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***Presented by The Sudbury Regional Breast Health Coalition
for the
Ontario Breast Cancer Information Exchange Partnership
Community Capacity Building Project
2001-2003***

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Section 1.0 Introduction

1.1 Background

In 2002 it was estimated that 20,700 women in Canada would be diagnosed with breast cancer and 5,400 would die of their disease (NCIC, 2002). When breast cancer strikes, its impact is felt in many ways: physically, emotionally, socially, psychologically, and spiritually. To make informed decisions about breast health, women and their family members need access to the right information presented in a user-friendly fashion at the time it is needed, regardless of where one lives. Individuals are demanding a more customer focused and interactive system for information exchange and support. The advent of Internet-based tools and computer technology affords the convenience, quality, and immediate access to information and facilitates communication and information exchange among support groups. (*Virtual Community Feasibility Project: Building Capacity for Tomorrow*, Final Report, OBCIEP, May 2000).

During the past several years in Canada many breast cancer groups have been developed for the purpose of sharing information and providing support for breast cancer survivors. More recently they 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, OBCIEP) and national (e.g., Canadian Breast Cancer Network) levels. By working together, these groups strive to avoid duplication, make the best use of scarce resources and better serve the needs of the women in their jurisdictions. A virtual community for breast cancer information and support makes use of web-based technology and various tools such as websites, bulletin and resource boards, hyperlinks to other sites, e-mail exchange, chat rooms, and document libraries to enhance the collaboration among a network of organizations and groups with a stake in the provision of breast cancer information and support.

1.2 The Vision

The OBCIEP vision of a virtual community model, is to enhance linkages and share access to information, to provide an inventory of all stakeholders and services within the network, and to facilitate the identification of information and service gaps, action plans, and new ideas. The vision of the breast cancer virtual community includes public sites accessible by anyone online hosted by various network member group organizations. These public sites are often hyperlinked to each other and are the responsibility of the owner group. The “private space” proposed for these sites would be password protected and is where the business of the network would be conducted. Fundamental to the success of this type of model is the participation by regional and local groups at the provincial level.

The Sudbury Regional Breast Health Coalition (SRBHC) in Ontario identified a need in its local and regional area to provide a source of information about breast cancer support and information services to a population often isolated across a wide geographic area. The SRBHC provided a proposal to the OBCIEP to become one of their pilot sites to develop a virtual community. Northeastern Ontario did not have a website listing all the resources available on breast health/breast cancer and it was recognized that more and more people were searching the web to have access to this type of information. Strategies were developed to reach the populations that are isolated from the larger centres or who do not have access to computers in their homes and/or require training to learn how to access services already available on the Internet.

1.3 Sponsoring Organization:

Ontario Breast Cancer Information Exchange Partnership

The OBCIEP is a coalition of organizations who have a stake in the dissemination of information about breast cancer. The Coalition emerged from the Ontario Breast Cancer Information Exchange Project, originally established in 1993.

The new Coalition has 37 member organizations and is committed to ensuring information about breast cancer is available to all people in Ontario. By providing a neutral forum for networking and information exchange at the provincial level, the OBCIEP fosters co-operative problem solving and co-ordinated action concerning issues related to breast cancer information dissemination. Whatever the activity, the fundamental philosophy of the OBCIEP remains in the forefront- that the development and dissemination of information about breast cancer be guided by those directly affected by disease.

In 1999 the OBCIEP began a feasibility study on the development of a national virtual community for breast cancer information and support. The Virtual Community project, that included a workshop held in Toronto in March 2000, 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.

This project, conceived as the first step toward establishing a virtual community, was funded through the Population Health Fund of Health Canada as part of the Phase II Canadian Breast Cancer Initiative focussing on Community Capacity Building.

1.4 Project Partners:

Co-Sponsors and Partner Organizations

Canadian Cancer Society – Ontario Division

The Canadian Cancer Society 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 fundraising efforts in communities across Canada.

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

The Canadian Cancer Society 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 Canadian Cancer Society's Cancer Information Services (CIS) or by contacting local Canadian Cancer Society offices. As well, the Canadian Cancer Society and CIS direct women to services in their local communities that will help them cope with their breast cancer. The Canadian Cancer Society also provides emotional support to women with breast cancer through programs such as 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. The Canadian Cancer Society 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.

