

Community Capacity Building Project

Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario

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Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario

Introduction

During 2001 in Ontario, 7,200 women will be diagnosed with breast cancer and 2,100 women will die of their disease (NCIC, 2001). When breast cancer strikes, its impact is felt in many ways: physically, emotionally, socially, psychologically, and spiritually. The impact of breast cancer upon a woman, and her family and friends, can be profound and often creates a myriad of issues with which she must cope (Ferrell et al, 1998; Pelusi, 1997; Hilton, 1996). Many women have questions they want answered but say they do not know where to obtain the information they need (Alliance of Breast Cancer Survivors, Breast Cancer Action, Burlington Breast Cancer Support Services, Sudbury and District Breast Cancer Support Group). To make informed decisions about breast cancer women and their family members need easy access to the right information presented in a user-friendly fashion at the time it is needed, regardless of where they live. Additionally, women benefit from access to peer support or interaction from other women who have confronted a breast cancer diagnosis and experienced living with the illness (Gray et al, 1997). These benefits include sharing information, understanding and a sense that one is not alone.

In Ontario, there are more than 700 agencies and organizations involved in disseminating information about breast cancer and/or providing support for breast cancer survivors across the province. The groups included grassroots community-led support groups, volunteer groups, community-based health care agencies, and cancer care programs or institutions. To date, these groups have not achieved entirely effective communication among themselves nor do they necessarily work in collaboration with one another (OBCIEP, 1999). The groups are not entirely aware of what each other is doing specifically nor do they know what resources are available for women from the various groups. As a result, duplication of effort, especially in producing new resources, and gaps in the service of meeting women's needs for information and support still exist. The gaps are particularly evident in small towns and rural settings.

Some progress has been made over the past several years in Ontario in fostering collaboration between and among these groups, especially at the provincial level (OBCIEP Evaluation Report). However, this collaboration needs to be enlarged if the capacity of local/regional communities to provide breast cancer information and support to survivors is to be enhanced. The project described in this proposal has been developed for the purpose of promoting such regional/local collaboration.

Purpose of Project

The ultimate aim of the project was to enhance the capacity of regional/local communities to respond to and meet the information and support needs of women with breast cancer and their families by fostering regional/local collaboration. This particular project was implemented to achieve the following purposes:

- enable regional/local communities to assess their current capacity to meet needs for breast cancer information and support and determine relevant strategies/activities that will increase their regional/local effectiveness; and,
- demonstrate how participation in a virtual community will enhance the capacity of regional/local groups to be effective in meeting needs for breast cancer information and support.

Sponsor and Partner Organizations

The sponsor for this capacity building project was the Ontario Breast Cancer Information Exchange Partnership. The specific partners for the project included the Canadian Cancer Society and Willow, Breast Cancer Resources and Support Services.

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 new Coalition has 38 member organizations and is committed to ensuring information about breast cancer is available to all people in Ontario. 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.

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, website and various communication tools used by our member organizations. Without duplicating the efforts of 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.

Whatever the activity, the fundamental philosophy of the OBCIEP remains in the forefront—the development and dissemination of information about breast cancer is guided by those directly affected by the disease. The strategic directions for the OBCIEP are set by a Coalition of Stakeholder Organizations consisting of 38 cancer and breast cancer organizations from across Ontario. Of all the organizations involved, over half are grassroots and breast cancer survivor-directed groups.

In 1999, the OBCIEP provided leadership for the development of a strategic or action plan for Ontario regarding breast cancer information and support entitled, "The 1999 Ontario Action Plan for Breast Cancer Information and Support". This report was produced following a Think Tank Conference held in April 1999, with funding from Health Canada. The Think Tank was attended by 120 representatives of breast cancer organizations and breast cancer survivors from across Ontario. The new project proposed in this document is based directly on the needs regarding breast cancer information and support that were identified at the Think Tank Conference. The OBCIEP is in a unique position to be the sponsoring organization for this new initiative in capacity building. We have developed a network of relationships over the past few years together with a reputation for effective collaboration and provision of a neutral ground/environment, in which organizations can work together on a common goal.

Canadian Cancer Society – Ontario Division

The Canadian Cancer Society (CCS) 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 (CBCRI). The CBCRI, formed in 1993, is now the primary funder of breast cancer research in Canada.

The CCS 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 Cancer Information Services (CIS) or by contacting local CCS offices. As well, CCS and CIS direct women to services in their local communities that will help them cope with their breast cancer. CCS 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.

CCS 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 CCS 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. Most recently, the Ontario Division made its commitment to the work of the OBCIEP very clear by funding the full-time salary for the position of the OBCIEP Co-ordinator.

Willow, Breast Cancer Support and Resource Services

Willow, Breast Cancer Support and Resource Services 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.

Project Methodology

Project Management

A Project Management Group was formed to oversee the capacity building project. The representatives included Fran Turner, Project Coordinator, and representatives from the three sponsoring organizations, Dr. Margaret Fitch (OBCIEP), Patricia Payne (CCS), Dallas Petroff (Willow), Irene Nicoll (OBCIEP), and five other individuals: Andrea Docherty and Jan Lewkin of the Thunder Bay Breast Health Coalition, Mary Stewart of Breast Cancer Action Kingston, Jackie Manthorne of the Canadian Breast Cancer Network, Sharon Bell-Wilson of the Canadian Breast Cancer Foundation – Ontario Division, and Sylvia Shedden of the Ontario Breast Screening Program. The group met by teleconference twice at the outset of the project and Fran Turner maintained contact by sending updates and interim reports via e-mail throughout the duration of the project.

Project Organization

The immediate target group for this capacity building project included the regional and local breast cancer

organizations in Ontario who have a stake in the dissemination of information about breast cancer or the provision of support to breast cancer survivors. It was anticipated that their clients—women at risk for breast cancer, women living with breast cancer, breast cancer survivors and others touched by the illness—would be the ultimate beneficiaries of this work. There were two objectives established in the original project proposal:

1. Create an opportunity for groups and organizations in 12 regional/local communities to engage in dialogue/conversation (to be called Community Conversation Gatherings) about:
 - the breast cancer information and support needs in their own area;
 - where gaps exist in meeting those needs; and,
 - how to implement relevant strategies to meet the critical needs.
2. Create an opportunity for regional/local groups to enhance their local effectiveness by participating in a virtual community established to enhance collaboration among the broad range of stakeholders in the breast cancer community of Ontario.

Project Process – The Plan

Twelve regions or sites in Ontario were selected by the management group to include both urban and rural settings in the province and to provide an opportunity for different kinds of communities to participate. The sites identified in the project proposal were: Thunder Bay, Sudbury, Sault Ste. Marie, North Bay, Timmins, Windsor, London, St. Catharines, Hamilton, Toronto, Kingston, and Ottawa. To learn about the current activity in breast cancer information and support, Fran Turner, Project Coordinator made the initial contacts with groups in each of the regions through individuals identified or recommended by the sponsoring bodies and their network partners. The project plan consisted of making an initial contact to discuss the concept of the project and the objectives of the community conversation gatherings and following up with a conversation and provision of a group planning binder. The binder entitled “Building Community Networks for Breast Cancer” included a promotional brochure and information on the community gathering, as well as tools to plan and organize the session. The binder information included:

- draft steering committee agenda guide and checklist
- information on early detection, treatment and living with breast cancer
- resources for community capacity building
- consultation tool kit
- health promotion, sponsorship, and communication
- information technology, the Internet and virtual communities
- evaluation tools

A complete steering committee binder is being submitted with the final report to Health Canada.

An important aspect of the planning materials was an emphasis on a multi-disciplinary group within the community, either in the planning or participation stage, becoming a local steering group. Groups were encouraged to invite local representatives from the schools and libraries, local politicians, local departments of health, local business representatives, etc. to attract a broad base support for the gatherings, and to solicit representation from groups typically not invited or officially represented at breast health meetings. The topic themes were to be designed around breast cancer information retrieval and dissemination with a focus on electronic communication sources.

It was intended that the local steering group would identify and perhaps include others in the community in the planning process to identify needs related to breast cancer support or information. It was hoped that this steering group would represent the community’s range of stakeholders in breast cancer information

and support as well as other community groups such as other support groups, coalitions, public health nurses, OBSP representatives, physicians, representatives from palliative care, women's groups, librarians, local media and politicians. It was anticipated a collaborative effort would emerge to design a larger community conversation gathering. The meeting would involve large and broad community representation and would focus on identified needs. It could be a focus group, or brainstorming session, for example, and might include exhibits from various community groups involved with breast health, cancer issues, and/or other community-based initiatives.

Project Process – The Reality

In each region the first step included contacting a member of a local or regional coalition or support group by phone or e-mail to discuss the project. Following the call, the Project Coordinator sent a brochure (describing the capacity building project), a steering committee agenda template, and a suggested participant list. This local individual would then present the idea of having a community conversation gathering to her local or regional group. Often there were questions before or after the group meeting about expenses, meeting topics, size, publicity, presentation format, etc., which required clarification before the local/regional group agreed to participate.

The brochure was revised several times to describe the intent of the community capacity building (CCB) project simply and clearly. The revised brochure included descriptive examples of some of the diverse themes and formats for the gatherings. These descriptions offered potential steering committees an understanding of the flexibility of the project. Fran Turner learned from talking with local contacts who had received the information brochure at an early point in the process that these tools, intended to be helpful, were actually intimidating. As a result, in the last groups contacted, the steering group information was not distributed until the Project Coordinator had an opportunity to speak at length with the groups who decided to participate.

Often the path to a local supporter for the gathering was not direct—the original contact person would refer the Project Coordinator to someone else in the community (for example, a member of a coalition might direct her to a support group, or vice versa). This process added to the time needed to organize the gatherings and waiting for a response from the various contacts and potential meeting organizers and their committees required patience.

By mid-December, 13 sites had been contacted but only three were at the stage where they had either held steering group meetings (Kingston and St. Thomas) or had one scheduled (Sudbury). Two potential sites had determined it was not possible to participate in the project because of intense breast cancer activity already organized at regional and local levels (Windsor and Woodstock). It was apparent that a great deal of activity was ongoing in these areas and that many groups (both local and regional) had developed their action plans well in advance of the CCB project. With pressure already on their volunteers, holding an event in addition to those already underway or planned was considered impossible by the groups. It became clear that to offer the groups access to the funds and research participation in the community capacity gatherings and to meet the timelines defined in the project outline, the Project Management Group and Project Coordinator Fran Turner had to adapt the gatherings to match with the activities in each community. This realization was significant in that it pointed out how busy and organized many of the local support groups in Ontario have become over the past few years. The prospect of receiving financial support was not sufficient to encourage groups to stretch already overly busy volunteers or to alter their predetermined plans.

By January 2000 it became apparent that the CCB Project Management Group had to be more flexible in its approach if the desired 12 sites were to be found as anticipated in the original project outline. For example, it was originally suggested (but not required) that the steering groups be multidisciplinary. As the project proceeded, Fran Turner simply worked with groups who were willing to participate. Also,

when groups were contacted, the desire to help with projects that they might already be interested in, or were in the process of working on, was discussed together with finding a way to engage in community capacity building. Consequently, there was more interest and more groups found ways of folding in the concepts and suggestions for the community capacity format with their own activities. As some groups that had initially declined participating in the project reconsidered, new groups contacted responded positively and the revised approach proved successful.

