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# A formative evaluation of the Ontario breast cancer information exchange project

Michelle Marie Monforton-Everest
*Wilfrid Laurier University*

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# A FORMATIVE EVALUATION OF THE ONTARIO BREAST CANCER INFORMATION EXCHANGE PROJECT

By

Michelle Monforton Everest

Bachelor of Arts (Honors Psychology), University of Western Ontario, 1990

THESIS

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# ABSTRACT

In 1993 The Government of Canada allocated 2.7 million dollars to fund five Breast Cancer Information Exchange Pilot Projects for five years. The Ontario Breast Cancer Information Exchange Project (OBCIEP) is one site of this innovative approach to linking breast cancer stakeholders and women with breast cancer and coordinating available information sources to improve access to information about breast cancer for women, their families and health care professionals. Formative evaluations are conducted to learn from a novel program such as the OBCIEP. This paper outlines a collaborative approach to evaluation using qualitative methods and analyses The results of the evaluation are discussed in terms of community psychology and evaluation theory and practice, as well as the historical roots of the women's health movement

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# PREFACE

I think that it is important for the reader of this document to understand my connection with the subject of breast cancer and how I became involved in this research The beginning for me was facilitated by my involvement with a faculty that encouraged students to pursue academic goals that were personal in nature. Through a process of networking with many committed individuals, I eventually became connected with Sunnybrook Health Science Centre and Toronto-Sunnybrook Regional Cancer Centre which host the Ontario Breast Cancer Information Exchange Project. I feel the opportunity to conduct a process evaluation in collaboration with the Project membership has not only allowed me to apply and expand my community psychology skills, but to delve into an issue that has haunted myself and my family. My mother has lost two sisters to breast cancer. In our family, the disease appears early and is aggressive. I have always been aware of the effect the loss of my aunts has had on my grandmother, and the risk passed along to my mother. I have always ignored however, the effects that being in a high risk bracket for breast cancer has had on me. While the primary purposes of this research were to provide practical input to the OBCIEP and to complete a Master's level thesis, it also served to raise my awareness of issues related to breast cancer. In doing so, I have faced fears and been comforted by the dialogue that is occurring around action on this disease.

# INTRODUCTION

Breast cancer rates for Canadian women are the highest in the world except for women living in the United States. These rates vary across the country ranging from the low in Newfoundland to the highest in British Columbia (Gaudette, 1993). Improved screening techniques and resulting early diagnosis may be partially responsible for an increase in survival rates for women with breast cancer (Goel, 1993). Of every four women diagnosed with breast cancer, three will survive at least five years (Gaudette, 1993). Although survival rates have improved over the past decade, death rates have risen. Furthermore, rates of new incidences for breast cancer have had their greatest increase over this same period (Goel, 1993).

In September 1991, The Standing Committee on Health and Welfare, Social Affairs, and the Status of women of the Canadian Federal Government commissioned the sub-committee on the Status of Women to direct its efforts towards a study of breast cancer and breast implants. With regards to breast cancer, the goals involved raising awareness of the disease and tracking research dollars spent within the country. Chaired by Barbara Greene, M.P., the sub-committee's report was published in June 1992 with the title, *Breast Cancer: Unanswered Questions*. Two major findings were clear from this report. First, that serious knowledge and information gaps exist at various levels along the continuum of illness experiences for the individual woman with breast cancer and oncological specialists. Second, that the sub-committee was unable to determine how much money is being spent specifically on breast cancer research in Canada. The individuals responsible for this poignant document stated that they began to see themselves as "activists" as a result of this work (Greene, 1992, p.2). An official government response to the document and its forty-nine recommendations was requested within one hundred and fifty days. Three of the recommendations (#'s 10, 27, 28) pertained to "Centres of Excellence" for breast cancer.

In December of 1992, Benoit Bouchard, Canada's Federal Minister of Health, responded on behalf of the federal government to Breast Cancer: Unanswered Questions. The Government Response to the Fourth Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors, and the Status of Women on Breast Cancer outlined three important financial expenditures which supported the sub-committee's recommendations. First, twenty million dollars was allocated for breast cancer research over a four year period. Secondly, the federal government would fund a national workshop to discuss the state of affairs of breast cancer in Canada. Thirdly, there was a commitment made to support five "Centres of Excellence" or Breast Cancer Information Exchange Pilot Projects across the country for a five year period.

The significance of the second and third expenditures is that they incorporated an acknowledgment of the need for consumers to be involved in social action around the issues of breast cancer. Breast cancer stakeholders in North America have voiced their concerns and have used research and organization as advocacy tools. While the need to address inadequacies in our health care system through collaborative efforts with consumers is not new (Canadian Cancer Society, 1991; Greene, 1992), financial expenditures for this purpose have not occurred in the past with respect to breast cancer. The National Forum on Breast Cancer (NFBC) held in Montreal, Quebec in the fall of 1993 was the first instance of such funding. The Forum set out to explore four theme areas: Research; Prevention and Screening; Treatment and Care; and Support, Advocacy and Networking. A major purpose of this Forum was to engage women with breast cancer, researchers, voluntary workers, lobbyists, health care providers, policy makers and private sector representatives in dialogue in an effort to lay the foundations for resource mobilization and the formation of effective partnerships (NFBC final report, 1993). In essence, the NFBC was a step towards acknowledging the toll that breast cancer has taken on our families and our communities. It provided a significant catalyst for social action about breast cancer in Canada.

The second commitment by the federal goverment to collaboration for breast cancer is through the federal funding of 2.7 million dollars over five years to five Breast Cancer Information Exchange Pilot Projects. Breast cancer stakeholder organizations across the country submitted proposals to host the projects. In the end, pilot projects were established in five regions: namely, Atlantic Region, Prairies and the Northwest Territories Region, British Columbia and Yukon Region, Quebec Region, and Ontario Region. Each region has developed its own set of objectives to respond to the respective regional needs. Each is working to achieve the objectives set out by the Disease Prevention Division, Systems for Health Directorate at Health Canada. These include:

- to assist persons living with breast cancer, and their families, care givers, and those at risk of contracting breast cancer in making informed decisions about a variety of concerns related to breast cancer
- further our understanding of the feasibility and effectiveness of various information strategies

- encouraging partnerships among all those involved in the collection and dissemination of breast cancer information (Health Canada, Breast Cancer Initiative, Summer 1995).

In essence, the projects are working to address the issues that women and other stakeholders have identified as important. It is a novel funding approach designed for information sharing. The Ontario Breast Cancer Information Exchange Project serves the Ontario Region. It is housed at the Toronto-Sunnybrook Regional Cancer Centre (T-SRCC) and hosted jointly by the T-SRCC and Sunnybrook Health Science Centre (SHSC). Its organizational structure includes a Project Team, Executive Committee and an Advisory Panel. The Panel consists of representatives from over twenty-five breast cancer stakeholder organizations in Ontario. Over fifty per cent of the positions on the Advisory Panel are occupied by breast cancer survivors. It is the body that is responsible for setting the strategic direction for the Project.

The OBCIEP exists as an infrastructure which links the many organizations that have a role in breast cancer in Ontario. They are not a front-line provider of but are designed to be a catalyst for cooperation and concerted planning around the disease for stakeholder organizations in Ontario. They provide neutral ground for organizations to exchange information about each other's mandates, activities, and resources. This central connection, which was previously lacking in Ontario, is a communication network that hopes to avoid duplication of efforts and fill informational gaps regarding breast cancer that still exist for women, their families and health care providers. The OBCIEP objectives acknowledge the role of its partner organizations as the front-line providers of breast cancer information in

Ontario and its unique role as a catalyst among the existing organizations. The objectives that guide the OBCIEP include:

- facilitating easy access to state-of the-art, user-friendly information regarding breast cancer and other breast concerns
- serving as a catalyst for cooperative activity regarding exchange of information about breast cancer and other related concerns
- filling identified gaps, when appropriate, in collaboration with partners

The day to day activities of the Project include maintaining communication with the stakeholder organizations in order that they remain connected to the Project. This is necessary so that the representatives are able to participate in setting the strategic direction at bi-annual Advisory Panel meetings. The Project also plays a role in raising awareness about the on-going roles, activities and resources of the Project partners. This is accomplished in large part by the publication of a newsletter twice a year and information bulletins (Appendix 3). OBCIEP activities designed to identify or fill identified gaps in information are accomplished through workgroups which consist of Advisory Panel representatives, Project Team members and students.

Due to the unique nature of the pilot projects and the enthusiasm and hope that has been placed on collaboration/stakeholder consortiums as a means towards making gains with regards to social action on breast cancer, evaluation is mandatory. Program evaluation offers the opportunity for assessment and feedback in a timely fashion for the purpose of program improvement, accountability, and/or assessing its efficiency and effectiveness. Formative evaluations are designed to assist the programs themselves by measuring criteria of interest and the program's goals and objectives (Posavac and Carey, 1992). For this purpose to be achieved however, the program must be evaluable (Rutman, 1977), and the methods used to assess processes or outcomes must be designed appropriately. The overall goal of program evaluation is more simply, to improve the quality of client centered services (Posavac and Carey, 1992). In order to gain knowledge about an innovation like the OBCIEP, formative evaluations that focus on how members perceive the facets of the organization are useful (Dearing, 1994).

A formative evaluation of the Ontario Breast Cancer Information Exchange Project serves three distinct purposes. The first two purposes were desired by the OBCIEP. First, it provides an opportunity for OBCIEP stakeholders, especially breast cancer survivors to voice their views about how the Project is doing, and provide input about Project activities and foci. Second, it provides the Project itself with practical information at the mid-point of its funding period that will highlight successes, identify perceived weaknesses, and help plan future directions. Third, it contributes to the available literature about collaborative action research for the discipline of Community Psychology. The discipline of Community Psychology offers an ideal paradigm for conducting program evaluations in the health care sector. Most appropriate when discussing women's history with health care and traditional medicine, it offers the opportunity for consumer empowerment through the conducting of collaborative evaluations that provide practical feedback to the program itself and the clients served (Patton, 1990; Parlett and Hamilton, 1976, in Patton, 1990). The paradigm offered by this discipline is ideally suited to evaluating the functioning of a unique stakeholder consortium which provides an infrastructure for the exchange and diffusion of health information in an effort to empower consumers and catalyze action around breast cancer.

# LITERATURE REVIEW

## Community Psychology

In addition to serving distinct purposes for the program itself, the formative evaluation of the OBCIEP was developed into a Master's of Arts thesis in Community Psychology. It is useful to understand the academic training and background offered by this discipline in order to appreciate its appropriateness for conducting this research project. The development of community psychology as a separate and distinct entity within academic psychology developed during the 1960's as a result of the growing unrest within the discipline. Particularly the case with clinical psychology, there was a concern for the lack of attention to socio-environmental factors which contribute to community mental health crises (Heller and Monahan, 1977; Serrano-Garcia, Lopez and Rivera-Medina, 1987). Issues of concern during the sixties included an over reliance on, and unproved effectiveness of, mental health treatment facilities and psychotherapy in meeting the needs of consumers (Heller and Monahan, 1977).

Community psychology as a discipline evolved from many directions within academia including, psychology, sociology, social work, and anthropology. Its specific roots can be traced to a conference held in May 1965 in Swampscott Massachusetts (Heller and Monahan, 1977; Serrano-Garcia, Lopez and Rivera-Medina, 1987). Community psychology maintains a multi-disciplinary focus to this day. This has been beneficial because it makes a variety of tools and approaches available to practitioners who are committed to working towards social change by resisting the status quo (Serrano-Garcia et al, 1987). This inter-disciplinary history however, may partially contribute to the fact that community psychology is still finding its way as it tries to articulate the values and ethics which are to guide research and action.

In 1980 the Canadian Psychological Association formally recognized the sub-discipline of community psychology (Walsh, 1988). This occurred at a time when community psychology in the United States was undergoing an identity crisis of sorts. Although there is evidence that there are distinctions between Canadian and American versions of the discipline (Walsh, 1988), the American influence on Canadian academics is very real. As the American arm of community psychology was struggling to identify its niche and articulate its purpose, the influence on areas of theory, practice and research were felt throughout North America (Rappaport, 1981).

The primary distinction between community and other areas, especially clinical psychology in the 1960's was a shift from treatment and rehabilitation to a focus on prevention (Heller and Monahan, 1977). In 1981 Julian Rappaport stated that it was because the discipline had not moved beyond its focus on prevention that it had become stagnant. His belief was that the term prevention carried with it the connotation of "need" as opposed to "rights" for individuals. Furthermore Rappaport felt that prevention also carried with it the suggestion of "professional experts as leaders" (Rappaport, 1981). In place of prevention an empowerment model was proposed to revitalize the discipline and re-focus research efforts. The suggestion was to move beyond the narrow sphere of mental health and work towards proactive collaboration with "whole" individuals and communities (Rappaport, 1981). Empowerment however, has been a troublesome term for community psychology due to the difficulty in specifying its definition.

> The concept suggests individual determination over one's own life and democratic participation in the life of one's community...psychological sense of personal control or influence and a concern with actual social influence, political power and legal rights (Rappaport, 1987, p. 121).

Practitioners of community psychology offer an ecological perspective which looks at individual, small group, and community levels of analysis and intervention. The challenge to this approach involves remaining focused on the positive aspects of mental health and fostering skills to emphasize community strengths. In order to do this there must be an awareness and avoidance of the negative connotations associated with viewing psychological well-being from a pathological standpoint (Heller and Monahan, 1977). This is especially true when carrying out interventions with populations who have been adversely affected by the inequitable distribution of socio-economic, political, and legal resources. Through collaborative efforts with consumers, community psychologists can work to facilitate the conditions for individuals to have the opportunity to empower themselves through peaceful and democratic means. To ensure a more equitable research relationship between academics and consumers, community psychology has come to use participatory or collaborative research approaches where "the people studied make decisions about the study format and data analysis"(Reinharz, 1992). In order to be effective and appropriate, community psychology researchers must be committed to applying their skills through collaborative research efforts if they are to return power to our communities and avoid the connotations of control that are associated with the professional label.

Perhaps the way around, as well as towards, a definition of empowerment is to engage in research such as that of John Lord and D'Arcy McKillop Farlow. They have explored the suggestion (Kieffer, 1984, in Lord and Hutchison, 1993) that in order to help define the phenomenon of empowerment which is described as "the process whereby people move from being dependent and powerless to feeling a sense of control and participatory competence"(Lord and Farlow, 1990), we must study individuals, and groups of people, who feel a sense of control over their life situations and the ability to deal with societal circumstances. In the absence of an agreed upon "phenomenon of interest" for community psychology, as well as in the wake of the debate as to whether or not such a construct is necessary (Rappaport, 1987), community psychologists attempt to forward the discipline through the conducting of value-based research that is useful from both a practical and a theoretical standpoint. Such work is termed action research.

> Action research is based on a cyclical process whereby the researcher carries out the investigation, applies the results through a planned intervention, and then follows this up with an evaluation (Serrano-Garcia et al, 1987)

## Evaluation

> The purpose of applied research and evaluation is to inform action, enhance decision making, and apply knowledge to solve human and societal problems...The art of evaluation includes creating a design and gathering information that is appropriate for a specific situation and particular decision-making context (Patton, 1990, pp. 12-13)

Michael Patton defines evaluation as "any effort to increase human effectiveness through systematic data-based inquiry" (Patton, 1990, p. 11). When this "examination of effectiveness is conducted systematically and empirically through careful data collection and thoughtful analysis" (Patton, 1990, p.11), it is called evaluation research. The social sciences expanded the art of human service evaluations in the 1960's as a result of the need to assess the effectiveness, and to some extent monitor the many government-sponsored social programs that were proliferating in North America. Programs characteristically were aimed at assisting individuals and families in lower socio-economic stratas. Large expenditures towards innovative human and social service projects mandated assessing the utility and effectiveness of such programs (Posavac and Carey, 1992). The term effectiveness however, is multi-faceted. The challenge faced by social scientists was to develop evaluation methods that were suited to assessing the processes and outcomes of human service programs without relying on the historical tendency of assessing success exclusively by monetary return. Appropriate evaluation research was to include indicators of program success that acknowledged societal priorities such as individual and community health and happiness. (Posavac and Carey, 1992).

## Qualitative Methods

When an evaluation study is appropriate (Rutman, 1977) and desired, it is imperative to apply the most suitable research method. While quantitative and qualitative methods of data collection are not mutually exclusive in evaluation studies, one, or a combination, might be most appropriate to a given situation. Qualitative methods are especially suited to evaluation research when the focus is not on the program's desired outcomes, but on its processes (Patton, 1990). Process evaluations are designed in order to take a more in-depth look at program activities and desired outcomes, as well as informal details of the program such as stakeholder interactions (Patton, 1990). There has been an evolution in skilled evaluation techniques which have moved away from purely scientific methods applied by professionals, to a more collaborative, organization-centered approach. Some assumptions of qualitative research include: a commitment to understanding people and programs within their own context; that the inquiry will be non-intrusive and focused on what is naturally occurring in the program; and finally, it is assumed that the strengths and weaknesses of the program will emerge from the inductive analysis of the qualitative data which is obtained in a personal manner (Parlett and Hamilton (1976), in Patton, 1990). In order for these three assumptions to be fulfilled, the process of evaluation must be truly collaborative from beginning to end. The evaluator, stakeholder groups, and the program itself must have shared values and purpose in order for an effective qualitative research process to develop.

> Participatory evaluation...a process controlled by the people in the program or community. It is something they undertake as a formal, reflective process for their own development and empowerment ( Patton, 1990, p 129).

## Qualitative Methods - Tools

> Qualitative methods permit the evaluator to study selected issues in depth and detail (Patton, 1990).

The open-ended interview is one method of data collection that permits evaluators to study selected issues in depth and detail. A basic approach involves the use of standardized questionnaire guides which delineate a sequence of questions to be asked of research participants. The intention of this tool is to ask each interviewee each of the questions in the same words and sequence (Patton, 1990). The limitations imposed by standardized open-ended interview protocols involve reducing the "flexibility and spontaneity" (Patton, 1990, p. 280) of participant responses. The advantages however, include reducing the opportunity for interviewer bias to be introduced and easing the process of data analysis.

## Qualitative Methods - Analysis

> Because each qualitative study is unique, the analytical approaches used will be unique (Patton, 1990, p. 372).

Data analysis is facilitated through the use of standardized open-ended interviews since the delineated questions are organized according to the topic areas that are of interest in the evaluation (Patton, 1990). Where the program evaluation involves interviewing multiple stakeholder groups with the same interview protocol, cross-case analysis can be a useful method for organizing the emerging data. Cross-case analysis involves incorporating responses from different people, or groups of people, to individual questions or simply analyzing participants' differing perspectives according to the specified topic areas. The data is then organized according to emergent themes which describe important program processes such as decision making and communication. Collaboration between the evaluator and program stakeholders ensures that issues of interest are identified and assessed. Qualitative data collection and participatory evaluation techniques result in studies which provide practical information and serve to humanize social science research (Patton, 1990).

## Women's Health Movement

Yet another significant example of social change that occurred in the 1960's involved the growth of a movement among women that challenged male-centered societal values. In particular, the women's health movement gained momentum throughout the 1960's to reject a patriarchal system of health care that focused on disease and abnormality, rather than women's experience of health and illness (Cogswell and Arndt, 1980). Through organization, questioning, and articulating needs, the rights of professionals to make unchallenged judgments (Posavac and Carey, 1992) was yet again being scrutinized.

## Information

The quest for health information was central to the women's health movement. The movement of the 1960's and early 1970's is characterized by a number of activities aimed at improving the health status of women. The goal of the movement was to regain control of health by regaining knowledge of women's bodies which have been historically relinquished to the male dominated medical establishment through societal structures and medicalization (Koehler-Reissman, 1983). "Consciousness-raising" activities such as developing a body of literature, discussion of herstories, and various attempts to demystify the language of scientific medical knowledge were used to facilitate the process of women regaining control over their health. The women's health movement has laid the foundation for advocacy around breast cancer. Women and their families have clearly articulated their need and desire for pertinent and timely information and input into health decisions. Prior to presenting at the NFBC, the Support, Networking, and Advocacy (SAN) sub-committee surveyed breast cancer survivors for their views on their experiences with information on treatment, care and diagnosis, and their needs for support, networking and advocacy. Of the 2272 questionnaires distributed to treatment centres, support groups, Canadian Cancer Societies and through informal networks throughout the country, 1150 women responded rating the importance of the information they received at diagnosis and their satisfaction with that information. It was indicated by these respondents that the types of information they wanted most was about their medical condition, the possible physical effects of cancer, treatment options and their side effects. The next group of information that was most sought by women at the time of diagnosis was about relieving physical discomfort, being able to talk to other women with breast cancer, information on diet and nutrition, information on available services, and where to go for information (SAN, 1993) Lussier and Martel of Vie Nouvelle, a Montreal-based self-help group for people with cancer, heir families and friends, participated in a poster session at the NFBC which indicated that of the 204 respondents to their 1990 needs assessment, 68.6% of the clients said they did not get enough information about their medical condition (Lussier and Martel, 1993). The need for current and timely information is in the fore-front for women from the earliest stage of diagnosis through to recurrence and palliation (Canadian Cancer Society, 1991). In many cases women with breast cancer are unsure where to get the information they need (OBCIEP Consortium, 1993).

> The problem today is less a shortage of knowledge than a shortage of capacity to sort and select knowledge from all that is readily available (Eveland, 1985, p.3).

## The OBCIEP as Innovation

An innovation is "an idea, practice, or object that is perceived as new by a unit of adoption" (Rogers, 1983, in Eveland, 1985, p.3) and a "departure from the status quo" (McKinney, Barnsley, and Kaluzny, 1992, p. 284). The "essence of diffusion is change"

(Eveland, 1985, p. 8), making diffusion theory a form of social change theory in which the innovation is accepted or adopted because it is the "right thing to do" (Dearing, 1994, p.23). The history of the academic study of diffusion of innovation dates back to the 1940's and has multi-disciplinary roots not unlike those of community psychology. The focus of diffusion of innovation research in the past has focused more on variables related to the adoption of an innovation. Novelty is inherent to innovation. The success of a new approach which is gauged by diffusion and adoption, will be facilitated if the innovation is in touch with the needs and values of potential adopters, and does not differ too radically from the established way of doing things (Zaltman, Duncan, And Holbek, 1973, in McKinney et al. 1985). The success of an innovation depends on the diffusion of the ideology of the innovation (Dearing, 1994, p.24). While the focus on innovation adoption has produced much valuable research and scholarly debate, for the past decade diffusion of innovations models and research have focused more on the implementation of innovations (Dearing, 1994). James Dearing, a communication theorist specializing in diffusion theory and research states that the shift in focus for diffusion of innovations research has occurred due to a need to reflect on "what the diffusion of innovations model has, and has not taught us about social influence and change in modern societies" (Dearing, 1994, p.3)

It is important to understand the development of an innovation in order to learn from it. Since the success of an innovation is often a long-term prospect, assessing its effects are difficult, if not impossible (Dearing, 1994). Formative evaluations are well suited to studying the implementation of an innovation because by using proximate measures of behavior changes that are related to the processes, you glean information about innovations that are not fully developed or implemented (McKinney et al, 1992). This information can be used for feedback or reinvention purposes, while also contributing to innovation diffusion theory (Patton, 1977, in Eveland, 1985).

The establishment of five federally funded Breast Cancer Information Exchange Pilot Projects is considered an innovation . As a collective whole they have been established to facilitate networking among breast cancer stakeholders and prevent the duplication of efforts The Ontario Breast Cancer Information Exchange Project (OBCIEP) with its regional perspective is an innovation that seeks to provide an infrastructure for information exchange among breast cancer stakeholder organizations in Ontario. The hope is that through this structure, information about breast cancer will be shared and diffused throughout the province through OBCIEP partner organizations. It is valuable to evaluate the processes by which the OBCIEP is operating at its mid-point in order to learn how this unique pilot program has been implemented and operating to date.

# OBCIEP PROGRAM DESCRIPTION

## Background

It is important to note that a coordinated effort among breast cancer stakeholders was cited by Bouchard, as the most constructive way to address the knowledge and research inadequacies uncovered by the sub-committee on the Status of Women (Greene, 1992). The National Forum on Breast Cancer (NFBC) was the first time that breast cancer survivors sat down with oncological "experts" to discuss the issues. The Information Exchange Pilot Projects were created with this same vision in mind. Breast cancer stakeholder organizations across Canada submitted proposals to host the projects.

In Ontario, a breast cancer stakeholder consortium was formed in May 1993 to prepare and submit the proposal to receive funding from the federal government, Department of Health Canada, to operate the Ontario Breast Cancer Information Exchange Pilot Project. The consortium consisted of five representatives from the Toronto-Sunnybrook Regional Cancer Centre and Sunnybrook Health Science Centre (an Oncology Nurse Researcher, RN, Ph.D.; Medical Coordinator of the Breast Screening Program, M.D.C.M; A psychologist, Ph.D, C.Psych ; A Health Promotions Manager, M.S.; And an Assistant Administrator, M.H.Sc), and representatives from twelve partner organizations: Alliance of Breast Cancer Survivors, Bayview Support Network, Canadian Breast Cancer Foundation, Ontario Division of the Canadian Cancer Society, Centre for Health Promotion at the University of Toronto, Community Hospice Association of Ontario, National Council of Jewish Women, Ontario

Breast Screening Program, The Volunteer Network of the Ontario Breast Screening Program, Ontario Public Health, YMCA and OCTRF Division of Epidemiology and Statistics. What became clear to the proposal development team was that Ontario was in a rather unique position relative to other Canadian regions in that a variety of breast cancer stakeholder organizations were already established. It became apparent however, that these organizations were not communicating with one another which had resulted in the duplication of efforts. The Ontario Project made a concerted effort to design its role not as another front-line provider of services, but as a catalyst for cooperative activity among existing organizations to avoid the duplication of efforts and fill gaps in information. The submission was successful. The OBCIEP Advisory Panel has been increaseds to include other organizations than the original partners that have a role in breast cancer (Appendix 2).

