Two Navigation Programs:
Further application of the Knowledge Exchange Decision Support (KE-DS) Toolkit

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Contents

Executive Summary

The Canadian Strategy for Cancer Control (CSCC) was established in 1998 to make recommendations for needed improvements in the cancer control system in Canada. The Canadian Partnership Against Cancer (CPAC) has a mandate to implement the Canadian Strategy for Cancer Control goals to create change in the cancer care system in Canada. The Cancer Journey Action Group[1] (CJAG) focuses exclusively on supportive care for cancer patients who are increasingly surviving their disease. The KE-DS Toolkit is commissioned by CJAG and one of a number of toolkits.

An environmental scan of cancer survivorship in Canada prepared for CJAG illustrates that accessing cancer care is a complex and, at times, confusing and disjointed experience for patients and their families (Ristovski-Slijepcevic, April 2008). Internationally and nationally cancer care providers are shifting to a chronic disease management strategy – in essence a long-term care strategy - in light of increased demand for services for survivors and their families and support providers. The challenge facing providers is how to best approach this problem.

The CIHR Team for Supportive Cancer Care and CJAG have identified Patient Navigation as one solution. While a variety of navigator models are currently operating throughout Canada and the United States (such as professional, virtual or peer led), these approaches share the common goals of eliminating barriers to care, improving patient satisfaction and enhancing the decision making abilities of patients. A gap in the research exists, however, regarding the effectiveness of patient navigation programs in improving outcomes during cancer survivorship (Wells et al. 2008:1999). A better understanding of the efficacy of navigation programs and their impact on patients and their families will lead to a better understanding of the potential benefits of navigation in relation to supportive cancer care.

The purpose of this report is to describe and discuss two CJAG funded pilot Navigation projects through the lens of a Knowledge Exchange Decision Support (KE-DS) Model[2]. Utilizing the ethnographic approach of 'thick description' the reflective sections provide a detailed retrospective account of the two Navigation pilot experiences[3] the better to allow for an understanding of the subtleties of the process of planning and implementing an initiative in a health care setting.

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[1] One of eight action groups comprised of collaborative networks of experts created to address CPAC priority areas.

[2] Knowledge exchange (KE) as used in this context derives directly from the current CIHR definition (CIHR, 2008). The Knowledge Exchange Model for Supportive Care is designed to show the complex set of interactions between creation, synthesis, assessment and evaluation of relevant information, strategies for dissemination and translation for a range of stakeholders, and the collection, storage and facilitation of access for all users.

[3] There are marked differences between these two projects, including the type of navigation program piloted (one on one, peer led approach and a systems approach), the setting (a clinical institution in an urban environment and a rural, community setting), and the targeted patient population (newly diagnosed, Chinese speaking cancer patients and women with breast cancer).

The Chinese Peer Navigator Project is a systemic approach to address the informational and supportive care needs of Chinese patients diagnosed with cancer at the Vancouver Cancer Centre (VCC). The Northern Health Navigation project in Prince George was a pilot for breast cancer patients. While the common understanding of navigation is an individual 1:1 care program, due to human resource constraints, Northern Health (NHA) projected a 'system' approach to guiding the patient through his/her care.

To contribute to this improved understanding, some members of each project team participated in a retrospective exercise where they considered the application of the KE-DS Toolkit to the development and implementation of their respective navigation projects. The report documents the implementation of the Knowledge Exchange Decision Support Toolkit at these two sites as part of the first phase of CJAG/CIHR funded activities in knowledge exchange and transfer. The proposed KE-DS Model and Toolkit elaborate how alternative choices may have diverse consequences that often stretch far beyond immediate patient outcomes. The model provides a synthesis of the socio-medical dynamics in policy and practice; it adopts a critical perspective which delineates issues of power and dominance, as well as describing the impact of the intervention (i.e. supportive cancer care). Best practice decisions occur in a series of fairly well-defined stages (that one could also repeat and backtrack): 1) recognition of problem, 2) formulation of possible intervention, 3) generation of alternatives, 4) information search, 5) judgment or choice, 6) action, 7) feedback. This broad "problem solving" approach is the one adopted for the proposed model to ensure a comprehensive understanding of the specific problem/deficit as well as a thorough examination of the consequences of alternative courses of action.

The proposed model is comprised of several component dimensions/contexts, and provides a comprehensive, transparent approach to best practices. However, it is designed with ease of application in mind and should not be too onerous to use. The model for decisions in health care was developed incorporating four key dimensions:

1) Population and health services context
2) Economic context
3) Broad social context (including ethical, legal, and political concerns)
4) Quality of scientific knowledge about the health issue and/or its intervention

The Model process assumes the inclusion of all stakeholders and it provides the opportunity to align local (or sub-population, or stakeholders) "wants" with population health needs, provides guidelines within which the appropriate information is sought and examined, and draws on a number of disciplinary perspectives, incorporating theories of epidemiology, sociology, economics and systems science. It is a means of applying critical theory to health care evaluation.

Introduction

The Larger Context: Commitment to Supportive Cancer Care

Addressing the needs of cancer survivors has become a major priority for a number of cancer programs both internationally and in Canada. Cancer patients are increasingly surviving their disease, requiring that cancer care providers switch to a chronic disease management strategy – in essence a long-term care strategy. In the context of post-treatment, it has been recognized that the formal cancer system is "front end loaded" with limited program development or resources invested in survivorship programs. There is an increased demand for services for survivors and their families and support providers. The challenge facing providers is how to best approach this problem.

The Canadian Strategy for Cancer Control (CSCC) was established in 1998 to make recommendations for needed improvements in the cancer control system in Canada. The Canadian Partnership Against Cancer (CPAC) funded by the Federal government in November 2006 is an independent corporation charged with accelerating action on cancer control across Canada.

CPAC has a mandate to implement the Canadian Strategy for Cancer Control goals to create change in the cancer care system in Canada. In order to draw on cancer control knowledge and expertise widely dispersed throughout Canada's health care system and make it readily accessible to all stakeholders, collaborative networks of experts were established for each of the priority areas determined by the Canadian Strategy for Cancer Control. Of the eight Action Groups created to implement the recommendations, the Cancer Journey Action Group (CJAG) led by Dr. Margaret Fitch focuses exclusively on psychosocial and supportive care.

The focus of the Cancer Journey Action Group (formerly Rebalance Focus) is to ensure improvements in quality of life through psychosocial and supportive care interventions, and to help shift the emphasis in cancer care from a medical approach to a more patient/family/supporters centred approach. The Cancer Journey Action Group established evidence-based practice that draws on knowledge; its generation, creation, evaluation and exchange, and was of primary importance to this shift in emphasis. A multidisciplinary team of academics and researchers collaborated with this Action Group and were successful in obtaining CIHR funding for a program of research entitled: Promoting Equity in Access to Cancer Supportive Care (Ref. Grant #AQC-83559). In this research program the aim is to delineate the concept of access and stimulate policy efforts to improve access to supportive care. The definition of access, adapted from the literature, encompasses four dimensions: availability, utilization, effectiveness and equity. The focus of this program of research is on supportive care at specific transitions in the cancer care continuum. The two most important are the transitions at the point of diagnosis and at the point of completion of primary treatment when the patient moves from the acute care system to the community care system and home. The second transition also corresponds to the period now called 'survivorship'. An environmental scan of cancer survivorship in Canada prepared for CJAG illustrates that accessing cancer care is a

complex and, at times, confusing and disjointed experience for patients and their families (Ristovski-Slijepcevic, April 2008).

In an effort to facilitate access and continuity of care, the CIHR Team for Supportive Cancer Care and CJAG have identified Patient Navigation as an approach to assist patients and their family members with navigating their way through the cancer care system, and to develop strategies to overcome the barriers met along the way. While a variety of navigator models are currently operating throughout Canada and the United States (such as professional, virtual or peer led), each approach shares common goals of eliminating barriers to care, improving patient satisfaction and enhancing the decision making abilities of patients. A literature review by Wells et al (2008) illustrates that while little is known regarding the efficacy and cost-effectiveness of navigation programs due to the difficulty in measuring these indicators, there was some evidence that illustrates an increase in participation in cancer screening and follow-up care. The process of facilitating patient awareness and familiarization with the health care system could potentially lead to a better understanding of available supportive care resources. A gap in the research exists, however, regarding the effectiveness of patient navigation programs in improving outcomes during cancer survivorship (Wells et al. 2008:1999). A better understanding of the efficacy of navigation programs and their impact on patients and their families will lead to a better understanding of the potential benefits of navigation in relation to supportive cancer care.

A key building block to the CIHR funded research program is the creation, application and evaluation of a Knowledge Exchange Model for Supportive Cancer Care that fosters evidence-based clinical practice, system management, and health policy development in cancer prevention and control in general, and with a focus on patients' (and their families') needs in particular. The implementation of this Knowledge Exchange-Decision Support Toolkit (KE-DS Toolkit) is part of the first phase of CJAG/CIHR funded activities in Knowledge Exchange and transfer (Kazanjian and Howett 2008). This report describes and discusses two CJAG funded pilot navigation projects through the lens of the KE-DS Toolkit that was recently developed for CJAG (Kazanjian, Howett & Chan 2009).

Knowledge Exchange, the KE Model for Supportive Cancer Care

CJAG's focus on the generation, creation, evaluation and exchange of knowledge is central to their mandate to shift the emphasis of cancer care from a tumour-centred approach to a person-centred one that provides supportive care, as appropriate.

Knowledge Exchange

Knowledge Translation (KT) and Knowledge Exchange (KE) are relatively new concepts being used in health services and policy research. The term KE is based on the premise that a gap exists between the production of research knowledge and its implementation as evidence-based practice, planning and decision making. The process of bringing research evidence to practice has yielded various frameworks, models and toolkits for KE in many disciplines. All delineate, in various ways, a complex set of interactions between the creation of new information, synthesis, assessment and evaluation of that information, strategies for dissemination and translation for a broad range of stakeholders, as well as the collection, storage and facilitation of access for all users.