For most of the groups, their steering committee meeting was one of their regular meetings, or a committee of their coalition, support group or dragon boat team membership. Usually no representative from OBCIEP attended the planning meetings (Fran Turner participated in three planning sessions with groups in Sudbury, Kingston, and St. Thomas) although there was frequent communication by phone and/or e-mail in the course of the planning process. Each group received a copy of the “Building Community Networks for Breast Cancer” Binder that contains many valuable resources for general meeting and event planning, group collaboration, and Internet resource management.

Community Capacity Building Conversation Gatherings Summary

The following are brief summaries of each of the functions held to date in conjunction with the community capacity building project. The Virtual Community for Breast Cancer Support and Information was addressed at each session either through a formal address and/or the handouts and surveys included in each participants’ registration package. Agendas, promotional materials, meeting notes (where available), and evaluations for these gatherings will be included with the final report to Health Canada.

Sharbot Lake, March 28

The Sharbot Lake gathering was one of the first to be held and became the model for the CCB project. The preliminary work was spearheaded by Breast Cancer Action Kingston (BCAK). Others invited to work with BCAK were a primary care nurse and a public health nurse who work in the rural areas around Kingston, a representative of the local CCS unit and a non-health related representative from the Catholic Women’s League who works with area parishes. At a Steering Group Meeting it was determined that there was a need in rural communities to provide education and encouragement to seek regular breast screening and general medication check-ups. The theme for the workshop became “Breast Cancer: Problems and Solutions for Rural Women”. In the months before the event there was a news article about the upcoming event in the Kingston area and considerable publicity for the event generated by BCAK. Information was distributed with the group’s newsletter that has a readership of several hundred. There was also advertising in local papers. The meeting was held in a church hall in Sharbot Lake located about 70 kilometers north of Kingston.

Forty-one were in attendance including breast cancer survivors, some Kingston breast health resource people, a local family physician, and a well water specialist. Participants were assigned to one of four focus groups which each dealt with a specific area on the cancer spectrum—prevention, early detection, treatment and survivorship. Questions for each group were the same and geared to explore the local milieu. In the morning the focus groups dealt with identifying problems; the afternoon session explored ways the problems could be addressed. In each group there was a facilitator and a recorder. Major points were recorded on a flip chart and shared with the whole group by each facilitator for further comments. A member of the Steering Committee assumed responsibility for having the comments transcribed and distributed to those requesting copies. On display were booths by the Catholic Women’s League, well water, prosthetics (hair), the breast health assessment centre at Hotel Dieu Hospital and others. The weather was good and some commented on this as a factor contributing to their attendance.

Thunder Bay, March 28

Several months passed before the Thunder Bay Breast Health Coalition agreed to participate in this project because they were extremely busy with activities during October and felt unable to commit to any kind of new involvement until the new year. A number of the women involved in the coalition are breast cancer survivors and are active volunteers despite low energy reserves and the commitments and activities that make up their daily lives. The support group often had pre-planned meeting dates and a full agenda of pressing issues. If the item about participation in a new project is not covered at an early meeting, it may be a month to six weeks until the next meeting is scheduled. Therefore the group did not agree until January to participate in the CCB project.

Ultimately a conference was organized as a forum. Presentations at the forum were entitled: “What is High Risk and What Can You Do?” by Cindy Sinnott RN, CCN(O) from Research and Clinical Trials, Northwestern Ontario Regional Cancer Centre and “Genetic Factors..... Explained” by Linda Spooner RN, BSN Genetic Counselling, Thunder Bay District Health Unit. The presentations were followed by a question and answer period.

The Coalition was disappointed in that the forum was not as well attended as their previous offerings. Although the meeting attracted about 70 participants, bad weather played a role. A strike at the Thunder Bay District Health Unit, a main outlet for their ticket sales, was considered another factor in the forum attendance.

St. Thomas, April 18

A public health nurse who works in breast health, specifically early detection and screening, was instrumental in organizing the St. Thomas gathering. She chairs a women's health issues group in Elgin County founded by women interested in all issues around breast health.

The steering group consisted of 10 women and included some women from the health interest group-one of who is an articulate school principal and a breast cancer survivor. Some of the others attending were involved with some aspects of cancer (e.g., Victoria Order Nurse with palliative care, an area resident who is a social worker at the London Regional Cancer Centre, a nurse from the local Ontario Breast Screening Program, the Community Care Access Coordinator) and a representative from the Ontario Women's Health Network. It was decided that the gathering should focus on the need for a women's health resource centre. The group examined the services currently available in the area and specifically what services were needed in Elgin County for women with breast cancer. Ideas on how a resource centre could be developed and maintained for women and their families at different phases of the breast cancer continuum were reviewed.

Promotion in the community about the gathering was on the local cable channel and in newspapers and by invitation. About 18 people attended the two-hour session in a local church hall. Two local physicians who had been invited sent their regrets at the very last minute, but agreed to respond to the questions which were discussed in a focus group format. Those attending included several women who had participated on the steering committee and workers from the local hospital's radiology department, a nurse practitioner, and several survivors. A number of attendees expressed gratitude at the end of the session about the opportunity to connect with others in their community who shared concerns about resources for women with breast cancer.

Sudbury, April 19

The gathering in Sudbury focussed on the examination of current and potential online services to aid and support breast cancer services in the Sudbury district and greater Northeastern Ontario area served by the Northeastern Ontario Regional Cancer Centre (NEORCC). Twenty-two invited guests included local

OBSP representatives, nurses, a professor of social work, a computer information services manager, librarians, a cancer information specialist, and breast cancer survivors. The first part of the four-hour session consisted of presentations by health professionals at the NEORCC, the information services manager, librarians, and the professor of social work who discussed “cybermoms”. “Cybermoms” was a social work project conducted in Sudbury where unwed mothers were provided with computers and online services in their homes to network with health care and social work professionals and each other. The project was considered a success by the comments of the participants and allowed the group in attendance to see the benefits of online communication. The librarians discussed the development of webpages and the services offered by the local community libraries that not only teach individuals to use computers and navigate the Internet, but also teach people to act as educators to teach others. Many remarked on these two particular presentations, as many attendees had not been aware of the “cybermoms” project or the services available through the local library service to assist patrons to access online services.

The second part of the evening was a brainstorming session where participants broke into four groups and considered questions related to the development of a breast cancer information and support website for the Northeastern Ontario region. The questions focused on who should keep the information current, what questions and concerns people had about the creation of a website, what important considerations (barriers) must be dealt with, where should computers be available and who should conduct the training. The questions prompted many discussions of unresolved issues but all were in agreement that these issues required further discussion prior to the creation of a regional website. The staff at the NEORCC, who organized the session are producing a written record of the evening’s proceedings.

Cobourg, April 28

The initial contact in the Oshawa area was an active member of the local support group. It became apparent the group was very busy with other projects and many members were also very tired because of dealing with their own health concerns. A member of the Cobourg local breast cancer survivor dragon boat team was receptive to participating in the project, and so was the executive of the team who acted as the steering group. It was decided that an open house format would suit the dragon boat team as a means of promoting the physical fitness potential of women with breast cancer. Advertisements in local papers and notices on the local cable television station were used to promote their event. Special guests on hand included the mayor and, to promote the fitness component for breast cancer survivors, a physician, a breast health educator from the Canadian Cancer Society, a fitness instructor, and a racing coach.

Approximately 40 attended the open house, a number of whom were women newly diagnosed with breast cancer who had come for information and support. The group is now considering making the open house an annual event and adding more structured events to the day.

North Bay, May 15

The North Bay local dragon boat racing team was interested in participating in the capacity building project and together with assistance from the Project Coordinator, organized an event. This was the first large, formal event that the group had planned. The steering committee consisted of the three members of the team (all breast cancer survivors) who decided to hold their meeting as a seminar entitled “Living Beyond Breast Cancer”, a two-hour session held in a local conference facility. Two speakers were invited, a surgeon specializing in breast disease from Sudbury and a breast health program coordinator also from Sudbury. The regional OBSP administrator acted as moderator for the evening. There was opportunity for questions and discussion and many attendees who wanted to comment were unable to do so due to time constraints. Most of the 60+ who attended were women at some phase of the breast cancer continuum and health professionals. There was much enthusiasm about this event and the planning groups and participants were pleased with the attendance, the interest, and the discussion.

Ottawa, May 15

A program co-coordinator for the Ottawa Regional Women's Breast Health Centre organized a gathering for representatives of breast cancer support and information groups in the eastern Ontario region to review, discuss, and distribute copies of the information tool "My Personal Breast Cancer Binder" and to review the status of the "Patient Care Maps" being developed for patients receiving breast cancer treatment at Ottawa local treatment centres. These items were developed as part of the Centre's attempts to standardize breast care for women served by the Ottawa Regional Cancer Centre. Invitations were extended to representatives of groups as far away as Pembroke, Cornwall and Renfrew and the gathering afforded an opportunity for the distribution of over 100 administration and breast cancer patient copies of the binder. The binder was developed with assistance from the Canadian Breast Cancer Foundation and solicited donations.

The hour-long informal session reviewed the binder contents, updates, and information on how support and health care personnel should counsel women to use the information. The binder is to be made available to every woman in the Ottawa Regional Cancer Centre treatment area who is diagnosed with breast cancer and funding has been secured for the project until April 2003. There was ample opportunity for the 31 participants to ask questions and issues were raised about future updates, translating the information other languages (the French language version is already in production), and the method of ordering copies for those newly diagnosed. A short session with a smaller group of representatives from local Ottawa hospitals took place at the end of the session to discuss the status of the "Patient Care Maps" developed for the cancer treatment hospitals in the area. The breast assessment and perioperative breast "caremaps" outline for patients the care to be offered and the outcomes expected during the diagnostic and operative time periods.

Burlington, May 16

The Burlington gathering was a workshop for 12 breast health educators of the Breast Cancer Support Services, Burlington, which offers a program on breast health formed in response to the local need for breast self-exam workshops and education dealing with breast health. Most of the educators are women living with breast cancer. One is a nurse with St. Elizabeth's and another, an assistant for a local politician, is a daughter of a survivor. The all-day session was held at a local hotel's meeting facility. A high level of commitment to educate women about breast self-examination and knowledge was evident in the group discussions.

The workshop was a training session where participants discussed techniques for teaching breast examination, and reviewed updates and changes in the "Mammacheck" technique. (Mammacheck <http://www.breastcancersupport.org/BSEMammacheck.html>). They had model breasts that each participant palpated. These same models are used in the training sessions to acquaint women with normal and abnormal breast texture. Time was spent discussing the role of heredity in breast cancer and the need to dispel the myth that family history is a primary factor in susceptibility to breast cancer. Concern was expressed and strategies were discussed about women who do not check their breasts for fear of finding an abnormality. The group also reviewed the printed material that is distributed at their educational sessions.

St. Catharines/Niagara, May 26

Several contacts were made in this area did not become promising until the local breast cancer education and research group was approached. The Project Coordinator working with the planning group was successful in organizing a CCB gathering with their second annual education conference. While the theme of the conference was total mind and body health, there was considerable emphasis on environmental issues and their relationship to breast cancer and alternative therapies.

The all-day conference “A Call to Women” attracted a registration of 170 and focussed on aspects of total health and well being. A plenary session entitled “Hormone Balance for Whole Body Health” began the program and rotational workshops repeated throughout the day included “Yoga and Rebounding for Breast Health”, “The Healing Kitchen”, “Nutritional and Herbal Supplements for Breast Health”, and “Mind-Body Healing”. A vegetarian buffet lunch and healthy snacks made up the menu for the day. A number of organizations and vendors of holistic foods and vitamins, books, environmentally friendly foods, and cleaning products also participated.

