

CANCER CARE NOVA SCOTIA

A PLAN FOR ACTION

The Comprehensive, Integrated, Accountable
Cancer Management Strategy

Prepared for
Mr. E.G. Cramm
Deputy Minister of Health
by the Cancer Action Committee

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Table of Contents

Letter of Transmittal

Executive Summary	1
Summary of Recommendations	3
Introduction	9
The Need.....	9
Background	9
What is a Cancer Management Strategy?.....	10
Goals of Cancer Management	11
The Framework	11
The Touchstones Of Nova Scotia Cancer Care	11
Comprehensive.....	11
Integrated	12
Accountable	12
Implementing <i>Cancer Care Nova Scotia</i>	12
<i>Cancer Care Nova Scotia</i>	13
Mission	13
Mandate	13
Governance of <i>Cancer Care Nova Scotia</i>	14
Board of Directors.....	14
Chief Executive Officer	15
Functions of <i>Cancer Care Nova Scotia</i>	16
Informatics	16
Strategic Planning.....	17
Prevention	17
Screening and Early Detection	18
Management Modalities	18
Formulary Services	20
Supportive care.....	20
Rehabilitation/Restorative.....	21
Palliative care	21
Education.....	22
Research	23
Standard Setting	24

Clinical Practice Guidelines	24
Approval Function	25
Cancer Resource Planning	27
Funding	27
Human Resource Planning	27
The Cancer Network	27
Location Of Cancer Care Services	29
Evaluation of <i>Cancer Care Nova Scotia</i>	29
Appendix A: Terms of Reference	
Appendix B: Bibliography	
Appendix C: Proposal to Establish a Cancer Control Research Council in Nova Scotia	
Appendix D: Implementation Schedule	

Executive Summary

Nova Scotia needs a comprehensive, integrated, accountable plan for cancer management. After reviewing evidence, the Cancer Action Committee has developed a plan for the management of cancer care.

“Cancer Care Nova Scotia” will:

- (a) coordinate and extend to all Nova Scotians comprehensive, integrated, accountable, patient-focused cancer care;**
- (b) evaluate the effectiveness of cancer care; and**
- (c) ensure the best use of resources.**

The plan will facilitate the strategic planning of patient-centred, comprehensive and integrated care, involve key stakeholders, both provincially and regionally, and set standards for the eight components of cancer care: **prevention, screening/detection, diagnosis/treatment, palliation, supportive care, restorative/rehabilitation, education, and research.**

Cancer Care Nova Scotia will involve caregivers, both professional and volunteer, cancer patients, survivors and family members, agencies, community groups, facilities, planners and researchers in the planning, standard setting and evaluation of cancer care.

Nova Scotia’s cancer management plan will be guided by three critical touchstones: **comprehensive, integrated, and accountable. Its mission will be:**

to act as the catalyst and leader for cancer care in Nova Scotia, and to promote high quality cancer care through the development of standards and the evaluation of cancer care.

Cancer Care Nova Scotia will require a broad, legislated mandate to direct the management of the cancer system and to provide the leadership and coordination necessary to improve overall cancer management.

Cancer Care Nova Scotia will serve as a provincial advisory body to the Department of Health, Regional Health Boards and care providers. It will **not** be a service provider. Cancer care will be delivered by health care professionals and facilities across the province. This arrangement will allow **Cancer Care Nova Scotia** to focus on its leadership, coordination and standard setting role.

To be successful, **Cancer Care Nova Scotia** must be given the authority to change the management of cancer care. This includes advising the Department of Health and Regional Health Boards on resource needs for cancer care including financial, capital equipment, human and the location of services. It must have a mandate to review, audit, and set standards for cancer care providers and facilities. A major function will be to provide timely cancer information, trends and analysis to care providers, planners and the public.

The Action Committee believes their recommendations will help to:

1. promote the physical, psychological, social and spiritual well being of people living with cancer;
2. reduce the incidence of cancer;
3. reduce the cancer mortality rate;
4. improve the quality of life for people living with cancer;
5. focus on outcomes;
6. develop standards for cancer care providers and facilities;
7. enhance compliance with evidence-based protocols;
8. strengthen all components of cancer care;
9. develop a central role for family physicians; and
10. develop the cancer registry and a cancer epidemiology unit as a more complete health system resource.

Summary of Recommendations

Recommendation 1

That ***Cancer Care Nova Scotia*** be established as a body corporate by a Legislative Act and be independent of any one facility.

Its mandate will be to:

1. implement a comprehensive, integrated, province wide patient centred cancer management plan;
2. act as the catalyst and leader for the complete continuum of cancer care programs: prevention, screening/detection, education, research, treatment, support rehabilitation and palliation;
3. establish multi-disciplinary clinical planning teams (tumour groups) to develop practice guidelines, standards and multi-disciplinary research initiatives;
4. develop linkages with regional and community health services to ensure continuing development of regional programs and support services for cancer patients and their families;
5. develop an integrated cancer informatics service;
6. develop standards and processes to accredit/credential cancer providers and facilities;
7. evaluate cancer care and services throughout the province;
8. co-ordinate strategic planning for all cancer care components;
9. participate in the development of a funding methodology to support cancer care; and
10. advise on the location and specific types of cancer services to be offered within the province.

Recommendation 2

That ***Cancer Care Nova Scotia*** will be governed by a Board of Directors. There will a maximum of 15 members initially appointed by Order- In-Council. The membership should reflect major stakeholder groups and consumer representatives from persons who have experienced cancer. Representation should achieve balance among the stakeholders and reflect the geographic diversity of the Nova Scotia population. The inaugural board will serve for three years and will be replaced by a nomination process to be developed by the Board. The Board will report to the Minister of Health.

