
Expanding Breast Cancer Networks in Atlantic Canada to Include Women with Gynecological Cancers

Patsy Beattie Huggan



ACKNOWLEDGEMENTS

The Atlantic Centre of Excellence would like to extend appreciation to the four Atlantic Breast Cancer Networks and their partner organizations for their participation in this research.

We would also like to thank Patsy Beattie Huggan for her work on this project, including assisting with the research design, conducting the stakeholder consultations and developing the report.

Dr. Barbara Clow, Executive Director, Atlantic Centre of Excellence for Women's Health (ACEWH), Dalhousie University served as Principal Investigator for the project.

This project was supported by a financial contribution from the Women's Health Contribution Program, Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

BACKGROUND

In 2008, the Atlantic Centre of Excellence for Women's Health, with funding from the Canadian Partnership Against Cancer and in partnership with the breast cancer networks in the four Atlantic provinces, conducted a profile of support services available to women in the region, focusing on services tailored to those with breast, cervical, ovarian and uterine cancers. This research revealed that support services are much needed throughout the region and that those best served by existing services were women with breast cancer. Few support services targeted women with cervical, ovarian and uterine cancers (Clow, Hemmens & Mason, 2008).

Several studies have shown that various types of informational and psychosocial supports for women facing a cancer diagnosis provide valuable contributions to women's overall health and well-being, as well as to their overall understanding of the disease (Ahlberg and Nordner, 2006; Bilodeau and Degner, 1996; Von Ah, Kang and Carpenter, 2007; Danhauer, Rutherford, Hurt, Gentry, Lovato, McQuellon 2007). Ahlberg and Nordner, (2006) found in their study of women with ovarian cancer that support groups provided welcome and beneficial opportunities to share experiences and exchange information with other women going through a similar experience. Danhauer and colleagues (2007) found that young women undergoing treatment for breast cancer benefitted emotionally from contact with other young female breast cancer survivors. Extending beyond the scope of emotional and social supports, Bilodeau and Degner (1996) explored the link between women's choices around breast cancer care and treatment and the places in which they gathered information. Their study found that generally women prefer information regarding treatment and care to come from personal, one-on-one sources, such as those found in informal peer support groups.

During consultations for the profile, the researchers learned about a model and precedent for expansion established by the Manitoba Breast Cancer Network and encountered both interest in and concern about expanding services to better meet the needs of women with cervical, ovarian and uterine cancers. Breast cancer networks in some provinces have already begun to plan for and proceed with this type of expansion while others have elected not to expand in this way at this time.

Following up on these consultations and the previous research project, this study was designed to provide new insight into the desirability and feasibility of expanding existing breast cancer networks to include women with cervical, ovarian and uterine cancers. It was proposed that comparison of the different trajectories of the four breast cancer networks would further enable identification of barriers to and opportunities for expansion, both of which may affect perceptions of desirability and feasibility.

It is of interest that three of the Atlantic breast cancer networks were launched when funding for the Atlantic Breast Cancer Information Project, which had been supported by the Canadian Breast Cancer

Initiative (CBCI) since 1993, came to an end. At that time, funding for breast cancer information delivery was transitioned to the Community Capacity Building Component (CCBC) of the CBCI, and the provinces were encouraged to form provincial networks and apply for funding through this source. The purpose of these networks was build capacity to promote awareness, education and support related to breast cancer.

The first project of the three newly launched networks was developing information kits for those newly diagnosed with breast cancer. Newfoundland & Labrador, PEI and New Brunswick modeled their kits on the Pink Rose which had been launched a few years earlier in Nova Scotia and delivered through the breast screening program in that province. Although funding for a network was offered to Nova Scotia, it was not until a few years later that a network was established. Funding for community capacity building projects lead by the networks has continued through the CCBC program of the Public Health Agency of Canada. All the Atlantic networks have representation on Public Health Agency of Canada's Community Capacity Building Committee. Funding for the information kits is provided to each network by the Canadian Breast Cancer Foundation. Much of the activity of the provincial networks centers on distribution of information kits, other than in Nova Scotia where the kit for newly diagnosed women continues to be distributed by the breast screening program. The efforts to expand these networks to embrace other women's cancers are at different levels depending on the province, the maturity of the organization, and the sense of readiness.

Comparing and contrasting the decisions and actions of the four breast cancer networks in Atlantic Canada with respect to expanding services to include women with gynecological cancers, provides insights on the ways in which organizational history and stability, perceptions of the need for and potential impact of expansion, and the experiences of expansion are linked to local and organizational views on the desirability and feasibility of expanding breast cancer networks. This knowledge has deepened our understanding of conditions and attitudes that make expansion desirable and/or feasible as well as those that make it risky, unwelcome or impossible. This findings of the research will help Atlantic Canadian and other Breast Cancer Networks to better assess the desirability and feasibility of expanding breast cancer networks to include women living with gynecological cancers and it will provide perspective a deeper understanding of expansion for organizations that fund and support the Breast Cancer Networks, such as the Canadian Cancer Society, the Canadian Breast Cancer Foundation, the Canadian Breast Cancer Network, and the Canadian Partnership Against Cancer.

METHODS

Research Design and Ethics

The research design was created in September 2009 by the Principle Investigator from ACEWH, the consultant hired to help carry out the work, the Canadian Breast Cancer Network and other regional affiliates. The research design is qualitative in nature using an inductive analytical framework exemplified by grounded theory. Data was to be collected from a staff and partners of the four Atlantic Breast Cancer Networks - New Brunswick Breast Cancer Information Partnership Inc., PEI Breast Cancer Information Partnership, Breast Cancer Action Nova Scotia and its Cancer Network, and the Lupin Project of Newfoundland & Labrador.

Data was to be collected from 8-12 individuals via questionnaire and interview. Each representative from Atlantic breast cancer networks was to be initially contacted by email and invited to take part in the research. If they expressed interest, they would be contacted by telephone to set up a time for the interview and discuss the consent process. A copy of the consent would then be sent out via email for review and signing. During the telephone discussion, each representative would also be asked to send a pre-written invitation to other potential organizations who they feel could contribute to the research asking them if they would be interested in taking part and if they are could they please contact ACEWH. Those organizations that contact ACEWH will be provided with an overview of the research and consent process and sent a copy of the consent form for signing. An interview time was also be set up. The interviews were intended to take place either in person or via the telephone and will be no longer than one and half hours. All interviews were to be audio-taped (with permission) and transcribed.

The interview was designed to collect information on each organizations desirability and feasibility of expanding the Atlantic breast cancer networks to include other female gynecological cancers. Prior to the interview, a questionnaire was to be sent to the representative from each of the four Atlantic Breast Cancer Networks via email for completion. The questionnaire was designed to collect organizational information such as organizational structure, mandate, funding levels and sources, in-kind supports, and programs.

