

Where Do We Go From Here?

Support services for women with breast, cervical, ovarian and uterine cancer in Atlantic Canada

A Report Prepared

for the Canadian Partnership Against Cancer Corporation

by

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EXECUTIVE SUMMARY

In the fall of 2007, the New Brunswick Breast Cancer Information Partnership initiated a discussion with the breast cancer networks in the four Atlantic Canada provinces to explore the potential for collaborating and expanding their work to include other cancers that are specific to women – cervical, ovarian, and uterine cancers. The Breast Cancer Networks committee that emerged out of these discussions then approached the ReBalance Focus Action Group – Awareness Project of the Canadian Partnership Against Cancer to fund a study of women’s cancers in Atlantic Canada followed by a regional Think Tank. The application was successful and the Breast Cancer Networks committee commissioned the Atlantic Centre of Excellence for Women’s Health in Halifax, Nova Scotia, to develop a profile of women’s cancers in New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island. In addition to gathering incidence and mortality data on the four cancers, the Centre was tasked with investigating the number and nature of existing supports and services for women faced with a diagnosis of breast, cervical, ovarian and uterine cancers in Atlantic Canada. Research included collection of cancer data from published reports and contact with provincial cancer agencies as well as an environmental scan of supports services and interviews and focus groups with cancer survivors in New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

The analysis of cancer statistics demonstrated a significant gap between the number of women diagnosed with and dying from breast cancer as compared with those diagnosed with and dying from cervical, ovarian and uterine cancers. Similarly, while many services and supports in Atlantic Canada are generic – available to any and all cancer patients – programs that are specifically tailored to the needs of women with breast cancer are far more common than those for women with cervical, ovarian and uterine cancers.

The analysis of services revealed a large number and variety of supports and services for people living with cancer in Atlantic Canada. Many cancer survivors reported positive experiences with services and supports available through the publicly funded health care system and from organizations in the voluntary sector. At the same time, some cancer patients chose not to utilize support services, preferring to rely on family and friends to meet their emotional and social needs. But many women living with cancer also spoke of large gaps; they did not have access to supports and services when and where they needed them and might not even know what was available or if they were eligible for specific services. Even information that was available – through websites, print materials and from health care providers – was not necessarily complete, reliable, accessible or timely.

This profile of women’s cancers in Atlantic Canada has led to a number of conclusions and recommendations. Although not-for-profit and publicly funded supports have developed tremendously in recent years, particularly in the area of breast cancer, many women living with cancer remain underserved as a result of geographic or social dislocation, type or stage of

cancer, financial and technological barriers, etc. More effort is needed to reach out to women, especially women in the earliest stages of diagnosis and care, and women from vulnerable or disadvantaged populations.

The findings of this research have led to several key recommendations for those interested in improving services and supports for women living with breast, cervical, ovarian and uterine cancers:

- Encourage health care organizations – formal and informal – to ensure that the information they distribute is timely, accurate and reliable as well as available in a variety of formats;
- Foster new research on the needs of women from vulnerable and disadvantaged communities who are faced with a diagnosis of cancer;
- Explore the possibility of adopting and adapting the processes and products developed by breast cancer support networks in Atlantic Canada to meet the needs of those with other women’s cancers; and
- Promote the creation of publicly-funded cancer patient navigator programs throughout Atlantic Canada.

1. INTRODUCTION

1.1 Background

In 1998, Health Canada formed and funded four Atlantic provincial partnerships, through its component Community Capacity Building (CCB) for the Canadian Breast Cancer Initiative (CBCI), to provide support and information for people impacted by breast cancer. Within Atlantic Canada, a committee was formed from key breast cancer information partnerships to address the increasing need for expanded information networks. The formation of the Public Health Agency of Canada in 2001 and the reallocation of CBCI CCB funding to this unit meant that the New Brunswick Breast Cancer Information Partnership (NBBCIP) could initiate a project co-funded by the Public Health Agency of Canada's CBCI CCB component and the Canadian Partnership Against Cancer (CPAC) to undertake two tasks: to develop a profile of women's cancers in Atlantic Canada, including the extent of women's cancers and existing supports and services; and to hold a regional 'Think Tank on Women's Cancers'. The ultimate goal of this partnership has been to explore the need for and feasibility of establishing an Atlantic Canadian Coalition for Women and Cancer.

In December 2007, the Atlantic Centre of Excellence for Women's Health was commissioned to develop the profile of Women's Cancers in Atlantic Canada. Data on cancer epidemiology in Atlantic Canada was collected, tabulated and analyzed while an environmental scan, interviews and focus groups provided information on existing supports and services (see "Methodology").

On March 31, 2008, the Atlantic Invitational Think Tank on Women's Cancers was held in Halifax, Nova Scotia, sponsored by the New Brunswick Breast Cancer Information Partnership Inc., the Lupin Partnership (Newfoundland and Labrador), the Nova Scotia Breast Cancer Network, and the Prince Edward Island Breast Cancer Information Partnership. More than 45 participants from Atlantic Canada, Ontario and Manitoba met to learn about the research and to explore the possibility of partnership among those committed to supporting women faced with a diagnosis of breast, cervical, ovarian, and uterine cancers. Feedback from the Think Tank has been incorporated into this report and a separate report on the Think Tank is available from The Quaich, Inc., Prince Edward Island (available online at http://www.thequaich.pe.ca/cat_prod_det.asp?id=126).

1.2 Atlantic Provinces

The four provinces comprising Atlantic Canada are New Brunswick (NB), Newfoundland and Labrador (NL), Nova Scotia (NS), and Prince Edward Island (PE). The respective populations of the provinces are:



New Brunswick 729,498; Newfoundland and Labrador 512,930; Nova Scotia 908,007; and Prince Edward Island 135,294.

Because cancer treatment facilities and support services tend to be concentrated in urban areas, focus groups and interviews with cancer survivors and their loved ones were conducted in Moncton, Halifax, and Charlottetown. Interviews were also conducted via telephone with 3 cancer survivors living in rural Newfoundland and Labrador. Altogether, 22 cancer survivors and key informants, in 4 focus groups and 9 interviews (7 key informant and 2 survivor), provided the research used in this report.

1.3 Terms and Concepts

Various terms and concepts are used in this report and, to avoid confusion or misinterpretation, they are defined here. Some of these definitions are widely used while others are not, but they are applied consistently throughout the report.

- Much of the statistical data reported here comes from the Canadian Cancer Society/National Cancer Institute of Canada annual reports, *Canadian Cancer Statistics*. While these data are developed in conjunction with Statistics Canada and the Public Health Agency of Canada, they are *estimates only*, based on extrapolation from historical epidemiological trends.¹ When information on actual cases of cancer are cited, the sources and the nature of the data will be identified in the report.
- “Cancer incidence” refers to the number of new cases of cancer diagnosed in a given period.
- “Cancer prevalence” signifies the number of people living with cancer at the time of reporting. Much of the information presented on this topic is drawn from the Canadian Cancer Society/Canadian National Institute of Cancer annual report, *Canadian Cancer Statistics 2007*. These numbers are estimates only, based on extrapolation from historical trends.
- “Cancer mortality” denotes the number of people who have died from cancer in a given period.
- “Women’s cancers” refers to cancers that are sex-specific – affecting only women – as well as cancers that appear mainly – though not exclusively – in women. Cervical, ovarian and uterine cancers are sex-specific while breast cancer affects both sexes but is far more common in women than in men. For example, an estimated 170 men in

¹ Since the research was conducted and this report written, the latest cancer data, *Canadian Cancer Statistics 2008*, has been released. While the specific numbers have changed, the proportions have not, with the result that the analysis and recommendations reported here continue to hold for women in Atlantic Canada.

Canada developed breast cancer in 2007 as compared with more than 22,000 women. For the purposes of this report, women's cancers are breast, cervical, ovarian and uterine cancers.

- "Support" is interpreted quite broadly in this report to mean programs and services that assist women psychologically, emotionally, socially, physically, and economically as they deal with the possibility and/or the reality of a diagnosis of cancer. Supports may be found in publicly-funded health care (i.e. family physicians and psychosocial oncology support) as well as in voluntary sector organizations (i.e. non-profit support networks and charities).
- "Survivorship" refers to those women who have successfully completed treatment and are in remission, and the attitudes that reflect this awareness

2. METHODOLOGY

The Atlantic Centre of Excellence for Women's Health collected statistical information on the incidence, mortality and age distribution of the aforementioned cancers in the Atlantic Region. The Canadian Cancer Society, its provincial counterparts and other cancer service providers assisted in providing information used in the statistical scan.

Researchers working at the Atlantic Centre of Excellence for Women's Health conducted an Internet-based environmental scan between January and March 2008 of the emotional, physical and financial resources available to women living with breast, ovarian, cervical and uterine cancers in Atlantic Canada. Telephone calls to well-known organizations and support service providers confirmed the scope of their services, which were included in the scan. The resulting document was sent for review to prominent members of cancer communities in each of the four Atlantic provinces, and their feedback was incorporated into the final document (see Appendix A: Annotated Directory of Services).

Following the completion of these scans, researchers worked closely with the Centre's community partners in the cancer service industry to recruit by referral female survivors of breast, ovarian, cervical and uterine cancers for interviews and focus groups. Recruitment took place over a four-week period, during which time researchers established contact with participants, reviewed the research process and secured informed consent from those who chose to participate. 22 women took part in the examination of cancer care services via focus groups or individual interviews.

Focus groups were held in each of the Atlantic provinces where a group of three or more women in a close geographical area could gather to participate; the focus group for women in Newfoundland and Labrador was conducted over the telephone due to the distance separating the participants. Within each of the four provinces concerned, 9 interviews were also conducted, 7 of those interviews with key informants in the cancer care spectrum of services and 2 with cancer survivors. Key informants consist of those women in cancer service provision

who are directly involved with care and support offered to cancer patients and survivors. Throughout the study, interview and focus group guides were identical. The Health Sciences Research Ethics Board of Dalhousie University granted permission to carry out this examination.

All interviews and focus groups were tape recorded and transcribed by an independently contracted transcriber. The researchers reviewed and analyzed the transcripts, searching for common themes within individual experiences.

The limitations of the methodology included time constraints; as the project began and ended within an eight-week timeframe, numbers of interviews and participants for focus groups were slightly smaller than projected. Although the sample size was small, comments from the participants enabled the opportunity to capture the unique voices and experience of women who chose to participate in this research.

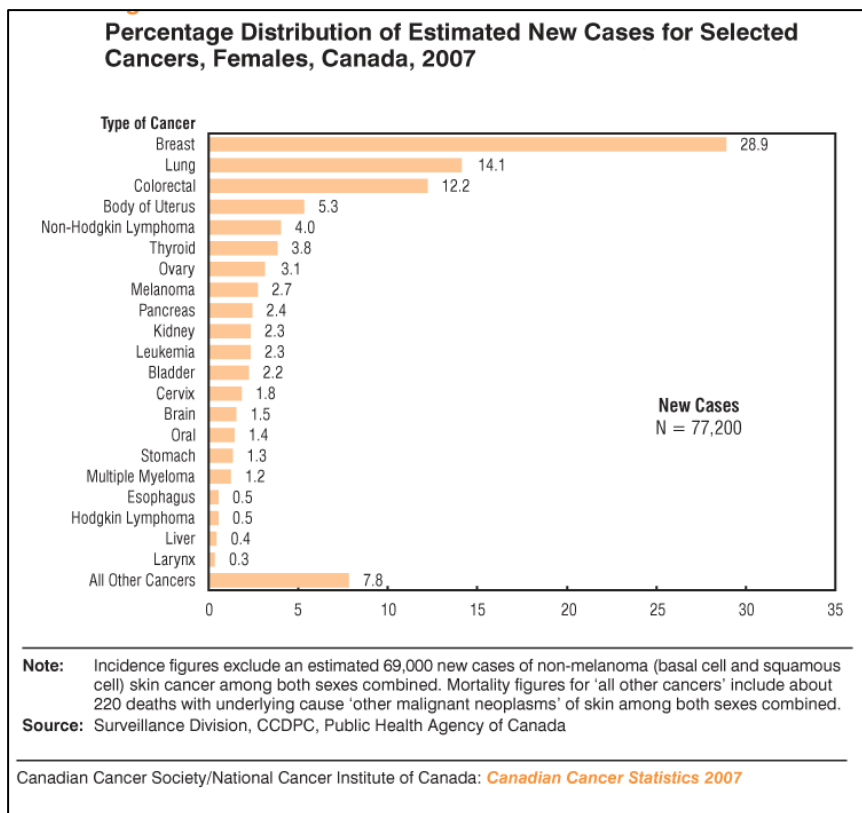
Research findings were presented to participants of the Atlantic Invitational Think Tank on Women's Cancers on March 31, 2008 at Halifax, Nova Scotia by Dr. Barbara Clow, Executive Director, Atlantic Centre of Excellence for Women's Health and Erin Hemmens.

