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Chronic Disease Prevention Division - Public Health Agency of Canada

**BREAST CANCER INFORMATION DISSEMINATION STRATEGIES**  
**—FINDING OUT WHAT WORKS**

**Sponsoring Organization:**

**Ontario Breast Cancer Information Exchange Partnership**

790 Bay Street, Suite 950

Toronto, ON M5G 1N8

Contact Person: Dr. Margaret Fitch, RN, PhD, Director

Tel: 416-480-5891

Fax: 416-480-6002

E-mail: [marg.fitch@sw.ca](mailto:marg.fitch@sw.ca)

Irene Nicoll, Coordinator

Tel: 416-351-3815

Fax: 416-351-3812

E-mail: [irene.nicoll@sw.ca](mailto:irene.nicoll@sw.ca)

**Project Partners:**

**Canadian Cancer Society – Ontario Division**

1639 Yonge Street

Toronto, ON M4T 2W6

Contact Person: Patricia Payne, Senior Manager, External Relations Cancer Control

Tel: 416-488-5400 ext 2322

Fax: 416-488-2872

E-mail: [ppayne@ontario.cancer.ca](mailto:ppayne@ontario.cancer.ca)

**Canadian Breast Cancer Foundation - Ontario Chapter**

20 Victoria Street, 6th Floor

Toronto, ON M5C 2N8

Contact Person: Beth Easton, Director of Allocations and Health Promotion

Tel: 416-815-1313 ext 400

Ontario toll-free: 1-866-373-6313

Fax: 416-815-1766

E-mail: [beaston@cbcf.org](mailto:beaston@cbcf.org)

**Willow, Breast Cancer Support and Resource Services**

785 Queen Street East

Toronto, ON M4M 1H5

Contact Person: Dallas Petroff, Executive Director

Tel: 416-778-5000

Fax: 416-778-8070

E-mail: [execdir@willow.org](mailto:execdir@willow.org)

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Thunder Bay District Health Unit

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## BREAST CANCER INFORMATION DISSEMINATION STRATEGIES—FINDING OUT WHAT WORKS

### PROJECT SUMMARY

In 2002 the OBCIEP Coalition of Stakeholders identified the issue of distribution and dissemination of existing breast cancer information as a major priority. The stakeholder representatives agreed that a number of valuable breast cancer resources have been developed and updated in recent years and that a variety of distribution methods are in use. Distribution of booklets and brochures occurs through breast cancer clinics, breast screening centres, Canadian Cancer Society offices, the Cancer Information Service and Willow Breast Cancer Support & Resources Services. Online information is posted on a number of regional, provincial, and national breast cancer and health promotion web sites. The Coalition was in agreement that the current challenge is to get these resources, in their various formats, into the hands of those who need the information. The ongoing challenge is to determine the best methods of distributing appropriate information when needed. It was agreed that the development of new resources is not as critical as defining and utilizing appropriate dissemination strategies for the wealth of information that has already been developed.

A project proposal was designed to examine the current status of dissemination of breast cancer information, to understand which strategies work best and to share those lessons. The study used three approaches to explore the issue. Interviews and focus groups were conducted with breast cancer survivors to discover what information, if any, they had received, what they did with the information, what additional information they wanted, and what barriers they believe exist for women in obtaining information. Focus groups were held across the province with women who had been diagnosed with breast cancer in the last three years for the purpose of learning about recent experiences in obtaining breast cancer information.

Focus groups with health professionals and information providers offered insight into the resources and dissemination strategies utilized by them and what, in their opinion, are the most successful dissemination strategies. The study also reviewed how health care professionals see their role as distributors of information about breast cancer to patients, what they perceive are the barriers or challenges to breast cancer survivors and how they would characterize the health care professional experience in distributing information about breast cancer.

Thirdly, strategies perceived as effective "best practices" were selected for more in-depth assessment. Those groups or individuals utilizing selected dissemination strategies were approached to participate in a detailed review of their strategy. The review provided the opportunity to study their approach, understand its effectiveness and how and why it works.

The following report presents the methods used, the lessons learned, and the accumulated recommendations from this current review of breast cancer information dissemination in Ontario.

## **BREAST CANCER INFORMATION DISSEMINATION STRATEGIES—FINDING OUT WHAT WORKS**

### **INTRODUCTION**

In 2004 it is estimated that 7,900 Ontario women were diagnosed with breast cancer and 2,000 expected to die of their disease (National Cancer Institute of Canada, 2004). When breast cancer strikes, its impact is felt in many ways: physically, emotionally, socially, psychologically, and spiritually. To make informed decisions about breast cancer women and their family members need access to the right information presented in a user-friendly fashion at the time it is needed, regardless of where the women and their families live. Individuals are demanding more customer focused and interactive avenues for information exchange and support.

In Canada many breast cancer groups have developed for the purpose of sharing information and providing support for breast cancer survivors. Networks have emerged at regional (e.g., Thunder Bay Breast Cancer Coalition), provincial (e.g., Ontario Breast Cancer Information Exchange Partnership) and national (e.g., Canadian Breast Cancer Network) levels. By working together, these groups and networks strive to avoid duplication, make the best use of scarce resources and better serve the needs of the women in their jurisdictions. Electronic communication has increased the efficiency with which people can interact and seek information although people seeking breast cancer information have stated that electronic communications should not replace all other forms of contact or information exchange. Printed and multi-media information tools are also important.

While there has been a decade of work on developing various forms and types of information resources on breast cancer and collaboration, women continue to comment that they are not receiving information. In many settings, including breast cancer meetings held across Canada during the last three years, this need is often repeated: "there is a lack of appropriate information available at the time it is needed" and that information required at different points along the breast cancer continuum is not available. It is perplexing that, at a time when more information on breast cancer is available than ever before, in many different forms (print, audio, video, and online), OBCIEP's Coalition partners identify this persistent expression of women's needs as a priority for action for the breast cancer community.

### **PURPOSE OF PROJECT**

The aim of this project was to help groups and individuals who are engaged in the dissemination of information about breast cancer learn the best strategies or practices to use so all women will have easy access to that information. The project objectives were to:

1. Gain an understanding of what women mean when they say "no information was available for me" (what is [still] not working)
2. Understand the perspectives of those engaged in the dissemination of breast cancer information about current approaches to providing information (what is being done?)
3. Identify best practice approaches in the dissemination of breast cancer information (what is really working well?)
4. Study or evaluate the best practice approach for disseminating breast cancer information (document the best practices)
5. Profile the successes with partners so all can benefit from the information (document how the best practices worked).

## SPONSORING ORGANIZATIONS

The Ontario Breast Cancer Information Exchange Partnership sponsored this project along with co-sponsors are the Canadian Breast Cancer Foundation - Ontario Chapter, the Canadian Cancer Society - Ontario Division, and Willow Breast Cancer Support & Resource Services. Nine other organizations partnered with OBCIEP on this project and are described below.

### **ONTARIO BREAST CANCER INFORMATION EXCHANGE PARTNERSHIP**

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of organizations who have a stake in the dissemination of information about breast cancer. The coalition emerged from the Ontario Breast Cancer Information Exchange Project, originally established in 1993.

During the initial years of the information exchange project in Ontario, the OBCIEP responded to the specific needs of Ontarians by facilitating access to state-of-the-art, user-friendly information about breast cancer and serving as a catalyst for co-operative activity regarding the exchange of information about breast cancer. Representatives of 30 stakeholder organizations from across the province with input from their own networks guided the initiative in the areas where Ontario's breast cancer community lacked a concerted, organized effort. These areas included dialoguing with organizations involved in providing breast cancer information, sharing information about existing resources, responding to the needs of women and health care providers, and identifying and filling information gaps. As gaps were identified, various member organizations are encouraged to take leadership in filling those gaps.

The primary role of the OBCIEP is to assist organizations, involved in the dissemination of information, to respond to the information needs of their clients. We accomplish this by sharing information about breast cancer resources through our newsletter, web site and various communication tools used by our member organizations. In collaboration with others, we also develop information resources for women, their families, and health care professionals to fill identified gaps. In addition, our activities involve the evaluation of existing dissemination strategies to ensure that people can easily access quality, state-of-the-art information when they need it.

OBCIEP is committed to ensuring information about breast cancer is available to all people in Ontario. The strategic directions for the OBCIEP are set by a Coalition of Stakeholder organizations consisting of 36 cancer and breast cancer groups from across Ontario. Of all the organizations involved, over half are grassroots and breast cancer survivor-directed groups. By providing a neutral forum for networking and information exchange at the provincial level, the OBCIEP fosters co-operative problem solving and co-ordinated action concerning issues related to breast cancer information dissemination. Whatever the activity, the fundamental philosophy of the OBCIEP remains in the forefront—that the development and dissemination of information about breast cancer be guided by those directly affected by the disease.

OBCIEP has and its network has an established record of assisting and enhancing the provincial network for breast cancer information and support. Regional and provincial needs assessments have been completed as part of three previous studies. *The Think Tank on Breast Cancer Information and Support, April 1999* identified a need to present information for decision making and to find new and varied strategies to disseminate information to breast cancer patients and their families. *Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario, 2001* identified information and support access as continuing issues for breast cancer survivors as well as a lack of knowledge about the information and support services that already exist. *The Virtual Community Feasibility Project, 2000* and study *Implementing a Virtual Community for Breast Cancer Information and Support in Ontario, 2003* investigated ways of connecting women to various forms of information and support using new technologies. Surveys and focus groups conducted as part of the virtual community studies and creation of two northern Ontario regional web sites on breast cancer

information revealed ongoing issues with the current state of information resources and access to existing services. Both breast cancer survivors and health professionals participated in these studies that were shared with the OBCIEP's provincial network of agencies and peer support groups concerned about breast cancer.

#### **CANADIAN BREAST CANCER FOUNDATION - ONTARIO CHAPTER**

As a leading national volunteer-based organization dedicated to the fight against breast cancer, the Canadian Breast Cancer Foundation works collaboratively to fund, support and advocate for relevant and innovative breast cancer research, meaningful education and health promotion initiatives, early diagnosis and effective treatment, and a positive quality of life for those living with breast cancer.

The Ontario Chapter is the largest and oldest of four CBCF Chapters across the country. Through fundraising and grant-making, CBCF Ontario Chapter facilitates informed and effective service delivery, promotes community development, fosters partnership and coalition-building, and stimulates health promotion and health care strategies to meet the breast care needs of women in Ontario to reduce the impact of the disease on families and communities. Information is provided on the CBCF Ontario Chapter web site at [www.cbcf.org/Ontario](http://www.cbcf.org/Ontario).

#### **CANADIAN CANCER SOCIETY - ONTARIO DIVISION**

The Canadian Cancer Society is a national community based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. In partnership with the National Cancer Institute of Canada, it achieves its mission through research, education, patient services and advocacy for health public policy. These efforts are supported by the network of volunteers and staff and the fund-raising efforts in communities across Canada.

The Canadian Cancer Society is a leader in the fight against breast cancer. It is a founding and funding partner of the Canadian Breast Cancer Research Initiative, now the Canadian Breast Cancer Research Partnership (CBCRP). The CBCRP, formed in 1993, is now the primary funder of breast cancer research in Canada.

The Canadian Cancer Society is a leader in providing current, reliable information about all aspects of breast health and breast cancer. Information about breast cancer is easily obtained by calling the Canadian Cancer Society's Cancer Information Specialists or by contacting local Canadian Cancer Society offices and on the web site at [www.cancer.ca](http://www.cancer.ca). As well, Canadian Cancer Society and its Cancer Information Specialists direct women to services in their local communities that will help them cope with their breast cancer. The Canadian Cancer Society also provides emotional support to women with breast cancer through programs such Reach to Recovery and Cancer Connection. This latter program matches breast cancer survivors with newly diagnosed women to offer support via telephone.

The Society is a partner organization in the Canadian Breast Cancer Initiative and, as such, participates with other breast cancer organizations to ensure that the needs of women with breast cancer are met in the best ways possible. The Canadian Cancer Society also strives to improve the quality of life of those affected by cancer, reduce tobacco use and increase support for research. This is achieved through vigorous revenue development, sustained volunteer development and effective planning, evaluation and resource management.

The Ontario Division of the Canadian Cancer Society has played a key role in the evolution of the OBCIEP, participating in the Advisory Panel of Stakeholders and the development of many of the information tools over the past several years. The Ontario Division has made its commitment to the work of the OBCIEP very clear by funding the full-time salary for the position of the OBCIEP Coordinator since 2000.

## **WILLOW BREAST CANCER SUPPORT & RESOURCE SERVICES**

Willow Breast Cancer Support & Resource Services (Willow) is a survivor-directed, charitable organization that provides information and emotional support to individuals diagnosed with breast cancer, their families, and caregivers, as well as to health care professionals dealing with the psychosocial needs of their patients. Founded in 1994 by a group of survivors, Willow, Breast Cancer Support and Resource Services is committed to ensuring the accessibility to information and support to all communities including geographic, ethno-cultural, linguistic and disabled, through a Canada-wide toll free line, a comprehensive resource service, an interactive web site, and training workshops.

### **PARTNER ROLES**

The project co-sponsors were involved in all stages of the project design, planning and implementation. Nine OBCIEP Coalition partners, regional partners and local support group contacts provided assistance with the promotion of the study to their members and assisted with the recruitment of interview and focus group participants. Most of these organizations either provided or arranged space for the meetings and the refreshments participated in promoting and hosting the breast cancer survivor focus groups. Each group is briefly described below.

*Breast Cancer Action Kingston* is a survivor led, independent, charitable organization, working to educate and support women and men living with Breast Cancer, their families and the community. Services include public education on breast health, a lending library, a breast cancer support group and exercise classes. They host a web site at [www.brcanactionkingston.com](http://www.brcanactionkingston.com).

*Breast Cancer Action Ottawa*, founded in 1992, is a survivor-directed, voluntary organization with a mandate to inform, educate and support women and men living with breast cancer, their families and the community. Breast Cancer Action also provides public education on breast health, special workshops for breast cancer survivors, a lending library, a breast cancer support group and exercise classes. Their web site is [www.bcaott.ca](http://www.bcaott.ca).

*Breast Cancer Support Services* in Burlington is a self-help organization created by women for anyone who has concerns about breast cancer or general breast health. BCSS is the only support centre in the Hamilton and Halton area that deals specifically with breast cancer. They offer a variety of education, support and outreach activities including a support group. They host a web site at [www.breastcancersupport.org](http://www.breastcancersupport.org).

*The Breast Cancer Research and Education Fund* in St. Catharines was founded in 1990 and carries out community-based research that draws links between the physical environment and human health and group explores information and research in the alternative/complementary treatment area. They offer breast cancer support group activities and more recently have focussed on public education. Their web site is found at [www.breastcancerref.org](http://www.breastcancerref.org).

*Sarnia Living with Breast Cancer Group* meets in the Lambton County Unit of the Canadian Cancer Society and offers information and support to women with breast cancer in the Sarnia area, a population about 70,000 near the Canadian-USA border about 115 kilometers northeast of Windsor, 300 kilometers west of Toronto. Activities include a peer support group that discusses all aspects of breast cancer and guest speakers are invited periodically who will provide information relevant to the discussion.

*The ABC (After Breast Cancer) Group* is a Living with Cancer Support Group operating in a community of about 30,000 in and around Woodstock, about 140 kilometres west of Toronto. The Oxford group holds four meetings each month except in June and July. The regional *Reach to Recovery* program, where trained volunteers offer support to women immediately after a breast cancer diagnosis, before

surgery, in the hospital (this is usually when the free resource kit is distributed) or any time during treatment, is coordinated by the Oxford County Unit of the Canadian Cancer Society.

*The Hospice of Windsor and Essex County Inc.* is the oldest and largest community-based hospice in Canada. Established in 1979 and located in the City of Windsor its mandate is to support, educate, and empower those who are affected by or are caring for a person with a life-threatening illness. The Hospice resources include Wellness Centre programs in healing and wellness, patient and family education and support groups, including a monthly breast cancer support group. There is a full lending library and resources available online at [www.hospicewindsorsex.com](http://www.hospicewindsorsex.com).

*The Dryden Breast Cancer Support Group* is a group of women formed in the early 1980's to offer support to those whose lives have been affected by breast cancer. Dryden is a logging and mining community of 9,000 people located about 320 kilometers northwest of Thunder Bay.

*The Thunder Bay Breast Health Coalition* was founded in January 1993 and its goal is to increase breast health awareness among all women and share information about breast abnormalities to health care providers. The Thunder Bay Breast Cancer Support Group, the Thunder Bay District Health Unit, the Regional Cancer Care, Thunder Bay Regional Health Sciences Centre, the Canadian Cancer Society - Ontario Division, Northwestern Region, and the Ontario Breast Screening Program, Northwestern Unit participate. Their northwestern Ontario regional web site link is [www.breasthealthnw.ca](http://www.breasthealthnw.ca).

## PROJECT ORIGINS

### OBCIEP STAKEHOLDERS' VIEWS

In September 2002 the OBCIEP Coalition of Stakeholders gathered in Toronto for an annual review of activities. Coalition members discussed the ongoing issue that breast cancer survivors continue to report that "no information was available" to them. Questions were explored about addressing information gaps that currently exist. The Coalition members believed strongly that the development of new resources was not as critical as determining appropriate dissemination strategies for the valuable information tools that have already been developed. The question was the focal point of an afternoon workshop during the meeting. Coalition members shared perspectives on why women may feel information is not available to them. Their observations were based on the representatives' experiences in survivor groups, cancer organizations, and provincial and national breast cancer groups. A summary of their discussion follows.

It was acknowledged that people often do not seek information on breast cancer information until they need to and at a time when they are experiencing emotional distress following the diagnosis. While everyone reacts differently to a cancer diagnosis it was noted that many people feel a sudden need for information. There is a need for timely, clear, accurate and available information in different formats in areas where patients need to access it. Although women obtain information, they can be overwhelmed by the amount they have to understand.

In addition, there are a number of issues Coalition members reported about the specific nature of the information itself:

- Conflicting information and messages, e.g. efficacy of BSE and mammography;
- Lack of understanding of resources and services—who do you call for what?;
- Gaps in—understanding medical information, challenge of not finding the right information and resources/people to address emotional reactions to the information; and,
- Need for creative, effective campaigns to consolidate messages on awareness, prevention, healthy lifestyles to reduce risk, and cancer.

Coalition members also observed issues regarding access to information. There is confusion about "who does what" and where to obtain specific information. A variety of organizations appear to offer similar information and services. A "virtual library" of services (like the inventory being developed by the Canadian Breast Cancer Network) which will include culturally sensitive information on breast cancer may provide needed clarity. The simplicity of a "one-stop shopping" approach was recommended, i.e. one phone number to call to receive information on breast cancer or support.

Since the advent of the worldwide web, a wealth of information is easily available but people need help to identify appropriate, credible and accurate information. A "buddy" or navigator to assist the person with disease and their family can be invaluable in this role. Different groups experience different problems with access to information. While older women (55 years and older) are now using the Internet more frequently, they have different issues with access than younger women who are more familiar with using computers (hardware), browsing methods, and search engines (software).

Non-English speaking women and those with particular ethnic or culture needs such as Aboriginal women have fewer resources tailored to their needs. In the Willow Breast Cancer Support & Resource Services national study *Hopes and Needs, A Profile of the Needs of Francophone Women with Breast Cancer and the Resources Available to Them* (March, 2000) nearly half of the francophone breast cancer organizations reported gaps in the French language information available. The respondents in the study expressed a need for more written and audio-visual support tools in French to help women make informed decisions about treatment.

#### **WHAT BREAST CANCER SURVIVORS HAVE SAID**

Breast cancer survivors in Ontario are asked routinely about information and support needs. In 1999 the OBCIEP hosted a workshop where 120 representatives from over 60 community-based and provincial breast cancer and health care organizations explored ways to enhance accessibility of breast cancer information and support in the province. The report on the Think Tank (*Think Tank on Breast Cancer Information and Support*, April 1999) highlighted the key priorities identified under Education and Care Delivery as:

- Customize the way information is presented during the care planning process to provide women with the time they need to make decisions;
- Find approaches for making informed choices more widely available;
- Find new ways of disseminating information to patients and their families using a variety of strategies;
- Provide simple information at point of diagnosis so people are not overwhelmed, especially at the beginning;
- Ensure every cancer centre provides patient information (including support group information, readings, etc.); and,
- Develop specific resources material to give to patients when they are discharged from hospital and link the information sources to general hospitals where cancer-related surgery may be done.

In 2000 and 2001, at 10 community conversation gatherings held throughout the province, participants reported on areas of need in response to the question "to what extent are information and support needs for women with breast cancer being met in your community?" The results are summarized in Table 1.

These data provide encouragement in that a response rate of over 80% was observed by combining the "somewhat" and "very much" categories. However, given the resources expended to create and distribute breast cancer information, the response rate of 29% in the "very much" category was considered disappointing. This raises questions about the effectiveness of the dissemination strategies used.

**Table 1. To What Extent are Information and Support Needs Being Met?**

	<b>Information Needs</b> <i>N = 305</i>	<b>Support Needs</b> <i>N = 289</i>
Very Much	29%	28%
Somewhat	51%	56%
Not very much	18%	14%
Not at all	2%	2%

Respondents: 337: 136 survivors, 169 friend or relative of survivors, 62 volunteers in cancer agency, 116 employed in health care field (respondents could check more than one area)

More recently the Canadian Breast Cancer Network's study regarding the perspectives of young and rural women with breast cancer indicated that "too often information about resources and/or services was non-existent, outdated, or unhelpful" (*Perspectives of Rural Women with Breast Cancer*, 2001). By contrast, in the CBCN study of young women, one respondent spoke about "being bombarded with pamphlets and booklets" but that none of the information was pertinent to her situation. The report states that "generally breast cancer survivors want more and improved access to information to aid them to cope with breast cancer" (*"Nothing Fit Me": The Information and Support Needs of Young Women with Breast Cancer*", 2002). In both studies women recommended that standardized information packages on breast cancer be available to women at the time of diagnosis with additional information staggered over the course of treatment and treatment follow-up.

Despite the efforts to produce and distribute information resources that address most of the issues facing most women with breast cancer, there remains a strong impression that breast cancer survivors perceive the information about breast cancer is incomplete or is not reaching, at the right time, those who need it most. *Breast Cancer Information Dissemination Strategies – Finding Out What Works*, was designed to increase understanding of this perspective and to identify where learning from best practices regarding dissemination could be beneficial to the breast cancer community.

## PROJECT DESCRIPTION

### PARTICIPANTS

The OBCIEP Operations Group acted as the Project Management Group to review the work plan, examine preliminary results, and participate in the data analysis. The group includes:

Margaret Fitch	Director, OBCIEP
Beth Easton	Canadian Breast Cancer Foundation - Ontario Chapter
Stasey Tobin	Canadian Breast Cancer Foundation - Ontario Chapter
Raylene Godel	Breast Cancer Survivor
Irene Nicoll	Coordinator, OBCIEP
Eleanor Nielsen	Breast Cancer Survivor
Patricia Payne	Canadian Cancer Society - Ontario Division
Dallas Petroff	Willow Breast Cancer Support and Resource Services

The group reviewed and approved the work plan attached as Appendix I along with the project Logic Model in Appendix II. Students Kamiel Kruze, Charlotte Fung, Aileen Choi, and Julia Ivonoffski provided transcription services and assistance with the analysis the focus group discussions.

Other individuals who assisted with promotion and arrangements for the interviews and focus group

included:

Janet Dikland	Breast Cancer Action Kingston
Anita Bloom	Breast Cancer Action Ottawa
Dianne Hartling	Breast Cancer Action Ottawa
Cathy De Grasse	The Ottawa Regional Women's Breast Health Centre
Mary Kovacs	Breast Cancer Research and Education Fund, St. Catharines
Karin Perry	Breast Cancer Research and Education Fund, St. Catharines
Barb Diaze	Breast Cancer Support Services, Burlington
Adrienne Winslow	Breast Cancer Support Services, Burlington
Joanne Western	Sarnia Living with Breast Cancer
Helen Cole	Lambton Unit, Canadian Cancer Society, Sarnia
Diane Butler	After Breast Cancer (ABC) Support Group, Oxford County
Kristi Cross	Oxford Unit, Canadian Cancer Society, Woodstock
Sandra Kroh	Hospice of Windsor & Essex County, Windsor
Andrea Van Patter	Dryden Breast Cancer Support Group
Rhonda Usenik	Thunder Bay District Health Unit
Sandra Theriault	Thunder Bay District Health Unit
Kathy Thompson	Thunder Bay Breast Health Coalition

All 36 OBCIEP Coalition members received the project proposal and were informed that interviews and focus groups were being held. As focus groups were arranged contacts from the OBCIEP network of support groups were alerted that a meeting was being planned in their area and a notice of invitation was e-mailed for circulation to members. Preliminary results from the interviews and focus groups were shared with all project partners and feedback was requested. The information was circulated to all project partners and the project participants (breast cancer survivor and information provider interviewees or focus group participants).

## METHODOLOGY

### Interviews

The Project Advisory Committee recommended that interviews be conducted as a first step in the project.

Interviews with women who had been diagnosed with breast cancer would begin to enhance our understanding of what women mean when they said "no information was available for me." The interviews would provide a view to the appropriate language and issues for breast cancer survivors and the findings could then set the stage for the focus groups to follow.

