

BHCRI Breast Cancer Society of Canada/QEII Foundation for Breast Cancer Research Award

Project Protocol: *Supportive Care for Women with Advanced Breast Cancer (ABC-SC)*

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Lay Abstract

Over the next ten years, more than 3,000 women living with advanced breast cancer will need supportive care. In Nova Scotia, a number of researchers are testing hypotheses and innovations that have the potential to improve supportive care for women with advanced breast cancer. For the most part, these researchers are working independently from each other without a formal means of communicating and applying their research findings for the benefit of these women. Using a participatory action research process, we will bring together a group of innovative, young researchers with experienced cancer researchers. This process will be guided by Kelley's conceptual model of change. In year one, the Research Team will develop, consider, and present how their own research could improve supportive care for women with advanced breast cancer. In year two, they will have additional opportunities for collaborative research development and advising on the design of approaches to improve supportive care for women with advanced breast cancer. The impact of this knowledge exchange process will be assessed using semi-structured interviews.

Supportive care for women with advanced breast cancer has many dimensions. The impact of this research is expected to include: new insights and interventions by cancer patient navigators who screen for distress; a framework for guidelines for pain and other symptom control using medications; development of a study of physical activity; greater understanding of factors that influence the likelihood of receiving supportive cancer care including the impact of having diabetes and/or cardiovascular disease, living in a rural area, minority culture status, and socio-demographic factors; data to demonstrate the importance of listening to the views of next-of-kin; and an analysis of the type and extent of costs of supportive cancer care.

Scientific/Technical Abstract

Supportive care (SC) for persons living with cancer is a multifaceted set of services and activities that provide information, and instrumental, symptom, and psychosocial care. SC relates to activities of daily living, access to health services (including non-medical services), and symptom management. While more than 3,000 women with advanced breast cancer (ABC) are expected to need SC in Nova Scotia over the next ten years, research on how to provide SC for persons with cancer is in its infancy.

Dalhousie University and Capital Health researchers who are early in their research careers and have expertise in SC have joined with experienced cancer researchers to build the ABC-SC Team to carry out research to improve SC for women with ABC. The areas of SC expertise of the new investigators are: psychosocial support (JH), physical activity for persons with cancer (MK), pain and symptom management using medications (JF), costing care (DH, TY), knowledge exchange (RU), and screening (JP, JH). One ABC-SC researcher focuses primarily on breast cancer (DR). Some have carried out limited breast cancer research (GJ, RU, GP, MK, TY, JP). For others (JH, JF, DH, FB), breast cancer research is a new endeavour.

The ABC-SC research objectives are:

- 1) To describe and examine selected sources of SC for women with ABC in Nova Scotia, including sources, quality indicators, and costs of SC, and
- 2) To use and evaluate a participatory knowledge exchange process to expedite the development of SC research, and thereby improve SC for women with ABC.

Descriptive and multivariate statistical methods using administrative data (GJ, JH, JF, RU, JP, DR, GP, FB) and survey findings (MK, DH, TY, FB) will be used to inform the further development of SC. A semi-structured interview of ABC-SC Team members will be used to evaluate the participatory knowledge exchange (KE) process that is proposed to expedite SC research development. The KE intervention process has seven components: 1) Team norms, model for participation, and KE framework; 2) Production of findings for review, reflection, and momentum; 3) Work-in-progress sessions for informal dialogue, research development, and collaborative thinking; 4) Support for projects and capacity development; 5) Structured full Team meetings to share, reflect, discuss next steps, and network; 6) Visiting Scholar as a catalyst for creativity; and 7) Enablement of dissemination of findings.

SC for women with ABC has many dimensions. The impact of this research is expected to focus on six dimensions: new insights and interventions by cancer patient navigators who screen for distress; a framework for guidelines for pain and other symptom control using medications; development of a study of physical activity; greater understanding of factors that influence the likelihood of receiving quality supportive cancer care including the impact of having diabetes and/or cardiovascular disease, living in a rural area, minority culture status, and socio-demographic factors; data to demonstrate the importance of listening to the views of next-of-kin; and an analysis of the type and extent of costs of supportive cancer care. The development and assessment of this innovative research collaborative in Nova Scotia will benefit not only women with ABC in this province, but also the estimated 75,000 women across Canada who will be diagnosed with ABC in the next ten years as well as those in other countries, and by adaptation, persons with other forms of cancer across the cancer continuum.

Project Description: Supportive Care for Women with Advanced Breast Cancer (ABC-SC)

Background

Supportive care (SC) for persons diagnosed with cancer includes “those health services and related activities designed to help patients and their families with their cancer experience during the diagnostic, treatment, follow-up, and palliative phases. Thus, supportive cancer care includes not only issues of physical or symptom support, but other domains, such as instrumental and social care, the need for information, psychological support, and spiritual needs.”¹ Cancer Care Ontario states that SC is meant to help people living with cancer who have a range of physical, informational, emotional, psychological, social, spiritual, and practical needs.² Research on how to best provide SC for persons with cancer is in its infancy.

SC is to be provided at all stages in the cancer care continuum.^{1,3,4} Studies have shown that persons with advanced cancer are more likely than those at an early stage diagnosis to need support for activities of daily living, access to health services (including non-medical services), and pain management.³⁻⁵ Information, including issues relating to co-morbidities, has also been identified as a SC need.¹

In Nova Scotia over the next ten years, more than 3,000⁶ women with advanced breast cancer (ABC) will need SC. Dalhousie University and Capital District Health Authority (CDHA) researchers are carrying out cutting-edge research that has the potential to provide new insights into the provision of SC for women with ABC. For the most part, these researchers, who comprise the ABC-SC Research Team, have had limited or no prior experience working together (see team member description below; CVs are enclosed). Within the group, there is a range of SC expertise (both clinical and research) as well as expertise in leading large, innovative, interdisciplinary research teams and in knowledge brokering. Increased collaboration amongst

these researchers can develop capacity in SC research in Nova Scotia as well as in the application of research to improve programs, policy, and practice.