## Goals and Objectives

The ultimate goal of the Pilot Projects, as defined by Health Canada, is:

> to assist persons living with breast cancer and their families, caregivers, and those at risk for developing cancer in making informed decisions about a variety of concerns relating to breast cancer.

The OBCIEP works to achieve this goal by operating in accordance with its program objectives which include:

- facilitating easy access to state-of-the-art, user friendly information regarding breast cancer and other breast concerns
- Serving as a catalyst for cooperative activity regarding exchange of information about breast cancer and other related concerns
- filling the gaps, when appropriate, in collaboration with partners

## Organizational Structure

The Ontario Breast Cancer Information Exchange Project consists of three primary organizational bodies and work groups which encompass the program's personnel resources (Appendix 1). Work groups are established as necessary to enlist membership participation in specific projects or activities.

The Advisory Panel consists of thirty representatives from all of the breast cancer stakeholder organizations who are partners in the OBCIEP, many of whom are breast cancer survivors. One family member also sits on the Panel. (Appendix 2). It is perceived as the guiding force of the Project. Over fifty percent of the positions on the Advisory Panel are occupied by breast cancer survivors.

The Project Team is responsible for the day to day operation of the OBCIEP. This team is comprised of five representatives from the Toronto-Sunnybrook Regional Cancer Centre, Sunnybrook Health Science Centre and a Project Coordinator. The Project Coordinator is the one full-time staff person in the OBCIEP.

The Executive Committee is a link between the Advisory Panel and the Project Team. It consists of the six members of the Project Team and five members of the Advisory Panel who are breast cancer survivors. The Executive ensures input and guidance from the survivor's perspective for the Project's operational activities.

The OBCIEP is unique among its peer projects in that the operational services are provided by a multi-disciplinary team. The "expertise" for the Project, however, is spread among the Advisory Panel. Some of the general qualifications and experience provided by the partner organizations, breast cancer survivors and family members include:

- experience in delivering cancer care information to hard-to-reach, diverse populations, linking with community-based organizations, volunteer development
- experience with and knowledge of the breast cancer care system
- access to intended audience groups and experience with media relations
- experience with networking and social marketing
- expertise in information diffusion
- expertise in fund-raising and access to the corporate sector

## Activities

The OBCIEP has organized its activities into three main themes. Different members of the Project Team provide leadership for each theme area. The major activities for each theme, and their desired outcomes, are outlined in the program logic model (Table I). The following section identifies the foci of each theme. Note that "encouraging cooperation among stakeholder organizations" as mention in Theme 1 occurs through all parts of the Project.

### Theme I: Coordinating Breast Cancer Information

The activities within this theme relate to the linking of existing resources, and encouraging cooperation among stakeholder organizations.

### Theme II: Access to Information By Women and Their Families

The activities within this theme involve responses to gaps in breast cancer information identified by women and their families.

### Theme III: Access to Information by Health Care Professionals

The activities within this theme relate to overcoming the barriers faced by health professionals in accessing state-of-the-art information about breast cancer.

## Program Principles

All Project activities are guided by the program principles which include:

- the Project is survivor-driven
- Advisory Panel sets the strategic direction for the Project activities
- the Advisory Panel has Ontario-wide representation
- the Project is a catalyst for organizations involved in breast cancer information exchange, rather than a front-line service provider

## Consumer Contact

The individual consumer can come into contact with the OBCIEP both directly and indirectly. Although "Unanswered Questions" (Greene, 1992) originally conceptualized Centres of Excellence along a "clearinghouse" model, this is not the direction that the Project has chosen to take. This was a conscious effort based on the environment of Ontario which has a number of breast cancer stakeholder organizations in operation. The OBCIEP has chosen to be a catalyst for cooperative activity among these organizations rather than another front-line service provider. A person (whether representing himself/herself, or an agency) desiring specific information regarding prevention, treatment, or emotional support may make a direct "request for information" from the OBCIEP. In this case there would be a referral made to an appropriate organization. This redirection maximizes the use of existing resources, and avoids duplicating services that are already provided by the OBCIEP's partner organizations. It is believed that the stakeholder groups within OBCIEP are best suited to know the various diffusion strategies needed to reach the diverse intended audience groups which require breast cancer information. For the most part, the majority of consumers come into contact with the Project indirectly, through those organizations. For that reason, it is difficult to estimate the numbers served by the OBCIEP.

### Funding Sources

The OBCIEP is funded by the Health Services Directorate, Health Programs and Services Branch, Health Canada. The funding period is five years, to be terminated March 31, 1998. The OBCIEP, like the four other Information Exchange Pilot Projects, receive a total funding amount of five hundred thousand dollars ($500,000) for five years. The Project receives one hundred thousand dollars ($100,000) each year in quarterly payments of twenty-five thousand dollars ($25,000). The annual disbursement must be spent by year end, which is March 31 of each year. Additionally, the host facilities, Toronto-Sunnybrook Regional Cancer Centre and Sunnybrook Health Science Centre provide office space and facilities free of charge. The project is eligible to apply for funding from other sources on an ad-hoc basis. The

OBCIEP is committed to exploring the option of continuing the Project beyond the five year commitment made by Health Canada, if so directed by the Advisory Panel.

## Budget

The Advisory Panel is responsible for approving the activities and is briefed on the projected expenditures. How the money is spent is operational, and therefore detailed approvals occur at the Project Team level. Health Canada has relatively little input into the specific direction or nature of expenses.

# PURPOSE OF THE EVALUATION

## Goal

The overall goal of the mid-point evaluation is to assess the processes by which the Ontario Breast Cancer Information Exchange Project is operating at the end of year two, of its five year Health Canada funding period, and to determine if changes are required. In other words, to answer the question "How is the OBCIEP doing"?

## Objectives

The specified objectives of the evaluation are:

- to develop a better understanding of communication among OBCIEP stakeholders
- to assess the clarity with which the OBCIEP stakeholders view the Project, and their role within it
- to examine the Project activities and processes to date, and make future recommendations

The goal and objectives were developed by the evaluator in partnership with the Project Director and Coordinator. While the Advisory Panel had given approval to conduct a mid-point evaluation at the previous Advisory Panel meeting, the entire membership had the opportunity to approve the specified evaluation goals and objectives after an oral presentation and brief discussion at the semi-annual meeting held on April 22, 1995. Four members of the Panel self-selected to participate in a visioning and discussion roundtable with myself and the Project Director regarding the mid-point evaluation.

# RESEARCH CONSIDERATIONS

## Evaluability of the Program

According to Leonard Rutman, a program can be evaluated if and only if certain criteria are met (Rutman, 1977). First, the program must be explicitly articulated. The Ontario Breast Cancer Information Exchange Project is clearly articulated. Accurate information is kept regarding project direction. Some of these records include:

- keeping minutes of all Project Team, Advisory and Executive meetings
- keeping a membership list and up-dated list of activities
- developing a "Request for Information" form for tracking purposes
- writing quarterly, and annual reports
- budget updates

Second, the goals, and/or the outcomes of the program must be clear. The definitive aim of the project is clearly articulated, and outcomes have been stated. The Project Team and the Advisory Panel are ultimately responsible for specifying project outcomes.

Third, a rationale should link the program to the stated goals and/or effects. The activities and specified outcomes of the OBCIEP are consistent with the program objectives (see Table I). It was concluded that the OBCIEP satisfied the preconditions for an evaluable program.

## Research Challenges

A number of challenges to the evaluation process had to be identified and overcome:

### Developing trust between the evaluator and the OBCIEP membership.

This was achieved in part by identifying that the evaluator and the stakeholders of the OBCIEP shared the same values and vision for the evaluation. These links were enhanced by practicing inclusivity in decision making and defining evaluation roles and responsibilities early in the research process.

### Maintaining consumer/stakeholder participation through all phases of the work.

The success of the formative evaluation was facilitated by having stakeholder participation throughout the evaluation process for guidance and a check on relevance. The consumers on the Executive Committee of the OBCIEP served as an informal evaluation committee to the evaluator. Initial drafts of the methodology and interview protocol were circulated for input and approval by the Executive Committee. Other members of the Advisory Panel had the opportunity to assist and advise at the semi-annual Advisory Panel Meeting. This occurred as part of the "Round Table" agenda item of the April 22, 1995, Advisory Panel meeting. Members self-selected to participate in a forty minute discussion and visioning exercise with myself and the Project Director.

Achieving evaluation goals within desired time period and within allocated resources.

The entire membership of the OBCIEP meets twice a year. This restriction on meeting opportunities necessitated a research schedule which would have a draft of the mid-point evaluation report ready for the November 18, 1995 Advisory Panel meeting. This allowed the entire membership the opportunity to be presented with a written draft and hear an oral presentation of the report, as well as review recommendations. Recommendations were also reviewed with the Executive Committee and the Advisory Panel prior to inclusion in the final evaluation report. Creative use of allocated time and resources to reach evaluation goals were achieved by maintaining a close working relationship with the Project Director and Coordinator. The process of data collection was facilitated by an enthusiastic and supportive OBCIEP membership who efficiently scheduled interview times.

### Ethical Considerations - Risks and Benefits

It was believed that there were no risks associated with the research. Participation in the evaluation was entirely voluntary, and confidentiality was assured by the evaluator. Among the benefits that participants may have gained as a result of their participation in the evaluation included the opportunity to provide input openly and confidentially regarding the OBCIEP structure, activities, and processes. Additionally, participants received a preliminary report which included the Advisory Panel findings for discussion at the semi-annual Advisory Panel meeting held on November 22, 1995. Formal Project recommendations received approval from the Project's Executive Committee and Advisory Panel prior to inclusion in the final evaluation report.

## Ethical Considerations - Confidentiality

All interviews were conducted by the primary researcher. Audio-tapes of the interview sessions were transcribed by her, and erased subsequent to data analysis. At no time would a participant's name be used in relation to the data in any discussion or report. Maintaining the confidentiality of the Health Canada representative is more difficult as she is identifiable as the official liaison for the five Breast Cancer Information Exchange Pilot Projects. This participant had the opportunity to review a draft copy of the OBCIEP mid-point evaluation report and endorse or revoke her permission to use specific excerpts from her interview.

## Communication of Findings

Throughout the evaluation, the Project Director , Project Coordinator and myself "checked-in" to update progress, incorporate interim feedback, and make necessary changes. This assured that support for the evaluation was maintained through a collaborative research relationship. The mid-point evaluation findings were communicated in a variety of ways. First, a draft preliminary report was circulated prior to the November 18, 1995, Advisory Panel meeting so that participants would have the opportunity to discuss the Advisory Panel research findings. Second, I presented the findings orally and discussed the process of conducting the research at the semi-annual meeting. Finally, members received a copy of the final report which included the accepted evaluation recommendations by mail in April 1996 .

# METHODOLOGY

## Design Considerations

The approach to the evaluation was guided by the needs of the OBCIEP and conducted in consultation with the Project Director and Coordinator as noted by the following:

1. A variety of data pertaining to the OBCIEP were reviewed so that an historical perspective on the Project was appreciated and its organizational structure was understood. Included in these materials were such documents as the original proposal to operate the Project, minutes of Project Team, Executive Committee, and Advisory Panel meetings, activity and resource information kept by the Project Coordinator, and annual reports. The objectives of the evaluation, time, and budgetary constraints did not allow for in-depth, systematic analysis of these documents. The information contained however, was taken into consideration when planning the evaluation and in considering the emerging data during the analysis phase.
2. The mid-point evaluation was qualitative in nature. Due to the focus on process, this mode of inquiry was deemed most useful.
3. The study took the form of a stakeholder approach to information gathering. Data was collected from the Advisory Panel members, Executive Committee members, and Project Team members, as well as a representative from Health Canada. All thirty-six members of the OBCIEP were potential interviewees for

this study. One hundred percent of the OBCIEP membership agreed to participate and were interviewed for the mid-point evaluation.

4. The evaluation design evolved in collaboration with the Project Director and Project Coordinator. Additional input was sought on an ad-hoc basis with the OBCIEP Executive Committee and the Advisory Panel when feasible in order to incorporate the input and suggestions of members who were breast cancer survivors.
5. Where appropriate, ethics approval was sought and received by the Wilfrid Laurier University Ethics Review Committee.

## Data Collection

The active data collection process consisted of my organizing the logistics of the personal interviews with the Project Team and telephone interviews with members of the Advisory Panel and Executive Committee. The first three interviews were treated as pilot interviews for fine-tuning the standardized open-ended questionnaire. Each interview was audio-taped and transcribed. Transcriptions were used for purposes of data analysis. At the time of each interview participants were asked and, or informed of the following.

- permission to audio-tape the session
- research records would be kept confidential. No names or identifying information would be used in discussions or reports
- participation in the evaluation was entirely voluntary. The participant could refuse to answer any question or withdraw from the study at any time
- feedback of the evaluation findings would be presented at the Fall 1995 Advisory Panel meeting

All interviewees agreed to become involved (n=37). All interviews were conducted between August 1, 1995, and September 10, 1995. The methodology used for the evaluation consisted of document review and a standardized open-ended interview guide.

## Research Questions

The research questions were designed to measure topic areas that were of interest to the Project. Information diffusion literature base was used by the Project as a foundation for the interview questions. The research questions were designed to assess members' perceptions about the OBCIEP's attributes. These include participants' thoughts and feelings about: the objectives, activities and principles; their ability to contribute to Project directions and decisions; their perceptions of the role the OBCIEP is playing and its potential future role within breast cancer spheres. The final interview protocol was approved by the Executive Committee prior to the commencement of data collection (Appendix 4). Pilot interviews and approval by the Executive Committee which includes breast cancer survivors, served to provide a check on credibility of the tool. A modified interview guide was designed for the Health Canada representative (Appendix 5). Where appropriate, additional open-ended or response-driven questions were asked of interviewees along with, or in lieu of pre-defined questions for the purposes of clarification or to further explore emerging themes.

# DATA ANALYSIS

The method of qualitative data analysis is inductive in nature. Of interest was what was collectively stated by the Advisory Panel members, Project Team, and the Health Canada representative. Since the Executive Committee consists of representatives from the Advisory Panel and Project Team their information is not presented separately, but rather within the context of their Advisory Panel or Project Team status. A matrix was created to organize the data by research question for the Advisory Panel members (Table 2). The emerging themes within each stakeholder group were assessed. More specifically, the analysis involved the following aspect.

- a total of thirty seven interviews were audio-taped. All interview tapes were transcribed verbatim by the evaluator. Only basic verbal and no expressive content such as pauses or emphatics were included in the transcriptions.
- a hard copy of the data was printed.
- a matrix was constructed in order to organize the data and ease the process of first round data analysis for the Advisory Panel members' interview data. This involved identifying overall themes, response patterns, and operational suggestions that evolved from the interview data. In addition, the matrix offered the opportunity to go over the evaluation results with the Project Director and Project Coordinator while maintaining the confidentiality of participants.
- the general question categories were used as broad framework categories for the first round of analysis within each stakeholder group.
- the second round of analysis allowed sub-themes and unexpected findings to emerge by way of analytic induction.
- quotations were used when reporting the research to illustrate emerging themes and to personalize the findings wherever possible.

# RESEARCH PARTICIPANTS

The research participants for the mid-point evaluation consisted of thirty (30) members of the Advisory Panel, six (6) members of the Project Team, and one Health Canada representative. All potential interviewees for this study agreed to participate in the mid-point evaluation.

## Advisory Panel

The participants from the OBCIEP Advisory Panel included thirty (30) members (29 female, 1 male). Fifty-three percent (53%) of the Advisory Panel is occupied by breast cancer survivors. Thirty percent (30%) of members were involved in the original proposal development stage of the Project, fifty-three (53%) joined at the commencement of the Pilot Project, and seventeen percent (17%) have been involved less than two and a half years. Fifty-seven percent (57%) of the Advisory Panel members perceive that they represent a stakeholder organization, ten percent (10%) see themselves as representing a breast cancer support group, and seven percent (7%) feel they represent both a stakeholder organization and support group. Twenty-three percent (23%) perceive that they provide individual representation on the Panel. Three percent (3%) stated that they represent a non-stakeholder organization. Half (50%) of the Advisory Panel members are involved in aspects of the OBCIEP beyond their Advisory Panel role. This would include participating in working groups, reviewing documents, etceteras. Thirty-seven percent (37%) are involved solely with the Advisory Panel. Thirteen percent (13%) sit on the Executive Committee.

### Project Team

The participants from the Project Team consisted of five (5) health professionals (4 females, 1 male) involved with cancer care at Toronto-Sunnybrook Regional Cancer Centre and Sunnybrook Health Science Centre. This includes the Project Director. The sixth participant from the Project Team was the Project Coordinator.

### Health Canada

The participant from Health Canada served as a key-informant to the mid-point evaluation. Health Canada was interviewed in an effort to gain input from the full range of stakeholders involved with the Ontario Breast Cancer Information Exchange Project. This perspective in particular, is unique in that it provides a national perspective. The interviewee oversees the five Information Exchange Pilot Projects across the country and has an early history of involvement with government funding of recent breast cancer initiatives.

# THE FINDINGS

All participants were provided with a list of the OBCIEP objectives, principles and activities which was used as a reference tool during the interview session (Appendix 6). Analysis of the interview data resulted in the identification of five (5) broad theme areas across stakeholder groups. These included:

- thoughts and feelings about the Project objectives and activities
- thoughts and feelings about the Project principles
- decision making and connection to the Project
- the contributions of the OBCIEP
- whether or not the OBCIEP should continue at the end of its funding period

The findings within each of the broad categories are reported separately for the Advisory Panel, Project Team and Health Canada to allow for the response pattern within stakeholder groups to be illustrated and sub-themes to be explored in more detail. Quotes are used to illustrate the themes and to provide a voice to participants.

## Regarding the Objectives and Activities - Advisory Panel

One hundred percent (100%) of the Advisory Panel members feel that the OBCIEP is making steady progress towards its objectives. The major factors that were identified as those that might hinder the Project's progression towards its objectives included:

| | |
|---|---|
| 23% | participation/membership issues |
| 22% | politics, organizations being territorial |
| 15% | funding |
| 10% | size of Ontario |
| 10% | no hindering factors perceived |
| 20% | other miscellaneous factors |

Ninety percent (90%) of respondents feel that the theme activities are helping the Project meet those objectives, and nobody felt that they were not. Three percent (3%) were unsure that the activities are useful in meeting the OBCIEP's objectives. It was inconclusive from seven percent (7%) of the interviews whether or not this was the case.

### Future Activities and Directions

Some suggestions for future activities and directions that the Project might undertake were provided. Most Advisory Panel members felt reaching health professionals should be a focus of future Project activities.

> I know there has been talk about a handbook for health professionals
>
> There is the gathering of the information and there is the making sure it gets out. (health professionals) don't look for information. Some do, but most don't, and the information has to be fed to them.
>
> Access to information by health professionals. We definitely have some gaps there...To make them aware of what we are lacking and how the information can be shared.

The most common future Project direction suggestion was an emphasis on recurrence and palliation.

> I guess the other thing is that you are never really cured so there is also the after. Whether it is the medical or psychological supports.
>
> Processes need to be initiated so that people can approach that difficult time as comfortably and in control as possible
>
> Long term aspects, particularly in terms of new chemotherapy for the treatment of recurrent or metastatic breast cancer.

Other activities and suggested directions for the future included:

- focus on prevention and awareness

- discuss genetic predisposition to breast cancer and its inherent ethical considerations
- exploring user-friendly public education information via electronic links
- research on the environment and its role in cancer
- coordinate breast cancer support groups
- explore multicultural issues

Regarding the Objectives and Activities- Project Team

All six (6) Project Team members felt that the OBCIEP is making progress towards its objectives. Factors that were identified as those that might hinder the Project's progression towards its objectives included:

- time, energy and resources
- challenges to collaboration within a politically charged environment

Most team members were concerned about the workload exacted by the Project and stated concerns about membership participation in Project activities.

> The overall sense of where we are with activities is that I don't think we can keep up at the pace that we have been going. Yet, expectations are that we should at least keep up if not do better. I think we are at a bit of a crisis around activities. We can't possibly keep the excitement level at what it was at the first year.
>
> There is just a concern that I think I have with that...I think there is a lot going on. One thing I would really like is the Advisory Panel to start taking control of some of these things as well. We may not be here after five years. For example, the guide, who is going to keep that updated? How is that going to be done? That kind of thing. I think we need more buy in from the Advisory Panel members. Even for them to take control of some of these activities that we have identified as important.
>
> The major issue for us is grappling with how much you actually roll up your shirt sleeves and actually do the work of filling the gap versus how much you try and convince somebody else to do it.
>
> All of us feel we are strained for time. Its just awesome to try and keep up with the amount that we generate. Its been like that since the Project inception and it hasn't stopped. I think personally that we have approached times, particularly

> for the Project Team, we sort of approach burnout and manage to veer away from burnout. It is still a very realistic possibility if we are not careful.

All respondents felt that the theme activities are helping the Project to meet those objectives as indicated by their response to question number fifteen of the interview protocol (Appendix 4).

### Future Activities and Directions

All Project Team members made reference to moving along the spectrum of care and being more involved with palliation and recurrent disease informational issues in the future. Other suggested activities and directions included:

- issues affecting hard to reach groups such as families in the North and aboriginal/first nations groups
- assistance for the children of women with breast cancer

### Regarding the Objectives and Activities - Health Canada

The liaison identified the first two objectives of the OBCIEP as in keeping with what Health Canada had specified as appropriate in their request for proposals. A specific reference was made to the third OBCIEP proposal "to fill identified gaps, when appropriate, in collaboration with OBCIEP partners".

> This last one is an addition. It was not specific in the call for proposal that we wanted the projects to develop materials. The emphasis was a lot more that we know there is a lot out there, just make sure it gets to the right people. If it is a bonus that they develop material, that is great.

The liaison felt that the OBCIEP was making steady progress towards those objectives. The large geographic area that the Project is charged with covering was noted as a factor that might hinder the progression towards the objectives. A national perspective was offered.

> One difficulty that I find common across the country is the large area that the Projects have to cover. I think in a way Ontario is quite fortunate when I compare to the Prairie provinces, which includes Manitoba, Saskatchewan, Alberta, and the Northwest Territories. They really have a big problem because they are dealing with four different provinces, four different health care systems. Ontario is one central, they all operate the same way, under the same health care system. So that is an advantage, by comparison to the others. But it is still a problem.

It was noted that monetary factors might hinder the Project's progression towards its objectives.

> "We are very much aware that the resources for this Project are too small."

### Future Activities and Directions

The interviewee indicated that Health Canada's role was not to dictate activities or directions for the Projects, but to support and assess their effectiveness. She definitely felt that the Project activities were helping the OBCIEP to meet its objectives. Specific comments about the current activities were as follows,

> I find that it is quite impressive. The benefits go back to the core group. It is amazing how much time these people give to the Project. It is incredible. We are fortunate because it is pretty well standard across the country. Everybody has dedicated to the cause. The approach that they have taken here, Ontario is quite different from any of the others by looking at three different themes. They are not focusing only in one area, so it is quite nice what they are doing.

When asked about future directions for the OBCIEP, there was praise for some of the ideas that had been noted in the Project's strategic plan regarding advanced disease and palliation.

> They want to look at facing the fact that it is a disease that is not always cured. It is fine to help women get information about when we discover a lump, but it doesn't stop there. Although there is so much to do in discovering a lump, I think the whole spectrum is quite important too. I am really happy they are looking at the wider picture.

Regarding the Principles - Advisory Panel

Seventy-three percent (73%) feel the OBCIEP principles are practiced within the Project. Thirteen percent (13%) have a concern with one of the five principles. For example,

> There is a problem with Ontario-wide representation. We've tried and we continue to try. It is not that easy to get Ontario-wide representation.
>
> I don't agree that the Advisory Panel sets the strategic direction. The AP meets every six months...I am not sure enough people are able to attend meetings sufficiently regularly in order to set the strategic direction.

Four percent (4%) have concerns with more than one of the principles.

> I don't agree that the Advisory Panel sets the strategic direction. I think some would argue that it does because the word ""strategic" is in there. Strategic always makes everything look very broad, and anything can be strategic. It doesn't set the direction, it kind of endorses it, maybe... And the Unconventional Therapies book was being a provider of information.

Another four percent (4%) did not feel they knew whether or not the OBCIEP principles are practiced within the project. Six percent (6%) of the interviews yielded inconclusive results.

### The Role of Survivors

The Advisory Panel members' feelings about the role of survivors and the Panel's role in setting the strategic direction for the Project were probed. Some of the notable excerpts about survivor input include:

> I think it has been quite vocal and up front in anything that I have been involved with. I think it has really given me, as a health professional, a different perspective that I needed to hear. I find it really helpful.

> I think it is the most important part of the whole thing. The survivors have found that they have not had the proper treatment sometimes. Or they have been in a decision situation where the information is not available and they don't have enough knowledge to know in which direction to go. I think the whole project revolves around the survivor and what does the survivor need from the doctor, from the community, from the government, from the research that comes out.