An open invitation, via e-mail, to breast cancer survivors was sent to all OBCIEP network partners who then forwarded the invitation through various means (e-mail, web site, mail, etc.) to survivors in their respective regions. Interested individuals responded by telephone or e-mail directly to I. Nicoll, Coordinator at OBCIEP and interview times were scheduled. With permission, interviews were taped. Four questions were posed about the nature and effectiveness of breast cancer information received at various points on the cancer continuum—at diagnosis, during treatment and when treatment ended. The complete project introduction and questions asked at this stage are provided in Appendix III. The detailed summary of results is included in Appendix IV.

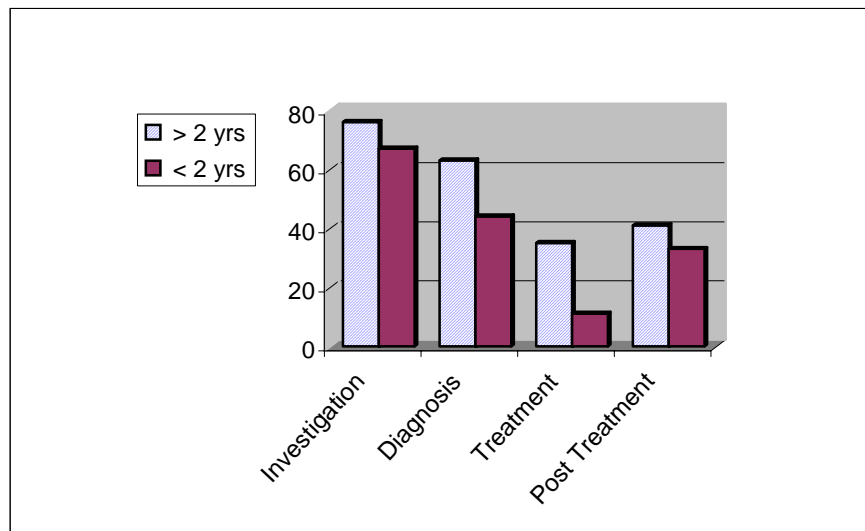
The interviews yielded information about:

- If and how women receive breast cancer information;
- What information they did obtain and if it was what they wanted;
- Their understanding of the information they received;
- What barriers and challenges they faced in obtaining the information;

- If the information was relevant to them and if it was used;
- If the information affected their behaviour or stimulated them to take a course of action;
- What information was helpful and what dissemination methods worked well;
- Where and how women would like to have received the information; and,
- How women might have been made aware of breast cancer information and support services before a diagnosis prompted the need to know.

I. Nicoll conducted 28 interviews from November 2003 to January 2004. The youngest participant was 32 the oldest 76. Time since diagnosis ranged from less than three months to 17 years. The responses were tabulated separately for those diagnosed within the last two years or less and those diagnosed more than two years ago to see if there was a difference in responses. Generally those more recently diagnosed reported that they had received information more frequently at each stage than those diagnosed two years or more, but the difference was not significant. (see Figure 1.)

**Figure 1. Percentage of Women Reporting that "No Information" Received by Stage**



There appears to be little information provided when screening abnormalities are detected and even at diagnosis over 40% of the respondents reported receiving no information about breast cancer. The treatment stage appears to show the most improvement in that about 90% of those diagnosed within the last two years reported receiving information about treatment options, procedures and side effects compared with about 65% for those diagnosed two years ago or more.

### Emerging Themes from the Interviews

The tapes from the interviews were reviewed to determine if there were common concerns that arose during the conversations. Three themes were clearly evident: the shock of diagnosis; the onus being on the patient to search for information; and the different types of information that breast cancer survivors sought.

Many women spoke about experiencing **shock and disbelief** on hearing the news of their diagnosis. This shock and, in some cases panic, then had a profound effect on how and if they sought information about their disease. Many admitted that they had received information at some point during their treatment but did not review it. "I was given comprehensive folder of information at the surgeon's office prior to surgery. But I didn't look at it," said one participant. Women talked about the fear cancer generated and how it impeded their ability to think calmly and approach their treatment decisions and information search. "I think a lot of people wouldn't even ask their doctors for information because I think your first

reaction is panic and denial", said one woman. "Your mind just goes to jelly," said another.

The second theme identified was that **the onus was on the women themselves as cancer patients to search for information and find their own answers**. "At one point in my life I had high blood pressure," one woman said, "my doctor was so fast to slap me with information on high blood pressure. But having cancer . . . nothing." "Breast cancer" is used to describe a general illness but remains a complex disease that varies in characteristics and form in different women. Individual information needs do not seem to be well served by the public resources currently available. Women talked about the difficulty they experienced in finding specific information about their particular disease or in receiving information that they did not understand. "To find for example if your estrogen receptors are negative or positive," said one woman, "you're told what they are but you don't know what it means." Many others spoke about their entire experience in the cancer care system with varying degrees of appreciation, anger and surprise about inefficient and fragmented services. "You don't go into the medical system assuming you have to become your own advocate," said one woman. "The system is a challenge to navigate," said another.

The third theme focussed on **the different types of information women want** and the wide variations they prefer in format, content and methods for distributing the information. Specific topics were identified—breast reconstruction and lymphedema for example—on which women believed more information should be available. They also talked about different formats and what they believe to be the most effective ways of distributing information. Women talked about information tools in audio or video format that they found useful and the value of talking to others who had been through the experience. "I just wanted to know what I had to do to get better," said one woman, "I prefer to talk to somebody about things."

*I thought the diagnosis was a death sentence so to be able to have a woman come visit me who had had breast cancer two years before . . . two years seemed like an enormous amount of time, just enormous. And that was ten years ago. That had the greatest impact on me.*

Women also recommended that information tools be in plain language, not medical terms, and that more efforts be made to provide information tools in languages other than English, in graphic and pictorial formats, and formats sensitive to ethnic and racial groups. They identified useful resources that did not specifically relate to breast cancer information. "What was probably most helpful at the time had nothing to do with breast cancer information but more relaxation tapes and music, that type of thing," said one woman.

### **Focus Groups**

Focus groups were organized to learn multiple viewpoints from breast cancer survivors and from health care professionals and other information providers who work with women dealing with breast cancer. The emerging themes from the interviews provided a stimulus for the conversations held throughout the province. The focus groups enhanced our understanding about women's experiences in receiving information and about information providers' experiences in responding to the information and support needs of those dealing with breast cancer. Summaries of these discussions follow.

### **FOCUS GROUPS WITH BREAST CANCER SURVIVORS**

OBCIEP contacted network partners across the province to arrange focus groups with breast cancer survivors. The discussions were designed for those who had received a breast cancer diagnosis within the last three years. Some groups such as Breast Cancer Action Kingston and Breast Cancer Action Ottawa were long supporters of OBCIEP and its project initiatives. Contacts in southwestern Ontario were renewed with some long-term partners who had not participated directly in OBCIEP projects. Partners were contacted by telephone contact by OBCIEP, and dates for the focus groups determined by the partner groups. Focus groups were scheduled in Kingston, Ottawa, St. Catharines, Burlington, Sudbury (with Francophone women) Sarnia, Woodstock, Windsor, Dryden, Thunder Bay and Toronto. Subsequently the Sudbury session had to be cancelled due to lack of participants. Interview data from another study of Francophone women by Dr. Stephanie Austin was reviewed for this report. Breast cancer coalitions and support groups hosted many of the sessions and others were held in local meeting facilities. A sample promotional notice for the focus groups appears in Appendix V. The full focus group schedule appears in Appendix VI.

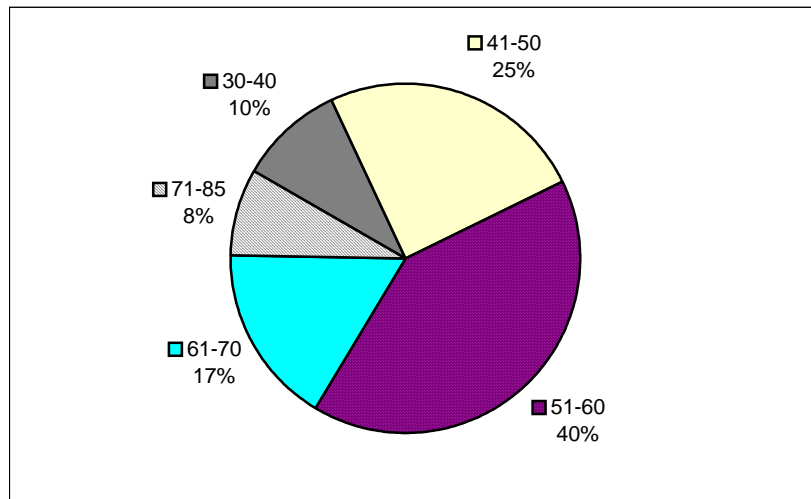
The three themes expressed in the preliminary interviews—the shock of diagnosis, the onus on the patient to search for information, and the different types of information women want—were used as a springboard for focus group discussions held with breast cancer survivors and information providers across the province. The themes were presented with quotes from the interviews in the information packages prepared for the focus groups (shown in Appendix VII). Participants were asked to describe if the themes reflected their experiences and subsequently were asked what advice they would give about dissemination strategies. The same information package was used at both the breast cancer survivors' and information providers' sessions.

### **PROFILE OF BREAST CANCER SURVIVORS**

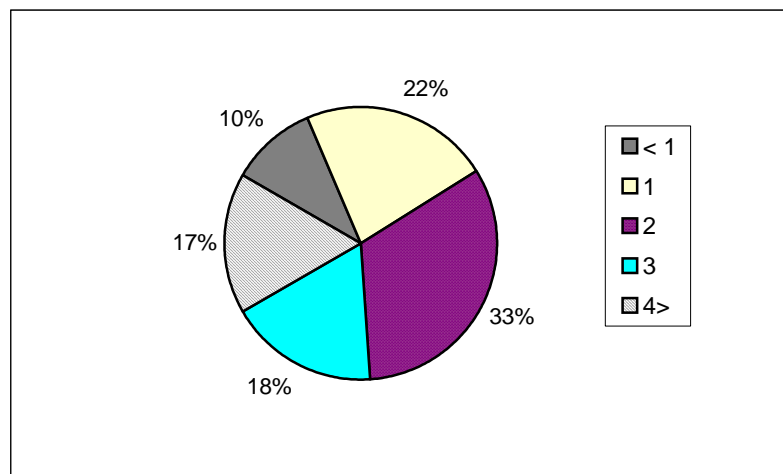
Breast cancer survivors in the focus groups were asked to complete a demographic sheet (without identification information) about current age, age at diagnosis, educational status, language, and their participation in breast cancer support groups. (See Figures 2-4.) A summary of this detail from the participants is in Appendix VII. One hundred and twenty-seven (127) participated in the eight focus groups; two participants did not complete a demographic form. In three cases (Sarnia, Woodstock and Windsor) the groups were sufficiently large to be separated into two to three smaller groups and facilitated by I. Nicoll and S. Keller-Olaman, a researcher with the Ontario Breast Cancer Community Research Initiative (OBC CRI). Dr. M. Fitch acted as facilitator in all but one location.

Participants' ages ranged from 33 to 84, ages at diagnosis from 28 to 81. The average age of the participants was 55 and the average age at diagnosis was 52. Over 83% or 104 of the 125 who completed the demographic forms had received their diagnosis within the last three years. Sixty percent self-identified as members of breast cancer support groups. Of those about one third reported joining at diagnosis, another third during treatment, and the remainder when treatment ended. The reported education level was high—46 or 37% of the participants had high school level education and 52 or 50% had some college or university, 16 women or 13% had graduate level degrees. Over 90% indicated English as their first language.

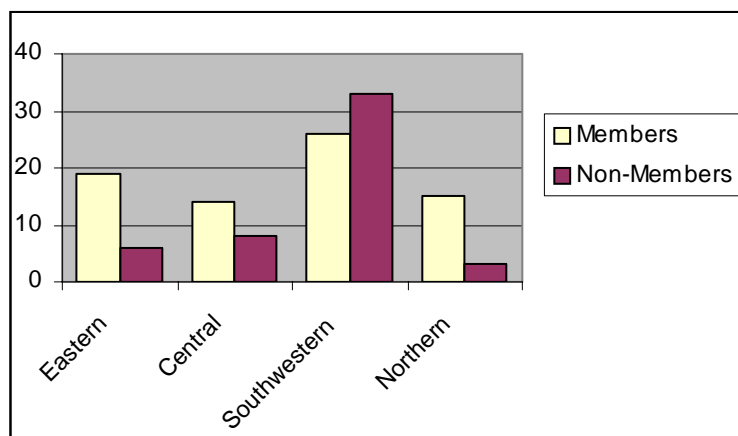
**Figure 2** Age in Years of Breast Cancer Survivor Focus Group Participants, *N=125*



**Figure 3** Years Since Breast Cancer Diagnosis for Breast Cancer Survivor Focus Group Participants, *N=125*



**Figure 4** Support Group Members and Non-Members by Region, *N=125*



## WHAT WE LEARNED

The women who attended the focus groups for breast cancer survivors generally agreed that the three themes, the shock of diagnosis, the onus on the breast cancer patient to become her own advocate, and the different types of information women want, were reflective of their experiences. A great deal of discussion took place about the shock of diagnosis and many participants were able to relate in detail the circumstances of the investigative and diagnostic procedures that led to the cancer diagnosis. In sharing their stories another prominent theme emerged pertaining to the health care system, specifically good and bad experiences with medical professionals and the cancer care system. These experiences became a significant part of the focus group discussions and were raised by participants at every group. Some stories reflected the caring and professionalism displayed by most practitioners but a few exposed some areas that require attention. Women offered advice to newly diagnosed women and to health professionals about the delivery of breast cancer information. The three main themes that spurred the discussion as well as experiences with the medical system are explored below.

### THEME 1 - THE SHOCK OF DIAGNOSIS

*What now? What do I do now? Where do I go for help?*

Breast cancer survivors talked at length about the emotional devastation they experienced when they were diagnosed with cancer and how those feelings affected their information search. They also talked about managing medical information, timing of and access to appropriate information resources, and the effects of carrying the burden alone. They commented that not everyone wants the same information and that individual preferences should be respected.

#### The Emotional Impact

*I never thought the sun would ever shine and I would smile again. For 10 days. It was horrible. It was terrible.*

While great strides have been accomplished in early detection and treatment of cancer in recent years, it was clear from our discussions with women in the focus groups that cancer still terrifies people. Even before their diagnosis had been confirmed participants spoke about grappling with a potentially "life-ending disease". They talked about accepting that they would not see their children grow up and missing their partners. Said one woman, "I was already planning my funeral." Some of the words used to describe reactions to the diagnosis included "shocked", "terrified", "like being on a roller coaster", "numb", "scattered", "lost", "a nightmare", "in the twilight zone", "absolutely stunned", "lost control", "sad", "a bizarre feeling", "in a haze", "a surreal feeling", "I was a mess", "it was overwhelming", and "being in a fog". Such responses were reported at every focus group. Disbelief and denial were other common reactions as many who were diagnosed had no symptoms and felt "otherwise very healthy". Some examples of their comments include, "this is crazy, this can't be happening"; "I'm 80, I'm not going to have breast cancer"; "I'm too young"; and "I took care of people who had cancer but I never thought it would happen to me" (from a health care worker who worked in a cancer treatment facility). Some reported guilt feelings about what they had done to "cause" their cancers and the impact their diagnosis may have on their families, particularly on the health of their daughters and granddaughters. "I felt like I was being punished for something", said one participant.

The fear and panic triggered by the breast cancer diagnosis has a profound impact on how women respond to information about their disease, if at all. A frequently heard comment was from women who admitted receiving information about breast cancer (usually in the form of booklets or pamphlets, sometimes information packages prepared by local breast cancer support groups) who did not read the information. "I was given that information, the photos, the book . . . and I couldn't bear to look at it",

admitted one participant. During this period they described the difficulty of knowing what information they needed, not knowing the right questions to ask, and not being able to make a decision. The "fog" lasted different periods of time for different women.

### **Access to Information**

Participants reported a wide range of experiences in receiving information at the time of diagnosis (great differences even within same geographical region). Many reported receiving nothing, some verbal information from the doctors or surgeons and others received written information in the form of brochures, pamphlets, and recommended web sites. Many however said they left their doctors' offices empty-handed. "There wasn't any talk of giving out brochures or anything" said one woman. "They didn't hand (out) any information", said another and added, "It would have been good to get written information because not listening—that was me! He talked. I didn't hear anything." "It would have been good to get the written (information)", agreed another participant, "because you're not listening—when the surgeon says 'you have cancer', that's the end of the discussion." Women talked about not being in the right frame of mind to inquire about treatment options. "You can't focus on anything, you can't ask questions", said one woman. "Hearing (the news) from people you don't expect to hear it from, all those things push you to a point of not being able to ask questions, not knowing what questions to ask", reported another. Others noted the difficulty of simply getting some information initially during the investigative stage. "It's not as convenient as it might be, especially if your first step is with your GP. I actually ended up taking pamphlets to my GP's office. They had none and that's not good."

### **Understanding the Information**

The nature and volume of information in itself it can be overwhelming and potentially increase stress. This is due in part to managing the volume of information some women found and also being able to understand what they were reading. "Another thing about the information you get is you panic", said one participant. "You read that 10,000 women people are going to get it in one year and 4,000 people are going to be dead in that year . . . you think it's the same people." "Reading the biopsy report was probably the scariest thing for me" said another. Women commented that they often felt disconnected from the information on the page. "After the surgery, after I'd received the literature from which I felt truly disassociated--it didn't mean anything to me at that point", admitted one woman. Some even questioned the value of information. "To be honest I don't know if information is a good thing", observed one woman, "which person wants it or doesn't want it?"

### **Timing of Information and Support**

Participants noted the difficulty of "timing" information and the critical need for support, particularly in the first stages of treatment. Rather than medical information on breast cancer and treatment many felt that emotional support and/or guidance from a credible person in the medical system (someone with knowledge of the process) was much more critical at the early stages. While some knew of support groups, had contact with other women who had experienced breast cancer, or were directed to resources by doctors, many did not know how to connect with support services. Many women admitted they were not emotionally able to search out the services on their own. "I wish I had known all of this. I wish I had somebody one on one", admitted one. "I could have called the Cancer Society, I didn't think of it at the time. It would have saved me some sleepless nights." "I didn't know where to go and I was too embarrassed to ask", indicated another. "I didn't even know where to start looking, I didn't." Others said they needed help but were not in a state to seek it out. "Nobody asked", said another. "I could've opened a phone book but I think there's that aspect there, you open the phone book, you're asking for help. And I don't need help . . . I needed somebody to call me."

### **Isolation**

Some breast cancer survivors spoke of not sharing the news of their diagnosis or their concerns. "I don't want my whole family falling apart because of this" indicated one participant but admitted that not

sharing the news only increased the feeling of isolation. Others talked about the additional pressure this silence caused for fellow breast cancer survivors. One participant stated, "a few of the women went through treatment, went through everything . . . and didn't leave work, didn't tell anyone at work . . . I just can't imagine the burden that brings along with everything else . . . it's awful to go through the whole thing like that."

Some commented philosophically about information and how it influenced, or did not, their response to their diagnosis. "You can't know what you need to know sometimes soon enough and so when you do know what you need, you don't want to know now because you already did that once and it didn't get you what you thought", observed one woman. There was also a "resignation to fate" reported by some that decreased the importance of information. "You get the sense that knowing more information isn't going to make a difference so you just sort of shut that part out for a while", said one. Another admitted, "I'm too lazy to look up the information. I think what's going to happen is going to happen." Others felt that short of being told their diagnosis was an error, no information truly helps.

*You want somebody to say the one thing nobody in the health care system or those who are trying to help breast cancer women can say and that is 'you're going to be okay'".*

## **THEME 2 - THE ONUS IS ON THE PATIENT: BEING YOUR OWN ADVOCATE**

*You have to put . . . trust in the medical system but on the other hand you have to be your own advocate too.*

Many participants reported that whether or not they received information from their medical team, the onus was chiefly on them as a cancer patient to identify resolve their own information needs and learn about and understand their own medical treatments. Many found that they were left to decipher the information they were given and had to search out the more detailed information perhaps important only to them and their particular disease. Some were disheartened by the health care system felt that they had to "keep on top" of the doctors to ensure they were receiving the prescribed treatment. "I was surprised that I had to be so assertive with the doctors" said one woman. Another agreed, "You don't go into the medical system assuming you have to become your own advocate". "Things moved very quickly for me. Maybe because I didn't sit back . . . They had no choice, I just didn't stop (pushing for treatment)", said another. One participant claimed, "You've got to take charge. You can't always rely on them to call you back and say 'how are you feeling?' You know how you're feeling. So I really kept a handle on it." Some women indicated they received general information about breast cancer and treatment but had to search out the more detailed information pertinent to them and their particular disease. "I guess you have to say what kind of info do you want . . . and when do you want it? Because everybody's probably gonna give you a different answer on that. And I don't think it's so much the . . . pamphlet, we all can get a pamphlet and read it", said one participant.

*I wanted to know . . . whether it was good or it was bad, it made no difference, but I needed to know. I didn't find out anything anyway. You had to find it yourself. You were left on your own.*

### **Finding and Understanding Information**

Some women felt that procedures and options were not well explained and information on different therapies or the side effects of recommended therapies were not presented at all. "I had two female oncologists telling me to have a mastectomy and two male oncologists saying I should have radiation," said one participant. Many also reported a lack of support from their medical team if they did not choose the prescribed treatment or requested information on alternative therapies. Some reported researching on their own to find out about alternative therapies or other options for treatment not offered or discussed by

their doctors. "I just scrambled on the Internet trying to make heads or tails out of all this information", admitted one woman. "I did a heck of a lot of research . . . I phoned a publisher and got names of naturopaths. I did this and that until I found one that I was going to visit" said another. "I even brought an information book about lymphedema. I gave it to my doctor and I bought myself one. Because he didn't know what it was", admitted another participant.

*I kind of did my own research, now the research that I found that was most important was the breast guideline through the Canadian Medical Association on the CMA website. Now nobody in the whole system had ever mentioned those to me which I find surprising because they are there for our use and yet you have to find them yourself.*

Many sought information outside the medical system and enlisted the service of family, friends, and colleagues who were breast cancer survivors to assist them through their treatment journey. Some noted that the task was less of a burden through the assistance from family, friends and other survivors. "My sister-in-law has melanoma helped me with some questions", indicated one woman. "My volunteer told me, meaning she told me, when you go see your oncologist, even your family doctor for the surgeon, you ask them for all the papers, for all the information. If it wasn't for her, I probably wouldn't even ask them", said another. "My husband was on the computer constantly," another participant indicated. Many reported that seeing and talking to other women who had experienced breast cancer had biggest impact—it calmed them down and provided a lot of first-hand information from people who had been through it, provided a "road map" for experience that medical system did not provide. "I think most of us found our own information" said one participant.

*I had my surgery before my family doctor even knew about it. But if I had not pushed, it could've been another couple weeks before I got to see a surgeon and had surgery.*

### **Taking Charge**

Women talked about keeping tabs on their own condition and reporting their doctors. "So I went in two or three times a week to have my blood monitored. I thought, 'if you're not going to do it I'll do it myself,'" said one participant. "What I can see with young women . . . they're getting very knowledgeable and becoming very assertive and asking questions and expecting answers, which I think is great because they're empowering their own life and their own being to do this."

*But the onus is on you to look after yourself. They (medical staff) don't have the time. They just keep going.*

Some have turned their experiences into community activism through local support groups. Volunteers prepare information packages, make visits to newly diagnosed patients as part of the local support group or some other program, and lead other health promotion initiatives. "We're hoping to get into the factories, where there's a lot of women and make them available of breast health, that's our next thing and then the schools", said one support group member.

### **THEME 3 - DIFFERENT TYPES OF INFORMATION WOMEN WANT**

*The hardest thing I found with the information was finding where I slotted into a spot.*

Participants acknowledged that each woman's interest in obtaining information is as distinct as her particular disease. Some want to know everything, others nothing and many reported that their information needs changed during their treatment. It was agreed that while general information on breast cancer is usually available to women, information specific to an individual woman's disease and interest was a challenge to find. "Finding yourself in the information" became a major challenge for some

women. Women identified a number of topics on which they believed more information should be easily accessible:

- Lymphedema
- Breast reconstruction
- Environmental factors
- Chemotherapy and "chemo" brain
- Drugs - Tamoxifen vs Arimidex , hormone replacement therapy, estrogens
- Support for spouses
- How to talk to their children (young children, teenagers)
- Information for young women
- Supportive/emotional support for those who chose alternative or non- conventional treatment methods (i.e. only natural therapies, choose to remain "breastless", i.e. choose neither reconstruction or prostheses)
- Understanding applicability of "survival/life span" statistics, risks/chances of recurrence(s)
- Nutrition
- Fatigue
- Post-surgery care, hygiene
- prostheses, wigs
- Coping with hair loss
- Alternative therapies
- Post-treatment
- Recurrence/metastatic disease

There was agreement that a significant number of women do not want information at all, of any kind; "for as many people that want information, there are just as many people that just, I don't want to hear it." While women respected each individual's need and desire to be informed, they also pointed out that information needs can change over time and opportunities to receive information should not be reduced to one or two points in the treatment continuum. The medical or technical aspects of the disease were often sought first but many reported that they also appreciated reading or hearing of others' experiences.

