

**Setting the Stage for the Future:
Understanding the Information and Support Needs
of Women with Cancer in PEI**

Research Report

August 2011

Prepared by:

Dr. Colleen MacQuarrie and Lorraine Begley
Psychology Department, University of Prince Edward Island
Charlottetown, PEI

For:

Canadian Cancer Society, PEI Division



This project is made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the view of the Public Health Agency of Canada or the Canadian Cancer Society.

ACKNOWLEDGEMENTS

The authors of this study wish to thank the Women's Cancers Project Advisory Group of the Canadian Cancer Society for their support, contribution, and review of drafts of this survey. The members of that advisory group are: Ann Millar, Canadian Cancer Society; Drs. Rosemary Herbert and Philip Smith of the University of Prince Edward Island; Judy Donovan Whitty of the PEI Breast Cancer Support Group and the Canadian Breast Cancer Network; Liz Dobbins of Health PEI's PEI Cancer Treatment Centre; Pat Charlton of Health PEI's Primary Care Division; Pauline MacAusland of the PEI Women's Institute; and Emilie Chaisson of Ovarian Cancer Canada.

Thank you is also due to Kim Vriends of the PEI Cancer Registry for willing support and assistance in providing the opportunity to reach the study participants while protecting the anonymity of cancer survivors who received the survey. We wish to thank the women who took the time to share their experiences with us, by responding anonymously to the survey.

We also wish to thank the six women cancer survivors whose recommendations contributed to the validation of this survey and to the five women who participated in the focus group. They shall remain unnamed to protect their privacy.

TABLE OF CONTENTS

Executive Summary.....	4
The Survey.....	7
Demographic Information.....	7
Health, Diagnosis, and Treatment.....	9
Economic Concerns and Financial Details.....	12
Information Needs.....	17
Comments From Survey.....	32
Medical Reports, Second Opinions, and Referrals upon Diagnosis.....	32
Information Needs.....	32
Preferred Conversation Partners.....	32
Valued Information Sources.....	33
Most Helpful Information Enabling an Informed Decision.....	33
Timing of Information.....	33
Information Needs Between Testing and Diagnosis.....	34
Improving the Cancer Journey.....	34
Information Lacking.....	35
Support Lacking.....	35
Barriers to Support or Information.....	36
Advice for Women	36
Preferred Information Medium.....	37
Additional Comments.....	38
Focus Group Analyses.....	40
Conclusions.....	42
Appendix A.....	43

EXECUTIVE SUMMARY

In April 2011, we undertook a survey of women survivors of breast/ gynaecological cancers in an effort to solicit feedback about their information and support needs and identify any gaps they experienced in the cancer journey. The survey was followed with a focus group to better understand some of the issues emerging from the survey.

Being diagnosed with breast or gynaecological cancer is a dizzying event that upended the world for many women in this study. Much of the cancer journey is focused on testing, diagnosis and treatment, even as women struggle to continue in their lives, often as central caregivers in their family and protecting loved ones from the fear that they feel themselves.

Financial issues were a central concern, especially plaguing women in low income households. For these women, the unexpected diagnosis placed increased pressure on already limited economic resources. This circumstance, along with the impact of lost income and unexpected costs associated with cancer care, placed severe stress on women and their families as they attempted to focus on dealing with the foreign world of cancer.

One of the most startling findings, in this vein, relates to the ongoing economic impact that a cancer diagnosis has on women's income even after the treatments have ended. Women reported an increase in the percentage of households without adequate income to meet their needs during the cancer treatment stage. The percentage of women reporting inadequate income during treatment increased by ten percentage points between the pre-diagnosis stage to the treatment stage. Of genuine concern is the reality that most of the women who reported their household income was enough to meet their needs before the diagnosis lost economic ground during treatment and remained without sufficient resources even after treatment was completed. For them, the economic impact of the cancer journey does not end.

Women diagnosed with breast or gynecological cancers face different economic realities before being diagnosed with cancer as well as different experiences throughout the cancer journey. Their need for information across the journey differed, with breast cancer survivors requesting information on home care services more urgently than gynecological cancer survivors who felt this was not applicable to them. Information about coping physically with the cancer was also more important to women diagnosed with breast cancer. Larger percentages of women with gynecological cancers experienced a more financially difficult journey. Women diagnosed with cancers that spread or recur also report harder economic circumstances.

Another issue reported by a variety of respondents was the need for financial coverage to address the exceptional costs of cancer drugs and pain medication when outside of the hospital. This

issue also extends to concerns for financial support for prostheses, wigs, and personal medical devices required in the treatment and after treatment period.

Most survey participants felt that the information provided was “very important” at the time of diagnosis. Respondents spoke of the feverish search for all information available during the testing or diagnosis period. One issue that recurred repeatedly was the need for clear and accessible information on all the services and supports available for women undergoing cancer treatments or in the after treatment stage. Women spoke about learning of necessary services by speaking with other survivors. These conversations may have occurred after the need for the support had passed or after the respondent had spent valuable time and money on a service or product and found out too late that it was easily accessible, less expensive, or possibly even covered financially by a little known program. There was frustration that survivors had to search, sometimes unsuccessfully, for services. They did not feel they had the necessary information to even know where to go for help or available programs. The Canadian Cancer Society (CCS) and the PEI Breast Cancer Information Partnership provide kits for women with breast cancer that are well received at different stages of the cancer journey.

The CCS is the source of many programs and much information about cancer care on Prince Edward Island; however only one third of respondents rated the CCS as an important source of information, far behind medical specialists, the PEI Cancer Treatment Centre, family or friends, information kit/booklets/brochures, their family doctor, or cancer screening programs. For whatever reason, the connection with the CCS and its many services is lost. Survey respondents wanted to connect with the CCS and often reported that a representative of the CCS should be on hand at the time of diagnosis. Participants noted that no one from the CCS contacted them during the cancer journey. A cancer diagnosis and the journey through treatment and recovery, combined with the ongoing organizing of a woman’s personal responsibilities, is so onerous that having to initiate that additional contact with the CCS was too much for a number of women. Easier access to the information, the programs, and the CCS itself is a recommendation made by survey respondents. The CCS has to become more visible and accessible to women with breast and gynecological cancers.

Respondents indicated they needed information about at home help, particularly during the treatment stage. However when asked about their satisfaction with homecare most reported that the question was not applicable. The need for information and the low response for the question on satisfaction may indicate the needed services were either not available or the women were unable to access the services, possibly due to financial considerations. The only care at home rated highly by respondents was informal care provided by family and friends. Yet, women also reported being hesitant to ask for or accept such care for fear of placing unwelcome burden on this network.

While approximately 60% of survey respondents were very satisfied with how their fears were dealt with by medical professionals, there is a substantial group who are not. The question of “why” remains. Women’s fears were not limited to their medical situation but also extended to their personal lives. Thus women pointed out a gap in how their fears both medical and personal were dealt with; this may be an avenue in need of additional support.

A surprising finding was the reports of ageist attitudes experienced by older survivors. The average age of respondents to the survey was 64.9 years. Over one-third of respondents (35.3%) are women age 70 or older and over forty percent (40.9%) of women reporting a recurrence or a spread of the cancer are over age 70. A woman over age 85 reported having a mastectomy in the past five years and another older woman talked of a general practitioner expressing lack of concern when a thickening of the breast was felt two years earlier. There are frustrated requests for information for women over age 70. Another 70+ woman spoke of finding what she could online. There were requests for information about clinical trials for older women who were long term survivors. Finally one senior survivor reported that her cancer journey would have been better if she had the support and interest of the family physician.

The aging population and entry into old age by the baby boom generation in 2011 is an alert that many more older women with expectations of quality health care are on the door step. Addressing the concerns expressed by older women in their quest for information, clinical trials, programs, and supports for this generation is an opportunity that service providers must embrace. In addition, it is an ethical imperative. Addressing the considered responses of one-third of study respondents is sage advice for organizations aiming to serve the needs of women survivors of breast and gynecological cancers.

WOMEN AND CANCER: A SURVEY OF SURVIVORS

The Canadian Cancer Society, PEI Division, with financial support from the Public Health Agency of Canada, undertook a project to understand the information and support needs as well as the gaps in service for women with breast and gynecological cancers. The research was conducted in order to build a foundation on which stakeholders can build policy, procedures and programming. In April 2011 the Canadian Cancer Society, the PEI Cancer Registry, and the University of Prince Edward Island cooperated on a mail out of over 500 surveys to women who had been diagnosed with breast or gynecological cancers in the past five years. Following the collection and analysis of survey data, a focus group of five women was organized in June 2011 to discuss and add depth and context to a number of issues arising from the quantitative and qualitative data. The survey instrument is Appendix A.

1. DEMOGRAPHIC INFORMATION

One hundred fifty one women, aged 36 to 94 years, participated in the Women and Cancer Survey of Survivors. Table 1 details participants' demographic information. As can be seen in this table, almost 60 percent (59.7%) were age 60 or older, including 35.3% age 70+ and 11.5% age 80+. Past practices had excluded women over age 70 from research but the Project Advisory Group made an early and firm commitment to ensure that women were not excluded from the survey on the basis of age. We are encouraged by the response rate from women over age 70. The majority of women were married or partnered, with respondents evenly split between rural and urban postal districts. While all women were relatively well distributed across educational categories, considering the age of the majority of respondents, it is surprising that almost forty percent (38.8%) report having a university degree or some university or college education.

