategy for Cancer Control (CSCC) and has a seat on the council.
- In addition to initiatives in radiation therapy, systemic therapy, surgical oncology, hereditary cancer, community cancer care, oncology nursing, psychosocial oncology, the Canadian Cancer Patient Education network (C-CPEN), cancer pathology and staging, CAPCA partners with the CSCC on standards and clinical practice guideline development and human resources (CAPCA is leading the development of the HR database). It also actively participates in supportive and palliative care initiatives of the CSCC.

Through the involvement of its two major cancer centers, New Brunswick has actively participated in CAPCA activities. It will be important however for New Brunswick to position itself to more effectively connect with these initiatives at all levels and have a province wide mechanism through which it can actively implement the outcomes of these activities consistent with its own priorities.

5.3 The Canadian Strategy for Cancer Control (CSCC)

Not unlike other OECD countries, in response to the current and future burden of cancer, Canada has established a cancer control strategy. This development occurred in the latter part of the 1990s as a joint initiative of Health Canada, CAPCA and CCS/NCI (c). Through a broad consultative and stakeholder conference process six priorities were established which are:

- Standards
- Clinical practice guidelines
- Rebalance focus (supportive care, psychosocial oncology, palliative care)
- Human resources
- Prevention
- Research

Activities in these priority areas are being guided by a 27 member council which consists of all provincial cancer agencies/programs, CAPCA, CCS/NCI (c), Health Canada, ICR (CIHR), the Council of Paediatric Hematology/oncology, CCAN, and the chairs of action groups which have been formulated to address the priorities and develop plans for implementation. The council and the chairs of the action groups are now actively engaged in the development of a multiyear business plan as the basis for acquiring the resources to move forward with the plan.

The council is supported by a secretariat nested within Health Canada and functions presently on a modest budget that is insufficient to enable significant change to occur – hence the need for the business plans.

The council is also actively pursuing a strengthened connection to the Federal/Provincial/Territorial Minister of Health/Deputy Minister Council to achieve a broader base of support and engage the support of senior policy makers at the federal, provincial and territorial levels.

The purpose of the priorities and the activities of the action groups are to create a Canada wide framework for consistent implementation in the provinces, in keeping with provincial priorities. In this regard, provinces are being encouraged to establish mechanisms – in addition to provincial cancer agencies/programs – through which implementation can be coordinated. An example could be the establishment of provincial cancer advisory councils within each province that can serve as the vehicle to coordinate the activities of all stakeholders, establish provincial priorities, provide guidance to implementation and monitor progress.

Again it will be important for New Brunswick to effectively position itself by developing a provincial cancer control mechanism to more effectively connect with the strategy and the action groups and to coordinate implementation within the province consistent with its own cancer control priorities. What can be learned from the CSCC experience is the importance of strong high level government commitment and an appropriate level of funding – both of which have not been achieved.

5.4 Cancer Strategies of 11 OECD Countries

In 1999 Bennet et al of the University of Ottawa tabled a report on the cancer control strategies of 11 countries of the Organization of Economic Cooperation and Development (OECD). The report is based on self assessment documents published by federal authorities. While this report deals only with these programs falling under a national jurisdiction, there are some useful lessons learned that are applicable to a provincial or regional setting. Amongst the countries studied, eight had either identified or were identifying national strategies and three had not. What can be learned from the experiences of these countries that contribute to success?

Cancer strategies are only successful if

- It is a coordinated effort.
- It is senior government or ministry of health led.
- There is a broad based, inclusive, multi-stakeholder national advisory body.
- There are clearly defined steering committees or project teams for implementation.
- Specific steps in strategy development, implementation and review are followed such as:
 - Define who is responsible.
 - The provision of reliable and consistent data collection and analysis.
 - Establish the 'horizon' or vision and goals.
 - Establish cancer control priorities.
 - Identify target cancers.
 - Set baseline indicators and target reductions in mortality and incidence.
 - Define cancer control strategies to achieve target reductions.
 - Monitor and refine each initiative at defined endpoints.

There are also lessons to be learned through experiences with cancer control initiatives in specific theme areas:

- **Prevention**
Pursuing specific anti-tobacco, nutritional and lifestyle initiatives in partnerships with researchers (evidence based), NGO's and Federal/Regional authorities.
- **Screening**
The importance of a high level of compliance for target populations supported and tied to education programs and undertaking effective strategies for the disadvantaged.
- **Diagnosis**
Staging and consistent specimen evaluation.
- **Palliative Care**
Palliative care service development to meet need and the provision of specialized key personnel.
- **Research**
Infrastructure for a multidisciplinary and multiinstitutional approach to clinical research, the importance of a collaborative approach with a focus on common cancers.
- **Education**
Well developed public, patient and professional education – aligned with the strategy.
- **Surveillance**
Broad based integrated surveillance, consistency of data, and interpretation of data and standardization of reporting indicators.
- **Advocacy**
Involvement on councils and boards.
- **Treatment**
Coordinated and evidence based treatment through a linked system of care providers with timely access.

Along with material gathered about the experiences of specific countries, these lessons learned will be taken into account in the New Brunswick solution.

5.5 Cancer Control in Selected Countries-Lessons Learned

Many countries have developed cancer control plans. Some have received a modest amount of financial support and some have not. Most are challenged by effective implementation but notwithstanding this, there are some useful lessons to be learned in addition to the experiences of the 11 OECD countries.

5.5.1 New Zealand

During 2001/2002, through a partnership of the New Zealand Cancer Control Trust (NCO) and the Ministry of Health, a cancer control steering group was charged with the responsibility to develop a cancer control strategy. The steering committee is comprised of a number of experts and reports to the ministry of health. It is supported by a secretariat to carry out administrative functions, provide support for five expert working groups and implement the decisions of the steering committee. Priorities include improved prevention, screening, access to the best treatment and access to palliative care. There is a commitment to broad based stakeholder involvement because cancer involves so many organizations. Effective implementation continues to be a challenge.

5.5.2 Australia

In 1997, Australia established the National Cancer Control Initiative (NCCI) to advise government on cancer control. Through a cancer strategies group supported by government (which included both federal and state health managers) the NCCI developed a consensus-based set of priorities which includes 13 actions for implementation in areas such as primary prevention, screening, early detection and treatment. Through a collaborative effort the NCCI has also undertaken to optimize cancer care in Australia by improving processes and focusing on a few key priorities. The NCCI is also involved in pioneering new approaches to cancer control, translating new research results into demonstration or pilot projects that can lead to service programs. There are, however, challenges in that while Regional Health Boards exist, there is not a highly developed system at the implementation level.

5.5.3 European Countries

As reported to UICC (Union internationale contre le cancer) several countries such as Denmark, Italy, Germany, France and Israel have developed national cancer control plans. Denmark has a Ministry of Health appointed responsible body with regional steering groups for implementation. Italy has also identified a responsible body but it is not clear how implementation is being handled. France has a Ministry of Health mandated plan coordinated by the French Cancer League (NGO). France is also served by the French Federation of Cancer Centers through which specific strategies amongst twenty member cancer centers are coordinated. Initiatives include clinical practice guideline implementation and staging. The Ministry of Health of Israel has created a commission on cancer control and while Germany has a cancer plan there is no government financial support and hence it is being coordinated by five NGOs. The Organization of European Cancer Institutes (OEI) – a structure for collaboration amongst major European centers also serves as a vehicle for cooperative efforts in implementing selected initiatives.

5.5.4 England and Wales

There are some very interesting and relevant developments in England and Wales. As a consequence of poor cancer outcomes in England and Wales an Expert Advisory Group on cancer was set up in 1993 and issued in 1995 – The Calmine-Hine Report, a Policy Framework for Commissioning Cancer Services. This report identified the need to develop cancer networks extending from primary care to cancer units in hospitals through to more comprehensive cancer centers. In the year 2000 a Cancer Action Team led by the National Cancer Director and reporting to the Secretary of State for Health developed a broad based comprehensive National Health Service Cancer Plan within which the responsibilities for cancer networks were identified. A Manual of Cancer Services Standards was published in 2001, which outlines the structure of the networks. Thirty-four cancer networks have been established through England and Wales, each serving 1.5-2 million

people. A joint Commission for Health Improvement/Audit Commission Report was released in 2001 outlining how well the NHS has met the recommendations of the 1995 Calmine Hine Report.

A few things are noteworthy about the approach in England and Wales

- It is government led – and at a high level.
- There has been a substantial financial investment – approaching 570 million pounds by 2003/04.
- The NHS Cancer Plan is broad based, comprehensive and was developed in an inclusive way.
- There is a National Director supported by a Cancer Action Team reporting to the Secretary of State for Health.
- There are country wide standards, performance targets, performance contracts and performance indicators.
- Networks cover a wide geographic area and coordinate, integrate all levels of care from point of entry up to and including major cancer centers. There is a clear definition of the role and scope of services for each level.
- Each network has a management structure that includes a lead clinician, a lead nurse and a lead manager as well as a primary care lead.
- Each network has strategy groups for each element of cancer control as well as tumour site specific guideline groups.
- Networks are governed by management boards that are broad based and bring together all levels/all service providers and NGOs.
- There is user group involvement.
- The network management is supported by an executive group.
- Each network has a set of values and principles as well as clearly defined objectives.
- Network responsibilities include planning and developing all local services, improving patient centered services, implementing their plans and the requirements of the NHS and monitoring performance.

It is still early days in the implementation of this approach and as expected while there have been some successes (several networks have developed very well and can serve as a model to apply to a population such as Sussex and Avon/ Somerset/ Wiltshire) there continue to be issues.

According to the audit, access has improved significantly however there is still variation with diagnostic services presenting significant problems. There also continues to be variation in access to palliative care. Although patients feel better informed and some areas of human resource availability have improved, there is still a need for better communication and sensitivity to patients' needs. While there are some excellent examples of well designed and effectively led networks, the role of the networks should have been more clearly defined at the outset and there is still a need for greater accountability and leadership at the network level. There is a need for more top down direction as well as bottom-up initiative. It is also very clear that networks need to be well supported.

Again while it is early and improvements are needed, this model shows promise where there is a desire to maintain responsibility for cancer control delivery within a broader health delivery model and not establish a distinct and separate cancer agency approach.

6.0 THE NEW BRUNSWICK CONTEXT

6.1 The Health Care System

In order to propose an appropriate cancer control accountability framework, it is not only important to consider Canadian and world wide best practices but also the health care system within which such a system must fit. The purpose of this section of the report is to understand the NB health care structure, its vision, its goals, the opportunities and the initiatives that will have relevance for a proposed framework.

New Brunswick has a population of 752,000 (adjusted 1996 census) and an annual health care operating budget of \$1.5 billion (28% of total provincial budget). Although the reviewers were provided with an estimate of expenditures on cancer there is no distinct cancer budget. In general, it is within the RHA's budget and is difficult to define precisely.

As defined in the Health Authorities' Act, the province is divided into seven regions and there are eight Regional Health Authorities, there being two RHA's in Region 1. These were put in place during 2002. It is worth noting that this is a large number of RHA's considering the population and comparisons to other jurisdictions. The reviewers were advised that no immediate plans are contemplated to change this arrangement.

The DHW is committed to:

- A single patient focused, community based and integrated system.
- Health promotion, disease prevention.
- Timely access and appropriate service.
- Providing services in the official language of choice.

In keeping with this, discussions regarding the developing provincial health plan may see a focus on five areas which are:

- Improved access and delivery of care. This includes better palliative care, improvements to the prescription drug program, safe services and evidence based practice.
- Population health including initiatives in physical activity, nutrition and tobacco cessation.
- Recruitment and retention of health professionals through an integrated strategy for health human resources.
- Ensuring sustainability through the application of best practices and a team approach.
- Enhancing accountability – building on the report card initiative.

The Health Authorities Act specifies the role and responsibility of the Minister and the Regional Health Authorities. It makes clear that the minister shall specify the responsibilities of the regions and in doing so will consult with them. In general the minister is responsible for building a provincial health plan, establishing priorities, establishing provincial standards, defining the health services to be delivered by each RHA, developing an accountability framework, approving RHA plans, providing funds and evaluating performance.

In support of the foregoing the Department of Health and Wellness is organized under the Deputy Minister into five divisions which are:

- Administration and Finance
- Institutional Services
- Mental Health Services
- Public Health and Medical Services
- Planning and Evaluation

In addition, there is a Director of communications. At the ministry level there is no specific disease management focus although there have been discussions about chronic disease management with some early consideration of areas such as hypertension and diabetes through a committee process.

Provincial initiatives also include an epidemiology service engaged in surveillance/monitoring, population health assessment and research, with responsibility for the provincial cancer registry. There is a provincial drug program which includes several initiatives to meet the needs of specific groups.

There is a provincial telehealth program with a toll free 24 hour bilingual province wide triage and information service regarding non-urgent conditions. Each Health Region is governed by a Board of Trustees. Each board is comprised of 15 members initially appointed by the MOH. As of 2004, eight members of each board will be elected and seven will be appointed by the minister. Boards are served by both a medical and a professional advisory committee. The chief executive officer for each region reports to the deputy Minister of Health, while the Boards are accountable to the minister.

Regional Health Boards are responsible for

- Identifying needs within their region.
- Defining services that are required.
- Defining how resources will be used to meet needs as expressed in a regional health and business plan
- Implementing and managing specialized services in accordance with the provincial health plan.
- Ensuring citizen input.
- Reporting on outcomes.

Boards are expected to provide 3 year regional health and business plan – in accordance with the provincial health plan.

The province has also defined the levels or degrees of care within the system with clarity of role and relationships for each level and which includes primary, secondary and tertiary levels. In keeping with Federal priorities there has been significant work done on primary health care including a vision and a commitment to implement four strategically located Community Health Centers. These developments have important implications for an integrated cancer network. Within the vision for primary health care there is reference to appropriate access, a collaborative practice model, evidence based practice and health promotion and disease prevention. CHCs will be governed by RHAs.

This report is very high level and general about the overall health system. The reviewers are of the opinion however that it does provide a very useful and helpful backdrop within which an appropriate accountability framework for cancer control for New Brunswick can be developed. In short, with the application of best practices an accountability framework can be developed that fits well with the present system and does not require revolutionary change to the existing structure. In fact, many of the requirements that presently characterize the regional health system can be simply applied to a cancer control framework. Before addressing the solution, it is important however, to examine in more detail the present cancer control system in New Brunswick. This is the subject of the next section.

6.2 The New Brunswick Cancer System

Before moving forward to provide a solution, it is important to understand the present state of cancer control in New Brunswick including its strengths, issues/challenges, opportunities, risks/threats, and its historical evolution.

6.2.1 Overview

Previous reference was made to the regional health system in New Brunswick which is comprised of seven health regions and eight Regional Health Authorities. As noted, there has been a substantial shift from an institution/interventional delivery model to a regionally coordinated, patient centered service delivery model with a greater emphasis on population health, health promotion and disease prevention. Within this system all regions have a hospital(s) with various levels of services.

Major referral hospitals are located in Saint John, Moncton and Fredericton. There are two fairly well developed tertiary cancer centers located in Saint John at The Saint John Regional Hospital and in Moncton at the Dr. Georges-L. Dumont Hospital. The facilities at each hospital include both Radiation and Medical Oncology and each are affiliated with medical schools outside of the province and teaching universities within. Chemotherapy programs with medical oncologist support and other cancer control elements are offered from The Moncton Hospital and in Fredericton from the Dr. Everett Chalmers Regional Hospital. The other four regional health authorities and twelve outreach centers throughout the province provide chemotherapy at various levels. There is a provincial cancer registry located at the Saint John Regional Hospital which is supported by the provincial epidemiology program. Some basic cancer research takes place at the Dr. Georges-L. Dumont Hospital and some limited clinical trials activity takes place in a few locations. A provincially structured breast cancer screening program operates at sixteen sites throughout the province. Cervical screening is carried out in a decentralized way. However, a provincial cervical screening pilot project, involving four regional health authorities is currently under review. Hereditary cancer screening is carried out at The Isaac Walton Killam Hospital in Halifax. Cancer pathology and diagnostic imaging services are provided within the hospitals. Several palliative care units are in place, complemented by volunteer based hospice programs and a provincial palliative care association. Several cancer prevention initiatives have been taken at the provincial and local levels.

There is no clearly defined provincial leadership structure for a cancer control program. As a result, each region acts rather independently with consequent fragmentation, variation in practice, little provincially coordinated forward planning to guide them and no clear framework for consistent decision making. While acting independently, there have been some very good developments at the regional level involving committed people who are very supportive of change.

6.2.2 Recent evolution of cancer control at the provincial level in New Brunswick

Although a provincial structure is not in place, several initiatives at the provincial level have taken place directed towards improved coordination and towards establishing the elements of a provincial approach. Briefly, and without detail these include a 1985 cancer services review, the establishment of regional cancer committees in 1991, the formation of the Cancer Services Advisory Committee (CSAC) in 1996. In 1994, the Provincial Breast Screening Program was established. In 1998, the CSAC tabled the Cancer Services Action Plan for New Brunswickers which identified five priorities/strategic directions included in which was the need to pursue provincial initiatives in a number of areas (including CPGs) supported by provincial coordination.

It is also worth noting that recognition was given to the importance of addressing the CSAC recommendations by funding two positions for cancer care consultants within DHW. A higher priority for cancer services was also signaled by the establishment of the Cancer Care Steering Committee through which advice is provided to DHW and the Deputy on the implementation of the Cancer Services Action Plan with a goal to strengthen the cancer system. While this is not a fully developed cancer control accountability framework, it was a step in the right direction and has led to the undertaking of an external review to propose such a framework.