*I don't think I was ready . . . I needed time to settle down and clear things up in my head first and then I wanted more . . . but initially I didn't want any (information).*

### **Types of Information**

The format of information varied as much as the content women preferred. Many commented on the medium itself that they preferred: "I really enjoyed a video, a half an hour video round table of six young women, all different types of scenarios . . . what they experienced."; "I like the idea of a book . . . I can choose to put it down when I'm overwhelmed"; "I found you needed to be with the people (support group) who had it to get the right answers"; "I found this breast cancer group on the Internet . . . it was very good because you could get up in the middle of the night and say 'what about this question' . . . You send it in and about six people would answer you." Some women liked the convenience of the Internet to learn information but noted the difficulty of assessing good from poor information sources and were intimidated by the sheer volume of information

*I did some reading. I tried the net. Um, its way more information than I wanted to know. So, I gave that up real quick.*

A variety of formats was preferred—written, audio or video tapes, telephone contact, interactive online chat rooms or message boards, and one-on-one or group interaction with medical professionals or breast

cancer survivors. A "one size fits all" approach was not recommended for breast cancer information.

Participants acknowledged there are many different personalities involved and different ways of making information available that creates a challenge for health professionals and other information providers—"there are lots of different ideas and strategies that need to be combined"; "if there was a phone number . . . that would cater to all people . . . for those who have no computers . . . the phone number for those who don't read very well." One of the major information gaps is the "limbo" many experienced after their last treatment in the cancer centre. "I felt like I'd been in this safety net for six months" said one participant, "and that's where my lack of information came from, the last treatment . . . exactly what do I do now?"

### **Navigation**

Participants voiced a need for a road map or path for their treatment, to offer some insight and understanding about the steps in the treatment procedure. "Let me know what to expect", one woman suggested. They felt that this would provide some reassurance that what they are experiencing is not unusual or different from other women who received a similar diagnosis. "It was the little things more than the big things," said one participant. "I thought I was the only one having a bone scan . . . everybody has to have it. I've spoken to somebody who also had breast cancer to see if they had the same, just so I knew we were both normal." Others wanted specific information from their medical team. "I want to be alive a year from now, so help me make the right choice," said one participant.

The random nature of how women found out about local support groups and other information resources became evident in these discussions. There was no consistency within or across any region of the province or even within specific regions. Word of mouth, chance news items or posters seen by women often lead them to support groups rather than referrals by the cancer centres or doctors. Many women learned about different surgical procedures or treatments available to them from other breast cancer survivors or reading, not necessarily from a member of their medical team.

Some regions appeared to have effective, informal information networks. In Windsor most participants were pleased with treatment and information resources at the Windsor cancer centre and the local hospice. In Woodstock the local volunteers strive to visit every newly diagnosed woman where permission is granted and almost all focus group participants had received a call or visit from a contact in the local support group. The Ottawa Regional Women's Breast Health Centre offers a structured breast assessment/treatment program and sees most women in region, but not all. Some who were not referred were not even aware that it existed "I mean I kick myself in the butt right now," said one participant. "I didn't even know there was a breast centre."

## **EXPERIENCES IN THE HEALTH CARE SYSTEM**

For many women the news of the diagnosis ushers a raw introduction to the current health care system. To each woman a diagnosis of breast cancer is a life changing if not a life threatening event. To many health professionals it is only one more case of breast cancer, sadly routine. Complaints about the medical system concerned the lack of respect shown by medical and administrative staff, poor communication with professionals, and difficulties with access to services.

### **Coping with Cancer Care - The Negative Experiences**

#### **Insensitivity**

Many participants shared stories about how they learned of their diagnosis. Some reveal shocking lapses of judgement by some health care professionals while others are more examples of a cancer care system stretched to capacity. Reported experiences ranged from severe errors—mis-diagnosis, lost test results, test results confused with those of another patient—to incompetence, rudeness, and insensitive behaviour

on the part of surgeons, doctors, radiologists, nurses, and administrative staff working in medical offices and hospitals.

*I went to see my oncologist...I said, "I think I have lymphedema swelling." He said, "No, you just have fat arms."*

While almost all expressed sympathy for the overworked and often under-staffed medical team, many stories revealed a lack of compassion and sensitivity shown by some health professionals. "I was yelled at by a technician when they did the biopsy," said one participant, "He said to me 'my God, you've got cancer!'" Another told of her arrival at the cancer centre for a chemotherapy treatment in late October to find a female skeleton adorning the wall of the clinic, a thoughtlessly placed Halloween decoration. One woman told of having a clipboard thrust in her face for her signature when she was still on the examining table in a hospital gown without her glasses. Another reported she was in the operating room for a procedure where students gathered to watch. "I felt like I was a piece of beef hung on a rack—I had about 12 people looking at me and I was freezing." Participants recognized that staff in cancer centres may become desensitized to dealing with cancer but they expressed surprise at the insensitivity shown by some family physicians in delivering the news. "My family doctor gave me no information," said a participant. "She just said, 'well, it's cancer' and 'which surgeon would you like to see?'" Another said she was told by her family doctor, "'It's cancer, go to a surgeon.' Like, 'Get out of here!'"

### **Communication Issues**

Poor communication about the diagnosis between women and health professionals and even between and among health professionals was reported. Women reported hearing the news of their diagnosis from a variety of sources: surgeons, breast screening personnel, family physicians, and, in some cases, technicians. Some were astounded to learn the news from messages left on telephone answering machines that any family member or work colleague could hear. Messages were left on Friday evenings when it was impossible to call back (often by the office secretary, not the doctor), and some were simply referred to a surgeon but had no clear idea why they were being referred. "What I am doing in the surgeon's office already, before I even know I have cancer?" asked one participant. Some women expressed anger and disappointment at hearing the news from specialists or medical personnel whom they did not know. They felt that their relationship was with their family physician and he or she should have assumed the responsibility for delivering the news. Others disagreed. "You're just so overwhelmed" acknowledged one participant, "no matter what they say, how they say it, where they say it, nothing is going to stick in your mind at that point because you're still dealing with what they told you." "You're in a fog" agreed another woman, "but you go in and do what you're told."

*I had written (my questions) all down and I was all ready to go. And he (the doctor) grabbed the paper and walked across to the other side of the room and was "yes, no, no, yes, no, yes, no, um hum."*

Women also reported a frustration with the health care system particularly in cases where they had suspected something was wrong but felt their concerns were not treated seriously. Several spoke about suspicious lumps or abnormalities that they questioned, were told they "were nothing" and later were diagnosed with cancer. Women often reported a mistrust of doctors and/or the medical system that was triggered by mishaps, errors, abnormalities not investigated in a timely manner, or what were perceived to be false reassurances by the medical team that everything was fine, only to find out later that an abnormality was malignant. "What if they made a mistake on the pathology report?" one participant admitted thinking. "Do they know what they're talking about?" Another shared, "I found a lump and saw the practitioner who said 'oh, no, it's nothing' . . . he did a biopsy and said it was suspicious but it came back negative . . . and I said well I still want it removed. They removed it and it was cancer and it had spread . . ." A few people expressed frank distrust of the doctors, the system and research: "Nobody in

my family ever had it . . . after all the research that's gone into it and the billions of dollars . . . the oncologists will say 'we don't know' (the cause). They know. I'm sure they know", said one participant.

### Information Obstacles

Women's experiences in obtaining and deciphering information about breast cancer were often fraught with frustration. Their experiences ranged from information that they felt was purposely withheld, to poorly explained and incorrect information. Many were surprised that they did not receive any information about breast cancer at the time of diagnosis, particularly when they were then asked to select a treatment option. Others felt restricted when no options, only one course of action, was recommended. "Sometimes you don't have a choice. You're not given anything. They say, 'this is what you have and this is what you should do'" reported one participant. Many reported that having options presented without a recommendation was equally stressful as they felt unskilled and emotionally ill-equipped both emotionally and skilled academically to make the decision. "Even the nurse said to me 'we're going to give you all the information but you have to make the choice'. I went home and said to my husband, 'I'm not a doctor, how do I do that?'"

They shared stories about doctors using medical terms to describe their condition that they did not understand. "The doctors don't tell . . . I've never had a straight answer on what a spindle cell cancer is.", said one participant. Some felt that procedures and options were not well presented.

*My work is in health care. I have a university degree. I'm well versed in medical terminology. I found my first three-hour oncology appointment extremely overwhelming. I didn't find they explained things well at all . . . I'm thinking, 'how does someone who is not in that field, make any sense?'*

People reported a lack of support if they did not choose the recommended treatment option(s)—"my oncologist shut me down right away if I dare talked about any other alternative therapies or anything like that. Especially if in his mind it wasn't scientifically approved", said one woman. Women also reported that doctors did not give them complete information about different treatment options or side effects, like lymphedema. "Some doctors believe in self-fulfilling prophecies", said one participant. "If you talk to somebody about lymphedema then you know you're going to have it . . . or if you tell them that somebody gets sick during chemo then you know you're going to make yourself sick worrying about it." "Through my radiation I was told, 'oh, it will be fine'", reported one participant. "I lost four pounds in one week, it really did affect me . . . and then I come to find out that lots of people get sick with radiation, but I didn't find this out until afterwards."

Women who are members of breast cancer support groups expressed disappointment that their efforts to supply doctors (usually family practitioners) with breast cancer information packages or pamphlets have been a constant struggle. Many family practitioners, surgeons and oncologist are not willing to keep supplies of information to hand out to newly diagnosed patients, even when the materials are provided to them. "We made up these resources . . . and placed them in every doctor's office, every hairdresser, the library, blah, blah, blah. And I think they're still under the desks in the doctors' offices", reported one support group member. "Doctors are our biggest obstacles", she added.

One participant related conflicting experiences about receiving information. "All of a sudden his nurse came in with all this information, on chemo, on radiation, on mastectomies, everything. And I didn't even know for sure if I had cancer. So it was just obviously overwhelming to get all this stuff and not even knowing what I needed to look at. But then when I found out it was cancer and they sent me a week later to the cancer clinic, they didn't even have my results yet and I asked the oncologist, where can I get information? Do you have any pamphlets, anything I can read, anything I can tell my young children? Then she said, 'oh here's a website. Go look on there' . . . so it was totally two different experiences."

### **Waiting Times and Fragmented Services**

Many commented on the fragmentation of the health care system, where patient test results and files are not shared routinely between hospitals and cancer centres, even those physically connected to the same facilities. Women reported having to complete the same forms over and over again for different specialists and to report information about symptoms and side effects repeated to different specialists. "It's like the left hand doesn't know what the right hand is doing", reported one participant. "When I did get to the oncologist they didn't even have my file", reported another participant. "The man spent most of the time on the phone trying to get my information." A number of participants shared stories of lost test results, test results confused with other patients' results, being told incorrect test results, and rude behaviour by hospital and cancer centre administrative staff. Others complained of the lack of patience of some doctors in "pushing" clinical trials and insensitivity shown at appointments. Communication among health professionals and with patients was also a huge issue. "You're a number" said one participant.

*The question I had was why does it take so long for treatment? I had to wait four months for the radiation treatment . . . could something start up in those four months? Time again, you know. Time to wait for your results. Time to wait for your treatment.*

A common complaint was the well-known frustration with waiting times for treatment and trying to negotiate a fragmented medical system. "This waiting, and waiting, and waiting, it's just hell and I've heard it from so many people" said one participant. Extended waiting periods were reported by women at all focus groups but by far the most extreme examples were shared by women in the northwest. There was agreement among most participants that "waiting is the worst". "You sit at home and start worrying . . . waiting for the results" said a participant. Offered another, "from the diagnosis until I got the pathology report I was just lying in my bedroom." "You're disempowered in contacting the cancer centre," reported another woman. "They call you. And so you wait and you wait and you wait . . ."

By contrast many felt they were rushed to making decisions about treatment before they were fully informed to do so. Some women described the process after diagnosis as equally punishing as the hearing the news although the circumstances described were quite different. Some talked about the speed of activity after the confirmation of cancer that left them reeling to the laborious and devastatingly stressful periods of waiting for follow-up treatment. "My stuff happened so fast" reported one woman. "I went for my mammogram and from there I went into the surgeon . . . and it just went boom, boom, boom . . ." and then waited weeks (some waited months) for adjunct therapy".

Women reported the effects of "revolving door" staff in some centres where continuity of care and communication is an enormous challenge. "I've had four oncologists in four years" reported one woman from northwestern Ontario. "At the cancer clinic, I haven't had the same doctor twice in five years" said another.

### **"The Light at the End of the Tunnel" - The Positive Experiences**

*You're going to be okay is what my doctor said. It's treatable, curable, fixable whatever. You're going to be okay . . . I just left his office and said "I know breast cancer isn't going to kill me . . ."*

For every horror story about the medical system there were also reports of doctors and nurses who went out of their way to arrange prompt treatment and to help their patients understand the treatment process. Many women shared stories about their family physicians and surgeons, some of whom they did not know well, keeping their offices open after hours to talk with them about their diagnosis and explaining treatment options. What women appreciated most often was the time that health professionals spent with them until they felt comfortable. "First I spoke with the nurse for about 15, 20 minutes and she was

fabulous" reported one participant. "Then I had the doctor and I was the last appointment of the day. He spent, I didn't leave there until it was after six o'clock. He drew pictures for me; he spelt words out for me. I went in there, I had prepared myself for a mastectomy. And he says what the hell do you want a mastectomy for because you don't need one." "I had super support from my doctors" reported another participant. "I can't praise them enough and I also got a lot of help right here. I came down to the cancer office and she had exactly what I needed." Women expressed appreciation about dealing with the same people during their treatment. "I went to the cancer clinic I got inundated with information. I was often with the social worker. I had the same two docs the whole time" said one participant.

*I didn't get my answers 'til I went . . . to see the radiation oncologist. She answered more questions in five minutes because (she) answered them in English.*

High praise was often reserved for members of the nursing staff. "I sat and talked with (the nurse) for a good hour and a half", said one woman. Women fortunate to be connected to a breast cancer program or treatment site commented on how much they appreciated having contacts throughout their treatment experience. "Superb", "fabulous", and "fantastic" were some of the words used to describe these nurses. "My VON nurse saw me right after treatment and called me all the way through my chemo", reported one participant. Another said, "and those nurses spent a ton of time sitting with me and hand holding and talking and just you know, even one of my oncologists would spend 20 minutes listening to me cry and you know what, you're gonna be ok, sort of thing." Another reported that the social workers were her "best friends" and all were grateful when doctors, nurses, social workers, librarians or other staff returned their phone calls.

*I immediately went and they sent me to the oncologist. She sat down with me for two and half hours and wrote five pages of notes . . .*

Many women spoke of being uplifted by the positive and caring attitude shown by their doctors and nurses both in and outside of the cancer treatment centre. On learning of her recurrence of breast cancer one participant said "when I went to the cancer centre I said 'as long as you give me hope . . . I'm not ready to give in' and they said 'oh there's plenty of hope'. So you need to hear that, you need to see that light at the end of the tunnel . . . that was three and half years ago. They need to give you that, I mean I know they can't give you a guarantee."

*My doctor was absolutely wonderful and he got all that information, he pulled a chair up beside me, I was in his office for about an hour and a half and he went word for word, everything.*

Many of the women expressed appreciation for their health professionals who referred them to resources and support groups for more information. "He's one of the best. And he actually does refer patients for emotional support", was said of an oncologist working in Ottawa. Another reported that she met with "my family doctor and also with my plastic surgeon because when I made the decision that it was best to do the mastectomy . . . he offered me right away to go and speak to women that had the same surgery."

"I called that cancer number where they hook you up with someone so I called that and that lady was wonderful" said one participant. Services such as the Canadian Cancer Society's Reach to Recovery and the Cancer Information Service and Willow information telephone lines were cited as services that helped women cope. "My biggest thing was what was I, what was I gonna do with this empty space that was here after my mastectomy. I mean that troubled me for weeks . . . then this lovely lady from, oh my God, an angel from heaven came you know Reach to Recovery." "When the girl came from hospice, she brought me a bunch of literature. It was the very next day, she called me that night I got home to see if everything was okay and she came the next morning. They were very good." "It's comforting to hear, what other

people have obstacles they've gone through" noted one participant, "and they're great now and they're doing fine and those are good things and positive energies to put into whatever treatment you're thinking about going through."

### **ADVICE TO WOMEN**

Breast cancer survivors were asked to consider recommendations to newly diagnosed women, health professionals and other information providers about the most effective methods of distributing information on breast cancer. They were asked to identify information resources they found most useful and what resources or support they would like to see. A summary of their responses is presented below.

#### **"Good information can make for good decisions"**

*I think that one of the biggest things to overcome is the fear that we all have of cancer and breast cancer itself . . . the information has got to get out there. It has to be a subject that people can talk about comfortably because if you are afraid of something you can't go and fix it properly.*

Overall the focus groups participants expressed the belief that, despite the challenges in obtaining and understanding information about breast cancer, it was important that those affected by the disease make every effort to empower themselves with information. "I think (searching for information) is the one thing you do have control of . . . you don't have any control over a lot of things", said one participant. "I think getting the information gave you sense of control, that you were on top of it." These women believe that having the information calms some of the fear and panic a cancer diagnosis often unleashes and that in itself creates a calmness of mind to approach information about the disease. Resources and services mentioned most frequently by participants included Dr. Susan Love's Breast Book, local support groups, Canadian Cancer Society information pamphlets, Cancer Information Service, Willow, and the Look Good, Feel Better program.

*. . . Just get on the information highway and get as much (information) as you can because it seems to help your fears of it, it doesn't take it away, it might lessen it.*

The benefits of having information far outweighed the "not knowing" option. "I was really educated so I could make a good treatment decision", one participant said. Women offered a number of recommendations to newly diagnosed women about managing information, whether it is in verbal, written, or other form. They also discussed "timing" of information, when different types of information may be needed, when to pay attention and when to take much needed breaks.

#### **Recommendations to Women**

Women recommended that newly diagnosed women optimize all forms of breast cancer information and support. Some of the key recommendations from them are captured below:

- Pay attention to "good" sources of information that includes the cancer centre and hospital librarians; nurses, doctors, oncologists and family physicians but "go in with your guns loaded," recommend one woman. "Take somebody with you. Have those questions asked . . . (at diagnosis) that's such a crucial time." "Ask every question because no question is a stupid question," offered another, "it is such a shocking thing and there's so much (to deal with)."
- Recognize that your information needs may change over time and leave yourself open to the many forms and ways different types of information can reach you. "I needed emotional information and the book that we had from women's breast health centre, that thick book had factual information, but it also had stories of people who had gone through it, and were fine. And that nice story that's what I needed to hear that I wouldn't have looked for."

- "I would say to any newly diagnosed woman to seek out their local breast cancer support group."
- Be cautious about statistics that can be misleading, frightening, and sometimes outdated and/or misunderstood. "Do not look at the statistics" was a frequently heard comment.
- "Buyer" beware however—be cautious of information you do receive and do not "necessarily take everything you hear as gospel truth".
- Managing information is essential so consider "just in time" or staging information—read about each stage of treatment as you go through it to keep from being overwhelmed. Some remarks included "take a day or two and back off"; "you can't absorb everything all at once . . . you have to take one step at a time and one treatment at a time"; take the "information you need at the time that you need it"; and, "(the doctor) did say it's . . . it's something you are going to be with all your life it's something . . . you should take one step at a time, first thing is surgery. Think about that. Don't think beyond that. Then think about the next step and the next step as you go along."
- Take time you need to digest the information you find and determine your treatment decision, do not feel rushed and do not be intimidated by your medical team. "If it's been in my system for ten years . . . then another week isn't gonna hurt while I go home and just kinda screw my head back on a little and see what I need to do", said one woman.
- Seek out supportive health professionals recommended many women. "If you can't talk to your oncologist, your doctor, your surgeon, then you need to find somebody else because you have to be able to talk to them because like they say, you are putting your trust in them . . . so you need people around you that support you and that you're comfortable with."

*. . . Reach to Recovery those kinds of things . . . I still remember the doorbell ringing . . . I remember what time she came in the house. That's how vivid, or how important they were. Every woman should have that chance.*

### **Other Tips Breast Cancer Survivors Offered to Women Dealing with Breast Cancer**

- *"Make yourself number one, look after yourself. And get yourself a buddy if you need one."*
- *"Don't be stubborn. Admit you need help. . . . Admit that you don't know and that you need to know and get those questions answered."*
- *"Trust your instincts, there's always hope . . . and if you can't be your own advocate get somebody there who can be."*
- *Take someone with you to appointments to ask questions, take notes, and listen to information being provided by nurses and doctors and/or take a tape recorder*
- *"Ask for all the documentation from the doctor. You're also entitled to that. So get your pathology report. Get your surgical report. Keep a file."*
- *"Keep a diary . . . a record of all appointments, the date, who you saw"*
- *"I think you have to be true to yourself too. I found that when people called and wanted to come over . . . I said, very honest I said, 'this is not a good day'. . . you have to look after yourself. That's important."; "A good attitude helps a lot."*
- *"Match up with someone about your own age, similar type of cancer and treatment . . . it was helpful to have somebody who had been through it already and who knew what you were dealing with . . . it was most beneficial."*
- *But also be aware that talking to others can help but their stories may or may not be pertinent to your particular experience "we all experience things differently"*
- *"I found my experience working with Reach to Recovery visitors when I was diagnosed with breast cancer I thought 'well you know these ladies, like look at them there's nothing wrong.'"*

*They enjoy life, their grandchildren, like I thought you know their life goes on it's what you make of it so to me the actual visit with the person was more support for me than reading anything.*

- *"Connecting with a good support group of women who's gone through it. That would be number one. And number two would be, finding through Hospice or through any agency, any support that would be beneficial to you. Because all of us deal differently, and cope differently."*
- *"I think that women sticking together and a survivor with someone else is your, is the key. I mean the professionals will tell you a lot of stuff too, but you know, I think us sticking together helps. And passing on the information . . ."*
- *Participants acknowledged difficulty friends and family had in dealing with their disease and accepting assistance however awkwardly it was offered " . . . let people love you . . . my friends came out of the woodwork and I've seen them in ways I've never seen them before."; "my kids didn't know how to treat me"*
- *Many recommended that women connect "with your oncologist, or nurse practitioner or whoever that will just help you emotionally once you get diagnosed and just sort of can give you hope that you know you're going to be okay . . . 'we're going to do our best for you'."*
- *"I find it very rewarding, very healing for me having gotten involved in the volunteering part. Because I think, and I thank the women that I visited and have helped me through it, that had gone through it, because when you know somebody's gone through it, I think you can connect. There's a real bond there."*

## **BREAST CANCER SURVIVORS' ADVICE TO HEALTH PROFESSIONALS AND INFORMATION PROVIDERS**

### **"Treat us as people first"**

Breast cancer survivors offered many suggestions to health professionals and information providers about the delivery of breast cancer information and the delicate nature of talking to a woman who has just learned she has breast cancer. Because the news of the diagnosis is devastating to people they emphasized that positive messages from the health professionals were extremely important, particularly in the early stages of diagnosis and treatment. They acknowledged that health professionals, especially those in cancer centres, deal with hundreds of patients in a week and may come to adopt a "business as usual" demeanor but to the individual woman her cancer diagnosis is a life-changing experience. "The more ominous and grave they look, the more depressing it gets you" said one participant. The medical team was encouraged to display optimism and encouragement as "they really have to give you hope". One participant indicated that when her doctor said her breast cancer "is treatable, curable . . . you're going to be okay" she knew that attitude made an important difference. Many indicated that a "road map" or document that spelled out the steps in their treatment would have been of assistance to alleviate concerns and remove the some of the mystery of the process. Their recommendations to health professionals and information providers focus on supporting the cancer patient through treatment and assisting patients to manage information and connect them to peer and other supports. One woman told of being handed a hug binder and being advised by the nurse "there's a lot of reading there, you may not want to read it all right now, but if you read anything, read page 29." The woman realized that the nurse was sensitive to the fact that she was overloaded and could not absorb any information but provided a link to another type of support, "the one kernel of information . . . that worked, that helped".

*They always say, breast cancer's unique, no single two women have the exact same . . . so I think they have to treat us as people first and realize . . . the holistic approach treating not just the disease, but treating your body, treating your mind.*

### **Advice to Family Physicians**

*The problem is that there's just so much information out there. It's not a lack of information. It's just not the right information at the right moment.*

Many survivors felt that the family physician should play a larger role in cancer care management. The family physician (for those who have them) is most likely to have some history with a woman and should be the individual to deliver and handle the news of the diagnosis. Several women expressed disappointment or even anger that they had to learn about their diagnosis from a radiologist or surgeon whom they had never previously met. They suggested that the diagnosis be the only information given at one appointment and that either a follow-up appointment or phone call be scheduled where the physician could provide more detail about the woman's disease and treatment options when she has had a chance to accept the news. As one woman said of her discussion with her doctor, "I was not getting one word she said except cancer." There was general agreement that no woman should leave a physician's office after hearing a diagnosis of breast cancer without some form of information. The information could be a pamphlet, a card with an information telephone number, a list of recommended breast cancer information web sites, a local support group brochure, etc., but something that would lead a woman and her family to more information.