Timmins, May 31

Several attempts were made to approach contacts in the Timmins area and eventually a breast cancer support group member volunteered to assume responsibility for the project, but not as a project of the support group. Instead she worked with a pharmacist from Shoppers Drug Mart where she is employed and a dynamic nurse with the VON Algoma Palliative Initiatives in Northeastern Ontario. She chose lymphedema as the topic, an issue not frequently addressed yet one which is troublesome to many of the women in the support group. She knew of a physiotherapist in North Bay who was interested in addressing this topic as a formal presentation. With assistance of two colleagues on the steering committee, she sent invitations were sent to local physicians, chiropractors, massage therapists, nurses and physiotherapists. There was also an advertisement in the local paper about the presentation. Most of the 30 participants were breast cancer survivors although the audience included physiotherapists and nurses.

There was a high level of energy in the presentation and in the resulting discussion. A major concern was raised about elastic sleeves, the most successful modality for dealing with lymphedema, that were not covered by the Assistive Devices Program in the region. There was no physician to prescribe them and no physiotherapist identified to work with women who needed the sleeves. The third agent required for the process was a pharmacist and was available and keen to have the other elements in place to provide women with the sleeves through the ADP. There was interest among the physiotherapists present to become involved with the program and to find a physician to provide the medical back-up. As a result of this meeting there was collaboration among the support group personnel, the physiotherapists, and the pharmacist to provide the ADP program to women in the area.

Recently the energy of the support group had been low and participants felt that the CCB gathering rekindled enthusiasm for future meetings and working together to put the ADP program in place.

Sarnia, date to be announced

Project Coordinator Fran Turner was approached recently by a local unit manager of the Sarnia Canadian Cancer Society, and a session is currently being planned. It is anticipated that it will include participation by representatives of the two First Nations in the area.

Online Resources and the Breast Cancer Information and Support Virtual Community

During the course of this CCB project a number of breast cancer information resources were reviewed, updated, and posted online. Each of the project’s sponsoring partners initiated or completed updates of their websites and online resources. The OBCIEP is still completing a comprehensive review, update and restructuring of its website.

The Canadian Cancer Society initiated a full update of its web design and resources beginning in 2000. Several publications produced by the CCS – Ontario Division are now posted on the Canadian Cancer Society national website. The new and/or updated resources pertaining to breast health (available in French and English) are:

Resource	URL (online address)
Questions and Answers about Breast Health	www.ontario.cancer.ca Under Information>Specific Cancers>Breast
Hereditary Breast Cancer	www.ontario.cancer.ca/hereditarybreastcancer
Making Decisions about the Removal of My Breast: What Do I Prefer?	www.ontario.cancer.ca/breastsurgery
Information on Support	www.ontario.cancer.ca Under Services>Emotional Support
General Information Cancer Information Service	www.ontario.cancer.ca Under Information>Information Specialists

Willow researched and updated the publication *Coping with Your Financial Concerns when You Have Breast Cancer*, formerly published as guide to those living in and around the Greater Toronto Area to a provincial-wide resource. It also updated and posted online its guide to breast cancer support groups across the province, formerly published as the *Guide to the Galaxy*, that includes over 80 support groups in Ontario with telephone numbers and e-mail addresses where available.

Resource	URL (online address)
Coping with Your Financial Concerns when You Have Breast Cancer	www.willow.org/publications
Ontario Network Support Groups	www.willow.org/network

The OBCIEP website is currently undergoing a major revision as its basic structure is being altered to accommodate tools for the development of a private as well as public site. This will create the basis for the virtual community for breast cancer support and information groups across the province of Ontario. Recently the information technology department at the Toronto-Sunnybrook Regional Cancer Centre developed a similar site structure for Cancer Care Ontario and the basic template is being reproduced for the OBCIEP. With the creation of the structure, the site will be able to be updated on a regular basis by the OBCIEP staff without going through the TSRCC information technology department that currently hosts the site. The work has begun and the first stage should be complete by July 2001.

Several resources were reviewed and/or updated for content. Those reviewed specifically for this project are:

Resource	URL (online address)
OBCIEP Fact Sheets*:	
Tamoxifen	www.tsccc.on.ca/obciep/tamoxifen.htm
Hormone Replacement Therapy	www.tsccc.on.ca/obciep/hrt.htm
Treatment Induced Menopause	www.tsccc.on.ca/obciep/tim.htm
Benign Breast Disease	www.tsccc.on.ca/pdf/BenignBreastDisease.pdf
Ductal Carcinoma in Situ	www.tsccc.on.ca/pdf/DuctalCarcinoma.pdf
Living Beyond Breast Cancer**	www.tsccc.on.ca/livingbeyond
Living with Metastatic Disease**	www.tsccc.on.ca/metastatic

*Fact Sheets also available in French, **updates completed, awaiting posting online.

Links have also been added to all coalition partners who have websites and the process of updating links to all information sources, OBCIEP partners, and breast cancer support and information bodies is ongoing.

Evaluation

The evaluation process is distinguished by the two project objectives designed to increase community capacity: the creation of opportunities for dialogue among local groups in the form of community conversation gatherings and the creation of the opportunity for local support groups to participate in the virtual community for breast cancer information and support.

Community Conversation Gatherings – Participants’ Surveys

Each participant in the community conversation gatherings was provided with a registration kit consisting of an OBCIEP brochure, the most recent OBCIEP newsletter, a description of the proposed virtual community model, various items added by the local steering committee and an evaluation survey. All participants were requested to complete the surveys. The surveys were collected and tabulated by the Project Coordinator, sometimes with the assistance of the local steering group representatives. Two surveys were used, the initial Needs Survey #1 was revised midway through the project to include more suggestions for gaps in information and support. Copies of the two Needs Surveys are included as Appendix B and C. To date a total of 308 surveys have been tabulated which represents 60% of the total number of people who attended the community gatherings. The composition of the groups varied. Some consisted of primarily health care professionals and survivors, while other gatherings attracted a wide range of registrants.

Community Conversation Gatherings – Steering Committee Interviews

It was planned that two steering group members and two participants from each of the gatherings would be interviewed two months after their respective gatherings were held. Later it was determined that two interviews were sufficient for each of the small community gatherings. The objective of the interviews was to determine the effect of the gatherings on the community at large and the response of participants to the virtual community model. At the time of this report 28 interviews (or 78% of the total planned) are completed, 19 steering committee members and nine participants have been interviewed.

The interview questions appear in Appendix E and a summary of the interview comments is presented in Appendix F.

Project Outcomes

Key Outcomes

PLANNED: The key outcomes identified in the original project proposal were to establish 12 regional/local steering groups; to plan and hold 12 Community Conversation Gatherings in Ontario; to produce and distribute a report that documents the needs of each community; and, to produce a plan for resolving identified gaps in meeting those needs. The sponsoring organizations also planned the production of two resource kits to aid in community capacity building and to provide several new online resources for easy access by breast cancer survivors and groups.

ACHIEVED: Ten local steering groups were established, 10 community conversation gatherings held, and an additional gathering is being planned in the Sarnia area. This report includes program agendas, a compilation of all surveys for the 10 gatherings, and reports (where produced) as part of Appendix G. Copies of the final report to Health Canada will be distributed to all steering groups, project partners, and members of the OBCIEP Coalition of Stakeholders. It will also be posted on OBCIEP’s website when the website is restructured by the fall of 2001.

All three major project partners, as detailed on page 13 produced a number of new and updated online resources.

Project Benefits

Several benefits emerged from this project. They were identified by the individuals who were interviewed and by the project coordinator and are summarized and highlighted below. A more detailed description of the benefits as described by the individuals who were interviewed is presented in Appendix F.

Collaboration

One of the primary objectives for the project was to move the focus on collaborative activity surrounding breast cancer information and support to the regional/local level rather than having it remain at the provincial level. Based on the program planning, the gatherings, and the final surveys and reports, it is clear that the gatherings facilitated networking and information sharing among breast cancer coalitions, support groups, survivors and others. Plans for future activities have been proposed and are at various stages of planning. Several groups had representation from various local, regional, and provincial organizations that included members of community health units, public libraries, information technology specialists, cancer centre nurses, and breast screening experts. Professionals in different fields met with members of breast cancer support groups in a variety of meeting formats and focus groups to discuss concerns of women with breast cancer.

For example, in North Bay, the presentation on lymphedema brought together a pharmacist, support group members, and physiotherapists that set the groundwork for providing arm sleeves for lymphedema patients as part of the Assistive Devices Program. The Sharbot Lake gathering brought together public health representatives, a rural nurse practitioner, a local journalist, a water purification expert and a representative to the Catholic Women's League. Many of the local women who attended that gathering commented that one of the best places to contact local women was through the existing church and community groups. This provides information for effective collaboration in a rural community. As well, new alliances were formed. In Sudbury local librarians, a social work professor and an information technology expert presented information to survivors and representatives from the breast screening program and cancer centre about community services and information technology training. In Thunder Bay the breast cancer coalition through collaboration with other breast cancer stakeholders acts as a model to women about the benefits of collaboration and to other groups such as the local prostate cancer support group.

Awareness

The public gatherings themselves created awareness about the ongoing information and support activities within local breast cancer communities. At each meeting, regardless of the key topic of the session, most of the steering committee members and a number of the participants commented that their own awareness, as well as public awareness, was increased about the depth of ongoing activity, breast cancer information resources, and the role of the players within the community. The community conversation gatherings also provided an opportunity for survivors and their family members, for health professionals and for those interested in cancer and health care professionals to share ideas about the needs of the breast cancer information and support community.

A number of sites (Thunder Bay, North Bay, Timmins, Cobourg, and Niagara) advertised their events through the local media including newspapers, local cable television and radio. In the Kingston area, two news articles relating to the conversation gathering were published. Invitations to the community conversation gatherings were issued in other areas including St. Thomas and Timmins. Although a number of family physicians were invited to community conversation gatherings because their work is critical to timely diagnosis and follow-up, they failed to attend. Their absence was disappointing. However, physicians in the St. Thomas area, who did not attend, agreed to complete a survey that dealt

with the issues addressed in the focus groups.

Knowledge About and Access to Breast Cancer Information and Support

Information gleaned from the written surveys and interviews indicates that there is more awareness of sources and resources for breast cancer information now than in past years. The surveys indicate that information and support needs are being met "somewhat". This shows room for improvement but also indicates that many feel that it is improved over the past few years. This perspective was reflected in the post-session interviews.

Examples of how the community conversation gatherings increased knowledge and access include the following:

- Cobourg: The planning group, a dragon boat team who had never before hosted an open house, is considering making it an annual event because it offered a number of women newly diagnosed with breast cancer a chance to be directed toward sources of support (through the support group) and information (through the public health nurse)
- Sharbot Lake: Many participants revealed a concern that incorrect information was being published in the local press about breast cancer and that the information provided by the local Canadian Cancer Society offices was outdated—they feel local media had a responsibility to provide valid, objective information and that they should be challenged to educate the local population on cancer issues, e.g. cancer is not “contagious”. Rural women expressed concerns about having to travel distances for physician appointments, screening, test and treatment;
- Breast Cancer Action Kingston and its surrounding communities distribute information about breast cancer in hair salons (in Kingston) and in grocery stores in rural areas;
- Breast Cancer Action Kingston and Burlington Breast Cancer Support Services both have computers that are available for use by the public to search information; and,
- Ottawa: The dissemination of the *My Personal Breast Cancer Information Binder* ensured that providers of supportive care received their own administrative copies and learned how to guide women through the material and how to receive updates. Peer counsellors as well as health providers were involved. Subsequently individuals who had attended the Ottawa community conversation gathering shared the information with their agencies and prepared presentations using material from the binder. While the Ottawa meeting was a regional initiative the event helped to improve and standardize supportive care locally and provided an opportunity for community groups to meet and learn about each other’s initiatives and to learn what is available in the community.