Over five hundred (510) invitation letters and surveys were mailed to PEI women who had been diagnosed with either breast or gynecological cancers in the past five years. Women diagnosed with non-invasive, in situ cancers were not surveyed. The invitations offered the option for respondents to complete the survey either online or by pen and paper. The latter were to be returned in an enclosed, addressed, stamped envelope. Forty-one survey packages were undeliverable, two women requested no further contact, one person called on behalf of her mother requesting no contact, and one woman said she had never had cancer. The response rate was 32%. Only two surveys were completed online – one by a 70+ year old woman; the rest were returned by mail.

Table 1.

Demographic information of survey participants

Postal District	n=130
Rural	48.5% (63)
Urban	51.5% (67)

Age	n=139
Age (average age)	64.9 years (11.5)
Age 80 or above	11.5% (16)
Age 70-79	23.7% (33)
Age 60-69	31.7% (44)
Age 50-59	24.5% (34)
Age 40-49	7.2% (10)
Age 30-39	1.4% (2)

Marital Status	n=139
Married/Partnered	64.3% (90)
Single	10.7% (15)
Divorced	6.4% (9)
Widowed	17.9% (25)

Educational Experience	n=135
Some High School	12.9% (18)
High School Diploma/G.E.D	20.7% (29)
Community College/Vocational School Diploma/OJT	17.1% (24)
Some University or College	21.4 % (30)
University Degree	17.4 % (24)
Other	7.1% (10)

2. HEALTH, DIAGNOSIS, AND TREATMENT

Table 2 describes women’s current health and past diagnosis (or diagnoses). Over eighty percent (83.5%) of women reported their current health as “good” or “excellent”. The prevalence of breast cancer among study participants represents 76.5% of the sample while 23.5% of respondents reported cancer of gynecologicals: cervical, endometrial, fallopian tube, ovarian, uterine or vulvar. No women reported a diagnosis of vaginal cancer.

Table 2.

Women’s self reports concerning their health and past cancer diagnosis n=139

Present Health Report	
Very Poor	.7 % (1)
Poor	1.4 % (2)
Fair	14.4 % (20)
Good	61.2 % (85)
Excellent	22.3% (31)

Last Diagnosis, if more than one cancer site diagnosed.	n=151
Breast Cancer	79.3% (130)
Cervical Cancer	7.3% (11)
Endometrial Cancer	1.3% (2)
Fallopian Tube Cancer	.6% (1)
Ovarian Cancer	6.6% (10)
Uterine Cancer	5.3% (8)
Vulvar Cancer	1.3% (2)

RECURRENCE OR SPREAD OF CANCERS

Information relating to cancer recurrence and treatment is available in Table 3. Among approximately 148 question respondents, 8.9% (13) reported the cancer had spread and 14.1% (21) reported a recurrence of cancer. Survivors reporting recurrence or spread of cancers reported breast, endometrial, ovarian, and vulvar cancers. In this analysis respondents reporting recurrence or spread of cancer are combined for a total of 23 respondents. Among the 23 respondents who experienced a recurrence of either breast or gynecological cancers, those with breast cancer were statistically $\chi^2(3, N,21)=9.60, p<.05$ more likely to report a recurrence of the cancer. Respondents who reported the cancer had spread (n=13) *were not* statistically more likely to report breast cancer rather than gynecological cancer.

Multiple treatments were common, with many women receiving more than one type of treatment. Almost all women (91.4%) required surgery as part of their treatment plan. Over forty percent reported receiving chemotherapy (42.8%) or radiation (55.7%). Only three respondents reported receiving other treatments. As reflected in Table 3, combinations of therapies are commonly reported along with surgery.

Surgery was significantly more prevalent ($\chi^2(1, N, 151)=8.00<.05$) among breast cancer survivors than among gynecological cancer survivors. Such surgeries included, but were not limited to, hysterectomies, vulvectomies, lumpectomies, mastectomies, and reconstruction. Other treatment options showed no significant differences by cancer site.

Table 3.

Cancer recurrences, spread, and treatment(s) n=148

The Cancer has Recurred 14.1% (21)

The Cancer has Spread 8.9% (13)

Treatments and Multiple Therapy Combinations

	Those who had:		Also had:		
	Totals	Surgery	Chemotherapy	Radiation	Other
Surgery	n=151 91.4%	-----	n=132 40.9%	n=136 55.9%	*
Chemotherapy	n=145 42.8%	-----	-----	n=62 63.9%	*
Radiation	n=149 55.7%	-----	-----	-----	*
Other	*				*

3. ECONOMIC CONCERNS AND FINANCIAL DETAILS

There is a significant negative economic impact on women as they undergo breast or gynecological cancer. Undoubtedly economic concerns contribute more stress to that already associated with a diagnosis of cancer. One woman explained the impact, “It is much easier to get through this process if you don’t have to worry about other things as you go through the treatments.”

Women’s household income, income sources and details regarding the ability to meet financial demands are summarized in Table 4. This table shows that, at the time of their treatment, only one third (36.5%) of women were working full (27.2%) or part time(9.3%) at paid employment and almost half reported being retired or semi retired. Almost half of respondents (46.4%) reported they are full time homemakers. There may be overlap in these numbers as some retirees may also be full time homemakers or find post-retirement employment.

INCOME ADEQUACY

Most women reported having enough or more than enough household income to meet their needs throughout the cancer journey. It is important to note however that a sizeable percentage, between eight and eighteen percent of respondents, reported not having enough income to meet their needs at various points in the cancer journey. The largest percent of women who report inadequate income report the inadequacy occurring “during” treatment (17.9%), doubling the percentage who reported inadequate household income “before” treatment (8.3%). Of particular concern is that the percentage of respondents, reporting that their income is not enough to meet their needs, rose “during” treatment but failed to decline to the pre-diagnosis level in the “after” treatment stage. The “after” treatment percentage (14.7%) remained much higher than the 8.3% reporting inadequate household income before treatment.

INCOME AND MARITAL STATUS

Among unmarried and married/partnered women there is a significant difference in those reporting adequacy of income across the cancer journey. Unmarried/unpartnered women battling breast or gynecological cancers reported inadequate income in all phases of the cancer journey at significantly higher rates than married/partnered respondents, approaching one third (32.6%) of unmarried/unpartnered respondents in the “during” treatment stage.

Table 4.

Income, Income Adequacy, Source of Income

Household Income		(n=119)	
<\$15,000	10.5%	(11)	
\$16-\$30,000	35.25%	(37)	
\$31-50,000	23.8%	(25)	
\$51-\$74,000	15.2%	(16)	
\$75,000 or more	15.2%	(15)	

Income Adequacy	Before treatment	During treatment	After treatment
	n=121	n=127	n=118
Not enough	8.3%	18.1%	14.4%
Enough	73.6%	66.1%	67.8%
More than enough	18.2%	15.7%	17.8%

Income Inadequacy (not enough to meet needs)	Before treatment	During treatment	After treatment
Married/Partnered	n=81 1.3%	n=81 9.9%	n=74 6.8%
Unmarried/partnered	n=46 20.0%	n=46 32.6%	n=44 7.3%

Income Inadequacy (not enough to meet needs)	Before treatment	During treatment	After treatment
Breast cancer survivors	n=97 6.2%	n=101 14.9%	n=94 10.6%
Gynecological cancer survivors	n=24 16.7%	n=26 30.8%	n=24 29.2%

Source of Income/Stage of Career	
Private Health Insurance	62.3%
Working Full Time	27.2%

Working Part Time	9.3%
Homemaker Full time	46.4%
Retired or Semi-retired	47.7%
Medical or Disability Leave	16.6%
Canada Pension Plan	45.7%
Guaranteed Income Supplement	17.9%
Income Assistance	2.6%

INCOME AND RURAL/URBAN LOCATION

There is a significant difference in reported household income between rural and urban areas $\chi^2(5,N,119)=12.48<.05$). The majority of both the lowest (90%) and highest (62.5%) income categories live in urban areas (Table 5).

Table 5.

Household Income Differential Between Rural and Urban Respondents

Household Income	All Respondents N=119	Rural	Urban
<\$15,000	10.5% (11)	10.0%	90.0%
\$16-\$30,000	35.25 (37)	60.0%	40.0%
\$31-50,000	23.8% (25)	62.5%	37.5%
\$51-\$74,000	15.2 (16)	56.3%	43.8%
\$75,000 or more	15.2 (15)	37.5%	62.5%

No significant difference was found between rural and urban respondents' self-assessed adequacy of income across the cancer stages. Despite the results not achieving significance, we can see that a larger percentage of urban residents reported inadequate income in each stage of the cancer journey. Up to one fifth of urban residents reported their income was not enough to meet their needs during the treatment phase (Table 6).

Table 6.