Knowledge exchange (KE) is a collaborative, interactive process between researchers and decision-makers that: i) involves the planning, production, dissemination, and application of existing or new research in practice and ii) results in mutual learning.⁷ Though the discourse on KE primarily involves interactions between “producers” and “users” of knowledge to support the application of research to practice, the concept applies to individuals within the same profession (e.g., researchers, clinicians), who routinely work within their own disciplinary and organizational boundaries (e.g., “silo-ing”). Such silo-ing is common in academia and health care settings, and hinders the transfer of knowledge across boundaries.⁸ For health researchers, interaction and collaboration is an important step toward developing improved research agendas, particularly ones that better address the multidisciplinary nature of health care, and ultimately improving the quality of care.

Implicit to KE is a focus on collaborative or participatory action research (PAR), where individuals (e.g., researchers, key stakeholders) work together to identify, produce, and apply knowledge. PAR focuses on bringing about change in practices,⁹ with participants advancing a specific plan for addressing the important issues on which they are collaborating.¹⁰ Kelley¹¹ has presented a research-based model of change that encompasses collaborative processes (Figure 1). This model emphasizes the importance of antecedent conditions (e.g., existing infrastructure, collaborative practices), a catalyst for change (e.g., funding opportunity, new ideas), creating the team (e.g., getting the “right” people, building relationships), and growing the program (e.g., strengthening the team, engaging the community). Capacity development requires broad-based participation, cultivating and building on local capacities, continual learning and adaptation, and integration of activities across disciplines/boundaries to address complex problems.¹²

The ABC-SC Team is comprised of innovative, young researchers and experienced cancer researchers, who span research and clinical boundaries. **Dr Melanie Keats** (MK), Assistant Professor, examines the impact of physical activity on cancer-related health outcomes; investigates the prevalence, determinants, and activity preferences of cancer survivors; and explores the effectiveness of novel interventions to promote physical activity.¹³⁻¹⁶ **Dr Janice Howes** (JH), CDHA psychologist, co-leads the examination of a new distress screening tool that was recently introduced for use by cancer patient navigators across the province.¹⁷ **Dr Judith Fisher** (JF) is a pharmacy post-doctoral fellow with expertise in monitoring pain and other medications^{18,19} and in reviewing literature on medication guidelines.²⁰ **Dr David Haardt** (DH), Assistant Professor, is an economist and has an interest in people's health and employment, and cost-benefit analysis. **Dr Tallal Younis** (TY) is a medical oncologist and Clinical Research Scholar with clinical research expertise as well as expertise in the cost-effectiveness of breast cancer therapies. **Dr Jennifer Payne** (JP) is a CDHA chronic disease epidemiologist and Assistant Professor with expertise in using administrative data and breast cancer screening. **Robin Urquhart** (RU) is a doctoral student and Knowledge Broker with expertise in knowledge exchange within large interdisciplinary research teams²¹⁻²⁴ and experience in qualitative research methods.²⁵⁻²⁷ **Dr Geoff Porter** (GP), surgical oncologist and Professor, is the CDHA lead for a major new emerging team (NET) ACCESS colorectal cancer research project funded by the Canadian Institutes of Health Research (CIHR).²⁸ **Dr Danny Rayson** (DR) is a medical oncologist and Professor, who has a strong breast cancer clinical research track record. **Dr Fred Burge** (FB), Professor and Research Director of Family Medicine, leads a next-of-kin follow-back survey,²⁹ and is the co-Principal Investigator with **Dr Grace Johnston** (GJ), Professor and epidemiologist with Cancer Care Nova Scotia (CCNS), of a major CIHR-funded Interdisciplinary Capacity Enhancement (ICE) grant to the Network for End of Life Studies (NELS).³⁰

This ABC-SC research will tackle two questions:

- 1) What can be learned by „mining“ existing Nova Scotia SC research, using an ABC lens, to improve SC for women with ABC?
- 2) Does an adapted PAR approach facilitate KE within the ABC-SC Research Team and subsequent SC research development for women with ABC? If so, how?

Methods

This ABC-SC study has two research objectives:

- 1) To describe and examine selected sources of SC for women with ABC in Nova Scotia, including sources, quality indicators, and costs of SC; and
- 2) To use and evaluate a participatory KE process to expedite the development of SC research, and thereby improve SC for women with ABC.

To achieve Objective 1, each of the eleven investigators will reflect on their existing base of SC research (Figure 2), explore the application of their work to address the SC needs of women with ABC, and present their insights and findings to the ABC-SC Team. The ABC-SC budget includes project funding (\$2,500 x3) to support this work. In addition, the budget provides for the production of new analyses for the Team’s collective review:

a) Descriptive statistics will be produced from the 3x3 NELS linked administrative data set (Table 1) to examine indicators of quality SC³¹: palliative radiotherapy,³² discontinuation of chemotherapy, dying out of hospital, and timely palliative care for women dying of ABC in relation to age, urban/rural status,³³ socioeconomic status of community, cardiovascular, diabetes and other disease co-morbidities, living in a long term care facility,³⁴ and cultural factors (Aboriginal, immigrant, or African Nova Scotian community). After the presentation and discussion of descriptive statistical findings, multivariate logistic regression analyses will be carried out to control for confounders. Recursive partitioning will be used to identify interactions

among predictors of quality SC. The algorithm, or decision tree, generated in the latter approach is particularly useful in terms of data presentation and understanding the relative importance of the predictive variables.³⁵ The Team has expertise with these methods.^{36,37}

b) Costs of home-based SC (e.g., caregiver hours, pain medications, etc) for persons in Halifax in their last months of life with cancer will be determined using survey data from a cross-Canada study of urban centres.³⁸ By Year 2, rural (Colchester East Hants) survey data will be available for analyses and comparison.³⁹ Nova Scotia-specific cost data have not been previously analyzed.

c) Two systematic literature reviews will be led by JF. The first will examine literature related to pain management among persons with ABC, and the second to SC for persons with ABC, including management of other symptoms. These reviews build on previous work.^{18,20}

