

**Virtual Community Feasibility Project:**  
**Building Capacity for Tomorrow**  
**Final Report**

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**Submitted by**

**Ontario Breast Cancer Information Exchange Partnership**

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## **VIRTUAL COMMUNITY FEASIBILITY PROJECT: BUILDING CAPACITY FOR TOMORROW**

*. . . I believe our collective vision is and should be to provide the Canadian population with as many opportunities as possible to play an active role in their own health, the health of others and the health system. Canadians should be equal partners in making decisions affecting their health...better decision-making through information will lead to improved health, greater access to services, better quality care and reduced costs for all Canadians. Most importantly, it will play a key role in creating a system that is accountable to the public and integrated around their needs.*

Alan Mymark, Oct, 1998

*Digitize your information. Make it available so that it can be found easily. Allow as many people to reach it as possible. Tell anyone and everyone "where" it is. World Wide Web URLs (page addresses) and FTP path names are the business cards of the future. Do not send your information to people when you feel the need; allow people to get it for themselves at any time. Information alone will not make progress any faster; it is availability that matters; because once it can be found, and absorbed, it can be applied.*

[www.interweb-tech.com/nsmnet/docs/march.htm](http://www.interweb-tech.com/nsmnet/docs/march.htm)

### **INTRODUCTION**

In 1999, 18,700 women in Canada were diagnosed with breast cancer and 5400 died of their disease (NCIC, 1999). The impact of breast cancer upon a woman, and her family and friends, can be profound, creating a myriad of challenges (Ferrel et al, 1998; Pelusi, 1997; Hilton, 1996). If they are to cope successfully with these challenges, access to information about breast cancer and support are critical. To make informed decisions about breast cancer, women, their families and friends, and health care providers, all need easy access to the right information provided in a helpful format at the time it is needed, regardless of where one lives. The value of talking with other breast cancer survivors has also been documented (Gray et al., 1997). The benefits include sharing information, sharing a common experience, and realizing that there are others available to help them. They do not have to make the journey by themselves.

Canadian women are outspoken about the inadequacies surrounding the availability and access to breast cancer information and support (Alliance of breast Cancer Survivors, Breast Cancer Action, Burlington Breast Cancer Support Services, Sudbury & District Breast Cancer Support Group). These inadequacies include, among others, difficulty accessing information, poor quality of existing information, conflicting information and insufficient materials in language other than English. In terms of support, many women do not have access to support groups, especially in small town and rural settings. Additionally, many women find it difficult to attend group meetings because of other commitments (e.g., child care) or illness related factors (i.e., fatigue) or the feeling that a group setting is not the best one for them. In general, women/consumers are demanding a more customer focused and interactive system for information exchange and

support. People want convenience, quality, and immediate access. They also want services tailored specifically to their unique, individual needs.

During the past several years, across Canada, many breast cancer groups have developed for the purposes of sharing information and providing support for breast cancer survivors. These groups have developed in response to the needs breast cancer survivors have been voicing and their perception of the current inadequacies. More recently these groups have begun to interact for the purpose of sharing resources and enhancing access for their respective members. Networks have emerged at regional (e.g., Thunder Bay Breast Cancer Coalition), provincial (e.g., Ontario Breast Cancer Information Exchange Partnership) and national (e.g., Canadian Breast Cancer Network) levels. By working together, these groups hope to avoid duplication, make the best use of scarce resources and better serve the needs of the women in their jurisdictions.

To work effectively together, these organizations need to be able to identify issues, discuss possible solutions, identify priorities, share draft documents, and communicate efficiently between face to face meetings. Additionally, face to face meetings, whether drawing individuals from across a province or across the country, are costly affairs.

With the growing acceptance of the computer as another necessary home appliance, communication and business transaction methods are changing. In increasing numbers people are using the Internet to access information (Litrides, 1997). Women now constitute 31.5% of all Internet users. According to this same Internet usage survey, a frequent activity is using the Internet for references (96.7%) (Graphics, Visualization and Usability Centre's World Wide Web User Surveys, 1996). Breast Cancer survivors have also begun to use the Internet for accessing support. (Church, Farber, Hilliard, personal communication)

The project described in this document was mounted to explore the feasibility of using Internet based tools to foster work in the dissemination of breast cancer information and the provision of support for breast cancer survivors. The project goals, methods and findings will be described together with recommendations for the breast cancer community to consider as future actions. The work was funded through the Population Health Fund of Health Canada as part of the Phase II Canadian Breast Cancer Initiative focused on community capacity building.

## **PROJECT GOALS**

The stated goals of this project were as follows:

- to identify and propose models for the development of an Internet-based virtual information network (virtual community) to strengthen networking and collaboration between and amongst local/regional, provincial/territorial and national stakeholders including both individual women with breast cancer and agencies and organizations;
- to complete an environmental scan and comprehensive summary of existing virtual communities, and the policies and procedures, risk management, training, and funding and technical issues, and proposed solutions;
- to prepare a final report and recommendations for future actions regarding a virtual community for breast cancer information and support.

As a goal, enhancing collaboration and networking is fundamental to the vision of enhanced breast cancer information exchange and support in Canada. This project was conceived as the

first step toward establishing a virtual community. Before such a community can be created it is necessary to understand what is required (technology, equipment, training, finances, etc) and how potential users might work within such a community. During the course of this exploratory project the perspectives of women living with breast cancer, and agencies and organizations with an interest in breast cancer information and support, were sought.

## **SPONSOR AND PARTNER ORGANIZATIONS**

The sponsor for this project was the Ontario Breast Cancer Information Exchange Partnership. The specific partners for the project included the Canadian Cancer Society, Canadian Breast Cancer Network and the Canadian Breast Cancer Foundation.

### **Ontario Breast Cancer Information Exchange Partnership (OBCIEP)**

The OBCIEP is a coalition of organizations who have a stake in the dissemination of information about breast cancer. The 38 member coalition is committed to ensuring information about breast cancer is available to all people of Ontario. By providing a neutral forum for networking and information exchange, OBCIEP fosters co-operative, problem-solving and co-ordinated action concerning issues related to breast cancer information dissemination.

The primary role of OBCIEP is to assist organizations involved in the dissemination of breast cancer information to respond to the information needs of their clients. This is accomplished by sharing information about breast cancer resources through a newsletter, web site, and various communication tools used by the member agencies. Without duplicating the efforts of others, OBCIEP develops information resources for women, their families, and health professionals to fill identified gaps. In addition, OBCIEP activities involve the evaluation of current dissemination strategies to ensure that people can easily access quality, up-to-date information when they need it.

### **Canadian Cancer Society (CCS)**

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

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

The CCS is a leader in providing current, reliable information about all aspects of breast health and breast cancer. Information about breast cancer is easily obtained by calling the CCS's Cancer Information Services (CIS) or by contacting local CCS offices. As well, CCS and CIS direct women to services in their local communities that will help them cope with their breast cancer. CCS also provides emotional support to women with breast cancer through programs such Reach to Recovery and Cancer Connection. This latter program matches breast cancer survivors with newly diagnosed women to offer support via telephone.

The Society is a partner organization in the Canadian Breast Cancer Initiative and, as such, participates with other breast cancer organizations to ensure that the needs of women with breast cancer are met in the best ways possible.

CCS also strives to improve the quality of life of those affected by cancer, reduce tobacco use and increase support for research. This is achieved through vigorous revenue development, sustained volunteer development and effective planning, evaluation and resource management.

### **Canadian Breast Cancer Network (CBCN)**

The CBCN was established following the National Forum on Breast Cancer. At the Forum it was recommended that a national network of support and advocacy groups be developed.

Immediately after the Forum a group of nine survivors from across Canada volunteered to begin the formation of a national network of groups and individuals who represent the interests of those Canadians and their families who live with breast cancer.

CBCN was officially incorporated and registered as a charitable organization in November, 1994. The mission is to provide a national link between all groups and individuals concerned about breast cancer and to represent the concerns of all Canadians affected by breast cancer and those at risk. Its principle goals are 1) to communicate with, support and inform organizations who are concerned about breast cancer, 2) to promote education and awareness about breast cancer at the national level, and 3) as representatives, advocates and educators, to focus national attention on breast cancer and to ensure that the concerns of Canadians affected by breast cancer influence decisions of research and health care policy.

### **Canadian Breast Cancer Foundation (CBCF)**

The CBCF is the largest national charitable organization dedicated exclusively to supporting the advancement of breast cancer research, education, diagnosis, and treatment. From coast to coast, through chapters and branches, the Foundation addresses the needs of Canadians. In its mission to eradicate breast cancer, the majority of funds are earmarked for research directed at finding a cure. At the grassroots level, a significant budget is dedicated to awareness, education and treatment programs targeted specifically to different cultural groups and communities across the country.

## **PROJECT METHODOLOGY**

### **Project Management**

A Project Management Group (PMG) and a Project Advisory Group (PAG) were formed at the onset of this project. The PMG consisted of representatives from the sponsor and partner organizations as well as experts regarding the technology of virtual communities and a representative from Health Canada (see list of members in Appendix A). This group provided strategic direction and feedback for the project initiatives. The PAG consisted of representatives from provincial breast cancer networks and breast cancer survivors. They provided access to support groups and organizations within their respective jurisdictions. They were also actively involved in designing the recommendations set forth later in this report.

The two project groups were established to ensure:

- representative users (local, provincial/territorial, national) could be consulted regularly and easily, both individually and collectively, regarding issues;

- two-way exchange, with groups putting forth their ideas on what is of concern to them as well as new innovations and developments, provided opportunity for information dissemination and support; and
- opportunity for feedback regarding concerns and making plans for taking collective action about an issue.

### **Project Initiatives**

Four specific initiatives were mounted to accomplish the goals of this project. The initiatives included a literature review, a scan of existing websites about breast cancer, surveys regarding Internet use and access, and a stakeholder workshop. Each initiative will be described together with the findings below.

### **Literature Review**

A number of studies conducted in recent years have reviewed the use of personal computers to access information on cancer and other health-related matters. (see Appendix B) On-line self-help groups have the potential to address the problems of accessibility and anonymity inherent in traditional face-to-face groups by reaching multiple-users while allowing patients to communicate at a time, place, and pace convenient for them. While the benefits to the users have been documented, few studies have been conducted about computer support networks. Research suggests that patients and caregivers find online services acceptable and worthwhile, and have shown consistently a need for ongoing information and support in the process of coping with cancer.

### **Internet Use and Tools**

The Internet has become a truly international bastion of information exchange, helpfulness and co-operation. The Internet serves both as a vehicle for communication and as a repository of knowledge. Internet sites, whether in the form of World Wide web pages, FTP data/binary repositories or newsgroups can be used to draw attention to issues, offer information, tips, and bring more robust networking capabilities to community organization efforts. However, the value of these technologies is not in themselves, but in how well and how transparently they support the exchange of information. In February 1995, there were 27,000 World Wide Web sites alone. This number is reportedly doubling every 53 days ([www.interwebtech.com/nsnmnet/docs/march.htm](http://www.interwebtech.com/nsnmnet/docs/march.htm)).

Webster's dictionary defines community as "any group...having interests, work, etc. in common; a sharing in common". Wellman and Gulia (1995) suggest that the Internet supports two forms of community, "personal communities as well as group communities". They differentiate the two community types by stating:

*. . . the Net supports personal communities as well as group communities. The distinction is crucial for understanding how community works in contemporary societies, both on-line and in "real life". A group community is a social network of people who interact with one another regularly to provide sociability and support. This could be members of a village, a densely-knit urban neighbourhood, a kinship group, a set of friends, or an on-line discussion group. By contrast, a personal community is an individual's network of informal interpersonal ties, from a half dozen intimates to hundreds of weaker ties.*

Communities make it possible for people to feel safe in and be familiar with environments. They help to bring like-minded people together, making it possible to learn from others and create movements and activity on a larger scale. Communities can create change and can help make sense out of the overall organization of things. Through the use of the Internet, our potential as a global community can be enhanced. Wellman and Gulia (1995) point out that:

*The architecture of the Net facilitates weak and strong ties that cut across social milieus, be they interest groups, localities, organizations, or nations, so that the cyberlinks between people become social links between groups that otherwise would be socially and physically dispersed.*

A prime factor in the popularity of the Web today could be its ease of use and installation. Today's improved web browsers such as Netscape and Microsoft Internet Explorer do not require any technical knowledge for installation or for usage. Even children at the elementary level can point and click to "go places" on the Web. Most users today access the Internet through home (55.4%) or work (34.3%). Unfortunately, those who do not have a computer at home or at work are left out of the information superhighway. Today, however, even that barrier is whittling away, as coffee shops, software vendors, and other shops in large cities along with public libraries are starting to provide fee-based and, in some cases, free access to the Internet (Mei Sei Yeoh, 1996).

CD-ROMS and the Internet are converting the way individuals on a global scale communicate and access information. The World Wide Web not only provides a means to access information from all over the world but provides opportunities for electronic publishing away from traditional printed forms. Applications in new interactive media technologies notably have the greatest potential in the areas of education and research. For education purposes, interactive programs available on CD-ROM or the Internet can accommodate each individual learner at his or her own pace. Also, these programs have the capabilities to enhance traditional texts by incorporating sound, video, animation, graphics, and 3-D working images. Therefore learners have the opportunity to tackle complicated subject material such as science and mathematics while exploring and taking part in the interaction (Wilson, 1997).

Increased consumer use of the Internet has, however, put an additional strain on service providers who already face a triple-edged dilemma. Demand for services are increasing while funding sources, although increasing, are spread across growing numbers of organizations. This means that as needs for existing and new services increase, funds to provide for these services are harder and harder to obtain or to raise. With the advent of new technologies for the diagnosis, treatment and care of women with breast cancer, the shelf life of most print and audiovisual materials produced by traditional means had become more limited. Dissemination involved additional costs. The problem is further compounded by the need to develop language-specific materials. The Internet provides a platform for easy, efficient and cost-effective changes to posted materials.

While properly organized conceptually and technically, the Web can serve as a highly effective foundation for collaboration, which will bring together the diverse worlds. The ease and relative low cost of networking enables seamless communication transcending traditional barriers of geography, culture, status, and, to some extent, language. Information retrieval, though

constrained by issues of bandwidth, availability, and "findability", is generally easier and quicker. On the other hand, isolated and idiosyncratic developments of Web servers does lead to information overload, insufficiency and chaos (Day, 1997). There are today over 135,000 Web pages containing the words breast cancer (www.altavista.com; May, 1999).

A growing trend in Web design offers a potential solution for the existing dichotomy. Virtual communities, as they are often called, represent a collection of Internet based tools. There is no one definition or combination of elements that comprise a virtual community. Specific elements that could be used in a virtual community include a web site and server, bulletin boards, chat rooms, listservs, e-mail and Internet conferencing. Virtual communities provide an efficient vehicle for the dissemination of information through the organization of information resources, search and resource linking capabilities and asynchronous and synchronous interactions (Chelleppa, 1996). A short description of the various Internet based tools follows.

#### Web Servers and Web Sites

Web servers define the hardware (physical machinery) and software (computer program) which house the Web site. Web sites serve as a hub for access to the host site. More importantly, the hyperlinked nature of the Internet promotes the retrieval of information by association, so that one site may simultaneously provide the springboard to a host of related information of different types and at several levels.

#### Bulletin Board System (BBS)

Electronic bulletin boards can be one component of a Web site. Based on need, a network of bulletin boards can be housed on one Web site. Dedicated bulletin boards can be set up for specific access for specific users. Bulletin board operation is asynchronous. In essence, the bulletin board is an open system that members can dial into in order to send email, join discussion groups, and download files. Since the 1970's BBS's have provided an early means for home users to get online. Originally, BBS's were free-standing local systems, but now many provide access to Internet email, telnet, FTP and other Internet services.

#### Chat Rooms

On-line synchronous discussion is a feature of some Web sites. These are a form of interactive online communication that enables typed conversations to occur in real time. When participating in a chat room discussion, your messages are instantaneously relayed to other members in the chat room while other members' messages are instantly replayed to you.

#### File Transfer Protocol (anonymous)

This service allows free public access to archived documents, tiles and programs via the File Transfer Protocol (FTP). It is not necessary to have a user ID and password when logging onto an anonymous FTP site. The user ID "anonymous" bypasses local security checks; often email addresses serve as courtesy passwords.

#### List Service (listserv)

This service is an automated mailing list distribution system. List servers maintain a list of email addresses to be used for mass mailing. Subscribing and unsubscribing to the list is accomplished by sending a properly formatted email message to the list server.

### Search Engine

This component is a program or web site that enables users to search for keywords on web pages throughout the World Wide Web.

### E-mail

Electronic mail provides for instant asynchronous communication to any other Internet-based e-mail account. Transfer of messages is quite rapid. This tool allows for the simultaneous transfer of data files to Internet-based e-mail.

### Internet Conferencing

Internet conferencing is real-time interactive communications between multiple users. Data, voice, and video are components that can be used and transferred as part of the conferencing interactions.

### **Scan of Existing Web Sites**

An environmental scan was undertaken to identify the current status of virtual community approaches. The scan focused initially on a list of 179 web sites with the term breast cancer in their title. Given the time available for this project, it was decided that only these sites would be included in the scanning exercise. (The list of Web sites is included in Appendix C.) Of note, a subsequent scan of sites designed for other topic areas had to be accessed and reviewed to find a full range of virtual community models.

Each breast cancer web site was accessed and reviewed to determine

- 1) its purpose;
- 2) the type of group/organization sponsoring the web site;
- 3) the website master; and,
- 4) the degree of interaction within the web site. In particular, the contact information of the webmaster was needed for subsequent survey activity (see description below).

Of the 179 web sites listed, the large majority were American (163). Eight were Canadian and 8 originated from other countries (i.e., Japan, United Kingdom, Australia, Brazil). The search for the web sites on the project list, revealed 37 could not be found or could not be accessed. Of the 146 sites that could be accessed, the following categorization was made:

- 35% were from groups or organizations (16% of those were clearly labelled as support groups)
- 21% were from commercial enterprises
- 14% were from government agencies or institutions
- 13% were from private citizens
- 6% were from universities/research groups
- 6% were fund-raising groups/foundations
- 5% unclear as to origin/purpose

Most of the websites provided contact information, especially through e-mail addresses. In terms of interactions, approximately 15% offered some degree of interaction within their site. Most offered an e-mail address as the interactive component and had hyperlinks to other breast cancer sites. Several had a Bulletin Board function, but only 5 of the 146 incorporated a chat room component.

The environmental scan resulted in the following conclusions:

- there are many existing Internet-based services (web-sites) that serve individuals;
- the majority of the existing web sites are not highly interactive;
- few, if any, web sites are organized to bring organizations together and facilitate their collaborative efforts; and
- electronic (virtual community) tools can be used in various ways to enhance information exchange and collaboration.

### **Survey Initiatives**

For the purposes of this work three surveys were developed and circulated. Each will be described below together with the findings generated.

#### Survey 1: Goals for a Virtual Community

A survey was developed to identify the appropriate goals for a virtual community. The intent was to use the data to develop a vision statement for a virtual community concerning breast cancer information and provision of support for breast cancer survivors (See Appendix D).

The survey listed a wide range of goals related to information dissemination and the provision of support. The goals were identified through reviewing the writings related to the information pilot projects and community capacity building initiatives funded by Health Canada. Some of the goals focused on collaborative activities between and among breast cancer groups while others focused on access by individual women wanting information or support. Respondents were asked to indicate whether or not a particular goal was appropriate to be working toward through the use of virtual community tools. A list of tools together with a brief description of each tool was included in the survey package for each respondent. The survey was distributed by e-mail to all members of the PMG and PAG. Analysis consisted of calculating the frequency of responses for each goal listed on the survey.

There was unanimous agreement among the respondents that the following goals would be appropriate for a virtual community:

- to use technology as a tool to enhance the provision of support and information dissemination about breast cancer through a network of agencies/organizations working collaboratively;
- to enhance the shared access to information about breast cancer and support resources;
- to enhance the links and working relationships between and among local, regional, provincial, and national groups;
- to provide access to an inventory of all the players/stakeholders in the network;
- to identify issues and concerns;
- to share ideas and concerns with others on committees/work groups;
- to develop action plans;
- to hold meetings "on-line" (in real time); and
- to decrease travel time and costs.

The next highest level of agreement (88.9 – 89.0%) occurred with regard to the following goals:

- facilitate access to state-of-the-art, user-friendly information regarding breast cancer;
- encourage communication and networking between women and groups within communities across a geographical area;
- avoid duplication of material and services;

- have access to an inventory of what organizations exist and contact people;
- learn what events and activities are happening in other agencies (get ideas about events that you can do in your own agencies; helps to avoid duplication);
- make it easy for women to get in touch with organizations if they want certain resources, information or support;
- have easy distribution of agendas, background information for meetings, and minutes
- have easy communication between and among members between meetings; and
- have the ability to distribute draft materials and receive feedback.

The remainder of the goals received varied levels of support (see Table 1).

In essence, the survey respondents perceived the primary reasons for making use of a virtual community approach were to promote networking and enhance collaboration between and among groups of care providers. Enhancing such interaction would ultimately contribute to the ability of the various groups to better serve their consumers/constituents. The interaction would enhance the ability of the groups to meet the needs of women with, or facing, breast cancer.

The results of this survey were used to formulate a vision statement. The statement was presented for discussion at the stakeholder workshop (described below). The final statement is presented in the recommendation section of this document.

#### Survey 2: Internet Access and Use

For the purpose of this project a survey was developed to assess Internet access and use by breast cancer groups (see Appendix E). The survey contained questions about the respective group's goals or objectives, how well a virtual community would help the group achieve its goals, barriers to becoming part of a virtual community, interest in using Internet based tools, and whether the group offered an Internet based service. Additionally, two questions were formulated to assess the value of, and barriers to, individual women joining the virtual community. A list of the existing types of Internet based tools was circulated with the survey. The list contained the name and a short description for each tool.

The survey was circulated in three ways, depending upon the capacity of the organization to receive it: e-mail, fax or regular mail. The mailing list for the survey was generated by asking the members of the PAG to forward a list of the breast cancer groups/organizations in their respective province/territory. This was a successful strategy in that groups/contacts were

**Table 1: Survey Results Regarding Goals Considered Appropriate to Pursue Using a Virtual Community Approach**

ITEM	Is this goal/objective appropriate for us to be striving towards through a virtual community approach?		
	Agree	Uncertain	Disagree
<b>Overall Goal of a Virtual Community:</b>			
1. To use technology as a tool to enhance the provision of support and information dissemination about breast cancer through a network of agencies/organizations working collaboratively.	100.0%	-	-
<b>Objectives in using technology:</b>			
2. To increase the efficiency of the work of breast cancer networks.	66.7%	33.3%	-
3. To enhance the shared access to information about breast cancer and support resources.	100.0%	-	-
<b>Goals for Breast Cancer Networks served through a virtual community approach:</b>			
4. Facilitate access to state-of-the-art, user-friendly information regarding breast cancer.	89%	-	11%
5. Serve as a catalyst, or motivational centre for co-operative activity regarding the dissemination of information about breast cancer and the provision of support to breast cancer survivors.	66.7%	33.3%	-
6. Ensure that breast cancer survivors are highly involved in identifying priorities for action.	58.7%	33.3%	11%
7. Make participation economically feasible for survivor groups.	77.8%	11%	11.1%
8. Ensure a significant number of survivors are involved in the work of the breast cancer network.	66.7%	11.1%	22.2%
9. Enhance the links and working relationship between and among local, regional, provincial, national, groups.	66.7%	-	33.3%
10. Integrate, co-ordinate and utilize existing resources as effectively and efficiently as possible.	66.7%	-	33.3%
<b>Other Possible Goals:</b>			
11. Serve as a clearinghouse for information and support.	-	50%	50%
12. Provide a comprehensive library and resource.	22.2%	33.3%	44.4%
13. Serve as a “drop-in” centre for information and support.	33.3%	44.4%	22.2%
14. Provide “training” on-line.	33.3%	66.7%	-
15. Encourage communication and networking between women and groups within communities across a geographical area.	88.9%	11.1%	-
16. Avoid duplication of materials and services.	88.9%	-	11.1%
17. To actively share materials and resources with related agencies.	66.7%	11.1%	22.2%
18. Decrease social isolation of women living with breast cancer. (women can connect any time and do not need a staff person to channel calls and volunteers can respond “from home” at any time)	66.7%	22.2%	11.1%
19. Disseminate information directly to women. (women do not have to come into a centre, wait for mail or fax or even talk on the phone—they can select from a prepared menu of information available and download materials such as fact sheets, press releases, self-help information, inventories, and/or key articles to a personal computer)	77.8%	11.1%	11.1%

ITEM	Is this goal/objective appropriate for us to be striving towards through a virtual community approach?		
	Agree	Uncertain	Disagree
<b>Accomplishing the Day to Day Work of the Network through a virtual community approach:</b>			
20. Have access to an inventory of all the players/stakeholders in the network.	100.0%	-	-
21. Have access to an inventory of what organizations exist and contact people.	88.9%	-	11.1%
22. Have access to an inventory of what resources exist in each organization.	77.8%	11.1%	11.1%
23. Have access to listing of what resources each agency is currently working on.	77.8%	11.1%	11.1%
24. Have access to a listing of where resources can be obtained.	77.8%	-	22.2%
25. Be able to get new resources out to people. ( or at least the information that the resource exists and where it can be obtained)	77.8%	-	22.2%
26. Keep folks up-to-date in new developments or available resources.	77.8%	-	22.2%
27. Continue to disseminate existing materials easily.	55.6%	11.1%	33.3%
28. Identify gaps in resources. (both information and support)	77.8%	11.1%	11.1%
29. Mobilize energy to fill gaps (find people/agencies who will work on filling the gaps; make plans to work together and get the work done)	77.8%	11.1%	11.1%
30. Learn what events or activities are happening in other agencies (get ideas about events that you can do in your own agencies; helps to avoid duplication)	88.9%	-	11.1%
31. Learn from one another what works and what does not work, what projects are underway, what is useful to fill certain types of gaps.	77.8%	11.1%	11.1%
32. Make it easy for women to get in touch with agencies or organizations if they want certain resources, information, or support.	88.9%	-	11.1%
<b>Accomplishing Committee (task force, project) Work:</b>			
33. Easy distribution of agendas, minutes, background materials for meetings.	88.9%	-	11.1%
34. Easy communication between/among members between meetings.	88.9%	-	11.1%
35. Able to distribute draft materials and receive feedback.	88.9%	-	11.1%
36. Identify issues and concerns.	100.0%	-	-
37. Share ideas and concerns with others on committee/work group.	100.0%	-	-
38. Develop action plans.	100.0%	-	-
39. Hold meetings "on-line" (in real time)	100.0%	-	-
40. Decrease travel time and costs.	100.0%	-	-

identified in all provinces and territories. A contact list of groups was also obtained from the Canadian Breast Cancer Network. The various lists were cross-referenced and efforts were made not to contact a group more than once for the same purpose. The lists contained a wide range of organizations including self-help support groups, professionally led support groups, community based agencies (volunteer and professional), outpatient cancer programs and in-hospital cancer programs. Given a virtual community would need to include all types of organizations, the full range was included in the survey to obtain a cross section of perspectives.

In all instances a telephone call was made initially to inform the group representative or contact person about the survey, tell them the survey was being sent and determine how that individual would like to receive the survey. Approximately three weeks after the initial contact and the distribution of the survey material, the group representative was contacted again if the survey had not been returned. The second call was placed for the purpose of encouraging the individual to return the survey. Surveys were sent out a second time if the contact person wanted another copy.

A total of 385 surveys were distributed and 173 were returned (44.9% response rate). Responses were received from a cross-section of groups (e.g., professional, support groups, cancer society units, hospitals, regional cancer centres, networks/coalitions) and from across all provinces/territories of Canada.

The respondents were asked how well they thought a virtual community would help them to achieve their goals or objectives (see Table 2). Overall, 28% of the respondents indicated they

**TABLE 2: Opinions Regarding How Well a Virtual Community Would Help to Meet Organizational Goals**

TYPE OF GROUP	PROPORTION OF RESPONSES IN EACH GROUP				
	Very well	Somewhat	Not very well	Unsure	No data
Professional Groups (n=11)	36	27	9	9	18
Support Groups (n=65)	25	32	8	3	4
Cancer Society Units (n=28)	29	39	11	14	7
Hospitals/Programs (n=24)	38	13	13	33	3
Regional Cancer Centres (n=13)	40	33	7	13	7
Networks/Coalitions (n=13)	31	15	8	38	8
Other (n=17)	6	71	-	18	5
All Groups (n=173)	28	33	8	25	6

thought the virtual community approach would serve their purposes very well while 33% thought it would to some extent. However, 25% were uncertain about the benefit of a virtual community in meeting their goals. Some indicated that their uncertainty stemmed from not entirely understanding how this type of approach would actually work. Others indicated a concern that face-to-face interactions should not be replaced exclusively with electronic interaction. Others expressed concern about whether women would have the skills to access this medium. Many respondents perceived that women who were older would have difficulty using the computer.

Many respondents indicated that saw potential value or benefits in a virtual community. Cancer programs, hospitals and professional agencies saw benefits which included:

- sharing information, ideas and concerns with others including health care professionals, community members and survivors;
- having the ability to get up-to-date information in their own/read up on topics for yourself;
- having the capacity to refer others to the information on a web site or other related web sites; and,
- having the ability to let people know about existing programs (provide profile for organizations/agency).

Local support groups and Cancer Society Units saw the benefits of participating in a virtual community as:

- enhancing and promoting what we do/enhancing the communication about what we do;
- offers a good resource to the group;
- improving access to information and resources;
- helps to connect with others;
- allows group to reach a wider audience (especially rural);
- could be a “one stop” resource for information; and,
- could help with priority-setting and decision-making.

Respondents were asked to indicate the types of issues they would face if they were to participate in a virtual community (see Table 3). All types of groups indicated concerns. Overall, the primary concerns were maintenance (52%), set-up (49%), training costs (49%), access to the Internet (45%), software (45%) and hardware (41%) costs, and security/privacy/confidentiality issues (38%). The type of group with the highest proportion of respondents who expressed concerns was the support groups across all items except maintenance costs. Sixty-six percent of the support groups indicated an issue with the rate limiting steps of access to the Internet and set-up concerns. One other area of concern many respondents wrote about was the issue of duplication. Many thought there were a great number of web sites already and adding new ones seemed like duplication. The respondents encouraged collaboration with existing sites.

Several issues were raised by a few respondents. These issues included:

- support groups do not have money to purchase computers/software;
- working through a computer isolates an individual from human contact;
- storage for computer equipment if a group purchased it;
- access by ethnic and First Nations women; and,
- misinformation on the Internet.

**TABLE 3: Issues Perceived in Becoming Part of a Virtual Community**

TYPE OF GROUP	PROPORTION OF RESPONSES IN EACH GROUP*						
	Access to Internet	Hardware Costs	Software Costs	Set-up Concerns	Training Costs	Maintenance Costs	Security/ Privacy Issues
Professional Groups (n=11)	27	36	36	27	27	18	18
Support Groups (n=65)	66	54	54	66	63	57	38
Cancer Society Units (n=28)	46	32	36	39	36	61	46
Hospitals/ Programs (n=24)	50	38	46	50	38	46	33
Regional Cancer Centres (n=13)	27	33	27	47	53	60	33
Networks/ Coalitions (n=13)	31	38	54	38	54	46	46
Other (n=17)	12	12	24	18	35	53	41
All Groups (n=173)	47	41	45	49	49	52	38

\* Respondents could answer more than one option.

**TABLE 4: Interest in Using Internet-based Tools**

TYPE OF GROUP	PROPORTION OF RESPONSES IN EACH GROUP				
	Bulletin Board System	Chat Room	File Transfer Protocol	List Server	Search Engine
Professional Groups (n=11)	45	18	7	27	55
Support Groups (n=65)	48	43	25	23	51
Cancer Society Units (n=28)	43	36	14	21	36
Hospitals/Programs (n=24)	46	17	29	21	58
Regional Cancer Centres (n=13)	60	40	27	40	67
Networks/Coalitions (n=13)	69	54	31	38	54
OTHER (N=17)	35	18	12	41	47
All Groups (N=173)	48	35	23	27	51

The respondents were asked to indicate their interest in using various virtual community or Internet-based tools (see Table 4). Overall, 51% of the groups indicated an interest in using a

search engine and 48% wanted to make use of a Bulletin Board System. However, looking at the proportion of specific group types who wanted access, 69% of the networks/coalitions wanted to access a Bulletin Board System and 54% wanted to make use of a search engine; 67% of the regional cancer centres wanted the search engine and 60% wanted the BBS. Almost half of the support groups (51%) wanted the search engine capability and access to the BBS (48%).

Only about a quarter of the groups who responded actually offer Internet-based services (see Table 5). Regional cancer centres (60%) and networks/coalitions (46%) had the highest proportion of members who offered these services. Only 12% of the support groups offered the services.

**TABLE 5: Groups Offering Internet-based Services**

TYPE OF GROUP	Proportion of Respective Group Offering Service
Professional Groups (n = 11)	18
Support Groups (n = 65)	12
Cancer Society Units (n = 28)	32
Hospitals/Programs (n = 24)	12.5
Regional Cancer Centres (n = 13)	60
Networks/Coalitions (n = 13)	46
Other (n = 17)	47
All Groups (n = 173)	26

Of those groups who offer Internet-based services, the tool described most frequently was the use of a web site or web page containing information about the group, its mandate and services. Often links to other cancer related sites were also in place. The primary reasons these services were developed included the demands and concerns of clients for information, to improve communication and increase the profile of the groups/organizations so that women would know about them. A few respondents are planning for added functionality on their sites (i.e., bulletin board system, chat rooms, etc). The primary reason these groups are adding functionality is that they want more interactions with their clients/members. Several made the comment that they see the Internet as the primary way by which people are going to obtain information in the near future and they want to be prepared for that.

The successes experienced by the groups who offer Internet-based services include "fabulous contact", many phone calls and inquiries, more referrals, and easy on-line access to information. However, many of the groups admitted that they had not actually measured their successes through systematic evaluation.

The groups indicated they had experienced difficulties in establishing their Internet-based services. The types of issues they mentioned included the following: initial difficulty learning about the technology (what tools would be most helpful for them), obtaining funding to establish the service, deciding what information should go on the web site, maintaining current information/email addresses, lack of expertise when something goes wrong, few people who know how to work with the computer in group, and lack of expertise to expand the service.

Respondents recognized that information systems expertise is needed to establish and support an Internet-based service. They also emphasized the need to ensure that the information on the web page is correct and current. In turn, this means there is a need to constantly update the information (material).

The main idea respondents had about services that should be added to the existing Internet service concerned peer support. Many respondents suggested that peer support ought to be added, but they were also worried about it being seen as a replacement for the face-to-face contact they thought was so important. In the words of one participant,

*. . . most of our services are not on the Internet and at this point we feel that human contact, specifically voice contact, is an essential part of what we do.*

### Participation by Individual Women

Within the context of this survey, two questions were posed about participation of individual women in a virtual community. One question focused on the benefits that could exist for individual women belonging to a virtual community. The majority of respondents cited access to a wide range of information and support as the major benefits. The full range of benefits identified by the respondents included:

- quick, easy access to reliable, current information (about cancer, treatment, drugs, support services, etc);
- access to support at any time;
- an opportunity to interact with others who are in the same situation and share common experiences (gives a sense of connection);
- reduction in feelings of isolation, particularly for those in rural and remote settings (gives a message that one is not alone);
- access could be from the privacy of one's own home and at the pace that is comfortable for the individual woman;
- interaction can be anonymous;
- augments problem-solving/decision-making; and
- enhances communication and networking.

The words of one respondent provide an excellent summary of the perspectives provided by the respondents about what women need and should be able to obtain from participating in a virtual community:

*An information site with recognized standards, that is reliable, responsible, and lists factual data; quick and easy access to good and reliable information for women dealing with breast cancer, or for friends and family to learn more about what they can do to understand and help; information on support; meeting others dealing with breast cancer and all its issues; information on support services and practical aids.*

The other question posed about the participation of individual women in a virtual community focused on what barriers currently exist, making that participation difficult. The majority of respondents identified the barriers of 1) access to a computer and, 2) computer literacy. The full range of barriers identified included:

- lack of access to computers,
- fear in using computers,

- lack of computer literacy/technical knowledge,
- lack of access to the Internet,
- lack of awareness about Internet-based services,
- concerns about confidentiality and privacy,
- information overload resulting in confusion and anxiety,
- poor quality information/unreliable information ,
- missed benefits of social interaction from face-to-face exchange,
- literacy level and language, and
- costs associated with purchasing computers (hardware and software).

Several respondents described concerns about computer use contributing to isolation from human contact. Others described not having the mental energy and physical energy required to sit at a computer for any length of time. Especially during treatment, women said it was hard to find that energy or stamina. On the other hand, a young mother described how she liked the Internet access because

*I sit down after the children are in bed, or in the middle of the night, and people are out there. I just simply can't get to the group meetings in the evening. I have children I have to care for.*

The conveniences of having access to information within the comfort of one's own home was cited as desirable for those who had responsibilities that precluded them from attending face-to-face meetings, had difficulties attending group meetings, e.g. transportation, disabilities, etc., felt they were not comfortable in a group setting, or wanted anonymity during their search for information/support.

The surveys with the breast cancer groups and organizations resulted in the following conclusions:

- breast cancer organizations/groups want to provide services (information and support) to their clients;
- representatives of breast cancer groups are not entirely familiar with Internet-based tools and how they can be used to advance the objectives of their organizations/groups;
- representatives of breast cancer organizations see potential to use some Internet-based tools to enhance their work.

### Survey 3: Perspectives on Establishing Virtual Communities

A survey was designed to elicit perspectives on establishing virtual communities (see Appendix F). The target audience for this survey included webmasters or information technology specialists. The survey items focused on issues concerning set-up, utilization, maintenance, and costs of a virtual community as well as solutions for these issues.

The webmasters were identified during the environmental scan (described above) of existing websites. The survey was sent, together with a cover letter explaining the project, via e-mail to each individual identified. A follow-up e-mail was sent two weeks later if a response had not been received.

A total of 110 surveys were sent. Only 8 surveys were returned, despite follow-up contact. The primary reason for the non-response was that the information requested in the survey was the

type of information these individuals shared during their business enterprise. To answer the survey would have meant sharing information they usually are paid to share.

The webmasters who did respond to the survey provided some insight into the potential issues that would have to be considered in establishing a virtual community. The primary issues they identified included set-up policies (membership criteria, moderated or monitored approach), selection of software, training of users (initial and ongoing), and maintenance of a site (problem-solving re malfunctions and keeping information current). None of the issues were seen as insurmountable, but rather as aspects that needed to be worked through in establishing a virtual community.

### **Stakeholder Workshop**

A stakeholder workshop was held March 31, 2000 once survey information had been gathered from the various sources. The purpose of the workshop was to provide a forum for members of the breast cancer community to contribute to a vision for a virtual community regarding information and support.

The specific objectives around which the agenda was organized were:

- to review data regarding perspectives on virtual communities collected from a range of stakeholders;
- to review potential model components of a virtual community for breast cancer information and support; and,
- to engage in dialogue about recommendations regarding the development of a virtual community for breast cancer information and support.

The individuals invited to the workshop included the members of the Project Management and Project Advisory Groups as well as representatives from breast cancer support groups in Ontario. The list of participants is presented in Appendix F together with the background material distributed prior to the workshop, the workshop agenda, and material distributed at the workshop.

Early in the workshop, the participants provided feedback regarding the vision statement regarding the use virtual community technology to enhance the distribution of information about breast cancer and the provision of support to breast cancer survivors. Their comments are incorporated into the vision statement presented with the recommendations of this report.

The dialogue about the vision statement generated a discussion regarding the target audience for this virtual community. Confusion existed among the participants at this point in the day about whether the virtual community was for individuals or for groups. Questions were raised about the benefits of a virtual community for both audiences and the need to identify the "added value" of establishing a virtual community for breast cancer information and support was emphasized. Other questions focused on organizing the virtual community and how it would be managed. A concern was also expressed about the loss of local identity if a group joined a collaborative network/group.

A demonstration of the Internet-based tools was provided for the workshop participants. Within the group there was a wide range of familiarity with these tools. The invitee list was created purposely to incorporate this range in familiarity so that various perspectives would be brought

to bear on the recommendations. The demonstration was offered to allow a common and basic understanding of the tools, how they worked, and what might be accomplished by using them. A list of the sites accessed during the demonstration is presented in Table 6. The feedback about the demonstration indicated that participants found this activity very helpful (see Appendix G).

**Table 6: Internet-based Tools**

Asynchronous (not real time)	Document libraries <ul style="list-style-type: none"> <li>▪ <a href="http://www.vh.org/">www.vh.org/</a></li> <li>▪ <a href="http://www.who.org/hlt/">www.who.org/hlt/</a></li> </ul> Discussion Groups (Newsgroups, Forums, Chat Rooms) <ul style="list-style-type: none"> <li>▪ <a href="http://www.pdamd.com/">www.pdamd.com/</a></li> <li>▪ <a href="http://www.2chicks.org/">www.2chicks.org/</a></li> </ul> Mailing Lists (listserv) <ul style="list-style-type: none"> <li>▪ <a href="http://www.h17.org">www.h17.org</a></li> <li>▪ <a href="http://www.liszt.com">www.liszt.com</a></li> </ul>
Synchronous (real time)	Chat rooms <ul style="list-style-type: none"> <li>▪ <a href="http://chat.lycos.com/">http://chat.lycos.com/</a></li> </ul> Web/Video conferencing <ul style="list-style-type: none"> <li>▪ <a href="http://www.envoyforum.com">www.envoyforum.com</a></li> </ul>

Another key activity of the workshop was the presentation of the information gleaned from the surveys. Participants had the opportunity to review the data and asked questions. The purpose of sharing the data was to allow the participants to understand the current status of Internet-based services and the concerns/issues survey respondents described. These data provided a context of the current situation or environment and thus facilitated the design of an appropriate model for a virtual community focused on breast cancer information and support.

Finally, a draft model for a virtual community was presented to the participants. Small groups were organized and the following questions were discussed:

1. In the model we have proposed, what do you feel will work? What are the strengths of the model?
2. In the model we have proposed, what do you feel won't work? What are the weaknesses of the model?
3. What suggestions/solutions do you have to overcome these weaknesses?

The notes generated from these discussion groups are included on Appendix G and the comments have been incorporated into the model draft and recommendations below. The primary overall themes from the discussion groups were:

- the proposed model for the virtual community (having public and private spaces) was a new idea for most people attending the workshop;
- most participants could see several strengths within the proposed model, especially for enhancing collaboration between and among groups;
- implementing the model would require "buy-in" from breast cancer groups;
- obtaining the necessary "buy-in" would require education (training about using computers) and promotion about the benefits or the "value added" by the virtual community;

- computer access and computer literacy remain primary concerns;
- funding to support the implementation of the model is critical;
- breast cancer networks in the provinces/territories are at various stages of development and may not be ready to implement a virtual community approach; and,
- a critical issue is who will carry this initiative forward? (probably a champion is needed or one organization should take responsibility).

The participants provided feedback about the workshop. Their written comments are included in Appendix G. Overall participants found the workshop to be very helpful in terms of networking and understanding virtual communities. For quite a few, the lack of exposure to Internet-based tools prior to the workshop had been a barrier to thinking about how a virtual community could be of benefit to their organization. The demonstration assisted them to see how the tools could be used. Although participants expressed excitement about the potential for the virtual community, they also cautioned about moving forward slowly. They thought that breast cancer networks needed to form, members needed to get used to the idea of communicating through electronic means, and members needed to have an opportunity to be exposed to the Internet tools in a supportive situation.

## **PROPOSED MODEL FOR A VIRTUAL COMMUNITY**

This project was undertaken to explore the feasibility of a virtual community for breast cancer information and support. It was undertaken in a context on many breast cancer organizations beginning to work collaboratively at a local/regional, provincial/territorial, and national level. Dialogue about national collaboration regarding breast cancer information and support has occurred and a model has been proposed (November, 1999). Groups in several provinces are in the process of formalizing a provincial network as a basis for such collaboration.

Given the collaborative efforts between and among breast cancer organizations and groups over the past several years, the following assumptions need to guide the future thinking about virtual communities:

- breast cancer organizations want to collaborate and work in a network style to provide better service than they can alone (collaboration will enhance their ability to access information and resources);
- as collaborative breast cancer networks emerge in each province, they will want to interact with other breast cancer networks across Canada;
- the resolution of issues surrounding breast cancer will need action at local/regional, provincial/territorial, and national levels; and
- a successful network ultimately means organizations/groups will do a better job of meeting their clients' needs.

Also, there are facts about Internet-based tools that are of relevance to the design of a virtual community model for breast cancer information and support. The key facts are:

- Internet-based tools exist which can assist collaborative interaction;
- innovative use of a combination of Internet-based tools can enhance the capacity of a network of organizations to accomplish its work;
- Internet-based tools are already in use by organizations,
- Internet access is growing exponentially as bandwidths increase;

- the process of creating personal on-line communities will become more powerful and easier to use in the very near future; and,
- public expectation for easy access to the Internet and the digital economy is growing rapidly with the advent, in the near future, of high-speed digital access and local wireless networks.

## **VISION FOR COLLABORATION**

Given these conclusions and assumptions, the following vision is proposed as the basis or foundational context for future efforts:

### **Vision for Networks for Breast Cancer Information and Support**

A network is a formalized relationship between and among organizations/agencies created for the purpose of accomplishing goals together that any one organization/agency could not accomplish on its own.

The creation of networks between and 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.

By working collaboratively, stakeholders will be able to:

- learn from one another;
- maximize the use of resources;
- minimize duplication and overlap;
- build one existing structures and processes (capacity);
- identify actual gaps in service delivery; and
- mobilize energy/effort to fill gaps.

The network can serve as a catalyst or motivational centre for co-operative activity regarding the dissemination of information about breast cancer and the provision of support to breast cancer survivors. It can facilitate access to state of the art, user-friendly information about breast cancer and about support resources. It can foster the integration, co-ordination and utilization of existing resources as well as the creation of new resources to fill identified needs/gaps.

The network can encourage communication between and among women and breast cancer groups within communities across a geographical area and work in such a way so as to ensure that breast cancer survivors are highly involved in identifying issues and priorities for action.

## **PROPOSED VIRTUAL COMMUNITY MODEL**

The virtual community model described below, and depicted in Figures 1 and 2, is proposed for future consideration by the breast cancer community. The model builds on the existing context of

Internet activity by breast cancer groups and adds value in terms of collaborative activity, access to information, and sharing of resources.

**Ultimate Goal for a Virtual Community Approach**

To enhance the capacity of the stakeholder organizations to meet the needs for breast cancer information and support

**Purpose of a Virtual Community**

To use technology as a tool that would enhance collaboration between and among a network of organization/groups with a stake in the provision of information about breast cancer and support for breast cancer survivors

**Objectives of the Virtual Community**

- to enhance shared access to information about breast cancer;
- to enhance linkages and working relationships between and among local/regional, provincial/territorial, and national groups;
- to provide access to an inventory of all the players/stakeholders in the network;
- to facilitate the identification of issues and gaps;
- to facilitate sharing of ideas and concerns with others participating in network activities (committees/task groups);
- to facilitate the development of action plans; and,
- to hold meetings "on-line" and so decrease costs associated with frequent face-to-face meetings.

The model for the virtual community makes use of a web-based technology and various tools (see Table 7) and is based on the assumption that a network exists composed of organizations with a stake in breast cancer information and support working together.





**Table 7: Virtual Community Including Public and Private Space/Access**

<b>PUBLIC SPACE</b>	<b>PRIVATE SPACE</b>
Function: Area anyone can access at any time	Function: For access by organizational representatives for the purpose of conducting the business of the network, need a password to access
Tools: Information about the network/organization Members (list/descripton/contact/website link) Bulletin Board (anyone can post) <ul style="list-style-type: none"> <li>▪ Events</li> <li>▪ Activities</li> <li>▪ Stories, poems, etc.</li> <li>▪ Newsletters</li> </ul> Resource Board <ul style="list-style-type: none"> <li>▪ Lists of resources (where to obtain)</li> <li>▪ Annotated lists of resources</li> <li>▪ Selected brochures, pamphlets</li> </ul> Fact sheets ababout breast cancer "Hot links" to major sites E-mail exchange <ul style="list-style-type: none"> <li>▪ Threaded conversations</li> <li>▪ Ability to post questions and answers</li> </ul> Chat Rooms (anyone can join in)/Dialogue Board <ul style="list-style-type: none"> <li>▪ Real-time conversations</li> </ul>	Tools: Document Library (for network business) <ul style="list-style-type: none"> <li>▪ Post agendas, meeting notes, minutes</li> <li>▪ Post meeting dates</li> <li>▪ Share background documents, reports,</li> <li>▪ Educational documents</li> <li>▪ Work on draft documents</li> <li>▪ Obtain feedback on work</li> </ul> E-mail exchange <ul style="list-style-type: none"> <li>▪ Threaded conversations</li> <li>▪ Seek input on issues/questions</li> </ul> List serve (automatic sending of information) <ul style="list-style-type: none"> <li>▪ Flag by organization/geography</li> </ul> <u>Long-term</u> "Chat Rooms" (among member organizations) <ul style="list-style-type: none"> <li>▪ Real-time meetings/conversations</li> </ul>

The conceptualization of the model is that there will be "public space" and "private space" associated with website activity (see Figure 1). Various electronic tools can be utilized in either space (see Table 7). The public space refers to the existing websites established by the respective network member groups/organizations. These are sites that anyone can access anonymously and are under the jurisdiction of the "owner" group. The information/content on that public Web site is the responsibility of the owner group. The Web site has the respective organization's identity and any changes to the site are made according to the organization's own policies. These public sites could be hotlinked/hyperlinked to each other for easy reference by anyone accessing one of them. Participating in the networks' virtual community would not change these sites.

The private space is the new feature being proposed in this document and would have to be created. This space would be password protected. Only individuals who have authorized passwords would be able to access this space. Through an easy process, all member group/organizations would be given a password for access. This private space would be where the business of the network would be conducted. Information and documents of interest only to network members would be shared and worked on in this space. Figure 2 illustrates how the structure might work. Local/regional organizations that are members of the provincial network would have a private space in which they could conduct their business together. Each provincial network would have a password to work with other provincial/territorial counterparts on a national level. All of this activity could easily be housed on one server. The private site could make use of a variety of electronic tools. Document libraries could assist in sharing pertinent documents (i.e., agendas, minutes, background information for meetings,

drafts, etc.). E-mail exchange could enhance the timeliness of feedback and issues identification. Bulletin boards could provide information of interest to the members about events and meetings. List serves (automatic sending of information) could alert members to new information. A long-term goal might well be the establishment of a real-time chat room or video conferencing for network meetings.

The basis for the idea of a private space is that there is business the network has to conduct that is not of relevance to the general public. Once documents have been finalized and agree upon, they can be posted in the public space if they have applicability to the general public. Groups do not require their own web site in order to participate in this private space. They do, however, require access to a computer with the capability for Internet access.

Fundamental to the success of this type of model is the participation by regional/local groups at the provincial/territorial level. "Buy-in" to the model would need to be sought through conversation and demonstration at the local level. Strategies would need to be developed to:

- ensure there is access to a computer (with Internet access) by at least one representative of the respective local/regional group;
- ensure there is education and coaching/mentoring about the use of computers easily available to regional/local representatives;
- clarify where the leadership will be for implementing the virtual community concept in an area; and,
- provide incentives to use the electronic tools or encourage participation in the virtual community.

The costs associated with establishing this type of private space is estimated at \$55,000. This includes \$20,000 for hardware, \$15,000 for software, and \$20,000 for development and implementation. Access to computers and training for the local/regional groups is not included in this cost estimate. Ongoing maintenance and support is approximately \$5,000 each year.

The proposed model has at its target audience, the groups and organizations involved in the dissemination of breast cancer information and the provision of support for breast cancer survivors. By facilitating their access to information and resources, they will, in turn, be better able to provide for their clients - women living with, or at risk of developing, breast cancer. This does not negate the issue that women need information and ought to be able to access public web sites as individuals. The model leaves in place the many public web sites that these women could access but leaves the responsibility for those sites with the existing "owner" groups. The new feature would provide added access to a new tool for working together as groups or organizations.

Nevertheless, it is important to acknowledge that many women may still experience difficulty in accessing public sites. Regional/local groups likely need to consider what role they might play in helping women achieve better access to computers, computer training and Internet access in their local areas. If organizations feel an obligation to help clients access information, this could reasonably extend to helping them learn how to use the technology itself. Additionally, as the world marches ever faster toward virtual based scenarios for sharing information, discrimination could arise for those who do not have easy access to computers (i.e., those living in poverty, those with reading disabilities, etc.). This observation underscores the need for continuing to use

various methods to share information and provide support. Virtual communities are but one method.

## **CONCLUSION**

This project was undertaken to establish the feasibility of using a virtual community approach to foster the work of disseminating information about breast cancer and providing support to survivors. Based on the information we gathered, it is clear that a virtual community approach has the potential to enhance collaboration between and among stakeholder organizations in breast cancer.

However, there are two fundamental considerations that exist in moving forward to establish a virtual community. One consideration is the technology. Currently the technology exists and the creation of a model as proposed in this document is fairly easy and would not be extremely costly. However, it would require some investment of funds.

The second consideration is the "buy-in" from breast cancer organizations and groups. The group members would need to understand, and appreciate, the value of working through a virtual community approach. Such an approach would not replace what they are doing in their delivery of human, face-to-face care, but it would augment their ability to access information and resources for their clients from other groups. Strategies would need to be implemented to achieve the buy-in required to implement a virtual community approach. These strategies would need to focus on education, promotion and financial concerns. Breast cancer groups are at different stages in their development of collaborative networks and, therefore, in their capability to provide leadership in implementing a virtual community. Some are ready and willing to begin implementing a virtual community approach such as is outlined above. With appropriate funding their efforts regarding a virtual community could serve as demonstration or pilot projects.

### **Recommendations to Health Canada**

1. Circulate this report to the appropriate representatives in all provinces/territories involved in breast cancer network development and to the national community capacity building committee, when it is established, for consideration of adoption and implementation of the virtual community model.
2. Make funding available for provincial/territorial breast cancer networks to implement the virtual community model within their respective regions, including funding for training and mentoring, and at a national level.
3. Take appropriate steps to ensure access to computers (ones that would allow participation in the virtual community) in local/regional governmental offices for representatives of breast cancer groups.

### **Recommendations to Breast Cancer Agencies/Groups**

1. Take appropriate steps to ensure access to computers (ones that would allow participation in the virtual community) in local libraries for group members or individual women.

2. Seek ways to provide mentoring for individual members who want to access the Internet, including skills in searching for information and assessing its credibility.
3. If the group has an Internet-based service, ensure there are easy links to other relevant breast cancer web sites.

### **Recommendations to Breast Cancer Networks**

1. Review the content of each provincial/territorial network of this report and assess own readiness to implement the virtual community model in own network area.
2. For networks that are ready/prepared to engage in establishing the private space aspect of the virtual community model, implement the ideas in a demonstration or pilot project approach.
3. For networks with current public Internet-based services, ensure there are easy links to partner organizations, web sites and other major cancer sites.

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## APPENDICES\*

- Appendix A** Members of Project Management Group and the Project Advisory Group
- Appendix B** Literature Search References
- Appendix C** Scanned Websites
- Appendix D** Survey 1: Goals for a Virtual Community
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- Appendix G** Virtual Community Workshop Materials
- Evaluation Form
  - Evaluations
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  - [www.gov.on.ca:80/MCZCR/english/citdiv/voluntar/mygo.htm](http://www.gov.on.ca:80/MCZCR/english/citdiv/voluntar/mygo.htm)

\*Not included. If you wish copies of some or all of the appendices listed, please contact the OBCIEP at [admin.obciep@cancercare.on.ca](mailto:admin.obciep@cancercare.on.ca) or call 416-351-3815.