Knowledge exchange (KE) as used in this context derives directly from the current CIHR definition (CIHR, 2008). The Knowledge Exchange Model for Supportive Care is designed to show the complex set of interactions between creation, synthesis, assessment and evaluation of relevant information, strategies for dissemination and translation for a range of stakeholders, and the collection, storage and facilitation of access for all users (Kazanjian and Howett:2008).

Traditionally, within evaluation research, a full-scale needs assessment would provide the required evidence on questions of health service need. For the purposes of moving to the next stage of our systematic process, seeking at least a few answers to what supportive cancer care needs are is appropriate. A need exists when the practitioner or policy maker has evidence that there is a discrepancy between an acceptable situation and the existing situation. Is there such a discrepancy? Is there any public expression of such a need and/or public support for filling the gap?

Need identification is the process of describing the health care requirements of a target population and the solution to a current problem. Evaluation of need pertains to assessment of the importance and relevance of the problem and the solution. Thus, needs analysis includes problem identification, solution identification, and ultimately, evaluation of problem and solution.

In the broadest context, confronted with a choice of interventions or programs, practitioners and policy makers may have a number of possible alternatives; selecting the alternative that includes notions of equity and utility and is grounded in principles of social justice is the most appropriate. A decision model that reflects these attributes and rationalizes choices between approaches or strategies in terms of equity and utility is arguably more useful. The rationale for

the development of an evidence-informed model is centred on basic principles of justice in health care: equitable access to all effective health care which society can afford.

The Knowledge Exchange – Decision Support (KE-DS) Toolkit: Defining and Refining
The proposed KE-DS Model elaborates how alternative interventions may have diverse consequences that often stretch far beyond immediate patient outcomes. The Model provides a synthesis of the socio-medical dynamics in policy and practice; it adopts a critical perspective which delineates issues of power and dominance, as well as describing the impact of the intervention (i.e. supportive cancer care). It is a decision support tool with a series of fairly well-defined stages (that one could also repeat and backtrack): 1) recognition of problem, 2) formulation of possible intervention, 3) generation of alternatives, 4) information search, 5) judgment or choice, 6) action, 7) feedback (Kazanjian and Pagliccia, 1998). This broad "problem solving" approach is the one adopted for the proposed Model to ensure a comprehensive understanding of the specific problem/deficit as well as a thorough examination of the consequences of alternative courses of action.

The proposed Model is framed to be a deliberation process with consistent dimensions, with defined yet modifiable indices of each dimension and an accompanying evaluation/ measurement component. The four dimensions are:

1. Population and health services context
2. Economic context
3. Broad social context (including ethical, legal, and political concerns)
4. Quality of scientific knowledge about the health issue and/or its intervention.

Depending on the subjective importance of the dimension, different weights can be assigned to the dimensions by the decision-maker.

The KE-DS Model (Figure 1) has prominent features that exist in other knowledge translation models (Tetroe & Graham et al. 2008; Logan & Graham 1998), furthermore it offers a more functional view of knowledge exchange. Firstly, by virtue of its comprehensive nature with the coverage of all dimensions of concern, the Model process assumes the inclusion of all stakeholders and it provides the opportunity to align local (or sub-population, or stakeholders) "wants" with population health needs. Secondly, it provides guidelines within which the appropriate information is sought and examined. Different forms of information and knowledge are acknowledged, and there is an attempt to integrate and synthesize them (the dotted line around the evidences used for each context signifies this integration, Figure 1). Thirdly, the Model draws on a number of disciplinary perspectives, incorporating theories of epidemiology, sociology, economics and systems science; and applies critical theory to health care evaluation.

Figure 1
Knowledge Exchange for Supportive Cancer Care Model & Toolkit Overview
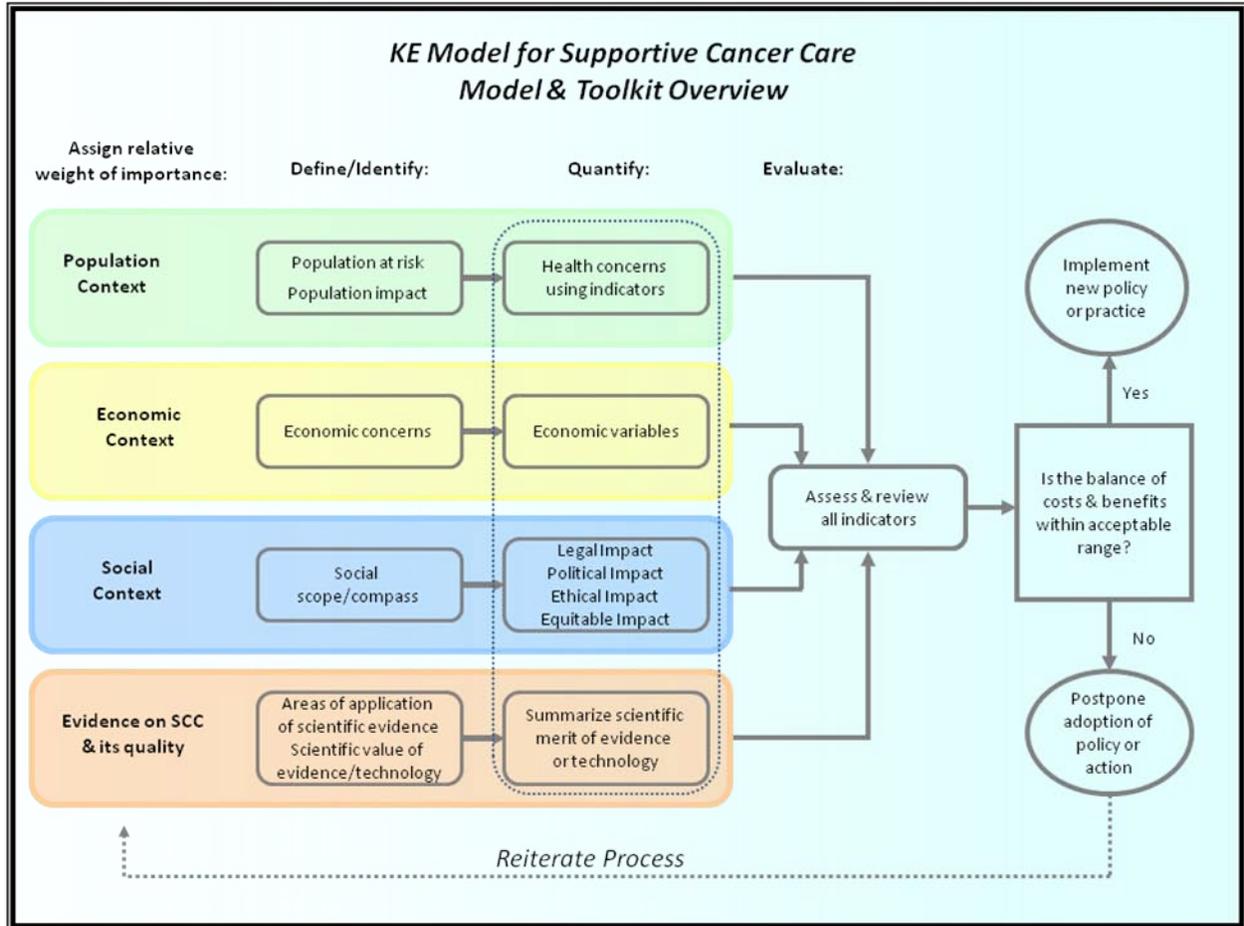
Methodology

As the aim of this project is to gain an understanding of the planning and implementation processes phases of two different navigation projects, the research team utilized a method of analysis grounded in cultural anthropology, where investigating people's experiences is the primary focus of the discipline. Established by Clifford Geertz in the 1970s, "thick description" is an ethnographic approach to elucidating an understanding of a specific event or behavior within the social context that it occurs. The use of thick description is not meant to expound an explanation for why people do the things they do, but rather to gain an understanding of the social context in which it occurs and the meanings that people ascribe to their actions, beliefs and symbols (Geertz 1973). Following this approach, it is impossible to understand an event, institution or behavior without also gaining an understanding of the context, or "web" of meanings, in which the event, institution or behavior occurs. Thus, a description rich in detail is necessary in order to grasp the nuance and subtleties of the situation. States Geertz: "Culture is not a power, something to which social events, behaviors, institutions or processes can be causally attributed; it is a context, something within which they can be intelligibly –that is thickly – described" (1973:14).

Following Geertz's assertion that the context is equally as important as the behavior itself, the following sections of this report aims to illustrate the use of the KE-DS Toolkit within the social environment that the two project teams operated within. A detailed retrospective account of their experiences allows for an understanding of the subtleties of the process of planning and implementing an initiative in a health care setting. There are marked differences between these two projects, including the type of navigation program piloted (one on one, peer led approach and a systems approach), the setting (a clinical institution in an urban environment and a rural, community setting), and the targeted patient population (newly diagnosed, Chinese speaking cancer patients and women with breast cancer). Their experiences, therefore, are unique to the context in which they occurred and cannot be directly compared. Their reflections on the use of the KE-DS Toolkit will lead to a better understanding of the strengths and weaknesses of the model in terms of both applicability and ease of use. The reflections from the two navigator teams were collected through interviews, informal discussions and correspondence with some members of project team staff and management, and a review of project documents.

Two Navigation Programs: Overview

A primary goal of the Cancer Journey Action Group is to shift the focus of cancer care from a tumour-centered approach to a patient centred approach that better serves the needs of patients and their families. One approach to meeting this goal is to increase the availability of and access to supportive care services, particularly among underserved groups, such as Aboriginal, minority, non-English speaking and rural/remote communities. The Northern Health Navigation Program (NH Navigation Program) and the Chinese Peer Navigator Project (CPN Project) were developed in an effort to reach this goal.