During this time - specifically the latter part of the 90's and up to the present time - New Brunswick has held a seat on the board of CAPCA and also on the council of the Canadian Strategy for Cancer Control (CSCC). Through those connections New Brunswick has been able to make a contribution to Canadian wide efforts in cancer control but unfortunately without a provincial architecture in place it has not been able to implement developments occurring in those forums consistently throughout New Brunswick. Connection to national associations on the part of some of the professional staff has enabled isolated but good initiatives to occur in some parts of the province.

6.2.3 Strengths of the Current System

Notwithstanding the absence of a fully developed provincial structure for cancer control and several issues which will be described later, a number of noteworthy and positive developments have occurred.

- The reviewers were very impressed with the large number of committed and hard working people who want change and who are knowledgeable about what is needed. The reviewers found people to be optimistic and professional with a high level of consistency about a vision for a provincial accountability structure.
- Noteworthy are a number of spontaneous initiatives occurring throughout the province including
 - The levels of care approach for systemic therapy from River Valley Health.
 - Strategic plans for cancer services developed by regions.
 - Some excellent palliative care initiatives including inpatient units, hospice care and a committed provincial association.
 - The involvement by several professionals in national committees.
 - Regionally based outreach programs with a strong commitment to helping and serving other regions.
 - The commitment of those regional cancer committees that are active.
- The reviewers also noted the reasonably well developed infrastructure that characterizes the New Brunswick Health Care System. There is reasonable facility capacity which means good access to diagnostic services and to surgery. There is also timely access to most cancer services such as radiation therapy, although there is some variation as a consequence of technologist shortages. There is still, of course, the need for better coordination of access from the point of entry into care to definitive treatment. Delays in breast cancer treatment from the time of detection of a screening abnormality is one example. The Extra-Mural Program is well developed and the province is proud of its initiatives in telehealth.
- There are also some positive developments at the provincial level.
 - The Breast Cancer Screening Program is an excellent example of a provincial approach to one element of cancer control. It might be viewed as a microcosm of what might characterize a broader based provincial cancer control structure. The reviewers noted the provincial approach to standards and performance expectations in this area and how they have been assimilated for example by River Valley Health.
 - The priorities defined by the Cancer Services Action Committee are well developed but particularly impressive, was the consistent support for these throughout the province and evidence of involvement by many stakeholders including NGOs and volunteers.
 - There are a high percentage of new cancer patients captured by the cancer registry which has recently been meritoriously recognized.
 - As part of a chronic disease management strategy there have been significant developments in cancer prevention at the provincial level.
 - Of significant interest is the commitment of the Minister of Health and Wellness for the

development and implementation of a cancer strategy and for evidence based decision making. The latter point is worth emphasizing because quite apart from its application in the clinical setting, world wide evidence would support the establishment of a coordinated and integrated cancer control framework. Where this has been done, evidence shows lower cancer mortality and improved survival and these are the most important measures of effectiveness in cancer control.

- The Province has also done excellent work on the development of comparable health and health system indicators which includes a significant number concerned with cancer.

6.2.4 Opportunities

There are indeed many challenges to address, not the least of which is to develop and implement a structure and process for cancer control in New Brunswick. There are however, a number of developments that create an opportunity to move forward with this more easily than one might have originally thought. Consider the following:

- With no provincial system currently in place, New Brunswick has the opportunity to learn from others across Canada and around the world and take advantage of best practices/lessons learned.
- There is a good body of cancer control work that has been done at the Canada wide level through CSCC and CAPCA that New Brunswick can take advantage of and link to. There is the opportunity to assimilate work that has already been done.
- The Province has already undertaken significant work in health care reform a great deal of which is well aligned with the development of a cancer control accountability framework.
 - there is a commitment to a single patient centered community based health care system;
 - the priorities for the health care system are not only compatible with but will enable and support improvements in cancer control;
 - very good work has already been done on performance indicators, public accountability, and efforts to promote healthy lifestyles.
- New Brunswick can build on the many positive and spontaneous initiatives that have occurred in cancer control in the various regions referred to elsewhere in this report.
- Federal health care priorities provide opportunities in areas such as primary health care reform, drug coverage, home care, medical and diagnostic equipment and telehealth.
- New Brunswick is very fortunate to have committed, hard working and motivated people who support a vision for a single provincial cancer control accountability framework, and who want change and who strongly endorse the priority areas identified by the Cancer Services Action Committee.
- Important as well is the commitment of the Minister to implement a cancer strategy and evidence based practice.

Yes, the challenges are many but so are the opportunities.

6.2.5 Risks/Threats

What are the major risks and threats to New Brunswick in cancer control? How might they impede the development of a provincial system?

- A major threat is the burden of the disease itself which continues to grow due to aging, prevalence (therapeutic advances) lifestyles, and risk factors in youth. Does the province have the conviction and the resources to effectively move forward and respond to this burden or will it allow its relentless advance to go unchecked?

- Inequalities and inequities in the present system mean not only disillusionment for some but also a challenge to shift them to support other initiatives which in itself could have a negative impact.
- Rising costs of care due to new technological developments. Drugs are a case in point where driven by increasing prevalence and new evidence based therapeutic developments, costs have increased enormously over the past five years and promise to rise even at a greater rate over the next five years.
- Human resource shortages pose a significant risk to the integrity and sustainability of the system. Shortages impede timely service delivery and could also compromise available time for people to actively participate in a new provincial structure. If unresponded to, the Human Resources issue will only get larger.
- There is a substantial risk of disillusionment if nothing is done, particularly in view of the need and the expectations that have been created.
- If no action is taken, there is a clear risk that New Brunswick will be left behind the rest of Canada and the world and will experience even greater challenges as the number of new cases and mortality continue to rise.

6.3 Issues/Challenges

The reviewers had the opportunity to gather information of a general nature and in all areas of cancer control. Our focus was on understanding the issues in each area that may have relevance to the need for a provincial cancer control accountability framework. There was no in depth analysis of each area of cancer control with the possible exception of systemic therapy where for reasons of cost and safety, as well as the expertise of one of the reviewers, more attention was given. As a consequence, this issue analysis is high level and consistent with the terms of reference of the review to propose an accountability framework. Each area of cancer control will be touched upon in a manner to indicate the importance of a provincial structure with some general recommendations.

6.3.1 General Issues/Challenges

The following represents an overview of issues and challenges that were quite uniformly expressed through written submissions and interviews.

- There is significant fragmentation in the system amongst regions, facilities, and communities with poor linkages between physicians, oncologists and the various levels of care. The patient care process varies region to region very much depending on where you live or the part of the system where you receive your care. There are similar variations in access, centre to centre, and through the care process from the point of entry. Fragmentation also means the absence of critical masses of expertise in centers of excellence.
- Some individuals expressed concern about safety of care in chemotherapy. In some areas systems are in place and in other areas there are none. There is no overall provincial approach to safe medication practices nor is there coordination amongst the initiatives that have been undertaken in this area.
- Stakeholders are concerned about New Brunswick's poor performance as measured by incidence/mortality in several areas compared to the rest of Canada and particularly to the Western Provinces.
- While there are exceptions, in most areas of cancer control there is no provincially coordinated initiative – key examples would be standards and clinical practice guidelines. Other examples would be human resource planning, cancer research and the availability of strategic information arising from surveillance. There is also comparatively isolated regional and facility planning with different strategies in different regions. Regions also prioritize differently which contributes to variation, fragmentation and a haphazard approach. There are no criteria for designating levels or to serve as the basis for siting services.

- There is no clear mechanism to relate to the department as a whole and regions are expressing concern about the ‘vacuum’ at the top, the absence of a ‘game plan’ and asking the question ‘who is in charge’. There is a perception that the department struggles with making cancer related policy decisions and sometimes does not know where to turn to assess proposals.
- Many patients and providers are concerned about punitive drug costs and that the standard of care is being adversely affected by ability to pay. The same punitive approach does not apply to other therapeutic modalities.
- There is the challenge of adequately serving anglophone, francophone and aboriginal cultures in a needs-based and sensitive way.

6.3.2 Specific issues in various areas of cancer control

- **Planning and Priorities**

While the DHW has established priorities with input from the Cancer Services Steering Committee, there has been no action on the five priorities and there is no vehicle through which the priorities can be effectively pursued. Stakeholders strongly expressed the need for ‘one plan, one path, one program’ – a unitary structure for the province. Through such a mechanism long range provincial planning needs could be addressed, there could be consistent prioritization amongst the regions, there could be clear definition of levels of service and what constitutes a provincial program. Through such a vehicle, what are sometimes difficult decisions could be made. The reviewers for example, had the opportunity to read a few provincial program proposals; brachytherapy, cervical screening and gynecology being a few examples. These will not be commented on individually but they exemplify the need for a provincial mechanism to establish priorities and make cancer control policy decisions. Long range capital planning, and the development and replacement for radiation therapy equipment are issues as exemplified by the varying state of equipment and the need to address CT simulator capacity.

- **Cancer Research**

Cancer Research is not well developed in New Brunswick. There is a small basic science program in cancer research at the Dr. Georges-L. Dumont Hospital and some limited clinical trials research in a few locations. Considering the importance of cancer research in determining policy and in enhancing recruitment and retention efforts (parenthetically there is the risk of losing two medical oncologists at River Valley due the lack of clinical trials support), a provincial structure is going to be required to determine the appropriate scope and depth of cancer research activities and the infrastructure that would be required to make it work. A more effective vehicle is also needed to interact with national bodies (ICR, NCI(C), CFI) to gain infrastructure support. A coordinated provincial approach to cancer research may enable the development of a cancer research foundation dedicated to raising money for this purpose.

- **Surveillance**

In addition to cancer research, surveillance is a key input into policy and program development as well as in the area of monitoring and evaluation. Surveillance therefore needs to be well developed and connected to a provincial cancer control structure. Neither of these is presently the case. It should be noted that in New Brunswick, cancer is not a notifiable disease but the registry is capturing a high percentage of new cases. Strong surveillance support is also needed for each cancer control element that should exist at the provincial level as well as to support clinical outcomes analysis and a consistent approach to staging.

To serve these interests the cancer registry needs to become more comprehensive in data capture and needs to be well integrated with other data bases. The current registry has three staff and there is insufficient support at the provincial level for epidemiologists to carry out the needed analytical

work to develop information to serve both provincial and regional structures. The current available resources are well below other comparable jurisdictions. Enhancements to these areas should be part of a multiyear development plan. It will also be important that New Brunswick surveillance activities be well connected to the Canadian Council of Cancer Registries and to the Canadian Cancer Surveillance Strategic Alliance – a partnership of Health Canada and CAPCA.

- **Human Resources**

There is not a dedicated and clearly defined mechanism for cancer human resource planning at the provincial level that is constructed based on needs (as determined by incidence, prevalence, standards and productivity expectations). There are also examples of maldistribution of health professionals with examples of a lack of concentration, of available expertise. There are examples of non-competitive compensation for some physicians both within the province and in comparison with others in similar jurisdictions. There are physician outliers both at the high end and the low end of compensation, indicative of significant internal disparity. There are also, a significant number of oncologists who are over the age of 55 and poor clinical trials support poses a threat. New Brunswick has recently succeeded in recruiting a number of radiation oncologists and medical oncologists, however, there are significant challenges that face the province in ensuring a stable cohort of manpower in these scarce specialities.

There is a marked shortage of these two medical specialities in Canada and recruitment is at present highly competitive. As previously stated a problem that was identified in the review is inconsistent approaches to funding oncologists in the province, particularly for medical oncologists, which would inevitably result in difficulty for both recruiting and retaining medical oncologists in the long term. A provincial approach to a fair, consistent and market-based funding structure for oncologists is highly recommended.

Of particular note was that oncologists fully qualified in the United States who are practicing in New Brunswick on temporary license currently suffer significant financial penalty whilst going through the very protracted process of completing their Canadian Examinations. Since these are well trained and well-qualified oncologists, this disparity in salary is a disincentive to recruiting these well-trained individuals and may have an adverse impact on their retention. Most provinces currently pay well qualified foreign medical graduates, particularly those from United States, at the same level as Canadian graduates, even though they are required to go through the process of sitting their basic medical examinations, their internal medicine fellowships and their medical oncology examination again.

Currently, New Brunswick will fund a speciality training positions in medical or radiation oncology if a successful candidate from the province obtains a seat in a program elsewhere in Canada. It would be more proactive and better linked to human resource plan if they were to negotiate a commitment of a funded position in one or more training programs into which a candidate for a New Brunswick appointment could be placed. This would be an enhancement of the number of graduates eligible for employment in New Brunswick.

Physicists and radiation therapists are also not paid at a competitive level and the payment of a retention bonus to radiation therapists had a negative effect on nursing morale. There is such a level of concern amongst physicists and RTs that a dedicated bargaining unit has been proposed for physicists, RTs and dosimetrists.

There are also insufficient numbers of appropriately trained oncology nurses and an insufficient number are graduating to meet needs. It is hoped that the nursing resource strategy will help

address this issue. A province / nation-wide shortage of pharmacists has created greater demands on the profession which has a major competitive market in the private sector. The need for clinical pharmacists in the delivery / administration of chemotherapy is imperative and the lack of such caused the cessation of chemotherapy services in 2 RHAs this past year. In 2002, 21% of provincial positions in hospitals were vacant. The supply of pharmacists will improve somewhat with recent additions of seats at Dalhousie University, but the expected continued high demand in the private sector will require competitive remuneration and attractive clinical opportunities by the hospital sector. Pharmacists will take on even more critical roles in developing effective cancer management and treatment programs.

Notwithstanding a net increase in the number of physicians from 1997 to 2003, there are serious human resource concerns in all key oncology disciplines which adversely impacts on the provinces' ability to deliver timely and accessible care – and without a provincial approach to planning in this area it will only get worse. There are of course significant HR challenges across Canada, so the solutions are not easy. Those provinces that do not have a good planning process in place will be disadvantaged.

New Brunswick needs to recognize the interdependent nature of oncology HR issues and develop a specific plan for the key disciplines of oncology nursing, medical and radiation oncology, radiation therapy, physics and pharmacy, using accepted oncology needs based planning standards that take into account both workload and productivity. Such a plan should be connected to the total provincial cancer plan and CSCC and CAPCA efforts. New Brunswick should actively participate in the HR database development. The latter will provide strategic information to define future HR needs and enable the province to be better positioned to plan recruitment and to provide information to technical training schools, colleges, universities and both undergraduate and postgraduate programs. Further consideration should also be given to financial incentives for recruitment and retention and an oncology compensation system that is equitable and reasonably competitive and is defined in written contractual agreements. The concentration of scarce human resources in centers of excellence should also be a strong consideration in future planning. Attempts should be made to develop an affiliation with a medical school such that some postgraduate training could be given and recognized in New Brunswick. The availability of elective rotations may also be helpful in generating interest in locating in New Brunswick for oncology practice.

In any arrangement there needs to be more emphasis on cancer control human resource needs and the acceptance of some social responsibility rather than just on academic departmental needs. Some effort might also be made to target funds for oncology slots over and above present approved positions. Subsidized education and relocation grants may also be of assistance. In any human resource planning structures both anglophone and francophone medical education coordinators should be included.

- **Financial**

The reviewers were provided with a general assessment of cancer costs which included inpatient/day surgery, radiation oncology, chemotherapy clinics, drugs, physicians' salaries as well as breast and cervical (pilot) screening. This totalled just over \$61,000,000.00. In any province it is very difficult to aggregate all cancer costs since they are embedded in general operating budgets and the financial resources used, permeate throughout so many areas of an institution. Without case costing this will never be done well and of course it makes interprovincial comparisons impossible. Even provinces with cancer agencies only have well developed budgets for a segment of cancer control with anywhere from 40-60% of costs not being captured in agency budgets. In general, costs for inpatient care, surgical services, diagnostic services, palliative care services and home support lie outside of

provincial cancer agencies budgets. The issues for New Brunswick in the financial area are more concerned with the absence of a provincial structure. Some of these issues are:

- Without a clear plan and a set of priorities the distribution of financial resources can be ad hoc and sometimes determined by political pressure leading to inequities.
- The absence of clear performance expectations from the provincial level means that regions will distribute global resources according to their own priorities which may differ from region to region.
- Within the regions there is also competition for resources amongst various programs. This can lead to differing uses of financial resources among regions due to different approaches to prioritization with resulting variation.
- The per capita costs for chemotherapeutic agents in New Brunswick compare favourably with other well developed jurisdictions, however, chemotherapy budgets are within regional pharmacy budgets. Without a standardized approach to the use of chemotherapeutic agents at the provincial level, the regions determine themselves which drugs to use, resulting in differing practices. This variation is compounded by the fact that patients are expected to pay for their own oral chemotherapeutic agents outside the hospital system which not only leads to financial hardship but the risk of non-compliance.

Even with a provincial structure in place, it is unlikely that a dedicated and complete cancer control budget could be developed or would even be necessary for an effective program. There are of course some exceptions. Some areas lend themselves to a provincial budgeting approach such as screening programs, core support for research, a cancer registry with epidemiologic support, salaries for oncologists and chemotherapy costs. It is important however, that within a provincial plan with priorities, that a clear set of performance expectations and deliverables for cancer control be defined for the regions and spelled out in a performance contract. Part of this would involve having the regions develop a three year cancer control plan within the overall provincial plan.

- **Capital Resources (facilities and equipment)**

The reviewers were very impressed with the size and general ambience of cancer centers and chemotherapy units that were seen as well as the general state of capital equipment, particularly in the diagnostic area. The following are some issues that need addressing within a provincial framework.