> I see it happening. I believe it is happening. I hope there is not a we-they situation. I don't get that sense.

### Survivor-driven

There were wide ranging interpretations about the principle regarding the survivor-driven nature of the Project.

> I don't know how much work is done by the professionals and how much work is done by survivors. It is a question I have.

> I think there is a danger that one could get too carried away with the survivor driven aspect of it. I think there are a lot of different people that have things to contribute who may not necessarily be survivors...I think there is room for balance there because it is a social problem that affects many many people besides the women and men who are directly affected by the disease.

> This is exactly the way I feel about what is needed. It has to be survivor-driven, and it is.

> That is an asset, because you have been there. You know what is needed out there in the public. That is a must

## Strategic Direction

Some notable excerpts regarding the Advisory Panel's role in the Project outlines the differing perspectives of the term "strategic direction".

> I think there has been occasions where I have wondered if any of the things we have talked about or recommended were being put into action...I have to remember we are advisory. They don't have to use verbatim what we are suggesting. It is taken under advisement and further discussed by the Executive Committee which has more operational responsibilities than we do.
> I think that is one of the things about the Project, I think the members do have a voice in setting the agenda. No question.
>
> I think the Advisory Panel members are given enough information that they are quite well able to support the direction or give input. I think the AP is involved. I think their suggestions and comments are respected. I think they have a lot of input.
>
> ...when it says the Advisory Panel sets the strategic direction, I think it is a wonderful principle, but I am not sure there is a mechanism whereby Panel members would actually vote on going this way or that way. Taking path A or path B...Its not a criticism, it's a comment.

## Regarding the Principles - Project Team

All six (6) of the Project Team members felt the OBCIEP principles are practiced within the Project. More specifically, the answers included:

> "Yes, and we work hard to try and adhere to it. If we feel we are getting off the rails, we try to bring it back on"
>
> "I think they are being worked on, all of them"
>
> "I think in general, yes. I think so"
>
> "Very definitely...from my perspective, yes"

Overall, there was a feeling that the OBCIEP has been true to its role as a catalyst to cooperative activity and that Ontario-wide representation has been a problem. Specific questions probed the Project Team members' feelings about survivor input and the role of the Advisory Panel in setting the strategic direction for the Project.

### Survivor-Input and the Survivor-Driven Nature of the Project

Project Team participants were asked specifically about their thoughts and feelings about the survivor input within the Project and generally about the Project principles which includes "the Project is survivor-driven". References to the terms survivor input and survivor-driven were sometimes used inter-changeably or together in a response. Some of the specific response excerpts from the Project Team about survivor input included:

> It is essential not only because it is politically appropriate, but because the thrust for these projects was really survivor-driven. It is a process of accountability in some ways.
>
> Survivor involvement can at times be a double-edged sword. Without a doubt we have certainly had some experience where people have had certain special interests which is not the full context of the Project. It is sometimes hard to make certain that the survivors themselves feel comfortable working within that full context.
>
> I value it two hundred percent. I think that we try to incorporate that on a number of different levels, the Executive Committee, Advisory Panel, working group levels and even informally checking it out with various survivors. So I think it is really key. We really can't make full decisions without their input.
>
> "It is a real challenge."
>
> I think it is central to the working of the Project. Some of the comments I made earlier also allude to the fact that it is important. It is the driving force. How you achieve it is the crucial part, so that survivors feel they have the input and that input is being acted on. I think sometimes we can fall down because

> we act on what we are given, but may not complete the communication loop that shows people how we have acted on it. As I say, to me it is crucial, front and centre. Within the Project Team we really try to keep close tabs that we are true to that principle.

The Project Team members also spoke of their perceptions and concerns about the survivor-driven nature of the OBCIEP in referring to the Project principles.

> I think we should always make sure when we are striking a working group that there is a balance between survivor representation and professionals Maybe even weighing more on the survivor side, because that is appropriate. I know we have had criticism of people feeling that they were token in a working group.

> ... there is a major portion of some of the conceptual work that isn't necessarily survivor-driven. Beyond that point the Project has always been very very careful to make certain there is survivor involvement.

> I think survivor-driven is only partially successful. I think that is always only partially successful in enterprises like this. I am not feeling particularly disappointed about it. I think we have learned some things about it. I'm sure there are other people who will be disappointed about it... I don't think it is ever entirely successful...

> Survivor input is very important, but so is everyone else's whose life is touched by breast cancer, including professionals. I think we might need to expand that to say that it is survivor-driven and health care driven as well.

Regarding the Principles - Health Canada

While the Health Canada representative would be unable to assess whether or not she felt the stated OBCIEP principles were practiced, there were some general comments made about the principles.

> They are very good. They include certainly everything we had in mind when we started thinking of these Projects. It has to be survivor driven was a weighted requirement. The panel had to be fifty per cent survivors, and it is

> happening. Ontario-wide representation, I don't know how much you can do. I think that an effort has been made, and that is not easy. A catalyst, that again is what we were hoping.

The interviewee felt that she was unable to specifically assess the role of the Advisory Panel setting the strategic direction for the OBCIEP.

> I think you are fortunate here to have a core group that does an awful lot of the work. If the panel is happy with that. I think that is where the problem might be. If the panel were to feel excluded, but I don't know if they do.

## The Role of Breast Cancer Survivors

Some dialogue ensued on the issue of the role of survivors within the OBCIEP and the survivor-driven nature of the Project.

> My feelings are really from an outsider point of view, from talking to a few people that I have met in meetings. I have the feeling that people are quite happy. There are exceptional women. I haven't met every one of them, but some of them have impressed me tremendously, total devotion.

## Making Decisions and Feeling Connected - Advisory Panel

Overall, forty-six percent (46%) of Advisory Panel members feel involved in the decision making processes of the Project. An additional seven percent (7%) also feel involved in the Project decisions, but attribute this to their role with the Executive Committee. Thirty-seven percent (37%) of respondents did not feel involved in the OBCIEP decisions. An additional ten percent (10%) also did not feel involved in the decision making processes, but qualified their responses by saying that was by choice. These people felt that the Project was accessible to becoming more involved.

Thirty-six percent (36%) of the Panel members feel connected to the Project during the time period in between Advisory Panel meetings. Seven percent (7%) stated that they feel connected at times, and an additional seven percent (7%) could not respond due to non-attendance at Advisory Panel meetings. Most importantly, fifty percent (50%) of respondents do not feel at all connected to the OBCIEP between meetings. Some comments to note included:

> Yes, no question in my mind about that. I am with this other sub-committee and I feel connected in that way.
>
> Sometimes, depending on whether I am involved in something. So sometimes yes. Its a long period of time in between, but I have found that as time has gone on we get more mail more frequently.
>
> Not really. I don't really feel connected and part of that is because I am busy doing other things. I read the things that come in. You read it and you put it away and you don't see anybody for six months.

The Executive Committee was formed at the first Advisory Panel meeting in order to bridge the time gap between semi-annual meetings and to provide a mechanism for survivor input to be shared with the Project Team on a more regular basis. Forty-three percent (43%) of Advisory members see the formation of the Executive as being useful to the Project. Seven percent (7%) did not see the Executive Committee as a useful tool, and seventeen percent (17%) were unsure about this point. Thirty-three percent (33%) of the interviews yielded inconclusive results in this regard.

## Making Decisions and Feeling Connected - Project Team

The Project Team of the OBCIEP is responsible for the day to day operations of the Project. In this respect team members are intimately connected and tied to the decisions of the Project. The principles of operation dictate that the Project operates in response to the strategic direction of the Advisory Panel which is comprised of fifty per cent survivor membership. Viewpoints and concerns were voiced with regard to the Project Team's perception of the Advisory Panel's role in setting the strategic direction for the OBCIEP.

> I think that has been difficult because we only meet twice a year and because there is so much business at the meetings. I think we have attempted to try and make that happen, but probably not with huge success. Probably more strategic direction has arisen from the Project Team than is ideal. Again, I don't know whether it is possible to really change that and continue to be productive. I think there is a real tension there.
>
> The Advisory Panel gives advice, that is why it is called an Advisory Panel. It really made sense to me, so I am starting to feel that they provide the strategic direction very generally.
>
> I don't really feel that the Advisory Panel has set the strategic directions consistently the way I originally envisioned. I recognized at the beginning perhaps that there would be a little more direction, but I was hoping by now we would see more issues being raised by members of the Advisory Panel. I am just not seeing that yet...I imagined by this point in time in our life that the Advisory Panel would be much more outspoken, forthright. That they'd be bringing issues to the agenda from their respective organizations, bringing ideas. I don't see that happening...The Executive Committee has begun to take a more active role at the panel meetings.

## Making Decisions and Feeling Connected - Health Canada

The Health Canada participant was unable to assess this facet of the Project. She is professionally connected to all five pilot projects and has been involved with this breast cancer initiative prior to its request for proposals.

## Advisory Panel Meetings - Advisory Panel

The fact that eighty percent (80%) of respondents feel in touch with the Project at the semi-annual Advisory Panel meetings signals the importance of such meetings for connecting the Panel and enabling input. Ten percent (10%) of Panel members did not feel connected to the Project at these meetings. This question was not applicable to seven percent (7%) of the members due to non-attendance, and the results were inconclusive for three percent (3%) of the interviews. Additionally, ninety percent (90%) of the Advisory Panel find the semi-annual meetings useful and informative. Three percent (3%) did not, and the question was inapplicable to seven percent (7%) of members.

### Highlights and Lowlights

There were definite trends in the responses to members' feelings about the high points of the Advisory Panel meetings.

| | |
|---|---|
| 56% | networking/information sharing |
| 20% | project updates |
| 14% | roundtables |
| 20% | other miscellaneous responses |

Forty-three percent of the Panel felt there were no low points of the Panel meetings. Low points that were noted included:

| | |
|---|---|
| 22% | long day |
| 14% | long presentations |
| 7% | little or no opportunity for input |
| 14% | other miscellaneous responses |

### Meeting Attendance and Clarity

Due to the importance placed on the semi-annual Advisory panel meetings for membership input and feeling connected to the Project, analysis was undertaken to explore Panel membership attendance patterns in relation to clarity about the OBCIEP mandate and its audiences. Clarity of the Project mandate would include the interviewee making some reference to the OBCIEP as a vehicle to provide access to information about breast cancer/ benign breast disease during the interview session. Clarity of the audiences reached by the Project would include references to women, families, and health care providers.

## TABLE 3 ATTENDANCE AT AP MEETINGS AND CLARITY OF OBCIEP MANDATE AND INTENDED AUDIENCES

| | # OF MEETINGS ATTENDED | | | | |
|---|---|---|---|---|---|
| | 4 | 3 | 2 | 1 | 0 |
| TOTAL SAMPLE | 30% (9) | 30% (9) | 23% (7) | 10% (3) | 7% (2) |
| clear about OBCIEP mandate | 56% (5/9) | 56% (5/9) | 86% (6/7) | 67% (2/3) | 0% |
| partially clear about OBCIEP mandate | 22% (2/9) | 33% (3/9) | 14% (1/7) | 33% (1/3) | 0% |
| unclear about OBCIEP mandate | 0% | 11% (1/9) | 0% | 0% | 100% (2/2) |
| inconclusive from interview | 22% (2/9) | 0% | 0% | 0% | 0% |
| clear about OBCIEP audiences | 11% (1/9) | 11% (1/9) | 0% | 67% (2/3) | 0% |
| partially clear about OBCIEP audiences | 11% (1/9) | 44% (4/9) | 29% (2/7) | 0% | 50% (1/2) |
| unclear about OBCIEP audiences | 78% (7/9) | 22% (2/9) | 71% (5/7) | 33% (1/3) | 50% (1/2) |
| *of which* | | | | | |
| • *mention OBCIEP partner organization* | *57% (4/7)* | *50% (1/2)* | *20% (1/5)* | *0%* | *100% (1/1)* |
| • *mention support groups* | *0%* | *50% (1/2)* | *60% (3/5)* | *0%* | *0%* |
| • *other* | *43% (3/7)* | *0%* | *20% (1/5)* | *100% (1/1)* | *0%* |
| inconclusive from interview | 0% | 22% (2/9) | 0% | 0% | 0% |

### Advisory Panel Meetings - Project Team

The Executive Committee within the OBCIEP serves as a mechanism to provide more frequent survivor input to the entirely non-survivor membership of the Project Team. Most of the Project team members made a reference to the semi-annual Advisory Panel meetings as an important forum for gaining wider membership input and strategic guidance. Most team members specifically stated that they found the semi-annual meetings useful and informative. The majority also felt that their involvement with the Project has contributed to networking and breast cancer awareness raising in a personal and/or professional manner.

### Highlights and Lowlights

High points of the Advisory Panel meetings for the Project Team included:

- reaching tangible goals through concrete vehicles
- presentations by Advisory Panel members
- roundtables, issue feedback, and idea generating discussion
- networking with members and celebrating successes

Low points that were noted were as follows:

- expressions of special interest, self-serving agendas, non-collaboration
- too much review, long presentations
- low energy, no dialogue or active feedback

### Advisory Panel Meetings - Health Canada

As an outside observer, this liaison was unable to make specific characterizations of connectedness and decision making among the OBCIEP membership. The Health Canada representative had the opportunity to attend one of the OBCIEP's semi-annual Advisory Panel meetings. Some general impressions are noted in the provided response.

> I found that the meeting was more devoted to telling the panel what the Executive had done. I wondered at the time whether the panel member were happy with that, but nobody told me anything. It was just an impression I had... So I asked myself at the time what the input of the panel was. They have discussion groups, but I didn't feel the participants were prepared to give their input. I don't know if it gave a lot of results.

The representative felt it was interesting to find out what Ontario had accomplished, but would not characterize that as a meeting high point. A low-point for the participant was the perception that members may not always be prepared to provide input at Advisory Panel meetings.

## OBCIEP's Contributions - Advisory Panel

Advisory Panel members were asked to respond to the question "Overall, what kind of contribution do you feel the OBCIEP has made to breast cancer?" The pattern of responses were as follows:

| | |
|---|---|
| 29% | information awareness & access to information |
| 27% | coordination of breast cancer stakeholders/leadership role |
| 12% | concrete accomplishments-book, booklet, reports. |
| 8% | avenue for survivor input/linking survivors & professionals |
| 2% | other miscellaneous contributions |
| 22% | participant response did not answer the question |

On a personal level, interviewees were asked if the Project had contributed to either networking or awareness-raising within the breast cancer climate. Sixty percent (60%) felt being involved with the Project had contributed to networking. Thirteen percent (13%) felt it had made no contribution, and thirteen percent (13%) were not sure whether or not it had contributed. The final thirteen percent (13%) of the interviews yielded inconclusive results. Almost three-quarters, or seventy-three percent (73%) of the respondents felt that the OBCIEP has contributed to personal breast cancer awareness-raising. Ten percent (10%) felt there has been no contribution, and an additional ten percent (10%) were not sure. Seven percent (7%) of the interviews were inconclusive in this regard.

## OBCIEP's Contributions - Project Team

Project Team members were asked to respond to the question, "Overall, what kind of contribution do you feel the OBCIEP has made to breast cancer? ". Team members responded in general terms:

> I think the Ontario program in particular has addressed some very fundamental needs.

> Well it is a drop in the bucket. Given the constraints that exist in the health care system and in the world generally, I think it is a pretty decent drop.
>
> I really think that we have achieved a lot in a short period of time, and have made a difference. It is not that we are spinning our wheels. We are really addressing needs and bringing people together in new ways.

Specific gains that the respondents felt the OBCIEP had made were noted.

> Well I think there are significant contributions in certain areas, like the guide was a significant contribution. The family physician and perceptions of surgeons I think is going to be very interesting when it gets out. The sense of looking at breast cancer information dissemination gaps and engaging the agencies I think that is something we are going to have to work out in a very defined way.
>
> I think it is the notion of identifying gaps, coordinating body. Its role as a catalyst and coordinating body is probably its main value. I think there is a value for having an organization who is removed from it all in a way that they can look at the whole picture.

## OBCIEP's Contributions - Health Canada

The Health Canada representative did not offer any views on specific contributions that the OBCIEP may have made to breast cancer to date, but seemed optimistic about its potential significance.

> Well I am quite positive in thinking that it has and it will make a difference. Just getting people to talk to one another. Involving patient/survivors makes them aware of the difficulties as well as finding out more about what their needs are. All these different groups working together, researchers, doctors, oncologist, lay people. It is very interesting to follow.

### Should the OBCIEP Continue - Advisory Panel

| | |
|---|---|
| 70% | feel OBCIEP should continue beyond Health Canada funding period |
| 7% | do not feel OBCIEP should continue |
| 13% | not sure whether OBCIEP should continue |
| 10% | inconclusive from interview data |

Many interesting comments and suggestions were provided in response to the question "If the Project were to continue, what should it do?".

While a few people responded that it was to early to assess the future and that brainstorming and evaluations would be important intermediary steps, many members thought the Project should continue as a neutral, coordinating body. Essentially, to continue in what it is doing as a site for up to date information exchange.

> It should link up as many organizations and support groups that it can...to catalyze information exchange.
>
> Sort of a nucleus of activities that are happening on the province...getting people together for meetings that wouldn't happen if somebody else was running them.
>
> Look at partnerships and how information can be disseminated.
>
> Keeping up the database
>
> Its got to continue to update all of its activities and evaluate them
>
> Stay on the cutting edge of change.
>
> Yeah, I'm worried that there are too many cross sections, too many groups here and there vying for the same dollar. Somehow it should be coordinated.

Some members talked about how the responsibilities and activities of the OBCIEP could be broken down and allocated to existing breast cancer organizations and networks.

> One approach is to look at Network survivor groups, maybe they should be getting funding for updating women & families.

The role of Willow, a new breast cancer information and support centre located in Toronto was mentioned by a few survivors as a possible avenue to explore. One such comment was,

> I wouldn't want the Willows project to become THE authority in the province without there being a tie to the OBCIEP. To me they are two really big thrusts that should be coordinated somehow.

Should the OBCIEP Continue - Project Team

Most of the responses around the issue of continuation were reserved and suggested a need to evaluate and assess before taking a firm position on this issue. There was a definite trend towards possible continuation, but in an altered form from the present Project structure. The most common postulation was to continue pieces of the Project through OBCIEP stakeholders, or to partner the Project with an existing organization. Comments on this subject included:

> What do I think of Ontario? Well I think it should be part of the whole net. It should be a network which is easily accessible, through which women can get information. Whether that would ultimately come down to an affiliation to something like the Cancer Information Service, is something that would have to be discussed.
>
> I can see one of two things. One being that there would be one central group for all of Canada that might oversee, rather than the regional pieces, the larger perspective across Canada. Try to maintain some of the initiatives that have gotten underway. Updating information as appropriate and so on. The other would be that an organization, or a group of organizations could take on a piece or pieces of the Project. So Willow for example.
>
> You know, I always thought that we would do such a good job after five years that we wouldn't have to exist anymore. The networks that we created, or

> facilitated to create would keep going. I'm not sure if that would happen though... One suggestion has been that all the Pilot Projects, all five, meld into a national project. Do things more nationally than regionally...I really think that we have a purpose that other organizations don't have, the whole catalyst, facilitating approach. Because we are neutral, that is a big thing. We don't favor any one group or any one position.

Should the OBCIEP Continue - Health Canada

The Health Canada liaison personally felt that the Pilot Project(s) should continue and offered an idea about a possible role for the OBCIEP in the future.

> I hope that somehow it is going to be able to continue, at least the networking will continue. We certainly put in as a request that the Projects try to become sustainable. That was not a must, it was a wish...Well I think the important thing is this networking. The development of material can be done by the cancer society, by the cancer foundations, and a lot of groups like that. But this networking has got to be facilitated, otherwise it won't happen.

The participant offered her view that Health Canada's role is to monitor the progress of the pilot projects and assess their effectiveness of this novel approach at the end of five years.

> It is a pilot test, it has never been done; a totally new venture. We thought maybe we could try it. Instead of yet producing even more pamphlets it was time to make sure that partnerships developed across the country and networks be established. So our role is one hundred percent in there and now we follow these projects across the country. We have a profound interest in finding out whether it makes a difference or not. Whether it was a good idea to start with... It is totally new...This being a pilot we are really watching the creativity of the different Projects. When we did this we certainly didn't have an answer. that is why they are pilot. We just had the idea that maybe this was one approach...bring the communities together.

In summary, the representative reiterated the primary purpose of the OBCIEP and the other Breast Cancer Information Exchange Pilot Projects:

The prime purpose is to facilitate the networking of the regions, of the different partners. The people who produce information, the people who distribute the information, the people that meet the women and give them information. So it is really not so much to develop new material, but to really improve the networking between all the people that do have information. To make sure that women can access it easily.

# OUTSTANDING ISSUES

The evaluation findings highlighted a variety of issues that are outstanding to the Project at this time. These include:

- the need to clarify the roles and responsibilities of each organizational body
- the need to clarify the question "who do Advisory Panel members represent?" - themselves or an/their organization
- the need to diversify the membership of the Advisory Panel to reflect the geographic, linguistic, and ethnic diversity of Ontario
- the need to clarify the role of the Advisory Panel as advisory or as a proactive decision making body
- the need to define the terms "survivor-driven" and "strategic direction"
- the need to find effective communication media that connect the Advisory Panel in the time period in between semi-annual meetings to foster ownership of the Project and facilitate survivor input into decision making
- the need to clarify which organizational bodies or persons do the work mandated by the on-going activities of the Project
- the need to discuss what will be measured at the end of the funding period to adequately assess the success of the Project
- the need to discuss how, or if the OBCIEP has a role beyond 1998 in the breast cancer arena

# RECOMMENDATIONS

> In formative evaluation, research questions should focus on potential adopter perceptions of innovation attributes (Dearing, 1994, p.24)

The mid-point evaluation methods and analysis for this evaluation were structured according to the needs of the OBCIEP. The research questions were designed to assess how the OBCIEP stakeholders perceived the attributes of the Project, namely, its objectives, activities, principles, and future directions. The basis for the questions was from existing theoretical material; regarding information dissemination and innovation diffusion. The findings have provided the OBCIEP with the information to assess its progress to date and make plans for the future.

Based on the evaluation results, the evaluator provided the Project Coordinator with a draft of possible directions for evaluation recommendations. The following recommendations were included in the final evaluation report.

1. Clarify roles and responsibilities of Advisory Panel, Executive Committee and Project Team members and produce written guidelines.
2. Review membership of the Advisory Panel to ensure the appropriate organizations are represented.
3. Review the format of the Advisory Panel meetings on a continuous basis to ensure they meet the needs of the Project and its members.
4. Renew emphasis on partnership building in all OBCIEP activities and encouraging other organizations involved in breast cancer to do the same.
5. Maintain and strengthen the communication and feedback in all directions among all members of the Project and among other organizations involved in breast cancer information dissemination.

6. Develop a process for a five year evaluation.
7. Reinforce and emphasize the role of the OBCIEP in identifying and communicating gaps in breast cancer information exchange.
8. Initiate immediate planning for the end of the Project's funding period, March 1998.

These recommendations were reviewed by the Executive Committee and approved by the Advisory Panel prior to inclusion in the final report. The recommendations are scheduled for implementation during the 1996-1997 fiscal year.

# DISCUSSION

Three purposes have been accomplished in conducting a formative evaluation of the OBCIEP.

> In formative evaluation, research questions should focus on potential adopter perceptions of innovation attributes (Dearing, 1994, p.24)

First, It has provided an opportunity for the Project stakeholders, especially breast cancer survivors, to voice their views about how the OBCIEP is doing and provide input about activities and foci.. This is what the women's health movement has been striving for, a recognition of the right to define their own experiences and "provide a slice of the social world" (Reinharz, 1992, p. 19).

The second purpose accomplished in conducting a formative evaluation of the OBCIEP is best stated by McKinney et al.

> Evaluation can provide practical information about innovations that are not fully formed by examining the characteristics of the key stakeholders. Their social system, communication, and the linkages between them. (McKinney , et al, p.272).

The evaluation has provided the OBCIEP with practical information at the mid-point of its funding period that has highlighted strengths, identified weaknesses, and provided input from the membership that can be useful for future planning or Project reinvention.

Thirdly, the evaluation of the OBCIEP contributes to the available literature about collaborative action research for the discipline of community psychology. Community

Psychology offers an ideal paradigm for conducting evaluations of innovations such as the OBCIEP. An innovation is a "departure from the status quo" (McKinney et al, 1992, p. 284). Evaluation activity may contribute to the diffusion of the innovation. The "essence of diffusion is change" (Eveland, 1985, p.8). Community psychologists are committed to social change and the challenging of the status quo. The evaluator and the discipline share many of the values of the Ontario Breast Cancer Information Exchange Project. Some of these include: a belief in inclusive decision making practices, sharing the professional role, sharing resources for a common purpose, and access to information.

Lord and Hutchison stated that studying the process of empowerment contributes to the concept and meaning of empowerment (Lord and Hutchison, 1993, p. 19). In the same vein, doing community psychology research contributes to clarifying the paradigm of the discipline. Similarly, evaluating innovations such as the Ontario Breast Cancer Information Exchange Project contributes to learning about how novel approaches can contribute to the available literature about social change in the area of women's health care. In 1992, 5900 women in Ontario were diagnosed with breast cancer (OBCIEP consortium, 1993). That same year in Canada it was estimated that 5200 women who had been diagnosed with breast cancer would die from the disease. Another way to state this fact is that fourteen women die from breast cancer each day in our country (Scott, 1993). These numbers represent our grandmothers, our mothers, our sisters, our aunts, our friends. We must listen to women and their families to understand their experiences with the disease. We must understand why a Project like the OBCIEP, or a conference like the National Forum on Breast Cancer have become important priorities. Finally, we must continue to believe in the power of people to exert influence and effect social change.

