

Enhancing Access to Psychosocial Care, Information and Support for Cancer Patients and Family Members

Project # 6785-15-2006

**Dr. Margaret I. Fitch
Odette Cancer Centre, Toronto**

June 2008

ACKNOWLEDGEMENTS

Project Lead

Dr. Margaret I. Fitch, Project Lead, Head of Oncology Nursing and Supportive Care, Odette Cancer Centre and Chair, Cancer Journey Action Group, Toronto

Report compiled by:

Dr. Sue Keller-Olaman, Researcher for Ontario Breast Cancer Information Exchange Partnership (OBCIEP), Hamilton, Ontario (co-author, Chapter 2)

Kathy Thompson, Project Coordinator OBCIEP, Thunder Bay, Ontario (co-author, Chapter 2)

Irene Nicoll, Program Director, Cancer Journey Action Group, Canadian Partnership Against Cancer, Toronto

Contributors:

Dr. Joanne Stephen, Research and Clinical Practitioner, BC Cancer Agency, Fraser Valley Centre, Fraser Valley, British Columbia (*Chapter 1*)

Stasey Tobin, Consultant, Whitby, Ontario (*Chapter 3*)

Dr. Jennifer Nelson and Laura Cleghorn, Cardinal Consultants, Toronto, Ontario (*Chapter 4*)

Project Partners:

British Columbia Cancer Agency
Canadian Cancer Advocacy Network
Cancer Care Nova Scotia
CancerCare Manitoba
Canadian Cancer Society – Ontario Division
Lung Cancer Canada

Ontario Breast Cancer Community Research Initiative
Ontario Breast Cancer Information Exchange Partnership
Ovarian Cancer Canada
The Thunder Bay Breast Health Coalition
The Young and the Breastless
Younger and Wiser

Special Thanks:

The project team also wishes to acknowledge the valuable contributions of Janet Canavan, Canadian Cancer Society – Ontario Division, Hamilton, Ontario; Sandra Cook, Patient Navigation, Cancer Care Nova Scotia, Halifax, Nova Scotia; Anne Plante, Clinical Nurse Specialist, Hôpital Charles Lemoyne, Greenfield Park, Québec; and Fran Turner, Ovarian Cancer Canada, Toronto, Ontario; and support from the Canadian Partnership Against Cancer.

The Enhancing Access to Psychosocial Care, Information and Support for Cancer Patients and Family Members project was funded by the
Public Health Agency of Canada.

Thanks are extended to all volunteers that participated.
We are grateful to all participants, project partners, and community organizations for their valuable input.

SUMMARY

Purpose

The project sought to enhance access to supportive care for cancer by increasing access to psychosocial care, information and support for cancer patients and their family members. Four initiatives were undertaken to achieve this goal, two with the purpose of examining the use of technology to enhance support, namely online professionally-led and phone peer-led support groups for survivors, and two resource development initiatives. One resource is a cancer patient navigation manual. The aim of the manual is to provide guidance for health providers or administrators who are interested in developing a cancer navigation program framed to facilitate access, continuity and coordination throughout the cancer experience. The second resource is a psychosocial learning kit for volunteers. Cancer patients and survivors run the risk of needlessly suffering physical and psychosocial symptoms but the right interventions can significantly reduce their physical, emotional, social and spiritual distress. The kit was designed to help volunteers learn about the psychosocial needs of cancer patients throughout their cancer journey and the types of assistance patients may find useful.

Population Groups

The professionally-led and peer-led online support groups are targeted to potentially all people affected by a cancer diagnosis in Canada. For this project the emphasis was on recently diagnosed survivors who sought professional assistance or those who are unable or unwilling to attend a traditional peer-led face-to-face support group. Efforts were made to recruit from rural and remote locales where residents have few if any options to seek group support in their communities. In ongoing work the scope will increase to include all diagnoses, longer-term survivors, caregivers and possibly other groups such as group facilitators.

Health providers, administrators, researchers, planners, cancer patients, their caregivers and families and volunteers will be interested in the navigation implementation manual. It is the first publication of its kind in Canada that provides the background, rationale, implementation steps, and case studies that addresses navigation from the perspectives of the patient, the caregiver, the health provider, and the system.

Although the focus of the learning kit is on educating volunteers, the population groups to benefit from the learning kit include those affected by a cancer diagnosis; any individuals diagnosed with cancer, their caregivers and their families and the many cancer information and support groups who regularly train and use volunteers.

Primary Activities

As noted above, the project is comprised of four initiatives.

Online professionally-led support groups for cancer patients and caregivers spanned ten weeks and included participants from British Columbia and Yukon Territory. Data was collected prior to starting the group, during and after the completion of the group.

Online peer-led support groups were planned with participants across Canada. Responding to a preference to meet by teleconference instead of online three separate six-week teleconference support groups were completed with breast, ovarian and prostate cancer survivors. Participants resided in six different provinces. Data was collected prior to starting each group, weekly email feedback provided information on what was and was not working, and a final evaluation interview was conducted after each group was completed.

A requisite for the navigation manual was a series of cancer patient navigation workshops across Canada that showcased navigation programs. The navigation manual was created through a review of current literature on navigation programs, consultations with key informants and workshop attendees to provide an overview of navigation programs and implementation steps. Background and rationale for navigation programs is also addressed. The manual will feature the professionally-led model of navigation.

The learning kit for volunteers followed an environmental scan and consultation with those experienced in psychosocial training programs. Information was collected about their programs, resources and training. Synthesis of the information led to the kit that was intended to be used as part of a training module or in-service to educate volunteers about the psychosocial needs of cancer patients and the various services available to them, depending on their needs. The deliverables included a learning kit guidebook, a comprehensive PowerPoint presentation that can be tailored to individual organizations' needs, and handouts.

Major Outcomes

One online professionally-led support group (young women with breast cancer) was successfully completed. Website development, training facilitators and setting up this innovative approach in Canada consumed a large portion of the project time. Two other groups, for prostate cancer survivors and caregivers, were finishing as this report was written. Complete evaluation data from these groups will be appended to this report.

Three telephone peer-led support groups were completed with breast cancer, ovarian cancer and prostate cancer survivors. The responses from the participants showed that the peer-led groups are well received and provide a positive and uplifting experience as well as informational and emotional support. Further work will continue on piloting peer-led support using various forms of technology based on this project's findings. Working with the professionally-led group, a common teleconference/online support group evaluation framework is planned.

The navigation manual built on the learning from the experiences of patient navigation programs in various communities across the country. The manual currently includes background, rationale, implementation steps with a focus on the professionally-led model of navigation. The peer-led and virtual models profiles will be added.

Many experts informed the development of the comprehensive volunteer learning kit. The kit is designed to be modified to fit within existing training modules or to be adapted to meet local needs. Dissemination and evaluation are planned.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	2
SUMMARY.....	3
Purpose	3
Population Groups	3
Primary Activities	3
Major Outcomes	4
INTRODUCTION.....	7
Sponsoring Organization	7
Background	8
Enhancing Access Project	9
Determinants of Health	9
Project Goal	10
Objectives	10
Project Initiatives at-a Glance	11
STRUCTURE OF REPORT.....	12
CHAPTER 1: PROFESSIONALLY-LED SUPPORT GROUPS	13
Professionally-led Groups: Overview	13
Professionally-led Groups: Methods.....	15
Professionally-led Groups: Preparation to Implement Groups	18
Professionally-led Groups: Findings	21
Professionally-led Groups: Discussion	30
Professionally-led Groups: Lessons Learned and Recommendations	32
Professionally-led Groups: Next Steps.....	33
CHAPTER 2: PEER-LED SUPPORT GROUPS	35
Peer-led Groups: Overview	35
Peer-led Groups: Methods	36
Peer-led Groups: Findings	40
Peer-led Groups: Discussion	53
Peer-led Groups: Lessons Learned and Ongoing Issues	53
Peer-led Groups: Lessons Learned and New Issues.....	55
Peer-led Groups: Recommendations	58
Peer-led Groups: Next Steps.....	59
CHAPTER 3: NAVIGATION MANUAL	62
Navigation Manual: Overview	62
Navigation Manual: Methods.....	62
Navigation Manual: Development.....	63
Navigation Manual: Discussion	63
Navigation Manual: Next Steps.....	65

CHAPTER 4: LEARNING KIT FOR VOLUNTEERS	66
Volunteer Learning Kit: Overview	66
Volunteer Learning Kit: Methods	66
Volunteer Learning Kit: Findings	67
Volunteer Learning Kit: Discussion	68
Volunteer Learning Kit: Next Steps	68
 CONCLUSION	 71
 REFERENCES	 73

INTRODUCTION

Sponsoring Organization

For over 25 years, the Odette Cancer Centre, (formerly the Toronto Sunnybrook Regional Cancer Centre) has been the base of one of Canada's most comprehensive cancer prevention, research, teaching and treatment centres. As the cancer program at Sunnybrook Health Sciences Centre, the Odette Centre offers specialized programs that span the spectrum of care. The Centre is a Cancer Care Ontario partner and is fully affiliated with the University of Toronto. As one of North America's largest Cancer Centres, it provides tertiary and quaternary services for more than 229,000 patient visits per year. The Centre has more than 500 multi-disciplinary healthcare professionals and serves the Greater Toronto and surrounding areas east of Oakville, west of Oshawa, and south of Orillia. The Odette Cancer Centre has a central leadership role in providing cancer care across the region and promoting collaboration to achieve excellence in the delivery of that care.

In particular, the Odette Cancer Centre has a strong supportive care program. It possesses a strong commitment to providing care that is person-centred and attends to more than the physical needs of patients and their family members. There is a history of working collaboratively with patients and families to design and implement programs that assist individuals in coping with the impact of cancer and achieving quality of life goals. Additionally, there is a history of outreach and working with community and volunteer based agencies to ensure patients, survivors, and family members have access to the assistance they require in a timely manner.

The primary partners in this project were Cancer Care Nova Scotia, CancerCare Manitoba and the British Columbia Cancer Agency. Collaborating partners included the Ontario Breast Cancer Information Exchange Partnership, Thunder Bay Breast Health Coalition, Ontario Breast Cancer Community Research Initiative, the Young and the Breastless, Younger and Wiser, Canadian Cancer Society, National Ovarian Cancer Association, Lung Cancer Canada, and the Canadian Cancer Advocacy Network.

The **Canadian Partnership Against Cancer** is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians (www.partnershipagainstcancer.ca). The Partnership aims to bring together cancer survivors, patients and families, cancer experts and government representatives to implement the first pan-Canadian cancer control strategy. The vision is to be a driving force to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada.

The **Cancer Journey Action Group** of the Canadian Partnership Against Cancer (formerly known as the ReBalance Focus Action Group) was created to provide leadership to "rebalance the focus" of cancer care. Its mission is to shift cancer care from a predominantly tumour-centred focus to a patient-centred approach that would take into account the needs of the whole person (i.e., psychological, social, spiritual, informational, practical, emotional, and physical) during clinical care and treatment. The Cancer Journey Action Group was also involved in steering and partnering the project initiatives. Dr. Margaret Fitch is Chair of the Action Group and Dr. Joanne Stephen, Anne Plante, and Sandra Cook are members of the Action Group.

Background

An estimated 166,400 new cases of cancer and 73,800 deaths from cancer will occur in Canada in 2008. On the basis of current incident rates, almost 40% of Canadian women and almost 45% of men will develop cancer in their lifetimes (Canadian Cancer Statistics, 2008). Therefore, survivorship issues are vitally important with the expectation that new cases of cancer will climb each year. The diagnosis of cancer impacts not only physical health, but social relationships, psychological functioning, emotional well-being, and spiritual aspects (Fitch, 2005; Ashbury, et al, 1998). Concerns may include recurrence, telling family members, uncertainty around treatment decisions, social relationships, financial concerns and fear of recurrence. In addition, family members themselves are impacted by a cancer diagnosis (Krisjanson & Ashcroft, 1994; Fitch & Allard, 2007; Fitch & Abramson, 2007).

Accessible supportive care services are therefore critical to address the needs of those affected by cancer. Supportive care is an umbrella term that covers a range of services, provided by a wide range of individuals and organizations to help patients and families cope with cancer and its treatment—from pre-diagnosis, through the process of diagnosis and treatment, and onto cure, continuing illness or death and bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. Supportive care needs can be informational, physical, social, emotional, spiritual, nutritional and practical.

The Canadian Strategy for Cancer Control (CSCC) identified the need to “rebalance the focus” of cancer care as one of its priorities for action. The current primary cancer care systems, processes and resource allocation still focus on diagnosis and treatment despite the fact that health status and disease outcomes are a function of a multitude of determinants that encompass individuals’ holistic needs across the disease trajectory. The Strategy also identified that the current cancer system is fragmented, sometimes inaccessible, and described as a maze. There is a lack of community based coordinating structures and a reliance on the family physician to coordinate services without adequate resources or training (Supportive Care/Cancer Rehabilitation Working Group Report, CSCC).

Repeatedly, information, support and communication are cited by cancer survivors as being essential for patients and family members if they are to deal with the many changes that occur during their journey with cancer (Canadian Cancer Society, 1992, 1997, 2003). Accessing the necessary information and support remains a challenge across Canada for cancer patients and their family members (CSCC, 2005). Additionally, patients continue to experience difficulties in communicating with the health care providers about supportive care needs (Ontario Breast Cancer Information Exchange Partnership, 2004, 2005).

The idea of having access to a range of supportive care services and being able to select the one(s) most appropriate for their own needs has been described by patients and survivors in various national forums (National Forum on Breast Cancer, National Forum on Ovarian Cancer, National Forum on Prostate Cancer, National Leadership Forum).

To date, this menu of services does not exist in Canada in a manner that would allow easy access by all cancer patients to the services. Furthermore, a full range of services does not exist in many regions. This work in Canada is therefore challenged by

geographic barriers, financial resource constraints, and a fragmentation between the cancer providers and community/volunteer based services.

To ensure that these challenges were addressed and access to supportive care was improved, the CSCC established the ReBalance Focus Action Group (now the Cancer Journey Action Group under the Canadian Partnership Against Cancer). Its mandate is to provide leadership to change the focus of cancer care so that patients' and families' needs are better served. Ultimately, the goal is to increase the quality of life for those living with and after a diagnosis of cancer.

Enhancing Access Project

The Cancer Journey Action Group is promoting the vision of “accessible, effective, and high quality psychosocial care, support and information for cancer patients and family members no matter where they live in Canada” (CSCC, 2002). In looking at the challenges to achieving this vision, it became clear that innovative approaches would be necessary. The Cancer Journey Action Group therefore acknowledges that approaches need to build on what is already known, embrace best practices from other jurisdictions, be designed collaboratively with intended users of the service, and prepare us for care delivery in the future. To identify specific priority areas for action, several environmental scans and national workshops were conducted. Four priority areas were highlighted as requisites to improve access to supportive care and therefore influence the quality of life of individuals living through a cancer experience:

- Online support groups (professionally-led)
- Online support groups (peer-led)
- A resource /manual to guide those establishing or implementing navigation programs
- Volunteer education

Determinants of Health

Coordination of Information and Support for those with Advanced Disease

The four initiatives in this proposal aim to provide better access to information and support for women with breast cancer as well as other populations. Online support groups will achieve key outcomes in these areas. Effective navigation programs help patients/survivors know what resources are available and how to access the necessary ones in a timely manner. Awareness on the part of health care professionals and volunteers about the needs patients have for information and support is expected to increase access to these resources.

Social Support Networks and Outreach to Diverse Populations

The initiatives relating to online support groups propose the formation of Internet-delivered, real time support groups for cancer patients. The Internet has the potential to overcome geographical and social barriers. It offers promise as a tool for enabling social support networks among women with breast cancer and other cancer patients who live in more distant communities.

Personal Health Practices and Coping Skills

Both professional and peer-led approaches to support groups have the potential to enhance personal health and coping. Practical outcomes of both approaches include increased knowledge, improved health habits, increased adherence to treatment plans, better doctor-patient relationships, and new coping skills. Reduced feelings of stress and anxiety will likely be achieved.

Health Services

All initiatives address the issue of limited access to psychosocial care, relevant information and meaningful support. Navigators are strategically available to cancer patients at critical times (e.g., at diagnosis, when palliative) and are able to screen patients at high risk for distress. Early referral to appropriate support programs can reduce fear and apprehension. Patients are asking for Internet-delivered options and assistance in finding their way through the cancer system. Effective navigation programs will enhance their ability to know about services early in their cancer experience and to access those they believe are relevant in an easy and timely manner. Navigation programs result in better patient preparedness and increase patient ability to make informed decisions. Enhancing the education of health care providers and volunteers regarding the types of assistance cancer patients need and the resources that are available will help with early identification of difficulties and solutions.

Development of Partnerships/Networks/Coalitions

The initiatives required collaboration among and between several regional and provincial networks and partnerships. The work was built on existing partnerships with the Canadian Cancer Society – Ontario Division; Lung Cancer Canada; Odette Cancer Centre; the Ontario Breast Cancer Information Exchange Partnership; Ovarian Cancer Canada; the Thunder Bay Breast Health Coalition; Wellspring; and Willow Breast Cancer Canada. It also formed new project linkages provincially with the BC Cancer Agency; CancerCare Manitoba; Cancer Care Nova Scotia; the Young and the Breastless; and the Younger and Wiser.

Project Goal

The goal of this project was to enhance the supportive care of cancer patients and their family members by increasing access to psychosocial care, information and support. To achieve this goal, four initiatives were undertaken, guided by the priority areas described above.

Objectives

Each of the initiatives was undertaken separately and had their own specific goals. The four project objectives were to:

1. Implement and evaluate online support groups led by professionals
2. Implement and evaluate online support groups led by peers
3. Produce and evaluate an implementation manual for patient navigation programs
4. Produce and evaluate a learning kit for volunteers.

Project Initiatives at-a Glance

Professionally-led Online Support Groups

The aim was to implement and evaluate three online pilot professionally-led support groups (OSG's) with cancer patients in British Columbia, Alberta, and Manitoba. The synchronous OSG modality of The Wellness Community, in the United States provided the initial model to adapt to the Canadian context. The preferred participants were cancer patients/survivors who live in rural and small town regions, who currently have few options for professionally-facilitated psychosocial care. Each group was professionally facilitated by clinicians who are expert in psychosocial oncology and trained in the provision of online group support. Due to legal issues around cross-provincial online practice, the revised goal was to complete the three groups within British Columbia. Two groups have been completed and two more are concluding at the time this report was written.