- Considering the smaller size of the province, facilities are not as well concentrated as one might expect. This does not easily enable the development of critical masses or centers of excellence.
- Plans are fairly well developed to relocate and expand the chemo unit (ambulatory) at The Moncton Hospital. It would have been preferable to unify this unit within The Dr. Georges L. Dumont Hospital. As a minimum these two facilities should work very cooperatively together and be considered a single integrated program within the region. It is also difficult to recruit to smaller units and the workload for the single medical oncologist at The Moncton Hospital is excessive.
- While capital equipment resources for diagnostic services are good – in fact there may be excess capacity for some modalities which means capital resources may not be as available for other needy areas – there is need for a coordinated provincial approach to capital equipment planning. This is particularly true for radiation therapy equipment. There is a need for coordinated and standardized development between the two units expressed as a multiyear replacement and development plan based on reasonable productivity standards, technological advances and predicted obsolescence all

tied to the percentage of present and predicted incident cases that will benefit from radiation therapy. The scope should include equipment for assessment, treatment planning as well as radiation therapy itself. This strongly implies the need for a provincially led and coordinated approach to radiation therapy within which a number of other issues can be addressed. These are described later.

- **Cancer Prevention**

The reviewers did not delve deeply into the present state of cancer prevention in New Brunswick. However, a few observations would be in order. There are several good initiatives including a provincial anti-tobacco strategy, a healthy learners program, a community action partnership on healthy eating and physical activity and a community nutrition information program. Noted also was the linkage to chronic disease prevention and the Atlantic Wellness strategy. During a site visit the reviewers noted the cancer risk screening clinic at The Moncton Hospital.

As New Brunswick moves forward with its cancer prevention strategy, it will be important to define measurable targets in cancer prevention and actions to support their achievement based on evidence of effectiveness. It will be important to build strong linkages to the CSCC and become part of the national primary prevention strategy and other national efforts as well as strong linkages to the regions within a provincial plan to achieve program delivery. Cancer prevention should be part of the provincial cancer control accountability framework including a provincial group and a seat at the leadership table to ensure integration with other cancer control activities. This structure should include public health both at the provincial and regional levels. These initiatives should assist in addressing the comparatively high incidence and cancer causing risk behavior rates in New Brunswick.

- **Cancer Screening**

There are many positive attributes to the Breast Cancer Screening Program including a provincial structure, standards, performance expectations, a high percentage of those at risk who are screened and quality assurance activities. However, there is only partially dedicated staff support and no clearly defined medical leadership at the provincial level. There is a need to improve on the percentage screened of those at risk in rural/aboriginal communities and to build the cancer registry further to enable it to capture screening data.

In general, there is not an organized provincial cervical screening program. Pap smear testing and laboratory interpretation are decentralized throughout New Brunswick. Through a CHIP grant however, several health authorities worked together on a pilot project to implement a comprehensive cervical screening program for four regions. This was done because of the comparatively low percentage of those at risks who are screened and because of a desire to standardize, improve quality control and improve follow up. Through this effort, momentum has been built towards a provincial approach. Consideration should be given to a provincial program that amongst other things could include centralization of cervical cytology interpretation. However, the mortality rate for cervical cancer is low at 3/100,000. The priority given to this has to balance the momentum that has been developed against the benefits and priorities of other cancer control initiatives. The program submission would also have to be more robust.

Colorectal screening is occurring in a random and ad hoc manner. Evidence now clearly indicates the significant reduction in cancer mortality in those screened through an organized system. Again it is a matter of provincial policy to determine the priority of this in relation to other initiatives. Suffice to say that CAPCA, CSCC and CCS/NCI(c) have fully endorsed the development of organized

approaches to colorectal cancer screening and that costs are being incurred for screening that is currently taking place, in an adhoc manner.

Not unlike cancer prevention, policy regarding screening should be addressed at the provincial level as part of a provincial cancer control accountability framework.

- **Diagnosis**

In general, there is well developed diagnostic service capacity in New Brunswick, particularly in areas such as MRI and CT scanning with timely access for cancer patients. There is interest in acquiring PET scanning capability. There is a New Brunswick Association of Pathologists and pathologists do participate in multidisciplinary rounds. Some raised concerns about variation in pathology practice, the need for better developed tumour site expertise and the need for a provincial approach to cancer pathology standards/referral mechanisms. Issues such as consistent and uniform staging comparable to the rest of Canada as well as standardized synoptic and electronic reporting were also raised. Consideration might be given to establishing a formal provincial network in cancer pathology as part of an overall provincial structure.

- **Treatment modalities (radiation therapy, systemic therapy and surgical oncology)**

There are several issues in common amongst these important modalities of cancer treatment. Again with the possible exception of systemic therapy it was not possible to undertake an in depth analysis of each. A few issues will be touched upon that have implications for the development of a provincial structure.

- **Radiation Therapy**

Some of the issues that characterize radiation therapy have already been touched on in the human and capital resource section. There is a reasonable level of machine capacity relative to needs. However, there are some waits for access at one centre that are longer than accepted standards largely due to radiation therapy technology shortage.

Radiation services are divided between two centers – one in Moncton at the Dr. Georges-L. Dumont and another at the Saint John Regional Hospital. It would have been preferable considering the size of New Brunswick to have had one large radiation therapy center to allow for the presence of a critical mass of experts, some tumour site specialization, and more concentration of high technology diagnostic and therapeutic equipment. The present arrangement is not likely to change however. This division without a cooperative framework or a provincial structure has led to a lack of standardization for treatment, productivity, common definitions and principles for access/waiting times. There are inequities in resource distribution and in compensation arrangements for radiation oncologists. There has been less than full cooperation between the two centers which is surprising considering that both make up an important provincial resource. The divided system without optimal cooperation and the absence of a provincial structure contribute to less than optimal coordinated provincial planning for this service.

It will be important that these two units be considered a collective provincial resource and work cooperatively together within a Canadian system of radiation therapy standards (rather than by different standards emanating from different countries). It will be important that a long term radiation therapy resource plan be developed within a cooperative provincial approach and within unified provincial leadership. Such a structure

should also address the development of standards for all areas of radiation therapy practice that can guide provincial planning. The work of the CAPCA Radiation Therapy Policy Advisory Committee in this area should be taken into consideration as well as the best practices of those provinces who have undertaken a provincial approach. Such a structure would also be useful in determining the scope and siting of a single one of a kind program such as brachytherapy. Waiting lists should also be managed as part of a provincial system.

- **Systemic Therapy**

Not unlike radiation therapy there is no formal provincial systemic therapy program nor is there a single unified provincial chemotherapy budget or standards for safe chemotherapy practice at the provincial level. The RHAs determine their own formularies and there are variations in the use of drugs throughout the province. Many patients are not covered for the expense of oral drugs which produces financial hardships and the risk of non-compliance. Regional health boards in the smaller regions have found it difficult to support the costs of cancer drug therapy, which has usually been recommended by one of the larger centres. Patients moving from an oncology opinion in Moncton, Fredericton or Saint John or where possible, are treated in smaller hospitals where funding is scarce. Although to date, we are not aware that any patients have been denied therapy, it would make more sense for the funding to travel with patients and it would be appropriate for hospitals to access a comprehensive provincial drug budget. This will allow for excellent provincial pharmacoeconomic planning and prompt implementation of new therapies. Coverage for “take home” drugs dispensed through retail pharmacies is a burning issue for patients in New Brunswick. This was brought to the attention of the reviewers by patients, physicians and charitable organizations, during the review. It is recommended that New Brunswick consider incorporating oral chemotherapy drugs in their hospital budget and dispensing them free of charge to patients. This allows for consistent and equitable access to effective therapies and at the same time protecting patients’ safety when receiving complex combinations of chemotherapy regimens. Overall costs may be reduced by avoiding the common patient choice of accepting the more costly therapy given intravenously rather than oral therapy, likewise managed by a provincial oncology drug budget.

Patients have identified challenges in paying for a variety of hormone therapies for breast and prostate cancer; however, developing a budget for these drugs at present would impose severe strains on the DHW. The current approach of patients and their insurance companies covering part or all of the costs of these agents is not unreasonable, when compared to standards elsewhere in Eastern Canada, where similar practices prevail. The problem is somewhat more difficult in New Brunswick because of the very limited coverage for the costs of drugs.

Patients expressed a deep concern about the lack of coverage for supportive drugs such as granulocytes colony stimulating factor and erythropoietin for management of low white blood cell counts and anemia. This again is a very costly undertaking and in the majority of provinces across Canada, these drugs are not covered by the hospital system, but through a combination of drug benefit plans and third party insurance coverage. Unfortunately, no change could be recommended at this point.

Concern has been expressed about safe chemotherapy administration in remote locations because of low volumes, pharmacy staffing shortages, workload pressures and the absence of provincial medication safety standards. A provincial approach to systemic therapy would

necessarily incorporate written policies and procedures for the safe administration of chemotherapy and the safe handling of these potentially toxic anti-cancer drugs. This is a major advantage of a provincial approach to cancer control and would necessarily require clearly stated standards for physicians, pharmacists and nurses checking all chemotherapy orders linked to review of haematological and biochemical blood tests, written protocols and guidelines, as well as established processes for confirming that therapy is being delivered in the appropriate dose, schedule and diagnostic category to each patient. Likewise, safety standards for handling of these drugs need to be written and available to all centres. Education programs for staff to ensure understanding and compliance with these guidelines would be an important step. The reviewers would like to comment that some centres do this well, but there are some inconsistencies that need to be addressed in order to support optimal protection of patients in the long-term.

Information technology support to provide access to all current treatment protocols would be of enormous benefit and should be the goal of a provincial approach to excellence in systemic therapy.

There is also no provincial approach to nursing certification; however, some regions have addressed this issue by developing their own process. In some regions chemotherapy orders do not provide clear direction to nursing or pharmacy staff. The safe mixing of chemotherapeutic agents particularly in remote areas is a significant issue.

The increasing prevalence of cancer and the emergence of new chemotherapeutic agents every year mean substantial cost increases each year for this area of treatment. This underlines the importance of standardization, a provincial formulary and central coordinated purchasing for these agents. Treatment guidelines should be developed on a collaborative provincial basis and they should be reflective of new knowledge in cancer therapy. The process of developing guidelines should be led by the experts in the province and should utilize available guidelines developed by larger provinces, such as Ontario and British Columbia.

The oncologists in New Brunswick have expressed an appreciation of some of the flexibility they have around access to new drugs. This is a commendable approach that should not be undermined by the development of guidelines to assist in the treatment of the most common types of cancer. Overall, the cost of intravenous cancer drugs in New Brunswick reflects patterns elsewhere in Canada and was not considered to be excessive.

Unlike surgery and radiation oncology (where workload is driven by growth in incidence of 2.5-3% per annum), the growth in systemic therapy is driven largely by the expansion of new and effective drug programs that either cure cancer or prolong life for patients living with cancer. Consequently, the growth in numbers of patients receiving active treatment in Canada is treble or quadruple the rate of growth in incidence and typically runs between 8-10% per annum. This growth rate drives workload for physicians, nurses and pharmacists and drives growth in the cancer drug budget.

In planning for cancer drug budgets, Ministries of Health can anticipate that a growth rate more than 20% per annum is typical in this rapidly developing and dynamic area of health care. Access to new drugs over the last ten years has led to significant improvements in survival for early breast cancer, metastatic breast cancer, both early, newly diagnosed and

advanced stage colon cancer, lymphomas, leukemias and a variety of other rare cancers. Although costly, this has led to more patients' surviving longer and in some circumstances, more patients continuing with active treatment for longer periods. There are inequities in workload distribution amongst medical oncologists (particularly at The Saint John Regional Hospital and The Moncton Hospital) and insufficient support for clinical trials which poses a significant recruitment and retention risk. There is also not a clear provincial policy on the siting of the various levels of care for chemotherapy administration throughout the province. This not only compromises policy decisions about resource and staffing distribution but may contribute to unsafe practice. People do not know what should be done, where it should be done and why. There is also a need to improve coordination between the unit at The Moncton Hospital and that at The Dr. Georges-L. Dumont Hospital. These two units should be considered part of a single service and improved radiation oncology consultation to The Moncton City Hospital should also take place.

Notwithstanding these many issues, there have been helpful initiatives undertaken in some of the regions. Some have addressed the development of safety manuals, some have introduced nursing certification programs and one region has posed a level of care approach to more clearly define the roles, responsibilities and relationships amongst chemotherapy providers.

Remarkably, there is no provincial forum within which medical oncologists, nurses and pharmacists come together and address these issues within a provincial cancer accountability framework. Several elements of a provincial systemic therapy program/network should be established to address these very important and significant issues. Through such a structure linkages should be further built with CAPCA's systemic therapy policy advisory committee and the interprovincial drug strategies working group to take advantage of work on standards, guidelines and work on a core clinical dataset.

- **Surgical Oncology**

As previously mentioned, there is reasonably well developed surgical oncology capacity in terms of OR's and beds and there are several committed surgeons with skill and a high level of interest in further enhancing surgical oncology practice. They expressed a need for some concentration and coordination of service delivery for rarer forms of cancer and for some of the more common cancers. Several felt that breast, lung, colorectal and prostate cancers lend themselves to an interdisciplinary programmatic approach where there is some concentration as well as coordination among the elements of cancer control such as prevention, screening, diagnosis, treatment etc. They also expressed the view that rarer forms of complex cancers such as liver, pancreas and stomach should be dealt with in one location. They were also concerned about the absence of a surgical oncology database and the need for outcomes analysis support so that current levels of performance could be better understood and serve as the basis for continuous improvement. They felt that the formation of a provincial surgical oncology network connected to a provincial accountability framework would be a positive development and would enable a better connection to CAPCA's surgical oncology policy advisory committee where some progress is being made with a database. It would also enable a linkage to the developing core clinical data set under the aegis of the Canadian Cancer Surveillance Alliance.

The review team briefly addressed the issue of gynecology. A proposal has been tabled to establish this as a provincial program. Currently gynecology is divided between Saint

John and Moncton. Following models developed elsewhere it is suggested that gynecology be a part of a provincial surgical oncology network rather than a distinct provincial program. The principles of practice for surgical oncology have a great deal in common with gynecology as they do for a number of other surgical subspecialties that should also be part of this structure.

- **Clinical Practice Guidelines**

No coordinated and standardized effort towards the development of clinical practice guidelines has been undertaken in the province of New Brunswick. As a result, there is no standardized basis to guide clinical decision making or resource use. Practice can therefore vary from person to person and region to region. Some have taken advantage of the web based guidelines that have been developed in other jurisdictions throughout Canada and have used these to guide their own practice.

It is well known that the consistent application of evidence based practice will lead to better outcomes as measured by cancer mortality and survival. While New Brunswick should not 'reinvent the wheel', it should create a structure through which there can be review and adaptation of guidelines developed elsewhere and have them made suitable for consistent application throughout the province. New Brunswick simply does not have the depth or diversity to enable these to be developed from "scratch" in the province. And in fact, there is no need to do this considering that the "world of oncology" is using the same evidence to craft guidelines. It should also be noted that both CAPCA and CSCC have combined efforts to create a Canada-wide approach to guideline review and adaptation. New Brunswick should be part of this process by establishing a provincial group and a leader – connected both to the cancer control accountability framework and to the aforementioned Canadian wide effort.

- **Palliative Care**

There are several positive developments in palliative care for Canada and New Brunswick but there continue to be issues. The CSCC has identified palliative care as one of its priorities and the Research Action Group of the CSCC has placed palliative care research as its number one priority. National norms of practice in Hospice Palliative Care have been adopted in Canada and these are being used to guide developments across Canada. There are however, significant unmet needs in palliative care across Canada. Fifty percent of cancer patients will die within five years and need access to these services. Yet only 15-25% of patients have access to programs and only 5% have access to the professional expertise they need.

New Brunswick has a few major hospital based palliative care units as well as some volunteer hospice based programs in some areas of the province, the latter being described by some as 'patchy'. There is a provincial palliative care association and some very good work has been done in Region 2 which could be extended and be part of a provincial system. There continue however to be gaps and issues that characterize palliative care which include:

- A relatively poor knowledge base among providers and the public.
- A greater emphasis placed on curing than is placed on the needs of the dying and their families.
- Limited access and poor coordination.
- Limited capacity.
- The need for more support for end-of-life issues and bereavement support.
- The need for more education, training and support for volunteers.

- The need for better integration with other elements of the cancer program.
- The need for earlier referral.
- The need for provincial standards for palliative care as well as for pain and symptom control.

Apart from the Hospice/Palliative care association, there is no provincial structure to develop or adopt standards, to achieve coordination or to link with other elements of a cancer control system. The absence of a provincial structure also poses a serious handicap to policy development as well as coordinated provincial planning to meet growing palliative care needs. A provincial palliative care group linked to a cancer control accountability framework needs to be put in place for New Brunswick. It is suggested that not unlike the CSCC that supportive care and psychosocial oncology also be part of this structure. This would also enable a good connection to the rebalance focus action group of CSCC which is structured in a similar fashion.

- **The Care Process**

Specific aspects of care have been dealt with in other sections. This particular section is concerned with the overall coordination of care from the point of entry, movement through the system and ongoing care in the community. Patients and providers expressed the view that care is good when patients finally get into the cancer centre and that follow up through the extramural program is also very good. Several key issues were identified about the overall care process however:

- Care is not systematic, it is fragmented.
- Care and practice vary from physician to physician and region to region.
- Care depends very much on individuals and their particular knowledge base.
- The role of family physicians in the overall care process is not clear in areas such as detection, diagnosis, treatment, and referral and follow-up.
- Patients get isolated from family physicians who do not always feel in the communication 'loop'.
- There is no reimbursement for travel and some experience too much travel time for what are sometimes brief treatments.
- Information to support informed decision making for patients and families varies.
- Referrals are dependent upon physician patterns rather than patients' needs.
- There is no time to address psychosocial issues and support groups are not uniformly available or consistent in their approach throughout the province.
- Patients and physicians often do not know where to go or how to 'navigate' through the system.
- There is a lack of clarity regarding roles/responsibilities and levels of care.
- Some have expressed the need for centers of excellence and a disease site focus for major cancers. The notion of some degree of centralization raises fears of restrictions being placed on the scope of care in some regions and conflicts with the notion of 'closer to home'. The issue of care in the community relative to accepted standards of practice must be resolved, and an appropriate balance achieved that supports consistent evidence based care. This means some degree of centralization but also strong linkages and evidence based information for communities.

