

DEVELOPING AN EVALUATION FRAMEWORK AND TOOLS WITH A  
COMMUNITY AGENCY

BY

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University**

**of Manitoba in partial fulfillment of the requirements of the degree**

**of**

**MASTER OF NURSING**

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## **Abstract**

Breast Cancer is a disease that affects one in nine women (Statistics Canada, 2000). The magnitude of this disease and the lives it touches merits close consideration in terms of providing services to women and others who have been affected by this disease. One of the services is the Breast Cancer Centre of Hope in Winnipeg, Manitoba. This agency provides a variety of services for women along the spectrum in the breast cancer experience. It is assumed that this agency provides a valuable service, however, the Centre has yet to undergo a formal evaluation of its services.

The objectives of this practicum were to develop evaluation tool(s) and to outline an implementation and analysis plan for the staff at the Breast Cancer Centre of Hope, utilizing the tenets of the Primary Health Care model. The process involved a development stage that included numerous meetings with staff at the Centre to establish the purpose of the evaluation and to pull out the evaluation needs. The second part of the practicum was to develop evaluation tools and an implementation process for the evaluation tools.

In the practicum, the Primary Health Care model served a dual purpose. First as a means of conducting the practicum, and secondly as the framework for developing the evaluation tools. Staff input was sought to develop ideas and to validate information as part of the Primary Health Care philosophy of including the community (the staff in this instance) in the process. Changes were made in response to the staff input. The questionnaires for evaluation were then developed using the Primary Health Care model

as the concepts driving the specific questions.

The process demonstrated that the Primary Health Care model can be employed as a framework for evaluation tool development, as well as a guide for the evaluation process. The limitations, benefits and recommendations are discussed.



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## **Chapter One**

### **Introduction to the Problem**

The health care field is constantly expanding and changing. The changes encompass technological advances, specializations and delivery modes. Acute care is one of the recognizable modes of delivery within the health care system. People enter into this system when they are ailing, and receive assistance. However, the focus on the acute health care system has left many gaps in health service delivery, such as prevention of illness or health promotion. Health service users are proactively seeking services that address self-care and health promotion needs. Presently, there is a movement toward providing health care in the community, that invites and actively promotes the participation of the citizens who use the system (Manitoba Health, 1997a).

One of the most politically active populations in the health care field are the breast cancer survivor groups and women with breast cancer undergoing treatment (Anglin, 1992; Gray, 1992). Breast cancer is a disease that affects women of all ages, cultures and economic standing. In Canada, one in nine women will be diagnosed with breast cancer sometime in her life (Statistics Canada, 2000). As a result of the potential impact breast cancer may have on the lives of so many people, various services have been developed that target women with breast cancer.

Services at the Breast Cancer Centre of Hope in Winnipeg range from screening women for breast cancer, addressing physical health, and genetic counselling for women with breast cancer and/or at risk for breast cancer. Many services offer support through telephone contact and volunteer peer support. One way to confirm the value of these

services is to evaluate the service. Evaluation can discover areas of excellence and need, and provide staff and funding bodies with valuable information about the impact, or outcomes of the services provided.

The Breast Cancer Centre of Hope in Winnipeg provides resources in terms of information and support for women with breast cancer. The services are provided through numerous sub-programs. The staff at the Centre would like to evaluate the efficacy of these services. Evaluation tools must be developed that are relevant to the Centre and the sub-programs, using a framework that provides content guidance for the evaluation (i.e., the methods chosen, survey questions, focus group guide, or interview guide), and identifies the priorities that need to be examined.

Therefore, the objectives of this practicum were to develop evaluation tool(s) and to outline an implementation and analysis plan for the staff at the Breast Cancer Centre of Hope, utilizing the tenets of the Primary Health Care model.

This chapter will outline the impact that breast cancer has on the lives of women affected by this disease. This is followed by an examination of the importance of evaluation research, followed by a brief description of the Breast Cancer Centre of Hope. This will be followed by a description of the framework of the agency and the guideline for the process of the development of the evaluation tool. The framework of the agency is interwoven within the process of collaboration in the development of the evaluation for the Breast Cancer Centre of Hope.

### The Impact of Breast Cancer

In Manitoba, breast cancer is the primary diagnosis in approximately 28% of

women who are diagnosed with cancer (Statistics Canada, 2000). In Canada, the estimated number of new diagnoses of breast cancer is at 19,200 for the year 2000, more than twice the number of the estimated 8,400 new lung cancer cases in women (Statistics Canada, 2000). Although the rates of breast cancer have been increasing over the years, the mortality rate has been decreasing (Statistics Canada, 2000). In the year 2000, the estimated incidence rate of breast cancer was at the highest level ever, with 106 per 100,000 women diagnosed with breast cancer (Statistics Canada, 2000). Breast cancer accounted for 97,000 years of life lost for women in 1997. (Health Canada, 1999). The estimated rates of mortality from breast cancer show a decrease to 27 per 100,000 for 2000 (Statistics Canada, 2000). This represents a yearly decrease in mortality from previous years since 1977 (Statistics Canada, 2000). It is encouraging that the mortality rate has declined, but these statistics need to be viewed with cautionary enthusiasm.

Whether the decrease in mortality is due to earlier detection, improved treatments, or changes in risk factors is unclear (Statistics Canada, 1999). Earlier diagnosis may give treatments a better chance to work and leave women with a better prognosis (Statistics Canada, 2000). However, earlier detection is more likely to occur in women who have benign breast disease rather than breast cancer (Olivotti, et al., 2001). Breast cancer is considered to have a very good prognosis, relative to many other cancers (Statistics Canada, 1999); with the overall ratio of cancer deaths to new cases at 49%, breast cancer has a deaths to new cases ratio of 30% or less (Statistics Canada 1999).

Breast cancer has a major impact on the lives of many Canadian women, their families and the workplace. Women's lives are affected through altered relationships due

to emotional stress, treatment schedules and financial burdens placed on them by their cancer experience. The lives and schedules of family members of women with breast cancer are also affected by the new demands placed on the women. Although the rates of incidence of breast cancer are higher in women over sixty-five, many women still in the workforce are affected with this disease. This means that employed women will experience lost work days for treatments and the need for time for emotional healing (Wang, Cosby, Harris & Liu, 1998). Additionally, many of these women are part of the "sandwich" generation, with responsibilities of looking after aging parents and their own families. A diagnosis of breast cancer interrupts this routine and has ripple effects on many people other than the woman diagnosed with breast cancer. In addition, for older women the diagnosis of breast cancer may have deleterious effects on their social life and independence (Cameron & Horsburgh, 1998; Neil & Briefs, 1992; Newschaffer, Pemberly, Desch, Retchin & Whittemore, 1996). A woman who is undergoing treatment for breast cancer may not have the energy to meet all of her previous responsibilities, or the knowledge of how to access other resources. These examples underscore the significance of attending to the needs of women with breast cancer and providing them with resources to aid in coping.

The diagnosis of breast cancer raises questions and uncertainty. Despite the advances that have been made in diagnosis and treatment of breast cancer, women are still very fearful of what the future holds for them. While methods of dealing with these fears vary amongst women, there are commonalities in how women cope with major life events. Women must deal with immediate treatment decisions in the face of fear and



anxiety. Finding social and emotional support and gathering information are two common methods of coping with the anxieties and fears related to breast cancer. Support is an outlet for anxieties and fears and for validation of these feelings (Ali & Kalil, 1991; Chalmers, Thomson & Degner, 1996). Information seeking and management of the information is also crucial to help women gain a sense of control over the uncertainties of breast cancer and aids in treatment decision making (Hack, Degner, Dyck, 1994; Shaw, Wilson & O'Brien, 1994). Services for women with breast cancer have included social and emotional support and access to resources and information. Most programs developed to assist women with breast cancer, do not formally provide both of these resources, yet social support often informally includes information exchanges between members. This indicates that the need for information and support services are important and necessary to enable women to cope with their experience with breast cancer. Yet, these services, as obviously important as they are, need to be evaluated.

### The Importance of Evaluation

It is vital in this time of soaring health care costs to provide sound rationale and evidence of the need for, and effectiveness of services provided (Manitoba Health, 1997a, 1997b; Vingilis & Burkell, 1996). Effectiveness in health care services is tied in with indicators of quality and outcomes of service (Mark, 1995; Shavelson, McDonnell & Oakes, 2002; Trochim, 2002). The question that stands out is, how are these indicators and outcomes measured? To date, a number of tools have been used to evaluate services and programs. Patient satisfaction is one indicator of quality, and provides some insight into patient perception of outcomes of a service (Charles, et al, 1994; Cleary, Edgman-

Levitan, McMullen & Delbanco, 1994; Hill McPhil, 1997). Evaluations have also provided information on the impact of financial constraints on health care, including outcomes for patients, program utilization and effectiveness and areas for improvements (CNRC Advisory Committee, 1995; Hilton, 1996; Rossi & Freeman, 1993; Vingilis & Burkell, 1996). In Manitoba, evaluation research has been utilized to demonstrate the impact, or lack of impact of hospital bed closures on the health of the citizens of Winnipeg (Vingilis & Burkell, 1996). The data obtained from evaluation research would aid in decision making about sustaining or changing health service programs to provide effective care (Manitoba Health, 1997a).

Evaluations provide rationale or evidence for the development of new programs or the continuation or refinement of existing programs. However, the development of these evaluation tools can be costly in terms of staff input or outside sourcing (Bea van Beveran & Hetherington, 1997; Fitz-Gibbon, 1987a). As well, implementation of the evaluation can be costly in terms of finances and staff resources. As a result, the evaluations tools that are developed may be implemented incorrectly, inconsistently or quickly due to the inability to make time for the correct implementation. In addition, the tool itself may not be adequately reviewed to determine the efficacy and appropriateness for the population or program being evaluated. These methods pose problems in that the end result may not reflect the services or needs of the agency evaluated. The kind of evaluation tools used are important to determine existing and future needs of the agency. Therefore, the development of evaluation tools that are specifically developed for an agency have inherent value for the staff and the funding bodies.

### Setting: The Breast Cancer Centre of Hope

The Breast Cancer Centre of Hope is an information and resource centre for women with breast cancer. This Centre was developed under the direction of women living with and surviving breast cancer, as well as health care experts in the field of breast cancer. Through research, the National Forum on Breast Cancer and personal communication, women with breast cancer told health care professionals that they wanted a place to access resources and information, without having to go back and forth between agencies (Personal communication, Barbara Shumley, September, 1997). Women also indicated that they wanted the service to be free standing and separate from their physicians and oncologists. The women wanted a place that was their own, without the influence of the medical system (Personal Communication, Barbara Shumley, September, 1997). The Centre was also developed to respond to women's needs for information and support identified in the literature. Appendix A provides an overview of the mandate and goals of the Centre.

The needs of women with breast cancer expressed through the myriad of venues, make a strong case for the existence of a centre such as The Breast Cancer Centre of Hope. It is equally important that the Centre be monitored to ensure it fulfills the mandate of providing information, support and facilitating client involvement in treatment decision making. If the centre does not meet the needs of the women using it, then the program may need refining. Evaluation tools specifically designed for the Breast Cancer Centre of Hope could help staff at the centre to determine which programs are meeting needs, which programs are used and which services need to be refined or improved.

The Breast Cancer Centre of Hope is the only centre of its kind in Canada. It is a Nurse Managed Centre. Other centres provide volunteer telephone information links, but they do not provide the same physical space. In 1995, the Breast Cancer Centre of Hope began operating from individual offices, expanding in 1997 to an inviting and comfortable resource centre with comprehensive breast cancer information and support services.

The Breast Cancer Centre of Hope provides information and social and emotional support through counselling, education, peer support, group support and referrals to other sources of support. It also houses a multi media resource library, including Internet access, pamphlets, videos, books, journal articles and newsletters. This Centre, developed through a collaborative process by women with breast cancer, and health care professionals, provides clients and their families with access to the breast cancer resources that have been identified in the literature and advocacy endeavours.

By providing accurate and contemporary information, the Breast Cancer Centre of Hope aims to facilitate the empowerment of women with breast cancer (Breast Cancer Centre of Hope Pamphlet, 1997). Given that information arms women with the knowledge to actively participate in their own care (Gray, Fitch, Greenberg & Shapiro, 1992), the Breast Cancer Centre of Hope then represents more than an information centre. The mandate of the Breast Cancer Centre of Hope includes the provision of information and support for women with breast cancer, and the promotion of active involvement in treatment (Breast Cancer Centre of Hope, Annual Meeting Minutes, 1999). In becoming active in their treatment, women are taking control of their experience. The support services offered are also grounded in the Primary Health Care model in that volunteers

make up the matrix of the peer support systems in Winnipeg and in the rural communities. By inviting and facilitating community participation in the core services of providing support and information, the Centre is putting the Primary Health Care model into action. These concepts that are embodied in the Primary Health Care model, were used as the overall conceptual framework for the development of the evaluation tool. The work by Bea van Beveran and Hetherington (1997) was also used to guide the process of the development of the evaluation tool(s). This model encompasses the philosophy of the Primary Health Care model, in that the process advocated includes active collaboration and input from the staff of the Centre being evaluated (this is elaborated on later in the chapter).

#### Framework of the Agency

The overlying framework guiding the programming and everyday operation at the Breast Cancer Centre of Hope is the Primary Health Care model. "Primary Health Care is both a philosophy of health care and an approach to providing health services." (Canadian Nurses Association, 1995, p.1). According to the World Health Organization (WHO),

Primary Health Care is:

"...essential health care based practical, scientifically sound and socially acceptable methods made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination." (WHO, 1978, p.34).

The facilitation of empowerment and the social context of health and healthcare systems sets Primary Health Care apart from other models such as the Health Belief Model, which is more focussed on individual responsibility for health. The Primary Health Care model fits well with the philosophy of nursing and is considered a "natural extension of nursing"

by the Canadian Nurses Association (1995, p.1) and others (Rover, 1985; Salmon, Talaschuk & Tichy, 1988; Schoultz & Hatcher, 1998). This makes the Primary Health Care model an appropriate and timely model to base an evaluation framework for components of a community health care agency, run by nurses, such as the Breast Cancer Centre of Hope.

Primary Health Care has, at its core, a mandate to involve the community and foster empowerment and self-reliance (Sturt, 1997; WHO, 1978; WHO, 1988). There are five major principles, or concepts in the PHC model. They are: 1) equity, 2) holistic care, 3) acceptable care, 4) empowerment, and 5) intersectoral development. These tenets are easily recognized in many community health centres and many community programs. Primary Health Care eschews the traditional biomedical model that focuses on individual treatment and cure of disease, and instead centres health care around the community and what the community can do to promote its own health (Chanecka, 1998; Glittenberg, 1988; WHO, 1978).

The Breast Cancer Centre of Hope embraces the philosophy of the Primary Health Care model through its everyday operations. The breast cancer community is involved in the planning and implementation of the programs from the inception of the Centre to the daily operation of the Centre. Volunteers are involved in developing new programs, such as the Volunteer Peer Support Group, the Community Cancer Network and "Worker Bees" days. These programs will be investigated in more detail as part of the process of developing the evaluation tool.

The Centre also embraces other components of the Primary Health Care model,

such as commitment to appropriate care, equity (including accessibility to care), and holistic care through the regular activities of the agency and the special events. There are a number of community outreach programs that have been developed to address access issues for women living outside of Winnipeg. They have developed their library resources to provide a variety of information, that is appropriate for the population using the Centre. The staff at the Centre strive to provide care for all aspects of the women coming to them for information and assistance.

The operationalization of the Primary Health Care model in the Breast Cancer Centre of Hope necessitates the need for an evaluation model that also embraces the Primary Health Care model. The guidelines developed by Bea van Beveran and Hetherington (1997), integrates the philosophy of the Primary Health Care model through participation and empowerment of the staff in the process of the development of the evaluation tool(s).

#### Evaluation Guideline

The guidelines that were followed for the development of the evaluation tool(s), operationalize the philosophy of the Primary Health Care model. Bea van Beveran and Hetherington (1997), outline five dominant reasons for doing evaluations:

- 1) Justification from the perspective of the funding agencies,
- 2) Defining organizational programs and goals,
- 3) Program enhancement,
- 4) Understanding participant and care-giver satisfaction, and
- 5) Justification in pragmatic terms (p119).

These authors indicated there are five steps that guide the process for developing an evaluation tool. The five steps in this process are: 1) understanding the reason for

undertaking the evaluation, 2) securing resources, 3) creating enthusiasm and establishing credibility, 4) developing consensus about goals and objectives, and, 5) refining the program. These steps encompass the philosophy of community participation and ownership of the process, the process being the development of an evaluation tool for the Breast Cancer Centre of Hope. The following section delineates how the guidelines facilitate the process of developing an evaluation tool. The section also highlights the collaborative process between the developer and the staff, that reflects the principles of the Primary Health Care model.

#### Collaboration and Guidelines

The first step in the development of an evaluation is “understanding the reason for undertaking the evaluation”(Bea van Beveran & Hetherington, 1997, p 120). The premise of this step is that there has to be a reason for the evaluation. That reason will shape the content and context of the evaluation. For example, an evaluation that is developed to measure the cost effectiveness of a program will look different than an evaluation that is developed to measure client satisfaction.

Step two consists of securing resources (Bea van Beveran & Hetherington, 1997, p121). Securing resources not only means funding sources, but the resources to develop and implement the evaluation. Evaluations are often costly, in terms of money and staff commitment. This step fits well with the Primary Health Care model in that the services should be what the community can afford. Even if the money can be found through funding, the agency must question whether it can sustain an evaluation if the evaluation demands too much time from the staff.



To this end, step three, creating enthusiasm and establishing credibility (Bea van Beveran & Hetherington, 1997, p122), becomes important. This part of the process starts to build a relationship between the developer of the evaluation and the staff. In any development of an evaluation, there is a time commitment required of the staff. As well, staff may feel threatened by the prospect of an evaluation because they may feel they themselves are being evaluated as opposed to the program. These issues make it imperative that the person developing the evaluation gain the confidence and cooperation of the staff. This is accomplished through active participation by the staff in the process of developing the evaluation tool. Active participation may be realized through staff meetings, where brainstorming and idea sharing about the evaluation and the process can be openly discussed with the staff. This allows empowerment of the staff through the valuation of their opinions and the inclusion of their concerns within the development of the evaluation.

The fourth step includes developing consensus about the goals and objectives. This ensures that the developer of the evaluation and the staff are working toward the same goals. There has to be an understanding of what needs to be evaluated and how it will be evaluated. Again, this is accomplished through meetings with the staff and active solicitation of staff input from the person developing the evaluation. Both these steps encompass the tenets of the Primary Health Care model, and the overall philosophy of the model.

Finally, the last step, is observing and fine tuning the program. Bea van Beveran and Hetherington (1997), state that it is essential the existing program has no obvious

gaps in service before an evaluation is undertaken. If there are obvious gaps in the program, then the evaluation will reflect that gap. That gap may be affecting another aspect of the program, which may be missed if the focus is on the gap. There is little value in identifying the problems in an organization that are already known to the agency. Therefore, it is suggested that known problems be corrected before the evaluation is implemented. Therefore, it is recommended that any obvious needs in the program be addressed.

The development of an evaluation tool or tools within the Primary Health Care model meshes well with the framework outlined by Bea van Beveran and Hetherington (1997). Both the model and the framework promote the participation of the people involved in the process, and validate their participation as an integral part of the process.

### Conclusion

Evaluations are a vital aspect of health care services. The use of an evaluation framework provides guidance that allows accurate measurement of pre-determined indicators of effectiveness, outcomes or quality (Mark, 1995; Vingilis & Burkell, 1996). The development of evaluation tools to conduct evaluations is a time consuming and difficult proposition. Staff working within the programs, often do not have time to engage in this endeavour, despite understanding the importance of the evaluation. Therefore, proper planning of the development of evaluation tools is essential in that the tools must provide usable data for the program. Otherwise, the time spent in implementing the evaluation is wasted. Finally, in developing tools for an evaluation, it is also important that a method for delivering the evaluation and analysing the data be planned during the

development of the evaluation plan and in conjunction with the agency. This will ensure that once the data has been collected, the staff is able to use the data in a timely and efficient manner.

Developing evaluation tools for the Breast Cancer Centre of Hope will allow staff to review the services offered and identify areas for change or refinement. Evaluation tools will also allow the Breast Cancer Centre of Hope to provide empirical data to support their services and the continuation of services by providing evidence of use and effectiveness. In this time when health care funding is stretched to the limit, providing evidence of effectiveness for a service such as the Breast Cancer Centre of Hope, helps to support the continuation of these services that lie outside of the traditional biomedical model.

This practicum will assist in the evaluation of the Breast Cancer Centre of Hope by working with staff within the Primary Health Care framework to develop evaluation tool(s), and provide guidelines to facilitate the implementation and analysis of the completed evaluation tool(s).

## **Chapter Two**

### **Literature Review**

This chapter will review the literature on program evaluation, and client satisfaction. These two areas are essential in the development of evaluation plans. The review will then look at the conceptual framework that was employed in the practicum, that is, the Primary Health Care model. The Primary Health Care model will be reviewed in the context of an evaluation process. Finally, evaluation in practice will be reviewed to give the reader an idea of how the evaluation plays out in practical terms. This chapter will identify what is important in the development of an evaluation plan, and how the Primary Health Care model can be employed to guide the development of the evaluation.

#### **Program Evaluation**

Program evaluation is "... the process of assessing the performance of a program (Hilton, 1996, p.174). Thompson (1992), describes program evaluation as "...the systematic application of social research procedures for assessing the conceptualization, design, implementation and utility of social intervention and human service programs." (p567). This concept is echoed through much of the literature on evaluation (Drummond, Stoddart & Torrance, 1987; Quinn Patton, 1982; Rovers, 1985). The major goal of evaluation research in health care, is diverse, but is, ultimately, the production of useful information that can be used to improve the program, and thereby improve the health of the target population (CNRC Advisory Committee, 1995; Rovers, 1985). Literature on program evaluation provides diverse information on evaluations. This section will review various types of program evaluations. The benefits and limitation of certain models will

be reviewed, along with the evaluation process, which includes looking at the process and design and an exploration of the client/patient satisfaction literature.

### Types of Evaluation

In understanding program evaluation, it may be helpful to first define what types of program evaluation exist. Types of program evaluation vary with the type of organization, the goals of the evaluation and the available resources to conduct the evaluation. The variables being measured also affect the process and outcome of the evaluation (Schalock & Thornton, 1988). The literature on program evaluation separates program evaluation into formative and summative, process and outcome oriented, impact and evaluation by objectives, as only some of the categories. This section will briefly describe various types of evaluation.

The first type of evaluation to be discussed is formative. A formative evaluation is used to advance program development and improve on the present programs (Fitz-Gibbon, 1987a; Fugate Woods & Catazano, 1988; Hilton, 1996; Rossi & Freeman, 1993). Formative evaluation looks at how the program works and what it is trying to accomplish, short term and long term (Fugate Woods & Catazano, 1988; Hilton, 1996; Seltiz, 1953). Formative evaluation can be used to evaluate components of a program instead of an entire program (Fitz-Gibbon, 1987a).

A formative evaluation is often used to evaluate programs in the early stages, in order to assess the program's progress and suggest improvements (Fitz-Gibbon, 1987a; Fugate Woods & Catazano, 1988; Rossi & Freeman, 1993; Smith & Glass, 1987). Formative evaluations have the benefit of providing information on the program that can

be used while the program is in operation (Fitz-Gibbon, 1987a; Hilton, 1996). Fitz-Gibbon (1987a) suggests that the formative evaluation model allows evaluators to “conduct small-scale pilot project studies and experiments with newly developed program components.” (Fitz-Gibbon, 1987a, p 14). The benefit of taking a formative evaluation approach is that the formative evaluation can be used to evaluate components of a program instead of the whole program. This allows focussed attention to areas of concern for the program staff.

A formative evaluation may include a mini impact study, or a review of the program (Smith & Glass, 1987). The rigour can be as exacting as an experimental study, or, it can be an informal evaluation (Rossi & Freeman, 1993). A formative evaluation is not meant to determine whether a program will continue, or the cost/benefit of the program, or even whether it is better than another alternative (although, through the design, this very question may in fact be answered). The thrust of the formative evaluation is that it exists to determine if the mandate of the program is being followed, and if the program has been of value to the participants.

In contrast to the formative evaluation, the summative evaluation is usually conducted after a program has ended (Smith & Glass, 1987; Thompson, 1992). Summative evaluations are used to assess whether a program has had the desired effect (Fugate Woods & Catazano, 1988). One may be expected to describe the program, to produce a statement about the programs, to note any unanticipated outcomes, and possibly to make comparison with alternative programs (Fitz-Gibbon, 1987a). The classic case of this would be a situation where a group has been exposed to an intervention, such as a

smoking cessation program. The pre and post-test scores could be compared to determine if the program helped participants in stopping smoking. The use of summative evaluation is limited to a program that has ended, and therefore has a somewhat narrower application than a formative evaluation. As in formative evaluation, some authors feel that summative evaluations are optimally conducted using some type of experimental design (Fitz-Gibbon, 1987a; Gomby, 1999; McKenzie & Smeltzer, 1997; Orchard, 1994).

Unlike a summative evaluation which looks at specific results, outcome evaluations focus on overall, intended and unintended results of the program (Thompson, 1992). Hilton (1996), and Schalock and Thornton (1988) describe outcome evaluation as determining the effectiveness of the program in meeting its objectives. This makes it essential to clearly define what the goals of the organization are (Schalock & Thornton, 1988). This evaluation is limited by that caveat of knowing the goals, as some programs, early in their inception, do not have their goals clearly identified, and therefore cannot develop relevant outcome measurements (Bea Van Beveran & Hetherington, 1997; Green, 1979; Schalock & Thornton, 1988; Stetcher & Davis, 1987b; Thompson, 1992). Regular outcome measurement cannot relate cause and effect, and does not provide information needed to address areas for improvement (CNRC Advisory Committee, 1995; Hatry, 1994). Some authors criticize outcome measurements, as they do not go into the necessary depth to tease out the actual impact of the program, but only describe what the program has produced (Hatry, 1994; Rossi, Freeman, 1993; Schalock & Thornton, 1988). Impact evaluation provides more detail on how the program has affected the users.

“Impact analysis focuses on a program’s effectiveness, or impacts on the targeted

population.” (Schalock & Thornton, 1988, p20). According to Green (1979), impact evaluations look at short term goals. While this may be true in the respect that funding agencies and the government may require evaluations based on yearly budgets, impact evaluations may also be useful in evaluating long-term goals. Impact evaluation compares the effect of the program on participants to what they might have done if the service had not been available, or they had used a different service (Schalock & Thornton, 1988). Obviously this calls for speculation on the part of the evaluator. However, the speculation should be based on realistic alternative scenarios (Stetcher & Davis, 1987a; Schalock & Thornton, 1988). An easier way to compare is, of course, to use a comparison group, one that is matched for specified demographic variables. This can also be a difficult task, especially since the number of participants (experimental group) and the number of people in the comparison group (control group), have to be large enough to produce significant results. Small sample sizes will invalidate the results in that the small sample may bury significant results, or skew results that would not be quite so significant in a larger population (Hassard, 1996).

Schalock and Thornton (1988), propose an Impact Analysis Model as being: “Experimental Group mean - Control Group mean = Estimated Impact.” As this model indicates, direct comparison of two groups results in the derivation of the actual impact. It is difficult to estimate the impact of any program as many other variables may confound the results and nullify the findings that demonstrate program effectiveness. In a review of an impact evaluation, Vingilis and Burkell (1996) point out a number of flaws, one of which is the lack of causal relationship between the program being evaluated and the



outcome being evaluated. Yet impact evaluation or aspects of this evaluation are incorporated into other types of program evaluation.