Peer-led Telephone Support Groups

Volunteer cancer organizations have recognized the benefits of peer support for a number of years (e.g., "Cancer Connection" phone support). As support options evolve however, (i.e., more survivors and increased desire for computer-based resources) it is important to examine the extent to which online peer-led group support can benefit survivors. The project aim was to complete four national online groups with cancer survivors, facilitated by cancer survivors who have been trained in the provision of group support. Cancer patients/survivors with limited access to peer support groups were the preferred participants. The initial plan was to run four separate online groups for women diagnosed with breast cancer; women with ovarian cancer; women with lung cancer; and men with lung cancer. Eventually three groups were recruited but preferred to meet by telephone rather than online. Participants resided across Canada. The three groups included women with breast cancer, women with ovarian cancer and men with prostate cancer. Each group spanned six sessions with feedback requested after each session and more in-depth evaluation at the completion of the six sessions.

Manual or "implementation guide" for establishing navigation programs

The aim of the navigation manual is to provide guidance for health providers or administrators who are interested in developing a cancer navigation program framed around a biopsychosocial approach. This work built on the learning from the experiences of patient navigation programs in various communities across the country. Case studies, key program components are highlighted and suggested steps to develop a navigation program are included. The manual provides practical information with an emphasis of implementation but also provided information to support the concept of navigation to decision-makers.

A learning kit on psychosocial/supportive care developed for volunteers

The kit was designed to help volunteers acquire a broad understanding of the psychosocial needs of cancer patients throughout their cancer journey and the types of assistance they may find useful, and therefore bring person-centred care to the forefront. Approaches for assessment, talking about difficult topics, and processes for screening for emotional distress and for referral to health professionals are some of the topic areas included. The learning kit deliverable was a PowerPoint presentation and accompanying speaker notes, designed to be used in workshops by agencies and institutes that wish to develop a training module or enhance an existing module.

STRUCTURE OF REPORT

The remainder of this report is divided into five sections.

The first, second, third and fourth sections are labelled Chapters and are the core of the report. Each chapter is dedicated to a single initiative, presented in the same order as the original funding proposal;

- Chapter 1: Professionally-led support groups
- Chapter 2: Peer-led support groups
- Chapter 3: Implementation guide for navigation programs
- Chapter 4: Learning kit for volunteers

Each chapter is organized around broad headings to provide relevant background, information about the approaches used to inform and develop each initiative and the outcomes. The following headings are used in each chapter, although there is some variation with subheadings;

- Overview
- Methods
- Findings
- Discussion
- Next Steps

The final section, the Conclusion, looks across the report and summarizes the extent to which goals were achieved. The intent is not to review the effectiveness of each initiative but to comment on the overall achievements and lessons learned. This section also links back to the introduction and discusses how the vision for this work is moving forward.

The Project Evaluation Form brings together the achievements and learning's from the entire project.

CHAPTER 1: PROFESSIONALLY-LED SUPPORT GROUPS

Professionally-led Groups: Overview

Background, Partnerships and Intersectoral Collaboration

In 2004 and 2005, the Canadian Strategy for Cancer Control Rebalance Focus Action Group funded two national workshops to determine national interest in OSG's. The Wellness Community (a community based cancer support organization located in the United States) was identified as an international leader in providing OSG's, and were invited to present their model. Psychosocial oncology program leaders, clinicians and researchers were invited to learn about The Wellness Community's work, to consider relevance for their own setting and establish interest in forging a national collaboration. Eighteen professionals from six provinces, the Vice President of Research and Development and a researcher with The Wellness Community, met in Vancouver, BC. An outcome of these workshops was a commitment to train a cohort of expert oncology-based clinicians in OSG facilitation, and to pilot professionally-led OSG's in Canada. A formal partnership was established with The Wellness Community, with the objective of training and technology-sharing. Facilitators from British Columbia, Alberta, Manitoba, Ontario and Nova Scotia were trained during 2005-2006. In 2007, funding was received to support three pilot OSG's.

The Principal Investigator Dr. Joanne Stephen of the BC Cancer Agency in Fraser Valley, Burnaby, BC has a long-standing linkage with one of the populations targeted for inclusion in the initiative: young women with breast cancer. Members of this population have participated actively in numerous activities leading up to the initiation of the first OSG. Previous needs assessment and evaluation data, and Dr. Stephen's clinical expertise with this population, significantly shaped the planning and implementation of the online intervention.

Goals and Objectives

The objective of this initiative was to implement and evaluate three professionally-led online support groups (OSGs): a young women's breast cancer group, a prostate patient group, and a group for family caregivers. These patient groups were chosen as likely 'early adopters' of OSG's because of socio-demographic and disease-relevant factors (e.g., younger age, higher distress, aloneness). The intent was to establish the knowledge base needed for moving the work forward into program development; to work through developmental issues and share knowledge with partners in the initiative. An important focus has been the identification of procedures and protocols that address professional and ethical/risk management issues, and development of the activities and role functions needed for OSG implementation. The protocols developed here, and the lessons learned, will be transferable to others looking to set up a program of professionally-led OSG's.

Initially, the groups were to be composed of participants in the provinces of British Columbia, Alberta and Manitoba. However, it was discovered that current jurisdictional and legal issues of providing cross-provincial online practice prevented cross provincial

implementation of the OSGs. In light of these issues, the revised goal was to pilot the three demonstration groups within British Columbia, although cross-provincial collaboration and information sharing has continued to be an objective.

The specific goals of the current initiative were to:

- Set up and operate three OSG's (young women with breast cancer, prostate patients, and family caregivers) and gather preliminary data regarding participant interest/motivation and benefits
- Describe in-depth the program logistics, including facilitator training, role and feedback, so that other provinces could determine feasibility in their own setting, and if appropriate, set up and offer OSG's

Goals, Groups and Timelines

A great deal of developmental work was required to initiate the pilot groups, due in large part to the need to satisfy organizational and program development requirements. This initial work was lengthier than expected, and delayed the projected rate of progress. These developmental issues have been described elsewhere (interim report to the Cancer Journey Action Group, May 2008) and represent a key learning.

The provision of professionally-led support groups is an emerging area with little precedent and the steering group is working through many issues. Some experts have expressed the view that professionally-led online support groups are risky because of legal, privacy and safety factors. However, patients are already seeking and accessing online support, and it is the view of Dr. Stephen and her colleagues that online services are most likely to be safe and effective when delivered by professionals who develop and maintain specialty expertise.

Furthermore, the goals for the three groups differed and thus the setting up activities and data reporting in this report differs for the pilot groups. The young women's pilot group was initiated first, and the other two groups did not move forward until the OSG team was confident in procedures. The young women's pilot group was intensively researched and evaluated; focused considerably on procedures and set up; and involved the Project Coordinator more extensively. An additional young women's group was offered after the first pilot, and thus is reported on the two groups completed.

In contrast, the prostate and caregiver pilot groups were set up with the intent to prepare for program development; the goals were to develop program capacity and feasibility; and more responsibilities were given to the facilitators, to mirror what happens in regular program practice. Different evaluation aims and capacity for data collection were a consequence.

The young women's pilot group was completed and evaluated within the timeline, whereas the other two groups were still in progress at the time this report was prepared. This report describes set up and program logistics, facilitator role and feedback, and participant characteristics for all three groups. However, data on participant benefits is presented only for the young women's groups.

Professionally-led Groups: Methods

This section of the report details the activities, roles and functions that were undertaken and developed in order to set up, implement and complete professionally-led OSG's.

Initial Preparation, Technology and Training

Preparing the Organization for Delivering OSG's

It was necessary to determine the feasibility of developing a sustainable OSG program within the BC Cancer Agency. An early activity involved consultation within the organization in order to determine potential barriers as well as supports for setting up OSG's. These consultations involved both the Program Leader and the Principal Investigator.

The Quality, Safety and Risk Management Coordinator was consulted to ensure that OSG's would be acceptable to the organization, and under what conditions. The Coordinator advised, in consultation with the Health Care Protection Program (HCPP), that social workers/counsellors who were employees of the BC Cancer Agency would be covered under HCPP. Its direct services were organized to assist its member health care agencies in the management of risk through adequate risk financing, claims management and the provision of risk management advice. This provided reassurance that in the event of a patient complaint or lawsuit, the individual counsellor would be protected.

The Privacy Officer was consulted resulting in a clear understanding of the privacy legislation needed for compliance. Over a series of discussions, it was established that it was acceptable to the organization to host OSG's through an American server provided that there was an absolute separation between personal information and usernames. This guided the development of the current telephone enrolment procedure, and the set up of chat rooms and use of surveys to ensure no personal information entered the United States.

A senior technology officer of the BC Cancer Agency was consulted several times over the course of preparatory work. Initially, the question was "can OSG's be developed and supported within the scope of current or future organizational resources?" Later, consultation was to provide external advice on the value of partnership with The Wellness Community for use of technology structures and platform. In short, it was advised that currently there were no resources to do the work locally; that in the future, the organization may have a portal system that could be used for OSG's; but that outsourcing was acceptable to the organization and the costs associated with partnership were reasonable.

These early consultations provided information that proved useful for developing the informed consent procedure and acceptance of the Research Ethics Board to conducting research, justification for the costs associated with partnership with The Wellness Community, and continued association with The Wellness Community on matters of technology and data security.

Identifying and Linking with Participant Groups and Promotion

The three populations targeted for the pilot OSG's were identified through two means: self-identification (young women), and expert consensus opinion (prostate and

caregivers). As stated, Dr. Stephen had previously-established ties with the British Columbia community of young women with breast cancer. At a national conference of nearly 100 young women with breast cancer, online support groups were identified by the participants as a priority need. Young women with breast cancer are avid users of web-based resources, predicted to be early adopters of professionally-led OSG's, and overall report greater levels of distress than their older counterparts.

Dr. Stephen sought consensus opinion from the Patient and Family Counselling staff of the BC Cancer Agency regarding priority underserved populations: they named prostate patients and family caregivers of palliative patients. Prostate patients tend to under utilize psychosocial resources, perhaps because of gender-associated discomfort with emotional disclosure and sharing, and the anonymity of OSG's have been identified as facilitative for this purpose. Family members caring for a dying patient are a highly burdened and distressed population, and often unable to travel to conventional sources of support. The convenience of the OSG modality was thought to be especially appealing.

Differences in promotion and recruitment for the young women's, prostate and caregiver online support groups reflect the divergent goals previously described (namely, research focus versus program development focus). The young women's study included a lengthy, multi-sector promotion and recruitment process in an effort to draw attention and awareness for the needs of women in the survivorship phase of breast cancer and inform a large number of participants. Also, the entire province of British Columbia and the Yukon Territory were targeted. In contrast, promotion and recruitment strategies employed for the prostate and caregiver groups reflect the clinical sphere of influence and mandate of the group facilitators, who interact within a single geographical catchments area.

Promotional strategies and activities for the young women's OSG included: teleconferences, videoconferences and rounds presentations to medical staff, radiation nurses and therapists, and the wider community oncology health professional network. Flyers, posters and postcards were created and distributed within the cancer centres and community oncology clinics. Telephone and fax promotions to doctor's offices, pharmacies and community centres, email distribution lists to members of the oncology health professional community and breast cancer survivorship groups, and postings on breast cancer survivor websites were all utilized for promotion. Lastly, the public media were engaged; television and radio interviews were broadcast, and provincial and community newspaper articles published.

Consistent with current clinical practice, the OSG facilitators for the other two groups each took responsibility for promoting their own group. Both facilitators promoted the groups within the Patient and Family Counselling Program, and the Canadian Cancer Society. Staff counsellors referred participants to the groups, and information about the programs was added to the Canadian Cancer Society resource information line for callers. Promotional flyers for both groups were sent to nurse educators, community oncology social workers, and local cancer groups. In addition, for the prostate group, the facilitator contacted oncologists and surgeons who specialize in the treatment of prostate cancer, and met with peer leaders from local prostate community groups. For the caregivers group, the facilitator contacted the Caregivers' Association and palliative contacts within the community.

These activities were initiated approximately three months prior to the target start date of the three groups.

Facilitator Training

All facilitators received 10 weeks of training, by co-facilitating online groups with cancer patients, under the guidance of experienced Wellness Community clinicians. The training included the text based skills of learning how to convey emotion through type, how to make process comments to keep the group moving smoothly, how to challenge inappropriate behaviour, and when to let the group members support one another and when to take a more active role. During the 10 week training, facilitators participated in weekly online supervision meetings to discuss concerns and to increase familiarity with working in the online environment. Once this intensive training was over, facilitators joined a monthly online Canadian supervision group, facilitated by a Wellness Community clinician.

The following requirements were determined for OSG facilitators:

- Graduation from an accredited Masters program in Social Work of a Masters program deemed to be equivalent by the Agency (i.e., Master of Counselling Psychology, Master of Clinical Psychology).
- Registration with the Board of Registration for Social Workers of BC or the British Columbia Association of Clinical Counsellors.
- Minimum of two (2) years experience in clinical social work/counselling in an interdisciplinary setting including experience in individual, marital and family counselling, group work.
- Minimum of two (2) years experience in group work.
- Employed as a Social Worker/Clinical Counsellor with the BC Cancer Agency, Patient and Family Counselling
- Comfort with computer use

The facilitators reported that the training experience with The Wellness Community was extremely valuable and essential to providing high quality support online. Facilitator training also involved IT training with the Project Coordinator prior to implementing their groups. This was done to ensure they could access the chat platform, locate weekly transcripts, monitor discussion boards, and access IT support if needed.

Learning the Technology

A motivator in partnering with The Wellness Community, in addition to their experience facilitating OSG's, was the ability to utilize existent, expensive-to-develop, technology. The Wellness Community provides an advanced electronic platform that enables secure, password protected group chat and discussion board communication. Adaptations were needed to the platform only, which were far less costly than developing a completely new platform. Information technology provided by The Wellness Community included web pages that detailed project and promotional information targeted to each group, online consent forms and the electronic consent submission process, point of access links to the chat rooms and session transcripts, secure bulletin boards, and development and hosting of the electronic surveys and access to the program used to record and retrieve the data. The Wellness Community also provided technical support to the Project Coordinator and the OSG participants including training on the system, written technical documentation and chat instructions, and a live help line.

Due to technical problems participants can be temporary booted from the system but are usually able to rejoin immediately. The following message was included as part of our patient technical education, in case of a system wide failure. This event involved participants and the facilitator being booted off the chat and unable to log back in for a lengthy period of time during a session.

> The chat system is housed on a secure server, but occasionally there can be glitches in the system that can cause participants to be logged out of the chat. If this happens, please attempt to log back in. If you are unsuccessful, wait a minute and try again. In the case of system wide shut down during the chat, your group facilitator will be working with IT support to get the chat back online, and they will contact all group members through email - if this happens watch your email for updates. <

Project Coordinator Role

A program coordinator was required to assist with the set up and implementation of the OSG program. Many of the coordinator responsibilities were linked to the developmental nature of setting up and evaluating the groups. The coordinator was responsible for tasks including: creation and submission of the Ethics Board application, schematizing and ensuring adherence to program protocol, developing promotional material and initiating the promotional campaign. The coordinator was also responsible for all technology tasks such as webpage content development and ongoing communications with IT personnel related to website and survey development.

Once the groups were about to begin, the coordinator was also responsible for telephone eligibility screening, ensuring informed consent and online privacy and safety awareness, and the enrolment of participants into the electronic chat program. The coordinator was the point person for participant contact and provided patient education and group welcome emails, IT training when needed, weekly emails between sessions, troubleshooting, and ensured evaluation assessments were completed. She also connected with the facilitators, providing IT training, updates on participants, and collected facilitator feedback on the weekly sessions.

Professionally-led Groups: Preparation to Implement Groups

Once interested participants learned about a suitable OSG, they were to be contacted by the Project Coordinator, and in the case of the prostate and caregiver groups, the facilitator. The first contact was to begin building alliance with participants, to discuss the OSG in general terms, and to ascertain suitability, which was accomplished during the screening interview:

Screening Interview

The screening interview consisted of: collecting demographic information, ensuring eligibility for the program, and assessing psychological suitability (see Appendix A). The suitability component of the interview included questions regarding drug/alcohol misuse, suicidal ideation, mental health issues which would affect a patient's ability to participate in a group process, history of trauma or stress within the last two years, and ability to converse online in English.

Group participants were also asked about their ability to commit to group norms and expectations: to attend every possible group, arrive on time and stay for the entire session, maintain group's common and shared focus, treat each other with respect, and maintain confidentiality.

Patient permission was obtained to confirm diagnosis and cancer registry status, and the name and contact information of the patient's primary physician was obtained. For the caregiver group, caregivers had their identity confirmed and patient diagnosis verified, either through an internal referral or an affiliated health care provider, or a letter from the family doctor, or through the patient giving informed consent to verify patient status through the internal cancer information system.

Patients who were ineligible for the online environment were advised of options for support in their home communities. For the purposes of the demonstration groups, catchment was limited to a local area that did include a few communities that were more remote/rural. The services within this catchment were better known by the facilitators, and thus referral to other supports was easier.

Once a participant was confirmed as suitable for joining an OSG, he or she would become enrolled in the study and assigned to a group. In the case of the prostate and caregiver groups, this was a second interview with the project coordinator; in the case of the young women, enrolment was the latter part of the interview with the Project Coordinator.

Enrolment

The enrolment interview provided an opportunity to collect further research information, identify participants' computer skill levels and technical features of their home computer systems, and ensure informed consent. Participants were asked about their previous experience with both face-to-face and online support groups. Information was collected on the reasons for seeking online support and participants were asked to rate a variety of standard reasons from most important to least. Level of computer familiarity, type of home computer system and method of internet access was also assessed to ensure participants would be able to access the platform, and identify those individuals who would need additional technological support.

The interview also consisted of a detailed review of the consent form, which provided an overview of the study design, with a focus on the steps taken within the study to protect privacy and confidentiality, and steps the participant must take to protect confidentiality of other group participants. The housing of the electronic surveys is described, as are potential risks to the participant regarding privacy and confidentiality. Participants were given opportunity to ask questions to ensure informed consent. At the end of the interview, participants were asked to select a password to use to login to the study website.

The coordinator confirmed each participant's diagnosis through the BCCA Registry. The Project Coordinator manually activated the participant's username and password in the electronic system. The process involved the creation of an electronic user profile for each participant and enabling their access to the specific chat group.

Participant Orientation

Once a participant was registered in the electronic system, the coordinator sent out an orientation email containing the participant's specific login information (username and password), instructions for accessing the system and completing the electronic questionnaires, and an attachment document of chat instructions. Participants were instructed to practice logging into the chat platform to ensure tech requirements could be met and to become familiar with the chat. The coordinator was available by telephone to assist participants with navigating the system, and to walk through browser upgrades and Adobe flash program downloads if needed. Intervention material was mailed out if appropriate.

A facilitator welcome email was sent a few days prior to the first group. The email was an informal introduction and participant guidelines, and was sent through the coordinator's email address to maintain facilitator privacy (see Appendix B).

Running and Evaluating the Online Support Groups

Maintaining Engagement in Online Support Groups

Both the project coordinator and facilitator had a role in maintaining engagement in the OSG's. Each week the coordinator sent emails to the members that were informal and friendly in tone. The objective of these messages was informational (i.e., to reminder of group schedule and transcript review, to encourage compliance with 'homework') but also to strengthen alliance with the Project Coordinator who functioned as a primary contact throughout.