During the review several solutions were touched upon. These included such things as:

- * The development of a patient navigation system.
- * The provision of consistent information to patients and caregivers about the care process and evidence based standards/guidelines.
- * The establishment of a network of traveling clinics in various parts of the province.
- * The development of a disease site focus for major cancers with linkage to various providers throughout the province.
- * Clear definition of the roles and responsibilities of all levels of care and care providers throughout the system and how they are connected.
- * Establishing a new model of primary care delivery that is interdisciplinary, patient centered and clearly connected to other levels of the cancer delivery system.
- * The development of comprehensive and strategically located community health centers which could serve as a hub or focal point for many elements of cancer control from prevention through to palliation. They could become a local coordinating resource for patients and for primary care givers effectively linking them with other levels and also become the focal contact point for information about all aspects of cancer control. Such centers could also serve as the 'home base' for a patient navigation system.

All of these solutions, and there may be others, have merit. This whole area of primary care should be addressed within the cancer control accountability framework by establishing a group specifically charged with the responsibility to address this issue. Such a group could also provide a useful connection to other primary health care reform opportunities for cancer in Canada and could also link to CAPCA's regular biannual community cancer conference program. The establishment of two area wide cancer advisory committees with appropriate management support could serve as the vehicle for coordinating the implementation of the changes in the care process.

7.0 THE SOLUTION - A PROVINCIAL CANCER CONTROL ACCOUNTABILITY FRAMEWORK

This section of the report deals with the proposed solution. This will encompass principles, the overall purpose (mission/vision) for the system and options. A limited number of options are identified with some discussion of the advantages/disadvantages of each (in keeping with the principles). A recommended/preferred option is described in considerable detail.

7.1 Principles

Considerable experience in developing cancer control systems is now available to guide the development of an accountability framework for New Brunswick. While many countries throughout the world and provinces throughout Canada still have a way to go, there are many lessons that have been learned that contribute to a body of thinking on critical success factors in any cancer control system. The published literature also provides useful guidance on what elements are important in producing the best possible cancer control outcomes. These sources of information, along with the stakeholder interview process held in New Brunswick, led to the derivation of the following principles:

- Clarity of mission/vision and overall purpose for the system that is supported and understood by all and serves as the basis for planning. A suggested mission/vision/purpose will be described later.
- The importance of a single organized system of cancer control that is unified, integrated, multilevel, clearly connected at all levels and which enables the consistent application of standards (including professional practice standards)/clinical practice guidelines leading to consistent and standardized regional and local service delivery. The system should be both vertically and horizontally integrated and derived through a blend of a top-down/bottom-up process. There should be recognition of the importance of critical masses and centers of excellence.
- The system should be patients' needs based and well coordinated from the point of entry into care, through all levels and for follow-up. Timely information should be provided that supports informed decision-making on the part of patients, their families and caregivers.
- There should be a well recognized process for the development of a provincial strategy (including goals and targets) that is based on evidence and which recognizes the key steps identified through the experiences of OECD countries – described elsewhere in this report. Within this there should be recognition that cancer control planning should be looked at broadly and that various elements are interdependent. This includes program, facilities, capital and human resource planning all of which should be well coordinated and carried out in a 'lock-step' fashion.
- A recognition that cancer control is a process – research to policy to practice if you will – and that the activities at all levels should be grounded in this recognition. In brief, policy and program development must be determined by data / evidence that are gathered through research and comprehensive surveillance. Surveillance also provides the support for evaluation / outcome analysis at all levels. The NCI(C) framework for decision-making in cancer control is a useful way of representing this process and is outlined in Figure 1.
- That the cancer control program should be broad-based including all recognized elements from prevention to screening, diagnosis, treatment, rehabilitation and palliative care, that each of these elements are linked / interdependent and that effectively dealing with them means the provision of supporting enablers such as research, surveillance, human resources, technology and planning.
- Overall leadership for the system should be clearly defined and the roles and responsibilities for all levels should be clearly spelled out and understood by everyone.
- The program should be provincial in nature accountable directly to the Deputy Minister and well coordinated with the relevant Department of Health and Wellness portfolios.
- There should be a performance measurement process in place for the system that fits within well recognized

Canadian and provincial frameworks and addresses the key elements of cancer control. Such a process can also serve as the basis for identifying performance targets.

- The program should be characterized by equity as it relates to access, funding, cultural diversity and the patients' right to receive care in the official language of their choice. With regard to the latter, patients should be well informed on matters of access and expertise so that in choosing the language of care they do so with full knowledge of any differences in the system. For example, patients may prefer care in a particular language but access may be faster in the language not of their choice. They should be so informed and allowed to choose.
- While it is desirable to have care delivered closer to home, this goal must be balanced by the need for consistent standards that are influenced by volume and the availability of expertise of a number of interdependent disciplines.
- The program should be transparent and inclusive. In recognition that no single organization can 'do it all'. A broad base of stakeholders, including survivors and Non-Government Organizations (NGOs) should be part of the process.
- There should be respect for the current Regional Health Authority system in New Brunswick with the development of mechanisms to achieve effective coordination with and involvement of key regional leaders.
- The system should be of the best possible quality and cost-effectiveness and compare favourably with other Canadian jurisdictions in achieving results.
- There should be respect for the report and the priorities of the Cancer Services Advisory Committee tabled in 1998.
- There should be well developed linkages within the 'Atlantic Region', as well as at the interprovincial and Canadian-wide levels. This includes professional associations, CAPCA and the CSCC.

Figure 1: Reducing the Burden of Cancer

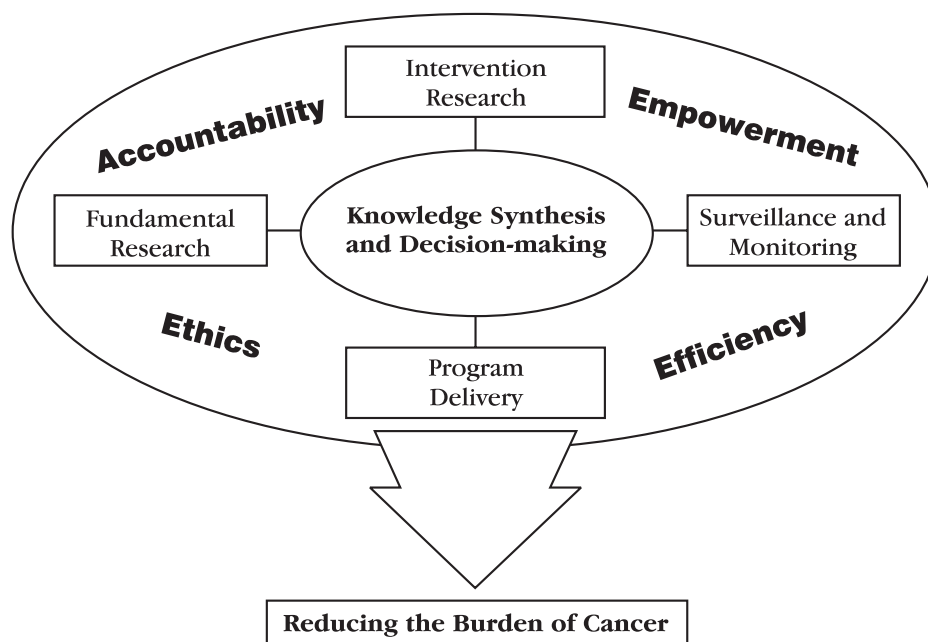


Fig. 1: National Cancer Institute of Canada (NCIC) Framework for controlling cancer, showing five categories into which all cancer-control activities can be assigned and four overarching principles. The central category represents the unifying purpose of cancer control: to reduce the burden of cancer.

7.2 Mission/Goals

To set the stage for a structure it is important to identify and understand what is to be achieved. What are the high level purposes and goals to be achieved for the system? It is not the purpose here to elaborate this fully – this needs to be done by the new leadership – but to simply emphasize its importance and provide some examples.

The desired measurable outcomes for the system are those that usually characterize any organized system of cancer control. These are to:

- reduce the incidence of cancer;
- reduce mortality and improve survival;
- improve the quality of life of those living with cancer.

This generally means the achievement of goals such as:

- reducing the risk for people to develop cancer;
- diagnosing cancer early;
- providing patient centered evidence based and consistent care.

Drawing on the previously stated principles, other goals might include:

- tackling inequalities by delivering equity in care and access;
- an integrated approach to planning and improvement for all elements of cancer control;
- high quality / cost-effective and comparable services;
- evidence-based practice through the right professional support and care at the best possible standard;
- recognition for cultural and language diversity;
- patient and stakeholder involvement;
- cooperation and commitment across the system.

The purpose of the new structure might be:

- to oversee the development, deployment and evaluation of the cancer plan / strategy;
- to ensure the plans' coordination and integrated implementation;
- to advise and inform government and all stakeholders on matters related to cancer-control;
- to serve as the vehicle for coordinating cancer control efforts with the rest of the provincial health system as well as with the Canadian wide cancer control activities.

7.3 Options

As previously mentioned, there are a limited number of options that can be considered. Within some options however, there are choices between different approaches that can be taken – options within options if you will. Major elements of one option may also be shifted to another. The key is assuring that it all fits together and is consistent with the principles previously outlined. Four options are presented with a brief comment on the pros and cons of each. A preferred option will be described subsequently in considerable detail.

The range of options includes the status quo at one end and a full provincial cancer agency at the other with two gradations in between.

7.3.1 Option #1 – Status Quo

This option retains the currently structured Cancer Care Steering Committee supported by the presently available staffing arrangements within the Department of Health and Wellness. This option could be strengthened by the creation of sub groups that would address the priorities of the Cancer Service Action Committee as well as responding to requests for approval for new initiatives coming from the regions. While this option retains the integrity of the RHA system, it does not respond effectively to the previously enumerated principles, does not position New Brunswick to move forward in a timely fashion, places NB “out of sync” with other Canadian and World-Wide initiatives and of course it is doubtful that if this was a desired option, consultants would have been retained to propose a cancer control accountability framework. This option is, therefore, not recommended.

7.3.2 Option #2 – The Establishment of a New Brunswick Cancer Control Agency

This review includes a description of the various models in place throughout Canada. Eight out of ten of Canada’s provinces have a provincial cancer agency. They vary somewhat in scope, role in resource allocation and extent of decentralization. They are, however, more similar than dissimilar and as they progress they are developing more and more common elements. The most fully developed agencies have a governing authority (in the most complete sense), a CEO supported by a broadly based cancer control executive team who together are responsible for a provincial cancer control program encompassing prevention through to palliation. Responsibilities include governing and managing the operation of cancer centres, screening programs, registries, research and community oncology units and in some cases provincial programs in radiation and systemic therapy, as well as provincial coordinating networks in rehabilitation, palliative care, surgical oncology and community oncology. The role includes responsibilities for standards and clinical practice guidelines. The responsibilities to fulfill these roles are described in a cancer act or other enabling legislation and funding is provided directly to the agency by the Minister of Health. This excludes funding for hospital based care (surgical oncology, in-patient care) for primary care, diagnostic services and palliative care. An agency’s role in cancer prevention is usually part of a broader based provincial initiative.

Advantages

- The full development of a Cancer Agency would position New Brunswick with the majority of other Canadian provinces, most of whom have enjoyed success and positive outcomes as measured by cancer mortality and survival. It would also position New Brunswick more effectively within CAPCA and the CSCC enabling implementation of various Canadian-wide cancer control initiatives. This option would also meet most of the principles.

Disadvantages

- The implementation of a full Cancer Agency would represent a huge change for New Brunswick and would likely require the development of a special cancer act or the creation of other enabling legislation. This arrangement would also mean the delegation of responsibilities for cancer control to a body other than DHW. Although the Department of Health and Wellness could retain some involvement, it would be more remote and also would not facilitate effective coordination with the current RHAs system or DHW portfolios. An agency structure would create additional challenges because it ‘separates off’ one part of the structure and leaves the challenge of coordinating its role with that of the RHA which will retain governing responsibilities for a significant part of the cancer system. It would, therefore, threaten the integrity of and the governing role as presently defined of the Regional Health Authorities. There would be the additional challenge of adding significant resources – in this time of restraint – as well as ‘collecting’ resources within the current system and reassigning them to a provincial cancer agency.

While some may disagree, one has to wonder if provincial cancer agencies did not currently exist,

would they actually be created in the present environment. They were created through the '30s, '40s and '50s as consequence of the Cody Commission report which had concerns about radiation safety, standards, the importance of concentration of this resource and the anticipated costs. At the time regionalization did not exist nor had the importance of integrating all aspects of cancer control and service delivery, been fully appreciated. While agencies have been maintained and developed to meet these challenges, recent developments in health care governance and management – notably population based integrated systems of health service delivery with a greater emphasis on disease prevention and health promotion raise the possibility of other models that can be equally or possibly even more effective. The cancer agency model is, therefore, not recommended for New Brunswick.

7.3.3 Option #3(a) – A New Brunswick Cancer Control Network (managed)

This model encompasses many of the features of a provincial cancer agency. A cancer network can be defined as a structural framework to develop and implement a cancer control plan with a goal of delivering evidence-based and consistent cancer control – in this case throughout New Brunswick. It aspires to achieve a reduction in cancer incidence and mortality, improve survival and improve the quality of life of those living with cancer. It has the responsibility for strategy, plans, policy, priorities, standards, guidelines, evaluation / outcomes analysis, coordinates implementation and defines the roles and responsibilities of all components of the system from primary care to tertiary and back. The scope encompasses all elements of cancer control from prevention to palliation, as well as those things that enable including research, surveillance, capital equipment and facility planning and human resources.

The structure creates the performance expectations to be fulfilled by the current RHA structure for all elements of cancer control. It brings together a broad base of stakeholders and provides the unified linking central point of contact for all of those involved in cancer control, including providers, survivors, non-government organizations and government.

This approach requires:

- The appointment of a provincial cancer control leader reporting directly to the Deputy Minister of Health. This leader should also be a member of the RHA CEO council.
- The appointment of a cancer control leadership team comprised of the leaders of each of the elements of cancer control, including clinical practice guidelines and the enablers. Each of these leaders is responsible for a sub network of the particular element of cancer control which is provincial in scope and which involves the development of a strategies / plan for each element, as well as standards, policies and guidelines.
- The appointment of a cancer control executive which includes the provincial leader, area-wide subnetwork leaders and the cancer control secretariat. This group is responsible for coordinating implementation.
- The appointment of two area-wide cancer advisory committees led by each of the two major centers who are responsible for implementation and ensuring a seamless, patient centered delivery system – connected to all regions.
- The appointment of a provincial cancer advisory council reporting to the Minister of Health. This structure includes survivors, NGOs, government, area-wide cancer advisory committees and the provincial cancer control leader. It does not govern but is advisory and has input into the cancer control plan and can participate in evaluating progress. It is the single point of contact for all stakeholders.

This model requires strong core support from the Department of Health and Wellness with augmentation to the current staffing arrangements to create a robust secretariat. It also involves the provision of funding support to the overall leader, the leaders of cancer control groups, as well as support for regional structures. In short, it is a managed and supported network.

Advantages

- This structure does not require special legislation, the transfer of budgets, nor does it pose a threat to the integrity of the RHA system – in fact, it may enhance their commitment to cancer control.
- The network has many features in common with provincial goals and initiatives such as evidence-based practice, performance contracts, and performance indicators and is a population-based approach to comprehensive health service delivery.
- It positions New Brunswick to effectively connect within the Atlantic Region and with CAPCA and CSCC at the Canadian-wide level.
- It is interdisciplinary/inclusive/top-down bottom-up and provides the basis for recognizing cultural and language diversity.
- It can be implemented in a gradual and stepwise manner.
- It can meet most, if not all, of the principles outlined in 7.1.

Disadvantages

- It is a relatively new idea for Canada and there could be some unanticipated problems although these could be reduced by benefiting from international experiences, as well as the experiences of cancer agencies that have much in common with this approach.
- Human resource shortages in key areas of cancer control may compromise the ability to fill the leadership positions.
- While the budget for this arrangement is modest compared to the other provinces that have agencies, it could still be a challenge.
- It should be recognized that the structure, once well underway, will be proposing additional developments in cancer control that will require resources over and above the needs of the proposed accountability framework.

Option #3(b)

A variation on option #3(a), in addition to the other elements defined, including area wide cancer advisory committees, is to have a governing board for all elements of cancer control (plans, policy, standards, guidelines, performance contracts, evaluation, etc.) except regional service delivery which would be the responsibility of the RHAs. This would mean, however, that the Cancer Control governing authority would govern a small budget for provincial functions (including some provincial programs). While this arrangement may be perceived to add some ‘clout’ to the cancer system, it would tend to place responsibility at some distance from the Department of Health and Wellness and may not facilitate integration with the various Department of Health and Wellness portfolios. There is also the potential that an additional board could reduce the commitment of the RHAs to the cancer control program – the perception being that this ‘belongs to someone else’. It is the opinion of the reviewers that this arrangement would not add value, would constitute some degree of over-kill and would add to what are probably too many health boards in New Brunswick. There would also be additional time and costs associated with maintaining a board structure.

7.3.4 Option #4 – New Brunswick Cancer Control Network (loosely structured)

This option is similar to Option #3 but would be developed on a lesser scale. The key elements described for Option #3 would be in place but it would not constitute a managed and supported network. Rather it would be more of an advisory committee structure with a smaller secretariat. Certain selected areas could be given priority and some resources for implementation

In some respects, it would be similar to the CSCC in structure and secretariat support. The CSCC has

suffered because of insufficient implementation support and it is likely that this model would have the same fate in NB. Having said this, there could be some advantages such as:

- fewer resources would be required;
- it could be implemented gradually;
- it could progress to a full option # 3(a) over time.