Income Not Enough to Meet Financial Demands Across the Cancer Stages by Rural/Urban

	Rural	Urban	All Respondents
Before treatment n=121	5.5%	11.3%	8.3%
During treatment n=127	15.5%	20.3%	18.1%
After treatment n=118	11.3%	18.0%	14.4%

INCOME ADEQUACY AND BREAST OR GYNECOLOGICAL CANCER SURVIVORS

Survivors of gynecological cancers are significantly more likely than breast cancer survivors to report that their income does not meet their needs in each of the three stages of the cancer journey. Gynecological cancers survivors reported their income is inadequate in all stages of the cancer journey at a rate two to three times that of breast cancer survivors. Almost one-third (30.8%) of gynecological cancer survivors reported their income is not enough to meet their needs “during” treatment. The percentage of cancer survivors struggling economically in the “after” treatment period never returns to the pre-diagnosis level but remains at the elevated level. In the “after” treatment period fewer breast cancer survivors reported income inadequacy than “during” treatment. Importantly, neither group of survivors reported returning to the “before” treatment levels of adequate income (Table 7.)

Table 7. Income Adequacy by Type of cancer

Income	% of Breast Cancer Survivors			% of Gynecological Cancer survivors		
	Before treatment n=97	During treatment n=101	After treatment n=94	Before treatment n=24	During treatment n=26	After treatment n=24
Not enough	6.2	14.9	10.6	16.7	30.8	29.2
Enough	80.4	73.7	75.5	45.8	38.5	37.5
More than enough	13.4	11.9	13.8	37.5	30.8	33.3

INCOME RELATED TO SPREAD OR RECURRENCE OF CANCERS

In Table 8 we see that those with recurrence or spread of cancer reported not having enough income to meet their needs “before” treatment (22.7%) significantly more often $\chi^2(2,N,121)=17.75p<.05$) than those who experience no recurrence or spread (5.1%) “before” treatment.

As well 22.2% of the respondents reporting no recurrence or spread of cancer reported their income “before” treatment to be more than enough to meet their needs. This compares to 0% of respondents in whom the cancer had recurred or spread reporting more than enough income. No significant differences were reported in “during” or “after” treatment income.

Household income: Among those reporting recurrence or spread of cancer 23.8% were in the lowest household income category compared to 5.8% for those not reporting recurrence or spread of cancer. As well those reporting recurrence or spread of cancer had no (0%) representation in the highest household income category of \$75,000+ compared to those not reporting recurrence or spread of cancer who were represented by 15.5% in that household income category.

Table 8.

Income Inadequacy Across Stages by Survivors Reporting Spread or Recurrence of Cancer

Income	% of Survivors Reporting Spread or Recurrence			% of Survivors Without Spread or Recurrence		
	Before treatment n=22	During treatment n=20	After treatment n=19	Before treatment n=99	During treatment n=107	After treatment n=99
Not enough	22.7%	25.0%	15.8%	5.1%	16.8%	14.1%
Enough	77.3%	75.0%	84.2%	72.7%	64.5%	64.6%
More than enough	0%	0%	0%	22.2%	18.7%	21.2%

RURAL/URBAN LOCATION AND CANCER DIFFERENCES

There is no significant difference between household location and either type of cancer or spread or recurrence of cancers.

QUESTION DESCRIPTIVES

At your most recent diagnosis, did you receive:	(n)	Yes (%)
Copies of your medical reports	n=143	37.4
Information about services available	n=139	80.6
The choice to get a second opinion	n=130	38.9
A referral to an Oncologist	n=142	91.0

Respondents indicated a very high percentage receiving a referral to an oncologist (91.0%) and information on services available (80.6%). From there, the figures decline by approximately fifty percent in response to both the choice to get a second opinion (38.9%) and to receive copies of medical reports (37.4%).

There was no significant difference between breast and gynecological cancer survivors in their reports of receiving copies of medical reports, getting a second opinion, or a referral to an oncologist. The question about receiving information about services available came close to indicating a significant difference, but did not. Four-fifths (83.8%) of breast cancer survivors received information on available services. Among survivors of gynecological cancers this figure falls to 68.8%.

4. INFORMATION NEEDS

IMPORTANCE OF INFORMATION AT EACH STAGE OF CANCER JOURNEY

The Women and Cancer Survey of Survivors partially focused on women's reception of and satisfaction with information related to their diagnosis. The survey requested that women rate the importance of various types of information at different stages of their journey with cancer (at diagnosis, "during" treatment, and "after" treatment). Many women rated all information to be "very" important" at all three stages of their cancer journey. Of course, the type of information found to be most important to women depended on the nature of their diagnosis. Ratings of information concerning intimacy and sexual changes, reconstructive surgery, and non-medical services (wigs, make-up), for instance, varied depending on the individual and their particular cancer experience. Other types of information, however, were rated to be "very" important" by survivors of all cancer types (i.e., information concerning diagnosis, physical and emotional coping, conventional treatment options, after-treatment issues, resources to support after-treatment issues, support from others who had a similar diagnosis, financial help, services available, and home care supports) (Table 9).

Respondents were clear in their need for information across all three stages of the cancer journey but in particular at the time of diagnosis. Almost all (97.8%) respondents to the question reported that it was “very” important to obtain information about their diagnosis, treatment, and after treatment concerns *at the time of diagnosis*. The importance of information about the specific diagnosis remained elevated across the three stages of the cancer journey with a decline to 84.4% in the “after” treatment stage, and a similar decline in the number of respondents. A high percentage (97.1%) reported that information about the type of cancer was “very” important at diagnosis but declined to approximately three-quarters of question respondents at later stages.

Information on the emotional impact and coping was “very” important to 70-80% of question respondents across the three stages, declining to 65.4% for respondents needing information on coping in the “after” treatment stage.

The need for information about communicating with the family circle was “very” important for 82.7% of respondents to the question at diagnosis but dropped to the 60-70% range during and “after” treatment. Information about intimacy and sexual changes remained “very” important across the stages for slightly over one-third of respondents to that question (35-36%).

Almost all (95.5%) rated the need for information on conventional treatment options as “very” important at diagnosis but declined considerably across the span of the journey to 66% in the “after” treatment phase. A similar decline was seen across the information needs about alternative/complimentary therapies. About one-third (67.0%) of question respondents indicated this information was “very” important at diagnosis, dropping to an average of 57% “during” and “after” treatment.

Approximately one-third (34.5%) of question respondents reported the need for information on reconstructive surgery was “very” important at diagnosis and declined slightly in the following two stages. Gynecological cancer survivors rated this question as “very” important “during” treatment at a slightly higher rate than did breast cancer survivors.

Receiving the pathology report at diagnosis was “very” important for nine-tenths (91.9%) of question respondents. Fewer respondents rated it as important at later stages of the journey with declines to 73% and 69% reported.

Increasing percentages of question respondents rated post-treatment issues such as nutrition, stress, relaxation, counselling, intimacy, sexuality as “very” important as the “after” treatment phase approached. Only 53.7% indicated it was “very” important at diagnosis with an increase to 66.1% in the “after” treatment stage. However over one-fifth of question respondents in each stage reported this information was “somewhat” important. Considering the “very” important and “somewhat” important categories 86.1% rated both the during and “after” treatment stage as an important stage at which to receive this information. Similarly, the information need for resources to support after-treatment issues was highest in the “after” treatment stage. Over two-

thirds (64.3%) of question respondents indicated a “very” important need for this information at that stage. This represents an increase of twenty percentage points from the diagnosis stage. However more than eight out of ten question respondents in both the during and after-treatment stage rated the information need as somewhat or “very” important (86.1/89.3%).

Non-medical services such as make-up, wigs et cetera were less important at diagnosis than “during” treatment with 36.1% rating the need as “very” important at diagnosis compared to 46.9% rating it as important “during” treatment. Throughout the cancer journey stages well over half of question respondents indicated the need for this information was somewhat or “very” important.

Slightly more than half of question respondents to all stages rated the need for information on peer support programs as “very” important. However considering those who rated the need as either “somewhat” or “very” important, over eighty percent of question respondents to all stages indicate a need existed. The need declined somewhat in the “after” treatment stage.

Information on financial help or available services was either “somewhat” or “very” important to approximately two thirds of question respondents to all cancer stages with the greatest need “during” treatment.

Information on clinical trials and new research was “very” important to approximately one-half of question respondents to all stages with a slight decline in the “after” treatment stage. Over three-quarters (76.1%) of question respondents rated the need for information to be either “somewhat” or “very” important at diagnosis.

One-half (50.5%) of question respondents rated the need for information on homecare and supports as “very” important “during” treatment, an increase from 43.6% in the “diagnosis” stage. Two-thirds (66.1%) scored this need as either “somewhat” or “very” important in the “during” treatment stage.

Information on job/employment issues were “very” important for more than one-third of question respondents with the highest responses in the “during” treatment stage (39.3%).

INFORMATION NEEDS OF ELDERLY WOMEN

Respondents over age 70 expressed frustration in their written statements about the adequacy and quality of supports and medical attention for women in their age group. A representative of this age group explained the need for “support and interest from the family physician, [and] a package that is targeting my age group, not people 30+ years younger.” Older women may not be provided with the support or opportunity to self-educate as this 75 year old woman explained, “Wasn’t given much material.”