To achieve Objective 2, an adapted PAR approach⁴⁰ (Figure 3), using Kelley’s conceptual model of change¹¹ (Figure 1), will be used to engage Team members, support effective KE processes/practices, and strengthen members’ capacity to develop and carry out ABC-SC research. A key characteristic of PAR is its cyclical nature, whereby “thinking” and “doing” processes are repeated throughout the research. These processes may be conceptualized as a repeated iteration of three steps: *Looking*, or building a picture and gathering information; *Thinking*, or interpreting, reflecting, and explaining; and *Acting*, or resolving issues, judging the value, effectiveness, and outcomes of the activities, and formulating solutions to move forward.⁴¹ This “strengths-based” approach will strive to enhance existing research/KE capacities and develop cutting-edge SC research through collective problem solving and reflection.^{11,42} The KE processes that proved effective in enabling research productivity and leading to new knowledge and innovations in the NELS ICE and NET ACCESS research team grants will be implemented by the ABC-SC Coordinator with guidance from GJ and RU. The seven KE intervention components are:

- 1) Team norms (Table 2), models for PAR (Figures 1 and 3), and a KE framework (Table 3) to guide the Team’s development and productivity;
- 2) Production of new findings for Team review and reflection, and to provide momentum;
- 3) Work-in-progress meetings year-round to share co-investigator research amongst Team members to enable informal dialogue, further research development, and innovative collaborative thinking on how to improve SC for women with ABC;
- 4) Potential for support (\$2,500x3) for project development/presentation, providing young researchers with opportunities to develop capacity in receiving peer review funding;
- 5) Three structured full Team meetings (Sept 2011, Jun 2012, Jun 2013) to share findings, reflect on progress, discuss next steps, and network, with the overarching goals of Team development and productivity;
- 6) A Visiting Scholar to serve as a catalyst for creative, collaborative research-to-practice thought and initiatives (Dr Allan Kellehear⁴³ will be invited to serve this role);
- 7) Visibility and publicity of investigators’ work through dissemination of findings in website, newsletter, and annual meetings, as well as via existing dissemination mechanisms (e.g., Grand Oncology Rounds, disease site groups).

The evaluation of the PAR/KE process will involve one-on-one semi-structured interviews with ten co-investigators; RU will lead the analysis. These interviews will provide a depth of knowledge beyond what is observed and that cannot be attained using quantitative methods:

“[w]e cannot observe how people have organized the world and the meanings they attach to what goes on ... We have to ask people questions about those things” (p.341).⁴⁴

Patton⁴⁴ and Rubin and Rubin⁴⁵ will be used to refine the interview questions and guide the interview process (see Appendix 1 for draft interview guide). The semi-structured format will permit the interviewer to remain focused, yet provide the freedom to probe issues and ask for

clarification concerning issues that arise.⁴⁴ Interviews will be tape-recorded, transcribed, and supplemented with field notes. Following each interview, the interviewer and RU will review the transcript to determine whether or not the issues were discussed in sufficient depth and, if not, revise the questions before the next interview.⁴⁵ Analysis of interview data will follow the thematic analysis approach presented by Braun and Clarke,⁴⁶ involving coding, collating codes, and generating, reviewing, and refining themes. This approach is similar to the analysis steps outlined by other researchers.^{10,45,47} In addition, the ABC-SC Coordinator and co-Principal Investigators will maintain records of group processes, including learning and reflection activities, rationales for actions, actions and products, and evaluations and other feedback. These records will be used to corroborate and augment findings from the thematic analysis of the interviews.¹⁰

Expected Findings

We anticipate the main findings from this research study will be: new descriptive and analytic data on the quality and costs of SC, and predictors of women with ABC receiving SC; the identification and refinement of ABC-SC research in Nova Scotia, including development of new areas of research; and an improved understanding of whether a participatory KE approach can lead to expedited SC research development and increased capacity in ABC-SC research.

A list of findings that are expected to be produced by the co-investigators is provided in Table 4. These deliverables will emerge over time (Table 5). Examples are noted below.

Physical activity can be a form of SC for persons living with cancer on and off active treatment. An example is dragon boating for breast cancer survivors.^{48,49} Preliminary data indicate that physical activity is a supportive intervention for palliative care patients.⁵⁰ Through this ABC-SC study, MK will explore physical activity as a SC intervention for women with ABC.

Prior to this call for applications, FB had not considered a focus on ABC; however, such a focus became worthwhile and viable in the context of the ABC-SC study. Thus, further examination of unmet needs and preferences for SC, in the context of an ongoing next-of-kin follow-back survey, are to occur as part of this research.

DH will analyze cost data for Halifax (year 1) and Colchester East Hants (year 2) to investigate how different SC components, such as caregiver time and pharmaceuticals, contribute to the cost of care for persons with advanced cancer in an urban area and a rural area of Nova Scotia. Care giving time is a major cost for family members of persons with advanced cancer in Canadian cities³⁸; for the first time, we will examine Nova Scotia data.

In preparing this ABC-SC proposal, JF identified a gap in the knowledge related to SC medications in the oncology literature. There are clinical guidelines on pain management and SC using medications in the palliative and pharmacy literature. A synthesis of the literature is needed as it applies to SC for women with ABC. JF has proven abilities in this form of review.^{18,20}

Overarching the individual progress of the ABC-SC researchers, the investigator interviews will lead to greater knowledge on the optimal development of ABC-SC research capacity. Effective components of this model can be adapted for other cancers and for SC research for survivors of early stage breast cancer.

Anticipated Impact

Within one year, we will have an interdisciplinary team that is studying SC for women with ABC. Within 2-3 years, we anticipate having new research protocols that address SC for women with ABC that capitalizes on the expertise of the co-investigators. The impact of this research is expected to focus on six dimensions of SC: new insights and interventions for distress screening; a framework for pain and other symptom control guidelines using medications; development of a study on physical activity; greater understanding of factors that influence the likelihood of

receiving quality SC, including the impact of having diabetes and/or cardiovascular disease, living in a rural area, minority culture status, and socio-demographic factors; data to demonstrate the importance of listening to the views of next-of-kin; and an analysis of the type and extent of SC costs for women with ABC. Thereafter, further development of SC research may occur.