I am connected to the breast cancer issue through a maternal family history with the disease. This research has served to help me move beyond the fear and the loss I have experienced. It has allowed me to critically become informed of the myriad of issues associated with the disease. I have been greatly touched by the breast cancer survivors that I have encountered over the last two years. They are a true inspiration in that they embody the concept of "living with cancer" and hope for action on the disease. My interactions with academics and health professionals also helped me to orient myself to this important research project. I had the wonderful opportunity to work with Dr. Ross Gray and Dr. Juanne Clarke on an evaluability study of the National Forum on Breast Cancer. This provided me with an orientation to the T-SRCC and SHSC as well as the recent federal government initiatives for breast cancer research and action. With the guidance of Juanne Clarke I was able to complete a course and build an annotated bibliography on women and medicine. The literature for this course included historical perspectives of the medicalization of women from a variety of academic disciplines and theoretical perspectives. It served to round out my academic training and provide a solid framework to understand the significance of a structure like the Ontario Breast Cancer Information Exchange Project. I feel that the OBCIEP and its four Breast Cancer Information Exchange Pilot Project counterparts have been established in large part due to the cumulative efforts of the women's health movement which began in the 1960's. These Projects are unique due to their mandate to include the voice of breast cancer survivors and front-line stakeholders in the organizational structures in an effort to coordinate information and resources, and catalyze action around the disease. This research has attempted to capture the spirit of the OBCIEP. By collaborating with survivors and other stakeholders in the planning of the evaluation, and including members' voices wherever possible in reports that relay the findings, this researcher hopes to include the human side of breast cancer. This is a side of women's health research that is often neglected. Interviewing itself acts as an important method of information gathering and sharing.

> ...because this way of learning from women is an antidote to centuries of ignoring women's ideas altogether, or having men speak for women (Reinharz, 1992).

This women's health movement coupled with more recent advocacy around the disease, have stated that the ultimate goal for women in the health care arena is to seek out information that allows them to participate in decision-making in order to regain control of their health. In attempting to make sense of the multitude of issues involved in this research, I have been strongly influenced by the writing of Ivan Illich, Paulo Freire and feminist writers such as Betty Cogswell and Jane Arndt.

Ivan Illich has stated that the more services are offered in our society, the more will be consumed. In the case of medicine, this leads to an iatrogenic effect in which the consumer becomes dependent on the services offered and those who offer them. In turn, there is a loss of control over one's ability to partake in his or her own care which is counterproductive to good health (Illich, 1976). Betty Cogswell and Jane Arndt have attempted to chronicle the history of the medicalization of women. Through a detailed account of women's relationship with a male-dominated health care system that has been oppressive, if not misogynistic, they attempt to highlight the roots of medicalization. The strength of the influence of the health care system is in part attributed to holding a monopoly on the technical and medical information which is required for women to become informed decision makers and participate in their own care (Cogswell and Arndt, 1980). The process of demystification has been central to the women's health movement. This entails women working together to understand the medical terms and technical knowledge and sharing it with others (Merieskind and Ehrenreich, 1975). The result is a sense of confidence and increased ability to dictate their own health care within the structures that exist in our society.

I have interpreted the historical medicalization of women in macrocosm, and the issues of women and breast cancer in microcosm, much in the way I experience Paulo Freire's *Pedagogy of the Oppressed.* In this book, Freire details how teaching illiterate people to read and write facilitated a process by which these people could critically evaluate their social situation. The exclusion of the women's experience of health and illness coupled with denial of the opportunity to participate in informed decision making about their care, is an example not unlike that offered by Freire, of education acting as a subversive force. In this instance we are talking about medical education and knowledge. While self-help or mutual-aid are popular interventions that have attempted to address issues of social support and making sense of medical jargon and treatment options for women with breast cancer, these groups may not in themselves provide the structure to influence societal change. Self-help groups have organized and are often active in advocacy around the disease. An organization like the OBCIEP however, may provide an opportunity to move beyond the limitations of self-help. I see the OBCIEP as a structure that contributes to the ability to participate in decision making about the disease in a more political sense. Women and front-line workers are working cooperatively with health care providers to share information and make decisions about the disease. It challenges the status quo of women passively accepting the advice of "professionals" and may contribute to a sense of empowerment.

Empowerment is a difficult construct to define. Emilie Whitmore proposed that in the absence of a comprehensive definition we should embrace its underlying assumptions which are inherently desirable. These assumptions are built into the texture of feminist teaching and are central to the women's health movement. They include:

- individuals are assumed to know their own needs better than anyone else and therefore should have the power to define and act upon them
- all people possess strengths upon which they can build
- empowerment is a lifelong endeavor
- personal knowledge and experience are valid and useful in coping effectively (Whitmore, 1988, in Lord and Hutchison, 1993).

While no intervention activity or individual can empower another person (Rappaport, 1987) , the conditions for empowerment can be facilitated by that activity or persons involved in the activity.

> What defines an intervention as empowering is not its specific content but rather its adherence to the values of empowerment (Prilleltensky, in press).

The mid-point evaluation of the OBCIEP focused on the processes of the organization. Although there were no specific questions about whether or not participation in the Project facilitated the process of becoming empowered, or was a vehicle towards social change, such statements did evolve through the course of interview conversations. Many of these spontaneous statements are consistent with the assumptions of empowerment.

> Well it gives a certain sense of power. That' s always helpful because as survivors you feel a contribution and a step forward.
>
> It feels really great. I am an activist. I believe in advocacy. I believe in women's issues. I believe if it was a male thing it would have been cured years ago...I truly believe that. Since the 1930's nothing has been done and I think something might have been done. It is the old power and control issue. I really believe in women's rights and that this is one of the largest issues there are...its not just because I have had breast cancer. It comes down to dollars and cents and they are putting a price on women's heads. I disagree. I am a firm believer in advocating for breast cancer issues.

Other spontaneous remarks offered by participants included the need for their feelings and voices to be heard, and for information.

> You know what they say, you really don't know until you've been there...it puts the project in perspective of really what is necessary by tapping into the most important resources which are the feeling comments of the survivor
>
> I think the survivor input is crucial. If it wasn't there then I think this whole thing is a bit of a farce. Because you can't have people representing a group and not have representatives from that group present with a strong voice. It just doesn't work for the people you are trying to represent
>
> I just don't want anybody to lose sight of what we are trying to accomplish. We are looking at the human side and the need for more research and the need for more information getting to the patient.

Participants also noted how the Project is assisting in these regards.

> Well! I think it has facilitated a network of a variety of disjointed agencies. Through that network it has also helped to improve the quality of some of the things the agencies have been providing, and access to information
>
> I see it as to accomplish trying to find the information gaps that exist for women. Especially for women diagnosed with breast cancer that reflects the woman's needs specifically, more than the medical community

The spontaneous nature of these comments may indicate the depth of the emotion felt about these subjects and their presence within the OBCIEP structure.

The OBCIEP is an innovation. If the essence of an innovation is information (Eveland, 1985), and information is a means towards empowerment (Freire, 1995; Illich, 1976), then the OBCIEP may facilitate the process by which women with breast cancer become empowered.

> Provided with the proper tools for such encounter, the individual can gradually perceive personal and social reality as well as the contradictions in it, become conscious of his or her own perception of that reality, and

> deal critically with it. In this process the old, paternalistic teacher-student relationship is overcome...he or she comes to a new awareness of self, has a new sense of dignity, and is stirred by new hope...And as those that have been completely marginalized are so radically transformed, they are no longer willing to be mere objects, responding to changes around them; they are more likely to decide to take upon themselves the struggle to change the structures of society, which until now have served to oppress them (Shaull, in Freire, 1995, pp. 12-15).

The women with breast cancer who contributed to this study are committed to working for change in the health care arena with regards to breast cancer. A great deal of weight is placed on the recent federal initiatives such as the National Forum on Breast Cancer and the Breast Cancer Information Exchange Pilot Projects as avenues for inclusion of the survivor voice and action on the disease. One OBCIEP member said it best.

> Of course survivor input is important. That is one of the principles of the project. Every survivor holds that dear to their hearts. I don't think that you would find a survivor that wasn't committed to that.

# FINAL THOUGHTS AND REFLECTIONS

The process of conducting this research in collaboration with the OBCIEP was an extremely positive experience. My values, training, and approach to evaluation seemed to be a good match with those of the Project itself and its membership. Early in the process we discussed our mutual goals and defined the role I would play with the organization. The entire membership was committed to carrying out a mid-point evaluation and supported the process throughout. I would like to thank all of the people who played a role in linking me to the OBCIEP and in helping me to complete this work.

The purposes of the evaluation for both the Project and myself did not allow for some of my personal interests and biases to be explored in depth. I kept an on-going account of my ideas, postulations, and feelings while conducting interviews and analyses. I have included some excerpts from my notes to highlight areas which would be interesting to further explore (Appendix 7). I feel the only avenues for doing justice to these issues would be in a separate discussion or report.

After becoming immersed in the data and activity surrounding the breast cancer issue, it is easy to see why Barbara Greene and her research team began to see themselves as activists while drafting *Unanswered Questions* (Greene, 1992). It goes beyond being shocked by the statistics or having personal experience with the subject matter. I have learned a lot over the past year. I myself have become more informed about women's health, breast cancer and the many consumer-driven initiatives that are occurring in North America. I have met a number of people that have left me with the feeling that there is life after breast cancer and that there are positive changes in sight. I am not as afraid of the disease as I was when I began this journey. As you look through this document it is the feeling statements of survivors that reinforce what is pivotal to effecting change in the way women are viewed within our health care system. There is value in including the human side of health and illness through the narrative accounts of health care consumers. I have a vested interest in this and hope that I have contributed in some small way.

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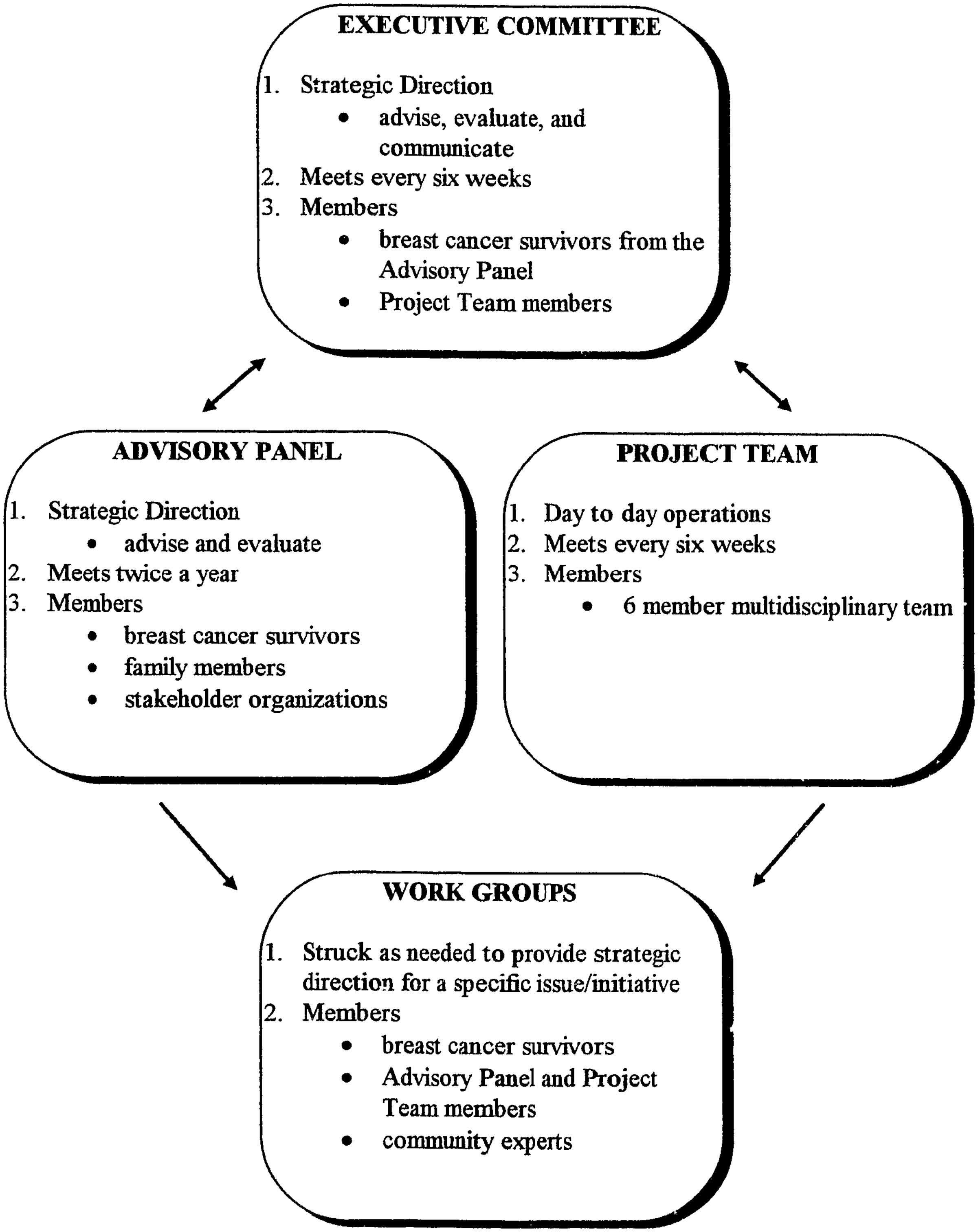
## APPENDIX 1

# OBCIEP ORGANIZATIONAL CHART



**EXECUTIVE COMMITTEE**

1. Strategic Direction
    - advise, evaluate, and communicate
2. Meets every six weeks
3. Members
    - breast cancer survivors from the Advisory Panel
    - Project Team members

**ADVISORY PANEL**

1. Strategic Direction
    - advise and evaluate
2. Meets twice a year
3. Members
    - breast cancer survivors
    - family members
    - stakeholder organizations

**PROJECT TEAM**

1. Day to day operations
2. Meets every six weeks
3. Members
    - 6 member multidisciplinary team

**WORK GROUPS**

1. Struck as needed to provide strategic direction for a specific issue/initiative
2. Members
    - breast cancer survivors
    - Advisory Panel and Project Team members
    - community experts

# APPENDIX 2

## OBCIEP ADVISORY PANEL REPRESENTATION

**• Breast cancer survivors/Family members**

**•Cancer Survivor Organizations**

- Alliance of Breast Cancer Survivors
- Bayview Support Network
- Burlington Breast Cancer Support Services
- Grey-Bruce Breast Cancer Support Group
- Breast Cancer Support Group of Thunder Bay
- Peterborough Breast Cancer Support Group
- Breast Cancer Action Ottawa
- Breast Cancer Research and Education Fund (Ontario)
- Niagara Breast Cancer Support Group
- Sudbury and District Breast Cancer Support Group
- Breast Cancer Support Network for Ontario Project
- Canadian Breast Cancer Network

**• Stakeholder Organizations**

- Cancer Information Service
- Canadian Breast Cancer Foundation
- Canadian Cancer Society, Ontario Division
- Centre for Health Promotion, University of Toronto
- Community Hospice Association of Ontario
- Division of Epidemiology and Statistics (OCTRF)
- Grand River Hospital
- Hamilton Regional Cancer Centre
- National Council of Jewish Women
- Native Women's Association of Canada
- Ontario Breast Screening Program
- Ontario Public Health
- Princess Margaret Hospital
- Volunteer Network - Ontario Breast Screening Program
- Wellspring
- Willow - Ontario Breast Cancer Support and Resource Centre
- Women's College Hospital
- YWCA of Canada

## APPENDIX 3

# BREAST CANCER info exchange

Spring 1995, Volume 1 Issue 1

Ontario Breast Cancer Information Exchange Project

Welcome to the first edition of the *Breast Cancer Info Exchange* - the official publication of the Ontario Breast Cancer Information Exchange Project (OBCIEP). The purpose of this newsletter is to inform Ontarians about breast cancer information activities across the province. Specifically, this publication will highlight the initiatives of the OBCIEP and its partner organizations.

For those readers who are unfamiliar with the OBCIEP, we are one of five projects funded by Health Canada aimed at improving access to information for women, their families and health care professionals about a variety of concerns related to breast cancer. Funding was announced in August, 1993 and the monies were received in December, 1994.

The most important aspect of our Project is that all the activities evolve from a breast cancer survivor perspective. The Project's direction is set by an Advisory Panel of which over half of its members are breast cancer survivors and family members. Their ideas about gaps in breast cancer information are critical to the Project.

The Project's focus is to not be a "front line" provider of information about breast cancer. When we completed our initial assessment of breast cancer activities (as described on page 2), we quickly realized that *many* organizations already existed in Ontario with a role in providing breast cancer information. The major issue was that few of these organizations worked closely together. Consequently, we perceived that the best purpose for the OBCIEP was to serve as a catalyst or a motivational centre for these organizations to work cooperatively. We wanted to facilitate access to information. By adopting this role, we hope it will prevent duplication while eliminating any informational gaps.

The following pages will provide you with a better understanding of the Ontario Breast Cancer Information Exchange Project, its activities and partners. We hope you find this information valuable. Please contact us if you have any questions, concerns or comments; we welcome your feedback.

## the inside news

◆

*Breast Cancer Info Exchange* is a quarterly newsletter of the Ontario Breast Cancer Information Exchange Project (OBCIEP) designed to inform Ontarians about breast cancer information activities across the province. Funding for the OBCIEP is provided by the Health Services Directorate, Health Programs and Services Branch, Health Canada

Editor Natalie Parry
Contributors Pamela Chart, Margaret Fitch, Ross Gray, Marlene Greenberg, Nina Lowe,
Desktop Publishing: James Tomlinson

2075 Bayview Avenue
Toronto, Ontario M4N 3M5
Phone (416) 480-5899
Fax: (416) 480-6002

## APPENDIX 3b

**info exchange**

*The Ontario Breast Cancer Information Exchange Project's direction has been divided into three themes: Coordinating Breast Cancer Information, Access to Information by Women and Their Families, and Access to Information by Health Professionals. In the following pages, the specific activities of the OBCIEP are described under their respective themes.*

Theme I: Coordinating Breast Cancer Information

## Database of Organizations with a Role in Breast Cancer

Our first initiative was an assessment of existing breast cancer resources and activities in the province. A survey was conducted to identify the organizations in Ontario which were involved with breast cancer and to determine their role in the dissemination of breast cancer information.

The questionnaire was sent to a variety of health and social service agencies including hospitals, public health units, community health centres and community-based organizations. To date, 719 surveys have been distributed and 476 (66%) have been returned. Of the total returned, 388 (82%) indicated they have a role in disseminating breast cancer information.

The information collected included a profile of the agency and its activities and the information they provide to their clients. This information has been entered into an electronic database, and the Project plans to use it to develop regional directories in partnership with local and partner organizations.

### Analysis of Breast Cancer Information Gaps

One of the survey questions asked for the respondents' perceptions of informational gaps regarding breast cancer. A report is currently being written that summarizes the responses and compares them to informational needs identified by breast cancer survivors. This report, which will include recommendations for action, will be completed by June, 1995 and distributed to the survey respondents.

## Multicultural Focus

The Advisory Panel strongly recommended that the Project identify and respond to the informational needs about breast cancer of different cultural communities. Consequently, one of our partners, the Scarborough YMCA, hosted a community consultation to which breast cancer survivors from all communities were invited.

In small groups, issues of availability and accessibility to information about breast cancer were raised and possible strategies to overcoming barriers were suggested. Using the information collected, the Multicultural Working Group will collaborate with OBCIEP partner organizations to develop strategies for improving access to information about breast cancer for different cultural groups.

◆

## Mid-Point Evaluation

Having completed two years, the Project is currently conducting a process evaluation. The purpose of the evaluation is to assess the Project's structure and activities and to make future recommendations. Individuals connected with the Project will be interviewed during the summer and a final report will be submitted October, 1995.

## APPENDIX 3c

**info exchange**

Theme II: Access To Information By Women And Their Families

# A Guide To Unconventional Cancer Therapies

Breast cancer survivors on our Advisory Panel told us they had to search hard for information about unconventional therapies They recommended that one of our first initiatives be a resource on the topic. They, as well as traditional and holistic health practitioners, were involved with the decisions about the resource's format and about what information it should contain.

The book was launched in October, 1994 and, to date, over 3,000 copies have been sold across Canada and internationally. We attribute this positive response to the open-minded approach we took to the topic.

The book describes more than 100 therapies, their possible role in fighting cancer, important issues specific to each therapy, their availability and suggestions on where to find more information. The information is provided without either supporting or rejecting any particular therapy.

An evaluation study of the Guide will soon be underway. Individuals who purchased the Guide will be contacted by mail and asked to complete a short survey with items related to satisfaction with the Guide, how it has been used, suggestions for improvements and impact on decision-making Physicians' attitudes and use of the Guide will also be examined in the future

**The Guide costs $10 plus shipping and handling. To order your copy, contact R & R Bookbar**
**14800 Yonge Street, Unit 106, Aurora, Ontario L4G 1N3 Telephone: (905) 727-3300 Fax: (905) 727-2620**

# *What You Need To Know About Breast Cancer* Booklet

The Burlington Breast Cancer Support Services asked for assistance to update and revise their excellent booklet entitled, *What You Should Know About Breast Cancer.* We organized a Working Group of breast cancer survivors to spearhead the revision process and to find ways to distribute the booklet more widely.

This information booklet provides, from a breast cancer survivor perspective, important information on the nature of the disease, treatment options, ways to navigate the cancer system and lists of relevant books, organizations and resources.

A national focus has been achieved by collaborating with the other regional Information Exchange Projects, and through Health Canada's and Avon Canada's financial support and leadership in the distribution of the booklet.

By the fall, regionally-specific versions of the booklet will be available in both English and French.

# Northern Ontario Initiative

Northern Ontario has been recognized as an area where many breast cancer informational gaps exist. Recognizing that the expertise lies in the North, our Advisory Panel agreed that an initiative based in Northern Ontario would be the most appropriate approach.

We solicited proposals for breast cancer information projects from groups located in the North. To be eligible for funding, the projects had to respond to the informational needs during the first six months from when a women detects a change in her breast, involve a partnership between at least two groups and have substantial participation of breast cancer survivors in all aspects of the project.

Two creative projects were awarded a one-time grant of $10,000 each—one from the Thunder Bay region and the other from the Sudbury region. Look for project details in the next edition of the *Breast Cancer Info Exchange*

## APPENDIX 3d

THEME III: Access To Information By Health Care Professionals

### Physicians

Our Advisory Panel underscored the important role family physicians have in providing information to their patients. Yet, it is acknowledged that they have neither the time nor the capacity to review and catalogue all available information. Consequently, the OBCIEP contracted Insight Canada Research to conduct a survey of family physicians to determine their informational needs, their perspectives of their patients' needs and preferred strategies for accessing information.

The results of the survey were released in October, 1994. They indicated that more physicians refer their patients to their own traditional information sources such as medical journals, textbooks and professional consultations rather than to organizations who provide patient-oriented materials such as the Cancer Information Service, Canadian Cancer Society, Ontario Breast Screening Program or Regional Cancer Centres.

This finding implies that it is essential for the OBCIEP to provide physicians with a guide through the breast cancer and benign breast condition information labyrinth. Specifically, the survey respondents identified the need for a source book and access to a central database of information to assist them in identifying and eliminating information gaps. The OBCIEP plans to develop such a guide as well as a resource on benign breast disease.

### Surgeons

Breast surgeons are involved in care during a critical period when informational needs are high and varied.

Currently, little is known about their perspective of women's informational needs. Consequently, a survey of Ontario breast surgeons' perspectives was carried out in April, 1995. The results will be available shortly.

### Nurses

The contribution of the nursing profession is rich indeed. Through the spectrum of disease, nurses are critically in touch with not only the medical but also the practical and emotional needs of patients.

A Working Group, with representatives from a variety of nursing backgrounds, has been struck to investigate nurses' breast cancer informational needs through the spectrum of the disease.

*To discover some of the new and exciting breast cancer initiatives that are happening across Ontario, turn to page 6 for the listing of our Advisory Panel Resources and Activities.*

# APPENDIX 3e

## Partner Profiles

*The OBCIEP's strategic direction is set by an Advisory Panel comprised of breast cancer survivors and representatives of stakeholder agencies. Below are profiles of two partner organizations.*

## Cancer Information Service

*By Patricia Payne*

755 Concession Street, Hamilton L8V 1C4 (905)387-1153 or 1-800-263-6750 outside Hamilton

The Cancer Information Service (CIS) is dedicated to helping answer questions about cancer and related issues.

Founded in 1985, the CIS is a joint program of the Canadian Cancer Society (Ontario Division) and the Ontario Cancer Treatment and Research Foundation.

From Hamilton, CIS provides province-wide, bilingual service through a toll-free telephone number. All calls are confidential and people can remain anonymous if they choose.

CIS has information on every site of cancer and more than 100 related subjects. CIS also gathers information about relevant community resources and programs to share appropriately.

In addition, CIS has a wide variety of written materials which can be mailed to the caller free-of-charge. The computer database, PDQ, and other databases are accessed to provide people with cancer-related information and details about treatment in clinical trials.