Recommendation 3

That the Board of Directors hire a Chief Executive Officer and establish an appropriate administrative structure necessary to develop and implement **Cancer Care Nova Scotia**. All positions must be filled through open competition.

That a search committee be charged with finding a suitable candidate for Chief Executive Officer of **Cancer Care Nova Scotia**. This committee should include representatives from Dalhousie University Faculty of Medicine, Department of Health, and the Cancer Action Committee.

Recommendation 4

That **Cancer Care Nova Scotia** should have appropriate information technology to support cancer research and planning, and the surveillance and analysis of cancer information for all stakeholders.

Recommendation 5

That **Cancer Care Nova Scotia** lead the development of intersectoral cancer prevention strategies by including relevant government ministries, health professions, advocacy groups and non-government organizations.

Recommendation 6

That the planning, standard setting, and evaluation of cancer screening programs be facilitated through **Cancer Care Nova Scotia**.

Recommendation 7

That cancer treatment policies and clinical practice guidelines be developed through interdisciplinary teams known as tumour groups.

Recommendation 8

That the Department of Health make available to **Cancer Care Nova Scotia** Tele-medicine facilities to allow province wide electronic conferencing for tumour groups and other activities.

Recommendation 9

That **Cancer Care Nova Scotia** assume responsibility for a provincial cancer formulary service in order to:

- ensure consistent drug availability across the province;
- develop, communicate, and maintain appropriate guidelines for the preparation of cancer pharmaceuticals;
- monitor the use of cancer pharmaceuticals, including adherence to treatment guidelines;
- integrate the use of cancer pharmaceuticals into a provincial cancer information system; and
- advise the Department of Health on new cancer agents in a timely fashion.

That the cost of cancer pharmaceuticals, (excluding antiemetics, colony stimulating agents and other treatment enhancers), established by clinical guidelines and provided on an ambulatory basis, be borne by the Department of Health, consistent with prevailing terms, conditions and the policy of insurer of last resort.

Recommendation 10

That all cancer patients should have access to professionals who can appropriately address their physical, social, emotional and spiritual needs.

Recommendation 11

That there be uniform and timely access to cancer rehabilitative/restorative services throughout the province.

Recommendation 12

That a province wide palliative care component be fully developed and implemented.

Recommendation 13

That Dalhousie University be encouraged to develop an interdisciplinary academic Department of Oncology.

Recommendation 14

That **Cancer Care Nova Scotia** promote, facilitate and foster a full spectrum of cancer research from behavioural and outcomes research to research into basic mechanisms of disease.

That **Cancer Care Nova Scotia** develop the proposal "To establish A Cancer Control Research Council in Nova Scotia" submitted by the Nova Scotia Regional Research Development Plan Working Group, October 1995, to the National Cancer Institute of Canada (Appendix C).

Recommendation 15

That cancer treatment policies and clinical practice guidelines, known as tumour groups, be developed through interdisciplinary experts drawn from across the province.

That patient focus groups should be available to each tumour group.

That consistent nursing policies and procedures, approved by **Cancer Care Nova Scotia**, be used by all agencies.

Recommendation 16

That all facilities, (hospitals, clinics, etc.), wishing to provide cancer care services, be required to undergo an approval process developed by **Cancer Care Nova Scotia**, which endorses the facility's ability to meet standards of care.

That all individuals who institute, direct, or provide cancer care services be reviewed and approved according to standards developed by **Cancer Care Nova Scotia**.

That **Cancer Care Nova Scotia**, when established, be given legislated authority to conduct reviews and audits of individuals and facilities providing cancer care within the province and to conduct appropriate follow up reviews.

That material gathered during the course of such reviews and audits be protected under the Evidence Act as a "Peer Review Function".

That those persons conducting such audits be indemnified by **Cancer Care Nova Scotia**.

That **Cancer Care Nova Scotia** direct tumour groups to establish review and audit programs for their specialty so that such reviews commence within one year of the formation of the tumour group.

That **Cancer Care Nova Scotia** provide tumour groups with the necessary support to carry out this review and audit function.

Recommendation 17

That **Cancer Care Nova Scotia** develop a Nova Scotia Cancer Network to foster the broad exchange of cancer information.

That **Cancer Care Nova Scotia** provide necessary operational support.

That the Nova Scotia Cancer Network be open to all groups or organizations involved in any aspect of cancer care.

That **Cancer Care Nova Scotia** and the Department of Health participate in this network.

That the Nova Scotia Cancer Network hold regular public meetings at least once a year.

Recommendation 18

That the family physician role in cancer care coordination be strengthened to become a key communicator with patients/family. To do so they must be kept fully informed of the diagnosis and ongoing care of the patient.

Recommendation 19

That Regional Health Boards and facilities wishing to expand or establish new programs in cancer care, must be endorsed by **Cancer Care Nova Scotia**. Only approved programs will be funded.

Recommendation 20

That **Cancer Care Nova Scotia**, in its annual report to the Minister of Health, provide evidence on how the changes in management of cancer care have contributed to improved cancer outcomes.

Introduction

The Need

The need for systematic and creative approaches to decision making and priority setting in cancer management has intensified. An estimated 129, 200 new cases of cancer and 61, 800 deaths from cancer will occur in Canada in 1996.¹ Nova Scotia has the highest cancer mortality rate for women and the second highest for men in Canada. Given the large number of cases and the high costs associated with cancer care, further developments in cancer management are needed, including those that can achieve a reduction in the use of tobacco products.

Background

During 1993, The Metropolitan Hospital Advisory Committee, (MHAC), reviewed the organization and delivery of oncology services in the central region, and within limitations, across the province. The resulting report presented a vision for the organization and delivery of cancer services in the province of Nova Scotia.