We expect to influence SC practice in Nova Scotia in that numerous co-investigators are practicing clinicians (DR, GP, FB, JH, TY) who have opportunities to apply their learning from ABC-SC to their practice and to share with peers in Nova Scotia and at venues outside of the province. Our findings will also inform SC program/policy development and refinement. Marianne Arab, Manager, Supportive Care, CCNS, is a Collaborator on this study (Letter of Support in Appendix 2). She will participate in ABC-SC activities. RU has established a relationship with Ms. Arab relating to SC for cancer survivors. Through NELS ICE, GJ has a strong relationship with the Nova Scotia Department of Health and Wellness. Through ABC-SC, using previous insights on breast cancer KE,⁵¹ GJ will advocate for improvement in SC at the primary care and chronic disease management levels. JF has a positive track record with the provincial drug monitoring program⁵²; her ABC-SC learning will be used to inform their policies and practices. Additional connections to policy development and refinement are anticipated through other co-investigator relationships with policy-makers. Since Canada has made SC a key priority within its national cancer control strategy,^{53,54} and is the global leader in the provision of caregiver support through the Compassionate Care Benefit⁵⁵ as well as in breast cancer advocacy⁵⁶ and research, we anticipate that our findings will be relevant and useful to provincial and national SC policy development.

This research is expected to lead to publication of papers on improving SC for women with ABC, presentations to research and practitioner audiences, new investigator support and development, insight into productive research team development, and submission of new research

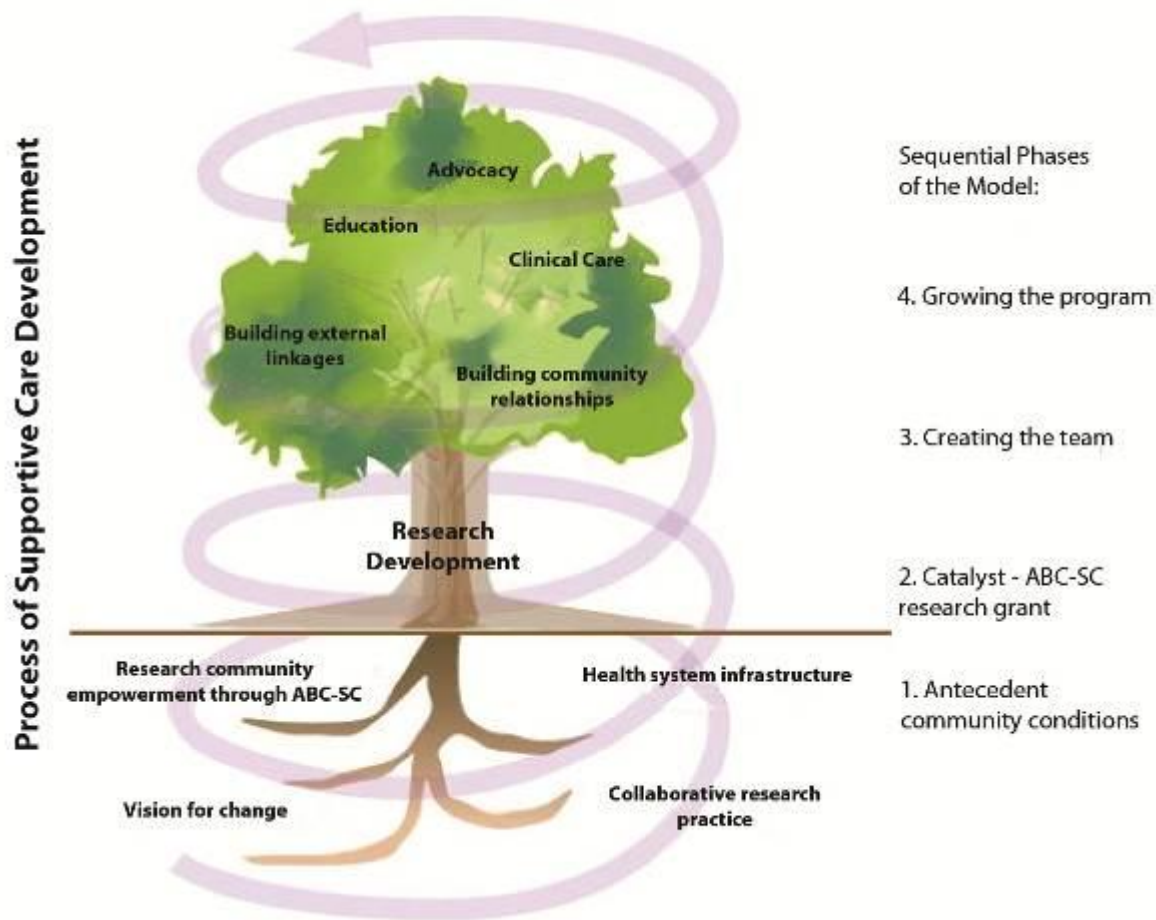
grants, including an adapted “NET ACCESS” grant that uses linked administrative databases to study breast cancer. This grant would go beyond the traditional “medical” cancer care services to include SC. Furthermore, in the next year, FB is planning to lead the submission of a major grant to CIHR on community based primary care; he would like to build on the work of ABC-SC. As such, this ABC-SC study is a foundational step toward building research to improve SC for women with breast cancer.

The goals of SC for persons with advanced cancer are to prevent, control, or relieve complications and side effects related to therapies and spread of the disease, and to improve the quality of life. SC can be provided in many forms including, but not limited to, screening for distress, psychosocial and caregiver support, pain and other symptom control, physical activity, and access to palliative services. This research will improve the knowledge of such services in Nova Scotia and capacity to further study and improve services for women with ABC. It can also benefit the estimated 75,000 women across Canada who will be diagnosed with ABC over the next ten years as well as women in other countries, and adapted for other types of cancer.