Since the CIS began, it has spoken to more than 100,000 people. The most frequently asked questions are about the particular sites of cancer. The site CIS is most often asked about is breast cancer

CIS is staffed by oncology nurses and other trained professionals and volunteers working under their guidance.

## Breast Cancer Research and Education Fund (Ontario)

*By Meryle Berge* 8 Pearl Ann Drive, St. Catharines L2T 3B3, (905)687-3333

The Breast Cancer Research and Education Fund (Ontario) is a non-profit, independent, charitable organization dedicated to promoting the advancement of breast cancer research and providing breast cancer education and support services.

Incorporated in 1990, the Fund established the Niagara Breast Cancer Support Group in 1991 Both the Breast Cancer Fund and the Support Group are survivor-directed and have developed a network of women living with breast cancer.

Some of the services are:

- ❖ an answering service
- ❖ emotional support through meetings and peer counselling
- ❖ information and education by means of a lending library presentations, workshops and seminars
- ❖ networking and advocacy by participation in national and international conferences and through dissemination of information surrounding breast cancer issues.

The Fund's trademark is *Fight Back! Stop It Before It Starts!* As primary prevention is one of the main focuses, the environmental links to breast cancer have been given top priority. You are invited to attend our International Conference on Breast Cancer and the Environment on November 3 and 4, 1995 at the Skyline Brock Hotel in Niagara Falls

# APPENDIX 3f

## info exchange

Advisory Panel

*Listed below are our Advisory Panel member organizations with descriptions of some of their activities and resources. Contact them for more information.*

Resources & Activities

### KEY

📖 books, pamphlets
✉ newsletter
📼 video
🖭 audio tape
👥 support groups and information presentations
☎ telephone support and information

### PROVINCIAL AND NATIONAL ORGANIZATIONS

**Canadian Breast Cancer Foundation**
790 Bay Street, Suite 1000, Toronto M5G 1N8
(416) 596-6773, 1-800-387-9816
👥 Golf Classic July 24, Awareness Day October 20, Run for the Cure October 22
📖 BSE pamphlets in 9 languages, Resource Handbook, *Side By Side* $3.00 +S&H

**Canadian Cancer Society**
Contact local CCS office
👥 Living With Cancer support groups, Reach To Recovery one-to-one visiting, breast health presentations by trained volunteers

**Cancer Information Service**
755 Concession Street, Hamilton L8V 1C4
(905) 387-1153 or (800) 263-6750 (outside Hamilton)

**Community Hospice Association of Ontario**
40 Wynford Drive, Don Mills M8S 1B3 (416) 510-3880

**National Council of Jewish Women**
4700 Bathurst Street, Willowdale M2R 1W8
(416) 633-5100

**Ontario Breast Screening Program** (800) 668-9304
In addition to the 10 original OBSP sites, there are now pilot affiliated sites in Cambridge, Guelph, Owen Sound, Pembroke, Peterborough, Renfrew and Sault Ste. Marie. Fourteen sites have received Canadian Assoc. of Radiologists Mammography Accreditation while the others are in the process of application.

**Ontario Cancer Treatment and Research Foundation** 620 University Avenue, Toronto M5G 2L7
(416) 971-9800

**Ontario Ministry of Health, Public Health Branch**
15 Overlea Boulevard, 15th Floor, Toronto M4H 1A9 (416) 327-7386

**YWCA of Canada**
276 Merton Street, Toronto M4S 1A9 (416) 487-7151

### EASTERN ONTARIO

**Breast Cancer Action**
Billings Bridge Plaza, PO Box 39041, Ottawa K1H 1A1
(613) 736-5921
👥 support for patients, survivors and families, open meetings, *Make Waves* aquatic program for women with cancer, *Helping Yourself Master Stress* $50-100 sliding scale, *Young Women's Breast Health Project*
📖 *Lymphedema: A Breast Cancer Legacy*
📼 *Surviving The Fear* featuring breast cancer survivors

**Peterborough Breast Cancer Support Group**
428 Cameron Street, Peterborough K9J 3Z3
(705) 745-5479 or 799-5496
👥 support group meetings for survivors, daughters and mothers
telephone support
newsletter

### CENTRAL ONTARIO

**Breast Cancer Research and Education Fund (Ontario)**
8 Pearl Ann Drive, St. Catharines L2T 3B3 (905) 687-3333
👥 *International Conference on Breast Cancer and the Environment,* November 3-4, Niagara Falls $30.

# APPENDIX 3g

## info exchange

**Breast Cancer Support Network for Ontario Project**
Burlington Mall, 777 Guelph Line, Burlington L79 3N2
(905) 634-2333
†† *Facilitator Training Workshop* October 12-15
🕮 *Running A Self-Help Group for Breast Cancer*

**Burlington Breast Cancer Support Services**
Burlington Mall, 777 Guelph Line, Burlington L79 3N2
(905) 634-2333
†† support meetings, BSE presentations
✉ newsletter $15/year

**Hamilton Regional Cancer Centre**
**Supportive Cancer Care Research Unit**
McMaster University, HSC-3H5, 1200 Main Street West,
Hamilton L8N 3Z5 (905) 525-9140 ext 22860

### NORTHERN ONTARIO

**Northwestern Ontario Breast Screening Program**
68 North Algoma Street, Thunder Bay P7A 4Z3
(807) 343-1690 or 1-800-668-9304
†† information sessions on the mobile screening service, musical play *Bosom Buddies* premiering April '96 chronicling the lives of 6 women in a support group

**Thunder Bay & District Breast Cancer Support Group**
(807) 345-3645 or 757-7226
†† monthly support group meetings $20/month, annual *Luncheon of Hope* in October
🕮 *I've Found A Lump—Now What?*

### SOUTHWESTERN ONTARIO

**Darlene Betteley**
154 Brandon Avenue, Kitchener N2M 2J5 (519) 743-9465
†† helps women one-to-one in her home, speaks at women's groups
📼 Quality of Life lecture, 1994

**Kitchener-Waterloo Hospital**
835 King Street West, Kitchener N2G 2G3 (519) 749-4300
🕮 Breast Cancer Resource Library for anyone in the community affected by breast cancer

### METROPOLITAN TORONTO

**Alliance of Breast Cancer Survivors**
20 Eglinton Avenue West, Box 2035, Suite 1106
Toronto M4R 1K8 (416) 487-9899
†† support network for women and their families, *Women's Mobilization on Breast Cancer Initiative*
☎ telephone support
🕮 book and tape library
✉ newsletter

**Bayview Support Network**
2075 Bayview Avenue, Toronto M4N 3M5 (416) 480-6898
†† survivor and caregiver support groups, open meetings for members and public
☎ telephone peer support line
🎥 *Been There* (members $16, non-members $20)
📼 cassette (non-members $6)
✉ newsletter

**Centre for Health Promotion**
100 College Street, Suite 207, Toronto M5G 1L5

**Princess Margaret Hospital**
500 Sherbourne Street, Toronto M4X 1K9 (416) 924-0671
🎥 *Breast Self-Examination* $5 + $10 S&H

**Toronto-Sunnybrook Regional Cancer Centre**
**Sunnybrook Health Science Centre**
2075 Bayview Avenue, Toronto M4N 3M5 (416) 480-4662
🕮 *Community Cancer Resource Guide* for Greater Toronto Area. Send a cheque for $5 to the above address c/o Health Promotion

**Women's College Hospital**
76 Grenville Street, Toronto M5S 1B2 (416) 323-6400 x4424
†† support group and educational sessions
🕮 *Benign Breast Disease*
📼 *Breast Cancer Relaxation*

**Wellspring**
81 Wellesley Street East, Toronto M4Y 1H6
(416) 961-1928

**YMCA of Greater Metropolitan Toronto**
Contact Membership Director at any YMCA
†† monthly clinics on various health issues throughout Toronto, cost incl in membership fee

# APPENDIX 3h

## info exchange

## Information Projects Across Canada

*The Ontario Breast Cancer Information Exchange Project is only one of five Pilot Projects across the country funded by Health Canada. All are mandated to improve access to breast cancer information but each Project's activities differ as they are based on regional needs. Below is a brief description of each Project.*

### Atlantic Breast Cancer Information Project

**1 Rochford Street, Suite 1, Charlottetown, PEI C1A 3T1**
**Telephone: (902) 892-9531 Fax: (902) 628-8281**
**Project Coordinator: Tamara Casebolt**

Some of the key activities include the development of an electronic database of breast cancer information and the production of a national pamphlet entitled, *Breast Cancer: Question You Might Want to Ask.*

### Quebec Breast Cancer Information Exchange Network

**3840 rue Saint-Urbain, Montréal, QC H2W 1T8**
**Telephone: (514) 843-2930 Fax: (514) 843-2932**
**Project Coordinator: Isabelle Trépanier**

The Network's first priority is to encourage professional and community involvement through regional community consultations and a symposium on the breast cancer situation in Quebec. They will also be creating a resource directory and supporting numerous regional activities.

### Breast Cancer Info Link, Prairies/NWT

**331-29 Street NW, Calgary, AB T2N 4N2**
**Telephone: (403) 670-2113 Fax: (403) 283-1651**
**Project Coordinator: Joanne Pawelek**

A lot of time has been spent consulting and connecting with the community. Future initiatives include the development of a breast cancer resource manual, an educational program for aboriginal women, and a video supporting women with breast cancer.

### BC/Yukon Breast Cancer Information Project

**565 West 10th Avenue, Vancouver, BC V5J 4J4**
**Telephone: (604) 872-4400 Fax: (604) 879-9267**
**Project Coordinator: Jennifer Bradbury**

The major focus has been the expansion and marketing of the existing 1-800 Cancer Information Line. Other activities include the development and distribution of information teaching packages to 22 First Nations' community health representatives. They also have conducted a study to determine the informational needs of women in their region.

**OBCIEP**
**2075 Bayview Avenue**
**North York, ON M4N 3M5**

# APPENDIX 3i

# Nat Pak

### *Information from your Project Coordinator*

May 10 1996

Well, it's time for another *Nat Pak* (lovingly labeled by Sandra at the last Advisory Panel meeting)!!!

Many information pieces have crossed my desk since the meeting including news from the following organizations:

- Willow
- BC & Yukon Breast Cancer Information Project
- Canadian Breast Cancer Research Initiative
- DES Action Canada *(They have a new breast cancer resource available, written by Sharon Batt.)*
- Breast Cancer Support Network for Ontario Project
- Wellspring
- National Cancer Institute

Also included is information about a new group called *Frontier Breast Cancer Fund* I have talked with the Director, Marty Christie, and she stated that she would like to work with other breast cancer organizations. She may have already contacted your group If you have any additional information about them or suggestions how we could work together, please let me know.

I have also enclosed a letter from a woman who is a Medical Make-Up Specialist Together with her business partner, she does free presentations entitled, *The Reality of Cosmetic Enhancement,* to support groups and health professionals

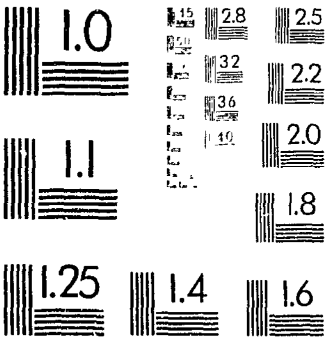
Finally, I copied a review of *A Guide to Unconventional Cancer Therapies* from the Pediatric Oncology Group of Ontario News In no uncertain terms did they like our book. Their comments are very interesting and lead me to the conclusion that they did not understand the purpose of why we wrote it. Oh well, we can't be liked by everyone!

That's all for now Enjoy your reading. Don't forget, if there is anything you would like me to share with the other Advisory Panel members, just send it to me and I will include it in the next *Nat Pak.*

[illegible]

# 2 OF/DE 2

PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT



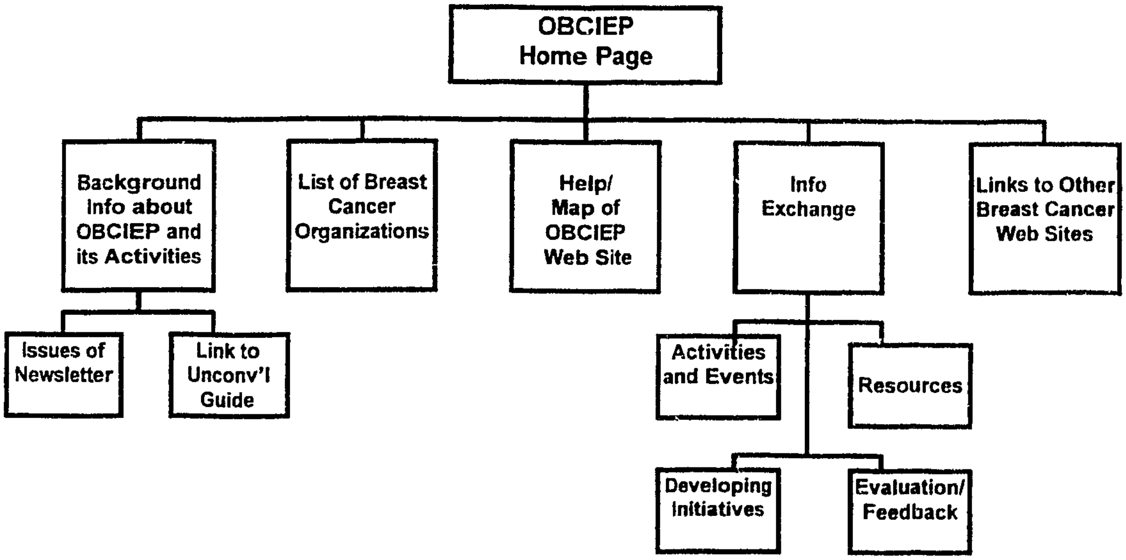
PRECISION$^{SM}$ RESOLUTION TARGETS

# APPENDIX 3j

As I informed you earlier, the OBCIEP did not support the proposal from the Atlantic Project to establish a national web site on the Internet However, we have been very fortunate to hire Elijah Beckford through Employment Canada's Job Strategy, in collaboration with the Toronto-Sunnybrook Regional Cancer Centre, to establish our own web site.

When Elijah first came on board, I circulated a survey asking what Advisory Panel members thought should be mounted on the web site *(Thanks to everyone who responded.)* Based on the feedback received and discussions with Elijah, we have developed an outline, illustrated below.

**Elijah and I would welcome (and strongly encourage) further feedback and suggestions.**



The Info Exchange web page will be the most exciting section. Two interactive forums will be established where people can post information about breast cancer resources and activities. Another forum will be established were users can ask for feedback about initiatives they are currently developing (i.e., Do materials already exist on this topic? Would other organizations like to collaborate?). An evaluation form will also be incorporated into this section of the web site where people can provide comments about the web site, the OBCIEP and its activities.

Barring any technical difficulties, we hope to have this site up and running by the Fall.

[illegible]

## APPENDIX 4

## INTERVIEW GUIDE

1. **Could you tell me about your involvement with the Ontario Breast Cancer Information Exchange Project?**

    How did you get involved with the Project?

    How long have you been on the Advisory Panel?

    Besides the AP, have you been involved in other aspects of the Project?

2. **Who do you perceive you speak for and/or represent on the Advisory Panel?**

3. **In your opinion, what is the OBCIEP designed to accomplish?**

4. **Could you tell me about the audiences reached by the Project?**

    In your opinion, are there other audiences that should be reached by the Project, who currently might not be reached? Explain.

    Do you have any suggestions on how this would be best accomplished?

**Regarding the objectives of the OBCIEP**

5. **What are your thoughts and feelings about these objectives?**

6. **In your opinion, are there factors which hinder the progression towards the Project objectives? Explain.**

7. **In your view, is the Project making steady progress towards its objectives? Explain.**

# APPENDIX 4b

## Regarding the principles of the OBCIEP

8. **What are your thoughts and feelings about these principles?**

   In general, do you feel that these principles are practised within the OBCIEP? Explain.

   Do you have any suggestions about how the practising of such principles might be further improved?

9. **Survivor input is seen as an important aspect of the Project's functioning. What are your thoughts and feelings about the survivor input within the OBCIEP?**

   Do you have any suggestions for improvement regarding the survivor input issue?

10. **The Advisory Panel is charged with setting the strategic direction for the OBCIEP? What are your thoughts and feelings about the Advisory Panel's contributions within/to the Project?**

    Do you feel involved in the decision making processes? Explain

    Do you have any suggestions for facilitating more involvement with the Advisory Panel?

11. **What are your thoughts and feelings about the semi-annual Advisory Panel meeting format?**

    Do you find these meetings useful and informative? Explain

    In your opinion, what are the high-points of the meetings?

    In your opinion, what are the low-points of the meetings?

    What do you think about the Saturday schedules?

    Do you have any suggestions for change?

    Do you feel in touch with what is happening with the Project at the AP meetings? Explain.

## APPENDIX 4c

Do you have any suggestions on how this sense of "keeping in touch" might be fostered with the Advisory Panel?

13. **The Advisory Panel is comprised of a number of people who are either breast cancer survivors, family members, and/or persons active within organizations dedicated to various aspects of breast health. Could you speak about how your involvement with the OBCIEP has influenced your (and your organization's) work in breast cancer?**

    Has the Project influenced networking in any way? Explain.

    Has the Project facilitated awareness-raising regarding other individuals and/or organizations involved in breast cancer? Explain

14. **The OBCIEP is comprised of three primary bodies: the Project Team, the Advisory Panel, and the Executive Committee. What are your general impressions of the ways in which communication is achieved between these bodies?**

    As an AP member, do you feel connected to the Project in the time period between AP meetings? Explain.

    The Executive Committee was formed in order to link the Project Team with the Advisory Panel and survivor perspective In your opinion, has this been useful? Explain.

    What are your thoughts and feelings about how the Project Team communicates with the Advisory Panel members? Explain.

    Do you have any suggestions about how communication between all bodies might be further improved?

**Regarding the activities in Themes I, II, and III**

15. **What are your thoughts and feelings about the activities in each of the Project Theme areas?**

16. **In your view, do the Project activities help the Project to meet its objectives?**

## APPENDIX 4d

17. **Do you have any ideas or suggestions about future activities that the Project might undertake?**

18. **Overall, what kind of contribution do you feel the OBCIEP has made to breast cancer?**

19. **To date, the Project has concentrated on the first six months following the detection of a mass in the breast. In your opinion, which general direction could the Project take in the future?**

20. **In your view, what do you think should happen with the Project at the end of the Health Canada funding period?**

    Do you feel the project should continue? Explain

    If yes,

    What should the Project do, in your opinion?

21. **How does it feel to be involved with the OBCIEP?**

22. **What else should I have asked you about the processes of the Ontario Breast Cancer Information Exchange Project?**

    Are there any other comments you would like to make about the Project, its structures, or activities - anything that I did not cover in the interview?

## APPENDIX 5

## INTERVIEW GUIDE (HEALTH CANADA)

1. **Could you tell me about your involvement with the Ontario Breast Cancer Information Exchange Project?**

    In your view, what is Health Canada's role in the Project?

2. **In your opinion, what is the OBCIEP designed to accomplish?**

3. **Could you tell me about the audiences reached by the Project?**

    In your opinion, are there other audiences that should be reached? Explain.

    Do you have any suggestions on how this would be best accomplished?

### Regarding the objectives of the OBCIEP

4. **What are your thoughts and feelings about these objectives?**

5. **In your opinion, are there factors which hinder the progression towards the Project objectives? Explain.**

6. **In your view, is the Project making steady progress towards its objectives? Explain.**

### Regarding the principles of the OBCIEP

7. **What are your thoughts and feelings about these principles?**

    Do you feel that these principles are practised within the OBCIEP? Explain.

    Do you have any suggestions about how the practising of such principles might be improved?

# APPENDIX 5b

8. **Survivor input is seen as an important aspect of the Project's functioning. What are your thoughts and feelings about the survivor input within the OBCIEP?**

   Do you have any suggestions for improvement regarding this issue?

9. **The Advisory Panel is charged with setting the strategic direction for the OBCIEP? What are your thoughts and feelings about the Advisory Panel's contributions to the Project?**

10. **Having had the opportunity to attend an OBCIEP Advisory Panel meeting, what are your thoughts and feelings about the semi-annual Advisory Panel meeting format?**

    Do you find these meetings useful and informative? Explain

    In your opinion, what are the high-points of these meetings?

    In your opinion, what are the low-points of these meetings?

11. **Do you feel in touch with what is happening with the Ontario Project? Explain.**

12. **The Advisory Panel is comprised of a number of people who are either breast cancer survivors, family members, and/or persons active within organizations dedicated to various aspects of breast health. Could you speak about how your involvement with the OBCIEP has influenced your (and your organization's) work in breast cancer?**

    Has the Project influenced networking in any way? Explain

    Has the Project facilitated awareness-raising regarding other individuals and/or organizations involved in breast cancer? Explain

13. **What are your general impressions of the ways in which communication is achieved between the OBCIEP and Health Canada?**

    Do you have any suggestions about how communication between these bodies might be further improved?

## APPENDIX 5c

Regarding the activities in Themes I, II, and III

14. **What are your thoughts and feelings about the activities in each of the Project Theme areas?**

15. **In your view, do the Project activities help us to meet the Project objectives?**

16. **Do you have any ideas or suggestions about future activities that the Project might undertake?**

17. **Overall, what kind of contribution do you feel the OBCIEP has made to breast cancer?**

18. **To date, the Project has concentrated on the first six months following the detection of a mass in the breast. In your opinion, which general direction should the Project take in the future?**

19. **In your view, what do you think should happen with the Project at the end of the Health Canada funding period?**

    Do you feel the project should continue? Explain.

    If yes,

    What should the Project do, in your opinion?

20. **What are your thoughts and feelings about Health Canada role in funding collaborative, stakeholder-driven projects such as the OBCIEP?**

21. **What else should I have asked you about the processes of the Ontario Breast Cancer Information Exchange Project?**

    Are there any other comments you would like to make about the Project, its structures, or activities at this time?

# APPENDIX 6

## OBCIEP INTERVIEW SUMMARY PAGE

### The Project operates according to the following objectives:

- to facilitate easy access to Ontarians to state-of-art, user-friendly information regarding breast cancer and other breast concerns
- to serve as a catalyst for cooperative activity regarding exchange of information about breast cancer and other related concerns
- to fill identified gaps, when appropriate, in collaboration with OBCIEP partners

### The Project operates according to the following principles:

- The Project is survivor-driven.
- AP sets the strategic direction for the Project activities.
- The AP has Ontario-wide representation.
- The Project is a catalyst for organizations involved in breast cancer information exchange, rather than a front-line service provider.
- Access to information is not restricted.

## ACTIVITIES TO DATE

### Theme I: Coordinating Breast Cancer Information

- Creation and maintenance of a database of organizations with a role in breast cancer and the information materials they provide
- Analysis of breast cancer information gaps
- Community consultation regarding ethnocultural issues.
- Production of a newsletter distributed province-wide.