The survey data, however tell an incongruous story. Women in this age group frequently showed a statistical difference in the need for information; respondents over age 70 rated many support and information needs less critically than did women below this age. The need for information, shown strongly in respondents under age 70, may illustrate a generational difference wherein medical doctors are seen to hold inaccessible knowledge. Although not reaching the level of statistical significance, older women rated their family doctor as “very important” or “somewhat important” (92.3%) as a source of information more frequently than did women under age 70 (82.4%).

The lower level of support or information seeking behaviour among older women may represent an expression of the cultural devaluation of older women. Because of this, older respondents may feel information on reconstructive surgery, after treatment issues and resources, other treatment options, the need for information about coping emotionally and physically with cancer, prosthetic services, clinical trials, intimacy and other issues may not be justified for their age group. Because of the divergent stories told by the qualitative and quantitative data regarding age related demands for information or supports, the lower levels of importance attributed to these issues among the older group most certainly should not be taken at face value. Further investigation of these questions is required.

INFORMATION NEEDS OF BREAST CANCER SURVIVORS AND GYNECOLOGICAL CANCER SURVIVORS

No significant differences in information needs were indicated between survivors of breast and gynecological cancers with the exception of:

- coping physically with the cancer (such as fatigue, pain, nausea) at all three stages of the cancer journey.
 - 90.7% of breast cancer survivors reported information on this aspect of coping to be “very” or “somewhat” important at diagnosis, compared to gynecological cancer survivors at 78.5%.
 - 97.7% of breast cancer survivors reported needing information on this aspect of coping “during” treatment, compared to gynecological cancer survivors at 84.6%.
 - 89.7% of breast cancer survivors reported needing information on this aspect of coping “after” treatment, compared to gynecological cancer survivors at 80.7%.
- information on non-medical services such as make-up, wigs etc. where a statistical difference was seen in both the diagnosis and the treatment stages.

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

- Survivors of breast cancers rated this issue as “does not apply” as a lower rate “during” diagnosis (22.8%) than did gynecological survivors (48.1%).
- Survivors of breast cancers rated this issue as “very” or “somewhat” important at a higher rate “during” treatment (66.7%) than did gynecological survivors (50.0%).
- information on Home Care and Supports at the diagnosis stage.
 - At diagnosis 56.0% of respondents with gynecological cancers rated this issue as “does not apply” compared to 23.9% of breast cancer survivors

Table 9.

Importance of Information Across Stages

RATING SCALE:

1 means Very important.

2 means Somewhat important.

3 means Not very important.

4 means Not at all important.

5 means Does not apply

At each of the three stages of the cancer journey how important is it to get information about	Stage of cancer journey:			
	Rating	At Diagnosis	“During” treatment	“After” treatment
Your diagnosis, treatment, and/or “after” treatment concerns?	1	97.8	89.3	84.4
	2	.7	8.9	10.1
	3	.7	-	3.7
	4	-	-	.9
	5	.7	1.8	.9
	n=	135	112	109
Information about the type of cancer	1	97.1	77.5	71.7
	2	2.2	16.7	20.2
	3	.7	2.9	4.0
	4	-	1.0	1.0
	5	-	2.0	3.0
	n=	136	102	99
Coping with your diagnosis, treatment, and/or “after” treatment concerns	1	71.8	78.8	65.4

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

and/or “after” treatment concerns	2	16.1	15.9	22.1
	3	3.2	.9	4.8
	4	1.6	-	2.9
	5	7.3	4.4	4.8
	n=	124	113	104
Emotional wellbeing (for example issues about family relations, fear, body-image)	1	77.7	79.6	72.4
	2	13.8	13.0	14.3
	3	5.4	3.7	6.7
	4	1.5	1.9	2.9
	5	1.5	1.9	3.8
	n=	130	108	105
Communication with family/children about cancer	1	82.7	68.2	64.4
	2	15.0	26.2	24.0
	3	1.5	3.7	6.7
	4	-	-	1.9
	5	.8	1.9	2.9
	n=	133	107	104
Cancer and relationship with my partner Intimacy/sexual changes	1	35.9	35.0	36.0
	2	16.2	22.0	24.0
	3	17.9	16.0	12.0
	4	7.7	6.0	7.0
	5	22.2	21.0	21.0
	n=	117	100	100
Conventional treatment options (surgery, chemotherapy, radiation)	1	95.5	80.6	66.0
	2	2.3	14.6	13.0
	3	.8	1.0	10.0

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

	4	-	-	1.0
	5	1.5	3.9	10
	n=	131	103	100
Alternative Complementary therapies	1	67.0	56.8	56.7
	2	13.0	23.2	20.0
	3	2.6	4.2	5.6
	4	4.3	5.3	5.6
	5	13.0	10.5	12.2
	n=	115	95	90
Reconstructive surgery	1	34.5	30.9	31.7
	2	6.9	8.2	10.9
	3	9.5	10.3	5.9
	4	8.6	10.3	10.9
	5	40.5	40.2	
	n=	116	97	101
The Pathology report	1	91.9	73.2	68.8
	2	4.9	14.4	9.7
	3	.8	3.1	8.6
	4	.8	3.1	2.2
	5	1.6	6.2	10.8
	n=	123	97	93
Post-treatment issues (such as <i>nutrition, stress, relaxation, counselling, intimacy, sexuality</i>)	1	53.7	60.0	66.1
	2	22.0	26.1	20.0
	3	13.0	7.0	9.6
	4	4.9	2.6	.9
	5	6.5	4.3	3.5

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

	n=	123	115	115
Resources to support “after” treatment issues	1	44.3	48.1	64.3
	2	32.2	38.0	25.0
	3	11.3	6.5	6.3
	4	4.3	2.8	1.8
	5	7.8	4.6	2.7
	n=	115	108	112
Non-medical services such as make-up, wigs	1	36.1	46.9	40.4
	2	17.6	15.9	14.0
	3	11.8	8.0	12.3
	4	5.9	4.4	7.9
	5	28.6	24.8	25.4
	n=	119	113	114
Peer support programs (i.e., Cancer Connection etc.)	1	52.8	53.8	48.2
	2	29.3	30.8	29.8
	3	8.9	10.3	14.0
	4	3.3	1.7	3.5
	5	5.7	3.4	4.4
	n=	123	117	114
Financial help/services available	1	44.4	46.7	43.3
	2	17.1	19.6	19.2
	3	7.7	6.5	6.7
	4	3.4	3.7	4.8
	5	27.4	23.4	26.0
	n=	117	107	104
Clinical trials /new research	1	51.7	50.0	46.1

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

	2	19.0	18.3	17.6
	3	6.0	7.7	10.8
	4	3.4	4.8	4.9
	5	19.8	19.2	20.6
	n=	116	104	102
Home care and supports	1	43.6	50.5	38.2
	2	17.1	15.6	20.6
	3	6.0	3.7	6.9
	4	2.6	1.8	2.9
	5	30.8	28.4	31.4
	n=	117	109	102
Effect on job/ employment	1	36.0	39.3	34.3
	2	13.2	12.1	15.2
	3	8.8	8.4	6.7
	4	2.6	1.9	3.8
	5	39.5	38.3	40.0
	n=	114	107	105
Other	1	36.4	30.0	27.3
	2	-	-	-
	3	-	-	-
	4	9.1	10.0	9.1
	5	54.5	60.0	63.6
	n=	11	10	11

HOW HELPFUL WERE THESE SOURCES OF INFORMATION?

Table 10 shows that over one third (36.7%) of question respondents rated the Canadian Cancer Society as a “very” helpful source of information. This contrasts with rating as “very” helpful the respondent’s specialist (92.6%), the PEI Cancer Treatment Centre (77.7%), family or friends (67.5%), information kit/booklets/brochures (63.0%), their family doctor (61.7%) and cancer screening programs (60.6%) as being “very” important sources of information.

Considering both “somewhat” and “very” helpful sources of information ratings, medical specialists were rated the highest (99.3%) followed by information kit/booklets/brochures (91.7%), family or friend (88.0%), family doctor (85.9%), the PEI Cancer Treatment Centre (83.5%), cancer screening programs (73.1%) and the Canadian Cancer Society at 66.1%.

Between breast cancer and gynecological respondents there were few significant differences in the value of the sources of information with these exceptions:

- Cancer screening programs (such as mammography or pap clinics),
 - 63.3% of breast cancer survivors rated this as “somewhat” or “very” helpful compared to only 38.2% of survivors of gynecological cancers
- Family doctors,
 - 72.7% of breast cancer survivors rated this as “somewhat” or “very” helpful compared to only 53.0% of survivors of gynecological cancers
- Information kits/booklets/brochures.
 - 69.3% of breast cancer survivors rated this as “somewhat” or “very” helpful compared to only 52.9% of survivors of gynecological cancers

Table 10.