Northeastern Ontario Regional Cancer Centre

The Northeastern Ontario Regional Cancer Centre (NEORCC) opened in 1990 and its mission is to control cancer and its impact on the people of northeastern Ontario, through partnerships with patients, their families and other individuals and agencies. Currently the Centre treats over 2,100 new cancer patients each year. Breast cancer is the largest cancer site.

The catchment area for NEORCC is 310,000 square kilometers and it services a population of 603,778 spread over the following districts: Algoma, Cochrane, Manitoulin, Muskoka, Nipissing, Parry Sound, Sudbury, Greater Sudbury Division and Temiskaming. NEORCC has developed several innovative programs with its community healthcare partners and is recognized provincially as a leader in providing cancer care "closer to home". However for some patients, travel and stay away from home is necessary to receive treatment.

NEORCC's involvement in this specific project included staff from the Library, the Prevention Program, the Ontario Breast Screening Program (OBSP) and the Sudbury Regional Breast Health Program (SRBHP). Its community partners were the Canadian Cancer Society, The Circle of Strength Sudbury Breast Cancer Support Group and the Sudbury and District Health Unit. NEORCC was in a unique position to host the pilot project, as there was a network of local and regional health care and support organizations already working together and grappling with the challenges of reaching remote communities over long distances.

Willow Breast Cancer Support & Resource Services

Willow Breast Cancer Support & Resource Services is a survivor-directed, charitable organization that provides information and emotional support to individuals diagnosed with breast cancer, their families, and caregivers, as well as to health care professionals dealing with the psychosocial needs of their patients. Founded in 1994 by a group of survivors, Willow Breast Cancer Support & Resource Services is committed to ensuring the accessibility to information and support to all communities including geographic, ethno-cultural, linguistic and disabled, through a Canada-wide toll free line, a comprehensive resource service, an interactive website, and training workshops.

1.5 The Sudbury Regional Breast Health Coalition

The SRBHC has representation from:

- **Canadian Cancer Society (Sudbury & District)**
Representing the agency: Nicole McGaughphey-Paparo,
- **Cancer Care Ontario/ Northeastern Ontario Regional Cancer Centre**
Representing the agency: current-Jami van Haften, Librarian, past-Claire McChesney, Program Leader for Prevention and Carreen O'Connor, Corporate Educator.
- **Circle of Strength/Sudbury Breast Cancer Support Group**
Representing the agency: Jane Pitblado and Anita Lovin
- **Ontario Breast Cancer Information Exchange Partnership**
Representing the agency: Irene Nicoll, Coordinator
- **Ontario Breast Screening Program-Sudbury Hub Site**
Representing the agency: Carolyn Jackson, Northeastern Ontario Administrator and Sharon Bowes, Health Promotion
- **Sudbury & District Health Unit-Main Office**
Representing the agency: Maureen McMillan, Public Health Nurse
- **Sudbury Regional Breast Health Program**
Representing the agency: Carole Mayer, Program Coordinator of Clinical Services
- **Willow Breast Cancer Support & Resource Services**
Representing the agency: Nancy Hammell
- **Project Coordinator**
Chantal Rancourt

- **Programmer**
David Evans, NEORCC
- **Secretary**
Rachelle Foster, NEORCC
- **Past Secretary**
Nicole Cummings, NEORCC

Services received from individuals outside the Coalition

- **Research Consultant**
Denise Gauthier-Frohlick, NEORCC
- **Logo Design**
Sandra Rinaldo, SDHU
- **Translation Services**
Cancer Care Ontario (CCO)

A Steering Committee was formed in the spring of 2001, representing a broad spectrum of services that included health promotion, screening, early detection, diagnosis, treatment, support and others. The Steering Committee hosted a Community Conversation Gathering called 'Building Community Networks for the "Breast Cancer Conversation Gathering Program" in April 2001. As a result of the presentations relating to existing resources and services in the community, and the open discussions concerning local needs, consensus was reached to develop a virtual community for people to have timely and accurate information about breast health/cancer, services available in the community and northeastern Ontario regions. The Steering Committee elected to form the SRBHC with the purpose of securing funding to pursue the development of a website. The Coalition submitted a proposal to the OBCIEP that was accepted under a broader proposal submitted by the OBCIEP through the Breast Cancer Initiative of Health Canada.

Section 2.0 Partnerships

2.1 The Goal

The ultimate project goal of the SRBHC was the creation of a virtual community for breast health/cancer information and support in northeastern Ontario regions.