### Theme II: Access to Information by Women and their Families

- Publication of a book on unconventional cancer therapies
- Request for proposals to fund activities that respond to information needs in Northern Ontario
- Partnership with the Burlington Breast Cancer Support Services and the other regional Pilot Projects to revise and update the "*What you need to know about Breast Cancer*" bookleT

### Theme III: Access to Information by Health Professionals

- Survey and report of family physicians' information needs and perceptions of their patients' needs about breast cancer and benign breast disease
- Survey of surgeons' perceptions of their patients' informational needs regarding breast cancer and benign breast disease
- Survey of nurses' information needs and perceptions of their patients' needs about breast cancer and benign breast disease

# APPENDIX 7

## Journal Entries and Personal Reflections

*It would be interesting to ask more questions about views on survivor input from survivors and non-survivors working within breast cancer stakeholder organizations. One member expressed resentment about feeling excluded from some activities etcetera because she was "lucky enough not to have breast cancer".*

*Regarding Julian Rappaport's reference to "professional experts as leaders"- I wonder how much effect my socialization has affected how I view the Project and who I see as in charge? I compiled a list of positive comments made by Advisory Panel members to give to the Project Team because they seemed to be overburdened by their workload.*

*The breast cancer survivors on the Advisory Panel are there as representatives of their organizations. It is not always clear whether or not these women are speaking for themselves as individuals or for their agency. It is also unclear how and what information is brought from the OBCIEP to respective agencies. It would be interesting to explore this further. Also, note that my belief is that the individual voice of the survivor is intrinsically important, but the objectives of the Project require that women be representatives of a larger group in order to maximize information diffusion.*

*A quote from one survivor was "You can work with breast cancer until you are living it and eating it". The intensity of the subject matter was inspiring at times, and exhausting at other times for me.*

*There are a lot of practical issues that have to be studied in order to learn from these kinds of consumer and professional run organizations. Each group has its own way of doing things and its own language. Communication is key and it may not come naturally. I wonder if within the Project the consumers still ultimately defer to the ideas of "professionals" even though they have input into the direction of initiatives? I wonder if the professionals within these kinds of organizations find it time consuming to deal with lay people?*

*Can true advocacy/social change initiatives be funded by the government?*

*Can a five year allotment of "seed" money to fund Information Exchange Projects be interpreted as a true commitment to breast cancer on the part of the government/or is it a panacea?*

*Does an emphasis on <u>prevention</u> for breast cancer contribute to the concept of "blaming the victim"?*

*How can we as women benefit from the positive aspects of a novel approach such as the OBCIEP and use it to as a springboard to a movement that promotes, and a society that values ,the inclusion of consumers' voices in health care decisions?*

# TABLE 1: PROGRAM MODEL FOR THE OBCIEP

| HEALTH CANADA GOALS | OBCIEP OBJECTIVES | ACTIVITIES AND OUTCOMES FOR KEY TARGET AREAS | | | | | |
|---|---|---|---|---|---|---|---|
| | | THEME I* ACTIVITIES | THEME I OUTCOMES | THEME II* ACTIVITIES | THEME II OUTCOMES | THEME III* ACTIVITIES | THEME III OUTCOMES |
| to ensure that women, their caregivers, and health professionals are able to make informed decisions about breast health | to facilitate easy access for Ontarians to state-of-the-art, user friendly information regarding breast cancer and other breast concerns | creation and maintenance of a database of organizations with a role in breast cancer and the information they provide | increase awareness and ease of access to information | publication of a book on unconventional cancer therapies | increase in ease of access to information on unconventional cancer therapies | survey and report of family physicians' information needs and perceptions of their patients' needs about breast cancer and benign breast disease | increase communication between health care professionals and breast cancer stakeholders and increase access to information |
| | | | | request for proposals to fund activities that respond to information needs in Northern Ontario | fill information gaps in Northern Ontario | | |
| | to serve as a catalyst for cooperative activity regarding exchange of information about breast cancer and other related concerns | analysis of breast cancer information gaps | increase knowledge of breast cancer resources in Ontario | | | survey of surgeons' perceptions of their patients' information needs regarding breast cancer and benign breast disease | increase communication between health care professionals and breast cancer stakeholders and increase access to information |
| | | community consultation regarding ethnocultural issues | increase access to information by ethnocultural populations | partnership with the Burlington Breast Cancer Support Services and the other regional Pilot Projects to revise and update the "What You Need to Know About Breast Cancer" booklet | increase ease of access to resources that facilitate informed decision making | survey of nurses' information needs and perceptions of their patients' needs about breast cancer and benign breast disease | increase communication between health care professionals and breast cancer stakeholders and increase access to information |
| | to fill identified gaps, when appropriate, in collaboration with OBCIEP partners | production of a newsletter distributed province-wide | increase awareness of the OBCIEP activities through networking | | | | |

| | |
|---|---|
| * THEME I | Coordinating breast cancer information |
| ** THEME II | Access to information by women and their families |
| *** THEME III | Access to information by health professionals |

TABLE 2

# OBCIEP MATRIX KEY

## SURVIVOR

| | |
|---|---|
| yes | • *person identified as breast cancer survivor* |
| no | • *not a breast cancer survivor* |

## AP MEMBER

| | |
|---|---|
| yes | • *member of the OBCIEP Advisory Panel* |
| no | • *not a member of the AP* |

## EC MEMBER

| | |
|---|---|
| yes | • *member of the OBCIEP Executive Committee* |
| no | • *not a member of the EC* |

**REP CAPACITY** *(def'n)*: The interviewee's perception of whom they represent on the OBCIEP Advisory Panel. Based on the response to *"Who do you perceive you speak for and/or represent on the Advisory Panel?"*. May or may not be the same as their official representation capacity.

| | |
|---|---|
| stakeholder org | • *represents a breast cancer stakeholder organization* |
| | • *may be connected to more than one support group* |
| | • *represents a breast cancer support group* |
| stk org & support grp | • *represents both a breast cancer stakeholder organization and a breast cancer support group* |
| non-stkhldr org | • *represents an organization whose mandate does not include breast cancer issues* |
| individual rep | • *represents herself* |
| family member | • *represents family members affected by breast cancer* |

## TABLE 2b

**INITIAL INVOLVEMENT** *(defn)*: Interviewee's perception of how they first became involved with the OBCIEP

| | |
|---|---|
| invited to RFP | • *member invited to assist in developing the proposal submitted from T-SRCC to Health Canada to house the Ontario Breast Cancer Information Exchange Pilot Project* |
| invited to AP | • *member invited to sit on AP after project awarded to T-SRCC* |
| sent by org | • *member sent by their organization to be a representative for that organization on the OBCIEPP Advisory Panel*<br>• *includes members who have replaced previous reps* |
| inconclusive | • *unable to determine from interview data* |

**HOW LONG ON AP** *(defn)*: Interviewee's assessment of how long they have been involved with the Project

| | |
|---|---|
| "x years" | • *the numerical amount of time the member has been involved with the Project* |
| beginning,inc RFP | • *involved during proposal development, >2½ years* |
| beginning, after RFP | • *involved since the commencement o Project, 2½ years* |

**# OF AP MTGS ATTENDED** *(defn)*: The number of AP meetings attended by the interviewee. Based both on self-disclosure and interviewer deduction. The actual number of meetings attended appears in brackets.

n.b. "?" = cannot tell from interview how many meetings have been attended

**INVOLVED IN OTHER ASP.** *(defn)*: Whether or not the member is involved with aspects of the Project other than the AP. Based on the response to the question *<u>"Besides the AP, are you involved with any other aspects of the Project?"</u>*.

| | |
|---|---|
| no | • *involved only with the Advisory Panel* |
| WG-"x" | • *involved in a specific workgroup* |
| other-"x" | • *involved in another aspect of the Project's functioning* |
| EC | • *involved with the Executive Committee* |

**CLEAR RE: MANDATE** *(defn)*: Whether or not the interviewee was clear about the OBCIEP mandate. Based both on self-disclosure and interviewer deduction. Clarity of mandate would involve reference to the Project as providing access to information about breast cancer/ benign breast disease to women, families and health professionals. Based on the response to the question *<u>"In your opinion, what is the OBCIEP designed to accomplish?"</u>*.

**CLEAR RE: MANDATE (... cont'd)**

| | |
|---|---|
| yes | • *interviewer deduction that the interviewee is clear about the OBCIEP mandate based on their indication that the Project is a vehicle to provide access to info about bc/bbd.* |
| no(SA) | • *interviewee indicated he/she is unclear about the OBCIEP mandate* |
| no(ID) | • *interviewer deducted that the interviewee was unclear about the OBCIEP mandate based on no reference to the Project as a vehicle to provide access to information about bc/bbd.* |
| partial | • *interviewer deducted that the interviewee was neither entirely clear or entirely unclear about the OBCIEP mandate. See "MANDATE COMMENTS" for elaboration.* |
| inconclusive | • *unable to deduct from interview data* |

**MANDATE COMMENTS** *(def'n)*: Interviewee comments about the OBCIEP mandate. May include mandate comments from the text of the interview.

**MANDATE CONCERNS** *(def'n)*: Interviewee comments about the concerns that they have about the OBCIEP mandate.

**SUPPORT MANDATE** *(def'n)*: Whether or not the member supports the OBCIEP mandate of providing access to information about bc/bbd.

| | |
|---|---|
| yes | • *interviewee clearly indicates that he/she supports mandate* |
| no(SA) | • *interviewee clearly indicates that he/she does not support mandate* |
| no(ID) | • *interviewer deducted that he/she does not support the mandate* |
| inconclusive | • *unable to deduct from interview data* |

**CLEAR RE: AUDIENCE** *(def'n)*: Whether or not the interviewee was clear about the OBCIEP's intended audience. Clarity of audience would include reference to women, families, and health care professionals. Based on response to the question *"Could you tell me about the audiences reached by the Project?".*

| | |
|---|---|
| yes | • *member is clear about the OBCIEP's intended audiences. Mentions women, families, and health care providers.* |

# TABLE 2d

**CLEAR RE: AUDIENCE (... cont'd)**

| | |
|---|---|
| no(SA) | • *member indicates that he/she is not clear about the OBCIEP audiences.* |
| no(ID) | • *interviewer deducted that the member is not clear about audiences based on no reference to women, families, or health care providers.* |
| partial | • *member makes reference to one or two of the intended audience, but not all three.* |
| inconclusive | • *unable to deduct from interview data.* |

**AUDIENCES MENTIONED** *(def'n)*: Indicates the audiences mentioned by the interviewee as those reached by the Project. Comments taken form text.

**OTHER AUDIENCES** *(def'n)*: Indicates the audiences that the interviewee felt should be reached by the OBCIEP. Based on the response to the question *"In your opinion, are there other audiences that should be reached that currently might not be reached by the Project?"*. Comments taken form interview text.

**COMMENTS** *(def'n)*: Interviewee comments regarding the OBCIEP objectives.[1] Based on the response to the question *"What are your thoughts and feelings about these objectives?"*.

**SUPPORT OBJECTIVES** *(def'n)*: Whether or not the interviewee supports the OBCIEP objectives.[2]

| | |
|---|---|
| yes(SA) | • *interviewee states clearly that he/she supports the OBCIEP objectives* |
| yes(ID) | • *interviewer deducted that the member supports the objectives.* |

---

[1] Interviewees had a summary sheet for reference during the interview which outlines the Project objectives, principles, and activities to date, by Theme area.

[2] The OBCIEP objectives include:

- *to facilitate easy access to Ontarians to state-of-art, user-friendly information regarding breast cancer and other breast concerns*
- *to serve as a catalyst for cooperative activity regarding exchange of information about breast cancer and other related concerns*
- *to fill identified gaps, when appropriate, in collaboration with OBCIEP partners.*

**SUPPORT OBJECTIVES (... cont'd)**

| | |
|---|---|
| no(SA) | • *interviewer clearly indicates that he/she does not support the OBCIEP objectives* |
| no(ID) | • *interviewer deducts that member does not support objectives* |
| inconclusive | • *cannot deduct from interview data* |

**OBJECTIVE CONCERNS** *(def'n)*: Specific concerns about the OBCIEP objectives mentioned by the interviewee.

**HINDERING FACTORS** *(def'n)*: Factors identified by the interviewee as those which may hinder the Project's progression towards its objectives. Based on response to the question *"In your opinion, are there factors which hinder the progression towards the Project objectives?"*.

**STEADY PROGRESS** *(def'n)*: Whether or not the respondent feels that the Project is making steady progress towards its objectives. Based on the response to the question *"In your view, is the Project making steady progress towards its objectives?"*.

| | |
|---|---|
| yes | • *interviewee indicates that he/she feels steady progress is being made towards the OBCIEP objectives.* |
| Yes (Q) | • *qualified yes. See OBJECTIVES COMMENTS for clarification* |
| don't know | • *interviewee unsure whether or not steady progress is being made* |

**COMMENTS ON PRINCIPLES** *(def'n)*: Interviewee comments regarding the OBCIEP principles. Based on the response to the question *"What are your thoughts and feelings about these principles?"*.[3] ref to survivor-driven, ref to AP sets strategic direction, ref to Ontario-wide representation, ref to catalyst rather than front-line, ref to access to info is not restricted- in response to the fore-mentioned question.

---

[3] OBCIEP principles include:

- *The Project is survivor-driven*
- *AP sets the strategic direction*
- *The AP has Ontario-wide representation*
- *The Project is a catalyst for organizations involved in breast cancer information exchange, rather than a front-line service provider*
- *Access to information is not restricted*

# TABLE 2f

**COMMENTS ON PRINCIPLES (... cont'd)**

| | |
|---|---|
| yes (+) | • *a positive reference made to the principle* |
| yes (-) | • *a negative reference made to the principle* |
| yes (+-) | • *a neutral reference made to the principle* |
| yes | • *a reference to the principle, inconclusive whether +,-, or +-* |
| no | • *no reference to the principle* |

**SUPPORT PRINCIPLES**

| | |
|---|---|
| yes(SA) | • *interviewee clearly indicates support for OBCIEP principles* |
| yes(ID) | • *interviewer deducted that interviewee supports principles* |
| yes(Q) | • *qualified yes. See PRINCIPLES COMMENTS for clarification* |
| inconclusive | • *cannot assess from interview data* |

**FEEL THEY ARE PRACTICED** *(def'n)*: Whether or not interviewee feels the principles are practiced within the Project. Based on the response to the question *"Do you feel that these principles are practiced within the OBCIEP?"*.

| | |
|---|---|
| yes | • *interviewee feels principles are practiced within the Project.* |
| yes(Q) | • *qualified yes. Comments added.* |
| no | • *Interviewee does not feel the principles are practiced within the Project.* |
| inconclusive | • *cannot assess from interview data.* |
| don't know | • *interviewee indicates he/she does not know whether or not principles are practiced within the Project.* |
| DN(Q) | • *interviewee indicates he/she does not know if principles are practiced and adds comments.* |

**SURVIVOR INPUT COMMENTS** *(def'n)*: Interviewee comments about the survivor input within the OBCIEP. Based in part[4] on the response to the question *"Survivor input seen as an important aspect of the Project's functioning. What are your thoughts and feelings about the survivor input within the OBCIEP?"*.

---

[4] As with other categories, pertinent data is taken from comments made throughout the entire interview.

## TABLE 2g

**AP STRATEGIC DIRECTION** *(def'n)*: Whether or not the interviewee feels the OBCIEP Advisory Panel sets the strategic direction for the Project. Based in part on the response to the question *"The Advisory Panel is charged with setting the strategic direction for the OBCIEP. What are your thoughts and feelings about the Advisory Panel's contributions to the Project?".*

| | |
|---|---|
| yes(SA) | • *interviewee clearly indicates that he/she does feels that the AP sets the strategic direction for the Project.* |
| yes(ID) | • *interviewer deducted that the interviewee feels that the AP sets the strategic direction.* |
| no(SA) | • *interviewee clearly indicates that he/she does not feel that the AP sets the strategic direction for the Project.* |
| no(ID) | • *interviewer deducted that the interviewee feels that the AP does not set the strategic direction.* |
| don't know | • *interviewee indicates that he/she is not sure whether or not the AP sets the strategic direction.* |
| inconclusive | • *inconclusive form interview data* |

**COMMENTS** *(def'n)*: Interviewee comments regarding the OBCIEP Advisory Panel.

**FEEL INVOLVED IN DECISIONS** *(def'n)*: Whether or not the interviewee feels involved in Project decisions. Based on the response to the question *"Do you feel involved in the decision making processes?".*

| | |
|---|---|
| yes | • *interviewee indicates he/she feels involved in decisions.* |
| yes(Q) | • *Qualified yes. Comments added.* |
| no | • *interviewee indicates that he/she does not feel involved in OBCIEP decision making.* |
| no(Q) | • *Qualified no. Comments added.* |

**AP MEETINGS COMMENTS** *(def'n)*: Interviewee comments about OBCIEP Advisory Panel meetings. Based on the response to the question *"What are your thoughts and feelings about the semi-annual Advisory Panel meeting format?".*

**USEFUL AND INFORMATIVE** *(def'n)*: Whether or not the member finds AP meetings useful and informative. Based on the response to the question *"Do you find these meetings useful and informative?".* Comments added as necessary.

**USEFUL AND INFORMATIVE (... cont'd)**

| | |
|---|---|
| yes | • *interviewee feels AP meetings are useful and informative* |
| no | • *interviewee does not feel AP meetings are useful & informative* |

**HIGH POINTS** *(def'n)*: Interviewee comments about the high points of AP meetings. Based on the response to the question *"In your opinion, what are the high points of the meetings?"*.

**LOW POINTS** *(def'n)*: Interviewee comments about the low points of AP meetings. Based on the response to the question *"In your opinion, what are the low points of the meetings?"*.

**SATURDAYS** *(def'n)*: Interviewee comments/feelings about AP meetings being held on Saturdays. Based on the response to the question *"What do you think about the Saturday schedules?"*.

**IN TOUCH AT AP MEETINGS** *(def'n)*: Whether or not interviewee feels in touch with what is going on with the Project at the semi-annual Advisory Panel meetings. Based on the response to the question *"Do you feel in touch with what is happening with the Project at the AP meetings?"*.

| | |
|---|---|
| yes | • *interviewee indicated that he/she feels in touch with OBCIEP at AP meetings.* |
| no | • *interviewee indicated that he/she does not feel in touch with OBCIEP at AP meetings.* |
| Yes (Q) | • *qualified yes. Comments added.* |
| No (Q) | • *qualified no. Comments added.* |
| don't know | • *interviewee unsure.* |

**EC COMMENTS** *(def'n)*: Interviewee comments/feelings about the OBCIEP Executive Committee.

# TABLE 2i

**NETWORKING** *(def'n)*: Whether or not the interviewee feels that his/her involvement with the OBCIEP has contributed to networking. Based on the response to the question *"Has the Project influenced networking in any way?"*.

| | |
|---|---|
| yes | • *interviewee feels Project has influenced networking* |
| no | • *interviewee does not feel Project has influenced networking* |

**AWARENESS-RAISING** *(def'n)*: Whether or not the interviewee feels that his/her volvement with the OBCIEP has contributed to breast cancer awareness-raising.Based on the response to the question *"Has the Project facilliated awareness-raising regarding other individuals and/or organizations involved in breast cancer?"*.

| | |
|---|---|
| yes | • *interviewee feels Project has influenced awareness-raising* |
| no | • *interviewee does not feel Project has influenced awareness-raising* |

**SEE EC AS USEFUL** *(def'n)*: Whether or not the interviewee sees the OBCIEP's Executive Committee as a useful organizational body. Based on the response to the question *"The Executive Committee was formed in order to link the Project Team with the Advisory Panel and survivor perspective. In your opinion, has this been useful?"*.

| | |
|---|---|
| yes | • *interviewee feels EC is a useful body within the OBCIEP* |
| no | • *interviewee feels EC is not a useful body within the OBCIEP* |
| yes(Q) | • *qualified yes. Comments added* |
| no(Q) | • *qualified no. Comments added* |
| don't know | • *interviewee unsure whether or not EC is useful within the OBCIEP* |

**COMMUNICATION WITH STAFF** *(def'n)*: Interviewee comments about communication with OBCIEP staff. Based in part on the response to the question *"What are your thoughts and feelings about how the Project Team Communicates with the Advisory Panel members?"*.

**THEME I GENERAL COMMENTS** *(def'n)*: Interviewee's general comments about Theme I activities, etcetera. Based in part on the response to the question *"What are your thoughts and feelings about the activities in each of the Project Theme areas?"*. ref to database, ref to info gap analysis, ref to ethnocultural consultation, ref to newsletter

| | |
|---|---|
| yes | • *interviewee makes a reference to the activity.* |
| no | • *interviewee does not make reference to the activity* |

## TABLE 2j

**THEME II GENERAL COMMENTS** *(def'n)*: Interviewee's general comments about Theme II activities, etcetera. *"What are your thoughts and feelings about the activities in each of the Project Theme areas?".* ref to unc. ther. book, ref to rfp northern, ref to BBCSS booklet

| | |
|---|---|
| yes | • *interviewee makes a reference to the activity* |
| no | • *interviewee does not make a reference to the activity* |

**THEME III GENERAL COMMENTS** *(def'n)*: Interviewee's general comments about Theme III activities, etcetera. *"What are your thoughts and feelings about the activities in each of the Project Theme areas?".* ref to physicians' survey, ref to surgeons' survey, ref to nurses' survey

| | |
|---|---|
| yes | • *interviewee makes a reference to the activity* |
| no | • *interviewee does not make a reference to the activity* |

**HELP TO MEET OBJECTIVES** *(def'n)*: Interviewee feels the Project activities help the Project to meet its objectives. Based on the response to the question *"In your view, do the Project activities help the Project to meet its objectives?".*

| | |
|---|---|
| yes | • *interviewee feels activities help the Project to meet its objectives* |
| no | • *interviewee feels activities do not help the Project to meet its objectives* |
| don't know | • *interviewee unsure whether or not activities help Project to meet its objectives* |

**OVERALL CONTRIBUTION** *(def'n)*: Interviewee's assessment of the Project's overall contributions to breast cancer. Based on the response to the question *"Overall, what kind of contribution do you feel the OBCIEP has made to breast cancer?".*

**CONTINUATION COMMENTS** *(def'n)*: Interviewee comments regarding the continuation of the OBCIEP beyond the five year Health Canada funding period. Based on the response to the question *"In your view, what do you think should happen with the Project at the end of the Health Canada funding period?".*

**PERSONAL FEEL SH. CONTINUED** *(def'n)*: Whether or not the interviewee feels the Project should continue. Based on the response to the question *"Do you feel the Project should continue?"*.

| | |
|---|---|
| yes | • *interviewee feels OBCIEP should continue beyond Health Canada funding period* |
| no | • *interviewee does not feel OBCIEP should continue beyond Health Canada funding period* |
| don't know | • *interviewee unsure/unable to assess whether or not he/she feels OBCIEP should continue beyond Health Canada funding period* |

**FEELS TO BE INVOLVED** *(def'n)*: Interviewee brief comments about how it feels to be involved with the Project. Based on the response to the question *"How does it feel to be involved with the OBCIEP?"*.

## TABLE 21

# TABLE 2: OBCIEP MATRIX

| | *Interview #2* | *Interview #7* | *Interview #8* | *Interview #9* | *Interview #10* | *Interview #11* |
|---|---|---|---|---|---|---|
| ***SURVIVOR*** | yes | yes | no | no | yes | yes |
| ***AP MEMBER*** | yes | yes | yes | yes | yes | yes |
| ***EC MEMBER*** | no | no | no | no | no | no |
| ***REP CAPACITY*** | stakeholder org | support group | stakeholder org | stakeholder org | Individual rep | stakeholder org. |
| ***INITIAL INVOLVEMENT*** | invited to AP | sent by organization | sent by organization | sent by organization | invited to AP | sent by organization |
| ***HOW LONG ON AP*** | beginning,after RFP | 1 year | beginning, after RFP | beginning, inc RFP | beginning, after RFP | over a year |
| ***# OF AP MTGS ATTENDED*** | 4(4) | 2(2) | 3(3) | 0(0) | 4(4) | 2?(2) |
| ***INVOLVED IN OTHER ASP.*** | no | no | no | no | WG-nurses survey | Reviewed guide, some multiculturalism |
| ***CLEAR RE: MANDATE*** | yes(ID) | partial | partial | partial | partial | yes(ID) |
| ***MANDATE COMMENTS*** | Purpose is to fill and identify gaps for men, women and meds | Purpose is to make info user-friendly for women | To communicate and coordinate information to avoid duplication | Allows our organization to disseminate information Allows for non-surv. input | Each member brings information in and takes information out | More an information gathering body It streamlines the information |
| ***MANDATE CONCERNS*** | | | | | We represent women with bc, but are not mandated to touch inds | The Project neutralizes the politics of bc stakeholder organizations in Ontario. |
| ***SUPPORT MANDATE*** | yes(ID) | inconclusive | inconclusive | inconclusive | yes(ID) | inconclusive |
| ***CLEAR RE: AUDIENCE*** | inconclusive | partial | no(SA) | no(SA) | no(ID) | inconclusive |
| ***AUDIENCES MENTIONED*** | the organization's audience | Women from support groups People who bought the guide | The general public, meds , hospitals, and support groups | My organization | | The audience that I personally reach in Toronto, Ontario, and Canada |
| ***OTHER AUDIENCES*** | work with meds through the College of Physicians & Surgeons | Physicians, social workers etc. | The general public. | More non-survivor driven groups | Individual women with breast cancer | Multicultural community. There is no native link |
| ***COMMENTS*** | support change to BBD focus Project strength is as a catalyst I am pleased with what what we have done | | They are important and require evaluation at the end of the Project | The objectives are good | | They are looking at gaps, but nothing concrete yet Toll free line might help access to the Project Making steps not strides It's connecting people |

TABLE 2m

# TABLE 2: OBCIEP MATRIX

| | *Interview #12* | *Interview #13* | *Interview #14* | *Interview #15* | *Interview #16* | *Interview #17* |
|---|---|---|---|---|---|---|
| ***SURVIVOR*** | no | no | yes | yes | yes | yes |
| ***AP MEMBER*** | yes | yes | yes | yes | yes | yes |
| ***EC MEMBER*** | no | no | no | no | no | yes |
| ***REP CAPACITY*** | stakeholder org | stakeholder org | stakeholder org | a st org & support grp | inconclusive | stakeholder org |
| ***INITIAL INVOLVEMENT*** | sent by organization | sent by organization | sent by organization | inconclusive | invited to RFP | invited to RFP |
| ***HOW LONG ON AP*** | beginning, after RFP | six months | befinning, after RFP | beginning, after RFP | beginning, Inc RFP | beginning, Inc RFP |
| ***# OF AP MTGS ATTENDED*** | 4(4) | 1(1) | 4(4) | 3(2) | ?(4) | 2(2) |
| ***INVOLVED IN OTHER ASP.*** | Other- Facilitate the distribution of materials | WG-nurses survey | WG-nurses survey | no | WG nurses survey<br>WG-unc ther book | EC |
| ***CLEAR RE: MANDATE*** | no(SA) | yes(SA) | yes(ID) | partial | inconclusive | partial |
| ***MANDATE COMMENTS*** | Get information to women and to organizations that serve women | I think it is true to its objectives | Coordinates the most up to date info Responds to expressed needs. | To fill info gaps so no one goes without information | Too academic and professional | Easy access to information for women with breast cancer |
| ***MANDATE CONCERNS*** | Not sure the Project has yet helped every type of women who gets bc. | | | | I thought there would be more focus on survivor/layman. | |
| ***SUPPORT MANDATE*** | inconclusive | yes(SA) | yes(ID) | inconclusive | no(SA) | yes(ID) |
| ***CLEAR RE: AUDIENCE*** | no(SA) | yes | partial | no(ID) | no(SA) | partial |
| ***AUDIENCES MENTIONED*** | Women and organizations who serve women with or at risk of bc. | Women who want info on bc, meds, women with bc. | The Project members each have their own spheres of influence. Women with bc. | All of Ontario, Canada, small support groups. | Those people who received the guide. | Women with breast cancer and others who suffer with cancer |
| ***OTHER AUDIENCES*** | Women who live in remote areas Women who are less resourceful. | Individuals with breast cancer and families. | I can't think of any. | Support groups in remote areas. | Breast cancer survivors who don't know the Project even exists. | More rural and Northern audiences. |
| ***COMMENTS*** | The first obj. is unclear. Fulfills catalyst role by bringing people together. We will identify gaps, but won't get to filling them. | I think they are achievable. I hope they are achievable. I think they are clear. | I agree with them or I wouldn't be on the AP. There is a need for each of them | Serving as a catalyst is vital and necessary | The first two objectives are for professionals only. | They are the objectives that we decided upon |