All data collected through this process was to be subjected to substantive coding to identify the main perspectives, opinions and concerns of the participants. Selective coding will then be used to cluster data into themes about feasibility and desirability of expanding the breast cancer networks to include other female gynaecological cancers and thematic analysis will lead to preliminary explanation for organizational decisions on what direction to take.

The research design was submitted to the Dalhousie University Health Sciences Research Ethics Board in November 2009. It was approved in December 2009.

Research Activities

An external consultant from The Quaich Inc., a consulting firm from Prince Edward Island with extensive research experience, was hired to conduct the project research. During a national meeting of breast cancer networks organized by the Canadian Breast Cancer Network, the consultant had the opportunity to connect with members of each of the provincial breast cancer networks in Atlantic Canada and introduce them to the project. As part of her discussion with these individuals she asked for suggestions for other organizations in their province to invite to take part in the research. The suggestions were brought back to the Principal Investigator at ACEWH and after much discussion, the decision was made to pre-select an organization or individual from each province to ensure the best information possible would be collected.

As per the protocols outlined in the Ethics Review application, the consultant then followed up with the lead person from each Network by sending them an email outlining the purpose of the study, an overview of how the interview and questionnaire would unfold, and a request to invite an individual from a pre-determined organization in their province who could contribute to the research. The partner organization selected for Nova Scotia was the Canadian Breast Cancer Foundation, Atlantic Chapter, for PEI the Director of Chronic Disease Prevention, for New Brunswick Ovarian Cancer Canada, Atlantic Region, and in Newfoundland & Labrador Cervical Screening Program at Western Regional Health. It was determined that partners in the health system and health charity organizations would provide a comprehensive range of perspectives.

Attached to each email were the consent form and a formal invitation. The formal invitation provided more detail on the research and why they were invited to take part in the study and an overview of the research team, their qualifications and a telephone number to call for more information. All representatives from the Networks agreed to take part in the research and forwarded their signed consent forms to the consultant. Signed consent forms were returned to the interviewees by fax and post. The consultant then sent out the organization questionnaire to the four provincial networks and contacted each representative to set up interview times.

Due to limited response from the organizations asked by the Network partners to take part in the research, the consultant sent out a personal email to each explaining the research project, extending a formal invitation to participate and a copy of the consent form. All responded to her email and were followed up by telephone to discuss the consent process and set up an interview time.

All eight invitees returned their signed consent form and completed the interview by telephone. At each interview the telephone script included in the ethics review application was read and interviewees were asked for their consent to record the interview and to use direct quotes in the final report. While all

agreed, two individuals requested that they review the final report before they would approve direct quotes. Two individuals also asked that their honorarium be donated to their provincial networks. Each interview last approximately one hour. All interview questions were reviewed prior to beginning the dialogue in order to provide interviewees with the scope of the interview. Interview questions were those included in the research protocol:

- a) Should the breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers? Why or why not?
- b) Can the breast cancer networks be expanded to include services for women living with cervical, ovarian and uterine cancers? Why or why not?
- c) If the breast cancer network in your province were to be expanded in this way, what resources would be needed?

Each interview was transcribed by the ACEWH and reviewed by the consultant. Unfortunately, during one interview, the tape recorder did not work so only the field notes from the consultant were available for analysis. The consultant then sent each interviewee their transcribed notes for review to ensure that they were comfortable with what they had shared and that it did not compromise their confidentiality. All interviewees indicated they were comfortable with their interview findings, and the data was analyzed.

The original plan was to use a substantive coding process but due to the nature of the data collected, manual coding was conducted instead and the data was analyzed for common themes about feasibility and desirability of expanding the breast cancer networks to include other female gynaecological cancers. The thematic analysis will lead to preliminary explanation for organizational decisions and the potential for future decisions to expand the networks. The coding and analysis were carried out by the consultant. As for the questionnaires completed by the Networks, they were also analyzed by the consultant.

FINDINGS

Profile of the Atlantic Networks

The profile of each of the Atlantic breast cancer networks was compiled from information gathered through the organizational questionnaires and interviews. This information is placed in context by a search of the Internet for historical information on the origin of the networks, as familiarity with this information assists in understanding the provincial similarities and differences that exist in terms of these organizations and places the interview findings in context.

Origins of the Atlantic provincial networks

In June 1998, the Canadian Breast Cancer Initiative (CBCI) Phase II was renewed with objectives to reduce the incidence of breast cancer, reduce mortality, improve the quality of life of those affected by breast cancer and strengthen their support networks. The announcement of a Community Capacity Component of the Initiative to assist Canadian Breast Cancer Networks become key players at the national level and to support the capacity of groups to participate in the breast cancer field meant some activities funded in Phase 1 (1993-1998) were terminated and a new direction initiated. In the Atlantic Region it meant that the Atlantic Breast Cancer Information Project came to an end and provincial networks were created. PEI, New Brunswick and Newfoundland & Labrador formed their networks in 1998 as informal partnerships. Three years later, the Nova Scotia network was initiated in 2001 as a project of Breast Cancer Action Nova Scotia. While all networks have historically received a portion of their funding from the Community Capacity Building Component of CBCI and participate at the national level in the national Community Capacity Building Committee, which operates with the National Collaboration Model (Appendix A), each network reflects its own provincial context. The four networks collaborated on the Atlantic Invitational Think Tank on Women's Cancers held in Halifax, March 2008.

Prince Edward Island Breast Cancer Information Partnership (PEI BCIP) was formed in 1998.

The Partnership's mission is to ensure that easily accessible, reliable and up to date information about early detection treatment and follow-up care of breast cancer is available to those affected by breast cancer on PEI. The mission and mandate were reviewed by the Partnership in a facilitated session in January 2010 as part of a review of the governance structure. The newly drafted terms of reference state that "shared leadership of PEI BCIP is drawn from the Partnership and must be representative of the Partnership's interests, mission and goals. The roles shall be limited to terms of 2 years: Co-Chairs representing different organizations/groups will communicate meeting times, facilitate meetings, etc; Secretary will record and distribute the meeting minutes; Treasurer will provide a financial update at each meeting; Community Capacity Building Committee (CCBC) Representative will represent the Partnership on the national Community Capacity Building Committee."

There is no advisory committee or board of directors, no paid staff, and 8 volunteers who represent various organizations such as the Breast Screening Program, PEI Support Group, Canadian Nurses in Oncology (PEI), Canadian Breast Cancer Network, Atlantic (PEI Board Member), Canadian Breast Cancer Foundation (PEI Board Member), Canadian Cancer Society, Reach to Recovery Program, Dept. of Health.

PEI BCIP meets monthly to 1) share information about developments, issues and resources related to breast cancer and 2) develop joint strategies to meet the information and support needs of women at various stages of their breast cancer experience.