In September 1995, the Department of Health struck the Nova Scotia Cancer Action Committee, with a mandate to develop an action plan for a coordinated and systematic approach to the management of cancer. Building on the recommendations of the MHAC report, the committee developed a comprehensive, integrated and accountable systematic approach to planning, evaluating and standards setting within a regionalized system. The final report was to be submitted to the Deputy Minister of Health. (Terms of reference Appendix A).

Membership was drawn from all areas of cancer care including, Dalhousie Medical School, Dalhousie Faculty Of Health Professions, Family Practice, Nursing, Radiation, Medical, Surgical and Pediatric Oncology, Palliative Care, Regional Hospitals, the Nova Scotia Cancer Society, the IWK/Grace Health Centre, Department of Health and Planners from the QE11. Consumer input was facilitated by the Cancer Society. The committee met bi-weekly for a six month period.

¹Canadian Statistics 1996. p9

Since the MHAC review, health reform has significantly changed health care delivery in Nova Scotia. The committee, therefore, began with a review of the MHAC Report: "Oncology Services, A Strategy for Comprehensive Cancer Control in Nova Scotia". The committee decided that, with modifications, the recommendations contained in the MHAC report provided an appropriate foundation for a plan to develop a provincial cancer management strategy for Nova Scotia.

In addition, expert opinion both from across the country and from within the province, was presented on all components of cancer care. Various models and reports on cancer care in other provinces were reviewed by the committee. (Appendix B)

The Cancer Action Committee developed an action plan outlined in this report. The plan establishes a provincial cancer management strategy called, ***Cancer Care Nova Scotia***.

"Cancer Care Nova Scotia" will:

- a) coordinate and extend to all Nova Scotians comprehensive, integrated, accountable, patient-focused cancer care;***
- b) evaluate the effectiveness of cancer care; and***
- c) ensure the best use of resources.***

What is a Cancer Management Strategy?

It is a comprehensive, integrated systematic approach for the identification, development, promotion, and diffusion of effective and ethical cancer prevention, screening and care services, with the active participation of individuals and groups.

It is the application of existing knowledge to planning, evaluating and standards setting covering the spectrum of approaches to prevent, cure or manage cancer.

A cancer management strategy focuses on the eight components of cancer care: **prevention, screening/detection, diagnosis/treatment, palliation, supportive care, rehabilitation/restorative, education, and research.**

The Goals Are To:

- promote the physical, psychological, social and spiritual well being of people living with cancer;
 - reduce the incidence of cancer;
 - reduce the cancer mortality rate;
 - improve the quality of life for people living with cancer;
 - focus on outcomes;
 - develop standards for cancer care providers and facilities;
 - enhance compliance with evidence-based protocols;
 - strengthen all cancer control components;
 - develop a central role for family physicians; and
 - develop the cancer registry and a cancer epidemiology unit as a more complete health system resource.
- (Adapted from the MHAC report)

The Framework

The framework for cancer care should be patient-centred, comprehensive and integrated, care built on compassion and partnerships.

Broader representation and involvement of key stakeholders, both provincially and regionally, are essential to ensure a consistent approach. Regional involvement and accountability by all stakeholders needs to be strengthened.

The cancer management strategy will involve: caregivers, both professional and volunteer; cancer patients, survivors and family members; agencies, community groups, facilities, planners and researchers in the planning, delivery and evaluation of cancer care. The strategy should be planned provincially with wide stakeholder participation. Certain aspects of cancer care will be delivered regionally while other aspects require central delivery. **Cancer Care Nova Scotia** will be guided by three critical touchstones: **comprehensive, integrated, and accountable.**

The Touchstones of Cancer Care

Comprehensive Advances in Cancer Care have occurred across the spectrum, from screening to palliation, creating new diagnostic tests, new therapies and new specialities. **Cancer Care Nova Scotia** must be able to track cancer incidences and trends, to do analysis and recommend changes supported by evidence.

A piecemeal approach is no longer acceptable. A comprehensive cancer management strategy will ensure the best possible use of current resources that builds on existing strengths and partnerships.

Integrated The cancer management strategy must achieve integration at various levels. Information from a variety of sources will identify emerging trends and support a range of planning activities across the range of cancer care. A reliable and accessible information base can achieve an integrated systems approach. Clinical practice guideline development, standards setting, health human resource planning and research will ensure quality of care. This responsive system will include outcome evaluation and cost-effectiveness studies. The system will be flexible enough to respond to change as well as to create change.

Accountable The cancer control strategy must have "built in" accountability, similar to the principles of Total Quality Management. Facilities and individuals providing cancer services must learn to "close the loop" of clinical care through the rigorous examination of policies, procedures and practices for cancer patients. This cycle of planning, implementation and evaluation will become the standard for cancer care in Nova Scotia.

Adherence to evidence-based guidelines should result in improved survival statistics for cancer patients. **Cancer Care Nova Scotia** will ensure that providers of cancer services, whether individuals or facilities, are reviewed regularly by their peers.

Implementing **Cancer Care Nova Scotia**

Presently, cancer care is delivered through a diverse spectrum of service providers, organizations, agencies and groups. The focus on treatment has caused other components of cancer care, such as research and volunteer services, to develop in relative isolation. The result has been a loosely linked constellation of cancer related services and activities. The present approach to cancer management must be realigned if Nova Scotia is to have high quality cancer care now and in the future.

Cancer Care Nova Scotia will begin the task of:

- coordinating the eight components of cancer care;
- ensuring continued high quality planning and coordination of service covering the full spectrum of cancer care; and
- maximizing resources. (Appendix D for implementation schedule)

Cancer Care Nova Scotia

The goals and philosophy for an improved cancer care strategy in Nova Scotia require the creation of **Cancer Care Nova Scotia** with a broad, legislated mandate to direct cancer care (MHAC Recommendation 2.2.).