Disadvantages would include:

- emphasizing certain areas could cause fragmentation and would fail to recognize the interdependent nature of cancer control elements;
- the pace of progress would be slow as it has been for the CSCC;
- borrowing on people's time and goodwill would lead to some frustration and disillusionment;
- this option would be perceived as a reduced commitment;
- it would be too 'soft' to give sufficient direction to the RHAs;
- New Brunswick would continue to lag behind the rest of Canada in Cancer Control Outcomes.

The reviewers do not recommend this option.

7.4 Preferred Option - A Managed New Brunswick Cancer Network

7.4.1 Introduction

A very general overview of this option has already been provided. What follows is a more detailed description of each component of the system and how it all fits together. The elements of the system have been constructed in a manner to recognize the unique needs and developments in New Brunswick including existing cancer services and the current design of the health care system. The reviewers have also drawn upon Canadian-wide and international experience / best practice.

7.4.2 Overall Structure

The overall structure of the proposed network is depicted in Figures 2, 3 and 4. Figure 2 outlines the key elements of the cancer control accountability framework in New Brunswick. Figure 3 includes this but adds the DHW structure and Atlantic Region/ Canada wide relationships. Figure 4 shows the network secretariat/ administrative support structure for the overall network. It is best described as a managed network that embodies sub networks for various aspects of cancer control and for service delivery coordination/ integration. The term 'managed' is used advisedly and is indicative of the importance of dedicated leadership and management support within a structured system. This is in contradistinction to a loose or less well defined network without sufficient management support and where effectiveness, based on experience in other jurisdictions, has been suboptimal. If the managed network option is chosen by New Brunswick, it could be identified as:

- the New Brunswick Cancer Control Network (NBCCN);
- Cancer Care New Brunswick (CCNB);
- the New Brunswick Cancer Control Program (NBCCP);
- New Brunswick Cancer Network (NBCN).

Of course, there are other naming options.

For purposes of this document, the reviewers have chosen to call this option the New Brunswick Cancer Network (NBCN). The word 'control' is not used because for some it has negative connotations. The phrase 'cancer care' is not used since it suggests a limited scope. The suggested name is simple, unique in Canada and is reasonably descriptive. So what are the components of the system, what are the roles of each and how do they fit together to make up the NBCN?

Figure 2 - NEW BRUNSWICK CANCER NETWORK

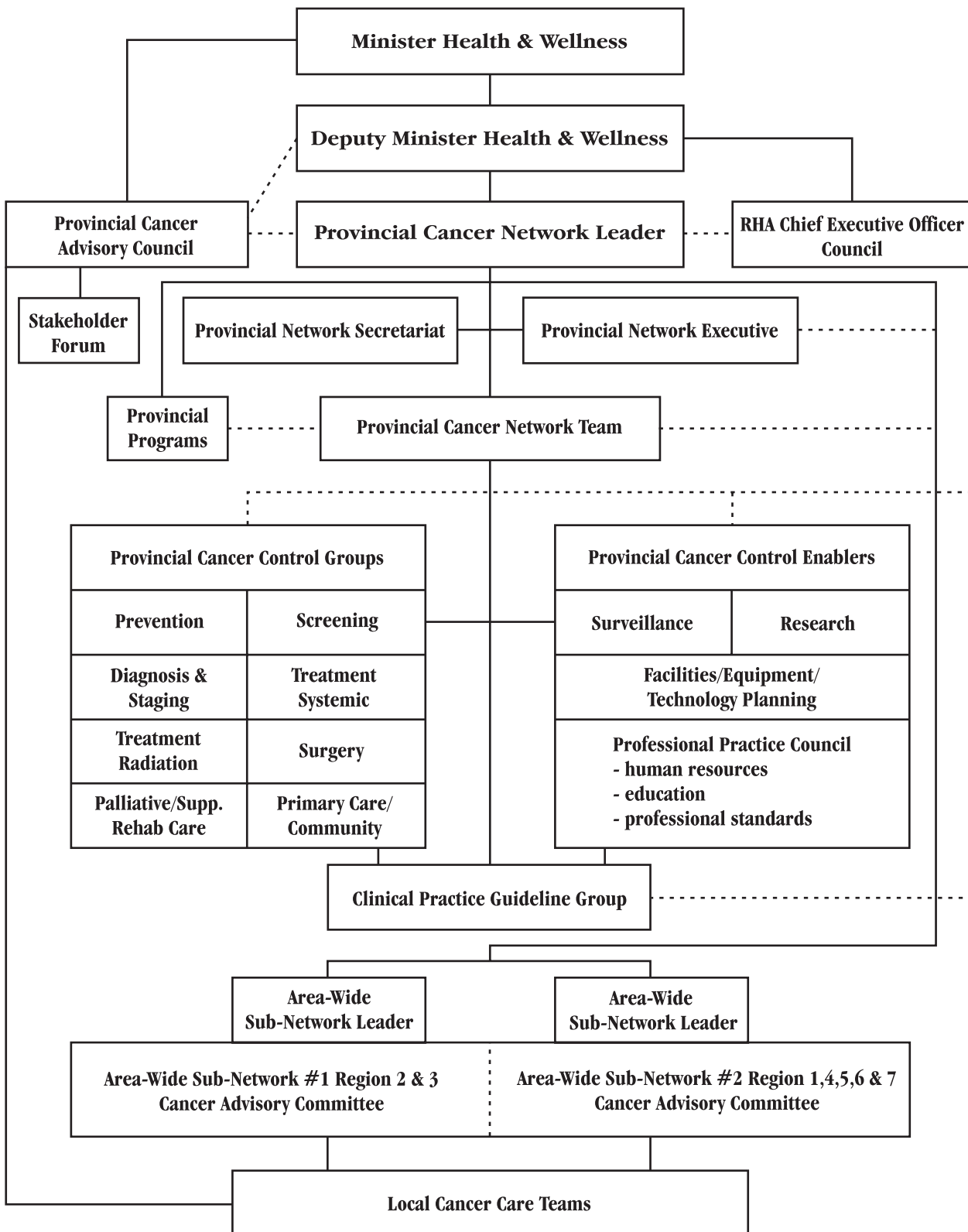


Figure 3 - NEW BRUNSWICK CANCER NETWORK/RELATIONSHIPS

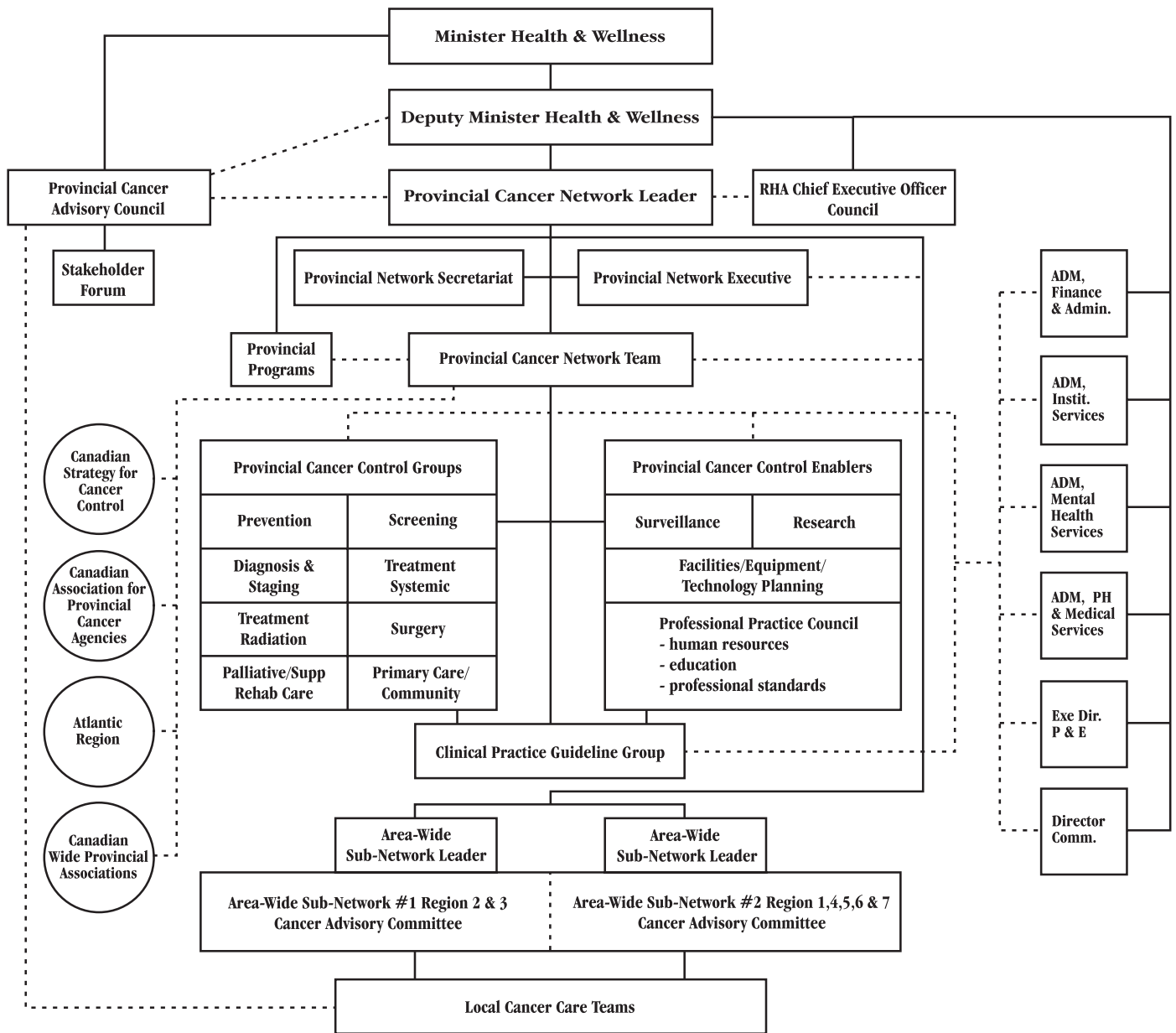
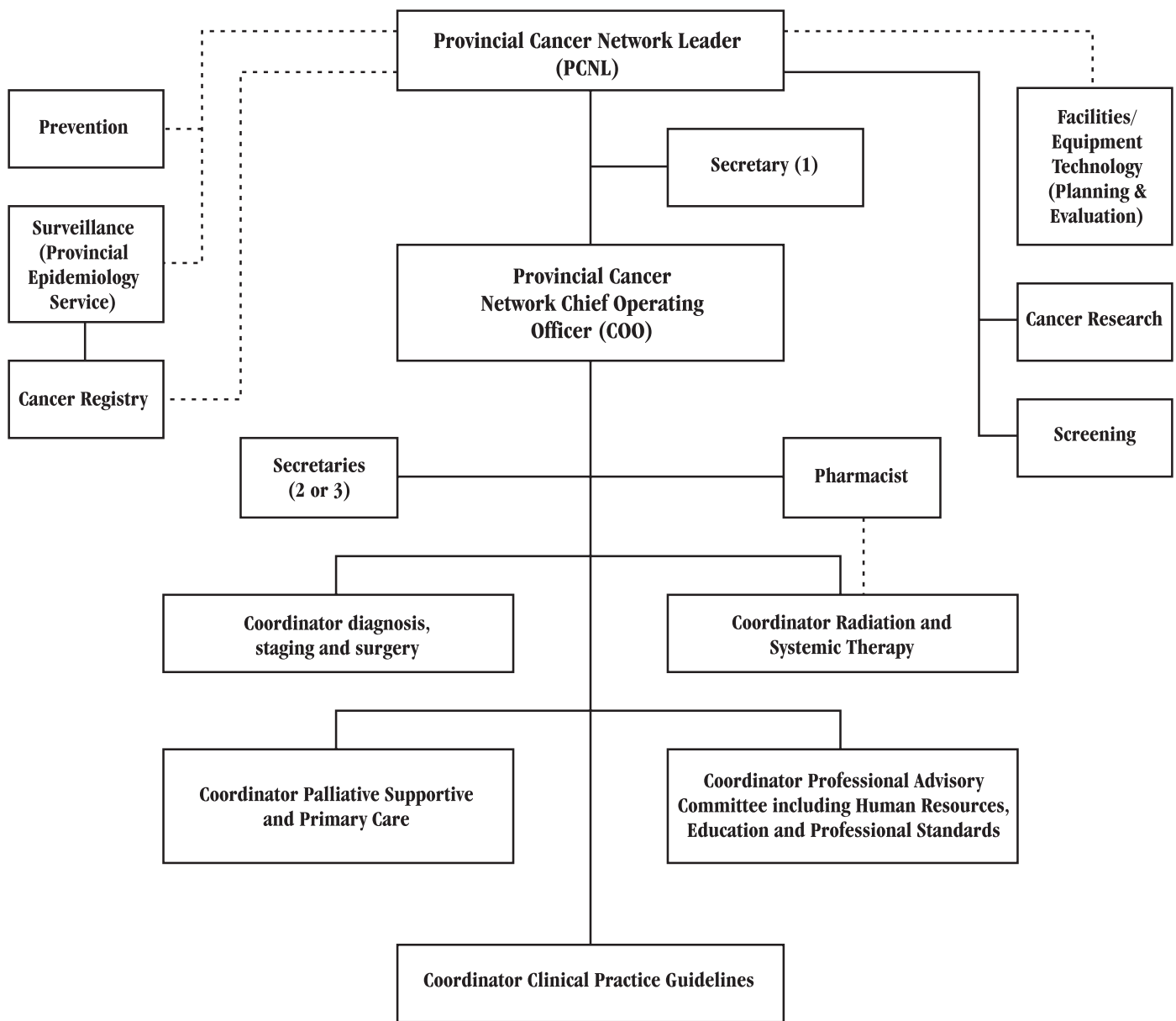


Figure 4 - NETWORK SECRETARIAT/ADMINISTRATIVE SUPPORT STRUCTURE



7.4.2.1 Provincial Cancer Network Leader

This is a key position in the NBCN – the identifiable ‘face’ for cancer control – fulfilling the role of Chief Executive Officer for the system – a role comparable to that of the leaders of other provincial cancer agencies / programs throughout Canada – although set within a network rather than agency system. The leader should have a sound knowledge and experience in cancer control with strong credentials in oncology bringing a high level of credibility to the position both within New Brunswick, as well as to the Atlantic Region and Canada-wide initiatives of CSCC and CAPCA. It would also be desirable that he/she be capable of leading a complex health care initiative. The leader must also possess the necessary skills to work with a diverse group of stakeholders and function in an interdisciplinary manner.

The Department of Health and Wellness should assume responsibility for the cancer network and provide for program implementation and funding. In this regard, the leader should report directly to the Deputy Minister. Such an arrangement would underline the provinces commitment and is consistent with high level reporting that characterizes other jurisdictions. Reporting at a lower level has tended to be an indication of lesser commitment and reduced effectiveness has been the result.

This position should be considered a peer with the CEOs of the RHAs and should have a seat on the RHA CEO council.

This position encompasses overall responsibility for the cancer control network and includes mission / vision / strategy, programs, plans, cancer control policy, standards, guidelines, performance measurement, performance contracts, implementation and the management of relationships with all groups and stakeholders. In this regard the leader would be responsible for:

- all network cancer control advisory groups and enabling groups;
- leaders of area-wide sub networks;
- the cancer control network leadership team;
- the cancer control secretariat;
- the network executive;
- managing the relationship with the various Department of Health and Wellness portfolios;
- provincial programs for breast, cervical screening and systemic therapy as well as others that may develop;
- working closely with the Provincial Cancer Advisory Council and the RHA CEO group;
- managing relationships with comparable programs in the Atlantic Region and being the provinces’ representative on the CAPCA board and on the Council of the CSCC.

This role encompasses substantial responsibility and time commitment. At the beginning it would probably be a full-time position but as the network matures the time commitment could reduce. The position should be supported by a well-developed secretariat with a lead position in the secretariat that is similar to a chief operating officer position.

7.4.2.2 Network Secretariat/Administrative Support Structure

Supporting the role of the Provincial Cancer Network Leader and the work of the cancer control groups / enablers / clinical practice guidelines is a secretariat/administrative support structure. This is comprised of the Provincial Cancer Network Chief Operating Officer (COO), coordinators and secretaries. For purposes of completeness and for defining the relationships of other Department of Health and Wellness cancer initiatives, positions for prevention, surveillance, registry, facilities/equipment/technology/ planning, research and screening are also depicted. Most of these are already funded (except research) and some require augmentation (surveillance, registry and screening).

7.4.2.2.1 Provincial Cancer Network Chief Operating Officer (COO)

This position is accountable to the PCNL and is responsible for providing leadership to the coordinator positions. The position will also work closely with the PCNL in providing support to the Provincial Advisory Council, to the executive and to the PCN leadership team. The position will coordinate the development of the annual plans and budgets and will, along with the Department of Health and Wellness portfolios coordinate the development of performance contracts / performance measures. A major role in supporting implementation of the new provincial structure will also characterize this position.

7.4.2.2.2 Coordinators

Five coordinator positions are recommended to support the activities of the cancer control groups, enablers and clinical practice guidelines. Each coordinator will cover one or more areas and in doing so will work with and support the chairs and the activities of the provincial cancer control groups, enablers, clinical practice guidelines. This will include policy analysis, goals/objectives/agendas and follow-up actions. In the case of Systemic Therapy and if a decision is taken to establish a unified provincial chemotherapy budget, as a minimum a full time pharmacist will be needed in addition to the foregoing.

With respect to other areas depicted in the chart, the following comments/assumptions are made:

- Cancer Prevention is part of a broader initiative and resources are in place at the provincial level. The cancer related aspects of prevention will have accountability to the PCNL and the leader will be part of the PCN team.
- Through provincial epidemiology a surveillance structure is in place and accountable within the Department of Health and Wellness. The part concerned with cancer surveillance will link to the PCNL and to the leadership team. There will also be a linkage to cancer prevention and to the registry for quality, data elements and strategic information development.

