



# Cancer Survivorship

## Roundtable Report

June 1, 2007

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## 1. EXECUTIVE SUMMARY

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On June 1, 2007 a group of 110 people from the Nova Scotia cancer community attended a one-day Roundtable Discussion on Cancer Survivorship hosted by *Cancer Care Nova Scotia*. All participants had the opportunity to learn, interact, provide feedback, and benefit from the expertise and experience of others affected by cancer.

The Roundtable was the culmination of a sequence of strategically planned activities. These activities were intended to create awareness, to generate thought and to encourage dialogue as a means of engaging a broad range of health professionals, cancer survivors, and health policy makers and administrators in thinking about and focusing efforts on survivorship. The last of these activities was the Roundtable.

The purpose of the Roundtable was to develop an Action Plan for Cancer Survivorship in Nova Scotia. Specifically, priority outcomes and activities required to achieve these outcomes were to be identified through the engagement process. Consensus was achieved amongst the participants on the following priority actions:

- Develop evidence-based long term follow-up guidelines for all types of cancers;
- Develop, implement and evaluate individualized follow-up care plans for primary care physicians and cancer survivors;
- Make psychosocial care a key component of the follow-up care plan;
- Optimize physical, psychological and spiritual health, well being and mindful living;
- Provide education and awareness for all involved parties;
- Ensure linkages between survivors and community resources/supports;
- Maximize the use of technology to facilitate and coordinate care; and
- Raise awareness of the need for increased financial investment to support survivorship.

Responsibility for these priority actions was identified as resting with a range of organizations, with specific accountabilities not part of the process for the event. *Cancer Care Nova Scotia* will continue to champion this issue and specifically will facilitate discussions with organizations to align priorities with mandates to ensure action.

At the end of the day, 97% of Roundtable participants agreed they now have a better understanding of available resources and what needs to be developed with respect to cancer survivorship.

“The very differing perspectives and experiences prodded me to rethink my opinions, past experiences, gaps in my knowledge, (and) the exchange of ideas was enlightening”. (*Roundtable Participant*)

## 2. INTRODUCTION

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### **SURVIVORSHIP – WHY NOW?**

There are many reasons why cancer survivorship is an important issue at this time. The most compelling is the increase in the number of cancer survivors, a projected increase of 20 percent in Canada over the next five years, and 40 percent over the next ten years. Nova Scotia has among the highest rates of new cancer cases, and cancer deaths, in Canada. More than 28,000 Nova Scotians are living with cancer and 5,000 new cases are diagnosed each year. A large proportion of our population will enter the 60+ age group over the next 20 years. Since cancer is common in older people, this will increase the incidence.

Most importantly perhaps is that cancer survivors say it's important. There is anecdotal evidence of general dissatisfaction with post-treatment care, with cancer survivors reporting too little attention being paid to their many psychosocial concerns, such as depression, fear of recurrence, sexual dysfunction, and financial issues. Relatively little is known regarding cancer survivors' preferences for care, but there is a growing recognition of the need for flexible options for survivors who may have different needs and circumstances.

Now is the time to respond and to do so effectively. As we are being challenged to service the needs of cancer survivors for long-term follow up care, we must know how co-morbidities are affected by previous cancer treatments and to understand the move from an acute condition to chronic disease management. Survivors know the issues, they have made them clear. It is time to frame what we need to do and to act on it.

To act now does not imply that we must start from "scratch". Our health system has many of the fundamentals already in place including:

- Competent and interested health care providers;
- A growing community of survivors through events that profile and celebrate cancer survivorship;
- Patient navigation services;
- The Cancer Patient Family Network – an organized approach to give a voice within the cancer system to cancer patients, survivors and families;
- Increasing research in health services, as evidenced by Dr. Eva Grunfeld's work to determine effective survivorship care plans and strategies; and
- Significant participation by health professionals in education initiatives such as the Interprofessional Core Curriculum across the province.