The facilitator maintained engagement through the use of skills to optimize the online experience. These included establishing the framework of the meeting, keeping the group focused around the therapeutic orientation (i.e., support, skills), and providing a safe environment for members to connect with one another in productive and meaningful ways. The facilitator also set and modeled norms around group conduct.

An asynchronous electronic discussion board was provided to the young women with breast cancer OSGs but not the caregiver or prostate OSG's. It was intended to function as a secure place for members to connect between sessions, a place for reflection, that allowed sharing of the lessons learned, and facilitate communication on members' experiences of the week's topic. The women used the board to check in between sessions, inform of absences, and exchange email address for further communication once the group ended.

Evaluation

A number of different methods to gather evaluation information were used during the OSG's. Participants completed a number of psychological surveys prior to beginning the group, and at the end of the planned number of sessions. Additionally, after each online session, the facilitator completed an email feedback form for the Dr. Stephen and the Project Coordinator, regarding 'what worked', "what didn't work", presence of IT problems, and participant absences. Lastly, the Dr. Stephen interviewed participants at the completion of the OSG's (see Appendix C).

Concluding the Online Support Group

Each group differed with regards to termination plans, and currently, we have completed only the young women's group. In this group, the facilitator raises the issue of closure two weeks prior to ending, and invites participants who wish to exchange emails to inform the Project Coordinator, who then distributes among willing participants at the end of the 10 weeks. To date, all women have elected to share emails. In addition, the young women are provided with contact information to a virtual community for young women with breast cancer (www.breastcancernowwhat.com).

Due to the particularly high and time-sensitive need of the caregiver group, it has been decided that the facilitator will offer another group immediately following the planned eight weeks, and invite both current attendees and those on a wait to list to join for another eight weeks.

Evaluation of Initiative

As professionally-led OSG's are innovative and untested in Canada, the evaluation plan sought primarily to measure procedural, technical and therapeutic process indicators, and secondarily, patient-reported outcomes. Two groups (for young women with breast cancer) have been completed, and two other groups (prostate and caregivers) are still underway. It was thus possible to track and evaluate procedural and technical indicators for all of the groups; to gather a proxy-measure of therapeutic process for all groups (facilitator reporting on group process); and to describe the young women's experience of being a participant in OSG's. The data reported below were gathered from enquiries, the screening and enrollment interviews, weekly facilitator debriefing notes, and interviews with the three facilitators, and two cohorts of young women (n=11).

Professionally-led Groups: Findings

Recruitment and Retention

Important early questions were: are OSG's appealing to the targeted populations? Will participants sign up and participate in OSG's? If not, why? Thus an important area of evaluation related to promoting the groups and fielding enquiries including reasons for refusal, numbers enrolled, and monitoring attendance once the groups were underway.

Recruitment

Recruitment methods targeting young women resulted in 60 enquiries where the Project Coordinator was able to discuss the OSG's and nature of involvement with the potential participant.

Of the 60 enquiries, 11 women were made aware of the program through BCCA internal staff: via the oncologists (n=2), from nursing (n=1), through Radiation Therapy (RT) (n=3), and from the Patient and Family Counselling department (n=5). Five women learned of the OSG through the Community Oncology Network, and four became aware through local breast cancer community channels. Media and posters netted five and seven responses, while website postings resulted in two inquiries. Dr. Stephen presented the program at a provincial conference for young breast survivors, which led to one response. The majority of responses (n=25) came from a database of women who had participated in other BCCA studies and were informed of the study through a telephone and letter promotion campaign.

Of 60 enquiries, 31 young women agreed to take part in the pilot groups. Thus over 50% of women who made enquiries enrolled to take part in OSG's. The most common reason for declining to participate was the time commitment necessary for participation ($n = 10$) in the OSG. Seven women expressed interest in the OSG's but were "not ready yet" for reasons including still in treatment, recent recurrence and not feeling emotionally ready. Smaller numbers of women gave other reasons: not interested in an online group ($n = 5$), did not have a computer ($n = 4$) or not available during the scheduled group times ($n = 4$).

Recruitment methods targeting prostate patients yielded 24 men who made contact with the facilitator. Referrals came from oncologists ($n=1$), nursing ($n=4$), counseling staff ($n=17$) and community organizations ($n=2$). Of these, seven enrolled in the OSG, representing less than one third of enquiries. Reasons for not participating included a preference for face-to-face groups, unfamiliarity with computers and chatting online, time conflicts with the planned group, and perceived lack of need.

Thirteen caregivers enquired about the OSG and had discussion with the facilitator. Referrals came from counseling staff ($n=6$), community oncology colleagues ($n=2$) and posters ($n=3$). Reasons given for declining included time conflicts and perceived lack of need. The interview revealed that one of the potential members had enquired only because his wife thought it was important, but he felt that he did not need the support.

In summary, referrals were received through cancer centre staff and health professional colleagues in the community; to a lesser degree, through posters and media channels (see Table 1.1). In the case of the young women, enquiries were also received from invitations made directly from previously obtained contacts. The main reason for refusal among all groups was conflict with the scheduled time of OSG.

Table 1.1 How potential participants heard about the OSG's

Promotion Methods	Breast Cancer Survivors	Prostate Cancer Survivors	Caregivers
Doctors	2	1	
Nursing	1	4	
Radiation Therapy	3		
Counselling Staff	5	17	6
Community Oncology Network	5		2
Community Organizations	4	2	2
Media	5		
Posters	7		3
Website Forums	2		
Presentations	1		
Other Studies	25		

Attendance

The 31 individuals who enrolled in the OSG program either took part in one of three OSG's completed or underway (n=16), or are waiting (n=10), or dropped out (n=5). Reasons for withdrawing included: lack of time (n=3); unwilling to wait (n=1), and unknown (n=1). Attendance has been high in the young women's OSG's; among the 11 participants who completed the two groups under evaluation, the attendance rate has been 84% over the two groups. Participants' attendance rates are shown in Table 1.2.

Of the seven men with prostate cancer, only four men logged on to the OSG sessions to date. There have been four sessions and these figures suggest that not all of the seven will be participating. Attendance rate over four sessions is a low 39%.

Seven caregivers enrolled in the OSG, but prior to sessions starting, two caregivers withdrew. One withdrew because of the patient dying (no longer caregiving), and the other withdrew because of technical difficulties in accessing the chatroom from work, which was needed because of the scheduled time of group sessions. Most of the remaining caregivers attended all sessions, to make a 72% attendance rate over four sessions.

Table 1.2 Attendance in OSG to Date

	Number of Participants	Number of Sessions	Total Number of Possible Visits	Actual Number of Visits
Breast	11	20	110	92
Prostate	7	4	28	11
Caregivers	5	5	25	18

Characteristics of OSG Participants

Age

The average age of young women participants was 43, with a range of 32-48 years. Participants living with prostate cancer ranged in age from 55-70, with a mean age of 61. The average age of the caregivers was 55, with an age range of 45-75 years.

Education

Education levels tended to be high though varied somewhat within the groups. Two young women with breast cancer had completed grade 12, whereas sixteen of the 18 participants had college level or higher education, with two having completed Masters degrees. Six of the seven men with prostate cancer had some college education, with one participant having completed a Masters degree. The one participant with lower education (completed grade 12 only) did experience more difficulty navigating the chat system and needed additional technological support. The caregivers all had college level education or higher, with one participant having completed a PhD.

Sex

The groups were divided by sex: all participants in the young women's group, and the caregiver group, were female, and clearly all the participants in the prostate group were male.

Previous Experience with Support Groups and the Internet

Previous experience with support groups was similar among the three different groups: in each group, fewer than half reported previous experience with cancer support groups, with the prostate cancer participants reporting the least experience. The large proportion of both young women with breast cancer, and caregivers, reported being 'very comfortable' with internet and computer use (72% and 85% respectively), whereas fewer than half of the men with prostate cancer reported such high comfort (42%). However, 100% of participants in each population group indicated that they used the internet to seek health information (see Table 1.3).

Table 1.3 Characteristics of those Participating or Registered for an OSG

Group	n	Age range (average age)	Has previous experience with face-to-face cancer support groups	Very comfortable with computers	Uses internet to seek health information
Breast	18	32 to 48 years (43 years)	7	13	18
Prostate	7	55 to 70 years (61 years)	2	3	7
Caregivers	7	45 to 75 years (55 years)	3	6	7

Region

Young women with breast cancer enrolled from across the province and the Yukon Territories. Most participants lived in the more densely populated Lower Mainland (8), but they also lived in smaller and rural communities in the Interior (n=2), Vancouver Island (n=6), Northern British Columbia (n=1), and Yukon Territory (n=1). As described previously, men with prostate cancer and caregivers had been recruited only from the catchments area of the Lower Mainland of British Columbia.

These data suggest that the young women and caregivers overall were younger and more educated compared to the men with prostate cancer and were more comfortable using the internet. Nevertheless, all used the internet for seeking health information, and relatively few had previous experience with support groups.

Setting Up Procedures

At the close of the first pilot group with young women the Dr. Stephen conducted a semi-structured interview to evaluate aspects of the setting up procedure, including preparation by the Project Coordinator, usability of the technology and length and format of the OSG's. Participants voiced appreciation for the availability of the Project Coordinator throughout the set up. Despite being familiar with the internet, the women

reported that her instruction and telephone coaching increased their comfort and confidence with the new online medium.

There had been a few technological “glitches” that interrupted sessions over the course of the 10 weeks, but participants were overall unconcerned. They reported that the technology was user-friendly, even when experiencing the format for the first time. Frustration was expressed over one technological failure that disconnected participants from a session without allowing for closure.

With regards to format, timing and structure, participants consistently reported that a minimum of 10 weeks was needed in order to allow for group formation and adjustment. One session per week was determined to be appropriate. The length of 1.5 hours per session was perceived to be somewhat lengthy for the first session, but a suitable duration once the group had ‘bonded’ and when at least five members were in attendance. Participants endorsed the structured format of the sessions (with pre-assigned topics) as it provided a starting point for discussion and kept the group focused. Yet within the structure, participants appreciated the facilitator’s willingness to allow a degree of flexibility in the flow and course of the discussion.

As a result of this initial feedback, the first session was focused on introductions (initially, the women had introduced themselves on the Discussion Board) and feedback afterwards indicated this to be preferable, and the 1.5 hours to be appropriate for the first and subsequent sessions.

In sum, participants had few challenges with getting started or with the technology, and found the medium acceptable. The coaching of the Project Coordinator was valued and needed. One and a half hours has been viewed as needed, provided that the OSG is not poorly attended. Ten weeks has been considered a suitable length of time overall – the eight weeks was considered too short for the caregivers.

Facilitator Perspectives on OSG’s

The three facilitators were interviewed just prior to the completion of this report. One had completed three groups and was currently facilitating a third; the other two facilitators had completed three sessions of their respective groups. The interview explored three key areas: training and supervision, use of therapeutic skills, and perceived benefits of the OSG’s to the participants and facilitator.

Training Experience

The facilitators of all three groups reported that the training and supervision was essential and prepared them for facilitating their own groups. They described drawing on their clinical skills but stated that the text-based instruction allowed them to gain comfort with the medium and to “bridge the gap of understanding to this new group form.” They expressed that the co-facilitation and private feedback model used by The Wellness Community in training led to modeling of skills by the experienced clinicians, and provided the valuable learning of real-time debriefing during the groups. The training was intensive enough to become internalized as one clinician described: “I draw on my training all the time. I think about what Sue [the trainer] would say. She is my internal voice. I hold back, wait. I can hear her voice”. Participation in the ongoing supervision groups also provided the clinicians with valuable learning resources: good peer support, networking, problem solving and debriefing.

Utilization of Therapeutic Skills

The facilitators were all emphatic that they were drawing on their therapeutic skills in the OSG's. The clinical skills of reframing, normalizing, emotional support, pacing, clarifying, monitoring group process, appropriate self disclosure, and positive reinforcement were all identified as being utilized in the online sessions.

Perception of Benefit to Participants

The facilitators all perceived that the participants were experiencing emotional support in the OSG's. They stated that groups openly expressed that they are feeling supported, for instance, statements such as "*thank God we found this group*" and "*I am not alone*" were common in sessions. Other indicators were use of emotion icons of "hugs" and "hearts" being sent. This was evident even in the men's group. The facilitator of the prostate group reported: "*I see support within the participants building. I think the one's who are looking for support are finding it...the three members are exchanging emails and hugs at this point.*"

Perception of Benefit to Facilitators

All facilitators expressed enthusiasm for their OSG involvement and indicated that they would recommend OSGs to both their own patients and other facilitators. They expressed the belief that OSG's are a powerful, yet safe vehicle for support to persons who are isolated. The facilitator with the most experience qualified her endorsement by stating that she would not recommend OSG's for persons who were extremely depressed or anxious, and who didn't have resources to access the technology. They uniformly agreed that the modality was enjoyable as well as meaningful: they expressed that OSG facilitation was "*fun*", "*stimulating*" and "*energizing*." The clinician in the caregiver group clinician stated that she found the work to be less emotionally taxing than face-to-face counselling:

The screen provides a separation. If I was hearing those words face-to-face I would be highly impacted, but online I did not dream of everybody dying. I was still thinking about it but not in a traumatized way.

There was acknowledgment too that the medium was fatiguing at times because of the high level of concentration required in reading and responding to text quickly. The more experienced facilitator also described occasional uncertainty and concern: "*When someone is quite distressed, depressed or angry, it is challenging to access the therapeutic tools. It can be draining and scary because when you log off you don't know how that person really is.*" Nevertheless, this facilitator concluded that OSG facilitation was gratifying and enhanced her face-to-face clinical work: "*It helps your skills and keeps you on your toes, it has been very educational, meaningful and rewarding.*"

Overall, the facilitators endorsed the value of the training and belief that the OSG format permitted therapeutically valuable exchanges. They received feedback within the sessions that the OSG was of value to the participants, and trusted and enjoyed the format though acknowledged it could be tiring. However, the most experienced facilitator identified limits of the medium too, stating that she was less comfortable with the format for persons experiencing intense mood reactions.

Participant Perspectives on OSG's

Eleven young women who completed the first two groups were interviewed approximately one month after the groups ended. Of key interest for evaluation were the

following perceptions: what was helpful and hindering about counsellor-facilitated OSG's; hopes and expectations for the OSG's; feelings of support, safety and communication within the OSG; and what was learned and any experienced changes since participating in the OSG.

On Professionally-led OSG's

Participant feedback uniformly suggested great value of professional facilitation in the OSG's. There were no comments suggesting a hindering impact, and the responses uniformly indicated that the participants felt a sense of strong rapport with the facilitator. One participant stated:

It was a necessary component to have a counsellor facilitate the chats for me. I loved how she kept us on topic, stimulated conversation and gave valuable feedback. I especially remember how she directed us through a group breathing exercises... on line, very cool!

All participants described the benefit of the facilitator for keeping the discussion flowing and centered on the chosen topic: she “*helped keep the topics moving*,” “*kept us on track*,” “*kept everything flowing very smoothly*”, and “*helped focus me*.” The participants noted that the facilitator contributed to the enjoyment of the OSG by ensuring that each member had an opportunity to contribute.

The psycho-oncology expertise of the facilitator was another recognized benefit. The facilitator's ability to lead the group in experiential exercises (e.g., deep breathing) was mentioned, as was the facilitator's ability to answer a wide variety of questions, to probe issues and provide valuable feedback. One participant articulated this sentiment clearly, “*Despite having direct experience with breast cancer, we don't tend to have the breadth of experience that a counsellor might have to help anticipate issues and bring up important topics that we may overlook*.” Comments suggest that the OSG was deepened by the facilitator's use of reflection, clarification and thought-provoking questions. Her suggestions for further reflection and application during the week were taken up, helped to anchor insights and knowledge gained during discussion. The following statement captures this:

Having a counsellor was critical. I don't think we would have moved forward without the counsellor. I got a lot out of the chat. More than that, she helped me to apply it, make it more real for me and I was surprised by how I was able to approach things differently. I tried doing things differently. I even wrote a letter to my husband using the skills I learnt.

Perceptions of Safety and Belonging

Several women specifically identified experiencing a sense of security from the facilitator's ability to establish boundaries, to name what members described as “crises” and respond to the needs that were identified in the group. More generally, the participants reported feeling safe to share openly about important and private matters during the online chats. There was variation in the degree to which they did so, and in their enthusiasm for online sharing.

One woman, for instance, indicated that although she was able to talk about private issues, it was “not the same” as face-to-face interaction. Another stated: “*I felt like I could talk about private, important things most of the time. Sometimes it was challenging*”

for me as I am not all that outgoing but I felt that I participated in most of the discussions.” Yet another woman said “I think that I was able to communicate intimately in the same way I communicate with others in general. The longer I know someone and learn to trust the experience with them the more open I become.” For this woman, duration of interaction was the key to feeling safe.

Several participants expressed a sense of unexpected pleasure in how open the sharing was. One young woman wrote: “I was surprised by my ability to talk about private things....I think the semi anonymity and feeling safe gave way to the freedom to speak”. For this woman, there was an additional aspect of safety associated with the OSG, as is indicated in the following quote:

I live in a small town older ladies who are cancer survivors get together and have tea parties. I've not been invited but a young woman told me that it is social and not much gets discussed of any depth... no one really wants everyone in town to know their business.

Another aspect of safety was described by a young woman who had previously attended a face-to-face support group, an experience she described as “horrific”. Reportedly, all the other women had more severe diagnoses and treatment effects, and as a consequence, this participant felt depressed and unable to share her feelings, thoughts and experiences which “did not count”. In contrast to her previous experience, this participant found the OSG “safe, supportive and non-judgmental”.

Participant Hopes and Expectations

The young women articulated a number of reasons for participating in the OSG: hope for helping others, for finding a sense of direction and practical help, to, most commonly, reducing feelings of aloneness. The hope for shared experience, for ‘talking’ with others that had gone through similar experiences, was paramount and reflected in almost all of the responses.

I felt disconnected and alone in my experience; talking to other young women with breast cancer did help me feel less so. I think I needed some understanding and support from people in the same situation as myself.

Responses to the question regarding whether expectations had been met were largely positive. Participants offered comments like “I felt I had found new sisters”, “helpful to ‘speak’ with someone else who had the tram flap done”.

Several women indicated that their experience had been better than expected. As one woman explained, “I was not sure in the beginning, but soon realized how important talking to other people who had traveled the same path as I had, helped”. Another woman articulated that she didn’t expect to have such a sense of common experience with group members and found it “neat to not be alone.”

One participant expressed some disappointment because she didn’t have common experiences. This woman was older and had older children, had gone through more treatment, and had been impacted by side effects to a much greater degree than the other women in her group.