As cancer research expands its focus to explore the economic, social and systematic barriers to accessing care, patient navigation has been proposed as an approach to address these barriers. While there is no standard definition of what patient navigation involves, one definition states that "[the] term is used to denote a system or professional role primarily intended to expedite patient access to services and resources, and improve continuity and coordination of care throughout the cancer continuum"[4]. Patient Navigator programs are often designed to meet the needs of underserved populations, although not exclusively. There is great variation in terms of who occupies the patient navigator role - a review by Wells (2008) indicates that nurse practitioners, nurses, social workers, health educators, clinic staff members, research assistants, cancer survivors and volunteers have all provided the service. Other types of navigation include a virtual support-group style approach and a system-level approach where the focus is not the individual patient but rather the facilitation of discussion and activity with specific clinical areas or departments.

The CPN Project is a volunteer, peer based approach and the NH Navigation program is a systems-level approach. The documentation of the project teams' experiences in implementing two Navigator programs leads to a better understanding of the use of new models of practice to enhance access to supportive cancer care, an objective of both CJAG and the CIHR funded *Promoting Equity in Cancer Supportive Care* initiative of which these two projects are part. To contribute to this improved understanding, some members of the two project teams participated in a retrospective exercise where they considered the application of the KE-DS Toolkit to the development and implementation of their respective navigation projects. The KE-DS Model is a comprehensive model; it is designed to assess and understand the properties, effects and impacts of a program or intervention in the context of supportive cancer care. The KE-DS Toolkit provides a method for recognizing and engaging stakeholders at multiple levels in addition to identifying and appraising the evidence on effectiveness efficiency and appropriateness of the intervention.

The Navigation teams' reflections contribute to a better understanding of the applicability of the Toolkit in two different health care settings, and have assisted the KE-DS research team in highlighting areas for improvement and ease of use. In the future, the project teams will be equipped with an evidence-based approach to consider the planning and design of their

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[4] Prepared by the Sociobehavioral Research Centre, BC Cancer Agency, 2005

interventions, the development of comprehensive indicators, a framework for evaluation, and the development of a knowledge exchange flow between research and practice.

This report is a retrospective of their use of the KE-DS Toolkit. The Chinese Peer Navigator Project team began came together in August 2008 and received the KE-DS Toolkit in October of 2008, and the Northern Health Navigation Project received the toolkit in the Spring of 2009. The reflections from the two navigator teams were collected through interviews and informal discussions with project team members, and a review of project documents.

BC Cancer Chinese Navigator Project

Establishing the need

The initial proposal for this project was developed in 2006 with the assistance of an interdisciplinary advisory group. In 2008, the proposal was revised and submitted to the Canadian Partnership Against Cancer. In March of 2008, the BC Outreach team prepared a report[5] for the Cancer Journey Action Group based on an environmental scan of current practices and existing resources available to the Chinese-speaking population[6] in British Columbia. The findings of the scan illustrate that funding and resources appear to be the biggest challenge for individuals working with this population. The BC Cancer Agency identified a need for culturally and language based services through their development, 10 years ago, of a multilingual Social Work position to work with the Chinese-speaking cancer population. Furthermore, members from the only language-specific and professionally led Chinese Cancer Support Group (which has been in existence since 11/2006) noted the need, as did members of BCCA's established Volunteer Program.

While the need for the Chinese Peer Navigation project was identified in 2006, more recent research continues to support the initiative. A qualitative study conducted at the Vancouver Cancer Centre's Chinese Cancer Support Group (Bell & Lee 2009); focus groups conducted with Chinese cancer survivors and their care givers; and a literature search on Patient/Peer Navigation programs further contributed to documenting and confirming the need for psychosocial services for the Chinese community (Hoey et al. 2008; Sheppard 2008; Corbin et al. 2007; Ferrante et al. 2007; Giese-Davis et al. 2006; Campbell et al. 2003). Findings from this research illustrate that there is a lack of information on cancer illness and available supportive resources in general, and that this is particularly true for the Chinese community where language barriers prevent access to existing materials and services.

Site Description

The Chinese Peer Navigator (CPN) project is a pilot project established at the Vancouver Cancer Centre (VCC), and operates through Volunteer Services. The project is a volunteer based service established to address the needs of Chinese speaking, newly diagnosed cancer patients living in all parts of British Columbia as well as the Yukon.

The CPN project utilized an empowerment model to develop a cultural and language based supportive care service delivery model. The purpose of this program is to address the informational and supportive care needs of Chinese patients diagnosed with cancer. The team met this aim on two fronts: by developing the navigator role and implementing the program

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[5] An environmental scan with key informant interviews regarding supportive cancer care resources and services for non-English speaking populations in Canada. Outreach Team Report, March 2008

[6] According to Statistics Canada, the Chinese population accounts for approximately 29% of the total population in Vancouver. http://www12.statcan.ca/census-recensement/2006/dp-pd/prof/92-591/details/page.cfm?Lang=E&Geo1=CSD&Code1=5915022&Geo2=PR&Code2=59&Data=Count&SearchText=Vancouver&SearchType=Begins&SearchPR=01&B1=Visible%20minority&Custom. Accessed July 31, 2009

with Volunteer Services at VCC, and developing a set of bilingual communication and information tools to be used by the patient.

This program consisted of the recruitment and training of Chinese-speaking cancer survivors, the development and implementation of a volunteer based navigator program, and the collection of data from newly diagnosed Chinese speaking cancer patients concerning their experience with the Chinese Navigator program. The Navigator service was available approximately two to three times a week for three months, and interactions ranged from a brief introduction to a half hour meeting. A total of 35 shifts lasting four hours each were worked. Each interaction between the patient and the navigator was documented by the navigator through the completion of an open ended questionnaire. Depending on the length and depth of the interaction, another questionnaire may have also been completed that documented patient information.

Program Goals:
- To offer informational and supportive care for Chinese speaking cancer patients
- To develop a sustainable peer navigator program
- To build a Training Manual and Toolkit that can be adapted and utilized by other Centers working with a diverse patient population

Program Objective:
- To formulate a cultural and linguistically specific navigation program for Chinese-speaking patients (include defining roles of navigator, program delivery process, recruitment and training of navigators, development of program materials) to increase patient knowledge of services and support accessibility to services.

Identifying Stakeholders

The project team consisted of an epidemiologist, two social workers, the coordinator of volunteer services, a research coordinator (who is also a social worker), and a research assistant. There were a number of stakeholders consulted during the planning and implementation phases of the project. An interdisciplinary advisory committee was established at the beginning of the project and consisted of members of the project team who worked in VCC (two social workers and the coordinator of volunteer services), an individual with experience in patient education and community based work with volunteers, the head of library services, a nurse leader and an oncologist. The advisory committee met approximately four times during the seven month project.

22 key informant interviews were conducted with health care providers who were selected by the project team. Some of these informants were selected because of their interaction with head and neck cancer patients (the initial target population), and others because of their knowledge of systems, treatment, and/or procedures in clinical areas. Topics discussed included their thoughts on the current state of care for Chinese speaking cancer patients, what things could be done to improve care, their thoughts and concerns around establishing a peer

navigator program, and ideas about what would be the most effective way to establish this program. These interviews served to highlight potential logistical issues within VCC, as well as content development of the program.

In terms of community involvement, in 2006 the initial advisory group conducted an environmental scan of resources and the Patient and Family Counseling program. Two community organizations were contacted and telephone interviews were conducted, and a member of the advisory committee is also a community representative in addition to her BCCA role.

Overall, the support from the key informants was extremely positive – the need for a service that was language based and culturally relevant was expressed by many of the participants. A number of these key informants were contacted throughout the planning and implementation phases to assist in clarifying logistical and health care issues at VCC. Contacts were also established to educate and inform health care providers of the peer navigator program and to also have their 'buy in'. In addition, the project team formally received approval by presenting the project to the BCCA Head and Neck Tumour Group, and the project coordinator also attended some front line staff meetings in key areas once the service was underway.

Population of Interest

Initially the project team intended to limit the patient pool to head and neck patients who were on their first visit to VCC. There are about 4,600 new cases of head and neck cancer in Canada each year. This type of cancer is more common in men than in women (the ratio is about 3:1), and is more common in people over 50[7]. This tumour site was chosen for the focus of the initiative as The Patient and Family Counseling program had conducted a previous literature search and key informant interviews to better understand the issues faced by patients with head and neck cancer.

The team soon realized, however, that the number of Chinese head and neck patients coming to VCC was not large enough to warrant the scheduling of navigators on a weekly basis. The target population was then expanded in order to allow the navigators to use the skills that they had learned with a broader population, to build competency, to increase visibility, and to support sustainability for the program.

The changing parameters of who would be included or excluded from the service were part of the learning process of implementing a pilot project - the project team was aware that the number of potential patients would be small. As the funding and implementation timelines were tight and a full assessment was not feasible, targeting a small population to develop the program materials, recruit navigators and implement the program was deemed the best strategy. However, a better understanding of the patient population in terms of their attendance at VCC, particularly the estimated number of first visit Chinese head and neck patients coming through VCC would have avoided this confusion and allowed for a clearer

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[7] http://www.bccancer.bc.ca/PPI/TypesofCancer/HeadnNeck/default.htm

description of who would be targeted. Identifying the population of interest proved to be an iterative process that required continual attention and consideration. Because it was necessary to ensure that the program would be sustainable, the parameters of who were targeted and considered "at risk" needed to be revisited throughout the planning stages of the project and the first month of implementation.

The demographic information of the patients who were served by the CPN was not collected – navigators estimated the age of the patients. Many patients brought family members or friends, particularly those who did not speak English, and adult children were often relied upon for support and discussion outside of the clinical examination.