Three additional full-time equivalent positions will need to be added to provincial epidemiology to allow for strategic information development, evaluation and outcomes analysis.

- The Cancer Registry will report directly to the PCN leader. Registry staff developmental needs should be addressed to enable enrichment of data elements and integration with other databases.
- Although a research position is identified, further work is needed on a provincial cancer research plan before such a position is filled.
- That facilities / equipment/technology planning resources are already in place in the Planning and Evaluation portfolio of the Department of Health and Wellness.
- For Breast Cancer Screening, the need for a dedicated full-time coordinator reporting to the PCNL should be reviewed. There should also be a sessionally-funded medical leader who could be the chair of the provincial steering committee. Should a decision be taken to move forward with a provincial cervical screening program, and a colorectal screening program, then these along with hereditary cancer screening should be part of a unified provincial screening structure accountable to the PCNL. If the other screening modalities are added, then the supporting structure would need augmentation.

7.4.2.2.3 Secretaries

Four additional secretarial positions are proposed in this plan. One will provide support to both the PCNL, the PCNCOO, the Provincial Advisory Council and the PCN leadership and Executive teams. The other three will be a shared resource for the cancer control/enabling/CPG groups and may also provide support during peak workload times to the secretary for the PCNL/PCNCOO.

7.4.2.3 Provincial Cancer Advisory Council

This is also an important part of the structure that should be established, reporting to the Minister of Health and Wellness with strong linkages to the Network leader and the Deputy Minister. Such structures are being developed in other provinces and several of the OECD countries previously referred to have them. They are not a governing body. Rather, in brief, they are a vehicle to achieve the following important roles:

- provide an opportunity for unified and coordinated multi-stakeholder input being the single contact point;
- to provide advice on the provinces' cancer strategy and have the opportunity to review progress;
- to monitor / track the province's implementation of the priorities of CSCC and CAPCA;
- to coordinate a periodic and broader stakeholder forum (possibly every 2 years) to obtain wider input;
- ensure a coordinated and consistent approach to public and community involvement.

The Council should observe the following public participation values as defined by the International Association of Public Participation. These are:

- the public should have a say in decisions about actions that affect their lives;
- that public participation can influence the decision;
- there will be active seeking out and facilitation of the involvement of those potentially impacted;
- participants have a say in defining how they will participate;
- participants are informed of how their input affected the decision;
- participants are provided with the information to participate in a meaningful way.

The advisory council should be comprised of patients / survivors, non-government organizations (such as the Cancer Society, Breast Cancer Foundation, etc.) volunteers, other advocacy groups, as well as representatives from the two area-wide networks, the Department of Health and Wellness and the Network leadership. The exact size of the group would have to be determined based on the spectrum of stakeholders. The council would need well developed terms of reference, a process for appointment / terms of office, a mechanism for appointing the chair and a determination of the frequency of meetings. It may be useful to draw upon the experience of BC and Alberta both of which are currently in the process of establishing these structures. The council should have support from the secretariat.

7.4.2.4 Provincial Stakeholder Forum

A forum to enable stakeholders at all levels to periodically come together to be informed of progress and provide feedback on how the system is working, should be put in place. Planning for this activity should be the responsibility of the Provincial Cancer Advisory Council. It is suggested that this forum take place every two years and that it might involve 100-150 people. Such a forum could take on a facilitated workshop format to ensure effective and integrated input around key issues.

7.4.2.5 Provincial Cancer Network Team

This is a multidisciplinary group of 14-16 members reporting to the provincial leader and comprised of leaders of cancer control functions/programs/enablers, the two area-wide network leaders and supported by the secretariat. The Chair of the Provincial Cancer Advisory Council sits as an observer. At the provincial level, it recommends provincial cancer control goals, targets, strategies, programs, plans, standards, policies, guidelines and priorities, all of which should be expressed in a multi-year development plan in consort with other DHW planning processes. This structure is guided by a principle of cancer control, namely, Research » Policy » Practice. This group also serves to coordinate/integrate the various functions of cancer control in recognition of their interdependency. It also assesses and recommends on proposals coming from the field, from area-wide networks or from the various cancer control functions/enablers. It also hears and is sensitive to the perspectives of the Provincial Cancer Advisory Council and the RHA CEO Council. It advises on the requirements to be specified in the performance contracts for the regions which will serve as the basis for consistent and equitable resource allocation. It regularly reviews performance measures within an agreed-upon performance measurement framework and monitors progress towards achieving cancer control targets.

7.4.2.6 Provincial Cancer Control Functions/Enablers/Programs

The provincial cancer network team is served by a number of subgroups for each of the cancer control functions/programs/enablers. In general, the role of each of these groups is to recommend safe practice standards, guidelines and policies and propose a multi-year plan to address the needs for this particular area. This work is characterized by establishing goals and targets and monitoring performance. The goal is to establish the basis for consistent and equitable resource allocation to the regions. Groups should be established for each of the following areas:

- Prevention
- Screening
- Diagnosis
- Treatment
 - o Systemic
 - o Radiation
 - o Surgical
- Clinical Practice Guidelines
- Palliative/Supportive Care
- Research
- Surveillance
- Primary and Community Care
- Human Resources
- Facilities/equipment/technology planning
- Professional Practice Council (which should include education/information)
- Provincial Programs

The composition of each of these groups should be interdisciplinary and should be networked throughout the province. Some groups should include stakeholders who may have a particular interest, knowledge or involvement in the area. Examples of the latter would be volunteer involvement with supportive / palliative care and cancer society involvement with prevention and information. Groups should also involve appropriate DHW portfolio representation. For example,

public health should be part of prevention, medical services and medical education coordinators should be included in human resources along with medical and nursing resource advisors, and surveillance should include the provincial epidemiologist along with program analysis and evaluation. In addition, the leaders of each of these groups should be connected to Canada-wide initiatives of professional associations, as well as to CAPCA and CSCC. The Chair of the CPG group for example, should be connected to the joint CSCC/ CAPCA CPG initiatives. The prevention leader should be connected to the Prevention Action Group of CSCC. The leader of supportive and palliative care should be connected to the Rebalance Action Group of CSCC (which includes palliative care, psychosocial oncology and supportive care). Through these connections, NB can take advantage of work done elsewhere (as well as making a contribution) and will not necessarily have to develop de novo or reinvent standards. For example, with CPG's, NB does not have enough depth or concentration to have a large number of tumor-site specific subgroups (breast, lung, colorectal, prostate, lymphoma, etc.). Rather than attempting to develop its own site specific guidelines, NB can become part of a Canada-wide initiative and have a high level NB CPG group for purposes of adaptation (of guidelines developed elsewhere) endorsement and dissemination.

The scope of the review does not permit full elaboration of each of the areas of cancer control, however, there are some particular areas that are worthy of further elaboration. While the principle thrust of this document is networking, there are particular areas that lend themselves to a partial or full programmatic approach (note – we need to distinguish between a full provincial program and a provincial one-of-a-kind service – such as prostate brachytherapy).

Provincial Programs

Breast screening is a well-developed full provincial program and cervical screening for example could be developed along similar lines at the provincial level. There has been the suggestion that gynecology develop as a provincial program. It is the review team's opinion that this should be part of a provincial surgical oncology network, rather than be constituted as a provincial program. In an area such as systemic therapy, some provinces have moved forward to establish a full provincial program integrating all disciplines (medical oncology, pharmacy and nursing) and have a single unified evidence-based provincial chemotherapy budget with standardization of protocols and safety procedures. In this regard, there are three options for NB:

- a simple network for standards / guidelines / protocols / safety to serve as the basis for regional performance and resource allocation;
- the above, plus a single unified provincial chemotherapy budget;
- the above, plus full integration of staff with a provincial staffing budget for the key disciplines that are distributed to the regions.

Certainly, the first option should be implemented and the second should receive serious consideration. Even with provincial standards, there is the risk of some variation at the regional level which could lead to inequities and unbalanced use of a progressively increasingly expensive resource. A full provincial program, as defined in option three is probably not necessary.

Diagnosis

In the area of diagnosis, early attention should be given to cancer pathology, including standardization of reporting, electronic reporting and staging.

Radiation Therapy

There is significant division within the radiation therapy area. It will be important that a unified provincial group be formed to address radiation therapy as a single provincial resource. This does not mean a full provincial program but within the general terms of reference previously defined, the

development of common approaches to equipment planning and acquisition, staffing levels, wait list standards and management, as well as productivity standards for machines and personnel. This includes balanced distribution of workload and patient centered allocation of treatment time as a cooperative effort between the two centres.

Cancer Research

There is limited cancer research activity in NB. Considering its importance to cancer control and in recruitment and retention, NB should address the development of a cancer research plan. There should be provincial leadership for this and it may be valuable to get some assistance in defining a future research role by engaging the consulting advice of the ICR and/or CAPCA's research policy leader. Certainly, there is a need to address clinical trials – where more infrastructure is required. There are also issues as to how NB can tap into Canadian-wide opportunities and whether a dedicated research fundraising foundation should be created.

Surveillance

Surveillance is another key input into cancer control. Previous reference was made to the functioning of the present registry and the creation of information through analysis with an appropriate level of epidemiologic support. Both the registry and provincial epidemiology need to be strengthened to broaden the base of registry data, better integrate it with other data bases and allow for improved data/outcome analysis to support the needs of various disciplines and to provide information that will inform a cancer strategy and allow for effective evaluation.

Professional Practice Council

Most organizations have established either a professional advisory committee or council to provide interdisciplinary input. The RHAs in NB have such a mechanism as do some provincial cancer agencies. It is suggested that NB establish as part of the Cancer Control Accountability Framework, a Professional Practice Council. This would be an interdisciplinary body to lead a common approach to developing professional standards and to ensure coordination of professional roles. This will be important as it relates to human resources planning. It is suggested that this group play a role in interdisciplinary professional education, as well as patient education/information and establish a connection to C-CPEN – The Canadian Cancer Patient Education Network.

Primary and Community Health Care

Later in this document, more will be said about the development of a clear definition of service delivery levels. One of these is primary/community health care. There should be a specific interdisciplinary group that is structured to provide advice on how to further develop this important area that has such an impact on entry into the system, initial diagnosis, continuing care and follow-up. And yet, it is so often unstructured and disconnected. Many issues in this area have been repeatedly defined – some of which were referred to earlier – and include delays in diagnosis, lack of clarity as to who is in charge, sub-optimal follow-up care, poor communication between oncologists and primary care givers and difficulty in navigating the 'system' both for patients and caregivers.

An interdisciplinary primary/community care group can address these issues, as well as actively participating in all other aspects of cancer control planning. Such a group could propose and better define the role of strategically placed Community Health Centres which could be the focal point for patient navigators, as well as ensuring the development of primary health care in keeping with federal priorities/opportunities both of a general nature and those that are specific to cancer.

Human Resources

The area of human resources needs special attention. This important ‘enabling’ function could either be addressed through an interprofessional group specifically structured for this purpose or it could be an activity of the professional practice council. The latter may be preferable since it is appropriately structured and it would reduce the number of groups that need to be managed and supported. Wherever this responsibility is placed, it should be connected to the appropriate Department of Health and Wellness (DHW) portfolios include the medical education coordinators and connect to the CAPCA human resources database and to the CSCC human resources action group. The human resources structure should address present and future needs in key oncology disciplines, based on the incidence of cancer and standards for staffing, productivity, workload and machine (RT) capacity.

Facilities/Capital Equipment/Technology Planning

The detailed role of a facilities, capital equipment and technology planning group will not be elaborated here. Suffice to say for purposes of this document, that a multi-year capital equipment development and replacement plan should be developed, particularly for radiation therapy equipment. This plan would be based on the incidence of cancer, predicted benefit from radiation therapy and productivity standards for machine throughout. It would also take into account the predicted obsolescence of this equipment.

7.4.2.7 Role of Cancer Network Executive

This group would be comprised of the NBCN leader, the ‘COO’ of the secretariat, one other senior ministry staff person and the leader of each of the area-wide networks. The most senior staff support person for each of the area-wide networks could ‘sit-in’ on meetings.

The purpose of this Executive would be to:

- act on behalf of the network team between meetings, develop agendas for the leadership team, coordinate the assignment of issues to appropriate groups for resolution and address day to day matters that arise;
- to develop and monitor an implementation plan that arises from the leadership team and ensure its effective coordination between the two area-wide networks;
- develop the details of the performance contract.

7.4.2.8 Region Health Authority (RHA) Chief Executive Officer (CEO) Council

While this group is not, as yet, a formal structure, the CEO’s do meet and discuss common issues/concerns. Being part of this forum would enable the NBCN leader to share cancer control matters, receive feedback on plans and to be made aware of issues at the regional level that require resolution. It may be helpful if the RHA CEO council became a more formal structure with terms of reference and agendas and be chaired by the Deputy Minister.

7.4.2.9 Role of the Department of Health and Wellness

The Department of Health and Wellness should accept responsibility for the NBCN and create a provincial policy legitimizing the network. It should review and approve of strategies, plans, priorities and policy. Based on recommendations from the NBCN leadership team, it should ratify the cancer control requirements for the regions and build these into the performance contracts/performance expectations. Using the cancer control performance measurement framework, the DHW should identify for its own purposes those performance measures that will inform it of the effectiveness of the network. The DHW should also provide the financial resources to support the effective operation of the network, as well as providing the resources for a ‘robust’ secretariat that

can effectively support the various activities – both at the provincial and area-wide network levels. It should also ensure DHW portfolio involvement in the appropriate cancer control/enabler groups and ensure coordination with other DHW initiatives.

7.4.2.10 Area-wide Networks

The reviewers recommend the establishment of two area-wide cancer sub-networks for NB with one network serving Regions 2 and 3 and the other serving Regions 1,4,5,6 and 7. Although on the surface this would appear to be unbalanced in terms of the number of regions, the total population of each of the two areas is reasonably close and the arrangement aligns well with current referral patterns as well as interregional relationships. Another compelling argument for two is that essentially there are two ‘lead’ cancer centres in NB (one in Region 2, the other in Region 1) each of whom can serve as the ‘hub’ or ‘focal point’ for the area-wide sub-network. There is also the opportunity to build on work that has already been done.

The reviewers did consider other options. Considering the size of NB, it might make sense to have only one provincial cancer region. This could be a viable option if there was only one comprehensive referral cancer centre in NB. Seven regions would be excessively large and there is no logical base for leadership and infrastructure costs would be greater. The reviewers briefly discussed the notion of four regions, but there would be no logical division and two regions in this arrangement would not be directly served by the two lead cancer centres. As for the arrangement that is proposed, it is essential that the centre at the Dr. Georges L. Dumont Hospital and the program at The Moncton Hospital be integrated and although on two sites be considered a single unit with unified leadership and programs.

The organizational elements of the area-wide sub-networks are a multi-regional cancer advisory committee, a management team and a lead centre that takes responsibility to coordinate this ‘inter-regional program’.

7.4.2.11 Area-wide sub-network Cancer Advisory Committees

This is a multi-regional and inter-disciplinary structure that has the following responsibilities:

- identifies needs across the cancer control spectrum;
- develops a multi-year plan;
- implements the requirements of the performance contract determined through local needs and provincial requirements for all elements of cancer control;
- ensures that cancer control services are managed and organized effectively with clear arrangements for coordination of care, referral, communication and continuing care;
- monitors area-wide performance;
- acts as a forum for patients/advocates and NGO’s and ensures effective communication amongst all levels and cancer control components.

The structure of the advisory committee will require careful further consideration; however, it should include the RHA’s in the sub-network, patients/advocates, NGO’s such as the Cancer Society, direct care providers in key oncology disciplines, at least one CEO and one RHA board member, a primary health care/community cancer care lead and public health. A representative who could be the chair or his/her delegate – should sit as a member of the Provincial Cancer Advisory Council. The chair is appointed by the provincial cancer network leader on the advice of the area-wide sub-network cancer advisory committee. The Committee itself reports to the Provincial Cancer Network team.

In addition to the above, some regions may establish local cancer care teams at the management level to ensure local patient-centred coordinated care.

7.4.2.12 Sub-network Management Team

A core management team consisting of a lead clinician (oncologist), lead nurse and administrator would provide the support to the activities of the sub-network cancer advisory committee. It is likely that these positions already exist. The need for further resources to support any extra work in building or maintaining this structure would need further evaluation. This team is responsible for day to day management of the sub-network and implements approved plans developed at the provincial and sub-network levels. They would work closely with other key management positions at the various levels of the sub-network, including those responsible for the various elements of cancer control, the designated primary care lead(s) and local cancer care teams, if these are appointed. The lead clinician who would come from the lead centre would be appointed by the provincial network team and would sit as a member of the provincial network team and on the provincial network executive.

7.4.2.13 The ‘Lead’ Centres

It is proposed that leadership for the two sub-networks be “nested” in the two major cancer centres in Moncton and Saint John. By fulfilling this role, it will be important that the needs of the sub-networks as a whole are recognized in a balanced and equitable manner, in keeping with accepted standards and consistent care delivery.

7.4.3 Levels of Cancer Control Service Delivery

It is important to clearly define roles and responsibilities for cancer control service delivery in a structured system of levels of care throughout the province. Partial work has been done on this, but it needs to be extended to encompass the entire province and should extend across the spectrum of cancer control. That is, each component or level will have a clear definition of the scope of work and the resource base to carry out its responsibilities for prevention, screening, diagnosis, treatment and supportive/palliative care. Not only must there be clarity of roles and levels, but there must be clearly defined linking, referral and communication mechanisms to ensure seamless cancer control and care delivery.