## DEFINITION OF CANCER SURVIVORSHIP

There are many definitions of cancer survivorship. Among them are the following:

- Living with, through and beyond a cancer diagnosis (*Lance Armstrong Foundation*);
- Three “seasons” of survival – permanent, extended and acute, each with unique sets of concerns (*From Cancer Patient to Cancer Survivor: Lost in Transition*);
- The period of health and well-being experienced by survivors after active cancer treatment (*National Cancer Coalition Society*); and
- Five years post treatment, off medication with no evidence of disease (*Pediatric definition*).

The focus for the action plan is on the period or “season” following active cancer treatment because of the increasing survival rates and the strong desire to organize and expand the cancer system to address these needs; and because much has already been done in the acute care and prevention or early detection phases. There is an obvious need to move beyond these phases and begin to address the long-term needs of a growing population of our citizens.

## APPROACH TO ACTION PLANNING

### Building Process

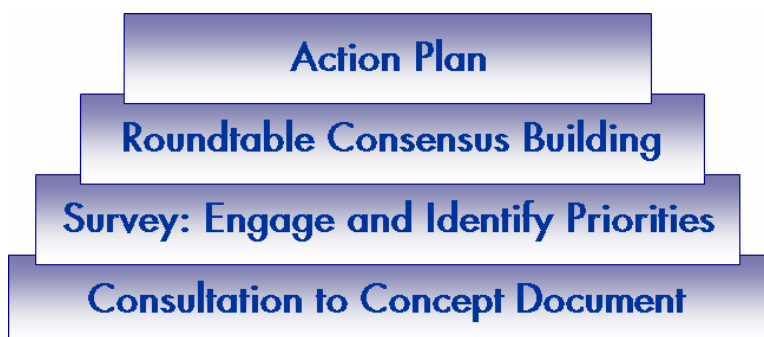
The approach entailed a four-step building process which culminated in the survivorship Roundtable. As a first step, *Cancer Care Nova Scotia (CCNS)* drafted a discussion document entitled “Cancer Survivorship – Implications for Clinical Practice, Research and Well-Being”. This document provided the context and high level overview of the issues related to cancer survivorship.

Step two involved dissemination of a survey, along with the discussion document, to a broad cross section of individuals associated with the cancer system in Nova Scotia, including survivors and their families, health professionals, government partners, and cancer related organizations. More than 250 individuals responded to the survey, identifying a high degree of consensus around the key issues. These responses were consolidated to reduce duplication and support discussion at the roundtable event.

Step three involved the Roundtable Discussion which provided the forum for dialogue and consensus building. This event facilitated the development of a survivorship action plan, the

foundation for moving the survivorship agenda forward. Step four will entail more detailed development of the plan and the implementation to bring it to reality.

#### Four-Step Building Process



#### The Priorities

The four priority issues identified through the survey which were the focus of discussion at the Roundtable event are as follow:

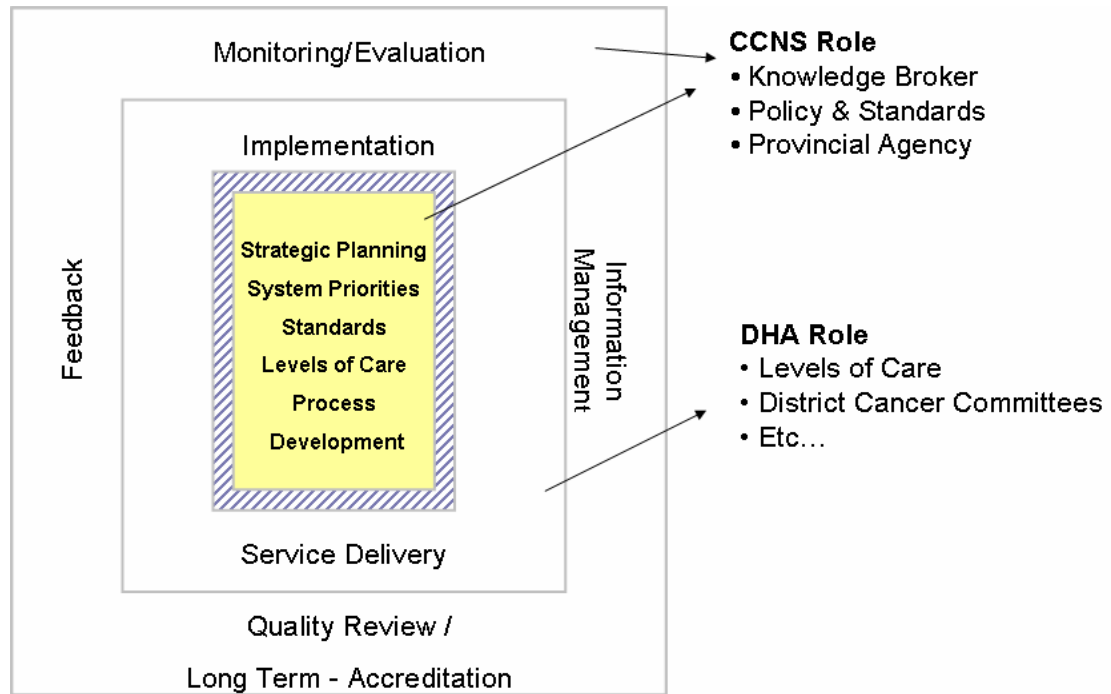
- Navigating long term follow-up care;
- Addressing psychosocial and physical concerns;
- Education and awareness for health care professionals, survivors and their families; and
- Clinical standards and guidelines.

#### Cancer System Roles and Responsibilities

CCNS is a provincial program responsible for the quality of service delivery in the cancer system in Nova Scotia. CCNS is not responsible for service delivery; that responsibility rests with the District Health Authorities (DHA). The role of CCNS can best be described as cancer system planning, including identification of provincial priorities, and developing and monitoring policies and standards. CCNS is also responsible for focusing, facilitating and supporting cancer related efforts in Nova Scotia and acting as the champion of change in the system.

The diagram below presents an overview map of the primary roles which CCNS and the DHA's play in the Nova Scotia cancer system.

### Nova Scotia Cancer System



### Advisory Committee

The CCNS working group associated with planning the Roundtable Discussion was supported by an Advisory Committee. Members of the Advisory Committee provided expert advice and input into the discussion document, development of the survey and formulation of the Roundtable Discussion agenda and format. A list of Advisory Committee members is found in Appendix A.

### 3. BACKGROUND

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In keeping with the building blocks theme, the keynote speaker and panelists provided a context for the dialogue and embellished the framework that had already been developed through the discussion document and survey.

#### KEYNOTE SPEAKER

Dr. Eva Grunfeld, a clinician scientist, is a national leader in cancer health services and outcomes research, Director, Cancer Outcomes Research for CCNS and professor in the Department of Medicine at Dalhousie University. Dr. Grunfeld presented research and evidence to support the four priorities and set the stage for subsequent discussions by the participants. Highlights of her presentation are found in Appendix B.

#### PANELISTS

To further contribute to the depth and breadth of the roundtable discussions, four panelists presented their varied perspectives on cancer survivorship. The panelists were:

- Annette Penney, Nurse Coordinator for Long-Term Follow-Up Care of the Pediatric Oncology Program at the IWK Health Centre;
- Dr. Rob Rutledge, a radiation oncologist at the Nova Scotia Cancer Centre;
- Dr. Mike MacKenzie, a family physician in Antigonish; and
- Steve Webster, a four-time survivor of cancer.

These panelists are representative of the stakeholders in cancer survivorship. They shared their knowledge, expertise and, professional and personal experiences with participants in the room with a focus on the four priority issues.

## 4. ROUNDTABLE DISCUSSION

Building on the knowledge assembled through the discussion document, the survey, and at the Roundtable Discussion event through the keynote presentation and the panelists' perspectives, participants engaged in dialogue and planning to address the cancer survivorship agenda. They identified assets and gaps and developed action plans related to the four priority issues by identifying priority outcomes and key activities required to move the survivorship agenda forward.