3. AN OVERVIEW OF WOMEN'S CANCERS

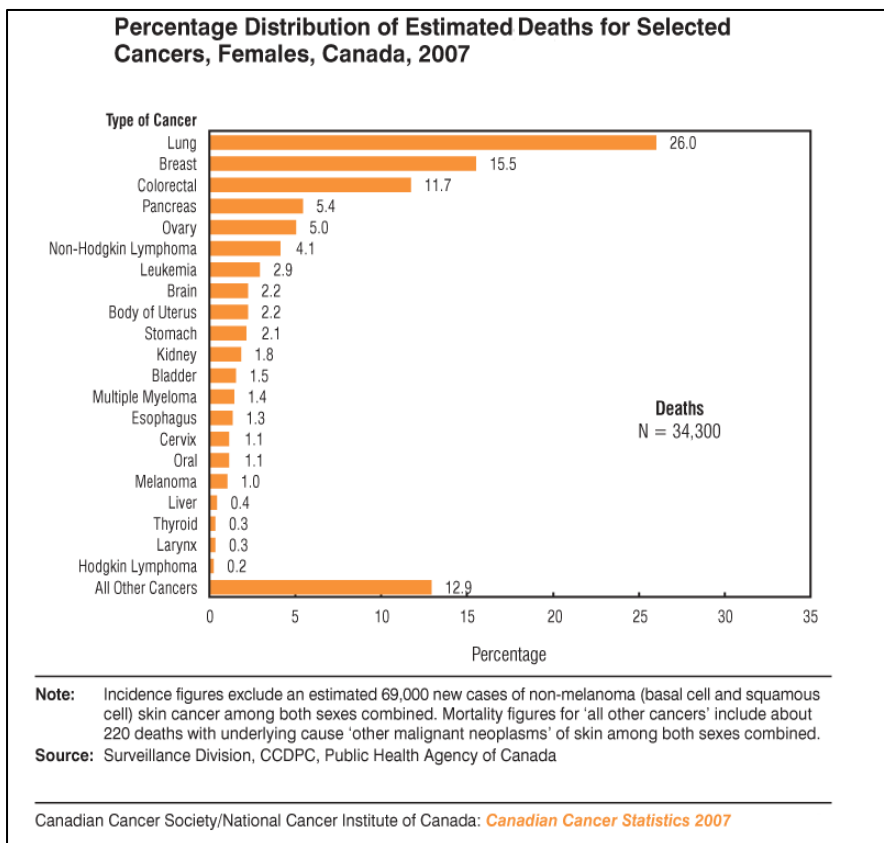
1. Women's Cancers in Canada

In Canada, the number one cancer diagnosis for women is breast cancer, followed by lung and colorectal cancer. Cervical, ovarian and uterine cancers affect far fewer women than either breast or lung cancer. Indeed, the combined total of these three women's cancers is still less than the incidence of lung cancer and represents just over one-third of the number of new cases of breast cancer.²

² As mentioned above, since the research was conducted and this report written, the latest cancer data, *Canadian Cancer Statistics 2008*, has been released. While the specific numbers have changed, the proportions have not, with the result that the analysis and recommendations reported here continue to hold for women in general and for women in Atlantic Canada.



In contrast, breast cancer is not the main cause of cancer deaths among women in Canada. Morality rates for lung cancer are nearly double the rate of breast cancer deaths. Meanwhile, the number of deaths attributed to cervical, ovarian and uterine cancers is only slightly more than half the number due to breast cancer and less than one-third of those due to lung cancer.



While women are more likely to be diagnosed with breast than lung cancer, they are more likely to die from lung cancer. These patterns are cause for concern because the rates of lung cancer among women have been rising steadily in recent years while rates among men have been falling.³

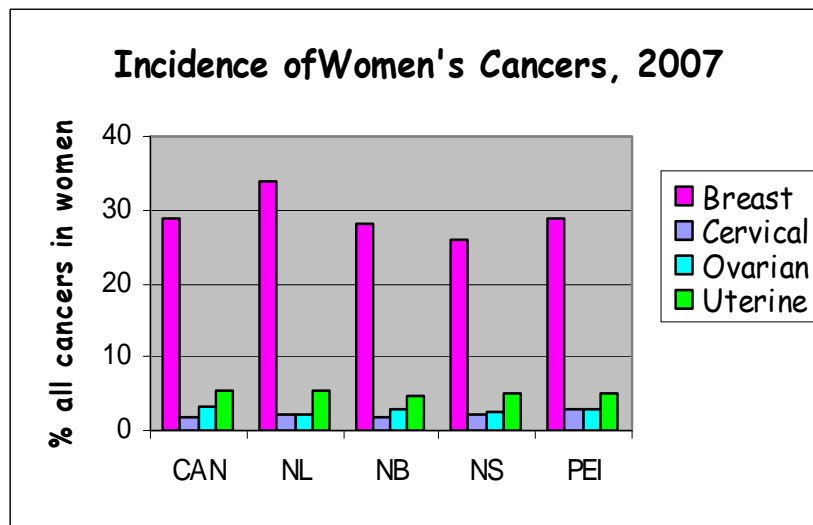
These figures and trends raised some serious questions about focusing on “women’s cancers” as opposed to the cancers that most affect women. Because the sponsors and funders of the project were interested in exploring the potential for adopting and adapting breast cancer support programs for women living with cervical, ovarian and uterine cancers, the decision was made to continue the research on women’s cancers and this decision was later validated by participants at the Think Tank.

a. Women’s Cancers in Atlantic Canada

Cancer incidence and mortality rates in Atlantic Canada have been among the highest in the country for many years. In 2007 and 2008, the highest rates of cancer in Canada are found in the Atlantic region. Some types of cancer, specifically lung cancer, are also more common in Atlantic Canada than in most other parts of the country.

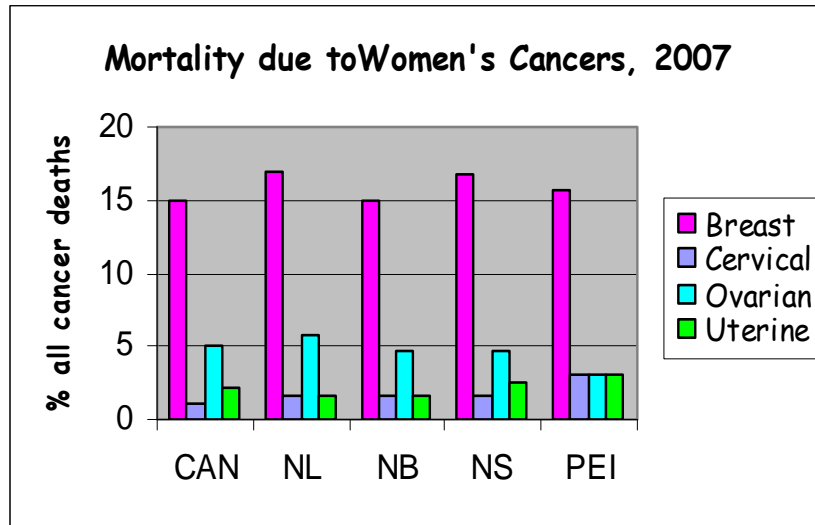
Nonetheless, patterns of cancer incidence and mortality in Atlantic Canada tend to mirror those of Canada as a whole.

Women are far more likely to be diagnosed with breast cancer and lung cancer than with cervical, ovarian or uterine cancer – by a wide margin in both cases.



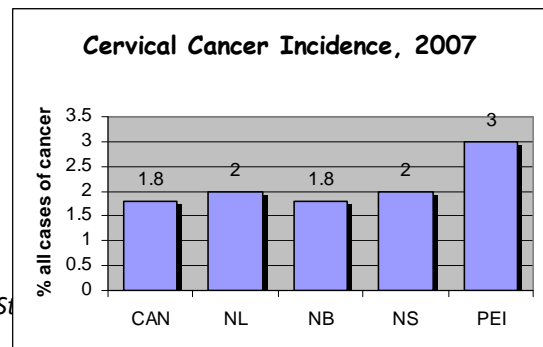
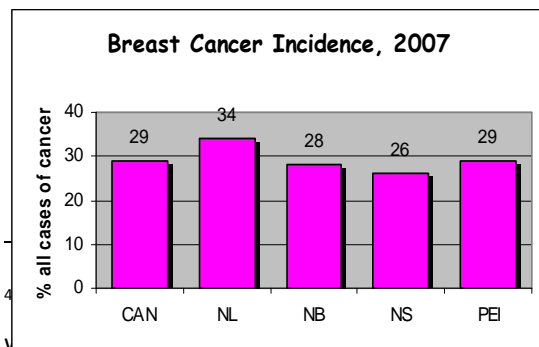
³ Canadian Cancer Society/National Cancer Institute of Canada. (2007) *Canadian Cancer Statistics 2007*. Toronto; 1-2, 25-26; Canadian Cancer Society/National Cancer Institute of Canada. (2008) *Canadian Cancer Statistics 2008*. Toronto; 1-2, 43.

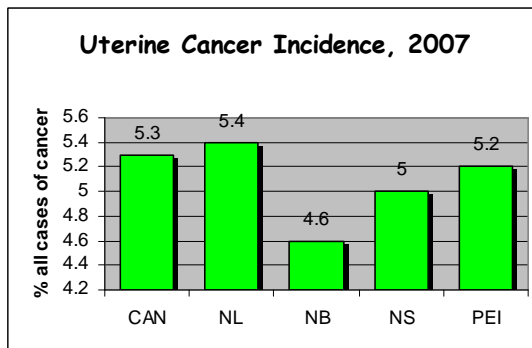
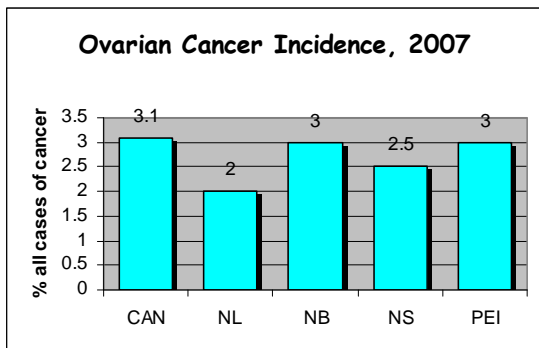
Women are also more likely to die as a result of breast cancer than as a result of cervical, ovarian or uterine cancers. But lung cancer is still the principal cause of cancer deaths among women across the Atlantic region.⁴



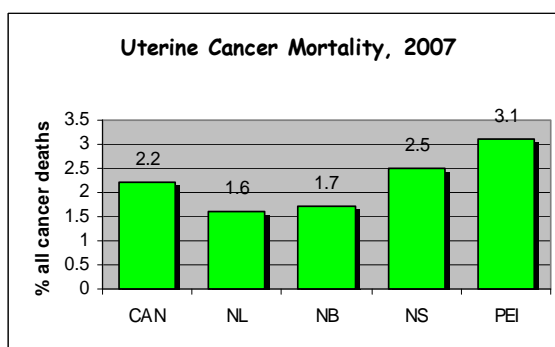
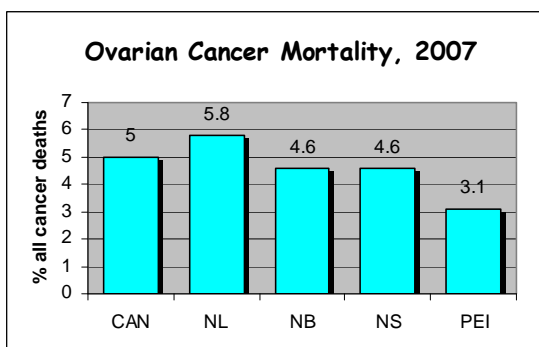
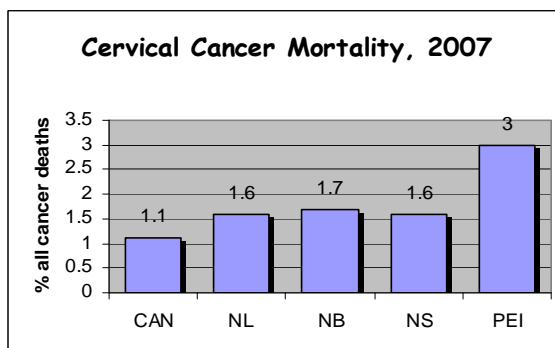
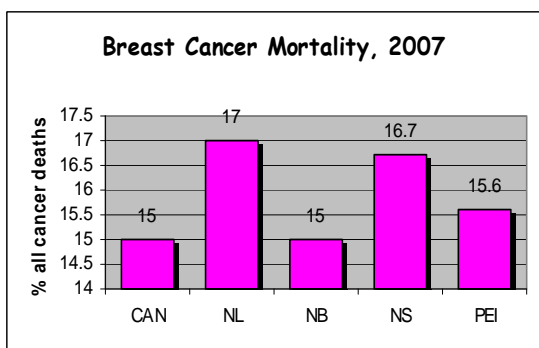
Although national statistics and regional comparisons are important, they can sometimes gloss over or mask significant differences between provinces and among types of cancers. This is especially true for cancers that affect small numbers of women: variations in cervical, ovarian and uterine cancer incidence tend to be eclipsed by the figures on breast cancer. By comparing specific types of cancer across the Atlantic region, we get a clearer picture of where the incidence varies significantly from the national average as well as from one province to another. It is essential to note that the scales for these graphs are different, with breast cancer incidence being measured at up to 35 percent of all cases of cancer as compared with cervical, ovarian and uterine cancers being measured in the range of two to six percent of all cases of cancer.