Its Mission will be:

to act as the catalyst and leader for cancer care in Nova Scotia, and to promote high quality cancer care through the development of standards and the evaluation of cancer care.

Cancer Care Nova Scotia's mandate will be to provide the leadership and coordination to improve cancer care in Nova Scotia. It will serve as a provincial advisory body to the Department of Health and Regional Health Boards on cancer management, particularly around the standards of cancer care. **Cancer Care Nova Scotia** will **not** be a service provider. Instead, cancer care will be delivered by the health care facilities across the province (MHAC Recommendation 3). This arrangement will allow **Cancer Care Nova Scotia** to concentrate on its leadership, coordination and standard setting role.

To succeed in its mandate, **Cancer Care Nova Scotia** must be given the authority to change the management of cancer care. This includes advising The Department of Health and Regional Health Boards on resource needs for cancer care, including financial, capital equipment, human and the location of services. **Cancer Care Nova Scotia** should have a mandate to review and audit care providers and facilities. It will also develop standards that can be used by credentialing bodies to sanction providers to deliver cancer care. A major function of **Cancer Care Nova Scotia** will be to provide timely cancer information to care providers and the public.

Recommendation 1

That Cancer Care Nova Scotia be established as a body corporate by a Legislative Act and be independent of any one facility.

Its Mandate will be to:

- 1. implement a comprehensive, integrated, province wide patient centred cancer management plan;**
- 2. act as the catalyst and leader for the complete continuum of cancer care programs: prevention, education, research, treatment, support rehabilitation and palliation;**
- 3. establish multi-disciplinary clinical planning teams (tumour groups) to develop practice guidelines, standards and multi-disciplinary research initiatives;**
- 4. develop linkages with regional and community health services to ensure continuing development of regional programs and support services for cancer patients and their families;**
- 5. develop an integrated cancer informatics service;**
- 6. develop standards and processes to accredit/credential cancer providers and facilities;**
- 7. evaluate cancer care and services throughout the province;**
- 8. co-ordinate strategic planning for all cancer care components;**
- 9. participate in the development of a funding methodology to support cancer care; and**
- 10. advise on the location and specific types of cancer services to be offered within the province.**

Governance of Cancer Care Nova Scotia

Board of Directors *Cancer Care Nova Scotia* should be guided by a Board of Directors comprised of stakeholders from across the cancer care continuum. The Committee recommends a flexible approach to membership on the Board. In addition to the Department of Health and Regional Health Boards, the Provincial Tertiary Centres, Dalhousie University and the Nova Scotia Division of the Canadian Cancer Society should be recognized on the Board.

This Board will continue to develop the mission, goals and objectives for **Cancer Care Nova Scotia**.

The role of the Board will be (1) to review the performance of the Chief Executive Officer; (2) to ensure that the mission, goals and objectives of **Cancer Care Nova Scotia** are achieved; and (3) be an important interface between **Cancer Care Nova Scotia** and other parts of the

cancer care system.

Representation from the four regions will link **Cancer Care Nova Scotia** with the facilities and individuals within the regions involved in cancer care.

The Board will guide **Cancer Care Nova Scotia** on the strategies needed to improve cancer care and will function as the policy making body. The Board will also have an important public relations role. As leaders of the cancer care system, they will be available to “market” **Cancer Care Nova Scotia** to the public.

Recommendation 2

That Cancer Care Nova Scotia will be governed by a Board of Directors. There will a maximum of 15 members initially appointed by Order- In- Council. The membership should reflect major stakeholder groups and consumer representatives from persons who have experienced cancer. Representation should achieve balance among the stakeholders and reflect the geographic diversity of the Nova Scotia population. The inaugural board will serve for three years and will be replaced by a nomination process to be developed by the board. The Board will report to the Minister of Health.

Chief Executive Officer

Cancer Care Nova Scotia will be directed by a Chief Executive Officer. Since the nature of **Cancer Care Nova Scotia** will be unique in this country, the search committee will look for an individual with superior leadership and visioning skills, as well as experience in Cancer Care. The role of the Chief Executive Officer will be to direct **Cancer Care Nova Scotia** in the fulfilment of its mission, goals and objectives. The search committee will define the job description for the Chief Executive Officer.

Recommendation 3

That the Board of Directors hire a Chief Executive Officer and establish an appropriate administrative structure necessary to develop and implement Cancer Care Nova Scotia. All positions must be filled through open competition.

That a search committee be charged with finding a suitable candidate for Chief Executive Officer of Cancer Care Nova Scotia. This committee should include representatives from Dalhousie University Faculty of Medicine, Department of Health, and the Cancer

Action Committee.

Functions of Cancer Care Nova Scotia

To enable **Cancer Care Nova Scotia** to fulfil its mandate a number of operational functions should be established: informatics: strategic planning, evaluation, tumour group development and resource planning.

Informatics New and innovative ways of handling information offer opportunities for improved cancer care. An early task for **Cancer Care Nova Scotia** will be the creation of a Cancer Epidemiology Unit for cancer surveillance, trending and analysis. This unit will begin by linking the cancer registry at the QE11 with other cancer databases in the province.

The informatics section will develop statistical methods of cancer surveillance for the province. It will support the work of the tumour groups by developing methods to review cancer treatment, as well as methods to judge Nova Scotia's performance against other provincial cancer programs.

In order to build the information base upon which strategic decisions will be made, **Cancer Care Nova Scotia** will require data from various sources. The sources of data will be varied. This information gathering process should be as "automatic" as possible. This will require the cooperation of other Government Agencies including the Vital Statistics Unit, MSI, and hopefully a new provincial health data base.

Accurate clinical information is also essential. In particular, first contact information from care providers must be made available to **Cancer Care Nova Scotia** on a timely basis. The Committee believes that this important principle should be recognized in the funding provided for clinical services.