Rating and Ranking of Helpful Sources of Information by Percent

		Very	Somewhat	Not very	Not at all	Does not apply
1	Medical specialist (such as an Oncologist, Surgeon, Other) n=135	92.6	6.7	-	-	.7
2	PEI Cancer Treatment Centre n=121	77.7	5.8	3.3	4.1	9.1
3	Family or friend n=117	67.5	20.5	3.4	3.4	5.1
4	Information kit/booklets/brochures n=108	63.0	28.7	.9	1.9	5.6
5	Family doctor n=120	61.7	24.2	5.8	3.3	5.0
6	Cancer screening programs (such as mammography or pap clinics) n=119	60.5	12.6	5.0	1.7	20.2
7	Canadian Cancer Society n=109	36.7	29.4	4.6	11.0	18.3
8	Prince County Hospital n=100	34.0	6.0	2.0	-	58.0
9	Internet (Please tell us which websites you found useful) n=81	28.4	16.0	3.7	6.2	45.7
10	Pharmacy n=101	23.8	22.8	5.0	6.9	41.6
11	Books / magazine/newspaper n=102	20.6	35.3	6.9	6.9	33.3
12	Patient Navigator n=87	16.1	6.9	4.6	5.7	66.7
13	Patient support group n=93	11.8	16.1	2.2	4.3	65.6
14	Other cancer charities specific to type of cancer (Please specify) n=48	10.4	8.3	-	8.3	72.9
15	Radio/TV n=86	5.8	16.3	12.8	12.8	52.3
16	Library n=84	3.6	10.7	4.8	4.8	76.2

SATISFACTION WITH CANCER JOURNEY

Satisfaction with aspects of the cancer journey were rated by respondents. Large percentages of respondents to these questions responded with “does not apply” to approximately one-half of the questions. Many of these respondents may have understood this to mean that the service indicated was either not available or that they did not access it. This is particularly evident in the questions related to need for help (Table 11).

INFORMATION

The item rating highest satisfaction of question respondents was the level of understanding of verbal information provided by the cancer care team (82.2%), followed by the help that was available from family and friends (79.4%).

MEDICAL INTERACTIONS AND DECISION MAKING

Medical care is an important aspect of the cancer journey. Over ninety percent (91.8%) of respondents report being “very” or “somewhat” satisfied with their involvement in their care. However being “somewhat” satisfied is not a strong endorsement for this important issue. A finer analysis of this question shows that only three-quarters (74.6%) of question respondents were “very” satisfied in their involvement in decisions about their care with 17.2% indicating they were only “somewhat” satisfied. Over one-fifth of question respondents were only “somewhat” or “not very satisfied” with their involvement. Interestingly 3.7% reported that this question did not apply to their situation.

Similarly, an area that deserves attention is the 60.3% of question respondents who reported being “very” satisfied with how their fears were dealt with by medical providers. Almost one-third, (30.5%) report being only “somewhat” satisfied. The remainder were “not very”, “not at all” satisfied, or report the question “does not apply” to their care in this area.

Only 43.8% report being very satisfied with being informed of their right to access referrals or second opinions; 16.5% report being somewhat satisfied and 21.5% report this does not apply to their diagnosis.

HELP NEEDS

Satisfaction with available help was an issue for many respondents. Interestingly, many of these women rated as “does not apply” questions on the need for help, perhaps responding to social and cultural conditioning. Between forty and seventy percent of question respondents rated as “does not apply” the formal help available from community groups such as the Canadian Cancer Society (39.3%), help with responsibilities at home (58.9%), help with at-home medical needs (59.3%), help with financial needs (62.9%), and help that was available from homecare and support (70.7%). The help they rated as “very” important (79.4%) was informal help from family/friends/neighbours. Only 6.6% rated this latter type of help as “does not apply.”

Forty-five percent (45.5%) of 33 respondents who said that home care and support “does not apply” also responded to an earlier question that it was somewhat or “very” important to get information on home care and supports.

Among breast and gynecological cancer survivors there was only one significant difference in their satisfaction with aspects of the cancer journey. The difference reached significance among respondents’ perception of the help that was available from community groups (i.e. Canadian Cancer Society). Among those with a recurrence or spread of cancer, 21.7% said they were “somewhat” or “very” satisfied with the help. Among those without a recurrence or spread of cancer, this figure rose to 38.8%.

Among women under and over age 70, a significant difference exists in satisfaction with the length of information materials. Only 42.9% of older women reported being “very satisfied” with the length of materials compared to women under age 70 who were “very satisfied” (57.8%). In a similar vein, women over age 70 were significantly less likely to rate information kits/booklets./brochures as “very helpful” (48.5%) compared to women under age 70 (69.6%).

Table 11.

Satisfaction with Aspects of Cancer Journey

		Very	Somewhat	Not very	Not at all	Does not apply
1	How understandable the verbal information was from your cancer care team? n=135	82.2	16.3	-	-	1.5
2	The help that was available from your family/friends/neighbours? n=136	79.4	9.6	3.7	.7	6.6
3	How readable the information was that you got? n=133	75.2	19.5	1.5	1.5	2.3
4	Being involved in decisions about your care? n=134	74.6	17.2	3.7	.7	3.7
5	The length of the information material? n=123	62.6	26.0	2.4	1.6	7.3
6	How fears dealt with by medical providers? n= 131	60.3	30.5	3.1	1.5	4.6
7	Being informed of your right to access referrals or 2 nd opinions? N= 121	43.8	16.5	12.4	5.8	21.5
8	Your access to support programs? n=129	32.6	20.9	8.5	7.8	30.2
9	How your employer responded to your needs? n=122	30.3	6.6	2.5	.8	59.8

Setting the Stage for the Future: Understanding the Information and Support Needs of Women with Cancer in PEI

10	The help that was available from community groups (i.e. Canadian Cancer Society)? n=122	26.2	18.0	7.4	9.0	39.3
11	The help that was available for your at-home medical needs? n= 123	20.3	6.5	4.1	9.8	59.3
12	The help that was available to support your responsibilities at home? n=124	16.9	11.3	2.4	10.5	58.9
13	The help available for your financial needs? n= 124	16.1	8.1	5.6	7.3	62.9
14	The help that was available from an outside agency (i.e., Homecare and Support)? n=123	12.2	6.1	1.6	11.4	70.7

COMMENTS FROM PARTICIPANT SURVEY

MEDICAL REPORTS, SECOND OPINIONS, AND REFERRALS UPON DIAGNOSIS

The majority of women surveyed provided no additional comments regarding medical reports, second opinions, or referrals upon diagnosis. Of those who did, most provided very positive and constructive feedback. For instance, women noted the importance of not only receiving the medical report, but also having the doctor explain the information so that they can thoroughly understand the report's content. Concerning a second opinion upon diagnosis, several women explained they did not feel this to be necessary. Additionally, one woman explained that her diagnosis proceeded to treatment so quickly that there was no time to seek this second voice. By and large, when a second opinion was requested or required, women reported that they were able to receive one. Having a choice of oncologist rather than being assigned to one is a recommendation by several respondents. Finally, in discussing referrals, the vast majority of women surveyed were referred to a specialist and valued the information that they provided (gynaecologist, oncologist, surgeon. etc.).

INFORMATION NEEDS

A strong voice of a long term survivor talked about the difficulty she had in finding information for survivors over age 70. Of particular interest was clinical trials for older women. "I did what I could myself online," she explained. Others spoke of the need for resources after surgery, improved information on alternative therapies, prosthetics, dealing with depression, and help with the questions to ask of information providers. Several women spoke of the need for more attention and a longer, less abrupt end to follow-up care to provide reassurance after treatments and testing were complete. One respondent requested a sign to post in order to alert visitors that the patient is resting so as not to disturb this important aspect of recovery.

PREFERRED CONVERSATION PARTNERS FOR CANCER CARE

When asked, "During your most recent diagnosis, who did you most prefer to talk to about your cancer care?" many women listed their family doctor, oncologist, surgeon, nurse, or family members. Additional responses included the nurse practitioner, friends, partners, a Canadian Cancer Society representative, and religious or spiritual representatives and/or communities. Importantly, several women noted the value of talking with other cancer survivors, or women who had undergone similar surgeries and experiences. Of special value were nurses who were also survivors. One participant explained that she luckily found a survivor to talk to in her cancer support group. On the other hand, some participants noted that they found it difficult to talk to

anyone at all, or preferred to talk to female health professionals due to the nature of the diagnosis. Finding a survivor with whom to share the cancer experience was of great benefit for many women.

VALUABLE SOURCES OF INFORMATION

Women wrote about sources of information they found were important to them in their journey, including the hospital's library, cancer survivors who visit and deliver information, the PEI Breast Cancer Support Group, the Look Good Feel Better Program, Palliative Care home calls and publications provided by the medical specialist. Various and mostly unnamed websites providing information on cancers were also noted; the Canadian Cancer Society's site was specifically named four times and the Mayo Clinic once.