Participant Learning and Change

All of the women indicated that they gained information and a new perspective. This learning appeared to be a result of interaction with the other group members and facilitator, as well as the self-help psycho-education component. Talking through the ups and downs of experience was of benefit, also, *“it was good to spend more time on [the skills and] make a concerted effort on [them], which I likely wouldn’t have done on my own.”*

In terms of specific skills, participants described learning relaxation and coping techniques, and learning how to *“reframe the situation”* and continue to make use of this technique. Although one participant said the skills were not new to her, she described the benefit of reflecting on them. Another young woman began to pursue her own search for further information and understanding as a result of the information provided during the chats. Similarly, women noted growth in their awareness of breast cancer and its challenges as questions that previously went unanswered were made clear.

The young women also expressed learning to appreciate the difficulty of their experience stating, *“Half the battle may be just recognizing how difficult a thing we are going through and that we do need coping skills and techniques.”* Agreeing with this, another participant said, *“I learnt to honour the experience as best you can.”*

Emotional growth was noticed by several women in a tentative manner. One woman stated that she feels *“a little better adjusted, emotionally”* and another stated, *“[I’m] not a thunderbolt but I’m feeling optimistic and energetic, not stuck anymore.”* Alternatively, one woman expressed disappointment that she did not feel better mentally.

A change theme frequently stated by the participants was *“I am not alone”* in their experience and concerns. Many of the women reflected a sense of empowerment as they witnessed the strength and courage in each other and began to recognize it in themselves. Pulling these two ideas together, one woman stated, *“I am not alone. This club we are in, albeit not by choice, has made me focus on how strong I really am.”* The following quote also captures this sentiment:

I learnt that I was not alone and that there are other women who have issues that I do. I learnt that these woman had great strength and courage and I felt great respect towards them and very lucky to have met them and witnessed their courage and humour.

Similar to the theme of empowerment, one woman noticed a change in her ability to be assertive stating, *“I realized there are things I need to do and decided now I’m going to do a few things to make myself feel good”.*

In summary, the participants in the young women’s groups described positive healing experiences taking place within their group. They described valuing the professional skills and knowledge of the facilitator which led to more focused discussion, a sense of safety and open sharing about important matters. The woman appreciated the skills and wellness focus of the group and overall felt they had learned from their participation. They particularly appreciated having opportunity to connect with others who had similar experiences and felt that the online sessions had been of great value.

Unfortunately, it was not possible to interview the participants in the other two groups for this report. It is likely that the evaluative reports would differ. On the basis of facilitator reports and attendance rates however it can be inferred that the men in the prostate group appear less likely to report positive benefits (only three consistently participate) whereas it is anticipated that caregivers would.

Professionally-led Groups: Discussion

The primary aims of this project were to pilot test and evaluate three online support groups (OSG's) for selected groups of patients and family members affected by cancer. The intent was to establish the knowledge base for moving work forward elsewhere—to identify and work through developmental issues, and develop the necessary procedures and protocols. By working through the organizational, professional and technical issues, by operating three OSG's in British Columbia, and by tracking recruitment information and interviewing a subset of OSG participants, we were able to achieve the objectives of the project. This is the first project to pilot professionally-facilitated online support groups for cancer patients and family caregivers in Canada, and a great deal was learned. There were considerable challenges as well as successes that should inform future work.

It is our belief that most of the challenges experienced during the project were an outcome of the innovative nature of professionally-facilitated OSG's. While many health providers and patients are familiar with internet-based, un-moderated chat groups, newsrooms and bulletin boards, professionally facilitated 'real time' groups are much less common. Health providers and their managers and directors perceived the delivery of OSG's within the cancer care context as risky. Developmental issues related to security, privacy and safety needed working through and there were no precedents. The goal of offering one cross-provincial group was rejected as being too risky by both organizational risk managers, and facilitators who were reluctant to offer professional service outside of their jurisdiction. To a lesser degree, working through technology and web development components of the project was a challenge to the team, who were not skilled in web development or issues related to use of technology. However, the greatest challenge related to promotion and recruitment. The work of initiating and maintaining a promotion campaign was far more time consuming than expected, there were fewer numbers of referrals than expected, and the recruitment numbers overall were disappointing. Start dates had to be pushed back to fill groups and despite this the groups still had smaller memberships than anticipated.

We suspect that the 'newness' of OSG's has something to do with recruitment challenges. For instance, assumptions were encountered such as "elderly patients do not use computers" which may have dampened enthusiasm to refer. However, there are a few other likely reasons for disappointing recruitment.

Firstly, the team focused efforts towards "word of mouth" referrals from health care providers within the cancer centre and in the community. While this is an effective strategy over the long term it does not represent a quick and efficient strategy. Health professionals are extremely busy and learning and communicating new initiatives to patients is a challenge. Within the BC Cancer Agency for instance, nursing staff (who had previously been a primary referral source) currently spend little time in clinics except when directly interacting with patients, with whom they spend limited time, and schedule

fewer follow up visits. As a consequence, there are no longer the informal, collegial exchanges that previously occurred between counselling and nursing staff (to discuss a new initiative) in clinics, nor the lengthier discussions between nurses and patients that might suggest a referral (communication must ensure delivery of a vast amount of treatment-related information). Communication to health care providers outside the cancer centre is even more challenging, often restricted to email newsletters and yearly professional conferences. Repetition and a more intensive effort than the team were able to sustain is needed to raise awareness and maintain the memory of OSG's as a potential resource.

A second distinct challenge related to recruitment was the catchments area was small and local for the prostate and caregiver group. This not only limited numbers of potential members but in the case of the prostate group also limited OSG's to a population already well-served and perhaps less motivated. In fact, prostate patients were particularly challenging to recruit: they held the lowest proportion of enrolments and the fewest attendances per session. This may be due in part to the existence of strong prostate survivor programs within the catchments. It is also the case that this particular sample was slightly less educated and less versed with computers which may have contributed. Also, only this group had members currently in treatment and schedule conflicts accounted for some of the absences. Lastly, men tend not to utilize psychosocial supports as much as women. The caregiver group was entirely comprised of women even though open to males also. The numbers are too few to make any generalizations but do suggest caution in offering male-only groups.

A third challenge likely relates to the relatively poor marketing skills and resources attached to the project. There was some media attention to the project but it was limited to the launch of the young women's group only as a news item on several radio shows and newspapers. There was no budget for ongoing advertisement in the public media. Postcards and posters were developed for the young women's group only, distributed locally and adapted for the other two groups. The animated youthful woman on a computer likely did not appeal to men but a budget was not developed for targeted materials. More broadly, the language and wording of the promotional materials and other communications were developed by the psychosocial team. It is possible that others with marketing skills could do a better job. While many people might embrace the reality and experience of a professionally-facilitated online support group, fewer find appealing the idea of counselling support and of sharing powerful feelings like fear, anger and loss with strangers in a group. There is a natural reluctance among many to 'opening a can or worms' and the benefits of emotional expression are better understood among professionals than others. We repeatedly hear that OSG's, as with face-to-face groups, are 'better than expected' once patients are encouraged to attend.

Despite these challenges, those who participated attested to the value of the pilot groups. Furthermore, a foundation has been built and future OSG's are likely to be more efficiently implemented. While others are likely to have to undergo a similar process, development and set-up should become increasingly straightforward. Protocols for privacy, safety and patient education and informed consent have been developed, can be adapted for others, and as OSG's become more familiar to health providers and patients, recruitment challenges are likely to recede.

Professionally-led Groups: Lessons Learned and Recommendations

The following represent some of the learnings and suggestions for others embarking on OSG development.

Professional facilitation adds great value to OSG's

Based on feedback from participants and transcript review it is evident that professionally-facilitated online groups provided a high quality experience for participants. The interaction within the groups was focused, meaningful and helpful to the group members. The presence of a professional facilitator provided a sense of safety that enhanced the emotional quality of exchanges. The impacts appeared to extend beyond the session time as participants applied what they learned between sessions. It can be inferred that these groups were not merely social in nature, but rather, healing and therapeutic. It is unfortunate that only the young women's experiences have been heard; it will be important to have the other groups' feedback also.

Counsellor feedback indicated that developing the text-based facilitation skills was essential to their group work, and they all endorsed the value of the training provided through The Wellness Community. The training provided opportunity to learn and practise new skills as well as ask questions and develop an understanding of the online process from experienced facilitators. The quality of the group experience is likely due in large part to facilitator knowledge and skill, and it is recommended that future work with professionally-led OSG's engage trained psycho-oncology experts.

The need for a technology-informed contact person

Based on feedback from participants and the facilitators, it is clear that an available and knowledgeable "point person" is needed for the many tasks related to setting up, running and evaluating OSG's. The Project Coordinator did not have specialized technological skills prior to the project but was able to learn what was needed over the course of the project. However, the use of the technology was unfamiliar enough to both group members and facilitators that the Project Coordinator needed to spend considerable time communicating and coaching, both on the phone and through email. Each new group required considerable web-based set up: communications were required prior to setting up the groups, as well as throughout the sessions and afterwards, and for completing web-based surveys. Many questions were addressed when participants needed a person on the phone, and an entirely web-based contact would have been a barrier to participation. It would not be been feasible to offer these OSG's within current organizational structure and staffing as the facilitators and a program secretary alone did not have the skills nor time to set up and run the next groups. It remains to be seen whether the tasks could be transferred once a number of groups had run and all "bugs" ironed out.

The need for technology consultation and expertise

None of the project team had technological skills or knowledge, and over the course of the project, this led to a number of challenges. Learning was trial and error as a consequence of not ensuring a detailed and thorough IT orientation and consultation at the beginning of the project. The team did not have a realistic awareness of the developmental time required to create web structures, and to make and test textual changes to the website. This led to frustration on the part of both the clinical and web development teams, and delays to start up of the second round of groups. The

partnership with The Wellness Community and access to their expertise proved a saving grace, as they handled all aspects of technology, and had anticipated some of the possible challenges that the project team had not. For instance, they had suggested the team have live help for the first sessions and indeed at least one participant needed the live help during the start up session for three of the four OSG's. Lastly, the technology was user friendly and well-developed but there were occasional problems where individuals were "dumped" or the entire site collapsed. Fortunately, the latter occurred only once, but developed awareness of the need for a contingency plan to be communicated prior to group start up.

The need for new methods for marketing and promotion

The online medium represents a new way of delivering psychosocial services, and to be successful, there must be enough members to fill groups. We have found that six persons with one facilitator is optimal, but to achieve that number eight should be enrolled. How best to promote these specialized types of groups remains unanswered. Recruitment through established routes of health care professionals need to be strengthened and widened in order to reach patients living outside of the local catchments, where psychosocial resources are relatively rich. We suspect too that promotion targeted outside of traditional health care settings would be helpful, as would web-based promotions. Dedicating time to developing a promotional plan, and maintaining linkages is also recommended. It may be that once groups are well established, ongoing promotional activities will be less time consuming.

Resolve barriers to cross-provincial OSG's

An objective had been to offer cross-provincial groups, but unfortunately this was not possible due to organizational and professional barriers. Cross-provincial collaboration will be key to making professionally-led OSG's accessible to underserved Canadian populations living with cancer for reasons of professional capacity as well as reaching large enough numbers of the targeted populations. A national lobbying effort for national regulatory bodies is needed and tools such as reciprocity agreements between provincial cancer agencies would be extremely helpful. For this to happen, it will be important that national collaborative efforts continue to be supported.

Professionally-led Groups: Next Steps

With support from funds from the Canadian Institute of Health Research and the Cancer Journey Action Group of the Canadian Partnership Against Cancer, additional demonstration OSG's will be conducted through 2008 and early 2009 in and outside of British Columbia. Efforts will continue to resolve the cross-border issues; more facilitators will be trained; and new and innovative means of promoting professionally-led OSG's, perhaps including collaboration with the peer-led groups, will be investigated and documented. Investigation will continue on developing and testing a common evaluation framework for both the professionally-led and peer-led groups.

Acknowledgements (Professionally-led Online Support Groups)

We acknowledge the members of the following subgroups who have contributed to this and other development work:

<p>National Group Mitch Golant, WA Joanne Stephen, BC Richard Doll, BC Gina Mackenzie, BC Karen Flood, BC Gregory Huebner, BC Fred Crawford, BC Heather Rennie, BC Shelley Gordon, BC Nancy Payeur, BC Michael Specca, AB Jessica Kenney, AB Jill Turner, AB Kate Collie, AB Christine Coral, AB Helen MacRae, AB Bunty Anderson, MB Jill Taylor-Brown, MB Karen Fergus, ON Sue Keller-Olaman, ON Lise Fillion, QC Deb McLeod, NS</p>	<p>BCCA Group Joanne Stephen, Research Lead Gina Mackenzie, Program Leader Karen Flood, Clinician Heather Rennie, Clinician Fred Crawford, Clinician Gregory Huebner, Clinician Michelle Rahn, Researcher Jennifer Macdonald, Coordinator</p>
<p>The Wellness Community Collaborators Mitch Golant, VP Research & Development Bill Shaffer, Senior Director Virtual Community Lynn Ryker, Director of Online Initiatives</p>	<p>Steering Committee Members Joanne Stephen, BC Michael Specca, AB Jill Taylor-Brown, MB Karen Fergus, ON Sue Keller-Olaman, ON Lise Fillion, QC Deb McLeod, NS</p>
<p>Western Research Team Joanne Stephen, BC Michael Specca, AB Jill Taylor-Brown, MB</p>	

CHAPTER 2: PEER-LED SUPPORT GROUPS

Peer-led Groups: Overview

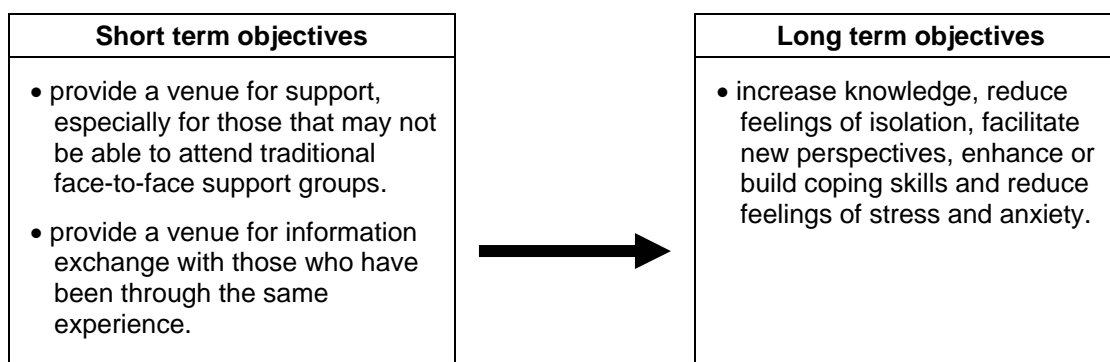
Traditional face-to-face support groups have been shown to benefit cancer survivors, helping them cope with their experiences. These have included professionally-led, peer-led and self-support groups (Galinsky et al., 1997). Benefits include timely education about cancer and treatments, help with coping after a cancer diagnosis, relief from isolation, emotional support, and help with relationships with family members (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 (Dunn et al., 1999).

However there are barriers to accessing face-to-face support groups such as feeling too unwell to attend, time commitments or living too far away. As noted in the introduction, the Cancer Journey Action Group identified peer-led online support groups as a promising method to access support regardless of where a person lives. The need for a menu of information and support options was also identified. Earlier work by OBCIEP had indeed found it is important to offer a range of information and support choices. Women affected by breast cancer for example, perceive a lack of support options at specific times and do not always know what some services offer and how they may be helpful (Fitch, Nicoll and Keller-Olaman, 2007).

Therefore, in 2004 OBCIEP began to explore the benefits and feasibility of providing peer-led group support via the telephone or via the Internet. That four-year project entitled “Breast Cancer Information and Support—Preferences to Guide Service Development” (OBCIEP, 2008) was informally known as the “Hub” project as it articulated a vision for cancer information and support like hub, a “one-stop shopping” resource where cancer patients, survivors, and caregivers could choose a number of different options tailored to their particular needs. As part of that project a website was developed to provide trustworthy information, links to credible sites and a landing page for the online support groups (www.CancerSupportNetwork.ca). The initial focus was on breast, ovarian, lung, and prostate cancer with the intention of expanding the content to include other cancer sites. In addition, collaborative relationships were established with those developing professionally-led support groups in Canada as explained in Chapter 1. The connection provides the opportunity to share learning, ensures a degree of consistency between peer-led and professionally-led groups, facilitates the establishment of a common evaluation framework and moves the vision closer to reality by providing support options that cancer patients and their families can select depending on their individual preferences.

This peer-led support group initiative therefore expands upon work already conducted by OBCIEP. To date, OBCIEP has found that support using technology (online and teleconference) exceeds participants’ and facilitators’ expectations and benefits include a sense of connection, reduced loneliness and emotional support. Challenges include matching participants within groups according to their personal needs, attendance and confidence with the online format. This chapter describes the process of piloting three peer-led groups with breast, ovarian and prostate cancer survivors.

Objectives of Peer-led Support Groups



Some key considerations that differed in this project compared to earlier work are the working with men in the prostate cancer support group, the length of time of the groups and the frequency of sessions (see Table 2.1). There is evidence that men benefit from support groups but may seek information in different ways to women and prefer a relatively more structured topic-driven type of support (Coreil & Bebal, 1999; Thaxton et al., 2005; Ross, et al., 2007).

Peer-led Groups: Methods

To demonstrate how this project builds upon our body of knowledge, a comparison with the support groups run as part of the OBCIEP Hub project is shown below (Table 2.1).

Table 2.1 Comparison of two peer-led support group research efforts

	OBCIEP Hub Project	Enhancing Access Project
Number of groups	Seven	Three
Group types	Six breast cancer One ovarian cancer	One breast cancer One ovarian cancer One prostate cancer
Method	Teleconference and Online	Teleconference
Number of sessions	Weekly sessions for six weeks	Two met weekly (six weeks) One group met monthly for six months
Facilitation	One group was co-facilitated	Two groups were co-facilitated
Meeting format	Determined by the group	A list of topics/agenda was suggested to guide the sessions
Meeting reminders	If requested	All participants reminded each week to attend their sessions (via email)
Weekly feedback	Sought from participants and facilitators	Sought from participants and facilitators
Final evaluation	Final interviews with participants and facilitators	Same but with additional evaluation questions provided by the Canadian Cancer Society evaluation survey.
Evaluation framework	Qualitative	Effort to build an evaluation framework that aligns with professionally-led support group efforts

Recruitment

Posters and flyers were used to recruit participants for the peer-led support groups (see Appendix D for selected samples). Emails via organizational mailing lists and personal connections with organizations were successful in making initial contact with many participants and facilitators and ultimately recruiting them for the groups. For example, most of the ovarian cancer group were recruited through a list provided by Ovarian Cancer Canada. Ovarian Cancer Canada used several methods to attract women for both the earlier peer-led project and the present initiative that included:

- notices in their e-newsletter that goes across the country
- notice on their website
- notices and posters sent to gynaecological oncology units and nurses
- notices sent to survivors in the Ovarian Cancer Canada database.