Sharing of cancer information must be improved and will be an important goal of the Informatics Section. The improved health outcomes which result from care provided according to evidence-based protocols require that such protocols and their amendments are available on a timely and user- friendly basis. This information is invaluable to oncologists, nursing specialists, family physicians, dietitians, social workers and researchers. This can be done through computer networks within facilities, as well as public networks such as Internet. Patients and families of those diagnosed with cancer also have legitimate information needs, which may be satisfied in this way. The Canadian Cancer Society's Information Service could be an integral part of this strategy.

Recommendation 4

That Cancer Care Nova Scotia should have appropriate information technology to support cancer research and planning and the surveillance and analysis of cancer information for all stakeholders.

Strategic Planning

Planning Many of the cancer components have developed in isolation to one another and have no linkages or partnership. **Cancer Care Nova Scotia**, with appropriate stakeholders, will facilitate the strategic planning of each cancer component, as well as any new initiatives that are developed in the future.

Cancer care will be coordinated and planned at a provincial level to ensure (a) adequate human and financial resources, (b) development of standards of care and (c) improved organization, and (d) sufficient critical mass to ensure expertise.

The committee made a number of recommendations on each component within the cancer continuum as it related to **Cancer Care Nova Scotia's** mandate.

Prevention The Department of Health is committed to the prevention of disease and promotion of healthy lifestyles. Healthy public policy plays a central role in fulfilling this commitment.

The Department of Health has already launched a comprehensive tobacco strategy with three aims: to reduce the incidence and prevalence of smoking; to reduce tobacco purchases by minors; and to increase the awareness of and compliance among retailers with federal and provincial acts on tobacco sales.

Cancer prevention is important in any provincial cancer strategy. **Cancer Care Nova Scotia** must be involved in identifying health promotion and prevention strategies that work and in developing action orientated programs and opportunities for implementation. **Cancer Care Nova Scotia** can identify needs for healthy public policy.

Recommendation 5

That Cancer Care Nova Scotia lead the development of intersectoral cancer prevention strategies by including relevant government ministries, health professions, advocacy groups and non-government organizations.

Screening and Early Detection The Nova Scotia Gynaecological Screening and Breast Screening programs are two major cancer screening programs in the province. Both programs should be integrated into **Cancer Care Nova Scotia**.

These programs should integrate their databases with the future database at **Cancer Care Nova Scotia**. Specific expert advice on these programs will come from the appropriate tumour group.

Recommendation 6

That the planning, standard setting, and evaluation of cancer screening programs be facilitated through Cancer Care Nova Scotia.

Management Modalities There are several problems with the clinical management of cancer in Nova Scotia. The lack of an integrated approach to treatment is the most serious. The committee believes that creation of provincial tumour groups is the most practical way to address this.

Clinical management is divided along several lines: **treatment specialty**, (Radiotherapy, Chemotherapy, Surgery, Pediatric); **Geographic**, (centralized vs. regionalized); **Teaching Centres**, Academic facilities vs non-academic facilities, and **Methods of Physician Renumeration**, salaried and "fee for service".

Tumour groups are designed to cut across all these boundaries by bringing together clinical management specialists and health disciplines from all geographic areas to develop guidelines for treatment of cancer problems and review of cancer programs. This integration of cancer management must be achieved so that Nova Scotians will benefit from future developments in cancer therapies.

Tumour groups will be provincially based with experts from all parts of Nova Scotia. The committee believes that participation in tumour group activities should be considered part of the clinical workload of salaried cancer specialists, not an additional "after hours" committee function. To remove impediments to the participation by "non salaried" specialists, the

committee suggests that sessional fees be available as remuneration for time spent away from clinical practice.

Recommendation 7

That cancer treatment policies and clinical practice guidelines be developed through interdisciplinary teams known as tumour groups.

The committee believes that there is great potential in the tele-medicine network being developed by the Department of Health. The committee hopes that this network will be expanded and made available to **Cancer Care Nova Scotia** for Tumour groups functions and other province wide conference activities. Allowing experts residing outside Metro to participate electronically would be a further enhancement of the provincial nature of tumour groups.

Recommendation 8

That the Department of Health make available to Cancer Care Nova Scotia Tele-medicine facilities to allow province wide electronic conferencing for tumour groups and other activities.

Formulary Services Chemotherapy has become a major treatment arm. The cost of providing cancer chemotherapeutic agents has risen dramatically over the past several years and is likely to continue to increase, as new agents are developed. The introduction of genetically engineered compounds and gene therapy will be expensive. **Cancer Care Nova Scotia** must be able to monitor the use and cost of these agents, both on an inpatient and outpatient basis. The Committee believes that **Cancer Care Nova Scotia** should assume the responsibility for directing and reviewing cancer formulary services within the province.

This service will develop and provide guidelines and standards for the preparation and administration of chemotherapy. These will be used as auditing and approval standards.

Recommendation 9

That Cancer Care Nova Scotia assume responsibility for a provincial cancer formulary service in order to:

- ***ensure consistent drug availability across the province;***
- ***develop, communicate, and maintain appropriate guidelines for the preparation of cancer pharmaceuticals;***
- ***monitor the use of cancer pharmaceuticals, including***

- ***adherence to treatment guidelines;***
- ***integrate the use of cancer pharmaceuticals into a provincial cancer information system; and***
- ***advise the Department of Health on new cancer agents in a timely fashion.***

That the cost of cancer pharmaceuticals, (excluding antiemetics, colony stimulating agents and other treatment enhancers), established by clinical guidelines and provided on an ambulatory basis, be borne by the Department of Health, consistent with prevailing terms, conditions and the policy of insurer of last resort.