Population Impact

Research shows that the time between consultation with the GP or specialist and the first appointment with the oncologist is characterized by high anxiety and stress as a result of uncertainty and unanswered questions. Because of this, the initial strategy was to contact patients *before* they arrived at VCC in order to offer reassurance that there would be a Chinese speaking navigator waiting to greet them, take them to their appointment and offer some caring support. Unfortunately the logistics of contacting patients before they came to VCC was simply too difficult. The considerable time constraints of the project did not permit enough time to adequately promote the service with referring physicians; however a mail out to referring physicians in the Lower Mainland was done.

The project was promoted by way of posters in VCC in the elevators and waiting rooms, and via a mail out to referring physicians and community organizations in the area. While a media release was discussed (newspapers and radio), due to the tight time constraints and resources, it was decided to keep the scope small and manageable. The project team agreed to further promote recruitment of more volunteers after they had reviewed patient, peer navigator and health care provider feedback regarding the pilot program. In addition, the team needed time to revise the training program with feedback from the navigators. The project team also needed to consider how many navigators were needed and how to sustain this with the volunteer program – recruitment of volunteers includes responding to interview calls, reviewing applications, short listing, interviewing, reference checks, and general orientation to the cancer centre. Given the time frame and the need to shift from a pilot project to a dedicated service within BCCA, these were important considerations.

While the majority of patients were not aware of the navigation service prior to their arrival at VCC, the navigator was able to greet the patient when they checked in at the main reception desk and then escort them to their appointment if they wished. Two patients were aware of the program before they came for their first appointment at VCC. The program was promoted to physicians by way of a direct mail out to those in the lower mainland.

The project team developed a number of bilingual communication and information tools for the CPNs to give to the patients (see Appendix 1). These tools were compiled into a booklet and

handed out to patients by the navigator with the hope that this would increase patient's self efficacy and preparedness. In order to meet the standards of best practice, all materials developed needed to be reviewed by a number of healthcare professionals to ensure accuracy. Once these materials are developed, they must be translated and then undergo a second review process. The development, translation and production of these tools proved to be extremely time consuming for the research coordinator and assistant, and towards the end of the project a bilingual communications assistant was hired to assist in the development of tools.

Measuring the population impact was difficult given the limited scope of resources and time (the pilot project ran for approximately 8 weeks). The desire to expand the role or supplement it with a telephone line was discussed but was not implemented due to the logistical issues and training required to implement such a service. As this was a feasibility project, activity measures were collected in order to gauge the acceptance of the service by patients and their families[8]. , As well, the navigation service and the development of resource tools were intended to improve the care available to patients, and to increase the access to these resources, components that are difficult to measure during such a short pilot project.

Throughput Results
Approximately 62% of patients accepted the service. Patients were very receptive and grateful that VCC had set up this service specifically for the Chinese community (many of the patients who did not accept the service were appreciative of its existence). Being able to ask the CPNs questions and not worry about being understood appeared to be a huge relief. As well, the fact that the CPNs had their own cancer experience seemed to comfort many patients as their presence instilled a sense of hope.

Approximately 38% of the patients refused the service. The reasons for this varied greatly: some patients had family support and presence so did not need the assistance of a navigator, many patients spoke English and felt comfortable finding their way around, and a few patients did not want anyone to know they were receiving treatment. As well, at times the navigator was unable to see all new patients during their shift as appointments were too close together.

- 75 patients were greeted by a navigator
- 47 patients accepted the service (62%)
- 35 patients agreed to be contacted to discuss their experience with the navigator (83% of all patients asked – *not all patients were asked*)
- 17 patients requested a follow up visit with a navigator (36%)
- 3 patients had more than one visit with a navigator

The CPNs completed two questionnaires that documented their experience with the patient, as well as patient information about their needs, support systems and ability to access information. Many of the CPNs found this documentation stressful and somewhat difficult as

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[8] Acceptance was defined as agreement to allow the navigator to escort them to their appointment

they were being asked to recall things from their interactions. Furthermore, these forms were often filled out at the end of their shift when they may have been rushed.

Economic and Social Context

There were a number of social factors that had an impact on the manner in which the program was implemented and received. Primarily, the project team considered the social and economic context of two groups when developing and implementing the project: the patients and the institution[9].

Patients

The evidence that this project was based on (focus groups, literature reviews and key informant interviews) and the anecdotal evidence gathered by the CPNs suggested that the Chinese population encounters a number of barriers when faced with cancer:

- A reluctance to ask questions of health care professionals who, as experts, should not be questioned, as well as not knowing what to ask
- Lack of knowledge about services available
- Feeling isolated and uninformed
- Difficulty in getting to their appointments
- A worry of overburdening their family and friends
- Younger family members not fully translating the health care providers diagnoses/comments to protect parents / grandparents
- Reluctance to call support lines or services if it is not Chinese specific

As the CPN program required minimal effort on behalf of the patient to take part (that is, they did not have to book an appointment or seek out the navigator), the use of the service was relatively straightforward. The navigator approached the patient and escorted them to their appointment and during this time introduced the service and themselves. While this ensured that many Chinese speaking patients were introduced to the program, the depth of this interaction was often fairly limited, particularly when there were many new patients coming that day or when there was not much time before the patient's appointment. If patients wanted a more involved meeting with the navigator, they were encouraged to call the Project Coordinator and set up a time to meet with one. This first appointment is also a time of great stress for the patient where they are given an enormous amount of information. The CPNs commented that at times they felt as though they were burdening the patient with too much information, a concern that the advisory committee had also voiced.

Once the program had been running for a few weeks and the CPNs had met a number of patients, the project coordinator began receiving a number of phone calls from patients requesting information, asking for assistance in booking services such as the Volunteer Driver service, and wanting to book an appointment with a CPN. Due to the limited availability of the

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[9] Institution refers to the interaction of professionals and systems, policies and guidelines operating within an organization.

CPNs, it was difficult to coordinate an appointment time that coincided with that patients' next appointment; however this interest illustrated a need for informational and supportive services that went beyond the introduction that the CPNs gave at the first meeting. These issues illustrate future directions that the Chinese Peer Navigator role might develop into.

Institution

Because the CPN Project operated within an institutional setting, the social relationships and the communication between VCC staff (who were not part of the project and advisory teams) and the project team emerged as a significant factor in the implementation and operating phases of the program. The institution itself was the channel through which the program was offered, and because of this, it was imperative that the staff (administrative and professional) were on board. Some of the issues that emerged were:

- Overlapping roles– for example, overlap between the Patient Escort role and the CPN role. The need for both roles, however, soon emerged as the project got underway and the navigator role became more clearly defined. The navigator role is set apart from other positions in VCC as it is language and culturally based, and all of the navigators themselves are cancer survivors. These three components were greatly appreciated by the patients. As well, the CPNs expressed during the focus group discussion that at times they felt their service was not needed if the medical interpreter was present
- Concerns over protocol, standards and policies – patient confidentiality is paramount. Access to patient information (i.e. names), duties of the navigators, program materials – were they accurate? Who participated in developing them? Who translated them?
- Credential issues – during key informant interviews, a few concerns were expressed regarding the fact that navigators are peers and not health care professionals
- Concerns over the short time limit and the ability to adequately train volunteers, implement protocol, disseminate information to staff, evaluate the project
- Different understandings of what the Navigation program entailed.

Identifying and understanding the many facets of the social context proved to be perhaps the most important and difficult component of implementation. Identifying the supports and the barriers to implementation in the clinical setting was central to the success of the initiative.

Discussion

Background and Context: Planning for the Project

Utilizing evidence to implement a service or program is a multifaceted and complex process, particularly as this process involves a number of social actors and institutions that likely have different ideas regarding development and implementation strategies. Approaching the development and implementation process in a systematic way brings a sense of transparency to the process, and encourages thoroughness when considering who is being consulted, who the initiative is serving, and what barriers and supports can be anticipated. The principal

investigator, research assistant and research coordinator found the KE-DS Toolkit to be well suited to the initial stages of planning and development.

The CPN project team effectively drew on existing research to establish the need for a psychosocial initiative that assisted patients and their families in navigating the cancer system at the early stages of their diagnosis/treatment. Previous research illustrated the need for and the potential benefits of offering this type of initiative to the Chinese community, and interviews with stakeholders illustrated a need for this type of service within the clinical setting.

The project team considered the scientific context at the beginning of the project. The need for supportive cancer care that was culturally and language based had been considered – the next step was to review the scientific evidence related to supportive cancer care and on navigation programs in order to identify the most appropriate model for this population. While there was a substantial amount of research on navigation projects, very few were peer led, and there appeared to be only a few that were both peer led and language/cultural based.

In terms of the economic context, a separate research team was considering the economic costs of running and implementing a navigator program in a clinical setting. There were many costs associated with the actual project itself, such as the printing of materials, costs to promote the service, recruiting volunteers, and staff time utilized for training. These costs will impact the sustainability of the program, and understanding the program costs was part of the learning process.

Explicit and implicit use of evidence and knowledge

The project team was supported by a Multidisciplinary Advisory Committee. This committee brought their experience and expertise in working with other supportive cancer care projects in British Columbia. As well, this team established a list of key informants who the CPN project team interviewed during the planning and development phases. These two groups served as an excellent source of information, and offered ideas and feedback on the project.

Members of the project team and the advisory committee came from a diversity of professional and clinical backgrounds, and therefore brought an array of expertise and experience. Coordinating times when all members can meet and provide timely feedback to materials or issues that arise is a challenge faced by many project teams, particularly those who include a diversity of stakeholders such as occurred here.