### **Advice to Health Professionals and Information Providers**

*There needs to be a bit of everything. We all learn in different ways.*

Breast cancer survivors made recommendations to health professionals and information providers to improve the provision of information and support care services. Frequently mentioned suggestions to improve the cancer care system include:

- Develop a province-wide, structured, coordinated effort to disseminate breast cancer information in a standardized package with region-specific information such as contact information to local support agencies that involves the entire medical team and local support groups
- Create a documented "road map" or "clinical pathway" that describes the treatment process in detailed steps and includes references to local doctors by name and descriptions of local support agencies—something "to tell you . . . what was going to be happening next . . . what the steps are", said one participant
- Introduce nurse navigators to act as regular ongoing contacts for breast cancer patients throughout treatment and to provide accurate, updated information and support for women and their families
- Reduce waiting times for appointments, tests results, treatment, and follow-up
- Ensure that those who need additional support receive it
- Offer guidance to women in managing information resources
- Offer breast cancer and coping information continually as people's needs for information change over time so "the dissemination of information can't just be through one point".
- Respect your patients—remember that you are treating a whole person, not simply a disease, and be aware of rushing patients from appointments, being too booked to take time to answer questions, or "tossing out statistics" as an answer to disease related questions
- Promote widely existing services such as the Cancer Information Service (1-888-939-3333), the Canadian Cancer Society web site at [www.cancer.ca](http://www.cancer.ca), and Willow's services (1-888-778-3100), [www.willow.org](http://www.willow.org), and regional and local support services; many health professionals are not well informed about the full range of services provided by these groups
- Provide information in languages other than English, in plain language, and in graphic or pictorial formats that are designed for different cultural groups

## FOCUS GROUPS FOR INFORMATION PROVIDERS

### PROFILE OF INFORMATION PROVIDERS

Information providers participated in focus groups and interviews. Focus group participants included nurses, social workers, support and information group personnel who had contact with breast cancer patients/clients at various stages on the treatment continuum. Most worked in screening centres, hospitals, cancer centres, and for information and support group organizations such as the Canadian Cancer Society, Willow and regional breast cancer action or breast health coalition groups. Focus groups were held in Ottawa with six participants, Thunder Bay with seven, and Toronto with 10, and two separate interviews were conducted with personnel in working in Woodstock and Toronto.

Representatives (nurses, social workers, information specialists, health promotion specialists, diversity consultants, librarians, managers, and volunteers) from the following organizations attended the sessions:

- Breast Cancer Action Ottawa
- Canadian Cancer Society, unit offices in Ottawa and Toronto
- Cancer Information Service, Canadian Cancer Society
- Marvella Koffler Breast Centre, Mount Sinai Hospital, Toronto
- Northwestern Ontario Breast Screening Program, Thunder Bay
- NorWest Community Health Centre, Armstrong/Thunder Bay
- Ottawa General Hospital (Cancer Centre)
- Ottawa Regional Women's Breast Health Centre
- Princess Margaret Hospital, University Health Network, Toronto
- Regional Cancer Care, Thunder Bay Regional Health Sciences Centre
- Thunder Bay Breast Cancer Coalition
- Thunder Bay Breast Cancer Support Group
- Thunder Bay District Health Unit
- Wellspring, Toronto
- Willow Breast Cancer Support & Resources Services

Information providers were asked to complete a survey about their approach to providing breast cancer information, their greatest challenges, and resources they recommend to breast cancer patients. The survey questions appear in Appendix VIII and a summary of the responses in Appendix IX. Twenty-four questionnaires were completed. A profile of the respondents appears in Table 2 and Table 3 below.

**Table 2. Information Providers by Employer and Function**

Employer		Function	
Hospital/Cancer Centre	9	Nurse	11
Support/Information Groups	8	Information/Support	6
Breast Screening Centre	5	Social Worker	3
Other	2	Administrator/Program Manager	4
<b>Total</b>	<b>24</b>		<b>24</b>

**Table 3. Point of Interaction with Breast Cancer Patients/Clients**

At Diagnosis	17	37%	<i>*Participants could check more than one option.</i>
During Treatment	15	33%	
After Treatment	14	30%	

The same three themes expressed in the preliminary interviews with survivors of breast cancer—the shock of diagnosis, the onus being on the patient to search for information, and the different types of information women want—were used also as the foundation for focus groups with information providers. The information providers reviewed the same summary notes and themes presented from the interviews. Health professionals examined the challenges they face in meeting patients' information needs in a time of constrained budgets and increasing administrative and patient workloads. They proposed strategies for tackling the issue of information dissemination.

### THEME 1 - THE SHOCK OF DIAGNOSIS

#### Coming Out of the Fog

Several information providers had personal experience with breast cancer were able to bring a unique dual perspective to the discussions as health care or information providers and breast cancer survivors.

*I'm a health professional. I knew the contacts, but when you're given the cancer diagnosis, it just falls apart. You fall apart. Your family falls apart. So I may have known maybe where to go, maybe not, but I couldn't and my family couldn't. We were just wiped out.*

The information providers agreed entirely with the view presented by breast cancer survivors that the most crucial period for a woman occurs during investigation of a breast abnormality and the diagnosis of cancer. "Some of the most distraught people (have) had a mammogram and they're waiting for further tests and they are completely beside themselves and don't really know where to go, or where they fit in" said one information specialist. Information providers were in agreement that most women need time to absorb the news of their diagnosis before they are able to move on to deal with treatment and recovery. They also felt that the deliverer of news of a diagnosis could influence a woman's response to the news. They believe it is helpful if a long-time caregiver like a family physician delivered the news.

In practice, providers acknowledge that many patients do not read information, even when it is provided. "Some people come with this (information binder) and say they've never opened it . . . they'll say, "I've got it at home and I haven't turned the front cover." "I've on occasion spent upwards of an hour on the phone with somebody while they're crying, while they're talking, while they're doing whatever and getting them the information. And sometimes at the end of the hour I don't even send them the package because they don't want it," said one information specialist. "We've had good patient feedback on that (patient information) binder which we give out", said another nurse, but "sometimes people do throw it away or they put it away cause they're not ready for it." The situation is more severe for those who experience a recurrence of breast cancer. "There's a different need too when the cancer does come back within that certain time period . . . the fear is . . . at a different level."

They also see women's anxiety acerbated by family friends. "Everybody knows the best thing for them and that's what overwhelms them . . . telling them what is right for them and telling them what they should do and how they should behave and how they should react and what protocol they should be taking", observed one participant. Information providers view their role in this part of the process as helping women cope with the news and assisting them search out information pertinent to their disease and to their preferences.

### **Recognizing Key Stages and Preferences for Information and Support**

Most information providers agreed with breast cancer survivors that most people do not absorb information well just after learning news of their diagnosis. Although a strong emotional response lingers, within a week or two there is not as much "shock and the denial that would block the capacity to understand", and most women assimilate information more appropriately. It is at this point where providers view their role "to respond (when) the woman is ready to ask for information." This view is supported by the feelings expressed by survivors who said that they only came "out of the fog" when they began treatment and felt prepared to deal with information. Even basic level information is appreciated at this stage said one participant, "when people are suffering through a diagnosis like this, the thing is to make it as easy as possible for them." While women can obtain information from the Internet, books, and cancer agencies they also want the comfort of hearing it from their own caregivers, from someone who "has that knowledge base." Patients value the counsel and support providers offer in their information search. "They want to know that there is someone there," said a nurse.

*I think that being able to talk the person long enough so that you understand what information is appropriate, what information is going to help them at this stage with their treatment decisions is really a key aspect.*

Learning and understanding the steps in treatment is another source of stress for women. "There's another element of anxiety which is different than the fear related to mortality", said one nurse. "Some of what you're able to assist with at the time is the anxiety around where I'm going, who am I going to see, what is going to happen at that appointment?" While many want treatment quickly they also appear to need to time assess their situation and if they feel rushed through surgery and treatment the emotional reaction(s) to their diagnosis will come back. "Some are ready, some want information, some want as much information as you can give them, and others only want a little bit" said a social worker.

Information providers expressed their belief that seeking information was important and can make a difference in a woman's respond to her disease. Referring to a study with English-speaking women but of diverse ethnic backgrounds, one nurse commented, "85% of women who had breast cancer were information seekers . . . women are very interested in getting information. . . . who goes to doctors, who identifies health problems, who's responsible for care of the children and their health problems? It kind of fits a bit of the female profile." But they also acknowledge that this information search may be unlike any other most women have conducted.

*It's not the kind of information (women) seek out until they have to. And when they have to, they're kind of not in an emotional state where they would search for information the same way they would if they were looking for a recipe to cook artichokes or something.*

Providers shared their belief that those women who share the news and their search for information with family and friends seem to have a more proactive approach than who attempt to keep it secret. "It's just so much more of a supportive environment around them rather than them trying to hide it and sneaking in by themselves", said one information specialist, "they can get the information and then they can just relax and look through it. It just seems like those people tend to be doing better than the others."

The providers group noted that information was only one element of the process. "Sometimes women will call and they will ask for information but when you pursue the conversation it's more than information they want, it's, they want to know that there's someone there . . . it's the knowledge that if they need help to maneuver the system they know who to call if they get into trouble," said one participant. They also acknowledged that many women need guidance in sorting through the information maze. Said one nurse, "they will say 'I need to know what's good for me, what source is good for me. I can't read these two hundred (web) sites that I got. What should I be looking at? What's good for me?'"

## THEME 2 - PATIENTS AS ADVOCATES

Information providers reviewed the many issues raised by breast cancer survivors about patient advocacy. Providers' current challenges were defined as the constraints on time and resources in cancer treatment; the devastating effects of waiting times; and, understanding and managing information for individuals affected by breast cancer.

### Screening for Information and Support Needs

Providers were not surprised to learn that breast cancer survivors felt that the onus was on them as cancer patients to find and decipher information about their disease. Spending time with patients to determine their information needs was identified as a key element of screening that some participants acknowledged is lacking. Time constraints reduce nurses' ability to screen appropriately in all cases. Nurses indicated that one of their greatest challenges is to understand where women are in their cancer journey and in their information journey. Nurses indicated that they attempt to pick up cues that women may need further attention although women may not ask for help. "I don't think we always do a good job of having the patient know what they need to know in order to participate in decision making", admitted one nurse. Nurses supported patients in searching for information but noted that information on each individual's situation might be difficult if not impossible to find.

*We don't have the time to do that one to one all the time. So what we do is kind of build in standardized information provision and then the issue for the physicians, nurses, social workers, is to screen for people who need additional support.*

Information providers acknowledged the devastating effect of waiting for treatment and the struggle with conflicting messages and information women face in their cancer journey. Patients struggle to come to grips with their diagnosis but often have no details of the treatment plan commented one participant. "They think that they should be aware of all the good, the appropriate information but I'm not sure...where they should be informed that it's not available."

They also commented that while women appreciate having treatment options they become frustrated if these options are not well explained. Many still want a health professional to work with them to determine an appropriate treatment plan instead of hearing "these are your options and these are the risks and please make your decision yourself. "Misinterpreting information can create its own problems. "You hear 'well it's a grade 3 so they're dying.' They don't understand stages. They've been thrown a lot of medical information that they don't understand and that sometimes affects their treatment decision," commented one participant. They acknowledged that women frequently express anger about their lack of informed choice in breast cancer treatment. "They were given options but they really didn't understand the options" said a nurse. "And later . . . they understand a lot more and they said, 'why did I make that decision'? That was not the right decision." They noted also that for some women the experience of receiving and researching information on their disease could be more stressful than doing nothing.

### Providing Guidance and Support in Searching for Information

Providers agreed with breast cancer survivors' assessment of currently available information resources. "There's a lot of information about the same areas but there's not a lot of information about very limited topics but very little information about what might be needed for the individual" indicated one participant. "Everyone can give about 20 different opinions about having a lumpectomy or mastectomy but yet they will have very little information about...drugs or drugs they can take or the benefits of vitamins or alternatives or anything else." Resources are scarce for those who do not choose to have treatment. "There's that very clear expectation that if you got to the cancer centre, you're going to have treatment" said a nurse, "very little information is around about choosing not to have treatment." But they cautioned that information has limits. "My mother just passed away of breast cancer", said one participant, "and

what I found in that whole experience was that no one had the 100% answer. So no matter how many options you're given, and how much information you're given, it's not like cut and dry."

They commented that women now seem to be better informed and can access a lot of basic information about breast cancer and its treatment. The Cancer Information Service and Willow reported that the information requests they receive now are much more detailed when breast cancer patients have digested their initial diagnosis and "then want to know more about their own particular situation."

Nurses commented that they are frequently asked for guidance about resources women find. "I find that with the Internet, a lot of people do a lot of research but they will come to us saying 'I'm getting so confused,' said one participant, "according to the internet this is what they recommend but my oncologist is saying something else." Several spoke of hearing the women's frustrations attempting to sort through information from health professionals, American versus Canadian web sites, well-meaning friends and family, and the media when the information may not be appropriate to them or based on myth, hearsay, or is simply inaccurate. While they can suggest to patients that they have someone accompany them to appointments, in practice they see that many find the interaction with health professionals very personal and prefer to be on their own. While sharing stories with other breast cancer survivors can be helpful information providers talked about the challenge presented by recommendations from other patients that may not be appropriate for a woman and may not be "medically sound advice".

### **Information and Support Management**

Despite some challenges, information providers agreed that advising newly diagnosed women to learn about their disease is a valuable recommendation. "Breast cancer" is used to describe all forms of a complex disease that may differ completely from one individual to another so women should be advised to review their pathology reports and what they have been told by the surgeon to determine exactly what they have, suggested one participant. They saw value in advising women to pay attention to opportunities to receive information, even when you are not ready to read it -- "if they could learn where to get the information then, then they know in the future where to get more." There was agreement that if the support needs of breast cancer patients are addressed in a timely and appropriate way, it often improves how the patient copes with the cancer experience. One nurse discussed the outcome of a study in her institution which found that people often did not use information resources provided but admitted that just the fact that resources existed reduced their anxiety. "Some don't need (information) and that's there too. But if it can reduce anxiety by knowing that it's there, that's helpful," said one participant.

They also agreed that receiving information has a significant impact on the choices women make for themselves. Said one nurse, "that study . . . that looked at the choice of mastectomy or partial mastectomy, they found 97% of the people in the experimental group actually chose lumpectomy over mastectomy whereas 76% {not in the experimental group} chose lumpectomy over mastectomy. So if you provide information, it's good information. There's clearly different medical outcomes which is, I think, very important."

*There's two issues for us: one is making sure that people get the information and that is proper to what they need in terms of both decision-making and episode of care preparation, and the other is screening for when people need additional support to understand the information.*

Providers cautioned about the information overload. They counsel trust in the medical team and recommend "information breaks". "(Patients) come to a point where they want too much," said a nurse, "You have to get off of it and go with what your oncologist is telling you because he is the expert. He knows. He knows you."

### THEME 3 - DIFFERENT TYPES OF INFORMATION WOMEN WANT: GAPS AND CHALLENGES

Information and health care providers spoke at length about the challenges they face within the current health care system. They shared their frustrations about learning and accessing current resources in breast cancer information; the diversity in scope and random nature of services available within regions and from institution to institution within the same region; cultural issues and information resources; lack of funding; and reaching women in rural and remote areas.

#### Issues with Existing Information and Support Delivery

While some information services exist province-wide (Cancer Information Service, Willow), it was clear there is a wide diversity in breast cancer information and support services provided at cancer centres and/or hospitals within the province. Information providers commented on the inadequacy of giving a generic response to the unique individual's information needs and those individuals whose needs are not addressed.

*There is all that high-end stuff out there . . . what isn't served is the low literacy or non-Internet-based sources of information for the elderly or people who are using computers.*

Most large centres offer information classes and basic information on various aspects of treatment, (surgery, chemotherapy, radiotherapy, etc.) which may or may not be tailored to breast cancer patients only. The nurses acknowledged that the information sessions are not particularly well attended compared to the number of people in the institution undergoing treatment. The participants recognized the random nature of services provided was noted and how the commitment of one individual or group can make a difference. "One of these surgeons' wives was a nurse at the hospital and she made sure every breast cancer patient got these things. She was in the hospital and because she had an interest in it that's what she did. So it can be done. It's done in other hospitals in Ontario," said one participant. Nurses at one breast assessment centre noted in their clinical observations that women who have access to information and support early in the process approach their treatment and follow-up with less distress than those who do not have that access. They also noted that these women notice a huge change once they enter the cancer system. "They graduate to the [cancer centre] and all of a sudden a lot of those key people that they could call and would get a call back right away and would get...support and information ...suddenly it's not as easy", commented one nurse. In other centres the regional cancer centres are often the only place women only have access to detailed information on breast cancer. "When they go to the multi-disciplinary clinic . . . you can say, this is what's coming in your way, but then you need to get the information to them before they get to the multi-disciplinary clinic," said a nurse.

*Cancer Information Service, a lot of people don't know that we exist . . . we're also hooked up to the . . . OCRN, the Ontario Clinical Research Network for clinical trials. They've got us on their database if you have questions call. But then again that's not been really widely promoted either.*

Participants recognize the challenge in knowing all updated resources on breast cancer and where to access them but noted that existing services are often underused. Information specialists from both the Cancer Information Service and Willow commented that they are as likely to be asked questions about where to buy wigs and prostheses as questions on breast disease and treatment.

Coordination of constantly changing programs and funding are other issues. Breast screening centres in northwestern Ontario play a more active role in assisting people undergoing investigation but that role can be lost once the woman begins treatment. "When there was a woman with an abnormality we wanted them referred to the program and then we would follow through, but the doctors were just continuing through, not necessarily providing the information", said a nurse. Since last year the program has not

been operating as the coordinator's position, vacated last year, has not been filled.

### **Inconsistency in Services**

The groups commented that there is a huge diversity among the various cancer treatment centres in Ontario with respect to access to various support and information services such as social work, nurse navigators, breast health centres, screening centres, resources in languages other than English, treatment learning classes, etc. The current system depends on "catching" those in need commented one participant, "we kind of build in standardized information provision and then the issue for the physicians, nurses, social workers, is to screen for people who need additional support." They noted also that waiting lines for treatment sometimes force patients to seek care elsewhere (either in the province or in the United States) which complicates their recovery (away from home) and support needs. "That's the other thing. Some women don't even have physicians," noted one participant and there are few places within the system to help these women. Participants expressed that many women who do not have family physicians and are more likely to ignore a lump and do not know where to find information

*And it depends on the nurse, the nursing practice. Some clinics are for new patients only where you do have a bit more time with the patients. Others are mixed in with follow-ups and it's just, keep it going, and hope that you remember to tell them that there's a lot.*

Providers also expressed frustration that programs and resources are often developed by a single institution or agency but then cannot be continued and/or reproduced due to cost constraints. Other providers or centres do not learn about these services and resources and they are then forced to develop their own programs and "reinvent the wheel". Often centres can only afford to provide copies for their own patients. For example, *Getting Back on Track* is distributed to patients treated at UHN-Princess Margaret Hospital but is available to the public in PDF format on the Internet for those who have access. They also acknowledged there is a huge challenge to inventory all breast cancer services available within a community (or the province) and keep it up to date and attest to its credibility.

Nurses who were also breast cancer survivors talked about similar issues as other survivors like bringing information/questions to their surgeons or doctors that were ignored; feeling left to search out information for themselves. Some had used their professional contacts and friends to find specific information and services. "Why? I mean, that's not fair really. It wasn't fair to me. Why did I have to search that stuff out? Why isn't it there for everybody so everybody has the same chance?" said one nurse who is also a breast cancer survivor. More people are requiring information on financial aid while going through treatment and not a lot of information is available about on that topic.

Providers agreed that local support group attempts to have information kits distributed at local hospitals/cancer centers meet with varying degrees of success due to issues of patient confidentiality. Generally they agreed that peer support was a positive patient support and acknowledged the struggle local groups face in reaching new breast cancer patients. "(They) were begging people to let them in to the hospital because they have this whole service where they'll follow up and give them a package, they give them a temporary prosthesis," said a nurse, "it's a really good thing, but they have to be allowed to contact the patient." They also acknowledge that many health professionals do not value the support that a local peer support groups can offer. "When you see some of the mainline medical models or different things is support right in there? No. It's not," said one participant.

### **Cultural Issues and Language Barriers**

*There's no way the Canadian Cancer Society can be confident in dealing with 290 languages at any given moment in time.*

Non-English language information resources and particularly support services can be difficult to find in Ontario, even in French (*Femmes francophones atteintes due cancer due sein: Qu'est-ce qu'elles ont à dire? Qu'est-ce qu'elles à faire?*, Austin, 2004). Breast cancer resources in other languages are more difficult to find, if they exist at all. Trying to help those women with information about medical information related to their condition is equally challenging, even representatives from the Canadian Cancer Society admit it is "hit and miss". Other providers indicated that trying to keep Chinese and Spanish speaking translators and counsellors on board has proven very difficult. Many challenges continue to exist in coordinating services through Aboriginal navigators. Some centres use the services of translators but they are often overbooked and not always available.

There are serious issues around loss of control of information when family members are being asked to act as translators. Even when health professionals cannot verify what the patient is being told there is often suspicion that the patient is hearing only what the family chooses to tell them. "The doctor's communicating with the younger English-speaking person and the older person has no idea what's going on," said cancer centre employee. "They have no idea that they're being treated for cancer here which blows my mind. I don't know how it happens, I don't know how it's legal but it happens. You see it happen all the time."

*Cancer is a taboo in many cultures. The idea of having cancer is like a death sentence... so they not only have to deal with the actual impact of the information, they have to deal with the impact of the culture.*

In some cultures cancer is a death sentence and is not spoken of; also, a disease of the breast or any other sexualized part of the body is not addressed. "There are some communities . . . where it's a very personal struggle. Not even a husband would know" said one participant, "and women are basically suffering totally alone, by themselves." These issues create great barriers to health professionals and information providers in attempting to communicate with those affected by breast cancer. To assist these individuals counsellors seek agencies or services that already exist within the patient's community where support may be available. "There are ethno-specific agencies that are very embedded in communities and they're doing an excellent job and a lot of support work", said one information specialist. "And we love it when people are connected with those groups already and at least try and make those connections as well."

### **Funding Issues**

*There are no new dollars that I know of, that are available to us. . . . so I think we have to be very creative, again, by using what's available in our community to meet the needs of these women, information needs. And I think we have to work together, really, we have to work together. There's no way around it now.*

All organizations—hospitals, cancer centres, information agencies, support organizations—struggle with funding, fund raising and allocation of funds to projects. Long-standing services like the Cancer Information Service and Willow's information line have capacity limits. The difficult balance is ensuring the services are used to capacity without overloading the service. For example, "Can Talk" is a pilot test of a new service of the Cancer Information Service where the public can ask a question in one of 110 languages and an interpreter will translate the Information Specialist's answer. Now in its experimental stage the service costs about \$3 per minute. CIS has not advertised the program widely as they are wary about overextending the service. "Can you imagine?" said one representative, "we'd be flooded and the service will be shut down in less than four months."

While the costs of providing services in many languages and producing resources to reach multicultural groups can be staggering, the seemingly simpler task of maintaining a broad-based service or resource can

be equally challenging. Information agencies like Health Canada often produce brochures that are available for a time but are not then reprinted or made available online. "I think the other frustrating part is sometimes information either pamphlets or whatever are developed and then you can't get them. You can get them for a while and then they're not available," commented one participant. "I think people for a while were so committed to developing information, that everybody had an invested interest in developing their own," said another participant. "I think now people are realizing that now none of us have time to develop something that's already been developed, that we might be able to use."

### **Rural and Remote Communities**

*This patient had a mastectomy and was just discharged out of the hospital, back to a (northern) community with no follow-up with anything.*

Information providers dealing with remote and rural communities, particularly those in northwestern Ontario talked at length about the challenges of serving the needs of breast cancer patients in those areas. Issues related to access to health care and to maintenance of services in those centers with cancer treatment facilities exacerbated the challenges. "We're losing another surgeon. We're losing an anesthetist," said a participant in northwestern Ontario. There is also lack of coordination of services in the north and particularly to the Aboriginal community where health providers admit making inroads is a constant challenge due to cultural differences and snags in bureaucracy. "We were trying to pilot project with the Aboriginal navigator and it's a huge challenge," said a rural community nurse. "The fellow died . . . before it could be arranged because there's these difficult competing jurisdictions . . ."

They commented on the difficulty of coordinating home care services (where they exist) and to coordinate care for breast cancer patients once back at home because details of medical file are not passed on to community nurse. They also talked about the additional burden placed on patients who have to travel for treatment. "Often times they have to come to the doctor's office to discuss their surgery. I find that really almost cruel because then they have to get home . . . that's three or four hours or wherever, that's another issue that they're dealing with. That's a huge trip." Those who live away from treatment centres do not have the luxury of travelling back to use library facility there or talking with health care team. They felt that rural community nurses, who are left to deal with many health care situations, might not be well equipped or well versed in dealing with medical and emotional supportive care issues for breast cancer patients.

### **INFORMATION PROVIDERS' RECOMMENDATIONS**

Information providers discussed the current state of support in Ontario and recommendations for themselves and health care institutions in dealing with the information and support needs of women dealing with breast cancer.