Ongoing Collaboration

While the gatherings introduced new partners they also enhanced existing partnerships of local groups and local representatives of provincial groups. In Sharbot Lake for example, local representatives from the Canadian Cancer Society, the Ontario Breast Screening Program, and the Kingston Regional Cancer Centre took part in the planning and evaluating the gathering. Future plans for the development of a rural women’s health centre, with an initial focus on breast health, will involve all partners as well as representation from the local public health units. In Sudbury information technology professionals and librarians have already been working with local breast cancer and information groups and look forward to more collaboration on the development of a website for breast cancer information and support for women in Northeastern Ontario. Sudbury’s CCG acknowledged the need to involve the outlying communities and to encourage more active participation of local support groups. There is a huge potential for a multiplicity of groups to collaborate on a regional website, particularly in an area where there is a sparse population scattered over a large geographical area.

Identified Gaps in Information and Support

As indicated, there is a constant need, and challenge, to maintain updated sources of information, particularly written sources of information in sufficient quantities to distribute to newly diagnosed women. The other ongoing challenge is the requirement of the development and maintenance of effective distribution methods to ensure that all women who want and need information are aware of how and where to obtain it. In general there is agreement that family physicians must do more to ensure that women receive information packages or at least a list of telephone numbers and a list of online sources of information.

Most frequently mentioned information gaps as identified in the participants “Needs Feedback Form” (see Appendix D) included:

1. dissemination of current information
2. information for young women
3. information when a breast abnormality (cancerous or non-cancerous) is diagnosed
4. daughters of women with breast cancer
5. information for cultural minorities

While the number of people obtaining breast cancer information from online sources continues to increase, it was reported that women particularly those over the age of 50 prefer written sources of information that they can read at their leisure and then review with a support group member or with a health care professional. There is still a need for the distribution of several sources of information for women at different points along the diagnostic continuum (prevention to palliative care). Excellent sources of information exist from several sources such as the Canadian Cancer Society, but some areas still have difficulty obtaining sufficient updated copies of these materials at reasonable prices or free of charge. These printed materials should be readily available in pharmacies, libraries, grocery stores, etc., places where individuals visit as part of their regular routine. Many support groups have limited sources of funding as their primary activity is to provide support and not all engage in fund raising to support their activities.

The establishment of a central local resource person as a locus of information about breast cancer information and resources was also suggested for the Sharbot Lake area. With the availability of new and vast amounts of information online those who use online services have expressed a need for assistance in navigating through it. A central resource or clearing house would help to identify sites with the best available information on specific topics and could serve to warn the public about questionable or unreliable sources or pieces of information.

Although some groups may need information about fundraising, they may not be aware of information and assistance currently available. The Canadian Breast Cancer Network, for example, offers an online course on fundraising and the Canadian Breast Cancer Foundation has local mentors to assist applicants to file proposals for their education grants.

Along with a frequently voiced dissatisfaction about the waiting time for treatment and access to support services, some of the specific gaps addressed in the interviews include:

- Ottawa— *My Personal Breast Cancer Information Binder* needs to be translated/adapted for multicultural groups and that all women within the region served by the Ottawa Regional Cancer Centre receive the binders and updates;
- for those who live north of Sharbot Lake—for those living north of the area, it was noted that travel time to reach the cancer centre and doctors in Kingston can take hours and can impact decisions made about making and keeping appointments;
- Timmins—after diagnosis and treatment women seem to be “let go” and do not know where to go in

the next phase; women who are treated at the regional cancer centre initially receive a lot of information but after are unsure of who to contact to receive more;

- Sudbury—a hospital website that describes the diagnosis phase and treatment options would be useful; one woman reported that after discovery of the lump she waited five weeks for chemotherapy and access to a social worker—at a critical time when support, not simply information about the disease is needed. She also expressed concern that there is little information about the metastatic phase of breast cancer.
- There was widespread concern about the challenges for women with children, particularly with young families, young women with a high family risk for breast cancer, and all young women seeking information on breast health.

Mobilization

The Building Community Networks Resource Binder, prepared during this project for all steering groups that participated in the program (appended to this report) contains a wealth of information for local community groups on leadership, planning, adult education, fostering collaboration, and fundraising. The information provided was to fill a perceived need in anticipation of the community conversation gatherings. While groups indicated their appreciation of the material, it became clear that many had mastered skills in planning, event coordination, and collaboration within their own communities.

Some groups identified needs regarding group activity. Steering Committee members in St. Thomas acknowledged that they needed new strategies and guidance in sustaining action to support their advocacy for the creation of a women's health centre in their area. The Cobourg group realized that a public relations plan may help their visibility within the community.

The greatest issue facing all groups in every area of the province is securing sustained funding to launch and maintain new programs. While several sources of funding and support exist, such as the Canadian Cancer Society, the Canadian Breast Cancer Foundation, and the regional cancer centres, groups are finding that the cancer centres and traditional institutions are already strapped by personnel and funding shortages, so their ability to assist site specific information and support groups is severely limited.

Online Resources

The survey comments by the community gathering participants indicate that the majority of women are not using the Internet themselves (36% indicated that they used the Internet for breast cancer information “somewhat” or “very much”, only 25% use the Internet for information or support). It appears that the main group of consistent users of Internet sources for information is women under the age of 50. Many women who do not have access to computers or the Internet are receiving information secondhand through family members and friends. Many health care professionals noted that they themselves do not seek out information over the Internet directly but they should be aware of what their patients are reading and how to help their patients navigate through the wealth of information available.

While information technology is recognized as a powerful tool, not all women have access. It was noted in Sharbot Lake that rural women are less likely to have access or the skills (while paradoxically they might be the group to most benefit.) There are also issues about literacy, culture and information needs of elderly women for whom breast cancer may be one of several health issues. These are some of the factors that currently limit the usefulness of information technologies for those subgroups of women with breast cancer.

While the use of internet resources among individual women appears low, it is rising and many health professionals who participated at the community conversation gatherings indicated that over time an increasing number of their patients are coming to appointments with questions about information they

have obtained from an internet source. Certainly representatives of regional and provincial groups see benefits of group to group communication using web-based technology and have expressed interest in the proposed pilot project for establishing a site for Northeastern Ontario.

Lessons Learned

The community capacity building project was proposed on the basis of the priorities identified by the participants of the Think Tank on Breast Cancer Information and Support held in 1999. At that time over 120 representatives of groups from across Ontario who provide information and support to breast cancer survivors participated. They identified two priorities that would assist their efforts in providing help to women: to strengthen and extend the network of breast cancer organizations involved in information dissemination and provision of support, and to maximize the use of technology to enhance information dissemination and provision of support.

Two years after these priorities for action were defined by the Think Tank participants it was evident that many grassroots groups have developed skills in planning, mobilizing, and providing service to breast cancer survivors and their families. They have formed their own regional coalitions and built collaborative relationships with provincial and community partners, or simply developed breast cancer support groups. Some of these groups operate at a highly sophisticated level with their annual activities planned well in advance and with well-formulated agendas they know they can realistically accommodate.

What became evident in the informal discussions and work with these groups is the enormous passion which so many bring to the work they do for other women with breast cancer in their communities. These highly committed groups work with limited resources and in many cases their members continue to contribute despite low energy during active cancer treatment and ongoing concerns about their own health and uncertain futures. This drive behind small local support groups and large regional coalitions is the need to make a difference for other women, especially younger women. This is an enormous incentive in women's involvement in support groups, coalitions and dragon boat teams. There is clearly a strong movement deeply concerned about ensuring those affected by breast cancer have easy access to information and support and that women, particularly young women, have access to information about general breast health and about breast self-examination. They indicate that provincial agencies like the Ontario Breast Screening Program have a role to play in providing increased screening.

There are many local and regional initiatives in progress across the province. Groups approached in Windsor and Woodstock, for example, who chose not to participate in the CCB project were pursuing local and/or regional projects. In Woodstock the group was working with Cancer Care Ontario representatives, women from the local Mennonite community and a women's literacy group to develop low literacy information on breast cancer.

Communities in Northern Ontario demonstrated a very strong regional sense. The Sudbury steering group wanted to ensure that that invitations were extended to representatives from the smaller local communities, and plans to pursue the involvement of those communities in the next phase of their information technology work. The North Bay dragon boat team (who were encouraged to participate by the regional administrator of the Ontario Breast Screening Program based in Sudbury) invited speakers (a surgeon and a coordinator of the regional breast health program) to their event from Sudbury. The Timmins event hosted a speaker (a physiotherapist) from North Bay.

Fostering trust among local groups is still a challenge. Many groups/individuals expressed some doubt about Toronto-based projects. Furthermore, there was a mistrust of urban-based initiatives in general. For example, in Sharbot Lake participants were not completely at ease with Breast Cancer Action

Kingston since it is a city group. The perception seems to be that residents of small communities are used for research purposes and then the professionals leave. Rural and small town groups in particular need to be approached sensitively and as much as possible key individuals in their own community need to be involved. In some communities concerns were voiced about provincial groups that did not respond well to local needs.

Clearly there are skilled individuals in local communities and working with them is tremendously important. During the course of the project, it was emphasized that different regions of the province have different priorities and employ varying solutions to tackle similar problems. Any approach to local groups however must acknowledge that regional variation exists both for resources and needs. One solution will not suit everyone. There is a healthy diversity in how support groups operate across the province. Some focus only on support, whereas others assume responsibility for education and awareness projects. A virtual community by which they could reach one another and share resources is one potential way of linking and supporting these various groups.

An emerging concern voiced by many groups was the challenge of continuing the work identified or begun at the community conversation gatherings without the prospect of committed support. Funding is usually cited as the greatest obstacle. Now that the work has begun, how can it continue? Many stated a need for direction continuing support to sustain interest and progress on the groups or initiatives identified at the community conversation gatherings. There is a real fear that women will become cynical as they are surveyed and “focus-grouped” endlessly about what they need but programs or resources are not established to address their concerns. It was noted that the gatherings created expectations and while there is a sense that Health Canada, Cancer Care Ontario, OBCIEP and regional groups have a responsibility to follow-through with these initiatives, there is also recognition that many of those groups are dealing with their own funding restrictions.

Groups want to be informed about upcoming grant and funding opportunities and some require assistance to prepare proposals and to complete grant applications. They want active participation in developing their own local initiatives, some of which are unique with innovative solutions to difficult problems.

Groups indicated a need to be educated about different methods for acquiring funds. Those groups interested in fund raising must be made aware of potential funding sources and training resources to teach them to write grant proposals. A number of groups are already skilled in using local resources for event sponsorship, such as the Breast Cancer Research and Education Fund Group in St. Catharines. It is also worth noting that if a regular process existed for dispersing money that groups can depend on, they will have the ability to plan ahead. However, when the availability of funds is uncertain, or if timelines are too short, it is extremely difficult for local groups to respond to a prospective need thoughtfully.

Recommendations

Recommendations are based upon reviewing the surveys and interview and are directed to the organizations identified:

Health Canada

1. Facilitate the development of breast cancer groups (coalitions or support groups) by maintaining flexible funding systems that allow groups sufficient time to plan activities over an appropriate period of time. For example, the recent change to a two-year Community Capacity Building grant proposal process is viewed as a welcome development.