Economic evaluations take many of the aspects of a variety of models. Outcomes and impacts may be observed, with the focus being the cost in relationship to those aspects. The cost/benefit analysis has impact analysis imbedded within the evaluation. Cost/benefit analysis is a type of evaluation that is often used to justify the continuation of programs and to determine if programs are efficient (Drummond, Stoddart & Torrance, 1987; Lave, 1980; Schalock & Thornton, 1988). In order to determine efficiency, it is necessary to validate the impact of the program. Cost/benefit has not traditionally been the purview of the human service community. "The literature suggests that benefit-cost analysis does not provide a sufficient basis for making decision concerning public health programs but that it is a highly useful tool for informing decisions." (Lave, 1980, p272). This is because it has been difficult to measure the intangible benefits of many of the human service programs (Lave, 1980; Schalock & Thornton, 1988; Thompson, 1992). Yet, it is undeniably important that attributes such as emotional well-being, empowerment and increased self-confidence are vital determinants of the success of human service programs (Dunn, et al., 1999; WHO, 1978). While it is not impossible to measure the intangibles, it would be an indirect measurement at best, which cannot preclude the effect of mitigating variables on the attributes measured. Confounding variables, such as history and the concurrent use of other services may blur the lines of impact for causality, therefore diluting or magnifying the impact of one program.

There are a number of other variations of the economic evaluation that will not be

discussed in this section. Different authors make distinctions between cost minimization, cost-effectiveness, cost-utility and cost-benefit ( Drummond, Stoddart & Torrance, 1987). The differences lie mainly in the focus and purpose of the evaluation (Dunn, et al., 1999). These differences are not relevant at this time as the evaluation focus is not economic.

The final type of evaluation discussed in this section is process evaluation. Process evaluation means different things to different authors, in different settings. Hilton (1996) states that process evaluation monitors the implementation phase. In policy evaluation, "...process evaluations examine the organizational methods, including rules and operating procedures, used to deliver programs. " (Howlett & Ramesh, 1995, p171). The purpose in the policy scenario is to monitor for efficiency and to simplify if possible. Schalock and Thornton (1988), describe process analysis as describing, "...the general environment in which the program operates including who are the persons served, what services are provided, how much does it cost and how could the program be replicated." (p20). They aver that the benefit is that process analysis allows others to replicate the program and provides useful feedback. It also produces the data that can be used for impact and cost/benefit analyses.

While all three definitions have differences, they all look at how the program runs, while it is ongoing. The differences between process, impact and outcome are evident in that process evaluation collects information on structure and process; " If information is collected on structure and process, then efficiencies and deficiencies in intended outcomes can be strengthened (in the case of efficiency), or resolved (in the case of deficiencies)." (CNRC Advisory Committee, 1995, p9). The evaluation may occur in the early stages of

the program, and focusses mainly on how the program is being delivered. Are the staff helpful, knowledgeable, and sufficient, are the objectives appropriate? Questions typically seen in process evaluation ask; "How often did you use the service,? Are the hours accessible? Where did you hear about the service?". These questions can identify valuable data for program accountability and revision. "Process evaluations are important to examine whether the program users are members of defined target groups and to identify barriers to optimal use." (Baylis & Myers, 1990, p 343). This is also reflected in Schallock and Thornton (1988) and Grusky and Tierney (1989), who put forward the concept that the two basic stakeholders in an evaluation are the service providers and service users. Both of these "data sources" are discussed later in this chapter under data sources and patient evaluation literature. Ultimately, in process evaluation "...the object of interest is professional practice, and the standard of acceptability is appropriate conduct of practice." (Green, 1979, p106).

Drummond, Stoddart and Torrance, (1987), and Schallock and Thornton (1988), postulate there are three central questions for process analysis: (1) (a)who is the target population, (b)will the program work with this population?, (2)(a) what services are provided, (b)are they viable services?, and, (3) what are the costs? These three questions parallel the underlying concepts of the Primary Health care model. The Primary Health care model is built around the idea that the community is the target population (community is defined by many parameters), that services provided should be appropriate to the community, at a cost the community can afford (Walt & Rifkin, 1980;WHO, 1978).

The different models of evaluation discussed above provide background on

program evaluation. The descriptions of the models also provide some insight into the purpose and goals of an evaluation. These models often overlap, or complement each other. It is important to know that each model has commonalities in terms of process and design of evaluation plans. However, the models do not really identify how the evaluation may be developed, or the process of developing the evaluation. The question that now becomes clear, is who develops the evaluation and how? In other words, what is the process in developing an evaluation plan?

### Evaluation Process and Design

The process of developing an evaluation plan can be difficult. The process entails that the evaluator be knowledgeable in the evaluation models and different evaluation designs. This knowledge should help the agency under evaluation focus on what to do, how to do it, and within a budget. This section on process and design will explore these questions, and provide information that will lead one through the process of developing an evaluation plan.

The first step in developing an evaluation plan is to decide who will undertake the task of doing the evaluation. Morris, Fitz-Gibbon and Freeman (1987a), discusses why an outside evaluator may be called on to develop and implement an evaluation. Although staff may have a good idea of what is happening in their program, they may have difficulty separating themselves from their work (Bea Van Beveran & Hetherington, 1997; Fitz-Gibbon, 1987b). This may skew their ability to truly, objectively evaluate their program (Bea Van Beveran & Hetherington, 1997; Fitz-Gibbon, 1987b). An evaluation of the program may be seen as an evaluation of the work done by the staff, and therefore

may be threatening to staff (Bea van Beveran & Hetherington, 1997). Developing an evaluation also takes valuable time, which many staff are unable to give up without sacrificing some other area of their work (Bea Van Beveran & Hetherington, 1997; Morris, Fitz-Gibbon & Freeman, 1987b). These reasons provide sound rational for the expense of hiring an outside evaluator.

Once the evaluator has been chosen, the next step looks at how the evaluation tool is developed. The literature repeatedly advises that the evaluator spend time in examining the needs and wants of the agency/program undergoing the evaluation (Bea Van Beveran & Hetherington, 1997; Donabedian, 1986; Fitz-Gibbon, 1987b; Wye, 1989). The process of developing an evaluation plan varies between the needs of the place being evaluated, the purpose of the evaluation and the financial means to carry out the evaluation (Bea Van Beveran & Hetherington, 1997; Fitz-Gibbon, 1987b; McKenzie & Smeltzer, 1997). While some agencies will conduct evaluations simply to fulfill a legal requirement set out by their board, funders, or government (Fitz-Gibbon, 1987b), others conduct evaluations to refine and improve their programs (Bea Van Beveran & Hetherington, 1997; Donabedian, 1986; McKenzie & Smeltzer, 1997; Morris, Fitz-Gibbon & Freeman, 1987b). That is why a systematic and careful examination of the program is required to start the process of developing an evaluation plan.

Bea Van Beveran & Hetherington (1997), Morris, Fitz Gibbon and Freeman (1987b), McKenzie and Smeltzer (1997), and Stecher and Davis (1987c), all agree that the first step in developing an evaluation plan is finding out what the staff think and feel about the evaluation. Meeting with staff in a non-threatening environment, and allowing

them input into the process of developing the evaluation provides a venue for staff buy-in and staff venting of concerns (Bea Van Beveran & Hetherington, 1997). Having staff cooperation is essential when the evaluation will, ultimately, affect them and their program. Identifying goals and objectives of the agency are priorities in starting the evaluation plan (Bea Van Beveran & Hetherington, 1997; McKenzie & Smeltzer, 1997; Stetcher & Davis, 1987b.). It is helpful to reach a consensus on what those goals are with the program staff, in order to formulate a clear picture on what is going to be evaluated. What does the program hope to achieve? Does the program exist to provide social services to single mothers, and via those service, increase the independence and empowerment of the women who utilize the program? Establishing the goals helps the evaluator determine what needs to be measured.

What needs to be measured can be labelled as the indicators. Indicators, refer to the aspects of the program that may provide information on the quality of the program (Charles, et al., 1994; Cleary, et al., 1994; Gerteis, 1993; Hill McPhil, 1997; Hseish & Kagle, 1991; Oswald, et al., 1996; Wensig, Grol & Smits, 1994). Establishing common goals is the first step in teasing out those indicators. The other piece that is required to identify indicators to be measured, is identifying the actions that comprise that indicator. These actions, for lack of a better term will be labelled as variables. For example, "caring" in nurses is often identified as an important indicator of quality care (Larsen & Ferketich, 1993; Nelson, et al., 1999; Oswald, et al., 1996; Pascoe & Attkisson, 1983; Robinson-Wolf, 1998). Yet, how is caring demonstrated? When caring is broken down into the variables of communication, organization, touching, understanding, it becomes a

measurable entity (Hall & Dornan, 1988; Linder-Pelz & Struening, 1985; Mitchell-DiCenso, 1996; Williams, 1994). Granted the whole may be more than the sum of its parts, but since caring may mean different things to different people, the individual variables of caring provide specific actionable data. Actionable data is data that a person can respond to. If, for instance, a patient rated communication from their nurse as very dissatisfying, but that the nurse was very organized, the evaluator could take that to the nurse and suggest that they work to improve their communication skills, but that their organizational skills were excellent. If the question had just been about caring, the patient may have answered "somewhat satisfied" with the caring, but since no individual variables had been measured, no actionable data would have come of it.

Data is a vital aspect of any evaluation. Where the data comes from should be addressed early on in the evaluation process. As part of the process of developing the evaluation plan, the evaluator should be in close contact with what are termed as "Key Stakeholders" (Rossi & Freeman, 1993; Smith & Glass, 1987; Stetcher & Davis, 1987b; Thompson, 1992). These are people who have a vested interest in ensuring the efficient and quality operation of the program under review. These people may be staff, funding agencies, other services or agencies that feed into the program (i.e. through referrals or collaboration). This strategy also facilitates staff ownership of the evaluation process which is essential in order to carry the evaluation through to the end (Bea Van Beveran & Hetherington, 1997).

Data sources do not only consist of people. There are a variety of records that many programs collect that can be used to help develop the evaluation plan. Once it has

been determine what data is already available, it can then be determined what additional data is needed. These data sources will be elaborated on in the section of the conceptual framework that is discussed after evaluation design.

The development or choice of the evaluation tool is tied in with the design of the evaluation. To a great extent, the tool development is dictated by the design choice. However, the standard tests, surveys, interviews and focus groups are the common tools used to conduct evaluations. In conjunction with this, the mode of implementation is also tied to the design. Therefore, the next section will address design issues for evaluations.

### Evaluation Design

The most accepted or preferred evaluation design is the experimental or quasi-experimental design (Fitz-Gibbon, 1987a; Morris, Fitz-Gibbon & Freeman, 1987b; Smeltzer & McKenzie, 1997; Stetcher & Davis, 1987a). Researchers argue that the experimental design allows comparison of a group undergoing the program (the experimental group) and a control group that was not subjected to the program. By having this comparison, a causative effect of the program would be easier to establish (Gomby, 1999; Stetcher & Davis, 1987a). The quasi-experimental design is mentioned as an extension of the experimental design due to the difficulty of actually developing a "true" experimental design (Morris, Fitz-Gibbon & Freeman, 1987b; Stetcher & Davis, 1987a). The difference between the two designs will be discussed during the explanation of this process.

The experimental evaluation design requires planning before the program is implemented in order to establish randomization of the program participants. The



experimental design in evaluation is the same as any other experimental design. The control group is the group that is not exposed to the program under evaluation, the experimental group is the group exposed to the program. Both groups, ideally would be comprised of participants who have been randomly assigned to either the control group or experimental group. The pool would, ideally, be comprised of a fairly homogeneous group, that is, the group would be equal in various demographic variables, such as age, socio-economic status, and education. Pre-tests would be administered to both groups to establish baseline scores, and hopefully establish that the groups are starting from a similar place. If the post program test in the experimental group are statistically significant from the control group, then cause and effect can be more clearly linked to the experimental program (hopefully the outcome was the intended outcome for the experimental group). The main benefit of the experimental design is that one may be able to establish cause and effect. Without going into all the possible threats to the validity of any experiment, one should note that the causative effect may still not be able to be established even with the rigour of an experimental design.

The quasi-experimental design is much like the experiment save for some minor adjustments that are made due to barriers to a "true" experimental design. There may not be randomization of participants, there may not be a pre-test, only a post-test, or, comparison groups may not be equal (Gomby, 1999; Stetcher & Davis, 1987a; Orchard, 1994). These are barriers that occur in the community all the time, and therefore, make the quasi-experimental design, the second-best choice for many evaluators. The quasi-experimental design may not be able to establish a cause effect link as the experimental

design may, but it can at least assist in determining if the program being evaluated is harmful, or may be helpful (Gomby, 1999 ). There are even more threats to the validity of a quasi-experimental design, however, it is an acceptable form of design for many evaluators (Gomby, 1999 ).

The advantages of the experimental design is that it can help establish cause and effect and the rigour of the design also allows generalizability of the results. This means that the outcomes can be generalized beyond the group who went through the program, they can be generalized to other people in the same demographic parameters. The disadvantages are finding a group large enough, that can be randomized. Organizing the evaluation to have a pre-test and post-test requires time and the financial means to carry out and ensure that the rigour of the experimental process is carried through. This is not feasible for all agencies. The quasi-experimental design has some of the same problems involved. The quasi experimental design presents more problems in terms of lack of randomization or lack of pre-test. Threats to validity are even more relevant in the quasi-experimental design since the groups are not randomized, and that may not have a pre-test as a baseline comparison. There are other types of evaluation designs that can be used that do not focus on cause and effect as much as they focus on user perception of services, and whether or not the users feel that the program has the intended outcomes.

A survey with varying scales and questions is often employed as a tool to solicit user perception of services. It should be noted at this point that user perception is an essential part of an evaluation since the program should be meeting the needs of the user. The section on user or patient satisfaction will delve into the details of how perception is

measured and why it is important.

### User, Client or Patient Satisfaction

Client input is a strong identifier of how the program is performing (Thompson, 1992). Patient satisfaction is not clearly a model, design, nor is it clearly a process. However, it is relevant and central in the process of developing an evaluation plan that uses the Primary Health Care model as a framework. For these reasons, user satisfaction literature will be discussed at this juncture, to provide background information on user satisfaction that can be transferred into the evaluation process.

An integral part of a service oriented program evaluation is client, or user satisfaction. In assessing the performance of a program that has a mandate to provide services to a population, it follows that client satisfaction should be a large part of the evaluation. After all, the people who are using the service are the best judges of whether the service has met their needs.

Patient satisfaction has its roots in quality improvement work within the health care sector (Donabedian, 1980; Gerteis, 1993; Nelson, et al., 1996). Patient satisfaction measurement emerged as an elemental piece of quality improvement in that without a means to measure patient satisfaction, quality improvement would always be lacking a key determinant. The importance of satisfaction measures have been demonstrated in the literature as being greater patient compliance and enhanced communication with health care professionals, earlier discharge and quicker recovery times, leading to decreased health care costs (Berwick, 1997; Charles, et al., 1994; Cleary, et al., 1994; Donabedian, 1988; Hill McPhil, 1998; Hoogstraten, 1998; Hsieh & Kagle, 1991; Linder-Pelz, 1982;

Nelson, 1996; Sitzia & Wood, 1997; Wakefield, et al., 1994; Williams 1994). Therefore, patient satisfaction is a valuable tool in improving health care and the health status of people. The review on patient satisfaction will define what patient satisfaction is, how it is measured and its application in program evaluation.

There are a number of theories that have been offered on what constitutes patient satisfaction. Linder-Pelz (1982) and Linder-Pelz and Struening (1985), discuss patient satisfaction as the individual's perceptions and attitudes on the health care they are receiving and have received. Other researchers have explored the concept of expectations of health care and what has actually been delivered (Judge, et al., 1992; Ware, et al., 1983; Wensing, Grol & Smits, 1994). This gap between the expectations and actual care is the process that people go through to determine their satisfaction. These theories with the exception of slightly different wording, are, for all intents and purposes, the same.

A key element to measuring patient satisfaction is describing the attributes, or determinants of satisfaction. Communication with doctors and nurses, humaneness, emotional support by health care providers, dissemination of information, and respect for the individual are only a few of the determinants that researchers have used to measure and describe patient satisfaction (Andrzejewski & Laga, 1997; Farris-Kurtz, 1990; Gerteis, 1993; Judge, et al., 1993; Larson & Ferketich, 1993; Linder-Pelz, 1982; Linder-Pelz, Struening, 1985; Owens & Batchelor, 1996; Oxler, 1997; Pascoe & Attkisson, 1983; Ware, et al., 1983; Wensing, Grol & Smits, 1994). The diversity of identified determinants makes the task of studying patient satisfaction challenging. Comparison between patient satisfaction studies becomes more difficult as different measures and

different determinants are used. Yet through the studies, common themes do emerge as to the most salient determinants of satisfaction. How these determinants are measured varies between studies.

Researchers have clearly identified communication and caring issues as “listening posts”, or indicators for client satisfaction (Cleary, et al., 1994; Gerteis, 1993; Sitzia & Wood, 1997; Wakefield, et al., 1994). Listening posts are the fundamental determinants of satisfaction. Examples of some listening posts are satisfaction with how nurses treat patients, and how well physicians communicate information to patients. These determinants are easy to identify and are indicative of overall satisfaction, to a certain degree. That communication and caring issues are fundamental to patient satisfaction is not surprising given how important information and the physician patient relationship and roles are to health care service users (Bilodeau & Degner, 1996; Degner, et al., 1997). Research indicates that being able to talk to health care professionals, whether they be physicians or nurses, is essential for positive evaluations of care (Charles, et al., 1996; Cleary, et al., 1994; Hill McPhil, 1998). Communication covers aspects such as information sharing, relationship with health care professionals, and perception of respect from health care professionals (Gerteis, 1993; Larsen & Ferketich, 1993). The determinant of caring is demonstrated through attitudes of the health care professionals. Things such as paying attention, listening and providing feedback indicate to patients that the health care professional does care about them (Larsen & Ferketich, 1993). Therefore, it becomes essential to the evaluation that these indicators be measured.

Satisfaction studies can look at direct or indirect measurement of satisfaction.

Whether it is measured directly, or indirectly, it is the discrepancy between what the patient expected, or wanted, against what they received. Direct measurement may have patients comparing what service was provided and the outcome. Indirect measurement attributes may be how the nurses treated the patient, how families were treated, and the efficiency of staff (Cleary, et al., 1992; Gerteis, 1993; Larson & Ferketich, 1993; Linder-Pelz, 1982; Wensing, et al., 1994; Robinson-Wolf, et al., 1998). Regardless of the type of measurement, it is the subjective evaluation of satisfaction against the personal expectations in a given situation that underlie this concept. User satisfaction of a service is a pivotal aspect of an evaluation. It provides a valuable feedback loop to assess how well the program is meeting the needs of the users and thereby achieving the goals set out by the mandate. It also parallels the tenets of the Primary Health Care model in that it keeps the needs of the community in the forefront.

It is interesting to note that the term, patient satisfaction, is the most frequently employed term throughout the research on satisfaction in the health care field. Terms such as patient, client, consumer or user satisfaction have all been used in this genre of research. The power dynamics of the relationship between the health care professional (especially the physician) influences the use of terminology. The semantics of the terminology of "patient" satisfaction imply a physician or health care professional dominated relationship (Charles, Gafni & Whelan, 1997). The term "user" connotes a voluntary relationship between the health care professional and the person using a service. The voluntariness of the relationship helps to equalize the power relationship between the health care professionals and the user of the service. Therefore, the term "user" is

preferred term to be used in the evaluation.

It is evident that user satisfaction is not only important in program evaluation, but is also very relevant to the program evaluation for an agency using the Primary Health Care model as a framework. The inclusion of user satisfaction in an evaluation ensures input of the community's needs in the evaluation. By doing so, user satisfaction reflects the principles of the Primary Health Care model and brings in valuable information. How satisfaction is measured differs between evaluations, but direct and indirect measurement both result in data that allows programs to make revisions if necessary. It also ensures user input into a program in which user participation may be fundamental to the mandate.

#### Conclusion of Evaluation Literature

There are a number of models for evaluation, each with their own strengths and weaknesses. Combining evaluation models may aid in overcoming some of the drawbacks, but present difficulties in managing and financing such an extensive evaluation (Thompson, 1992 ). What is important is that the evaluation be conducted in a systematic manner which will allow for consistency and useful results. A model, or framework will aid in guiding the course of the evaluation so the consistency can be maintained and the results will produce actionable data, that can be used to improve the program. User satisfaction literature suggests that community input into the evaluation results in the ability to target areas of need. Overall, the information in the literature strongly supports the development of evaluations to maintain, refine and improve programs that will best meet the needs of the community they are serving.

A variety of programs, such as community service agencies or Nurse Managed

community agencies can use the models mentioned above. However, the models themselves will not specify the information that needs to be elicited from the evaluation. For this reason, an overlying framework of the Primary Health Care model will be used as an evaluation framework to help guide the direction of the specific questions in the evaluation tool(s). The Primary Health Care framework will guide the areas for evaluation and will produce results that are relevant to the philosophies and practice of the Breast Cancer Centre of Hope.

#### Primary Health Care as a Framework for an Evaluation

With the proliferation of community based health programs in a fast changing social environment, evaluations have become more challenging. This is due, in part, to the lack of evaluations developed to address community health services (CNRC, Advisory Committee, 1995). A variety of confounding factors can impact the evaluation before it can be completed (Rossi & Freeman, 1993). For example, the program can undergo change, before it is time for evaluation, or, as in one case, the “control” groups (programs that are being used as comparison), adopted the intervention before an evaluation could be carried out (McKenzie & Smeltzer, 1997; Rossi & Freeman, 1993). Rossi and Freeman refer to this as the “volatility of social programs” (p.27). This makes evaluation within a dynamic organization difficult. The Primary Health Care model is defined, in part, by the dynamic flow of the influence of the community’s needs. Therefore, an evaluation based on the Primary Health Care model that is responsive to the varying sociol-economic and cultural needs of the community seems to make sense (McDonald, 1993; WHO, 1978). This section will explore the Primary Health Care model as a conceptual framework,



addressing the origins of Primary Health Care, the five tenets of Primary Health Care and the data sources that may be used in an evaluation using the Primary Health model as the framework.

Using the Primary Health Care model as a framework for an evaluation addresses some of the issues of a dynamic organization. The use of the Primary Health Care framework adds to the body of knowledge on the Primary Health Care model, evaluation and the nursing contribution to the practice of the Primary Health Care model. The Primary Health Care framework also recognizes the ever-changing dynamics of a community based program through the five tenets of: (1) equity, (2) holistic care, (3) acceptable care, (4) empowerment and (5) intersectoral development. Through these tenets, the Primary Health Care model embodies change, through the process of developing conduits in the health care system for change to occur.

Primary Health Care is not well accepted as a viable health care model in affluent communities (Chanecka, 1998; Edwards, et al., 1998). The model is seen as a solution to the health care problems of medically under served populations (these population are usually economically disadvantaged), but has been rejected by communities that can afford to pay someone to look after their health (Baum & Sander, 1995; Chanecka, 1998; Rover, 1986; Sturt, 1997; WHO, 1988). Affluent communities seem to eschew the community participation that is foundational to the Primary Health Care model in favour of a technocratic health care system that has a "cure" for all ailments (WHO, 1988). While this may be a simplification of the barriers to implementing the Primary Health Care model, it is valuable to understand that this bias does exist. It is therefore worthy to

note that women with breast cancer are not considered to be an under served population, especially those in urban areas. In utilizing the Primary Health Care model as a framework, the evaluation will demonstrate the effectiveness of Primary Health Care as a framework for an evaluation, and provide support for its' use in practice and theory.

### Conceptual Framework

"Primary Health Care (Primary Health Care) is both a philosophy of health care and an approach to providing health services." (CNA, 1995, p.1). Primary Health Care is considered to be the most appropriate system to provide health services to the world's population. Health of the world's population has long been a concern of the WHO. In 1978, members of the WHO met in Geneva and expressed a need for, "urgent action by all governments, all health development workers, and the world community to protect and promote the health of all the people of the world..." (1978, p.2). The resulting Declaration at Alma Ata was for all countries, individually and collectively to strive for "Health for All" (HFA), by the year 2000 (Glittenberg, 1988; Holzemer, 1992; Walt & Rifkin, 1990; WHO, 1988). Primary Health Care eschews the traditional biomedical model that focuses on individual treatment and cure of disease, and instead centres health care around the community and overall health (Broom & Woodward, 1986; Chanecka, 1998; Cotroneo, et al., 1997; Glittenberg, 1988; WHO, 1978).

### Five Tenets

Primary Health Care has, at its core, a mandate to involve the community and foster empowerment and self-reliance (McDonald, 1993; Sturt, 1997; WHO, 1988; WHO, 1978). There are five major principles or tenets of the Primary Health Care model. They

are: 1) equity, 2) holistic care, 3) acceptable care, 4) empowerment, and 5) intersectoral development. These tenets are easily recognized in many community health centres and many community programs. It is vital to understand what each tenet represents in order to associate the model with a program.

Equity refers to universal and fair access to health care services. This is often a concern for rural and under developed areas, where traditional services such as physicians and hospitals are not readily available (Chanecka, 1998; Glittenberg, 1988; WHO, 1988, 1978). Barriers to access may be physical, geographical, or social. For example, a women who wants to go to a Women's centre for assistance to find a job, may not be able to make the appointment due to babysitting problems. Access is certainly compromised in this instance. In developing an evaluation, this barrier would become an indicator to measure..

Holistic care is the second concept of the Primary Health Care model (WHO, 1978). Holism refers to the breadth of service that health care systems should provide. Services should be promotive, preventive, curative and rehabilitative. This concept provides the impetus for health care systems to reallocate their priorities from curative and treatment focussed aspects, to include effective health promotion budgets and to include post discharge rehabilitation (Baum & Sander, 1995; Cotroneo, et al., 1997; Salmon, Talaschuk & Tichy, 1988). The model provides an example of how this concept could be realized, but does not limit initiatives to the suggestions outlined: "Since these services reflect and evolve from the economic conditions and social values of the country and communities, they will vary by country and community, but will include at

least:...education concerning prevailing health problems and methods of preventing and controlling them; and appropriate treatment for common disease and injury.” (WHO, 1978, p.34).

Acceptable care is the third Primary Health Care concept. Acceptable care does not mean second rate, or “make do”, as some communities have thought (Button, et al., 1998; Edwards, et al., 1998; Rover, 1986). Services should be effective, culturally acceptable, affordable and manageable. Effective services assume that careful assessment and planning have been carried out and that the services available are useful as well as needed (Deeb, et al., 1992; Manitoba Health, 1997b; WHO, 1988, WHO, 1978). Additionally, the services must be culturally appropriate. Self-help groups often meet this criteria (Cotroneo, et al., 1997; Edwards, et al., 1998; Holzemer, 1992). Affordability is an issue, particularly, for under developed and industrialized countries with underserved and underfunded areas and programs (Edwards, et al., 1998; Hatcher, et al., 1998).

Empowerment is perhaps the key concept to this model. Empowerment seeks to make communities self-reliant and health care and health promotion a self-perpetuating cycle that links all concepts together (Deeb, et al., 1992; McDonald, 1993; Smith, 1991; WHO, 1988, 1978). Self-reliance is encouraged through grass-roots involvement of the community in policy and service development (Salmon, Talaschuk & Tichy, 1988; Schoultz & Hatcher, 1997; Williams, 1991). Through involvement, communities can identify and prioritize **their** needs, lobby as a unified, and more influential voice for equitable and acceptable health care (Pross', 1986, theory on the “Continuum of Interest

Groups” would support this assertion), ensure care is culturally and practically relevant, and that different government sectors become involved.