Nonetheless, in the following graphs, differences among the provincial rates of women's cancers emerge more clearly. With the exception of ovarian cancer, the incidence of women's cancers in Newfoundland and Labrador is consistently higher than the national average. The incidence of cervical cancer in Prince Edward Island is much higher than elsewhere in Atlantic Canada and much higher than the national average. Meanwhile, New Brunswick has an incidence of uterine cancer that is well below the national average.

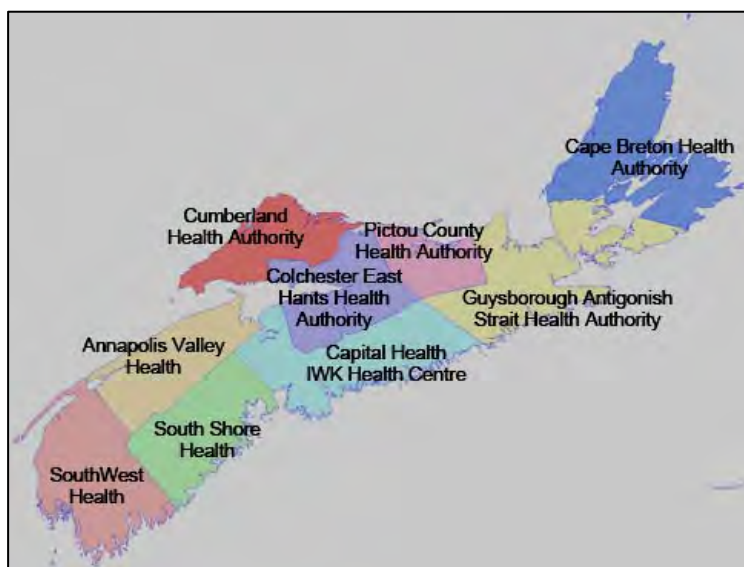




Differences in the rates of cancer mortality are also apparent and some of them are predictable. Prince Edward Island, with the largest number of new cervical cancer cases, also has the greatest share of deaths due to cervical cancer. But other relationships are less predictable. For example, Newfoundland and Labrador has the smallest number of new ovarian cancer cases – well below the national average – but the largest number of ovarian cancer deaths – well above the national average. The incidence of breast cancer in Nova Scotia is close to the national average, but breast cancer mortality in the province is considerably higher than the national average.

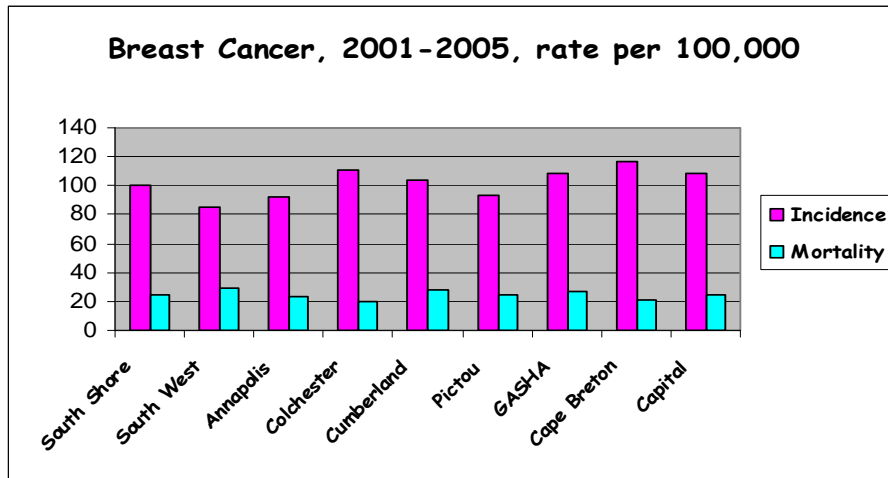


Regional and provincial data can, in turn, hide internal geographical variations in cancer incidence and mortality rates. Although county, municipal and regional health data are not consistently available in every jurisdiction, an example based on Nova Scotia data may prove instructive.



If we examine breast cancer rates in each of the district health authorities of Nova Scotia, we find small but perhaps significant differences in both incidence and mortality. Cape Breton Health Authority and Colchester/East Hants Health Authority have the highest rates of breast cancer incidence while Pictou and Annapolis Health Authorities have among the lowest⁵. Moreover, the relationship between incidence and mortality is neither direct nor simple. SouthWest Health Authority has the lowest incidence of breast cancer but one of the highest mortality rates.

⁵ Statistics taken from the 1007 Canadian Cancer Statistics Document, produced by the Canadian Cancer Society, The National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries and the Public Health Agency of Canada. Numbers are estimates based on projections and are rounded. Percentages are calculated from provincial population statistics from Statistics Canada 2001 Census Report.

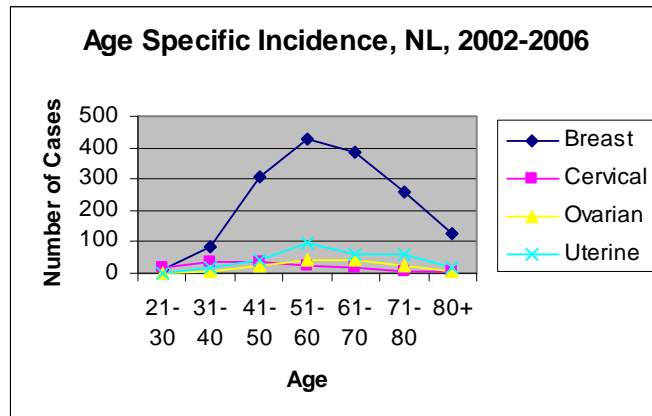
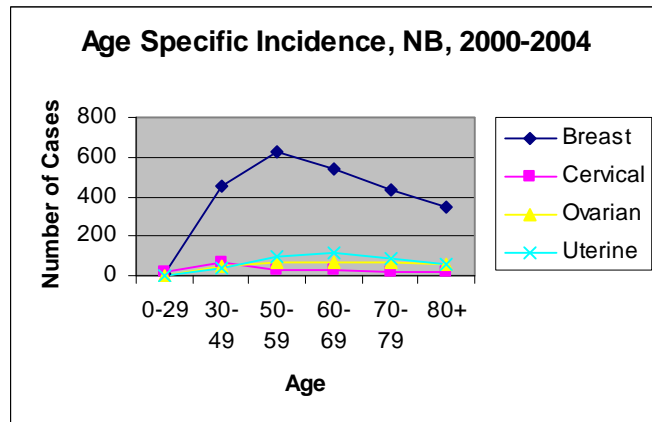


2.3 Determinants of Health, Determinants of Cancer

In addition to geography, many variables, such as age and sex, affect cancer incidence and mortality rates. Although we do not consistently collect or report on these variables in Canada, we do have some data from Atlantic Canada that underscores the importance of using a determinants of health framework to understand women's cancers in Atlantic Canada.

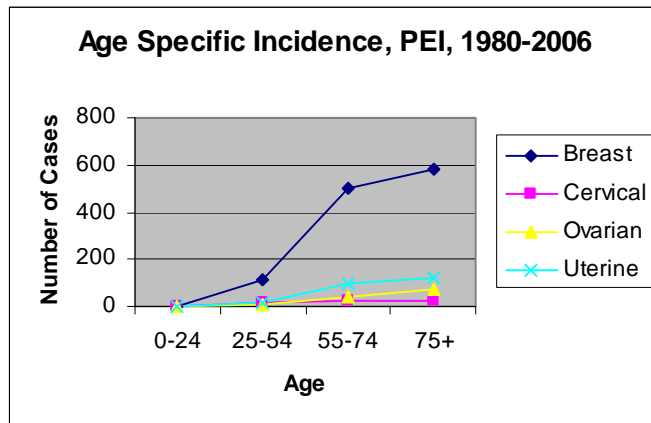
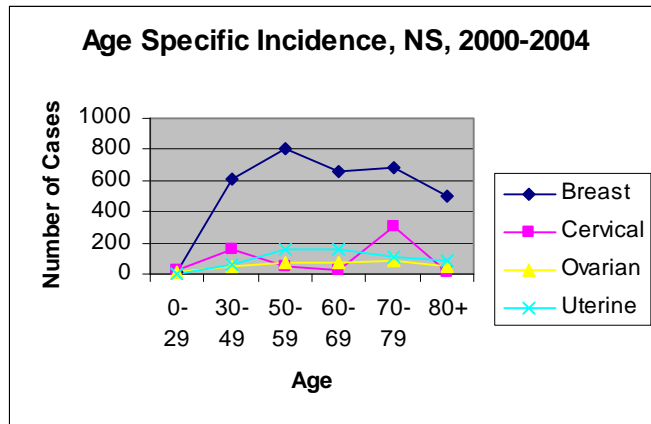
In the first example, data available from provincial cancer agencies points to the role of age and geography in the incidence of women's cancers. The likelihood of developing breast cancer in mid-life appears similar across three of the four Atlantic provinces, while the incidence of ovarian and uterine cancers is also quite consistent. But women in Nova Scotia seem to be at increased risk of developing cervical cancer in their later years as well as in their reproductive years. Meanwhile, the data for Prince Edward Island looks radically different, with breast cancer rates increasing dramatically after age 50.

Just as with national and provincial data, we need to approach these statistics with caution. Prince Edward Island looks unique, in part because the period for which data were

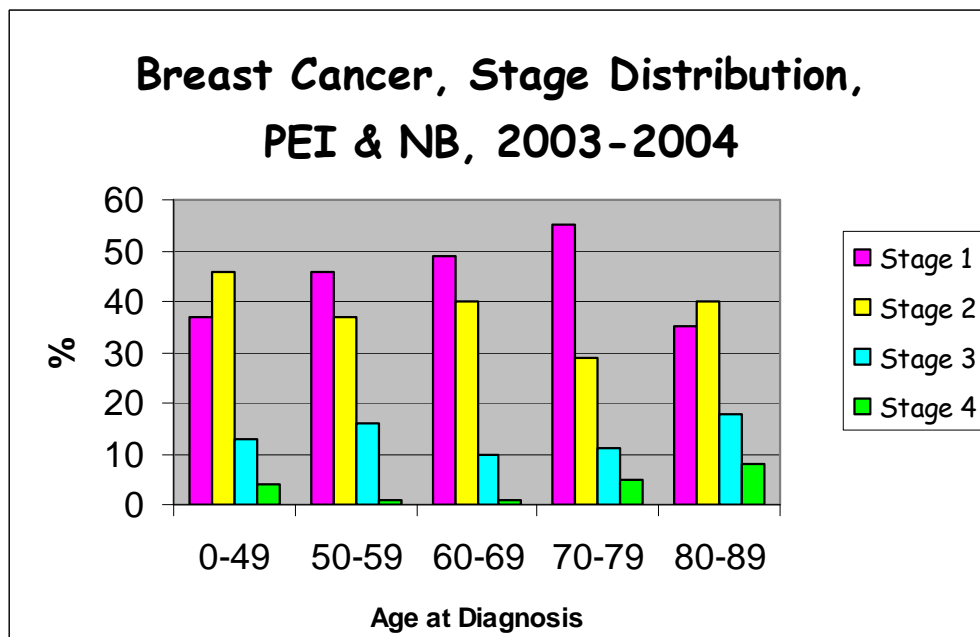


collected and the age ranges reported upon are much larger. Newfoundland and Labrador data looks similar to that of Nova Scotia and New Brunswick, but it covers different years.

Nonetheless, the information contained in these graphs helps us to understand that most women's cancers tend to be diagnosed in mid-life or later with the exception of cervical cancer, which tends to affect younger women as much or more than older women. Considering which women get cancer is the first step towards identifying who needs help and, perhaps, what kinds of help they need. Younger women with cervical cancer may worry about infertility while women past their childbearing years would not.



Another example, based on data from New Brunswick and Prince Edward Island, correlates age of diagnosis and stage of disease for women with breast cancer. Again, the results are not necessarily intuitive. Women diagnosed with late stage breast cancer – when the disease has already spread to other parts of the body and long-term survival is unlikely – are as likely to be under 50 as over 70 years of age. Similarly, women under 50 and over 80 years of age are most often diagnosed in the second stage of disease, when the cancer is large and/or has already established itself in the lymph nodes. Women between 50 and 80 years of age are much more likely to be diagnosed at the earliest stages of breast cancer, when the disease is most amenable to treatment and cure.



There are many possible explanations for these patterns. Women under 50 and over 80 years of age may be diagnosed later in the course of the disease because breast screening programs are targeted at women during the in-between years. Alternatively, menopause may make it easier for women and their doctors to find breast lumps. But higher rates of screening among women between the ages of 50 and 80 cannot explain the greater numbers of women diagnosed with stage three breast cancer. Thus, while cancer statistics are clearly necessary for planning and delivering effective, appropriate and timely supports for women living with breast, cervical, ovarian and uterine cancers, they can also complicate or even stall this work by resisting analysis and interpretation.