There are very few peer led navigation initiatives in operation and therefore there was little in the way of evidence to inform the planning of the initiative. This, along with the importance of learning from the stakeholders involved in the planning of the project, led to an iterative process of defining the scope of the project. At times there was a difference in understanding amongst members of the project team in terms of what was feasible to accomplish given the time constraints. The objectives of collecting research data and producing materials within the limited time available were at times at odds with developing and implementing the program in a sustainable manner. Defining the "patient-centered health outcomes" was an iterative

process. The outcomes included assessing the feasibility of offering a peer led navigation service, as well as offering caring and informational support to newly diagnosed Chinese cancer patients. As well-managed programs have standards, guidelines, procedures, policies and contracted agreements with staff/volunteers, communication between all involved in the planning and implementation is of paramount importance. Having "clearly stated agreed-on expected patient centered health outcomes", as advised by the Toolkit, will assist in this communication.

"The population at risk" was identified as non-English speaking cancer parents. This was further narrowed to Chinese speaking patients. Literature reviews, individual studies, focus groups, recommendations from stakeholders and experiential evidence was all drawn upon to establish this population as one "at risk". The target population was again narrowed to head and neck cancer patients. This tumour group was selected due to the high rate of head and neck cancer amongst the Chinese population, as well as the extremely invasive nature of the disease (the tumor and its treatment may affect speech, eating and appearance). As the program got underway, however, it was decided that including all Chinese speaking, newly diagnosed cancer patients would make the best use of navigators skills, time and training, and would then employ "norms of utility and equity". The process of defining the population is iterative, and the project team adapted to the social and physical context in which the project was being offered by expanding the patient group. The peer navigator service can potentially be developed for use by all patients in a diversity of contexts and environments.

In terms of promoting the program, the project team drew from a number of strategies. All promotional materials were bilingual in order to target both English and Chinese speaking populations. Cultural values and ideals were considered by the project team when developing materials and training the navigators. For example, CPN name tags were not put on white paper as white signifies death in Chinese culture; the CPN was aware of the need to greet all individuals who accompanied the patient as there were often many family members / friends; lunch for the CPN during training was served hot as cold foods are generally disliked.

Learning from the experiences of the navigators was very important to the project team. Some members of the project team developed two questionnaires that the navigators filled out during their shifts. The first questionnaire was to document the experience of the navigator (this was to document the effectiveness of the training, whether or not they had adequate support, and the types of encounters that they had with patients and health care staff). The second was to gain a better understanding of the patient's situation, such as what types of support they had available to them, their language proficiency and what format they prefer their resources in. This information was not used to illustrate the impact of the program, but instead to gain a better understanding of who the population of impact is, and a better understanding of the experience of the navigator. For the most part, the navigators did not like filling out the forms as they often felt rushed and sometimes had difficulty recalling information. The project team also held a focus group for the navigators where they were encouraged to discuss their experiences. This may have been a more conducive approach to gaining an understanding of the experiences of the navigators.

Social actors and socio-medical dynamics

As this navigation project was implemented in a clinical setting, there were a number of social contexts and actors involved. The structure of VCC and the social environment in which the project operated within affected all aspects of the program planning and implementation. Understanding the correct channels to move through in terms of learning VCC policies and procedures was key. The input from health practitioners was vital to the success of the initiative, and the advisory committee and key informants were invaluable for understanding the processes of VCC. It may have been beneficial, however, for members of the project team who did not have experience working at VCC to have consulted with more members of the nursing and admissions staff when working out the logistics of the navigator shifts. The research coordinator explained the Peer Navigator Program to the nurses and admissions clerks on the appropriate floors once the program was underway – perhaps holding these information sessions before the program was implemented would have led to increased awareness about the initiative, and less confusion during the initial navigator shifts. In a large organization such as VCC it is impossible to speak with all volunteers and staff; however, speaking with those staff who will directly interact with the navigators on a daily basis, at as early a stage as possible, would be beneficial to the planning and implementation of the program.

The confidentiality policies and practices in place at VCC are implemented to ensure that confidentiality is held to the highest regard. There were concerns voiced regarding access to patient information (patient names) by navigators. As this was a pilot project, the project team could not anticipate all of the procedures that would need to be addressed – indeed, developing new procedures as needed was part of this process. As this project team was multidisciplinary, a briefing of procedures already in place for all project team members, particularly those who do not have a clinical background or experience in VCC, was important.

Implementing the program in VCC also involved the development of materials for the project. Perhaps the most time consuming issue that was not anticipated by some members of the project team was the development and translation of promotional and informational materials. The project team did not predefine the materials that were to be developed – rather, this was an ongoing process that incorporated the expertise and experiences of the key informants and the advisory committee. In order to meet the standards of best practice, all materials developed needed to be reviewed by a number of healthcare professionals to ensure accuracy. Once these materials are developed, they must be translated and then undergo a second review process. While time and funds were allocated for this process in the proposal, some members of the project team did not anticipate the extent of this process. A closer review of the literature and further discussion with other project team members who had experience with this process would have been beneficial.

As the Chinese Peer Navigator project was a pilot project, there was a great deal of learning that occurred throughout the process of planning and implementing the program. Attention to procedures, policies and guidelines, as well as meeting the standards of best practice was

important to ensuring the creation of a sustainable program at VCC, which the project team was successful in doing.

Northern Health Initiative

Establishing the Need

The breast health survivorship workshop brought together a wide range of stakeholders to discuss what is working and what the concerns are with the current breast cancer services in Prince George starting from screening to survivorship (living through and beyond the cancer experience).

Comments from the workshop were complied into the following sections: suspicion to diagnosis, diagnosis to surgery, surgery to chemotherapy/radio-therapy decision, therapeutic treatment, treatment to supportive care, and survivorship. The comments ranged from inconsistent service timelines to patients' voicing their need for "*social/emotional/ psychosocial component prior to surgery".* A Prince George Regional Hospital Journey Map was also created to document the process, the people involved, the timelines, and the issues from suspicion to supportive care.

Through the workshop and the set of exercises to understand the "current state", the planning team went on to discuss what the "ideal" journey would look like and identify areas where they need to redesign in order to get to the ideal state. An ideal journey map was created. In the ideal journey, the number of steps in the patient journey is significantly decreased. And in most instances, the target timeline to get from one service to another is also shorter than current experience.

There were seven problems identified as priorities to approaching the ideal journey[10]. They are:

1. **Patient information in mammography**	Can NH provide patient with more information about breast lumps and abnormalities? What type of evidence/information should be provided? How is it best to provide such information?
2. **GPs are on the Fast Track system**	Can all GPs participate in the Fast Track program so that patients will be able to get a follow-up ultrasound and/or diagnostic mammography from a suspicious screening directly (without having to have a GP consult in between these appointments)?
3. **Biopsy booking**	Can we improve coordination of services to reduce delays in biopsy (ordering, booking)?

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[10] Abstracted from the Northern Health Authority's *Breast Cancer Survivor Workshop Summary*, June 4th, 2008

4. **Patient Education**	The development of Patient Journey Maps for patients and families so patients and families to not feel "lost".
5. **GP education**	How to engage with GPs, who are the significantly involved in patient's breast cancer journey, to discuss ways they can improve patient outcomes?
6. **Follow-up process**	How to ensure patients do not get 'lost' while waiting for services?
7. **Pre- and post-operative surgery teaching**	Patients have stated that they would like more discharge information and teaching

The planning team created smaller working teams to tackle each of the issues with the exception of issue #2 which the team decided to defer to a later time. The ultimate goal is to provide a seamless journey for the patient, from prevention to survivorship with as few bumps as possible. The interventions relate to the overall goal; the interventions address concerns with education, communication, and patient support so to reduce anxiety for the patient and family during the journey as well as support the patient to be able to self-manage their care.

Site Description

"Historically, cancer control in northern British Columbia has faced several challenges: lifestyle, geography, risk factors and access have all contributed to lower survival rates for some types of cancer when compared with other regions of the province. The impact of cancer on the population is a key concern for the citizens of the area, along with their care providers and health care planners.

By 2012 in northern B.C., 1,200 new cancer cases will be diagnosed annually, and 11,000 people will be living with a history of cancer. Life expectancies for northerners are from three to four years shorter than those for B.C. residents overall. The area has the highest standardized mortality rate in B.C. for most causes of death including cancer."
– The Northern Cancer Control Strategy Business Plan

The programs and services to improve cancer control and outcomes for residents of northern B.C. are the jurisdiction of both the BC Cancer Agency/Provincial Health Services Authority and the Northern Health Authority (NHA). One of the many programs that have been established recently is the Northern Health Navigation Program.

The Northern Health Navigation Program started a year and a half ago according to the navigation coordinator (approximately Fall/Winter 2007), who was appointed to the position at that time. The need for a Navigation Program in NHA was identified from the results of the BC-wide Ambulatory Cancer Services Patient Survey in 2006. The Ambulatory Outpatient Clinic Manager noted the patient satisfaction on *coordination and continuity of care*, *physical comfort*, *emotional support*, and *information, communication & education* were particularly

low.[11] At the time NHS did not have a navigation program in place (cancer or otherwise). Based on the findings and the existing gap in navigation services, the ambulatory outpatient manager was encouraged to develop a Northern Health Navigation Program by creating a position for a navigation coordinator.

The common understanding of navigation is an individual 1:1 model. The navigation models in many other Supportive Cancer Care initiatives across Canada are based on a nurse-led model (Wells 2008). However, it was felt that rather than designing the program to have a navigator to "hold the hand" of the patient as he/she goes through the system, NHA would look towards using the 'system' to guide the patient through his/her care. As hiring to achieve a 1:1, navigator to patient ratio across the service delivery area of Northern Health is not realistic due to the limited health human resources in the area, the team decided that a system approach would be more suited. In this approach, the focus is not only on assessing what types of services are required to address patient and family needs, but also how the existing services are coordinated and structured. The role of the navigator is to work with the providers of these existing services to facilitate access and coordination across the system.