The final major concept is the necessity of intersectoral cooperation. In order for the Primary Health Care model to work, all government sectors must work in tandem to effect change in the health of communities. There is an assumption made that health is not just affected by the health care system that has been controlled by the biomedical model, physicians and treatment/cure, but that the whole environment affects health (Deeb, et al., 1992).

Using the Primary Health Care model as a framework allows the evaluator to validate the programs offered many communities. The “intangibles” that had once been difficult to define and measure (Thompson, 1992), may now be labelled under one of the five tenets. As well, the tenets reflect not only the what the program does, but how the evaluation may be planned. The process of developing the evaluation should reflect the five tenets as much as the end product will reflect the Primary Health Care model.

#### A Primary Health Care Process

A process that reflects the Primary Health Care model is essential to the continuity of the evaluation plan. The Primary Health Care model should guide the process in such a way that the principles of the model are incorporated into the development and implementation of the evaluation. Bea Van Beveran and Hetherington’s (1997) guidelines for the process of developing an evaluation plan fit very well with the Primary Health Care model.

The process involves five steps, which may run concurrently, or consecutively.

The five steps are: 1) understanding the reason for the evaluation, 2) securing resources, 3) creating enthusiasm and establishing credibility, 4) developing consensus about goals and objectives, and 5), refining the program. How these steps relate to the Primary Health Care model is the subject of the next segment.

Understanding the reason for the evaluation ensures that all parties involved in the evaluation are clear on the need for the evaluation. Evaluations are not conducted to weed out staff, provide rationale for downsizing or to close down programs. Evaluations are used to identify and define issues that affect the program in question. This section of the model relates to all of the tenets of the Primary Health Care model. There may be accessibility issues that need to be addressed, or the program staff may want to know if the service they provided is beneficial, or up to certain standards. Equity and acceptable care are two tenets in the Primary Health Care model. The reasons may encompass one or all of the five tenets. Given that the Primary Health Care model is a dynamic model with fluidity between tenets, it is not surprising, nor is it confusing that one reason may address multiple tenets. For example, if an agency wants to determine if the referrals they provide are appropriate, the agency really wants to know if; 1) the referral services are accessible to the clients they are referring (equity), 2) if the referral services are providing the intended services that the client can afford (acceptable care), 3) if the work the agency has done to connect with other agencies and sectors is worthwhile (intersectoral development). Not all evaluators will view this the same; not all will categorize the reasons as falling under certain tenets. Yet understanding the rational for the evaluation can be framed within the Primary Health Care model with ease and provide continuity

throughout the evaluation process.

Securing resources is another step in the process delineated by Bea Van Beveran and Hetherington (1997) and supported by Stecher and Davis (1987b). The Primary Health Care model advocates that health care should reflect what the community can afford and sustain (WHO, 1971). Since many agencies would like to be able to evaluate their programs on an ongoing basis, sustainability is a big issue. The process in securing resources and funding reflects this part of the Primary Health Care model. If the agency cannot afford a large scale evaluation, then the evaluation needs to be designed to meet the budget. Staff resources are another aspect of securing resources. Is the staff able to give up time to implement the evaluation? How much time, and can they analyse the results? These are questions that should be answered before the evaluation is decided on.

The third step in the process, is creating enthusiasm and establishing credibility. As the Primary Health Care model promotes community ownership of health care, so does this step promote staff ownership of the evaluation process. It is a necessity that the staff take ownership of this process in order to sustain the process through to the end and continue past the initial evaluation.

The fourth step is developing consensus about the goals. This step melds with the previous step in that it also facilitates ownership of the evaluation process through having the staff identify the indicators that needs to be evaluated.

As important to the Primary Health Care model as the five tenets, are the methods in which the tenets are measured to facilitate an accurate evaluation. The data sources that are employed to gather information, shape the evaluation and reflect the framework. The

data sources must reflect the concepts of community driven services, the needs of the community and they must be appropriate to what is being measured or evaluated.

### Data Sources

What kind of data is collected is key to applying the Primary Health Care framework to an evaluation. As mentioned previously, the data and data collection should reflect the tenets of the Primary Health Care model. Therefore, it is important to recognize the different data sources and how they can be used to implement a Primary Health Care framework evaluation.

There are many ways in which data can be collected. Rossi and Freeman (1993), and Green (1979), list some of the more common data sources. One source mentioned was existing data bases. These existing data bases may include census information, written records (through chart audits), or vital statistics. This method can work well, for basic information. However, depending on the criteria, relying solely on this information source can result in incomplete evaluations. A good example of this can be seen in Vingilis and Burkell's (1996), critique of the Manitoba Centre for Health and Policy Evaluation's summative assessment of hospital bed closures in Winnipeg. The critique identifies the shortfalls of excluding the "human" input into the evaluation process. Numbers, on their own, can be misleading. The second source of information mentioned by Smith and Glass (1987) are Social Indicators. Social Indicators can be identified through surveys, or, again, looking at existing records. For example, the Canadian Cancer Society uses social indicators and trends to identify how many new cases of breast cancer will be diagnosed in a year and how many women will die from breast cancer. This can



then be used to determine priority funding for treatment. The difference between the existing data sources and social indicators lies not only in the information itself, but in the method of applying the information. The social indicators are used to identify trends, and evaluations and revisions are based on changes in trends. Existing data such as census information, or hospital records may not identify trends, but instead give a "snapshot" of one aspect of a program.

In addition to the "hard" evidence of this objective data, there are other data sources to look at. These data sources are not immediately accessible. Key Informant interviews, surveys, and focus groups are just a few of the methods used to elicit evaluation information from the human sources (Rossi & Freeman, 1993; Smith & Glass, 1987). Rossi and Freeman (1993), describe key informants as experts in the field that is being evaluated. The problems with relying on key informants is that they may not accurately reflect the reality of the situation (Thompson, 1992). Rossi and Freeman (1993), provide an example of this. A statewide key-informant survey showed that health enhancing behaviour was consistently underestimated by key informants, when compared with actual reported rates of health enhancing behaviour. However, key informants can aid in directing the development of an evaluation, as well as provide valuable feedback on programs, and facilitate the community to take ownership of the process.

Agency records are another source of data, yet less reliable than census or medical records (Rossi & Freeman, 1993). The standards in individual agencies do not necessarily have the consistency that is required to use the records for evaluation research. The third data source are surveys. "When it is necessary to get highly accurate information on the

extent and distribution of a problem and there are no existing credible data, the evaluator may need to undertake original research using sample surveys or complete enumerations.” (Rossi & Freeman, 1993, p75). The efficacy of this, is, of course, limited by the questions put forward on the survey, and by how many people respond to the survey.

Other data sources that are similar but differ from key informants are stakeholders (Grusky & Tierney, 1989; Policy Planning & Research Development, 1990; Smith & Glass, 1987). Stakeholders, as the name implies, have a vested interest in the organization being evaluated. Stakeholders may be employees of the organization, board members or people involved with the organization indirectly (Barker, et al., 1994; Rossi & Freeman, 1993). For example, health care professionals may refer clients to a community agency, but these health care providers may not be directly involved in the programming at the Centre. Davis and Reis (1988), incorporated stakeholders into their evaluation on post-partum services. By including stakeholders, the evaluators obtained more of a multi-dimensional picture of the program. One result they found was that stakeholders, who were potential referees to the program, were unaware of it. In this case, revisions could be made to the program that focus on increasing awareness of the program, and thereby increasing utilization and reaching more people in need. The Primary Health Care model recognizes the need to include the community in all aspects of health care planning, from assessment, to implementation to evaluation (WHO, 1979). Stakeholder involvement provides an avenue for this community involvement.

User interviews and opinions are also important sources of data (McDowell, Black & Collishaw, 1988; Policy Planning & Development Branch, 1990; Rossi & Freeman,

1993; Seltiz 1953; Smith & Glass, 1987). The movement toward involving consumers in health care and services provided impacts on the decision to include them in the evaluation (WHO, 1978). These data sources can be elicited through surveys, as mentioned earlier, or less frequently, through focus groups or interviews. The latter two methods are more time consuming and labour intensive, with a smaller sample size, but results in rich and thick qualitative data. Seltiz (1981), relates a situation when an educational program showed no beneficial results, but when parents were asked, they related a great improvement in their children in their enthusiasm and positive attitude toward school. Without the input from the parents, the program may have been dismissed out of hand. With the input from the parents, the evaluators may be able to investigate alternative effects of the program. Seltiz (1981), also points out, that client satisfaction should be an important part of the evaluation. It may also be that some results are untenable to quantitative measurement. The Primary Health Care model recognizes the intangibles as essential for a successful health care model. Health for instance, is difficult to define, and even more difficult to succinctly measure. One can only measure aspects of health, not health in total, and even health is more than the sum of its parts. Therefore, the addition of the "intangibles" through interviews adds to the quality of data, and is a logical step when using the Primary Health Care model to base an evaluation on.

Lastly, a method not mentioned by Rossi & Freeman (1993), or Smith & Glass (1987), is a literature review. The literature becomes important in evaluation when the literature can become a comparison to judge the new information against. The evaluator may need to compare the program against what is reported in the literature due to an

inability to collect pre-program comparison data. The professional judgement in creating this comparison is considered a viable and legitimate means of evaluating data (Rossi & Freeman, 1993).

In summary, data sources are as important to a useful evaluation as the framework being used. Data sources, taken individually, do not provide a well developed picture of the program under scrutiny; they only provides one piece of information. This presents problems, as outlined in Vingilis and Burkell (1996). As well, when evaluating health services, under the Primary Health Care framework, it is crucial that input be sought from the people involved with the program, whether they be staff or users of the program. The next section looks at all the elements of the evaluation process. Multiple data sources and methods were employed in the evaluations in order to gain a three dimensional picture of the programs undergoing evaluation.

#### Evaluations in Practice

The Canadian Cancer Society (CCS), National Cancer Institute of Canada (NCIC) and the Centre for Behavioural Research and Program Evaluation (CBRPE), have worked in tandem to evaluate some of the myriad of programs that are under the auspices of CCS. The evaluations have been specifically tailored to the needs of each program, which were determined by a variety of methods, with process analysis being the starting point (recall that process analysis is part of impact analysis). While relationships to specific types of evaluations will not be expressly identified, it can be noted throughout the principles of the various types of evaluations. As well, although the Primary Health Care model was

not used as the framework for these evaluations, the principles have been woven through, and are seen in the extensive involvement of the users of the services and the surrounding communities. Three evaluations, the *Emotional Support Program/Cansurmount*, program, *Facts On* pamphlets, and *Nutrition Guide for People Living With Cancer*, will be reviewed to highlight the evaluation process.

*Emotional Support Program/Cansurmount* are programs that were developed to provide emotional support to women who have recently undergone breast cancer surgery. An evaluation of this program was conducted in 1998 (Canadian Cancer Society, 1999). The purpose of this evaluation was to determine the appropriateness of the program and the utilization of the program monitoring tool, the data collection protocol, participant feedback and volunteer visitor statistics. People who had used the program were called and asked to answer questions based on the different aspects of the *Emotional Support Program/Cansurmount* program, such as visitor match, how often and how much time the visitor spent with them and first contact. It can be noted that these aspects closely parallel communication and caring issues that research has demonstrated to be important (Larsen & Ferketich, 1993).

The evaluation revealed a number of interesting findings. Overall client satisfaction with the program was high, and clients felt the program was very beneficial. The visitor program was found to be a good source of information, and with the exception of a few respondents, the participants felt they were able to discuss all their concerns. It is interesting that the issues of sexuality, chemotherapy and alternative treatments are parallels to what has been identified as gaps in information in the literature (Bilodeau &

Degner, 1996; Scharf, 1997; Steginga, et al., 1998). The evaluation also supports the previous literature that asserts that emotional support is beneficial in the experience of women with breast cancer (Beder, 1995; Wang, et al, 1999).

In terms of recommendations and program improvements, and the evaluation process, the evaluation was deemed to be successful. The questions covered the listening posts of timing (when the visit occurred), relationship with the visitor and value of the visit in terms of information and support. One shortfall was noted in the satisfaction survey, that there was not ample opportunity for participants to express their views on the support group format of Cansurmount. Another obstacle in the evaluation was that the Cansurmount group was a small sample, and therefore the results do not have much strength to generalize any claims (Schalock & Thornton, 1988). Recommendations that followed from the study are of note in that only one recommendation dealt with clients of the program, the remaining ten recommendations addressed the evaluation process.

The evaluation used a multi-method approach. The critique of the evaluation process focussed on visitor match and timing. It also looked at outcomes of the program, such as had the program been beneficial, what was the effect of the program? These questions fall within the formative evaluation genre. However, as an end product of the evaluation, which was a finite project, the questions that addressed the efficacy of the evaluation could be considered to be part of a summative evaluation. While the Primary Health Care model can be seen in the inclusion of user input, this evaluation does not utilize the framework in looking at intersectoral cooperation, or equity. The results of the this multi-method approach demonstrate the effectiveness of mixing methods to obtain

results that provide actionable data, that is relevant to program development. However, it does not address larger community issues that could be addressed with the Primary Health Care model used as a framework.

The second evaluation to be discussed is the "*Facts On...*" series evaluation (NCIC, 1997). "*Facts On...*" are a series of pamphlets distributed by the CCS that provide information on various cancers. They are meant to be a quick, easy and reliable resource for the general public on site-specific cancer. These pamphlets are an integral part of the volunteer programs, and therefore, an evaluation that would distinguish the information gaps and ascertain the effectiveness of the pamphlets was thought to be essential. "This series ("*Facts On...*"), represents a considerable commitment by the CCS in terms of time, energy and money. Therefore, the CCS undertook an evaluation of the *Facts On* series to ensure that these pamphlets are achieving their intended objectives." (NCIC, 1997, pi).

This evaluation differed from the previous one reviewed in that it was more focussed on the primary task of ensuring the pamphlets were relevant and applicable to the target population. Again, a multi-method approach was used, in an attempt to tap into the diversity of the distributors of the pamphlets and the receivers. A mix of interviews, along with a focus group of people who had/have cancer and their families were conducted in order to obtain a three dimensional evaluation of the *Facts On* series. Each part of the evaluation combined aspects that were pertinent to the participants, ranging from the distribution of the pamphlet to the actual information contained. The preliminary analysis was utilized in the development of the volunteer and recipient surveys.

While the interviews and the divisional survey really looked at process evaluation,

with a mix of cost/benefit, the volunteer and recipient surveys look more at impact and outcome variables. The volunteer survey does incorporate process variables in the survey, as the process is a vital part of promoting the benefits of the *Facts On* series. The questionnaires were designed to elicit information of key “listening” posts. User input was solicited to make changes and improvements to the pamphlets.

The combination brings aspects of the formative and summative evaluation together. The summative being valid as some people may have ended their contact with the CCS with the termination of their treatment for various reasons. This evaluation uses more of the Primary Health Care principles than the previous evaluation. Not only does this evaluation have significant user input, it also addresses equity issues through the investigation into the distribution process, and holistic and acceptable care by revisiting the information in the pamphlets.

The third evaluation being reviewed was conducted by the CBRPE, is the *Evaluation and Revision of the Nutrition Guide for People Living With Cancer* (1995). The objectives of this evaluation were to determine the nutrition needs of people with cancer or long term survivors of cancer, and to revise the Nutrition Guide to reflect these needs. A multi-method approach was used to elicit input from the factions that would be developing and using the Nutrition Guide.

Group interviews were conducted, and analysed using grounded theory. The Nutrition Guide was revised based on the analysis of these interviews. The revised guide was then given over to a group of experts for review. The experts included dietitians, nurses, and physicians who are involved in the care of people with cancer. The reviews



were collated and analysed. The results identified areas for revision, such as technical terms and dietary recommendations for common side effects of treatment, such as diarrhea, constipation and chewing difficulties. The final results clearly demonstrated that there were gaps in the information provided, especially in specialty diets. There was also confirmation that the Nutrition Guide was appreciated and utilized by people with cancer, even if they did want to see changes in the content.

Once again, the participatory nature of the evaluation needs to be underscored. The participation of the people involved in using the services lends validation to the end results (Schalock & Thornton, 1988). The validation is realized through the integration of the user ideas into the final analysis. Additionally, it allows the users to take ownership of the program they are evaluating and reinforces to them that their input is valuable. It is a theme that is repeated throughout the evaluations that have been done through the CBRPE, and is repeated many times. It is also repeated throughout the Primary Health Care model. In addition to user input, this evaluation comes closest to addressing intersectoral cooperation by bringing together people from various disciplines to work together to revise the information.

The participatory approach is also repeated throughout many evaluations, including the three previous evaluations reviewed. The multi method approach was also repeated throughout the evaluations. It is clear that in practice, a single methodology is rarely used, and then only for very specific reasons. A general evaluation calls for a well rounded picture of what is going in the organization. The process, the outcomes and impacts and satisfaction are all important aspects of an evaluation that need to be addressed.

### Summary of Evaluation Literature

There are a number of models that can be used when embarking on an evaluation. Each model has strengths and weaknesses and has been used in practice. However, most evaluations that are conducted actually use a multi-method approach, thereby shoring up weaknesses and utilizing the strength of various models. Community health services have used various models for evaluation, and more often, a mix of models, as health behaviours are a product of multiple influences (VanAssema, et al., 1995). The problem as can be identified, is that there is no model that has been developed for a community health service (CNRC, Advisory Committee, 1995).

In addition to models, there are other aspects of evaluations that are important. These are the data sources. How the data is collected shapes the evaluation as much as the model used. In using the Primary Health Care model, user input is vital in order to reflect the tenets of Primary Health Care, as is the process of developing the evaluation. Sources of data are also valuable in that they provide background information and further evidence of programs outcomes.

In actuality, evaluations often use multi-method approaches. No particular models are used in most evaluations. Although the evaluations still result in valuable information, using a framework allows for more consistent results, that can be replicated and compared in the future. As well, using the Primary Health Care framework for a Community health service allows the introduction and integration of the Primary Health Care model into the fabric of the service. It also aids in securing the perpetuation of the use of the Primary Health Care model in practice.

## **Chapter Three**

### **Methods**

The methods chapter will review the process employed in the course of the practicum to obtain information and develop the information into an evaluation plan. This chapter will describe the setting, project design and recruitment, the various meetings and the methods of analysis.

The purpose of this practicum was to develop evaluation tool(s) and to outline an implementation and analysis plan for the staff at the Breast Cancer Centre of Hope, utilizing the tenets of the Primary Health Care model.

#### Setting

The Breast Cancer Centre of Hope is situated in Winnipeg Manitoba. A description of the Centre is included in the Introductory Chapter and therefore will not be repeated in this section. The Centre is comprised of four full time staff members who deliver the programs, and two part-time administrative staff. Three of the staff are Master's prepared nurses and one is prepared with her Master in Theology.

#### Project Design and Recruitment

This practicum was carried out over the period from June 2001 to April 2002. The practicum included ten meetings with the staff at various points to define the evaluation needs and pursue feedback from the staff on the results of the previous meetings. For one meeting the staff met as a group and the remainder were individual meetings. Permission to interview the staff was granted by the Director prior to initiating the practicum. Permission was also granted by Cancer Care Manitoba to conduct the practicum.

There were two meetings with the Director and two meetings with each of the

three staff members involved in the practicum. There were also two staff meetings, where the staff, as a group were given input into the process and encouraged to come to a consensus on goals and objectives.

Letters were sent to each staff member prior to each meeting and are included in Appendices B and C. The purpose of the letters was twofold. The letters were an invitation to the staff to participate in the process. Secondly the letters provided some guidelines, or questions for the staff member to think about before the interview, in order to allow them to reflect on the key issues before the interviews.

The interviews reflected the use of the Primary Health Care Model by reinforcing with the staff the importance and value of their participation in the evaluation process. The staff were encouraged to provide information and input into the process of developing the evaluation plan through the interviews.

In addition to meetings with the staff, the practicum student attended an event sponsored by the Breast Cancer Centre of Hope, and reviewed several documents. The event was a film, geared toward women living with breast cancer. The documents were a key part in the developing stages of the Centre and provide background information on the foundation of the Centre.

Meetings with the Student's advisor and the Director of the Centre also took place to discuss progress and the planning to move the practicum forward.

### Meetings and Interviews

#### Director

The purpose of the first meeting was to establish some direction for the development of the evaluation plan, including permission to speak with the staff and

identify strategies to gather information. In keeping with the Primary Health Care model and the Bea van Beveran and Hetherington (1997) guidelines, the meeting was set up with the Director of the Breast Cancer Centre of Hope, to ensure buy in from the community (staff of the agency) involved.

This first meeting allowed the student and Director to establish some guidelines to make a plan and provide the Director with a venue for input into the process. This meeting also established that there are many programs within the Breast Cancer Centre of Hope. It was determined that each program would best be described by the staff member who held the main responsibility for that program. These programs are the heart of the agency and are the reason for an evaluation. However, in order to understand the programs, it was necessary to understand the context in which the programs have developed.

The discussion then turned to the philosophy of the Centre, and how that philosophy reflects the philosophy of the Director. In discussing the philosophy of the Director and the agency, the Director was able to provide guidance as to where additional information about the agency and evaluation needs may be discovered. Suggestions were made as to who key stakeholders may be, and how to access these people. Certainly the staff were noted to be key informants, as well as other people who had worked with the agency at its inception. There were some suggestions made as to events and meetings that the student could attend to help develop a working sense of the agency. There were also documents related to the agency that were identified by the Director as being vital to understanding the process that the agency went through in its initial development. This information sharing facilitated an understanding of agency practices and helped to

develop an evaluation plan that best fit the needs of the agency.

This first meeting established that the Director and Cancer Care Manitoba were agreeable and enthusiastic about having an evaluation plan developed for the agency. This agreement was important to initiate the process of developing the evaluation plan as it verifies the principles of the Primary Health Care model (WHO, 1978) and follows the guidelines of the Bea van Beveran and Hetherington (1997) process. The second product of this meeting was to gain permission to access staff for interviews. Again, this is in keeping with the framework and guidelines being used in this evaluation plan. Thirdly, it helped identify strategies to allow the student to become integrated into the agency and to understand the practical operationalization of the agency. In accordance with this, the next steps for the student were to review the documents and attend events organized by the Breast Cancer Centre of Hope.

#### Event and Document Review

The event that was attended was a film "How Can We Love You" sponsored by the Breast Cancer Centre of Hope. The film was a follow-up to an event held the previous year. The presentation this year featured a film and discussion group post film, as well as a "Train the Trainer" workshop the following day, for women who wanted to tour the Centre and conduct the debriefing post film. The purpose of attending this event was to witness and experience one type of service that the Breast Cancer Centre of Hope provided for women with breast cancer. In doing this, the student would gain a better understanding of what types of indicators of service should or could be measured.

In addition to attending this event, two documents were examined in an attempt to further understand the Breast Cancer Centre of Hope as it has developed over the years;

“Comprehensive Breast Cancer Program” (1995) and “Phase II - Collaboration and Partnership: Planning for Manitoba’s Breast Cancer Information and Support Needs”(2001). These two documents provided information on the development of the Centre as well as reports from health care partners (e.g. other agencies, organizations, etc.). These documents allowed further insight into the practices of the agency. This in turn provided insight into the indicators of care that may need to be measured. These documents were used as background information and brought to the staff meeting, that formally introduced the evaluation project to the staff.

#### Staff Meeting #1

The first meeting took place on June 20, 2001 at the Breast Cancer Centre of Hope. Three of the four staff members were present.

The purpose of the meeting was multifold. The meeting served to establish a contact with the staff at the Centre and establish the link with the student. This link would serve to open the door to candid discussion between the student and staff on the evaluation needs of the Centre, including a review of the overall programs, goals and mandates of the Centre. The first meeting also initiated the use of the Primary Health Care model in inviting the active participation of the staff in the process of developing the evaluation plan. A letter was sent to the staff before the meeting to allow the staff time to germinate their ideas about the purpose of the Centre and the goals.

The staff were apprised of the student’s agenda, that is, to develop an evaluation plan that includes a tool, or tools, and a method to implement the evaluation. The Bea van Beveran and Hetherington (1997) guidelines were described to the staff to ensure that the staff would feel a part of the process and thereby start to take ownership of the process.

The student (a facilitator in these interviews) had to ensure that the meeting stayed within the context of the process of the evaluation plan.

The first component discussed was the mission statement, philosophy and goals of the Breast Cancer Centre of Hope. The Director brought with her a two page document (Appendix A), that delineated the mission statement of the Centre and the goals. After receiving the document, the student opened up the floor for discussion on the goals and whether or not there was consensus on the stated goals. As all staff members but one had been involved in developing and articulating the goals, staff consensus was quickly reached. The one goal that had not been overtly stated within the goals of the document was the goal of empowerment. Although it was agreed amongst the staff that empowerment should be added to the list of goals, consensus could not be reached as to what empowerment meant to the staff. However, the staff did agree that empowerment meant promoting autonomy through the provision of information and support, and that this was interwoven into the stated goals (Field Notes, June 20, 2001).

The meeting then progressed to discussions around what the staff felt the evaluation might look like. To bring some order into this discussion, the group decided that the evaluation may best be planned around the goals. It was felt that indicators could more clearly be developed if the vital aspects of the goals were identified. While this did not happen as a linear process in this meeting, it did lay the groundwork for discussion of the programs and assigning which goals belonged to each program. This was imperative in understanding the indicators within their programs, which is discussed later in this chapter.

At this point it was evident that the staff were enthusiastic and were willing to



sacrifice their time to be a part of the evaluation process. The staff proposed various ideas about what they would like to see in an evaluation, and their enthusiasm was evident. It was important that the student be able to focus their enthusiasm into a channel which could produce viable expectations. The staff, although adamant in their wish for this broad scope of exploration, were happy to confine the scope of the evaluation to how the programs at the Centre have impacted the clientele.

Once the issue of the scope of the evaluation was addressed and agreed upon, the group then moved on to how the evaluation plan could be organized. The staff decided that the programs really fell under three umbrellas, (1) volunteer programs, (2) community capacity building programs and (3) patient services/support programs. The staff wanted to be able to determine if they were meeting their self-identified goals, and if there were any gaps in their delivery of services. It was quickly realized that the list of goals was extensive (ten), and therefore, it would be helpful to prioritize the goals, to know which goals were most important to be measured.

As it happened, the goals were not prioritized as much as they were assigned to each program. Later, goals were linked with the indicators of quality service that were explored in the interviews with the staff involved in the separate programs.

The last part of the discussion addressed any concerns the staff may have had about how the evaluation may impact them. The staff acknowledged that the evaluation would take their time, but they were committed to the process. The staff saw far more benefits arising from the proposed evaluation than the cost in terms of their time and effort. Furthermore, the staff felt that the cost in terms of their time would, in the end, validate their work through empirical evidence that would be generated by an evaluation.

There was acknowledgement that the staff did feel some degree of trepidation, but overall they were confident that the evaluation would generally result in positive feedback. The evaluation planning stage also provided staff with the incentive to identify and delineate their own work, providing them with an opportunity to reflect on their work and program.

#### Individual Interviews with Staff

The interviews with individual staff members were used to gain more specific knowledge about the programs. This knowledge could then be used to tease out some indicators of quality service, that is, measurable aspects of the program. The indicators were chosen by the staff members. This served two purposes; (1) to have the staff take ownership of the evaluation process, and (2) to derive indicators that are reflective of the program. Both of these purposes fold into the Primary Health Care model (WHO, 1978) and the guidelines of Bea van Beveran and Hetherington (1997). The staff members were very cooperative and enthusiastic, and this positively reinforced their participation in the process. The three staff members in charge of the programs were interviewed twice. Each interview had guidelines to elicit specific information, however, each staff member was encouraged to lead the interview in whatever manner they felt comfortable. Then individual interviews were conducted at various points in the timeline and for the purpose of this chapter, will be grouped together to protect the individual identities of each staff member. Additionally, the process for each interview was the same, and therefore, the steps used in each interview were the same.