2.2 The Objectives

The OBCIEP had three main objectives:

- The creation of a regional website for northeastern Ontario that would serve as a pilot project for the province.
- The development of a functioning "virtual community" for breast cancer information and support groups in Ontario.
- The facilitation of focus groups within their regions to determine the needs of the regional populations including French speaking populations, First Nations communities and older adults.

The SRBHC objectives were:

- 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. The committee wanted to enhance shared access to information about breast cancer and support resources.
- To enhance the links and working relationships between and among local and regional groups in northeastern Ontario.
- To provide access to an inventory of all the players/stakeholders in the network
- Facilitate access to state-of-the art, user-friendly information regarding breast health/cancer.
- Encourage communication and networking between women and groups within communities across the geographical area of the Northeast.

2.3 Partner Roles

The OBCIEP worked with co-sponsors the Canadian Cancer Society-Ontario Division, Willow Breast Cancer Resource & Support Services, and the SRBHC. The SRBHC also approached NEORCC to be the sponsoring agency for the project. The group received support from NEORCC for ongoing technical maintenance of the site. The Coalition will continue with the mandate to maintain the content of the website and explore potential further developments.

The project partners were involved in all stages of the project design, planning and implementation. As a member of OBCIEP, the SRBHC continues its mandate to work within the region to provide leadership and direction.

Section 3.0 The Project

3.1 Project Description

A virtual community uses Internet-based software and technology as tools to distribute information and enhance communication among groups and individuals. The model proposed by OBCIEP for the breast cancer virtual community was to enhance the capacity of stakeholder organizations to meet the need of providing breast cancer information and support. The SRBHC identified key stakeholders, services and information providers in order to develop their new website. Using a consultative process with feedback from focus groups and evaluation sessions, a user-friendly online resource was developed.

Since 1995 programs have been developed in the Sudbury area that meet the information needs of women and families affected by breast cancer. Listed are samples of initiatives that have enhanced the public's awareness about breast health/cancer:

- The OBSP and the Sudbury District Health Unit work very closely together to promote information about the importance of early breast cancer detection.
- The SRBHP has a resource library for women and men undergoing investigations for breast problems.
- A network of twenty breast health/cancer satellite libraries was established in the region in 2002 in addition to the existing patient library at NEORCC.
- Patients can call directly from NEORCC or from the HRSRH In-Patient Oncology Unit to the Cancer Information Line maintained by the Canadian Cancer Society. The Canadian Cancer Society materials specific to breast health and breast cancer are available to clients/patients through the SRBHP, NEORCC, HRSRH and others.
- The Circle of Strength/Sudbury Breast Cancer Support Group has developed information packages to be given to newly diagnosed breast cancer patients at the SRBHP. The recognition of the importance for patients and families to have timely access to accurate information is based on a needs analysis conducted in 1997 by Carole Mayer entitled *Bridging the Gaps in Breast Health - The Sudbury Regional Breast Health Program*.
- In October 2000, the SRBHP received funding from the Canadian Breast Cancer Foundation Ontario Division to host an education day "In Touch - A Festival of Breast Health". Eight agencies worked together to bring awareness to the public about breast health and the importance of early breast cancer detection.

Emerging from planning discussions around the OBCIEP Community Conversation Gatherings (*Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario*, Community Capacity Building Project 2000), the SRBHC proposed a pilot project to develop and implement a virtual community model. The proposal was the first stage in the implementation of a province-wide virtual community. Through the pilot project OBCIEP established and assessed requirements for working procedures, security, equipment, training and maintenance required to sustain a breast cancer virtual community. The experience learned in the northeast region was invaluable to the development of information technology resources for the breast cancer community throughout the province. The pilot project identified

implementation and access barriers and solutions to overcome those barriers. It also served to link the existing resources and websites among breast cancer support and information groups. Finally, through their needs assessment, planning and program implementation activities, it allowed ongoing collaboration and information sharing among breast cancer groups.

3.2 The Northeastern Ontario Breast Health/Cancer Website

The Virtual Community Feasibility Study (OBCIEP, 2000) 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 gathered, it was clear that a virtual community approach had the potential to enhance collaboration between and among stakeholder organizations in breast cancer. Two fundamental considerations were identified in moving forward to establish a virtual community. One was technology—currently the technology exists and the creation of a model as proposed in this document is fairly easy and is not extremely costly. The second consideration is the "buy-in" from breast cancer organizations and groups.