The NH Navigation Program was initially a (pilot) project within Prince George Regional Hospital (PGRH). At the time when the navigation coordinator was appointed, cancer care patient navigation was not considered a formal program. Rather there were bits and pieces of planning, design, and redesign work that needed to be done within the cancer control/cancer care portfolio[12]. The navigation coordinator reported to the Ambulatory Clinic Manager. It is the only resource dedicated to the project and is not a full time position. The navigator coordinator has a background in nursing and her experience reflects her clinical knowledge and medical professional context/relationships. The other staff involved in the project was a cancer control project lead. At the time of the project's initiation, a number of human resources changes occurred. The Executive Director of the Northern Cancer Control Strategy was recently appointed March 2007; and the Ambulatory Clinic Manager was subsequently promoted as well. Cancer Control as a priority in Northern Health was becoming more prominent, although launching of related programs and setting of priorities within the portfolio is still at the planning stages.

As a pilot project, the navigation coordinator needed to tackle areas that are actionable. As a group the Executive Director of Cancer Control, the Nurse Manager, the Project Lead, and the Navigation Coordinator set the priorities for the navigation pilot project. They considered two factors: where is the need (i.e. what are the top cancer tumor groups in NH); and where there is a good likelihood for participation in the project by the overall group (i.e. stakeholders in cancer control). They decided to look at breast health first as it is one of the largest cancer tumor groups, along with colorectal and prostate cancer, and there is an enthusiastic group of

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[11] Survey results:
http://www.northernhealth.ca/About/NH_Reports/documents/NH2006ambulatoryoncologysurveyresults.pdf

[12] Since then, the initial project has grown to become a program and has regional responsibility. It is one of the strategies in the NH Cancer Control Business Plan.

clinicians within the PGRH that would like to improve the current system for breast cancer patients.

The breast cancer clinic in Northern Health is currently run by the Northern Health Authority (NHA) and not the BC Cancer Agency (BCCA). The plan is to have a BCCA cancer centre in Northern Health in the future. There is still a gap in the coordination of cancer control services and there is a need to have consistent services across BC, e.g. to provide the same access to services for rural/remote and northern BC as the urban centres.

Once the team had identified the area to focus on, the next step was to identify and document the problems in the service delivery for breast cancer patients and who needs to be involved to identify the problems and solutions.

Identifying Stakeholders

The core planning personnel for the Northern Health Navigation Program are the navigation coordinator and the cancer control project lead.

The first planning exercise was to identify the current patient journey for breast cancer patients. The breast cancer survivorship workshop was held in June 2008. The purpose of the workshop was to identify the difficulties in the current patient journey. To ensure there is representation from different parts of the cancer patient journey, a number of stakeholders were asked to be involved in the navigation program planning group. Stakeholders included: radiologist, mammography service, nursing, social worker, patients, general practitioner of oncology (GPO), executive lead, planning support, navigation coordinator, and survivors.

From the current journey map and inputs from the survivorship workshop, the group devised what an 'ideal journey' for patients in Prince George would look like (the ideal breast cancer journey map). The group was also able to identify seven problems areas as priorities.

General Practitioner (GP) engagement was limited although much effort was put towards obtaining their input. The strategies used in engaging GP:

- Posted the process maps in the physician's lounge
- Posted the process maps in cancer care clinic
- Navigator coordinator solicited inputs from GPs at physician's lounge
- Put information in the GP's mailbox
- Requested GPs to attend meetings & input sessions
- Presented the navigation information at General Rounds (a once-a-month meeting)

The current planning structure consists of 1) an advisory committee that provides input around navigation program priorities and vet ideas, and 2) small working groups that work on the priorities identified by the advisory committee. Many of the stakeholders from the survivorship

workshop are involved in the committee. A working group is formed to work on specific assignment(s) and disbands when the assignment(s) is/are complete. Meetings are based on the timeline of their specific assignments. Group members self-identify their interest in the initiative and sometimes specific stakeholders are asked to join. A usual working group consists of three to five people. The navigation coordinator and the cancer control project lead are on both the advisory committee and the working groups.

Population of Interest

The population of interest identified is the women of Northern BC. It is an ambitious goal, but the navigation coordinator and the project lead believe that the services are for any women that may come into contact with the NH cancer control programs during their life. The focus of the intervention, however, is women diagnosed from mammography who require follow up.

What was the implementation experience?

During the interviews, the navigation coordinator and the project lead (the core planners) revisited the goals of the navigation project. The long term goals stayed relatively the same.

> Long-term Goal 1: seamless journey for the patient – cancer journey from prevention to palliative care, with as few bumps as possible

> Long-term Goal 2: decrease patient's and families' anxiety and provide support

The medium-term goals are those that were harder to tackle and require more coordinated effort to accomplish (i.e. short-term goals that were promoted to medium-term goals). GP engagement turned out to be more challenging than anticipated. The plan was to design a website for GPs to access information about cancer control. This is still underway. It is not yet known how this initiative will be evaluated.

> Medium-term Goal: GP understanding of cancer control and GP education

The other issues became tangible short-term initiatives that are being implemented in Prince George Regional Hospital:

- The provision of information to educate patients about what they can expect during screening when the mammography program is underway.
- The provision of resources and/or information handouts at various stages of the journey: pre-operatively, discharge teaching, chemotherapy, and through to supportive care.
- Planning is underway for a breast health clinic for newly diagnosed patients (jointly with BCCA).
- Clarification of roles and coordination of the services for biopsy is still underway.
- A peer support program – to provide patients with some kind of outlet to talk to other women who have gone through the same journey. Peer support was identified at the beginning of the journey mapping exercise, but it was not the priority at the beginning of

the navigation project. The navigation coordinator stated that, "in the last two months it has become more evident that peer support service is necessary". Feedback from the social worker and also from patients who the navigation coordinator sees in the PGRH cancer clinic prompted the navigation program to revisit this issue.

Both the navigation coordinator and the project lead felt that these short term initiatives contributed to the bigger program goal because the initiatives are bringing in the emotional support and informational support from the first point of entry into the system, and are empowering patients to self-manage their care. They feel that if patients have control of their care, they have better outcomes. These efforts, therefore, are not solely focused on reducing patient anxiety, but also improving cancer survivorship.

When discussing how they would know if they have achieved success, they expressed that it is not easy to measure success with these long-term goals. They felt that patient anxiety and patient satisfaction are difficult to measure (e.g. Staniszewska and Ahmed, 1999; Linder-Pelz, 1982). They expect to rely on qualitative measures (e.g. surveys), and less on other empirical measures, to assess the patient impact from the navigation program. Improving patient throughput would be another measure to evaluate achievement, but they felt that this is not the ultimate measure because it is the patient's perspective and experience that is the most important.

Economic and Social Context

The economic context and social context originated from two perspectives: the patient and family, and the organization.

Figure 1: Social & Economic Matrix

The intent is to improve patient satisfaction and to reduce patient and family anxiety throughout their care journey. From an organization's perspective, considerations around the linkages with GPs and also health human resource issues guided the project.

Economic Context from a Patient's Perspective

The planning team did not deliberately consider interventions strictly to reduce costs for patients; however, when revisiting the economic context from a patient's perspective a number of planning decisions did have an impact on patient's economics.

- The creation of a breast clinic in Prince George will create a smoother patient journey. An extra visit for biopsies will be reduced and thus reducing time and cost for patients;
- The navigation program is promoting the "Northern Health Connection Bus" to reduce travel cost for patients;
- The social worker's hours has been increased for patient support. Cancer patients can call with their questions and issues.

Economic Context from an Organizational Perspective

Meeting health human resource needs is one of the biggest challenges to rural/remote and northern British Columbia and Northern Health. Cost-savings are indirect results of a systems approach to patient navigation, which was designed to leverage health human resources. It was not a primary objective to design interventions that averted spending.

- The biggest challenge for cancer control in Northern Health is health human resources recruitment, with radiology recruitment and retention being the most difficult. This issue is attended to by the corporate human resource department. The health human resources issue influences the project planning for the navigation program both explicitly and implicitly.
- The navigation program is leveraging human resources by coordinating with the Care North program and utilizing Care North coordinators to promote GP education and engagement.
- Physician website is a more cost-effective method to get the GP education material across the health authority.
- Northern health is evaluating and implementing telemedicine network to increase service delivery to remote geographic areas.

Social Context from a Patient's Perspective

"The challenges imposed by long distances and harsh weather add to the problems faced by northern patients who need to travel to access specialists, screening services, diagnostic tests and treatment. The full range of services are often not available in one location thus requires patients to travel to multiple locations at multiple times" (The Northern Cancer Control Strategy Business Plan, 2009).

From the Ambulatory Cancer Services Patient Survey (December 2006), patients rated Northern Health community cancer services to be strong in providing clinical information and services within time expectation. The areas where Northern Health community cancer services scored relatively low were around coordination of care, psychosocial support (resources such as information, education, and communication).

- Coordination and continuity of care
- Physical comfort
- Emotional support
- Information, communication & education

These are the areas that the Northern Health Navigation Program is trying to address despite the complexity of service delivery due to "geographical vastness, transportation difficulties, and the complexity of the cancer diagnosis" (Northern Cancer Control Strategy Business Plan, 2009).

Social Context from an Organizational Perspective
Engaging general practitioners in health authority redesign strategies/projects remains to be a challenge. Because GPs are not part of the health authority, many of the conventional strategies to communicate and create effective teams (in an organizational setting) do not apply. To serve a wide geographic area such as northern BC, health organizations and service providers need to be better coordinated. Creating partnerships with the northern GP population remain to be the biggest hurdle for the health authority.

Discussion

Cancer patient navigation in Northern Health started with a breast patient navigation project in Prince George. A representative team of stakeholders were invited to share their experiences about the current breast cancer patient journey, what are the current challenges, and ideas for improvement. Engagement with GPs is still limited despite efforts from the nurse navigation coordinator. From the breast cancer survivorship workshop held in June 2008 seven problem areas were identified as priorities. Led by an advisory committee, working groups were created to tackle the issues ranging from patient education to staff training/role clarification. The ultimate goal is to provide a seamless journey for the patient and the family. This includes provision of advice and support (clinical and psychosocial) through all treatment phases (from screening to survivorship), and information on alternative treatment and other support services in the community.