The purpose of the first individual interviews with the staff was to establish a rapport with each person and open the dialogue between the student and staff. The staff were sent a letter of invitation to participate in an interview at a time convenient for them

(Appendix B). The letter explained the purpose of the interview and provided the staff with an idea of what would be discussed in the interview.

The interviews started with the staff members defining their goals for the evaluation plan. The goals identified by the staff were: (1) more empirical evidence of the benefits of the services provided by the Centre and, (2) that the evaluation could be a forum for the continued development of the “different” services that the Centre offers (different in terms of non-medical focus).

The individual interviews were an opportunity to reiterate the goals as discussed in the staff meeting earlier and discuss the specific details of each program. The first interview explored how the goals meshed with the program, and how the program met these goals (through what actions were these goals realized) and the identified indicators of quality programming. Each program, Volunteer, Patient Services and Community Capacity Building contained sub-programs. Each sub-program was examined individually, and the actions and indicators of quality service were identified. The actions were defined as tasks that were an integral part of the delivery of the service, such as telephone contact in the Patient Services program. The indicators were specific responses that would be able to indicate that the program is providing a quality service to the clientele.

At the conclusion of the interviews, the staff re-iterated their hopes that the evaluation would provide evidence for the biomedical community that the services at the Breast Cancer Centre of Hope do improve the health of the women who access the Centre. The “evaluation should strengthen the value of the “person”, as a subject, not an object.” (Field Notes, July 6, 2001, p18).

Summaries of each meeting were sent to the respective staff members. Then a second meeting was requested with the staff (Appendix C). The second meetings were used as follow ups to obtain feedback on the first meeting, correct errors or misconceptions and provide an update on the evaluation process. Summaries of the previous meetings were provided for the staff a week prior to the second meeting in order to allow them time to review the document.

The staff were asked if they felt that the summaries sent to them were accurate. Minor changes were made in accordance with staff response. Then the discussion progressed to the sub-programs. In the second interviews, the programs were not divided into actions to realize goals and indicators of quality programming. Instead, each sub-program was discussed by looking at the crucial elements of each sub-program. The meanings behind each element were fleshed out and discussed to ensure understanding by both parties. After discussing the crucial elements of each sub-program, the overall programs were discussed with a view toward identifying the crucial elements of the three main programs, Volunteer, Patient Services and Community Liaison. These elements were the overriding concepts that guided the actions in the programs.

#### Interview #2 Director

The second interview with the Director of the Breast Cancer Centre of Hope took place following the meetings with the individual staff. The purpose of the meeting was to review and discuss the findings from the summaries of the previous interviews with staff members. The Director had been sent copies of all the summaries two weeks prior to the meeting, in order to allow her time to read and absorb the information in the summaries.

The interview started off with the Director and student discussing the progress of

the practicum, and the benefits of the second interviews with the staff members. The benefits of the interviews were both to the student and to the staff. The student was able to clarify and review the concepts gleaned from the previous interview, such as the concept of value and appropriateness. The second interview also provided a venue to reconnect with the staff and re-establish a working relationship between the student and the staff.

The benefits for staff were also discussed as was a review of the differences between the programs in terms of focus. The Patient Services program by necessity focuses on the individual, and providing service to the individual. The Volunteer Program, although providing individual service, has expanded enormously in terms of focus. Where the Volunteer Program initially focussed on the volunteer needs of individuals, the program now includes a broader focus of aggregate needs.

The interview with the Director also addressed some of the concepts from the Primary Health Care model. Concepts that had emerged from the summaries were discussed and explored. Clarifications were made by the student and support for the project was reiterated by the Director. And finally, the interview dealt with issues around the macro (community based) and micro (individual client based) approaches that are used to meet the mandate of the Centre.

#### Method of Analysis

The methods employed to analyse the information were varied. Notes were taken during the staff meeting and individual meetings. Notes were taken on the film attended and the documents reviewed. The methods included reviewing the notes of the meetings, transcribing the notes and organizing the responses in categories, according to the direction of the interviews.

The first meeting with the Director was recorded in the field and analysed for themes that applied to the Primary Health Care model. As some of the information was direction for the student, this information was not examined for themes, but instead was used as a guideline for further development of the evaluation plan.

The information garnered from the event attended and the documents was used as background information for the development of the framework of the evaluation. The evolution of the Breast Cancer Centre of Hope can be seen, in part, through the documents reviewed. This is important as the framework should be reflective of the agency goals and objectives.

The interviews were analysed in two stages. The first round of interviews were divided into three sections. The first section identified goals, the same goals that were identified in the staff meeting. The general programs were then broken down into subprograms. In each subprogram, actions to realize goals were identified. These actions were the practical application of the goals. The actions were then linked with indicators of quality care. The indicators of quality care were meant to be measurable variables that could be folded into the evaluation plan. The measurable variables were important to establish from the outset as these variables would lay the foundation for the evaluation tools (Cleary, et al., 1994).

The information from the first individual interviews was combined with the staff meeting information to produce a summary that was reflective of both meetings, without duplicating the summaries. As the first staff meeting really laid the foundation for the individual interviews, it was not fruitful to separate the staff meeting results from the individual meetings. Combined, both the individual and the staff meeting created a more

rounded picture of the evaluation needs of the Breast Cancer Centre of Hope.

The second interviews were summarized, following the purpose of the interviews. The clarifications were outlined, and updates were made. Then the identification and explanation of the two (sometimes, three), crucial elements were explored. These summaries were sent back to the staff members to allow them the opportunity to make any changes or revisions that they felt were necessary.

To analyse the first and second interviews, the actions to realize goals were matched with tenets of the Primary Health Care model and the crucial elements from the second interviews were also matched with tenets of the Primary Health Care model. The identification of the tenets as they were compared with each program and subprogram served to identify the framework upon which to build the evaluation design and tool. Knowing that certain tenets were key in a program guided the development of the tool to ensure that these key concepts would be included.

### Conclusion

This chapter addressed the methods used in the practicum. The purpose of the interviews, meetings and documents were described and the analysis of information derived from the meetings and interviews was described. Multiple interviews were employed in order to provide feedback for the staff and to maintain a dialogue between the student and the staff.

## **Chapter Four**

### **Findings**

This chapter addresses the findings of the practicum. As stated in chapter one, the objectives of this practicum were to work with the staff at the Breast Cancer Centre of Hope to: (1) develop evaluation tool(s) that incorporate the Primary Health Care model as a framework (2) outline a guideline for implementation consideration and (3) assist in developing an analysis plan for the evaluation. This will allow the staff of the Centre to conduct the evaluation with confidence that the results will accurately reflect the services provided at the Centre.

The findings chapter will present the information in the sequence of occurrence of the events, meetings and interviews. The concepts that emerged through the interviews have been linked to the Primary Health Care tenets to allow the reader to follow the process of merging the Primary Health Care framework with the development of the evaluation process.

The various meetings, events and documents elicited much information in terms of identifying the services and priorities of the Centre. Although the vernacular of the staff did not directly mimic the language of the Primary Health Care model, the findings did reflect the tenets of the Primary Health Care model.

#### **Preliminary Stages**

The first meeting with the Director, the community event, a premiere of the film "How Can You Love Me?" and the document "The Comprehensive Breast Program", laid the basis for the staff meetings and the individual interviews. Background knowledge on the Centre was essential in order to guide the meetings and interviews, as well as



laying the foundation for the tenor of the evaluation tools. The findings from the first meeting and the review of the documents were organized in relation to the principles of the Primary Health Care model (see Tables 1 & 2).

**Table 1:** First Meeting With Director

<b>Meeting with Director and "How Can You Love Me?" Event</b>	
<b>Tenet/Principle</b>	<b>Finding</b>
Holistic Care	<ul style="list-style-type: none"> <li>- Multiple pieces in each program</li> <li>- Various programs and events were mentioned as examples of how the Centre provides diverse services</li> <li>- Spontaneous support given to man in audience at film in response to his statement that cancer had beaten him</li> </ul>
Acceptable Care	<ul style="list-style-type: none"> <li>- Addressing gaps in services, such as awareness of the program</li> <li>- Train the Trainer workshop for the film "How Can You Love Me?"</li> <li>- Services being expanded to include support of the spouses and partners of women with breast cancer</li> </ul>
Empowerment	<ul style="list-style-type: none"> <li>- Programs are built on vision of shared power and collaboration</li> <li>- Only health care professionals at film were staff from the Centre and student, indicating a large degree of community ownership of the event</li> <li>- Audience surrounded a man in need of support, took his care into their own hands as opposed to letting staff provide support</li> </ul>
Equity	<ul style="list-style-type: none"> <li>- Provide funds for women outside of Winnipeg to attend events thereby breaking down geographical barriers</li> <li>- Open invitation to breast cancer survivors, family, friends and community at large to view the film "How Can You Love Me?"</li> </ul>
Intersectoral Development	<ul style="list-style-type: none"> <li>- Community Capacity Building approach is used in programs</li> <li>- Building Networks of agencies and people within the city, province and country</li> <li>- The various connections to programs demonstrate the foundations of the Intersectoral development</li> </ul>

**Table 2: Document Review**

<b>Document "Comprehensive Breast Cancer Program"</b>	
Holistic Care	<ul style="list-style-type: none"> <li>- Inventory of services to see what is out there and to identify where services are lacking</li> <li>- Development of programs and guidelines set up to provide screening services programs for breast cancer across the spectrum</li> <li>- Variety of services and programs to be developed, that run from information services to support services</li> </ul>
Acceptable Care	<ul style="list-style-type: none"> <li>- Purpose of advisory council was to develop a comprehensive breast cancer program across Manitoba</li> <li>- Model based on comprehensive care throughout the breast cancer spectrum and development of programs and guidelines set up to provide screening services programs for breast cancer across the spectrum</li> <li>- Identify gaps in care</li> <li>- Development of evaluation to see if expected outcomes have occurred</li> </ul>
Empowerment	<ul style="list-style-type: none"> <li>- Establishment of Breast Cancer Advisory Council to address needs of women with breast cancer</li> <li>- Women had expressed a desire to have a resource centre away from physician offices, a place that could be owned by them</li> </ul>
Equity	<ul style="list-style-type: none"> <li>- Start of toll free number at Canadian Cancer Society, where women can get information on breast cancer</li> <li>- Recommend expansion of outreach program with Cancer Care Manitoba</li> </ul>
Intersectoral Development	<ul style="list-style-type: none"> <li>- Build on existing resources, build links and bridge gaps in the breast cancer community</li> <li>- Expansion of contacts and networks to have input into the development of services for the breast cancer community</li> </ul>

### Staff Meeting

After this preliminary work was completed, the next step was to introduce the project to the staff, through a staff meeting. The results of the meeting provided support

for the development of the evaluation using the Primary Health Care model as the framework. The tenets of the Primary Health Care model reverberated throughout the meeting in terms of infrastructure and the delivery of programs as shown in Table 3.

**Table 3: Staff Meeting**

<b>Staff Meeting June 20, 2002</b>	
Holistic Care	<ul style="list-style-type: none"> <li>- The Centre provides information and support to people along the continuum of care from screening to diagnosis, treatment, end of life care and health promotion</li> <li>- Wanted evaluation to measure whether the goals of the Centre have been met, reflecting truly holistic care</li> </ul>
Acceptable Care	<ul style="list-style-type: none"> <li>- Centre provides information along the continuum of care</li> <li>- Client satisfaction is important in the evaluation</li> <li>- Staff want to look for any gaps in services they are providing</li> </ul>
Empowerment	<ul style="list-style-type: none"> <li>- Gained consensus on mandate and goals of the organization. Goals were delineated by staff and owned by staff</li> <li>- Empowerment not overtly stated in goals, but is embedded within the goals, philosophy and paradigm of the Centre</li> <li>- Some staff equated empowerment with the promotion of individual autonomy, some felt that empowerment was advocating for the patient</li> <li>- The staff did agree that they promoted autonomy and empowerment through provision of services and information that were directed by the people using the Centre</li> <li>- Staff demonstrated enthusiasm for project, taking ownership</li> <li>- Staff pushed for inclusion of evaluation of community links</li> </ul>
Equity	<ul style="list-style-type: none"> <li>- Equitable access very important, have toll free telephone numbers for province, community contacts and regional programs</li> </ul>
Intersectoral Development	<ul style="list-style-type: none"> <li>- The services at the Centre impact on people, agencies and organizations outside of the Centre</li> <li>- Staff pushed for inclusion of evaluation of community links</li> </ul>

The last part of the staff meeting was reserved for feedback from the staff on their

feelings about the evaluation. Often, staff will feel threatened or intimidated by an evaluation as it may be seen as a reflection of their performance as well as the program (Bea van Beveran & Hetherington, 1997). Exploration of those feelings before the evaluation occurs may lay some of the initial anxieties to rest (Bea van Beveran & Hetherington, 1997). The staff did have some trepidation going into the evaluation as it would leave them vulnerable to criticism. However, they overwhelmingly felt that the benefits would outweigh any of the risks they faced. The staff were looking forward to having their program “empirically” validated through research. Although the staff know that their services and efforts were making a difference in women’s lives, their evidence is anecdotal. The staff also hoped that the results could be used for applying for funding as the evaluation would again, provide empirical evidence of the benefits of the Centre. The ability to use the information from the evaluation to raise public awareness about the role of the Centre was also appealing to the staff. Lastly, the staff were appreciative of the opportunity to sit down and share ideas, reflect on their programs, and articulate what they do for the public and the work they do within the agency, with each other.

#### Individual Staff Interviews

The staff interviews were more focused than the previous meeting with the Director and the staff meeting. These interviews provided the core information required to develop evaluation tools. The interviews took place in two stages, with the first set of meetings providing indicators of quality care for each subprogram within the umbrella programs of Volunteer Services, Patient Services and Community Capacity Building Program. The indicators can be used as the “sign posts” of measuring the programming. For example, the Volunteer Program has a number of indicators of quality care, such as

volunteer satisfaction, client satisfaction and impact. These sign posts, or indicators are the basis upon which the evaluation questions can be developed. The indicators are shown in detail for the all the subprograms in Appendix D.

The second set of interviews with the staff, followed up on the information derived from the first interviews. The content of the first interviews were validated and then further refined to identify two or three crucial elements of quality care in each subprogram. The crucial elements were used as the two or three basic concepts that would best describe the essence of the programs and subprograms. For example, In the Support Services program, client satisfaction and appropriateness are two crucial elements in the subprogram of Patient Services. This means that ensuring client satisfaction is key to making sure the program is meeting the objectives of the Centre and the goals of the program.

The similarities between the first and second interviews were compared to the tenets of the Primary Health Care model. The common tenets between the indicators of quality care and the crucial elements were identified for each subprogram. The results of this analysis are shown in Appendix E. These tenets, along with the indicators of quality care and the crucial elements then become the basis from which the evaluation tools should be developed.

The details of the information about the programs were discussed. This information provided the basis for the understanding of the evolution of the process of developing the evaluation.

#### Volunteer Program

The Volunteer Coordinator had articulated the actions that were required to carry

out the program. The actions, such as general volunteer work, peer support work or producing a newsletter, became known as the subprograms (Appendix D). Each subprogram had defined indicators of care, that is, specific areas or issues that reflect the program. The indicators in the general Volunteer Program reflected the need to look at volunteer satisfaction, purpose and impact.

Inherent within the scope of satisfaction, purpose and impact were the linkages to the Primary Health Care model. The tenets of the Primary Health Care model were seen in the first interviews with the staff and carried over into the second interviews, where the crucial or key elements of each subprogram were identified. In addition to this, the crucial elements for the entire program were also identified. These elements were the overriding concepts that guided the actions in the programs. It was interesting to note that the key elements in the subprograms were seen to be embedded within the crucial elements of the umbrella program.

#### Patient Services Program

The Patient Services Program consisted of two subprograms, (1) Support Services and (2) Patient Services. This distinction was made between the support services and patient services as the Nurse Educator felt her program had two distinct processes. The support services include the one on one counselling with women with breast cancer, telephone contact and peer support. Patient services was seen to include information provision, prosthesis bank and the general environment.

The support services are provided through a variety of methods. While use of the Internet may be becoming more popular (Scharfe, 1997), this Centre still sees most of their clients in person, or contacts clients by telephone. This is a large part of what the

Nurse Educator does and is therefore a focus of what she would like evaluated. The indicators for the Patient Services Program are actionable indicators, meaning the staff have the ability to make changes to their program based on the results of the evaluation.

The difference between support service and patient services is fine at best. This distinction was discussed in relation to the fact that although they are different in focus, they are often delivered together as complementing each other. For example, a woman coming in for counselling, may go home with information books, thereby combining the support and patient services. Yet patient services is still different in that it provides more practical support. As well, there is a prosthesis bank that the staff would like to know if, (1) it is being used and (2) if the devices are of good quality. Since many rural women access the services through mail, or telephone, the service extends to well outside of the city limits. The evaluation should reflect the rural/urban mix as well.

In determining the crucial elements of the program, the crux often came down to whether the service was appropriate. The appropriateness of the service was contextual within each program or subprogram. "Appropriate" included whether the service offered the right information, at the right time, whether there was too much or too little information, and whether there was too much or too little follow-up. Also embedded within the term appropriate was the concept of client satisfaction. If the client did not receive the appropriate care, would they be satisfied with care received?

Additionally, it was clear that consistency and accessibility were important to this program. The information received by the client should be consistent with what they receive from their physician, oncologist and other people working with the woman with breast cancer. If the information is not consistent, then this may give way to anger,

frustration and confusion on the part of the recipient. The information and services should also be accessible. Although there are telephone contacts, situations such as fitting the prosthesis cannot be done over the telephone. Since a system has been implemented to address this issue, it is important to know if this system works.

#### Community Capacity Building Program

This program accesses resources and people outside of the Breast Cancer Centre of Hope's staff team. The programs may access other care professionals in the community and institutions, as well as lay people in the community. The goals of the Community Capacity Building program are varied, but revolve around developing, establishing and maintaining links amongst members of the breast cancer community. The discussion of this program required more background information and explanation of the program as it was a fairly new program within the Centre and was still in the developmental stages. It became evident that the dynamic process of this, and all the programs, needed to be incorporated into the evaluation tool(s).

A series of events led to the creation of the Community Capacity Building program. There was a federal initiative to develop a breast cancer network that would help to link all breast cancer services for women. The Breast Cancer Network was developed as a result of funding from Health Canada. The network consists of a Representative from each Regional Health Authority (RHA) that has volunteered to represent their region. The Community Capacity Building approach is embodied in the volunteers' ability to make autonomous decisions based on their community's needs. The Network has been developed in phases, with the third phase now in operation. A table reviewing the stages this development can be seen in Table 4. The table demonstrates how the process evolved



from being directed by the government to having ownership of the process and the network by the users with development of strategies to sustain the network. The stages are described below in Table 4.

**Table 4: Breast Cancer Network**

<b>Preamble on the History of the Breast Cancer Network</b>
<p><b>Phase 1:</b> The funding was specifically targeted to allow people from across Manitoba to come together in one location to meet and discuss issues around disseminating information and support on breast cancer to women in Manitoba. The Breast Cancer Centre of Hope was the administrative arm of the network. The funds were funnelled through the Breast Cancer Centre of Hope, to allow a central distribution of funds, at a community level (instead of a government level). Therefore, Hope becomes the centre of a network that encourages sharing of ideas and stories amongst each other.</p>
<p><b>Phase 2:</b> Funding available to enhance information and support services in these networks. This funding may have been used to transport the network contact to a workshop in Winnipeg, to purchase needed supplies, or bring in speakers. The Breast Cancer Centre of Hope was the centre for the distribution of these funds. While the Centre did not dictate what the networks could buy, the Centre did require that the networks provide rational for their use of the funds. This ensured accountability of funds at the community (grassroots) level and the administrative level.</p>
<p><b>Phase 3:</b> Phases 1&amp;2 allowed for the development and expansion of the networks, while phase 3 aims for sustainability of the networks. Now that the infrastructure is in place, with Hope the "administrative" Centre, the staff at Hope are now looking at strategies to help sustain this network. Strategies that are being employed to sustain this network need to be evaluated.</p>

The programs and indicators of care in the Community Capacity Building program really revolved around aggregate needs and services as opposed to individuals. The benefits of the programs are important to identify as this will allow this program to continue to build on the present activities and change those that do not fulfill the needs of the target population. The indicators focused on the ability of the program to provide the right support and right information, regardless of which part of the program was involved.

The subprogram of Community Partners brought the discussion into a different realm. This subprogram is crucial, yet difficult to evaluate as the Indicators of Quality Programming are difficult to track. For example, one of the actions to maintain this program is dialogue between the Community Partners and the staff at the Breast Cancer

Centre of Hope. Although this program is under the direction of one staff member, the contact with staff is not necessarily restricted to this one staff member. As well, the real concept behind this action is the nature of the partnership that is developed as opposed to the actual dialogue.

The Shared Initiatives was the second action that was a part of this Community Partners. The Shared Initiatives are really the outcomes of the dialogues with the Staff at the Centre. If the partnerships are realized, then the ultimate desired result would be a shared initiative, between the Centre and the community partner. The example presented was a poster that was developed between the Community Cancer Network Program and the Breast Cancer Centre of Hope. The staff member would like to be able to determine if the dissemination of this poster would cause a higher awareness of the Breast Cancer Centre of Hope. While this may be captured through indirect measures, it was agreed that measuring the direct impact would not be feasible. Therefore, the crucial elements of the Shared Initiative were the outcomes and shared expertise.

#### Summary of the Staff Interviews

Once this process of interviews and analysis was completed, the information was once again compressed down, this time to the key elements identified for each umbrella program, the Volunteer Program, Patient Services Program and the Community Capacity Building Program. The overall key elements of each umbrella program were identified by the staff members. Then, the key elements for the overall programs were compared to the crucial elements of the subprograms to check for congruency. The result of this analysis is shown in Table Five and provides the reader with an easy reference to the crucial and key elements within the context of each program. The language that was often used in

describing the elements was, itself, reflective of the Primary Health Care model and is embedded within the elements themselves.

**Table 5: Key Elements of Umbrella Programs**

<b>KEY ELEMENTS OF UMBRELLA PROGRAMS</b>		
<b>Program</b>	<b>Key Elements Overall</b>	<b>Key Elements of Subprogram</b>
Volunteer Program	Empowerment, Supportive Care	Community , Productivity, Empowerment, Relevance, Equity, Community Activism
Patient Service Program	Appropriateness, Accessibility	Client Satisfaction, Appropriateness, Helpful, Appropriate Follow-up, Accessibility, Group Peer Support, Consistency in Information
Community Capacity Building Program	Value, Appropriateness, Partnerships	Appropriateness, Value, Accessibility, Value of Partnerships, Existence of partnerships... beginning stages of intersectoral development, Outcomes, Shared experiences.

The final sections in this chapter look at the information garnered from the final interviews with the Director of the Centre. The final interviews helped to coalesce information and add to the final development of the questionnaires.

#### Interview # 2 with Director

The second meeting with the Director of the Breast Cancer Centre of Hope helped to bring the information together and ensured that the information imparted to the student reflected the overall mission of the Centre. The benefits for staff were discussed, as well as clarification on some points from the previous interviews.

The interview with the Director also reviewed the differences between the programs in terms of focus. The Patient Services program by necessity, focuses on the individual, and providing service to the individual. The Volunteer Program, although providing individual service, has expanded enormously in terms of focus. Where the Volunteer Program initially focussed on the volunteer needs of individuals, the program now includes a broader focus of aggregate needs. The Survivors Conference is one example of how the program has expanded to include the needs of the aggregate as opposed to the individual. Through feedback last year, the organizers of the last Survivors Conference discovered that women would like an opportunity to involve their spouses. In response to this, there will be a parallel conference for spouses this year.

The interview with the Director also addressed some of the concepts from the Primary Health Care model. These concepts were discussed in context of the program(s). Access was discussed in terms of what programs can be expanded outside the city limits. While the majority of clients in the Centre do come from Winnipeg, there are still a large number of women with breast cancer that could benefit from the programs at the Breast Cancer Centre of Hope. The Centre is trying to take the play "How Can You Love Me?" into the rural areas to address this access issue. This plan brings the message and mandate of the Breast Cancer Centre of Hope to the people who are may be unable to make the trip into Winnipeg.

Appropriateness was discussed in more detail. The Director did add some clarification to the term. The term "Appropriateness" needs to be examined across the breast cancer experience spectrum. Therefore, it becomes more of a challenge to ensure that the service is appropriate for the person at that time in their life. This is especially

challenging in a situation such as the conference, where survivors at all stages of their experiences will be attending. Some women will be at a stage where they will be more interested in quality of life issues, while others may be more concerned about treatment options.

Finally, the interview dealt with issues around the macro and micro approaches that are used to meet the mandate of the Centre. At the beginning of the interview the student and Director spoke about the differences in the programs. One of the really outstanding differences was the difference in focus of the programs. The Community Capacity Building Program has a role that gives less direct contact with breast cancer survivors than the Patient Services Program or the Volunteer Program. The Community Capacity Building Program is a more macro view in of the Centre and that program is focussed on building relationships in the community, with the community as opposed to developing relationships with individuals.

#### Interview #3 With Director

The third interview with the Director occurred after the staff had an opportunity to review the summary elements and the evaluation map (see Chapter 5). They were in agreement with the findings with the exception of the omission of the tenet of empowerment in the Patient Services Program and the Community Capacity Program. Upon further discussion, it was decided that further clarification of the tenets and how they relate to the measurement indicators would help to explain why empowerment may not be included. However, in practical terms, empowerment is very much a part of both programs, and the omission of empowerment in the findings, does not exclude the inclusion of the tenet in a macro view.

## Conclusion

The findings chapter reviews the information that was generated from the various means of data collection. The meetings, interviews, events and documents all provided insight into the evaluation needs of the Breast Cancer Centre of Hope. The findings were presented in table format to better display the results and enable the reader to follow the progression of the practicum work and the use of the Primary Health Care framework as a guiding process.

In the next chapter, the results of the interviews have been further refined to develop a conceptual model, or conceptual map, which helps to illustrate the connection between the tenets, indicators and the programs. As well, the tenets and indicators have been linked to dimensions of quality as outlined in the (Achieving Improved Measurement) Program, which is the program used nationally for accreditation of community programs (Canadian Council on Health Services, 2002).

## **Chapter Five**

### **Evaluation Map**

In the process of developing and analyzing the plethora of information derived from the various sources, an evaluation map was developed to assist in visualizing the connections between the tenets of the Primary Health Care model, the umbrella programs and the evaluation elements. The evaluation map for this practicum is described in the following pages, and illustrates the linkages between the Primary Health care model and the findings from the interviews. The evaluation map is outlined in Figure 1.

In addition to using the Primary Health Care framework, the evaluation map also draws on many elements found in the Canadian Council on Health Services Accreditation (CCHSA) (2002) AIM (Achieving Improved Measurement) program. The purpose of the AIM program is to provide a framework for community health agencies in their pursuit of measuring concepts for quality improvement. AIM incorporates the Primary Health Care model (personal communication, Jeannette Edwards, November 14, 2002), and population health framework (CCHSA, 2002) into a framework that defines quality dimensions and identifies descriptors, or indicators of those dimensions. For these reasons, the description of the map has also included links to the AIM program.