Ontario College of Family Physicians/Ontario Medical Association

1. Communicate to family physicians across the province that women (those in the age group at risk of breast cancer and those younger women who find lumps) report some practitioners are minimizing their concerns about breast abnormalities and that women feel they are not being referred for appropriate screening.
2. Communicate to family physicians that their offices can be a valuable source for information for women concerned about breast abnormalities.

While most abnormalities are not diagnosed as cancer, this is still a tremendously difficult stage for women and they often leave the doctor's office with no information on how to access information or support. Simple materials such as the Canadian Cancer Society/Willow bookmarks with telephone numbers for the Cancer Information Service and Willow, or a sheet of paper with telephone numbers or website addresses of local or regional information support services would be of tremendous reassurance, information and benefit. The Cancer Information Service is an excellent resource for information about benign breast disease, breast health, and breast cancer.

Ontario Breast Screening Program

1. Review screening guidelines and respond to the need expressed by women throughout the province about availability of screening at local clinics for women under the age of 50, particularly those women who have a family history of breast cancer.
2. Review the need for a provincial-wide program to promote and teach high-quality breast-self examination techniques and to focus on breast health, not only breast disease.

Recommendations for Support Groups/Coalitions

1. Investigate and review breast cancer resources on the Internet, where access is available.
2. Investigate funding opportunities through the Canadian Breast Cancer Network, the Canadian Breast Cancer Foundation and local sources of funds. Many of these organizations provide information and assistance in applying for the funds.
3. Make an annual activity plan—this works effectively for many groups as it helps maintain focus and avoids overextension of volunteers resources.
4. When conducting an event, use evaluation techniques—for example, an educational needs poll for participants can be useful as an element in planning for future events.

Recommendations for Other Provincial Breast Cancer Information and Support Groups

1. Investigate ways, such as online resources, telephone conference, etc., to facilitate formation of support groups in rural areas as currently under review by the Canadian Breast Cancer Network.
2. Maintain collaboration and support among local groups, especially in smaller centres where there are fewer resources available. Create an atmosphere of sharing and trust in your local area.

Ontario Breast Cancer Information Exchange Partnership

1. Keep coalition partners informed of different funding opportunities through national, provincial, and regional sources. Provide information through the OBCIEP newsletter about the proposal and evaluation processes and where additional assistance can be obtained.
2. Provide partners with 10 to 15 recommended Canadian and American websites as sources for breast

cancer information and support as well as information on how to assess websites for accuracy, legitimacy, and timeliness.

3. Contact library services across the province to inform them of the need for training and assistance to women seeking information on breast cancer through the Internet.
4. Investigate connecting with university or graduate programs to connect breast cancer survivors to information and communication technology applications and to each other.

Immediate Next Steps for OBCIEP

The OBCIEP will communicate with all CCB project partners and coalition partners the results of the community conversation gatherings to date, the outcome of the meeting planned for Sarnia, and the progress on CCB project activities. It will also inform all partners on the status of the update and revision of the OBCIEP website in preparation for the creation of a provincial virtual community for breast cancer information and support groups.

The OBCIEP will:

- address the four recommendations assigned in this report;
- communicate the recommendations to the Health Canada, the Ontario College of Family Physicians, the Ontario Medical Association and the Ontario Breast Screening Program, provincial bodies, and support groups;
- distribute copies of the final report to all project and coalition partners; and,
- monitor the activities initiated or stimulated by the community conversation gatherings and share the information with all coalition partners.

Appendices

- Appendix A CCB Project Management Group
- Appendix B Needs Survey #1
Distributed at Sharbot Lake, Thunder Bay, St. Thomas, Sudbury, Cobourg, Ottawa
- Appendix C Needs Survey #2
Distributed at North Bay, Burlington, Niagara/St. Catharines, Timmins
- Appendix D Needs Survey Compilation
- Appendix E Evaluation Survey - Interview Questions
- Appendix F Steering Committee/Meeting Participant Interviews
- Appendix G Project Overview
OBCIEP Promotional Brochure
Programs/Evaluations from Community Conversation Gathering Sites
OBCIEP Participant Package Inserts

Appendix A - Community Capacity Building Project Management Group

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Appendix B – Needs Survey #1

Survey #1: distributed at Sharbot Lake, Thunder Bay, St. Thomas, Sudbury, Cobourg, Ottawa

1. To what extent are **information** needs for women with breast cancer being met in your community?

very much somewhat not very much not at all

2. To what extent are **support** needs for women with breast cancer being met in your community?

very much somewhat not very much not at all

3. Where do gaps related to **information and support about breast cancer** exist in your community?

<input type="radio"/> primary prevention	<input type="radio"/> sources of information
<input type="radio"/> early detection/diagnosis	<input type="radio"/> support groups/services
<input type="radio"/> breast self examination (BSE)	<input type="radio"/> research
<input type="radio"/> breast screening/mammography	<input type="radio"/> statistical data
<input type="radio"/> other diagnostic tests	<input type="radio"/> palliative care
<input type="radio"/> treatment options	<input type="radio"/> other. Please list:
<input type="radio"/> alternative therapies	_____

1. Do you currently use **on-line resources** to provide you with **information** about breast cancer?

very much somewhat not very much not at all

2. Do you currently use **on-line resources** to provide you with **support** about breast cancer?

very much somewhat not very much not at all

3. Please indicate how on-line resources might be more helpful in providing information and support related to breast cancer:

-
4. Check as many of the following as apply:

I have been diagnosed with breast cancer

- I am related to, or am close friends with, someone who has breast cancer
- I am a volunteer for a cancer organization
- I am employed in the health care field

Appendix C – Needs Survey #2

Survey #2 – distributed at North Bay, Burlington, Niagara/St. Catharines, Timmins

Check as many of the following as apply:

- I have been diagnosed with breast cancer
- I am related to, or am close friends with, someone who has breast cancer
- I am a volunteer for a cancer organization
- I am employed in the health care field

1. To what extent are **information** needs for women with breast cancer being met in your community?

- very much somewhat not very much not at all

2. To what extent are **support** needs for women with breast cancer being met in your community?

- very much somewhat not very much not at all

3. Please place a check mark beside all of the topics listed below that you think need to be better understood in order to help plan relevant programs and services for women with breast cancer and their families and friends?

- challenges specific to younger women
- challenges specific to women over age 70
- challenges specific to women living in rural or northern areas
- challenges specific to women living in poverty
- challenges specific to aboriginal women
- challenges specific to women belonging to minority cultural groups
- how the arts (drama, literature, etc.) may help a woman dealing with illness
- how information can be presented in ways that make it accessible to the greatest possible number of women and their families

how care in the home can best meet the needs of women

please turn over....

...continued from other side

- how the link between hospital care and home care might be improved
- issues related to breast reconstruction
- experiences of well women at moderate or high risk of breast cancer
- challenges for women during the period when a breast abnormality is discovered, prior to a possible cancer diagnosis
- challenges facing women who stay well following initial treatment
- challenges for women serving on health system committees as representatives of, and advocates for, other patients
- challenges facing women dying of breast cancer
- challenges facing male partners of women
- challenges facing daughters of women with breast cancer
- challenges specific to lesbian women
- how women respond to reports that environmental problems may contribute to breast cancer

4. Please look back through the topic areas listed in 3 above and circle the **3 topics** that you think we most need to understand better.

5. Do you currently use **on-line resources** to provide you with **information** about breast cancer?

♪ very much ♪ somewhat ♪ not very much ♪ not at all

6. Do you currently use **on-line resources** to provide you with **support** about breast cancer?

♪ very much ♪ somewhat ♪ not very much ♪ not at all

7. Please indicate how on-line resources might be more helpful in providing information and support related to breast cancer:

Appendix D – Needs Surveys Compilation

From Needs Surveys #1 and #2

Identification of Participants (check as many of the following as apply):

	<i>N</i> =	Diagnosed with breast cancer	Relative or close friend	Volunteer in cancer organization	Employed in health care field
North Bay	48	34	26	8	16
Sudbury	9	3	5	2	5
Timmins	25	14	9	3	7
Thunder Bay	59	13	38	12	10
Ottawa	23	7	8	5	17
Sharbot Lake	41	16	17	7	20
Cobourg	29	17	16	8	2
Burlington	8	1	5	5	4
Niagara	81	26	36	7	30
St. Thomas	14	5	9	5	5

To what extent are **information** needs for women with breast cancer being met in your community?

	<i>N</i> =	Very much	Somewhat	Not very much	Not at all
North Bay	48	7	27	7	1
Sudbury	9	2	6	1	0
Timmins	25	1	12	8	3
Thunder Bay	59	24	26	4	0
Ottawa	23	7	12	4	0
Sharbot Lake	41	6	16	14	1
Cobourg	29	13	7	5	0
Burlington	8	5	2	0	0
Niagara	81	22	38	8	0
St. Thomas	14	1	9	3	3

To what extent are **support** needs for women with breast cancer being met in your community?

	<i>N</i> =	Very much	Somewhat	Not very much	Not at all
North Bay	48	8	26	6	1
Sudbury	9	2	7	0	0
Timmins	25	1	15	7	1
Thunder Bay	59	21	24	1	0
Ottawa	23	8	13	1	0
Sharbot Lake	41	4	19	11	4
Cobourg	29	12	10	3	0
Burlington	8	5	2	0	0
Niagara	81	19	37	8	0
St. Thomas	14	0	9	4	0

From Needs Survey #1

Where do **gaps** related to information and support about breast cancer exist in your community?

	Thunder Bay	Sudbury	Ottawa	Sharbot Lake	Cobourg	St. Thomas	Totals
<i>N</i> =	59	9	23	41	29	14	175
Primary prevention	13	5	9	21	10	5	63
Early detection/ diagnosis	11	3	6	16	8	6	50
Breast self- examination	1	2	5	16	2	6	32
Breast screening	5	1	4	12	2	2	26
Other diagnostic tests	6	1	5	11	7	2	32
Treatment options	4	3	6	18	8	8	47
Alternative therapies	10	4	11	20	12	6	63
Sources of information	3	4	7	25	7	8	54
Support groups	3	3	3	21	4	11	45
Research	4	1	11	16	8	8	48
Statistical data	1	2	6	18	0	6	33
Palliative care	1	2	4	9	3	3	22

*top three topics in bold

Other Gaps Identified:

Thunder Bay

Compression sleeves needed for lymphedema problems
 Mammograms for younger women
 Especially for remote northern locations
 Ultrasound for younger women
 Prevention for younger women
 Lymphedema and ADPR compression sleeve—means of payment for vendor (doing measurements) No one to do
 After surgery arm exercises
 Gynecologist will not do breast exam nor pap smear??
 1 central local source would be nice

Sudbury

Gaps in all the above
 There are issues in all the above
 Services for “hard to reach”
 We have services; dissemination issue
 Communication of where to go for information

Ottawa

- Metastatic breast cancer
- Scams versus true research-based information
- French-language support groups
- Financial support
- Great amount of information available, challenge is accessing information as required
- Physicians do not inform patients about support services

Sharbot Lake

- I don't really know
- Need to direct more info to well women
- Not sure
- Larger centres e.g. Brockville have support groups, but not in rural
- More forum presentations like this one I attended March 28 put on for women to attend
- What can we do to improve the testing/diagnostic procedures/tools
- Provide free BSE clinics for women under 50

Cobourg

- New to Cobourg—not yet too familiar with the above

St. Thomas

- Breast cancer survivor groups for support
- Communication among health care providers
- One-stop service area so faster diagnosis-treatment-support time
- Clinical breast exam

From Needs Survey #2

Please place a check mark beside all of the topics listed below that you think need to be better understood in order to help plan relevant programs and services for women with breast cancer and their families and friends?