#### **Addressing the Emotional Impact**

*If I get diagnosed with . . . cervical cancer or breast cancer or whatever, the chances of me being able to read and understand it at that moment, I wouldn't be able to do it. But if you were to hold my hand and say, "you know, this is what you could do" and sit and talk . . . if there's somebody that could do that with me I would respond to that.*

Information providers talked about the importance of the personal connection with people dealing with breast cancer. "Information is not enough," said a participant. Participants commented that women welcomed encouragement as much as facts and figures. "They sometimes just want reassurance too that the doctor is doing the proper treatment . . . and you can talk about the practice guidelines and how they

came into being and so it just reassures them . . . And that's one of the things that we try to encourage no matter where the person is in the province, there are guidelines that the doctors follow." The groups commented that those being investigated for an abnormality who never receive a cancer diagnosis also experience panic and often need information and support. "Biopsy equals breast cancer equals death," said a nurse. "And that's . . . one of those things that you have to have somebody there to talk about, that says . . . that's not necessarily true. There's lots of survivors."

Given the current constraints in health care many noted that the medical team can use community and volunteer services to their advantage. "The surgeon's going to tell them what applies to the job he's going to do but he's not going to spend an hour discussing pros and cons of lumpectomy versus mastectomy. It'll be a ten-minute discussion. I think that the key thing is to make them realize that there are other groups that can offer them more," said one nurse. As there is a broad range in the volume and nature of information women want, the challenge for information providers is "for the health care team member to figure out what is the best way to disseminate that information."

Information agencies note that the trend is that more information is demanded, probably by younger women. Breast cancer has affected this newer generation and young women are more interested and more aggressive in their search for information than the previous generation. "In the beginning in 1996 or so . . . we found we were getting a lot of requests for, what I would call, basic introductory information to breast cancer" said an information specialist. "We get a much lower number of requests for that type of information I think because the breast centres and hospitals are providing it at diagnosis and I think that's been one change that I've seen over the years that has affected the kinds of requests for information that we get." As a result many of the information requests submitted to information and support groups are more in-depth and detailed. Women are looking for information pertinent to their condition and factual information about the effectiveness of their treatment. They want to know "the advantages and disadvantages of treatment," said one participant, "And what are the percentages of it being cured? Like how effective is it? What's the current research on it? What happens if I don't take it? What are my chances?"

Peer support can be instrumental in encouraging women to ask questions of their health professionals. "Sometimes they're asking us questions which really they should be directed to their health care team and they're reluctant to ask that question again. And I think just encouraging people to say, 'You know, this is a valid question and you obviously . . . want an answer to that question and you want it clarified so do ask again'. And sometimes all the encouragement people need to get answers to those questions" indicated an information specialist.

### **Timing of Information**

Information providers speculated on the best methods of ensuring women receive information at the time of diagnosis, or earlier, particularly when many are treated in the provincial cancer care system that may not be managed by their family physician. They determined that the family physician still had a major role to play in informing their patients. They recognized the issues at stake for family physicians to be able to hand out information packages or lists of resources and/or recommended web sites to patients about breast or other forms of cancer and other diseases. "I think that's utopia," said one participant, but others argued that many physicians would be willing to distribute information if the material was provided. "You've got to try these things at least" suggested another participant.

Information providers agreed with breast cancer survivors that the sooner information can be provided to women the better, even if the women do not look at the information until later. Readily accessible information is needed that is current, reliable and not expensive to maintain. Typically the family physician does not manage care once cancer has been diagnosed and "you're launching over into the cancer system" as one provider described. The patient sees a series of specialists depending upon the

treatment regime prescribed. To ensure that information is available to women throughout treatment, as each woman will respond accordingly to her need, providers recommended that information be available at many points in the system, and that doctors are not necessarily viewed as the primary contacts for information.

*It's the common complaint that the doctors don't get it. I mean the cancer center's been told that for all the years I've been there. From some sense this is depressing because we haven't made any difference despite of a lot of effort.*

Nurses who work in cancer treatment centres acknowledge that they no longer have the same one-on-one time with patients. They discussed the development of directories that clinics, cancer centres, and they could use to refer to their patients and alternative methods of reaching breast cancer patients. Information providers generally believed that encouraging local support groups to visit patients and distribute materials were positive steps. Community resources and contacts from a peer support standpoint were seen as critical. Having newly diagnosed women in contact with women who had already had the experience sends a powerful message.

Targeted messaging to the public before breast cancer strikes was also discussed. Reaching a broad audience about breast health in a health promotion campaign was another way to get the message out. "I don't have breast cancer but I am interested in breast health" said one information provider, "so that kind of marketing could maybe reach a broader audience of people in terms of getting that through."

*If you had something in the phonebook like a 1-800 number or in the newspaper, every Saturday or something . . . and you want to speak to somebody, you can call that number . . . at least that's a start.*

### **Advocating for the Patient**

*What kind of information do (women) need because everybody's needs are different. So they need someone to help them find the information that is relevant to them.*

Different forms of advocacy for patients were discussed. There was patient advocacy and support in assisting the patient deal with the diagnosis and treatment and advocacy on behalf of the patient that treatment was being assessed and administered properly. Providers recognized that if the issues pertain to treatment there is a delicate balance between advocating for better care and the risk of alienating the health care team. "You gotta feel safe to the person you're complaining to. You don't want to complain to the cancer clinic. I was afraid of what affect from the care I got there," admitted one participant who was also a breast cancer survivor. However providers agreed that there had to be some way that patients have support in dealing with the "system". "You have to have to somebody there that will say to them, you're right, this is wrong. This is wrong. What can we do to expedite something else for you?" said one participant.

Advocacy in the form of emotional support was discussed. Participants discussed current challenges in providing assistance to people learning about breast cancer for the first time and how either health professionals or breast cancer survivors can offer assistance with this process. "Having somebody there at that time of after screening, that there's a problem, somebody has to be there that's gonna say, you know, you're not necessarily gonna die. That's not the way that breast cancer is nowadays," said a nurse. "A lump can mean a lot of different things," said another participant, "just that information sometimes can be helpful to people . . . there's a whole range of things." The continuity and comfort with those contacts was considered a key feature of a truly supportive care system.

The introduction of nurse navigators to act as contacts and formal support for breast cancer patients was discussed. Nurse or patient navigators act as contacts and patient advocates throughout the patient's treatment experience. Said one participant, "that nurse doesn't have to be the total support, it could also be like a case manager, where she has her things in place . . . and immediately offering this help and helping them, reviewing the books, and doing all that stuff." Breast cancer survivors spoke very highly of the breast cancer navigators in the Kingston area who work in a facility that is not physically connected to the cancer centre.

### **Maximizing Existing Services**

*Be aware of what's in your community. Don't duplicate, but make sure you're aware.  
And then maximize the use of that resource.*

Information providers advised that each provider and all medical staff should be aware of existing services and use them to capacity. Information services like the Cancer Information Service and Willow can be accessed by health professionals and those affected by breast cancer alike. Every opportunity to promote these services at wellness days and other health related events should be used although there was agreement that effective promotion may be difficult to measure. Typically women do not seek information about breast cancer until they need it. Providers also agreed that they should work together to ensure that the same messages are being communicated and conflicting or confusing information is kept to a minimum. The use of lay language rather than medical terminology in resources would be an improvement. They felt that the limitations within the health care system should be recognized and professionals' time used efficiently. "When you look at surgeons and this isn't a knock against them, but they're not good at delivering information", said one participant. "They have surgeon minds, surgeon heads. They're not communicators."

*I think there's a need to outreach to (family physicians) and to say, look this is available.  
There's all this information here . . . they're overwhelmed with things and other illnesses  
and I just don't think the information is out there for them very easily and I think it's  
important to share with them.*

Simply distributing information brochures may not be enough. Information providers recognize that those affected by breast cancer need help in identifying, deciphering and managing information. They also need reassurance that the appropriate action is being taken for them and their disease and many people who need information often are missed. Improvement of screening processes was cited as a key objective to identify people who are having difficulty. Screening is essential to determine each individual's need for information and guidance said one participant. "It may mean the nurse comes through in discussing what these options mean. It may be the psychological issues around coping with the whole process and understand what the decisions are going to mean in terms of patient and the family. But I think that screening component is very important for a clinical point of view," said a nurse. They recognized that support through the information search process was critical for some women. To tackle an information search and to make sense of the results is overwhelming for many but with assistance from a credible health professional or information provider those individuals can reap the benefits of a guided information search and make treatment and health promotion decisions independently.

As every woman is different, developing and distributing information in multi-formats (written, audio, visual, graphic, pictorial, and in many languages and geared to different cultural groups) is essential and requires "necessary duplication because one of those formats is going to connect". Using existing peer networks to provide support for non-English speaking women and/or where a formal breast cancer support group does not or cannot exist can be found through churches, temples, and other social gathering places. Helping women formulate questions for their health care team is also seen as an invaluable

service.

### **New Services and Resources**

A number of alternatives and ideas were explored to improve the state of breast cancer information dissemination, particularly directed to breast cancer treatment facilities. Many of the suggestions pertained to improving the support needs of women and helping to manage information about their disease to ensure they feel comfortable making decisions about treatment.

*I think to have an organized process, where you weave in supportive care with the diagnostic aspect as women go through it and receive their diagnosis . . . it's having that support built in through that experience, for women and her family.*

One suggestion was the development of a framework, template, or inventory of services for health professionals so everyone from a busy family physician to cancer treatment professionals can learn what is being done in all parts of the province and share strategies that work. The framework could include an inventory of the most current and/or “best” resources (online, paper, video, audio, etc.) recommended for use by information providers. Another suggestion was the widespread introduction of nurse navigator/breast focussed nursing support already established in some of the Atlantic provinces and at Hotel Dieu Hospital in Kingston that would be a woman's primary contact during and after treatment.

*Have a document that states these are the steps that you can give to the women that these are the steps you are going to go through. At each step, these are the things you want to be looking at . . .*

Another aid for breast cancer patients is a patient critical pathway or map that outlines the steps in treatment along with treatment centre locations, health professionals' names and contact information and timelines for treatment. A project to launch this type of resource is being piloted in Ottawa.

Nurses talked about full multi-disciplinary team that would include doctors, surgeons, nurses, social workers, and physiotherapists, among others. The team could provide support and teaching where appropriate but at least one nurse or social worker would be dedicated to the counselling and information provision throughout the course of care.

The need for improved communication and coordination with supportive care services, community and nurse practitioners in rural and/or remote was also addressed. "I think it would be good to see if in the clinic, or in the cancer centre, you identified a person in a rural area", said a nurse working in northwestern Ontario, "that you would contact the nurse practitioner there or the provider and that they could be involved in the case management so that in some way there's some flow of information going on and then you can work through the different issues that are happening. But that's not happening right now."

## **EXAMPLES OF BEST PRACTICES**

### **COMPONENTS OF BREAST CANCER INFORMATION AND SUPPORT DISSEMINATION**

Breast cancer survivors identified a number of components that they believed were essential in providing a good information and support system. These elements were identified from concerns the women identified in the focus groups and interviews and the programs they identified worked for them. They felt that a good information and support dissemination program should provide:

- Information or links to information early in the process, even prior to diagnosis
- Time for news of a cancer diagnosis to sink in and contact with a health professional for support

- A consistent health professional contact or information provider to answer questions pertinent to a woman's particular disease
- A road map or critical pathway to spell out steps in treatment, let women know what to expect
- Consistent medical team to coordinate treatment
- Encouragement, optimism and honesty
- Resources in a variety of formats for a woman to consult
- Information about existing services in the community
- Referrals to peer support
- Links to support and information at end of treatment phase

There were two information and support systems that emerged as examples of best practices in our focus groups. One is a structured operational breast centre affiliated with an urban cancer treatment centre and the other is a peer support program supported by a provincial cancer agency. While each service is different in scope and in practice they both address many of the components of a viable support system as defined by breast cancer survivors. While neither addresses all of the elements identified by breast cancer survivors, breast cancer survivors themselves identified these programs as beneficial and expressed satisfaction at the focus groups about these services.

### **OTTAWA REGIONAL WOMEN'S BREAST HEALTH CENTRE**

*I think we all have a common goal that women have the information they need to be able to make the decisions that they feel is right for them.*

Ottawa Regional Women's Breast Health Centre, affiliated with The Ottawa Hospital Regional Cancer Centre is a regional program that provides a comprehensive service to women with breast abnormalities and their families and assists health professionals to ensure a coordinated diagnostic work-up of breast problems. Women receive an accurate and prompt diagnosis of their breast abnormalities, and treatment options are discussed. Women and their families are offered information and emotional support on site and are directed to appropriate resources in the community to meet their needs. "We based this process on what women have told us they need and what we know they need to have as far as medical care. And we've set out very clearly what outcomes we'd like that patient to have", said Director Cathy De Grasse.

The program consists of three components:

- Diagnostic and supportive care that is provided by breast experts in a coordinated and compassionate manner, and consultation for women at a higher risk for the development of breast cancer;
- Education on breast health, assessment, and treatment of breast problems for health professionals;
- Research into the prevention, diagnosis and treatment of breast disease, and support of women and their families throughout their experience.

Services at the Centre include diagnostic imaging services (mammography, ultrasound, and core needle biopsy), high risk breast assessment, coordination of diagnostic services and presentation of treatment options and supportive services regarding breast health and disease. Supportive services include information, practical guidance, emotional support and physical management of symptoms. The program was the first assessment affiliate of the Ontario Breast Screening Program and is reviewing the possibility of becoming a screening affiliate. In 2003 the Centre recorded 4,500 visits (new clients and follow-up appointments) and conducted over 15,000 diagnostic imaging procedures. Personnel includes five nurses, a social worker, a research coordinator who is also a nurse, and five surgeons, two family physicians, and two medical oncologists run 11 to 12 half-day clinics each week. Self-referrals are possible but the Breast Center prefers professional referrals to maximize their effectiveness in the community.

Each patient who has been diagnosed with breast cancer will be scheduled for a pre-surgery appointment that last from one and a half to two hours. A primary nurse is assigned to the patient and most cases remains the contact for the patient throughout the patient's care at the Centre. The nursing staff is available to answer questions by telephone throughout the patient's treatment phase. About 15 to 25 calls are received each week. The pre-op visits can be long but one nurse pointed out, "it takes time up front, but it saves time in the long run." The pre-op visit is often the only meeting required with follow-up contact by telephone with the primary nurse. The social worker is introduced to every woman who is diagnosed with breast cancer and offered the option of available services that includes emotional and/or peer support. Typically a patient will have one to two post-operative appointments at the Centre before follow-up treatment begins at the Ottawa Hospital cancer treatment facility. "Women, from diagnosis to talking to us on the phone or meeting with us, for them it's forever," said a nurse, "their anxiety is at the highest level until they meet with us and they have a plan. Then their relief is unbelievable."

A key element of the education and support service provided is a 160-page spiral bound information and educational resource that is provided to every woman who is diagnosed with cancer. The book entitled Personal Breast Cancer Information Guide was developed originally in 2001 through an educational grant from the Canadian Breast Cancer Foundation. It was revised and reprinted through donations to the Breast Centre and from a local women's golf tournament that raises thousands of dollars for the resource each year. The book includes organizational hints and information on the practical issues such as appointments, medical test results, questions for the health care team and even a decision guide to assist women in determining a treatment option. It also addresses emotional support, lifestyle issues, and information on breast cancer disease and treatment. Each section includes a personal story written by a breast cancer survivor or family member, a list of available resources and where applicable, information on community/local resources. The book also includes a glossary of terms, an index, a complete reference list and a feedback form. The chapter titles include:

- How do I use this information guide?
- My personal journey
- I have been diagnosed with breast cancer
- How will my breast cancer be treated?
- How do I cope during my treatment?
- Should I change my lifestyle practices?
- What happens after my treatment is over?
- What about my family's needs?
- What are the issues for women with recurrent disease?
- Miscellaneous information

The book is distributed with a relaxation audiotape and includes sections for patients to journal and pockets to store test results, medical reports and contact information.

*A women there who became my contact . . . phoned me. And one of the first words she said to me was, "this is not a death sentence. It's serious, but it's not a death sentence." And we spoke for an hour at that point.*

As a joint effort between the Breast Center, Breast Cancer Action Ottawa, and the local Canadian Cancer Society Unit, the three campuses of the Ottawa Hospital and a multi-disciplinary committee that included doctors, pharmacists, nurses, and breast cancer survivors, etc., a patient care map for patients in breast cancer surgery was piloted. The care map is slated to become a regional resource that will standardize care within the catchment area of the Ottawa Hospital. "I watch the women come through the door with a diagnosis of breast cancer . . . and then watching those women go through and come back through after surgery," said a nurse in the Breast Centre, "And listening to them compared to the women we hear about

who don't have that. I think it's a dramatic difference."

Patients undergoing treatment have indicated that the model of care offered by the Breast Centre is sorely missed once they go to the cancer centre. Patients report the transition to the cancer care centre is a difficult one as they face the inefficiencies, multiple health professionals and little individualized attention other breast cancer survivors experienced. With the integration of the Ottawa Hospital with the cancer treatment facility it is hoped that the efficiencies in care will be created and this model, particularly the nursing model, can be introduced in the cancer treatment facility. The Centre itself is struggling with its own success in that many more women want to go to there but the Centre has its own limitations to meet the demand. New creative strategies are being explored to ensure all women receive the same level of care in the region whether or not they can attend the Centre.

### **OXFORD COUNTY REACH TO RECOVERY PROGRAM**

Reach to Recovery is program initiated by the Canadian Cancer Society over 30 year ago brings together breast cancer survivors with women who are newly diagnosed or who are currently undergoing treatment. Reach to Recovery volunteers are breast cancer survivors who have received training by the Canadian Cancer Society. Volunteers offer emotional support to newly diagnosed women and provide a free resource kit that may include information for the woman dealing with the disease, updated information for family members, a temporary prosthesis (if the woman has had surgery), and a list of community resources. The success of the program is dependent on significant volunteer support and its effectiveness varies in different communities across the country. During the focus group for this study we learned that the program appears to have a positive impact on the women in Oxford County and this particular program is described below.

The Reach to Recovery a program operating in Oxford County was well known to many breast cancer survivors who spoke with us at the focus group in Woodstock. This information and support program operates with information supplied by the Canadian Cancer Society but is conducted through peer support by volunteers. While not part of a comprehensive breast service the Reach to Recovery program in the region has received permission to deliver information kits to women who have had breast surgery and agree to receive a visitor. Some women contact the Canadian Cancer Society directly and organize a visit by request.

Doctors in the local hospital verify that a woman is interested in having a visitor a call is placed to the Canadian Cancer Society. "Usually we get the information the day after the surgery and quite often will have a visitor ready to go that day" said a volunteer. Within one or two days a Reach to Recovery representative makes a visit. Inside the information package are Canadian Cancer Society publications *After Mastectomy* or *After Lumpectomy* (as applicable) and *Taking Time*; a bag; a pillow; a ball and a rope with an exercise pamphlet; an Assistive Devices Program form and locations to find prostheses; and, the telephone number for the Cancer Information Service. Volunteers make the bags and pillows and the Canadian Cancer Society provides the information resources. All breast cancer patients in the region have to travel for treatment, usually to cancer centres in London or Windsor. The main complaint echoed by many in the group is that they were not linked with the program soon enough and made choices about surgery before being educated about their options.

The community is about 30,000+ people and the group maintains a list of about 230 names (another 120 have chosen not to receive mailings). Women can request at any time to have their names removed from the list. Mailings are sent twice a year to promote the annual fund raising dinner and other notices are included. About one third of the newly diagnosed attend regular support group meetings that are held in the evenings and afternoons in Oxford County. The Tillsonburg group has an average attendance of 10 to 12 and the Woodstock group six to eight.

The challenge for this group is ensuring that every woman who wants a visit receives one and confidentiality is still an issue. Recently a new approach is being attempted where a hospital staff member delivers information and extends the invitation for a visitor and some may refuse a visit not realizing what they are turning down. The group's intake is at the point after a woman has had surgery and they agree it is beneficial for women to research options and talk to other women before they make a choice. A number of the volunteers also volunteer with the local Ontario Breast Screening Program location and meet women when they are going for regular screening appointments. Information about the support program is promoted there too if volunteers are asked questions at that point.

This focus group notice was included in the group's spring mailing and drew the largest attendance of any focus group as 25 women participated. Only half self identified as members of support group. Many talked about having to find additional information and advocating on their own behalf with the medical team but there was a sense, not shared in every focus group, that these women had a basic knowledge of their disease and that the Reach to Recovery visit was beneficial. Not every question they had was answered, and there were exceptions, but they moved forward with the contact information they received to seek out more information on their disease. Many spoke of the visit with the volunteer as a point they recalled in their experience with appreciation.

### **SUMMARY OF FINDINGS**

The project revealed that the general response “I did not get any information or the right information for me” does in fact represent a wide range of different aspects and understandings among women affected by breast cancer.

From the focus groups, we were able to identify specific components of a good information dissemination system as defined by women themselves and for the most part confirmed by health professionals and information providers. We learned about the current status of health care and services, as reported by the women. In addition, we gained insight into some of the challenges faced by information providers. On the following page, Table 4 provides an overview of the main themes that emerged from the focus groups.

### **DISCUSSION**

The main goal of this project was to identify and describe what women mean when they report that there was a lack of appropriate breast cancer information for them. To achieve this goal, preliminary interviews were conducted with a group of women, to gain feedback regarding specific areas of concern to focus on.

Three major themes arose from our discussions: the shock of diagnosis, the onus on the patient to become her own advocate, and the different types of information that women want. These three themes informed a framework that was used to further understand information (and support) issues among focus groups of breast cancer survivors and among groups of information providers, across the province.

The present findings indicate that women dealing with breast cancer want: specific information on their disease; different types of information in a variety of formats; guidance from health professionals to decipher and manage the information; compassion from health professionals; and, options for contacting others dealing with similar circumstances. We have also learned about two sides of the current status of health care. Women's frustrations are the result of a lack of time, poor coordination, and a perceived lack of continuity of support services. Having said that, the mismatch between patients' expectations and the services that currently exist, is fully acknowledged by those working in the cancer care system. These

**Table 4: Summary of Main Themes Identified in the Focus Groups**

<b>Theme</b>	<b>Breast Cancer Survivors</b>	<b>Information Providers</b>
Shock of Diagnosis	Find impact of diagnosis overwhelming — emotional wallop has profound effect on how, when and if women seek or take up information about their disease.	Observe high levels of stress in those having breast abnormalities investigated or those recently diagnosed. Recognize that women need support and guidance at these stages.
Onus on the Patient	Report that women are left to find and decipher information on their own.	Face challenges in meeting this need and recognize that women are becoming increasingly specific about the information they want.
Experiences in Medical System	Expose well-known problems in the health care system —waiting times, fragmented services, time delays, shortage of funding, staffing constraints—but also a lack of respect and compassion by some health workers.	Acknowledge that services are not standardized (rural and remote areas face special challenges) and that screening and providing service for those who need additional support are not meeting current needs.
Different Types of Information Women Want	Recommend all types of resources in many different formats be available at different points along treatment continuum, i.e. - everyone seeks information and learns differently.	Note barriers to providing appropriate information in many languages, appropriate for different cultures and in multiple formats (usually due to funding constraints).
Recommendations to Women	<ul style="list-style-type: none"> <li>• Become educated about your disease, and information needs, and different options for support.</li> <li>• Recognize that your information needs may change over time and leave yourself open to the many forms and ways different types of information can reach you</li> </ul>	<ul style="list-style-type: none"> <li>• Confirm that information is power. Encourage women and their families to seek information about to breast cancer</li> <li>• Counsel women to accept that there may not be specific answers to every question they may ask</li> </ul>
Recommendations to Information Providers	<ul style="list-style-type: none"> <li>• Recognize support as essential particularly at diagnosis.</li> <li>• Be aware of existing services in the community to refer patients</li> <li>• Encourage family physicians to play a larger role in providing information and support</li> <li>• Develop a "road map" for patients, teach them the steps of cancer care, what to expect</li> <li>• Coordinate care, provide consistency in medical team/ patient contact</li> <li>• Help patients understand medical information and implications of treatment choices</li> <li>• Address issues for those in rural and remote areas</li> <li>• Treat patients with respect</li> </ul>	<ul style="list-style-type: none"> <li>• Maximize existing information and support services in the community</li> <li>• Develop a critical pathway or road-map for breast cancer patients</li> <li>• Focus attention on support services</li> <li>• Investigate nurse or patient navigator models of support</li> <li>• Work together to avoid duplication</li> <li>• Develop template/resource to help information providers stay updated on new and locally relevant resources, and how to obtain existing ones</li> <li>• Use existing networks in remote communities to improve communication and monitoring among health care and support agencies</li> <li>• Look for unique opportunities to work together, e.g. patient pathway project in Ottawa</li> </ul>

findings support previous research, such as the Canadian Cancer Society's 2003 patient needs study where 31% of cancer patients with an emotional need reported that a substantial barrier to fulfilling this need was not knowing what local support programs are available. Cancer patients are usually treated in outpatient clinics and have limited contact with nursing and other medical staff. The present study, however, shows that these types of issues are still relevant but also that the cancer care system may be under greater pressures than in the past.

Both breast cancer survivors and information providers had recommendations for women and health care and information providers on how to improve current circumstances (see Table 4). Of note, these recommendations highlight the importance of psychological support as an integral part of treatment and acknowledge that new and creative means are needed to meet this need as current cancer care services are stressed.

