Ontario Breast Cancer Information Exchange Partnership

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Breast Cancer Information and Support – Preferences to Guide Service Development

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1. Summary

1.1 Purpose

Building on the Ontario Breast Cancer Information Exchange Partnership's (OBCIEP) previous work, the purpose of this project was to enhance access to information and support by providing an innovative website that can be easily used to tailor reliable information and support options to suit the preferences of women at any stage of their breast cancer experience. In addition to the website, the expansion of support options was explored by piloting online and telephone peer-led support groups.

1.2 Population Group

Men and women affected by cancer were the population group. Breast, ovarian, lung and prostate cancer survivors contributed to the needs assessment. Many survivors involved with the needs assessment also provided valuable review comments as the website was being developed. Eligibility for the peer-led pilot support groups was receiving a cancer diagnosis within the past three years. The majority of the trained peer facilitators were survivors affected by the same diagnosis as their support group.

1.3 Primary Activities

The project consisted of three main areas of activity.

Needs Assessment
Phase one identified specific information and support preferences, expectations and needs among different groups of women affected by breast cancer, including rural and Aboriginal women. Feedback included: likes, dislikes and suggestions for how existing resources could be improved and coordinated.

Website development and piloting peer-led support
Phase two responded to phase one by developing a Cancer Support Network (CSN) website (www.CancerSupportNetwork.ca) that was accessible, relevant and enabled survivors to tailor information and support approaches. New options for peer-led support were also piloted; peer-led online group support through the CSN website and peer-led group support via the telephone. In total, seven peer-led support groups were piloted. Each group typically included up to six women plus a facilitator, meeting once per week (90 minutes) for six weeks.

Evaluation
Phase three involved evaluating the website and the peer support groups. The key areas of interest were: meeting needs of survivors; ensuring the website was user-friendly; alert to improvements/ new ideas; and, general delivery of phone and online peer support. Information for the evaluation phase was obtained from website postings, written surveys, email communication, telephone interviews.

1.4 Major Outcomes

Needs Assessment
For the needs assessment, nine focus groups were held in eight locations across Ontario. Sixty-four (64) participants including both women and men dealing with breast, lung or ovarian cancer contributed. Participants talked about their experiences in obtaining information and support (e.g., perceived gaps, how they preferred to receive information, specific information and support sought at different stages). They also discussed obtaining information through the Internet and shared their frustrations and preferences when searching for information and support online. The results formed a comprehensive pool of suggestions that guided the development of the CSN website.

Website Development and Piloting Peer Support Groups
The CSN website was designed in stages and evaluated by health practitioners, caregivers, and cancer survivors. Many of the reviewers participated in the focus groups. In total, over 150 individuals provided comments, criticisms and helpful tips on the creation of the website. One menu option of www.CancerSupportNetwork.ca provided details about the online peer-led pilot groups. The CSN website was the online location where the groups met.

The second part of Phase Two was to pilot peer-led online and peer-led support groups via teleconferencing. Seven groups were completed (three phone and four online; breast and ovarian cancer diagnoses). The phone and online peer-led support groups were reported to be effective in meeting information needs, providing emotional support and establishing a connection or bond with other survivors. The groups therefore benefited the participants in similar ways to more traditional face-to-face support groups.

Evaluation
The evaluation included website reviews and drawing together the frequent feedback and final interviews with the phone and online peer-led groups (participants and facilitators). While the evaluations indicated that the website was not the “draw” to the pilot groups, as had been anticipated. It was considered a useful resource for those seeking credible information sources about cancer.

Both facilitators and participants overall expressed the view that technology-based peer-led support is a valuable service. The establishment of ongoing online and/or teleconference peer-led support groups was considered extremely promising, particularly for hard to reach populations or those isolated by geography, cancer diagnosis, physical disfigurement or disability, or in some cases emotional distress. Issues that need to be addressed include facilitator training; promotion for the purpose of recruiting facilitators and participants; the structure and timing of the groups; coordination and support of the groups; and ongoing costs.

These issues and recommendations for the future are discussed in detail in this report.

2. Background

2.1 Sponsoring Organization

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of Ontario-based 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.

The mandate of the Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is to ensure information about breast cancer is available to all people in Ontario.

Whatever the activity, the fundamental philosophy of the OBCIEP remains in the forefront—that 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 36 cancer and breast cancer organizations from across Ontario. Of all the organizations involved, over half are grassroots and breast cancer survivor-directed groups.

The primary role of the OBCIEP is to assist the organizations, to respond to the information needs of their clients. By providing a neutral forum for networking and information exchange at the provincial level, the OBCIEP fosters cooperative problem solving and coordinated action concerning issues related to breast cancer information dissemination. In collaboration with others, OBCIEP also develops information resources for women, their families, and health care professionals to fill identified gaps. In addition, OBCIEP 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.

The project partners are the Canadian Cancer Society - Ontario Division, Ovarian Cancer Canada, the Thunder Bay Breast Health Coalition, and Willow Breast Cancer Support Canada.

2.2 Project Rationale and Development of Idea

Traditional face-to-face support groups have been shown to benefit cancer survivors as they help people cope with their experiences. These have included professionally-led, peer-led and self-support groups (e.g., Galinsky et al., 1997). Benefits include timely education about cancer and treatments, help with coping after a cancer diagnosis, relief from isolation, emotional support, and help with relationships with family members (e.g., Bui, Last et al., 2002; Hill, 2003). The helpfulness of peer support has been described in terms of the bond of common experience, reassurance about personal reactions and optimism about the future (e.g., Dunn et al., 1999).

Less is known however, about the difference non-traditional peer-led support can make, in particular those that are remote (not face-to-face). With the growth in technology, more recent avenues for providing this type of support are the telephone and Internet-based networks (BC Cancer Agency, 2004). Remote support options are particularly

important in light of the fact that some women are not able to attend support groups or live far from communities where support groups are found. As a result, there may be few opportunities to meet other women in similar circumstances. In addition, it is important to offer a range of information and support types. Earlier work by OBCIEP (e.g., Fitch, Nicoll and Keller-Olaman, 2007) showed that women affected by breast cancer perceive a lack of options at specific times and do not always know what some services offer and how they may be helpful. Women searched the Internet for information but were frustrated by too much or too little information on specific topics and not knowing what information to trust.

The present work is unique and blended the development of a website that could help meet information needs plus pilot online and phone peer support. As far as we are aware, there are no online (in "real time") cancer support groups available that are led by trained peer facilitators. To date, there have been a few studies looking at remote peer support groups (e.g., Curran & Church,1998), but no research examining the effectiveness of remote peer-led groups (see Dunn et al., 2003).

Objectives of Peer-led Telephone and Online Support Groups

Short term objectives:

- provide a venue for support, especially for those that may not be able to attend traditional support groups
- provide a venue for information exchange with those who have been through the same experience

Long term objectives:

- increase knowledge
- reduce feelings of isolation
- facilitate new perspectives
- enhance or build coping skills
- reduce feelings of stress and anxiety

Approval from the Sunnybrook and Women's Health Sciences Centre Ethics Board (now the Sunnybrook Health Sciences Centre) was received and all ethical requirements of this approval were adhered to.

3. Project Goals

The overarching project goal was to enhance the information and support of people living with a cancer diagnosis. The needs assessment, website development and peer-led support groups had specific goals too.

The needs assessment sought to:

- identify preferred means for accessing breast cancer information, barriers, and preferred types of information and support.

- learn about critical times during the cancer experience for specific information and support requirements.
- gain an understanding of website features and options that are trusted and/ or make an Internet site 'work' for women with breast cancer, and features that are least preferred.
- examine preferences and expectations when provided with a comprehensive menu of information and support options, including online emotional support.
- collect thoughts and experiences around the use of interactive website features such as discussion boards, chat-rooms, 'ask the expert', and online emotional support.

The goals of the website were to:
- complement existing services and information (credible websites) with new developments.
- ensure the CSN site was user-friendly, enabling women with breast cancer to tailor information and support at any time it is needed.
- provide peer-led support groups.

The goal of the evaluation was to:
- capture and describe what was working and not working throughout the website development and in the peer support group pilots.
- propose options for change and improvement where necessary.
- assess a range of outcomes including the usability of the website and effectiveness of the peer-led online support groups.

4. Project Activities

There were three main project activities conducted over the four-year period: 1) a needs assessment; 2) the website development; and, 3) piloting peer-led support groups using technology. Evaluation was also conducted throughout (see Evaluation section for details).

4.1 Needs Assessment

Data for the needs assessment was collected by surveying groups of people affected by breast, lung, ovarian, or other cancers. The participants were recruited through advertisements by project partners and OBCIEP coalition contacts, and the participants were all self-identified Internet users.

Data collection commenced in March 2005 and was completed during May 2005. Eight locations in the Greater Toronto Area and in northern Ontario were selected for the focus groups: Burlington, Toronto, Oshawa (south central Ontario), Thunder Bay, Dryden, Pic River, Manitouwadge (northwestern Ontario), and Timmins (northeastern Ontario).

Each session took approximately two hours, starting with 30 minutes for survey completion (see 11.5). Discussion of the focus group topics (see format in 11.6) followed

plus discussion of three pre-selected websites. If technology permitted, the three websites were projected on to a screen directly from the Internet:

- Irish Cancer Society's Action Breast Cancer -"Just Diagnosed" page http://www.cancer.ie/just_diagnosed.php
- The Wellness Community, California.http://www.thewellnesscommunity.org
- Breast self-exam site, Thunder Bay Breast Health Coalition http://www.breastselfexam.ca/

Alternatively, the participants were presented with a PowerPoint slideshow of several pages from each of the selected websites. It should be noted that one website emerged as a firm “favourite” in the initial sessions, and this website was added to later focus groups for discussion:

- Breast cancer.org (USA) http://www.breastcancer.org

For the needs assessment, extensive notes were written by two facilitators during the focus groups. The groups were also audio-taped to ensure all comments were captured. At the end of each focus group, the participants completed an evaluation of their session. The closed survey questions were summarized by noting the proportion of participants that responded to the various response categories. Responses to the open-ended survey questions were grouped into main themes. Similarly, any comments, opinions, and experiences expressed during the focus group discussions were organized into the main themes that emerged.

4.2 Website Development – www.CancerSupportNetwork.ca

It is worth noting that the emphasis was to utilize credible websites where possible rather than building a new site. The website development was conducted in stages and informed by the needs assessment and earlier OBCIEP work.

As each component of the website was developed, focus testing was conducted. The focus testing was done using an online system. Norlink (outsourced webmaster) developed the survey site which separated the results by type of cancer (breast, lung, ovarian and prostate).

Web Creation/Maintenance
The website was created using a content management system or CMS. A CMS system provides the ability to easily add, edit and delete web copy. The design and layout of the site was completed by the webmaster (Norlink) and their graphic designer, allowing the site content to be built by the project coordinator. The system uses WYSIWYG (What You See Is What You Get) technology in which content during editing appears very similar to the final product. It is commonly used for word processors, and web (HTML) authoring.

Emailing/Newsletter Capabilities:
Added to the CMS system were custom modules for managing emailing lists. Reviewers email addresses were entered into the system to allow direct communication through the website to each of the reviewers through email or newsletter formats. Communication

regarding each review section was done through this system, providing links to the hidden testing website for evaluation. Announcement of the launch of the website was also done in this way.

Graphic Design
A graphic designer first put together four designs for the home page using the theme of a flower, a vine, a pathway, and a tree. The designs needed to be simple yet colourful allowing for the option of expansion into other cancer sites. The needs assessment found a preference for a white background; bright colours, and large fonts, very clear icons (obvious where to click); the use of tabs either along the top or side of the screen; use of graphics where possible to explain or describe things; not too much written content per screen (not overcrowded); one page per screen. These design elements were incorporated into the four designs and were placed on the survey site and each was rated on various elements.

Left and Right Navigation
Once a design was chosen, a site map was developed and navigation placed onto the design. The left navigation was tested first. This navigation led to specific cancer information for each type of cancer. Participants were instructed to navigate the site and review it based on certain criteria. Then they were directed to the survey site to respond to the specific questions. Findings were incorporated into the navigation and content. The right navigation was then tested in the same manner.

HUB/Portal Site
The site was created as a portal or hub to other websites with trustworthy information that will lead people to other reliable sources of information. The topics within the sub-navigation (prevention, screening, diagnosis, treatment, recovery, etc) were researched and links to the websites with the most comprehensive information were posted. For each link, a brief overview was provided about what can be found at the site, who hosts the site and a notation if it is a Canadian site. The needs assessment showed that Canadian websites were desired and preferred over other countries and that short sentences with brief descriptions were also favoured. Canadian sites were included as often as possible.

When the user clicks on the link, a new window opens for the new site. This allows the user to easily return to the page on the cancersupportnetwork.ca website. All the links are color coded to the type of cancer (i.e. breast cancer – pink, prostate cancer – blue). If the site is not cancer specific, it is color coded green. This allows users to find information specific to their cancer if available.

Search Engine
A search engine was developed by the webmaster that allowed the search to be done on specific websites. A list of credible websites for cancer, and the specific cancer types was programmed into the search module. The search provides results from only those sites that were pre-determined to be credible. Over 70 sites were programmed into the search function (See Attachments for the programmed sites). The search function was also focus tested during the online testing. Reviewers were asked to use the search function to search the site and to search the world-wide web. The results showed that 95% of respondents had successful searches for information and 100% found it helpful to be able to search only specified sites. They also rated the summary of each article or

site found, the relevance column that the search engine generates, and whether their search was successful.

Font Size
For users with vision problems, an option to increase the font size was built into the website. The user can easily increase the font size of any page on the website by clicking on A+ to increase the size, or A- to decrease the font.

Bulletin/Discussion Board
A bulletin board, also known as a discussion board, or newsgroup was added to the site. The board was divided into four groups: breast, lung, ovarian and prostate cancer: The board was provided as a place where users could post, read and respond to messages, questions and articles on specific topics.

Glossary
The needs assessment determined that a glossary of terms or dictionary was overwhelmingly mentioned as a 'plus' for any site. Glossaries for specific cancer types, drug dictionaries and general cancer glossaries are included within the site.

How to Use the Site
A section which assists users on how to use the site, who hosts the site, purpose of the site, and how to contact us was integrated into the site design. In the search tips area, an article on searching the internet for health information is included. This details how to use the internet and explains how to know if a website is trustworthy.

4.3 Online Support Chat Component and Implementing Groups

Online Support Chat Component
Once the website was completed and fully tested, the chat component was developed. Several options were found and tested. After testing various options, a suitable software (*Flash Chat*) was found which was adaptable to the website and uploaded. *Flash Chat* was tested with the facilitators prior to the formulation of the groups. The feedback from facilitators was positive and the groups were formed.

Chat Room Technology
Privacy and security were of the utmost importance in developing the chat room. The chat rooms were password protected. Each room was set up for a different group. There were groups called Breast Cancer A, B, C. When logging into the chat, every participant entered into a waiting room or foyer. From there the participants used their password to enter the specific chat room where the meeting was held. In the waiting room (foyer), chatting could occur, but as the foyer wasn't password protected, the meetings were held within the chat rooms.

It was suggested that each person find an avatar to distinguish them from other members. An avatar is a small image (graphic) that appears when you post to the chat. These included smiley type faces, sports images, flags, etc.

The *Flash Chat* software proved to have too many technological problems for the groups. After several meetings were held and members were being "booted out" from

the chat on a continual basis, another chat software was purchased. At this time, *DigiChat* was being used by the Wellness Community (www.thewellnesscommunity.org/) and reported no significant issues with the technology (*DigiChat* software has been used to conduct online meetings and host auditorium-style chat events, for examples, see www.digichat.com). The cost of *DigiChat* was significantly more expensive than *Flash Chat*, but within the budget. Due to the way that the cancersupportnetwork.ca website was hosted, it was not possible to host the *DigiChat* on the same server. Therefore, the software was leased from *DigiChat* instead of purchased. *DigiChat* was much easier to use and learn than the previous software. No further technological issues were reported, with the exception of a power failure at the host server which caused the site to go down during a meeting in 2007.

Manual

A manual was devised to support the participants and facilitators (two different versions). The manual contained information about the online groups, a disclaimer, the roles and boundaries of the facilitator, attendance information, group format, confidentiality issues and online chat rules of the road. The facilitator version of the manual included additional information about confidentiality, removing/banning participants, and facilitator support. All participants were emailed a personal password and an electronic copy of the manual up to one week prior to the start of their group. A few participants requested and received a hard copy by mail.

As the popularity of the teleconference groups grew, two additional manuals were created, one for facilitators and one for participants using the online manual format with the addition of tips on conferencing calling and other support group "rules of the road" reflected in materials produced by the Canadian Cancer Society – Ontario Division, Wellspring, and Willow Breast Cancer Support Canada. All four manuals are appended to this report.

The original online participant and facilitator manuals were written for *Flash Chat*. More than half of the manual contained "how to" information on the technological aspects of *Flash Chat* (how to log in, moving from room to room, passwords, chatting, changing the look of the chat room, using avatars, emoticons, private messages, acronyms and abbreviations during chats). Once the *DigiChat* program was uploaded, the manual needed to be updated to reflect the new technology.

Recruitment

The participants and facilitators for the majority of the groups were recruited via advertisements through the project partners and OBCIEP coalition contacts. The ovarian cancer participants were recruited through Ovarian Cancer Canada (not all women had attended a face-to-face support group before). Though the online ovarian cancer pilot group was intended for Ontario participants only it proved impossible to proceed without going beyond provincial borders to recruit sufficient numbers of participants.

Screening Prior to Participation

After potential participants contacted OBCIEP (mostly through email), the project researcher or coordinator followed up with a telephone call to talk about the project in more detail, answer any questions and to obtain some information about the women. Questions included time of first diagnosis, attraction to an online/ phone group, expectations, preferred format (weekly topics or participants define their own issues),

level of experience with a computer, and demographic questions (see 11.7 for screening questions).

Peer-led Facilitation
Trained volunteer facilitators were recruited through Willow Breast Cancer Support Canada and/or Canadian Cancer Society – Ontario Division. The facilitators had received training about confidentiality, peer counselling skills (including empathy, setting and maintaining boundaries, role-playing, giving feedback) and received ongoing training about medical issues associated with cancer (see 11.8 for Precepts of Support Group Facilitation).

Running the Peer-led Groups each Week
Each pilot (telephone/online) support group met on six occasions over a six week period. In order to access their respective groups, at a pre-arranged time each week, the group members used their home computers to log in or used their home telephones to call a conference telephone number and also enter a pass code for their group. Each group was then linked together via the computer or together in a conference call for 90 minutes. When they had finished, they simply logged off or hung up. No special equipment was needed.

Debriefing Facilitators
Debriefing was established to help the facilitators process comments from their respective groups, to share their experiences, and to guide each other through any difficulties. An online chat was arranged for the following evening after each support group meeting. Three facilitators (breast cancer survivors) met with the project researcher to discuss any information they wanted to share, issues or concerns. The initial debriefs (Weeks 1 and 2 for first two online groups) were conducted via *Flash Chat* and *DigiChat* was used for Week 3. It is worth noting that the third facilitator took part in the discussions before her group had started. After the third week, the facilitators collectively asked to stop debriefing online as it was essentially another evening in their week when they were tied to the computer. Each debriefing for subsequent weeks and groups was then flagged by an email question (e.g., "any other comments or issues to discuss; anything else to debrief"?) within the facilitator's weekly evaluation questions. The chat option was always available if requested and personal emails and phone numbers were also shared among the researcher and facilitators.

4.4 Difficulties and Solutions

The Cancer Support Network Website

Maintenance of the HUB Site
Maintenance of the site became an issue before the site was launched. Prior to launching of the site, a software program was launched to detect any broken links on the website. The process of creating the website took well over a year to create and refine. Many of the links to websites had changed as those websites were updated and in some cases completely recreated. The Canadian Cancer Society did a major revision of their website just prior to the launch of the site and the software found over 200 broken links which needed to be changed prior to the launch.

Although the purpose of the site is to lead users to credible up-to-date information on other sites the host is not responsible for insuring that content is current. Maintenance is still required on the host site. It is essential to insure that links are not broken and that relevant and up-to-date links are included. Information is constantly changing, as are diagnostic tests, treatments, and protocols. Insuring that this information is included requires regularly scheduled maintenance of the site.

Initial use of *Flash Chat* for online groups
The first two pilot online groups started at the same time in the evening during the same week in September 2006. The *Flash Chat* software that had been tested on numerous occasions at different times of day with different numbers of people had worked well. With the first two groups online at the same time however, there were technical problems (e.g., being logged off repeatedly, not being able to log back in, not seeing the chat text). Because the main problem appeared to be related to high Internet use by the general population at that time of evening (leading to server overload), the two groups were asked to start at a later time for the second week. Unfortunately technical problems continued during the second meeting. We therefore changed to use *DigiChat* software and subsequently there were no problems from "Week 3" on. Because the third pilot online group started several weeks later, they only used *DigiChat* and did not experience any of the technical problems. As noted earlier, the manual was modified to describe *DigiChat* instead of *Flash Chat*.

Peer-led Support Pilots

Attendance
Support group dynamics were challenged by low numbers and by bringing new women to the group. It is possible that committing to a weekly online or telephone group is easier to ignore or forget than a monthly face-to-face group. Weekly meetings seem to be difficult for all participants to attend all the time in that there was at least one week where family, work or other commitments meant someone could not participate. Missing even two of six meetings means a participant misses over 30% of the group chat. In addition, some of the women mentioned repetition of personal cancer stories because new participants joined the group midstream when initial introductions had already been completed.

Participants in Different Time Zones
Some difficulties were reported with accommodating people living in different time zones (e.g., participants getting tired if the group was too late). For example, people wanting to connect after work means very different times depending if they live in Atlantic Canada or British Columbia. This could be related to the relatively low number of participants we had for the pilot groups. In the future, if many more people register for groups, there could be numerous time options for people living in all parts of the country.

Screening and Referral Options
There were several times when the peer facilitators clearly felt "stretched" and challenged by the limitations of the communication media to deal with the state of mind and actions of certain individuals in their group. Examples include participants that were reported to disrupt their group, monopolize the group discussion time (intentionally or unintentionally?) and create a downward pull on the spirit of the other group members ("*I cried for a week after that (session)*"; personal communication, 2007). In addition, the project coordinator and OBCIEP staff had to inform and mobilize appropriate individuals

and support services where participants dealing with extreme depression were located. Follow-up and debriefing were also part of this process.

These examples raised the issues about screening and referral. Although the peer-led facilitators are trained they indicated that they were not equipped to deal with participants that needed more than peer support. Although external professional advice and support for the facilitators was sought by OBCIEP, the peer-led facilitators would have preferred that the individuals could have been referred to a professionally-led group or a professional one-to-one counsellor.

Furthermore, the screening of the participants is mainly to confirm eligibility and the fact they are cancer survivors, rather than serve as a psychological screening. Referral options are part of the vision of this work and revision of the screening questions is already being explored.

5. Participation of Population Group

The project comprised of three main areas: a needs assessment, website development and piloting the peer-led support groups, and evaluation. The work followed a participatory approach. The development and implementation was conducted in close consultation with project partners, the advisory group and those experienced with group support, online support and information design. The participants also played an integral part, helping to ensure that the website and the peer-led groups were relevant and user-friendly.

Involvement of Survivors

Cancer Support Network Website
The needs assessment informed the website development and could not have been achieved without the survivors. Their input and feedback guided the website development. The website development fully embraced the fact that the information was being tailored and screened to meet the needs of the survivors.

Peer-led Support Group Pilots
The structure and format of each support group was shaped by suggestions from the participants. For example, a list of potential discussion topics was developed for each group and offered to the relevant facilitator. These lists were created from screening questions that asked the participants if there were particular areas they wanted to discuss in their group. In a few cases where participants did not like the way the group was working, the coordinator was able to advise the facilitators and changes were made.

Involvement of Facilitators
The initial planning group for peer-led support consisted of the OBCIEP coordinator, the OBCIEP project coordinators, members of project partners and two trained volunteer support group facilitators who had offered their time to be part of the pilot, both of whom were cancer survivors. The group planned all aspects of the first peer-led groups, such as duration of groups, how often they meet, group size, time since the participants were diagnosed, screening and evaluation questions.

Prior to the online peer-led pilot groups starting, the OBCIEP project team and the facilitators spent several sessions online as a practice phase (Winzelberg et al., 2003). One reason this was done was to ensure the technology was as user-friendly as possible for the participants and the facilitators. The facilitators provided valuable input at this stage.

Revisions Based on Feedback

Cancer Support Network Website
The website www.CancerSupportNetwork.ca went public 2006, primarily to gain as much feedback as possible. Survivors and facilitators assisted with the selection of sub-sections, wording and presentation of the manual that was devised and revised.

Peer-led Support Group Pilots
Feedback from survivors and facilitators guided the peer-led groups. After the first two peer-led groups, a meeting was held with the OBCIEP project coordinators and facilitators prior to the start of each new group. The facilitators were given suggestions of how the groups should be run based on suggestions from facilitators and participants that had already completed groups (e.g., have a list of potential topics prepared, do not run groups through the summer, aim for full commitment from at least four to five women, etc.).

6. Partnerships and Intersectoral Collaboration

OBCIEP was the leading organization and provided administrative support for the project and assumed responsibility for filing the quarterly financial reports, interim reports and the final project report. OBCIEP also kept all provincial Coalition members informed at each stage of the project.

The project partners were: the Canadian Cancer Society - Ontario Division, Willow Breast Cancer Support Canada (Willow), Ovarian Cancer Canada and the Thunder Bay Breast Health Coalition. These organizations have networks in Ontario at both the regional, provincial and national levels. The partners were involved in the oversight of all stages of project design, planning and investigation.

Specifically the work could not have been done without the Canadian Cancer Society - Ontario Division. The Society assisted with the needs assessment (recruitment and venues), recruited facilitators and helped recruit participants. Janet Canavan, Manager of Peer Support modified the teleconference skills training workbook and provided additional group phone training for facilitators if needed (e.g., some were trained only in face-to-face or one-to-one peer support). The Society participated in the online practice sessions.

The Thunder Bay Breast Health Coalition assisted with the needs assessment in northwestern Ontario and recruited a facilitator and recruited participants through its website, www.breasthealthnw.ca.

Willow Breast Cancer Support Canada provided trained facilitators and information from their facilitator training documentation and reviewed the manuals and peer-led group procedures.

Ovarian Cancer Canada was a crucial link to participants for the ovarian cancer phone and online support pilots. Of note, for most women in the ovarian cancer survivor phone group this pilot was the only support and contact they had to other ovarian cancer survivors and for some the first time they had experienced a support group. Their group therefore alleviated the isolation many of them had been feeling.

Lung Cancer Canada made focus groups possible (needs assessment recruitment). Wellspring, Toronto and Wellwood, Hamilton were valuable points of contact and information, especially around recruitment for the needs assessment, development of the manual and the evaluation questions. Wellspring offers a variety of support for cancer patients and caregivers, free of charge and many led by professionals. They do also offer peer one-to-one support and were willing to assist with recruitment for our pilot peer-led groups.

The working relationship between the project partners was positive and they were fully committed to the project. This is of great help when identifying gaps, service issues, setting priorities, planning activities for resource development, obtaining support from interested partners/ organizations, and informing related projects (e.g., the development of online professionally-led emotional support pilot being conducted in British Columbia by Dr. Joanne Stephen).

The project partners have also assisted in disseminating updates to their various partner groups and clients through regular communications vehicles such as websites, emails, and newsletters.

7. Results

The findings from the needs assessment are presented first, followed by the reviews of the website development. Results from the seven pilot groups are then brought together and common themes highlighted. Areas of contrast are described also. The peer support group findings include the women's expectations, how the groups unfolded over the six weeks, attendance, what the women believed worked, what did not work, suggestions for the future and effectiveness. In the main, the results are organized with the participants' feedback preceding the facilitators' comments. Major themes are presented. Any names used are pseudonyms. Many of the findings have been summarized and bulleted. Selected quotes are presented.

7.1 Major Achievements - Needs Assessment

A needs assessment was conducted to identify preferred means for accessing breast cancer information, barriers, timing and preferred types of information and support with a focus on technology and/or Internet based resources. Sixty-four (64) volunteers took part in the needs assessment the majority being women reporting a breast cancer diagnosis.

- 95% found cancer information from books or articles;

- 75% also sought cancer information online, and the Internet was the third preferred source;
- interactions with both health care professionals and with other patients were also important sources of information;
- most wanted very clear and brief explanations about cancer and treatments;
- nearly half (48%) said that the computer was helpful for support;

- participants want more information on areas such as:
  - financial concerns
  - alternative therapies
  - what clinical trials typically involve
  - treatment side effects
  - exercise options post-surgery
  - coping
  - links to psychotherapy options

- 46 participants reported that the Internet was convenient and helpful for seeking cancer information and learning about medical terms, awareness, decision-making, reassurance, current research and randomized controlled trials, finding available services/ agencies and linking useful sites.

Women reported frustrations using the Internet and reasons for leaving sites included:

- information gaps (e.g., couldn't find what looking for; inadequate information regarding drug therapies; alternative therapies; a dearth of information for lung and ovarian cancer patients relative to breast cancer information; few resources in languages other than English or French).
- unclear information (e.g., information overload or out of date; terminology that is too medical).
- credibility/relevance (e.g., not knowing which sites to trust. Some would first check who sponsored the website before reading the content. They were suspicious of sites sponsored by drug companies. Some were also turned away by doubting the credibility of the information source. Websites presenting alternative therapies were given as an example where they believed there was a lack of credible sources. Frustrations were also linked to the greater number of American websites, when more relevant Canadian content was sought and preferred.
- too slow/"getting lost": People familiar with the Internet are accustomed to rapidly delivered information. Websites with many features (e.g., video, flash displays) that take too long to load led to frustration and quitting a website. Similarly, if a site takes many seconds to switch from screen to screen, the participants give up. One further frustration was related to tracking back through links. Not all participants knew about opening a new page for each website. For these individuals, not being able to get back to where they started was very frustrating.
- difficulty in finding Information/visual issues: Many sites are difficult to navigate to find specific information needs. For some sites, the "search this site" function provides results that include media releases instead of general information about the topic. Many websites lack clearly identified and direct links to other sites that provide more detailed and/or corroborating information.

Visual Features
Objects that move on the screen were seen as distracting and upsetting to people who are already not feeling well. Exiting a website was also more likely if the site had:

annoying pop-up windows; graphics that zoom about the screen, a font size that is too small to read; any pulsing images, neon-bright colours; text that is too crowded or has too many highlighted words (too "busy" looking). In addition, some sites have far too much clutter on the home page making it difficult to know where to go or how to navigate through the site. In some cases the home page is so dense with text it is difficult and time consuming to figure out where to go next.

Search Features

The needs assessment found a preference for search tips, and engines built within the site people are browsing. For example, they did not necessarily want the direct answer to their questions on a hub site, but want to be linked to the source that has the answer. For example, when reading about clinical trials, they prefer links to the original research articles. There was frustration when searching for information using a search engine such as Google. At that time, many keyword searches provided links to sites to purchase books on the subject (i.e. Amazon) or other inappropriate sites. There was a desire to be able to filter out all the unwanted search results.

Summary

The needs assessment provides insight into the ongoing information and support needs of cancer survivors in Canada, and beyond. The needs assessment also situates the website development in the light of technical advances in general and highlights some of the considerations that need to be made in this rapidly evolving area.

7.2 Major Achievements - Website Development

The development of the website www.cancersupportnetwork.ca started in 2004-2005. Four reviews were conducted. The numbers of participants providing feedback are summarized below.

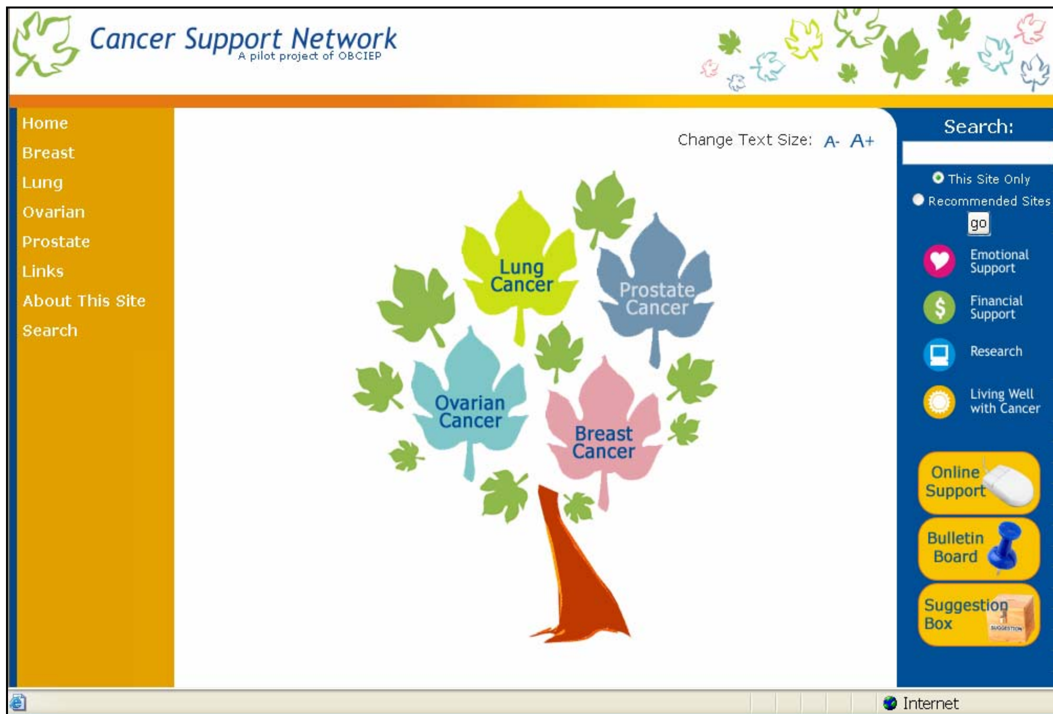
Reviewers by diagnosis (n)	1. Review Graphic Design	2. Review Left Navigation	3. Review Right Navigation	4. Review Search Features
Breast	70	52	35	18
Ovarian	3	7	4	3
Prostate	-	2	1	-
Lung	2	6	-	2
Total	**75**	**67**	**40**	**23**

In total 150 volunteer reviewers provided comments as the website was developed. Despite efforts to connect with as many survivors as possible, reviewer participation tapered off dramatically from review 1 to 4 (e.g., from n=75 to n=23).

Review #1: Graphic Design

Reviewers were questioned about the website design. Four designs were evaluated by the online reviewers. These included design concepts incorporating a flower with the various cancer sites within each petal, a vine with each cancer site within a leaf, a pathway with each cancer site within a cobble stone and finally a tree with cancer sites on the leaves. The tree and the flower scored the highest. All respondents were female

and this may have had an impact on the results. The tree design using maple leaves was chosen as the most appropriate home page symbol for the site as it was less feminine than the flower. The selected design is shown below:



Review #2: Left Navigation
Reviewers were questioned about the website navigation (left) for the various diagnoses. Responses were also questioned about the categories (e.g., general information, prevention, screening, diagnosis, treatment, recovery, clinical trials, ask an expert and glossaries), organization of the categories and about the links to other sites. Focus testing results showed that the site was easy to navigate, the categories, their format and level of detail met needs and expectations.

Review #3: Right Navigation
The navigation on the right of the home page was appraised (e.g., emotional support, financial support, research, living well with cancer). Focus testing results showed that these areas were the most appropriate for the website and that the information and links were easy to navigate.

Review #4: Search Features
Reviewers were questioned about the Search Feature that was developed for the website. As mentioned earlier, this function was built to only search websites that had been pre-screened by the project staff and deemed relevant and credible (see Attachments for the list of pre-screened sites). Overall, the reviewers were very pleased with the search feature. The Needs Assessment found that discussion boards were a useful place to find everyday information not often mentioned by health professionals. While most were happy to read replies, they were less likely to post a question themselves. The usefulness of a bulletin board is determined by the number of posts. Due to the lack of visitors to the website, there have been no postings to date.

Summary
From April of 2007 to December of 2007, there were 4,713 site visits and 16,046 pages viewed. The statistics are steadily rising each month.

7.3 Major Achievements - Peer-led Phone and Online Support Groups

A total of seven peer-led pilot groups were completed. Seven were conducted by teleconference and four were conducted online. Although all participants were familiar with computers, few had tried online chat programs before. There was an assumption that younger women would prefer the online option because they are very familiar with the technology and the convenience that suits their lifestyles and the older women would prefer to use the telephone. This however, was not always the case. The findings are combined unless there were contrasts of note between phone versus online or breast cancer survivors versus ovarian cancer survivors.

Peer-led Support Groups Completed

Diagnosis (Age range)	Group type and number held	Participants per group	Facilitator(s)	Dates
Breast cancer (45-64 years)	2 phone groups	4-5 (Southern and Northern Ontario)	Breast cancer survivors (Ontario)	June-July 2006
Breast cancer (42-65 years)	3 online groups	5 (Ontario)	Breast cancer survivors (Ontario)	Sept-Oct 2006 Nov 2006
Ovarian cancer (45-60 years)	1 phone group (2 women also had breast cancer)	6 (British Columbia, Saskatchewan, Manitoba, Ontario)	Co-facilitated (one a cancer survivor). Both Ontario	July-Aug 2007
Ovarian, young women (27-36 years)	1 online group (2 women with breast cancer also)	4 (Nova Scotia, Ontario)	Breast cancer survivor (Ontario)	Oct-Nov 2007

Expectations Prior to Participation
During the recruitment process the women were asked to describe what they hoped to gain from their phone or online group. Two broad themes encompassed the majority of their expectations; sharing experiences and information and connecting with others. Not surprisingly, these were often entwined within single comments. Sharing was typically framed in terms of hearing stories or needing to tell their stories and was also described in terms of giving information/ assistance rather than only receiving. It is worth noting that most of the women wanted to talk with survivors who had the same cancer as themselves about their experiences, struggles, and successes. Sharing was also described in terms of wanting to learn about specific topic areas from other women. Connecting was linked closely to emotional support. These women were seeking reassurance, seeking a level of support not available from their existing social networks and/ or did not want to feel alone.

EXPECTATIONS

1. Connection/emotional support

- *"Hope to connect with others that have been through a similar situation".*
- *how others (with) "head in the same place" are going;*
- *"nice to share and not feel isolated".*
- *"...shared companions, and hope we all feel better in the end".*
- *"…friends don't understand, and think they don't want to hear…I need to be part of a support group! I need the contact….I do have books and the net but that isn't want I want".*
- *Feeling at the end of the day that I'm not the only one. I'm at the end of treatment and quite emotional, my hair is growing back, but I feel I'm floating around.*
- *The contact. Family and friends are great, but now that treatment is over I want to talk with others that have been through it.*

2. Information sharing/seeking - general experiences

- *"Where to go from here - now I have completed treatments, but life does not seem back to normal".*
- *I've missed groups and I need to talk about it all, especially the surgery. I prefer to talk about experiences than topics.*
- *I have a positive outlook so would like to help others to see the positive side, but will get help for myself along the way.*
- *I've been in a face-to-face group, but at the time it didn't suit me, low energy. It takes a lot to be in a group. I was in a group after treatment and most of the others were recently diagnosed, so heads in a different place, so it wasn't for me. I've had time…. I'm more interested in giving out. In the past I had nothing to give, it was tiring me out.*

3. Information sharing/seeking - specific issues/topics.

- *"How others have handled returning to work".*
- *"…how they have dealt with the long-term effects of chemotherapy".*
- *" how to improve the way a diagnosis is given".*
- *"chemo brain".*
- *"cancer fatigue".*
- (e.g., for young ovarian cancer survivors, fertility and coping with the future were highlighted. Examples included; *"instant menopause, how to prepare my family, fear of the future").*

Prior to starting their group, each woman was also asked if there were specific topics she wanted her group to discuss. The following list was developed from the feedback and the information was relayed to the facilitators.

Topics suggested for group discussion

Breast cancer survivors:
lymphedema; reconstruction; drug herceptin; dealing with long-term pain at the site of surgery.

Ovarian cancer survivors: Instant menopause; post-traumatic syndrome; rebuilding self-confidence; financial coping; fertility – loss of motherhood; coping in marriage with the sense of loss; fear of death; parental options after cancer (surrogate mothers, adoption, etc.); hormone replacement therapy; talking to your kids about cancer.
Common topics suggested by both breast cancer and ovarian cancer survivors: Fear of recurrence; "chemo brain"; fatigue; treatments; sexuality and relationships; chemotherapy experiences; coping skills; food regimens including diet, vitamins, weight loss, nutrition; the healing process; physical and emotional.

Attractions of a Peer-led Phone Support Group

As part of the initial screening questions the women were also asked what attracted them to a peer-led telephone support phone group. The motivation to participate came from: the need to be part of a group more frequently, convenience or a lack of services in their community. Some women also felt that they were far enough in their cancer journey, that they could support others.

ATTRACTION TO PHONE SUPPORT (BREAST CANCER):

- *"we meet once per month (present support group) and I would like something more regular".*
- *"After coming home from work…do not have the energy to turn around and go out again".*
- *"It's like drive-thru support".*
- *"No group close to me and (poor) support in this city".*
- *"There is no support group in my town…there's no one to share with..."*
- *"Had time to digest and absorb what's happened…more interested in giving out to strangers, in the past I had nothing to give."*

Attractions of a Peer-led Online Support Group

The main themes regarding online were also linked to convenience, plus a desire to learn new things and the fact that there were fewer dynamics than face-to face groups. Convenience was framed in terms of the frequency of the meetings and the fact that they could participate from home. Ovarian survivors also mentioned their preference for an online group - linked to an inability to open up in a face-to-face meeting.

ATTRACTIONS TO ONLINE

1. Convenience

- *Being at home, privacy at home, after going through the treatment I'm tired. Online I can think about what to say and can read….I can plan my words more.*

- *I've been to support groups, but don't like their 'Gung-ho' and chip on shoulder attitude. I'm looking forward to it, good for people that are house-bound.*
- *The clinic I go to, I'm on my own regarding interacting. I already attend a face-to-face group but it's only once per month.*
- *I still have fatigue. Just exhausted. I wouldn't do face-to-face and it's at my street each month.*

2. Trying new things

- *I'm not a phone talker and interested to know 'what else is out there?' kind of idea. I like that there's a bigger input with a group.*
- *I like to learn new things and keep in touch with people. I like to share information too.*

3. Fewer dynamics

- *With website chat, you don't have the dynamics of face-to-face groups and don't need to talk about fundraising!*

Peer-led Group Structure

The importance of confidentiality was addressed in the first sessions plus there were introductions and sharing of personal cancer stories. This included the facilitators talking about their facilitator training and a little about their own circumstances. The introductory meeting provided an opportunity for participants to vent about work related issues (job loss due to prolonged illness), infertility (ovarian survivors), impact on their relationships and side-effects of treatment. The ovarian cancer phone group used the introductory meeting to vent about misdiagnoses and the emphasis on breast cancer information and research versus the lack of information and research into ovarian cancer. They talked about having a weekly agenda of topics they would like to discuss over the next five weeks. The ovarian cancer phone group was very vocal about its needs.

Phone Groups

During the initial screening interview, the majority of women indicated that they would prefer a free-flowing format rather than having set topics each week. As the weeks went by, the format of the phone groups was relatively free flowing. Although the facilitators had a list of potential topics on hand, each group as a whole was in control of what they wanted to discuss during each session. At the end of each meeting the facilitators would check in about the topic that would be discussed the following week. Some of the topic areas covered by the breast cancer groups included support at time of diagnosis and during treatment, recurrence, returning to work. Some of the topic areas covered by the ovarian survivor phone group included surgical menopause, coping with chemotherapy, lingering effects of treatment, mortality and getting on with life, coping with life after the cancer experience, healthy living strategies and ways of working through fears and anxieties, financial problems for single survivors (two have lost their jobs and are in danger of losing their housing), advocating for and informing others to avoid negative experiences.

Online Groups

The online groups also followed a relatively loose format and some of the topics that were discussed included: lymphedema (breast cancer groups), nutrition, exercise, side

effects, treatments and reconstruction. The facilitator (online/ovarian cancer) collected topics to discuss at future meetings: sexuality, employment, HRT, hysterectomy. The OBCIEP researcher or coordinator was logged in to the website for each online meeting to help with navigation or any questions that arose. It is important to note that the first two online breast cancer groups ran for eight calendar weeks in total, to help make up for the first two weeks which were disrupted by technical problems.

Weekly Attendance

Phone Groups

One ovarian cancer and two breast cancer pilots were held by telephone:

- the majority of women (breast cancer) attended only four out of six sessions
- the majority of women (ovarian cancer) attended all six sessions
- reasons for not taking part or leaving early included; forgetting about the group, doctor's appointments, vacation, family celebrations, picking up children or other family responsibilities and arriving home later than planned
- the final sessions (breast cancer) suffered from the poorest attendance (each group consisted of two women plus facilitator)
- after an ovarian cancer survivor missed a meeting, she asked to be reminded. A reminder was sent to all ovarian cancer phone group participants for Weeks 3 to 6.

There was therefore an inconsistent number of women in each breast cancer group each week. To help remedy the erratic numbers, and in agreement with the original group members, two new women were recruited at Week 4 (breast cancer). In retrospect, this was not seen as beneficial (see specific comments later in this section).

The ovarian survivor phone group initially started with six participants and dropped to five after one of the participants could not call in for the first meeting. The same woman could not make the second meeting due to previous commitments. She felt she should drop out of this pilot if she was to miss the first two meetings. One participant (ovarian cancer) had difficulties connecting for the first meeting. She attempted to connect using a cell phone but had difficulties with reception. She subsequently tried a pay phone booth. The background noise in that public area proved to be distracting for everyone and she left the call early.

By Week 4 or Week 5 the facilitators (ovarian survivors, phone group) communicated to OBCIEP that the group needed more time. After Week 5, it was decided to offer three more meetings to the group in a once a month format. The group was extremely pleased with the news and a monthly meeting day and time was agreed upon in Week 6. The three month offer was subsequently extended to six months.

Online Groups

Although the desired number of women was recruited for the first two online breast cancer groups (five or six plus the facilitator), they had the misfortune of experiencing the technical *Flash Chat* problems for the first two sessions. This likely played a role in the relatively patchy attendance of these first two groups. The third breast cancer group was the smallest with four women plus the facilitator but this was the most stable group overall in terms of consistent attendance (four each week plus the facilitator). With the

ovarian online group, they started with four participants with agreement that a fifth would join at the second meeting. Ultimately the fifth participant did not participate.

It is worth noting that one online participant, an ovarian cancer survivor, had difficulties connecting for one meeting because she could not find the password. She entered the chat foyer but misplaced the password to get into the room. No one noticed that she was waiting in the foyer looking for someone to provide the password. After each subsequent meeting, the facilitator checked the foyer to see if anyone was there waiting. Another participant lost her internet connection during the meeting and couldn't get back online. During the sixth meeting, a power outage with the server knocked everyone out of the room and no one could log back in. This meeting was rescheduled for the following week.

As a general trend, attendance was highest in the first few weeks and tapered off towards the end of the six weeks. Around three women regularly participated in the first breast cancer group, and four women regularly attended the second breast cancer group. With the ovarian group, typically only two survivors and the facilitator participated. Reasons for absences included:

- illness in the family and subsequent death
- tests and treatments
- fatigue
- pain
- conflicts with other schedules (family events, travel)
- forgetting that the group was on

It should be noted that the chat text was used to confirm attendance once all groups had finished. For example, on two occasions, evaluation feedback was not sent even though a woman had attended a meeting.

Withdrawal from participation

In total, three women asked to formally withdraw from their respective online groups. Reasons included:

- caring for a palliative relative
- finding the chat too confusing, not being able to keep track of things, combined with lack of time and energy after rushing home from work
- the online environment was too slow and frustrating

Efforts were made to replace these women with success which ensured an adequate pool for each group. All online group members had agreed to allow new women into the groups, equating it with drop-in face-to-face support. This meant however, that some women were joining their online group for the first time around Week 3. In addition, a facilitator experienced an electricity black-out and was not able to participate for one session.

Phone Groups – What did you like? What was working?

Once the groups had started, the women were emailed each week for their general feedback. Questions about what the women liked and disliked were asked each time and repeated at the end of the six weeks. All women started out satisfied with the peer group discussions. For the majority, there was no obvious increase or deterioration in

feedback comments across the six weeks. The skill and knowledge of the facilitators was praised, with mention of their welcoming approach, ability to include all women in the conversation, allowing enough time for everyone to contribute and asking questions or topic suggestions when there was a gap in the discussion.

The comments from all of the online groups were very similar though it was especially challenging to obtain regular weekly feedback from the ovarian online group. It is also worth noting that impressions of the facilitator abilities were also asked in the final interview.

The positive comments about the phone groups fit within five categories. Two mirrored the women's prior expectations; dealing with emotions and feeling connected. The feedback clearly demonstrated that the groups developed a strong emotional bond and this connection formed early on. One ovarian cancer participant referred to her group as "my girls". Anonymity was the third key benefit reported. The fourth category captured how mentally uplifting their experience was. The fifth category was related to the depth of their phone discussions.

PHONE: WHAT DID YOU LIKE? WHAT WAS WORKING?
Comments from Participants

1. Dealing with Emotions

- *"I felt better…I preferred the phone, I talked about things in the back of my mind, issues that I hadn't really thought of"*
- *"I found that going to (face-to-face) meetings, each person spoke a bit about their health, or what they'd been doing for the past month and then it became more of an information session on the latest treatments or fundraisers, which isn't necessarily a bad thing, but as far as support goes, I think I like this better – it's almost like talking to a "shrink". ☺"*
- *"Physically I know I'm OK, but psychologically I don't think I ever talked to anybody that made me feel that good. Emotionally I felt like there was a weight gone afterwards."*
- *"It took a huge emotional weight off of me that I was carrying around with me for a long while. I was surprised what a difference these six weeks made."*
- *"The wealth of information the ladies supplied to me as well as the emotional support was invaluable for me. More so than what I got from my physicians or friends."*

2. Connection/ Bond

- *"After Week 3, we started to see bonding going on. The support kicked in almost immediately."*
- *"A lifeline for rural women".*
- *- "I feel like, especially the last session, we built a certain level of relationship obviously by phone, but it was like there was more of a bond at the end."*
- *"I do feel a connection with these ladies even though we haven't formally met. - I think the phone idea works just fine".*
- *"feeling part of a whole rather than isolation due to the remote, small, northern Ontario community that I live in".*
- *"Each week it got more and more comfortable and closer and closer."*

- *"I think there was a connection made. We are a group that clicked really well. You hope it might happen…. but it might not."*

3. Anonymity

- *Enjoyed anonymity, could talk about things you think about but never say...just blurt them out ...It humanizes you…Cool, I'm not nuts, or morbid – so I like the anonymity"..*
- *"The phone group worked, especially for shy people…for myself, felt fine asking questions as I didn't have to see them".*
- *"I think it's been fantastic and a privilege for me to be included and for us all to have this wonderful, frank, personal and private conversation."*
- *"I was not enjoying it at the beginning but came to enjoy it at the end. When I signed on, I liked the idea that no-one knew me"*

4. Mentally Uplifting

- *"I was looking forward to it each week…having a connection with women in other areas…supportive to call in and catch up, compare notes…always felt uplifted, better each week".*
- *"Everything I did that day revolved around that phone call -- I could talk to my girls! My husband was really happy that I came out of it in a good mood, with energy and support. Living in rural Saskatchewan there is no support."*
- *"I feel like I've been part of something. I have this vision of a wise woman with a cape and she holds that around us…like a group hug. It's like that every time we talk."*

5. Thorough Discussion

- *"I've decided on what it is I like better about these phone sessions in comparison to the support groups you attend in person. They are a little bit slow I think getting going but it seems like we fish around until one particular topic hits more than one of us and then it really turns into a discussion about that topic."*
- *"I liked that there was a comprehension of one another's stories and situations. It had been something I had never had before."*

Similar positive comments (sharing, emotional support, connection) were repeated in the final interviews when the women were asked about their overall experience with the group.

Overall positive feedback was received from the phone facilitators (see comments below). One additional benefit of a phone group was raised—the relative ease of discussing sensitive or potentially embarrassing topics such as sex and relationships.

Comments from Facilitators: What did you like? What was working?

- *The phone group is ideal for people that are shy.*
- *The smaller group size (compared to face-to-face) means that all women are more likely to talk.*
- *"It was very intense, that's why there was so much bonding."*
- *The anonymity provided by the large range of locations - is a bonus, especially for women living in small towns. They can talk more freely about their situation without concern about being identified.*

- *The flow of the group works well, people listen to each other.*
- *The phone group works well for discussion of certain topics (e.g. sexual relationships).*
- *"I think that they have learned".*

Online Groups – What did you like? What was working?

Despite the early technical problems (for two online breast cancer survivor groups), overall the facilitators and participants liked the online option. In general, the women became more relaxed with the technology and with each other as the weeks progressed. The comments from the four online groups were combined and the key themes that emerged were related to: building connections, satisfaction with the format and learning new information. As evident in the quotes below, often the themes are entwined.

ONLINE: WHAT DID YOU LIKE? WHAT WAS WORKING?
Comments from Participants

1. Building Connections – helping each other

- *"The group went well. It took some getting used to, to communicate on-line, but there was definitely value for me in exchanging information and experiences with other women with breast cancer. I liked Carol as a facilitator. I will continue being part of the group". (Weeks 1 and 2)*
- *I really liked the idea of an online support group as a way of connecting with other breast cancer survivors. Although, I must admit it felt quite strange and awkward at first to tell someone about yourself and my encounter with breast cancer. But on the other hand, I felt comfortable communicating with the other women in the group because we had gone through cancer. It is sometimes much easier to talk to a stranger who doesn't know you….*
  Also, support groups such as this one and others would benefit newly diagnosed breast cancers patients…deal with all the questions and fears that they have. (Week 4)
- *"The three of us discussed last night how we all feel that we are getting to know each other better and better. Cyndy wasn't there and I missed her, and I think Brigit and Janet did too. Now there's a sign that our little group has started to bond! I always find our sessions informative and learn new things each time, and I feel the ebb and flow of receiving support and giving support is heartfelt". (Week 5)*

2. Satisfaction with Format

- *"I didn't enjoy face-to-face as much as online. I could relate better (online)".*
- *"I found it a really positive experience….it could be incredibly useful… Sometimes in a face-to-face group someone can take up a lot of space (monopolize conversation) and I would have a problem with that….but that doesn't happen with online…in part, easy to write something and 'send' and get your comments in too…"*

3. Learning / New information

- *"The online group went great on Tuesday night. I learned a great deal. I enjoyed it more because there were more people involved. The last time there were just three of us. This time there were six. Offered more info and more of a variety of opinions and comments. Looking forward to next week". (Week 4)*

- *“I enjoyed it. What I found this week is I'm not very fast at typing. Wow, some of the women seemed to type so fast it was hard for me to keep up. At times there were two of them that had a conversation going on between themselves. There was no problem, it went very well. These women have a lot of info to share. I think the online chat is great”. (Week 5).*

- *“Well, last night went well I think. We had five of us for awhile until we lost Karen. I thought it was particularly good last night as I felt as though we were actually able to help a couple of the girls. Angela is new and still in chemo with lots of questions. I remember that time and it would have been nice to have been able to ask questions of people who were there not too long ago. We also discussed other issues some of us have been having such as lymphedema and I think that was helpful to some degree as well. I did enjoy this one more than most, although for me, I still find the conversations all over the board. It sometimes feels like maybe someone is trivialized as maybe their question gets missed and the conversation goes off in a separate direction. …I can see where maybe others might be feeling left out sometimes. I'm also pretty quick on the keyboard so I tend to get lots in while others have got to be picking for the length of time it takes to answer sometimes. (Week 6)”*

- *“I'm finding the group to be a wonderful source of information. Of course, we all come from different "places" and have had different experiences with a common ground. And it's the different that helps a little bit more” (Week 6)*

Overall the efforts of the facilitators were applauded. Positive comments included: their efforts to check in with those who were quiet; being a survivor and knowing firsthand the cancer experience; knowledgeable; supportive; checking in if someone said something a bit off; directing the group; very helpful in answering questions; letting each person talk; asked if we had topics and if not would make suggestions.

In the main, the facilitators’ comments were similar to what the women had reported they liked about the groups.

Comments from Facilitators: What did you like? What was working?

Building Connections

- *“I thought Week 2 was wonderful, my group seemed to be really clicking”.*
- *“There was connection and interaction between the women….I think the members are definitely connecting and that people are beginning to discuss emotional issues a bit more”.*
- *“I asked near the end of group how they found it that evening. One member said she felt like we were getting to know each other and connected. I commented to them that the Chat format seems to work”.*
- *All members found it to be a positive experience. One member suggested that such a group could meet less frequently. I think that people like to be connected with other survivors…The weeks went very quickly. I felt that I was getting to know the members the last couple of sessions.”*

Satisfaction with Format

- *"An online group seems to get right to the point. I guess, not being in the same room as the other people, it is easier to talk. Also you know you're not going to meet the person on the street or in the grocery store. This I'm sure makes a difference. Also talking on line you don't have to worry about cutting some off in conversation....you can be having two maybe three conversations going at the same time. Everyone has the opportunity to speak on their time".*
- *"The interaction flowed more freely and natural more like a regular conversation. I think we are getting used to the Chat format. We had a very interesting conversation about the on-line versus in-person support groups. Two of the members are presently attending a monthly breast cancer support group. One of the members had been to one on the previous evening. Some of the comments were along the lines that the on-line group is "less intimidating" and that it is quieter. One of the members prefers the on-line group I think. It seems to suit her quiet, shy nature. There was also a discussion about the tendency of certain people to dominate an in-person group".*
- *"It went pretty well, but it was a small group…sometimes there were only a couple of people online. It would have been better if there were a few more people. They seemed to get a lot of information between themselves with suggestions and ideas. It's good to have a specific ovarian support group because there are issues specific to the cancer".*

Summary of the perceived benefits of online support:

- connecting online was easier, freer, easier to write something as opposed to saying to someone face-to-face
- meeting each week was helpful compared with the face-to-face groups that often meet once a month
- huge benefit to those living long distances from face-to-face groups
- beneficial to those who are shy
- easier for some to talk about sensitive topics such as relationship issues and/or sex
- everyone had an equal chance to voice their thoughts
- the facilitators liked the ability to private message in case they felt a participant was quiet and wanted to check in with them that they were okay

Phone Groups – What did you NOT like? What was NOT working?

The common drawback to teleconferencing that everyone shared was not being able to see one another and touch. However, after several meetings the group members overcame this challenge to some degree by starting to focus on vocal cues. Another common complaint was about the inconsistent attendance. The group dynamics were challenged by absences, low numbers in general and the flow of the group was also affected by new women joining part way through the six weeks. One woman described the group challenging with only four. Because topics were decided the week before, if some members did not attend or left early, the remaining women did not always find the topic especially relevant to them. In addition, some of the women mentioned repetition of personal cancer stories due to sporadic participation.

The diversity within the breast cancer survivor phone groups was also reported as an obstacle to connecting.

PHONE: WHAT DID YOU NOT LIKE? WHAT WAS NOT WORKING?
Comments from Participants

1A. Lack of Visual Cues

- *"Compared to face-to-face (where we exchanged phone numbers), I just couldn't call Mary and talk as we didn't have that connection".*
- *"I am still feeling a little awkward because I can't see people's faces. I might need a more visual connection than some people".*
- *"it was difficult trying to remember who had chemo, mastectomy – that took six weeks to learn, but once I knew, that helped to talk with the others".*
- *"The hard thing is not to be face-to-face, but it's the next best thing if you can't have it."*
- *"The voices were good, but when you are five in a room, you may hug each other hello, see someone's face, see if they are upset by their face, see how we all look now that we have all come through this. There's nothing like human contact."*

1B. Refocus on Verbal Cues

- *"We couldn't see the people, but we listened harder. For every word and how they express it. You pick up their feelings by intently listening. It's probably not as good as face-to-face, but if you work at it, it can be."*
- *"At first you think face-to-face is better, but perhaps people feel safer in saying things because we couldn't see each other. I discovered I didn't need the body language, because I had the voice."*

2. Challenge with Attendance

- *"One person had to leave early. After one hour we were down to three participants and only two had suffered from surgical menopause".*

3. Diversity: Looking for a Closer Match (breast cancer survivors)

- *"preference to be in a group with others in similar situations"*
- *"the group was so diverse (in age) that people didn't relate so well."*
- *"There was variety in the group – but if really want to talk, it's good to have people to share with, women with a similar situation".*

The facilitators also experienced difficulty with the lack of visual cues: the lack of eye contact and not being able to read body language were frequently mentioned challenges.

Comments from Facilitators: What did you NOT like? What was NOT working?

- *"when she paused, was she thinking of something else to say, was she formulating her next comments, was she tearing up.......without being in the same room with her and having the visual clues, it was difficult to make a judgment about what was an appropriate response" (Rachel, facilitator).*
- *"It's harder to figure out what other people are feeling and thinking when we can't see them. I am a very tactile person and there were times that I wanted to reach*

out and touch and I couldn't. That part of the group session was frustrating for me" (Anita, facilitator)

- *"With face-to-face, sense of satisfaction seeing someone relaxed, but on the phone – unless I hear from her, I don't know that" (Dorothy, facilitator).*

Online Groups – What did you NOT like? What was NOT working?

Throughout the six weeks, the online participants and facilitators were asked to describe what was not working. The biggest challenge was getting used to communicating online. Comments referred to confusion around who is 'talking', multiple threads of conversation, losing track of responses to questions and feeling that they could not type fast enough. Low attendance was a second challenge for the online groups. There was a lack of input giving a variety of opinions, experiences and solutions to many of the issues they collectively faced. It became difficult for the participants who missed a meeting to catch up on what has happened with the group. In addition, like the phone groups, many indicated that it was difficult to keep track of who they were communicating with made more difficult by inconsistent attendance. Some tried to take notes to help remember each others story and personal information. Other challenges included the diversity within the group. For example, one woman wanted to talk more about issues of infertility, while another who had a child wanted to talk about how to raise a child when dealing with cancer and a third was retired with grandchildren.

WHAT DID YOU NOT LIKE? WHAT WAS NOT WORKING?
Comments from Participants

1. Getting used to the Online Format

- *The group chat meeting went well. I liked the facilitator guiding the group. I enjoyed meeting the others. This was my first chat group. It was difficult to type, think and read at the same time. I guess that's the way chat groups work? (Week 1)*
- *I think the participants here will find that it is difficult for each person to "take a turn" or for "one person at a time" to speak because of the lack of visual cues. I've found that on-line chat with more than one other person involves a bit of scrolling back to read what may have been missed; the screen "jumps" when dialogue is posted, particularly if more than one person has replied. On the other hand, sometime a lot of patience in waiting for replies is needed. I think that as we develop familiarity with the format, everyone will become more comfortable with it.(Week 1)*
- *I'm still getting used to the chat group format and I think the others are too - sometimes the responses get a big confusing i.e. what previous comment the person was responding to as several people may have made comments at the same time. (Week 2)*
- *There are many conversations going on at once and not always about the same thing. I think it would be helpful if the facilitator tried to keep us stuck to one topic for that evening.*
- *I miss the spontaneity on-line and don't like it when the comments that come up have absolutely nothing to do with the thread before.*
- *I found the messages to be slow...didn't feel direction in who was to go and when. I may not know how to read the program...usually MSN will say that so and so is typing a message, this one didn't seem to say so… I would like to have an intro each time we meet...saying our treatment etc. and where we're from.*

2. Low Attendance and "Who is Who"?

- *"Our group was small, lots of no-shows…so when a brand new person came in…didn't kind of get to know everyone…you miss out on some of the base stuff, how old, kids, prognosis and you hate to rehash it every time someone gets back in".*
- *"The fact that there are new people each week, so little continuity. We have to reintroduce ourselves and tell our stories each time. Having profiles of all participants available would help resolve that problem. It would also enable us to communicate one-on-one if we wanted to, if individuals wanted to provide their email addresses. It would also be good if there were some sort of record of the resources various people mention, phone numbers, book titles, etc. are lost after you sign off".*
- *"..Not knowing the rest of the groups "story" makes it difficult through the conversation to keep track of everyone and for me it gets confusing".*

3. Diversity within online groups (looking for a closer match)

- *"I went in with a particular subject – I wanted to talk to other young women who were not able to be fertile. Connecting with a woman who experienced the same sense of loss would have been nice. I didn't get the information I wanted, but I don't think I was ready to hear it then. It was so fresh, I was still going through chemo and I was thinking about adoption."*
- *"It was tough though because there were a lot of women with issues of infertility. My issues were trying to raise a young child so therefore I couldn't discuss it because it would be difficult for them as it's a touchy subject for some people."*
- *"It was hard to get everybody's conversations in and hard to keep up. I belong to a support group (discussion board) where you post things as you want to and people can reply if they want. It was easy to branch off to other subjects because everybody could talk when they wanted. Not everybody got a chance to say what they wanted. "*

Further challenges for the online pilot groups:

- some felt that "less ground" was covered than in a verbal or face to face group (not a unanimous comment) because dialogue had to be keyed in.
- some found reading, typing messages, and taking in the conversation somewhat difficult at first.
- adding new people mid-way was disruptive and led to repetition of introductory stories and details.
- the inability of the *DigiChat* version used that does not offer the feature offered in MSN messenger that tells you when someone is typing a message, therefore the conversation can be disjointed as the facilitator may be answering a question posed three comments back; many felt it was the nature of the online chat program and it simply required getting used to the pacing.

What were the challenges to the online facilitators?

A number of challenges were cited by the facilitators of online groups. One facilitator was not able to join for one session due to an electricity black-out. The facilitators did not "unlock" the online chat room, and at times it was a challenge to bring the women back

on topic if they had begun a conversation before the facilitator had arrived. The facilitators also mentioned the overall challenge of keeping the women on topic. In addition, the wide range of attendance certainly played a role in how the facilitators perceived the success of their group.

Comments from Facilitators: What did you NOT like? What was NOT working?

Irregular Attendance

- *"With just a few on the chat, at times it is hard to keep the conversation on the right track, meaning doing our best to give support and not just have a conversation".*
- *"I felt good about the connection with certain women - it was difficult obviously as ladies mostly had disappeared by time group ended".*
- *"The numbers should be higher so that there's more interaction when one or two people don't come".*

Off Track Conversations/Keeping Order

- *"Several weeks have gone totally off track and while I have had good intentions to discuss certain topics along the cancer journey – it always seems to just become a chat group period".*
- *"I was a little late signing on but the women were already signed in. They were chatting away. Using it more as a chat line than a support group line. It took me a little while to get it back on focus….I also think if the chat could be copied so that we could refer back to it would be helpful".*
- *"The group doesn't seem to be interested in arranging a list of topics to be discussed. They seem to prefer less structure. That makes it more of a challenge for me to help them to stay focused since they don't want to focus on a particular topic for the session".*
- *"The most challenging thing was keeping order. I often felt like a teacher with a bad bunch of kids because they mostly went off chatting about their own things while my original intention was to discuss certain aspects of the cancer journey - it just never happened. Part of that challenge was never having the full complement of ladies in the group".*
- *Quite often I arrived on time to find a couple of ladies happily chatting about other stuff and when I would arrive I had no idea what they were talking about but they continued to chat on a personal level even after myself and other ladies had arrived.*

Role

- *"One challenge, how much do I put in my story and abandon 'facilitator' and become 'member'…have to keep both roles in balance".*

Feedback on the Manual

Following Week 3, three questions about the manual were included in the evaluation:

- have you found the manual useful?
- if you have only looked at parts of the manual - what parts?
- in your opinion, how could we make the manual more helpful?

These questions did not generate a great deal of feedback. Most said that overall the manual was useful. The abbreviations and acronyms were especially well received. Some women would have preferred to receive it earlier than they did. There were no suggestions regarding how it could be improved.

Comments about the Manual

- *The manual helped me a lot. Easy to understand for a computer dummy like me!*
- *I found the manual useful – read it all.*
- *It was quite helpful, especially acronyms, how to access.*
- *Need to get it well in advance.*
- *The manual seems pretty straight forward - I read through it once and didn't see anything missing or particularly difficult to understand.*
- *It is very informative. I read it all. I found the manual useful: the on-line*
- *Abbreviations, the explanation of the website, etiquette.*
- *No improvements at this time.*

Question: Suggestions for the Future?
The women were asked to offer suggestions of how we could improve any aspect of their group for the future.

Suggestions for Phone Groups
There were numerous suggestions for the phone groups, and they were grouped under two broad themes: matching and process.

Matching is an aspect of recruitment and refers to the assignment of women to their support group. Although most concur the benefits of learning from others that had "been there", as the weeks unfolded, many felt that the discussion would have been more inclusive if the women in each group had some basic common ground. For example, many of the women believed that future groups may be more helpful if they only include women at the same stage of their cancer journey. They believed a more homogenous group would be able to better relate to each other.

Process relates to the practicalities or logistics of running the groups. Some women mentioned the desire for a more structured agenda over the course of the groups (e.g., having prearranged topics to provide a focus at the start of each session). Alternatively, deciding each week on a topic for the following week. This way, it would give the women a better chance to prepare and think about relevant questions they have rather than being "put on the spot" each week.

Others acknowledged the time it takes to forge relationships and this shaped their ideas of extending beyond six weeks. Suggestions were also linked to a desire to stay connected after the groups had officially finished.

Comments on Phone Group Process

- *"Perhaps decide amongst the group on a topic to discuss for the following week, therefore having the chance to think about questions and their own situation".*
- *"It took me a while to come comfortable with the phone… felt good by Week 3"...*
- *"After six weeks, developed basic relationships – so longer would be better".*

To summarize, the phone group participants suggested:

- reduce the length of the meeting (less than 90 minutes) if relatively few women take part, otherwise 90 minutes works
- do not offer during the summer as there are many disruptions, e.g. vacation
- remind women about the group each week
- rather than a defined six week group, a drop-in phone or online option could be offered during the summer months
- a preference for the groups to run for eight weeks instead of six
- to maintain the relationships and connections forged over the six weeks, once the phone group is over move to an online chat or an e-group
- meeting once per week (frequency) was considered appropriate
- no more than four to five women plus the facilitator per group
- if co-facilitating, no more than six participants and two facilitators

Suggestions for Online Groups
In the main, the women felt that 90 minutes was an appropriate length of time for the group. The facilitators felt that the time was sufficient for what they needed to accomplish. Some felt it could be longer while two participants felt that an hour would have suited them better due to fatigue or lack of input. Most felt that once a week was ideal with the exception of one participant who was going through treatment and was not at home. Both the participants and facilitators felt meeting once a week helped the groups bond and feel more comfortable.

The main areas where the women suggested change for the online groups were:

- increasing attendance
- having at least four women per group
- not necessarily having it each week
- matching the women when possible
- having some predetermined discussion topics
- seeking more direction from the facilitators
- use of the profile feature

The following quotes are used to illustrate some of their comments.

SUGGESTIONS FOR FUTURE - ONLINE

- *“Occasionally one of us was not there so often it felt a little incomplete”.*
- *“At one point, too few – two of us and the facilitator…even with three it didn’t seem enough. Better when four or five”.*
- *“I think that it should be open-ended…once a month forever would suit me just perfectly. Eight weeks would have been better. The first week and second week we started to learn about one another. The last four weeks things started to pour out from the heart and mind. Then if someone missed week l or 2 they would still have six to seven weeks.”*
- *“I felt I was past the other women in the cancer journey…the other two had worries regarding…and I worried about that one year ago”….”on the other hand, the mix gave me new viewpoints”.*
- *“Others have a sense of ‘been-there-done-that’ versus newly diagnosed, more sensitive and worried, unsure…so felt perhaps that they weren’t being heard or taken seriously”.*

- *"Thought (facilitator) would have topics. Maybe she needed to take the lead more….if anyone signed on, wouldn't know she was the leader…I thought the whole point was to address topics".*
- *"Would be good if the facilitator laid the ground rules at the start, etiquette…and reminded the group now and then".*
- *"I liked getting to know a little bit more about each woman individually, aside from her cancer status, i.e. Married/kids/occupation/location. I know that I feel comfortable providing a personal "snapshot" of myself. I think that learning those kinds of details provides a "face" to this faceless communication".*

Facilitators' Suggestions for the Future

Suggestions from Phone Facilitators

The phone group facilitators did not describe a totally smooth road. One facilitator felt that she was not meeting the needs of all of her group due to its varying needs. They stressed that it was important to keep the groups relatively stable, i.e. not adding new people over the course of the six weeks. They recognized that bonds had started forming in the first two weeks and wanted to foster tight relationships rather than interruptions each week with new people. With problems due to attendance, the facilitators believed that summer was not a great time to hold groups. Facilitators also believed that the initial phone call with the participants should determine if they are truly committed to taking part over a six-week period. If not, a group should not be offered to them at that time.

Suggestions from Online Facilitators

Although the facilitators were happy with how the groups ran, their suggestions for future groups included: extending beyond six weeks to eight weeks; having a larger pool of women for each group (to ensure an adequate number attend); not adding new women to the group once it has started; exploring the idea of less frequent meetings; predetermining topics or an agenda to help cover more material/ ideas and to help bring some structure to the sessions; not holding the groups on the same evening; providing short biographies of all group members including facilitators; more visibility for the facilitator (e.g., being informed if women are private messaging each other during the group session).

Process suggestions included:

- meeting once a week for six weeks was adequate but longer preferred
- maintaining the meeting length of 90 minutes
- groups no larger than six participants
- if co-facilitation is used, allow the facilitators to meet by phone after the meeting to debrief
- reinforce that the facilitators are there to listen and not to feel that they have to run the group

The following quotes illustrate some of the online facilitators' comments.

SUGGESTIONS FOR FUTURE – Online Facilitators

- *"Five was about the right size. With an hour and a half, you wouldn't want to go more than six women. Five worked nicely. We were never at a loss for something to say."*
- *Six weeks was about right. They were offered to stay in touch…the few that may have wanted to. Most of them didn't want to continue. They got information, feeling that they were not alone. Once a month follow-up would've been nice".*
- *"Two hours would be too long. There was the time difference to contend with too. Sometimes I looked at the clock and couldn't believe an hour had passed. I needed the last half hour to tie things together and then to talk about what we were going to do the next meeting."*
- *"It would be hard to build up a rapport only meeting once a month."*

Tips for New Facilitators

Tips for New Facilitators of Phone Groups

The facilitators were asked if they had any advice for others that may be facilitating a telephone support group in the future. Both acknowledged that the key ingredients of good facilitation were always necessary, no matter what modality. One facilitator described how she wrote notes about each woman's circumstances and reviewed them 15 minutes before the group started.

The facilitators did indicate however, that the biggest challenge was the lack of visual cues. For example, when there were gaps in the discussion, there were no hints to see if a response was needed or if the speaker was pausing to formulate ideas and who wanted to talk next. With the phone, they also cannot see if a woman is happy to sit and just take it all in. Listening skills therefore come to the fore. It is worth noting here, that the facilitators were surprised how they did manage to keep track of who said what and did learn to quickly recognize the voices.

At times the facilitators felt obliged to fill the "dead air", to keep the discussion flow going. On the other hand, they did not feel that the facilitator should always do this nor have an agenda to follow ("It is what it is, the dynamic of the group and not necessarily the responsibility of the facilitator for it to unfold"). The following are some quotes from the facilitators.

- *"…with visual cues absent, strong listening skills become most important…"*
- *"take notes (for identification) and read them beforehand".*
- *"do not come with an agenda and list that you would like to cover"…(however)…"Having some topics/ ideas up my sleeve if it is helpful".*

Tips for New Facilitators of Online Groups

The facilitators were asked to share advice that they may have for new online facilitators. In addition to the skills they use with face-to-face groups, the four online pilot group

facilitators emphasized being familiar with the chat program and having plenty of practice to get use to this mode of communication. Some specific skills they highlighted:

- ability to type
- familiarity with chat program
- if necessary seek additional training and utilize practice sessions
- be aware of two roles – as survivor and facilitator and do not let survivor role overtake facilitation role
- check in if you don't hear from someone

– *"I used all of my facilitation skills…you need group therapy skills and typing and follow and track and keep flow going. Harder to pick peoples feelings and have to check in with them…same as face-to-face but have to be more aware of what they write – to sense the emotions, as no visual cues".*
– *"There should be training in (emerging) issues for people doing these types of groups. I had anticipated them, but it was hard...Provide resources on how to deal with that situation".*
– *"Pace of typing actually helped slow it down (which was good)."*

Co-facilitation

The ovarian cancer phone support group was the first OBCIEP teleconference pilot with two co-facilitators. Previously the peer-led online and telephone groups were all led by single facilitators. The two facilitators were both trained in facilitation, one had experience in group support, the other in one-to-one. One was a cancer survivor. As part of the first meeting, the facilitators had disclosed their personal background and connections with cancer to the group.

Some of the comments from the women addressed the co-facilitation context. For example, although the facilitators took turns each week acting as the lead, the group did not always perceive this. This certainly could be interpreted as a difference in personal approach. Having said that, it is difficult to say the extent to which perceptions may have been influenced by the knowledge that one was not a cancer survivor. For example, the women also expressed that the survivor ("Barb") could relate to their experiences more closely than "Rosemary". The following comments raise issues about facilitator training and facilitators being survivors. This is discussed further in the conclusion section.

Co-facilitators, taking turns to lead
– *"Rosemary would come into the group and would make some comments, but tended to be more of a listener. She only made comments as she felt she required it. I took that Barbara was more part of the group."*
– *"I think that it's great that Barb shares all that she does, but I think it would be nice to hear from Rosemary as well . . . what Rosemary has to say is valued by me."*

Shared experiences among survivors
– *"I don't think that it's 100% necessary to have gone through treatment, diagnosis, etc., but it's a huge contribution."*

– *"Perhaps because Rosemary has not gone through cancer it may have made me pull back a little. It wasn't a conscious thing. If I had only her one-on-one I would have difficulty explaining things."*

Additional Comments from the Co-facilitators
The two co-facilitators were pleased with the group and how it ran over the six weeks. One facilitator had difficulty not being able to see and touch the women as she described herself as a very "tactile" person. Having said that, the facilitators had very positive comments about their experiences and had few ideas for how the group could be improved. Benefits they perceived included; being able to assign women to a specific group, convenience, supporting those in remote areas and anonymity.

Co-Facilitation

Connecting with the group and overall impressions
– *"I was pleasantly surprised. I thought it was very good. At first you think face-to-face is better, but perhaps people feel safer in saying things because we couldn't see each other. I discovered I didn't need the body language, because I had the voice. It worked out better getting people together because you could still sit down and meet no matter what the weather – snow storms, etc. No need to find a location, etc for a physical group".*
– *"In some ways it's actually easier to do a phone group because you can jot notes down that you can't do in person".*
– *"…they can be put into the exact group with the exact cancer that they have being a larger group. There's more flexibility to hand-pick people that will mesh within the group. There's no concern about getting to the meeting due to weather, traveling issues, illness, etc. If you live in a smaller area you can be paired with your needs and desires. There's the anonymity that can make it easier to talk."*

Improvements
– *"Other than maybe letting the participants know that they could sign on a few minutes early. I can't see changing anything".*
– *"The participants should know what the facilitators' roles are".*

Both facilitators felt that co-facilitating was a positive experience and helped when certain situations called for "two minds". They also felt that debriefing after each meeting was helpful for planning and support of one another. One facilitator seemed more amenable to facilitating on her own and suggested she would have felt comfortable doing so after two to three weeks. The second (trained in one-to-one) expressed some reservation about facilitating alone. As mentioned earlier, one facilitator was not a cancer survivor. When asked about how effective she felt she could be without having had this experience, she felt that it didn't detract from her ability to facilitate but that perhaps the roles of the facilitators should be clarified with the group in the future. Although facilitator role is a sub-section of the manual that all received prior to their group, this may need to be clarified frequently to the group.

Co-facilitating brought different strengths
– *"Each week we took turns moderating. It allowed the other person to sit-back and take notes and listen a bit more intently. This helped because we could tell if we*

were getting in over our head… we rescued each other a bit too. I don't think I would like to do it without a co-facilitator. It would be harder alone, especially at the beginning. It's like having a safety net."

– *"Co-facilitating helped at first. After the first few sessions either of us could have handled the group alone. We would call each other after the meeting and discuss what happened. There were times we helped each other out of some situations. One person would always take the lead each week while the other sat back and just listened. This helps to have an extra brain to jump in when needed."*

Not being a survivor

– *"It could have been a drawback. At first meeting I explained that I wasn't a survivor but that I was in touch with cancer. Were people expecting a leader who would provide the answers? I don't think it interfered. I felt included in the group. A lot of the issues they were talking about related to menopausal or other issues and symptoms which are not exclusive to cancer. I wonder if the participants should be told what the roles of the facilitators and participants."*

Summary

Clearly the pilots demonstrated that a phone or Internet-based support group can provide many of the benefits of more traditional support groups. When we consider what we have learned through this pilot process, we have many suggestions for future phone and online support groups. For example, the free-flowing format was followed as the women had requested this prior to the groups starting. On reflection however, the women believed that some predetermined topics to guide some of the discussions would have been helpful. It was interesting that the facilitators also mentioned that having a topic framework would be helpful. Other suggestions for future groups are listed in the recommendations section.

Advantages of remote support include the availability to those home-bound, overall convenience and the offer of anonymity is appealing to some. On the other hand, online groups and phone groups lack personal contact and decreased visual cues. Participation in an online group also assumes that the individuals are literate, have relatively easy access to a computer and are not visually impaired (see Fernsler et al., 1997; Galinsky et al., 1997; Klemm et al., 1998; Klemm et al., 2003; Pereira et al., 2000).

7.4 Experiences and Knowledge Gained

This section focuses on the effectiveness of the peer-led groups and the lessons learned with the peer-led groups.

Knowledge Gained

The goal of this work was to enhance the information and support needs of cancer survivors. Leading survivors to trustworthy, up to date sources of information tailored to their needs at the time was the goal of the website. The evaluation showed that the site successfully met that goal. To create a website that meets the information needs for every type of cancer is a daunting task and one that is already done by other

organizations. The needs assessment proved that cancer users experienced many frustrations that caused them to give up on certain websites.

The needs assessment and website development made offering the peer-led online support feasible.

Were the Peer-led Phone/Online Groups Effective?
Nearly all women had established some goal for themselves in terms of what they hoped to gain from their peer-led group. In the main, their expectations were exceeded (e.g., uplifted, emotional support, shared experiences, discussion of specific topics). In addition, when asked, all women said that they would take part in a similar support group again (phone or online) and that they would recommend this type of group to friends and others. Although it was not one of the goals of the project, further indicators of success were the requests to share email addresses and the desire to maintain various levels of contact after the groups had officially finished.

The goal of the peer-led pilot groups was to support those who are unable to attend traditional support groups. Comments from the participants suggest that these pilot groups were successful in achieving that goal and the support group objectives—building connections, feeling supported, gaining new information, reducing loneliness. Meeting online takes some getting used to but most participants reported that they did become familiar with it and liked it. In addition, the telephone itself; aside from lack of visual cues was well received as a mode of information and support. In fact, some women suggested it is easier to be open with others on the phone because they are relatively anonymous and invisible.

The selected quotes are used to illustrate effectiveness.

Effectiveness

- *"It was beneficial and it was easier. Most of us are so busy, working…to be able to sit down with a cup of tea and chat with women in similar experiences in your own home's, a really positive thing".*
- *"The common bond between us was very evident and this allowed us to openly discuss whatever came to mind".*
- *"It's great how quickly (you) can get to know people over the phone".*
- *"Now its finished, would like to exchange emails so could keep talking with them"*
- *"A very interesting thing to do (online group). I felt a lot of support…surprised through words you can feel support…"..*
- *"I could say things objectively - I felt supported and connected…enjoyed it…quite amazing, the groups".*
- *"Can see how online romance starts – kind of like that with this! At start just odd, people using full sentences, correcting errors, capitals - and loosened at end….felt a connection, wanted to share emails and touch base in future with the group".*
- *"…I felt connected….yes, I would do it again. Not many friends have gone through breast cancer and they just don't get it".*
- *"Can be in bed…don't have to get dressed and get out! Many don't live near a support group and can't get out."*

- *“One thing that happened, so cool, our personalities came out…Can express a lot of who you are, especially in real-time rather than email where you have time to think about what to say”.*
- *“Enjoyed listening to others and sharing. At times I felt I was at a group face-to-face meeting”.*
- *“I really enjoyed this evening's group meeting (week 7) and felt I gained friends in the process. Overall, I really think the online support group is another avenue that is available to people dealing with cancer”.*
- *“My expectations were surpassed. I was first questioning if women would be connected but in the end I got a sense they were – as checking in and supporting each other….obviously some sort of need met”. (facilitator)*
- *“Would recommend online as most women don’t attend any groups…but women want to feel connected…Online useful and comfortable too – at home with a cup of tea”. (facilitator)*

Lessons Learned

There is much in the peer support piece of the project that reflects the challenges facing a new support program. These include “ironing out the wrinkles”, trying to identify what is not working at any particular time.

Not everyone benefits from support groups in the same way. A message that has been loud and clear is the need to match the women within a group as best possible. Most suggested that the match should relate to where the women are in their cancer journey. Given the number of women that participated, the most that could be realistically achieved was to ensure no two women from one community were in the same group.

The entire Cancer Support Network website was not needed to offer and run the peer-led groups. The website development and the online/phone groups almost diverged into two separate pieces and were not well integrated. The discussion board received no postings. In addition, those participating in the peer support groups were not especially drawn to the website. i.e., the website did not trigger interest in phone nor online support. The chat technology can be housed and a landing page build support but recruitment handled through links from other sites and other promotional methods.

Although a need for peer-led support groups was reported, recruitment was slow. All stakeholders involved in the project therefore need to also consider how to reach survivors (in addition to promotion of peer-led groups and providing links). The number of facilitators is obviously a limiting factor. Group support is a better use of a volunteer facilitator than one-to-one support.

The following lessons learned are in no particular order, and mostly relate to the practicalities of running a group.

Obtaining Feedback

Weekly feedback is extremely helpful to facilitate the smooth running of the group and the participants’ experience. If not possible, aim for every two weeks to help identify and support participants that are not coping and also help the facilitators deal with any issues.

Absenteeism
Weekly meetings seem to be difficult for all participants to attend all the time in that there was at least one week where family, work or other commitments or limitations meant someone could not participate. Fatigue, illness, and effects of treatment also affected the ability of many members to participate. It is essential however, for the group to consistently meet to get to know one another, and learn from each other, and the lack of participation had a huge impact on the group. Meeting schedules including duration and frequency therefore need to be examined in more detail. For example, we already know that attendance has been fairly consistent over a six month period for the ovarian cancer support pilot that requested monthly meetings once their weekly sessions had finished.

Offer Eight Week Groups
The majority of women reported that running the group for longer than six weeks would be beneficial. Eight weeks was suggested as a good goal. It is worth noting however, that some suggested that six weeks may be adequate if all women regularly attended.

Engender Commitment by Mandatory Attendance for Weeks 1 and 2
Many women felt that absences would not have been disruptive if all women had attended Weeks 1 and 2. It would then make it easier to know who is who and if a woman was new. Having said that, the women and the facilitators in particular, suggested that bringing new people to the group part way through did not work well and recommended this not be done in future groups.

Avoid Mondays
Monday meeting days are complicated because of long weekends and rescheduling missed sessions.

Email Exchange
The women also wanted to exchange emails so that if there were only two that were interested in a particular topic they could continue in a more in-depth one-to-one email conversation, rather than monopolizing the group's time. It is noted that if pursing this option consideration should be given to the lack of anonymity, effect on group dynamics, and potential risks associated with personal email.

Back-up Facilitator
A missing facilitator is an obvious obstacle. We learned the necessity to have a back-up person ready to step in and help if need be.

Personalising Text
Individuals may select an icon which is displayed beside their name. This feature is helpful to quickly identify who is 'talking' and to avoid confusion if two women have the same or similar names. The use of this feature should be encouraged for future groups. In addition, if it were possible to make the facilitators chat text unique, this would be helpful (e.g., the ability to have their text in a different colour or bold).

Provide Manual in Advance and Encourage Practice
The manual was sent up to one week before the groups began. In the future more time should be allowed for the participants to read the manual. Although participants were recommended to trial the chat program in advance and some did, in future greater encouragement and/or a practice phase should be considered.

7.5 Project Dissemination and Ongoing Activities

Dissemination

OBCIEP encourages the use of these findings by other groups and interested organizations to enhance information and support options for cancer survivors. At least one academic paper is planned for submission that focuses on the feasibility of the peer-led groups and their reported effectiveness.

The advisory group has had the opportunity to review ongoing interim and year-end reports, updates in the OBCIEP newsletter and the draft final report. The Project Advisory Committee members include:

- Dr. Margaret Fitch, Director, OBCIEP and Head of Oncology Nursing and Supportive Care, Odette (Sunnybrook) Cancer Centre
- Holly Bradley, Program Director, Wellspring
- Elaine Brown, Executive Director, Willow Breast Cancer Support Canada
- Patricia Payne, Senior Advisor, Canadian Cancer Society - Ontario Division
- Dallas Petroff, Executive Director, Lung Cancer Canada
- Elizabeth Ross, Executive Director, Ovarian Cancer Canada

Janet Canavan and Donna Czukar of the Canadian Cancer Society - Ontario Division and Fran Turner of Ovarian Cancer Canada also reviewed and provided input to the study reports.

Ongoing Activities

Developing and implementing peer-led support is clearly worthy of further investigation. This pilot work also raised some important issues about the processes and how to meet the needs of survivors. Due to a slow response, OBCIEP recruited the ovarian cancer survivor group participants outside Ontario. Recruitment was an issue and important to be aware of when trying to bring individuals with specific cancer diagnoses together. Expanding the group to include caregivers or creating separate support groups for caregivers alone may be one way to help reach and recruit more participants. Communicating with other chronic disease support groups (not necessarily cancer-related) may also be an option to glean ideas around recruitment and ensuring consistent attendance. To learn more about underlying motivations to stay involved the evaluation may need to ask specific questions about gaps in attendance (i.e., were participants less committed because they knew it was a pilot?).

Given the inconsistent attendance of some women, incentives could be used to encourage participation each week, or to find ways to build a spirit of commitment, and further examination of what attracted the women to their support group in the first place might be useful. For example, the women that were interested in the modality (phone or online options) may have a different level of commitment than if they were seeking a connection due to a lack of emotional support in their personal social networks. i.e., it may be better to match the women via their expectations and therefore tailor the discussions to better meet their needs. In the present project, each woman often provided multiple reasons, so perhaps in the future they could be asked about their most important reason for taking part. The extent to which meeting schedules (including frequency) may influence participation should also be examined.

OBCIEP has been fortunate to receive further funding for a new "Enhancing Access" project that will implement and evaluate peer-led online support for cancer survivors across Canada. The question is the extent to which the present results can be used to pilot similar groups for other cancer diagnoses (e.g., prostate, lung, colorectal) and possibly caregivers. This new project also links to a project that is exploring the feasibility and effectiveness of professionally-led support groups. Longer term, the website (or another online landing page) may provide an initial connecting point for people to learn about and register for groups such as: peer-led telephone support groups, online peer-led or online professionally-led support groups. Future technologies must also be on the research agenda.

8. Evaluation

The Website

Both the website development and the peer support groups were evaluated. The key areas of interest were: meeting needs of survivors, alert to improvements/ new ideas, general delivery of phone and online peer support. Information for the evaluation phase was gained from website postings, written surveys, email communication, telephone interviews.

The evaluation of the website involved close consultation with the participants. As each component of the website was developed, focus testing was conducted using an online system. Norlink developed the survey site which summarized the results by the respondents' types of cancer. The feedback gathered from the face-to-face focus groups conducted throughout the province was incorporated into the website design. Thorough evaluation of the CSN website was completed via additional interviews with health professionals and representatives of other health-outcome focused groups familiar with developing, implementing or utilising online strategies (e.g., Thunder Bay Breast Cancer Coalition / Breast Health Northwest, Canadian Virtual Hospice, National Ovarian Cancer Association).

Reviewers were recruited from focus groups previously conducted across the province, postings on cancer related discussion boards and through OBCIEP partners. Over 150 individuals had agreed to review the site as it was built.

Four online tests were conducted. For each test, email invitations were sent to all reviewers with links to the testing site and instructions on how to complete the review. An email address was provided for those who wished to opt-out of any future reviews. The findings were automatically tabulated through a program created on the website. Each review incorporated a rating scale for each question as well as ample opportunities for respondents to provide qualitative feedback through the comments sections after each question. Many of the comments received provided valuable information and insight. In many cases suggestions and comments received were incorporated into subsequent changes made on the site.

Measuring Website Usage

The website went live in April of 2006. All reviewers, OBCIEP partners and affiliates received an email invitation to visit the site (see attachment: Measuring Website Usage).

Usage statistics are collected and generated by Webalizer Version 2.01. This program collects daily statistics, hourly statistics, the top 30 URLs visited within the website, entry pages, exit pages, referring web pages, top search strings used to link to the website, and usage by country.

Peer Support Groups
The effectiveness of the peer-led support groups was assessed by asking the participants open-ended questions before starting, during, and after completing their group. To collect the information, the project researcher or coordinator contacted every participant and facilitator by email after each session for feedback and a more comprehensive evaluation was conducted via individual phone interviews at the end of the six weeks.

The weekly feedback questions asked the women how the group went generally for them, what they liked, disliked, reason for not attending (if relevant) and additional comments? The facilitators were asked similar questions. All responses received by email were stored in an electronic data file. The final evaluation was conducted by telephone after Week 6. The women were asked about their overall experience, impressions of the facilitator, comments regarding the process and technical aspects and possible improvements. The facilitators were also asked about overall impressions and so on, but they were also asked to comment on the skills they were using, training requirements for facilitators working in this area of support and their level of satisfaction in terms of connecting with the participants. (see 11.9 for the evaluation questions). During the interviews, detailed notes were written to capture the comments and suggestions.

9. Recommendations

9.1 Recommendations - Website

Existing organizations may want to evaluate their websites on the following criteria:

1. Evaluate ease of navigation on website with typical site users. For example, those recently diagnosed, in treatment, post treatment, caregivers, family, healthcare professionals.
2. Include links to trustworthy sites for further information, especially Canadian sites.
3. Evaluate the “Search this Site” function to insure appropriate keyword results.
4. Reduce the clutter and density of text on home pages.
5. Keep visual features simple.

9.2 Recommendations – Implementing Peer-led Support Groups

Screening
Some individuals are not suited to peer-led group support (i.e., may need referral to professional support due to psychological health issues). Therefore, modify screening

questions and establish criteria to ensure that any individual requiring alternative support is identified. Ensure support options suited to their needs are available for assistance/ referral (e.g., one-to-one or professionally-led group).

Matching group members
If possible match group participants at similar stages of disease/treatment. Mixing women at vastly different stages may not make the experience as fulfilling for all.

Matching by preferred format
Try to match those who prefer structured chats (topics predetermined for each week) and those who prefer a more free-flowing discussion. Some did not like it when the conversation thread was not cancer-related; some liked connecting with the other participants about issues other than cancer (issue is not related to format necessarily).

Mandatory Attendance
Recruit a core group of around eight individuals for each group and facilitate commitment to the full six weeks, or at least guaranteed participation for Week 1 and Week 2.

Absenteeism
Due to high absenteeism, consider different meeting schedules such as eight meetings over 16 weeks rather than once a week. Alternatively, consider weekly meetings for two or three weeks and then extend to biweekly or monthly. Some also said that attendance would be enhanced if they knew the discussion topics in advance and if possible, send reminders a day or two before each meeting.

Provide a topic framework
Despite asking for a free-flowing format, many of the women recommended predetermined topics for at least some of the weeks. They suggested that it would be fine for the chat to wander away from the topic after 20 minutes or so, but a topic would provide a clear direction to start versus a loose catch-up of the previous weeks chat.

A related recommendation is that it may be helpful to match those who prefer structured chats (predetermined topics each week) and those who prefer a more free discussion. Some did not like it when the conversation thread was not cancer-related while some liked connecting with the other participants about issues other than cancer.

Encourage use of *DigiChat* profile option
All agreed that we need to highlight and encourage the *DigiChat* profile option. This allows individuals to enter the level of details that they are comfortable with within the chat program (such as age, when diagnosed, treatment, region where they live, hobbies, email address etc). Any one in their group can then click on a name and display the profile. Photographs can be included if wanted and the facilitators could include their profiles too. This would avoid introductory story repetition each time there is a new person. It became very tedious and the women were not sure how much to say (whole story, bits of story, etc., as they knew they were boring participants who had heard it before). It was also seen as a great reminder of “who was who”.

Group format
For some groups, six weeks was not enough. Many suggested starting with an intensive six weeks and then offer to meet monthly for longer term support (more of a check-in). This connection could be via a discussion board or other text option.

9.3 Recommendations – Sustainability

Recruitment; Offering support
The project partners (and other interested peer organizations) are best positioned to recruit participants and to continue offering group peer support. This would include: recruiting and training their own facilitators (enhance knowledge and skills), supporting their facilitators and recruiting participants. We suggest that they could post a link on their individual websites to the Cancer Support Network site (or the website of whoever is the central coordinator).

Coordination
A project coordinator with dedicated time is required for group peer support to be available for a range of diagnoses - in the future. Coordinator tasks would include assisting with the logistics of group assignments across peer support providers (as required), supporting consistency across peer support providers, providing options for facilitator debrief/ support, discussion board maintenance, fielding support enquiries, information requests, ongoing evaluation and review. We suggest that the more centrally located project partners (such as OBCIEP or the Canadian Cancer Society) are best positioned to coordinate group peer support.

Promotion
If a website is developed, ensure a marketing plan is in place to launch and promote (e.g., for this project, the website and website information could have been promoted more frequently during the groups and the discussion board could have been promoted as a way for group members to connect once their sessions were completed).

Teleconference and Online Costs
Although both the online and teleconference options were offered to all participants, most selected to meet by teleconference. One can assume that the telephone remains the easiest, skill-free method of communicating—nearly every household already has a telephone—whereas many still do not have a personal computer. Many people are less comfortable using computers and/or do not know how to use keyboards. While it was speculated younger participants would prefer the online option, this was not necessarily true when they registered for the groups. The choice may also have been influenced simply by their preference to connect by voice.

Online chat software can be rented quarterly or purchased. *DigiChat* for example is about $150 USD per for three months and a one-time $50 set-up fee based on about 25 users. A user licence can be purchased for several thousand dollars based on more chat rooms and up to 500 users.

The pilot teleconferences on average cost about $90 per meeting depending on the size of the group and location of the participants. During a month where two weekly pilots and the monthly pilot ran concurrently the cost was $800. These expenses are not insignificant and any group or agency willing to host a teleconference support group

must consider the costs. Competitive services can be sourced but the use of phone lines, and potentially for many groups running simultaneously, can with volume become a major consideration or potential obstacle in offering this type of service. Maintaining regional groups, i.e. having participants living within a region, even a large region such as northwestern Ontario versus national can reduce costs of individual calls.

Talking versus typing: Web-based future
Explore lower cost options and be alert to innovations. Relatively new programs such as "Skype" enable individuals to make free calls over the internet to other people on Skype for as long as they like, to any location. It is free to download at present and has group discussion options. It would therefore be possible for organizations to offer computer-based verbal (Voice Over Internet versus text-based) peer support groups for free. However the software may only be available in future through purchase and require more sophisticated equipment with a microphone. These may mean that fewer individuals will have access to these tools.

9.4 Conclusion

The project created a referenced website that offers credible sources of information to those dealing with breast, ovarian, lung and prostate cancer. The objective was to create a site that assisted people with their information searches. The continued use of the site supports that this objective has been met. Another objective was to promote the peer-led support groups and it has been shown that the site was not as instrumental in marketing this service as hoped. Other promotion efforts will need to be investigated.

The project has demonstrated that using technology to offer peer-led support is a promising and worthwhile method of connecting those dealing with cancer to a valuable source of emotional support and link to information about their disease. Further study and exploration of this important peer support option will be conducted through the *Enhancing Access to Psychosocial Care, Information and Support for Cancer Patients and Family Members,* a Public Health Agency of Canada funded project. In addition, similar work is planned for 2008 by the Cancer Journey Action Group of the Canadian Partnership Against Cancer.

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11. Attachments/Deliverables*

Cancer Support Network Site: Measuring Web Usage Report

OBCIEP (October 2005). *Phase 1: Needs Assessment Report, Breast Cancer Information and Support – Preferences and Resource Development*

Promotional Poster for Online/Teleconference Support Groups

Online Support Groups with Peer Facilitators: Facilitator Manual

Online Support Groups with Peer Facilitators: Participant Manual

Teleconference Support Groups with Peer Facilitators: Facilitator Manual

Teleconference Support Groups with Peer Facilitators: Participant Manual

**Appended as separate documents*

11.1 Project Evaluation Form

PROJECT EVALUATION FORM

1. What?

The purpose of this project was to undertake research around the use of technology as a tool to facilitate support and information needs of women in Ontario affected by breast cancer. Project activities involved a needs assessment, website development and the piloting of peer-led phone and online support groups. The needs assessment informed the website development and by all accounts the website was reviewed favourably in terms of content and navigation. The website also provided a "home" for piloting the peer-led online support groups. Three peer-led phone groups and four peer-led online groups were completed. The pilot groups were feasible and overall reported to be effective in meeting the support needs of the survivors that participated (breast cancer and ovarian cancer survivors).

2. Why?

In terms of what we believed worked and did not work, the needs assessment successfully identified gaps in information, the types of Internet sites preferred by breast cancer survivors, and what aspects they find frustrating. The choices made about persisting with a particular website or not are affected by a wide range of options and features. In terms of informing the website development, the results led to a comprehensive list and outline of desired features. Utilising a participatory approach (survivors informing the initial development and frequent reviews), the website www.CancerSupportNetwork.ca was considered highly relevant to the cancer survivor population. Findings from the peer-led pilot groups underscore the complexity of establishing a new support option. Although many benefits were offered, we received useful suggestions to improve how the groups were planned and run. Many of the ideas were applied during the project.

3. So what? – making a difference

Technology can provide support via connections to those remote or isolated (for whatever reason). Technology also allows individuals to tailor information and support to their personal needs. The needs assessment was intended to build knowledge around the information and support needs of women affected by breast cancer. This was achieved by identifying gaps, setting priorities and planning activities for the website development. The website development was successfully completed. From April of 2007 to December of 2007, there were 4,713 site visits and 16,046 pages viewed. Although the statistics are steadily rising each month, issues linked to upgrades and maintenance is pertinent (as they are with any website). The project demonstrated that phone and online peer-led support groups are feasible and provide information and emotional support and decrease the isolation for women affected by breast cancer or ovarian cancer. This work also informs related projects (e.g., the development of professionally-led online emotional support being conducted within Canada).

4. Now what?

The needs assessment went well and would not be done differently in future except for attempting to recruit and obtain feedback from a larger group (including more Aboriginal women and Francophone women). In terms of the website and peer-led

groups, we did not need the entire website to offer and run the peer-led groups. We acknowledge that the chat technology needs to be housed somewhere, but the website content could have been reduced to a description of the groups being offered (including online and phone), contact information and a place for registration and log-in. We would then try to market and attract potential participants through links from other websites.

In hindsight, we also could have had a marketing plan for the website and placed requests that project partners play a more active role in recruiting facilitators and participants. We believe the partners' websites are more likely to attract potential participants with specific diagnoses.

As to running the phone and online groups, we learned that there are many reported advantages. However, not everyone benefits from support groups in the same way. Where possible, we endeavoured to incorporate any suggestions as subsequent groups were implemented. We believe that the groups were run successfully but obviously, with greater numbers we could have explored more of the suggestions (such as trialling eight weeks instead of six and matching women according to expectations or life stage).

5. Then what?

We have learned a great deal about the information needs of cancer survivors and about their preferences with online resources. We have also shared how peer-led groups (phone and online) can benefit cancer survivors. Because this project represents a first effort to explore peer-led phone and online group support, the findings have naturally led to more questions.

- are the groups effective for other cancers and other groups (such as caregivers)?
- what is necessary for the sustainability of these groups?
- how can we move forward with the vision of remote (phone or online) peer-led groups complementing the array of support options that are currently available or being developed for cancer survivors?

Support and interest has already been obtained from project partners around this work. Coordination and strong partnerships are integral to the ongoing development and implementation of phone and online support and information programs for cancer survivors. The recommendations highlight practical suggestions as well as the need for coordination. Working parallel to colleagues conducting professionally-led groups, there is a recognised need to develop and apply (where possible) consistent and objective measures of theoretically important variables. This will enable us to discern the separate and common benefits of the different types of support. We also need to be alert to new technologies (e.g., VOI replacing text-based communication on the Internet).

11.2 Cancer Support Network Launch Email

Dear Reviewers:

The Cancer Support Network website is complete and is available to the general public at: www.cancersupportnetwork.ca

Thanks to all of you who gave your time to review the website over the last year and a half. The site is designed to provide information and support to those dealing with breast, lung, ovarian and prostate cancer. Your evaluation was essential in ensuring the site is user-friendly and relevant to survivors.

The support component of the site now includes a bulletin board where you can post questions or messages, respond to questions/messages, or just read what others have posted. Please feel free to post and encourage others to post on the bulletin board. Posting is key to the success of the bulletin board.

The online support component of the site is still in the piloting stage. We are looking for participants for both the online "chat" and teleconference support groups we are running this spring.

If you are a breast, ovarian, lung or prostate cancer survivor and you are interested in participating, kindly send your name and contact information to: info@cancersupportnetwork.ca. Fee free to extend this invitation to anyone else you know who may be interested in these support groups.

We hope you will take a few moments to visit the site. If you would like to provide any feedback, just click on the suggestion box and send us your comments.

Irene Nicoll, Coordinator
Ontario Breast Cancer Information Exchange Partnership
Email: info@cancersupportnetwork.ca

11.3 Sites available in www.CancerSupportNetwork.ca "Search" function

Recommended Site Name	Site Address
A Breast In The West	www.abreastinthewest.ca
American Cancer Society	www.cancer.org
Association of Cancer Online Resources	www.acor.org
Breast Cancer Action *Nova Scotia* (BCANS)	www.bca.ns.ca
BreastCancer.Org	www.breastcancer.org
Canadian Breast Cancer Foundation - BC/Yukon	www.cbcfbc.org
Canadian Breast Cancer Network	www.cbcn.ca
Canadian Cancer Society	www.cancer.ca
Canadian Prostate Cancer Network	www.cpcn.org
Cancer Advocacy Coalition Canada	www.canceradvocacy.ca
Cancer Care Manitoba	www.cancercare.mb.ca
Cancer Care Online	http://supportgroups.cancercare.org
Cancer Care Ontario	www.cancersupportnetwork.ca
Cancer Du Sein.ORG	www.cancerdusein.org
Cancer Research & Prevention Foundation	www.preventcancer.org/
Cancer Survival Toolbox	www.cancersurvivaltoolbox.org
CancerBACUP	www.cancerbackup.org.uk
CANCERPAGE	www.cancerpage.com
Caregiver Media Group	www.caregiver.com
Centres for Disease Control & Prevention	www.cdc.gov
Dr. Susan Love	www.susanlovemd.com
Fighting Spirit	www.fightingspirit.org
Global Lung Cancer Coalition	www.lungcancercoalition.com
Government of Canada	www.sdc.gc.ca
Health Canada	www.hc-sc.gc.ca
Hope Air	www.hopeair.org
Imaginis	www.imaginis.com
Inflamatory Breast Cancer Support	http://www.ibcsupport.org
Inuit Tapiriit Kanatami (ITK)	http://www.itk.ca
IRC Chat Channel	http://www.aoma.com/cs
Lifetime TV	www.lifetimetv.com
Lung Cancer Alliance	http://www.lungcanceralliance.org
Lung Cancer Canada	http://www.lungcancercanada.ca
Lung Cancer Coalition	http://www.lungcancercoalition.com
Lung Cancer Online	www.lungcanceronline.org
LungCancer.Org	http://www.lungcancer.org
Mayo Clinic	www.mayoclinic.com
Medline Plus - US National Library of Medicine	http://medlineplus.gov
Mothers Supporting Daughters With Breast Cancer	http://www.mothersdaughters.org
National Cancer Institute	www.cancer.gov

National Cancer Institute of Canada	http://www.ctg.queensu.ca
National Coalition for Cancer Survivorship	http://www.cancersurvivaltoolbox.org
National Family Caregivers Association	http://www.nfcacares.org
National Kidney and Urologic Diseases Information Clearinghouse	http://kidney.niddk.nih.gov
National Ovarian Cancer Association	http://www.ovariancanada.org
Oncolink	www.oncolink.org
Online Peer Support for Cancer Survivors, Families and Friends	www.oncochat.org

11.4 Focus Group (Needs Assessment) Survey – Part A

Information & Support: Preferences & Resource Development, OBCIEP 2005

Part A. Survey

Before the focus group, we have a survey about your background, your use of the Internet, your information and support needs, and preferences. Please answer each question as honestly as you can. The information you give will be kept completely confidential. Should you have any questions, please contact Sue Keller-Olaman, 416-351-3808 or Irene Nicoll, 416-351-3815.

1. Background (questions 1a to 1e)

1a) Gender ☐ Male ☐ Female

1b) In what year were you born (please specify)?

Year of birth: ____

1c) What is the HIGHEST level of education you have completed (please specify)?

Education: ____

1d) WHEN were you first diagnosed with cancer? Year:_________________

1e) What TYPE of cancer were you diagnosed with (please specify)?

☐......breast
☐......lung
☐…..ovarian
☐…..other (please specify):

____

1f) Could you please tell us how much income you and all other members of your household received in the year 2004?

We don't need the exact amount; but could you please tick which category it falls into:

☐......less than $30,000
☐......between $30,000 and $60,000 ($59,999.99), or
☐…..more than $60,000?
☐…..don't know
☐…..prefer not to answer

2. Patterns of Internet use (questions 2a to 2f)

2a) WHERE do you have Internet access (check all that apply)?

☐......home
☐......work
☐…..at a relatives or friends
☐......library or community centre
☐…..other (please specify):

____

2b) What type of internet connection do you use (e.g., dial-up; high-speed (DSL/Cable modem?))

Type of connection:

____

2c) What do you primarily use the Internet for? (check all that apply)

Work	**Personal**
☐......email	☐......email
☐......work tasks	☐......personal (e.g., travel, recipes, weather)
☐......surfing / browsing	☐......surfing / browsing
☐......chat / discussion groups	☐......chat / discussion groups
☐…..other (please specify): __________________________	☐…..other (please specify): __________________________

2d) How much time do you typically spend on the Internet for personal use, each week?

☐......less than 1 hour
☐......2-5 hours
☐….. 6-10 hours
☐......more than 10 hours
☐…..other (please specify): _____________________________________

2e) What time of day do you typically access the Internet?

Time of day:

____

2f) When looking for health or cancer information, how long are you willing to stay on a specific Internet site?

Length (in MINUTES):

____

3. Seeking information and Support (questions 3a to 3f)

3a) Where have you found your cancer INFORMATION? (you may tick more than one):

☐......books or articles
☐......audio or video tapes
☐…..interactions with medical professionals (doctors, nurses)
☐......other patients
☐......family or friends
☐......the Internet
☐…..other (please specify):
____

3b) What mode have you preferred for INFORMATION? (you may tick more than one):

☐......books or articles
☐......audio or video tapes
☐…..interactions with medical professionals (doctors, nurses)
☐......other patients
☐......family or friends
☐......the Internet
☐…..other (please specify):
____

3c) Has the Internet helped you seek information related to your cancer?

☐ Yes ☐ No

If yes, How? ____

____

3d) Where have you found out about SUPPORT? (By support, we mean finding out about emotional help and support, seeking contact about support services, finding people to talk with, or how to join a group (you may tick more than one):

☐......books or articles
☐......audio or video tapes
☐…..interactions with or referrals by medical professionals (doctors, nurses)
☐......other patients
☐......family or friends
☐......the Internet
☐…..other (please specify): ____

3e) What mode have you preferred for SUPPORT? (you may tick more than one):

☐......books or articles

☐......audio or video tapes
☐…..interactions with or referrals by medical professionals (doctors, nurses)
☐......other patients
☐......family or friends
☐......the Internet
☐…..other (please specify):

____

3f) Overall, has the Internet helped you cope with your cancer?

☐ Yes ☐ No

If yes, How? ____

____

4. Where are there information gaps? (the example below emerged from a breast cancer project, but you can complete the question for any type of cancer)

Based on a previous OBCIEP project, women felt that more information should be available or more easily accessed - on the following topics.

Tick each of the topics with which you agree (that there should be more information available):

- ☐ alternative therapies
- ☐ chemotherapy and "chemo" brain
- ☐ coping with hair loss
- ☐ drugs - Tamoxifen versus Arimidex , hormone replacement therapy, estrogens
- ☐ environmental factors
- ☐ fatigue
- ☐ how to talk to their children (young children, teenagers)
- ☐ information for young women
- ☐ lymphedema
- ☐ medical research and studies
- ☐ navigation (some insight and understanding to the steps in the treatment procedure)
- ☐ nutrition
- ☐ post-surgery care, hygiene
- ☐ post-treatment
- ☐ protheses, wigs
- ☐ recurrence/metastatic disease
- ☐ sexuality (during and post-treatment)
- ☐ support for spouses
- ☐ supportive/emotional support for those who choose alternative treatments (i.e. only natural therapies, remain “breastless”, neither reconstruction or protheses)
- ☐ understanding applicability of "survival/life span" statistics, risks/chances of recurrence(s)

Is there anything missing from this list?

11.5 Favourite Websites Recommended by Focus Group Participants

It is worth noting that one focus group suggested a tapered approach to reduce information overload. For example, they would advise a newly diagnosed woman to first look at the Mayo site (easy to digest), then Susan Love, then Oncolink. Would also like the cancer clinics to endorse sites and perhaps provide a guide/ rating to indicate the level of information in sites (eg - 'easy/intro', 'more detailed'). See this as helpful for newly diagnosed - so not overwhelmed.

www.breastcancer.org – USA, frequently mentioned during the focus groups. *In addition to the info on the site, the women noted it has useful booklets to download .They thought the colours of the site were too bright and clashing though.*

www.bclist.org - Canadian, **The Breast Cancer Mailing List**, listserv, an online community for information and support

www.bcans.ca – Canadian, **Breast Cancer Action Nova Scotia,** includes chat rooms

www.susanlovemd.com – **SusanLoveMD.org** – USA – The Website for Women– *popular as up to date, easy to understand, good pictures, 'positive and inspiring', trusted – as most are familiar with her book.* They did not, however, like the font (too small - very hard to read), how crowded the pages were, and the fact that one page of content took more than one screen.

www.breastselfexam.ca - Canadian, **Breast Self-Exam** site – very popular due to use of colour, large font, option of using audio and video to display techniques

www.breastcancercare.org.uk – Britain, mentioned by women in Oshawa. They highlighted the useful information, forums, posting questions.

www.mayoclinic.com - Mayo clinic mentioned in Dryden and Thunder Bay. Easy to understand, alphabetical, weekly updates, and valued for reports of recent research, can post questions with fast replies (1-2 days), healthy living piece.

www.oncolink.upenn.edu – USA, mentioned by the women at Thunder Bay, as oncologists at the Cancer centre often refer them to this site for information. Praised for its comprehensive information, and non-jargon options.

www.komen.org - Susan G. Komen site mentioned at Thunder Bay. Good anatomy site. Has info for supporters ('co-survivors'), links to dictionary

11.6 Focus Group (Needs Assessment) Discussion Topics – Part B

Information and Support: Preferences and Resource Development
Part B - Focus Group Discussion (OBCIEP 2005)

1. Ice-breaker
Ask each participant to say 1-2 sentences about themselves as an introduction to the group (e.g., how long lived here and when diagnosed).

The following themes will guide the discussion about Internet practices and preferences. NB* Remind them that there are no wrong or right answers – the key is to hear personal impressions/ preferences.

2. What do you LIKE the most about using the Internet? (Content does not necessarily have to be cancer; could be travel, weather, recipes etc)

- What are your favourite Internet sites? Why are they your favourites?
- How do you know an Internet site is trustworthy?
- Which cancer Internet sites do you trust and why?
- Overall, what makes a website work or not work for you?

3. What do you like THE LEAST when using the Internet?

- What have you found frustrating with use of the Internet?
- Which cancer Internet sites do you NOT trust and why?
- Number of clicks before quit a site?

4. Chat-rooms, web boards, bulletin boards, online discussion groups.

- Found to be useful? / experiences from anyone?
- Some of the barriers/ reasons for NOT posting questions on bulletin boards?
- What would motivate you to post?
- Would you be interested in joining an online support group? (prefer typing or audio?)
- Barriers to providing personal information online (to register for online support?)
- If online support interests you, would you be interested in combining an online group with a face to face group? (i.e., would you like the option of getting to know online members if they were in close proximity).

Focus Group Discussion of Selected Websites
Two examples of the type of Internet 'hub' or portal site we are looking to create;

- Irish Cancer Society's Action Breast Cancer -"Just Diagnosed" page
  http://www.cancer.ie/just_diagnosed.php

- The Wellness Community, California.
  http://www.thewellnesscommunity.org

- Breast self-exam site, Thunder Bay Breast Health Coalition
  http://www.breastselfexam.ca/

Additional questions

Importance of:

Font
Colour
Domain name (full words, how memorable, length, abbreviations?)
Graphics
Internal search engines
Print-friendly pages
Download time
Tabs along the side or top

Ask for email addresses and interest to help review test site.

11.7 Screening Questions for Phone and Online Support

Cancer Support Network REGISTRATION FORM
Teleconference Support Groups

Todays date

Male / female

Age

Region where you live

Phone

Email

We are dedicated to providing you with the best support services. We therefore ask for some information about the people registering. We would please appreciate your help by completing the questions below. **All responses are strictly confidential**. However if you choose to not answer some of the questions, you may still be able to participate.

Please note: Once you have submitted your registration you will receive a follow-up phone call from OBCIEP.

Date of first diagnosis

Type(s) of cancer

Stage of cancer at diagnosis

If you are registering for a teleconference support group:

What are your expectations prior to joining the group?

What attracted you to trying a teleconference support group?

Are there any topics you would like discussed in the teleconference group?

11.8 Precepts of Support Group Facilitation

The Ten Precepts of Support Group Facilitation

Based on the Self-Help Model of Support

1. Each person is an expert on her own experience.
2. Each person's experience is unique and can offer something to other group members.
3. Witnessing and validation of members' stories fosters insight, self-respect and attitude shifts in a self-help and not a professional counselling way.
4. The facilitator's role is to empower the group and its members to support each other through the sharing of their experience, hopes and fears. Facilitate means 'to make easier'; does not mean 'to lead' or 'to do for'.
5. The group must be a safe container for the expression of *all* feelings. Uncritical curiosity, acceptance, compassion, confidentiality and the absence of judgements and expectations encourage self-disclosure.
6. Individuals continue to participate in a group for as long as it is serving their needs. When they leave it is not usually a negative reflection on the facilitator or the group.
7. If you have long-term members who come to the group with ideas about how to change the group, but they themselves come for reasons other than emotional support, they should not be the ones to influence how the group is run.
8. It is not up to the facilitator to provide information or solutions to all issues that arise. Interventions by the facilitator are necessary only at all times when the group needs to be brought back on track, or the group itself, after a generous amount of time, has not adequately responded to a member's *expressed* or *unexpressed needs*. Such interventions should take the form of open questions or the linking to previously shared experience, shifting the energy back to the group.
9. Periods of silence are okay, and some questions and needs are not answerable.
10. Trust the wisdom of the group.

(Source: Willow Breast Cancer Support Canada, www.willow.org)

11.9 Evaluation Questions – Phone and Online Support

After each week, the following questions were asked (via email):

Facilitator

- Can you please tell me how the group went generally for Week 1…2, 3, 4, 5, 6?
- What especially did you feel was 'working'?
- What (if anything) was not working?
- Any additional comments regarding Week 1…2, 3*, 4, 5, 6?

Participants

- Can you please tell me how the group went generally for you for Week 1 (2, 3, 4, 5, 6)?
- What especially did you like?
- What (if anything) did you not like?
- If you did not attend the group, can you please say why?
- Do you have any additional comments regarding Week 1 (2, 3*, 4, 5, 6)?

NB Following Week 3, three questions about the MANUAL were included in the evaluation:

- With regard to the manual, have you found it useful?
- If you have only looked at parts of the manual - what parts?
- In your opinion, how could we make the manual more helpful?

After the six meetings/sessions were completed, the following questions were asked (via a telephone interview): *Facilitator*

a. Overall experience
Overall, how do you believe the group went over the six weeks?
What do you believe worked very well?
What (if anything) did not work?
Did the group meet your expectations? How?

b. The process of the group/ technical aspects:
Can you please comment each of the following:

- the frequency of the sessions (i.e., was once per week okay, too little, too often?),
- the length of each session (i.e., was 80-90 minutes adequate?)
- the duration of the group (i.e., was six weeks okay, too long, too short?)
- the size of the group (i.e., too many, too few, what number would you recommend?)
- technical aspects (e.g., okay with passcodes, calling in, or any problems?).

c. Skills Required for Teleconference Facilitation
Drawing on your training and experiences with support groups, what skills did you rely upon or adapt to facilitate via the telephone/Internet?

What additional training would you recommend (if any) to other facilitators and/or to participants who are interested in this type of phone/ Internet support group?

How would you assess your satisfaction with this format in terms of connecting with the participants and meeting your objectives as a peer support facilitator?

d. Future:

- Would you facilitate another telephone/ online support group? Why/why not.
- Would you recommend this type of telephone/ online support group to women affected by breast cancer? Why/why not.
- Is there anything that would have made this group more helpful for you (for example, in terms of how the group was structured, timing, group roles and/or process, member participation and/or facilitation support).
- How else can we improve this telephone/online support group?

If you have any additional comments, please provide details:
THANK YOU.

After the six meetings/sessions were completed, the following questions were asked (via a telephone interview): *Participants*

a. Overall experience
Overall, how do you believe the group went over the six weeks?
Do you feel better now than the beginning of the support group? How? (open-ended, but examples/probes could include…)

- Coped better with cancer
- Felt supported emotionally
- Expressed my feelings about cancer
- Learned useful information
- Felt less anxious about cancer
- Connected with others

Were there topics that you wanted to discuss that were not raised? If so, please describe.
What did you like the MOST about this support group?
What did you like the LEAST about this support group?
Did the group meet your expectations? – how?

b. Overall, what are your impressions of your group facilitator/leader? (open-ended, but examples/probes could include…)

- Responsive to participants' different needs and viewpoints
- Emotionally supportive
- Knowledgeable about cancer and relevant issues
- Clear in explaining the goals of the support group
- Is there anything you would change about the way the group was facilitated? (to identify any problem areas).
- Other (please specify):

c. The process of the group/ technical aspects:
Can you please comment each of the following:

- the frequency of the sessions (i.e., was once per week okay, too little, too often?),
- the length of each session (i.e., was 80-90 minutes adequate?)
- the duration of the group (i.e., was six weeks okay, too long, too short?)
- the size of the group (i.e., too many, too few, what number would you recommend?)
- technical aspects (e.g., okay with passcodes, calling in, or any problems?)

d. Future
If you have taken part in face-to-face support groups, how was this experience different? (please specify good and/or bad comparisons)
Would you participate in another telephone/ online support group? why/why not.
Would you recommend this telephone/ online support group to others? why/why not.
Is there anything that would have made this group more helpful for you (for example, in terms of how the group was structured, timing, group roles and/or process, member participation and/or facilitation)?
How else can we improve this telephone/ online support group?

If you have any additional comments, please provide details:
THANK YOU.