#### The Development of the Evaluation Map

The goals of the Breast Cancer Centre of Hope are numerous and reflect the holistic approach taken by the agency (Appendix A). However, for the purpose of identifying the evaluation needs of the Centre, the goals have been synthesized from the mandate to reflect the general philosophy of the Centre. The synthesized goal is, "...to

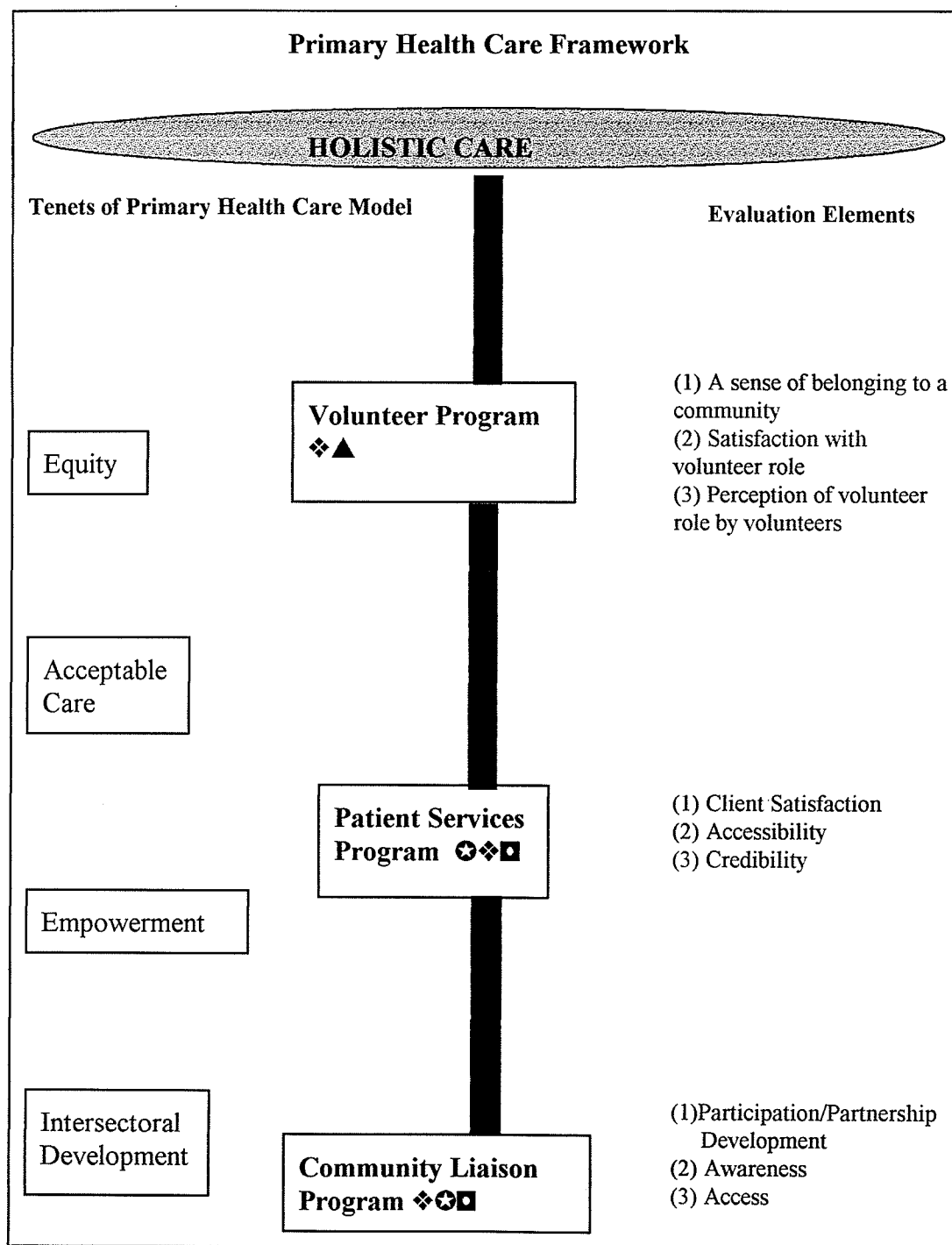
provide accessible, affordable, appropriate, holistic care to women with breast cancer and their families throughout the province of Manitoba.” Within this goal, there are four sub-goals: 1) to ensure community/client participation in the planning and delivery of services, 2) to ensure access to breast cancer services which are provided by the Centre to women in Manitoba, 3) to promote intersectoral collaboration throughout the province to address the needs of women with breast cancer and their families throughout Manitoba, and 4) to facilitate empowerment of women with breast cancer to participate to their desired level in their breast cancer experience. It is evident from these goals that the Centre practices under the framework of the Primary Health Care model. This model is incorporated into the development and delivery of the service programs.

#### AIM Program

There are four quality dimensions addressed in the AIM program that have been identified by CCHSA (2002). The first dimension is responsiveness. The descriptors for responsiveness include availability, accessibility, timeliness, continuity and equity of the service program. The second dimension is system competency. Appropriateness, competence of the staff, effectiveness of staff and programs, safety, legitimacy, efficiency and system alignment are the descriptors that match with this dimension. Client and community focus is the third dimension. The descriptors with this dimension are communication, confidentiality, participation and partnership, respect and caring, and, organizational responsibility and involvement in the community. Finally the fourth dimension refers to work life. The descriptors in this dimension are open communication, role clarity, participation in decision making, learning environment and well being. All



four of these dimensions and their descriptors are reflected in the evaluation map (Figure 1).



**Figure 1: Evaluation Map**

■ = Responsiveness  
♦ = Client/Community Focus

⊕ = System Competency  
▲ = Worklife

Accessibility falls within the dimension of responsiveness and credibility reflecting the system competency dimension in the Community Liaison program. The evaluation map is based on the client's perception of the program. Parts of the AIM program would seem to address factors outside of the client perception. However, upon closer inspection, the dimensions are adaptable to being measured through the client's perception.

The evaluation map has been developed in an attempt to provide a pictorial guide for the process of taking the interview information and developing the measurement areas for quality service. These measurement areas are further condensed to provide more specific indicators for identifying quality service. The indicators reflect the overall goal and sub-goals of the Breast Cancer Centre of Hope. The AIM dimensions and descriptors are superimposed over the specific elements to illustrate the congruity of this program with the evaluation map developed. The benefit of this of this process is the development of a framework to prepare for future accreditation.

### Critical Elements

The Critical Elements of each sub-program are seen in the summary of results looking at linkages (Appendix E). The key elements of the programs (Appendix D, under "Quality Indicators) were drawn out from the information shared in the interviews. The evaluation map outlines how these critical elements reflect the tenets of the Primary Health Care model and which tenets are key in each program at the Centre. The tenets are then defined and further elaborated on by the concepts (outlined in Table 6) that have emerged as the most important indicators of quality service. It is recognized that not every program will meet every tenet of the Primary Health Care model. However, not all clients

will require all aspects of care that the Primary Health Care model and the Breast Cancer Centre of Hope has to offer.

To illustrate the connection between the elements on the map, the programs have been separated into the Volunteer, Patient Care Services and Community Capacity Building Program. The specific elements, or concepts that define the success, or failure of the program have been extrapolated from the interviews. These concepts are indicators of quality service. The concepts are linked to the dimensions of the AIM program via symbols, representing each dimension. The legend for each dimension is shown in Table 6 and Figure 1. Each of the concepts is followed by more specific areas that could be measured, or the indicators of quality that provide more insight into the type of evaluation method that may be employed. It is essential that these concepts are evaluated as they may indicate success or failure of the program, and they reflect the goals of the organization. Table 6 provides an easy reference to which concepts are related to each program.

In the Volunteer program, the main concepts include the perception of volunteers of their role, a sense that the volunteers belong to the “group”, i.e., the group of volunteers, and the satisfaction with the volunteer role. The majority of the Volunteer program looks at the dimension of the client and community focus in the AIM program, with the focus on respect and caring and participation and partnership of the volunteers. The Volunteer program also addresses role clarity (in the worklife dimension). The more specific indicators are shown in Appendix E. The main concepts in the Patient Services program are client satisfaction with the various services, accessibility of staff, and the resources and credibility of staff and services offered. The concepts that have been

highlighted through the interviews are participation of the volunteers, awareness by the community and community organizations of the program and access to the program. The various elements in the Patient Care program reflect three dimensions of the AIM program. Client satisfaction reflects the client and community focus, and system competency. The concepts under scrutiny are participation of partners in the development of initiatives, other agencies being aware of this program at the Centre, access to the program and the value of the program to the participants. The Community Liaison program addresses three of the four dimensions. Participation/partnership development encompasses descriptors found in the system competency and the client and community focus dimension. Program awareness is covered in system competency. Program access is addressed by responsiveness and the value of the program is addressed in the client and community focus.

It should be noted that holistic care is so embedded within the philosophy and program delivery at the Centre that it does not come out as one of the measurable indicators or elements variables. There are a number of reasons for this. Holistic care is demonstrated in the variety of services and programs offered at the Breast Cancer Centre for Hope. These services are varied and diverse and are offered to women at any stage along the spectrum of their breast cancer experience. Additionally, holistic care measurements would overlap with the tenets of empowerment, acceptable care and equity as it overlies all the programs.

**Table 6: Concepts/Elements of Programs at the Centre****Specific elements/concepts for the Volunteer Program:**

- 1) A sense of belonging to the volunteer group, amongst the volunteer group ❖  
 Perception of belonging to group  
 Participation in group activities  
 Support from volunteer group
- 2) Satisfaction with the volunteer role ❖  
 Support provided by the agency  
 Feeling of being able to contribute  
 Self-satisfaction with role  
 Empowerment of self through role
- 3) Perception of volunteer role ❖▲  
 Role definition via volunteer perception  
 Volunteer role in different programs  
 Value of volunteer role

**Specific elements/concepts for the Patient Care Program:**

- 1) Client Satisfaction ■❖❖  
 Satisfaction with support services ,e.g. timeliness of response  
 Satisfaction with resources offered, e.g appropriate materials  
 Satisfaction with staff assistance, e.g. communication with staff  
 Satisfaction with Group Peer Support e.g. communication  
 Satisfaction with follow-up services e.g respect and caring
- 2) Accessibility ■  
 Hours  
 Availability of Staff  
 Availability of resources  
 Barriers to services (eg. geography)
- 3) Credibility ★  
 Information provided by Centre is current  
 Information provided by Centre is consistent with information provided by physician  
 Information provided by Centre is accurate

**Specific Elements/Concepts for the Community Liaison Program:**

- 1) Participation ★❖  
 Partnerships developed  
 Initiatives developed  
 Volunteer participation
- 2) Awareness of Program ★  
 Program known to other agencies  
 Purpose of program clear to participants and volunteers
- 3) Program Access ■

**Legend**

- = Responsiveness  
 ★ = System Competency  
 ❖ = Client/Community Focus

The evaluation map is a guide for following the process of discovering the concepts or areas for evaluation as well as the measurable indicators or elements. Figure 1 captures the essence of how the Primary Health Care model is incorporated into the framework for the development of the evaluation tool(s). Figure 1 also demonstrates the link between the programs delivered at the Breast Cancer Centre of Hope and the Primary Health Care model, setting the stage for the evaluation tool(s) to reflect the model. The tenets of the Primary Health Care model are reflected through the activities and potential outcomes for each program and sub-program.

### Conclusion

The evaluation map provides a visual guide into the process of the development of the evaluation tools. It brings the data, the analysis and the framework into focus for the reader. There are many pieces that go into the map, but are not overtly shown. The underlying assumptions that the goals of the Centre are embedded within the essential elements of the map and within the Primary Health Care model is vital in understanding the application of the map in the development of the questionnaires. The next chapter will briefly outline the questionnaire development and highlight the linkage between the map and evaluation tools.

## Chapter 6

### The Questionnaire Development

The questionnaires were developed using the information derived from the analysis of the interviews, readings, the community event and follows the evaluation map. The umbrella programs were each viewed separately as the focus for each program was too different to incorporate into one evaluation tool. In developing the questionnaires, the essential elements identified in the evaluation map, the indicators of care and the crucial elements were all employed in the creation of the evaluation tools. The questions were built around the elements of sense of community, client satisfaction and role understanding. This chapter briefly outlines the content of the questionnaires, which are included in Appendix F, and links the evaluation map to the development of the evaluation tools.

These questionnaires have been developed by using the key concepts as identified by the staff at the Breast Cancer Centre of Hope. Each questionnaire (Appendix F) has a “Blueprint”, that provides the rationale for the question (each question should relate back to a tenet or key concept). The question areas in the blueprint are not numbered, but the type of questions are briefly described in one column. The concepts referred to on the blueprint may be a combination of the essential and crucial elements from the information presented in Chapters Four and Five. The blueprint will combine categories of questions (in sequential order) if the rationale was similar enough to warrant grouping.

#### Volunteer Program

The volunteer program evaluations were separated into two groupings. The General Volunteer Program and the Peer and Group Support Program were distinct in the

determination of who would receive the evaluations. The Peer and Group Support recipients may have different needs than the volunteers and therefore should have a different evaluation. The strengths and areas for improvement should be identified in order to ensure that the program meets the needs of the volunteers and recipients.

The General Volunteer program refers to the volunteers not specifically involved in the Peer and Group Support program. The volunteers in the General Volunteer program complete a variety of tasks, from stuffing envelopes to organizing conferences. As there are a variety of tasks to do as a volunteer, the General volunteer evaluation focuses on the sense of community that hopefully develops when the women participate in volunteer activities at the Breast Cancer Centre of Hope and volunteer satisfaction.

With respect to the variety of volunteer opportunities available at the Breast Cancer Centre of Hope, the volunteer evaluation asks what task the volunteer participates in. Subsequently, questions are asked relating to the sense of community and client satisfaction and role understanding, which are part of the essential elements from the evaluation map. In addition to weaving these elements into the questions, the questions are also built around the concepts that were identified in the interviews with the staff. The questions also embed the tenets of the Primary Health Care model. Table Seven illustrates the linkages between the essential elements and Primary Health Care with the questions in the evaluation. This table facilitates the understanding of the coalescing of the information into a cohesive and clear evaluation tool.

**Table 7: Volunteer Program: Blueprint for Evaluation**

<b>Volunteer Program: Blueprint for Evaluation</b>		
<b>Question</b>	<b>Concept</b>	<b>Tenet</b>
General question - looks at access issues	Access	Equity



<b>Volunteer Program: Blueprint for Evaluation</b>		
The question regarding belonging. This comes from the discussion with the Volunteer Coordinator. This looks at empowerment and sense of ownership	Satisfaction	Empowerment
The next question looks at what makes the volunteers feel a part of the group, that is, what is working to make volunteers feel a part of the group	Belonging	Empowerment & Acceptable Care
I query whether a question is needed on what makes volunteers feel <i>unwelcome</i> . There are no assumptions about this, therefore it would have to be an open ended questions. However, the following question may sufficiently answered this.		
The volunteer activities are meant to give a description of the main activities and how many volunteers actually work in the different activities.	Satisfaction & Perception	Acceptable Care
The questions addressing how welcome volunteers are, are meant to address the feeling of belonging in the program. The series of questions about welcome are designed to look at the degree of the sense of belonging, which may help Hope to understand where they can make volunteers feel more welcome.	Belonging	Empowerment & Acceptable Care
There is one question on Orientation. Is this enough orientation, or should it be elaborated on.	Perception Satisfaction	Acceptable Care
Support from volunteers: Support is very important in this program in order to make it work	Satisfaction	Acceptable Care
Involvement in the volunteer experience relates to the concepts of participation and empowerment	Perception Satisfaction	Empowerment
The volunteer coordinator felt that satisfaction was tied in to the volunteers feeling they are making a contribution to the Centre, therefore there are a few question trying to get at this idea which was under the satisfaction concept.	Satisfaction	Empowerment

<b>Volunteer Program: Blueprint for Evaluation</b>		
The value of the contribution crosses over into the value as well as contribution phase, but asks a different question in that it does not assume that the volunteers feel valued in their role at the Centre	Satisfaction n Perception	Empowerment & Acceptable Care
After the General value questions come the questions addressing satisfaction...Satisfaction with the volunteer role, the volunteer coordinator and the Centre. The separate questions help to define where strengths and weaknesses are	satisfaction	Acceptable Care
The last questions are general questions that will hopefully tease out evidence of empowerment in some aspect.	All 3 Concepts	Empowerment

The Peer and Individual Support Group evaluation focuses more on access and satisfaction issues. It is essential to know if the recipients are satisfied with program and what aspects of the program they are satisfied or dissatisfied with. Table Eight demonstrates the congruencies between the essential elements and tenets of the Primary Health Care model.

**Table 8: Peer and Individual Support Groups: Blueprint for Evaluation**

<b>Peer and Individual Support Groups: Blueprint for Evaluation</b>		
Question	Concept	Tenet
<p>To Note: This is an evaluation that is looking at the client perspective of these services. There is an interesting cross over of client/volunteer, since many of the volunteers have received support services, either in group, or as an individual. Therefore some of the questions will address concepts in the volunteer program and some will address concepts in the patient care program.</p> <p>Because this is being given to people who have received service, the population will be self-selected.</p>		

<b>Peer and Individual Support Groups: Blueprint for Evaluation</b>		
This first question opens up the evaluation by asking what kind of services were received.		
Access to service is then addressed via the next set of questions, with opportunity for respondents to elaborate on their experience(s) to help identify more detail in access issues	Access	Equity
The support questions starts with general questions then move to specific questions on support, which will help lend credence to the support focus of the Centre.	Satisfaction	Empowerment & Acceptable Care
The questions asking whether people would recommend the service looks at the satisfaction of the client via a slightly different venue, either supporting or not supporting the previous questions on satisfaction	Satisfaction	Acceptable Care
The following questions again address satisfaction, with the service, as opposed to volunteer satisfaction with the volunteer program	Satisfaction	Acceptable Care
Looking at the Follow up issues also address satisfaction with the service.	Satisfaction	Acceptable Care
The last questions will hopefully evoke responses that may demonstrate a sense of empowerment gained as a result of the support provided the two programs.	Satisfaction and other concepts that may emerge	Empowerment, Acceptable Care

### Patient Care Services Program

The evaluation tool developed for the Patient Services Program is more inclusive than the previous two questionnaires. As the subprograms are enmeshed within each other, and difficult to evaluate in isolation, a more comprehensive questionnaire was developed. The development of the questionnaire followed the same process as the previous questionnaires. The essential elements of the Patient Services program are client

satisfaction, accessibility and credibility. These elements are combined with the tenets of the Primary Health Care model to produce an evaluation tool that will provide the Breast Cancer Centre of Health with information they can use to improve their programs and provide rationale for the continuation of the programs in the agency. Table Nine illustrates the linkages between the essential elements and the tenets of the Primary Health Care model.

**Table 9: Patient Care Services Program: Blueprint for Evaluation**

<b>Patient Care Service Program: Blueprint for Evaluation</b>		
Questions	Concept	Tenet
The first question addresses equity through asking the respondent how they got in contact with Hope. This may produce a variety of answers that will identify to Hope how they can increase awareness of their service. In fact, the first 4 questions address access issues	Access	Equity
The # of contacts with the Centre may help the Centre to understand how much time they have to provide the greatest impact of their services. This is the same for the question on the purpose of the contact	Satisfaction	Acceptable care
The more specific questions on satisfaction with regard to timeliness, support/counselling, referrals and communication with the nurse follow next.	Satisfaction	Acceptable Care
The questions that ask about follow up are essential, as the follow-up itself may be indicative of satisfaction (the next 3 questions).	Satisfaction	Acceptable Care
The following questions look more at the resources used at the Centre. The type of resource offered is good to know in terms of being able to project how much of each resource may be needed.	Satisfaction & Access	Acceptable Care & Access

<b>Patient Care Service Program: Blueprint for Evaluation</b>		
The expectation of resources is important to know in terms of satisfaction, if the resource is not what was expected, does this affect satisfaction, and more importantly, credibility. If the resource is not what was expected, how credible is the person providing the resource?	Satisfaction & Credibility	Acceptable Care & Access
Was the resource helpful looks at whether the client found it acceptable.	Satisfaction	Acceptable Care
Current Condition of resources relates to credibility. In rating the resources, credibility can be looked through low and high rating. Those that rate low should be changed and those that rate high, are good resources to keep.	Credibility	Acceptable Care
The questions addressing contradictions with the information given to the client from her physician and follow up speak to the credibility of service provided and to satisfaction.	Credibility & Satisfaction	Acceptable Care
The amount of information provided should be tailored to the need of the client. This question is a good check for the staff person to ensure that s/he is understanding the cues of the clientele.	Satisfaction	Acceptable Care
The next questions about prostheses really address the same issues as mentioned before, access, credibility and satisfaction	All	Acceptable Care & Equity
The question comes up about whether the person would use the Centre again.	Satisfaction	Acceptable Care
The question asking what was the most helpful service will help to identify what is important to maintain at the Centre and may identify where some weak areas are.	Satisfaction	Acceptable Care
The remainder of the questions really address empowerment outcomes. However, empowerment was not one the concepts defined through the 2 interviews with the Nurse Educator. Yet, it is still an integral part of the program.	Empowerment	Empowerment

### Conclusion

The questionnaires reflect the analysis of the interviews, readings and the community event, as well as the incorporation of the tenets of the Primary Health Care model. The linkages are clearly shown and the Primary Health Care model meshes well with the philosophy of the agency. The next step in the process was to formulate the implementation considerations for the evaluations.

## **Chapter Seven**

### **Implementation**

The next step in the process of developing the evaluation plan was to outline an implementation plan. This plan will provide guidance for the staff at the Centre to distribute the evaluation to the users of the service. Distribution of the evaluation must take into account the capability of the Centre to assume the burden of costs of the implementation. The costs can be in terms of time, monetary costs and investment of staff involvement. The implementation guide should provide the reader with the rationale for the type of evaluation tool chosen, barriers to distribution, such as geographical obstacles, staff time limits and availability of addresses, and costs.

#### **Rationale for Questionnaires**

There are a number of methods that can be employed when undertaking an evaluation. Focus groups, individual interviews, pre and post tests as well as surveys or questionnaires are all valid evaluation methods (Denzin & Lincoln, 2000; Morse, 1991; Schalock & Thornton, 1988). Focus groups and individual interviews are methods in which one may gather rich data (Denzin & Lincoln, 2000 ). Focus groups allow interaction between respondents and elaboration on responses. Also, they permit a fairly large number of persons to participate (typically eight to ten). The drawbacks of focus groups are the time and expense (McClaren, 2001). In order to be effective and have research validity, there should be at least two focus groups for any evaluative purposes (McLaren, 2001). This increases the time and expense of doing focus groups. As well, the time required for preparation and analysis is significant. When doing a focus group, it is

expected that participants will be compensated for expenses incurred, and may even receive a stipend for attending. As well, at least two researchers need to be present to run the group. If researchers have been hired, the cost will be significant. If the staff do the focus groups, the cost in terms of time would be too burdensome for the Centre; as well, there are ethical concerns with the staff serving a dual purpose of service providers and evaluators. Therefore, focus groups were not viewed at this time as an option for the evaluation.

Individual interviews are another method used for evaluation purposes. Individual interviews also produce a rich source of data. This method has the benefit of the evaluator being able to draw out information that may not be forthcoming in a less intimate evaluation method, such as a questionnaire (Denzin & Lincoln, 2000; Polit & Hungler, 1987). However, the drawbacks are similar to those of focus groups, in that the time commitment is significant. Again, not only the time for interviews, but the time spent in analysis is not the best option for the Centre at this time. In addition to the time constraints, individual interviews are not suited to involving large numbers of respondents. In this first evaluation, which is evaluative as well as exploratory, interviews with a relatively small percentage of respondents in comparison to the number of users would produce results with limited applicability.

Pre and post tests are an excellent method of determining if a program is working as it was designed to work (Cook, Cook & Mark, 1992). The real issues here are identifying what the program was designed to do, and controlling for extraneous variables to determine the effectiveness of the program under study. The pre and post test design is



not suitable for the Breast Cancer Centre of Hope, as the pre test phase would require that women would have to be tested before receiving services with Hope and after their contact with Hope. Women who receive services via telephone may not be able to participate in this. The other variation on this design, is to test two parallel populations, one population who has used the Centre and a demographically matched population of women with breast cancer (the control population) who have not used the Centre. The complications involved in this design are enormous, in gaining access to the control population, demographically matching the control population to a population for which information is scarce, and, in the time required to carry out the evaluation. Therefore, this type of design, and any type of quasi experimental design is not feasible for the Centre at this time.

Questionnaires were chosen for the Centre evaluation based on a number of factors. The literature provides a plethora of information about the needs of women with breast cancer and the services which they desire. This information may be used to inform the development of questionnaires. As well, the questionnaires are relatively easy to distribute, taking into account the time and financial limitations of the resources at the Centre and funds available for the evaluation. Additionally, an outline of an analysis plan will also be included, giving the staff at the Centre a guide for what to do after the responses for the evaluation are in. The next section looks at the specifics involved in implementation of the questionnaires for the evaluation of the Breast Cancer Centre of Hope.

### Questionnaire Implementation

Implementation of the evaluation plan has already been discussed with the Director with various scenarios being discussed (eg. distribution at a conference, mail outs, telephone surveys). The Volunteer Program and Patient Services Program each have unique challenges in planning for the implementation of the evaluations. Therefore, the Patient Services program and the Volunteer program will be discussed separately. The challenges of each program will be discussed and the proposed solutions outlined.

Implementation of the evaluation of the Patient Services program was seen as the more difficult of the two programs. The main reason for the difficulty was that there is not a comprehensive and exclusive list of women with breast cancer who have used the services of the Centre. However, the Centre does have a list of people who requested to be on the mailing list for the "Voices" newsletter. This list includes users of the Centre, family members of women with breast cancer, health care professionals, and lay people seeking information. There is no separation of clients and other recipients of the newsletter (and the proposed evaluation) in the address list, and therefore, there is no capability of sending the questionnaires to only the women with breast cancer who have used the Centre. So, the dilemma became one of who will receive the questionnaire. If there is a mass mail out, then people who have not had breast cancer will receive the questionnaire, and may fill it out. As well, the numbers of people receiving the newsletter is large. Given this, the questions that need to be asked in this situation are: (1) what criteria will be used to decide who should respond to a questionnaire, (2) how important is it to send questionnaires to only the target population, and (3) what is the most expeditious way to distribute the questionnaires, i.e., mail out, hand out, or internet.

The criterion for deciding who should respond is women with breast cancer who have used the services at the Centre. In order to target just women with breast cancer who have used Hope, there was the option of distributing the questionnaire at a bi-annual conference that the staff at the Centre organize. This conference is open only to women with breast cancer, and is well attended by women who meet the criterion. However, the two concerns about this method are: (1) not only women who have used Hope will attend the conference, and may fill out the questionnaire, and, (2) there is a self-selection process in the attendees of conference that may skew the results. Another method of distribution could be a notice sent out in the "Voices" newsletter, asking the target population to call in to the Centre and request a questionnaire. This method was deemed as too cumbersome, with many potential missed respondents. In discussion with the Director of the Centre, it was decided that the easiest method of distributing the questionnaire, was to send it out with the "Voices" newsletter, and include an introduction asking only those women who meet the criteria to respond. This method would allow maximum exposure of the questionnaire to the target population, with minimum extra costs to the Centre. There would be no way to determine the return rate of the survey, since there would be no accurate accounting of the number of target population recipients. A self addressed, stamped envelope would have to be included, which would increase the costs. The possibility of putting the questionnaire on the internet was discussed, however, technical support is not readily available and therefore this was not an option.

The questionnaires for the Volunteer program are much easier to distribute. The Centre has a comprehensive list of names and addresses of the volunteers and therefore

can access them with relative ease. Therefore, a mailout was seen as the best way to distribute the questionnaire. The Director felt that the Centre would be able to absorb the cost of mailing out the evaluation since the number of volunteers is finite and relatively low, approximately 100 people. The Director also suggested that some volunteers may receive their evaluation survey by picking it up at the Centre, since volunteers will be the ones assisting with assembling the mailout. Regardless of whether this is mailed, or given directly to the respondent, a self addressed, stamped envelope should also be included, to allow some measure of anonymity to the respondents.