Overall, we have clearly identified that both breast cancer disease and its management are complex and have a huge impact on women and their families. It can lead to constant uncertainty and many unanswered questions about mortality and quality of life issues. At a certain level there is no point of certainty or closure that breast cancer survivors can expect. For some, the realization that these circumstances cannot be controlled or are certainly not within their control is a constant struggle. The challenge for health care professionals is to understand where breast cancer patients are in their journey and which information and support options may be useful for a particular patient at any given point in time. This also presents a challenge to those dealing with breast cancer to assess their own information and support needs, to search out some of their own answers and to communicate their questions to the health care team. Below, we suggest implications for practice, education, and research.

### **IMPLICATIONS FOR PRACTICE**

Currently many health professionals admit that assessment of information and support needs are random, more "hit and miss" than the result of a streamlined, structured assessment and information delivery system. These gaps in screening for those who require additional assistance in seeking information and emotional support must be addressed. It is recommended that health professionals:

- Implement improvements to screening to ensure that those who need additional support and information receive assistance. A conversation is a basic intervention to determine what breast cancer patients need and what concerns them. Ideally this dialogue should occur many times throughout the treatment phase as necessary for the health professional to understand the questions patients have and where help is required.
- Establish standard approaches for information provision that might include distribution of information that would link patients to other information sources. An information package could consist of the Cancer Information Service or Willow information telephone numbers; pertinent written information from the cancer or treatment centre; and a directory of local support and information services
- Remember that all patients deserve to be treated with dignity and respect. Interactions with health professional emerged repeatedly as a pivotal point for those dealing with breast cancer.
- Provide a contact for breast cancer patients – someone who has knowledge of the disease and treatment protocol, someone who can assist women to determine appropriate information for their particular disease. This function can be addressed by a family physician, a nurse navigator, an oncologist, a surgeon, a social worker, among others.
- Collaborate with other breast cancer information and support agencies and peer support groups to investigate creative and innovative approaches to dissemination of breast cancer information and support services. One example is the patient care map program being tested in Ottawa that is the

result of a collaboration of two local information and support groups and a breast assessment centre.

- Recognize the limitations of the current system and maximize resources already available through existing channels.
- Keep informed about information and support services in their local communities to be able to refer patients to a range of potentially helpful information and support options.
- Connect with other community service agencies to assist ethnic and culturally diverse groups who may not seek help through established agencies.
- Investigate options within and outside of the health care system to communicate with women dealing with breast cancer and local and regional health care personnel managing their care in rural and remote regions.
- Promote existing resources and assist women to conduct their own information searches.

## IMPLICATIONS FOR EDUCATION

### Women Dealing with Breast Cancer

While it may seem unfair to burden the ill with additional responsibilities at a vulnerable time, the reality of health care today requires that patients take some responsibility for their own information needs in cancer care. People do not seek out information on cancer or on the cancer care system until they are forced to become a participant and the emotional impact of a cancer diagnosis makes this unwanted information search more trying. Yet most women in the focus groups believed that information was crucial to understanding the disease and making treatment choices. It is recommended that women dealing with breast cancer:

- Communicate with health professionals about their personal information needs and be prepared to do some work and/or enlist the assistance of family and friends to resolve some of their questions.
- Remain open to different types of information resources and forms of support as needs change over the treatment continuum.
- Be aware that the current information delivery systems will not automatically meet every person's needs for information and support.
- Make efforts to live with some unanswered questions as a new level of uncertainty may be a reality long after cancer treatment has ended.

### Health Professionals

In the 1999 report on the *Think Tank on Breast Cancer Information and Support* a key recommendation to medical schools and professional development training was an emphasis on perfecting skills in interpersonal relations and communications. The issue was raised in the Canadian Cancer Society's 2003 report *Breaking Down the Barriers* and in the 2004 National Cancer Policy Board study *Meeting the Psychosocial Needs of Women with Breast Cancer*. These findings should remind those directing the education of doctors and nurses that:

- All health professionals should be reminded that people do not choose to be part of the cancer system and that every patient deserves to be treated with dignity and respect.
- Health professionals should never lose sight of the fact that, at one point in time, for every cancer patient, it is a shockingly new and devastating experience.
- Health professionals should make psychosocial management a priority in professional education as well as in cancer treatment.

## **IMPLICATIONS FOR RESEARCH**

There is no doubt that more research work is needed in order to address the information and support needs of women affected by breast cancer. In the present study, the women wanted improved access to information options, plus the opportunity to receive information and/or support at multiple points along their cancer journey. In addition, the women wanted more information available via the Internet, yet presented in a user-friendly manner. Women are often seeking very specific information that is tailored to their own needs at any given point in time.

Further research should be encouraged to develop and evaluate innovative processes, products, and services that strive to address the gaps that the women have identified.

Indeed, OBCIEP have recently received funding for a new project to explore breast cancer survivors' preferences for information and support through Internet delivery. This research will also develop and pilot a web-based information and support 'hub' that draws mainly from existing resources, and allows women to tailor information and support to suit their needs. It is worth noting that one focus is to address the needs of those living in rural and remote communities where there are few established channels and services. The project will therefore explore creative ways to use technology, help to standardize approaches to information and support delivery, and respond to the individual woman's specific information and support needs.

## **DISSEMINATION OF STUDY FINDINGS**

Study results will be shared with all study participants, OBCIEP Coalition and corresponding members (made up of health professionals, information providers and peer support groups) and the readership of the OBCIEP newsletter Breast Cancer Info Exchange. Sections of the report will be communicated to appropriate agencies such as provincial medical schools, the Canadian Association of Nurses in Oncology, and the College of Family Physicians.

Data from this study will form the basis of an article to be submitted to relevant journals.

Some of the initiatives discussed in the focus groups, such as the inventory of resources for health professionals to share with patients may be drafted by OBCIEP and circulated for comment. OBCIEP will use its newsletter, e-mail communication and meetings to promote the Cancer Information Service and Willow Breast Cancer Support & Resource Services information lines to health professionals.

**REFERENCES**

*Breaking Down the Barriers, Study of Cancer Patient and Caregiver Needs in Ontario*, Canadian Cancer Society - Ontario Division, December 2003.

*Canadian Cancer Statistics 2004*, National Cancer Institute of Canada, Toronto, 2004.

Evaluation of a patient file folder to improve the dissemination of written information materials for cancer patients, Whelan T.J., Rath D., Willan A., et al, *Cancer*, pgs. 1620-1625, October 15, 1998, Vol. 83, No. 8.

*Femmes francophones atteintes due cancer due sein: Qu'est-ce qu'elles ont à dire? Qu'est-ce qu'elles à faire?*, Austin S., l'Initiative de recherche communautaire sur le cancer du sein de l'Ontario, Toronto, September 2004.

*Hopes and Needs: A profile of the needs of Francophone women with breast cancer and the resources available to them*, Report for Willow Breast Cancer Support & Resource Services, Toronto, March 2000.

*How the internet affects patients' experience of cancer: a qualitative study*, Ziebland S, Chapple A., Dumelow C. et al, BMJ Publishing Group Ltd., March 2004.

*Implementing a Virtual Community for Breast Cancer Information and Support in Ontario*, Ontario Breast Cancer Information Exchange Partnership, Community Capacity Building Project Report, October 2003.

*Information and Support Needs of Women with Recurrent and Metastatic Breast Cancer*, Summary of Telephone Survey Results, Alliance for Breast Cancer Information and Support B.C. & Yukon, February 2003.

*Information needs of women with metastatic breast cancer*, Gray R.E., Greenberg M., Fitch M.I., et al, *Cancer Prevention and Control*, pgs 57 - 62, 1998; 2 (2).

*Information Overload: Making Sense of Recent Breast Cancer Research*, Canadian Breast Cancer Network Webcast, June 14, 2004 with Dr. Shailendra Verma of the Ottawa Regional Cancer Centre.

*Meeting the Psychosocial Needs of Women with Breast Cancer*, National Academy of Sciences, National Cancer Policy Board, Institute of Medicine, Washington, D.C., January 2004.

*Needs and issues relevant to future breast cancer research in Ontario*, Report by the Ontario Breast Cancer Community Research Initiative, Gray R.E., Grassau P., January 2002.

*Promoting Regional/Local Capacity for Breast Cancer Dissemination Information and Provision of Support in Ontario*, Ontario Breast Cancer Information Exchange Partnership, Community Capacity Building Project Report, June 2001.

*Self-help groups: Oncology nurses' perspectives*, Fitch M.I., Gray R.E., Greenberg M., et al, *Canadian Oncology Nursing Journal*, pgs 76-81, 11/2/01.

*Supporting women during breast diagnostics*, De Grasse C., Hugo K., and Plotnikoff, R.C., *The Canadian Nurse*, pgs. 24-30, October 1997.

*Supportive care needs of women undergoing breast diagnostics and their families: A focus for nursing*

*interventions*, De Grasse C., Hugo K., Canadian Oncology Nursing Journal, pgs 185-190, 6/4/96.

*Supportive care provided by physicians and nurses to women with breast cancer, Results from a population-based survey*, Gray R.E., Goel V., Fitch M.I., et al, Support Care Cancer, pgs 10:647-652, 2002.

*The Community Contact Program in Newfoundland and Labrador, "I'd Rather Have a Person than a Book"*, Survey of the Community Contacts in Newfoundland and Labrador, Community Capacity Building Report, March, 2003.

*Think Tank on Breast Cancer Information and Support*, Ontario Breast Cancer Information Exchange Partnership, Community Capacity Building Project Report, April 1999.

*Virtual Community Feasibility Project, Building Capacity for Tomorrow*, Ontario Breast Cancer Information Exchange Partnership, Community Capacity Building Project Report, May 2000.

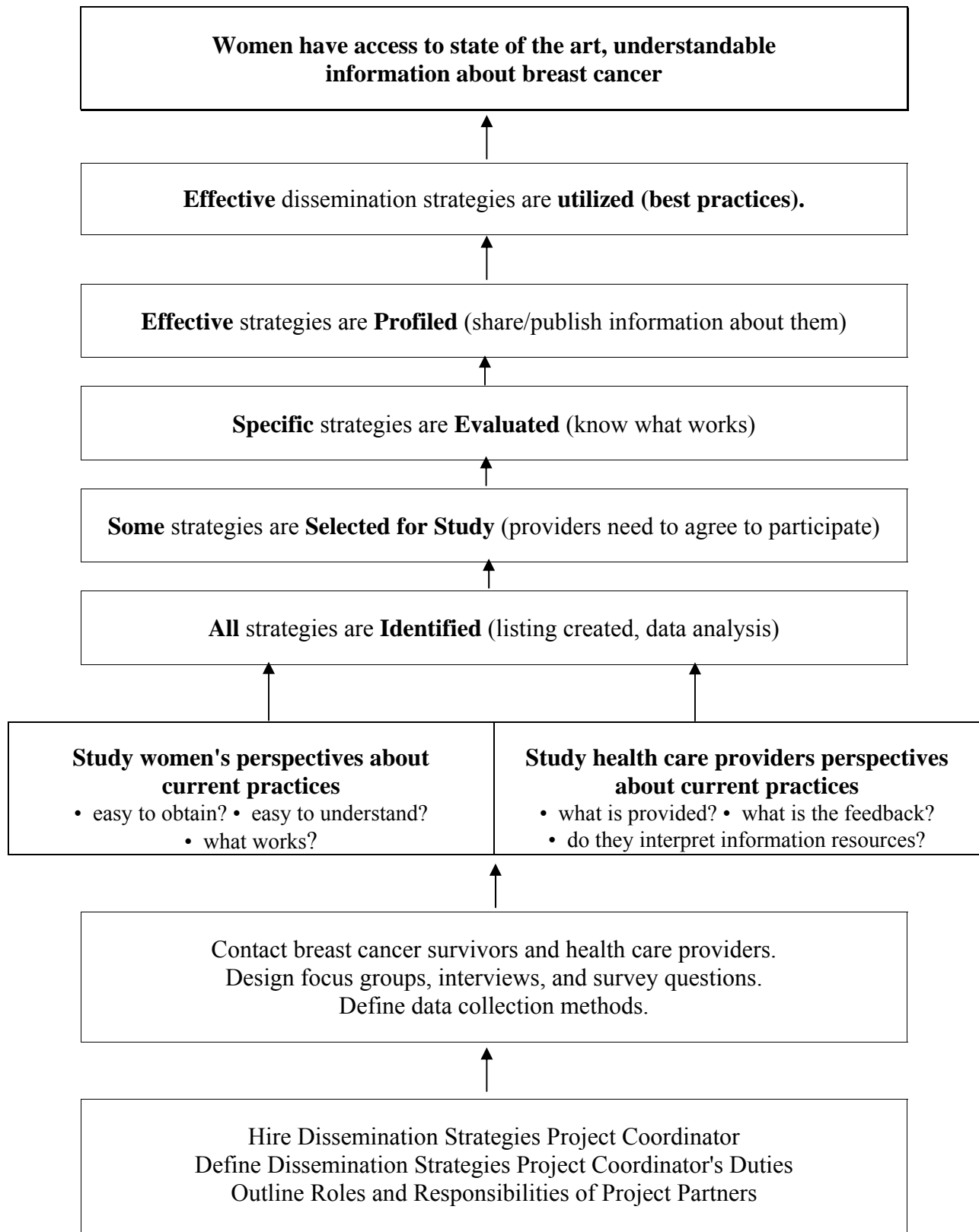
## Appendix I - Project Work Plan

**Goal: Profiling best practice approaches in the dissemination of breast cancer resources in Ontario**

<b>Objective 1</b>	<b><i>Gain an understanding of the current barriers to accessing information about breast cancer.</i></b>
<b>Activity 1</b>	<b><i>Develop survey, focus group/interview questions for needs assessment.</i></b>
Time Required	<i>One month.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners</i>
Training Required	<i>None.</i>
<b>Activity 2</b>	<b><i>Arrange and conduct a minimum of six focus groups with groups of breast cancer survivors in different regions of Ontario.</i></b>
Time Required	<i>Three to four months, concurrent with Activity 3.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners , support groups</i>
Training Required	<i>None.</i>
<b>Activity 3</b>	<b><i>Conduct interviews with and distribute surveys to breast cancer survivors in different regions of Ontario including French speaking and Aboriginal women.</i></b>
Time Required	<i>Three months.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners, support groups</i>
Training Required	<i>None.</i>
<b>Activity 4</b>	<b><i>Compile and evaluate results of needs assessment.</i></b>
Time Required	<i>One month.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow</i>
Training Required	<i>None.</i>
<b>Objective 2</b>	<b><i>Gain an understanding of health care providers' perspectives in current approaches to disseminating breast cancer information.</i></b>
<b>Activity 1</b>	<b><i>Develop survey, interview questions for needs assessment</i></b>
Time Required	<i>One month.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners</i>
Training Required	<i>None.</i>
<b>Activity 2</b>	<b><i>Conduct interviews and survey health care professionals.</i></b>
Time Required	<i>Three to four months, concurrent with some activities of Objective 1.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners, breast screening clinics, cancer treatment clinics</i>
Training Required	<i>None.</i>
<b>Activity 3</b>	<b><i>Compile and evaluate results of health professionals' practices.</i></b>
Time Required	<i>Two months.</i>

Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners, breast screening clinics, cancer treatment clinics</i>
Training Required	<i>None.</i>
<b>Objective 3</b>	<b><i>Compile a listing and identify best or better practice approaches for dissemination of breast cancer information in Ontario.</i></b>
<b>Activity 1</b>	<b><i>Create list of dissemination strategies and select for study.</i></b>
Time Required	<i>One month.</i>
Responsibility	<i>Project Coordinator, OBCIEP</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow</i>
Training Required	<i>None.</i>
<b>Activity 2</b>	<b><i>Identify and profile "best practices".</i></b>
Time Required	<i>One month.</i>
Responsibility	<i>Project Coordinator, OBCIEP</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow</i>
Training Required	<i>None.</i>
<b>Objective 4</b>	<b><i>To study and evaluate selected best practice approaches.</i></b>
<b>Activity 1</b>	<b><i>Conduct follow-up interviews with groups or individuals who use information dissemination strategies rated as successful by breast cancer survivors.</i></b>
Time Required	<i>Two to three months.</i>
Responsibility	<i>Project Coordinator, OBCIEP, CBCF, CCS, Willow</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners</i>
Training Required	<i>None.</i>
<b>Objective 5</b>	<b><i>To share information on best practices with network partners.</i></b>
<b>Activity 1</b>	<b><i>Share results with service providers on individual dissemination strategies.</i></b>
Time Required	<i>Three months.</i>
Responsibility	<i>Project Coordinator, OBCIEP</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow, OBCIEP Coalition Partners</i>
Training Required	<i>None.</i>
<b>Activity 2</b>	<b><i>Publish results in OBCIEP and other partners' communication vehicles, post final report online on OBCIEP web site and share report summary with selected provincial health care organizations.</i></b>
Time Required	<i>Two to three months.</i>
Responsibility	<i>Project Coordinator, OBCIEP</i>
Partners Involved	<i>OBCIEP, CBCF, CCS, Willow</i>
Training Required	<i>None.</i>

**Appendix II - Dissemination Strategies Project 2003-04 - Logic Model**



## **Appendix III - Interview Introduction and Questions**

### **Background and Invitation to Interview**

As you may be aware one of the common experiences voiced by those affected by breast cancer is the lack of information provided to them about the disease and its treatment. While the availability and amount of accurate information about breast cancer information and support has increased in the past 10 years, women continually report that "no information" was given to them at the time of their diagnosis or treatment for breast cancer.

To understand this discrepancy and to find a solution between this apparent gap between women's experiences and what breast cancer information providers believe should be happening, OBCIEP and its project partners are conducting a study about breast cancer information distribution. The goal is to find the most effective method(s) of making appropriate information available to all who need it at the time they need it.

With this background in mind, I wondered if you or some members of your support group would be willing to share your experience in receiving (or not!) information about breast cancer and support. There are 5 questions we would like to ask along with some background information. Individuals' identities will not be revealed. I would like to conduct some interviews by telephone but if some members would prefer to respond via e-mail, I can arrange for that too.

Can you let me know if you or some of your group's members are interested? I would happy to set up an interview at a time convenient for those who agree to participate. The interview should not take longer than 15 to 20 minutes.

If you have any questions or comments about this request, please let me know. Thank you!

Irene Nicoll, Coordinator OBCIEP  
416-351-3815

### **Introduction to Interview**

As you may be aware one of the common experiences voiced by those affected by breast cancer is the lack of information provided to them about the disease and its treatment. While the availability and amount of accurate information about breast cancer information and support has increased in the past 10 years, women continually report that "no information" was given to them at the time of their diagnosis or treatment for breast cancer.

To understand this discrepancy and to find a solution between this apparent gap between women's experiences and what breast cancer information providers believe should be happening, OBCIEP and its project partners are conducting a study about breast cancer information distribution. The goal is to find the most effective method(s) of making appropriate information available to all who need it at the time they need it.

Thank you for agreeing to participate in this interview. If you choose to, you can stop the interview at any point. If you have any questions during the interview please feel free to ask.

**Personal Data**

First we would like to collect some background information:

1. How old are you? How old were you when your cancer was diagnosed?
2. What level of education have you completed?
  - a) some high school;
  - b) high school;
  - c) some post-secondary education (community college/university); and,
  - d) college/university or other degree programs completed.
3. Where did you learn about your diagnosis?
  - a) your doctor
  - b) the surgeon
  - c) at a breast assessment centre/clinic
  - d) other? \_\_\_\_\_

**Interview Questions**

1. When you think back to the time just before your diagnosis, what was your experience in obtaining breast cancer information:
  - a. prior to diagnosis (during period when breast abnormality was being investigated)
  - b. once you were diagnosed, what was your experience in obtaining breast cancer information?
  - c. once your treatment started?
  - d. since your treatment ended?
2. What did you find particularly helpful in seeking information, either in what you found or what others found for you?
3. What would you have liked to see? What would have been most helpful for you?
4. Do you hear other women who have been treated for breast cancer talk about receiving "no information" about their diagnosis and/or treatment? Yes / No

If so, what do you think has happened to make women report this?

What do you believe are the barriers for women in obtaining this information?

## Appendix IV - Summary of Interview Results

### Summary of Interviews

#### Breast Cancer Information Dissemination Project November/December 2003/January 2004

# Respondents	28
Age	32 ↔ 75
Average	56
Age at diagnosis	32 ↔ 65
Average	51
Time since Diagnosis	0 ↔ 16
Average	5
Education	<ul style="list-style-type: none"> <li>▪ high school 8</li> <li>▪ college 7</li> <li>▪ university 13</li> </ul>
Diagnosis learned from	<ul style="list-style-type: none"> <li>▪ Family doctor 10</li> <li>▪ Surgeon 17</li> <li>▪ Screening centre doctor 1</li> </ul>

### Responses to Interview Questions

Information received:

*Time between abnormality being investigated and diagnosis*

- Nothing received 21
- Some information received 3
- Nothing reported but respondent had information through previous experience (family member illness and/or work related knowledge) 2

*At diagnosis*

- Nothing received 12
- Received some information (though not all initially at diagnosis) 6
- Verbal information only from health professionals 2
- Referral to or information from a local support group 2
- Referral to a web site 1

*During treatment*

- Nothing 7
- Binder of information 6
- Brochures, fact sheets, books on treatment 8
- Verbal information, assistance from nurses, surgeons 4
- Booklet and video 3

*After treatment*

- Nothing 9
- Books, brochures, shared stories (from support groups not health professionals) 6
- Brochures on treatment side effects 2
- Information kit, referral to support group 1

*What was most helpful to you? (respondents could identify more than one item)*

- Support group, Reach to Recovery contacts, 19
- Patient/nurse navigators, oncology nurses, VONs, 5
- Internet 3
- Willow workshops 2
- Relaxation tapes, meditation workshops 2
- Information provided by cancer centre, surgeon 2
- Nothing was helpful 2
- Canadian Cancer Society information 1
- Cancer Information Service 1
- Books by Susan Love and June Engel 1
- Dragon boat team 1
- Church 1

*What would you have liked to see? What would have been the most helpful?*

- Satisfied with information received, too overwhelmed, in panic, to absorb it
- Information should be distributed by doctors/surgeons, first points of contact at diagnosis and should include information about medical procedures AND coping
- Receiving information at appropriate times like a folder or guide on what to expect, information on breast cancer and medical/screening procedures
- Integrated system, one-stop shopping, not waiting times for assessments and treatments in different centres across province—system operates now like many silos, independent parts of whole system and patient is shuffled from one to the other
- System not good at providing coping, emotional assistance
- Books, other information provided with an offer of a follow-up visit by a knowledgeable volunteer/staff person who has been there, can help explain/navigate through information, provide personal support
- More interpretation/explanation by doctors of information they distribute either verbally or in writing, about statistics and specific medical terminology "estrogen positive receptors"—what does it mean to me?
- Better information and explanations about options for surgery and second opinions
- Practical tips on dealing with treatment side effects
- Information on lymphedema
- Specific information on survival rates for women with particular kinds of cancer diagnosed at a specific age
- Still looking for it!
- Updated books with tips on how to find current information

*Do you hear other women talk about receiving "no information" about their breast cancer diagnosis and treatment?*

Yes    18        No    3\*        Both    1        Don't know/did not reply    6

\*but expressed reservations/dissatisfaction about the information they did receive, 2

*What do you think is happening for women to report this?*

- Quantity and complexity of information can be overwhelming—access to information is not only issue, people need help sorting through, knowing the right questions to ask 7
- Young women still being ignored by system, presents special challenges for them 4
- Diagnosis produces shock —people not thinking clearly, or are in denial, not able to absorb much information initially 4

- Insufficient resources, medical staff, don't have time to provide extra information 3
- Some doctors may not encourage people to seek information, do not want them to become scared, discouraged, have little time to explain resources
- Needing assistance sorting through cancer organizations, who does what, e.g., not clear that Cancer Information Service can assist with finding support as well as medical information
- Feel isolated and alone when you chose a path different from the recommended option
- Access to general information improved but women now more details on lymphedema, side effects, and other treatments besides those recommended
- Difference in people—some demand to know everything, some only want to know what is told to them
- People gain more from talking to people who have gone through it, not just health professionals—connections to support groups not always available
- More information is more readily and openly available to women as breast cancer is more widely discussed through the media
- Not sure as information is available, hard not to know and hospital staff is very generous with information

*What do you believe are the barriers for women in obtaining this information?*

- Not connecting to support groups, people need to speak to people who have been through it 4
- Family doctors first and last point of contact, should do more in terms of providing and explaining information pre and post treatment 3
- Lack of persistence - people don't go into health care system initially assuming they have to be their own advocate, their expectations of the system are not met 2
- Lack of information now is not so much the issue as access to what is available though details on surgery options, lymphedema, etc. are still limited, 2
- People still need help navigating through information that is available
- Doctors don't have resources/time to deal in detail with every patients' needs for every disease
- Privacy -- not every person wants others to know that they have cancer (e.g. small towns)
- Fear - some people don't want any more information than they are told
- Confusion - information may be available but not understood
- Day surgeries limit the time people spend in hospital where they might receive a visit from a nurse/patient navigator
- Reluctance to use toll free numbers for information, want local resources
- Funds—good books are available but can be expensive as is access to Internet services
- Support groups can be very important and very helpful but may be hard for women outside larger city centres to access

## Appendix V - Sample Notice for OBCIEP Focus Group

# Ontario Breast Cancer Information Exchange Partnership Breast Cancer Information FOCUS GROUP

**When:** Wednesday, April 7, 2004 6:30 -8:30 pm

**Where:** Breast Cancer Action Kingston

One of the common experiences voiced by those affected by breast cancer is the lack of information provided to them about the disease and its treatment. While much information about breast cancer has increased in the past 10 years, women still comment that "no information" was given to them at the time of their diagnosis or treatment for breast cancer.