The primary service is the development and distribution of information kits to women newly diagnosed with breast cancer. The *Sunflower Seeds of Knowledge* kits are sent with positive biopsy results from the

lab to the surgeon/family physician who provides the kit at time of diagnosis. PEI BCIP also strives to increase awareness about breast cancer and PEI BCIP services through community presentations, earned media opportunities and a website developed in 2008.

Sources of support to carry out the work of the PEI BCIP work are largely provided through project funding from Health Canada/ Public Health Agency of Canada and the Canadian Breast Cancer Foundation, Atlantic Chapter. Additional funding comes from various community events, e.g. yards sales, golf tournaments. The Canadian Cancer Society, PEI Division provides meeting space, and some administrative tasks in-kind, e.g. photocopying, etc. The volunteer base is the key source of support – with 50% of membership being breast cancer survivors.

Funding is not predictable and is dependent on having resources to write proposals and meeting criteria of funding agencies. The only secure support at this time is the Canadian Cancer Society, PEI Division's contribution of in-kind resources. The Partnership looks for funding opportunities on a continual but informal basis. The grants from the above agencies have provided the main resources.

The New Brunswick Breast Cancer Information Partnership, Inc. (NB BCIP) was established in 1998 as an informal partnership, incorporated in 2002. Its mandate is to enhance education, awareness and support for citizens of New Brunswick affected by a diagnosis of Breast cancer. A decision to expand the mandate to include gynecological cancers was made in 2009. The name of the organization and the mission will be changed in March 2010 to reflect expansion to Breast and Gynecological cancers. The Partnership is currently managing a project funded by the Cancer Program of the Public Health Agency of Canada entitled *Developing an Integration Model of Women's Cancers into the NBBCIP, Inc. within a Bilingual Framework*.

The NB BCIP is managed by a Board of Directors with a bilingual chair and members representing the organizations such as the Canadian Cancer Society, and Health Zones of New Brunswick. All members report to the Board of Directors. Much activity of this Partnership depends of grant funding. The project manager manages all grants and reports to the Board of Directors. Grant work involves sub-committees who report to the Project Manager.

There are currently 20 volunteers involved in the Partnership with approximately ten members doing the majority of the work. NB BCIP employs a part time (.5 FTE) kit coordinator who stores and distributes the kits from a central location and a book keeper one day per month.

The primary service offered by the NB BCIP is maintenance of the *Purple Violet Kit*; other activities include awareness events, representation on Public Health Agency of Canada's Community Capacity

Building Committee and most recently development of a bilingual model to enhance the breast cancer partnership to a breast and gynecological cancer network.

Sources of support to carry out the work of the NB BCIP work are largely provided through project funding from Health Canada/ Public Health Agency of Canada and the Canadian Breast Cancer Foundation, Atlantic Chapter. The volunteer base is the key source of support – with 50% of membership being breast cancer survivors. In addition the Partnership has benefited by ongoing consultation with The Quaich Inc. through paid and in-kind contributions to project work.

There is no guarantee for stable financial resources from any previously noted funders and funding is dependent on having resources to write proposals and meeting criteria of funding agencies. On average four hours of volunteer time per month are allocated to seeking new resources to continue the work. Work is currently underway to ensure sustainability of the work of the Partnership by linking volunteer programs more closely with the health regions personnel throughout the province of New Brunswick.

The Lupin Partnership of Newfoundland and Labrador was created in 1998 as the Purple Lupin Partnership. Its mandate was to empower women with breast cancer so they are more informed and can have increased participation in their treatment options. Over time, as distribution of the Purple Lupin kits had become centralized membership commitment decreased. In 2005, the Partnership was reactivated and the structure and mandate renewed. In 2008 a decision was made to expand to other women’s cancers. The name of the organization was changed to the Lupin Partnership with an expanded mandate “to empower women with cancer so they are more informed and can have increased participation in their treatment options”. The Partnership is currently managing a project funded by the Cancer Program of PHAC entitled *Peer Navigation for Women’s Cancers* which is developing training for peer navigators in Newfoundland & Labrador to provide information and referrals for those diagnosed with breast and women’s cancers.

The Lupin Partnership is managed by two co-chairs and representatives from each region of the province who represent Regional Networks. There is no paid staff. The Partnership relies on volunteers to do the work of:

- Getting the Peer Navigator program started – resources are the first step
- Providing *Purple Lupin* information kits to all people diagnosed with breast cancer
- Developing information kits for women with the gynecological cancers
- Managing the retreat for women with cancer
- Advocating for enhanced services for people with lymphedema issues

Sources of support to carry out the work of the Lupin Partnership are largely provided through project funding from Health Canada/ Public Health Agency of Canada and the Canadian Breast Cancer

Foundation, Atlantic Chapter which funds the *Purple Lupin* kits. The volunteer base is the key source of support.

While funding is secure during the life of a project, there is no guarantee for stable financial resources from any previously noted funders. Funding is dependent on having resources to write proposals and meeting criteria of funding agencies. Time committed to searching for new money varies, some months many and others a few depending upon the need. Work is currently underway to ensure sustainability of the work of the Lupin Partnership by linking volunteer programs more closely with primary health care personnel throughout the NL health system.

Breast Cancer Network Nova Scotia was founded in December 2001, when key stakeholders aligned with breast cancer in Nova Scotia saw creating a network as a solution to learning who else was involved and what was being done throughout the province. The building of the network was taken on as a project by Breast Cancer Action Nova Scotia and is currently funded by the CBCI Community Capacity Building Fund. There are several members of the network from all nine District Health Authorities (DHA) in Nova Scotia. The Network experienced a lack of funding in 2004, and had all but disappeared until funding was provided through the Canadian Breast Cancer Network that revitalized momentum. Funding was subsequently resumed. The Network is “project-focused” and its current project is piloting an adolescent breast health program through the CBCI Community Capacity Building Fund managed by PHAC. Funding is relatively secure due to the longstanding efforts of its parent organization, Breast Cancer Action Nova Scotia.

Breast Cancer Action Nova Scotia (BCANS) was formed in 1996 as a survivor driven group that voices the unique concerns of people living with breast cancer. BCANS’ mandate is to change the legacy of breast cancer through networking, support, education and research. BCANS has maintained the same mandate since its inception. The mandate still serves for the organization.

BCANS is managed by a Board of Directors with four elected officers: Chair, Vice-Chair, Secretary, Treasurer and Directors. The Board meets the 4th Tuesday of each month (except August). Work is allocated to committees, each with a Chair. The Committee Chair reports to the Board at each meeting. An AGM takes place in April of each year. Volunteers make up the framework of BCANS. Volunteers serve on the Board, work on committees, help staff the office, and act as provincial representatives and advisory members. BCANS has approximately 30 volunteers.

There is currently one part time staff member, the Communications Director for BCANS who also serves as the Network Coordinator for the Breast Cancer Network Nova Scotia Project. Plans are to soon hire a part-time book keeper. Staff report to the Board with direct supervision provided by the Chair of the Board.

BCANS offers peer-to-peer support, a resource library, education talks (at the resource centre), two reputable websites (www.bca.ns.ca & www.abcn.ca), maintains an online resource directory and events calendar, conducts public education through presentations and booth displays, hosts guest speaker engagements at large in the community, addresses medical and nursing students, acts as a navigation contact for patients, advocates for patient care improvements, coordinates the Library Projects, and runs an annual fundraising dinner, dance and auction (as well as ongoing fundraising activities).

Sources of support to carry out the work of the BCANS comes from private donations, monies from 3rd party events, raffle tickets, and fundraising from the annual dinner, dance & auction. BCANS also has a key partnership with Lawtons Drugs. Other funding comes through grant monies for specific project work such with the Public Health Agency of Canada, the Dartmouth Community Health Board, the IWK Health Centre, Cancer Care Nova Scotia, and the Canadian Breast Cancer Foundation-Atlantic Chapter, etc.

BCANS has been able to maintain a strong intake from donations and fundraising. The partnership with Lawtons Drugs is secure. As well, BCANS has a strong reputation in securing project grants and implementing successful projects.

A Fundraising Committee is in place that works with fund raising opportunities and reports monthly. The time allocated to this activity varies. Grant opportunities have varies deadlines depending on the source.

Profile of Partner Affiliates

The **Canadian Cancer Society, PEI Division** (CCS PEI) located in Charlottetown works to control cancer, by focusing their work in 5 areas:

- Research
- Advocacy
- Prevention
- Information
- Support

From 1993-1998 CCS PEI was host of the Atlantic Breast Cancer Information Project. Since that time the CCS PEI has served as the host and administrative partner for the PEI Breast Cancer Information Partnership.

The Canadian Breast Cancer Foundation is the leading national volunteer-based organization in Canada dedicated to creating a future without breast cancer. Established in 1986 by a dedicated group of volunteers, the Foundation works collaboratively to fund, support and advocate for:

- Relevant and innovative research,
- Meaningful education and awareness programs,
- Early diagnosis and effective treatment, and
- And a positive quality of life for those living with breast cancer.

The Canadian Breast Cancer Foundation, Atlantic Chapter has provided funding for the Atlantic Evaluation of Breast Cancer Information Kits (2002), and since that time for the information kits provided to women in each province at the point of diagnosis. Board members represent the organization on some provincial networks. The Executive Director is on the Advisory Committee of the Nova Scotia Breast Cancer Network's adolescent breast health project.

Ovarian Cancer Canada is a registered Canadian charitable organization whose mission is to overcome ovarian cancer, providing leadership by:

- Supporting women living with the disease and their families
- Raising awareness in the general public and with health care professionals
- Funding research to develop early detection techniques, improved treatment and, ultimately, a cure

The Atlantic Regional Office has been actively involved in developing partnerships in the Region. The manager serves as a member of the executive for the New Brunswick Breast and Women's Partnership.

Cervical Screening Initiatives Program – Newfoundland and Labrador

The Cervical Screening Initiatives Program is a provincial program collaborating with regional health authorities, non-governmental organizations, health professionals and individuals to improve the coordination of cervical screening and increase participation in screening for women of Newfoundland and Labrador. The CSI Program was launched in 2003 with a gradual implementation across geographic regions and infrastructure. Each of the health regions has an advisory committee established to provide insight and direction for regional issues as they pertain to the ongoing implementation of the Cervical Screening Program. This multidisciplinary group is guided by a set of terms of reference, and work plan that will enable coordination of strategic directions that involve multiple disciplines, community organizations the front line health care providers and educators.

Unlike breast and ovarian cancers, there is no charitable organization representing this group. The Provincial Director is a resource to the Lupin Partnership of Newfoundland and Labrador in the provision of information on cervical cancer.

Interviews

Interviews were conducted with eight individuals identified as meeting the criteria for the research project (two in each province affiliated with the provincial network), following a consistent format in asking the questions:

- a) Should the breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers? Why or why not?
- b) Can the breast cancer networks be expanded to include services for women living with cervical, ovarian and uterine cancers? Why or why not?
- c) If the breast cancer network in your province were to be expanded in this way, what resources would be needed?

The transcribed interviews were later reviewed for recurring themes and insights. Transcripts were reviewed by type of organization the interviewee represented and then compared for consistency of theme. The first group were those who are directly involved in leading the Partnerships, the second group were those involved with departments of health and the third group was those who represented national charities. Where interviewees represented both the Partnerships and their employer, their responses were reported in the relevant perspective. The results of the analysis are reported by question, followed by a discussion of insights and observations.

Should the breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers? Why or why not?

Provincial Networks: Representatives of provincial networks were consistent in saying 'yes' to this question, although two of those interviewed had qualifications on this based on the readiness of their organizations.

When asked the question "why?" two provinces that had already expanded their services indicated their decision was based on a moral responsibility.

- *"...breast cancer has many, many resources. It has very sophisticated support services set up. And we have a moral responsibility to share that with other cancers"*
- *"there was consensus and total agreement that we should move forward because it was the right thing to do"*

Other reasons were that it “made sense” from a practical and financial perspective to share resources and avoid duplication.

Interviewees elaborated on the fact that evidence now exists that other women with other cancers are underserved and do not know where to find resources.

- *“The results of the profile that Dr. Clow presented at the meeting clearly stated the need. I think that was a big thing, we now had strong evidence within Atlantic Canada that these women need some help.”*

While cancer sites may be different there are many factors shared by those with breast cancer and other women’s cancers.

- *“So you don’t have to recreate the wheel...the emotions that I experience, the fear, the uncertainty, the where does this take me, all of those types of things are the same types of emotions. And where do I go looking for the kind of support that I need to deal with that? Those again are all the same.”*
- *“A lot of things they go through are similar...but again its different too...we would like to see women going through gynaecological cancers being as supported as we are... they are like our sisters but they are cousins right now”*

Women with other cancers have already been approaching breast cancer networks and patient navigators for support.

- *“The need has been identified through that experience with the navigators....many of the navigators knew of other survivors of the other cancers and the need became very apparent.”*

Breast cancer with its large number of survivors, has been successful in having an impact on improving access to information, support and delivery of services. Distribution channels, support links and relationships with the health system are well established. There is a view that others can benefit if we share lessons learned and build on the success of breast cancer networks.

- *“The lessons that we’ve learned through the Partnership should be good for everyone. Why not spread the good things that have happened throughout that?”*

The opportunity to become acquainted with the evidence during the Atlantic Invitational Think Tank in 2008, build on best practice, and to apply for funding from the Public Health Agency, are factors that have mobilized interest in Atlantic Canada.

- *“I think the encouragement of PHAC...the understanding that Manitoba had done it and it was working...and I think also the Atlantic meeting that we had held, that we saw the buy-in right across the Atlantic.”*

When asked “why not”, two organizations that have not expanded their networks replied that organizational readiness is a factor.

- *“This is a whole new area again so it’s just a matter of getting some help. And especially where, like I say, we are just newly developing ourselves”*
- *“I don’t think they (the Partnership) are ready just yet. I think they have a desire but I don’t think they are ready until they get their own clear mandate once again and know the direction they are going into...you really have to do your own housework before you invite somebody else in.”*

There was also a sense that there is now pressure to consider it in future plans.

- *“And there seemed to be a little bit of panic that all of a sudden we had to go that way. But you know we were assured by PHAC that that is not the case...But the pressure comes also from other provinces already doing work on breast and women’s cancers. And so they are doing it and so you are able to see it is possible. It seems like there’s an obligation that you have to follow suit.”*

One group expressed concern that their group is reliant on volunteers and not connected enough with the system at this point. She would also be concerned about demand on resources to take on and sustain the work.

- *“We really don’t have the resources to put into it at this point. And that primarily means peoplepower.”*

Other concerns addressed such factors as lack of knowledge about other cancers when one’s expertise and experience is breast cancer; the experience that people want to focus on their own cancer and might not be interested or able to reach out to others; and that change in organizational identity and branding would be required. Energy to maintain momentum to carry out developmental work was also mentioned as critical.

- *“How do we expand when our heads have been around breast cancer for so long and all we know is breast cancer?”*

- *Most people are action people. ...their goal is to give me a task and I will complete it. Whereas to work on a developmental model is somewhat different. So there have been some challenges.”*
- *“To build the partnership with Pathology and all of those things we already have within the breast cancer partnership would take energy because that creates more work for other people.”*

It appears from the interviews that factors such as the fear of the impact and organizational readiness could better be positioned if the question was “why not now?” Given the concern about taking on too much too quickly, there was a suggestion that there would be a it might be best to start small and plan for expansion over a two year period.

Health Car System: In the interviews with two individuals who work in provincial health care systems, there the answers to the question “should the networks expand?” ranged from “Yes” to “absolutely”.

They saw benefit in building on the success of breast cancer networks and their linkages to the health system.

- *“I think broadly that it makes a lot of sense for it to be expanded to include cervical, ovarian and uterine. I think that women with breast cancer have benefitted tremendously from such projects as the Seeds of Knowledge and similar projects around Atlantic Canada. That project was well received. It was well thought out, and the linkages with the lab, surgeons, family physicians and other healthcare providers were well considered, and background information collected to make sure it was successful.”*

The view they expressed is that an expanded network would reduce duplication, meet the current gaps in service for these underserved women and serve as a consistent resource to assist those who do not know where to go for information and support. Both people interviewed saw opportunity through an expanded network of reaching out to more people regarding cervical cancer in particular. Currently there is a stigma associated with anything specific to this site.

- *“There is a general reluctance with cervical cancer to establish themselves publically. There is an element of shame and it is not ‘sexy’ like breast cancer.*
- *“We have not been able to move the marker on screening for cervical cancer....I hope that in expansion of these networks into other areas, we can enhance early detection and screening”*

They also recognized the potential to expand this model to other cancers.

- *“PEI has a 30% higher rate of colorectal cancer among women than the national average....I would hope that while we need to start somewhere, at the end of the day, we can expand to other cancers as well”*

When asked the question “why not?”, the strain on resources was identified as a key concern. Would the expansion take away from work already committed to by the networks? How will it impact on the health system? And how will it impact volunteers?

- *“So a cautionary piece would be what is the impact on resources? ...who from the department would be involved in that?...how do we make it happen without taxing people who already have a heavy workload?”*

Charities: In interviews with representatives of three national charities affiliated with the networks, there was also the answer “Yes” to the question of “Should the networks expand”. One person cautioned that the actual decision to expand or not really rests with the networks. But all indicated that it “made sense.” There is a feeling that women with other cancers are underserved and in need of greater support.

- *“Because I think they are an under-served group in the sense that...I mean we deal with all cancers and we hear very little from these groups. We don’t know what is going on with these groups.”*
- *“It really just makes sense to sort of piggyback on what has already happened and what is already going well to serve more women.”*
- *“Where I sit as a woman, it makes perfect sense...but I don’t feel anyone is in a position to say this should or should not happen. I think we have to first and foremost go back to the women who are affected. Not the healthcare workers, not the charities like ourselves but the women who are affected and find out what they want in their network.”*

The national organizations represented indicate that they will not be changing their focus and will continue to work on behalf of their constituents. Their branding has resulted in gains in funds for research and programming. In the breast cancer area in particular there is an anticipation that with earlier detection there will be many more breast cancer survivors needing support, and therefore a greater responsibility to stay focused on their respective mandates.

Two organizations indicated that expansion could add value to the work of their organizations by assisting them to reach people who are difficult to reach.

- *“We have communication with the folks on an individual basis with these types of cancers but we don’t as a group per se...If there was a group of folks with ovarian cancer then there’s a touch point for us. If there’s new information that we’ve come across, new research or something that we need to get out to those folks then we have an avenue for doing that. Right now as an individual basis, we don’t.”*

- *“...really our main thing is to have women find out about us and to pass along our support guide....And so partnering together is not really re-doing what we are doing. It’s sort of taking something we do in a small part and partnering with another group who can help us do that better”*

The national charities see a role in continuing to fund the printing of information, books and resources that focus on their particular mandate and partner with the networks for distribution.

- *“We certainly will still provide support for breast cancer as we always have through the networks.”*

When asked “why not expand”, responses were based on some uncertainty as to where the idea to expand came from. In the world of health charities is the experience that people like to focus on their own cancer. There are shared but distinct issues.

There was a sense of caution that expansion could have implications for the volunteer base for the networks. Breast cancer volunteers may not be able to give support outside their own experience. As well, low survival rates of those with ovarian cancer and the stigma associated with cervical cancer may limit the volunteer base drawn from the other cancers to participate in the networks. Will this place unrealistic expectations on breast cancer survivors?

- *“How does someone who has just been diagnosed with stage one breast cancer, whose prognosis is probably excellent, talk with somebody who has just been diagnosed with stage three or four ovarian, whose prognosis is 5 years at best?”*

One solution was to reframe the imbalance of volunteers as ‘Women helping Women’.

- *So I do think predominantly we are going to see breast cancer survivors. But I don’t think that is a bad thing. I think there’s a lot of passion behind it. And its women helping women. So I still think that they’ll be the prominent volunteers...I ‘m not sure we would see as many people from the cervical cancer community even though their survival rates are much higher than ovarian or uterine for that matter.”*

In summary...it is the opinion of interviewees that the networks should take on the expansion of the networks. The reasons cited were that moral responsibility and that it makes sense. Factors that support the expansion of services are the evidence of need, the success of best practice in expanding to meet the need as demonstrated in Manitoba, the established experience of the networks to build on the success of breast cancer and funding opportunities

Factors that need to be considered are those of organizational readiness, demand on resources, workload, the size and ability of the volunteer base, the engagement of the health system in working with the networks, organizational leadership and ongoing relationships with funding organizations.

Can the breast cancer networks be expanded to include services for women living with cervical, ovarian and uterine cancers? Why or why not?

Partnerships: In response to this question all interviewees answered “Yes” but two who had not taken this route also stressed that their main question is “How?”

Within the provinces that expanded their networks funding made it possible to expand. However, in the interview they stressed that the context outside the funding opportunities drove their networks in that direction. Support groups and patient navigators were already providing support for women with other cancers, as were retreats and other programming but without the additional knowledge regarding the resources specific to that individual’s cancer. There was a demand for service that could not be ignored. Distribution channels already existed, the networks were established, and there was enthusiasm and commitment to move forward. They stress that both funding, volunteer commitment and a clear step by step plan make it possible. They stressed that accountability and sustainability are important factors to build into the plan.

When asked “why not?” the two provinces who had expanded could see no reason why not. However, both provinces that had not yet expanded again identified organizational readiness as a challenge. PEI recently lost its long time chair to cancer and is currently regrouping. It sees value in examining lessons learned about effective organizations and taking steps to revitalize the Partnership before considering expansion, establishing a clear mandate, leadership, and decision-making mechanisms. For Nova Scotia, concern re organizational capacity is a concern. Currently they are focused on a project to develop educational packages to promote adolescent breast health. While they do provide educational materials for women diagnosed with other cancers, they question the impact on the identity of their network where their expertise has been breast cancer for so long; and whether they would they have credibility with other cancer organizations. They also raise concerns about retaining volunteers if too much is expected of them.

- *“It’s hard to get volunteers...We have people who put in a lot of hours but do they want to do something like this? Probably not. You know, you would have to get someone totally crazy.”*

They also had concerns about continued funding from breast cancer related funders and where they would find stakeholders from other cancers.

- *“I think there is some angst, to be very honest, with Canadian Breast Cancer Foundation.”*

They also stated that they felt somewhat ambivalent as while both felt it would be good to be organizationally ready, they both agreed that a new focus often revitalizes.

- *“I don’t know if they are ready at this point. But sometime something new is good too. So there are both sides of looking at it.”*

Interestingly, the New Brunswick Breast Cancer Information Partnership had been at a point of collapse when the decision was made to expand. The expansion revitalized the partnership and attracted new partners such as the Canadian Cancer Society.

- *“Since the expansion we found that CCS is very much more interested and willing to participate. And I think another good example is NB Cancer Network. I heard lately that they are very willing to be actively involved in this partnership. This is a big turn-around which definitely supports sustainability of the Partnership itself”*

Health Care Systems: In response to the question as to whether the networks can expand, again the answer was “Yes” from both interviewees. Expansion was viewed as an opportunity to pool the volunteer base and to work more collaboratively with the health system. It was stressed that will be important to learn from the experience of building the breast cancer networks and to take a staged approach, building a team and integrating all personnel affected by the process. Both interviewees were optimistic that with the right supports, the network model could be expanded to all cancers.

- *“I think we need a staged approach and build on the successes.”*

When asked “Why not” the responses were that expansion and partnership building requires time, energy and funding, is complicated with so many parallel networks and cannot done on backs of volunteers. One person was strong in her belief that the health system needs to recognize the importance of this work and provide staff to support volunteers.

- *“This could happen on the backs of volunteers because of personal commitment. If it is needed, then the health system should take it on.”*

Charities: Again the response to this question was yes! The demand is there - people want support closer to home. And there are key volunteers who are passionate and committed. Working with the networks can provide a platform to use in working with other provinces.

- *“So I think it’s really innovative and just a really thought provoking idea to start it now and get that boat rolling because that seems to be where we are heading on a national front. And for NB for example, to do it on their level really says a lot about their volunteers.”*

Being strategic is important and organizations need to watch for opportunities to make an impact.

- *“We don’t have a lot of staff. So when we see a project the place where we see it moving the fastest, that is where we tend to move towards....”*

When asked “Why not”, potential conflict with fundraising was raised as was the reality of the smaller volunteer base from the other cancers, and the potential impact on women with other cancers if programming is focused on the largest group of survivors.

- *“So even as you move forward to the NB partnership, how does that affect out other work? Our walk in September raises quite a bit of money for other things as well as that. So it’s definitely a fine line we walk. But it all comes with growing.”*
- *“We had people complaining to us from the ovarian side, and rightly so, that it was too much about breast cancer. Well yes it was, because 90% of the women in the room were affected by breast cancer. So I am just wondering, I’m not sure this is a mix.”*

Summary

It was the overall opinion of those interviewed that the networks can expand, that there is a solid foundation of lessons learned, committed volunteers, funding, and a context where there is a demand for expanded service. There are opportunities for increased collaboration with the health system and a pooling of the volunteer base. The expansion could add value to national organizations which want to reach those with gynecological cancers. For those who have expanded they indicate that funding, volunteer commitment and a clear step by step plan have made it possible. For those who have experience with building the breast cancer networks advise that it would be wise to learn from that experience, and look for best practice in each province for building a team, creating a staged approach with a clear strategic direction.

Challenges identified are organizational readiness and capacity, concern that funding will not continue, fear that with expansion the identity and credibility of the organization may be threatened, that demand on the health system might be too much, that the volunteer base may not be strong enough, that women with other cancers may feel marginalized by not being the majority and that the expansion not take place on the back of volunteers, particularly breast cancer survivors. A solution to the latter

challenge was suggested – that of creating and promoting a campaign of ‘women helping women’ which might overcome some of the hurdles and draw on women’s capacities to give to each other.

If the breast cancer network in your province were to be expanded in this way, what resources would be needed?

Partnerships: As can well be imagined, those involved in the partnerships identified the longest list of resources required for expansion. These included:

- *Vision*
- *Leadership*
- *Clarity and transparency of mandate and processes - Clear organizational mandate, terms of reference and guidelines for partner decision making; clear guidelines and expectations for volunteers; clear identity and purpose for the public, i.e. branding, logo*
- *Partnerships - representation from other cancers*
- *Partnership agreements*
- *National connection - share resources, avoid duplication, collaboration on tools, contributes to sustainability*
- *Credible educational resources; people to find resources; distribution channels*
- *Paid coordinator; funding*
- *Accessible local support for women;*
- *Committed volunteer base; volunteer support; training*
- *Support from funder as a partner; flexibility*
- *System integration and plan for sustainability.*

The resources required most frequently are highlighted. It was cautioned that without these there will be competition and conflict; increased demands on administration and questions about who will pay and who will lead?

Health Care System: The interviewees identified a shorter but complementary list of resources.

- *Person with good epidemiology background to determine profile*
- *Partnerships; partner contributions*
- *Funding ; Staffing*
- *Stakeholder buy-in*
- *Passion; Dedicated people - team effort*
- *Champion*
- *People to review and compile information; Distribution system*
- *Political engagement; public awareness; media interest*
- *National connections*
- *Build on lessons learned in staged plan.*

Charities: From the three national charities there was advice on resources that included:

- Strong survivor base
- Funding; Paid personnel
- Partnerships, voice from each community
- Strategic plan, logic model, evaluation
- Training
- Clear identity - clarity of roles, branding, logo.

Summary

Resources identified were slightly different depending on the focus and experience of those interviewed, but the importance of leadership, commitment, clear identity, partnerships, funding, paid personnel, strategic plan, support for volunteers and a solid volunteer base, educational resources, training, and national connections cannot be missed. There are a number of resources that have been identified in retrospect that can benefit anyone intending to take this path. Most important is communication between partners, funders and stakeholders to secure the ongoing commitment to this direction.

Key Messages

At the end of each interview, the interviewer posed the question – “What message would you like to give to someone who is planning to take on expansion of the networks?” One of the most surprising responses came in a quote from someone who is enthusiastically involved in the expansion. Her immediate message was:

- *“Don’t do it!”*

When I asked for further explanation, I understood her comment more fully. She described the number of volunteer hours she had invested in the project, how it was the first time their organization had managed such a large budget and that the reporting challenges were incredibly time consuming. Her major advice for anyone thinking of taking on the work would be to:

- Look for funding for paid coordinator up front
- Promote a community capacity approach as it multiplies the impact on people’s lives
- Plan for sustainability from the onset, integrating the work with health and other systems
- Recognize the potential for other cancers.

Advice provided by others was:

- Start with research as a resource
- Give volunteers a manageable workload

- Continue collaboration with other provinces (NB BCIP and the Lupin Partnership have been collaborating this year on training manuals for community contacts/peer navigators, and development of a 'gyne' information kit.)
- Do it right!
 - *We have to do it right! My big point here today is that whatever we do, we have to do it right and we have to take the time to the proper research and collaborate.*
- Be Practical!
 - *"I think we really have to think about the practical aspects of it. Pie in the sky, yes, it would be great for all of this to happen. But there really has to be a process in place to make it happen. And I think there will be lots of bumps in the road. And as long as we are prepared for that, because resources themselves are an issue and it takes time and money....And you need community input in the sense that you need survivor input as well as those within the system and organizations....in my opinion, it has much more body, much more clout and it has much more everything if it has good community representation, if it's coming from everyone."*

CONCLUSION

Results from the interviews with eight key informants regarding the desirability and feasibility of expanding the Atlantic breast cancer networks to embrace other women's cancers have provided insight into the structure, resources and direction of the respective networks. While there was a unanimously positive response that the networks should and can expand, there was also recognition that this is a decision of each network and that there are many variables to consider.

For networks in New Brunswick and Newfoundland & Labrador, which are in the process of expanding, there is an appreciation of the moral responsibility that motivated them to apply for funding and begin to adapt the Manitoba Model to their context. With evidence, knowledge of best practice, opportunity for funding and committed volunteers, they are breaking new ground in Atlantic Canada, collaborating with each other and documenting lessons learned for others and themselves as they go forward.

- *And it's a big learning curve but I really do feel it's going to be something the rest of the Canadian provinces are going to look at and say how did that work, how did that bilingual project work? Which is a major thing in a bilingual country."*

Nova Scotia and PEI are of the opinion that it makes sense to do to expand to embrace other cancers but are taking a cautious approach, still unclear how they will manage it. Both networks indicate that they are not organizationally ready to expand to other cancers at the moment, and will benefit from networks Lessons learned from the other Atlantic provinces, the wisdom of those interviewed for this project in considering their decisions, and consultation with local communities will provide informed answers so they “can do it right”.

One of the key concerns is the demand on resources particularly since efforts to date have been dependent on volunteers. Another is the concern that the current volunteer base may dwindle if increasing expectations are made of breast cancer survivors, especially if they do not feel either knowledgeable of or interested in supporting women with other cancers. A strong recommendation from all those interviewed is that funding for a paid position is important. Clarity of purpose, support for volunteers, training, and a plan for sustainability are also essential.

To be fully successful, there will need to be ongoing communication between provincial government departments and the partnerships to see mutual benefit in sharing resources to build capacity in communities to meet the needs of underserved populations. There is also a need for clarity in communications with charities and the public as to what the new direction means for access to information and resources.

One charity not represented in the interview process is the Canadian Breast Cancer Network (CBCN), the organization which serves as the national voice of breast cancer survivors. Board members of CBCN sit on some of the provincial networks and therefore their perspectives are important to the work of the networks. During this research project CBCN was hosting regional consultations on breast and women’s cancers (2009-2010), creating an awareness of the similarities and differences and the partners involved in each region. The reports of these consultations have just been made public and would be of interest to review in light of the findings of this research.

REFERENCES

Ahlberg, K & A. Nordner (2006). "The importance of participation in support groups for women with ovarian cancer." *Oncology Nursing Forum* 33(4): 53-61.

Bilodeau, BA & LF. Degner (1996). "Informational needs, sources of information, and decisional roles in women with breast cancer." *Oncology Nursing Forum* 23(4): 691-696.