Supportive care is the link between the treatments people receive for cancer and needs that arise at all phases of the illness, from diagnosis to palliation. These include information about cancer, its prognosis, treatment options, outcomes and support systems available in facilities and in the community. Support services assist patients/families to cope with the diagnosis of cancer, and help prepare individual/families for changes in life that may come about from cancer and its treatment. These needs can be physical, social, spiritual, emotional or financial.

All professionals and volunteers involved in supportive care need to develop oncology expertise. Many groups and organizations have developed support services in response to the expressed needs of cancer patients and their families. In many instances, programs have developed independently from each other, resulting in a constellation of services which are not linked together nor accessible in many parts of the province.

Recommendation 10

That all cancer patients should have access to professionals who can appropriately address their physical, social, emotional and spiritual needs.

Rehabilitative/Restorative services are supportive care services focusing on the functions and quality of life. The goal is to return the patient to the highest level of functioning, with the greatest quality of life for the longest period possible. In the increasingly ambulatory oncology practice, these services will need to extend from the oncology centre into the community. The committee believes that more rehabilitative services on a more timely basis are required if this goal is to be met.

Recommendation 11

That there be uniform and timely access to cancer rehabilitative/restorative services throughout the province.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best quality of life for patients and their families. To meet this goal it is important to control pain, and other symptoms and to provide psychological, social and spiritual support. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anti-cancer treatment (World Health Organization).

Historically there has been the perception that cancer treatment centres were only responsible for the acute type of treatment required by cancer patients, and palliative care was not seen as part of the mandate. More than 50% of cancer patients will die of their disease following a period of illness characterized by pain, physical disability and varying degrees of emotional and spiritual distress. Therefore, there must be a “shift in the philosophy of cancer care, with increased priority given to the relief of pain and suffering, symptom control, psychosocial support, palliative care, support services and quality of life” (MHAC report).

As treatment is successful in lengthening the survival of patients with metastatic disease, palliative care will be required longer and will be dealing with more difficult symptom complexes.

The majority of care of patients with advanced disease will continue to be provided by family physicians. However, major advances in understanding the pathophysiology underlying the symptoms of cancer and the pharmacology of pain and symptom control have led to consideration of palliative medicine as a speciality in Canada, as it is in the United Kingdom.

There are a number of excellent palliative care services in Nova Scotia, but many other areas are still totally lacking services, and, in many other areas there are only a few components present. Palliative care needs to be developed as a province wide program with common provincial standards and with active linkages to acute care treatment services, community services education and research. The committee believes that ***Cancer Care Nova Scotia*** can facilitate those linkages.

Recommendation 12

That a province wide palliative care component be developed and implemented.

Education of cancer care professionals is primarily the responsibility of universities and academic health centres. The cancer system has relatively little input into core curriculum or educational program development. Greater integration between the educational programs and the patient care programs is required. To develop the education component of a coordinated cancer system the following initiatives need to be pursued: (1) the creation of an interdisciplinary Department of Oncology at Dalhousie University; (2) enhancement of oncology education and training in Cancer programs for health care professionals; (3) promotion of recruitment to cancer related disciplines, and the development of continuing outreach educational programs for health professionals. There should be close integration between the academic program responsible for education and research and **Cancer Care Nova Scotia**.

The Committee foresees an important role for **Cancer Care Nova Scotia** in coordinating and directing the education of the public on cancer care issues, from understanding how basic lifestyle changes can reduce cancer risk to an appreciation of the role of research in cancer management.

Recommendation 13

That Dalhousie University be encouraged to develop an interdisciplinary academic Department of Oncology.

Research is fundamental to the successful delivery of quality cancer care services and to the development of effective Cancer Care programs for prevention, treatment, support and palliation. Research contributes to an environment in which there is continuous learning and evaluation with a challenge to improve. Research is essential to provide evidence-based information for the design and evaluation of management strategies and in attracting and retaining excellent personnel capable of delivering a high quality cancer care.

The Committee believes that **Cancer Care Nova Scotia** must be a champion in the promotion of research into the various aspects of cancer control and should promote, facilitate, and foster a full spectrum of cancer research from outcomes and behavioural research to research in basic mechanisms of disease. **Cancer Care Nova Scotia** should identify research priorities with particular attention to identified gaps in oncology

research including the weakness in the translation of knowledge from the laboratory to the clinic and lack of adequate financial support for research.

The lack of face to face contact between researchers with common goals, the limitation in training opportunities for new researchers, the looming human resource shortage in research, the gap between the cancer patient /family needs and research priorities and the lack of emphasis on behavioural research has led the committee to recommend the development of the proposal "To Establish A Cancer Control Research Council In Nova Scotia".

Once province wide standards and treatment guidelines are established, **Cancer Care Nova Scotia** will be in a position to support research activities throughout the province. By concentrating on existing strengths rather than developing a duplicate approach, **Cancer Care Nova Scotia** will foster important alliances within the research community.

It is envisaged that cancer researchers will become an active participant in the cancer network. The role of the Network , bringing together persons affected by and working in cancer, will be strengthened by their participation.

Research must be pursued respecting a number of realities including the assurance of quality through peer review of research, the fostering of multidisciplinary research and by ensuring integration of cancer research scientists fully into the appropriate academic units in the universities, a real bench to bedside approach.

Recommendation 14

That Cancer Care Nova Scotia should promote, facilitate and foster a full spectrum of cancer research, from behavioural and outcomes research to research into basic mechanisms of disease.

That Cancer Care Nova Scotia develop the proposal "To establish A Cancer Control Research Council in Nova Scotia" submitted by the Nova Scotia Regional Research Development Plan Working Group, October 1995, to the National Cancer Institute of Canada (Appendix C).