Based on these issues, it was important to begin the implementation of a province-wide virtual community in a focussed (e.g. regionally specific) manner. By working with an existing regional network of breast cancer agencies, organizations, and support groups, the OBCIEP learned about specific barriers to the success of a virtual community. The barriers identified in the 2000 Feasibility Project were used as the basis for early discussion and planning the implementation with the group in Sudbury. The pilot project needed to include opportunities for the following activities to be undertaken collaboratively with regional stakeholders:

- ◆ assessment of barriers/needs of potential users (members of the virtual community)
- ◆ exploration of opportunities to overcome barriers
- ◆ assessment of education and training needs
- ◆ design and delivery of education and training sessions.

The SRBHC, by virtue of their project idea, understood the value of working through a virtual community approach. This approach does not replace what they are doing in their delivery of human, face-to-face care, but augments their ability to access information and resources for their clients from other groups. The program leaders were committed to this pilot project and were eager to work with OBCIEP to find creative solutions to implement a virtual community model for Ontario.

On April 19, 2000 a meeting in Sudbury entitled "A Community Information Gathering" focused and examined the current and potential online services to aid and support breast cancer services in the Sudbury district and greater northeastern Ontario area served by the NEORCC. Guests included health care professionals, partners from community agencies and women who had been affected by a breast cancer diagnosis.

The first part of the evening focused on reviewing the breast health/cancer services that were available to women in the community. Presentations that followed focused on the information available to the public on breast health/cancer issues and how that information could be accessed e.g. the Canadian Cancer Society Information Line. Potential Information technology available to the group to develop a website was reviewed and explored. A professor from the School of Social Work at Laurentian University presented a research project entitled

“cybermoms”. Cybermoms” is a social work project conducted by researchers at Laurentian University where unwed mothers are provided with computers and online services in their homes to network with health care and social work professionals and each other. This successful project was seen as a potential model by the participants who saw the benefits of online communication. The librarians discussed the development of web pages and the services offered by the local community libraries that not only teach individuals to use computers and navigate the Internet, but also teach people to act as educators to teach others. Many remarked on these two particular presentations, as many attendees had not been aware of the “cybermoms” project or the services available through the local library service to assist patrons to access online services.

The second part of the evening was a brainstorming session where participants broke into four groups and considered questions related to the development of a breast cancer information and support website for the northeastern Ontario. The questions focused on who should keep the information current, what questions and concerns people had about the creation of a website, what important considerations (barriers) must be addressed, where should computers be available and who should conduct the training. The questions prompted many discussions of unresolved issues but all were in agreement that these issues required further discussion prior to the creation of a regional website. The staff at the NEORCC, who organized the session, produced a written record of the evening’s proceedings and it was part of the OBCIEP final report to Health Canada, *Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario*, June 2001.

A project proposal for the development of a breast health website for the region of northeastern Ontario and the development of a virtual community for breast cancer organizations was submitted to Health Canada April 4, 2001 and received formal approval in August 2001.

3.3 Getting Started

The initial step in the project was to establish a local working group that became the SRBHC. The group included breast cancer survivors, health care professionals, local representation from the project partners, Canadian Cancer Society-Ontario Division, Willow, and librarians. Members of the SRBHC are listed under section 1.5.

A provincial project group was also established to review the local group's progress and offer feedback on the test website. This group was:

Margaret Fitch*	Director, OBCIEP
Beth Easton*	Canadian Breast Cancer Foundation - Ontario Chapter
Raylene Godel*	Reach to Recovery Volunteer
Eleanor Nielsen*	Dragons Abreast (breast cancer dragon boat team), Reach to Recovery Volunteer
Patricia Payne*	Manager, External Relations, Canadian Cancer Society - Ontario Division
Dallas Petroff*	Executive Director, Willow Breast Cancer Support & Resource Services
Alison Ahara~/~	Bayview Support Network, Connecting Rainbows, Markham

- *members of OBCIEP Operations Group, based in Toronto
- ~ survivor group does not have website
- ≈ survivor group does have website

In addition the test sites for both the Sudbury Pilot Project and the OBCIEP were shared with all 37 Coalition and over 80 support groups and other breast cancer organizations currently communicating with the OBCIEP through e-mail.

3.4 Pilot Project

The project work began in September 2001 with a meeting between the Operations Group and partner sponsors in Toronto with local project representation from the SRBHC. In November the SRBHC met with the director and a representative from the NEORCC Information Technology (IT) Department to discuss the project and the IT's role in maintaining the technical integrity of the site. It was agreed that the NEORCC IT would support the technical aspects of the site and that the local project management group would be responsible for content on the site.