Topic	North Bay	Timmins	Burlington	Niagara	Totals
<i>N</i> =	48	25	8	81	162
Younger women	29	10	6	49	94
Women > 70 years	14	10	4	23	51
Women living in rural or northern areas	25	16	4	25	70
Women living in poverty	25	11	6	38	80
Aboriginal women	15	8	5	21	49
Women belonging to minority cultural groups	10	7	8	20	45
How the arts may help a woman dealing with illness	25	13	3	50	91
How information can be accessible to greatest number of women	35	18	3	57	113
How care in the home can best meet the needs of women	37	18	2	59	116
Link between hospital and home care	20	19	3	63	105
Issues related to breast reconstruction	19	10	2	32	63
Experiences of well women at moderate/high risk	20	15	3	42	80
Challenges for women when breast abnormality is discovered	31	12	4	47	94
Challenges facing women to stay well following treatment	20	8	3	41	72
Challenges for women as health system volunteers, advocates	8	10	2	20	40
Challenges facing women dying of breast cancer	25	17	4	48	94
Challenges facing male partners of women with breast cancer	33	11	4	49	97
Challenges facing daughters of women with breast cancer	34	16	6	47	103
Challenges specific to lesbian women	7	3	1	13	24
How women respond to reports of environmental problems	22	16	5	45	88

*top three topics in bold

Please look back through the topic areas listed in 3 above and circle the 3 topics that you think we most need to understand better.

Topic	North Bay	Timmins	Burlington	Niagara	Totals
<i>N =</i>	<i>48</i>	<i>25</i>	<i>8</i>	<i>81</i>	<i>162</i>
Younger women	10	0	1	14	25
Women > 70 years	0	3	0	1	4
Women living in rural or northern areas	5	8	1	2	16
Women living in poverty	2	4	2	4	12
Aboriginal women	1	1		1	2
Women belonging to minority cultural groups	0	1	4	0	5
How the arts may help a woman dealing with illness	0	0	0	3	3
How information can be accessible to greatest number of women	8	6	2	22	38
How care in the home can best meet the needs of women	3	3	0	4	10
Link between hospital and home care	7	2	0	13	22
Issues related to breast reconstruction	1	2	0	1	4
Experiences of well women at moderate/high risk	2	3	0	13	18
Challenges for women when breast abnormality is discovered	10	3	2	14	29
Challenges facing women to stay well following treatment	6	4	1	6	7
Challenges for women as health system volunteers, advocates	2	2	0	1	5
Challenges facing women dying of breast cancer	4	1	0	15	20
Challenges facing male partners of women with breast cancer	8	2	0	13	23
Challenges facing daughters of women with breast cancer	13	7	0	14	34
Challenges specific to lesbian women	0	0	0	0	0
How women respond to reports of environmental problems	1	4	3	16	24

*top three topics in bold

From Needs Surveys #1 and #2, Questions on the Use of Online Resources

Do you currently use **on-line resources** to provide you with **information** about breast cancer?

	<i>N =</i>	Very much	Somewhat	Not very much	Not at all
North Bay	48	8	8	13	17
Sudbury	9	2	4	0	2
Timmins	25	1	9	4	10
Thunder Bay	59	10	10	3	34
Ottawa	23	6	8	3	6
Sharbot Lake	41	3	15	5	20
Cobourg	29	6	6	3	14
Burlington	8	0	2	3	3
Niagara	81	8	13	11	39
St. Thomas	14	1	2	3	7
Totals	337	45	77	48	152

Do you currently use **on-line resources** to provide you with **support** about breast cancer?

	<i>N =</i>	Very much	Somewhat	Not very much	Not at all
North Bay	48	0	6	13	23
Sudbury	9	1	2	1	3
Timmins	25	0	4	3	16
Thunder Bay	59	4	6	2	41
Ottawa	23	2	5	6	10
Sharbot Lake	41	0	5	2	31
Cobourg	29	3	4	4	18
Burlington	8	0	0	1	7
Niagara	81	2	4	8	53
St. Thomas	14	0	0	3	9
Totals	337	12	36	43	211

Please indicate how on-line resources might be more helpful in providing information and support related to breast cancer:

North Bay

Have someone become familiar where to find financial aid for single support workers—lack of funds can cause people to lose their home, etc.

There is a breast cancer survivor chat room on the Internet

Don't use online as I have no computer

Have not accessed info enough to comment

New treatments in other countries
 New treatments in USA and other countries
 Develop a list of most reliable resources on Internet. Need a web site with local resources (Nipissing District).
 Easier access or linkages
 Clear information regarding specific internet addresses. Identification of key cancer care and support organizations and their mandates. Currently somewhat overwhelming, confusing.

Sudbury

It's another tool—up-to-date, correct information
 Get the info to those that need it, when they need it
 Accessibility of computers and how to use and access the web info; library presentation very interesting
 Being able to talk to someone who actually has gone through it as soon as you are diagnosed and along with your treatment before and after
 More user friendly

Timmins

I do not have computer skills as yet. Until I am able to use a computer I cannot use on-line resources
 Updated information, especially from Mayo Clinic and places like that
 Can be done in home, privately and a little at a time and repeatedly as women can handle emotionally
 More sites with certification and more extensive info made available
 Education
 I find person-to-person (not on-line) contact more helpful and more personal!
 General:
 Great presentation. Very informative. Speaker very interesting, clear, concise, knowledgeable.
 Thank you.
 Louise: You are a great facilitator! Keep up the great work!

Thunder Bay

A one-stop web site recognized for accurate reliable and current information—RELIABLE, CREDIBLE
 Promotions by agencies through the media to public that this information is available and out there for all to access and use
 On-line sources can be overwhelming. Because of vast amounts of data—perhaps a better organization/comprehensive listing of sites—i.e., Canadian locations available to us in NW Ontario
 People who are in remote communities and are unable to get information would get it first hand
 Assist women newly diagnosed on what to expect, where to go for help and research on their own
 Would make the newest information available in a more timely manner—allow people to access info anonymously

Ottawa

Automatic delivery to people who sign on, or when they are interested in receiving information
 Regional information, statistics
 Chat rooms for patients/families
 Would increase the circulation of information
 Any guidance for our support groups would be much appreciated

Immediate information at our finger tips
 We could access information at any time
 Give out information to others more quickly
 All support groups under one link instead of or including each organization having one site

Sharbot Lake

I didn't know that it was on the Internet
 One needs to remember that there are many people, particularly in rural areas who are not computer literate and they need the help most
 A "one stop" location c links to other resources
 Chat groups
 Awareness of how to access; awareness of specific web pages/sites
 Up to date web sites. Good links.
 Only one small piece of the puzzle. How many, especially elderly women "surf" the net??
 Just need to access them—need someone who could access these for people
 If I knew reputable sites
 Notice of latest treatment

Cobourg

Have what is available in different areas for support and information
 Should be able to connect with other breast cancer (sic) within area
 Help women think it could happen to them and have a yearly mammogram
 E-mail
 On-line resources should have links to others of the same and links to support groups
www.herSource.com
 Information re location of support groups
 Since I have not used on-line resources, I cannot comment.
 I haven't used on-line support
 Not familiar with on-line resources
 People afraid to ask for help and support—privacy
 I found this service more than adequate
 Advertising in the community to familiarize women about these on-line programs and how to access them

Burlington

May be of use for rural women, links to correct or valid/accurate resources
 Link you with a wider base of people going through similar circumstances
www.breastcancersupport.org

Niagara

I am not on-line
 Standard treatment vs. naturopathic treatment choices available
 Advertising so that people can have the websites listed instead of searching on the Internet
 By having surgeons, the hospital and oncologists provide the information to patients
 Link to naturopathic doctors in area
 Include up-to-date information on breast cancer research advances outside of Canada, i.e., things available in the U.S. but not yet introduced here
 I am not able to complete this as I do not have breast cancer and am not aware of resources, etc.
 the workshop was great!
 Information on prevention

Links to women's websites

If it gave all the alternative treatments as well as mainstream

St. Thomas

Need to learn to access this source

Maybe have information tape available on all examinations and treatment for the public prior to them having their first tests

Only helpful if you have the Internet

One-stop shopping

Appendix E—Evaluation Survey – Interview Questions**Evaluation Survey**

Name of Participant: _____

Site: _____

Date of CCG: _____

Date of Phone Interview: _____

- *Thank you for agreeing to be interviewed for this phase of the community capacity building project that was held in your area.*
- *Your reflections and comments will give us an idea of whether this project has had an impact on your community.*
- *I'm happy to repeat or clarify the questions if necessary.*
- *If there is something that you want to say about the project that may not seem to fit in the context of the questions, please feel free to contribute it, as your reflections and observations are important.*

1. In what ways, if any, has participation in this project been helpful in providing information about breast cancer locally?
2. In what ways, if any, has participation in this project been helpful in providing support about breast cancer locally?
3. As a result of participating in this project, what gaps, if any, have been identified for meeting the needs of women with breast cancer locally?
4. As a result of participating in this project, do you or does the group have any plans about addressing those gaps that might have been identified?
5. In what ways, if any, has participation in this project been helpful in enhancing collaboration amongst groups and individuals involved with breast cancer?

What groups worked together on this project?

Had they worked together before?

6. Please comment about whether regional or provincial agencies or resources might have a role to play locally for women with breast cancer.
7. Are women in your area satisfied with the availability and the format of resources that they need?
8. Please comment about the use of on-line resources in your community.
9. Suggestions do you have about how the group's participation in the project might have been made easier? For example:
 - timing of project?
 - available information about the project?
 - resource binder?
 - participant packages?
 - support from project coordinator?
 - other?

Appendix F—Interview Comments

Respondents are members of the steering groups and participants at the community conversation gatherings who were interviewed by the Project Coordinator or the OBCIEP Coordinator. The comments are compiled according to themes that link with the CCB project objectives.

Collaboration

Kingston

- The project was helpful in enhancing collaboration among local health community workers, public health, Breast Cancer Action Kingston (BCAK), Canadian Cancer Society (CCS) unit offices, etc, and increased the trust among the players as it offered an opportunity for them to meet face to face.
- Working together in the project—Breast Cancer Action Kingston, nurse from Kingston Regional Cancer Centre, nurse practitioners from Sharbot Lake and surrounding area, public health nurse, a local water quality expert, health promotion and community development representative, breast screening nurses, a genetics counsellor, a social worker, personnel from CCS, and Catholic Women's League.
- About four of the six main planning bodies involved had worked together before, not all as a group.
- Main thing was getting like-minded people together. The bonding was the main thing.

Thunder Bay

- The coalition has consistently worked with a variety of agencies, and collaboration has been built up over the years. It is positive for women to see agencies working together. Through their collaboration they are setting an example to other groups.
- The project was a great way to bring awareness to provincial efforts—not many people know who OBCIEP is. But this project showed the audience that there was help from the province (OBCIEP) and from a national level (Health Canada grant).

Ottawa

- Groups feel they are a part of *My Personal Breast Cancer Binder (MPBC Binder)* since many contributed to the process. Different groups have become resources for one another.

Timmins

- Pulled in people with common goals.

Sudbury

- Brought together groups who may not have met together before. During the gathering, the in-depth knowledge of particular topics was very helpful, useful to assist in future project. Enormous potential of third generation web site.
- Brought together Sudbury Circle of Strength, local breast cancer information and support group, members of Sudbury Breast Health Coalition, Breast Screening Centre, Regional Cancer Centre, information technology expert from NEORCC, two local librarians, a social worker who had developed a program for young mothers to communicate and research information online.
- (*Participant*) If using information technology (IT)—partnerships need to be forged with libraries for information and education in using the technologies.