Ovarian Cancer Canada initially had 20 women interested in the groups though ultimately not all were available to participate.

Women who had been involved in the Hub Project breast cancer groups were asked to share the information about the initiative and those who had participated in online groups were invited to participate in a teleconference group. Similarly, the Cancer Support Network website reviewers were asked to promote the groups in their local networks and that recruiting was ongoing. Recruiting was done nationally.

When an adequate number of participants with the same diagnosis had registered a group was formed. Sufficient numbers of participants were recruited to run three groups with breast, ovarian and prostate cancer survivors. A facilitator was recruited to run a lesbian/bisexual support group for survivors but insufficient participants were recruited for this project. Recruitment for a young women's breast cancer group was stalled also due to insufficient participants.

Screening

Once participants had confirmed their interest in being part of a peer-led support group, they were contacted and interviewed. The screening interview collected personal information and expectations (See Appendix E). In addition, during the screening interview participants were asked about their preference for either an online or teleconference group. The final decision was made based on what the majority of participants' preferences and ultimately on the facilitator's preference.

Interestingly both the facilitators as well as most of the participants indicated a preference for teleconference rather than meeting via the Internet. In the prostate group one participant did not have access to a computer and one of the co-facilitators indicated a definite preference for meeting by teleconference.

Participants

The three groups of participants were breast cancer (n=4), ovarian cancer (n=5) or prostate cancer survivors (n=8). As a requirement to take part, all participants had been diagnosed with cancer within the past three years.

The ovarian group had begun by meeting weekly as part of the Hub Project. They continued on a monthly basis to form a comparison for this initiative after requesting to continue meeting beyond their six weekly sessions. The breast cancer support group used

one of the facilitators from the ovarian group who was a breast cancer survivor. Her preference was for teleconference. Some of the participants were recruited from previous online groups so that comparisons could be made between the experiences. Age and place of residence for each group can be seen in Table 2.2.

Table 2.2 Characteristics of peer-led support group participants

Diagnosis	Age range	Location
Prostate cancer	52-71 years	Southern Ontario, Northern Ontario, British Columbia and New Brunswick
Ovarian cancer	45-60 years	Ontario, Manitoba, British Columbia and Saskatchewan.
Breast cancer	50-64 years	Southern and Northern Ontario, British Columbia and Nova Scotia.

Two thirds of the ovarian cancer survivors had been diagnosed with other cancers (breast, fallopian). The majority of participants (72%) had completed post-secondary education (college or university). Some participants had attended a face-to face support group before. As noted above, all participants preferred the teleconference meeting option.

Facilitation

Each phone group was facilitated by one or two survivors/caregiver who are experienced in support (at group or individual level). The facilitators had either been trained by Wellspring or the Canadian Cancer Society. They were therefore trained in issues of confidentiality, peer counselling skills (including empathy, setting and maintaining boundaries, role-playing, giving feedback) and received ongoing training about medical issues associated with cancer. Their approach to peer counselling was framed around a self-help or empowerment model of health promotion.

Additional training was provided by the Manager of Peer Support at Canadian Cancer Society – Ontario Division. Training involved working through a modified Society training module via a teleconference plus practice with the technology. For example, an online group met (OBCIEP staff, Society staff and interested prostate cancer facilitators) to provide prospective facilitators a chance to experience the teleconference environment and online chat module before deciding on their preferred modality.

Running the Groups

Between September 2007 and February 2008, each support group met on six occasions over a six week or in the case of the ovarian group, over a six month period. In order to access their respective groups, at a pre-arranged day and time (typically a week day or evening), the group members used their work, home or cell phone to call a conference telephone number and enter a pass code for their group. Each group was then linked together in a conference call for 90 minutes. When they had finished, they simply hung up. No special equipment was needed. They were reminded of the meeting day and time each week or month by email. Some format details are set out in Table 2.3.

Table 2.3 Overview of the support groups

Survivor group	Found out about group via	Modality chosen	Facilitation	Frequency and Duration	Comments
Prostate (n=8)	Email Personal contacts Posters	Phone	Co-facilitated (two)	Weekly for six weeks	
Breast (n=4)	Email Facebook breastcancer.org discussion board	Phone	Single facilitator	Weekly for six weeks	Two participants had previously taken part in an online group
Ovarian (n=5)	Ovarian Cancer Canada	Phone	Co-facilitated (breast cancer survivor, caregiver)	Monthly for six months	Began as a weekly group for six weeks.

Evaluation

The effectiveness of the groups was assessed by asking the participants open-ended questions before starting, during, and after completing their group. To collect the information, the Project Coordinator contacted every participant and facilitator by email after each session for feedback (see Appendix F). A more comprehensive evaluation was conducted via individual phone interviews at the end of the six sessions.

The weekly/monthly feedback questions asked the participants how the group went generally for them, what they liked, disliked, reason for not attending (if relevant) and asked for any additional comments. The facilitators were asked similar questions. All responses were received by email and stored in an electronic data file.

The final evaluation was conducted by telephone after the final session for each group (see Appendix G). Participants were asked about their overall experience, impressions of the facilitator, comments regarding the process and technical aspects and possible improvements. Questions adapted from a Canadian Cancer Society survey that included a Likert type rating scale about aspects of support and some demographic data were added to the evaluation tool used in the Hub Project.

Prior to evaluation of the three peer-led groups communication between the peer-led and the professionally-led support groups about comparable outcomes and evaluation methods began. A formal evaluation framework that incorporated both the peer and professionally-led work was planned and has begun. Developing the framework and potential measures took considerable time and could not be completed prior to the evaluation of the three support groups. There was agreement on some general statements and possible outcome measures and efforts were made to make ensure that many of the process questions were the same. In addition, there was agreement to ask some common open-ended questions about effectiveness (e.g., how expectations were met (or not); was the support received what participants really wanted).

The peer facilitators were also asked about overall impressions 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 with connecting to the participants. During the interviews, detailed notes were taken to capture the comments and suggestions.

Peer-led Groups: Findings

This section briefly describe some of the feedback received after each session and is then organized around the questions asked during the final evaluation interview. Findings are combined where it makes sense to do so (for example, all the things that “worked well”). It is worth noting that the responses by-and-large mirror the major themes that emerged from the OBCIEP Hub Project briefly summarized in Table 2.4.

Table 2.4. Summary of findings from OBCIEP Hub Project

Questions	Teleconference Group	Online Group
What worked well	<ul style="list-style-type: none"> ▪ improved emotional outlook ▪ mentally uplifting ▪ bonding with participants ▪ anonymity ▪ thorough discussion 	<ul style="list-style-type: none"> ▪ building connections ▪ satisfaction with modality ▪ learning new information
What did not work	<ul style="list-style-type: none"> ▪ lack of visual cues ▪ irregular attendance ▪ looking for “like” participants (in age, disease stage, life stage, etc.) 	<ul style="list-style-type: none"> ▪ getting used to online format ▪ irregular attendance ▪ learning who was who without visuals ▪ looking for “like” participants ▪ challenges for facilitators to monitor chat
Suggestions for future groups	<ul style="list-style-type: none"> ▪ keep meeting length to 90 minutes or less ▪ do not offer groups during the summer ▪ consider eight rather than six sessions ▪ keep participants to four or five plus a facilitator ▪ after sessions switch group to online or e-chat group to maintain connections 	<ul style="list-style-type: none"> ▪ make efforts to ensure attendance ▪ try biweekly rather than weekly sessions ▪ have predetermined discussion topics ▪ match participants where possible ▪ have facilitators be more directive in managing the groups ▪ have participants use the profile feature on the chat program

The findings below focus on new learnings from the three teleconference groups such as how the men experienced peer-led support. Comments from the facilitators are included towards the end of this section. All names used are pseudonyms.

Format

There was an initial “settling in” period of approximately two weeks where the participants met and learned the format of the group. There was also a learning curve for the facilitators who had not run teleconference groups before. Some of the facilitators had

experience in the Hub Project. Initially there was some tepid feedback in but overall it became more positive as the weeks progressed.

I enjoyed it. I did not know what to expect and was a bit apprehensive but was soon at ease. Facilitator kept things moving along smoothly. Easy to communicate with others even if we begin as strangers (Breast Cancer Survivor).

In terms of important topics covered, the participants from each group provided the following feedback (Table 2.5).

Table 2.5
In your opinion, what were the most important topics discussed with your group?

Breast Cancer Survivors	Ovarian Cancer Survivors	Prostate Cancer Survivors
<ul style="list-style-type: none"> • Reconstruction • “Pink (ribbon) fatigue” – supporting all cancer-related causes • Side effects • Dealing with the health care team 	<ul style="list-style-type: none"> • Treatment • Life impact • Coping skills • Survivorship 	<ul style="list-style-type: none"> • Incontinence • Erectile Dysfunction • Diet and exercise

The male facilitators provided less feedback following each session compared to the women facilitators. This was interpreted as individual variation rather than a gender difference as there was no difference in the volume of feedback from the final interview.

Attendance

The three groups were well attended as noted in Table 2.6. There was full attendance at the breast cancer group. The prostate cancer group was also well attended, with only two men missing one session each. The ovarian cancer group had more irregular attendance, mainly due to conflict with work schedules. Of note, one woman in the ovarian cancer group moved to the United States for the winter but still called in monthly.

Table 2.6 Attendance at peer-led support group sessions

Group	Absenteeism	Reasons for Absence
Prostate	One session missed	Away on vacation
	One session missed	Work commitments
Ovarian	Three or four sessions missed by one woman	Work schedule
	One woman left one session early	She was facing emotional issues
Breast	One woman attended one meeting, part of another and did not attend further meetings	Attempting to participate from work, she became too busy

Positive experiences: What worked well?

Were needs and expectations met?

Expectations

Gender differences were reflected in the expectations of the group. The ovarian group commented most often about the unexpected bonding and support they received from one another, while the men commented about the positive sharing of information and experiences. The men were interested in having professional or expert guests participate at the meetings and expressed some disappointment that this did not take place. Generally the group support exceeded expectations for the breast cancer survivors.

I didn't know what to expect. But what I was greeted with was beautiful. A big group hug. (Ovarian Cancer Survivor)

Because I've never been in something like this and where I was in my treatment, I was more curious...I didn't have any expectations. I wasn't disappointed and it really struck me that this was the place that I can be with others who have ovarian cancer, for better or for worse. That was very important for me, because the information I can get elsewhere. (Ovarian Cancer Survivor)

Yes it did, probably exceeded them (expectations) in a few areas. People were quite open about the sexual dysfunction and how they were coping. (Prostate Cancer Survivor).

It didn't meet my expectations in the area of an expert being on hand each week. Somebody along those lines would have been a help, to give more credibility. The facilitators did their best and did a lot of home work. If they had a nutritionist there they would have had exact information. (Prostate Cancer Survivor)

It exceeded my expectations...the last one I was on was online and I enjoyed this so much more. (Breast Cancer Survivor)

Needs

The Canadian Cancer Society asks survivors in face-to-face support groups to rate the extent to which the group met their needs. This question was added to the evaluation survey of the three groups. The breast cancer and prostate cancer groups were consistent in terms of needs met. "Almost (all)" and "most needs met" were the common responses. The ovarian cancer group (100%) said "all" needs were met.

Support

"Was the type of support you received the type that you wanted?" was asked. The responses to the question demonstrated the change in belief that occurred as the groups progressed. For example, some participants said that initially they may have opted for a different type of support, but at the end of their six sessions, they could more clearly see benefits for themselves in peer-led phone support groups. For example, all women from the ovarian group indicated that the monthly teleconference was the type of support that they wanted.

Certainly face-to-face would have been ideal, but it's better than online because it's a live voice and you can hear the tone of voice. We all said we wished we could see faces, but the voice was good. (Ovarian Cancer Survivor)

Not when I started but it was when I finished. I would have wanted a face-to-face group but I've changed my mind. There was something about being in a group where because we were over the phone we were more open with each other. It wouldn't have been so open and emotional. I'm not sure if a face-to-face would have been as good. I think sometimes people hold back in face-to-face. (Ovarian Cancer Survivor)

It was one I would have chosen earlier in my diagnosis if I had availability to it. Had it been available at that time I would have jumped on it because it would have been easier because I was chasing down doctors and didn't have the time to chase down meetings. (Prostate Cancer Survivor)

Satisfaction with the Teleconference Group

Participants were asked if they would participate in another telephone support group and if they would recommend this format to others. All participants were unanimous about participating in a telephone support group again as well as recommending it to others. Some mentioned that it would depend on their circumstances at the time, energy level, work, and other responsibilities. When asked if they would recommend a teleconference support group to others, all responded "yes, definitely".

Yes, definitely. Living in the country with no one else around a support group is so important. There is probably another woman out there in a rural area that could use this. (Ovarian Cancer Survivor)

If I got another cancer or a heart attack or any health reasons, because it was a positive experience...it's not something I would normally say yes to. I'm out a lot and so this was a good way for me to do this. (Prostate Cancer Survivor)

Do you feel better now than the beginning of the support group?

A rating scale is used by Canadian Cancer Society to evaluate their peer support efforts. The participants of the three teleconference groups were asked to rate each item from 1 to 5 in order to get a sense of the type of support they experienced (1 = Not at all; 2, 3 = Some what; 4, 5 = Yes, a lot). While acknowledging the group sizes were small, average ratings were calculated to provide a comparison between the different peer-led groups.

As seen in Table 2.7, the women rated the emotional issues like coping, anxiety, hopefulness, support higher than the men. Becoming more informed about the disease and treatments were rated higher by the men (4.8) as many of their sessions focussed on information dissemination. Feeling supported is rated higher by the breast (5) and ovarian group (5) than by the prostate group (4.1) as was a decrease in anxiety. The group made it easier for the men to talk with others (4.6), whereas feeling more comfortable talking to the health care team was rated similarly by all groups (4.2 to 4.5).

Table 2.7**Aspects of support: Average ratings from the three peer-led groups**

Participating in a support group:	Average ratings		
	1 = Not at all	5 = Yes, a lot	
Survey Items	Ovarian (n=5)	Breast (n=4)	Prostate (n=8)
Helped me cope	4.8	4.7	4.0
Made me feel more informed about my disease and the treatments	4	3.3	4.6
Made me feel less alone in my experience	5	4.7	4.1
Helped me gain useful information	4.4	4.7	4.8
Helped me better understand my cancer experience	4.6	3.7	4.1
Decreased my anxiety	5	4.3	3.3
Made me feel hopeful about the future	4.8	4.3	3.6
Made me feel supported	5	5	4.1
Made me feel more comfortable talking to my health care team	4.2	4	4.5
Made me feel more comfortable talking with others (e.g., family, friends)	3.6	3.3	4.6

Overview of Benefits

Based on the responses that described the participants' needs, expectations and why they would recommend this type of support to others, several themes within the positive feedback could be identified. In the main, the positive feedback is similar to the major themes reported by the OBCIEP Hub Project. Of note, the information sharing and decision making theme resonated most with the prostate group, whereas the ovarian and breast cancer groups mentioned the emotional support and sharing as being of value for others.

The key perceived benefits of telephone peer-led support groups for this initiative are listed below one by one with quotes to exemplify each.

Anonymity

Gave me a good feeling about the fact that men can get together and talk about stuff like this. It's not easy for me to talk about erectile dysfunction and incontinence. Perhaps talking on the phone instead of face-to-face had something to do with that. (Prostate Cancer Survivor)

I'm quite comfortable but for some people the anonymity is important because you can talk more freely especially initially. (Breast Cancer Survivor)

Emotional support

Some of the advice they (participants) gave me was life-securing. I don't think they will realize what they said and how it will affect people. When you go through a crisis like I just have, it was something to cling to. If I ever got sick with cancer again, there's some words that they spoke that will never be forgotten and will get me through the darkest days. During the dark days I remember what Janice said to me.. "Why wait for the storm to pass, dance in the rain now." (Ovarian Cancer Survivor)

It was really helpful and supportive and it was worthwhile. Since I've been diagnosed it was the most important thing I ever did. (Prostate Cancer Survivor)

Connections

...Women coming together not knowing each other and bonding so fast, from such diverse backgrounds and talking about everything. It was amazing. Something like cancer brought us so close, yet we were so far apart. It was the bond. (Ovarian Cancer Survivor)

I think being grouped within a similar age and diagnosis timeline creates commonalities. I like being able to choose the topics of importance. I was surprised at how similar our concerns/issues were (Breast Cancer Survivor).

Openness and Sharing

...People were quite open about the sexual dysfunction and how they were coping. (Prostate Cancer Survivor)

...it did something for me that I wasn't expecting. I learned a lot about my pent up feelings that I didn't even know were there. The closeness of the group was unexpected at first. I expected a sterile conversation, clinical and it wasn't. People were open and honest and it was wonderful. (Ovarian Cancer Survivor)

Informational support

For people who need or want some type of information, opinions of other people...a multitude of experiences of others...you receive all of that stuff. You get it without having to be too personal. For people who are busy, want to share and want to hear what's going on. (Prostate Cancer Survivor)

It was so helpful to me. When people get diagnosed they don't get enough information from their medical team. (Prostate Cancer Survivor)

Convenience

Given the kind of workload that I have and my extracurricular activities, it was easy for me to do it as opposed to doing it face-to-face. Doing it on the phone made it more accessible. (Prostate Cancer Survivor)

..It's a time thing. Doing it on the phone was convenient. Face-to-face wouldn't have the same appeal because I would have to go out and I'm very busy. (Prostate Cancer Survivor)

Compared to the meetings I go to, this is a lot faster approach for people who don't have the time initially to seek out a group and go. The fact that it is weekly is better because you get the information quicker. (Prostate Cancer Survivor)

We can't hug or see who we are, but we can do everything else. To go just by our voices is nice...to experience and know so much from the voice. As we talk more ...it becomes easier. We do miss the eye contact and the physical being there. I don't see it as a hindrance, but as a great opportunity to talk from the privacy of our homes and to connect across the country. (Ovarian Cancer Survivor)

National Reach

The initiative aimed to include participants from across Canada. As the feedback shows, this was perceived as a further strength, particularly for the ovarian and prostate cancer groups.

It was great that they were from different parts of Canada..... because you can evaluate the ability of health care in different parts of the country...Toronto and Vancouver have better facilities. Many things are not available in smaller rural communities. (Prostate Cancer Survivor)

I enjoyed talking to people across the country...it was a very "Canadian" experience. (Prostate Cancer Survivor)

I learned so many things about how things are done across the country, how women from other regions have the same concerns as you do and it's not just in this vacuum in your own back yard. (Ovarian Cancer Survivor)

However, the time zone difference caused a problem for the breast cancer group as the participant from British Columbia was at work during the meetings and could not continue to participate.