In the rest of the discussion, I will elaborate on the NHA's experience of using the KE-DS model and what was learned throughout this process.

The KE-DS Model as an approach to reflect on the program's experience
The NHA did not have a formal, pre-determined strategy in designing the breast cancer patient navigation program. Ideas for the navigation program stem from a review of current processes. Reflecting on the planning and implementation steps and structures, the planning activities covered many concepts that are raised in the KE-DS framework. For example, the breast cancer survivorship workshop was an exercise involving a comprehensive group of stakeholders establishing a current need in breast cancer care (Step 1 in the KE-DS model, to identify the big

picture) and the seven priority areas (to identify the patient-centred health outcomes, i.e. the small picture). The planning activities aligned well with the steps detailed in the KE-DS toolkit.

The retrospective reflection of the planning process, however, highlighted to the planning team the benefits of deliberately using a formal framework in service/intervention/program planning and implementation. When talking about the economic context for patients, the reflection brought out things that they never considered as deliberately linked to the navigation program. The "Northern Health Connection Bus" was promoted to the breast cancer patients because it is a service that is already available in NH, and it will help bring patients down to Prince George for services. They promoted the bus because it 'made sense'. Travel is a concern for many northern remote residents and not just the women accessing breast health services. Nevertheless, by applying a formal framework (KE-DS), the planning team was able to articulate their own rationale for making certain planning and implementation decisions (e.g. promoting the "Northern Health Connection Bus" and not creating some other form of transportation services for breast health patients).

The system approach to patient navigation is markedly different from the individual-led navigation program (e.g. nurse, peer, tacit/self). The difference in approach is reflected in what problems and priorities were identified during the planning process. The stakeholders raised problems concerning access and coordination issues to *clinical services* as well as supportive cancer care. "The term 'Patient Navigation' denotes a system or professional role primarily intended to expedite patient access to services and resources, and improve continuity and co-ordination of care throughout the cancer continuum. Navigation should seek to address patients' informational, emotional, and practical needs during the cancer journey" (Doll et al. 2005). By using a system approach to patient navigation, the changes do not only pertain to assessing what types of services are required to address patient and family needs but also how the various types of services are coordinated and structured.

To assess the success of the program, the navigation coordinator and the project lead emphasized that the focus is on patient satisfaction (to be measured by patient survey). We discussed the need for process indicators during the phone interviews. Although improving patient throughput is important, process indicators were seen to be a second level indicator. "Patient satisfaction is key." Patient throughput and service access will contribute to patient satisfaction, but measuring patient satisfaction is not a direct indicator for the system improvement that NH is reinventing. The focus on patient satisfaction underplays the importance of system changes that NH is undertaking. According to the Northern Health Regional Navigation Framework (obtained through the project lead), patient throughput is one of the desired outcomes. So why not create a measure to evaluate what the program is achieving in this area; such as shorter wait times for biopsy appointments, and more timely and a higher volume of patient follow-up visits.

Would the intervention and targeted outcomes be different if the KE-DS toolkit was applied in the beginning of the planning process (i.e. prospective tool)? If during the breast cancer survivorship workshop the patients and family members were asked about their clinical,

economic, and psychosocial concerns about the current breast cancer services, would they have identified travel as an issue? The findings from the Ambulatory Cancer Services Patient Survey drew attention to the *coordination of care, emotional support, and communication* issues. The concerns from an economic context were not raised specifically in the patient survey or in subsequent planning endeavors. This might suggest why the planning team expressed that they did not deliberately consider patient and family costs and other financial issues when designing the program.

New Insights (for program participants to consider)

If the navigation program was to take up the KE-DS framework, what are the points to consider? The NH navigation program did not address social and economic dimensions as comprehensively as they did for the population need and population impact. The benefit of considering the social and economic contexts when developing the interventions would be having the social and economic issues identified up front.

Another drawback or limitation was the lack of academic literature and empirical data used in planning. Aside from the Ambulatory Cancer Services Patient Survey, the navigation program planning relied heavily on experiential knowledge, focus groups, and recommendations from stakeholders for information and evidence. Experiential knowledge can be very informative, especially when the dominant literature and empirical 'evidence' are based on the dominant discourse (i.e. care in urban settings) and do not fit the local context (i.e. the northern and remote setting). Still, it would be useful to review the literature on what a 'system-approach' to navigation would look like (regardless of context). Does a 'system-approach' to navigation even exist in other health care systems? In addition, it would be valuable to have some empirical information on the potential volume of patients affected by the breast cancer navigation program in Prince George. The empirical information can inform the evaluation plan and target setting for the program.

A broad-based group of stakeholders were involved with the planning and the implementation of the breast cancer navigation program (with the exception of the GPs). The planning team did a good job of making sure that they reached as many GPs as they could, using a variety of engagement technique (e.g. both push and pull strategies as discussed by Lavis, 2006). What if a major stakeholder group is not available for consultation? Can planning activities wait if there is no complete buy-in by the stakeholders? The NH navigation program chose to move on with the 'engaged' stakeholders and defined the priorities based on what they can tackle in the immediate period. Despite holding off on the issues related to GPs, the planning team is still working to improve GP engagement. Through this process the navigation coordinator now has developed relationships with more GPs in Prince George. Based on experience of engagement in Prince George, the navigation program will use a different strategy for the other Northern Health Service Delivery Areas[13]. The navigation program will partner with Care North, the

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[13] Health Service Delivery Areas are geographical areas under the service jurisdiction of a Health Authority. In 2001, the Ministry of Health in British Columbia created Health Authorities (6) and Health Service Delivery Areas (16) to streamline governance and management model.

Northern Health primary care strategy, to utilize Care North's care coordinators to communicate with GPs.

Was the KE-DS toolkit easy to use and was it useful to the program participants?

In the follow-up meeting with the Northern Health Cancer Control Program Leads and Executives (the Northern Health Navigation Program and the Cancer Transition Program), they expressed the process of working through the KE-DS tool was extremely useful. Particularly they found:

- This process helped them link the "evidence", e.g. things they considered, process of planning and implementation, to outcomes.
- The tool can be used to facilitate the documentation of the rationale of the intervention/project (how, why, what).
- "If you can answer the questions (in the toolkit), then you are on the right track" – project coordinator (Transition Care Program Lead).

Although all the participants had positive takeaways from the experience, they stressed that it takes time for uptake of "this type of thinking", i.e. knowledge exchange framework, and time to create a culture in using evidence-based processes. It challenges the planner/project lead to have a good understanding of what they are doing and where the gaps are in their planning and implementation process. Once they have identified their programming rationale, the gaps, and have documented some of the tacit knowledge, they needed to map the information back to the research jargon. The participants realized that it takes a lot of time to document the information coming out of the KE-DS process. They noted it was tremendously helpful to have the support of the KE-DS research team members to guide them through the toolkit (e.g. to go over the tool with tem, ask/prompt them on the questions, assist with the documentation process, and synthesize the discussions).

Areas for improvement:

- The language used in the KE-DS toolkit (i.e. in research) is not necessarily intuitive language for program staff. It took some time to understand what the document is referring to, but the comfort with the language improves with each meeting with the research team. The KE-DS tool and related documentation need to be at a lower level of conceptual abstraction so it can be more user-friendly (follow the tool and understand where it is going).
- The participants felt the questions in the tool were, at times, repetitive.
- It is not clear what the KE-DS tool considers as 'evidence'. It would be instructive to develop a guideline and criteria for evidence.

Conclusions: Further Exploration of the KE-DS Toolkit

The KE-DS toolkit has a good visual representation of a set of modules that aid stakeholders to identify desirable or preferable futures, identifying and appraising the evidence on effectiveness, efficiency and appropriateness of the intervention; and optimizes decision-making by integrating population, economic, and social contexts. If used more purposefully to develop and align performance indicators, performance targets with the program's objectives, the KE-DS toolkit can also be an effective evaluation tool (so usage is not only constrained to the beginning phase of the intervention, but also during program evaluation).

The KE-DS Model adopts a 'problem-solving' approach that "ensures a comprehensive understanding of the specific problem or deficit as well as thorough examination of the consequences of alternative courses of action" (Kazanjian 1995). The KE-DS toolkit facilitates the stakeholders in identifying areas to pay attention to, but it does not necessarily stipulate on how to resolve these issues.   Different strategies/techniques/processes maybe required to resolve issues. For example, with the Northern Health Navigator project, the KE-DS toolkit was able to identify GPs as a key stakeholder, but it does not have the strategies to get the stakeholders to participate. The navigator coordinator had a strategy to obtain GP feedback, but was met with limited success. What are the engagement strategies in the change management literature? What has proven effective in the grey literature or from the experiences of other colleagues? The KE-DS model can be used to understand change management and/or implementation science, which would be a separate project.

Furthermore, the KE-DS Model is not an implementation guide, but rather a tool for the project team to utilize in ensuring that various issues have been actively considered, such as approaching stakeholders and consulting the existing evidence. For example, because the Chinese Peer Navigation Project was implemented in a clinical setting, there were many actors, rules and protocols that needed to be addressed before implementation could take place, a process that required a site specific approach rather than a general Model.

In order for the project team to fully support the use of the model in an applied setting, the project team needs to be comfortable with the language and jargon used by the participants, for the learning of 'language' is bi-directional. The following are suggestions made by the project teams to facilitate support of the KE-DS approach.

a) Find opportunities to sit in on program meetings at the earliest time possible. This will help the team to pick-up the language being used at the operational/administrative level, and also recognize areas of the toolkit for refinement and reiteration.
b) The KE-DS tool needs to be presented with better connections between the prompt questions and the KE-DS Grid.
c) The toolkit is an iterative tool; it will be continuously refined. The KE-DS research as identified by project teams needs to be amenable to revising questions that can be asked differently and alternative methods of prompts so the participants can make the most out of this process.