Burlington

- Participants from public health, office of MPP, St. Elizabeth, several nurses. Trying to let more people know about this program. Hope to provide daylong training to enable others to take it to their communities across Canada.

Awareness

Thunder Bay

- Following the Forum, increase reported in calls and referrals to genetics counselor for her services. So, helpful to the general public attending the Forum and to the health professionals, who were not so well informed about the genetic factors in breast cancer.
- The presenter received a lot of calls after the presentation. Risk of breast cancer to women of younger age is a concern.
- Helpful about genetics as component in breast cancer. A number of younger women came with their mothers and were surprised about the risk of breast cancer to younger women and the need to start BSE at an early age. Another facet of breast cancer.

Kingston

- “Invaluable in understanding the issues” of rural women r/t diagnosis and treatment and the factors of time and distance in choice of treatment (opting for mastectomy versus lumpectomy to minimize travel and therefore visits).
- There is a lack of creditable sources for information. Where are the resources they can trust in the community? They want information, reliable public education.
- *(Participant)* The meeting was important, especially to the rural community who do not like to talk about breast cancer.
- *(Participant)* The people who came could have seen the article in the newspaper. The event was well advertised.

St. Thomas

- As a result of the process, there has been an increased awareness about the proposed women’s health centre.
- Cannot tell yet since the aim of sessions had been to develop a women’s information centre. Not a great attendance. But the value is that they can use his information to substantiate the awareness of the issue and the support for it. Good info for future planning.
- *(Participant)* the information to her colleagues in the Aylmer area (near-by community). Made contact with the OBSP nurse and has been invited to the clinic to refine breast exam. Now knows the technicians and can make direct contact if she has questions.

Cobourg

- Put up posters in a large rural area to create awareness of their team as a resource in the community.
- Possibly hold an annual open house or other event. Need to make themselves visible—public needs to be reminded that the dragon boat team exists, to help bring out other survivors. This was a learning experience. They are not public speakers. Invited mayor, and will invite him again. Will send packages to prominent community businesses to seek support. They want to draw other women, be strong for them.

Sudbury

- *(Participant)* The experience of breast cancer (middle class women) is not universal because economic factors make it a different experience for many women. IT is a powerful tool but accessibility has to be addressed. Also need to look at literacy, culture and elderly women for whom breast cancer may be one of several health issues.
- Provided opportunity for groups to sit down together to review inventory of services already available and identify services gaps, which would not have happened without impetus of CCB project.

- Meeting was chance to take “long view”, they took a step back from day-to-day services to look at whole picture of breast cancer information and support in the area.

North Bay

- Attendees included one family physician, student nurses, survivors other than Warriors of Hope members, so meeting increased awareness to a wider audience about available breast cancer information
- The meeting was heavily advertised and a spot on a local television station about a young patient with a strong family history of breast disease was featured which included telephone numbers to call for breast cancer information
- The physician speaker encouraged all women to be persistent with their doctors on checking breast lumps, even those that are benign should be checked—women in the area reported that their family doctors often would reassure them that 80% of abnormalities are benign and would not recommend any further investigation
- Up until this year, no; the Warriors of Hope have expended a lot of time and energy on increasing awareness about the resources currently available, have conducted lunch and learn sessions, initiated information dissemination through the media
- Brought people together and the information provided was good. Many were not familiar with the information presented.
- (*Participant*) Provided platform for North Bay Cancer Services, CCS, Health Unit in area, she now knows where they are and who to contact for information
- (*Participant*) Information was not provided to her at doctor’s office at time of breast abnormality being discovered.

Knowledge About and Access to Information and Support

Thunder Bay

- For the next forum genetics will likely be part of the program because of interest in the area generated from this presentation and because of developments in research.

Kingston

- Many indicated that local media, newspapers, radio, were sources of information on cancer for them and that they are finding those sources are not always providing up-to-date or reliable information, even the pamphlets in the local CCS office were suspect for being outdated; this may reflect more a fear of not receiving quality information than the reality, but the concern was raised. They felt local media had a role to play in providing good objective information and that they should be challenged to educate the local population on cancer issues, e.g. cancer is not “contagious”.
- This gathering just skimmed the surface. Small groups are important and this was a beginning. Do need printed materials distributed in pharmacies, libraries, grocery stores where people go as part of their daily lives. Also a central local resource person.
- Allowed people in Sharbot Lake to know they were not forgotten. Positive that available support could be identified, e.g., that BCAF is available.
- (*Participant*) It was good to have people openly talking about it, although one survivor went away discouraged.

St. Thomas

- (*Participant*) Need for a central resource centre to guide women through the process. Need for social support during the process. No support group for women with breast cancer—need to start one. There are different providers and levels of care, so women get lost.
- (*Participant*) Concern for the need to assess and better care for young women with breast cancer.

Especially a concern since the prognosis is worse—being found too late.

Cobourg

- Many of those who attended were women with breast cancer. The area covered by the team was broad. Team members at the open house attempted “buddy up” with survivors from their particular community.

Ottawa

- Assisted in providing a unified approach, so that all the agencies are starting at the same level. A high standard set by the binder is being taken to the larger community. The *MPBC Binder* provides good evidence-based information
- Make sure women in the region have access to the *MPBC Binder*. Ensure communities are getting binders. Updating binders with relevant current information. Also for multicultural groups.
- (*participant, nurse educator*) Helpful for her to train nurses working in the general surgery clinics to be aware of the information distributed to women and to help women who are using the *Binder* as an information resource.

Timmins

- Survivors were given a sense of hope that there is an effective method of controlling lymphedema and it is one of several options. Clinical data supports the best practice model that was discussed. Living in a smaller community, health professionals need to be more active, and maybe the participants and planning committee should be recruiting people to help.

Burlington

- Many women who eventually take workshops will have not only education but also the support to learn about their own breast health, be proactive. Survivors as well. And these workshops provide an opportunity for women to come together to learn and share.

North Bay

- Probably did not provide further support although information about the breast screening program was discussed, and access to screening offers some degree of support.

Sudbury

- A needs assessment completed in the area in 1997 showed that there was little information available to women who were diagnosed with a breast abnormality until they were diagnosed with cancer and were exposed to information resources at the local cancer treatment facility.
- Feels that more information is now available, but all of it is on paper and not everyone is aware of what local resources are available or where to access them.

Ongoing Collaboration

Kingston

- Brought together health care providers from local health units, regional health and support groups like Breast Cancer Action Kingston, the local and Kingston CCS unit offices, other women’s groups.

Thunder Bay

- Among local groups there has been much collaboration; not so much regionally.

St. Thomas

- The main partners in health care in the area prior to the project were the CCS, Cancer Care Ontario

and the Health Units who had “good” to “very good” collaboration.

- Local collaborative activity has been somewhat strengthened by the project as it has given the local health issues group more impetus to proceed with a project they felt was needed anyway, the CCB gathering confirmed that need and made them feel that they could tackle it for the community.
- (*Participant*) Should be more support for such gatherings to give out information in a participatory way. Outreach.

Sudbury

- Need more attention to survivor groups—an opportunity to meet with them in an exciting learning atmosphere.
- Big potential if groups at all levels can participate on website.
- Brought together some groups who had worked together before but the focus was different—this meeting provided a chance to review the “big picture” needs in information and support.

Ottawa

- *MPBC Binder* dissemination ensures that providers of supportive care had copies—provide guidance about direction and support for women with breast cancer. This was a step ensuring consistency and comprehensive attention.
- At a subsequent meeting (after the CCG) individuals that had attended the CCG were sharing the information with their agencies, doing presentations using material from the *Binder*.
- This event helped strengthen the foundation to improve supportive care.
- Since this CCG was part of a regional initiative, it seems every time participants (of the CCG) come together they learn more about who one another is (forge links) and learn what is available in the community. Peer counsellors as well as health providers were involved.

North Bay

- Carolyn Jackson from the Ontario Breast Screening Program was known to Louise Walker through her involvement in the Nipissing Breast Health Coalition; she had not previously worked with the Warriors of Hope group.
- Opportunity for members to work together. Coalition helped. Some difficulties with local office of national group—more support would have been helpful on a number projects
- (*Participant*) Meeting provided opportunity to share with community what groups are involved in breast cancer and what they are doing; included surgeon from Sudbury, representatives from North Bay Canadian Cancer Society, and North Bay Health Unit.

Gaps Identified

Thunder Bay

- Especially in genetics there is a need to keep up with current material. The coalition is going into their third printing of the pamphlet “If You Have a Breast Lump.” Constant updating is needed of this resource guide about agencies in the northwest. The pamphlet is sent to women across northwest Ontario.
- Concerned that when women call an agency on the list, feel lost and cannot access appropriate information.

Kingston

- Real concern that now the process has begun that it will continue—need direction and funds to follow-through with the process that was started, fear that women will become cynical as they are asked about what they need many times but no programs are put in place to deal with their concerns.
- Meeting created expectations and CCO and regional groups have responsibility to follow-through

with funds and expertise to address concerns.

- Women expressed desire for CURRENT printed information as opposed to online resources and not in book form which can be intimidating, but short, brochure, pamphlet-style documentation that they can read and review at home at their leisure.
- Also wanted option of face-to-face communication with health care/support workers who could answer their questions and guide them through the process.
- There is a lack of creditable sources for information. Where are the resources they can trust in the community? They want information, reliable public education.
- “Gap” equals a need. Developing community is important—going where people live. Developing a network of resources to get information.
- There need to be supportive people available—who know resources, have the information and can offer support
- Available, but women do not look at them until they need them. Usually the format does not need to be different for rural women unless the material is specific to Kingston. Adaptation of “urban” material to rural. Household mailings reach women.
- *(Participant)* Support or survivor group.
- For those who live north of the Sharbot Lake area, it was made known that it takes hours to get to the cancer centre and to the doctors in Kingston.
- Are not satisfied about having to wait so long for treatment, as they have to for most of their hospital care.

St. Thomas

- Major need identified: a co-ordinated approach to care and support for women, particularly those affected by breast cancer.
- The human touch is needed most to provide information. After that, literature.
- *(Participant)* Support.

Cobourg

- More support groups for an area so large. Need for more publicity about the team to draw women with breast cancer, especially younger women.
- Where are the younger women with breast cancer?
- More support groups for an area so large. Need for more publicity about the team to draw women with breast cancer, especially younger women.

Ottawa

- How the *MPBC Binder* can be disseminated to make sure no women are missed.
- Binder is in English; French version in the works. Needed for other languages, e.g. Hispanic community.
- Make sure women in the region have access to the binder. Ensure communities are getting *Binders*. Updating *Binders* with relevant current information. Also for multicultural groups.

Timmins

- After diagnosis and treatment women seem to be “let go” and they don’t know where to turn. Maybe the issue of lymphedema is a starting point to determine those things that can be done better. The turnout was excellent, although many professionals (physicians and massage therapists) who were invited did not attend. Some women drove the hour each way from Kapuskasing—it was impressive, and they must have felt a great need in order to come so far.
- Women who go to the regional cancer centre are given lots of material, but not aware of anything beyond that.