Figures

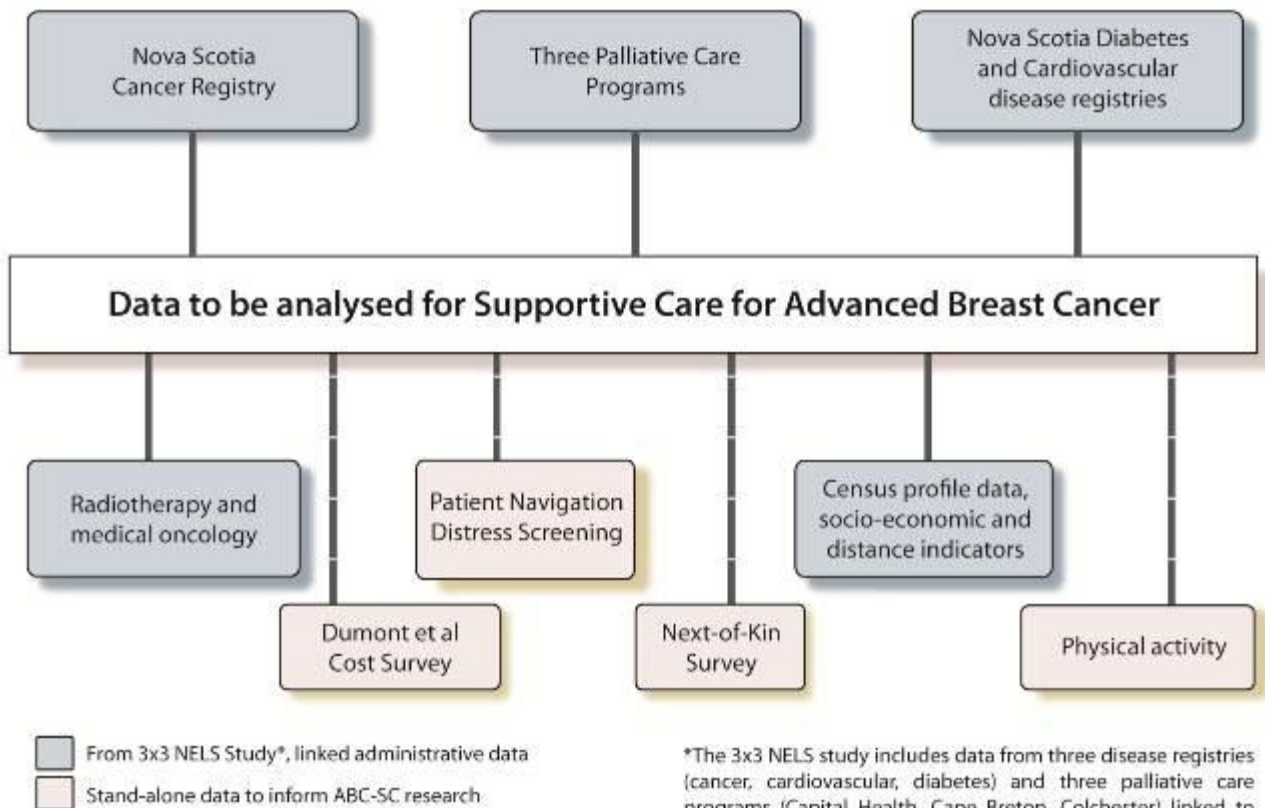
- Figure 1: Kelley’s Conceptual Model of Change, as applied to ABC-SC Research.
- Figure 2: Data to be explored in relation to ABC-SC.
- Figure 3: ABC-SC Participatory Action Research Process.

Figure 1: Kelley's Conceptual Model of Change,¹ as applied to ABC-SC Research.



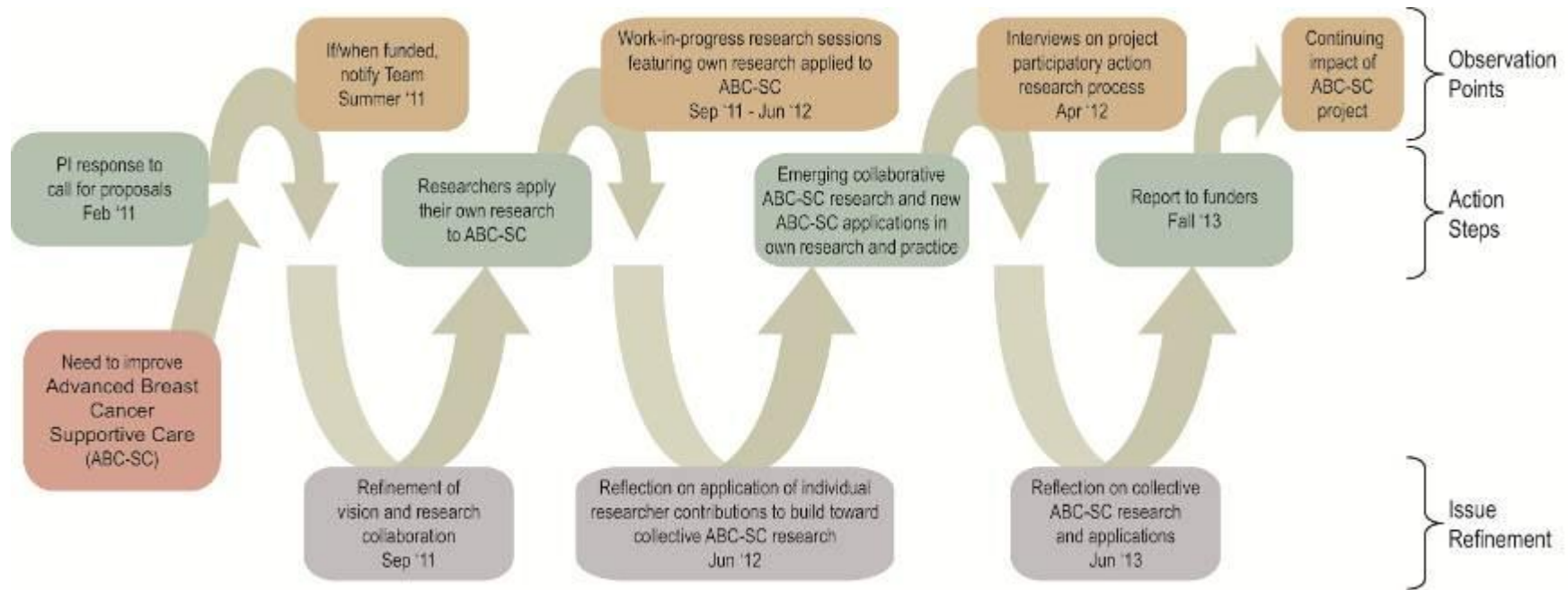
¹ Kelley ML. Developing rural communities' capacities for palliative care: a conceptual model. J Palliat Care 2007; 23(3): 143-153.