Finally, the incorporation of the KE-DS approach into the daily planning activities will facilitate an evidence-based approach to program planning and implementation. The research team acts as a guide to the participants - help interpret the (sometimes difficult) language in research and the steps in the toolkit. Ultimately, the toolkit and the information generated from the tool must sit with the user.

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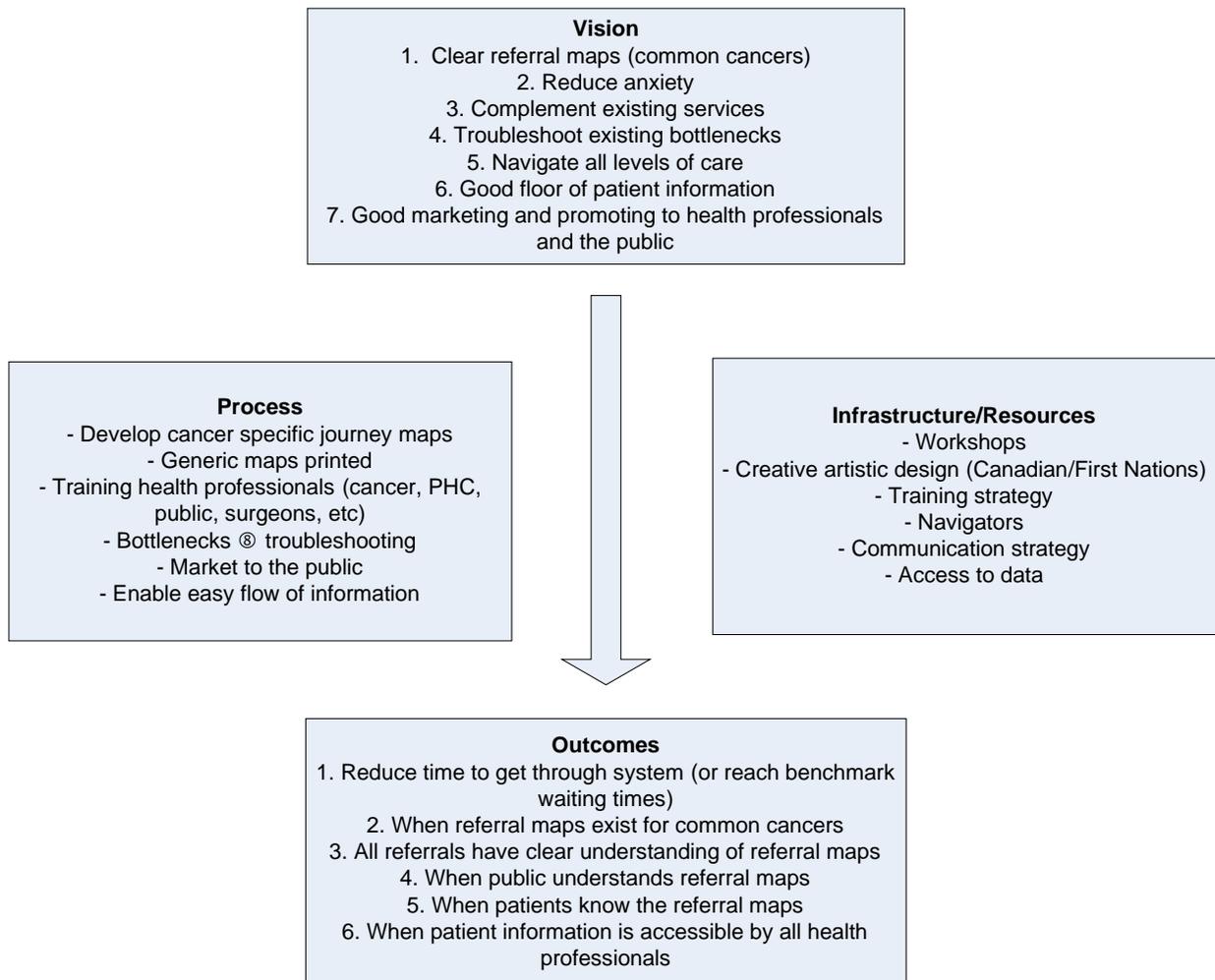
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Appendix 1: Resources/Tools Developed

Phase	*Tool*	*Purpose*
Program Implementation	Patient / Navigator Encounter Form	A survey questionnaire considering the personal support system available to the patient, language ability, and their preferred learning style. The navigator will ask the patient these questions during their time with them.
Program Implementation	Patient / Navigator Contact Form	An intake form that the navigator will complete after each encounter with a patient. The navigator will consider and record how they felt during the encounter, will describe what topics were discussed and if they encountered any barriers to providing their service.
Program Implementation	Library Resource Checklist	Bilingual tool developed for patients to assist in the request of informational material at the Agency's library
Program Implementation	Volunteer Driver Request Script	Bilingual script developed to assist patients with booking the Volunteer Driver Service to and from Vancouver Centre
Program Implementation	Floor by Floor Directory of Vancouver Centre	Bilingual floor directory
Program Implementation	General Tips	Bilingual tool developed to provide some general guidance to Chinese patients undergoing treatment at the Centre. This tool was developed based on the results of various focus groups held with the Chinese community, as well as with input from a social worker from patient and family counseling.
Program Implementation	Commonly asked questions	An easy to use reference tool for patients
Program Implementation	Spatial Map	A bilingual floor map of Vancouver Cancer Centre

Appendix 2: The Northern Health Navigation Program Framework

Regional Navigation Framework

Vision
1. Clear referral maps (common cancers)
2. Reduce anxiety
3. Complement existing services
4. Troubleshoot existing bottlenecks
5. Navigate all levels of care
6. Good floor of patient information
7. Good marketing and promoting to health professionals and the public

Process
- Develop cancer specific journey maps
- Generic maps printed
- Training health professionals (cancer, PHC, public, surgeons, etc)
- Bottlenecks ® troubleshooting
- Market to the public
- Enable easy flow of information

Infrastructure/Resources
- Workshops
- Creative artistic design (Canadian/First Nations)
- Training strategy
- Navigators
- Communication strategy
- Access to data

Outcomes
1. Reduce time to get through system (or reach benchmark waiting times)
2. When referral maps exist for common cancers
3. All referrals have clear understanding of referral maps
4. When public understands referral maps
5. When patients know the referral maps
6. When patient information is accessible by all health professionals

Appendix 3: The Northern Health Knowledge Exchange-Decision Support Grid - identifying the evidence considered, targets, indicators for the Northern Health Breast Cancer Navigation Program

Dimension	Indicators*	Target/Goal and Uptake	Evidence considered
1) **Population of interest:** Women of Northern BC	➢ Coordination & continuity of care – patient survey ➢ Patient awareness of journey trajectory and contact with system (next step and if they know where to find information) – patient survey ➢ System indicator – To be determined	**GOAL 1: Seamless journey for the patient – cancer journey from prevention to survivorship/ palliative care, with as few bumps as possible**	Northern Health Outpatient Cancer Care Patient Survey (Dec 2006) Workshop of future navigation journey (2008)
2) **Population Impact:** To increase each providers and patients understanding of the system To reduce patient anxiety To decrease patients lost in system	➢ # of GPs on Fast Track system ➢ Looking at impact GP website - # of hits, referral patterns change ➢ # of referrals to nurse navigator (anticipate increase and then decease once when other system components are in place) ➢ "Do you know who to contact? Did you feel it was the contact person was helpful? Appropriate?" – patient survey	**GOAL 1: GP understanding of cancer control and GP education** ➢ Positive diagnostic report will generate automatic booking for Bx and info will be sent to GP and Breast Health Clinic ➢ All patients on Fast Track ➢ Reduce visits for out of town patients **GOAL 2: Patients self-managing their care**	Workshop of current navigation journey (2008) Large planning/steering group feedback ➢ Resources for GP, what would they look like?
3) **Economic Concerns:**	➢ Fewer patients visits by out of town patients versus in town patients ➢ Reducing the number travel days	**GOAL 1: Reduce unnecessary costs for patients** ➢ Doing biopsies in the breast clinic will reduce an extra visit ➢ Promoting the "Northern Health	Organization human and financial information – limited resources to be dedicated to the navigation program ➢ Recruitment & retention of health human resources

Dimension	Indicators*	Target/Goal and Uptake	Evidence considered
	for out of town patients (costs and time)	Connection Bus" to reduce travel cost ➢ Increase social work hours for patient support. **GOAL 2: Advert costs for NH** ➢ Capacity building ➢ Physician website is a more cost efficient way to get the GP education material ➢ Leveraging human resources, e.g. Care North coordinators	Geographic distribution of service providers and patient population
4) **Social Context** Understand the social context for • Individuals • Communities • Organizations or other groupings • Institutions and systems	➢ # of GPs provided input to navigation program ➢ # of GPs that NH via Care North Coordinators/Navigation Nurses have spoken with ➢ Emotional support – patient survey ➢ Information, communication & education – patient survey	**GOAL 1: Decrease anxiety and provide support** ➢ Pre-op & post-op support for patient & family **GOAL 2: Bring in the emotional and informational support at the first point of entry into system** **GOAL 3: GP engagement**	**Feedbacks from stakeholders** Organization ➢ Primary care – Care North Program GP ➢ Solicited inputs by navigation coordinator Surgeons ➢ Participation in advisory group Patients & Survivors ➢ Participation in advisory group All NH health service delivery areas ➢ Meetings with individual HSDA to understand organizational cultural difference

*Indicators highlighted in red are still under consideration