According to the Canadian Cancer Society and the National Cancer Institute of Canada, “Canada is one of the few nations in the world with a population-based cancer registry system that allows cancer patterns to be monitored for the entire Canadian population.”⁶ Undoubtedly, people living in Canada have access to a wealth of information about cancers, but there are also striking gaps in our knowledge, particularly as they pertain to the social determinants of health. For instance, we have almost no information about the relationship between ethnic or racial identity and cancer. In Atlantic Canada, home to one of the largest indigenous Black⁷ populations, we have almost no data on cancer incidence and mortality rates for African Canadians. Similarly, information about cancer among First Nations, Métis, and Inuit women remains is far from comprehensive. The annual *Canadian Cancer Statistics Report* does not report on cancer among Aboriginal peoples in Canada and has not done so in close to twenty years.⁸ Information on other determinants of health, such as employment history, education and literacy, household income, family structure, sexual orientation, housing status and religion are similarly difficult or impossible to find. We need to add Canadian expertise on the social determinants of health to the impressive leadership Canada has shown in developing population-based cancer surveillance systems.

At the same time, although we have a great deal of information about *when* and *where* cancer occurs as well as *when* and *where* people die as a result of cancer, we often lack sufficient or appropriate evidence to explain *why* rates of cancer incidence or death are higher in one part of the country or in one segment of the population. While quantitative and epidemiological data are critical components of this work, we also need qualitative data and the voices of cancer

⁶ Canadian Cancer Society/National Cancer Institute of Canada. (2008) *Canadian Cancer Statistics 2008*. Toronto; 15.

⁷ Descendants of African Canadians living in Canada since the time of the American Revolution or who migrated here in the 18th, 19th and early 20th centuries refer to themselves as “indigenous Black” in order to distinguish themselves from more recent newcomers to Canada.

⁸ Each year the Canadian Cancer Statistics Report addresses a “special issue:” in 2007, this topic was breast cancer; in 2008, cancer among children and youth. Aboriginal people have not been discussed in this report since 1991.

survivors to explain variations in the incidence and survival of women’s cancers. This information will allow us to fashion better programs and policies to support women living with a diagnosis of breast, cervical, ovarian and uterine cancers.

4. PROFILE OF SERVICES

This table represents the services and supports available to women’s cancers patients and survivors in Atlantic Canada.

PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
CAN	Canadian Cancer Society	✓		✓		✓	
CAN	Ovarian Cancer Canada	✓	✓	✓		✓	
CAN	Canadian Breast Cancer Network		✓	✓			
CAN	Eyes On the Prize	✓		✓			
CAN	Hope Air						
CAN	Health Canada “It’s Your Health” Publications	✓					
CAN	The Look Good Feel Better Program		✓				
CAN	Canadian Virtual Hospice			✓			
CAN	Janac Sportswear	✓	✓	✓	✓	✓	Specialized sportswear for women after breast surgery
CAN	Willow Breast Support Service Canada	✓	✓	✓	✓		

CAN	Victorian Order of Nurses					✓	
ATL	Atlantic Breast Cancer Net			✓			
NB	The New Brunswick Breast Cancer Network	✓	✓	✓		✓	
NB	The New Brunswick Breast Cancer Information Partnership INC.	✓					
PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
NB	New Brunswick Breast Cancer Network (NBBCN) Support Groups		✓			✓	
NB	'Tit Bateau (Moncton-Dragon Boat Team)						Dragon Boat Team
NB	Breasts... Ahoy (Saint John- Dragon Boat Team)						Dragon Boat Team
NB	YMCA (Moncton)	✓	✓				
NB	Angel Fund (Moncton)						
NB	Supporting Sisters (Moncton)		✓			✓	
NFL	Canadian Cancer Society Newfoundland Division	✓	✓	✓		✓	
NFL	The Lupin Partnership	✓	✓	✓			
NFL	Realtime Cancer	✓	✓	✓			
NFL	Newfoundland Cancer Treatment and Research Foundation					✓	
NFL	The Gathering of Friends (Placentia)					✓	
NFL	Exceptional Patients Against Cancer (St. John's)					✓	
NFL	Sharing Our Strength (St. John's)					✓	
NB	Breasts... Ahoy (Saint John- Dragon Boat Team)						Dragon Boat Team
NB	YMCA (Moncton)	✓	✓				

NB	Angel Fund (Moncton)						
NB	Supporting Sisters (Moncton)		✓			✓	
NFL	Canadian Cancer Society Newfoundland Division	✓	✓	✓		✓	
NFL	The Lupin Partnership	✓	✓	✓			
NFL	Realtime Cancer	✓	✓	✓			
PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
NFL	Newfoundland Cancer Treatment and Research Foundation					✓	
NFL	The Gathering of Friends (Placentia)					✓	
NFL	Exceptional Patients Against Cancer (St. John's)					✓	
NFL	Sharing Our Strength (St. John's)					✓	
NFL	Avalon Dragon Boating Team (St. John's)						Dragon Boat Team
NFL	Cancer Coalition for Alternative Medicines (St. John's)		✓				
NFL	CCS Living with Cancer Support Group (Grand Bank)					✓	
NFL	Rays of Hope Cancer Support Group (Springdale)					✓	
NFL	Port Aux Basques Breast Cancer Support Group (Port Aux Basques)					✓	
NFL	Emotional Support Group (Corner Brook)					✓	
NFL	Marystown Cancer Support Group					✓	

	(Marystown)						
NFL	Burgeo Cancer Support Group (Burgeo)					✓	
NFL	Twillingate & New World Island Breast Cancer Support Group					✓	

PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
NFL	Breast Cancer Support Group (Stephenville)					✓	
PEI	Canadian Cancer Society PEI Division	✓		✓			
PEI	PEI Cancer Treatment Center	✓	✓				
PEI	YWCA Encore Program		✓	✓			
PEI	Charlottetown Breast Cancer Support Group (Charlottetown)					✓	
PEI	CCS Living with Cancer Support Groups (West and East Prince Counties)					✓	
PEI	The Queen Elizabeth Hospital (Charlottetown)						Provides patients with breast prostheses fittings, prostheses and mastectomy bras
PEI	Island Home Health Care (Charlottetown)						Sells products for women undergoing treatment
PEI	Silhouette 2 (Summerside)						Sells products for women undergoing treatment
PEI	Rita's Styles (Charlottetown)						Sells products for women undergoing treatment
PEI	Really You (Charlottetown)						Sells products for women undergoing treatment
PEI	Atlantic Prosthetics (Charlottetown)						Sells products for women undergoing treatment

PEI	Lynda Murphy R.N. (Charlottetown)						Fits prostheses
NS	Cancer Care Nova Scotia	✓	✓	✓	✓	✓	
NS	Queen Elizabeth II Cancer Care Program	✓	✓			✓	
NS	Breast Cancer Action Nova Scotia	✓	✓	✓		✓	
PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
NS	Bosom Buddies of Nova Scotia						Dragon Boat Racing
NS	Titz'n Glitz	✓	✓	✓	✓	✓	
NS	Nova Scotia Community Services Pharmacare Programs						
NS	MSI (Medical Services Insurance- Nova Scotia)						
NS	Biker's Memorial Fund- Atlantic Chapter						
NS	Canadian Cancer Society Nova Scotia Division	✓	✓	✓	✓	✓	
NS	YWCA Encore Program (Halifax)	✓	✓				
NS	Annapolis Breast Cancer Support Group (Annapolis)		✓				
NS	Antigonish Women Alike Breast Cancer Support Group (Antigonish)		✓				
NS	Barrington Passage Living with Cancer Support Group (Barrington Passage)		✓				
NS	Breast Cancer Support Group (Mavilette)		✓				
NS	Breast Cancer Support Group (Halifax)		✓				

NS	Breast Quest (Windsor)						Dragon Boat Team
NS	Canadian Cancer Society Cancer Support Group (Yarmouth)		✓				

PROVINCE	ORGANIZATION	LITERATURE (Pamphlets, Kits, Newsletters)	SESSIONS (Lectures, Seminars, Workshops)	INTERNET (Websites, Email/Chat Assistance and Support)	FINANCIAL (Subsidies, Funding Assistance)	PERSONAL / PEER SUPPORT (One-to-One, Group, Telephone, Online)	OTHER
NS	Caring For Cancer Patients (Truro)		✓				
NS	Chester Cancer Action Group (Chester)		✓				
NS	Cape Bretoners (Cape Breton)						
NS	Health Solutions (Halifax)						Sells custom products for women undergoing treatment
NS	Hope Chest Breast Cancer Support Group (Truro)		✓				
NS	Kentville Breast Cancer Support Group (Kentville)		✓				
NS	Kingston/ Greenwood Living with Cancer Support Group		✓				
NS	North-side Breast Cancer Support Group (North Sydney)		✓				
NS	Sackville Living with Cancer Support Group (Sackville)		✓				
NS	Sydney & Area Breast Cancer Support Group (Sydney and Area)		✓				

NS	Warrior Princess Breast Cancer Support Group (Fall River)		✓				
NS	Women Alike Peer Support (New Glasgow)						Dragon Boat Team
NS	Sunflower Lunches (Halifax)		✓				

5. THE HEALTHCARE SYSTEM AND NON-PROFIT SUPPORT ORGANIZATIONS

The Healthcare System

Across the spectrum of cancer care, there are gaps within the formal healthcare system that affect supports offered to those living with women’s cancers. Key informants and focus group participants are united in acknowledging the value of many existing services and supports; however, while cancer service providers feel the information and support they offer to women’s cancer patients is effective, by and large patients feels that the care they receive is lacking in scope, availability and timeliness.

For instance, a major finding in the data was that, whereas both cancer service providers and cancer patients see patient navigators as offering invaluable assistance, providers are aware that patient navigators are not consistently available throughout the formal healthcare system, leading to gaps in service provision. For their part, patients may not be able to receive support in the manner they choose nor in a timely fashion. Broadly, then, service providers see a need for greater breadth of services available to support cancer patients, and cancer patients see a need for information and social support that is widespread throughout the cancer care spectrum and accessible during various stages of diagnosis, treatment and survivorship.

Other areas of concern for cancer support services and organizations consist of financial infrastructure, accessibility and culturally inclusive policies.

Financial Infrastructure: Many not-for-profit cancer care services lack funding for individual assistance, leading to increased strain on family and social networks regarding expenses associated with treatment, such as transportation, accommodation and child care, and quality of life. One respondent explained the dilemma of seeking treatment that could improve one’s health, but that meant financial constraints for loved ones: “You’ve got to go [for treatment], but you still have to pay your hydro bill otherwise your family will be left in the cold”. The

intersection of health issues affects the financial status of those diagnosed with women's cancers:

somebody lives in the country, they have to come into town, they don't have a car, they're on a fixed income, how are they going to get there, then when they get here they're told o.k. they have to have this drug, that drug and you know just buying food is a problem, in the winter just getting enough oil to heat my house, I have to take the gas tank can to the gas station and fill it up and pour it in my tank. So there's . . . poverty, there's all those determinants of health that do impact people.

The need for cancer services in the voluntary sector to engage in large scale, frequent fundraising activities drains resources that could be better spent on individual support structures.

Equally troubling is the lack of secure funding for agencies and organizations. Key informants and patients that were questioned referred to the need for funding for medication; a key informant spoke of an older couple, both of whom had cancer, who had given up buying food and "were sharing their pain medication ... he would take it one day and she would take it the next day" because they could not afford two pain medication prescriptions. Long-term post-treatment support could be developed with the help of secure funding, whereas currently, assistance structures may not be obvious to those they are designed to help: Newfoundland and Labrador focus group participants were unaware of the province's travel subsidy fund to assist with expenses for cancer treatment. Focus group participants commented that "You don't hear 'financial help' [following diagnosis], you hear that very little, 'financial help'." The financial infrastructure of cancer support organizations, non-profit and government-funded, demands urgent scrutiny to serve those diagnosed with women's cancers better.

Accessibility: Cancer service providers in Atlantic Canada highlight the need to reach their target groups as effectively and consistently as possible. Some of the reasons for inefficient communication given were geographical isolation, particularly in Newfoundland and Labrador, the commitment of volunteers and insufficient numbers of patient navigators.

Cancer survivors maintain that the effects of rural isolation on those diagnosed with women's cancers are considerable; a focus group participant from a small community noted that "unless someone brings the information in to us, we don't know it's out there". The fatigue that can accompany diagnosis, often shown in low energy levels, can prevent survivors from taking the initiative to seek out information: "I just asked the nurse if there were any supports around and there were none and I didn't investigate much further."