MOST HELPFUL INFORMATION ENABLING AN INFORMED DECISION

Survey participants were asked, "During your most recent diagnosis, what information helped you make an informed decision on your care and treatment?" Several women said there was often only one route that could be taken. Moreover, an option that many women did desire, but did not have available to them, was to undergo treatment in Prince Edward Island rather than in Halifax, a different province, or in the United States. Women discussed the financial burden attached to this frequent travelling, and the challenge that it posed to fulfilling family responsibilities. When choices *were* available, women said that information provided by doctors, specialists (surgeons, oncologist, gynaecologists, etc.), pharmacists, and nurses contributed most to helping with their decision process. Information provided by CCS "Reach to Recovery" volunteers and other cancer survivors, and the Canadian Cancer Society information kit were also mentioned.

Women spoke of the value of the combination of information on options for treatment along with advice from medical practitioners. Marriage partners and family were frequently mentioned as aiding in decision making, as well as information from the Canadian Cancer Society, the Aboriginal Women's Association, and the Native Council of PEI.

TIMING OF INFORMATION

The majority of women noted that they did receive the necessary information in time to help them make a decision regarding their treatment options. Some expressed concern that the wait times for surgery were too long, as was the time between initial visit/testing and results/diagnosis. Others spoke of the short time between diagnosis and surgery, suggesting there was no time for receipt of additional information. One woman spoke of the efficiency of the diagnosis and testing phase, another of the family doctor misinterpreting as benign the thickening in her breast which was diagnosed as cancer two years later. Those who did not receive

information in a timely way explained the reasons were not due to lack of support or resources, but simply because test information had not been confirmed. Several women emphasized the extreme stress involved in waiting for results after tests had been completed. Indeed, one participant waited six months because her family doctor had gone on leave. Women noted the importance of receiving their diagnosis in a timely manner, as the disease grows each day.

INFORMATION NEEDS BETWEEN TESTING AND DIAGNOSIS

Respondents need to know what to expect when they are being investigated for evidence of cancer. Women want to prepare themselves with information on the implications of treatment options, the potential stages of the journey, survival rates, and wait times, depending on the test results. Participants often waited months between testing and diagnosis; women found this to be an emotional and unnecessary stress evoking period of time. Some women chose not to inform family of their possible diagnosis during this time, making it even more difficult to obtain the necessary information and support. Importantly, many participants did offer suggestions as to how one might alleviate stress and anxiety during this difficult period. Women also strongly suggested that those involved in the health care system make efforts to minimize the time frame between testing and diagnosis. Women noted that health care providers should also offer patients a time frame in which they should expect to receive their results. Other suggestions for this pre-diagnosis phase include: seeking emotional support; talking with a woman who has undergone a similar experience; taking personal time to absorb all of the information given to you; asking questions about all possible scenarios; talking to family members as well as supporters from outside of your family; relaxing, carrying on, and immersing yourself in work. By and large, suggestions were unique to the individual; it is therefore essential that the patient discover what is important for them, and what would help them, uniquely, at that time. An openness by physicians, nurses, and care providers to this individuality of need, and welcoming of a wide array of questions and concerns from the patient might help alleviate the stress of this period.

IMPROVING THE CANCER JOURNEY

One respondent credited the PEI Cancer Treatment Centre with being “phenomenal”, supportive, and caring but does not recall support directly from the Canadian Cancer Society. Women looked for a representative of the CCS to contact them following their diagnosis, others suggested having a CCS representative on hand at diagnosis would be advantageous. Another woman spoke of the information books scaring her and resulting in her being unable to cope emotionally. Others spoke of the difficulty absorbing the diagnosis and the need for diagnostic and treatment information from the doctor to be in writing to be absorbed at home. Another woman suggested having surgery and reconstruction done at the same time in Halifax would have improved her journey, as would having this option available on PEI. Improved continuity of care and follow up between Halifax and the PEI Cancer Treatment Centre would have improved

one respondent's experiences. There was a request for a booklet of stories from cancer patients explaining what to expect from the survivor's point of view. Closer proximity to family would have helped one woman. Others wished for a survivor to consult with about options as well as someone to explain treatment complications such as rashes and swellings.

INFORMATION LACKING

Much feedback concerning what information was lacking for women was in relation to health and care during and after treatment or surgery. Comments provided by women included, "I was not given information informing me of how I would feel after my surgery and treatments; I did not know what to expect", "was not thoroughly advised of just how "burned" I would get from the radiation. Thought it would be more like a bad sunburn vs. an actual burn," and "I was not told how long my recovery time would be, or how to deal with depression following my mastectomy". Indeed, a common theme in this section of the survivor survey involved women's unexpected treatment side effects, long recovery time, difficulty dealing emotionally following their treatments, and trouble getting housekeeping and medical care at home.

An experience shared by one woman consisted of unexpected, permanent, menopause resulting from one of her medications. She described this experience to be frightening and stressful, posing additional challenges to her home life. A woman over age 85 wanted "support and interest" from her physician, which she felt was lacking and an information package targeting older women was also a strong request. Clear, evident information on where survivors obtained their prosthetics and related services were frequently requested. Several women spoke of not receiving important information on programs and support services until urgent situations arose. Others required specific information about the type of cancer to pass on to other specialists.

From this, it can be concluded that women want information highlighting services available to cancer patients and survivors, information detailing not only their illness and treatment, but also details of the *effects* of such treatment and how it may influence their life in the future. Older women also want greater support from medical team members and information appropriately geared to their needs.

SUPPORT LACKING

Economic concerns were frequently voiced by respondents. One woman explained the situation clearly, "No support for medical stuff. Poorer people don't have the money for this." Women wrote of the need for a drug coverage program, financial support in order to cover costs of medication, travel, accommodations, and prostheses. Additionally, not only should this support be offered, but available support should be well advertised to cancer patients; women too often explained that they discovered a source or support only after their cancer journey, or were aware

that support existed but unaware of how to access it. Women suggest house calls in rural areas to help with completion of forms or providing information. Several women also mentioned that they would appreciate support “during” treatments (chemotherapy, radiation), perhaps from someone who had gone through similar experiences. Further supports suggested by women include mental health support, home care (assistance in changing dressings, doing house work, etc.), and support tailored for older women and those with rare diagnoses. One woman felt the need to have her oncologist speak more clearly so she could understand the information, but her request for clarity failed to achieve its aim. Overall, women generally felt very well supported by family and health care providers.

BARRIERS TO SUPPORT OR INFORMATION

Women noted both internal and external barriers to receiving support and information. For instance, some women discussed their own hesitation and uncertainty in knowing where to seek and actively ask for help when the family doctor proved unhelpful. When discussing negative aspects of her experience with cancer, for instance, one woman blamed herself for not being more aggressive, “I simply did not insist on more personal care”. Additional barriers to accessing support and information mentioned include:

- the time between booking appointments and seeing a specialist;
- a lack of supporters willing to listen;
- a lack of contact with supporters “after” treatment;
- pressure to have a fast recovery; difficulty in obtaining medical reports;
- low literacy rates;
- lengthy, frightening booklets or packages that proved “more overwhelming than helpful”.

One woman suggested that support services be contacted, on diagnosis, to provide “information, interpretation, and contact.” On a positive note, many women did express sincere thanks for the support provided by doctors and medical staff at the cancer treatment centers in both Charlottetown and Summerside.

ADVICE FOR WOMEN RECENTLY DIAGNOSED WITH CANCER

From the women’s many experiences, they were able to offer advice for others recently diagnosed with cancer. The majority of women providing this advice explained the importance of speaking with a woman who has survived the same type of cancer. Another woman cautions about listening to too many stories as each woman’s case is unique. Some suggest speaking with survivors about programs and support services they used in their journey. Others suggest reading all the material provided, seeking immediate treatment and regular screening. Still others highlighted the importance of researching information to prepare to both ask questions and to hear and understand the specialists’ responses. When questions are not answered and information

is not given, the patient must be her own advocate and request the high quality care that she deserves. One woman also suggested writing questions down as they come to mind, as each patient will encounter new questions each and every day. Furthermore, it was recommended that patients bring an advocate and second set of ears with them to appointments. Bringing a partner, family member, or friend who can take notes, is not afraid to ask questions, and who will help to remember all of the information given in each appointment was recommended.

In addition to seeking information and asking questions, women also noted the importance of “gratefully accepting help from friends and family”. It was suggested that women be open to talking with these supporters about their experiences: “Talk about it – let everyone know how you feel. It is all right to be scared, upset, and even angry. We are not perfect. Reach out and you will find people will reach back”.

Some final suggestions given by the cancer survivors involve seeking information regarding all aspects of the journey and using all resources available. Comments include, “Don’t do it alone”, “Think positively, stay active!” and “Lean heavily on family and friends, make yourself #1 in the world until you’re back on your feet.”

PREFERRED INFORMATION MEDIUMS

Approximately half of respondents use the internet but only 40% report using it for information about cancer. Some respondents relied on their family and friends to locate cancer related information electronically (Table 12).

Table 12.

Internet Usage		No	Yes
Respondent uses the Internet	n=150	49.3%	50.7%
Uses the Internet to access information about cancer	n=150	60.6	39.4%

PREFERRED HEALTH INFORMATION FORMAT

Almost three quarters of respondents to this question preferred to receive health information in printed format. The next most preferred format is orally through speaking with their medical provider (71.8%) or with an information specialist such as that provided by the Canadian Cancer Society (39.5%).