Standard Setting

Development of Clinical Practice Guidelines for Tumour Groups. The operation of **Cancer Care Nova Scotia** requires attention to evaluation, quality assurance and total quality management. The committee believes that there must be increasing attention given to the whole process that provides care, not simply the improved actions of individuals.

Evidence-based care will be an expectation of all health professionals. Clinical practice guidelines for all aspects of cancer care must be developed and delivered consistently throughout the province.

Across Canada the development of clinical practice guideline for cancer has been done according to tumour groups. ***“Tumour groups, are interdisciplinary groups of individuals with expertise in cancer control for specific malignancies. They develop provincial treatment and management protocols and cancer control strategies, they evaluate outcomes and provide consultation/ education to the province”.***²

This clinical guideline development approach (tumour groups), will be a lynchpin of improved cancer management for this province. It will require operational support from **Cancer Care Nova Scotia**. Tumour groups will be led by a coordinator who will be a provincial cancer care expert/leader. The composition of each group may vary but the guiding principal should be inclusion of whomever is required to get the job done. This will mean a multidisciplinary team, provincial in membership. The Committee foresees an important advisory role for consumers of the cancer care system in tumour groups.

Tumour groups teams will be the primary source of expert clinical opinion for **Cancer Care Nova Scotia**. The breadth of their activities will be broad and encompass the continuum of cancer care.

Tumour Groups have never been either formal or effective in Nova Scotia. They will have a great deal of work to accomplish. This task may be started by borrowing on the experience of other organizations and provinces which already have well developed treatment protocols.

² British Columbia Cancer Planning Documents.

Recommendation 15

That cancer treatment policies and clinical practice guidelines, known as tumour groups, be developed through interdisciplinary experts drawn from across the province.

That patient focus groups should be available to each tumour group.

That consistent nursing policies and procedures, approved by Cancer Care Nova Scotia, be used by all agencies.

Approval of Providers and Facilities

Approval Function **Cancer Care Nova Scotia** must have the legislated mandate to review, audit and set standards for cancer programs and providers within the province. This will ensure the highest standard of care is delivered across the province.

The Committee believes that both facilities and individuals active in cancer care should be reviewed on a regular basis. In reviewing facilities, **Cancer Care Nova Scotia** will examine the philosophy, physical facilities, and functions of cancer care units and examine service loads to determine if workloads are sufficient to maintain skill levels. Standards for such facilities have been developed by other provincial and national organizations. It will be the responsibility of **Cancer Care Nova Scotia** to determine which of these standards are applicable in Nova Scotia and to develop new standards where required.

To ensure that Nova Scotians have access to uniform care across the province, the Committee believes that all individuals who institute, direct or provide cancer care should be specifically sanctioned through standards developed by **Cancer Care Nova Scotia**. These standards would be incorporated in credentialling processes used by Boards. This will be precedent setting. As cancer care has become a multidisciplinary field, specific standards and processes will be required for different groups, (nursing, medical, etc.). This will involve working with credentialling bodies throughout the province.

The Committee recommends that tumour groups take operational responsibility for auditing the various components of cancer care recognizing that adequate resources must be allocated to this function. **Cancer Care Nova Scotia** can recommend to credentialling bodies the

withdrawal of cancer privileges where necessary. Every review must have followed up to ensure that recommendation have been implemented.

The Committee realizes this function will take time to develop as it will break new ground in cancer care.

Recommendation 16

That all facilities (hospitals, clinics, etc.), wishing to provide cancer care services be required to undergo an approval process developed by Cancer Care Nova Scotia which endorses the facility's ability to meet standards of care.

That all individuals who institute, direct, or provide cancer care services be approved to do so through standards and a process developed by Cancer Care Nova Scotia.

That Cancer Care Nova Scotia, when established, be given legislated authority to conduct reviews and audits of individuals and facilities providing cancer care within the province and to conduct appropriate follow up reviews.

That material gathered during the course of such reviews and audits be protected under the Evidence Act as a "Peer Review Function".

That those persons conducting such audits be indemnified by Cancer Care Nova Scotia.

That Cancer Care Nova Scotia direct Tumour Groups to establish Review and Audit programs for their specialty so that such reviews commence within one year of the formation of the Tumour Group.

That Cancer Care Nova Scotia provide Tumour Groups with the necessary support to carry out this review and audit function.

Cancer Resource Planning

Funding **Cancer Care Nova Scotia** should be actively involved in evaluating and monitoring the funding of cancer care services across the province in order to advise the Department of Health on a fair, efficient and equitable distribution of financial resources. The committee believes that the system must tie funding to services that produce the most cost effective health outcomes. This will require the development of appropriate outcome measures, indicators and information technology that can incorporate information on efficiency and effectiveness.

Human Resource planning A large number of health care providers from many disciplines provide services and support to patients and families with cancer. The committee believes that **Cancer Care Nova Scotia** should be part of the human resource planning body which establishes human resource requirements for cancer.

The development of Cancer programs in Nova Scotia will require establishing numbers and types of cancer professionals. Such human resource issues should be planned for and occur within prevailing agreements between the Department of Health and appropriate professional organizations.

The Cancer Network A positive development in the evolution of our Health Care System has been improved opportunities for public input and scrutiny. This process will continue in the years ahead. The committee believes that the cancer care system should also be an open one. Many stakeholder groups have emerged in the cancer field. Their aims and desires may parallel one another, but occasionally there is a divergence of opinion.

The Nova Scotia Cancer Network would provide a forum for groups and organizations involved in cancer care to exchange ideas in a timely manner. Support for the network would be through a secretariat, provided by **Cancer Care Nova Scotia**. At regular intervals, the Network would hold public meetings to foster an exchange of information on cancer planning, research, outcomes, controversies etc. All parties involved in Cancer Care should take advantage of these opportunities including government, universities, researchers, facilities, and cancer advocacy groups.