For others, the manner in which information is made available is inappropriate. A key informant repeated a question asked by one patient regarding the Internet: "How do I turn [the computer] on, never mind how do I look it up?" Information must be accurate, including up-to-date contact details for cancer services, and delivered by newsletter mail out, email, fax or service directory; this is a point upon which cancer survivors and providers agree. Information resources are

generally monitored by volunteers, who, while almost certainly dedicated, may not be providing uniform support; for instance, information kits can be distributed by an oncology nurse, patient navigator, family physician or another service provider, each facing different job demands.

Patient navigators were identified by providers and survivors are exceedingly useful supports – “we’re kind of guides that way” commented one provider in that role – but too few in number and erratically placed. Cancer patients saw navigators as the channel for communication across local, regional, provincial and national lines, guaranteeing that up-to-date information is communicated to and for cancer patients and survivors. Patient navigators saw themselves as best equipped to alert cancer service providers to patients’ support needs, such as the desire for information-sharing as well as social support groups and visits to women’s resource centres. Facilitating the transference of information from cancer services to patients is a system-wide concern; the goal is to contradict many patients’ belief that “every time you’re looking for [support or assistance], you have to go digging for it to find it.”

Culturally Inclusive Policies: The incidence of women’s cancers among marginalized populations requires targeted services and supports for these groups, and is a concern for cancer providers at every point of the cancer care spectrum. Often the circumstances of daily life, such as employment, need to be accounted for in different ways for low-income earners: “Like for myself I’m a seasonal worker and you can’t just up and go [for treatment]... if it’s happening during your working time, you’ve only got a set amount of time to work”. There may also be significant stigmatization facing those from marginalized populations, resulting in assistance delays or condescending attitudes: “I found when I went to fill out my travel claim, that they were doing an assessment on me. Now I found that to be very rude, very insulting. Listen if I had the money to do this on my own, why would I be accessing your money, taking away from other people that don’t have it[?]” Given the challenges of accessing services associated with cancer care, those diagnosed with women’s cancers find it easy to empathize with others who may face difficulties: “When you enter a [referral] center, ... appointments should be set up when you come ... and I speak English, imagine someone who doesn’t”.

Key informants in provider roles are aware of the diversity of women’s cancer patients and are consciously taking steps to address inequities of service and representation. One informant viewed her role as providing services for all women diagnosed with women’s cancers, and not only affluent women from majority communities typically seen in promotional material. Culturally inclusive policies can be implemented by educating oncology nurses from reserves, First Nations and black communities and printing brochures regarding screening procedures in Arabic and French, which are the most popular languages spoken in the Halifax Regional Municipality following English. Knowledge of local communities dictates the service needs of cancer patients and survivors; for instance, Labrador’s four populations (identified in that province as the three First Nations groups Inuit, Inu and Métis, and Settler/non-Aboriginal) and their respective languages demand that translation in speaking and writing are accounted for in all documentation.

There is also a greater impetus towards incorporation of diversity in cancer and healthcare policy, reveals a key informant who is increasingly sought out for advice on writing guidelines for diversity and inclusion. There is a deep-seated need for marginalized populations to be accounted for in cancer care services regionally, provincially and nationally.

Women's Cancers Supports

As outlined in the Summary of Services between CPAC and the Atlantic Centre of Excellence for Women's Health, the purpose represented in part by this report is to study the current state of women's cancer in Atlantic Canada in relation to information and education, and support. Accordingly, these components act as the categories in which women's cancers systems of care can be examined.

- Information and Education Supports
- Psychosocial Supports

Information and Education Supports

The information provided by cancer service organizations is paramount to helping patients and their loved ones gain a more complete understanding of the challenges presented by a diagnosis of cancer. In this report, "Information" refers to the materials, resources and personnel that explain medical procedures and offer medical support related to cancer treatments and survivorship. "Education" refers to the efforts undertaken by and directed towards patients and health professionals to understand cancer diagnoses and treatments and increase awareness of the hardships facing cancer patients and their loved ones.

Information and education on cancer comes in many forms, including printed literature such as books, pamphlets and service directories, inquiries and referrals undertaken by telephone, websites and email assistance available on the Internet and lending libraries offered by some branches of cancer services. Clinical descriptions of symptoms do not appear to be the focus of this information; rather, the emphasis is on what to expect in terms of the patient's health and relevant services descriptions and contact details. Often the information is provided as part of a kit that includes resources for a range of organizations, groups and other assistance, and may also contain psychosocial support gifts. Kits can be distributed by regional, provincial or national groups (see Appendix A: Annotated Directory of Services). The point at which these materials are distributed varies, as does the role of the person delivering them. Some patients and key

informants report that kits were received or distributed during the consultation following diagnosis, and in the weeks prior to surgery, and in the months following surgery. Some cancer survivors report receiving the kits from the hospital doctor, while others obtained kits from their general practitioners, nurses or patient navigators, and still others received information kits following telephone or email inquiries that they had made.

Printed literature has the advantage of being consulted by a patient when she feels it would be most useful:

When you first hear [your diagnosis]...you can't really hear any more information unless something is physically given to you that you can put on the kitchen table and it sits there for a few days or a week.

[After receiving my kit] I felt like I was walking out of there with a bomb in my hand, but after a few days I went through it and there's lots of information.

At that point I had no time to read. I had no time in my head to even open that kit, I didn't even want to open that box.

However, there is a danger that the patient may feel slighted by the offer of reading material during such an emotionally difficult time, perceiving it as a substitute for care:

So giving a pamphlet sometimes isn't helpful at all. . . .It's almost like an insult, read this and go home.

Although there are mixed responses to information kits, most focus group participants acknowledged that they are necessary. Some women may feel the need to consult supports in anticipation of receiving a diagnosis of cancer; the prolonged wait that many patients face for confirmation could be filled by information-gathering, yet this is rarely presented as an opportunity. However, there appears to be little consistency in the methodology of information distribution; an information package could be offered with a diagnosis, or during the weeks prior to surgery, or in the months after their treatment or operation. Focus group participants obtained kits from a surgeon, or a general practitioner, or a nurse, or patient navigator, or following telephone or email requests. This in turn affects the point at which women receive vital information,

You read and you find out that you have your mammogram...you go down the line of things, I wouldn't read any further, I only read as far as I was.

We don't have information and maybe as survivors, or thrivers... we ourselves should.

We need something to address long-term survivors and what their issues are, what their fears are.

or indeed, whether they receive information at all:

I guess I never asked for it so it was never presented to me... That begs the question of you didn't ask for it, it's hard to ask for something you don't quite know exists.

I realize now that when you're diagnosed...you get this whole packet, but I didn't receive that, I didn't know it was available, because no one came and talked to tell you what was available.

Key informants in cancer provider roles are aware of gaps in information availability and consistency, yet those in this study do feel that more informed decision-making, with regard to treatment and surgery options, has resulted from the distribution of information, regardless of the time or manner in which it is passed on to patients. Suggests of centralization of information supports would address issues of dissatisfaction with current content and delivery modes, and foregrounds the recommendation of widespread patient navigators in cancer treatment centres and hospital systems:

You needed someone who would kind of say this is what your results are and this may be where you're going, you'll be in touch with the surgeon, if you need to have radiation you will be in touch with [this person].

Telephone inquiry and referral services is another means by which patients can access information. In many situations, the telephone provides a reliable, inexpensive and accessible way to request resources from cancer organizations or learn about support groups:

We try to give [patients] the 1-800 number in Winnipeg, where they can call, give their diagnosis and they'll send them a package.

And some of those numbers are 24 [hours a day], 7 [days a week]; you can call them.

I got the phone book out and I called the Cancer Society and asked was there such as a thing as a cancer support group.

As one key informant in Nova Scotia noted, due to geographical disparity, telephones may be the only option to obtain information. Telephone contact also offers the option to arrange future personal contact,

[the doctor] talked with [a patient navigator] on the phone... and he came back and said she'll be in touch with you in less than an hour. So within the hour, she didn't just phone him, she came to speak to me.

leading to the possibility of psychosocial support, which inevitably overlaps with information:

My daughter helped me by alerting me that there was a breast cancer patient navigator at an 800 number that I could talk to, and I talked to her every few days for, I don't know how long, until I had my questions answered.

The challenges to obtaining information by telephone include the need for the patient to initiate contact,

I found just lifting the phone sometimes and calling...the local society... they have a wealth of information but you have to give them the opportunity.

the general reluctance of doctors to be available by telephone, the automation of telephone service menus,

[it's] like talking to one of these call center things ... you phone and, oh, this department, and that department, and you might be going through three or four departments.

and the desire in many patients for greater social support, even when gathering information:

I wanted more personal contact... I know you can call and there's somebody there all the time, but I didn't, so I have no idea what their services would have been like.

Internet websites, groups, forums, listservs and email options appear to be a popular method for obtaining information related to diagnoses or clarifying expectations of procedures and side effects. The media capabilities of the internet allow the posting of videos, which can include demonstrations, lectures or discussions; for instance, a telephone education series with cancer expert guest speakers is available on the internet as an audio file that users can access for free.

Websites can range from being quite helpful to very confusing:

The internet is a great access for information and information gives you some comfort...There's nothing worse than hearing, well, I've got this but I don't have a clue what it is. So to me, information was comfort.

The website, it was a little bit overwhelming...there were so many different links and so many avenues to go.

The validity of information can also present challenges:

[One website] is being monitored by a woman who had breast cancer and that's her job, being web mistress, that's her job, so you know you're not getting junk.

I'm not one to go to the computer, because as I said you can't believe a lot on computers, and I'm not one for numbers and I mean, when I first got diagnosed I

went on and plugged in ovarian cancer, you know 90% of the women die? I said, I don't want to hear that.

The Internet shares with printed literature the advantage of being accessible at the user's discretion, yet the very idea of accessibility on a computer poses a problem for some:

I'm not a computer whiz at all...I kind of fumbled my way through it and figured it out, but you probably have to be somewhat comfortable with computers.

The immediate contact afforded by email also acts as a means of information gathering:

They put me on a newsletter and when they sent it out, all the names were there, so I just sent everybody an e-mail and said...I had breast reduction and this is my diagnosis. I'm going for surgery next week, if you have any tips.

From the point of view of key informants, the Internet is an information clearinghouse that needs to be carefully organized, so that groups and services have the opportunity to communicate with one another, and patients and users have the opportunity to obtain information from a central source:

I tour cancer sites and I collect material [for] our resource directory. I have a on-line directory for Atlantic Canadians.

I'd love to see some kind of central database or something so [patients] could search on what's the current research on whatever, or some central place to go to for everything to do with breast cancer or women's cancers.

There's a big ad that says the Well Women's Clinic, they do pap tests, they do breast examinations, they tell you about cervical and ovarian cancer, they have literature, they have videos... it's a marvelous program. / But we don't have that...

Key informants within the formal healthcare system recognize that healthcare professionals can be educated regarding the kinds of services and supports cancer patients require.

We have a proposal put forward...to see if we can get funds to educate and train more lymphodema nurses across the province.

Sometimes I see family doctors in the hall and I'll quickly stop them and say I was talking to so and so yesterday and this is what I did for them...is there anything else you'd like me to do? (*Patient navigator*)

Another program...is... an awareness program and this is how we're trying to target health care professionals now. It's survivors that we've trained with the story of their cancer diagnosis, they go into medical schools, nursing schools, any health professions, I know they've done physiotherapy as well, so they go in and talk about the signs and symptoms of ovarian cancer.

Patients will also be educated to a higher level about their diagnosis if doctors, surgeons, nurses and oncology staff are more aware of the challenges faced by a new cancer patient:

I find sharing very important [but] if I want education, I can go somewhere else, I can find research.

Friends, family and community members equally can be educated about cancer diagnosis, treatment, prognosis, and survivorship challenges. Given that these people play such an important role in supporting cancer patients, it is essential that they learn what to expect when accompanying a loved one on this difficult journey.

It's hard, you're fighting your own emotions [and] you're battling with your community because they don't know.

If you're out there saying, 'Oh my God, this person got diagnosed with this kind of cancer, the doctor didn't say anything but I give her six months,' I can go up and smack you.

Those who are supporting cancer patients, and patients themselves, may grow to be information and education advocates for causes arising from cancer, including financial assistance, healthcare delivery and patient rights.

If you've got the patient that makes \$16,000 a year as a total family income, which is nothing, and the limit is \$15,720...there's absolutely no way that you can bend the rules and say they're only making \$16,000; there is no way that you can get help.