Least preferred formats, garnering less than one-third of endorsement by respondents were electronically (email, internet, radio/tv). Fourteen percent (13.9%) said they did not wish to receive information (Table 13).

Table 13 Preferred Health Information Format

Printed material	(n=149)74.2%
Through email.....	(n=142) 21.1%
Through online /Internet information searches.....	(n=142) 24.6%
Through radio or TV.....	(n=145) 28.3%
Through speaking with your medical provider.....	(n=149)71.8%
Through speaking with an information specialist (such as Canadian Cancer Society’s Cancer Information Service).....	(n=147) 39.5%
Do not wish to receive information.....	(n=143)13.9%

ADDITIONAL COMMENTS

Survey participants were happy to offer additional comments regarding their experiences with cancer. Comments expressing a common theme among participants can be found in Table 14

Table 14.

Additional comments provided by cancer survivors

“I have had cancer before and am scared that this will come again, as it is very likely. ”

“I did not have any follow up for 1 year. I believe that this is too long, as I fear that my cancer may come back. I am sure it will be an ongoing fear. One year is scary for me as a cancer survivor. ”

“With the current shortage of family doctors, there is a serious problem getting pap tests. It would be great to have more access to these clinics for women in all communities. ”

“I had to wait 16 months between mammograms. It was during this time that I found a lump in my breast. If I had a mammogram at 12 months, my cancer might have been discovered earlier and may not have gotten into my lymph nodes. There should be more opportunity for women to receive mammograms. ”

“Fatigue and loss of energy is a big factor after chemo and radiation, and it never goes away. Additionally, post check-ups do not allow me to see my oncologist to discuss this. ”

“After surgery and before leaving the hospital, each patient should be informed as to where to get prosthesis, a wig, and any other support needed. ”

“I was and still am coming to grips with being a cancer patient/survivor. ”

“The care that I received from my doctor and his team was and is excellent. ”

“The people at the cancer treatment center are the most kind, considerate and generous people. They made each step easier and were very knowledgeable. ”

“All that I can write is that I am so grateful that we as Islanders have the most wonderful Cancer Treatment Center in the world.”

“What you are doing for cancer patients is praise worthy. Thank-you. ”

“Thank-you. This has helped me express how I was feeling and still feel today. ”

“Ask what financial options are available if you run into expensive medication issues.”

“Medication is expensive and she doesn’t have medical drug coverage...Need drug coverage. So expensive.”

FOCUS GROUP

BACKGROUND

Focus Group discussions with five women recruited through the Canadian Cancer Society's support services examined issues raised through preliminary analyses of the survey. The women represented a rural/urban cross-geographic mix from Montague to Charlottetown to Summerside and ranged in age from 48 to 73. Two were married, one divorced, and two were widowed. Four rated their overall health as good, one as excellent. Two had a high school diploma, three had additional college training. At the time of treatment, just one had private health insurance and she was also the only one working part time. One was receiving only Canada Pension Plan (CPP) income, one was receiving CPP and Guaranteed Income Supplement. One woman indicated she lived on less than \$15,000 a year and that her income was not enough to meet her needs before, during, or after treatment. Two others reported incomes in the \$16-30,000 range with one woman indicating that her income was enough to meet her needs before treatment but not during nor after treatment. Another woman reported household income in the \$31-50,000 range and that her income was enough to meet her needs in the before and after treatment phases, but not during treatment. One woman reported her income in the \$51-74,000 range was more than enough to meet her needs before, during, and after treatment. Three participants used the internet to access information about cancer. All five women participated fully in the discussions, contributing diverse perspectives and experiences. The overall rapport and tone of the group was strongly conversational and engaged in the issue of improving women's cancer journeys on PEI.

FOCUS GROUP ISSUE: ASKING FOR HELP

Focus Group Participants held a long and insightful conversation about the issue of asking for assistance in their cancer journey. First, they expressed an uncertainty about asking for help. They need clear information about the who, what, when, where and how of getting help. At the time of their diagnoses, they were "broad-sided" and needed time to absorb the implications for their lives. They need to know who they can turn to later, as needs arise. Specifically, women want plain language and comprehensive information about who provides what kind of help, when you can access it, where you go to request it and how you request it. Women's cancer journeys occur in the context of already full lives that may be stretched with family caregiver obligations. Their health is one resource they can sorely afford to lose and that adds to their burden. Within the group one woman was a single parent and two older women described how they are the sole caregivers for aging parents and dependent siblings with mental and/or physical health issues. One married woman said, "I had no one to ask" in response to assistance at home during the cancer journey and described how her husband's standards for housekeeping do not come close to hers. The tangible help with keeping a home is lacking.

They indicated that cutting across the problem of asking for help are two other issues: the need for privacy, which was also echoed in the broader survey data, "I'm too private and don't reach out," and their pride, "I'm not good at asking for help." Pride held many aspects. Some confided they would be ashamed to have someone come into their home to help them because their house was in such poor condition due to their inability to clean. This creates a downward spiral. The other side of pride is the stoic belief that one keeps fears and worries to oneself. They are the caregivers, not the ones who receive care, "I think of everyone else above myself." "I hate for people to owe me a favour" or "I hated to put people out." Help is needed, but how the help is accessed is important.

FOCUS GROUP ISSUE: ECONOMIC STRESS

Economic stressors were a pressing issue women discussed at length. They were univocal in their response to the question of how to manage financially through the cancer journey, "It's tough!" They described how when ends don't meet, you do without. They raised the issue of how sick benefits through Employment Insurance ought not to be limited to 15 weeks, noting the cancer journey is a different kind of sick leave and should be recognized as requiring more long term support. They could not believe that some drugs were not covered financially and were dissatisfied that well documented complications to their treatments (ie. lymphodema) were not recognized as medical conditions. Further, many recommended or necessary medical devices/supports were not covered by insurance or the health care system. They were fearful of using credit because of the associated burden of paying off debts when interest makes it a worse problem. They were clear that red tape of support programs made the problem of finances worse because they would often wait until it was tight to ask for financial assistance and then there was a lag in their access to funds. They were critical of having to wait until treatments were completed to receive their travel assistance rebates, citing that other models must be possible. Transportation is expensive and women struggled with the additional cost.

The women described their struggles with feeling sick and their struggles with finances. They described how the two stressors came together in their cancer journey and how hard it was to manage.

FOCUS GROUP ISSUE: FEARS

Fears about the implications of cancer were concerns women did not feel appropriate to discuss with doctors. Some held their fear inside, "I got cancer, I'm going to die!" They also held the pain of how to deal with their family's fears while struggling with their own. Parenting with cancer was a challenge because children may fear both the parent's death and threats to their own health. Many worried that care obligations for ailing or dependent family members might be compromised, or worse, "Who would care for my mother or my brother if I died?" These fears were not ones that women felt they could discuss easily with family or friends and the focus group created an opportunity for women to voice their experience, "This is the first time I've

ever talked about this.” They cited a need for more groups, ”like this one where you can talk about it.”

CONCLUSIONS

A central finding of the research is that women on the surviving end of breast and gynecological cancers become poorer and less able to meet their basic needs during their cancer journey and a substantial proportion of them do not return to their pre-cancer income levels. Women’s health is jeopardized by their low incomes and this adds extra strain at a time when they are already sick and dealing with their treatments. When so many people on the cancer journey are struggling financially, the question arises whether this is a matter for government to address. This is an important public health issue.

Further, a significant proportion of survey respondents were over age 70. Their cohort reported the need for information and services to address their unique treatment journeys.

The diverse contexts of women’s cancer journeys need to be understood. Additional stress is created when women who are the primary caregiver in their family webs are in need of care. The stress comes from not feeling able or entitled to stop their caregiver role and ask for care themselves.

Women are looking for clear and accessible information about what is available to them. The cancer journey is tough and they need to easily find out what they are entitled to in terms of services and supports. A one stop comprehensive service that has a roadmap of what is available and how to get it would go a long way to improving their cancer journey.

Perhaps because of the complexity of the cancer journey and the ongoing challenges of becoming well, there was a clear message that women are looking for more peer support programs. From speaking with other survivors they were able to voice frustrations and fears to people who can listen, empathize, and are not threatened by their fears.

Appendix A Women and Cancer: A Survey of Survivors

*Women and Cancer: A Survey of Survivors**

***Cancer sites include *breast, cervical, endometrial, fallopian tube, ovarian, uterine, vaginal, and vulvar* cancer**

If you prefer to complete the survey on line please go to:

www.cancer.ca/pei/survey

If you would like someone to complete the survey with you, or you have questions about the survey, please phone Lorraine at this **toll free PEI number: 1-866-232-2833**.