Figure 2: Data to be explored in relation to ABC-SC.



*The 3x3 NELS study includes data from three disease registries (cancer, cardiovascular, diabetes) and three palliative care programs (Capital Health, Cape Breton, Colchester) linked to Nova Scotia Vital Statistics deaths and ecological measures from Statistics Canada 2006 census. The study population is all Nova Scotia residents who died in Nova Scotia from 1995 to 2009. There are approximately 8,000 deaths each year in the province for a total across the 15 years of 120,000 decedents.

Figure 3: ABC-SC Participatory Action Research Process.²



² Adapted from Figure 21.1 in “Chapter 21: Participatory Action Research” of *Social Research Methods* by Maggie M Walter (2009), Oxford, South Melbourne, Australia.

Tables

- Table 1: 3x3 NELS Study Variables.
- Table 2: Guiding Principles for our Team Relationship.
- Table 3: Knowledge Exchange Framework.
- Table 4: Investigator Team and Anticipated Findings/New Knowledge.
- Table 5: ABC-SC Project Time Line.

Table 1: 3x3 NELS Study Variables.

Nova Scotia Vital Statistics	Cancer Registry	Cardiovascular Registry	Diabetes Registry	Palliative Care Registries⁴	Census Profile Data⁵
Sex	Survival time	Survival time	Survival time	PCP referral	Distance from residence ⁶
Age					
Place of death ¹	Consults ³ in last nine months	Deaths in/out of hospital	Wait time from registration to assessment	Wait time from referral to assessment	Socio economic variables ⁶
Nursing home resident					
Diagnoses ²					
DHA, county	Receipt of radiotherapy; Medical oncology consult	Discharges to nursing home	Time to supportive care	Time to supportive care	Cultural indicators

¹ Hospital, nursing home, own home.

² An all causes classification will be based on the taxonomy developed by Alison Zwaagstra and adapted to the classifications used in the disease registry and other administrative databases.

³ Medical oncology, radiation oncology.

⁴ Capital District, Cape Breton District, and Colchester East Hants Health Authorities only.

⁵ 2006 Census information linked by census dissemination area to six digit postal code using Health Canada methods.

⁶ Postal codes that are missing from the NSVS records will be replaced by the last postal codes available in the cancer, cardiovascular, and diabetes registries to enable the development of district health authority (DHA), distance, and community socio-economic indicators with fewer missing values.

Table 2: Guiding Principles for our Team Relationship.

<p>Our values include:</p> <ul style="list-style-type: none"> • Team goals are developed and owned by all members • interactions are based on mutual trust and openness • knowledge translation begins within the Team • good governance is essential • public resources are to be used effectively and efficiently
<p>Our success depends on us:</p> <ul style="list-style-type: none"> • melding into a coherent, healthy team • exchanging knowledge between each other and external partners • translating our Team’s shared vision into a concrete research program • communicating and applying knowledge created in effective ways to improve access to and quality of supportive care for women with advanced breast cancer
<p>Our participatory knowledge exchange strategy will:</p> <ul style="list-style-type: none"> • help us understand and respect our differing roles • value different perspectives • include users to plan and disseminate knowledge • seek win-wins for us and our partners • operate within reasonable time frames • ensure that resource plans are in place for activities • develop formal partnership agreements • clarify and strive for fair and transparent governance mechanisms
<p>When our team is funded, we will develop our guiding principles for:</p> <ul style="list-style-type: none"> • project review, support, and approval • authorship and ownership of intellectual property • research grant preparation and submission • information sharing, data access, and exchange • collaboration agreements and expectations
<p>Our guiding principles will be grounded in the best available evidence for effective partnering including:</p> <ul style="list-style-type: none"> • our experiences and literature on effective partnering and mentoring such as: <ul style="list-style-type: none"> ➤ Dyer, S. <i>Partner Your Project</i>. Livermore California: Pendulum Publishing, 1997. ➤ Kilcher A, Sketris I. <i>Mentoring Resource Book. A Guide for Faculty, Researchers and Decision Makers</i>. College of Pharmacy, Dalhousie University, May 2003.

Table 3: Knowledge Exchange Framework.

Features³	Effective Knowledge Translation⁴	Our Application
Settings for initiatives	Policy makers at federal, provincial, health district levels; clinical practice at primary care, cancer, and other specialist care levels	1) Patient Navigator distress screening and other forms of supportive care 2) Policy development agencies and departments 3) Research and professional groups
Tools	Literature synthesis; statistical analyses of survey and administrative data; and interactive knowledge exchange	Work-in progress presentations, publications, newsletters, website, development of new research projects, collaborations, networks
Targets for leadership in change efforts	Clinicians, system managers, policy makers, advocates for supportive care for women with breast cancer	Surgical and medical oncology, palliative and primary care clinicians; government, health districts, health care institutions, supportive and chronic disease agencies
Content	Evidence based information; literature review; language that is clear, understandable, and respectful of target groups	Syntheses of existing and new knowledge on supportive care, reports from data analyses, research proposals, insights from listening and reflection
Guiding Model(s)	Knowledge exchange, Kelley’s model of change, participatory action research	Interdisciplinarity, review and reflection, mentoring, improved access to supportive care, quality improvement, learning organizations
Relevant disciplines	Medicine, psychology, pharmacy, exercise sciences, social work, health services administration, and varied research methodologies including epidemiology and economics	Distress screening, patient navigation, other supportive care, clinical care processes, health services research, database and survey analyses