A work plan outlining the tasks, activities, responsibility, and timelines required to meet the project's objective was reviewed by the SRBHC. The search then began for a project manager. A candidate was finally chosen in December 2001 and subsequently refused the contract offer as another opportunity had arisen in the information technology field. The last-minute refusal of this candidate in January 2002 delayed work on the project until a new candidate was selected. At the suggestion of the information technology staff a candidate was interviewed who could manage both the technical development of the site and the project management components. This person was hired as both the site developer and project manager in March 2002. The Coalition began to review the contents of a booklet developed by the Circle of Strength SBCSG entitled an "Information Guide About Breast Cancer". It became the source of information to develop the site content. The original work plan was reviewed and timelines set for completion of the project objectives. **(Appendix I)**

3.5 Project Outcomes

Progress on Phase I is reported below according to the activities outlined in the project objectives:

Objective 1

Develop and implement a regional website concerning resources for breast cancer information and support for Northeastern Ontario.

The breast health website at www.breastnorth.info was developed for northeastern Ontario. Deciding on a format to display the information in a clear, user-friendly manner became a time-consuming challenge for the group. At the same time that members were learning how to edit and update the site, they were also committed to assuming responsibility for the site.

The learning curve to some degree slowed the completion of the site content. The task was projected to take three months initially but expanded to eight months due to changes in committee personnel and summer breaks. The project experienced two major changes in the fall of 2002. Two key personnel who represented NEORCC on the SRBHC retired. The person who had been hired as project coordinator and site developer/programmer, took a full time job in the IT Department. This person continued to participate on a part-time basis as needed to complete the web development, design, and the online training module. A new project coordinator was hired in September 2002.

Activities

1. Establish a shared vision of a virtual community in breast cancer information and support.

The SRBHC adopted the *Vision for Virtual Community for Breast Cancer Information and Support* document developed by the OBCIEP. (**Appendix II**).

2. Review/adapt new and existing information resources for inclusion on the site.

The review of the existing information was completed according to schedule but updating of material and particularly adapting the existing information to a website format proved a sizeable challenge. Some information needed to be verified and updated with assistance from other health professionals, which took additional time. Displaying the information in a clear, user-friendly manner became a time-consuming challenge for the group. At the same time, members were learning how to edit and update the site, as they committed to assuming responsibility for the site content and the learning curve to some degree slowed the completion of the site content. In addition, the SRBHC had committed to provide the site content in English and French. All revised or new content had to be translated in French, which extended the timeline for completion of the site content.

3. Design web page with links to other breast cancer information resource.

Links to other resources are included on the site and more will be added as content is updated on an ongoing basis.

4. Develop policies, procedures, security, access, etc. which will facilitate future implementation and links to other regional network websites across the province.

Disclaimer, privacy statements, publication procedures (**Appendix III**) have been developed for OBCIEP and the SRBHC that can be adapted for any regional or local breast cancer information and/or support site. Samples from other sites such as the Canadian Health Network, the Canadian Cancer Society, the Canadian Breast Cancer Network, Willow Breast Cancer Support & Resources Services, and Breast Cancer Action Ottawa were compiled for review.

5. Address identified barriers (see Table 1) to implement the virtual community concept in a diverse geographic area.

The chief areas of concern identified in the OBCIEP Virtual Community Feasibility Study, 2000 were largely economic. The costs of establishing and maintaining computer hardware, software and Internet access were identified as the major issues for breast cancer support groups. Focus groups conducted within and outside Sudbury in 2002 found that the majority of the population has access and some exposure to computer use and online searches.

Contacts were identified in libraries throughout northeastern Ontario, which provide training within their facilities. Contacts at health care community centres and treatment centres were also identified. However, neither equipment nor personnel resources for training were found in the First Nation's community. Given the time and financial limitations of the project this significant need could not be addressed in this project.