To learn the difference between what women say is happening and what information providers believe should be happening, OBCIEP is conducting a study. The goal is to find the most effective method(s) of making appropriate information available to all who need it at the time they need it.

Dr. Margaret Fitch, Head of Supportive Care at Cancer Care Ontario and Director of OBCIEP will conduct a focus group on Wednesday evening 6:30 to 8:30 at Breast Cancer Action Kingston at 105 - 1379 Princess Street, Kingston. Participants will receive a \$50 honorarium and refreshments will be provided. We are particularly interested in talking to people who have been diagnosed within the last three years. Pre-registration is required.

**If you are interested in participating please contact  
Irene Nicoll at 416-351-3815 or by e-mail at  
[irene.nicoll@sw.ca](mailto:irene.nicoll@sw.ca) or [info.obciep@sw.ca](mailto:info.obciep@sw.ca).**

*The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of organizations working together to improve access to information and support for women and their families affected by breast cancer. [www.obciep.on.ca](http://www.obciep.on.ca)*

**Appendix VI - Focus Group Schedule****OBCIEP Breast Cancer Information Focus Groups, Spring 2004**

	<b>Date, Time</b>	<b>Location</b>	<b>Address, Contact Information</b>
1	<b>April 7</b> 6:30 - 8:30	Kingston	Breast Cancer Action Kingston 105 -1379 Princess Street Kingston, ON K7M 3E4
2	<b>April 21</b>  Noon - 2:00 pm	Ottawa  <i>Information Providers</i>	Ottawa Women's Regional Breast Health Centre 200 Melrose Avenue, 5th Floor, Grimes Lodge Ottawa, ON K1Y 4K7
3	6:30 - 8:30	Ottawa	Breast Cancer Action Ottawa Riverside Mall , 739A Ridgewood Avenue Ottawa, ON K1V 6M8
4	<b>April 22</b>  6:30 - 8:30	St. Catharines	Breast Cancer Research and Education Fund St. Paul's Church, 366 Paul Street St. Catharines, ON L2R 3N2
5	<b>April 27</b>  6:30-8:30	Burlington	Breast Cancer Support Services 695 Brant Street Burlington, ON L7R 2H4
6	<b>May 27</b>  6:30-8:30	Sarnia	Lambton County Unit, Canadian Cancer Society 118 Victoria Street North Sarnia, ON N7T 5W9
7	<b>June 1</b>  6:30-8:30	Woodstock	Oxford County Unit, Canadian Cancer Society 65 Springbank Avenue North, Unit 3 Woodstock, ON N4S 8V8
8	June 3  6:30-8:30	Windsor	Hospice of Windsor & Essex County Inc. 6038 Empress Street, Windsor, ON N8T 1B5
10	<b>June 10</b>  7:00-9:00	Dryden	Best Western Motor Inn, Henderson Suite 349 Government Street Dryden, P8N 2P4
11	<b>June 14</b>  Noon - 2:00 pm	Thunder Bay  <i>Information Providers</i>	Thunder Bay Health Unit 999 Balmoral Street, Thunder Bay, ON P7B 6E7
12	7:00-9:00	Thunder Bay	55+ Centre 700 River Street, Thunder Bay, ON, P7A 3S6
13	<b>August 5</b>  Noon - 2:00 pm	Toronto  <i>Information Providers</i>	OBCIEP, Meeting Room 704 790 Bay Street, Toronto, ON M5G 1N8

## Appendix VII - Focus Group Information Package

### Breast Cancer Information Dissemination—Finding Out What Works

While a lot of information about breast cancer has been developed in the last 10 years, it is still very common women say that "no information" was given to them at the time of their diagnosis or treatment for breast cancer.

To learn the difference between what women say is happening and what information providers believe should be happening, OBCIEP is conducting this study.

The goal is to find the most effective method(s) of making appropriate information available to all who need it at the time they need it.

Our provincial partners on the project include the Canadian Breast Cancer Foundation - Ontario Chapter, the Canadian Cancer Society - Ontario Division, and Willow Breast Cancer Support & Resource Services.

The study is funded by a grant from the Community Capacity Building component of the Canadian Breast Cancer Initiative of Health Canada.

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### Preliminary Interviews

As a first step 28 breast cancer survivors were interviewed by telephone between November 2003 and January 2004. The women interviewed were between the ages of 32 and 75 and were diagnosed between the ages of 32 to 65. Nine of the 28 interviewed had received a diagnosis within two years or less, 19 more than two years ago. The time since diagnosis overall ranged from six months to 16 years.

The women were asked about the kind of breast cancer information and support (if any) they were provided or found for themselves at the time of diagnosis, during treatment, and/or when treatment ended. They were also asked about information they would have liked to have received or found, as well as resources that they found particularly helpful.

While their stories and comments reflected the individual nature of each woman's experience, three common themes arose from our discussions. They are reflected below with some specific quotes from the interviews:

#### Theme 1

**In the beginning, the diagnosis is overwhelming and it is hard to take much in.**

*"Your mind just goes to jelly. All you can hear is the word . . . (cancer)."*

*"I was given comprehensive folder of information at the surgeon's office prior to surgery. But I didn't look at it."*

*"You're in, you're out, you're home. By yourself, with the big "C" word stuck on your forehead."*

*"I walked out of there (the doctor's office) completely bowled away . . . I just wasn't expecting a diagnosis like that."*

*"I think a lot of people wouldn't even ask their doctors for information because I think your first reaction is panic and denial."*

*"It would have been good to get the written (information) because you're not listening—when the surgeon says "you have cancer", that's the end of the discussion."*

*"You want somebody to say the one thing that nobody in the health care system or those who are trying to help breast cancer women can say, and that is "you're going to be okay"."*

## Theme 2

**In large measure, the onus is on you as a cancer patient to search out answers/information and make sense of it.**

*"You don't go into the medical system assuming you have to become your own advocate."*

*"I wasn't well served between the gap between diagnosis and the first appointment at the cancer centre. I was in no man's land."*

*"The system is a challenge to navigate"*

*"Like to find for example if your estrogen receptors are negative or positive—you're told what they are but you don't understand what it means."*

*"Sometimes I'm not sure if (women) are asking the questions as well in terms of trying to get the information . . .you really kind of stress that you need to be proactive for yourself and I think if you're not, then that can have an impact."*

*"At one point in my life I had high blood pressure. My doctor was so fast to slap me with information on high blood pressure. But having cancer . . . nothing."*

## Theme 3

**There are many different types of information women may want and a wide variation in how information is provided by health care providers.**

*"I would have liked a second opinion or more discussion about reconstruction options. I didn't get enough information there."*

*"Chemo brain . . . you're not functioning well and your doctor doesn't say anything about it".*

*". . . the whole thing about chemotherapy, radiotherapy, hormonal treatment, surgery, mastectomy versus lumpectomy . . . I never saw anything on paper about these other than what I read in Susan Love's book."*

*"I wasn't told anything about lymphedema—about the possibility of getting it—when I was in the hospital I was on the telephone and one of the nurses said to me "don't use that hand to hold the telephone", but she didn't say why."*

*"When I was having surgery I looked at the surgery data, when I finished surgery and was getting ready for chemo I started looking at the chemo data, closer to my radiation I looked at the radiation data . . . I tried not to get too much at once."*

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### **Discussion Questions**

1. How well do the themes resonate with your experiences searching for and making sense of information about breast cancer?
2. What advice would you offer to other women——
  - About searching for breast cancer information?
  - About searching through, making sense and managing breast cancer information?

And,

- What advice would you offer to health care professionals about how breast cancer information should be provided?

**Appendix VII - Summary of Demographic Information from Breast Cancer Survivors**

	Kgstn	Ott	St. Cth	Bur	Sar	Wood	Wind	Dry	TBay	TOTAL	%
Replies	12	14	11	11	14	25	20	10	8	<b>125</b>	
Non-replies			1		1					<b>2</b>	
<b>Average Age</b>	53	53	56	50	55	55	57	58	49	<b>55</b>	
<b>Average Age at Diagnosis</b>	52	49	55	48	53	54	55	53	45	<b>52</b>	
Age Range at Diagnosis: 28 to 81											
<b>Age</b>	33 to 81										
30-40	1	-	-	4	-	3	2	-	2	12	9
41-50	4	5	3	1	4	7	3	2	2	31	25
51-60	4	9	5	5	6	5	10	3	4	51	41
61-70	3	-	2	1	2	8	1	4	-	21	17
71-80	-	-	1	-	2	2	3	1	-	9	7
81-85	-	-	-	-	-	-	-	-	1	1	1
										<b>125</b>	
<b>Years Since Diagnosis</b>											
<1	1	-	2	2	2	5	1	-	-	13	10
1	1	2	5	3	4	6	6	-	1	28	22
2	7	2	2	2	4	11	6	5	2	41	33
3	2	3	1	2	4	2	5	2	1	22	18
4	1	2	1	1	-	-	1	-	1	7	6
5	-	2	-	1	-	1	1	-	1	6	5
> 5	-	3	-	-	-	-	-	3	2	8	6
										<b>124</b>	
<b>Education</b>											
High School	6	4	5	6	6	10	5	4	-	46	37
College/Univ	5	5	5	3	7	13	12	6	6	62	50
Grad Degree	1	5	1	1	1	2	3	-	2	16	13
Other	-	-	-	-	-	-	-	-	-	-	-
										<b>124</b>	
<b>Support Group Member</b>											
Yes	9	10	7	7	9	11	6	10	5	74	60
No	2	4	4	4	5	14	14	-	3	50	40
										<b>124</b>	
If Yes, joined group at/during:											
Diagnosis	2	5	3	3	3	1	1	2	1	21	27
Treatment	4	2	3	3	3	8	2	1	3	29	38
Post-Treat	4	3	-	-	3	2	4	7	1	24	31
Other	-	-	1	1	-	-	-	-	1	3	4
										<b>77</b>	
<b>Language</b>											
English	12	14	10	10	12	23	18	9	7	115	
French	-	-	-	1		1	1	-	-	3	
Dutch	-	-	-	-	1	1	-	-	-	2	
Filipine	-	-	-	-	-	-	-	1	-	1	
Slovak	-	-	-	-	1	-	-	-	-	1	
Ukranian	-	-	-	-	-	-	-	-	1	1	
Not Specified	-	-	-	-	-	-	-	-	-	1	
										<b>125</b>	

**Appendix VIII - Questionnaire for Information Providers**

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Spring 2004

Information Providers

**OBCIEP BREAST CANCER INFORMATION FOCUS GROUPS**

Employer

Hospital  Screening Centre   
Information/Support Organization  Other \_\_\_\_\_

Function

Nurse  Social Worker  Counsellor  Other \_\_\_\_\_

At what point do you interact with most clients/patients? (check 1 or more)

At diagnosis  During treatment  After treatment completed

What general approach do you take in providing breast cancer information?

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What resources do you usually provide or refer people to?

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What are two key challenges you face in providing breast cancer information?

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## Appendix IX - Responses to Questionnaire for Information Providers

### Information Providers Focus Groups and Interviews

Total: 24 questionnaires completed

#### Employer

	Ottawa	Thunder Bay	Toronto	Total
Cancer Centre/Hospital	1	2	6	9
Information/Support Organization	2	1	5	8
Breast Assessment Centre	3	2		5
Remote Healthcare		1		1
Other Health Care Professional		1		1
Total	6	7	11	24

#### Function

	Ottawa	Thunder Bay	Toronto	Total
Nurse Practitioner/ Nurse	3	5	3	11
Social Worker	1		2	3
Administration/Facility Manager		1	1	2
Community Services Manager	1			1
Counsellor			1	1
Diversity Consultant			1	1
Health Promotion		1		1
Information Specialist /Librarian			2	2
Program Manager, Peer Support	1		1	2
Total	6	7	11	24

#### At what point do you interact with most clients/patients? (check one or more)

At diagnosis	17	37%
During treatment	15	33%
After treatment completed	14	30%

#### What general approach do you take in providing breast cancer information?

- One on one counselling, use of general plus individualized information
- Developing evidence-based materials
- Coordination of a regional approach to information provision
- *Not overwhelming patients with verbal/written information*
- *"This is here (material)" or "I am here" when you are ready for it*
- *providing accurate, research-based information*
- Consistent with information tools, i.e. guide, community resources, etc.
- Open with patients' and families, support, reinforcement, teaching

- *I start finding out what they already know, enabling them to find gaps in their knowledge and directing them to sound, accurate sources of information (usually my colleagues) and ensuring that this is accessed easily and in a timely fashion*
- Offer whatever information is available for the given situation
- Provide the tools to enable the individual to be more confident in their ability to filter through the information available
- *Empathy, non-judgmental*
- *Traditional (medical information versus homeopathic)*
- Ensure it has a regional focus
- Ensure that information is low-literacy
- *Explanation as to what is involved in screening, getting a diagnosis*
- Work as part of a multi-disciplinary team, team members meet with patient
- Print information, chemo classes, referral to support group
- *Speaking with women and families - using pamphlet*
- Listen to patients' concerns, try to find support for patient and follow-up
- *On Breast Cancer Coalition—hope to give women information at right times—need "Primary Prevention"! Canada has one of the highest rates of breast cancer in the world, also Ontario does not have the lowest rate in Canada, why not?! Cancer Clinic does not put a high priority in involving themselves in the community working with others. Primary prevention needs to be looked at more! The Cancer Clinic rarely has anyone show up at Coalition meetings.*
- Providing pamphlets, telephone assistance
- Extensive discussion with client to determine what their needs are
- Support by talking with someone who has experienced the disease
- *I do not specifically provide breast cancer information as my work is focussed on developing the capacity of the Canadian Cancer Society to work with under-served communities and to support cultural competency and community development practices among staff*
- Peer support provides information on where to get breast cancer info, i.e. Willow, Canadian Cancer Society, library information, cancer-specific support groups
- *Clarify what information is needed*
- *I will provide information to the extent I am able, may refer to primary team for further clarification*
- *Refer to printed info, community agencies*
- Confirm that patient has received the "New Patient Binder"
- For new patients I point out in-house resources, library, dealing with cancer stress
- Sometimes mention Willow but in general I am more focussed on giving info regarding chemotherapy

- *Verbal discussion and try to follow-up with printed materials*
- Tailoring info according to learning style of the patient
- Recognizing level of need for info
- *Written—information "brief" given at surgeon's first visit, only when a patient is obviously not coping or has financial issues am I (social worker) called in*
- *I teach a pre-surgery class*
- Medical and psycho social information provision should be part of standard care received by all patients with breast cancer and their families
- Screening for individual patient and family needs for information specific to their needs

### **What resources do you usually provide or refer people to?**

- *Personal Breast Cancer Information Guide ("Blue Book")*
- Breast Cancer Action Ottawa, Canadian Cancer Society
- Cancer Centre, including library
- *Being available personally*
- *Written information*
- *Emotional support (S.W.) or bringing patients back to see their physician*
- Canadian Cancer Society, Ottawa Regional Cancer Centre, Breast Cancer Action
- Our guide and tape (music and surgery experience)
- *My colleagues (nurses, surgeons)*
- *Community resources if they need peer support*
- Peer support if requested
- Medical community re: Women's Breast Health Centre, Ontario Breast Screening Program
- *Canadian Cancer Society Cancer Information Service (CIS)*
- *Patient's own health care professionals*
- *Libraries at treatment centres*
- Brochures, pamphlets and web sites
- *Supportive care, cancer clinic*
- Printed material
- Supportive care program at Cancer Centre, Breast Centre
- Chemo class
- Look Good, Feel Better program
- *"If You Have a Breast Concern" pamphlet*
- *Cancer Information Service, Willow*
- Variety of web sites, telephone lines

- Many! Willow has thousands of articles about breast cancer and organizations that we refer to
- *Library, CIS, Willow*
- CIS
- CancerConnection program - Canadian Cancer Society; Willow, Wellspring, CIS, written material from the Canadian Cancer Society, and various publications by pharmaceutical companies
- *Patient and Family Library (PMH), Willow, Canadian Cancer Society, other health care team members*
- Blue patient binder, Willow resources, *Coping with Cancer Stress*, A. Cunningham, social work mostly
- *Support groups, web sites, pamphlets, etc, social workers*
- Refer to PMH info package binder
- Community agencies (e.g. Willow, Canadian Cancer Society, CIS, etc.)
- *Refer to Wellspring, Willow, often phone CIS regarding transportation and groups*
- *CancerConnection program*
- *Community Care Access Centres*
- New Patient Information Binder (PMH), breast surgery teaching class, survivorship booklet
- Medical and psycho social information to prepare patients for each episode of care (surgery, radiation, chemo, survivorship)
- Information needed in languages other than English (Breast Cancer Fact Sheet in 10 languages, chemo and radiation booklets in Chinese)

### **What are two key challenges you face in providing breast cancer information?**

- Up-to-date information
- Sustainability funding for materials
- Consistency across region
- *1. Knowing what is personally best for each patient (some patients don't want to know)*
- *2. Having available information to provide to patients to initiate them in the next phase of their care, i.e. Cancer Centre*
- lots of web sites if these are appropriate for particular patients
- some patients are fearful of new information
- *keeping myself up-to-date on the "latest"*
- *knowing how much to give at any given time within the women's journey to avoid overwhelming or overloading them*
- Verifying if the information at hand is the most current and accurate
- *Misinformation in media (or studies not reported accurately)*

- Getting women to take full advantage of our program
- The amount of literature/information available
  
- *Knowing what up-to-date "best practices" are*
- *Knowing who to refer people to, to talk about diagnosis Rx*
  
- Knowing where to access current information and research
  
- *Share with other cities, priorities! Share! What works there? Knowledge is power, sharing knowledge is more powerful*
  
- Getting the information to clients/patients
- Having appropriate information for the education level of the client
  
- Marketing the service (that exist)
- Keeping up with the flow of new information
  
- *Language, cultural barriers, working with people who have disabilities*
  
- Awareness of all the resources
  
- *Time*
- *Being with patient at time they are not overwhelmed with diagnosis or discussion of why chemo is recommended*
- *Often too emotional to give too much info*
  
- Lack of various multicultural printed materials
- Lack of appropriately medically-trained interpreters
  
- *Biggest challenge is where there are no resources—medication costs (not on formulary - Trillium, etc.)*
  
- Funding
- Development time

## Appendix X - Breast Cancer Survivor Focus Group Evaluations

### Kingston

#### What did you like about the session?

- opportunity to re-examine the process from diagnosis to treatment, surprised to know/remember I sat on literature I was given . . . we move at a pace appropriate for each of us
- I liked idea of a comprehensive bank of knowledge one could plug into rather than the hit and miss system we appear to have in place
- *The session allowed us to be open and honest*
- The chance to share experiences and information; I enjoyed it thoroughly
- *I liked the informal way it was run*
- I liked getting together with all the women and see that we all have a similar experience regarding our cancer diagnosis
- *Sharing of information*
- *Speaking independently*
- *Session was well conducted and handled professionally*
- *Liked it all, glad I participated*
- Well organized and structured, professional and respectful
- I felt comfortable in a comfortable environment
- Well prepared and knowledgeable with specific questions to discuss, it was very good
- *I enjoyed the round table discussion and that my experience may help someone else*
- I liked knowing there will always be a ongoing support of people that care concerning breast cancer, I enjoyed hearing everything
- *Informality, the meeting stayed mainly on the subject*
- *The time frame seemed very appropriate (as we were running down, it was over)*
- *The green peppers*
- Very informative session with excellent exchange of ideas
- Unable to pinpoint anything I did not like
- *I liked the ability to share our own stories and thoughts*

#### What did you not like?

- the complete departure from topic we sometimes achieved (interesting as they might have been at times)
- *some people did not speak—perhaps having each person talk on a specific issue*
- I enjoyed the session however it could have gone on longer. I think people still had things to say
- *I found the session short even though two hours had passed*
- I can't think of anything I didn't like, maybe hearing about horror stories while people were getting a mammogram
- *The purpose for gathering this data was not clear. When you collate these experiences what use will the information be put to?*
- We often went off track in regards to answering the specific questions. It's not that I disliked it, only that it was fairly evident that we wanted to share our own personal stories

#### What would you recommend for future sessions?

- use of round the table contributions
- *perhaps when individuals are invited to a focus group session, you could give them a specific question to think about ahead of time in order to help with the discussion that evening*
- I believe the session was well organized and presented
- *Longer session?*
- Make a small simple info book
- *Use of a video*

- I would be interested in knowing how many years individuals have dealt with cancer

**Is there anything that you would like to say that you didn't have a chance to raise during the discussion?**

- thank you for your interest and work on this topic
- *I am interested to know how you deal with your fears of cancer returning*
- Getting a tape recording when getting information about chemo, etc.
- *It's wonderful to see such a dedicated work being focussed on an important topic that affects so many women and their families*
- I really had problem with lack of direction after diagnosis - GP - surgeon - plastic surgeon — what happened to the oncologist in this? I wasn't sent to one till there was a problem; providing information to the patient from the GP as to what happens next and why
- *I'm not a great talker, I keep a lot to myself and I wish I had gone to Breast Cancer Action Kingston at the beginning*
- I believe I said everything I wanted to say regarding the questions that were asked

**Are there still areas where information gaps exist? If so, what are they?**

- especially in Kingston information on lymphedema information and treatment
- gap between diagnosis, surgery and treatment—no man's land before treatment
- *nutrition*
- I think all the information we need is out there, we just need to organize it into a more comprehensive, organized format
- *More information on the importance of strength training after treatment*
- *Lymphedema*

**Other Comments**

- *I'm on the International Women's Year Committee—would it be helpful to bring up Women's Health issues and information regarding breast cancer?*
- We are responsible for our own situation, we must be our own advocates or at least know to find ourselves an advocate
- Cancer is not an acceptable part of our society. People are too terrified of it to deal with it well. Until the aspect of horror is ameliorated by knowledge and openness women will have a difficult time dealing with the diagnosis
- There is a clinical trial I've heard of for prostate (I think) that helps people make decisions about which treatment to choose. Can something like that be made available, especially for young women with breast cancer?
- *Regarding the issue of the buddy system, you would go through a screening session and a course to enable you to help others*
- I had a very positive experience with regards to my diagnosis, treatment, surgery, etc, however as a retired nurse I worked in a very high stress area in a hospital and eight of my co-workers have been diagnosed with breast cancer, three have died, two are now terminally ill. I have expressed my concern re this to our personnel health nurse, our nurse clinician and my surgeon and I remain quite frustrated that I haven't been given any positive feedback re this. I was very fortunate that my breast cancer was less invasive than my co-workers as well I was the only one not on HRT.