³ Adapted from Davis D, Evans M, Jadad A, et al. The case for knowledge translation: Shortening the journey from evidence to effect. *BMJ* 2003; 327:33-5

⁴ Adapted from Davis et al (2003) with input from our own expertise and other literature

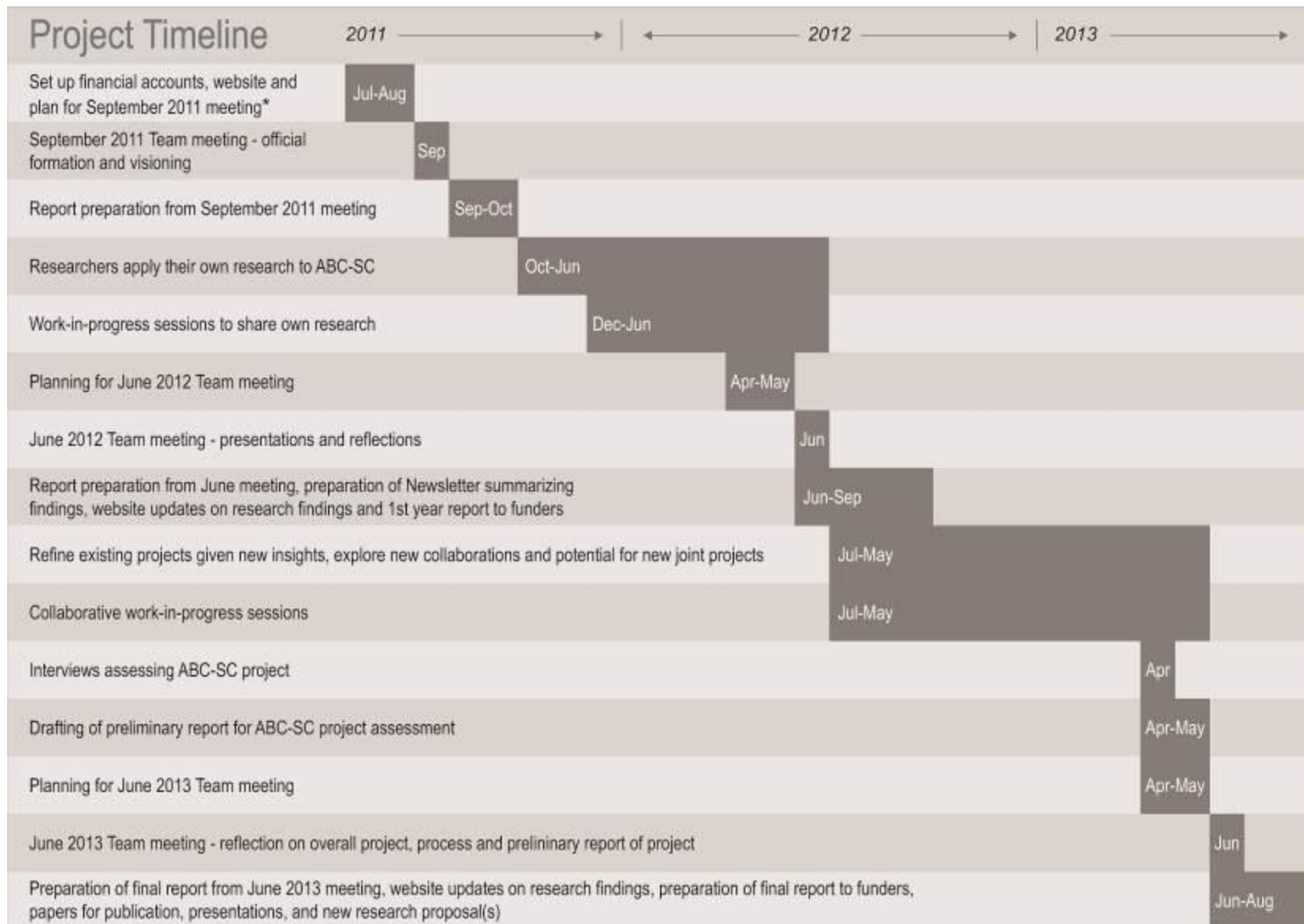
Table 4: Investigator Team and Anticipated Findings/New Knowledge.

<i>Principal Applicant(s)</i>	<i>Position(s)</i>	<i>Expertise</i>	<i>Anticipated Findings/New Knowledge</i>
Grace Johnston, MHSA, PhD	Professor and Graduate Coordinator, School of Health Administration, Dalhousie University; Senior Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia; and Principal Investigator, Network for End of Life Studies: Interdisciplinary Capacity Enhancement (NELS ICE), Canadian Institutes of Health Research grant	Epidemiology, health services research using administrative databases, cancer control, screening, palliative and end of life care, interdisciplinary learning, knowledge exchange, advocacy, mentoring	Focused data analyses on supportive care (SC) for women with advanced breast cancer; Greater understanding on the forms and cost of SC, and predictors of who has access to SC; Refinement of interdisciplinary research team development methods and knowledge exchange
Robin Urquhart, PhD Candidate	Knowledge Broker, Cancer Outcomes Research Program, Cancer Care Nova Scotia	Knowledge exchange and translation, health services research, linked administrative data methods, qualitative methodologies	Improved understanding of effective knowledge exchange processes toward building interdisciplinary research teams and whether a participatory model is useful toward expediting SC research capacity; Greater depth of knowledge on access to and quality of SC services for women with advanced breast cancer using administrative data
<i>Co-Applicants</i>	<i>Position(s)</i>	<i>Expertise</i>	<i>Anticipated Findings/New Knowledge</i>
Frederick Burge, MD, FCFP, MSc	Professor, Department of Family Medicine, Dalhousie University; and Co-Principal Investigator, NELS ICE	Family medicine, primary care, palliative and end of life care, survey and linked administrative data methods	Perspectives on SC by next of kin of women dying of advanced breast cancer; Insights into the redesign of community based primary care; New grant proposal to CIHR for community based primary care