TABLE 1: Issues Perceived in Becoming Part of a Virtual Community, Virtual Community Feasibility Project, OBCIEP, May 2000

Type of Group	Percentage of Responses (respondents could answer more than one option)						
	Access to Internet	Hardware Costs	Software Costs	Set-Up Issues	Training Costs	Maintenance Costs	Security/Privacy
Professionals 11	27	36	36	27	27	18	18
Support 65	66	54	54	66	63	57	38
CCS Units 28	46	32	36	39	36	61	46
Hospitals/Programs 24	50	38	46	50	38	46	33
Cancer Centres 13	27	33	27	47	53	60	33
Networks/Coalitions 13	31	38	54	38	54	46	46
Other 17	12	12	24	18	35	53	41
Total = 173	47	41	45	49	49	52	36

6. Identify activities necessary to sustain the project beyond the pilot stage.

Arrangements were completed in the spring of 2002 for the NEORCC Information Technology Department to assume responsibility for technical site maintenance and the SRBHC to be responsible for content on the site. Given the challenge of finalizing the content for the site before it went "live" in early 2003, the Coalition, believing in the worth of the project, agreed to continue working together, in view of the need to ensure maintenance of the site as well as to provide a base for future breast health initiatives.

7. ***Develop, review and evaluate website with partners, community members, and survivors.***

Site evaluations were conducted in December 2002 with 24 participants (health professionals, survivors, NEORCC administrative and volunteer workers). Their comments were reviewed and addressed prior to completion of the site. The original Community Conversation Gathering group that assembled in April 2001 was invited to the formal launch in January 2003. The site address was also shared with the provincial project management group and the 80+ members of the OBCIEP Coalition of Stakeholders and Corresponding members for feedback.

Objective 2

Develop program or access to programs to enable training regarding accessing online information.

The results of the focus groups indicated that access and training were not major issues for the local population except in this First Nation's community. Access and training were only two of many barriers to the aboriginal population using the Internet as a health information source. As locations within local areas for training and use of computers and the Internet (such as public libraries, community centres, local high schools, etc) appeared to be well known within the community, the Coalition did not pursue the development of local training programs. It was agreed access information should be part of the promotional material circulated with the news release of the site for those who do not have access to the Internet at home or in the workplace.

Activities

1. ***Conduct focus groups in "hard to reach" populations in four areas, Chapleau, Elliot Lake and Wikwemikong Reserve.*** (Consent forms, Letters of Introduction, Participant Notes and Thank you letters were given to all participants) ***Appendix IV***

Focus Group Sessions (Detailed summary in ***Appendix V***)

A research assistant was contracted to manage the focus groups that were held in early October.

Chapleau - October 2, 2002

Focus Group Team: Denise Gauthier-Frohlick, Chantal Rancourt, David Evans, Irene Nicoll

Ten participants participated at this session held at the Chapleau Branch of the Sudbury District Health Unit office and many of the participants spoke French or were bilingual. All participants except one had experienced browsing the Internet and all were unanimous in agreement that a website for northeastern Ontario would be useful. The group named several locations in Chapleau where members of the public could access the Internet free of charge and in some cases received training. They provided many suggestions as to how to

promote the new site and names for the site and importantly offered detailed suggestions on the type of information breast cancer patients and their families might seek on the site. A short preview of the site was provided on a laptop computer for participants to see and provide feedback.

Elliot Lake - October 9, 2002

Focus Group Team: Denise Gauthier-Frohlick, Chantal Rancourt

Ten individuals participated at this session held at the Elliot Lake Branch of the Algoma Health Unit. Perhaps reflecting the age of the participants in the area only half of the participants indicated they used the Internet regularly or were comfortable with computers, but four rated their browsing skills at beginner level, three at intermediate level. The group provided suggestions on information to provide on the site, where local residents could access and receive training on the Internet, and how the site should be promoted in their area. Many felt a website would be useful to people in the community but did not want to lose personal contacts, through telephone connections or face-to-face meetings, with the advent of technology.

Wikwemikong Reserve - October 16, 2002

Focus Group Team: Denise Gauthier-Frohlick, Chantal Rancourt

Seven people participated at this session, most of whom were health professionals working in the area. The discussions revealed a number of barriers the Coalition felt could not be addressed adequately given the time and funding limits of the project. It was reported that few people on the reserve owned or had access to computers. The unemployment rate at the reserve was extremely high and there were significant economic issues for families. The participants indicated that the aboriginal population, particularly the senior members, would not access the Internet for information even if access was not an issue. Elders seldom participated at group information sessions.

It was the participants' impression that cancer is equated to death in the aboriginal community more so than in the general population, and careful approaches would be needed to even broach the subject without causing undue stress. It was learned that information needed to be provided at low literacy level, preferably in native language and in graphic/visual aid formats to encourage members of the community to use the materials. Treatment options should address traditional healing methods. As has been noted in other studies, breast cancer is not seen as the most significant health problem facing First Nations populations so efforts in this specific area may not have a responsive audience.