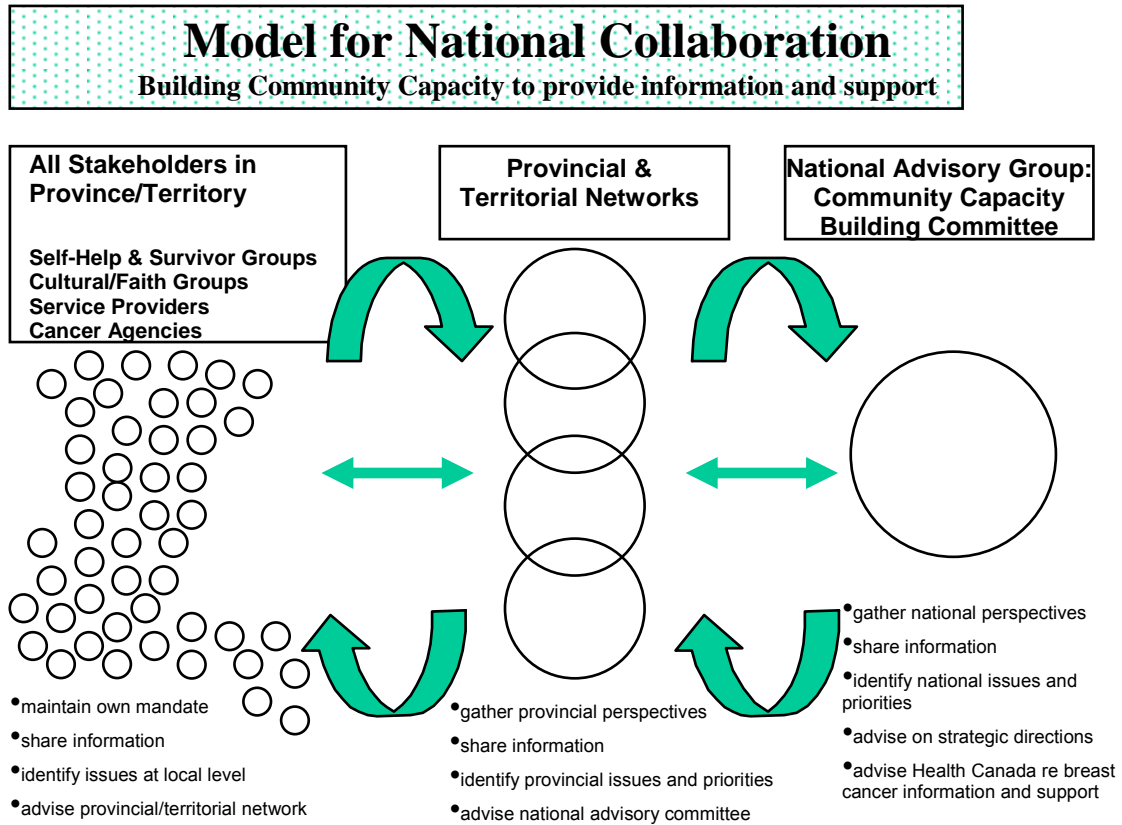
Clow, B; E Hemmens & S. Mason (2008). "Where do we go from here: Support services for women with breast, cervical, ovarian and uterine cancers." Halifax: Atlantic Centre of Excellence for Women's Health.

Danhauer SC; CA Rutherford; G Hurt; S Gentry; J Lovato & RP McQuellon (2007). "Providing psychosocial support for young women with breast cancer: findings from a wellness-based community collaboration." *Journal of Psychosocial Oncology* 25(1): 103-120.

Von Ah D; D Kang & JS Carpenter (2007). "Stress, optimism, and social support: impact on immune responses in breast cancer." *Research in Nursing & Health* 30(1): 72-83.

Appendix A

National Collaboration Model



Model for National Collaboration

Background

Representatives from agencies/groups across Canada, interested in breast cancer information and support, met in Toronto on June 21-22, 1998. Their discussions about issues regarding breast cancer information dissemination and support for breast cancer survivors emphasized the need to work collaboratively at local, provincial and national levels. Working collaboratively would facilitate the exchange of information, the building of partnerships and avoid duplication.

A working group was formed to explore potential models for collaboration. The original working group held two conference calls in the fall of 1998. The mandate of the group and the process for conducting the work was discussed during the initial call. During the second call, a variety of models were discussed

and a selection made of one model that would be presented to the larger group at its meeting in November 1998.

The model was supported in principle during the discussion at the November meeting. However, the working group was asked to develop a more detailed description of the model. This work was completed in the spring of 1999.

This document describes the model for collaboration between local, regional, provincial/territorial and national breast cancer groups. Collaboration is required to enhance the delivery of information and the provision of support to breast cancer survivors and their care providers.

Goal of the Collaboration

The ultimate goal for collaboration among local, provincial and national stakeholders in breast cancer is to improve access to breast cancer information and the provision of support for breast cancer survivors and their care providers across Canada.

Benefits of Collaboration

There are several benefits to organizations/agencies working collaboratively:

- learn from one another (about successes and challenges)
- maximize the use of resources
- minimize duplication and overlap
- build on existing structures and processes (capacity)
- identify actual gaps in service delivery

Principles for Collaboration

The following operating principles need to be followed within the collaboration:

- be open to a diversity of viewpoints
- be survivor-focussed or consumer-client-focussed
- practice inclusivity/include survivors and professionals, institutions, community-based and volunteer-based agencies
- work on issues across the spectrum of cancer experiences (i.e., prevention, diagnosis, treatment, supportive care, rehabilitation, recurrence, palliative care, survivorship)

Elements of the Collaboration Model

The model for collaboration builds upon local organizations and provincial networks, calling for their development where they do not exist. Representatives from local organizations form provincial networks. In turn, representatives from networks form a national advisory committee, the Community Capacity Building Committee. The ultimate aim of the collaboration is to improve access to breast cancer information and the provision of support for breast cancer survivors and their care providers.

Local Stakeholders Local stakeholders refers to the wide array of agencies, organizations and groups who provide a local or regional breast cancer service or who are interested in breast cancer issues. This could include self-help and survivor groups, cultural and faith groups, service provider organizations and cancer agencies or programs. The service may be focused on information dissemination, on providing support or a combination of the two activities. Each group maintains its own mission and service delivery process. The local stakeholder group may include community-based agencies (non-profit and volunteer) and institutionally-based agencies.

Within the collaborative model, all local stakeholders would be responsible for “coming together” to form the foundation for regional/provincial networks. They would be expected to participate as members of the provincial network in the following roles:

- share information with one another about the services they provide
- identify issues related to breast cancer information and support based on their own experiences with consumers/clients/women
- communicate pertinent issues concerning breast cancer information and support to the provincial/territorial network
- receive and disseminate information from the provincial/territorial network to own members/staff
- provide advice on resolving issues to the provincial/territorial network
- agree to work within the spirit of collaboration with other local stakeholders to improve the provision of information and support about breast cancer
- select the representative to attend the provincial/territorial network

Provincial/Territorial Networks

The provincial/territorial network is a group of local/regional/provincial stakeholders who have agreed to work together with a provincial or territorial perspective. The participating stakeholders must hold a perspective regarding the entire province/territory, not simply their own respective group. The network provides an avenue for the members to communicate and work together. The actual format of the provincial/territorial network needs to be decided by the respective stakeholders in each province/territory.

At the provincial/territorial network level, the following roles and responsibilities will exist:

- the representative from the provincial/territorial network to attend the Community Capacity Building Committee
- identification of gaps, issues and strengths regarding breast cancer information and support which have provincial/territorial applicability
- actively seek the provincial viewpoint on an on-going basis
- communicate any pertinent information on issues to the Community Capacity Building Committee and/or local stakeholders
- receive and disseminate information from the Community Capacity Building Committee
- assist member organizations to resolve issues and fill gaps regarding information dissemination and provision of support
- provide advice about resolving issues to the Community Capacity Building Committee share information with other provincial/territorial breast cancer networks