TABLE 2n

# TABLE 2: OBCIEP MATRIX

| | *Interview #18* | *Interview #20* | *Interview #21* | *Interview #22* | *Interview #23* | *Interview #24* |
|---|---|---|---|---|---|---|
| ***SURVIVOR*** | yes | no | yes | no | no | yes |
| ***AP MEMBER*** | yes | yes | yes | yes | yes | yes |
| ***EC MEMBER*** | yes | no | no | no | yes | no |
| ***REP CAPACITY*** | individual rep | stakeholder org | individual rep | stakeholder org | stakeholder org | support group |
| ***INITIAL INVOLVEMENT*** | invited to AP | inconclusive | invited to AP | sent by organization | inconclusive | inconclusive |
| ***HOW LONG ON AP*** | beginning, after RFP | 1 year | 1 year and a half | beginning, after RFP | beginning, after RFP | one year and a half |
| ***# OF AP MTGS ATTENDED*** | 4(4) | 0(0) | 1(1) | <4(2) | ?(4) | ?(2) |
| ***INVOLVED IN OTHER ASP.*** | EC | no | WG-unc ther book | no | EC | WG-unconventional therapies |
| ***CLEAR RE: MANDATE*** | yes(ID) | no(SA) | partial | yes(ID) | yes(ID) | partial |
| ***MANDATE COMMENTS*** | The role is as a catalyst To build bridges between stakeholders | It is about info needs Seems to be at needs assessment stage only | It brings med comm together with patients to share information | Brings together the bc stakeholders that provide the information | Want to facilitate access to info for patients, families, and physicians | To facilitate information exchange among groups in Ontario |
| ***MANDATE CONCERNS*** | | | Should be most concerned with communicating to meds and survivors first. | | Need more details Do not feel plugged into what the Project is doing. | |
| ***SUPPORT MANDATE*** | yes(SA) | inconclusive | inconclusive | yes(SA) | inconclusive | inconclusive |
| ***CLEAR RE: AUDIENCE*** | yes | no(SA) | yes(ID) | yes(ID) | yes(ID) | no(ID) |
| ***AUDIENCES MENTIONED*** | At this stage we are reaching the Project stakeholders | Medical practitioners and women with breast cancer | Medical community, patients, families | Stakeholders and agencies that responded to surveys | Survivors, families, health care professionals | Women touched by breast cancer |
| ***OTHER AUDIENCES*** | The larger end user community | | Not sure we are reaching doctors yet or survivors who are not on the AP | The general public. We can do this indirectly through stakeholder organizations. | | Other groups across Canada(vague). |
| ***COMMENTS*** | I concur with them | The target audience for the first objective is huge The Project should go beyond filling gaps to identifying duplications | Not sure we have achieved any of them yet | The intent is stakeholder communication and avoid duplication of services | They are appropriate because we agreed on them from the beginning | They are objectives we agreed to |

TABLE 2o

## TABLE 2: OBCIEP MATRIX

| | *Interview #25* | *Interview #26* | *Interview #27* | *Interview #28* | *Interview #29* | *Interview #30* |
|---|---|---|---|---|---|---|
| ***SURVIVOR*** | no | no | yes | yes | no | yes |
| ***AP MEMBER*** | yes | yes | yes | yes | yes | yes |
| ***EC MEMBER*** | no | no | no | no | no | no |
| ***REP CAPACITY*** | stakeholder org | stakeholder org | stakeholder org | stk org & support grp | stakeholder org | stakeholder org |
| ***INITIAL INVOLVEMENT*** | inconclusive | invited to RFP | invited to AP | invited to AF | inconclusive | invited to RFP |
| ***HOW LONG ON AP*** | beginning, after RFP | beginning, inc RFP | beginning, after RFP | beginning, after RFP | beginning, after RFP | beginning, inc RFP |
| ***# OF AP MTGS ATTENDED*** | ?(3) | 3(3) | 4?(3) | ?(3) | ?(3) | 2(2) |
| ***INVOLVED IN OTHER ASP.*** | WG-nurses survey | WG-unc ther and Theme III | WG-books | WG-unc ther and misc comments on docs | no | WG-BBCSS booklet |
| ***CLEAR RE: MANDATE*** | inconclusive | yes(ID) | partial | partial | partial | yes(ID) |
| ***MANDATE COMMENTS*** | Involving women with bc and doing a much needed inventory | Understand needs and exchange information To collaborate and find gaps | Make information accesible to bc patients in Ontario | Act as liasing body for bc information agencies and programs | Trying to find the information gaps that exist for women | To promote collaboration To improve access to info for women and families. |
| ***MANDATE CONCERNS*** | | It is challenging because so many people in Ontario are involved in the bc area. | | | | |
| ***SUPPORT MANDATE*** | inconclusive | inconclusive | inconclusive | inconclusive | inconclusive | inconclusive |
| ***CLEAR RE: AUDIENCE*** | partial | yes | yes(ID) | yes(ID) | partial | yes(ID) |
| ***AUDIENCES MENTIONED*** | Institutions and consumers from support groups | Anyone at risk or has bc Professionals involved in bc Those who care | The panel filters information out to our own systems | Women and families in Ontario with information needs Physicians | Women and families touched by breast cancer | Member groups and other groups involved in bc at this point |
| ***OTHER AUDIENCES*** | The general public, meds, family/friends, non-cancer hospitals. | Ethnocultural populations. People from lower socio-economic classes. | Minority and non-English speaking populations. Rural areas within the province | Have to reach out to physicians more Especially in Northern Ontario. | The general public. | The individual women who is not affiliated with an organization |
| ***COMMENTS*** | Not sure #1 achieved. Making headway in #2 Have looked at a number of ways to get at #3, like Theme III surveys | They are reasonable and obtainable | The objectives are good and I agree with them | Look good on paper, but are hard to achieve. We are working towards it & attempting to coordinate cooperation between agencies | Number one is a challenge Number two and three are being addressed nicely | Not sure we are there yet with number one and number three We are definately helping with objective two |

## TABLE 2p

# TABLE 2: OBCIEP MATRIX

| | *Interview #31* | *Interview #32* | *Interview #33* | *Interview #35* | *Interview #36* | *Interview #37* |
|---|---|---|---|---|---|---|
| ***SURVIVOR*** | yes | no | no | no | yes | no |
| ***AP MEMBER*** | yes | yes | yes | yes | yes | yes |
| ***EC MEMBER*** | no | no | no | no | yes | no |
| ***REP CAPACITY*** | non-stakeholder org | family member | stakeholder org | non-stkhldr org | stakeholder org | support group |
| ***INITIAL INVOLVEMENT*** | invited to AP | invited to RFP | invited to RFP | invited to AP | invited to RFP | invited to AP |
| ***HOW LONG ON AP*** | beginning, after RFP | beginning, inc RFP | beginning, inc RFP | beginning, after RFP | beginning, inc RFP | beginning, after RFP |
| ***# OF AP MTGS ATTENDED*** | ?(4) | 2?(1) | 3?(2) | ?(3) | 4?(4) | 2?(3) |
| ***INVOLVED IN OTHER ASP.*** | WG-Norther RFP and multicultural issues | no | no | presentations | Attended EC meeting in Calgary | no |
| ***CLEAR RE: MANDATE*** | partial | partial | partial | partial | inconclusive | yes(ID) |
| ***MANDATE COMMENTS*** | To catalyze action within the bc network and to identify info gaps | An information thing To provide suport for those touched by cancer | To ensure that information about breast cancer is exchanged | To coordinate breast cancer efforts | misc ref to objectives see text | We look at what information is needed and the best way to provide it |
| ***MANDATE CONCERNS*** | | | | | | |
| ***SUPPORT MANDATE*** | inconclusive | inconclusive | inconclusive | inconclusive | inconclusive | inconclusive |
| ***CLEAR RE: AUDIENCE*** | inconclusive | inconclusive | no(SA) | inconclusive | yes(ID) | no(SA) |
| ***AUDIENCES MENTIONED*** | Professional and volunteer agencies The medical delivery system | People who are interested and touched by cancer in some way | Partner organizations on the AP It is hard to assess this | Attempting to reach as wide audience of those involved in bc advocacy | The partner organizations patients families | Support groups, people who bought the guide |
| ***OTHER AUDIENCES*** | The indivisual woman who is not affiliated with anything | It is not intended for other things | Multcultural groups, the general public, and health professionals | Individuals affected by bc, but the Project is not really designed for that | Form unique partnerships to link with other organizations | Hard to say because I don't know exactly who the audiences are |
| ***COMMENTS*** | [illegible] they are clear and still relevant | It's doing what it was set up to do | It needs to be a catalyst Concerns about maintaining state-of-the-art info and identifying gaps on a continuing basis | misc-see text I don't think a single Project can do all things The Project is well organized and has made efforts | The Project must keep up with state-of-art to be different from other bc organizations | The original meetings outlined objectives and Themes They capture what we are trying to do I agree with the emphasis on BBD |

## TABLE 2q

# TABLE 2: OBCIEP MATRIX

| | *Interview #2* | *Interview #7* | *Interview #8* | *Interview #9* | *Interview #10* | *Interview #11* |
|---|---|---|---|---|---|---|
| *SUPPORT OBJECTIVES* | yes(SA) | yes(ID) | yes(ID) | yes(SA) | yes(SA) | Inconclusive |
| *OBJECTIVE CONCERNS* | Project is not on information highway yet. | | | I hope they are what they mean to be | | Need to highlight gaps and take concrete actions. |
| *HINDERING FACTORS* | The size of the task<br>Hard to reach busy meds.<br>The size of Ontario<br>Ethnocult. & linguistic issues. | Funding and the active participation of meds community. | None that I can see | Organizations are territoria'. Need to coordinate efforts provoncially and nationally. | Politics | Politics |
| *STEADY PROGRESS* | yes | yes | yes(Q), from what I ve seen and read. | yes | yes(Q), this last year | yes(Q), making steps, but need to make strides. |
| *COMMENTS ON PRINCIPLES* | Support those principles. Lack of aborig & francoph. on AP is a weakness | Survivor majority for guidance. Need professionals also | They are all important. Need not alter. | I am unhappy about the survivor-driven focus. Non survivors have a lot to give. | | Need guidelines to outline roles & responsabilities. Northern input troublesome. |
| *ref to survivor-driven* | no | yes(+-) | no | yes(-) | yes(+) | yes(-) |
| *ref to AP sets strategic direction* | no | no | no | no | yes(-) | yes(+) |
| *ref to Ontario-wide representation* | yes(+-) | no | no | no | yes(+) | yes(+-) |
| *ref to catalyst rather than front-line* | no | no | no | no | yes(+) | yes(+-) |
| *ref to access to info is not restricted* | no | no | no | no | yes(+) | yes(+-) |
| *SUPPORT PRINCIPLES* | yes(SA) | inconclusive | yes(ID) | yes(Q), except for the first | yes | inconclusive |
| *FEEL THEY ARE PRACTICED* | Inconclusive | yes | don't know(Q). Most likely. | yes(Q), as far as I know | yes | don't know |
| *SURVIVOR INPUT COMMENTS* | Felt surv. input was directed at first, but has improved. Should use AP mtgs wisely to benefit from mem. input. | Needs to be survivor driven. | Survivor input is of utmost importance. Must avoid us against them perspective. | Survivor input is important, but others have valuable insights to contribute. | An asset because we have been there, but burnout can be a problem. | There is survivor input in the AP and EC, but the Project is not survivor-driven. |
| *AP STRATEGIC DIRECTION* | yes(ID) | Inconclusive | yes(ID) | Inconclusive | no | yes(SA) |
| *COMMENTS* | It is working well. We are listened to and our influence is felt. We are not decision makers. | Seems to be efficient. Feel I have contributed. | It operates at a high level. Would like to see Northern Ontario members more involved. | I try to remember I am not there for myself, but to represent my organization. | I have been to all mtgs and didn't know about the guide. AP not too much to ask. | Asked for our opinions. Allowed to agree or disagree. |

## TABLE 2r

# TABLE 2: OBCIEP MATRIX

| | Interview #12 | Interview #13 | Interview #14 | Interview #15 | Interview #16 | Interview #17 |
|---|---|---|---|---|---|---|
| SUPPORT OBJECTIVES | inconclusive | yes(SA) | yes | yes(ID) | no(SA) | yes(SA) |
| OBJECTIVE CONCERNS | misc-see text | I don't have any problems with them. | A lot of activity and not a lot of cooperation in role as a catalyst. Is improving. | | Too academic, but they are on target the way it is set up. | |
| HINDERING FACTORS | Objectives are not sufficiently clear. Orgs are insular and jurisdictional. | Continuing monetary support | Territorial politics There is a difficulty with the North and multicult. representation. | Ontario is vast with many remote areas | | Time and that sort of thing. |
| STEADY PROGRESS | don't know | yes | yes | yes | Yes, but the structure is not my vision. | yes |
| COMMENTS ON PRINCIPLES | misc-see text | They are really the driving force of the Project | misc-see text<br>The Project has walked the talk. | Exactly the way I feel about what is needed | lack of Northern, not survivor-dr., AP does set strat. direction | They are terrific |
| ref to survivor-driven | yes(-) | no | yes(+) | yes(+) | yes(-) | no |
| ref to AP sets startegic direction | yes(-) | no | yes(+) | no | yes(+) | no |
| ref to Ontario-wide representation | yes(-) | yes(+-) | yes(+-) | yes(+-) | yes(-) | no |
| ref to catalyst rather than front-line | yes(-) | no | yes(+-) | yes(+) | yes(+) | no |
| ref to access to info is not restricted | yes(+) | no | yes(+) | yes(+) | no | no |
| SUPPORT PRINCIPLES | inconclusive | yes | yes | yes(SA) | inconclusive | yes |
| FEEL THEY ARE PRACTICED | Do not feel #2 or #4 are achieved. | yes | yes | yes | yes | yes |
| SURVIVOR INPUT COMMENTS | It is more than the woman survivor | I am impressed with the survivors' perspectives. The ball is in our court to listen | It has given me a new prespective as a health professional. | It has to be survivor-driven and it is. We know how hard it is to get info. | I think they should be chairing commitees. Theme III should not be chaired by professionals. | PT commited to listening to survivors. Work very hard for survivor driven. |
| AP STRATEGIC DIRECTION | no(SA), EC does | yes(ID) | yes(SA) | yes(ID) | yes(SA) | inconclusive |
| COMMENTS | Feel the AP is a rubber stamp. If the AP is there to advise, say so. Do not say it sets strategic dir. | It is hard to stimulate a lot of discussion with a large group. Some individuals dominate the discussion. | I think the contributions are on diferent levels. Good mix of surv & non-surv. Close contact with EC. | We are doing a good job and contributing. | I think AP probably sets the strategic direction. We should be more hands-on | Feel the opportunity to be involved exists. |

TABLE 2s

# TABLE 2: OBCIEP MATRIX

| | *Interview #18* | *Interview #20* | *Interview #21* | *Interview #22* | *Interview #23* | *Interview #24* |
|---|---|---|---|---|---|---|
| *SUPPORT OBJECTIVES* | yes(SA) | yes(SA) | yes(SA) | yes(SA) | yes(SA) | yes(SA) |
| *OBJECTIVE CONCERNS* | | see comments | see comments | | | |
| *HINDERING FACTORS* | There is the perception of a passive membership. Members must have ownership fr the work done | Money and time. | Not meeting enough for full AP input. Fear that EC could get myopic | None I am aware of | Don't feel hindered Manpower always helps | Nothing I'm concerned about |
| *STEADY PROGRESS* | yes | yes | yes | yes | yes | yes |
| *COMMENTS ON PRINCIPLES* | I believe there should be balance and not totally survivor-driven | They are very good | Project is AP driven not survivor-driven. All the others are good | They are quite sound and the Project adheres to them I support them | Well known to me due to EC role. They are on track | I agreed to them. |
| *ref to survivor-driven* | yes(+-) | yes(+) | yes(-) | no | no | no |
| *ref to AP sets startegic direction* | yes(+-) | no | yes(+) | no | yes(+-) | no |
| *ref to Ontario-wide representation* | no | no | yes(+) | no | yes(+-) | no |
| *ref to catalyst rather than front-line* | no | no | yes(+-) | yes(+) | no | no |
| *ref to access to info is not restricted* | no | no | yes(+) | no | no | no |
| *SUPPORT PRINCIPLES* | yes(SA), also see comments, | yes(SA) | inconclusive | yes(SA) | yes | yes(SA) |
| *FEEL THEY ARE PRACTICED* | inconclusive | yes(Q), as far as I can see. | yes, although I am not sure about the first one. | yes | Inconclusive. Problem with Ont-wide representation | yes |
| *SURVIVOR INPUT COMMENTS* | The survivors are given high curtosy, but we need to revisit this issue. | Cannot comment due to no direct knowledge. | This is the most important part. I am not sure the Project is survivor-driven. | Think it is important. The emphasis needs to be on survivor involvement in bc initiatives. | An important principle. There is survivor input. | It is paramount to any project. The staff help to ensure survivor involvement. |
| *AP STRATEGIC DIRECTION* | don't know | don't know | yes(SA) | inconclusive | inconclusive | yes(SA) |
| *COMMENTS* | I think the Project Team sets the strategic direction. | I am never at AP meetings. AP seems to set and meet tasks and objectives. There are a variety of activities. | I imagine that the AP are dedicated and have contributed. I am not sure due to being at only one mtg. | Members have input, a voice in influencing project direction. I have not attended all meetings. | Not sure there is a mechanism for AP to vote on directions. | It is critical. Surv/AP are the only information base from which to make judgement. |

## TABLE 2t

# TABLE 2: OBCIEP MATRIX

| | *Interview #25* | *Interview #26* | *Interview #27* | *Interview #28* | *Interview #29* | *Interview #30* |
|---|---|---|---|---|---|---|
| *SUPPORT OBJECTIVES* | Inconclusive | yes(ID) | yes(SA) | yes(SA) | Inconclusive | Inconclusive |
| *OBJECTIVE CONCERNS* | | I thought there would be more gains by now, but that will come. | | Must do something about the huge gaps. | I think we should be increasing the knowledge of the general public. | |
| *HINDERING FACTORS* | Human factor of keeping momentum going | It is herd to manage with so many people involved. It has been impressive so far. | Monetary factors | Breast cancer is very political | Reaching the general public. We need a sub-committee for this purpose | Dwindling attendence at meetings |
| *STEADY PROGRESS* | yes | yes | yes | yes | yes(Q), I think so | yes |
| *COMMENTS ON PRINCIPLES* | Misc see text | They tell it like it is. Reminds me that the Project is not a front-line provider. | Representation is heavy in Metro TO and should be wider | A Survivor-driven AP is most important and will make the project a success | Good in cayalytic/coordinating role. Northern, especially native rep is a problem | Not sure how much is done by professionals and how much by survivors |
| *ref to survivor-driven* | yes(+) | no | no | yes(+) | yes(+) | yes(+-) |
| *ref to AP sets startegic direction* | yes(+) | no | no | yes(+) | yes(+) | no |
| *ref to Ontario-wide representation* | yes(+) | no | yes(+-) | yes(+) | yes(+) | yes(+-) |
| *ref to catalyst rather than front-line* | yes(+) | no | no | no | yes(+) | yes(+-) |
| *ref to access to info is not restricted* | no | no | no | no | yes(+) | no |
| *SUPPORT PRINCIPLES* | yes(ID) | inconclusive | yes(SA) | yes(SA) | yes(SA) | inconclusive |
| *FEEL THEY ARE PRACTICED* | yes | yes | yes | yes | yes | yes |
| *SURVIVOR INPUT COMMENTS* | Survivor input is more vital than ours. It is good that it is surv-driven. | I think it is happening. It is not a we-them situation. | Important to be survivor driven. | Survivor input is most critical to understanding the need and desperation for information. | Open input occurs in a structured manner. I am in awe of the commitment. | Can only assess the input in projects I have been involved in. |
| *AP STRATEGIC DIRECTION* | yes(ID) | yes(ID) | inconclusive | yes(SA) | yes(ID) | yes(SA) |
| *COMMENTS* | AP brings provincial perspective and keeps the momentum. Input is given regarding startegic direction. | I have wondered at times whether talk has led to action Our role is to advise and not to make decisions | It is unclear how the AP input is used. The panel could be doing more. | AP is given enough information to support the startegic direction. We are involved and our input is respected | Well served as long as everyone is kept informed. | Had extensive input at the first meeting by voting. I think that was good. |

TABLE 2u

# TABLE 2: OBCIEP MATRIX

| | *Interview #31* | *Interview #32* | *Interview #33* | *Interview #35* | *Interview #36* | *Interview #3** |
|---|---|---|---|---|---|---|
| ***SUPPORT OBJECTIVES*** | yes(SA) | Inconclusive | Inconclusive | Inconclusive | inconclusive | yes(SA) |
| ***OBJECTIVE CONCERNS*** | | | I have concerns about keeping the information current. | see comments | Feel there are areas that won't be identified as gaps. | |
| ***HINDERING FACTORS*** | Keeping on top of all the breast cancer players. Some are self-interested | There is no continuity. If you miss a meeting you are out of it. It is a practical problem. | Project operates with minmal resources. There are turf issues, and a lack of behavioural science input | Logistical problems in getting people from the whole province together | The palliative care focus is slowing the Project's pace | Money. Determining appropriate ways to disseminating the information |
| ***STEADY PROGRESS*** | yes | yes | yes | yes | yes | yes |
| ***COMMENTS ON PRINCIPLES*** | They are good principles which the project adheres to | We advised on this and I accept them. No negatives against them | Misc -see text | see Theme II gen comments<br>Difficult area to draw people together | Where there are shortcomings, the Project is working on it | Need more survivors |
| ***ref to survivor-driven*** | no | no | yes(+) | yes(+) | yes(+) | yes(+-) |
| ***ref to AP sets startegic direction*** | no | no | yes(-) | yes(-) | yes(+) | no |
| ***ref to Ontario-wide representation*** | yes(+-) | no | yes(+) | yes(+-) | yes(+-) | no |
| ***ref to catalyst rather than front-line*** | no | no | yes(+) | yes(+-) | yes(+-) | no |
| ***ref to access to info is not restricted*** | no | no | yes(+) | no | yes(+) | no |
| ***SUPPORT PRINCIPLES*** | yes(SA) | yes(SA) | yes(ID) | Inconclusive | inconclusive | yes(SA) |
| ***FEEL THEY ARE PRACTICED*** | Project attempts to adhere to them. Ont rep. is difficult. | yes | All except AP sets strategic direction | yes | yes(Q), where there are shortcomings they work on it. | yes |
| ***SURVIVOR INPUT COMMENTS*** | I think they have consulted with survivors at every stage. | Without it there is no Project. They have had the experience within the system | Should be survivor driven. Not 100% sure it should be the majority. | You can get carried away with survivor-driven. BC is a social problem. | Survivors need to have a strong voice and remain current. They bring in their professional bc experience. | Representatives have strong voices and are listened to. |
| ***AP STRATEGIC DIRECTION*** | yes(ID) | Inconclusive | no | no | yes(SA) | yes(SA) |
| ***COMMENTS*** | They have put all the issues on the table. Good representation has been maintained. | At the first meetings we were asked to advise & set up goals & principles. | I'm not sure why the AP exists if it doesn't set the strategic-direction. I don't think it does. | I think the smaller group make more of the day to day decisions | The Director is open to suggestions. Survivors used to set the strategic direction. Need ownership to contribute. | The driving force. Suggestions are given serious consideration. |