Sudbury

- Organization of the overwhelming information. So much out there to access and need to ensure what is being accessed is appropriate.
- Interest in having another session, a whole session, about a third generation web site.
- Brought up issue of informing residents in Sudbury and surrounding areas of information that is available from different sources the local support group Circle of Strength, the cancer treatment centre, the regional breast health coalition.
- The community needs to know what information is available, where to get it, and this information should be available to them online.
- **(Participant)** I. A hospital website would be useful. This would help in filling the gap, especially for those situations—early in diagnosis phase (woman has had mammogram and does not know if it is breast cancer) and about treatment options. Often missing is information about the metastatic phase and information for younger women. II. What can women with children do? Care giving responsibilities are central to some women. It is not clear how to get help early in the diagnosis. After discovery of the lump, it was five weeks before chemotherapy and access to a social worker. This is a critical time when more than information about the disease is needed.

North Bay

- Along the continuum of care there is a huge gap in support at the point between pre-diagnosis, diagnosis of cancer, to cancer treatment—emotional support system is needed when women have an abnormality, whether it is cancer or not.
- Family physicians/surgeons need to assume some responsibility for providing patients with better information on how to access breast cancer information and support
- Time between getting diagnosis and treatment is long. There seem to be many organizations and resources and a clearer understanding is needed. Numbers of organizations seem overwhelming.
- **(Participant)** Feels that information is sorely lacking about and for women < 50 years old. As a woman with a family history of breast cancer (mother was 38 at time of diagnosis) she wants regular check-ups and monitoring, local screening unit will only provide service for women > 50 years and older. No help for people in her situation. Would help if family physicians would provide information about Cancer Information Services and CCS to patients directly. Also need to educate people that they can call CIS even if they do not have diagnosis of cancer. Majority of doctors in northern Ontario are predominantly male and she questions if this has an impact on how they treat women with breast abnormality—e.g. rather than referring women they tend to take a “wait and see” approach.

Burlington

- OBSP does screening only for women 50 years of age and older. Where do women go for help with BSE?

Mobilization**Kingston**

- A report of the session has been produced by the Steering Group, what is being considered is the development of a Rural Women’s Health Network, gathering helped to establish pathways for the future, the needs have been identified, now the “hows” including funding, have to be determined.
- Real concern was raised repeatedly that there be follow-up to the issues raised at the gathering.
- The Kingston Regional Cancer Centre and Cancer Care Ontario definitely have a responsibility to assist in health promotion in this area, money is the biggest need and the biggest issue.
- **(Participant)** It seemed to be a good exchange between people who were patients and the health professionals who listened to their concerns. It is easy to feel like a number. Hope something happens with this.

St. Thomas

- Women's health interest group needs to continue to prod people in the community about the need for a women's health information centre.
- Only the dragon boat team. Next time will make an effort to contact support groups and physicians. This was a learning experience.

Cobourg

- Would have been helpful to have a plan. Need to contact media.
- Possibly hold an annual open house or other event. Need to make themselves visible—public needs to be reminded that the dragon boat team exists, to help bring out other survivors. This was a learning experience. They are not public speakers. Invited mayor, and will invite him again. Will send packages to prominent community businesses to seek support. They want to draw other women, be strong for them.
- Want help in grant funding proposals—going to apply to the Trillium Foundation and others.

Ottawa

- Make sure the agencies hear about it. Approach local physicians and support groups.

Timmins

- There was a supportive feeling amongst the participants and possibly a seed planted for development of the Assistive Devices Program (ADP) program.
- Possibly there will be action on the ADP. Physiotherapists left gathering with more information, possibly they will become involved.
- Would do it again. Gathered information about the audience and will consider doing another presentation. High level of support and enthusiasm for this event.

Burlington

- First time that training was made available to the trainers themselves. First market of this project is local and now there are trained volunteers to teach in the community.

Online Resources**Kingston**

- Evaluations from participants indicated online resources are not accessed directly by the women in the area (ages 40 to 60+), although many use friends and family as information sources and those individuals may be accessing information through the Internet.
- This population has limited computer skills and probably will not develop them in their lifetimes.
- Need to do more research on this in the area—libraries do offer training and have computers but it is not clear that women know of this or that they would access information in this way.
- There is also the issue of determining credible information on the internet—many in the area are not trusting of the information supplied by the local media and CCS offices, so they may feel less comfortable with the vastness and variety available on the internet.
- Need to accept the electronic age and need to have a person to help bring them the information from this resource so they can make a decision.
- Starting at the bottom. Some women (older) won't leave phone messages much less approach a computer. Workshops on computers. A supportive resource person would be helpful.
- One member of the support group uses it and shares the information with other members.

Thunder Bay

- One major site is needed to make access to information easier. An information clearinghouse is needed.
- Especially helpful for breast cancer and lymphedema. Many women are becoming aware of the information available online and may use someone else to access it for them.

St. Thomas

- A Virtual Community might appeal to a segment of the community. The local area has a high rate of illiteracy and many do not have access to online information nor do they seek out the opportunity to use the local library services to use or to learn how to access online information.
- (*Participant*) Uses Internet increasingly. Women in the community are using it more and more, but unless they have a specific concern they likely will not use it.

Ottawa

- (*Nurse*) A lot of women, especially younger women, use online resources. Some even send what they find to me. Older women rely more on the family physician.
- Not the primary mode of information seeking for the majority. A select population uses on line resources. Question of the material—is it good, misleading, does the woman know how to use it?
- (*participant, nurse educator*) Many more women are coming in with questions about information obtained on the Internet, much of it obtained by others (family or friends) as everyone is not online—socio-economic status is a factor here although all school children are taught computer skills as a regular part of the curriculum.

Timmins

- Valuable. More and more women are taking control, seeking information on the Internet. But they need to be discriminating about the sites they visit.

Sudbury

- (*participant*) Need what is beyond simply passive information—support. Make sure people know about supportive care services. There is still stigma attached to seeking out these services.
- (*participant*) In the bigger web site there needs to be a partner site run by the support group which would be survivor-led and would link women in the north east in a virtual support group (a survivor-led sister site.)
- (*planner*) Did not comment on use of Internet generally but noted that if anyone in Sudbury or surrounding area was searching for information on available services in the area, there is no information available online

North Bay

- (*participant*) Generally in North Bay the use of online resources is high, she obtained a lot of information herself from online sources, found it more reliable than information from her family physician.

Burlington

- Definitely women are using them. Local women ask questions via the web page. We have Internet access and women come in to use it.

Focus to Regional or Local Level

Thunder Bay

- It was positive having the support of an “Ontario” group, not just local support.
- There wasn’t a regional representation attending on the evening because the forum took place on a

weeknight. Ideally these forums should take place throughout the region. One way of doing this might be through the region's cable network.

Kingston

- BCAK is an important resource to the rural community and it needs to focus on communication from BCAK to the community.

Ottawa

- There was good regional representation. Also Willow (provincial) representative was present. Provincial support would give this binder increased credibility. It is useful pretty much universally. It is also a template for other kinds of cancer. Do not want to charge women, since expenses during the course of treatment are a concern.
- Need to continue funding the *Binder*. There have been requests from other regions and provinces— How can others adapt the binder to their communities?

North Bay

- (*Participant*) Ontario Breast Screening Program (OBSP) needs to do more for younger women with family history of breast cancer to ensure that young women will be monitored appropriately without having to travel distances for care in another urban centre.

Burlington

- Want to see this knowledge (BSE health and training program) to go across the province and Canada.

Plans to Resolve Existing Gaps

Thunder Bay

- For the next forum genetics will likely be part of the program because of interest in the area generated from this presentation and because of developments in research.
- Ideally these forums should take place throughout the region. One way of doing this might be through the region's cable network.

Kingston

- A report of the session has been produced by the Steering Group, what is being considered is the development of a Rural Women's Health Network, gathering helped to establish pathways for the future, the needs have been identified, now the "hows" including funding, have to be determined.
- Real concern was raised repeatedly that there be follow-up to the issues raised at the gathering.
- Given nature of event there is also some sensitivity that the group of health experts and supporters were parachuted in for the day and then left, need to keep women in area informed and assured that their concerns were heard and will be acted upon.
- What happens after this? No one has been identified to take it on.

St. Thomas

- CCB gathering helped community to kick start a women's health centre, initially focussed on breast health, much needed in the area, reinforced a long-held belief that one was needed.

Cobourg

- Want help in grant funding proposals—going to apply to the Trillium Foundation and others. Possibly hold an annual open house or other event. Need to make themselves visible—public needs to be reminded that the dragon boat team exists, to help bring out other survivors. This was a learning experience. They are not public speakers. Invited mayor, and will invite him again. Will send packages to prominent community businesses to seek support. They want to draw other women, be strong for them.

Ottawa

- In rural areas there are not resources to the same extent. In Ottawa the group is active in getting out information. Some material (books) are not so accessible. At the regional cancer centre all women get the package. But physician's offices need to have this information.
- An issue is, now that there are more books—which are the good, credible ones?
- (*participant, nurse educator*) *MPBC Binder* is part of a five-initiative plan for the Ottawa regional area. Now that the binders have been distributed there will be follow-up and review conducted in the coming months.

Sudbury

- Have developed proposal with OBCIEP and other project partners to Health Canada to set up regional website for breast cancer information and support

Enlarging the Awareness of Needs**Kingston**

- Re: needs of rural women
- There was a team approach and it was a wonderful beginning. It would have been helpful to have a speaker to stimulate more focussed discussion.

Ottawa

- (*participant, nurse educator*) Until attending meeting where *MPBC Binders* were distributed she was not aware of the limitations of information and support outside the immediate Ottawa area

St. Thomas

- Also a major need for a local clinic that sees women through the process—especially those steps prior to diagnosis when a lump is identified. Waiting is difficult. A place is needed where that can be done quickly. Time is an important issue.

- *This seems relevant, although it's not directly connected to this particular project:* At her high school, a **participant** has information in the showers about BSE. The school takes on public service projects—e.g., students made pink ribbons for the cancer society. The students tell their mothers about it—raises awareness. Just getting students to say the word “breast” so that they are familiar with it, not embarrassed. Also involvement in CCS projects such as Relay for Life. Has also participated in the community’s Phone a Friend Campaign—Each person participating called 10 women over the age of 50 to ask if they had arranged an appointment for their mammograms.

Provincial Support

Kingston

- Meeting created expectations and CCO and regional groups have responsibility to follow-through with funds and expertise to address concerns
- OBSP is not easily accessible in the area in this expanse of counties. Perhaps transportation is needed to OBSP site in Kingston or Peterborough, or a mobile scanning vehicle.
- BCAF does not really know the rural people. Need to look at how an ongoing relationship can be fostered.
- BCAF does not really know the rural people. Need to look at how an on-going relationship can be fostered.

Ottawa

- (*participant, nurse educator*) If Ministry of Health legislated breast cancer patients’ rights to care, then hospital administrators would have to include a baseline measure of support for each patient in their policies and procedures

Sudbury

- Funding is a huge issue, there are no operating funds for any of these community-based initiatives. Regional and provincial agencies can help by providing funding or access to funding.

St. Thomas

- Money! The hospital in the area will not take on any more projects unless alternative funding can be found. To aid in this perhaps some assistance in helping local groups to learn about grant funds opportunities and how to apply for them, e.g. grant proposals. They are seeking other funding sources for the women’s health centre.

Timmins

- The province (Long Term Care?) should support and have a program in place for the approval of ADP.
- With some of the local groups of provincial agencies, there is an unfortunate history. If some people learn an event is being hosted they will not attend it because of the continuing negative feeling towards the local agency.

Appendix G*

The following pages include a Project Overview chart of all project sites, the project promotional brochure, and materials from each of the 10 community conversation gathering sites. The material includes samples of programs, handout material, advertising samples, and evaluation summaries where available.

**Web viewers—this section not included online. Copies may be obtained by contacting OBCIEP office.*