For all the questionnaires and respondents, there is the question of the need for ethical review of the evaluation proposal before distribution. If this evaluation were a part of a research project, the questionnaire and the implementation process would need to undergo ethical review. However, in keeping with the use of evaluations within institutions for the purpose of quality improvement and internal processes, the questionnaires do not need to undergo the same rigours as a research project. Therefore, approval by the Director needs to be given in order for the questionnaires to be distributed; and as well approval for the budget, for this evaluation will be needed. It is also important to note that this development of evaluation has been conducted in consultation with the staff at the Centre, with their feedback built into the questionnaires. Therefore, the questionnaires have already been scrutinized and reviewed for their appropriateness for the Centre.

### Costs

The cost to distribute the questionnaires will include the cost incurred by the

photocopying, self addressed stamped envelopes and the cost of the mailout to the Volunteer program recipients. The Director feels that these costs would be manageable for the Centre. The exact number of service users who would receive the Patient Services questionnaire is unknown. About 2000 newsletters are sent out with each mailing, with some of those mailings having multiple copies included. As the exact number of copies of the evaluations in each envelope are undetermined as of yet, determining the extra expense would be difficult. Therefore, the budget will include the cost of mailing for 1,500 evaluations. There would also be a cost in terms of return envelopes and postage. Again, the Director felt that this was a viable plan. A preliminary budget has been included in Appendix G. This budget also includes potential costs of data analysis.

#### Analysis

Analysis of the questionnaires is relatively simple in terms of statistical analysis. Ordinal and nominal level data will be collected; and the majority of the work in the analysis will be data entry. Cancer Care Manitoba does own some statistical analysis programs, such as SPSS; however, the availability of this program to the Centre is unknown. The Manitoba Nursing Research Institute offers data input and analysis services. The cost of data input is around \$12.00/hour and the statistical analysis is \$75.00/hour. There are opportunities with the evaluations for correlation between some of the responses, depending on how far the Centre would like to go in their analysis. Statistical consultation services are available and the costs are included in Appendix G. The use of the Research Institute, would, of course, add to the costs.

#### Conclusion

Planning for the implementation of the questionnaires has been an interesting process. The major factors in the implementation are the lack of a recorded client base, and cost. With the input of the Director, these problems have been addressed in a manner that represents a compromise between the ideal and the practical. There are as yet, many unknowns in the costs and the analysis and these unknowns have to be considered by the staff at the Centre. However, the dedication of the staff at the Centre to the evaluation bodes well for the completion of the questionnaires and the evaluation.

## **Chapter Eight**

### **Discussion**

The purpose of the practicum was, as stated in chapter one, to work with the staff at the Breast Cancer Centre of Hope to: (1) develop evaluation tool(s) that incorporate the Primary Health Care model as a framework, and (2) outline a guideline for implementation consideration. The practicum itself was an exercise of implementing the Primary Health Care model as a practice model for an evaluation process. This chapter will discuss the practicum process as it developed with respect to the Primary Health Care model and the implications this practicum has for nursing research and education.

Embedded within this evaluation process was the use of specific guidelines, the Achieving Improved Measurements (AIM) model, development of an evaluation map and development of the evaluation tools. Next, the evaluation process and tools are critiqued with respect to the information presented in the literature, what is similar and what is not similar. In addition to this, the limitations of the practicum and tools will be discussed. Lastly, the benefits of the practicum will be discussed as well as the recommendations as to how the results of this practicum could be further developed to provide new information to the Centre and to further knowledge development on evaluations.

#### **Primary Health Care Model and the Process**

The Primary Health Care model served a dual purpose in this practicum. It served as the conceptual framework within which the practicum was conducted and it also served as the framework for the development of the questionnaires. The tenets of the Primary Health Care model were used extensively, as well as the philosophy underlying Primary

Health Care. This model, in the end, proved to be a sound model upon which to base the evaluation process and develop the questionnaires. The section below will examine the use of the Primary Health Care model throughout the process of the evaluation planning and development of the questionnaires.

The planning process for the evaluation was one aspect of the practicum. In committing to using the Primary Health Care model as a framework for the development of the evaluation tools, there was an inherent commitment to using the Primary Health Care model as the framework to guide the process of the practicum. It should be clarified at this point, that the evaluation planning process refers to the various meetings, interviews, background research and ongoing interaction with the staff at the Centre for the purposes of developing the evaluation. This commitment set the tone for the various actions of the practicum. Part of the philosophy of the Primary Health Care model is active community involvement (in this case, the community is the staff) in whatever process may be initiated (WHO, 1978). To be true to the philosophy of the Primary Health Care model, staff were involved at the inception of the process.

As stated in chapter one, the Breast Cancer Centre of Hope already operated under the principles of the Primary Health Care model. The goals (Appendix A), and programs themselves illustrate the principles and reflect the five core tenets of the Primary Health Care model within the Centre and in any of their contacts with agencies outside of their Centre. The internal operations also reflect the application of the Primary Health Care model through the staff participation in decision making and program development. Therefore, the Primary Health Care model seemed to be a good fit. Using an approach that



the staff were already familiar with facilitated the cooperation of the staff. As well, given that community ownership is an integral part of the Primary Health Care model, it would naturally facilitate staff ownership of the evaluation process through involvement.

Various authors have supported the active involvement of staff in the process of developing an evaluation (Cousins, 2001; Haas, et al., 2001; van Assema, et al., 1997). Cousins (2001) found that the cooperation between staff and evaluators led to a greater understanding of the evaluation process and a greater appreciation on the staff's part for the *process*. This understanding and appreciation allows staff more ownership of the evaluation process. Haas et al. (2001) used working groups to lead evaluations of programs. This evaluation benefited by having those people directly affected by the evaluation, participate in planning the evaluation, thereby giving them some control over the process. However, many more authors do not make mention of staff involvement in the evaluation process at all (Austin et al., 1999; Charles, et al., 1994; Cleary, et al., 1992; Gerteis, et al., 1993; King et al., 2001; Klee et al., 2000; Nelson, et al., 1996). Yet, in a sense, the use of the Primary Health Care model proscribed the active participation of the staff in order for the process to succeed. To this end, staff were heavily involved in the process from the beginning. Meetings and interviews were the primary source of involvement for the staff, and were an integral part of putting the Primary Health Care model into practice.

### Meetings and Interviews

The first group meeting with the staff was meant to introduce the practicum, solicit staff commitment and solicit staff ideas to start the evaluation process. The

challenge in this meeting was to allow staff enough freedom to express their desires for the evaluation, but also provide realistic limitations for the evaluation. A common pitfall in evaluation, where staff are involved in the development of an evaluation, is that staff will allow the Director of the agency to drive the evaluation (Haas, 2001). In order to avoid this pitfall of allowing the Director, or the student to drive the evaluation, the staff members were encouraged to freely share their ideas. The part that became more difficult was having staff realize that some of their desires were not attainable within the scope of this practicum, or the resources of the Centre. However, as in keeping with the Primary Health Care model, the community does need to be aware of the limitations of the resources in implementing their ideas. Therefore, the staff were informed that the evaluation measurements they requested could not realistically be captured because the collection of such information would be too costly. There were also meetings with the Director, which provided opportunity to help realign the goals to make sure that the practicum was in keeping with the mandate and goals of the Centre itself. These meetings with the Director did not necessarily net new information, as did the interviews, but they helped to clarify thoughts and ideas.

The interviews with individual staff members were different from the meetings with the whole staff in that they were specific to each program, and therefore were more focussed, with questions provided for the staff to help them prepare for the interview. While the first interview was directed by the student, in that specific questions were posed, it was still in keeping with the Primary Health Care model in that the staff were asked to participate in such a manner that their input was valued and reflected in the

results. This helps to give staff a sense of ownership in the process. Unfortunately, the time lag between the interviews and feedback getting back to staff was lengthy, which led to the staff feeling disconnected from the practicum and the evaluation planning process. This was not in keeping with the philosophy of the Primary Health Care model. In an attempt to rectify this problem, a feedback loop was developed that set timelines to ensure timely response by the student, and allowed the staff another opportunity to provide feedback. This provided a number of benefits: 1) this step required more investment of time from the staff member, thereby gaining more commitment from the staff member, 2) it allowed staff to stay current and connected to the evaluation process, 3) it increased their feeling of ownership of the end result (the evaluation tools) because they had some assurance that their ideas are incorporated and 4) it validated contents of the interviews as seen through the eyes of the student and helped to ensure that timelines were reasonably well kept. This is a step that is recommended in the evaluation literature (Cockerill & Charles, 1998; McKenzie & Smeltzer, 1997; Morris & Fitzgibbon, 1987a; Williams, 1994). In fact, Sharp and Eddy (2000) counsel against the blind use of the traditional evaluation research process as the traditional process may not meet the needs of the agency under evaluation. The benefits outlined above are not only supported by the Primary Health Care model, they are also supported in the literature (Bea van Beveran & Hetherington, 1997; Cousins, 2001; Sharp & Eddy, 2000).

All the work with the staff did not come effortlessly. While the Primary Health Care model proscribed the participation of the staff in the evaluation process, it did not provide specifics as to how this could be accomplished. To gain perspective on the details

of the process, a set of guidelines was incorporated into the practicum. These guidelines, set out by Bea van Beveran and Hetherington (1997) in their five step framework, reflected the tenets of the Primary Health Care model through the promotion of the active involvement of staff, encouraging ownership, at least in part, of the planning process by the staff, and planning within their fiscal means.

The following section delineates how Bea van Beveran and Hetherington's (1997) guidelines facilitated the process of developing the evaluation tool. The section also highlights the collaborative process between the developer and the staff, that reflects the principles of the Primary Health Care model.

#### Collaboration and Guidelines

The first step in the development of an evaluation is "Understanding the reason for undertaking the evaluation"(Bea van Beveran & Hetherington, 1997, p 120). The premiss of this step is that there has to be a reason for the evaluation. That reason will shape the content and context of the evaluation. The need for an evaluation of the Centre was really driven by the staff. The first meeting with the staff highlighted the commitment of the staff to the Centre and to the evaluation process. The results of the first meeting demonstrated that the staff did indeed understand the reasons for the evaluation, as the reasons were defined by the staff themselves. They expressed their desire to have "empirical" evidence that their work was valuable and for the staff to understand where the program may need change. Also, the staff understood the mandate of the Centre well, and wanted to know if they were meeting that mandate through their programs. This process is supported by Morris and Fitzgibbon (1987a).

Step two of Bea van Beveran and Hetherington's guidelines consists of securing resources (p121). Securing resources for the evaluation for the Centre was not so much the issue as was finding a way to do the evaluation that fit within their budget. The Centre was able to provide some extra funds for administrative costs (e.g. copying of the questionnaires, adding to the mailouts, and such), but they were not able to budget for an independent evaluator to come in and do the whole evaluation. Therefore, the method of distributing and analysing the evaluation was built around the available funding.

Step three, creating enthusiasm and establishing credibility (p122), became one of the key aspects of the process. Developing a relationship between the student and the staff at the Centre was an integral part of the process. In view of the overriding Primary Health Care model, this step was a natural fit for this project. In order to have the community take ownership of the process and project, as promoted by the Primary Health Care model, creating enthusiasm and establishing credibility are important steps to ensuring this will happen. The enthusiasm for the evaluation came naturally. The staff were committed to having their programs evaluated and therefore it was important for the student to establish credibility.

Credibility can only be established through building of trust between people. In order for the student to gain credibility, it was important to ensure that the staff were included at many points within the process and that the staff believed that the student was capable of producing an evaluation plan. There are a number of ways to include staff, such as surveys, updates at staff meetings, communiques and personal interaction (Morris & Fitzgibbon, 1987b; Rovers 1985). In fact, many of these methods were used. The staff

were given feedback after their interviews, and were asked for validation of the feedback. This served to support the role of the staff member as a part of the evaluation process in that the staff member could ensure that what they said was valuable, and that it was important that it was reflected accurately. The second aspect of this tactic was that it allowed validation of the content of the meeting, endorsing the work of the student and lending credibility to the process and results.

It should be noted at this point that despite the care taken to obtain feedback and reflect the true goals of the evaluation, there were some surprises for the staff at the end. When the Executive Director presented the evaluation map to the staff, the staff were somewhat perplexed by some omissions. These omissions were a result of the prioritizing that the staff were asked to do. In an effort to make the evaluation manageable, staff were asked to identify the top three elements that should be evaluated. These were the elements that were the essence of the program. In doing this, some of the other pieces were given less priority. It has to be noted that just because some pieces were not in the top three of the priority elements, it does not mean that they are not important. It just means that when it came down to evaluating the key elements of the program, the three elements named were the ones that had the greatest immediate impact on the program. For example, the three key elements in the Patient Services Program did not tap into the empowerment tenet of the Primary Health Care model. Yet the staff felt that this was a very crucial piece of this program. However, because the focus in the program really was providing services, the holistic and appropriate care came across more strongly than did empowerment. Empowerment was still an important offshoot of the service provided, but not a direct

service provided. However, empowerment was captured in the evaluation questionnaires as it was such an integral part of the program and hence, the importance of empowerment needed to be captured in the evaluation.

The fourth step in the development of an evaluation includes developing consensus about the goals and objectives (Bea van Beveran & Hetherington, 1997). This step was actually one of the first steps in this practicum. The consensus about the goals and objectives was sought in the very first meeting with the staff. This was an important first step, as it is difficult to garner the enthusiasm needed without understanding that the evaluation is an integral part of the goals and objectives. This step was actually done in conjunction with understanding the reason for the evaluation. Fortunately, since the staff had previously identified the goals and mandate of the Centre, much of the work had been completed.

Finally, the last step of the development of the evaluation, is observing and fine tuning the program. There was one program that was in development when the interviews were being conducted, and therefore no questionnaire was developed for this program. This program has since developed more fully, and may be more appropriate for evaluation at this point.

While the guidelines by Bea van Beveran and Hetherington (1997), were helpful in getting the process started, further work was needed to bring the project together. The meetings and interviews netted enormous amounts of information. The information needed to be brought together in a way that made sense to the staff and reflected the integration of the Primary Health Care model. Out of this exercise came the critical

elements and the Evaluation Map.

### Developing the Evaluation Map

Integral to the process of gathering data from staff meetings and interviews, was the summarization and validation of the meetings and interviews. As mentioned previously, the amount of information generated was substantial, and difficult to organize at times. However, the organization of the summaries was made easier by directing the staff in the interviews to focus on specific aspects of their programs that impacted the success of the program, thereby making the summarization a part of the meetings. The process of sorting out all this information was vetted through the various contacts with the staff. This next section discusses the process of analyzing the information that led to the development of the evaluation map.

The first set of interviews specifically asked the staff for indicators of care in each of their programs. "Indicators" are prominent in the evaluation literature (Charles, et al., 1994; Cleary et al., 1992; Shavelson, McDonnell & Oakes, 1991). Indicators are aspects of the program that are exemplar of the key elements of the program. The key elements are the pieces of the program that cannot be left out if the program is to succeed. For example, key elements of the Patient Services Program would be telephone contact and one-on-one counselling. Without these two elements, the program would not be the same. So, in essence, these two elements define (at least partially) the Patient Services Program. These elements then became indicators of quality care.

To further understand these indicators, the second interviews with the staff looked at the top three elements of each program. This was a necessary step in order to grasp



what the essential elements of the program really were in order to develop a questionnaire that would produce information that the Centre could act on. One of the most important things in developing an evaluation is that the results of the evaluation produce actionable data. That is, the evaluation should be designed in such a manner that the staff will gain specific information on specific elements of the program, and that changes can be made to that program based on the results of the evaluation. The top three elements were deemed the crucial elements. These were integrated into the evaluation questionnaires.

The connection between the Primary Health Care model and the crucial elements was evident throughout the process, but not easily explained. Therefore, an evaluation map (Figure 1, Chapter 5) was developed to help visualize the connection between the Primary Health Care model and crucial elements, which drive the content of the questionnaires.

Although the Primary Health Care model was a useful framework for the planning process and developing the questionnaires, it did not provide a meaningful framework to summarize the findings of the information. The guidelines from Bea van Beveran and Hetherington (1997) were not meant to provide a framework for presenting findings. So the task then became to find a way to present the findings in such a manner that the Primary Health Care model could easily be identified as the underpinning conceptual model for the evaluation process and evaluation questionnaires. The Evaluation Map became the means of presenting the analysis of the information collected.

The findings clearly supported the use of the Primary Health Care model as the conceptual framework for the evaluation process and for the evaluation tools. Table Five

(Chapter 4) demonstrates the relationships between the activities carried out in the Centre and the Primary Health Care model, as well as the connection to the critical indicators and crucial elements. In order to be able to develop the questionnaires, it was important to further define the elements as they are seen within the Primary Health Care model, which became the concepts. The evaluation map was used to visualize these relationships. The real benefit of the map was that it provided a quick easy reference to check back on when developing the questionnaires, ensuring that the concepts and right tenets were teased out in the questionnaires.

#### Primary Health Care Model and Evaluation Tool Development

A lot of time was spent at the front end of this practicum in understanding the philosophy, mission statement and goals of the Breast Cancer Centre of Hope. The purpose of this front end work was to make sure that the evaluator and the staff clearly understood what should be evaluated with reference to what they are trying to accomplish at the Centre (Bea van Beveran & Hetherington, 1996; Trochim, 2002). The tools themselves were more straightforward in their development. The literature on evaluation tool development provides insight into the mechanics of the tool development, but the Primary Health Care model and the evaluation map were the shaping force behind the items themselves. This section critiques the process behind the tool development.

The decision was made by the student and her advisement committee that the Centre's programs were too unique to enable one evaluation tool to evaluate all three programs. It was important to ensure that the questionnaires would elicit information that the staff could use to improve and change their programs (Charles, et al., 1994;

Donabedian, 1986; Sharp & Eddy, 2001). Therefore, evaluation tools were developed for each program, and in fact, two were developed for the Volunteer Program, as this program had two very distinct populations to evaluate.

Two questionnaires for the Volunteer Program were needed to measure the distinct purpose of the General Volunteer Program and the Peer Support Volunteer Program. The target population and the concepts used for the General Program as opposed to the Peer Support Program necessitated the separate questionnaires. The evaluation of the Patient Services Program, however, was in fact, the opposite case. The Patient Services Program subprograms were too intertwined (i.e., counselling, resources and referrals) to be separated out from each other. As well, since this evaluation questionnaire would be sent to the same target population, it was decided to send out just one evaluation, instead of burdening clients with multiple evaluations for each subprogram, with the possibility of repeating the questions in each evaluation.

The benefit of using questionnaires for the evaluation is that they are relatively easy to distribute, and analyse. The Centre already has a system for mailing out the questionnaires with the monthly mailout of newsletters. This method would add little expense to their budget. The questionnaires have been checked to ensure that the concepts and tenets of the Primary Health Care model had been addressed, allowing the Centre to have consistency in their philosophy and goals, with their evaluation questionnaires. The questionnaires are tailored to each program and sub-program to allow the results to produce information that the staff can use to improve their programs and provide rationalization for the continuation of programs. The use of the evaluation questionnaires

can result in raising issues for further evaluation consideration in a different venue, such as interviews or focus groups. The questionnaires can lead to more detailed information in areas that may have been identified throughout the evaluation. Finally, the connection at this point to the AIM program allows the Centre to easily transition their evaluation process to meet the standards of the AIM program.

### The Evaluation Literature

The evolution of the evaluation plan was an extensive process. There were a number of steps involved in the process of developing evaluation tools. Although the Primary Health Care model has been used as a framework for developing and implementing programs (Button, et al., 1998; Hatcher, et al., 1998), it has not been used for the framework of building an evaluation plan. Rovers (1985) did use the Primary Health Model to develop a framework for evaluation, but did not integrate the model into the entire process. Instead a model was developed that the staff could use to engage the community in the evaluation. It did not include the staff in the development of the evaluation design. Incorporating the Primary Health Care model into the process was essential as the Centre itself embodied the principles of the model in the daily operations and in the management style taken by the Director (personal communication, Kathy Thomson, 2000). The meetings with the staff and interviews served not only to gather information, but also to engage the staff in the process, thereby putting into practice the tenets of the Primary Health Care model.

Traditionally, evaluations have been conducted “on” agencies, not “with” agencies. An outside source comes in to develop an evaluation plan (Drummond, Stoddart

& Torrance, 1987; Gomby, 1999; Nelson, et al., 1996; Trochim 2002) that meets the needs of program funders or; policy makers. Both of the stakeholders of program funders and policy makers have concerns that the programs they sponsor, either financially, or in principle are an effective use of finances (Hill McPhil, 1997; McKenzie & Smeltzer, 1997; Nelson, et al., 1996; Orchard, 1994; Stark, et al, 1995; Trochim, 2002). Certainly the staff at the Centre was concerned about these issues. They wanted to have the evaluation completed on their Centre, feeling that most clients would provide a positive response that would provide "empirical" evidence of the benefit of the Centre. By obtaining this empirical evidence, the staff felt that the funders would certainly be given the necessary information to continue to financially support the programs.

There is a lack of literature demonstrating the inclusion of staff in the development stages of an evaluation. However, Bea van Beveran and Hetherington (1997), strongly recommend the inclusion of staff to facilitate the successful development of an evaluation. It has been more than adequately demonstrated that the staff at the Centre are certainly a part of the evaluation process and that the staff support the evaluation wholeheartedly. This, as well as the extensive preparation, as recommended by Bea van Beveran and Hetherington (1997), bodes well for a successful evaluation. However, since most evaluations in the literature are reports of the authors' projects, there is a paucity of information on the benefits of the inclusion of staff in the evaluation process as opposed to an evaluation format that uses the evaluator as the only developer of the evaluation plan.

Haas, et al., (2001), determined one of the drawbacks to the evaluation they

conducted was the self-protective stance of principal practitioners in the programs being evaluated and the dependence on the Director to drive the evaluation (the principal practitioners being the staff). With an evaluation using the Primary Health Care model, the staff themselves are the ones driving the evaluation as they are the one determining the content of the evaluation tools. Cousins (2001) found that evaluations developed by outsiders, using the traditional approach of providing the technical guidance (i.e. development of evaluation plan) were not perceived by staff as being tools for change, but instead were tools for providing information for consideration. This type of finding could weaken the impact of the evaluation by not allowing the evaluation to guide change where needed. However, this same study by Cousins (2001) also found that staff who had taken a collaborative role with the evaluator found the experience to be rewarding and beneficial to their practice, even if they did not see the evaluation as a guide for change. This not only provides evidence for the inclusion of the staff in the evaluation process, but also the use of the Primary Health Care model as the framework for the process.

The other benefit of including the staff in the evaluation process is that they can provide a degree of reliability for the evaluation. The reliability can be shown through the congruence between the pre-evaluation conversations with the staff and the results of the implemented evaluation. This may give a type of intersubjective certifiability (Sharp & Eddy, 2001) in that the results are being supported via questionnaires and by staff perception. It is important to remember that the congruence would only be in general terms, not in specifics. After all, if the staff could predict all the responses, there would be no need for an evaluation.

The other part of the literature review that addressed the evaluation literature, was the type of evaluation used, i.e., formative, outcome, or summative. In the final product, this was not a factor in the development of the questionnaires. The questionnaires use a variety of formats, sometimes asking formative, outcome or summative questions. In fact, the literature does support this multi-type approach for evaluations (Bea van Beveran & Hetherington, 1997; Charles, et al., 1994; Cleary, et al., 1992; Cockerill & Charles, 1998; Haas, 2001; van Assema, et al., 1994-1995). It is especially relevant in a social/health agency that is dynamic and changing quickly. To box an agency into one type of evaluation is to risk missing important pieces of the program(s). While this was not a limitation to this evaluation, there were a number of limitations to this evaluation process. These are discussed in the next section.

### Limitations

There are limitations in every evaluation plan and every evaluation questionnaire. The nature of an evaluation is that one will never get all the information one would like. An evaluation is a snapshot in time, it is not a continuous feedback loop that flows dynamically back and forth between staff and clients. Therefore, it needs to be recognized that there will always be limitations that are inherent to an evaluation. The limitations in this evaluation process are similar to those reflected in the literature, as well as being unique to this Centre. Firstly, there are the common limitations, that one sees in the research field, but that are applicable to the evaluation process. The fact the clients are answering questions retrospectively (i.e., they are thinking back to their encounter with the agency) always introduces complicating factors such as history and life events

potentially altering the view of the agency (Rutman, 1992). As well, as noted earlier in this chapter, the expectation of the staff was that clients would respond positively about the services. This reporting bias is always inherent in every evaluation, however, the positive bias reduces as the number of response climbs to about the 30% return rate (Barkley & Furse, 1994). However, these limitations are not really unique to the Centre, and cannot be eliminated; the more concerning limitations address access issues and cost issues.

Even though the Centre has a means to distribute the questionnaires (a mailing list), the system is not specifically targeted to the client population. When the Centre first opened, there was a deliberate decision not to institutionalize (i.e., making this Centre as least like a clinic or hospital as possible) the Centre by taking names and keeping files. This was meant to give women the feeling that this was a Centre that was separate from the medical establishment (B. Shumley, October, 1997). Yet a mailing list was later compiled, with the list of clientele being open to everyone calling the Centre (professionals, family members, and other agencies). This means that individuals other than clients may receive the questionnaire(s). In order to ensure that only those who have used the services answer the questionnaire, instructions are at the beginning asking **ONLY** those women who have had breast cancer and who have used the service to fill out the questionnaire. While this does not entirely weed out non clients, there are also demographic items in the questionnaires that would allow further differentiation of clients and non clients.

Even with the limitations of the evaluation, the questionnaires will still net the



Centre information that will provide guidance to shape and refine programs. Although this was not stated as one of the purposes of the practicum, it certainly has been one of the goals of the Centre and is the purpose for even embarking on an evaluation.

The limitations of the Primary Health Care model as a framework was one of the biggest challenges in this practicum. The model is expansive, which can make it cumbersome to apply at times. Therefore, the development of more focussed indicators and elements was required to pull the information together in a meaningful way. This is discussed in the next section.

### Benefits and Recommendations

The entire practicum and evaluation process has much to contribute to the academic community and the research community (two entities which are not exclusive of each other) and other community agencies. The use of the Primary Health Care model as the framework demonstrated that the Primary Health Care model can be applied in an evaluation setting. Since the Primary Health Care model is endorsed and promoted by the World Health Organization (WHO 1978), and many governments across the world, it is important to use this model not only to develop programs, but also to evaluate programs. The benefit of using the Primary Health Care model to evaluate a program based on this model is that there should be congruency between the program goals and the tenets of the model, as was evidenced in this practicum.

One very important benefit that has been discussed, is the participation and ownership taken by the staff of the Centre. This evaluation planning process permitted staff to "sit back" and really contemplate what their program provided for their clients.

There was affirmation, in their minds, of the importance of the work they were doing and the service they were providing.

The direct benefits to nursing education are numerous, and sometimes subtle. The fact that this model was used in practice provides educators with an example of how to use the Primary Health Care model in a similar situation. People can avoid the known pitfalls, and focus on producing an evaluation that meets the needs of the program they are working with. Another benefit to education is connection between the crucial elements and the tenets of Primary Health Care. This connection, visualized in the evaluation map, testifies to the eminent practicality of the Primary Health Care model. This is not to say that the Primary Health Care model has not been used in program development before; it is quite the contrary, the model has been used successfully. Chanecka (1998) describes a program that was modelled around the Primary Health Care model that was very successful. The fact that the Primary Health Care model can be used to develop a program and be used as a framework for the evaluation speaks to the versatility and practicality. Also, the Primary Health Care model is integrated, sometimes unknowingly, into the very foundation of a program. The critical elements development, the crucial elements and the evaluation map helps one to visualize how the connections between the model and other elements of the program are linked.

Educational benefits also existed for the staff at the Centre. This was the first evaluation they had been involved in at the Centre. Inviting the staff into the evaluation planning process was a learning experience for both the student and staff. Staff at the Centre commented that in preparation for participating in the staff meeting and individual

interviews, they realized certain things about their programs that they had not really given thought to previously. Staff were appreciative of this opportunity, and felt that they came out of this planning process with a clearer understanding of their own programs and of the Centre.

The final educational benefit that will be discussed is the linkage developed to the Achieving Improved Measurement (AIM) program. The AIM program, concept was introduced later in the practicum. This program provides a framework for evaluating community agencies. There are a number of dimensions in this program (as explained in Chapter 5), that correlate to the crucial elements developed in this practicum. The AIM program is being used throughout the province to evaluate community agencies and programs, and therefore it was felt that the AIM program could be superimposed on the crucial elements to check for congruency. In fact, what was discovered was that the AIM program dimensions, the crucial elements and the tenets of the Primary Care model were, in fact, linked to each other. This discovery had a number of implications for the Centre and health care educators.

By including the AIM program in the practicum, the Centre could potentially save much time when it comes time for them to use the AIM program to evaluate their services. When the Centre participates in an accreditation in the future, the learning curve for them will not be as great as if they had had no exposure to the evaluation planning and development process. The evaluation experience can be transferred to subsequent evaluations and help to ease the preparation process for the staff, because the elements identified and the dimensions of the AIM program are very similar, the experiences of this

evaluation process can be transferred to an evaluation process using the AIM model.

The value of this practicum in terms of education is further reaching than what is practical to be discussed in this chapter. However, these benefits would depend on what one may choose to focus on. Each piece of the practicum, from the evaluation planning process, the questionnaire development, the development of linkages between the crucial elements and the Primary Health Care model have implications for education and research. While the list will not be explored exhaustively, the following will provide an idea of what can be done in the research arena with the information generated from this practicum.

The benefits to research are also numerous and are intermingled with the benefits to education. Immediate questions that arise from this practicum, are, where is the client/user input? Client and patient satisfaction literature does not widely support the use of clients, consumers, as active members of the evaluation planning process. However, in keeping with the Primary Health Care model, there should be extensive consumer participation in this area. Therefore, in order to facilitate consumer participation, the Centre may want to use the results to identify gaps in their programs (or in the evaluation), and conduct a focus group on those topics, to allow a deeper understanding of the impact of the services. The Centre may also try individual interviews if they required more detailed data, again using topics identified through the initial evaluation. The beauty of the Primary Health Care model is that all of this can be achieved using the model to guide the evaluation planning process and the content.

The evaluation planning process did demonstrate the practicality of the Primary

Health Care model from a research stand point. If the Primary Health Care model can be a framework for evaluation development, it may be the framework to use when evaluating a program or agency that evinces the Primary Health Care model as an integral part of its existence. The literature has supported using a variety of models ( Bea van Beveran & Hetherington, 1997; Charles, et al., 1994; Cleary, et al., 1992; Cockerill & Charles, 1998; Donabedian, 1986; Haas, 2001; van Assema, et al., 1994-1995 ), but these models do not have an underpinning that reflects the essence of the service. Using the Primary Health Care model as a framework for an evaluation for an agency or program that has the Primary Health Care model as the underpinning of their foundation may produce data that is more applicable to the agency as opposed to more generic data (eg., comfortable chairs, friendly staff and so forth). The reason for this would be that the Primary Health Care model would drive the content of any evaluation, thereby ensuring the content reflects the essence of the program. To demonstrate this there would, of course, need to be evaluations conducted on the same agency twice, using two different models. The costs for this would likely be prohibitive.

It is important to recognize that the use of the Primary Health Care model does not preclude the use of any certain type of evaluation design, or even the evaluation model. The questionnaires produced for this practicum draw on a variety of models in various questions, with some questions being summative questions, some formative and some outcome questions. This does not diminish the importance of the Primary Health Care model as the type of questions are overshadowed by the content of the questions. So by using the Primary Health Care model as a framework, one is able to utilize a variety of

methods and models and still remain true to the philosophy and core of the values of the model.

Evaluation research needs to be conducted using the Primary Health Care model as a framework in order to establish the credibility of the model in the research arena. It is an under utilized model in evaluation. This may be due to the fact that not enough people recognize the Primary Health Care model as a framework for evaluation, or that the model is not proscriptive enough (i.e it does not tell people what to do and what steps to take), that it is cumbersome at times to work with because it is so broad. However, it has now been shown to be an effective framework. It has also been shown that the use of other tools (such as the guidelines by Bea van Beveran and Hetherington, 1997) can work with the Primary Health Care framework to build an evaluation that reflects the agency and the model.

### Conclusion

Again, restated, the purpose of this practicum was to: (1) develop evaluation tool(s) that incorporate the Primary Health Care model as a framework, and (2) outline a guideline for implementation consideration. Using the Primary Health Care model as a framework was a challenging task. However, as can be seen, it is accomplishable. The tools developed clearly link to the goals of the Centre awhile still reflecting the Primary Health Care model. The guideline for implementation also took into account the Primary Health Care model, keeping in mind the financial restraints of the Centre. This practicum not only used the Primary Health Care model as a framework for the evaluation development, but also directed how the planning process would be conducted. Using the

Primary Health Care model in this way led to more staff participation and ownership. The Centre now benefits from having the questionnaires, and the student has been able learn the evaluation process from beginning to end. The proof that the Primary Health Care model can be used as a framework for an evaluation lends credence to the model and shows its versatility. The Primary Health Care model should be further explored as a framework for evaluations in every setting in health care. The process itself can bring many benefits, as well as the outcome.

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## Appendix A

### "Breast Cancer Centre of Hope Program Overview

The mission of Breast Cancer Centre of Hope is to enhance the quality of breast cancer care for all Manitobans by providing a compassionate and comprehensive breast cancer information, support and referral service. This is achieved through the combined expertise of nurses and trained volunteers. Specialist nurses provide information, counseling and timely referrals that are supplemented by a comprehensive peer support program where specially trained breast cancer "survivors" provide one-on-one support. A comprehensive lending library, a no-charge prosthesis bank and a quarterly newsletter are also part of the program. Programming at Breast Cancer Centre of Hope also addresses the information and support needs of Manitoba residents who do not access services at the 691 Wolseley location through several approaches including:

- a toll-free information and support line;
- rural volunteers, called Community Contacts, who disseminate resources to clients/ families in their home communities;
- Volunteer "information and support networks" in each Regional Health Authority across the province.

The Community Contact and Network volunteers each partner with Breast Cancer Centre of Hope to ensure that citizens across the whole province have equitable access to meaningful and relevant breast cancer information and support. Information and support programming is also extended through volunteer opportunities. Within the volunteer domain, breast cancer survivors are involved in: offering support through the peer support program; identifying gaps in services; contributing to program planning; and participating in program delivery (presentations, committee work, and conferences / workshops). A variety of breast cancer awareness activities including conferences, workshops, quality of life events (art exhibits, supportive yoga, support groups) are also facilitated through Breast Cancer Centre of Hope." (Breast Cancer Centre of Hope pamphlet, 2000).

## **Mission Statement and Goals of Breast Cancer Centre of Hope**

### **The Breast Cancer Centre of Hope**

#### **Mission Statement:**

"We are dedicated to excellence in cancer care for all Manitobans. We strive to prevent, endeavour to, and are committed to enhance the quality of life for people living with cancer." (Field Notes, Appendix 1)

#### **Philosophy:**

The philosophy of HOPE is the application of the Mission Statement.

"The service addresses the information and support needs of individuals and families who are concerned about breast health and/or breast cancer. The staff will work to ensure individuals have timely and appropriate access to information, treatment, support (peer and professional), by calling on existing provincial services" (Field Notes, Appendix 1).

#### Goals:

The goals of HOPE relate to the Mission Statement and Philosophy. The goals are listed below.

- 1) To provide reliable breast health/cancer information and support to citizens of Manitoba
- 2) To enable compassionate, trained peer support and promote communication between caregivers
- 3) To establish and facilitate two-way referrals to already existing resources
- 4) To support and understand on-going breast cancer research
- 5) To raise awareness of breast cancer through education and information
- 6) To establish linkages and foster collaboration among activities related to breast cancer across the province
- 7) to establish breast cancer outreach programming which recognizes multicultural and geographic diversities
- 8) To promote education of health professional/providers in rural areas
- 9) to promote public/patient access to appropriate and timely information and services along the continuum. For example, mammography, psychosocial support, family involvement/support, and consultation with medical professionals
- 10) To facilitate equal access to quality care for all Manitobans by giving consideration to geographical similarities and differences (Field Notes, Appendix 1).

Notes on Goals:

It is important to note that the staff decided goal #4, to support and understand on-going research was not a large part of their services at this time. Therefore this goal would not be looked at in reference to the development of an evaluation.

The other consideration is the extensive list of goals. As the list was very long, it was decided that it would be more meaningful to identify the main programs within HOPE and determine which goals are incorporated into the programs. Prioritization of goals was difficult as staff felt that all were very important, and the various programs contributed to the realization of the goals.

The four programs identified were:

- 1) Volunteer Programs,
- 2) Community Capacity Building Programs,
- 3) Patient Services Programs\*, and
- 4) Support Programs.

\*Patient Services program include information and resources, including the prosthesis bank.

**Appendix B:****Invitation to Participate**

Brenda Janz  
XXXXXXXXXXXXXX  
Winnipeg, Manitoba  
R3M 0G1

Breast Cancer Centre of Hope  
691 Wolseley Avenue  
Winnipeg, Manitoba  
R3G 1C3

Date

Dear:

Thank you for taking the time to meet with me to discuss the evaluation plan for the Breast Cancer Centre of Hope. The purpose of this meeting is to allow you an opportunity to discuss your program and what you would like to see in an evaluation.

In this meeting, we will specifically discuss the various subprograms within your program and the actions taken to fulfill the program objectives. As well, we will be looking at the indicators of quality care, i.e., the means by which you would measure the success of the program.

If you would like any further information to help prepare for this meeting, please call me @ (h) XXX-XXXX.

Thank you for your time, and I look forward to meeting with you.

Yours Truly,

Brenda Janz, R.N., B.N.

**Appendix C:  
Second Letter of Invitation**

Brenda Janz  
XXXXXXXXXX  
Winnipeg, Manitoba  
R3M 0G1

Breast Cancer Centre of Hope  
691 Wolseley Avenue  
Winnipeg, Manitoba  
R3G 1C3

Date

Dear:

Thank you for taking the time to meet with me again on XXXX 2002. The purpose of this meeting, as discussed briefly in our conversation, is to gain some feedback from you about the summary of the objectives (drawn from previous meetings), and to draw on your knowledge of your program to aid in developing the evaluation tool(s).

In order to help you prepare for this, I have included a copy of the summary of meetings. All programs are included in this, but I would ask that you focus on XXXX program (starting on p xx)

First, I would like us to review the summary of our previous meetings and determine if this summary reflects what you think was discussed (under section "XXXX"). Second, I would like to hear from you if you believe the summary captures the important elements of what should be evaluated in your program. Third, I would like us to delve a bit deeper into what you feel may be one or two of **the most crucial** elements of your program that should be evaluated. The intention is that we would be able, between the two of us, to decide the key elements that need to be measured and what these elements will measure. The indicators of quality care may help us in determining what should be measured and what may be left out of the evaluation tool(s), and help us to focus on what some of the key elements may be.

If you would like any further information to help prepare for this meeting, please call me @ (w)837-0309, (h) 269-4651.

Thank you for your time, and I look forward to meeting with you.

Yours Truly,

Brenda Janz, R.N., B.N.

## Appendix D Summaries of Individual Meetings

### Volunteer Programs:

#### Relevant Goals:

- 1) To enable compassionate, trained peer support and promote communication between caregivers (GOAL #2)
- 2) To establish linkages and foster collaboration among activities related to breast cancer across the province. (GOAL #6)

#### Actions to realize goals:

The actions to realize these goals come under the actions taken to establish sub-programs within the volunteer services.

#### **Volunteer Program (General):** Purpose/Objectives

- 1) Provide volunteers the opportunity to contribute to the breast cancer community that is suited to each individual volunteer.
- 2) Train and support volunteers to ensure that volunteers are satisfied and able to complete their tasks
- 3) Ensure that training and activities are tailored to ensure that volunteer work is connected to improving the quality of life of women with breast cancer.
- 4) Extend the reach of and mission of HOPE thorough developing volunteer services outside of Winnipeg
- 5) Foster a climate of courtesy, respect and accountability between staff and volunteers

#### Indicators of quality programming :

- 1) Volunteer Satisfaction, i.e., is the volunteer work meaningful, do the volunteers feel they are making a contribution to the breast cancer community.
- 2) The number of volunteers, where they come from and number of volunteer hours.
- 3) The output/outcome of volunteer hours, i.e., what happens, does the work get done, does volunteering make an impact on the volunteers and the women they interact with.

**Volunteer Programs (Peer):**  
Purpose/Objectives

- 1) Offer training in medical information, coping and listening to breast cancer survivors willing to become peer support volunteers
- 2) To match clients with survivor-volunteer, for the purpose of counselling, resource, and complement professional services
- 3) To provide survivor volunteers with opportunities to meaningfully contribute to quality of life to other women with breast cancer and other breast cancer survivors - enabling the volunteer to empower others and contribute to their own quality of life
- 4) To empower volunteers and clients through mutual contact and aid
- 5) To provide support to survivor-volunteers through group meetings and staff support.

Indicators of quality programming:

- 1) Client satisfaction: are the women who receive the volunteer-survivor feel satisfied with the match, the information and support received from the volunteer-survivor.  
It should be noted that this is being checked on an informal basis when follow up is done through another staff member.
- 2) Supporter satisfaction: are the volunteer-survivors satisfied with their role, the group support format and the staff support they receive. The volunteer coordinator monitors the stress of the demands and workload through individual contact.
- 3) Clustering of support groups: do the volunteers in each group find support from each other, is the training adequate.

These are the 2 main programs under the Volunteer Program that require an evaluation. There are three other sub-programs that are part of the larger Volunteer program.

**Newsletter:**  
Purpose/Objectives

- 1) Provide information about breast cancer/health in print to citizens of Manitoba
- 2) Raise awareness of breast cancer resources to citizens of Manitoba
- 3) Address equity and access issues through wide distribution of newsletter
- 4) provide a format that allows easy reading
- 5) Impart valuable information and support through shared stories that facilitate empowerment of survivors through their input

Indicators of quality programming:

- 1) Reader Feedback
- 2) Impact: are there new support groups, is information imparted being utilized (eg., if a new toll free phone number is printed, is that number being used as a result of the number being published)
- 3) Internal feedback, staff and contributors.

**Website:**

## Purpose/Objectives

- 1) Reach maximum number of people regardless of viewer locale
- 2) Raise awareness of HOPE
- 3) Provide attractive website with pertinent information.

Indicators of quality programming:

- 1) Number of hits, how many people look at the site
- 2) number of people staying on the site and reading some of the information
- 3) Colleague feedback.

**Special Events:**

These events include presentations, conferences, exhibits, etc. Volunteer is usually required in some way, but may not be the focus.

These events need to be evaluated on an individual basis, as the goals and objectives may be different for each event.



### **Support Services/Patient Services \*:**

\*Patient services and support services are often provided simultaneously. For example, when providing information on breast cancer treatments, the nurse at the Centre may also be providing emotional to the person asking for the information, or cross referring the person to another service. Therefore, the goals are shared between the two programs, and will be examined under the same section, with sub headings delineating between the two programs.

#### **Relevant Goals:**

- 1) To provide reliable breast health/cancer information and support to citizens of Manitoba (GOAL # 1)
- 2) To enable compassionate, trained peer support and promote communication between caregivers (GOAL #2)
- 3) To establish and facilitate two-way referrals to already existing resources (GOAL #3)
- 4) To raise awareness of breast cancer through education and information (GOAL # 5)
- 5) To promote public /patient access to appropriate and timely information and services along the continuum. For example, mammography, psychosocial support, family involvement/support, and consultation with medical professionals (GOAL 9).

### **Support Services:**

These goals are realized through:

- 1) Telephone contact
- 2) One on one contact
- 3) Peer support
- 4) General environment (addressed under Patient Services)

#### **Indicators of quality programming:**

##### **1) Telephone:**

Was the response from staff appropriate?  
Was follow up appropriate?

##### **2) One on one contact (counselling with women and families):**

Was counselling helpful?

- timely? Was amount of time spent with client appropriate, was service
- empowerment? Did the counselling help with client's coping?  
 Do client's like how staff encourage /facilitate client
- Did the counselling help with client's treatment decision making?  
 Was follow-up appropriate?  
 Were referrals appropriate?

These two activities take most of the time under the heading of this program.

3) Peer Support (women receiving the peer support):

- Was the peer support program accessible?  
 Was follow-up appropriate, enough, too little?  
 Did the peer support program provide the support for the woman?

Peer support criteria were also discussed under the volunteer programs.

### **Patient Services:**

These goals are realized through:

- 1) Resource dissemination
- 2) Prosthesis bank
- 3) General Environment

#### Indicators of quality programming:

1) Resource dissemination:

- Is the information up-to-date?  
 Is the information accurate?  
 Is the information contradictory to what the women have already received?
- Was the amount of information given appropriate?  
 Was website used?  
 Was computer useful?  
 Was the resource available in a timely manner?

2) Prosthesis Bank:

bank at

Was the bank accessible, to those in and out of the city?  
Are people in the rural area aware they can access the prosthesis

HOPE?

Did the client get the prosthesis that was right for them?

6) General environment:

Was the environment conducive to sharing confidences, opening up and asking for resources?

### **Community Capacity Building Programs**

#### Relevant Goals

- 6) To provide reliable breast health/cancer information and support to citizens of Manitoba (GOAL #1)
- 7) To establish linkages and foster collaboration among activities related to breast cancer across the province (GOAL #6)
- 8) to establish breast cancer outreach programming which recognizes multicultural and geographic diversities (GOAL #7)
- 9) To promote education of health professional/providers in rural areas (GOAL #8)
- 10) To facilitate equal access to quality care for all Manitobans by giving consideration to geographical similarities and differences (GOAL #10)

#### Actions to realize these goals

The community capacity building program consists of mainly four sub-programs. Programs may not be the most accurate description of these activities, as they are not necessarily generated by staff at the Centre. However the activities involved in the Networks, and Community Contact Program are an integral part of the Community Capacity building strategy.

#### Programs

- 11) Breast Cancer Network
- 12) Community Contact Program
- 13) Community Partners
- 14) Community Outreach

## **Breast Cancer Network**

### Preamble on the history of the Breast Cancer Network

The Breast Cancer Network was developed as a result of funding from Health Canada. The network consists of a Representative from each Regional Health Authority (RHA) that has volunteered to represent their region. The Community Capacity Building approach is embodied in the volunteers' ability to make autonomous decisions based on their region's needs. The Network has been developed in the phases, with the third phase now in operation.

Phase 1: The funding was specifically targeted to allow people from across Manitoba to come together in one location to meet and discuss issues around disseminating information and support on breast cancer to women in Manitoba. The Breast Cancer Centre of Hope was the administrative arm of the network. The funds were funnelled through the Breast Cancer of Hope, to allow a central distribution of funds, at a community level (instead of a government level). Therefore, Hope becomes the centre of a network.

Phase 2: Funding available to enhance information and support services in these networks. This funding may have been used to transport the network contact to a workshop in Winnipeg, to purchase needed supplies, or bring in speakers. The Breast Cancer Centre of Hope was the centre for the distribution of these funds. While the Centre did not dictate what the networks could buy, the Centre did require that the networks provide rationale for their use of the funds. This ensured accountability of funds at the community (grassroots) level and the administrative level.

Phase 3: Phases 1&2 allowed for the development and expansion of the networks, while phase 3 aims for sustainability of the networks. Now that the infrastructure is in place, with Hope the "administrative" centre, the staff at Hope are now looking at strategies to help sustain this network. Strategies that are being employed to sustain this network need to be evaluated.

### Actions to Maintain the Breast Cancer Network

- 1) Newsletter: Manitoba Breast Cancer Information and Support Network
- 2) Network exchanges (information from Hope Network Contact)
- 3) Dialogue with Network Representatives

### Indicators of Quality Programming

- 1) Newsletter (Appendix 3):
  - Are the recipients reading the newsletter
  - Is the information valuable?
  - Do they feel they have input
  - Do they feel their input is valued?
  - Do they want to have input (originally the network reps asked for the newsletter)
  - What gaps in information are there, anything they would like to see but haven't
  - Would they like more resources
  - Are the resources that are sent out useful (eg, MAMM)
  
  - Does the newsletter facilitate dialogue between regions
  - Is the Hope contact person accessible for assistance
- 2) Network Exchanges (Appendix 4):
  - Is the information provided by the Hope contact useful/relevant
  - Is the information in this memo redundant to the Newsletter
  - Is this sent out often enough, too often or not enough
- 3) Hope Network Contact Person
  - Is the contact person at Hope accessible to the other contacts
  - Does the contact person facilitate linkages between regions
  - How does the contact person at Hope facilitate linkages between regions
  - Does the contact person at Hope spend enough time with the network reps
  - Is the network organized
  - Are there any gaps

### **Community Contact Program**

#### Community Contact Program vs. Network Representatives:

The Community Contact Program was started with funding from Breast Cancer Info Links that originated in Alberta Canad. The Community Contact were volunteers who were "information brokers" for women seeking information on

breast cancer. While Hope does not have jurisdiction over this program, they do support the program by maintaining a dialogue with the Community Contact person. As well, the Community Contact person may be the same person who has volunteered for the Network Rep.

The main difference between the two programs is that the Community Contact person deals with women on an individual basis, and provides each woman with the information requested. The Network Rep will work at a community level to raise awareness and address issue around breast cancer as those issues relate to their community (Field Notes, August 29, 2001, p22). For example, instead of providing individual information, the network rep may purchase a supply of informational booklets.

#### Actions to Maintain Program:

- 1) Linkages Newsletter
- 2) Hope contact person

#### Indicators of quality programming:

- 1) Linkages Newsletter:  
Same as criteria for "Our Voice" in the volunteer section
- 2) Hope contact person  
Same as criteria for previous section on Hope Network Contact person

### **Community Partners**

#### What are Community Partners?

Community partners are other services in Winnipeg and the province that Hope may have close linkages with. Some examples of community partners are: the Breast Health Centre, the Community Cancer Program Network and the Breast Screening Program. The community partners are agency to agency connections. The agencies may share resources as part of mandate of the Breast Cancer Centre of Hope, and, the partnership itself reflects the goals of Hope. There is, most often, a key contact person with the community partner that the contact person at Hope dialogues with. This contact person may be the key to evaluating this part of the Community Capacity Building Strategy.

#### Actions to maintaining and building community partners:

- 1) Dialogue with contact person at Hope

## 2) Shared Initiatives

### Indicators of Quality Programming

- 1) Dialogue with contact person at Hope:
  - Was the person at Hope helpful
  - Were they able to provide information/resources that could be used
  - Was Hope receptive to their query
  - Would they access Hope again (client satisfaction) for 1) networking, 2) information
- 2) Shared Initiatives
  - Were there any shared initiatives as a result of the networking with Hope
  - Were these initiatives well received by the target population

## **Community Outreach**

### Community Outreach Is.....:

Community outreach refers to the educational programs, lectures, presentations and workshops that the staff at Hope may do. These are events that Hope would be invited to, eg. Asked to do a "Breast Health Clinic" at certain pharmacies in the city. Hope will provide the personal, expertise and information. Hope will be disseminating information, which may lead women to become more involved in the breast cancer community.

### Actions to maintain program:

- 1) Speaking Engagements
- 2) Resource Development

### Indicators of Quality programming:

- 1) Speaking Engagements:
  - That people go away being aware of Breast Cancer Centre of Hope
  - Was the information helpful/relevant
  - Did the speaker present well, i.e., voice modulation, speed of presentation, style of presentation, use of humour
  - What was the most NB piece of information heard at this presentation
  - What was the least helpful information heard
  - Would you recommend Hope to women with breast cancer
- 2) Resource Development:
  - Were the resource available

Were the resources relevant/helpful  
Did the resource have accurate information, was it current etc.

### **Priorities for Evaluation**

The priorities for evaluation as determined through meetings with the staff are unique to each program in that the specific indicators of quality programming are different. However, the general categories in which the indicators can be grouped are similar throughout the programs. The priorities that seem to come through in the discussions with staff are: 1) Client Satisfaction, 2) Client Empowerment, 3) Client Outcomes and 4) Communication. The following chart indicates how the programs and sub-programs fit under the groupings of evaluation priorities.