Recommendation 17

That Cancer Care Nova Scotia develop a Nova Scotia Cancer Network to foster the broad exchange of cancer information.

That the Nova Scotia Cancer Network be open to all groups or organizations involved in any aspect of cancer care.

That Cancer Care Nova Scotia and the Department of Health participate in this network.

That the Nova Scotia Cancer Network hold regular public meetings at least once a year.

Location Of Cancer Care Services Many facilities in Nova Scotia participate in cancer care. A certain “critical mass” of patients is necessary to ensure clinical expertise and to attract cancer professionals of the appropriate calibre.

Those hospitals with surgical programs perform procedures for the diagnosis and treatment of cancer. Cancer chemotherapy is administered in many facilities. Radiotherapy at the present is limited to the QEII.

Cancer in adults presents different challenges than those faced by children with cancer, their families and those involved in their care. The Committee acknowledges the expertise already developed through the Pediatric Hematology/ Oncology group at the IWK ~ Grace Health Centre. Most of the principles of care espoused in this report are followed in the care of pediatric oncology patients. The Nova Scotia Pediatric Tumour Group will build on the progress of the Pediatric Hematology/Oncology service (IWK~Grace), continue the process of partnership and program development and to evolve and incorporate stakeholders from throughout the province. The Pediatric Tumour Group will be responsible for the planning and coordination of care for children with cancer. The continued development of Pediatric Cancer Programs will follow the principles outlined in this report and will be supported by **Cancer Care Nova Scotia** in such areas as informatics, education, evaluation and planning.

The Nova Scotia Pediatric Oncology Group will include a network of providers, researchers, professionals and health care organizations at the local, regional, and provincial levels. The Nova Scotia Pediatric Oncology Group will be an integral part of the implementation processes to improve pediatric oncology care.

Pediatrics must have a strong representation at the Board level to provide advocacy for children with cancer among the larger population of adults with cancer.

The complex issues associated with cancer care are seriously testing the ability of health service providers and organizations to deliver high quality and efficient care to the whole population. While a number of outreach and affiliate programs are available, the difficulty in ensuring state-of-the-art management, let alone early screening and prevention programs to under serviced and rural populations in the province, will be a major challenge facing **Cancer Care Nova Scotia**.

Due to the centralized nature of the treatment centres, patients who live in smaller communities must travel for their radiation and complex chemotherapy regimes and symptom management. Patients return to their own communities, following treatment. The follow up is most likely to

be carried out by family physicians who may or may not be working in partnership with the cancer program. Partnership will require that family physicians, community nurses and volunteers have meaningful access in the operations of **Cancer Care Nova Scotia**. The facilitation of this access will be a key role.

Recommendation 18

That the family physician role in cancer care co-ordination be strengthened to become a key communicator with patients/family. To do so they must be kept fully informed of the diagnosis and ongoing care of the patient.

Recommendation 19

That Regional Health Boards and facilities wishing to expand or establish new programs in cancer care must be endorsed by Cancer Care Nova Scotia. Only approved programs will be funded.

Evaluation of Cancer Care Nova Scotia

Cancer Care Nova Scotia must develop an evaluation framework that will measure the changes in cancer outcomes that are brought about by this cancer management strategy.

Recommendation 20

That Cancer Care Nova Scotia, in its annual report to the Minister of Health, provide evidence on how the changes in management of cancer care have contributed to improved cancer outcomes.

Appendix A

Terms of Reference

Membership List

Appendix B

Bibliography

Guest Speakers

Site Visits

Atlantic Provinces Pediatric Hematology/Oncology Network: APPHON for Access. Collaborating to Create Excellence in Shared-Care Services. November 30, 1995.

Canadian Council on Health Services Accreditation, Standards for Cancer Treatment Centres "a Client Centred Approach", 1995

Cancer Treatment and Research Foundation of Nova Scotia, Proposal for a Nova Scotia Cancer Programme. April 20, 1994.

Metropolitan Hospital Advisory Committee: Oncology Services, A Strategy for Comprehensive Cancer Control in Nova Scotia, 1993.

Metropolitan Hospital Advisory Committee: Palliative Care Report. 1992.

Ministry of Health, Ontario: Cancer Action Plan. The Full Spectrum. April 1995.

Ministry of Health, Ontario; Life to Gain. A Cancer Strategy for Ontario, 1994.

National Cancer Institute Registries: Canadian Cancer Statistics 1996.

Report of the Ontario Task Force on the Primary Prevention of Cancer: Recommendations for the Primary Prevention of Cancer. 1995

Report of the Chief Medical Officer of Health, Ministry of Health, Ontario: Progress Against Cancer. 1994.

Guest Speakers

Mr. Dan Rice
Coordinator of Strategic Information Technology
Department of Health

Dr Don Carlow
CEO
British Columbia Cancer Agency

Ms Marianne Hood
Director Of Finance
QEII

Site Visits by the Chair

British Columbia Cancer Agency

Princess Margaret Hospital
Toronto, Ontario

Sharp Memorial Hospital
San Diego, California

Appendix C

A Proposal to Establish a Cancer Control Research Council in Nova Scotia

Appendix D

The Implementation Schedule

	Timeframe
1. Response to the Cancer Action committee report.	
2. Appoint Development Coordinator.	
3. Develop the legislation for <i>Cancer Care Nova Scotia</i> .	
4. Appoint the Board of Directors by Order-in-Council.	
5. Strike a Search Committee for the Chief Executive Officer.	
6. Advertise for Chief Executive Officer	
7. Hire Chief Executive Officer and necessary staff.	
8. Develop strategy for Tumour Groups	
9. Appoint Chairs of Tumour Groups.	
10. Recruit members for each tumour group.	
11. Begin development of the complete plan as outlined in this document.	