One person in British Columbia was able to join us once or twice because of the time difference, that was negative. It would have been better to get someone in the same or close to the same time zone. (Breast Cancer Survivor)

What did not work so well?

Participants were asked if there was anything that would have made the group more helpful to them. The prostate group had the most suggestions with no particular theme. The suggestions included sharing contact information and emails, having information and website links sent prior to the meetings, better training for teleconference facilitation, having professionals or medical experts participate in a session and having a chat room or discussion board to help maintain contact within the group.

The ovarian group mentioned having an ovarian cancer survivor facilitate and having two meetings a month, one for catch-up and the other topic driven.

Suggestions to change the format included expanding to monthly meetings after six weeks that had also been made by the OBCIEP Hub Project participants.

Six weeks was not long enough. I think three to four weeks would be enough time for education to get people talking to one another and then moving to monthly. (Prostate Cancer Survivor)

I would like for our group to get back together. I would like to share my email with the other ladies. (Breast Cancer Survivor)

Similar to earlier findings in OBCIEP Hub Project, areas of difficulty were identified as lack of visual cues, lack of energy that emanates from a face-to-face group, and conflicting schedules that affected group attendance. Suggested improvements included topic-driven meetings and exploring options to continue group interaction after completion of the six sessions.

Manual

Support group teleconference manuals that included group rules and tips were prepared for both facilitators and participants. Developed as part of the Hub Project the manuals were distributed to the three groups' participants and the facilitators. Although the manual was positively received, it was suggested that it include some excerpts or description of a typical session to illustrate how it unfolds. The prostate group also mentioned that they would like information about certain topics such as incontinence, nutrition information included in the manual that could be discussed during a session. Rather than producing a manual for each cancer specific group, referring the groups to information and links on www.cancersupportnetwork.ca website may be a more efficient way to provide timely and comprehensive information.

I found it very informative. I found it gave clear instructions on how to call in, and what would happen as I was dialing in. Because of this, I was more comfortable before the first meeting. (Breast Cancer Survivor)

It was very useful. First of all it gives you an idea of what will happen, how to phone contact, etc. For some it maybe easier than for others, so it helped. This was the first time I was on a conference call. (Prostate Cancer Survivor)

In the manual, you may want to put some of the type of information we are now sharing, BMI etc. that was sent out as a result of discussions. Also you might want to include some of the websites that are credible and some books that were suggested. It could enable others to read some of the material and then ask questions during the group as the issues arise. (Prostate Cancer Survivor)

Preferences for Online or Teleconference Groups

Two participants in the breast cancer group had previously attended online groups and were able to make comparisons and express their preference for the telephone group. One of the members felt that hearing voices allowed her to bond more than being online.

I enjoyed being on the phone. Last year I did the online and I find the phone better because you hear everybody's voice and online when you're

typing and trying to read everything everyone said, it's easier on the telephone. (Breast Cancer Survivor)

I enjoyed it more than I did the online. The online I still felt by myself. By phone, I couldn't see them, but they were there more so than online. The voice was there, the person was there...other than reading something online. I know the online was with real people, but it felt more human talking than tapping away at a computer. (Breast Cancer Survivor)

The last one I was on was online and I enjoyed it (this) so much more. It was easier on the phone to keep notes. Having the verbal cues was helpful and it was easier on the phone to communicate. Not everyone is a fast typer and the topic can change before you get your point of view across with the online. (Breast Cancer Survivor)

Because you hear somebody's voice, you seemed to bond more than online. I enjoy both because I've had a good experience with both. I think that with the phone that we were able to speak more openly. (Breast Cancer Survivor)

Finally, the participants were asked if there were topics they had wanted discussed that were not raised. The breast cancer survivors reported only one issue while the ovarian cancer group reported several:

Table 2.8 Topics the groups would have liked to discuss

Breast Cancer Survivors	Ovarian Cancer Survivors	Prostate Cancer Survivors
<ul style="list-style-type: none"> ▪ Anxiety over recurrence 	<ul style="list-style-type: none"> ▪ Fatigue (mentioned by all) ▪ Nutrition ▪ Mortality ▪ Help for single women ▪ Impact of surgical menopause 	<ul style="list-style-type: none"> ▪ Clarity around PSA testing ▪ Specific surgery options for incontinence

Peer-led Facilitation

Overall Impressions

The men described how their group took a few weeks to get going. For example, they felt they “stumbled” and did not feel connected until around the third week, due in part to the style of facilitation. The facilitators began with an information presentation style rather than an open sharing of information and a discussion. Participants comments included:

At the beginning of the sessions I thought both facilitators talked too much. Facilitators are supposed to get people involved and get feedback. As time wore on people got more comfortable and they would lay out stuff at the beginning and let people jump in. They were better as they went on.

The beginning the rules weren't clear and too much talking heads from the facilitators.

The facilitators spent much time giving... information. Without an agenda it was difficult to know where the facilitators were directing the session. Asking

questions of individuals might have generated more discussion, participant interaction, knowledge exchange.

This improved dramatically after the facilitators were made aware of the feedback, changed their facilitation style, and built confidence in running the group. In the follow-up interviews most participants in all three groups described their support group facilitation in a positive way.

She was wonderful, very informed, caring, considerate, strong, guiding, I think she was there in all of the ways that we needed her to be there. And in the midst of it all, her own personal experience she shared with us, we supported her back. (Ovarian Cancer Survivor)

She wasn't just a facilitator...she was knowledgeable about psychological and physical issues. Her facilitation qualities were great...she had a plan. (Ovarian Cancer Survivor)

You could hear the warmth in her voice. (Breast Cancer Survivor)

I think Richard did his homework before each session and worked hard in that area. He was friendly and easy to talk to and he tried to bring people out. (Prostate Cancer Survivor)

Co-facilitation

Two of the groups, ovarian and prostate, were co-facilitated. The co-facilitation had been requested by one or both of the co-facilitators. One of the facilitators for the ovarian group could not commit to the full six months and therefore someone had to take over the group for one of the sessions. In each co-facilitated group (for prostate and for ovarian survivors) one facilitator was identified by the group as the "leader". Personality and/or experience may have played a part in which person assumed which role as it was not decided in advance who would be the lead facilitator.

He was kind of the number two person of the facilitators and I think he filled that role well. (Prostate Cancer Survivor)

He listened more and jumped in when he thought it should go in a different direction. He didn't play the lead as far as facilitation went. Not sure if it was on purpose or just the way it worked out. (Prostate Cancer Survivor)

She sat back. I thought of her as a secondary facilitator. She was the listener. When Elaine wasn't there she came in and led the group well. (Ovarian Cancer Survivor)

Cancer Survivors as Facilitators

The ovarian group was co-facilitated by a breast cancer survivor and a caregiver who had not had cancer herself. Although most felt the facilitation was good, some indicated they would have preferred to have an ovarian cancer survivor facilitate and some felt that the non-cancer survivor facilitator did not relate well to their circumstances. Some comments included:

She wasn't knowledgeable about ovarian cancer, she didn't experience it. When it was common symptoms, she was very helpful. (Ovarian Cancer Survivor)

It would have been great to have an ovarian cancer survivor...I don't want to belittle them because they did a really good job. (Ovarian Cancer Survivor)

There was just some sense since she hadn't gone through it herself, that she was somewhere kind of different. (Ovarian Cancer Survivor)

Facilitators' Comments

Necessary Skills

The facilitators were asked to describe the skills they believed came to the fore when running the peer-led phone support groups. Given this is a new area of research it is no surprise one facilitator included "internal fortitude" and "self-starter" in their comments.

The facilitator has to be a person who is somewhat passionate about support groups and who has the internal fortitude to be a self-starter. Facilitators should be members of a support group for at least a year, be passionate about the idea of support groups, be a self starter, good listener, and have a sense of humour. They should also have the resources to get information about the disease that they can bring to the next meeting. (Prostate Group Facilitator)

Facilitator Training

In addition to skills and previous experience, the value of initial training and ongoing training was highlighted. All facilitators received training either through the Canadian Cancer Society or Wellspring and all felt that training was essential to a successful group. Some mentioned specific training for teleconferencing facilitation and keeping up-to-date with refresher courses.

I think training is important especially on the phone, things could really mess up if someone is negative, monopolizing the conversation, making it not very pleasant for the rest, it's extra stress on the facilitator. Continual training is important and certainly an initial training for group work because one on one is different than group dynamics. (Ovarian Group Facilitator)

I think to make sure that facilitators have had their (the Society's) refresher courses.....familiarize yourself with facilitating techniques. Make sure that they have a manual – Teleconference Support Group Facilitators Skills Review participants work book – 15 pages from the (Canadian) Cancer Society. For example, tips for teleconference calling (eight tips). Make sure it has been reviewed. (Breast Group Facilitator)

The Society handbook is a good jumping off point. The Society does updates every year so it's a good refresher. It should be reviewed with the facilitators by someone before starting, it doesn't have to be in person, that's definitely a good resource. (Ovarian Group Facilitator)

*The (Society's) facilitators' course talks about facilitating on the phone.
(Prostate Group Facilitator)*

Co-facilitation

The majority of facilitators felt that having a co-facilitator was helpful. One facilitator felt that it wasn't necessary, but suggested that the co-facilitation or participation could be used as a training ground.

Co-facilitation is not necessary if you have the right facilitator...there's no need. (Prostate Group Facilitator)

It's good to have co-facilitators to help problem solve. (Ovarian Group Facilitator)

The more that comes into the group the better. Two facilitators are better than one. (Ovarian Group Facilitator)

In each session, we should try to have a future facilitator listen or partially participate. If a facilitator hasn't been exposed to one of these meetings, it's like reinventing the wheel each time. I suggest that the secondary facilitator is there to learn and not necessarily participate. (Prostate Group Facilitator)

Group Process

Participants shared thoughts about meeting duration, frequency, and group size.

Duration

Generally facilitators were satisfied with 90 minutes duration. The prostate group felt the sessions could have been shorter at times, but this was by no means a major concern or complaint.

Frequency

There was general agreement among the breast cancer and prostate cancer participants, that weekly meetings suited their needs and schedules.

The ovarian cancer survivor group experienced both weekly and monthly meetings schedules. They found the schedule (first weekly for six weeks then monthly for six months) worked well. They believe there were more open and deeper discussions during the six months because they learned so much about each other in the initial six weeks. They believe they also made more of an effort to clear their calendar to make the monthly meetings because they were spaced further apart. The monthly meetings however, were not topic-based the way the meetings were during the weekly sessions. Some felt that they should have started the monthly meeting with a topic instead of just a check-in.

There was less structure the last six months, so it would have been nice to have had a topic to discuss part of the night. (Ovarian Cancer Survivor)

Sometimes we didn't get onto a topic and we got caught up with catching up. (Ovarian Cancer Survivor)

Six weeks or Six months

Half of the prostate group members felt that six weeks was fine, while others felt the sessions should extend beyond six weeks. No participant said that six weeks was too long.

If I had my choice, it should have gone longer than six weeks. The first few weeks people are trying to figure out their role, when to talk, what to do...the discussion points you can bring up. If it went on longer, we could have gotten into more detail. A lot of it was whizzing by. I would probably add two weeks and make it eight. (Prostate Cancer Survivor)

It would have been better if we could have carried on a bit longer. It's frustrating that the group didn't carry on. It takes a while to figure out how people operate. (Prostate Cancer Survivor)

The ovarian group was unanimous in agreeing that six months was too short and that the group should have been able to carry on indefinitely similar to a face-to-face drop-in support group.

For me it was too short. I could have used once a month for the next year. If a person goes through a crisis, being part of a support group there should be extra time to get together to have people rally around. (Ovarian Cancer Survivor)

Most support groups are ongoing. It would have been nice to continue on. (Ovarian Cancer Survivor)

Group Size

The prostate group was the largest of all groups run to date, with eight participants and two facilitators. The majority were comfortable with this size of group but felt a group should not be larger. Conversely, the breast cancer group had only three participants after one participant had to drop out. Although the breast cancer group thought their group could have been larger, they also felt that the small group size made the experience more personal and conducive to sharing. The ovarian cancer group initially started with six women during the weekly sessions, and then one woman left the group. During the six monthly sessions one woman had a conflict with her work schedule and was unable to attend four sessions. Most ovarian survivors felt that the group could have accommodated about six participants.

I thought at first it would be too large, but in the end ten was a good number because we had ten different experiences. If you had five or six, you might have missed out in a few of those really different experiences. I would have missed something. (Prostate Cancer Survivor)

Anything smaller wouldn't be as good. You might have been able to add one or two more, but not bigger than that. It gave people a chance to share. (Breast Cancer Survivor)

The size was just right to give us a chance to get into some good conversations. The numbers did change along the way and we could have had more. Six would have been very comfortable. With less, it's nice because we can talk a little bit more in depth. (Ovarian Cancer Survivor)

Peer-led Groups: Discussion

Overall, the three peer support groups were successfully implemented and demonstrated the ability of teleconference support groups to contribute effectively to meet the needs of cancer survivors. This project has expanded the learning from the OBCIEP Hub Project.

In particular, a great deal was learned from the prostate group that unfolded differently than any of the other groups to date. The men were clearly more information focused than emotional (e.g., requests to circulate information that they had or found to the other group members after certain sessions). In their weekly feedback, the men tended to talk more about the group process over the six sessions than the women (e.g., facilitation style, efficient ways to run meetings) and the men have been the only group so far to suggest that they would like an expert to be present for at least some of the sessions. The men were also more likely to mention how participation in their group aided decision-making processes (e.g., learning information that informed new decisions, information they wished they had known earlier).

Another interesting difference was related to the use of the term “information session” rather than “support group” in the recruitment efforts for the prostate group. A prostate group facilitator in British Columbia noted that many men do not respond to “support group” but would participate if they believed it was an information session. Following his suggestion the term support group was dropped from recruitment posters and reworked as discussion groups about “life after prostate cancer”. Ultimately this is what the prostate group ended up providing, information through personal experiences.

To summarize the gender differences observed through this work, the men demonstrated their support “exchange” in terms of seeking hard facts and between the facts they appeared to find emotional support. The men were more driven to problem-solve than listen and they need information to solve the problems. For example, one man was suffering from severe incontinence. He felt supported because the other men were giving him information and advice on what to do (e.g., kegel exercises) and where to seek help for his incontinence. An analogy is men standing around a car looking at the engine and each giving his advice on what to do. They appeared to bond through addressing issues not by acknowledging mutual emotional support. In contrast, women had information needs but were more likely to articulate perceived support in terms of emotions, bonding, closeness and connection with the other women.

Peer-led Groups: Lessons Learned and Ongoing Issues

The evaluation results are being used to improve the operation and value of each new peer-led support group. Issues identified in the Hub Project peer-led support groups emerged with these teleconference groups and were or are being addressed for future groups.

Recruitment

The recruitment process was difficult and lengthy for the prostate groups. Existing prostate cancer support groups were approached to assist in recruiting participants. Some groups responded to this request as if the study group was encroaching upon their territory. Some viewed the project as breast cancer focused due to the connection to OBCIEP and expressed reservations. There appeared to be a lack of trust with certain project partners.

Once appropriate contacts were made and several “champions” identified, the barriers were overcome and recruitment became easier.

Screening Participants

A tool needs to be developed to screen participants who may not be suited to online and/or teleconference group support. A referral process should be in place for both the Project Coordinator and facilitators to use in case of problems (e.g., ability to refer those needing more psychological support). A separate plan for each province may be required to ensure those in need have appropriate and adequate information to access services in their region.

Topic-driven Sessions

Requests for a predetermined list of topics that can guide discussions at each session are common. For example, the monthly ovarian cancer group suggested that topics could have been used to start their discussion time and then branch into a broader group discussion. This may avoid the entire session from becoming a social update.

Matching Participants

By coincidence the breast cancer group members were well matched by age, stage in life and cancer experiences. All of its members were dealing with survivorship issues, were not recently diagnosed nor were in treatment. Grouping participants with similar characteristics seemed to contribute to the success of this group despite the small numbers which is supported by comments from both the women and the facilitator.

However, there was a paradox about “matching” like participants in a group. At the outset, participants often expressed a preference to be grouped with people at a similar place in their lives and/or cancer journey. During the evaluations however, many expressed the benefits of diversity in the group as well as commonalities. The following quotes illustrate the contrast:

The range of participants in their personal cancer journeys—from undiagnosed to survivors with complications. It is a great mix of participants—excellent! I am looking forward to working with these guys (Prostate Cancer Survivor)

Being with all the same, so much I don't have to explain. (Breast Cancer Survivor)

Weekly Feedback

The prostate group had a disappointing start and this was reflected in the feedback from some of the participants. As noted, concerns were discussed with facilitators and changes made which resulted in an extremely successful group experience. In future the facilitators may be requested to encourage the participants to complete the weekly feedback questionnaires.

Optimum Number of Sessions

To date, no participant has said that six sessions is too long. Six sessions was proposed initially to fit with project timetables, budgets, and to ensure attendance (i.e., the fear being more meetings would not engage sustained attendance) but based on participants' comments, eight sessions may be preferable.

Coordination

These peer-led pilots reinforced the need for a dedicated project or peer-led group coordinator as noted in the OBCIEP Hub Project. At a minimum this role is needed to set-up the groups and monitor the group's progress with both the facilitator(s) and the participants. The individual in this role is the link between group members and the group facilitators and also serves to link both to additional information or support when required. The role can expand to marketing and promotion of the groups and liaison with partners who offer peer-led support through technology.

Collaborative Efforts

Other Canadian initiatives exist in the area of Internet-based or telephone-based support for cancer survivors. For example, "Caring Voices" is not peer-led, but provides a monthly online drop-in support group facilitated by a health professional operated from Princess Margaret Hospital (www.caringvoices.ca). Wellspring, based in Toronto, has piloted online information sessions. Interestingly both initiatives have struggled with attendance. "Caring Voices" do not reach their maximum of 10-15 participants each month (i.e., they have not had to turn people away) (personal communication, June 2008). In addition, "Sharing Strength.ca" (www.sharingstrength.ca) is a bilingual online resource with peer support through discussion forums and sharing stories and resources sponsored by AstraZeneca Canada. The Young Women with Breast Cancer support group have a website (www.breastcancernowwhat?.ca) that is linked with the professionally-led project based in British Columbia. Other national and provincial cancer support and information groups have expressed an interest in providing these types of services.

The benefits of partnering directly with some of these service providers is currently under consideration. There may be methods of creating efficiencies through linking into existing promotional vehicles to promote the availability of the service. The project team is reviewing other partnerships to pursue ongoing pilot cancer groups using technology.

Website Integration

As part of the OBCIEP Hub Project www.CancerSupportNetwork.ca was developed. The website provides a wealth of information and is used to advertise and provide an initial landing page for potential online participants. This website should be integrated into the teleconference option. By virtue of where the log-in page or online group is located, people are aware of the website but it should be used as a vehicle to promote both online and teleconference support group options. Access can be password protected for users to log in to a designated area of the site. A PDF version of the teleconference manual and other information that the facilitators and participants want to share can be posted on the protected area of the site. Participants can be encouraged to use the discussion board to keep in touch during and after the support group sessions.