### ASSETS AND GAPS

The table below provides an overview of the assets and gaps in the cancer system as identified by participants at the Roundtable Discussion.

**Table 1: Assets & Gaps – Identified by Roundtable Participants June 1, 2007**

Issues	Long Term Care Follow-up	Psychosocial & Physical Concerns	Education & Awareness	Clinical Standards & Guidelines
<b>Assets</b>				
Knowledgeable health care professionals	√	√	√	
Support groups	√	√		
Health related organizations	√	√		√
Not-for-profit & volunteer agencies	√			
Knowledge-based evidence	√		√	√
Screening tools	√			
Telehealth	√		√	

<b>Issues</b>	<b>Long Term Care Follow- up</b>	<b>Psychosocial &amp; Physical Concerns</b>	<b>Education &amp; Awareness</b>	<b>Clinical Standards &amp; Guidelines</b>
Other care models	√			√
Families		√		
Sunshine Room		√		
Increasing attention to survivors' needs		√		
Information sources / internet		√	√	√
Survivors' knowledge & experiences			√	
Community involvement			√	
Quality outcomes			√	
Patient navigator position			√	
<b>Gaps</b>				
Coordination & consistency of care	√			√
Outreach & communication tools (other than the internet)	√		√	
Various guidelines	√			√
Understanding financial burden	√		√	
Notification of potential for very long term side effects	√			

<b>Issues</b>	<b>Long Term Care Follow- up</b>	<b>Psychosocial &amp; Physical Concerns</b>	<b>Education &amp; Awareness</b>	<b>Clinical Standards &amp; Guidelines</b>
Incorporation of alternative medicine into traditional system	√		√	
Information e.g. directory of available resources, survival kits, holistic packages		√		
Infrastructure for support groups		√		
Accountability in quality of care		√		
Sensitivity in communicating health information		√		
Access to private practice health care professionals (funding)		√		
Supports for re-integration to work & school		√		
Response to cultural sensitivities		√		
Equitable access to navigation services		√		
Individualized follow-up care plans		√		
Stigma attached to psychological care		√		
Information gathering and transfer of knowledge			√	
Unclear roles and responsibilities			√	
Duplication in information dissemination			√	
Knowledge about certain types of cancers			√	

Issues	Long Term Care Follow-up	Psychosocial & Physical Concerns	Education & Awareness	Clinical Standards & Guidelines
Funds, Human Resources & time to deliver education			√	√
Incentives for physicians			√	
Better use of existing guidelines				√
Workload standards for health care professionals				√

## ACTION PLAN

The action plans for each of the four priority areas include many commonalities and similar themes. Above all, participants identified the need for an integrated and inclusive approach to support survivors and their families as the foundation on which the action plan must be built.

Principles underpinning advancement of the survivorship agenda include the following:

- All Nova Scotians must have equal access to care regardless of where they live or their cultural and social backgrounds;
- Development of this body of work must be based on sound scientific and clinical evidence; and
- The ability to share knowledge and information must facilitate improved collaboration, coordination and communication.

The need to plan for and provide long term follow-up care is the common thread that runs through all the action plans. Developing individualized long-term follow-up care plans emerged as the primary goal.

The following table demonstrates the priority outcomes that emerged for each priority issue and the following paragraphs describe the six most common priority outcomes that were identified at the Roundtable event.

**Table 2: Action Plan – Priority Outcomes Identified by Roundtable Participants June 1, 2007**

<b>Priority Outcomes</b>	<b>Long Term Care Follow-up</b>	<b>Psychosocial &amp; Physical Concerns</b>	<b>Education &amp; Awareness</b>	<b>Clinical Standards &amp; Guidelines</b>
<b>Long Term Care Follow-up</b>	x	x	x	x
Patient Navigators	x	x	x	x
Equitable access for vulnerable populations & rural areas	x	x	x	x
Enhanced role for family doctors	x	x	x	x
Individualized care plans	x	x	x	x
Financial support for system	x			
Information resources/sources & funding	x	x	x	x
Effective transition from active treatment	x	x	x	x
<b>Psychosocial &amp; Physical Concerns</b>	x	x		
Promoting healthy lifestyle		x	x	
Financial support for survivor		x		x
Support services for caregivers		x		
Accessibility to work		x		
Research		x		