## Appendix E

### Linkages Between Critical Elements and the Primary Health Care Tenets

Programs/Subprograms	Primary Health Care Tenets	Interview 1: Indicators of Care	Shared Tenets	Interview 2: Crucial Elements
<b>Volunteer Program</b>				
1. General	Equity (Eq)	1. (a) Volunteer Satisfaction (b) Volunteer Progress (c) Volunteer Outcome	HC, Em AC, ID	1 (a) Community (b) Productivity
2. Peer	Acceptable Care (AC)	2. (a) Client Satisfaction (b) Supporter Satisfaction (c) Volunteer Cohesiveness	HC, AC, Em	2 (a) Community (b) Empowerment
3. Newsletter	Holistic Care (HC)	3. (a) Reader Feedback (b) Impact (c) Internal Feedback	Eq, AC, HC	3 (a) Relevance (b) Equity (c) Empowerment
4. Website	Empowerment (Em)	4. (a) Quantity of logins (b) Length of logins (c) Colleague feedback	Eq AC	4 Website not well developed, and therefore will be deferred for analysis at this time
5. Special Events	Intersectoral Development (ID)	5. Each program has individual needs and needs to be examined on a case by case basis. 2nd interview provided a specific example.	Eq, HC, ID, Em. AC	5. "Together 2002" Conference (a) Empowerment (b) Community Activism

Programs/Subprograms	Primary Health Care Tenets	Interview 1: Indicators of Care	Shared Tenets	Interview 2: Crucial Elements
<b>Support Services/Patient Services</b>				
<b>1. Support Services</b> Telephone	Equity (Eq)	1 (in). Telephone (a) Staff Appropriate (b) Follow-up Appropriate	HC, AC	1 (i). Telephone (a) Client Satisfaction (b) Appropriateness
One on One Contact	Acceptable Care (AC)	1 (ii). One on One Contact (a) Helpful (b) Appropriate time spent (c) Facilitate Coping (d) Facilitate Empowerment (e) Facilitate Independent Treatment Decision Making (f) Appropriate Follow-up (g) Appropriate Referrals	AC	1 (ii). One on One contact (a) Helpful (b) Appropriate Follow-up
Peer Support	Holistic Care (HC)			
	Empowerment (Em)			
	Intersectoral Development (ID)	1 (iii). Peer Support (a) Accessibility (b) Follow-up Appropriate (c) Adequate Support	Eq, AC, HC	1 (iii). Peer Support (a) Accessibility (b) Appropriate Follow-up (c) Group Peer Support
<b>2. Patient Services</b> Resource Dissemination		2 (in). Resource Dissemination (a) Current Information (b) Accurate Information (c) Consistent Information (d) Quantity of Information (e) Resource Helpfulness (f) Resource Availability	HC, AC	2 (i). Resource Dissemination (a) Consistency in Information (b) Appropriateness

Programs/Subprograms	Primary Health Care Tenets	Interview 1: Indicators of Care	Shared Tenets	Interview 2: Crucial Elements
<b>Community Capacity Building Program</b>  <b>1.Community Networks</b>  1 (in). Newsletter: Manitoba Breast Cancer Information and Support Network (MBCI)          1 (ii). Network Exchanges          1 (iii). Hope Network Contact Person	Equity (Eq)  Acceptable Care (AC)  Holistic Care (HC)  Empowerment (Em)  Intersectoral Development (ID)	1(in).Newsletter (MBCI) - Recipient reading newsletter - Information valuable - Feel they have input (readers) - Is input valued - Do they want to continue with input - Any gaps in information - Is there a need more resources - Are resources sent useful  1 (ii). Network Exchanges (a) Information useful/relevant (b) Is information redundant from that sent in other newsletters (c) Information sent too often/not enough  1 (iii). Hope Network Contact Person (a) Accessibility (b) Facilitates linkages between regions	HC, AC, Em          AC, HC          Eq, AC	1. Newsletter (a) Appropriateness (b) Value          1 (ii). Network exchanges (a) Appropriateness (b) Value          1 (iii). Hope Network Contact Person (a) Accessibility (b) Value

Programs/Subprograms	Primary Health Care Tenets	Interview 1: Indicators of Care	Shared Tenets	Interview 2: Crucial Elements
<b>2. Community Contact Program</b>  2 (in). Linkages Newsletter  2 (ii). Hope Contact Person  <b>3. Community Partners</b>  3 (in). Dialogue with Contact Person at Hope	Equity (Eq)  Acceptable Care (AC)  Holistic Care (HC)  Empowerment (Em)  Intersectoral D Development (ID)	2 (in). Linkages Newsletter (a) Reader Feedback (b) Impact (c) Internal Feedback  2 (ii). Hope Contact Person (a) Accessibility (b) Facilitates linkages between regions (c) How are linkages facilitated (d) Time spent with contact enough (e) Network organized (f) Any gaps  3 (in). Dialogue with Contact Person at Hope (a) Person at Hope helpful (b) Information provide useful/relevant (c) Hope receptive to query (d) Would they access Hope again for networking and information	N O T  A P P L I C A B L E  AC, HC	2 (in). Linkages Newsletter Not Reviewed as program is not running  2 (ii). Hope Contact Person Not reviewed as program is not running  3 (in). Dialogue with Contact Person at Hope (a) Value of Partnerships (b) Existence of partnerships...beginning stages of intersectoral development

Programs/Subprograms	Primary Health Care Tenets	Interview 1: Indicators of Care	Shared Tenets	Interview 2: Crucial Elements
<b>4. Community Outreach</b>				
4 (in). Speaking engagements	Equity (Eq)  Acceptable Care (AC)  Holistic Care (HC)	4 (in). Speaking Engagements (a) Increased awareness of Hope (b) Information helpful/relevant (c) Presentation style (d) Most important piece of information heard (e) Least helpful information heard (f) Would they recommend Hope to other women with breast cancer	AC, HC, Em	4 (in). Speaking Engagements (a) Value (b) Accessibility
4 (ii). Resource Development	Empowerment (Em)  Intersectoral Development (ID)	4 (ii). Resource Development (a) Were resources available (b) Resource relevant/helpful (c) Information accurate, current, etc.	Eq, AC, HC	4 (ii). Resource Development (a) Value (b) Accessibility

## Appendix F Questionnaires

### Volunteer Survey

This survey has been developed to gather information from people who have been, or are presently **Volunteers** with the Breast Cancer Centre of Hope. The results of this survey will be used to enhance and improve the programs at the Centre so that we may meet the needs of the people who use the Centre, people like you. Please take some time to fill out this survey. There is an attached sheet at the end of the survey for any additional comments or questions you may have. If you would like to elaborate on any of the answers to your questions, please feel free to do on this sheet. You may attach additional sheets if you need more space. All results will be compiled and no individual responses will be identifiable.

Thank You for Your Time

- 1) How did you become involved in volunteering with the Breast Cancer Centre of Hope?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
  
- 2) To what degree do you feel you belong to the volunteer group at the Breast Cancer Centre of Hope?  
**A Great Deal** \_\_\_\_\_ **Somewhat** \_\_\_\_\_ **A Little** \_\_\_\_\_  
**Not Much** \_\_\_\_\_ **Not at All** \_\_\_\_\_
  
- 3) What makes you feel a part of the volunteer group?  
**Attending Meetings** \_\_\_\_\_ **Telephone Communications** \_\_\_\_\_  
**Individual Support from Other Volunteers** \_\_\_\_\_ **Common Purpose** \_\_\_\_\_  
**Support from Volunteer Coordinator** \_\_\_\_\_  
**Support from Other Staff at HOPE** \_\_\_\_\_  
**Other (Please Explain)** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
  
- 4) What volunteer activities do you participate in?  
**Peer Group Support** \_\_\_\_\_ **Individual Support** \_\_\_\_\_ **Conferences** \_\_\_\_\_  
**Newsletter** \_\_\_\_\_ **Office Work** \_\_\_\_\_  
**Other (Please Explain)** \_\_\_\_\_  
 \_\_\_\_\_

- 5) How welcome do you feel when participating in volunteer activities?  
**Very Welcome** \_\_\_\_\_ **Welcomed** \_\_\_\_\_  
**Neither Welcome Nor Unwelcome** \_\_\_\_\_ **Not Very Welcome** \_\_\_\_\_  
**Not Welcome** \_\_\_\_\_

- 6) How important are the following activities in making you feel welcome? Please check the response in each set of activities that best describes your experience.

Friendliness of the volunteer group

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Issues discussed in groups

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Setting

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Friendliness of Individuals in the group

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Activities available for volunteering

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Orientation to volunteer activities

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

Food Available

**Very Important** \_\_\_\_\_ **Important** \_\_\_\_\_  
**Neither Important Nor Unimportant** \_\_\_\_\_ **Not Very Important** \_\_\_\_\_  
**Not Important at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

- 7) How would you rate the support you receive from the other volunteers?  
**Very Helpful** \_\_\_\_\_ **Helpful** \_\_\_\_\_ **Neither Helpful Nor Unhelpful** \_\_\_\_\_  
**Not Very Helpful** \_\_\_\_\_ **No Support at All** \_\_\_\_\_
- 8) How would you rate the support you receive from the Volunteer Coordinator?  
**Very Helpful** \_\_\_\_\_ **Helpful** \_\_\_\_\_ **Neither Helpful nor Unhelpful** \_\_\_\_\_  
**Not Very Helpful** \_\_\_\_\_ **No Support at All** \_\_\_\_\_
- 9) Do you feel you are as involved in your volunteer experience as you want to be?  
**Yes, Very Involved** \_\_\_\_\_ **Yes, Involved as Much as I Want to Be** \_\_\_\_\_  
**Yes, Involved *Almost* as Much as I Want to Be** \_\_\_\_\_  
**No, Not as Involved as I Want to Be** \_\_\_\_\_  
**No, Not Involved Enough at All** \_\_\_\_\_
- 10) Do you feel you make a contribution to the Breast Cancer Centre of Hope through your volunteering?  
**Yes, A Significant Contribution** \_\_\_\_\_ **Yes, A Good Contribution** \_\_\_\_\_  
**Yes, A Small Contribution** \_\_\_\_\_ **No, Not a Significant Contribution** \_\_\_\_\_  
**No, No Contribution at All** \_\_\_\_\_
- 11) How would you rate the value of your contribution to the Breast Cancer Centre of Hope?  
**Very Valuable** \_\_\_\_\_ **Valuable** \_\_\_\_\_  
**Neither Valuable Nor Unvaluable** \_\_\_\_\_ **Not Very Valuable** \_\_\_\_\_  
**Not Valuable at All** \_\_\_\_\_
- 12) How valued do you feel by the Breast Cancer Centre of Hope?  
**Very Valued** \_\_\_\_\_ **Valued** \_\_\_\_\_  
**Neither Valuable Nor Unvaluable** \_\_\_\_\_ **Not Very Valued** \_\_\_\_\_  
**Not Valued at All** \_\_\_\_\_
- 13) How would you rate your satisfaction with your volunteer role?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_  
**Neither Satisfied Nor Dissatisfied** \_\_\_\_\_ **Not Very Satisfied** \_\_\_\_\_  
**Not Satisfied at All** \_\_\_\_\_
- 14) How would you rate your satisfaction with the support provided by the Volunteer Coordinator?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_  
**Neither Satisfied Nor Dissatisfied** \_\_\_\_\_ **Not Very Satisfied** \_\_\_\_\_  
**Not Satisfied at All** \_\_\_\_\_



- 15) How would you rate your satisfaction with the support provided by the breast Cancer Centre of Hope?

**Extremely Satisfied** \_\_\_\_\_ **Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not Satisfied at All** \_\_\_\_\_

- 16) (a) Has your volunteer role affected other areas of life, such as work or home, in addition to your breast cancer experience?

**Yes, Very Much** \_\_\_\_\_ **Yes, In Some Areas** \_\_\_\_\_  
**Only in My Breast Cancer Experience** \_\_\_\_\_ **No, Not at All** \_\_\_\_\_

- (b) Please describe how has it affected you.

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Thank You for Completing the Questionnaire

### Peer Support: GROUP and INDIVIDUAL

This survey is designed to solicit information from women who have used the **GROUP** and **INDIVIDUAL** support services available through the Breast Cancer Centre of Hope. Please check (✓) your answer and use the space provided for additional information. You may use the back of the page for any information that does not fit in the spaces provided.

Thank You

- 1) Did you receive peer support services from BCCH?

Yes \_\_\_\_\_ No \_\_\_\_\_

- 2) If you received peer support services, what kind did you receive?

**INDIVIDUAL Peer Support Volunteer** \_\_\_\_\_ **GROUP Peer Support** \_\_\_\_\_  
**Both** \_\_\_\_\_

- 3) How easy was it for you to connect to this service?

**Very Easy** \_\_\_\_\_ **Easy** \_\_\_\_\_ **Difficult** \_\_\_\_\_ **Very Difficult** \_\_\_\_\_

- 4) What made it easy? \_\_\_\_\_

\_\_\_\_\_

What made it

difficult? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

- 5) Overall, how would you rate your interactions with the:

- 1) **INDIVIDUAL Peer Support Volunteer?**

**Excellent** \_\_\_\_\_ **Very Good** \_\_\_\_\_ **Good** \_\_\_\_\_ **Fair** \_\_\_\_\_ **Poor** \_\_\_\_\_

- 2) **GROUP Peer Support?**

**Excellent** \_\_\_\_\_ **Very Good** \_\_\_\_\_ **Good** \_\_\_\_\_ **Fair** \_\_\_\_\_ **Poor** \_\_\_\_\_

- 6) How helpful was the **INDIVIDUAL** peer support volunteer?

**Very Helpful** \_\_\_\_\_ **Helpful** \_\_\_\_\_ **Neither Helpful Nor Unhelpful** \_\_\_\_\_

**Not Very Helpful** \_\_\_\_\_ **Not Helpful at All** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_

- 7) How helpful was the **GROUP** peer support?  
**Very Helpful**\_\_\_\_ **Helpful**\_\_\_\_ **Neither Helpful Nor Unhelpful**\_\_\_\_  
**Not Very Helpful**\_\_\_\_ **Not Helpful at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 8) How would you rate the support provided to you by the **INDIVIDUAL** support volunteer in relation to your breast cancer?  
**Very Helpful**\_\_\_\_ **Helpful**\_\_\_\_ **Neither Helpful Nor Unhelpful**\_\_\_\_  
**Not Very Helpful**\_\_\_\_ **Not Helpful at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 9) How would you rate the **GROUP** peer support for helping you in relation to your breast cancer?  
**Very Helpful**\_\_\_\_ **Helpful**\_\_\_\_ **Neither Helpful Nor Unhelpful**\_\_\_\_  
**Not Very Helpful**\_\_\_\_ **Not Helpful at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 10) How would you rate the **GROUP** peer support for helping you in relation to your volunteer experience?  
**Very Helpful**\_\_\_\_ **Helpful**\_\_\_\_ **Neither Helpful Nor Unhelpful**\_\_\_\_  
**Not Very Helpful**\_\_\_\_ **Not Helpful at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 11) Would you recommend the **INDIVIDUAL** peer support volunteer to other women with breast cancer?  
**Would Strongly Recommend**\_\_\_\_ **Would Recommend**\_\_\_\_ **Indifferent**\_\_\_\_  
**Would Not Recommend at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 12) Would you recommend the **GROUP** peer support to other women with breast cancer?  
**Would Strongly Recommend**\_\_\_\_ **Would Recommend**\_\_\_\_ **Indifferent**\_\_\_\_  
**Would Not Recommend at All**\_\_\_\_ **Not Applicable**\_\_\_\_
- 13) Did the Nurse at BCCH follow up with you after your **INDIVIDUAL** Peer Support visit?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_
- 14) Did the Nurse at BCCH follow up with you after your **GROUP** Peer Support?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_
- 15) If there was follow-up, what kind was it (Please  $\sqrt$  all that apply) ?  
 1) **INDIVIDUAL** Peer Support Volunteer  
**Telephone call**\_\_\_\_ **Letter**\_\_\_\_ **Meeting at BCCH**\_\_\_\_ **Other**\_\_\_\_  
 2) **GROUP** Peer Support  
**Telephone call**\_\_\_\_ **Letter**\_\_\_\_ **Meeting at BCCH**\_\_\_\_ **Other**\_\_\_\_

- 16) In your opinion, was this follow-up helpful?
- 1) **INDIVIDUAL** Peer Support Volunteer  
 Very Helpful \_\_\_\_\_ Helpful \_\_\_\_\_ Neither Helpful Nor Unhelpful \_\_\_\_\_  
 Not Very Helpful \_\_\_\_\_ Not Helpful at All \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 2) **GROUP** Peer Support  
 Very Helpful \_\_\_\_\_ Helpful \_\_\_\_\_ Neither Helpful Nor Unhelpful \_\_\_\_\_  
 Not Very Helpful \_\_\_\_\_ Not Helpful at All \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 17) How would you describe the amount of follow up you received?
- 1) **INDIVIDUAL** Peer Support Volunteer  
 Too Much \_\_\_\_\_ Enough \_\_\_\_\_ Not Enough \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 2) **GROUP** Peer Support  
 Too Much \_\_\_\_\_ Enough \_\_\_\_\_ Not Enough \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 18) If there was no follow up, would you have liked follow up?
- 1) **INDIVIDUAL** Peer Support Volunteer  
 Yes \_\_\_\_\_ No \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 2) **GROUP** Peer Support  
 Yes \_\_\_\_\_ No \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 19) (a) What was the best part of the **INDIVIDUAL** Peer Support volunteer program?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- (b) What was the best part of the **GROUP** Peer Support program?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- 20) (a) What is the most important thing you would like to see changed in the **INDIVIDUAL** Peer Support?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- (b) What is the most important thing you would like to see changed in the **GROUP** Peer Support?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

Thank You for Completing the Questionnaire

### Participant Survey

This survey has been developed to gather information from people who have used the Services provided by the Breast Cancer Centre of Hope. This results of this survey will be used to enhance and improve the programs at the Centre so that we may meet the needs of the people who use the Centre, people like you. Please take some time to fill out this survey. All results will be compiled and no individual responses will be identifiable.

Thank You for Your Time

- 1) From whom, or where did you hear about HOPE? \_\_\_\_\_
- 2) Approximately when did you first contact HOPE? Month \_\_\_\_ Year \_\_\_\_
- 3) How did you first contact HOPE?  
 Telephone \_\_\_\_ Drop-in \_\_\_\_ Appointment \_\_\_\_  
 Other (please explain) \_\_\_\_\_
- 4) How easy was it for you to get in touch with a nurse at HOPE?  
 Very Easy \_\_\_\_ Easy \_\_\_\_ Neither Easy Nor Difficult \_\_\_\_  
 Not Very Easy \_\_\_\_ Very Difficult \_\_\_\_
- 5) If you found it difficult to contact the Breast Cancer Centre of Hope, what made it difficult (Please check ✓ as many as apply)?  
 Distance from Centre \_\_\_\_ Rural Resident \_\_\_\_  
 No Access to Telephone \_\_\_\_ Hours of Centre too Restrictive \_\_\_\_  
 Transportation Problems \_\_\_\_ Child Care Issues \_\_\_\_  
 Telephone Messages Not Returned in a Timely Manner \_\_\_\_  
 Other (please describe) \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- 6) How many contacts have you had with HOPE (Including first contact)?  
 1 \_\_\_\_ 2-4 \_\_\_\_ 5 or more \_\_\_\_

- 7) What was the purpose of your **FIRST** contact with HOPE (check as many as apply)?  
**To Gather Information on My Breast Cancer** \_\_\_\_\_  
**(Including Verbal, Written and Audio Information)**  
**To Gather Information on HOPE** \_\_\_\_\_  
**To Get in Touch With Support Groups** \_\_\_\_\_  
**To Speak to Someone &/or receive Counselling or Support** \_\_\_\_\_  
**Other** \_\_\_\_\_
- 8) Were you satisfied with the response of the staff in general to your inquiries?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_ **Neither Satisfied Nor Dissatisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not at All Satisfied** \_\_\_\_\_
- 9) How would you rate your satisfaction with the staff member with whom you had most of your contact?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_ **Neither Satisfied Nor Dissatisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not at All Satisfied** \_\_\_\_\_
- 10) How would you rate your satisfaction with the amount of time your primary contact spent with you?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_ **Neither Satisfied Nor Dissatisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not at All Satisfied** \_\_\_\_\_
- 11) If you received support such as one on one counselling, emotional support or assistance with questions, how would you rate your satisfaction with these services?  
**Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_ **Neither Satisfied Nor Dissatisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not at All Satisfied** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_
- 12) If you were referred to another agency or service, how would you rate your satisfaction with this referral?  
**Extremely Satisfied** \_\_\_\_\_ **Very Satisfied** \_\_\_\_\_ **Satisfied** \_\_\_\_\_  
**Not Very Satisfied** \_\_\_\_\_ **Not at All Satisfied** \_\_\_\_\_ **Not Applicable** \_\_\_\_\_
- 13) (a) Did the Nurse at HOPE address all your concerns?  
**Yes, Definitely** \_\_\_\_\_ **Yes, Somewhat** \_\_\_\_\_ **Only a Little** \_\_\_\_\_ **No, Not at All** \_\_\_\_\_
- (b) If No, did the Nurse refer you to someone who could help you?  
**Yes** \_\_\_\_\_ **No** \_\_\_\_\_
- Comments** \_\_\_\_\_
- 
- 14) Did the nurse at Breast Cancer Centre of Hope follow up with you when referrals were made?  
**Yes** \_\_\_\_\_ **No** \_\_\_\_\_ **Follow-up was not required** \_\_\_\_\_
- 15) How would you rate your satisfaction with this follow up?

Extremely Satisfied \_\_\_\_\_ Very Satisfied \_\_\_\_\_ Satisfied \_\_\_\_\_  
 Not Very Satisfied \_\_\_\_\_ Not at All Satisfied \_\_\_\_\_ Not Applicable \_\_\_\_\_

Comments \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

- 16) If you contacted the Breast Cancer Centre of Hope for information and resources, how would you rate your satisfaction with these services?  
 Very Satisfied \_\_\_\_\_ Satisfied \_\_\_\_\_ Neither Satisfied Nor Dissatisfied \_\_\_\_\_  
 Not Very Satisfied \_\_\_\_\_ Not at All Satisfied \_\_\_\_\_ Not Applicable \_\_\_\_\_
- 17) How did you get the resources from Breast Cancer Centre of Hope (Please ✓ all that apply)?  
 Picked up \_\_\_\_\_ Mailed \_\_\_\_\_ Faxed \_\_\_\_\_ Courier \_\_\_\_\_ Bus \_\_\_\_\_  
 Other (please describe) \_\_\_\_\_  
 \_\_\_\_\_
- 18) What resources did you access (Please ✓ all that apply)?  
 Pamphlet \_\_\_\_\_ Book \_\_\_\_\_ Video \_\_\_\_\_ Audio \_\_\_\_\_ Prostheses \_\_\_\_\_ Wig \_\_\_\_\_  
 Other (please describe) \_\_\_\_\_  
 \_\_\_\_\_
- 19) Was the resource what you expected? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Why/Why not? \_\_\_\_\_
- 20) Was the resource helpful? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Why/Why not? \_\_\_\_\_
- 21) Was the resource current and/or in good condition? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Why/Why not? \_\_\_\_\_
- 22) If the resource was written material, please rate the following:  
 Currency of the information:  
 Excellent \_\_\_\_\_ Very Good \_\_\_\_\_ Good \_\_\_\_\_ Fair \_\_\_\_\_ Poor \_\_\_\_\_  
 Accuracy of the information:  
 Excellent \_\_\_\_\_ Very Good \_\_\_\_\_ Good \_\_\_\_\_ Fair \_\_\_\_\_ Poor \_\_\_\_\_  
 Relevancy of the information to your needs:  
 Excellent \_\_\_\_\_ Very Good \_\_\_\_\_ Good \_\_\_\_\_ Fair \_\_\_\_\_ Poor \_\_\_\_\_

Appearance of the information:

**Excellent**\_\_\_\_ **Very Good**\_\_\_\_ **Good**\_\_\_\_ **Fair**\_\_\_\_ **Poor**\_\_\_\_

Reading level of the information:

**Too basic**\_\_\_\_ **Adequate**\_\_\_\_ **Difficult**\_\_\_\_

- 23) (a) Have you received information from outside of Breast Cancer Centre of Hope that contradicts the information given to you by Breast Cancer Centre of Hope?  
**Yes**\_\_\_\_ **No**\_\_\_\_

b) Can you remember what information it was and what the discrepancies were?

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- 24) The amount of information you were given was:  
**Too much**\_\_\_\_ **Enough**\_\_\_\_ **Not enough**\_\_\_\_ **None**\_\_\_\_

- 25) If you received a prosthesis, was it easy to get?  
**Very Easy**\_\_\_\_ **Easy**\_\_\_\_ **Neither Easy Nor Difficult**\_\_\_\_  
**Not Very Easy**\_\_\_\_ **Extremely Difficult**\_\_\_\_ **Not Applicable**\_\_\_\_

- 26) What barriers, if any, did you encounter when trying to get a prosthesis from Breast Cancer Centre of Hope? \_\_\_\_\_

- 27) Was the prosthesis in good condition?  
**Extremely Good**\_\_\_\_ **Very Good**\_\_\_\_ **Good**\_\_\_\_  
**Fair**\_\_\_\_ **Poor**\_\_\_\_ **Not Applicable**\_\_\_\_

- 28) Based on you experience with Breast Cancer Centre of Hope would you use  
 The written material at Breast Cancer Centre of Hope again?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_

The prosthesis bank at Breast Cancer Centre of Hope again?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_

- 29) Based on your experience with Breast Cancer Centre of Hope, would you recommend  
 The written material to other women with breast cancer?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_

This prosthesis bank to other women with breast cancer?  
**Yes**\_\_\_\_ **No**\_\_\_\_ **Not Applicable**\_\_\_\_



- 30) What service did you find the most helpful (Please ✓ only one)?

Information & Support From Staff \_\_\_\_\_  
 Referral to Another  
 Agency/Person \_\_\_\_\_  
 Other (please  
 describe) \_\_\_\_\_

Volunteer Program \_\_\_\_\_  
 Referral to Another Group \_\_\_\_\_  
 (Peer Support, Survivors) \_\_\_\_\_

- 31) Did the information and services you received at HOPE help you with your treatment decisions (eg. chemotherapy, surgery, radiation, etc.)?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ My Decision Was Already Made \_\_\_\_\_  
 Only a Little \_\_\_\_\_ Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

Comments \_\_\_\_\_

- 32) Did your contact with HOPE help you in communicating with your Cancer Specialist?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ Only a Little \_\_\_\_\_  
 Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

If "Yes", how did HOPE help, and if "No", how could HOPE have helped you better?

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- 33) (a) Do you feel your contact with HOPE has left you feeling more in control of your treatment decision making for your breast cancer?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ Only a Little \_\_\_\_\_  
 Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

(b) Did the information and/or support you received at HOPE help you in other aspects of your breast cancer?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ Only a Little \_\_\_\_\_  
 Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

- 34) (a) Has your contact with HOPE helped empower you to take a more active role in your breast cancer care?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ Only a Little \_\_\_\_\_  
 Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

(b) Has your contact with HOPE helped empower you in other areas of your life?

Yes, Definitely \_\_\_\_\_ Yes, Somewhat \_\_\_\_\_ Only a Little \_\_\_\_\_  
 Unsure \_\_\_\_\_ No, Not at All \_\_\_\_\_ Not Applicable \_\_\_\_\_

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

- 35) Overall, how did your contact with HOPE help you cope with your breast cancer experience? Check (✓) as many as apply.

Helped With My Treatment	_____	Helped Emotionally	_____
Decision Making	_____	Helped Find Support Groups	_____
Helped to Communicate With	_____	Helped With Family Issues	_____
My Cancer Specialist	_____	Helped With Practical Issues	_____
Helped to Communicate	_____	(eg., transportation, child care)	_____
With My Family Doctor	_____	Did Not Help	_____
Helped to Communicate	_____	Other	_____
With Other Nurses	_____		

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

- 36) If you could suggest one thing to improve HOPE, what would it be?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Demographics and Health History

- 37) What stage was your breast cancer when you first contacted HOPE?

Stage I \_\_\_\_\_ Stage II \_\_\_\_\_ Stage III \_\_\_\_\_ Stage IV \_\_\_\_\_ Do Not Know \_\_\_\_\_

- 38) Did you contact HOPE:

Before Biopsy \_\_\_\_\_ After Biopsy & Before Surgery \_\_\_\_\_ After Surgery \_\_\_\_\_

Other \_\_\_\_\_

- 39) What type of treatment did you have for your breast cancer? Check (✓) as many as apply.

<b>Radical Mastectomy</b>	_____	<b>Partial Mastectomy</b>	_____
<b>Lumpectomy</b>	_____	<b>Lymph Node Removal</b>	_____
<b>Chemotherapy</b>	_____	<b>Radiation</b>	_____
<b>Alternative Treatment</b>	_____	<b>Hormonal (eg. tamoxifan)</b>	_____
		<b>Other</b>	_____

**Comments (please elaborate on alternative or other)** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

40) What was your age when you first contacted HOPE?

<b>35 or Under</b>	_____	<b>36 - 45 yrs</b>	_____	<b>46 - 55 yrs</b>	_____
<b>56 - 65 yrs</b>	_____	<b>66 - 75 yrs</b>	_____	<b>76 - 85 yrs</b>	_____
<b>86 yrs or Over</b>	_____				

41) What is your annual household income?

<b>\$20,999 or Under</b>	_____	<b>\$21,000 - \$30,999</b>	_____
<b>\$31,000 - \$40,999</b>	_____	<b>\$41,000 - \$50,999</b>	_____
<b>\$51,000 - \$60,999</b>	_____	<b>\$61,000 or over</b>	_____

41) What is the highest level of education you have completed?

<b>Less than High School</b>	_____	<b>High School</b>	_____
<b>Some Post-Secondary</b>	_____	<b>College Diploma</b>	_____
<b>University Undergraduate</b>	_____	<b>Master's Degree</b>	_____
<b>Degree</b>	_____	<b>PhD</b>	_____

42) Do you live: **Inside the Perimeter** \_\_\_\_\_ **Outside the Perimeter** \_\_\_\_\_?

## Appendix G

### Budget for Breast Cancer Centre of Hope Evaluation

Envelopes		\$000.00	(already rprovided with pre-existing mailing)
Stamps	600 x \$0.51	\$306.00	(Full cost of mailing is not taken into account as mail out is already occurring)
Copying of Questionnaires			
Participant Questionnaires	6 pages x 600 x \$0.07/page	\$252.00	
Volunteer Questionnaires	7 pages x 50 x \$0.07/page	\$ 24.50	
Data Entry			
Manitoba Nursing Research Institute (MNRI) Employees			
	\$13.00/hour x 10-20 hours	\$260.00	
Statistical Analysis			
Manitoba Nursing research Institute (MNRI)			
	\$75.00/hour x 5 hours	\$375.00	(as per recommendations by MNRI)
TOTAL		\$1217.50	