12 evaluations submitted

## Ottawa

### 1. What did you like about the focus group?

- People sharing their experiences
- *It was a very well rounded group*
- Material covered was very relevant, well organized
- *I enjoyed being able to contribute to the improvement of care*
- *I enjoyed the sharing and the opportunity to express my opinions and feelings*
- The wonderful information
- *Everyone had a chance to participate*
- The synergy of the group, it was wonderful to hear all of the opinions and suggestions of all the members. The group was the right size, any larger or smaller would probably have a negative effect on the outcomes.
- *Chance to hear from other women about their experiences and ideas*
- Very informative
- *Opportunity to have input to improve situation for others*
- *Everybody had a chance to speak, sharing with others*
- *Dr. Fitch and Irene were great — very well organized*
- The size of the group was important. It allowed for lots of different viewpoints yet everyone had ample opportunity to speak.
- *Great ideas*
- Well managed, great diverse points of view and size and set-up seemed ideal

### 2. What did you not like?

- *People talking about their own experiences*
- I saw we all worked together
- *An extension of the meeting from 2 to 2/12 hours would probably allow more "brainstorming" and more input*
- The discussion at times ranged so was frustrating to get things back on topic
- *Never enough time*
- I believe that too much time was spent on personal stories and some of the focus was lost

### 3. What suggestions would you make for future groups?

- Perhaps more structured, keeping on topic—people strayed
- *Chairperson to keep it on track*
- Keep the group to one of approximately this size and try to ensure that it is as diversified as this one was
- *Day group*
- A "gentle" reminder that there is a tendency to stray at the beginning of the session may help stay on track
- *Keep the good ideas flowing and educate people*

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- We are making great strides; people are more open about cancer
- We have all been touched by cancer and we need to fine tune, I think everyone is ready today
- *We need more interaction between the medical resources and community resources in order to find better ways of disseminating information*
- We need to educate
- *Information at the appropriate time is extremely important. There is no sense in learning about all the chemo drugs if you are not going to need chemo. There are always improvements in the medical*

*community through time so when you need it, that is the time to learn about it*

- The focus needs to be on the woman, as a whole person (physical, mental, emotional and spiritual), as well as support for spouses, significant others, kids, glad to see more is available for them
- *Women are caregivers and nurturers—we are taught that it is better to give than receive--when you are diagnosed with breast cancer you need to put yourself first and don't feel guilty*
- *Also, people want to help you, it makes them feel good so let them*
- I have heard from many women that verbal information or discussions, questions etc. are better fielded by women, nurses, social workers, etc. as there is more empathy

**5. Are there still areas where information gaps exist? If so, what are they?**

- Doctors' offices
- *From the surgeons before being released from hospital and after it is all done, meaning treatment is finished, information on what happens if the cancer returns*
- I think this was well discussed
- *GP— where it starts*
- GPs need to be better informed and to take women's concerns more seriously. Too often we have young women like 20's, early 30's say their GP told them they had nothing to worry about because they were too young for breast cancer but now that they have been diagnosed the cancer has spread and they not only need surgery but also chemo.
- *I believe that those in urban areas will eventually have access to the information they need, probably in the foreseeable future. The real challenge is to provide support to the women in the rural areas.*
- The book give to me through the women's breast health centre was a valuable, practical resource. Everything from the calendar, places to write down information to the information on what to expect at various stages, factual information and the stories of individuals including spouses
- *We've covered everything pretty well*
- Lymphedema—there are still doctors that do not recognize the condition! How can you expect information about something that "doesn't exist"?
- *Gaps appear especially at the GP level*
- *Here in town, perhaps the GP could at least be "trained" to send women to the Women's Breast Centre (might be easier for that step rather than re-educating the already overworked GP*

13 evaluations submitted

## St. Catharines

### 1. What did you like about the focus group?

- I like to hear women supporting each other. A lot of good ideas were suggested and hopefully some of them will be implemented.
- *Open, honest conversation*
- Gathering information from different people, sharing of ideas
- *A chance to share ideas, listen to others and get some things off my chest (no pun intended)*
- The opportunity to meet with other women and to have an impact on the information future breast cancer patients receive
- *A forum to share information*
- It was wonderful to relate and share advice and our experiences together
- *Friendly, ready to go, good leadership*
- *Organic tea?*
- Everyone had a chance to share
- *The open forum*
- Open sharing and opinions - good suggestions re: information

### 2. What did you not like?

- Nothing. It was very good and Marg was a very good facilitator and did very well at keeping us on track.
- *Maybe need 1/2 to 1 hour, I suppose, to continue with any further advice as I would like to help as much as possible*
- The time could be longer, 15 or so ladies have lots to say about such a serious condition
- *Could have discussed if more time allowed*

### 3. What suggestions would you make for future groups?

- None. I felt this format worked very well.
- *Discussion on healthy living with a view to presenting cancer*
- Perhaps giving a list of questions (topics of discussion) by e-mail for participants to reflect on ahead of time
- *Have a set of questions forwarded ahead of time so we could possibly have all kinds of wonderful answers and lost of advice. Otherwise, no real suggestions, it was wonderful!*
- Effects of tamoxifen and alternatives

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- No. I was able to say everything I wanted.
- *Too much time between diagnosis and treatment.*
- I had a chance to say my piece, thanks!
- *Information should also be provided on referrals to places for wigs.*
- Every surgeon and family doctor, as well as breast screening clinics should have a short but detailed list of web sites and support groups that can be reached for information

### 5. Are there still areas where information gaps exist? If so, what are they?

- Yes, but I feel this was all discussed tonight.
- *Between oncologists, doctors and patients*
- Most importantly where can I get the most accurate information about treatments, surgery, etc.
- *Yes, as we discussed.*

- I would have liked more information on antioxidants and radiation but my oncologist admitted he didn't know. I realize research in the field is in an early stage but women should know that they may be very beneficial and not harmful.
- *None that I can think of*
- I thought this was a successful evening -- than you
- *Drugs available and alternatives, i.e. tamoxifen, aromasin, letrozole*

11 evaluations submitted

## Burlington

### 1. What did you like about the focus group?

- That the research/study will benefit the patients
- Everyone had different experiences
- *Ability to voice opinions and hopefully able to help others with this information*
- The fact that everyone understand each other even if our experiences were different
- *Very relaxed about sharing feelings and information*
- The idea of the project was good
- Relaxed atmosphere; the people; clearly explained
- *Listening to all of the group members experiences*
- Finding out other people's reactions, knowing you are in good company
- *To be able to express your feelings and opinions*
- Friendly and informative
- Written information sheets
- Well organized
- *Sharing*

### 2. What did you not like?

- Sometimes the actual topic was not being discussed
- *Nothing (2)*
- The deviations of the group from the question that was asked to other very personal issues
- *Not enough time*
- I wish it was longer. I found it went too quickly.
- *Nothing really, it was very interesting*

### 3. What suggestions would you make for future groups?

- Longer time period with less people in group
- *Not sure as so much was said and I could have stayed much longer*
- A little more structure and direction from the leader
- *Let them talk it out*
- The facilitator was trying to keep the group focus, should have interrupted the group when they went off topic

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- I think I said it all
- *How did chemo affect the women around me in comparison to myself*
- *How to deal with insurance companies*
- There is a lot of information out there
- Maybe some education regarding using libraries and Internet resources
- Keep asking questions
- I am interested in helping myself with good nutrition
- *I have found conflicting information regarding supplements, soy, etc. Doctors don't want us to take any vitamins.*

### 5. Are there still areas where information gaps exist? If so, what are they?

- Clinical trials
- Treatment decision, e.g. what type of chemo to use
- *Not for myself—I have more information to read at home but after five years don't feel the need to read it at this point. I feel that all the information I received was good except that I only found out about Wellwood almost a year after I finished my treatments.*
- I still do not understand very much about the stages and grades of breast cancer
- *Depends on what you want . . . If you know what you want there is a lot of information available. You really must be your own advocate.*
- I found that there should be communication between the GP, the surgeon, and oncologist. They all work separately. I feel that the waiting time would be lessened if communication was opened.
- *Educate women before they get cancer*
- Doctors-Surgeons, definitely need to have packages of information

11 evaluations submitted

## Sarnia

### 1. What did you like about the focus group?

- Lots of time to voice opinions
- Organized well
- Facilitated well
- Kept on time
- *The open and truthful answers*
- Open sharing
- *Good discussion*
- Able to speak and not get interrupted — can speak freely
- *That it happened! (good luck!)*
- Freedom to speak freely
- Facilitator was always in control with directive questions
- Very informative (2)
- *Hearing different perspectives*
- More information available
- Different experiences discussed
- *Being able to share information*
- I liked hearing from fellow cancer survivors' stories that had the same difficulties in gathering specific information as I did

### 2. What did you not like?

- Nothing (8)
- *Length of time — maybe an extra hour*
- Learning where to find information
- *That we seemed to get off topic at times*

### 3. What suggestions would you make for future groups?

- Keep it open
- *Same format would be good*
- Keep in touch with new cancer patients
- *Perhaps begin with a 2-3 minute introduction of "your story in a nutshell" to identify our uniqueness*
- To have everyone participate
- It was effective as is
- More time
- *None*

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- No (8)
- *All was said, all had a chance to speak*
- Not knowing what specific questions to ask a health care person

### 5. Are there still areas where information gaps exist? If so, what are they?

- Doctors that speak in English (not medical terms)
- *Doctors should give more information about patient's condition*
- Yes (gaps exist)—who to contact for information needed as each individual may need different information
- *Physicians should be more informed, need pamphlets at doctors' offices*
- Information on cost of meds and prostheses

- *Brochures are not available in all doctors' offices where you first get the diagnosis*
- Information from the surgeon
- *Doctor protocol -- when do you call surgeon, oncologist?*
- Yes -- verbal answers from doctors to patients

13 evaluations submitted

## Woodstock

### 1. What did you like about the focus group?

- The open discussion format was beneficial for candor in the group
- *Meeting other women in similar situations*
- *Finding out that I actually was given good information at the time of diagnosis*
- Open dialogue among participants
- Sharing of personal experiences
- Size of group was good
- *Realizing that others experienced the same frustrations*
- Hearing advice and opinions from the others
- *The openness and revealing*
- The fact to share experience is very good
- The conversation was nice to hear and people talked so freely
- *Everyone talked freely about their experiences with chemo and surgery*
- Informative and supportive
- *Meeting with other survivors and getting a few things off my "chest" and others feeling the same too*
- Being part of a group who will make a difference in the future for women requiring information
- *Everyone had the opportunity to speak*
- The knowledge that other ladies had the same problems and the honesty of the ladies
- *Good size in numbers, relaxed*
- I found it interesting to see such different experiences and different ways of handling the gathering of information
- *Meeting others*
- *Hopefully offering information that can help others*
- It was a relaxed chat group that gave use opportunity to connect with our own experiences and shared ideas
- Thank you for the refreshments
- *I like the chance to ask questions that I had not found answers to before*
- It was small
- Participants were all recent cases
- Good to hear other people's experiences
- A chance to ask questions
- Hearing other people's stories, seeing people my age
- *People were very honest and open*
- *Good to be able to give perspective/advice*
- Sharing of information
- Face to face contact with other women

### 2. What did you not like?

- Nothing (6)
- *A few too many in the focus group*
- Leader didn't keep group on topic
- *Time limits*
- Everything good
- We were a bit squashed, so were slow getting started
- *I have no faults to find with this focus group*
- Enjoyed whole evening
- *It was all okay*

### 3. What suggestions would you make for future groups?

- It really was very well organized and structured, I couldn't make any suggestions
  - *Keep them to 8-10 people a group*
  - Extend length of time to 3 hour meeting—to allow time for discussion
  - *No*
  - Make sure you will contact different groups and nationalities if possible
  - *More time for discussion*
  - More structure
  - *Longer discussion on topics (2)*
  - Smaller groups
  - What are the symptoms after a year of breast cancer?
  - Rent a space if necessary
  - *Have introductions first*
  - *Same format, organized - agenda*
  - Continue to have them
  - Include family members too
- 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?**
- *How everyone is feeling one to two years after treatment*
  - No, very comfortable atmosphere
  - *No (8)*
  - What about the husband and wife relationship after?
  - *I was very lucky—I had the Canadian Cancer Society where I got all the information I needed*
- 5. Are there still areas where information gaps exist? If so, what are they?**
- Reconstruction options suggested before surgery (3)
  - *Lymphedema (2)*
  - *Type of breast cancer*
  - Can't think of anything
  - *Probably*
  - The fact about the breast getting bigger and the scar getting fat
  - *The doctors need to give out information or tell you where to get it*
  - What do you do after treatment ends? (end of your medical appointments)
  - *I think with the GP there should be more information provided at this point, possibly referring to meet someone through Reach to Recovery program, most comfortable and supportive*
  - Doctors need to give correct information—my surgeon gave incorrect information regarding chemo
  - *I have found the info I needed*
  - Use of natural supplements or alternatives to conventional treatments—I think there should more information available

23 evaluations submitted

## Windsor

### 1. What did you like about the focus group?

- It was very informative as a discussion group
- *Very information, hope it was of some help*
- The size of the group -- 3 small groups
- *Information given from others that I didn't know*
- I liked it very much
- *Good opportunity to share stories and get advice*
- The mediator and the way she directed the questions—excellent
- *All women have had breast cancer and we had a lot in common and were able to discuss it seriously*
- Concerns and issues were discussed and hopefully more awareness and information can be shared with others facing breast cancer diagnosis
- *That it was small; everyone could speak in the time frame given*
- Having a chance to hear how others cope
- *The sharing of information by women, it's wonderful to hear other women's stories*
- Information for my use
- Being able to contribute to such a program
- *Hearing what other women went through, how they cope with their cancer and how they got their information*
- Sharing of information, privilege to be among such strong women
- *Felt honoured to be asked my opinions*
- *Enjoyed talking with other survivors and hearing their experiences*
- *Small group was good—less intimidating to speak up*
- We had a thorough discussion. I was able to say what I wanted to say. Also, I learned a lot from the other women's experiences/sharing.
- *Common issues. Felt like I am not alone in my opinions and issues.*
- Meeting other ladies so willing to share their information.
- *Sharing information with other women.*

### 2. What did you not like?

- Liked it all
- *Off topic discussion*
- All seemed fine
- *Nothing (4)*
- Nothing, it was very helpful
- *Nothing to dislike*
- Really it was great overall

### 3. What suggestions would you make for future groups?

- Keep well informed
- *Maybe stricter guidelines—more direction*
- Got information, but have further (questions?)
- To come to the forums and listen
- *None (2)*
- Limit speaking time if narration becomes a "journal", if there is enough time set aside then it's okay of course
- *Keep information available. Have doctors give you literature when first telling you that you have cancer.*
- Mail information sheets to participants so they can think about what they want to say and get their thoughts in order.

- *We had a small group and it was really effective. Everyone got a chance to talk.*
- Do not be afraid of what to say. All information is good, go with a good attitude towards yourself and towards life.
- *Involve people, i.e. can give and their experience with having a loved one diagnosed with cancer*
- Keep on asking and talking about how to improve information and support
- *Maybe an activity to break the ice. A bingo could be funny using the new treatment words or something not as long—try to lighten up a bit.*
- Perhaps a speaker to speak on a specific topic.
- *This was a broad topic—maybe focussing in on one or two important issues for more indepth discussion.*

**4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?**

- No (6)
- *Psychologically felt lost control of my life and needed psychological treatment*
- *Received it with cancer treatment*
- People that have not gone through any cancer tend to be free with advice. Although well intentioned they don't ease the pain.
- You covered everything very well. Hope you are satisfied with our answers.
- *The fact that it was so wonderful to hear other women's stories leads one to believe that perhaps a publication containing such stories would be helpful to hand out to newly diagnosed women.*
- A woman should not be alone with her cancer. Her doctor should provide a volunteer to be with her.
- *Actually it shared more information than I thought it would*
- Try to start positive, creative visualization. Try to imagine the nurturing of your body and soul. Yoga. Quiet music. Poetry, etc. Try to keep your mind relaxed and open to be better at making decisions about treatment.
- *Felt comfortable and had time to voice my opinion. This focus group was an excellent experience and I appreciate having an input.*
- This has been a great opportunity to articulate my story and my hope for the future. I learned a lot from the ladies.
- *Wonderful evening for which I did say thanks*

**5. Are there still areas where information gaps exist? If so, what are they?**

- No (2)
- *Early information at GP's office—when you are told it is the worst time—even a phone number to call for information*
- Everything seemed to come out through verbal talk
- *Newsletters, maybe by e-mail with updates, new discoveries, etc, advice on health*
- Doctors—offer NO pamphlets, etc.
- *When first diagnosed, information should be given so you can read it at your leisure*
- A central (Internet) area for information that is sanctioned by the Canadian Cancer Society
- *Perhaps when too much time passes between chemo and radiation, and a patient gets concerned why things are not progressing faster, maybe the doctors could tell the patient and calm him/her down*
- Yes. Informing a woman she has cancer. Say it with a little more consideration to how she feels on the big "C". Inform people of book available at the Hospice and Cancer Society right away.
- *Information on being tired*
- Financial concerns
- Assistance with helping children cope
- *Information re: support system/group*
- *Information re: what to do after treatment is done*
- The doctors don't communicate well. Also, GPs need to be involved as the "clearing house" or

manager of your treatments.

- *Yes. Doctors information—not enough explanation of information*
- How to access support groups or other agencies that can help. Many thanks for a very positive experience.
- 1. Follow-up care - difficult in knowing what to do next
- 2. Family counselling - maybe by the doctor to sit down and explain to husband and children about your illness. I tended not to include my family in my illness--"I was fine"

20 evaluations submitted

## Dryden

### 1. What did you like about the focus group?

- All my questions were answered
- *Everyone was very honest*
- We get a chance to speak one by one and view our own opinions
- Enjoyed the session very much
- Was a great round table discussion
- Was happy this study included Dryden and Northwestern Ontario
- *The session was well organized and run in a timely manner*
- We could sit down and discuss our ideas, learn from them and hopefully brought some new light to the study
- *It was good to feel a fellowship with the group members*
- *It felt as though people really opened up and took part*
- The opportunity to discuss concerns openly, to hear what others have to say about their treatment
- The feeling that others have same concerns and the that those concerns will be brought to the attention of decision makers
- *The potential that what we've talked about will be acted on—and that our concerns will help others*
- *Sharing of experiences and thoughts (cathartic!)*
- *Moderator Margaret!*
- I liked everything—it was informative, interesting, and wonderful warm sharing, terrific!

### 2. What did you not like?

- Nothing (3)
- *Too short*
- I really can't say I didn't like or enjoy this evening—it was hopeful
- *I appreciated it all*
- I liked everything, there was nothing not to like, thank you

### 3. What suggestions would you make for future groups?

- Very much of the same information
- *Make the meeting longer—force everybody to speak not only two or five or whatever*
- Keep up the good work!
- *Maybe it could be a little longer*
- *I found the focus group encouraging*
- How we as patients can help to get the information out to others
- *Would have been able to possibly give more suggestions, had I time to do some thinking about the "themes" ahead of time—I wouldn't have minded a little "homework" before the meeting*
- I think this covered everything about our concerns and was very well correlated

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- Nothing—all the topics I wanted were answered
- *No*
- That there are also positive points living in Northwestern Ontario and getting treatment in Thunder Bay
- *I felt I had adequate time to have input*
- Thank you so much for coming
- Keep up the great work
- *The personal touch of a nurse or physician*

- I could have raised this point but chose not to. There is not a lot of information for patients whose cancer has metastasized. I found the information and support I needed from a book by Musa Mayer.
- *Follow-up is recommended—I sincerely hope that the combined efforts of your participating groups will ensure an easier time for future breast cancer patients*
- Thank you so much—a most enjoyable focus group!

**5. Are there still areas where information gaps exist? If so, what are they?**

- None (2)
- *In between treatment and diagnosis*
- I think all the areas were addressed by the group
- *I think we covered just about all of it*
- Clear medical reports
- Suggestions of places to go for information
- Suggestions of people to see, re: groups
- *As in #4 -- I received lots of written information at first diagnosis but nothing once the cancer was at stage 4*
- Waiting for test results
- Waiting for treatment
- Waiting for appointments
- *Wish we had an advocate to answer our questions and quiet our fears, because our doctors are so overworked, don't have time*

10 evaluations submitted

## Thunder Bay

### 1. What did you like about the focus group?

- This was a very dynamic group and it was great to listen to everyone's perspective about breast cancer and the journey
- Also that everyone could speak freely and not in a specific order
- *The fact that it was so open and not strictly structured*
- All of it! I thought Margaret was a wonderful facilitator and I liked that everyone had a chance to speak.
- *Informal meeting, easy to speak and small number of participants*
- *Everyone was validated in their experiences*
- *No pressure to speak*
- It was a nice, open group, lots of opportunity for open discussion
- *Loved listening to everyone's stories*
- *Great ideas, I wasn't alone in the process*
- Similar experiences or ideas
- *Sharing, accepting listening of moderator*

### 2. What did you not like?

- At times it raised a lot of emotions that were put rest
- The stipulation that one had to be a three-year survivor
- *Nothing--found it all very friendly*
- Not long enough
- *Nothing (2)*

### 3. What suggestions would you make for future groups?

- I think everything that was done was great!
- Perhaps a question as to how long a survivor everyone was would have been somewhat beneficial
- *The different age groups add something special and offer a wider range of information*
- Make it a longer session or a two-part session as us women like to talk a lot!!
- *Perhaps have focus groups with specific criteria, e.g. age—have different concerns at different ages and stages of life*
- No suggestions (2)

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- It was very open! Thank you, great focus group
- *Feel we could have spent more time on spousal support*
- I would like the health care profession to look at treating the person, not the disease and look at the holistic approach to this
- *Thank you so much!*
- No
- *No—I had excellent care during my cancer*
- It was important for my girls to understand and know information as I was going on for a positive journey
- Hopefully everyone has provided you with enough information without us going off in different directions

**5. Are there still areas where information gaps exist? If so, what are they?**

- Dissemination of information to women in the remote and rural areas
- *Regarding return to exercise and information about what exercise will help us after surgery*
- Stats—not always what they seem to be!!
- *No comment at this time*
- I think we are left to finding our own information often leading us to incorrect or inaccurate information
- It would be nice if patients could be provided a suggested reading list
- *Excellent format*

8 evaluations submitted

## Appendix XI - Evaluation of Information Providers Focus Groups

### Ottawa

#### 1. What did you like about the focus group?

- Well organized
- Based on specific themes
- Stimulated thoughtful process re: information provision
- *Discussion was well introduced and presented so we had a good grasp of what you were after/your goal*
- *It was easy to express our views, good probing questions*
- Hoping it will serve well the study, it is important to get all the players together
- Well moderated
- *Exchange of information*
- *Hearing the different challenges*
- *Recognizing the need for more collaborative efforts*
- Openness/willing to listen
- Dedication to provide continuity of care to women

#### 2. What did you not like?

- Have more regional representation
- *I personally feel there are too many groups (30-70) out in the community*
- *Money and efforts need to be channelled to provide continuity in the information provided*

#### 3. What suggestions would you make for future groups?

- Opportunity to hear the results of all of the focus groups and resulting recommendations
- *Seems fine*
- Try to invite all groups representatives event patients and physicians either GPs or surgeons
- *None*

#### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- We do have a new decision-support centre in the hospital that may be helpful
- *The need for a comprehensive tool that is adaptable to the various communities*
- No

#### 5. Are there still areas where information gaps exist? If so, what are they?

- New technologies for diagnosis, adjuvant therapies
- *As we said, not so much gaps as much as cohesiveness and consistency of information to avoid confusing women*
- Port-a-cath accessibility for chemo
- The B? Maybe in young women it should be done during lumpectomy or mastectomy
- *Accurate information is not being conveyed by volunteer agencies. This is confusing and anxiety-producing to patients and their families*

5 evaluations submitted

## Thunder Bay

### 1. What did you like about the focus group?

- Felt I could freely express myself both as a health care provider and a breast cancer survivor in the milieu
- *I liked Marg walking through the cancer continuum and stopping at each point*
- Lunch was excellent
- Hearing about other people's experiences
- Good range of professionals from various "points" in the patient journey
- *Very relaxed*
- *Good open-ended questions*
- I really liked the way in which you asked us for "our perspective"
- I didn't have to sound like an expert, I could just tell you what works for us
- *Identified gaps in this region for services and information*

### 2. What did you not like?

- A little more background on this project—some reading material or bibliography to take home with us
- Where was a physician? If they are so key, is it not imperative to have one at a meeting?
- *Large tables, less intimate setting*
- Nothing (2)
- *Not enough people who directly deal with patients*

### 3. What suggestions would you make for future groups?

- Include physicians
- A male perspective
- Include a few more agencies, e.g. a hospital employee!! (we are saying the hospital should be a key place to share information)
- *Include a physician, social worker from the cancer centre, someone interviewed in palliative care*
- Maybe more participants per group
- Maybe give some of the "questions" ahead of time so participants can think about it
- *Add a physician in the group*
- Can't think of any

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- Sometimes it is a concern if I am staying within my designated role in sharing specific information
- *No (2)*
- Need to address providing cancer care to rural areas (not just information)

### 5. Are there still areas where information gaps exist? If so, what are they?

- No one "safe" to talk to during process
- Someone with trust and someone to share emotions with
- Best practices information for all
- *Low literacy information, particularly on breast assessment*
- Physicians need to know what information is available

7 evaluations submitted

## Toronto

### 1. What did you like about the focus group?

- Allowed for sharing of information
- Good to hear the reality of situation
- Hope the study is utilized
- *Good diversification of career backgrounds*
- *Excellent opportunity to learn about resources available*
- Food was lovely
- Opportunity to connect with others in the same field
- Learn of what others are doing
- Actively participating in broad planning
- *Variety of organizations represented*
- *Learning that so much is actually available*
- Networking
- Learning about initiatives by other agencies
- *Excellent to share/learn*
- Informality—varied backgrounds of participants
- *It was great, I think a lot of good information was shared giving greater understanding of services provided*
- Learning about the issues patient's identified
- Sharing with the group
- Learning about the services of several of this group's member organizations which I was not aware of
- *Meeting colleagues*
- *Great lunch*

### 2. What did you not like?

- A bit more focussed, but not a big issue
- *Nothing, very well organized*
- Prefer a bit more structured group discussion
- Nothing
- *I've covered this ground many times before I'm afraid*

### 3. What suggestions would you make for future groups?

- Possibly focus on one theme—for example, methods of information distribution
- Capacity development for various community development approaches
- *Offer break before meeting starts*
- More focus on topic - went off track with good information and topics to explore
- I have never been in a focus group so I am not sure if OK to go "off" from questions asked
- *What do women really want in info provision*
- More time, more patients
- *Perhaps providing scenarios and discussing what info or services should be provided*
- More detailed questions

### 4. Is there anything that you would like to say that you didn't have a chance to raise during the discussion?

- First focus group
- *What women prefer in how info is disseminated (e.g. how, when, etc.)*
- No, thank you, excellent
- *No*

**5. Are there still areas where information gaps exist? If so, what are they?**

- Need to look closely at communities that do not or can not access English
- As well we need to understand that not all English speakers are alike, literary issues are important
- Understanding of disease and culture
- *Information on lymphedema (2)*
- I think that the various areas were covered, i.e. time between lump and diagnostic test to getting diagnosis; survivorship; and how to let people know that resources exist
- The information is there but how to get this to people who want it would be beneficial
- *As mentioned, big gaps in meeting multicultural needs of patients as well as women living in rural areas*
- Financial (2)
- Child care (2)
- *Provided my comments during the group*
- I think that the info exists
- People need to find out how they can access it → community organizations

10 evaluations submitted