Judith Fisher, PhD	Post Doctoral Fellow, Drug Use Management and Policy Research, College of Pharmacy, Dalhousie University	Systematic literature review, appropriate use of medications	Medication use for the management of pain and other symptoms among persons with advanced cancer; Framework for medications guideline development for SC, focusing on women with advanced breast cancer
David Haardt, PhD	Assistant Professor, School of Health Administration, Dalhousie University	Cost-benefit analysis, older people's health and employment	Greater understanding of how different SC components, such as caregiver time and pharmaceuticals, contribute to the costs of end-of-life care for cancer patients in Nova Scotia
Janice Howes, PhD	Psychosocial Oncology Clinical Leader and Chair, Supportive Care Site Team, Cancer Care Nova Scotia	Clinical psychology, Psychosocial oncology	Refinement of distress screening by cancer patient navigators; Improving SC for women with advanced breast cancer
Melanie Keats, PhD	Assistant Professor, School of Health and Human Performance, Dalhousie University	Behavioural medicine, exercise psychology, physical activity, oncology, survivorship, quality of life	Exploring the SC role of physical activity for women with advanced breast cancer
Jennifer Payne, PhD	Assistant Professor, Departments of Diagnostic Radiology and Community Health and Epidemiology, Dalhousie University; and Senior Epidemiologist, Capital District Health Authority	Epidemiologic methods, chronic disease surveillance, indicators of care, administrative data analysis, health services research	Screening for need for SC; Data analysis and knowledge translation related to SC for chronic disease co-morbidities for women with advanced breast cancer
Geoff Porter, MD FRCSC, FACS	Professor of Surgery, Ramia Chair in Surgical Oncology, Dalhousie University; and Surgical Oncologist, QEII Health Sciences Centre	Surgical oncology, health services research, outcomes research, quality indicators	Improved understanding of factors influencing access to and quality of SC services for women with advanced breast cancer; exploring opportunities to build a NET ACCESS-like team in breast cancer

<p>Danny Rayson, MD, FRCPC, FACP</p>	<p>Professor, Division of Medical Oncology, Dalhousie University; and Medical Oncologist, Nova Scotia Cancer Centre</p>	<p>Clinical trials, breast cancer, health services research, wait times, cancer genetics, translational research</p>	<p>Clinical trial development with focus on SC for advanced breast cancer (e.g., pain and symptom control, management of side effects from systemic therapies); understanding of factors (e.g., co-morbidities) that influence quality SC for women with advanced breast cancer</p>
<p>Tallal Younis, MBBCh, FRCP (UK)</p>	<p>Assistant Professor, Division of Medical Oncology, and Clinical Research Scholar, Dalhousie University; and Medical Oncologist, Nova Scotia Cancer Centre</p>	<p>Economic/cost analysis, health services research, outcomes research, breast cancer, clinical trials</p>	<p>Examining costs of various forms of SC, including medications for women with advanced breast cancer</p>

Table 5: ABC-SC Project Time Line.



* to be completed by NELS ICE coordinator - no award funds spent at this stage. ABC-SC begins September 2011.

Appendix 1: Draft Interview Guide to Evaluate ABC-SC

Interview Guide

1. What was your experience with the ABC-SC project?
Specific probes:
 - i. ABC-SC Team norms, participatory research model, and implementation?
 - ii. Development of your own research to focus on SC for women with ABC?
 - iii. Value of knowledge exchange across co-investigator research projects, including work-in-progress sessions?
 - iv. Project funding and new research development opportunities?
 - v. ABC-SC Team meetings (Sept 2011, June 2012) including interdisciplinary networking and reflection?
 - vi. Role of Visiting Scholar as a catalyst to advance ABC-SC innovation?
 - vii. Publicity and knowledge dissemination of individual projects and emerging collective research to improve SC for women with ABC?

2. What ABC-SC research project and Team activities did you find most useful? Why? What could have been improved? How?

3. Has your understanding of SC for women with ABC been expanded or refined as a result of your participation in ABC-SC? If so, how?
Specific probe:
How might your new understanding of SC, directly through your own research or indirectly through the research of others, improve SC for women with ABC?

4. From your perspective, what impact has the ABC-SC project had? What future impact do you expect ABC-SC project to have?

5. What further research is needed to improve SC for women with ABC?
Specific probes:
Would you advise an ABC-SC type process continue to be used? If so, what would be the next steps to further improve SC for women with ABC? If not, why not?

Appendix 2: Collaborator Letter of Support (Supportive Care, Cancer Care Nova Scotia)



1276 South Park Street
Bethune Building, Room 528
Halifax, NS B3H 2Y9

March 15, 2011

Dr. Grace Johnston
School of Health Administration, Dalhousie
5161 George Street, Suite 700
Halifax, NS B3J 1M7

Dear Dr. Johnston:

Re: Proposed project, *Supportive Care for Women with Advanced Breast Cancer*

Please accept this letter in support of the proposed project, *Supportive Care for Women with Advanced Breast Cancer*. As Manager of Supportive Care at *Cancer Care Nova Scotia*, I believe in the importance of this work and the value of working together to address the supportive care issues for women with advanced breast cancer in our province.

Specifically, by bringing together such an innovative and experienced team of researchers, I believe this project has the potential to have a real impact on the quality of supportive care services in Nova Scotia. Without doubt, local data and knowledge, as well as new and collaborative research, on issues such as distress screening, medications for pain and symptom control, physical activity, whether women receive appropriate and high quality care, and costs related to supportive care will help inform existing and new programs and policies. As such, I am pleased to work with your team and to provide my insight and knowledge into these important issues.

I hope you are successful in receiving funds for this project and I look forward to working with you.

Sincerely,

A handwritten signature in black ink that reads "M. Arab MSW/RSW".

Marianne Arab, MSW/RSW
Manager, Supportive Care
Cancer Care Nova Scotia

Many **Hearts**. Many Minds. One Goal.
10 Years On - Enabling Quality Cancer Prevention and Care

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