Priority Outcomes	Long Term Care Follow-up	Psychosocial & Physical Concerns	Education & Awareness	Clinical Standards & Guidelines
Education & Awareness	x	x	x	x
Interdisciplinary/interagency cooperation	x	x	x	x
Clinical Standards & Guidelines	x	x	x	x
Practice guidelines				x
Cancer specific best practices				x
Self-management tools				x
Communication between physician, patient & specialist				x

### Individualized Long Term Follow-up Care Plans

Individualized care plans must be established on evidence-based guidelines that integrate generic, cancer specific and individual data. These plans should serve as a vehicle to foster a trusting, open relationship between specialist, primary care physician and survivor. The plan needs to embrace the survivor in a holistic manner and include not just those concerns related to the clinical management of the individual but also address the psychosocial and physical concerns that come with transitioning from acute to long-term care.

An individualized care plan and approach should include not only identification and communication of diagnosis, treatment, ongoing care, long-term effects of treatment, and the importance of a healthy lifestyle but must connect the survivor to community resources to support the individual in managing his/her emotional and psychological concerns around returning to work or school, and financial and other personal issues.

The enablers in developing and managing an individualized care plan involve a variety of resources, including:

- An interdisciplinary team;
- Clinical standards and guidelines;

- Information and technology;
- Education and awareness; and
- Funding for the survivorship agenda and financial support for survivors.

## **Interdisciplinary Team**

An interdisciplinary team of specialists, family physician, navigator and others together with the survivor and his/her family form the nucleus of the team. Other health care professionals, health-related organizations, support groups, and spiritual and pastoral care workers may contribute to the plan and consequently, to the ongoing health and well-being of the survivor. Information, knowledge and education along with well understood roles and responsibilities will be necessary to empower the team to provide care and support to achieve the best possible long-term outcomes.

In addition to the individuals and organizations already mentioned, the survivorship agenda must be supplemented and supported by researchers, labour and employer organizations, and charitable and community organizations.

## **Clinical Standards and Guidelines**

Clinical standards and guidelines were addressed both from the perspective of increasing usage of existing resources and developing new ones to specifically address survivor-related issues. There is a sense that standards and guidelines already in existence could be better applied and used more widely across the cancer care spectrum.

Development of new standards and guidelines is required to support effective transition from active treatment to long-term follow-up care with a long-term goal orientation. They will need to provide for an enhanced role for family physicians and clearly define roles and responsibilities of the long-term care team. Vehicles for improved communication and collaboration to promote interdisciplinary opportunities to better coordinate care will need to be addressed. Clinical standards and tools to support patient self-management will need to be accessible throughout the province and appropriate to all cultures, and people in all income strata and literacy levels.

## **Information and Technology**

Information gathering, storage, access and dissemination will be key to ensuring members of the team have at their disposal the best information possible on which to make decisions. The ability to access and share information from a variety of sources including the internet, electronic health records and other databases was seen as a significant requirement in

developing the survivorship agenda. A web portal may be an important tool which could provide access to the following:

- Required information including best practices and late effects for all types of cancers;
- Survival kits and directories of support groups; and
- Electronic health records by physicians, nurses and other health care professionals.

In addition, a web portal was seen to provide a means by which to communicate across the province with a wide variety of individuals in a consistent and timely manner and would serve to improve inter-agency collaboration. Further, it would assist in the development of follow-up guidelines, support psychosocial care, leverage access to services in rural areas and allow patients to integrate general data into their individual care plans. There was recognition that centralized resources would be required to ensure ongoing integrity and currency of the information and data.

The increased use of telehealth to reach survivors and physicians remote from the primary care centres was seen as an important tool to ensuring equal access to knowledge, information and education, and promoting communication and collaboration.

## **Education and Awareness**

Education and awareness are enablers that facilitate communication, collaboration and understanding between the parties involved in a survivor's long-term care. They allow all parties to communicate on a level playing field because they are able to share knowledge and information of the issues. Education for patients and family physicians was seen to be particularly important to ensure they are able to participate actively in the development of an individualized care plan. Patient navigators provide a conduit between the patient and the system and act as an education resource.

## **Funding**

Discussion around funding included both the need for funding to develop and implement the survivorship agenda and financial support for cancer survivors. There is recognition that funding for the former will need to come from reallocation of funds already in the system with some new funding coming from both government and other sources. Financial support for cancer survivors to access treatment not supported by the public health care system was identified as an issue requiring further discussion.

## 5. CONCLUSION

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### WHERE TO FROM HERE?

Lewis Carroll in his great piece of literature, *Alice Through the Looking Glass*, gave excellent advice for planners, policy makers and people in general. He wrote,

“Would you tell me, please, which way I ought to go from here?  
That depends a good deal on where you want to get to.  
I don't much care where, said Alice.  
Then it doesn't much matter which way you go.”

The exercise of building a plan of action to make progress and effect change in the lives of cancer survivors benefits from the knowledge that the cat seemed to have. Knowing where you want to go determines the steps you need to take to get there. The Roundtable process has set the priorities or the roadmap for where we want to go. It is now critical to put our efforts into getting there.

What will it take to get there? Well there is no well-known quote that will guide us to that point. There is, however, tremendous leadership, participation, strength and knowledge to map the way forward. *Cancer Care Nova Scotia* will be working with its partners and stakeholders, the participants in the Roundtable and those who have identified that they are working on and committed to seeing accomplishment of these priorities. We will champion the work started almost 18 months ago; the work that began with the development of the conceptual discussion, the review of the evidence, the survey of stakeholders, and that culminated in the Roundtable. We will take the priorities which have been identified and validated and work with cancer survivors, health professionals, and policy makers to work toward the accomplishment of the priorities.

*Cancer Care Nova Scotia* will continue the work of Survivorship and will report progress and attainment publicly to ensure that the needs of survivors are met.

## APPENDICES

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**Appendix A – Advisory Committee Members**

**Appendix B – Key Note Speaker Presentation**

## **APPENDIX A – ADVISORY COMMITTEE MEMBERS**

**Emmie Luther-Hiltz, Co-chair**

Coordinator, Cancer Patient Family  
Network;  
*Cancer Care Nova Scotia*

**Anne McCormick**

Clinical Nurse Educator;  
Cape Breton Regional Healthcare  
Complex

**Judy Simpson, Co-chair**

Coordinator, Palliative Care;  
*Cancer Care Nova Scotia*

**Leslie McLean**

Clinical Nurse Specialist;  
QEII Cancer Care Program

**Mark Bernstein**

Division Head/Health Administration;  
IWK Oncology Program

**Dorianne Rheaume**

Radiation Oncologist;  
Nova Scotia Cancer Centre

**Susan Haley**

Board of Directors;  
*Cancer Care Nova Scotia*

**Barb Thompson**

Survivor

**Joanne Hughes**

Patient Navigator;  
South Shore Health

**Theresa Marie Underhill**

Chief Operating Officer;  
*Cancer Care Nova Scotia*

**Amy Lewis**

Research Coordinator;  
*Cancer Care Nova Scotia*

**Steve Webster**

Survivor

**Mike MacKenzie**

Medical Director, Palliative Care;  
St. Martha's Regional Hospital

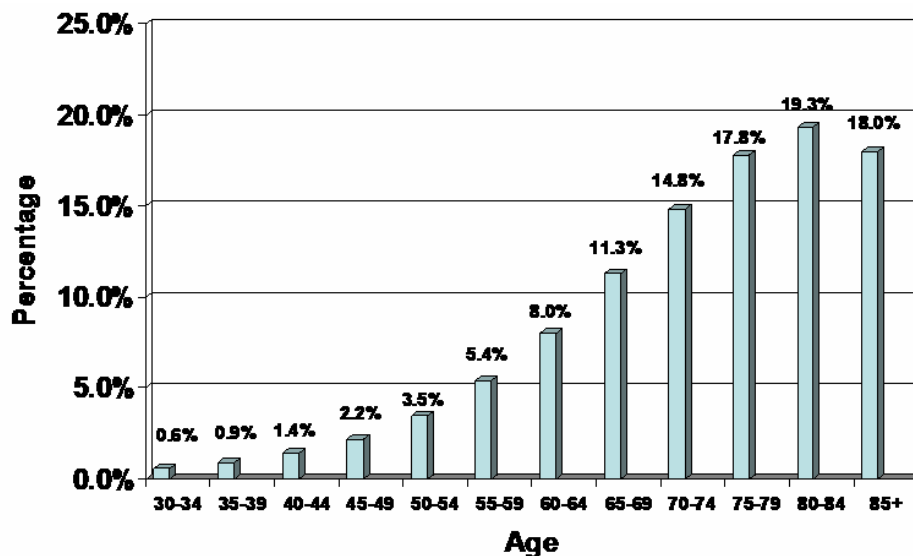
## APPENDIX B - SUMMARY OF KEY NOTE PRESENTATION

The Key Note speaker was Dr. Eva Grunfeld, Director of Cancer Outcomes Research Program, CCNS; Professor, Dalhousie University Faculty of Medicine.

### The Epidemiology of Cancer Survivorship

In Canada, there are approximately 160,000 new cancer cases each year. The number of survivors is expected to balloon with the growth and aging of the population. From 2000 to 2050 there is expected to be a doubling of cancer survivors. The following chart shows the increasing prevalence of cancer as the population ages. (*source: IOM report From Cancer Patient to Cancer Survivor, 2006*). With an aging demographic in Canada and Nova Scotia, this situation will become more acute.

Cancer Prevalence by Age



The challenge for health services is how best to manage the success associated with increasing incidence and improved survival, resulting in a large prevalence of cancer survivorship. With respect to incidence rates, 39% of Canadian women and 44% of Canadian men will develop cancer during their lifetime. Approximately one out of every four Canadians will die from cancer. The challenge for health services is to manage the success of cancer survivorship and the complexities associated with a large and growing prevalence.

## **Cancer Survivorship from a Cancer Care (Health System) Perspective**

Survivorship issues include not only routine follow-up care but general medical and preventative care as well. Because the majority of cancer cases occur among those 60 years of age and older, the majority have three or more other medical conditions. Accordingly, it is important to have both an oncology team and the family physician involved in the long term follow-up care.

Childhood cancer survivors are less likely to be seen at a cancer centre the longer they survive from date of their cancer diagnosis. When the cumulative incidence of late effects is superimposed, a very significant gap becomes evident as they are 15, 20 and 25 years from their cancer therapy. By this time they are experiencing their highest rate of morbidity but are not being seen at a cancer centre.

## **Models of Cancer Survivorship Care**

The Institute of Medicine (IOM). *From Cancer Patient to Cancer Survivor; 2005* report included among others, the following four recommendations:

- Raise awareness of cancer survivorship;
- Provide patients with a “Survivorship Care Plan”;
- Develop evidence-based clinical practice guidelines; and
- Test models of survivorship care.

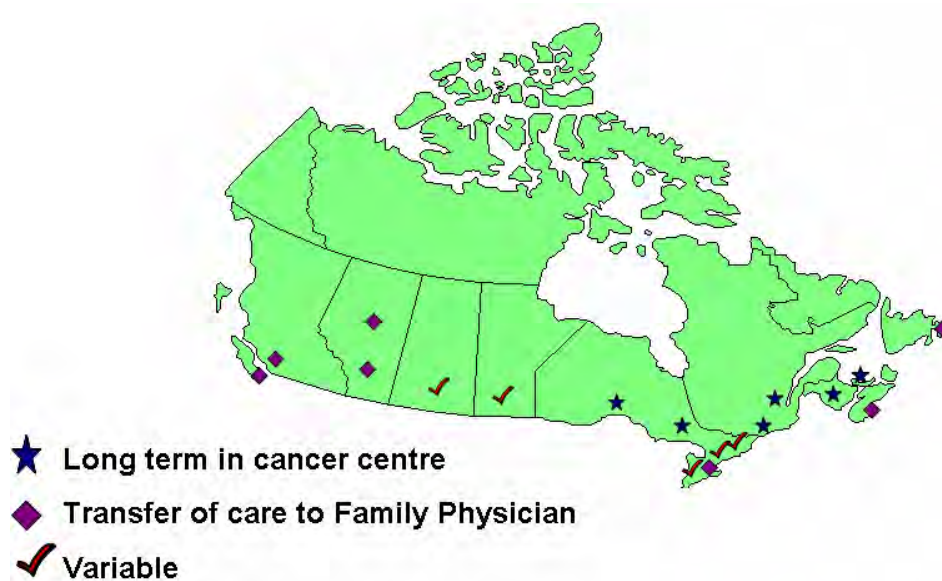
National guidelines have been published for breast cancer under the auspices of the Steering Committee for clinical practice guidelines for the care and treatment of breast cancer. Many provincial cancer agencies have developed guidelines as well. For example, *Cancer Care Nova Scotia* is finalizing guidelines on breast cancer follow-up and making local adaptations to other published guidelines.

Elements of a follow up care plan should include the following:

- Identifying information (patient and provider);
- Cancer treatment summary;
- Diagnostic tests completed;
- Risk of recurrence;
- Signs and symptoms;
- Recommended surveillance guidelines;
- Potential late effects; and
- Preventive care recommendations.

The role of the family physician is a primary consideration in developing a long term follow-up care plan. Current follow-up practices at selected cancer centres in Canada are shown in the diagram below.

### Current Follow-Up Practices at Selected Cancer Centres in Canada



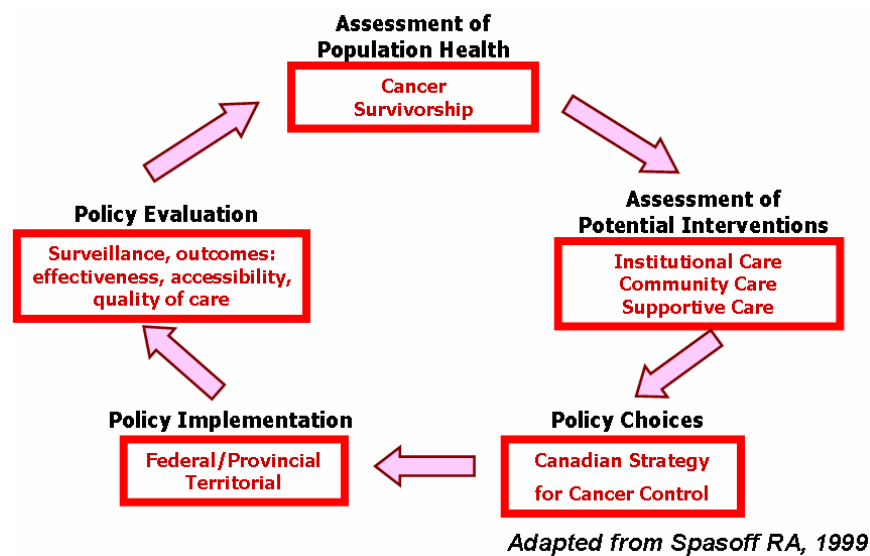
### Survivorship from a Cancer Control (Public Health) Perspective

Potential strategies include:

- Health care policies targeting the individual;
- Social policies; and
- Public health policies targeting the population.

An overview of the relationship between public health policy and survivorship is shown below.

## Public Health Policy and Survivorship



## Conclusions

Conclusions to be drawn from this research overview are as follows:

- The growing prevalence of cancer survivors;
- A change in perspective from acute life threatening disease to chronic disease;
- From the cancer care perspective, cancer follow-up care is the principal focus; and
- Increased activity suggests growing awareness and interest in cancer survivorship.