Canadian Cancer Society
Société canadienne
du cancer

PRINCE EDWARD ISLAND

PART A – DIAGNOSIS AND TREATMENT

General Instructions:

- Please give your opinion about each of the statements in this survey by checking the box that most closely represents your views. Please answer all questions as fully as you can. The survey takes 25 minutes to complete.
- Your individual answers are not shared with anyone. Your answers will be combined with others' answers and then analyzed together. Please **do not write your name** on this survey.
- Your consent to participate is assumed by completing the survey. You don't have to complete the survey. You don't have to answer questions that you don't want to answer. If you chose not to complete and return the survey, it will not affect your services or treatment.
- When you finish answering the questions, place the completed questionnaire in the enclosed envelope and drop it in the mail **by April 29, 2011.**
 - **Thank-you for your help.**

1. In the table below please tell us which cancers you have had and what year(s) you were diagnosed with breast and/or gynecological cancer(s).

Cancer Site	Check all that apply	Year of Diagnosis
Breast		
Cervical		
Endometrial		
Fallopian tube		
Ovarian		
Uterine		
Vaginal		
Vulvar		
Other (Please specify) _____		

2. Have you had a recurrence? ... No ... Yes
3. Has the cancer spread to other parts of your body? ... No ... Yes
4. At your most recent diagnosis what type of treatment, if any, did you have?

(Check all that apply)

- Surgery
 (Please indicate type of surgery _____)
 _____)
- Chemotherapy
- Radiation.....
- Other treatments or therapies (please specify) _____

- No treatment.....
- Don't know
- Treatment has not yet started.....

5. At your **most recent diagnosis**, did you receive:

a. copies of your medical reports?

... No ...Yes ...Don't know

b. information about services available?

... No ...Yes ...Don't know

c. the choice to get a second opinion about your diagnosis or treatment?

... No ...Yes ...Don't know

d. a referral to an Oncologist (cancer specialist)?

... No ...Yes ...Don't know

Please use the space provided to share any additional comments.

PART B- YOUR INFORMATION NEEDS

6. Think about how important it is to get information at specific periods of your cancer journey when you are: 1) first diagnosed, 2) during your treatment, and then 3) after-treatment.

Rate from 1-5 how important it is to get information at **each** stage of your cancer journey.

RATING SCALE

- 1 Very important.**
- 2 Somewhat important.**
- 3 Not very important.**
- 4 Not at all important.**
- 5 Does not apply**

<u>At each</u> of the <u>three stages</u> of the cancer journey how important is it to get information about:	STAGE OF CANCER JOURNEY		
	At Diagnosis	During Treatment	After Treatment
INFORMATION NEED			
Rate 1 to 5 for each stage of cancer journey			
Your specific diagnosis, treatment, and/or after treatment concerns			
Information about the type of cancer			
Coping physically with the cancer (such as fatigue, pain, nausea)			
Coping emotionally with the cancer (such as fear, anger, and self/body-image)			
Talking with family/children/partner about cancer			
Intimacy/sexual changes			
Conventional treatment options (surgery, chemotherapy, or radiation)			
Other treatments or therapies			
Reconstructive surgery			
The Pathology “lab” report			

RATING SCALE

- 1 Very important.**
- 2 Somewhat important.**
- 3 Not very important.**
- 4 Not at all important.**
- 5 Does not apply**

At each of the <i>three stages</i> of the cancer journey how important is it to get information about:	STAGE OF CANCER JOURNEY		
	INFORMATION NEED	At Diagnosis	During Treatment
After-treatment issues (such as nutrition, stress, relaxation, counselling, intimacy, sexuality)			
Resources to support after-treatment issues			
Non-medical services such as make-up, wigs etc.			
Support from others who had a similar diagnosis			
Financial help/services available			
Clinical trials/new research			
Home care and supports			
Job/employment issues			
Other (Please tell us.)			

7. During your most recent diagnosis, who did you most prefer to talk to about your cancer care? (i.e., family doctor, specialist, nurse, Canadian Cancer Society, etc.)
Please specify.

8. Think about your most recent diagnosis. Where did you get the **most helpful information** about your type of cancer?

I didn't get any helpful information..... (go to question 11)

I don't recall / can't remember (go to question 11)

Rate from 1 to 5 **each** information source.

RATING SCALE

1 Very helpful.

2 Somewhat helpful.

3 Not very helpful.

4 Not at all helpful.

5 Does not apply

During your most recent diagnosis, how helpful were these sources of information?	
SOURCE OF INFORMATION	RATING 1-5
Canadian Cancer Society	
PEI Cancer Treatment Centre	
Prince County Hospital	
Cancer screening programs (such as mammography or pap clinics)	
Pharmacy	
Patient Navigator	
Family doctor	
Medical specialist (such as an Oncologist/Surgeon/Other)	
Family or friend	
Patient support group	
Other cancer charities specific to type of cancer (Please specify)	
Library	
Books / magazine/newspaper	
Information kit/booklets/brochures	
Radio/TV	
Internet (Please tell us which websites you found useful)	

9. Overall, during your most recent diagnosis what information **helped** you make an informed decision on your care and treatment?
Please specify.

10. Overall, do you feel you received that information **in time** to help make an informed decision?

.....No Yes Don't know / Not sure

If not, what was wrong with the timing? _____

Please use the space provided to share any additional comments.

PART C-SATISFACTION WITH THE CANCER JOURNEY

11. Think about your most recent cancer journey. How satisfied were you with these aspects of your journey?

Rate **each** item below to show your level of satisfaction.

RATING SCALE

1 Very satisfied.

2 Somewhat satisfied.

3 Not very satisfied.

4 Not at all satisfied.

5 Does not apply

During your most recent diagnosis, how satisfied were you with:	RATE 1-5
How readable the information was that you got?	
How understandable the verbal information was from your cancer care team?	
The length of the information material?	
Being informed of your right to access referrals or 2 nd opinions?	
Being involved in decisions about your care?	
How your fears were dealt with by medical providers?	
How your employer responded to your needs?	
Your access to support programs?	
The help that was available for your financial needs?	
The help that was available for your at-home medical needs?	
The help that was available to support your responsibilities at home?	
The help that was available from community groups (i.e. Canadian Cancer Society)?	
The help that was available from your family/friends/neighbours?	
The help that was available from an outside agency (i.e., Homecare and Support)?	

PART D-GAPS

12. What information and support did you need **between testing and diagnosis**?
Please specify.
13. During your most recent diagnosis, what would have made your treatment journey better? Please specify.
14. What **information** did you need that you didn't get? Please specify.
15. What **support** did you need that you didn't get? Please specify.
16. What **barriers** to information/supports did you run into? Please specify.
17. What advice about accessing information and support do you have for a woman recently diagnosed with cancer? Please specify.

PART E-DEMOGRAPHICS

In this final section, we ask a few questions to help us to better understand the information.

18. What year were you born? 19__ __

19. Are you?

Married/partnered Single Divorced Widowed

20. How would you rate your overall health at the present time?

(Check one)

very poor poor fair good excellent

21. What is the highest level of education you have completed? **(Check one)**

Some high school

High school diploma/G.E.D.

Community college/vocational school diploma/on the job training.

Some university or college.....

University degree

Other _____

22. At the time of your treatment:

(Check all that apply)

	No	Yes
...did you have private health insurance?		
...were you working for pay full time?		
...were you working for pay part time?		
...were you a homemaker full time?		
...were you retired or semi-retired?		
...were you on medical or disability leave?		

...were you receiving the Canada Pension Plan?		
...were you receiving the Guaranteed Income Supplement?		
...were you receiving income assistance?		
...Other (Please specify)		

23. Is or was your household income **enough** to meet your needs during these three treatment stages of the cancer journey? (**Check one for each stage of treatment**)

	Before Treatment	During Treatment	After Treatment
My income was not enough to meet my needs.			
My income was enough to meet my needs.			
My income was more than enough to meet my needs			

24. My household income currently is (**Check one**):

- Less than \$15,000;
- \$16,000 to \$30,000;
- \$31-50,000;
- \$51,000- \$74,000
- \$75, 000 or more
- I choose not to answer.

25. Do you use the Internet?.....

No Yes

26. Do you use the Internet to access information about cancer?

No Yes

27. How do you generally prefer to receive health information? Check all that apply.

- Printed material.
- Through email
- Through online /Internet information searches
- Through radio or TV
- Through speaking with your medical provider
- Through speaking with an information specialist
(such as Canadian Cancer Society's Cancer Information Service).....
- Other (Please specify _____) ..
- Do not wish to receive information

28. Please record your postal code. C ____ _

Please use the space provided to share any additional comments.

Now, please place the questionnaire in the return envelope and drop it in the mail.

Enter your name in the Canadian Cancer Society prize-draw by **April 29, 2011** and you will be eligible to win a \$50 gift card.

If you chose to enter the draw your name will become known to the Research Manager. However your name **will not** be connected with your survey.

To enter, please register with Lorraine at lbegley@upei.ca or by calling toll free **1-866-232-2833** or by filling in the online ballot at www.upei.ca/survivorscontest

Thank you very much for participating in our survey. The purpose of this survey is to understand the information and support needs and gaps in services for women living with breast and reproductive site cancers. The results will provide better information and support services for women living with these cancers.

Thanks again for your participation. If you have any questions, please contact Lorraine at lbegley@upei.ca or toll free at **1-866-232-2833**.