These levels would encompass:

- Primary and community care
- Designated cancer units (likely more than one level – possibly three)
- Cancer Centres – radiation based with a critical mass of expertise

All of these levels should be coordinated and integrated and would be considered a composite comprehensive cancer service although where possible services should be planned to minimize travel, priority must be given to the maintenance of the highest standards – using agreed-upon standards/guidelines/protocols. If there are different methods of treatment to be used, these must be justified on a scientific basis.

These levels of service will be used as a basis for planning and resource allocation. The determination of the level will be based on volumes and a critical mass of professional expertise to ensure the maintenance of uniform standards. What follows are the implications of this for some specific areas.

Radiation therapy is currently provided in two centres in NB and additional radiation centres should not be developed in other locations in the foreseeable future.

Chemotherapy levels must be very carefully defined with the locations for delivery and level clearly specified. Again, there must be assurance if sufficient volumes of patients and professional staff that are

well trained/certified to deliver safe care within agreed-upon provincial standards/guidelines and protocols. There should be standards for professional competence and clarity of professional roles. In short, there must be clear definition of what will be carried out at each level, why it will be carried out at that location, how it will be carried out and what must be in place to support it.

For surgical oncology, the same general philosophy as has been expressed for chemotherapy should be in place. In addition, it will be desirable to establish a provincial policy on where certain, more complex cancer surgical procedures should take place. For example, it is probably desirable to concentrate the surgical management of pancreas, stomach, liver and sarcomatous tumors to a designated tertiary centre. It would also be desirable within each of the two area-wide networks to establish cancer control-based integrated programs for the four major cancers, namely:

- breast
- prostate
- lung
- colorectal

These four cancers make up close to 60% of incidence and mortality for all cancers. Any improvements in overall cancer outcomes are unlikely without unified and coordinated efforts in these four areas. Again there would be clear definitions of roles and responsibilities. This would include where care would be given and by whom, based on volumes and standards. The program would include coordination of care from entry to follow-up and would encompass an integration of prevention, screening, diagnosis, treatment, supportive care/palliative care using a multidisciplinary approach. The surgical oncology network would ensure the development and adherence to standards and would be responsible for developing an outcome analysis process to serve as the basis for feedback on performance and for continuous improvements.

A further word about primary/community cancer care. As part of the structure, it will be important to identify at the provincial and subnetwork levels a 'primary care cancer lead' to bring structure to this important area of care. These 'leads' would be involved at the policy and program delivery levels (provincial network leadership and subnetwork cancer advisory committee) providing strategic leadership, supporting the streamlining of care delivery, working with other cancer care providers to develop the tools to support better primary care and bringing forward issues that require attention and improved processes. In the role, the primary care lead would work closely with community health centres, patient navigators and groups of primary caregivers. Within the sub-networks, it may be desirable, in addition to an overall primary care lead, to have primary care leads for each region that would be part of the local 'cancer care team'.

Again, at the provincial level the primary care lead would be a member of the provincial network leadership team, would chair the primary care/Community Health Centre group and would be the focal position for primary care reform in cancer care.

8.0 LINKAGES

A great deal has already been said about linkages throughout the system. Cancer control is complex. There are many stakeholders, no single organization can do everything and there is a need for coordination at all levels. Linkages are also important to ensure consistency, input into policy and to take advantage of developments that occur elsewhere that can be locally adopted.

8.1 Interprovincial/National

It will be important that the NBCN effectively link with the initiative of the CSCC and CAPCA. Each of these Canadian-wide organizations has developed priorities for consistent application across the country. Network leadership should sit on the Board of CAPCA and the Council of CSCC. Network sub-groups should actively engage with CAPCA policy advisory committees and the action groups of CSCC. There should also be a continued effort to connect with other Canadian-wide professional associations, as well as those structures that deal with a particular element of cancer control (such as the Canadian Hospice Palliative Care Association).

8.2 Provincial/Regional/Community

A number of cooperative initiatives have been undertaken in the Atlantic region, including some in medical education, pediatric cancer and cancer genetics. New Brunswick, along with other Atlantic provinces, should identify together, other areas for collaborative activity – considering geographic proximity and economies of scale. Areas for cooperative activity could include research, registries/surveillance, standards, practice guidelines, human resource planning, chronic disease prevention and educational conferences. It is suggested, however, that as a matter of priority New Brunswick move substantially along with its network development so that it can address cooperative activity from a position of some strength and within a reasonably level playing field.

A great deal has already been said about all other relationships within the province and communities. These will not be repeated here.

9.0 PERFORMANCE CONTRACTS

An important process that helps to unify and bind the NBCN is the development of performance contracts that clearly specify the expected deliverables of the region/ area-wide sub-networks within an overall cancer control plan. It should be recognized that performance contracts can be major drivers of change and improvement. The principles that should govern the development of performance contracts are as follows:

- They should be part of the regular DHW performance contract process for the regions with area-wide sub-networks added.
- The performance contract must have specific purposes such as providing clear descriptions of responsibilities, objectives, performance measures reporting requirements, incentives and consequences.
- They should be based on requirements outlined by the provincial cancer network team for all elements of cancer control that are considered a priority.
- They should set the stage for input from the area-wide sub-networks, including the needs they identify and within a three-plan 'rolling' plan.
- There should be consultation about the process and the details with the RHA CEO Council. There must be enough time to allow for full collaboration on this matter between the DHW and the RHA's.
- They should create and maintain a balanced and equitable approach to resource allocation.
- They should identify specific performance targets for improvements in cancer control.
- The elements of the performance contract would be as follows:
 - service delivery expectations, including level of service, volumes and productivity;
 - adherence to performance outcomes within provincial standards, guidelines and safety requirements;
 - Cancer control performance targets for those areas of cancer control improvement that are specified, including access/wait times;
 - the achievement of financial and patient satisfaction targets;
 - implementation of provincial priorities/programs;
 - process improvements in service delivery (coordination, integration, information);
 - the development and maintenance of linkages throughout all levels of the system within the sub-network;
 - the development and maintenance of the subnetwork structure;
 - the identification of sub-network needs, the development of a three-year 'rolling' plan to meet the needs, including how resources will be used to meet needs, and regular reports on progress towards achieving the plan within an agreed-to provincial performance indicator framework;
 - the resolution of issues identified throughout the network, including feedback from the Provincial Cancer Advisory Council and other mechanisms for patient/family input.

10.0 PRIORITIES

The reviewers were asked to provide an opinion on those priorities that need attention. What follows are some principles and opportunities to guide decision-making as well as a brief note on each priority area.

10.1 Principles and Opportunities

- The process of establishing priorities should follow the principles that were previously identified through the analysis of the experience of 11 OECD countries. In essence, priorities should be driven by information created by the analysis of data, by research and by evidence of effectiveness.
- Priorities should encompass the elements of cancer control and the enablers and their impact on key direct measures/outcomes such as mortality, survival and incidence as well as impact on indirect measures which have a high likelihood of positively impacting on direct measures.
- Alignment with provincial health priorities and the priorities already established by the Cancer Services Advisory Committee.
- Seizing the opportunity to align with and take advantage of the work on priorities already done by the CSCC and CAPCA.
- Resolution of the key issues identified earlier in this report.
- Address and resolve NB's relatively poor performance in Cancer Control.

10.2 Specific Priorities

The following priorities are a blend of the outcomes of the CSAC, the CSCC/CAPCA priorities and priorities that arose as a result of this review.

- Immediately establish the NBCN so that a framework is created that provides the necessary tools for the rest of the system. Within this, address the organization and the levels of service delivery. The best way to start is to establish a multi-year phased-in implementation plan.
- Immediately address safety concerns by developing a provincial initiative in systemic therapy and ensure safe medication practices.
- Address the development of provincial standards for all elements of cancer control and effectively link with the action groups of CSCC, the advisory committees of CAPCA and other Canada-wide cancer-related associations.
- Address the development of a process for clinical practice guidelines adaptation, endorsement and dissemination through a linkage to the CSCC/CAPCA guideline initiative.
- Implement a human resource planning process under the professional practice council and link to the data base of CAPCA and the CSCC Human Resource action group.
- Improve surveillance by providing better support to the registry and augmenting epidemiologic support for better data analysis and strategic information creation.
- Establish a linkage to the Canadian Cancer surveillance alliance
- Establish provincial mechanisms for a coordinated and consistent approach to radiation therapy, surgical oncology, cancer pathology, palliative /supportive care linking effectively with CAPCA/CSCC initiatives.
- Address the development of primary/community care as it relates to cancer, including a 'patient navigator' system and linking with the primary health care initiatives of CAPCA/CSCC.

- Further develop and integrate cancer prevention at the provincial level, connect with area-wide networks and regional programs and link to the primary prevention initiatives of the CSCC.
- Initiate a process to define the vision and role for cancer research in NB, but immediately address clinical trials infrastructure needs.

11.0 CANCER CONTROL PERFORMANCE MEASUREMENT

What is proposed here is an integrated model for cancer control performance measurement. It is a combination of that proposed by the Canadian Institute for Health Information (CIHI) and the Canadian Council on Health Services Accreditation (CCHSA) applied to the spectrum of cancer control. It is consistent with the work of PIRC (performance indicators reporting committee of the Provincial and Territorial Ministries) and the balanced score card performance measurement approach addressed in the report of the Premier's Health Quality Council. It also includes organizational goals and the requirements of the performance contract.

Goals of the proposed performance measurement framework.

There are five goals. These are:

- assess provincial and area-wide performance;
- establish the basis for defining cancer control targets;
- support continuous improvement in cancer control outcomes;
- achieve comparability with other jurisdictions;
- serve in part, as a framework for defining elements of a performance contract.

The model can fit with the following principles:

- linkage to provincial health goals/organizational goals and performance contract requirements;
- a system-wide approach (i.e., not just clinical, but population-based);
- bench-marking capability/comparability;
- pyramidal – what is measured at the top is built on what is measured throughout the system;
- the provision of interpretative expertise so that data can be transformed into information and can guide/inform policy decision-making;
- the development of reporting tools for various audiences;
- a stratified reporting schedule – there are different periodicities for some indicators;
- ensuring data quality;
- keeping it simple;
- the use of high level 'dash board' indicators;
- measurement of those things that can be changed.

- **Types of measures**

There are two general types of measures to assess effectiveness in cancer control. These are direct measures and indirect measures. Direct measures include such things as incidence, mortality and survival. Any improvement in the system will take a long time to have visible impact on these measures – hence they have a long periodicity. Indirect measures are process measures that have a high likelihood of a positive impact on direct measures and hence can be considered surrogate. An indirect measure for example would be the percentage of those at risk screened for breast cancer. The proposed model encompasses both of these, but acknowledges that cancer mortality/survival are the most important measures.

- **Performance measurement matrix**

A performance measurement matrix integrating the functions of cancer control with the CIHI and CCHSA frameworks along with provincial requirements is illustrated in figure 5. Within most of the cancer control functions a performance indicator can be identified that aligns with the CIHI/CCHSA framework. Exceptions would be health status and determinants of health which would apply primarily to prevention and screening. The following are some examples: Under health status (deaths) would be mortality/survival, years of life lost data that would be indicative of effectiveness in prevention, screening, diagnosis and treatment. Within responsiveness might be the number of people dying in preferred location (home) as a palliative care indicator. Under competency (appropriateness) would be the level of compliance with CPG's an indicator for the treatment function. Under determinants of health (health behaviours) cancer risk behaviours such as smoking rates would be an indicator for prevention.

- **Responsibility for determining indicators and targets**

It is proposed that the responsibility for determining the specific indicators/targets in each area be that of the NB Cancer Network team, based on the advice of each of the cancer control advisory groups. The team would also determine periodicity and the reporting requirements for the area-wide networks/regions. It may be important to be selective initially and give specific attention to urgent/pressing issues, chemotherapy safety would be an example, high cost services, areas where performance is known to be well below best practice, where failure to meet standards will have serious adverse consequences, or where there are urgent access/service delivery issues.

Figure 5 - Cancer Control Performance Indicator Framework

Cancer Control Function									
	Prevention	Screening	Diagnosis and Staging	Treatment			Palliative Care Support/ Rehab	Primary Care Community Care	Information/ Education
				Systemic	Radiation	Surgical			
Category									
Health Status									
• deaths									
• health conditions									
• human function									
• well-being									
• Determinants of health									
• health behaviours									
• living/working conditions									
• personal resources									
• environment									
Community & Health System Characteristics									
• human resources									
• capacity									
• language and cultural diversity									
• support for labour force									
• costs per weighted case									
Provincial Health Goals									
Organizational Goals									
Requirements of Performance Contract									
Responsiveness									
• availability									
• accessibility									
• timelines									
• continuity									
• equity									
Competency									
• appropriateness									
• knowledge and skills									
• effectiveness									
• safety risk									
• efficiency									
• system alignment (clear & integrated)									
Client/Community Focus									
• communication									
• confidentiality									
• participation/partnerships									
• respect and caring									
• involvement in community									
Worklife									
• open communication									
• role clarity									
• participation in decision-making									
• learning environment									
• well-being									

12.0 BUDGET FOR CANCER CONTROL ACCOUNTABILITY FRAMEWORK

The following is an annualized operating budget to support the recommended cancer control framework. The budget has been calculated based on Department of Health and Wellness compensation levels for comparable positions. The budget is based on the following assumptions/limitations.

- The current financial allocation to cancer at the provincial level is \$156,137.00, two positions (in Planning and Evaluation which includes Breast Cancer Screening).
- That the provincial cancer network leader is a full time position.
- That cancer control group/enablers and CPG leaders will work one full day/week. It should be noted that due to limited manpower initial involvement may be less in some areas.
- That the two area wide subnetworks have the resources to fulfill their role with the possible exception of financial support for the subnetwork leaders to offset the need to 'backfill' their roles in clinical/administrative areas.
- That one secretarial position for every two to three positions is required.
- That one coordinator for every two to three major initiatives is required.
- That a policy decision will be taken to establish a provincial chemotherapy budget, requiring the support of at least one FTE pharmacist.
- No budget has been proposed for increases to screening. As a general comment the current breast screening program may require a dedicated coordinator and a medical leader. If a decision is taken to develop a provincial cervical screening program and a colorectal screening program these should be unified as part of a single provincial screening initiative (including hereditary cancer screening) with a commensurate increase in provincial administrative support.
- Augmentation to the qualifications of the registry staff is also required. Provincial epidemiology needs to be strengthened with additional epidemiologists and a statistician to enable strategic information development, outcomes analysis and monitoring.
- Provision has been made to pay physicians (other than chairs) who attend meetings. Current policy provides for \$600.00 per day for physicians attending required/approved meetings. If one assumes that a minimum of three physicians will be part of each of twelve distinct groups meeting six times/year, then this would require \$129,600.00 (12 x 3 x 6 x \$600.00) annually.
- Funding is proposed for the provincial primary care group leader. Additional funds may be required for primary care leads in the two area-wide sub networks or in other locations throughout the province. If it is determined that these are required and assuming as a maximum one primary care lead is needed for each region at two sessions per month at \$600.00 per session, an additional \$100,800.00 should be added.
- The report proposes a phased two year implementation program over three fiscal periods with the full costs not being realized until the 2005/2006 fiscal year.
- No additional resources have been proposed for cancer prevention.
- That facilities, equipment and technology planning can be handled in Department of Health and Wellness' Planning and Evaluation division.
- No resources for a research leader have been defined and that a cancer research strategy needs to be developed with outside consulting help before such a position is created.

BUDGET

Position	Salary	Budget
Provincial cancer network leader (1)	\$275,000.00 - 325,000.00	\$316,250.00 - 373,750.00 (with benefits)
Provincial cancer network COO (Band 8) (1)	\$79,638.00	\$91,584.00 (with benefits)
Coordinators (Band 6) (5)*	\$67,886.00	\$390,345.00 (with benefits)
Secretaries (4)*	\$35,178.00	\$161,819.00 (with benefits)
	Total	\$959,998.00 - 1,017,498.00
Chairs cancer control/ enablers groups (12)	\$55,000.00	\$660,000.00
Chairs area wide sub-networks (2)	\$55,000.00	\$110,000.00
Pharmacist (1) provincial chemotherapy budget	\$75,872.00	\$87,253.00 (with benefits)
Epidemiologists(2)Statistician (1)	\$106,522.00-\$61,906.00	\$245,001.00-\$71,192.00 (with benefits)
Physicians attending meetings		\$129,600.00
Travel, accommodations, meeting costs		\$250,000.00
Cancer Consultants (Band 6) (2) (includes screening)	\$67,886.00	\$156,137.00 (with benefits)
Cancer Registry (operational budget)		\$266,000.00
	Grand Total	\$2,935,281.00 - \$2,992,681.00
	Minus Existing Staff Salaries + operational expenses	\$422,137.00
	Incremental Costs	\$2,513,044.00 - 2,570,544.00

13.0 IMPLEMENTATION

What follows is a general implementation plan for the cancer control accountability framework. What is proposed – in keeping with the multiyear budget plan – is a 2 year phased, four step implementation plan leading to full development of the framework and its full operating costs during fiscal 2005-2006. What is proposed here is high level. A more detailed plan should be developed that would specify actions, those responsible, dates for achievement and fiscal impact. This could be expressed on a gantt chart or other similar format.

In order to bring structure to the implementation process, it is proposed that a 'transition' implementation team as a subgroup of the Cancer Care Steering Committee be formed. Its role would be to develop a detailed work plan (schedule) and monitor implementation until some key elements of the new structure are in place. For example, once the New Brunswick Cancer Network Executive has been formed it can assume the role of the implementation subgroup. Once the NBCN team is formed, it will assume the role of overseeing implementation and the Cancer Care Steering Committee can be 'retired'. A senior staff member of the Department of Health and Wellness should be assigned to support and coordinate the activities of the implementation group.

Assuming that the NBCN proposal is accepted by the Department of Health and Wellness, the following is a suggested four-phase implementation plan extending from October 1, 2003 to September 30, 2005.

Phase I

October 1, 2003 – March 31, 2004

The first phase is concerned with assembling the NBCN executive team comprised of the PCNL, PCNCOO and the two areas wide subnetwork leaders.

- Prepare job descriptions and candidate profiles for the positions of PCNL and PCNCOO.
- Advertise/shortlist and interview candidates. Select PCNL by February 2004. Recruit PCNCOO in parallel but delay final decision until PCNL has been selected so that he/she can make final decision.
- Prepare job descriptions, candidate profiles and recruit area-wide subnetwork leaders.
- Form the NBCN Executive who will take on responsibility for continued implementation.

During the first phase of implementation there are a number of policy issues that need to be addressed. Some of these are critical to the effective functioning of the Network and others, while not critical to the Network, need to be addressed before the full network is in place. Those things that should be addressed to ensure a well functioning network are:

- Enhancements to surveillance, through the addition of two masters level epidemiologists and one biostatistician – define needs during phase I.
- Clarifying the vision and future direction for cancer research in New Brunswick. It is suggested that during phase I an outside consultant be retained to develop a plan for cancer research in New Brunswick.
- The undertaking of some early steps to resolve critical human resource issues in radiation therapy, physics, pharmacy and medical/radiation oncology. While it is recognized that many human resources issues will take time to resolve, the availability of health professionals to support network activity is critical and an early start should be made.
- A number of issues have also arisen, which although not critical to the network do require attention. Some of these are:
 - Oncology Interactive Education;
 - the provincial brachytherapy submission;
 - a policy decision on the future of cervical screening.

Phase II

April 1, 2004 – September 30, 2004

- Secure appointment of the PCNL to the CSCC council, to the board of CAPCA and to the RHA CEO council
- Implement the additional staffing positions for surveillance
- Establish role and terms of reference for the
 - NBCN leadership team;
 - the subnetwork cancer advisory committees.
- Appoint the first chair and a small steering committee to define the structure and terms of reference for the Provincial Cancer Advisory Council
- Establish terms of reference for 'first wave' of cancer control functions/enablers, recruit chairs and establish the following groups as a matter of priority;
 - Systemic therapy – It is critical that safety issues be immediately addressed;
 - Radiation Therapy;
 - Primary Care;
 - Palliative/supportive care;
 - Professional Advisory Committee with initial emphasis on human resources;
 - Clinical Practice Guidelines.

It will be important to cross connect the leaders of these groups with CSCC and CAPCA initiatives.

- Appoint 'first wave' of coordinators and secretaries as well as recruiting a pharmacist to support the establishment of the provincial chemotherapy budget.

Additional activities would include:

- Defining the levels of service provision within the system.
- Defining the number, location and structural template for local cancer care teams.
- Have the cancer control groups/enablers formed to date establish short term performance expectations.

Phase III

October 1, 2004 – March 31, 2005

- Establish Terms of reference for the second wave of cancer control functions/enablers, recruit chairs and form the following groups:
 - surgery;
 - diagnosis and staging;
 - cancer prevention;
 - facilities/equipment/technology planning;
 - cancer research.

Additional activities during this phase would include:

- Convening the first meeting of the Provincial Cancer Advisory Council
- Appointing additional coordinators/secretaries
- Implementing the structure of the two area wide Subnetwork Cancer Advisory Committees
- Convening the first full meeting of the NBCN team
- Cross appointing chairs of cancer control groups/enablers to appropriate CSCC and CAPCA structures
- Defining area wide structures for the four main cancers – namely Breast, Lung, Prostate and Colorectal
- Defining location and responsibility for low volume complex surgical procedures (liver, pancreas, esophageal, etc.)

Phase IV

From April to September of 2005 the PCNL and the leadership team to develop multiyear plans, priorities, performance expectations for the regions (as expressed in a performance contract) and performance measures.

Subsequently, each region should be asked to develop a three year 'cancer plan' that is submitted through the two area wide sub-networks.

14.0 APPENDICES

Appendix I

Cancer Care Strategy CONSULTATION SCHEDULE		
Date	Time	*Full Team: Drs. O'Reilly, Carlow, Roy Group
Tuesday June 10, 2003	9:00 – 10:00 am	Cancer Care Consultants, Assistant Deputy Ministers, Deputy Minister (Full Team*) – DM's Boardroom – 5 th Floor, Carleton Place, 520 King Street
	10:15 am – 12:00 pm	DHW Service Heads: Provincial Epidemiology, Strategic Planning, Medicare, Hospital Services, Public Health; Dept. Finance, IT Staff. (Full Team) – DM's Boardroom
	13:00-15:00 pm	Cancer Care Steering Committee(Full Team) DM's Boardroom
	15:00-16:00 pm	(Dr O'Reilly and Dr Carlow – RHA 4) Drs. O'Reilly and Carlow to overnight in Fredericton. Dr. Roy to overnight in Campbellton.
Wednesday June 11, 2003	9:00-11:00 am	Drs. Carlow and O'Reilly - Meeting with Chief Executive Officers Fredericton - DM's Boardroom
	11:30-12:30 pm	Lunch – Canadian Cancer Society, NB Division – DM's Boardroom
	8:00-9:00 am	Dr. Roy – Site Visit RHA 5 Campbellton
	10:15-12:00 pm	Dr. Roy - Site Visit RHA 6 Bathurst
	14:30-16:00 pm	Dr. Roy – Site Visit RHA 7 Miramichi
	13:00-16:00 pm	(Drs. O'Reilly/Carlow) - Site Visit RHA3 Fredericton Full Team to overnight in Moncton
Thursday June 12, 2003	9:00-12:00 pm	Site Visit – RHA 1 Beauséjour - Oncology (Full Team)
	13:00 – 16:00 pm	Site Visit – RHA 1 South East (Full Team) Full team to overnight in Saint John.
Friday June 13, 2003	9:00-12:00 pm	Site Visit - RHA2 Saint John (Full Team)
	14:00-16:00 pm	Cancer Care Consultants-Summary, Boardroom 4D 4 th Floor, Carleton Place, 520 King Street

Appendix II

Dear Participants:

The following is provided to assist you in your participation in the external review of cancer control in New Brunswick. It includes:

- The structure of the review team
- The mandate of the review team
- The review process
- A number of questions to assist in the interview process and to guide those who may wish to make written submissions
- The schedule of visits/participating stakeholders

The Review Team

A three person external review team has been struck to undertake this assignment. The team is comprised of:

- **Dr. Donald Carlow** – Team leader. He is a Health Care Consultant, CEO of the Canadian Association of Provincial Cancer Agencies (CAPCA) past president/ CEO of the Ontario Cancer Institute/Princess Margaret Hospital and the BC Cancer Agency and a member of the Canadian Strategy of Cancer Control Council.
- **Dr. Susan O'Reilly** – Leader of the provincial systemic therapy program for BC, Academic Head of Medical Oncology at the UBC medical school and Chair of CAPCA's systemic therapy policy advisory committee.
- **Dr. Denis Roy** – Director of the Quebec Centre for Cancer Control, a member of the Canadian Strategy for Cancer Control Council, a board member of CAPCA and possessing qualifications in population health and epidemiology.

The Charge to the Review Team

The team has been asked to deliver the following outcomes:

- a) A proposed organizational structure responsible for planning, funding, distribution and monitoring of cancer care services in NB aimed at improving access to and coordinating cancer services across the province within an integrated cancer care services delivery system.

This structure will give consideration to:

- Existing resources and capabilities (strengths/limitations/gaps) within health regions.
- Trends and activities across other jurisdictions.
- Recommendations of the cancer services action plan.
- Alignment with the Canadian Strategy for Cancer Control.

The project will describe linkages between the various stakeholders and between providers and levels of care that may include acute and long term care, home care, hospices, volunteer networks, palliative and pastoral care and the Canadian Cancer Society – NB Division.

- b) A proposed Implementation Plan which:
 - Defines approaches, options, key involvement, roles, relationships, linkages and review points.
 - Identifies areas needing policies, standards and service guidelines.
 - Defines timelines and associated costs.
 - Defines monitoring and evaluation criteria

The Review Process

1. Internal/External Environmental Analysis

- **Current Cancer Control System in NB**
Through meetings with stakeholders, a review of written submissions, and the analysis of various other documents on Cancer Control in New Brunswick, the team will become familiar with the strengths, weaknesses, opportunities and threats regarding cancer control in NB.
- **The New Brunswick Health Care Context**
The review team will want to thoroughly understand the current and future directions in health care for New Brunswick to ensure that a proposed framework fits well within the overall system. Through interviews with DWH staff and the regions as well as reviewing various documents we will gain this perspective.
- **The Canadian Context**
Members of the review team bring a thorough knowledge of the current state and some of the future plans for cancer control in Canada and the various provinces. This includes the priorities of the Canadian Strategy for Cancer Control and the developments in various provinces towards improved cancer control. Awareness of the various provincial “models” with their strengths and weaknesses will enable “best practices” to be identified and to enrich a proposed framework.
- **International Context**
Members of the review team will bring an understanding of the developments and successes in developing and implementing cancer control plans in other countries. While health care systems may differ in other countries, multi-jurisdictional systems of cancer control (within National Strategies) have been developed with lessons learned that could be useful in the NB context.

2. Issue Identification/Issue Analysis

Through the aforementioned process issues will be identified and analyzed to set the stage for the development of framework options and priorities.

3. Options for a Cancer Control Framework

Options for a framework will be developed by the team in response to the foregoing. This will include an analysis of the advantage/disadvantage of each, along with the identification of priorities which will guide decision making and the implementation plan.

4. Preferred Option

A detailed description of the preferred options will be provided, with full rationale, and with full elucidation of a coordinated/integrated system that responds to the mandate set out for the team.

5. Implementation Plan

If accepted a multiyear, stepwise implementation plan will be proposed as set out in the mandate.

Questions - Guide for Stakeholders

The following questions are posed to guide stakeholders during the interview process and/or to form the basis for the submission of written briefs to the review committee. It is recognized that the list of questions is long. It would not be possible for every individual or group to respond to every question. We would therefore ask that participants address those questions that they are best prepared or the most appropriate to answer. For those who will provide written briefs, it is suggested that you might direct your attention to the following:

- What are the key issues in cancer control in NB?
- What would be your vision for a cancer control framework/system for NB?
- How do you believe NB should move forward in cancer control?
- Written brief may be submitted openly or in confidence to the chair of the review committee

1. Structure and Governance

- What are the key milestones in the evolution of cancer control in NB?
- Do you believe that there is a need for a clear and common vision/mission for cancer control in NB?
- How would you describe the organizational model that is the de facto cancer control system in NB?
- Describe the governance structure of cancer control in the province and regions of NB including overall governance, accountability framework, and linkages amongst the various levels of care and components of cancer control.
- Describe the main organizational features of the cancer control system including the institutions involved, professionals/providers, role of community based organizations, links between 1^o, 2^o, 3^o levels, mechanisms for hearing the voice of patients and advocacy groups.
- Are there criteria (explicit or implicit) for the designation of institutions and professionals as cancer care specialists?

2. Priorities and Planning

- How are plans for cancer control services developed including all components, as well as human resources and facilities?
- What efforts are currently being undertaken to align cancer control plans with the Canadian Strategy for Cancer Control?
- How are priorities for Cancer Control established? How is provincial cancer control policy established?
- What is the current status of the five cancer control priorities described in the cancer services action plan?
- How is epidemiologic data used to create information that will guide cancer control planning?

3. Perceptions Regarding Reform of the Cancer Control System

- What is working particularly well for cancer control in NB?
- What could be improved?
- What are the current pressures for change (positive and negative)?
- What do you perceive to be the top three priorities for improving cancer control?

4. Cancer Control Continuum/Specific Disciplines

- What is NB's overall approach to cancer prevention?
- How are the current screening programs governed and managed? Describe the scope, organization, governance and plans for screening programs?
- How are diagnostic services – imaging and cancer pathology/lab medicine – organized in support of a cancer control program?
- Describe how cancer staging information is captured throughout NB including the level of consistency.
- How are surgical oncology activities coordinated with medical/radiation oncology and other components of care?
- How are palliative care, supportive care, and psychosocial oncology developed and managed on an integrated and consistent basis for NB?
- To what extent is the cancer control program integrated/coordinated with primary health/community based cancer care?

5. Standards/Clinical Practice Guidelines

- What tools are used to guide consistent clinical oncology decision making? i.e. clinical practice guidelines
- How are standards developed to guide cancer service delivery and the activities of professional disciplines?
- How are cancer services evaluated by the Canadian Council on Health Services accreditation?
- How effective are your regional/hospital cancer risk management and quality management/improvement processes? How do you know if cancer therapy is safely delivered?

6. Access

- What do you think are the greatest challenges, problems in prompt delivery of cancer services?
- What proportion of patients require out-of-province cancer therapy?
- What are the issues with timely access to diagnostic and surgical services?
- How are access/wait times monitored?
- Are there consistent standards/definition for wait times/wait list management?

7. Monitoring and Evaluation

- What indicators does the DHW use to monitor the control of cancer for the province?
- How do the regions monitor their performance in cancer control?
- What are your cancer survival statistics showing about NB's performance? How do you compare to the rest of Canada?
- What is the public/patient perception of cancer care?

8. Resources

- How is/are the province/regions funded for cancer control activity and what mechanisms are used to assure equity/consistency?
- Are there standards for productivity amongst the regions and how do they compare?

-
- What is the total budget for cancer control services in NB? How are decisions made regarding the distribution of financial resources to the regions for cancer control?
 - What are your financial challenges/constraints in NB, relative to the rest of Canada?
 - How well do you think your hospital/region and DHW planning processes address needs for human resources (oncologists /surgeons/ nurses/ technologists, etc.), operating budgets, cancer drug budget, capital equipment and facilities?
 - What is the likelihood of additional resources being available for cancer control services for NB?

9. Academic Oncology/Research

- What is the scope of cancer research activity, how is it governed and managed and how well is it integrated with cancer control activities?
- What is the scope, structure and accountability for the academic oncology program?
- How are medical students, interns and residents exposed to oncology practice and how are they encouraged to pursue this as a career?

Schedule of Visits

In the conduct of its activities the review team will be inclusive and will consult a broad range of stakeholders including patients, advocates, volunteers, administrators, regions, health care providers, oncology practitioners, those involved in all elements of cancer control, the Provincial Cancer Care Steering Committee, academic leaders and representatives of the Department of Health and Wellness. The consultation schedule is as follows:

Appendix III

Submissions / Documents Reviewed

- Cancer Drug Usage - Prescription Drug Program
- Cancer Follow-up Care: The Perspective of Patients, Canadian Family Physician, July 2003 M. Baukje, I. MacDonald, S. Tatemichi
- Breast Screening Program RVH overview
- Breast Cancer Screening Services in NB, Policy and Standards
- Regional Health Authorities Act
- Renewing Health Care: Meeting our challenges together
Elvy Robichaud, Minister of Health and Wellness
February 2003
- Health Care System Overview
Nora Kelly, Deputy Minister of Health and Wellness
March 2002
- Regional Health Authorities
Orientation for RHA Board Members
March 2002
- Framework for Community Health Centres in NB
- Health System Planning
Andrée Robichaud
Ron Durelle
March 2002
- Governance expectations for Regional Health Authorities
Draft 2002
- New Vision New Brunswick
Bernard Lord's plan to change our future together
June 1999
- Health and Wellness Budget 2003-2004
Backgrounder
- Cancer Care Strategy Review
South-East Regional Health Authority
June 2003

-
- Cancer Prevention Initiatives
Marlien McKay
September 2002
 - Reporting to New Brunswickers
Health Care Report Card 2003
 - Health Performance Indicators
September 2002
 - Cancer Services Action Plan for New Brunswickers
September 1998
 - Highlights of the Report from the Premier's Health Quality Council
January 2002
 - Cancer in New Brunswick
1992 - 1996
 - Sustainability of the comprehensive cervical cancer screening program
Beauséjour RHA 1B
November 2002
 - Cancer Care Strategy Review
Pharmacy
South-East RHA 1SE
June 2003
 - River Valley Health RHA 3
Oncology Statistics
 - Health and Wellness news release
April 2003
\$120 million more for Health
 - Legislative Statement
April 1, 2003
Elvy Robichaud
 - Brief of the Chair of the Cancer Care Steering Committee
Restigouche HA
 - River Valley Health
Oncology Service Strategic Planning
April / May 2003
 - Dr. M. Burnell – letter
 - Presentation by Velma Wade
@ Leon Richard Cancer Centre
June 2003
 - Provincial Pilot Project
Brachytherapy
Dr. Santo Filice
June 2003

- Presentation to Review Team
Beauséjour RHA 1B
Richard Losier
- Terms of reference Cancer Services Committee
Beauséjour RHA 1B
- Hospice / Palliative Care Documents
Dr. Chris O'Brien, AHSC
June 2003
- Beverley Tedford
 - Hospital Liaison Officer, Nursing DHW
 - Response to Cancer Services Questionnaire
- The New Brunswick Context – Cancer
Pam Mitchell
May 2003
- Levels of Care Approach for Systemic Cancer Therapy Delivery in River Valley Health April 2003
- Cancer Care Steering Committee
Terms of Reference
- New Brunswick Cancer Care Strategy Review
June 2003
Dr. David Tees
- New Brunswick Cancer Care Review (Radiation Therapy)
Dr. E. Kumar
- Medical Education Coordinator
(Anglophone)
Job Description
May 2003
- Various International Documents
- Réseau Santé Nor'est
Qui sommes-nous?
Presentation to Review team
RHA 6
- Breast Cancer Screening Program
Acadie-Bathurst
RHA 6
- Quality Improvement – Cancer Care
Miramichi Cancer Care
- Restigouche Health Authority
Request for Chemotherapy Services