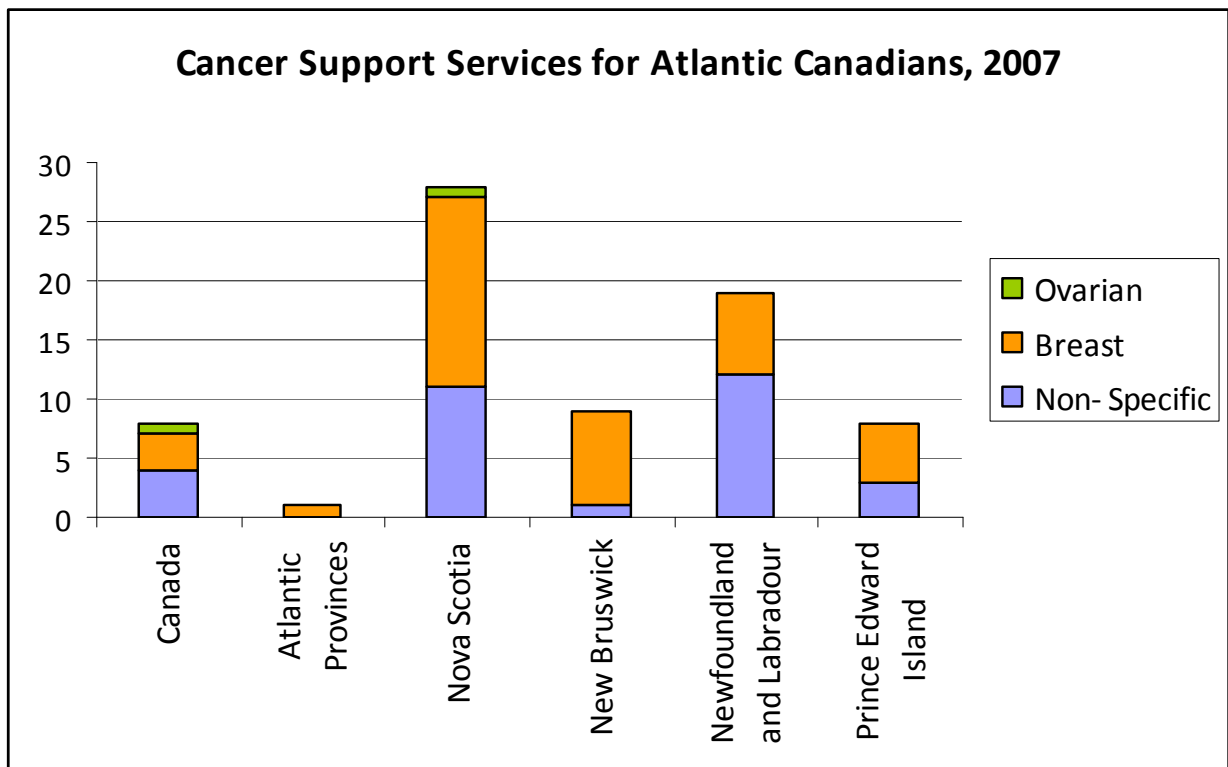
You need to manage your case. Don't assume that the medical community is looking after you personally.

You can ask for your test results, like your pathology report...I didn't know that. I didn't know I had a right as a patient to ask for those things.

Between printed literature, telephone and Internet forms of information gathering and education, cancer patients and their loved ones could be expected to have access to most, if not all, of the details for living with cancer. Yet, patients find difficulty in how information is procured, in knowing by whom it will be delivered and the level of exposure healthcare professionals have to specialized treatments such as lymphodema programs. Accessibility and accuracy of information also pose challenges. Healthcare professionals, patients, and friends, family and community members can be informed and educated to offer effective support to those dealing with a diagnosis of cancer.

Summary: Information and Education Supports should be

- **CONSISTENT:** Offered to every patient diagnosed with women’s cancer to ensure information supports are in place
- **STRUCTURED:** Distributed by a specific healthcare worker to ensure consistency of delivery
- **APPROPRIATE:** Relevant to the patient’s stage of treatment to avoid ‘information overload’
- **ADVERTISED:** Widely publicized and accessible to ensure target audiences are reached
- **PROFESSIONAL:** Displayed by as well as offered to healthcare workers who have a role in caring for patients affected by women’s cancers to improve communication between providers and patients
- **COMPREHENSIVE:** Available to women’s cancers patients to promote clinical understanding of women’s cancers
- **DIRECTED:** Designed to meet the needs of friends, family and community members to raise awareness about women’s cancers



Psychosocial Supports

While information and education represent a fact-based, rational approach to understanding the needs of women's cancer patients, supports tend to address the social and emotional challenges facing those diagnosed with cancer. In this report, "Psychosocial Supports" refers to services, groups, organizations and individuals that aim to assist patients diagnosed with women's cancers with physical, mental/spiritual, social and financial challenges in diagnosis, treatment and post-treatment stages.

There is an extensive range of supports offered to those diagnosed with women's cancers and their loved ones. Included are personal supports, such as peer and group meetings, physical supports like physiotherapy, financial supports, and medical supports, such as communicating between service branches and departments. There are also kits and services designed to nurture and support the cancer patient, but, as was echoed in the sections on information and education, awareness of these is erratic. The proposed solution, from many key informants and focus group participants, is to increase the number of patient navigators and the services about which they are knowledgeable. Having a patient navigator addresses the issue of centralization of information, as well as the availability of education for both professionals and patients.

Personal supports are found in meetings, individual or in groups, that offer social interaction on an equal footing with information and education. The value of shared stories and experiences among cancer patients cannot be underestimated.

I check[ed] on the internet for support groups in Charlottetown and I found the support group...and contacted a name that was there and she said come on over this afternoon and she had another lady from the support group and they were wonderful...

...my biggest help was a relative who, from the time I was diagnosed...said I'll go with you for chemo and I had to do a lot of travelling outside of the region for investigation and treatments and oncology and I was on my own.

Just being with those other women...some of them are 30 years survivors, and...you don't focus on your illness at those focus groups, you focus on interacting, having fun and doing things together, and to me that was very important.

What we do here is we make ourselves available so anybody newly diagnosed [is] given our numbers and we can go and visit.

...support groups, I think, would be great for anyone that has [cancer] or [is] going through it, because, like I said before, family sometimes you can do without and you know you're better off, I think I could be more open with a support group than with family...

With a support group you could just let it out and sometimes letting it out makes you feel a lot better than keeping it in.

Given the strong desire expressed by many women for cancer patients to communicate with others in their situation, personal supports should be as readily available as possible, and in person.

I didn't go to a support group because they were so far away...

At least if you want to cry, you cry with each other...if you want to holler, how can you bawl to somebody on the computer, you can't...

And to talk to someone on the phone...you can't see the expressions ... you need it, you can't touch and sometimes people need a touch...

Kits and packages are often offered in conjunction with personal supports, and act as a tangible reminder of emotional assistance that can be called upon. The fact that key informants know more about existing kits and support packages than focus group members do underscores the need to publicize these initiatives more widely:

We don't give any medical information, we don't give anyone false hope, we chat, we talk and that's the power of just chatting, telling each other stories and learning from each other and if someone is looking for information you find out through conversation o.k. well this is a good book or DVD or why don't you call so and so. We're kind of guides that way.

I don't even know what services are available, to be honest. I mean, I know you get oncology treatment, you get chemo, but what else is there? I have no idea.

Physical supports, including rehabilitation and leisure activity, are needed to enhance aspects of a patient's recovery, and should be offered in collaboration with other support networks in order to create a holistic healing experience.

It's amazing how well you feel when you come back from exercise.

What I did was I did the exercises before [surgery]...and put a line on the wall and three months' time, that was my objective to reach that line again...

Have a physiotherapist come in...she could walk you through the exercises, give you a sheet and ask you to do them before the surgery.

People need to know how important exercise is, it's good for the mind but apart from that, while you're having chemo it don't matter how dragged out you feel like, even if you just go for a five minute walk, you've got to do it.

Financial supports should be made available to complement other supports and alleviate stress while the patient is concentrating on her recovery. For many, money worries are paramount, given the costs of medication, treatment, health centre visits, travel and accommodation. Once again, that such supports exist needs to be communicated in a broad fashion, as these considerations can adversely affect personal relationships so crucial to well-being.

There's a lot of people that can't afford to have cancer, period. 'Cause I know when I went through cancer my first time and I was all finished my chemo, I still had some drugs...the drug you take before you have chemo, and I handed them to a woman who didn't have any drug plan, and they were \$20 per pill.

Finances is a big thing around here and there's no way you could jump in your vehicle and go to St. John's or Corner Brook just for a support group.

There's a lymphodema clinic. But that's something else that we tend to forget, that there's a cost factor that not everybody can afford.

Medical supports should be delivered to a high standard; accompanying services and supports that are not typically part of healthcare service delivery can be improved. Patients need to be confident they know of and can access relevant procedures, staff and services.

I don't have a whole lot of complaints about the medical system, but I would say in those first few weeks, there's a need for more support out there.

They should never send you home the next day after a mastectomy. ...They call it 'drive-through', and I think that's horrendously terrible to put a woman through.

At the local hospital the staff was very, very helpful, they were very supportive, chemo was not as unpleasant as I thought it was going to be and the support I got going through chemo was excellent; but as soon as the chemo was finished, you were dropped. Not their fault, they have no other choice, they have so many other people. But you're left hanging...

The nurse in charge of outpatient[s] was also responsible for the chemo; she was a great support for anybody. She was very busy... but she certainly made sure that you got whatever information you asked about.

Several focus group participants alluded to the fact that post-treatment stages, also known as survivorship, require at least as much support as any other: **“There should be a gold standard for monitoring afterwards, because we seem to be on our own.”**

Personal supports, physical supports, financial supports and medical supports have a great deal to do with information-gathering; support is realized, however, when that information is utilized to improve the lives of those with women’s cancers. There should be greater variety in supports that are offered, and those supports should be accessible and ongoing so that the lifestyle and/or recovery of women’s cancers patients is facilitated.

Summary: Psychosocial Supports should

- COOPERATIVE: Address all aspects of well-being, including personal, physical, financial and medical challenges, in order to promote a more rounded healthcare system
- SUPPLEMENTED: Combine with information and education in a kit or package to be accessible for patients who choose to use them as necessary
- CENTRALIZED: Be contained within the role of a cancer patient navigator to facilitate the services and experiences of cancer patients during diagnosis, treatment and post-treatment stages
- SUSTAINABLE: Draw on the experience of cancer survivors to assist cancer patients with the complex challenges of cancer care

RECOMMENDATIONS

Those living with women's cancers in Atlantic Canada face extraordinary challenges in maintaining their health and well-being throughout the physical and emotional demands of cancer diagnosis, treatment and survivorship. The formal healthcare system and non-profit cancer service organizations need to ensure that they offer information and education and a variety of supports to cancer patients for those that choose to use them in effective and meaningful ways to maximize patients' well-being.

The needs of women's cancer patients are paramount, and must be articulated, modified and implemented. There needs to be direct and ongoing contact with patients to identify what they require and desire so that services may be designed to reach these targets.

Key informants and others in the role of service providers feel that there is sufficient supports in place for cancer patients, but they are aware that contact and information-sharing may not reach or be sustained for all patients. Promotion of services and supports is an ongoing challenge for these groups.

Patients report that they are generally satisfied with the information and education that exists in relation to their diagnosis, but many report inconsistencies in information-sharing and education delivery that proves frustrating. Accessibility is a key concern for patients, featured in issues raised about language and translation, computer expertise, and communication across geographically diverse areas.

Challenges for service providers and cancer patients can be met by the creation and maintenance of publicity networks, both for cancer care organizations to centralize their services and for patients to access information and education relevant to their diagnosis or stage of treatment.

...we have our ads in the Chronicle Herald...We have an annual event, dinner, dance and auction and again that's more awareness for the public and it's a fundraiser. ...But it's a problem we have to work on. We have to get people more aware of us, for sure.

My role [as a service provider] right now truly is to ensure that the information is available...[and] disseminated right now out to those regional networks who are much more familiar with all the smaller areas in their region and to make sure that they have access to that information...

The formation of regional, provincial and national databases of information and resources has been proposed, as has the centralization of data on cancer care, statistics and healthy living for cancer patients. This service would prove useful to cancer care providers and cancer patients.

The regional, provincial and national endorsement and funding of patient navigators would help to bridge the gaps found in cancer care services and supports. Participants in this study demonstrated strong backing for navigation supports, most often a patient navigator to assist them in coordinating treatment and services.

You sort of need a department or coordinator with the health care system to do all this with everyone.

if we had [a navigator] whose only task every day was to navigate for female cancer patients, it would be so much easier; she would have it at her fingertips, this is what you need, this person will contact you or you contact them.

But you're trying to figure out what do I have to do next on your own, so if you had someone that could tell you these things, it would be great.

If you got the diagnosis at 3.00 on a Friday afternoon, there should still be somebody there that you can talk to. Not somebody...to say everything is ok, not necessarily somebody who's knowledgeable about cancer, just somebody who's knowledgeable about feelings and listening.

But wouldn't it be nice to have someone who's more experienced in that field and had spoken to women who had been there before, like a patient navigator that can help you...

And you just wish you had someone that could kind of oversee you, give you the feeling, that feeling of security, yeah, I'm being looked after, things are going to fall into place here.

The suggestion of volunteer navigators, made up of cancer survivors with experience of the medical system, was also raised.

You need volunteers there who have been there, sat there, heard it all, you need it right there when you're going through it.

You've already been through it so you know the steps that you take...you know that she needs time to talk and just sit there and listen. And she needs time to cry and have someone cry with her.

CONCLUSIONS

Mapping the range of services and supports for those living with women's cancers in Atlantic Canada reminds us of the extensive range of assistance that exists, but also clearly identifies gaps in which care for cancer patients can be improved.