Peer-led Groups: Lessons Learned and New Issues

Discussions about sustainability and advancing key areas of this work are ongoing. New issues emerged from this initiative to inform future groups and are reviewed below.

Screening Shared Information and Documentation

Guidelines and processes are needed to deal with written information that is shared with the group. Although a participant may tell the group about their experiences with an alternative therapy, sharing written documents adds an extra layer of complexity. The

liability of the hosting organization needs to be confirmed if facilitators share information that has not been reviewed and/or is not credible. Currently all written information must be distributed through the Project Coordinator for approval before being shared with the group participants.

Telephone versus Online Support Groups

The decision to have all groups meet via telephone for this initiative was driven mainly by the comfort level and preference of the facilitators. This preference was also expressed by the two individuals who participated in previous online groups before the teleconference group. For some, this technology may be difficult as they need to hear and/or see others and read body language to feel connected to others.

Hamilton-based Wellwood Resource Centre runs a well-attended facilitated drop-in online support group for teens whose families have been affected by cancer. Teens are already accustomed to online chatting through MSN Messenger and text messaging. They are accustomed to conveying their emotions with “emoticons” (happy/sad face icons) and are familiar with online chat “lingo”, e.g. “lol” for “laugh out loud”.

The cost of providing support via teleconference can become prohibitive. Therefore, the use of Voice Over Internet Protocol will be examined. VoIP allows people to make telephone calls using a broadband internet connection instead of a regular analog phone line at a fraction of the cost. “Skype” is an example. Participants who have access to a computer with a microphone and speakers can participate in a teleconference meeting free of charge. Those without a computer or the Internet can participate through Skype at a nominal cost.

Facilitator Training Strategy

Currently a training module is being developed for facilitators to facilitate support groups by teleconferencing and/or online. The manual developed for facilitators initially by the Hub Project will be expanded to include lessons on group facilitation along with tips to moderate discussions over the telephone and online.

Training new facilitators in these modalities by the introduction of co-facilitators as trainees is being explored. The trainee can listen in on groups to learn how different facilitators and groups interact. To date, most facilitators have done one-on-one phone support, or face-to-face groups, but have not led teleconference or online support groups. These are novel approaches to group facilitation and some may be hesitant to undertake a teleconference or online group of their own.

Along with a training module, the trainee co-facilitator idea has the potential to build the capacity of facilitators and may attract those who are interested but hesitant about the technology. Mentoring new facilitators by those experienced in a particular group is another option. This may involve a phone meeting beforehand and the ability to contact the mentor afterwards if they need any advice.

Evaluation

Who is attracted to peer-led versus professionally-led support? Are there certain groups that benefit more from professionally-led than peer-led? At the end of the day, are professional counsellors essential to address cancer survivors’ needs? To answer these types of questions, the initiative team began to develop a common evaluation framework for peer and professionally-led groups. This was created in collaboration with those piloting

professionally-led groups. Although there was agreement that aspects of process could be asked in the same way (e.g., duration, frequency of sessions), there was wide variation in outcome possibilities. The professionally-led group study team have a host of data collection tools available. In contrast, there is a dearth of valid tools to measure peer support program outcomes (e.g., Campbell et al., 2004). It was decided that logic models could remain separate for peer-led and professionally-led but that several statements could guide indicator and outcome selection and provide consistency. At this time, the agreed statements are as shown below.

Table 2.9 Agreed Statements to Guide Indicator and Outcome Selection

General Area	Statement
Beneficial Experience	Participants benefit from their group experience (subjectively and objectively).
Enhanced Access	Teleconference and online support interventions enable underserved populations to access information, support and therapeutic benefit.
Feasible	Teleconference and online support interventions are feasible to offer in community and cancer care settings.
Sustainable	Teleconference and online support interventions are sustainable endeavours.

Table 2.10 provides an overview of some of the perceived benefits plus areas for improvement that brings together learnings from the Hub Project peer-led support group work and this project.

Table 2.10 Summary of Findings: Peer-led Support Groups

Pros	Cons
Clear benefits reported (emotional and informational support)	Lack of visual cues
Majority would participate again and would recommend to others	Time zones can affect participation
Convenient and versatile	Small groups affected by absenteeism
Anonymous	Can take at least two sessions before participants feel comfortable with format
Sometimes the preferred option over face-to-face	Six sessions too short
Potential reach (provincial, national)	Recruitment slow to date
	Some reluctant to try the online option but less expensive to run

Although there are clear benefits for those participating, peer-led support group work still faces challenges in meeting the needs of cancer survivors, demonstrating effectiveness

and being sustainable. Continued efforts are essential and the following is a list of recommendations based on the present initiative.

Peer-led Groups: Recommendations

Recruitment

Different promotional campaigns should be tailored to men and women. As noted earlier, men do not respond to "support group" as well as "information session discussion". Efforts are required to target men to increase the number of male cancer survivors in the support or information groups as it has been demonstrated men find the groups beneficial.

Facilitator Preparation

It is important to continue sharing information about the participants with the facilitator. The information can be about their disease (date of diagnosis, stage, treatment, etc.), expectations, topics of interest, where they live, etc., assuming participants agree to share these details. It can help the facilitators establish a deeper understanding of the group members and engaging them in the support group process.

Integrate website into teleconference option

www.CancerSupportNetwork.ca should be promoted and modified to increase opportunities for all groups to use the information on the website and interact online with other group members through the use of the discussion board and open group chat rooms.

Number of Sessions

Because most participants wanted more than six sessions more sessions and various combinations of sessions should be considered. For example, six weekly sessions followed by four to six monthly meetings or four weekly sessions followed by four monthly or biweekly groups can be piloted. The schedule could be adjusted by asking participants and facilitators part way through the sessions about their preferences.

Topic-driven Sessions

Facilitators should have a list of topic areas produced from the suggestions that participants provide during their screening interview. In addition, facilitators should be encouraged to have some prepared topics or provide suggestions to the group.

Reminders

Email reminders should be sent the day before and the day of each meeting to keep all participants informed. Those who are having memory problems have expressed great appreciation for this assistance.

Time Zones

Every effort should be made to group participants regionally to minimize time zone differences of three to four hours.

Attendance

Innovative ideas—like the weekly email reminders—should be pursued to ensure regular participant attendance at meetings. As the optimum size of the teleconference and online groups is small, the group dynamic is affected if even one or two individuals regularly miss sessions.

Weekly Feedback

It is essential to encourage weekly feedback from the participants and facilitators. This helps to resolve early issues or problems when there is time to take action to remedy potential problems.

Professional Involvement

It is not unusual for face-to-face prostate groups to bring in professional speakers to various meetings. Balanced against possible costs and coordination, adding a few sessions with a physician, nurse, or dietitian could be arranged. Facilitators and participants could suggest topic areas and speakers.

Facilitator Training

New facilitators can be trained as co-facilitation “trainees” and/or a mentoring system with experienced facilitators. It is also important to develop partnerships with organizations that have a history of training peer-led facilitators such as the Canadian Cancer Society, Wellspring and Willow. This is particularly important if the organization hosting and organizing the peer-led groups does not have expertise in facilitator training.

Collaborative Efforts

Investigation of partnering with those undertaking similar peer support work should continue to maximize recruiting, web link, and information sharing efforts.

VoIP Options

Exploration of low-cost options of “telecommunicating” is worthwhile. Teleconferencing and long distance telephone connections can be expensive. Relatively new programs like “Skype” enable individuals to make cost-free calls over the Internet. Potentially organizations can offer computer-based verbal connections (VoIP—Voice over Internet Protocol) and provide peer-led support at no cost or relatively low cost. Other computer-based vehicles may become available and more widely used in the future.

Evaluation

A common evaluation framework between peer-led and professionally-led support groups should be pursued. The theoretical underpinnings of peer-led support should be explored. There are clear benefits to peer-led support groups yet the complex nature of support makes it difficult to define and measure. Possible investigations could include social comparison theory (Festinger, 1954), social support theory (Sarason and colleagues, 1983) or cancer threat appraisal. Future efforts may therefore illuminate the key aspects of peer-led support. Validated tools are needed where possible to make comparisons (Campbell et al., 2004).

Peer-led Groups: Next Steps

Recruitment

Recruitment has been ongoing for young women with breast cancer and for survivors of lung and colorectal cancer, and lesbian and bi-sexual women with cancer. There has been an expressed interest with young women, colorectal, lesbian and bi-sexual women and francophone women with ovarian cancer. Lung cancer has been the most difficult to recruit. This may be due in part to poor prognosis and inability to participate due to illness. Recruitment will continue for these groups and recruitment will also be aimed at longer

term survivors, caregivers, and general cancer groups. For example, a needs assessment may be required to determine the extent to which longer-term survivors need support and if group support is a method long-term survivors would find useful.

The most successful recruitment efforts have been through project partners, specifically for this project with Ovarian Cancer Canada whose recruitment strategy has utilized their national newsletter, website, notices in gynaecological oncology units and nurses and contacting survivors in their database. Interest has been expressed by the Canadian Prostate Cancer Network to provide online and teleconference support and to assist in further research initiatives. The Canadian Cancer Society – Ontario Division continues to be a strong partner in this endeavour in promoting the groups and recruiting trained group facilitators. Other cancer specific groups can also be approached to assist with recruitment.

Other avenues and innovative methods are needed to recruit both participants and facilitators. Recruitment posters and flyers posted in cancer centres, treatment centres, along with posts on cancer support group bulletin boards and on social networking sites like Facebook, MySpace and Nexopia. Project partners like the Canadian Cancer Society, Willow, Wellspring, and the other cancer support groups could post links to www.CancerSupportNetwork.ca regarding online and teleconference group options.

Telephone to Online

In addition to proposing a combination of weekly to monthly sessions, a “combination” group may be attempted, moving a teleconference group to an online environment after six weeks. The group members will have established some connection and may be more open to trying the online support together.

Facilitator Training

Well trained facilitators are essential to the success of each group. Training modules for those requiring additional skills and experience are being developed. Part of the training may include the supportive care learning kit for volunteers described in Chapter 4.

Partner Perspectives

Ongoing dialogue between those conducting the peer-led groups and interested organizations is the key to improving support for cancer survivors participating in group support and to ensuring the future of these groups as a support option.

Screening Tools

A new screening tool is needed for the first interview with potential peer-led participants. The importance of systematic screening is important to identify those in need of additional support. A first steps will be to adapt the screening interview currently used for the professionally-led groups.

Evaluation

Agreement has been reached on general statements that guide the future evaluation of peer-led and professionally-led work. Work has begun on selecting indicators and outcomes for future groups (see Table 2.11).

Table 2.11 Evaluation Components for Peer-led and Professionally-led Groups

Evaluation information	Peer-led	Common Features	Professionally-led
Inputs	<ul style="list-style-type: none"> ▪ Expectations ▪ Preferred format of group ▪ Desired topics 	<ul style="list-style-type: none"> ▪ Demographic information and cancer story (from screening interview/survey) ▪ Attraction to this type of support ▪ Experience with face-to-face support ▪ Computer skills 	Mental health history
Indicators/ Outputs	<ul style="list-style-type: none"> ▪ Weekly evaluation feedback (what is working, not working). ▪ “Week 3”: usefulness of manual? 	<ul style="list-style-type: none"> ▪ Feedback re any Technical issues. 	
Outcomes (after sessions completed)	<ul style="list-style-type: none"> ▪ Reports of experiences (e.g., reduced loneliness, connection, support, enhanced well-being, plus challenges) ▪ Reports about the facilitation. 	<ul style="list-style-type: none"> ▪ Aspects of group process (group size, duration of sessions, frequency of meetings etc) ▪ Expectations met? ▪ Was the support received what they ideally wanted? 	<ul style="list-style-type: none"> ▪ What worked (e.g., helpful? informative?) ▪ Usefulness of the workbook? ▪ What has changed? ▪ Expect anything to be different in the future as a result of participation?
Potential measures for future groups		<ul style="list-style-type: none"> ▪ POMS* ▪ Illness Intrusiveness Scale ▪ UCLA Loneliness** 	<ul style="list-style-type: none"> ▪ HADS (Anxiety, Depression screening tool) ▪ Brief COPE*** ▪ Group Experience Inventory

* POMS (Profile of Mood States) widely used measurement of general emotional disturbance, anxiety, confusion, depression, anger, fatigue.

** UCLA Loneliness used to assess subjective feelings of loneliness or social isolation.

*** Brief COPE assesses different coping dimensions, known as "Brief" as a longer version exists.

CHAPTER 3: NAVIGATION MANUAL

Navigation Manual: Overview

Navigating the cancer system is complex and challenging for patients, particularly at a time when they are making important decisions regarding treatment and care. Cancer patient navigator programs can increase access to cancer care and improve the coordination and continuity of care for patient and families. In 2007, the Cancer Journey Action Group held three cancer patient workshops to build a collaborative Canadian approach to planning an accelerated adaptation for navigation systems for cancer patients/survivors and their families.

The Cancer Journey Action Group of the Canadian Partnership Against Cancer was created to provide leadership to “rebalance the focus” of cancer care. The challenge is to help move the system from a predominantly tumour-centred focus to a patient-centred approach that would take into account the needs of the whole person (i.e., psychological, social, spiritual, informational, practical, emotional, and physical) during clinical care, treatment and beyond.

Cancer Patient Navigator programs have emerged as a specific strategy which aims to improve the cancer patient’s continuity of care and quality of life. The navigation workshops were developed particularly for those interested in understanding more about navigation and in implementing a program within their own jurisdiction.

Highlighting the experience in Québec and Nova Scotia, the workshops presented a planning framework for development of a patient navigation program. This included how to identify where the navigation model needs to focus and what information needs to be collected in order to evaluate and continuously improve navigation services. The specific objectives of the three Cancer Patient Navigation Workshops were to:

- Increase awareness and interest in navigation;
- Facilitate the planning and creation of new navigation programs by sharing resources, tools, care paths;
- Develop an action plan on how cancer patient navigation can best be implemented, enhanced and evaluated; and
- Build a repository of tools and best practices in navigation. The development of a navigation manual was planned as part of the repository.

Navigation Manual: Methods

The Workshops were held in conjunction with the Canadian Association of Provincial Cancer Agencies with funding support from the Public Health Agency of Canada and the Canadian Partnership Against Cancer.

The three Cancer Patient Navigation Workshops attracted in total approximately 315 participants: 85 in Winnipeg; 100 in Fredericton; and 130 in Edmonton. The participants included cancer survivors, nurses, social workers and other clinicians, provincial cancer

agency representatives, cancer information and support organizations like the Canadian Cancer Society, and policy and decision-makers.

Featuring the two successful models of navigation in Québec and Nova Scotia, the workshops presented a planning framework for development of a cancer patient navigation program. In addition, the workshops offered a forum for sharing experiences and information about developments and research in navigation across Canada. A Navigation Workshop proceedings report is being produced that will highlight the presentations and discuss examples of existing navigation programs in different settings.

Navigation Manual: Development

The writer, Stasey Tobin, attended all three Workshops and was assisted by an advisory group that included Dr. Margaret Fitch, Director of Oncology Nursing and Supportive Care, Odette Cancer Centre, Toronto, Ontario; Anne Plante, Infirmière en Soins Spécialisés en Oncologie Centre Intégré de Lutte Contre le Cancer de la Montérégie, Greenfield Park, Québec; and Sandra Cook, Program Manager, Patient Navigation and Surgical Oncology, Cancer Care Nova Scotia, Halifax, Nova Scotia.

The idea of synthesizing Canadian patient navigation experiences to produce a manual to assist in implementing or evaluating navigation programs, emerged from work done under the ReBalance Focus Action Group initially created as part of the Canadian Strategy for Cancer Control. The production of a document or guide was suggested as a method of identifying consultants who could be available to cancer agencies, provinces, researchers and/or others who are interested in using navigation models, and as a means providing information about implementing navigation programs. The consultation workshop process ensured broad input into the development of the navigation manual.

The primary purpose of the manual is to provide initial guidance for health care providers or administrators who are interested in developing a cancer patient navigation program using a bio-psychosocial approach. The objectives of this manual are to:

- Synthesize current knowledge to provide an understanding of professionally-led cancer patient navigation, delivered at the individual level, as a potential solution to patient needs;
- Outline the critical elements and key considerations for establishing and sustaining a professionally-led cancer patient navigation program; and
- Illustrate current models of cancer patient navigation.

Navigation Manual: Discussion

What Worked Well

The following contributed to the production of the manual:

- The Workshop website (www.cancerpatientnavigation.ca) background materials and the presentations at the Workshops together provided a solid basis of research and ongoing work in the field to date about navigation programs.

- Timely information, perspectives, and knowledge from those currently working on navigation programs were disseminated through the Workshop discussions and from direct contacts with experts currently working on navigation.
- Being able to work directly with experts in the field who have pioneered research in supportive care and program development and implementation of cancer care navigation programs in their own regions and nationally was a huge benefit.
- Sharing and collaboration enhanced the outcomes. For example, the Canadian Cancer Society - Ontario Division, shared the results of a recent patient navigation literature they had commissioned.

Challenges

Some of the challenges in completing the manual are listed below:

- The scarcity of information available on navigation program implementation and the variety of types of navigation programs made this uncharted territory to a certain extent. To develop the material required an iterative process which involved collaboration among group members.
- There was considerable confusion with the understanding of “navigation”. It was clear from the three workshops that "navigation" means many different things to different people. For some this is a form of case management whereas others see it as a new concept. In addition, many different forms of navigation are emerging (e.g. virtual, computer-based programs) that are contributing to the confusion.
- Competing schedules and major work responsibilities of advisory group members, located in Ontario, Quebec and Nova Scotia, presented challenges in scheduling teleconference and face-to-face meetings
- Time was limited at the Workshops to meet face-to-face with the advisory group and work on the manual
- The writer was hired prior to the Workshop dates, in retrospect they could have been hired sooner to liaise with the planning group and begin the research

Unanticipated Issues

The manual to date includes an introduction and a profile of one model, the professionally-led navigation program. The other models, the peer-led and virtual models will need to be profiled and included in later modules. The original vision of the navigation manual was a description of different types of programs and a description of what needs to be considered in deciding which program to implement. Through the course the Workshops and the initial development of the manual it became obvious the document needed to provide substantive information about the origin and existence of navigation programs. In addition, it was felt the manual needed to include support for navigators and decision-makers with information to promote the concept, write navigation proposals, program plans, etc.

The change in the manual concept necessitated a rewrite of the initial structure. Clarity was needed around the balance between technical and practical information for those who need information to act however enough substance and grounding had to be included to “sell” the idea to decision-makers.