Despite these observations, it was confirmed that a breast health website for northeastern Ontario would still prove useful at this time for health professionals working on the reserve. Health care workers could print information from the site and review it while conducting home visits for a variety of health issues. It was noted that a broader initiative is needed to educate the aboriginal population about general health care, including all cancers, and the sources of information that are available.

Summary

Key findings from the Virtual Community Feasibility Project conducted in 1999-2000 indicated that 66% of the support groups anticipated difficulties with access to the Internet and set-up concerns that included: money to purchase computers/software; isolation human contact; storage for computer equipment if a group purchased it; access by ethnic and First Nations women; duplication of information already available online; and, misinformation on the Internet. Although it is important to caution that the findings may not be representative of the general population, the findings from the northeastern Ontario focus groups, excluding the findings from the First Nation's community, indicated that most people not only have access to computers either at work or at home, but almost all participants indicated they had some experience browsing the Internet.

The focus groups did not identify Internet access or online training were major barriers to accessing the site. Based on these results, it was determined that training for support groups and people affected by breast cancer, was not a critical component accessing the NEO breast health site or the virtual community. It was confirmed that training is provided free of charge at public libraries and at some health care centres, information well known to people in communities.

The situation in the Wikwemikong community was clearly more challenging. It was indicated that there was high unemployment on the reserve and it was estimated that over 80% of the population had neither access nor training on computers and the Internet. There was a health centre where training could be provided but it was determined that without personnel to oversee the training and computer use in the centre, the Pilot Project could not conduct training on the reserve effectively. The challenges of reaching populations on First Nations reserves was felt to be beyond the scope of the pilot project but was seen as an issue to be addressed.

2. *Develop linkages to other areas in the northeast outside Sudbury.*

Initially the Coalition planned to provide computers in locations in remote areas with a basic handout to assist those unfamiliar with browsing the Internet to provide access to health websites. At the Community Conversation Gathering held in Sudbury in April 2001 the first four locations specified as the best locations for computers for Internet access were cancer treatment centres, the NEORCC patient library, libraries, and lodges.

On examination of the availability of computers and potential locations available to the public, Sudbury was chosen because NEORCC and the Sudbury Regional Hospital have a mandate to provide oncology services for northeastern Ontario. One computer is located in the NEORCC Patient Library, and the other computer is located in the SRBHP. In addition, both locations had access to Internet lines (although separate lines were installed to prevent any possibility of "hackers" accessing the hospital's database) and supervision of those using the computers was not considered a barrier. North Bay was also chosen, as there is a high volume of NEORCC patients who receive chemotherapy at the hospital. Elliot Lake was identified as the fourth site based on the feedback received from the focus group and their eagerness to provide the information to their community.

3. Evaluation of training programs, usage, feedback from users.

As indicated local training programs were not developed but a training "template" was developed and shared with libraries, screening and treatment centres as aids to users. **(Appendix VI)**. Training locations were identified and confirmed with local training providers such as public libraries, community centres, and schools.

On December 5th and 6th, the test site was reviewed by 24 evaluators at NEORCC. Most were health care workers from the Cancer Centre and the Ontario Breast Screening Program. Four breast cancer survivors and three non-medical staff also participated. The participants were given a summary of the SRBHC's website pilot project. A website evaluation questionnaire **(Appendix VII)** was also completed by all evaluators and their comments **(Appendix VIII)** were compiled and circulated. The Coalition reviewed the comments and assigned priority to changes and/or new content to be completed prior to the site launch. This site content was reviewed, updated, approved and submitted for translation.

3.6 BreastNorth.info Promotion

The Project Coordinator demonstrated the test website on October 24 and 25th at the Howard Johnson Plaza Hotel, Caswell Conference Centre in Sudbury as part of the Building Healthy Communities Together - "Healthy Women - Healthy Communities" - Conference 2002 hosted by the Sudbury & District Health Unit **(Appendix IX)**.

This conference was designed for health care professionals, social services, older adult agencies, recreation departments, educators, etc. The Project Coordinator displayed a poster presentation and demonstrated the test site to about 30 people over the two days. Other promotional materials about breast health/cancer were also on display.

The site was also promoted through the evaluation sessions held in Sudbury at NEORCC in early December 2002.