# TABLE 2: OBCIEP MATRIX

| | Interview #2 | Interview #7 | Interview #8 | Interview #9 | Interview #10 | Interview #11 |
|---|---|---|---|---|---|---|
| FEEL INVOLVED IN DECISIONS | Not a decision maker. Advise & give input. | yes | no(Q) If I wanted to I know I could be | no(Q), if I have something to contribute I call Natalie | no(SA) | yes(Q), to a certain point |
| AP MEETING COMMENTS | Mtg. frequency is good for continuity. May be time for mem. turnover. | Too much is covered. Would like more time for roundtables. | Won't commit more time. Most important meetings were the first two. | I think they have a valid purpose. | Bi-ann. good. The first year & half not useful, but informative. | Networking is important when meeting twice a year. |
| USEFUL AND INFORMATIVE | yes | yes | yes | N/A | see above | yes |
| HIGH POINTS | Staff reports are useful for my work. Networking. | Network with women. Discuss issues. | Sharing information and awareness-raising. | N/A | Roundtables | Updates, networking, open discussion about bc |
| LOW POINTS | Long presentations | Mem non-collaboration | none | N/A | Internet talk | Statistics, long reports inconclusive |
| SATURDAYS | Sat ok because of work | Keep same location | Like Sat., it is easier. | unable to attend | Wld like 2 day mtg. | |
| IN TOUCH AT AP MEETINGS | yes | no | yes | N/A | yes | yes |
| NETWORKING | yes | yes, especially by phone | yes | no | yes | don't know |
| AWARENESS-RAISING | yes, but org is connected | yes | yes | yes | no | no |
| EC COMMENTS | Satisfied with the minutes that we receive from EC. | I know they meet in between AP meetings to get things done. | The EC have more decision making power. | | We only find out EC's activities at AP or through Natalie | Decisions led by EC. |
| SEE EC AS USEFUL | yes(Q), for Project staff | yes | yes | don't know | don't know | No-see text |
| COMMUNICATION WITH STAFF | They are impressive professionals who pay attention to the concerns of survivors. | Effective from what I can see. | The information that the AP members reveive is adequate to what is going on in the Project. | | We don't communicate. We are only in touch at AP meetings. | They seem to do it well |
| THEME I GENERAL COMMENTS | Satisfied it is going well | gen- It is a lot I hope it works | gen- Excellent overall breakdown of what is needed to tackle the issue | I like that we can get into the database | Theme I is going nicely | Native link vital to Canadisn culture Theme is going nicely, no problems |
| ref to database | no | no | no | yes(+) | yes(+-) | yes(+-) |
| ref to info gap analysis | yes(+-) | no | no | no | yes(+) | yes(+-) |
| ref to ethnocultural consultation | yes(+-) | yes(+) | yes(+) | no | yes(+-) | yes(+-) |
| ref to newsletter | no | yes(-) | yes(+) | yes(+-) | yes(+) | yes(+-) |

TABLE 2w

# TABLE 2: OBCIEP MATRIX

| | *Interview #12* | *Interview #13* | *Interview #14* | *Interview #15* | *Interview #16* | *Interview #17* |
|---|---|---|---|---|---|---|
| ***FEEL INVOLVED IN DECISIONS*** | no | yes | no, but opportunity exists. Ideas are listened to. | Feel involved in the big decisions | no | yes, I have the opportunity because I am on the EC |
| ***AP MEETING COMMENTS*** | The structure is useful | The agenda is long. Would like to receive reports beforehand. | Intense. I've enjoyed them Diverse group of people. Attendence low at last mtg. | Great, but would like to see more AP involvement. | I think the focus could be different. We just come and listen. | Although it would be more comfortable if we met more often, that is not feasible. |
| ***USEFUL AND INFORMATIVE*** | yes | yes | yes | yes | yes, to a degree | yes |
| ***HIGH POINTS*** | Information exchange with Ap members. | Rountables and work presentations by staff. | Awareness-raising and updates. | Roundtables | Roundtables. | Networking and updates |
| ***LOW POINTS*** | | Hard tc digest all the info | It is hard to stay focussed | I can't think of any. | No input other than mdtbls | There is a lot of info Hard work |
| ***SATURDAYS*** | It is part of my job. | The best time for me. | Works great for me. | I don't mind them. | Not the best time for me. | Saturday works best. |
| ***IN TOUCH AT AP MEETINGS*** | Only with past activities | yes | yes | yes | yes | yes |
| ***NETWORKING*** | yes | no, due to time | yes | yes | yes, maybe a little | yes |
| ***AWARENESS-RAISING*** | yes | don't know | yes | yes | no | yes |
| ***EC COMMENTS*** | I think the EC sets the strategic direction. | | I feel the representation of the AP with the EC is very strong | I am a little unclear as to why three parts are needed | I don't know what happens with the EC except for the minutes we get. | Perhaps the Executive could do more to bridge the gap with the Advisory Panel. |
| ***SEE EC AS USEFUL*** | Inconclusive | can't comment | yes | don't know | maybe, don't know | yes |
| ***COMMUNICATION WITH STAFF*** | They are open to calls. | They have reached out a number of ways. | I think they do a good job. We are getting mail more frequently. | No thoughts on this. | Natalie does good job. Otherwise there is no connection. | Project team communicate and update well. |
| ***THEME I GENERAL COMMENTS*** | misc-see text | gen- I know about some of the activities. | gen-I think themes have come up with specific goals and has worked towards them | gen- I think the activities are great I think each theme is important | gen- I think they have been on target | gen- I am blown away by how much each theme has accomplished |
| ***ref to database*** | yes(-) | no | yes(+-) | no | no | no |
| ***ref to info gap analysis*** | yes(+-) | no | yes(+-) | no | no | no |
| ***ref to ethnocultural consultation*** | yes(+-) | yes(+) | yes(+-) | no | no | no |
| ***ref to newsletter*** | yes(+-) | yes(+) | yes(+-) | yes(+) | no | yes(+-) |

TABLE 2x

# TABLE 2: OBCIEP MATRIX

| | *Interview #18* | *Interview #20* | *Interview #21* | *Interview #22* | *Interview #23* | *Interview #24* |
|---|---|---|---|---|---|---|
| ***FEEL INVOLVED IN DECISIONS*** | yes, due to EC involvement | no | yes | yes | no | yes |
| ***AP MEETING COMMENTS*** | Tangible input is mainly obtained through roundtables. Perception of passivity. | N/A | Format is fine, but should be meeting more often. Mtgs. need human touch. | Format allows for input. It works really well. | A lot of work. It is important for survivor involvement | |
| ***USEFUL AND INFORMATIVE*** | yes | N/A | yes | yes | no, non-EC probably do. | yes |
| ***HIGH POINTS*** | The social aspect. The high quality leadership. | N/A | Informal discussions with AP members. | The commitment and enthusiasm of AP members. | Networking and finding out about activities. | Liase with Ontario wide network. |
| ***LOW POINTS*** | Passivity & mem leaving early. | N/A | none | none | none | none |
| ***SATURDAYS*** | Personally it suits due to work. | Hard to schedule in. | Saturday is fine. | Somewhat a problem. | Perfect | Perfect |
| ***IN TOUCH AT AP MEETINGS*** | yes, due to EC involvement | N/A | no(Q),can't comment | yes | no, not at AP or EC | yes |
| ***NETWORKING*** | yes | | no, already was ntwrkg | yes | yes | yes |
| ***AWARENESS-RAISING*** | yes | | don't know | yes | yes | yes |
| ***EC COMMENTS*** | I feel I am more involved because I am a member of the EC. | | Could be more continuity between EC and AP. | I assume it is useful My feeling is that the Director needed input at that level. | EC could improve decision making by more current PT activity info. | Not useful because we are not asked for much input. |
| ***SEE EC AS USEFUL*** | yes | Inconclusive | Inconclusive | don't know | yes | no (see comments). |
| ***COMMUNICATION WITH STAFF*** | On the surface the communication is excellent, but I sense confusion by the AP at the mtgs. | | Good communication team. | Staff is receptive to input. Written communication is excellent. | | No direct experience so I can't comment. |
| ***THEME I GENERAL COMMENTS*** | gen- Themes were all voted on and are on-going They are of high quality | gen- All great activities | gen-Themes are great Keep human side of issue I thought we would be farther by now See text | gen-I think activities are relevant and reflect the intent of the Themes | Priority should be to get someone to engage other cultures in bc issue | These were identified as the directions. |
| ***ref to database*** | no | yes(+-) | no | yes(+-) | no | no |
| ***ref to info gap analysis*** | no | no | no | yes(+-) | no | no |
| ***ref to intercultural consultation*** | no | no | no | no | yes(+-) | no |
| ***ref to newsletter*** | yes(+) | no | no | yes(+-) | no | no |

TABLE 2y

# TABLE 2: OBCIEP MATRIX

| | *Interview #25* | *Interview #26* | *Interview #27* | *Interview #28* | *Interview #29* | *Interview #30* |
|---|---|---|---|---|---|---|
| ***FEEL INVOLVED IN DECISIONS*** | yes | yes(Q), only in theme areas | no | no, but if I needed to be I could be | yes | no |
| ***AP MEETING COMMENTS*** | A survivor chair is an excellent idea. I Like group discussions. | Overall approach is successful & valuable. | Accomplish a lot in the long period of time between AP meetings. | It would be nice to have social time for discussion if not for the cost | | They are necessary and can't happen more often. |
| ***USEFUL AND INFORMATIVE*** | yes | yes | yes | yes | yes | yes |
| ***HIGH POINTS*** | Updates and sharing info with mems from dif areas. | Networking and information updates. | The sharing. | Learning about useful activities. | Charting new ground. | Networking and hearing about other groups. |
| ***LOW POINTS*** | The afternoon slope | none | Some of the presentations. | It is a long day. I get tired. | People missing mtgs | It is a long day. |
| ***SATURDAYS*** | Only day off if you work. | I don't mind Saturdays. | I could only make one mtg. | I don't have a problem . | good | Weekends are a drag. |
| ***IN TOUCH AT AP MEETINGS*** | yes | yes | yes | yes | yes | yes |
| ***NETWORKING*** | | yes | no, its there if I want it | yes | yes | yes |
| ***AWARENESS-RAISING*** | | yes | yes | yes | yes | yes |
| ***EC COMMENTS*** | The EC is important for the overall Project, but doesn't hinder AP s-d | EC has the operational responsabilities. I think it is essential | | Feel confident they are keeping in touch. | I don't see it as having made much change. It may be useful. | |
| ***SEE EC AS USEFUL*** | yes(Q), administratively | yes | don't know | don't know | don't know | don't know |
| ***COMMUNICATION WITH STAFF*** | It is wise to have a Coordinator so we are linked to one person in the time between AP mtgs. | The people seem honest, reliable and caring. | They communicate through reports and that's fine. | Information comes throug the Coordinator. I feel up to date on the activities. | The Project Team is fabulous. | They couldn't do a better job. Reports have just the right amount of depth |
| ***THEME I GENERAL COMMENTS*** | gen-We have gone beyond all three Themes. | Misc comments-see text | gen-Doing a good job. | Good Theme, but it may be time to redirect it. We need to be a service provider | gen-all three Themes are incredible. Have to involve ethnocultural communities | |
| ***ref to database*** | yes(+-) | yes(+-) | no | yes(+-) | no | yes(+) |
| ***ref to info gap analysis*** | no | no | no | no | no | yes(+-) |
| ***ref to ethnocultural consultation*** | no | yes(+-) | no | no | no | yes(+) |
| ***ref to newsletter*** | no | yes(+-) | no | yes(+) | yes(+) | yes(+) |

**TABLE 2z**

# TABLE 2: OBCIEP MATRIX

| | *Interview #31* | *Interview #32* | *Interview #33* | *Interview #35* | *Interview #36* | *Interview #37* |
|---|---|---|---|---|---|---|
| *FEEL INVOLVED IN DECISIONS* | yes | no | no | no | yes(Q), because of EC Involvement | yes |
| *AP MEETING COMMENTS* | It is a good forum for individual agencies. Time and travel needs considered | You miss one meeting and you haven't been there for a year. | I don't know if the AP has a role. | The main purpose is networking. | Effective. Attendence imperative since only meeting twice a year. | Formats are good. It is a long day. Need more time for networking. |
| *USEFUL AND INFORMATIVE* | yes | yes | yes | yes | yes | yes |
| *HIGH POINTS* | Staff presentation of the information collected | They are well run. Nobody tries to dominate. | Transfering the information gained to my work. | Networking | The whole picture is important. Guide a high pt. | Updates, guest speakers, & networking. |
| *LOW POINTS* | none | none | I can't adequately contribute | none | none | none |
| *SATURDAYS* | A good time for all day mtg | Sat. is not my favorite day. | Necessary for survivor input. | I think it is a good day. | understand the need | couldn't go during the week. |
| *IN TOUCH AT AP MEETINGS* | yes | yes | yes(Q), with difficulty | no | yes(Q), because of EC | yes |
| *NETWORKING* | yes, a wee bit | no | yes, emphasizes the need | no(Q), don't work in bc | yes | yes |
| *AWARENESS-RAISING* | yes | yes | don't know | yes | yes, to some degree | yes |
| *EC COMMENTS* | | I am not aware of the EC. | I haven't received minutes from an EC meeting in a long time | This group is more involved in decision making. This perspective is important. | Survivors on the EC should be willing to disagree and give the survivor viewpoint. | EC runs with what the AP directs. |
| *SEE EC AS USEFUL* | yes | don't know | Inconclusive | yes(SA) | yes | yes |
| *COMMUNICATION WITH STAFF* | The staff has been exemplary at keeping the AP and EC informed. | Excellent communication between the Project Team and Advisory Committee. | | It would help if the PT or EC, whoever is making decisions, would have a brief bulletin. | Margaret has been open to input bt partnber organizations and presents it to the Project Team and EC. | Only expect to hear from Natalie PT is very accessible. We get stuff in the mail. |
| *THEME I GENERAL COMMENTS* | Coordinating the information has been the biggest thing due to turf areas | I have had difficulty because the Themes run into eachother The whole thing is info dissemination | Concerns about the updating of database Newsletter is factual and may not get attention | Electronic communication would be faster I don't know what is happening with the ethnocultural consultation | The newsletter will help to bring organizations together, catalyze activities & promote a sense of ownership | gen-On target with each of the Themes There is overlapo with access to information due to Willow role |
| *ref to database* | no | no | yes(+-) | yes(+) | yes(+-) | no |
| *ref to info gap analysis* | no | no | no | no | yes(+-) | yes(+) |
| *ref to ethnocultural consultation* | no | no | no | yes(+-) | no | no |
| *ref to newsletter* | no | no | yes(+) | yes(+-) | yes(+) | no |

TABLE 2aa

## TABLE 2: OBCIEP MATRIX

| | *Interview #2* | *Interview #7* | *Interview #8* | *Interview #9* | *Interview #10* | *Interview #11* |
|---|---|---|---|---|---|---|
| ***THEME II GENERAL COMMENTS*** | Theme is going well | | | The guide is great No idea what to do about Northern | I was thrilled when I could come home with a book on unconventional ther | Don't have follow up info on Northern RFP Booklet was a make work project & deals with politics |
| ***ref to unc. ther. book*** | yes(+) | yes(+) | yes(+) | yes(+) | yes(+) | yes(+-) |
| ***ref to rfp northern*** | no | no | no | yes(+-) | no | yes(+-) |
| ***ref to BBCSS booklet*** | yes(+) | no | no | no | no | yes(-) |
| ***THEME III GENERAL COMMENTS*** | Not yet clear about vision with health professionals | Surveys are a good start. Important | | Family physicians probably have more information about women | Thrilled to come home with survey on Drs. | Want information on follow up to surveys & action to be taken. |
| ***ref to physicians' survey*** | no | yes(+) | no | yes(+) | yes(+) | yes(+-) |
| ***ref to surgeons' survey*** | no | no | no | no | yes(+) | yes(+-) |
| ***ref to nurses' survey*** | no | no | no | no | yes(+-) | yes(+-) |
| ***HELP TO MEET OBJECTIVES*** | yes | yes | yes | yes | yes | yes |
| ***OVERALL CONTRIBUTION*** | Leadership role nationally. We have concrete products. | Umbrella for bringing groups together to discuss the issues. | Education, awareness Bringing bc community together. | Sharing information and opening windows | The family doctors and surgeons surveys. | It has allowed people to network & do information sharing. |
| ***CONTINUATION COMMENTS*** | Not sure it should continue even though it is wonderful. | Other organizations could assume pieces e.g Willow | Should continue as a body that organizes the bc community. | would like to see it become a clearinghouse for bc information exchange. | We have put in a lot of work HC should see that this is needed | Has role to play as a nucleus A neutral role within the bc culture |
| ***PERSONAL FEEL SH. CONTINUE*** | don't know | yes | yes | yes | yes | yes |
| ***FEELS TO BE INVOLVED*** | N/A | It feels good | proud | can't say, I'm too peripheral | good | enjoy it |

TABLE 2ab

# TABLE 2: OBCIEP MATRIX

| | *Interview #12* | *Interview #13* | *Interview #14* | *Interview #15* | *Interview #16* | *Interview #17* |
|---|---|---|---|---|---|---|
| ***THEME II GENERAL COMMENTS*** | misc-see text | The guide was needed Unclear about our partnbership with BBCSS due to contect of Willow | | | | The guide ackowledges peoples' intelligence The avon distribution of the booklet was good |
| ***ref to unc. ther. book*** | yes(+) | yes(+) | yes(+) | no | yes(+) | yes(+) |
| ***ref to rfp northern*** | yes(+-) | no | yes(+-) | no | yes(+-) | no |
| ***ref to BBCSS booklet*** | yes(-) | yes(+-) | no | no | yes(+) | yes(+) |
| ***THEME III GENERAL COMMENTS*** | I haven't seen the final of any of them. It will be interesting. | Hope we find out the info needs of meds to help in reaching W's needs | The first two have been done and results tabulated. | I think theme III is really important. | Dr. Chart is very capable Would like a survivor chair. | |
| ***ref to physicians' survey*** | yes(+-) | yes(+) | yes(+-) | no | no | no |
| ***ref to surgeons' survey*** | yes(+-) | yes(+) | yes(+-) | no | no | no |
| ***ref to nurses' survey*** | yes(+-) | yes(+) | yes(+-) | no | no | no |
| ***HELP TO MEET OBJECTIVES*** | don't know | yes | yes | yes | yes | yes |
| ***OVERALL CONTRIBUTION*** | Bringing people together to exchange info and make change | Awareness. Linking survivors and meds together to assess information needs. | It is hard to tell because bc is in the forefront politically | Linking and passing on onformation to other groups. | It has done something, but it is not my vision | The contribution is huge. Awareness, information, the guide |
| ***CONTINUATION COMMENTS*** | It should not continue if it has done its job | Need funding to keep the information current and accurate | In principle there is a need for something like this | I don't think it would cost a lot to keep the province networking | Need money to continue Maybe we sould merge with Willow | Need money to continue I don't know |
| ***PERSONAL FEEL SH. CONTINUE*** | no | yes | yes | yes | don't know | yes |
| ***FEELS TO BE INVOLVED*** | A learning experience | really pleased | a privilege, proud | It feels really great | no particular feeling | great, worthwhile |

TABLE 2ac

# TABLE 2: OBCIEP MATRIX

| | *Interview #18* | *Interview #20* | *Interview #21* | *Interview #22* | *Interview #23* | *Interview #34* |
|---|---|---|---|---|---|---|
| ***THEME II GENERAL COMMENTS*** | | | Book was great, but not the most important priority Need info on conventional therapies | | | |
| ***ref to unc. ther. book*** | yes(+-) | yes(+-) | yes(+) | no | no | yes(+) |
| ***ref to rfp northern*** | no | no | no | no | no | no |
| ***ref to BBCSS booklet*** | no | no | no | no | no | no |
| ***THEME III GENERAL COMMENTS*** | The work of Dr. Chart is making a dent among professionals. | I wonder who will actually get this information. See text. | | | Uneasy about this because it is led by a physician It will produce some useful info. | There is a tremendous need for W's needs to impact physicians & surg's. |
| ***ref to physicians' survey*** | no | yes(+-) | no | no | no | no |
| ***ref to surgeons' survey*** | no | no | no | no | no | no |
| ***ref to nurses' survey*** | no | no | no | no | no | no |
| ***HELP TO MEET OBJECTIVES*** | yes | yes | yes | yes | yes | yes |
| ***OVERALL CONTRIBUTION*** | Awareness, collaboration, information and the guide | It is too early to assess the impact It is important because it is surv.-driven | Awareness and the book. I am not sure what else | Bringing stakeholders together and coordinating information. | It is an avenue for input. Stakeholder awareness and hope | A focal point. An organization that draws from different areas of bc stakeholders. |
| ***CONTINUATION COMMENTS*** | I would like to start a strategy now for a new proposal to Health Canada | Would have to begin now to create an infrastructure to keep activities going | Hope it continues & we can raise funds & awareness to do so. | It probably should continue for information exchange Should look at this now | Not sure We should discuss it in depth | I hope the organization is looking for permanent funding for breast health. |
| ***PERSONAL FEEL SH. CONTINUE*** | yes | yes | yes | yes | don't know | yes |
| ***FEELS TO BE INVOLVED*** | *very rewarding* | *don't feel involved* | *proud to be a part* | *exciting & invigorating* | *a feel good activity* | *sense of power* |

## TABLE 2ad

# TABLE 2: OBCIEP MATRIX

| | *Interview #25* | *Interview #26* | *Interview #27* | *Interview #28* | *Interview #29* | *Interview #30* |
|---|---|---|---|---|---|---|
| *THEME II GENERAL COMMENTS* | RFP was a unique way to address the needs of N Ontario | Willow seems to overlap Theme II We need some clarification on the Project's involvement in that | Book produced quickly Doing some meaningful and tangible things Have accomplished the most | I am glad we partner in these times of economic restraint | The book charted new ground | Most of the book revisions were done by survivors Theme II is well underway |
| *ref to unc. ther. book* | yes(+-) | yes(+-) | yes(+) | yes(+) | yes(+) | yes(+-) |
| *ref to rfp northern* | yes(+) | yes(+-) | no | no | no | yes(+ ) |
| *ref to BBCSS booklet* | yes(+) | yes(+-) | no | yes(+) | no | yes(+-) |
| *THEME III GENERAL COMMENTS* | I think we have done a phenominal amount of work in a short time | I feel involved in this theme | Where our work is. I was frustrated with the clinical reports. | Historical problem with physicians getting involved Not for lack of trying | It is important to find out how physicians assess woman's info needs. | Survey presented at last meeting was frustrating and confusing |
| *ref to physicians' survey* | no | no | yes(-) | yes(+-) | yes(+) | yes(+-) |
| *ref to surgeons' survey* | no | no | no | no | yes(+) | yes(+-) |
| *ref to nurses' survey* | no | no | no | no | yes(+) | yes(+-) |
| *HELP TO MEET OBJECTIVES* | yes | yes, in some areas | yes | inconclusive | yes | yes |
| *OVERALL CONTRIBUTION* | A tremendous step from where we were three or four years ago. | It has created an infrastruct for professional and survivor collaboration on useful projs | Don't know I don't think there is a general awareness of the Project. | It certainly has made a difference It is time to really market the OBCIEP | It is a tool that is needed to bring information out. Tremendous. | Linking orgs for information sharing Improving women's access to info about bc |
| *CONTINUATION COMMENTS* | I think Health Canada should continue the funding It would be cruel to stop now | Hope there could be sustained federal funding | Too difficult to answer now Should continue as a coordinating body | Should continue but in a slightly different form We have to get past the politics | I think it should be evaluated and on-going | Hope there is funding available We had to look at this in the RFP |
| *PERSONAL FEEL SH. CONTINUE* | yes | inconclusive | inconclusive | yes | yes | yes |
| *FEELS TO BE INVOLVED* | very exciting | I've found it very valuable | its good | happy to be involved | just delighted | feels good, contributing |

TABLE 2ae

# TABLE 2: OBCIEP MATRIX

| | *Interview #31* | *Interview #32* | *Interview #35* | *Interview #35* | *Interview #36* | *Interview #37* |
|---|---|---|---|---|---|---|
| *THEME II GENERAL COMMENTS* | Innovative & cost-effective publications They have listened to what the issues are for women | | I'd like a copy of the guide ther I am glad they are evaluating it. I would have liked to have seen Q's | Project has been a service provider by providing the unconventional ther guide | The guide is an example of state-of-the-art work I hope the environment is included in the future | No one else was going to do the unconventional ther guide I can't wait to get the booklet |
| *ref to unc. ther. book* | yes(+-) | no | yes(+) | yes(+) | yes(+) | yes(+-) |
| *ref to rfp northern* | no | no | no | yes(+-) | yes(+-) | no |
| *ref to BBCSS booklet* | yes(+-) | no | no | no | yes(+-) | yes(+) |
| *THEME III GENERAL COMMENTS* | It is a struggle keeping meds current. Issue is broader than bc. Good info collected. | Physicians don't always ask for information We have to make sure they get it. | I am waiting to see the physician's sourcebook. I wonder about its updating | I didn't know about the additional two surveys. How will they be used? | Encouraging, but there is a difficulty in reaching Health Care professionals. | On target We should continue to work with meds in order to fill gaps. |
| *ref to physicians' survey* | no | no | no | yes(+-) | yes(+-) | no |
| *ref to surgeons' survey* | no | no | no | yes(+-) | yes(+-) | no |
| *ref to nurses' survey* | no | no | no | yes(+-) | yes(+-) | no |
| *HELP TO MEET OBJECTIVES* | yes | yes | yes | yes | yes | yes |
| *OVERALL CONTRIBUTION* | Has linked and improved access to information by bc agencies. | It is all about disseminating information and therefore it is doing a positive thing. | The book and booklet were major contributions. | Have made strides in the areas on the summary sheet. | Awareness-raising. I hope it continues on the cutting edge. | Identifying and working to meet needs. The book and the booklet. |
| *CONTINUATION COMMENTS* | It should stop and go away. It will have been a failure if job not done by then | There is nothing wrong with terminating it if the job is done. | Necessary to secure funding in order to continue. Need to coord. activites. | It is hard to find a coordinating body like this | It is a social disease For this reason government should fund the bulk of it | Would depend on our achievements It would be nice to carry on. |
| *PERSONAL FEEL SH. CONTINUE* | no | inconclusive | yes | yes, if action continues | yes, if cutting-edge conts. | depends on achievements |
| *FEELS TO BE INVOLVED* | proud & impressed | good, very good | feel very peripheral | very worthwhile | very good, proud | contribute & get back |