Navigation Manual: Next Steps

The next steps to complete the production dissemination of the navigation manual include:

- Creating an evaluation survey to measure the manual's effectiveness.
- Promoting its availability to all cancer agencies and workshop participants.
- Identifying specific individuals who expressed an interest in starting a navigation program and interviewing them about the usefulness of the manual for their purposes. Revisions and/or additions to the manual will be made based on those comments.

The Cancer Journey Action Group of the Canadian Partnership Against Cancer is creating a consulting "SWAT" team to work with cancer treatment centres and other regional and provincial jurisdictions to implement navigation and distress screening programs. The team is developing a toolkit of resources about navigation, distress screening, standards and guidelines on psychosocial care, a diversity kit, and education and training tools. The navigation manual will become part of the toolkit of resources. A copy of the manual will be posted on the Ontario Breast Cancer Information Exchange website and in time on the website of the Canadian Partnership Against Cancer. The manual is appended to this report.

CHAPTER 4: LEARNING KIT FOR VOLUNTEERS

Volunteer Learning Kit: Overview

Without a clear understanding of the needs and issues of cancer patients and their families and how to address them, health care providers and volunteers are not in a position to assess, assist, or refer appropriately. Patients and survivors run the risk of needlessly suffering physical and psychosocial symptoms that with the right interventions could significantly reduce their physical, emotional, social and spiritual distress. Given that approximately 35% of cancer patients could benefit from interaction with a psychosocial expert and only about 10% are receiving referrals, questions need to be raised about how we can best help health care professionals and volunteers assess and refer individuals who could benefit from psychosocial intervention. What is needed is an initiative focused on volunteer psychosocial and supportive care education. The purpose of the volunteer learning kit was to produce and evaluate the effectiveness of a learning kit on psychosocial supportive care developed for volunteers.

The kit was designed to help volunteers learn about the psychosocial needs of cancer patients throughout their cancer journey and the types of assistance patients may find useful. Approaches for assessment, talking about difficult topics, and processes for screening for emotional distress and for referral to health professionals are included. It is hoped the project will increase the partnerships and intersectoral collaboration between patient/survivor groups and health care professions in aid of enhancing access and timely provision of psychosocial care, information and support.

Volunteer Learning Kit: Methods

The learning kit initiative was initiated by collating recent Canadian research on patient needs and psychosocial care (see *Works Consulted* in the Learning Kit Guidebook). A scan was conducted of other models of psychosocial volunteer training modules and also considered work on palliative care in Canada, at the national, provincial, and local levels, where volunteer programs are well developed. In the scan of models of psychosocial volunteer training, local programs that offered a component on psychosocial care were consulted. Questions were asked about their current training program(s), the psychosocial component(s) and the resources that they use.

The project consultants were able to attend a psychosocial training session at Princess Margaret Hospital, University Health Network in Toronto. Other informal consultations with other groups allowed the consultants to establish a sense of the content of their volunteer education programs. In the training sessions, new volunteers practice what they have learned through role-play, which also serves to familiarize them with the kinds of scenarios specific to the agency or organization.

The following is a list of individuals and resources consulted for the environmental scan of psychosocial training programs for volunteers:

- Jill Taylor-Brown, Cancer Care Manitoba
- Mary Elliott, Princess Margaret Hospital

- Jerold Rothstein, Chair, Task Group on Volunteer Best Practices and Quality Health Canada, Secretariat on Palliative and End-of-Life Care
- Maja Regehr, Healing Beyond the Body, Princess Margaret Hospital
- Holly Bradley, Wellspring
- Kathy Kwan, Canadian Cancer Society
- Palliative Care Volunteer Handbook, Cancer Care Nova Scotia
- Canadian Volunteer Model and other documents, Secretariat on Palliative and End-of-Life Care
- Canadian Hospice Palliative Care Association documents
- British Columbia Hospice Care Association documents
- PORT – Psychosocial Oncology Research Training
- Scan of recent Canadian research on psychosocial care

From the scan of Canadian research and consultations with individuals and agencies involved in psychosocial training, a prototype of a learning kit was developed on psychosocial/supportive care for volunteers entitled “Person-Centred Cancer Care: providing support through a psychosocial lens.” The core theme of the learning kit is the concept of person centred care defined by the Cancer Journey Action Group as “a high-quality, person-centred cancer system that meets the full range of needs of all Canadians and their families through all stages of life with cancer.” The learning kit addresses patient needs, supportive care, person-centred care; social inequalities, unequal access, and social factors affecting need and access; and available resources.

The learning kit consists of three parts:

- An introductory guidebook explaining the key components and goals of the training, and including a list of sources consulted.
- A lesson plan with accompanying slides and speaking notes, in PowerPoint. This includes a series of learning activities/exercises.
- A file of accompanying handouts for the exercises, resources for the participants to take away, and evaluation forms. The guide, presentation, presentation speaking notes, and handouts are appended to this report.

Volunteer Learning Kit: Findings

The programs examined consist of similar concepts and elements. Generally, the psychosocial components of the programs introduce the concept of patient-focused care, teach the volunteers about the wide range of needs of people and families living with cancer, and review basic communication skills (e.g. active listening, empathy).

One discovery was that volunteer training programs are very often produced locally, are kept “in-house” and are not available to the public. Some agencies and organizations are proprietary about these resources, which is understandable given the amount of time and resources that go into producing training programs. Other agencies have begun to market their training programs, and provide site-specific adaptations of a core program, which are offered to other agencies and organizations at a cost.

In the past three years in Toronto, several agencies and hospitals have created psychosocial components for their training programs. These recent initiatives formalize the supportive role of volunteers. The supportive aspect of volunteering in cancer care no doubt existed in the past, but in a less formalized way.

The consultants found, as did the other sites that have implemented their own programs, that there is little documentation of these practices. There is a need to know more about similar programs across Canada, better practices, and evaluation of these programs. Volunteer programs in palliative care may have well-established modules to share, but once again, the resources in this field are rarely made public. There is also a formidable amount of work by the Task Group on Volunteer Best Practices and Quality at the Health Canada Secretariat on Palliative and End-of-Life Care that could be relevant and applicable to the field of volunteering in psychosocial oncology.

Volunteer Learning Kit: Discussion

The design of a generalized learning tool on psychosocial issues, outside the context of a particular institution or organizational framework, presented certain challenges in itself. Volunteers may have very different roles and responsibilities in different settings – e.g., in some programs consulted, they perform hands-on patient counselling, while in others they may perform more functional or 'housekeeping' tasks. It is difficult to gauge the level of knowledge required by a volunteer about the individual patient and his/her life, as well as the particular skills required to assist individuals. Such requirements are also dependant on the institutional setting and its internal policies and procedures regarding the roles of volunteers. In light of these concerns, the learning kit has been designed as a general, evidence-based educational tool, to be adapted for different audiences as part of a broader training program. The aim is to provide volunteers with an overview of/introduction to the central tenets of patient-centred, supportive care, and psychosocial issues, not to instruct them explicitly in how to apply the knowledge—a task dependant on the individual organization's needs and policies.

Other challenges arose around timing and eliciting feedback about the development of the learning kit. In some cases, for whatever reasons, organizations did not respond to the consultant's request to learn more about their resources. In two cases, they attempted to set up focus groups to consult with experienced volunteers about the kit's development. At one site, the organization was too busy to participate in time for this phase of the project, and in the other, not enough participants signed up for the session. However, consultations are recommended with these groups in future as part of the broader evaluation plan. Accessing volunteer training resources requires time to build relationships and to create the conditions necessary for sharing materials. A national or provincial conference or meeting, or a dedicated session at an oncology conference could provide an opportunity for sharing programs and practices.

Volunteer Learning Kit: Next Steps

This project summary is accompanied by an evaluation framework and a dissemination plan to be implemented as next steps.

Evaluation Framework

The development of the prototype includes an evaluation framework that is intended to test the effectiveness of the learning kit. Using the Learning Kit Evaluation Form, we suggest that the learning kit be tested at evaluation workshops in six to ten settings. Depending on the budget available, the learning kit could be tested locally or nationally. In either case, it is important to ensure that the host institutions represent both hospital and community settings, large and small, rural and urban, and that they employ volunteers in a range of duties. Volunteers perform very different functions in these varied settings, and it is important to gather feedback from the range of sites that may want to implement the learning kit.

The evaluation will consist of a workshop with eight to ten participants where the full contents of the learning kit and the activities are reviewed. Along with volunteers-in-training, Volunteer Coordinators will be invited to attend the workshop. If Volunteer Coordinators do not wish to attend the workshop, they will be asked to review the learning kit on their own time. In either case, they will be asked to provide written feedback using the Volunteer Coordinator's Evaluation Form. The form contains the same questions as the general evaluation form, but also asks questions about adapting the learning kit for local use and integrating it with their existing volunteer training program. The evaluation forms will gather perspectives on the design, content and utility of the learning kit. Two facilitators are recommended to lead the evaluation workshop. One will conduct the workshop while the other will document the process of delivering the workshop, noting participant responses and looking for areas needing improvement. The provision of a meal, parking or transit costs, and honoraria in the form of cash or gift certificates for the participants are also recommended.

The participants at the Learning Kit evaluation workshops will also be asked to complete a Follow-Up Evaluation Form six to eight weeks after they begin their volunteer work. The form can be made available online or emailed to the participants to establish how the training has informed their practice.

After the testing in multiple sites and an analysis of the data collected from observations of the workshops and the three evaluation forms, the learning kit will need to be revised to arrive at a final version. Alternately, the evaluation activities may result in different findings based on type of institution, types of volunteer roles at that institution, or other factors, where several versions of the learning kit may be created for use in specific settings. The individual or team undertaking the evaluation of the learning kit should craft a careful approach to solicit the support of this initiative by agencies and organizations. It is, in one sense, the beginnings of the dissemination plan, and a good opportunity to encourage input on the final product in the hopes that these sites will take it up and use it in the future. For institutions that already have psychosocial training in place, this will be more challenging. But these sites are also very important to include because their volunteers and coordinators are experienced providers of psychosocial support, and their input is valuable. The offer to share the final product with the host institution is certainly one incentive to encourage participation.

Dissemination Plan

The learning kit will be made available online to agencies and organizations across the country. It will be published on OBCIEP's website at www.obciep.on.ca. The results will be circulated to all of OBCIEP's 36 stakeholder groups and over 60 corresponding members.

By publishing a summary in the OBCIEP newsletter, the information will reach over 4,000 individuals and organizations across Canada.

The learning kit will be central to the work of the Cancer Journey Action Group and will be eventually posted on its website as well, at www.partnershipagainstcancer. Other partner organizations in this project may post the kit and distribute it to their networks.

The Cancer Journey Action Group of the Canadian Partnership Against Cancer is creating a consulting “SWAT” team to work with cancer treatment centres and other regional and provincial jurisdictions to implement navigation and distress screening programs. The team is developing a toolkit of resources about navigation, distress screening, standards and guidelines on psychosocial care, a diversity kit, and education and training tools. The volunteer learning kit will become part of the toolkit of resources.

In addition, it has been recommended that the individual or team carrying out the dissemination plan should create a dissemination strategy targeting cancer institutions and agencies across the country, identifying the coordinator(s) of volunteer services and contacting them personally to inform them of the tool and discuss how it might be used in their organization. Contact should be made with provincial cancer organizations to encourage further dissemination. The document should be translated into French and similarly circulated in Québec.

As noted in the **Learning Kit Guidebook**, there are two important preconditions to implementing the kit that should be clearly communicated in any dissemination strategy. The first is that once adapted for local use, the learning kit is just one component of a program that should also cover training in:

- institutional policies and procedures
- the role of the volunteer (e.g. transportation, fundraising, peer support)
- ongoing training in communication (active listening, empathy, skill building)

The second precondition to implementing this tool is that the agency or organization should have the administrative resources necessary to manage and support volunteers trained in psychosocial care. Volunteers will need regular guidance from supervisors about information and referrals to assist patients, and they will need support and opportunities for debriefing.

Evaluation

A project to compile, review and evaluate programs across the country would also serve to move the field forward. In addition to knowing more about psychosocial training programs for volunteers, further work could engage in discussions about the implications of expanding volunteer roles and competencies to supportive care.

CONCLUSION

Every person diagnosed with cancer should have access to relevant information and support, no matter where they live in Canada. The overarching goal of this project was to enhance the supportive care of cancer patients and their family members by increasing access to psychosocial care, information and support. Four initiatives were undertaken to achieve this goal: professionally-led support groups, peer-led support groups, patient navigation manual and a learning kit for volunteers. The project evaluation is addressed in Appendix H and the resources are listed in Appendix I.

Professionally-led Support Groups

One professionally-led online support group (young women with breast cancer) was successfully completed and two others have concluded recently. Set-up, feasibility and jurisdictional issues within the Canadian context have taken a larger amount of time than first imagined. The initial findings however, support previous research that professionally-led online support groups do have the potential to provide effective psychosocial support and improve access. One outcome of the support groups (professionally-led and peer-led) is the decision to continue working together; to seek opportunities to build and share approaches and resources, and build a longer term vision. The common evaluation framework for example, leads to an organised approach, makes the best use of available resources and identifies priority areas for investigation.

Peer-led Support Groups

Three teleconference peer-led support groups were successfully completed and the reported benefits were similar to earlier peer-led support work. There were some new lessons learned including how men with prostate cancer approach and experience peer-led support groups. “Big picture” challenges include marketing and recruitment, adoption of online technology and outcome measurement. There needs to be more work to explore how peer support works. Using validated tools without inundating participants with surveys and using a common evaluation framework are steps to ensure that future endeavours are evidence-based and can be compared and reviewed as required.

Navigation Manual

The navigator role is an important aspect of supportive care. The manual proved to be a more complex endeavour than expected. Key informants were also the key planners and presenters at the cancer patient navigation workshops and had limited time to devote to the manual alone. It was also found that “navigation” can mean vastly different things to different people and as a result the scope of the manual changed during the project. Although this initiative clearly achieved its goal, the emphasis moved away from an overview of programs available and how they may be implemented to an implementation guide with background information to help promote the notion and application of navigation programs.

Learning Kit for Volunteers

The goal of the learning kit was to educate volunteers about the psychosocial needs of cancer patients and the various services available to them. Following an environmental scan, those experienced in psychosocial care were consulted about their programs, resources and training. One challenge was the timing of the initiative. Some organizations

did not have enough time to contribute to this learning kit and many ironically were occupied by developing or evaluating similar kits of their own. Work on these projects had either progressed beyond the point of collaboration or were tailored too specifically to the organization's needs to be modified. Working with a team of advisors this comprehensive learning kit is meant to be modified to many different users' needs. Dissemination and evaluation of the kit are next steps. Review of psychosocial training programs in general is important to move this area forward in Canada.

Final Note

Continued research and development is essential to being able to offer a menu of support options tailored to the needs of cancer patients, survivors, caregivers and families. The issues highlighted throughout the report will continue to be a focus of ongoing work and the next steps. Supportive environments, through management policy, organizational context and structures and resource allocations are also important.

The foundations of bridges and piloting and re-piloting models that can eventually be up-scaled to provide lasting improvements in supportive care for those affected by a cancer diagnosis are being created. Through alignment, coordination, education, service and resource development, the building blocks of a complete cancer psychosocial supportive model of care is being developed.

REFERENCES

Ashbury FD, Findley H, Reynolds B, & McKerracher K (1998). A Canadian survey of cancer patient experiences: Are their needs being met? *Journal of Pain and Symptom Management*, 6(5): 298-306.

British Columbia Cancer Agency – Sociobehavioural Research Centre. (2004). Improving access to psychosocial/supportive care: An investigation of the potential of technology. 44 pgs.

Bui, L., Last, L., Bradley, H., Law, C., Maier, B., & Smith, A. (2002). Interest and participation in support group programs among patients with colorectal cancer. *Cancer Nursing*, 25 (2), 150-157.

Campbell, H., Phaneuf, M., Deane, K. (2004). Cancer peer support programs—do they work? *Patient Education and Counselling*, 55, 3-15.

Canadian Cancer Society – Ontario Division (2005). Peer Support Program: “How are we doing?”, survey.

Canadian Cancer Statistics (2008). Accessed June 2008 from http://www.ncic.cancer.ca/vgn/images/portal/cit_86751114/14/35/195991821ncic_stats2004_en.pdf

Coreil, J., & Bebal, R. (1999). Man to man prostate cancer support groups. *Cancer Practice*, 7 (3), 122-129.

Festinger, L. (1964). A Theory of Social Comparison Processes. *Human Relations*, 7 (2), 117-140.

Fitch M.I. (2005). Needs of patients living with advanced disease. *Canadian Journal of Oncology Nursing*, 15(4): 230-235.

Fitch, M.I., & Abramson, T. (2007) Information needs of adolescents when a Mother is diagnosed with breast cancer. *Canadian Oncology Nursing Journal*, 17(1), 16-20.

Fitch M.i., & Allard, M.(2007) Perspectives of husbands of women with breast cancer: Information needs. *Canadian Oncology Nursing Journal* 17(2), 79-83.

Fitch, M., Nicoll, I., Keller-Olaman, S. (2007). Breast cancer dissemination strategies – Finding out what works. *Canadian Oncology Nursing Journal*, 17 (4), 206-211.

Goldsmith, D., McDermott, V., & Alexander, S. (2000). Helpful, Supportive and Sensitive: Measuring the Evaluation of Enacted Social Support in Personal Relationships. *Journal of Social and Personal Relationships*, 17 (3), 369-391.

Helgeson, V., Cohen, S., Schulz, R., & Yasko, J. (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19: 107.

Hill, M. (2003). How support groups work: exploring the role of support groups as a community-based resource for cancer patients in northern Ontario. PhD, Vanderbilt University, p 212.

Hupcey, J. (1998). Clarifying the social support theory-research linkage. *Journal of Advanced Nursing*, 27 (6), 1231-1241.

Krisjanson L, & Ashcroft T (1994). The family's cancer journey: a literature review. *Cancer Nursing*, 17, 1-17.

Ontario Breast Cancer Information Exchange Partnership, (May 2008). "Breast Cancer Information and Support—Preferences and Resource Development", final report.

Ontario Breast Cancer Information Exchange Partnership, (October 2005). "Phase I: Needs Assessment Report, Breast Cancer Information and Support—Preferences and Resource Development".

Ontario Breast Cancer Information Exchange Partnership, (December 2004). "Dissemination Strategies for Breast Cancer Information—Finding out What Works".

Ross, L., Kohler, C., Grimley, D., Green, B., & Anderson-Lewis, C. (2007). Toward a model of prostate cancer information seeking: Identifying salient behavioral and normative beliefs among African American men. *Health Education and Behavior*, 34, 422-440.

Sarason IG, Levine HM, Basham RB, et al. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality & Social Psychology*, 44, 127-139.

Thaxton, L., Emshoff, J., & Guessous, O. (2005). Prostate cancer support groups: A literature review. *Journal of Psychosocial Oncology*, 23 (1), 25-40.

www.breastcancernowwhat.com, website