The communication officer from NEORCC in consultation with the Coalition developed a communication support plan. **(Appendix X)**

The Regional Cancer Advisory Committee Northeast Regional Provider Network (RPN) for Prevention, Screening and Early Detection, part of the revised Cancer Care Ontario structure, partnered with the Coalition to produce 200,000 bookmarks and to purchase 5,000 pens to promote the site. The bookmarks were distributed to all the organizations listed on the website, hospitals, clinics, OBSP breast screening sites, community health centres and to the 150 family physicians in the Greater City of Sudbury. Also over 50,000 bookmarks and 2,000 pens were distributed to the District leads of the RPN for Prevention across northeastern Ontario. The remainder of the bookmarks and pens will continue to be used for promotional material at conferences, seminars etc.

Prior to the launch date, the Coalition worked diligently designing and sending invitations to different people in the community. The target audience was the management, staff and patients of NEORCC and HRSRH, organizations across the Northeast that are included in our website, local politicians and the list of attendees from the Community Conversation Gathering.

While some invitations were sent electronically others were sent by mail along with bookmarks and templates. **(Appendix XI)** A media release, targeting local newspapers, radio stations and television stations was also sent out on prior to the launch, followed by a media advisory. **(Appendix XII)**

The formal launch event was held February 26, 2003 and was covered by local media including the daily newspaper *Sudbury Star* and the local television network, *MCTV*. The taped interview was viewed on the 6:00pm news and on the 11:30 pm late night addition.

The *MCTV* news at noon edition had a live interview during the news at noon edition, the day after the launch. Radio interviews were aired in Sudbury in English on the *CJMX 105.3 Easy Rock* radio station, in the Parry Sound District on the Moose FM station, CKLP 103.3. The French radio station in Sudbury *Radio-Canada CBON 98.1* also aired an interview. An article was also published in the Elliot Lake local newspaper, *The Standard*.

The media across the northeast played an important role, making our website launch a success. **(Appendix XIII)**

OBCIEP highlighted the new website in the Winter/Spring 2003 issue of its newsletter *Breast Cancer Info Exchange*. The newsletter has a circulation of nearly 5,000 province-wide and nationally. **(Appendix XIV)**

HRSRH also promoted the website at the end of February in the 'Dialogue' the HRSRH Staff Newsletter **(Appendix XV)**.

In March 2003 SDHU newsletter Community Health Connections Volume 1(4) **(Appendix XVI)**

Since the site was launched, the feedback and comments received before and after the official launch have been very positive. The email address breastnorth@neorcc.on.ca is located on the website under the 'Welcome/Contact Us' module. The website was a 'good news' story and the organizations throughout the Northeast region were delighted that comments and feedback can be shared. Giving the organizations in the Northeast districts the opportunity to promote their organization and services on the site was clearly a positive accomplishment and outstanding responses have been received. The website is serving the needs of the vast northeast Ontario region that we live in. **(Appendix XVII)**

When developing the website it was the Coalition's intention to aid other groups that would have a similar project to create. The SRBHC has developed a template on "How to develop a community information website". **(Appendix XVIII)**.

Section 4.0 Key Outcomes of the Project

4.1 The key outcomes:

- A functioning website for northeastern Ontario, www.breastnorth.info , that contains updated breast health/cancer information and support resources as well as links to other relevant sites
- A structure and process to follow for replicating other sites in the province
- An evaluation of the website
- A Coalition of key stakeholders committed to sustaining the website

Section 5.0 Finances

5.1 Funding

Funding for this project was provided by a \$61,000 grant from Health Canada through the Community Capacity Building component of the Canadian Breast Cancer Initiative. The Regional Advisory Committee Northeast Regional Provider Network for Prevention, Screening and Early Detection donated \$10,000 for promotion of the website.

Section 6.0 Technology used on WEB

6.1 Technology overview

The web portal was written in ASP.NET and the Microsoft .NET Framework over a multi-tier application architecture. Dynamically-loaded user controls made possible cross-browser support for Netscape and Internet Explorer. ADO.NET and stored procedures provided access to the SQL database. Forms based authentication using a database for usernames/passwords and role-based security defined user access to portal content.

MESSAGE TO ONLINE READERS:

Due to length and format the Appendices are not included in this online version of the report. A full report will be posted online in future. In the meantime, those wishing a copy of the Appendices should contact admin.obciep@cancercare.on.ca.