The healthcare system and non-profit support organizations see challenges in ensuring effective services and supports for women's cancers patients, through funding, accessibility and culturally diverse policies. An analysis of information and education available for cancer patients shows that the printed literature, telephone and internet media that comprises information need to be consistent, structured, appropriate and well advertised, and education for specialized treatment methods for healthcare professionals would result in professional, comprehensive and directed care. The personal, physical, financial and medical supports in place for cancer patients can equally be improved. Ensuring that supports are cooperative, supplemented, centralized and sustainable will assist in providing a better range of systems and services for those affected by cancer.

Findings in this study reveal that service providers feel they are meeting the needs of those with women's cancers in the Atlantic provinces, though they are aware there are gaps in ensuring relevant information and education reaches those affected. Patients, in turn, feel that services and supports can be more flexible in terms of what is provided, when it is available and how they are able to make use of what is offered, given financial, geographical and social constraints they may be facing. Centralized networks for information-sharing and endorsement and funding for patient navigators would assist cancer service providers and cancer care patients in improving satisfaction levels and increase the level of cancer care within Atlantic Canada:

APPENDIX A: ANNOTATED DIRECTORY OF SERVICES

The following annotated Directory of Services provides more information on the range of supports offered by organizations in the “Profile of Services” earlier in this report, and is intended to catalogue major services existing at the national, provincial and regional levels for patients with women’s cancers.

National Programs

Canadian Cancer Society

Canadian Cancer Society Publications: Publicly accessible information on all cancers from the Canadian Cancer Society Library.

Cancer Connection: A free, one-to-one telephone-based service that matches people living with cancer, their families or caregivers with others who have had a similar cancer experience.

Cancer Information Society: A national, bilingual, toll-free service available to cancer patients, their families, the general public and healthcare professionals. Trained staff answer all questions related to cancer care and direct callers to services and supports in their area.

CanSurmount: A one-to-one visiting program by trained volunteers who have experienced cancer. Women who have had breast cancer surgery are offered emotional support by others who have had similar experiences.

Reach to Recovery: Matches newly diagnosed breast cancer patients with survivors for face-to-face conversations and support.

Living with Cancer Support Groups: Trained volunteer facilitators help group members share personal experiences and concerns. Groups are offered in communities across the Maritimes and can be found using the Canadian Cancer Society resource directory.

Ovarian Cancer Canada

Information Line: A toll-free Information line and email providing informational support to women with ovarian cancer across Canada. One trained professional handles all enquiries.

Telephone Education Series: A free nationwide information service for women with ovarian cancer from health care professionals to learn about issues relating to ovarian cancer. Past

recordings have addressed chemotherapy and its side effects, self-advocacy in care and finances, and sexuality, intimacy and ovarian cancer.

Some Buddy: A peer-to-peer support service matching recently diagnosed women with ovarian cancer and a 'mentoring buddy' previously treated for ovarian cancer. Contact can take place in person, over the telephone, or through email or letters to provide emotional support.

Seeds of Hope: The bi-annual newsletter of Ovarian Cancer Canada. It is published to inform and support women and their families who are affected by ovarian cancer.

You Are Not Alone Kits: Upon request, Ovarian Cancer Canada provides women diagnosed with ovarian cancer a complimentary support kit including a book entitled *You Are Not Alone: A Guide to Canadian Women Living with Ovarian Cancer*, a video/DVD companion to the book, a copy of Seeds of Hope and several brochures and informational cards.

Listen to the Whispers: Volunteers trained to give awareness presentations about ovarian cancer. Presentations are free of charge and can be arranged for community groups and women's groups.

Canadian Breast Cancer Network

The Canadian Breast Cancer Network (CBCN) is a survivor-directed, national network of organizations and individuals. It provides a national link between all groups and individuals concerned about breast cancer, coordinates national breast cancer research and runs a comprehensive website that individuals can access to answer any breast cancer related questions.

Eyes on the Prize

An international online support group for survivors of gynaecological cancers.

Hope Air

A national charitable organization that arranges free air transportation for financially burdened Canadians in need of medical treatment outside their communities. Flights on commercial, corporate and private aircraft are donated for families in need.

"It's Your Health" Publications

Easy to read pamphlets from Health Canada on over 150 different diseases affecting Canadians, such as breast cancer, mammography and cervical cancer, in order to equip individuals to make informed decisions about their health and safety.

The Look Good, Feel Better Program

A national program that offers workshops free to women living with cancer to improve appearance and self-esteem by using cosmetic techniques to camouflage some side effects of treatment. Workshops take place in various Maritimes cities.

Canadian Virtual Hospice

On-line resource for patients, families, volunteers and health care professionals. Provides general information on palliative care, features an 'ask a professional' section, has on-line support and features a search directory for palliative care services by community or region.

Janac Sportswear

An on-line shopping service for women's specialized sportswear clothing due to breast surgery. Janac Sportswear is popular with dragon boat racing teams.

Willow Breast Support Service Canada

Willow provides information on specific diagnoses and helps women with cancer evaluate options available to them.

Support Line: One-on-one telephone support from a trained breast cancer survivor. The support staff use Willow's Resource Library, one of the largest resource and information libraries in North America.

Mail-Out Packages for Women: Staff members use Willow's Resource Library to create individually tailored packages that includes specific information for each diagnosis.

Willow's Breast Cancer Support Network: Provides those diagnosed with breast cancer the fundamental knowledge and tools needed to start and continue running survivor led breast cancer support groups in their own community.

Coping with your Financial Concerns: An original Willow publication to assist people diagnosed with breast cancer deal with the possible financial strain during or after treatment and recovery.

“Living”

A tri-annual on-line newsletter written by women living with metastatic breast cancer. The stories provide supportive and factual information from a personal perspective.

Storytelling Circle

An online venue for survivors, and supporters of survivors, to share their stories about living with breast cancer.

Young Women’s Breast Cancer Support Network

This network is aimed at young women with breast cancer, and provides women with the tools to start their own survivor-led support groups.

Victorian Order of Nurses (VON)

A non-profit charitable organization that offers a range of health, wellness and community support services for individuals, families and organizations. Home health services offered by VON are aimed at assisting those suffering from long- or short-term illnesses and post-operative surgery patients to recuperate in their own homes.

Atlantic Specific Programs

Atlantic Breast Cancer Net

An internet portal that provides networking, information and advocacy services to the Atlantic Region. This website includes a ‘buddy’ connection to find a friend with a similar diagnosis, a directory of support groups, a calendar of activities sorted by region and monthly and weekly newsletters. ABCN is a program (created and maintained) by Breast Cancer Action Nova Scotia.

Provincial Programs: New Brunswick

The New Brunswick Breast Cancer Network

The New Brunswick Breast Cancer Network (NBBCN) addresses breast cancer issues through partnerships, support, education and awareness.

Peer-Led Groups: Informal breast cancer support groups in Fredericton, Moncton, Saint John, Saint Stephen and Sussex.

NBBCN Newsletter: Published five times a year, this publication is mailed to members, distributed at support group meetings and circulated at treatment facilities.

Financial Aid: Financial assistance and support is offered to individually-run support groups throughout the province.

Speaker Series: Guest speakers on breast cancer are provided as requested to various groups.

Professional Development: Financial assistance offered to physiotherapists who wish to take specialized courses in the treatment of lymphedema, a common side effect of breast cancer surgery.

Book Donations: The NBBCN have presented a number of breast cancer-related reading materials to their member support groups and the regional public libraries in New Brunswick.

The New Brunswick Breast Cancer Information Partnership Inc.

A coalition of breast cancer survivors, advocates and professionals from provincial breast cancer organizations make up provincial partnerships in New Brunswick, Prince Edward Island and Newfoundland. The partnerships offer 'flower kits' (Purple Violet, Purple Lupin and Sunflower Seeds of Knowledge), packages with information and resources given to newly diagnosed breast cancer patients by their physicians.

Canadian Cancer Society, New Brunswick Division

Financial Support: Can offer assistance with ground transportation costs for cancer treatments (chemotherapy and radiation), as well as provide some funding for exceptional assistance. Partners with the Easter Seals March of Dimes to cover the cost of 2 pieces of recycled

equipment for cancer patients in financial need. Other practical support items, such as temporary breast prostheses and wigs, are available free of charge.

Living With Cancer (LWC) Group Support: Offered by the Canadian Cancer Society (CCS), the group's monthly meetings invite participants to share their experiences with other members in a safe and supportive environment provided by the CCS trained facilitators.

Camp Goodtime: A yearly retreat for youth aged 7-16 who have experienced a cancer diagnosis within their lifetime. Camp Goodtime is sponsored by the New Brunswick Masonic Lodge and is free to the campers and one guest.

Regional Programs: New Brunswick

New Brunswick Breast Cancer Network (NBBCN) Support Groups

Open to all breast cancer survivors, these groups offer emotional support in a peer-led environment. Groups are held in Fredericton, Moncton, Saint John, St. Stephen and Sussex.

'Tit Bateau (Moncton)

A group of women living with breast cancer and breast cancer survivors supporting one another through dragon boat racing.⁹

Breasts...Ahoy (Saint John)

See above.

Focus on Healing

Focus on Healing – the Lebed Method is an 8-week therapeutic exercise program through the Moncton YMCA for women who have had breast surgery, node dissection, radiation,

⁹ Although dragon boat teams are an alternative source of support, they provide both educational and support for women. The educational and awareness-raising benefits of dragon boating is vital to widespread support for cancer care provision.

chemotherapy, and/or lymphodema, frozen shoulder, depression and pain. Information, exercise and a DVD for home use is included.

Angel Fund

Located in Moncton under the South East Regional Health Authority, the fund, which covers prostheses, bras, wigs, transportation, and the Focus on Healing program, provides financial assistance to women without private insurance.

Supporting Sisters

A support group providing emotional and informational assistance in Moncton for women with breast cancer.

Provincial Programs: Newfoundland and Labrador

Canadian Cancer Society, Newfoundland Division

Roots of Support: Roots of Support Groups provide face-to-face group support in communities across the province. Meetings are open to people affected by all types of cancer.

Annual Newfoundland and Labrador Breast Cancer Retreat: A weekend-long event in May that includes information sessions, presentations, and therapeutic opportunities for massage and yoga, as well as a panel discussion with health care professionals to address any health questions.

Daffodil Place (Opening September 2008): Accommodation for those in Newfoundland offering services and support to ease the financial burden of a cancer diagnosis for those travelling to St. John's for treatment. The Canadian Cancer Society's community programs will be delivered on site.

The Lupin Partnership

A volunteer organization in Newfoundland and Labrador providing up-to-date breast cancer information. In addition to web and pamphlet resources, the partnership assembles and

distributes Purple Lupin Kits. Future plans include information kits for women diagnosed with gynecological cancers and the development of regional networks across the province

Resource Guide: Offers a wide variety of breast cancer services and sources of support in Newfoundland and Labrador. Entries include breast prostheses retailers, provincial hospital services, support groups and community organizations.

Calendar of Events: With frequent updates, the calendar includes provincial support group schedules, community fundraising events, and national teleconferences and meetings.

Purple Lupin Information Kit: Available to any woman diagnosed with breast cancer in Newfoundland and Labrador, the Purple Lupin Kits provide information on treatment options as well as resource and emotional support.

Realtime Cancer

Accessible across Canada but based in Newfoundland, Realtime Cancer offers young adults the opportunity to share personal experiences about cancer and is committed to developing an independent and sustainable cancer resource.

Retreat Yourself: Realtime Cancer's professionally facilitated annual retreats encourage a sense of community and control for young adult survivors.

Survivor Conference: The survivor conference "Helping Survivors Thrive" builds on the lessons from the Retreat Yourself. Alumni can connect with one another and deal with long-term challenges resulting from their experiences with cancer.

Online Community: The Online Community is a constant support and connects young survivors across the country online 24/7. It offers survivor and supporter profiles and forums with more than 65 different discussion topics.

Awareness and Education: Programs have taken place in high schools in Newfoundland, Labrador and Nova Scotia.

We Get It – A Survivor Video: Filmed during the 2006 Retreat Yourself Conference, "We Get It" features the stories of eight survivors. In addition to the narratives, the film includes an educational piece around the young adult cancer gap for health care professionals and the general public.

Newfoundland Cancer Treatment and Research Foundation

Newfoundland's largest cancer treatment centre, NCTRF also provides a number of emotional and financial supports for patients, including breast prosthesis and wig loan programs,

psychosocial counseling provided by trained social workers, nutritional counseling, volunteer driving services, medical supply loans (such as wheelchairs), financial assistance, informational support and a breast cancer support teleconference network that connects women from over 200 communities in Newfoundland.

Regional Programs: Newfoundland and Labrador

The Gathering of Friends

In Placentia, the Gathering is open to people whose lives have been affected by all types of cancer.

Exceptional Patients against Cancer

An independent support group in St. John's for people with all types of cancer.

Sharing Our Strength

An independent support group in St. John's for women with breast cancer.

Avalon Dragon Boating Team

A group of women in St. John's supporting one another through dragon boat racing.

Cancer Coalition for Alternative Medicines

Monthly meetings in St. John's offer information about alternative medicines and nutrition from guest speakers and retailers.

Support Groups

There are numerous support groups throughout the province: Canadian Cancer Society Living with Cancer Support Group (Grand Bank), Rays of Hope Cancer Support Group (Springdale), Port Aux Basques Breast Cancer Support Group, Emotional Support Group (Corner Brook), Marystown Cancer Support Group, Burgeo Cancer Support Group, Twillingate & New World

Island Breast Cancer Support Group, Gander Cancer Support Group, Breast Cancer Support Group (Stephenville).

Provincial Programs: Prince Edward Island

Canadian Cancer Society Prince Edward Island Division

Emergency Financial Assistance: Provides individuals meeting financial need criteria with emergency assistance to undergo cancer treatment.

On-Island Travel: Qualified applicants receive financial assistance for travel expenses within the province.

Maritime Travel: Qualified applicants who receive treatment out of province can qualify for financial assistance through the Emergency Financial Assistance program.

Prince Edward Island Cancer Treatment Center

A multidisciplinary centre offering various support services for Prince Edward Island residents. The centre regularly hosts the Look Good Feel Better Program, offers free internet access for patients and their families and maintains a library.

YWCA Encore Program

A free 8-week program designed by medical specialists providing gentle exercises, warm water hydrotherapy sessions, relaxation techniques, information and support. The exercise program is specially designed to target areas that have been affected by breast cancer surgery and treatment.

Regional Programs: Prince Edward Island

Charlottetown Breast Cancer Support Group

Meets the first Monday of every month.

Canadian Cancer Society Living with Cancer Support Groups

Offered in West and East Prince Counties.

The Queen Elizabeth Hospital

This Charlottetown hospital provides patients undergoing breast cancer treatment with breast prostheses fittings, prostheses and mastectomy bras.

Island Home Health Care

This Charlottetown business sells breast prostheses, mastectomy bras, plus size bras, lymphodema sleeves, turbans, creams, lotions, silicone straps, bra extender and specialty bathing suits.

Silhouette 2

A Summerside business selling wigs and hair pieces for women undergoing cancer treatment.

Rita's Styles

In Charlottetown, this business sells wigs, hair pieces, hats and turbans for women in cancer treatment.

Really You

Sells wigs and hair pieces in Charlottetown for women undergoing cancer treatment.

Atlantic Prosthetics

A Charlottetown business that sells breast prostheses.

Lynda Murphy R.N.

Will fit for prosthetics in Charlottetown and travels to Summerside each month for the same.

Provincial Programs: Nova Scotia

Cancer Care Nova Scotia

Cancer Patient Navigation: Cancer Patient Navigators work with all cancer patients and their families to address physical, social, emotional and practical needs. They serve as the link between a patient and the cancer system.

Cancer Answers Lecture Series: Four lectures, each dedicated to a specific cancer-related topic, are held each year. Lectures are available through videoconferencing in provincial health districts and available to view through provincial libraries and some cable stations.

Oncology Interactive Education Series (OIES): An interactive and user-friendly computer software program, OIES has information for patients, their families and health professionals on 24 types of cancer. Each title in the series contains between 18 and 25 hours of learning material.

Queen Elizabeth II (QEII) Cancer Care Program

The Sunshine Room : Located within the Queen Elizabeth II Hospital in Halifax, this area is an environment for trained volunteers to deliver therapies to cancer patients. Services are free of charge and include massage therapy, reiki, therapeutic touch and reflexology. Head wraps are also available.

Professionally Led Support Group Programs

(Psychosocial Oncology Team at Queen Elizabeth II Hospital)

Living with Advanced or Metastatic Cancer - An educational group for patients and partners: This group helps educate cancer patients and an accompanying family member about the stages of cancer and the challenges they present.

Living Well With Cancer: Held at Dartmouth General Hospital, this group for patients and an accompanying family member focuses on health and healing while living with cancer. Topics include nutrition, managing symptoms, strategies for healing and wholeness and communication with health professionals, family and friends.

Finding Health in Illness – Mindfulness Meditation for Patients and Family Members and Staff: This six-week class provides an introduction to mindfulness meditation, which works with the challenges, stress and pain of illness to attain a basic sense of healthiness.

Skills for Healing Weekend Retreat: This fall weekend retreat focuses on developing wellness skills and includes discussion about nutrition, complementary therapies, managing stress and

the mind-body connection. Free to persons diagnosed with cancer and an accompanying family member, registration requires a \$40 deposit.

Tuesday Night Live: An open, ongoing support group for young adults living with cancer.

One-on-one Psychosocial Counseling

Book Club

Breast Cancer Action Nova Scotia (BCANS)

Breast Cancer Action Nova Scotia is a survivor-driven breast cancer support group devoted to networking, support, education and research.

The Atlantic Breast Cancer Net: An internet portal that provides networking, information and advocacy services to the Atlantic Region. The site provides information about contacting someone with a similar diagnosis, finding support groups, and offers articles and weekly/monthly newsletters.

Information Booklets: Two booklets written by cancer survivors that are available online or in hard copy: *In Our Own Words* for newly diagnosed women, and *In Our Own Words: How We Told Our Children* from mothers who shared their diagnoses with their children.

Navigating Your Path: A Guide For People With Advanced Breast Cancer: A booklet, available in print and on-line, compiled by persons with breast cancer experience, cancer navigators, provincial networks and the Canadian Breast Cancer Network.

BCANS Library Project and 9 Point Tour: A response to the need for more comprehensive breast cancer research materials available in provincial libraries, books were distributed to each library region. The 9 Point Tour will be held in one library in each of the 9 provincial district health authorities; national, provincial and community organizations have been invited to participate and share their resources.

Breast Cancer Network Nova Scotia: In development, this is a provincial network of individuals, groups and organizations that seek to improve services to people affected by breast cancer.

Breast Cancer Action Nova Scotia Website: An Interactive website that includes 24/7 online support, user profiles and biography pages, a breast cancer glossary, "Best of Tips & Hints" from the forum, searchable archives and online chat.

Free Public Educational Forums/Lectures/Workshops

Bosom Buddies of Nova Scotia

A group of breast cancer survivors supporting one another through dragon boat racing.

Titz'n Glitz

Offers short term financial assistance to women undergoing breast cancer treatment through community fundraising efforts such as the program 'Halifax on the Front Line Society'.

Nova Scotia Department of Health Pharmacare Programs

Cancer patients can access one or more of several programs, coordinated and administered by the provincial health department, that assist with drug coverage costs. Pharmacare programs are designed to assist individuals without private medical insurance based upon qualifying criteria. Social workers specializing in drug care costs for patients are accessible through the QEII cancer care centre.

Medical Services Insurance Nova Scotia (MSI)

MSI offers partial coverage for breast prosthesis up to \$150 every two years. The Canadian Cancer Society offers a matching contribution for those who fit their financial criteria.

Biker's Memorial Fund – Atlantic Chapter

Provides emergency financial support to cancer patients, when approached and requested to do so by other cancer care giving organizations.

Canadian Cancer Society Nova Scotia Division

The Lodge That Gives: Accommodation for cancer patients and their families living more than 50 kilometres away from the Nova Scotia Cancer Treatment Centre in Halifax. Cancer patients stay free and there are reduced rates, including meals, for a family member/support person. Supportive Care can be contacted for possible fee exemptions.

Regional Programs: Nova Scotia

YWCA Encore Program

A free 8-week program offered in Halifax for women with experience of breast cancer. It incorporates gentle exercise specifically designed to target areas affected by breast cancer surgery and treatment, relaxation techniques, warm water hydrotherapy sessions, information and support.

Annapolis Breast Cancer Support Group

Informal support group for women dealing with breast cancer. Offers guest speakers, networking opportunities and information.

Antigonish Women Alike Breast Cancer Support Group

A support group for women dealing with breast cancer that hosts guest speakers and provides opportunities for networking, social engagement and information.

Barrington Passage Living with Cancer Support Group

A support group for individuals in any stage of cancer and their families, friends and caregivers.

Breast Cancer Support Group

Provides group support in Mavillette to women and men diagnosed with breast cancer.

Breast Cancer Support Group

Offers breast cancer patients in Halifax a forum to share personal experience and gain support from others who are also experiencing diagnosis and or treatments.

Breast Quest

Breast cancer survivors' dragon boat racing team operating out of Windsor.

Canadian Cancer Society Cancer Support Group

A support group in Yarmouth that offers information, networking and support to those affected by cancer at any stage.

Caring for Cancer Patients

A non-profit, charitable organization in Truro established to help patients and their families overcome the obstacles in dealing with cancer therapies.

Cape Breastoners

A dragon boat racing team for breast cancer survivors in Sydney.

Health Solutions

Offers custom-made breast prosthesis, mastectomy products and lymphodema products and treatment in Halifax.

Hope Chest Breast Cancer Support Group

A support group for women in Truro affected by breast cancer. The group provides opportunities to listen to guest speakers and make use of information and support.

Kentville Breast Cancer Support Group

Informal support group with speakers, support and information for women in Kentville dealing with breast cancer.

Kingston/Greenwood Living with Cancer Support Group

General cancer support group for those living with cancer.

North-side Breast Cancer Support Group

A group for North Sydney women dealing with breast cancer that offers support and information.

Sackville Living with Cancer Support Group

A group for supporting those affected by and living with cancer.

Sydney & Area Breast Cancer Support Group

An informal support group for women with experience of breast cancer.

Warrior Princesses Breast Cancer Support Group

A Fall River group supporting women dealing with breast cancer.

Women Alike Peer Support

A dragon boat racing team for breast cancer survivors in New Glasgow.

Sunflower Lunches

A social support group for women with ovarian cancer. Meetings take place in restaurants in and around the Halifax region on a monthly basis.

APPENDIX B: INTERVIEW GUIDE FOR KEY INFORMANTS

Tell me about the supports and services that your organization offers to women living with cancer in your region.

What do you envision your role as being in these women's lives?

What are the limitations to the services/support you offer?

How do you make contact with the women you are supporting?

Probes: Patient referral, posters, clinics etc.

Are you aware of any existing gaps in the cancer services you provide to women?

APPENDIX C: TELEPHONE SCRIPT AND SCREENING QUESTIONS

Script: Thank-you for taking the time to contact me today. My name is Erin Hemmens and I am the Research Assistant at the Atlantic Centre of Excellence for Women's Health in Halifax, Nova Scotia. I am conducting research into women's experiences of locating, accessing and using cancer support services in Atlantic Canada. I would like to ask you a few general questions that will help me determine whether you would be an appropriate candidate for participating in the study. By answering these questions you are not giving your consent to participate in the study and you may withdraw from this telephone conversation at any time. You are not required to answer any of the questions, just the ones you feel comfortable with. The questions should take you approximately 1 minute to answer. Would you like to continue?

Have you lived with, or supported a women living with, breast, cervical, ovarian or uterine cancer within the last five years?

Are you yourself a survivor of one of those cancers, or a supporter?

Did you or the person you were supporting utilize, or attempt to utilize, supports or services that were meant to assist you/them through their cancer experience? E.g. did you/they go to group support meetings? Did you/they contact any local cancer support agencies?

Which Province do you currently live in?

Where did you hear about this study?

APPENDIX D: GUIDE FOR FOCUS GROUP PARTICIPANTS

General: Did you feel the need for support services after you or a loved one was diagnosed with cancer?

How/where did you find information on those supports and services?

Probes: Health care provider, library, phone book/yellow pages, internet, other survivors

Tell me about your experiences looking for, accessing and using those supports and services?

Probes: Were they easy to find? Were they conveniently located? Were there any services you would have liked to have access to but didn't? What services were those and why were you unable to access them?

What were your experiences using those services?

Probes: Did they meet your expectations? Did you find/receive the support you were looking for?

Did you find that the services were appropriate for you?

Probes: Were they culturally, generational, racially, religiously appropriate?

What would have made the experience of accessing and utilizing a cancer support service perfect for you?

Probes: What do you imagine an ideal situation would be for women who are newly diagnosed and/or undergoing treatment, how would you make it easier for them?

APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE FOR FOCUS GROUP PARTICIPANTS

Demographic Information:

Survivor Profile

Age:

Married/Children:

Education:

Average Household Income (please circle):

\$0 - \$20,000

\$21,000 - \$35,000

\$36,000 - \$50,000

\$50,000 – up

Ethnicity:

Rural/Urban:

Language(s):

Type of Cancer:

Year of diagnosis:

Current Stage/Grade (if known):

Treatment(s):

Outcome(s) of Treatment:

Supporter Profile (please answer these questions about the person you are/were supporting):

Age:

Married/Children:

Education:

Average Household Income (please circle):

\$0 - \$20,000

\$21,000 - \$35,000

\$36,000 - \$50,000

\$50,000 – up

Ethnicity:

Rural/Urban:

Language(s):

Type of Cancer:

Year of diagnosis:

Current Stage/Grade (if known):

Treatment(s):

Outcome(s) of Treatment: