



**BC Cancer Agency**  
CARE & RESEARCH  
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# Patient Navigation in Cancer Care



## Summary Report

Sociobehavioural Research Centre  
BC Cancer Agency  
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# Executive Summary

Cancer is a burden experienced by patients and their care providers throughout the full trajectory of the disease. Challenges include a myriad of physical, social, emotional, nutritional, informational, psychological, spiritual, and practical needs. In the current health care system, cancer patients report fragmentation of service, delays in access, lack of coordination between providers and inadequate information.

*Timely access to informational and emotional support around the time of cancer diagnosis is crucial in helping patients adapt and prepare for their journey in navigating the health-care system.*

The Canadian Strategy for Cancer Control, a consortium of stakeholders from across the country, identifies coordination of services as a key component in improving cancer care in Canada. To meet patient needs, the BC Cancer Agency (BCCA) has also identified the integration of cancer control programs in the community as a primary organizational objective. An imperative is to create models of integration and coordination using test-sites, with the intention of developing community-based approaches for cancer control. In the reported study, the Sociobehavioural Research Centre (SRC), located within the Provincial Rehabilitation Network of the BCCA, applied an evidence-based approach to the investigation of facilitative Patient Navigation models.

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.

## Project Description

The work described in this report comprised two phases. Phase 1 had the specific objective of articulating a model of Navigation, informed by the needs and perspectives of different stakeholders, clinical practice, and research literature. Phase 2 focussed on development and piloting of tools and methods, with specific objectives to: identify theoretically- and clinically-relevant outcomes; develop instruments that could be used to structure the Navigator intervention and measure outcomes; and pilot-test in two practice settings the developed instruments and the feasibility of conducting a rigorous empirical evaluation design.

### Phase 1

The team held a series of consultations with informants and stakeholders, including patients, oncologists within the BCCA, researchers in nursing and community health, decision-makers in regional health authorities, and family practitioners. To develop a framework, the team reviewed bodies of literature on social support, readiness for change, coping, and self-efficacy. From the discussions and literature review, the project team identified a range of potential outcomes from Navigation interventions.

*In addition to coordination and integration functions, the research team determined that 'patient preparedness' should be a core outcome and function of the Navigator role.*

### Phase 2

The team focused on a small subset of outcomes for which to develop and field test instruments. Validated instruments were used where possible. Several instruments were developed to measure outcomes of practical and theoretical significance. In addition, an assessment tool was developed to assist the Navigator shape an individually-tailored intervention and to collect data on patient needs systematically.

To test the feasibility of a prospective, controlled design, which could potentially produce the strongest method for testing effectiveness, the project team conducted a small study in the two sites to 1) pilot the questionnaires, and 2) test the feasibility of using a quasi-experimental evaluation design.

*The objective of the feasibility study was to answer a number of methodological, operational and program questions, to provide the basis for the design of a larger, regional survey, and future evaluation studies.*

In addition, the goal was to determine whether the questionnaires developed were acceptable in terms of length, ease of understanding and timeliness. Given the short period available, a test of the effectiveness of the Navigation interventions was not conducted.

In two project test sites, the team engaged Navigator informants from separate programs: one situated in an urban setting within a Breast Health Centre, led by a breast-health nurse; the other in a rural region led by a social worker, assisting cancer patients with all tumour sites.

In general, the methodology consisted of selecting a sample of patients around the time of diagnosis and before consultation with a surgeon or other oncology specialist. The time window was selected as that when patients are at highest risk of experiencing distress, and when the Patient Navigator may have the most beneficial impact.

## Research Findings

Although the sample size was small, findings from the feasibility study were found encouraging, specifically:

- 1) the questionnaires had good acceptability, were easy to understand and required short time for completion;
- 2) the response rates were good;
- 3) the tools can be used for future studies to test reliability and validity.

There were differences between the Navigation programs and in the backgrounds of the Navigators; however, each Navigator spent a similar amount of time with patients and provided similar services.

*In both programs, patient needs most often identified were: psychosocial support, help with understanding medical information, help communicating with others, and practical support.*

Family physicians were sampled to obtain an understanding of their perspectives on and preferences about the Navigator role, including how they would like to work with Navigators. In summary, these data indicate that the majority of physicians sampled do currently engage in some Navigator functions, but would value additional support of a cancer Navigator.

The findings support the importance of the general practitioner's role, and indicate that family practitioners would prefer to share Navigation responsibilities with other professional Navigators. The sample of doctors was small, however, and the findings may not be generally representative.

## Conclusions

A conclusion of this study is that Navigation should not be approached too narrowly or rigidly.

*Navigation work differs in diverse settings, and can be enacted by different professionals, who will differ in how they provide emotional and informational support, depending on population and specific health-system context.*

A singular model of Navigation is consequently not recommended, although Navigation should be in all cases systematic.

**The following core characteristics are recommended in order to structure future Navigation interventions:**

- intervention should be time limited and targeted to high risk phases and service delivery gaps;
- patient needs for information, support and practical help should be assessed;
- intervention should have the goal of 'patient preparedness';
- information should be paced;
- intervention should be supportive, but not psychotherapeutic.

The study data must be viewed with caution, since the pilot sample does not allow for strong conclusions. More studies are needed to test these questionnaires at a larger scale and with a controlled design.

**Based on the results, however, the following conclusions were drawn:**

- The theoretical framework and clinical model have face validity, and are clinically relevant and practical. They can be used by others involved in Navigation work, and should be tested empirically.
- The tools are useful and acceptable to patients and clinicians. Two of the developed tools in particular, the Patient Preparedness Questionnaire T1, and Patient Needs Identification Tool can direct and focus Navigator activities for individual patients, and in addition can be used as data collection instruments.
- The quasi-experimental design proved challenging to implement in a community setting, and if future work is to be conducted, the research team will need to be composed of investigators in different health jurisdictions, focusing on a small piece of Navigation.
- Including the family physician in Navigation work, including research, was identified as having potential value.

# Summary Report

## I. Background

The Canadian Strategy for Cancer Control, a consortium of stakeholders from across the country, identifies coordination of services as a key component in improving cancer care in Canada. The BC Cancer Agency (BCCA) identified the integration of cancer control programs in the community as a primary organizational objective. The imperative was to create models of integration and co-ordination using test sites, with the intention of developing community-based approaches for cancer control in other regions in the province. The BCCA has been interested in approaches to patient navigation for some time, and the Sociobehavioural Research Centre, located within the Provincial Rehabilitation Network of the BCCA, used an evidence-based approach to investigate facilitative models of Navigation.

The diagnosis and treatment of cancer may result in severe psychological morbidity for patients and their families. Although most cancer patients will eventually adapt to the diagnosis, about 30-50% will suffer significant emotional, psychological and social distress.

*Timely access to informational and emotional support around the time of diagnosis is crucial in helping patients adapt to their new circumstances, and be better prepared for navigating the health care system.*

The term 'Patient Navigation' is used to denote 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.

## II. Study Objectives

The BC work described in this report is comprised of a Phase 1: clarification of a model; and Phase 2: development and piloting of tools and methods.

**Phase 1 objectives** were to articulate a model of Navigation informed by:

- the needs and perspectives of different stakeholders, including patients, oncologists, family doctors, and decision-makers from regional health authorities;
- clinical practice – behaviours and functions fulfilled by health professionals as they enacted and evolved Navigator roles;
- research literature – developing evidence on psychosocial/supportive care needs of cancer patients, and evidence-based theories that could inform and guide the practice and evaluation of a psychosocial Navigation model.

**Phase 2 objectives** were to:

- identify theoretically- and clinically-relevant outcomes;
- develop instruments that could be used to structure the Navigator intervention and measure outcomes; pilot-test the instruments and the feasibility of conducting a rigorous empirical design in two practice settings.

## III. Clarification of a Navigation Model

Throughout the research process, the team held a series of consultations with informants and stakeholders in Navigation, including patients, oncologists within the Cancer Agency, researchers in nursing and community health, decision-makers in regional health authorities, and family practitioners.

Patient and expert consultant benefit when the patient understands the meaning of the information contained in their chart, and can engage in discussion about specifics and the immediate sequence of events. Navigators would therefore benefit both patients and doctors by coaching patients about proximate events, such as the next consultation or

procedure, and helping them develop a longer term sense of future events, while allowing room for the uncertainties.

Thus, in addition to the coordination and integration functions identified elsewhere, the research team determined that 'patient preparedness' should be a core outcome and function of the Navigator role.

## Test sites

Two test sites were identified, one in each of two of British Columbia's five regional health authorities: the Vancouver Island Health Authority (VIHA), and the Kootenay Boundary region (KB). Early in the research, the team engaged two Navigator informants from separate programs as project test sites. At the inception of this project, an investigator was designated to engage in dialogue with the Navigator and health professionals in each navigation program.

The VIHA program was situated in an urban setting, within a Breast Health Centre, and led by a breast-health nurse who provided a navigation service to breast cancer patients. The mandate of her program was to offer compassionate, quality care focused on each breast cancer patient's needs.

The KB program was situated in a rural region covering many thousands of square kilometres of winding roads and mountain passes, and was led by a social worker. Travel for patients and health professionals was a major challenge and a directing factor in how her role was conceptualized. The mandate was to help male and female cancer patients and their families across all tumour sites by providing information and emotional support, and where possible linking them with existing services.

## Identification of a psychosocial theoretical framework

The team reviewed four critical bodies of literature to develop a framework:

**Social support:** includes the structural aspects of social networks, such as the size of a person's social circle, or the number of resources provided, the functional aspects of social support including emotional support, or a sense of acceptance, and enacted support encompassing provision of specific supportive behaviours, such as reassurance or advice, in times of distress. Additionally, the subjective perception of support by the recipients was considered. While it is not clear which source of

support is superior, how support is conceptualized and mobilized may be critical in determining an intervention's ultimate success.

**Readiness for change:** This concept is helpful in deciding the needed type and sequencing of types of help and support. Whatever their best interests, patients may not in fact be ready to engage in decision-making about treatment choices. Anecdotal evidence and research on physician-patient interaction indicates that many patients are sufficiently upset about a positive diagnosis that they do not retain all information offered, and may then be unable to make prompt informed choices. Simply because the medical system desires the patient to act does not mean the patient is at the same point in decision-making.

**Coping behaviours:** This concept considers active coping which is problem solving, solution-oriented action; and passive coping which is more reflective, internal, and emotion-focused. Chronic health problems, however, cannot be readily fixed with a single course of action, and usually require emotional processing and acceptance. The choice of coping strategy will be significantly different when comparing, for example, the diagnosis of an early stage, localized melanoma which has an excellent prognosis, with a metastasised, rapid progression cancer in the colon, likely to require extensive emotional coping.

**Self efficacy:** can be defined as the confidence in one's ability to bring about desired actions and outcomes. Enhanced self-efficacy leads to improved behaviour, motivation, thinking patterns, emotional well-being, psychological adjustment, and health status. The research team became increasingly aware of the importance of '*Patient Preparedness*,' a concept which describes being accurately informed of a diagnosis, appropriate to the level of comprehension and complexity of the problem, together with having some understanding of the basic details of various tests, treatment options and outcomes. Psychological preparedness can lead to reduced post-surgical complications, reduced time spent in hospital, a reduction in medication usage, and longer cancer survival time.

*The underlying constructs of these theories point to ways of enhancing the individual sense of control, empowerment, and 'preparedness' in responding to stressful situations.*

The literature helped the research team define the roles of the Navigator operating within this expanded framework.

Both the literature and the clinical practice in the two BC programs highlight the critical role of facilitating patients' timely access to information and emotional support.

**The research team identified four themes as being core to a psychosocial Navigation model:**

**1. Driven by patient needs:** The aim should be to help patients to help themselves, with the understanding that timely access to appropriate information and services will ultimately assist patients in self-management.

**2. Context- or community- based:** To bridge gaps between patient and medical system effectively, the intervention must be flexible and responsive to local needs and strengths, mediating specific disconnects in their unique context.

**3. Time limited and targeted to high-stress phases:** The two BC Navigation programs demonstrate that a Navigator can realistically provide direct support for only a limited time period. It is therefore in the best interest of the patients and health system to have the interventions targeted at what have been identified as high-stress phases of the treatment trajectory, that is, at the time of initial diagnosis, immediately following treatment, and at the time of recurrence or a palliative diagnosis.

**4. The intervention is outcome-focused:** Navigation has the goal of 'patient preparedness' for consultation, treatment, and coping.

## IV. Development & Piloting of Tools

Once the characteristics of the navigation intervention were identified, the project team proceeded with 1) the identification of a range of potential outcomes from navigation, 2) the selection of measurable and theoretically-relevant outcomes, and 3) the operationalizing of outcomes in measures and tools.

The project team developed a comprehensive list of clinical and health-services outcomes that, in theory, should be possible, and then focused on a small subset of outcomes for which to develop and field-test instruments.

Validated instruments were used where possible. The project team developed several instruments to operationalize the notion of '*Patient Preparedness*' and to measure outcomes that were of practical and theoretical significance. In addition, a needs assessment tool was developed. The team also developed a questionnaire for surgeons and oncologists to rate the degree to which patients were prepared for the consultation.

### Measurement Tools

**Patient Preparedness Questionnaire - T1** measured the baseline level of patients' anxiety, interfering thoughts, and self-efficacy, and also included an additional section for demographic data: items on sex, age, marital status, ethnicity, education, and occupation.

**Patient Preparedness Questionnaire - T2** measured the above outcomes, as well as patient preparedness.

**Patient Preparedness Questionnaire - T3** contained two additional measures: Health resource utilization, and patient satisfaction. This questionnaire was intended to capture a number of outcomes related to patient informational and emotional preparedness. In the study, it was used as an interview at specific intervals.

**The Health Care Professionals Questionnaire (HCPQ)** was intended to capture surgeons' perceptions of patients' level of informational and emotional preparedness for the consultation. It is a brief questionnaire completed by the surgeon after the consultation.

**The Patient Needs Investigation Tool (PIN)** was designed by the project team to help the Navigator develop an individually-tailored intervention and to collect data systematically on patient needs. It was initially drafted based on cancer patients' needs identified in the literature with categories of needs, such as psychological needs, practical support needs, on the vertical axis; and sources of support, such as family and friends, community resources, and health professionals, on the horizontal axis.

## Pilot-testing the instruments

The team was interested in testing the feasibility of a prospective controlled design, which could potentially produce the strongest method for testing effectiveness. Thus the project team conducted a small study in the 2 sites to, 1) pilot the questionnaires, and 2) test the feasibility of using a quasi-experimental evaluation design.

*The objective of the feasibility study was to answer a number of methodological, operational and program questions, sufficient to provide the basis for the design of a larger, regional survey, and for planning future evaluation studies.*

In addition, the goal was to determine whether the questionnaires developed were acceptable in terms of length, ease of understanding, and timeliness. Given the short period available for running this pilot (3-4 months), a test of the effectiveness of the Navigation interventions was not conducted

In general, the methodology consisted of selecting a sample of patients around the time of diagnosis and before consultation with surgeon or other oncology specialist. The time window was selected because it is known to be critical, when patients are at highest risk of experiencing distress, and when the Patient Navigator may have the most beneficial impact. Thus an intervention aimed at providing pre-emptive emotional and educational support should target this pre-consultation time.

## Patient sample

To implement the study design in the VIHA site, the project team identified two groups of breast cancer patients. Patients in the Intervention Group were cared for in the Victoria area where the service of the Navigator was available. Patients in the Comparison Group received their care in the Nanaimo and Duncan geographical areas, approximately 60 miles from Victoria, where there was no Navigator available. Patients in both groups had to meet the following criteria: received first primary diagnosis of breast cancer; had not yet had surgery; older than 19 years of age, and English-speaking.

In the KB region, cancer patients could be men or women diagnosed with any form of cancer.

Some patients received surgery before radiation or chemotherapy treatment, whereas others received radiation or chemotherapy treatment before surgery. Patients were to be interviewed within one week after consultation with their surgeons (T1), within a week after consultation with their oncologists (T2), and a week after completion of radiation and/or chemotherapy treatment (T3). The patients' oncologists completed the HCPQ to assess their preparedness for the consultation visit. Patients were recruited from those who saw surgeons in the Kootenay Regional Hospital on the basis of these selection criteria.

## Response Rate

In Victoria, a total of 20 patients were eligible to participate, and 13 patients completed the questionnaires, resulting in a response rate of 65%. In KB, 12 patients met the criteria for inclusion and only two were not eligible. The response rate (33%) was lower than in Victoria.

## Health-care Professional Questionnaire

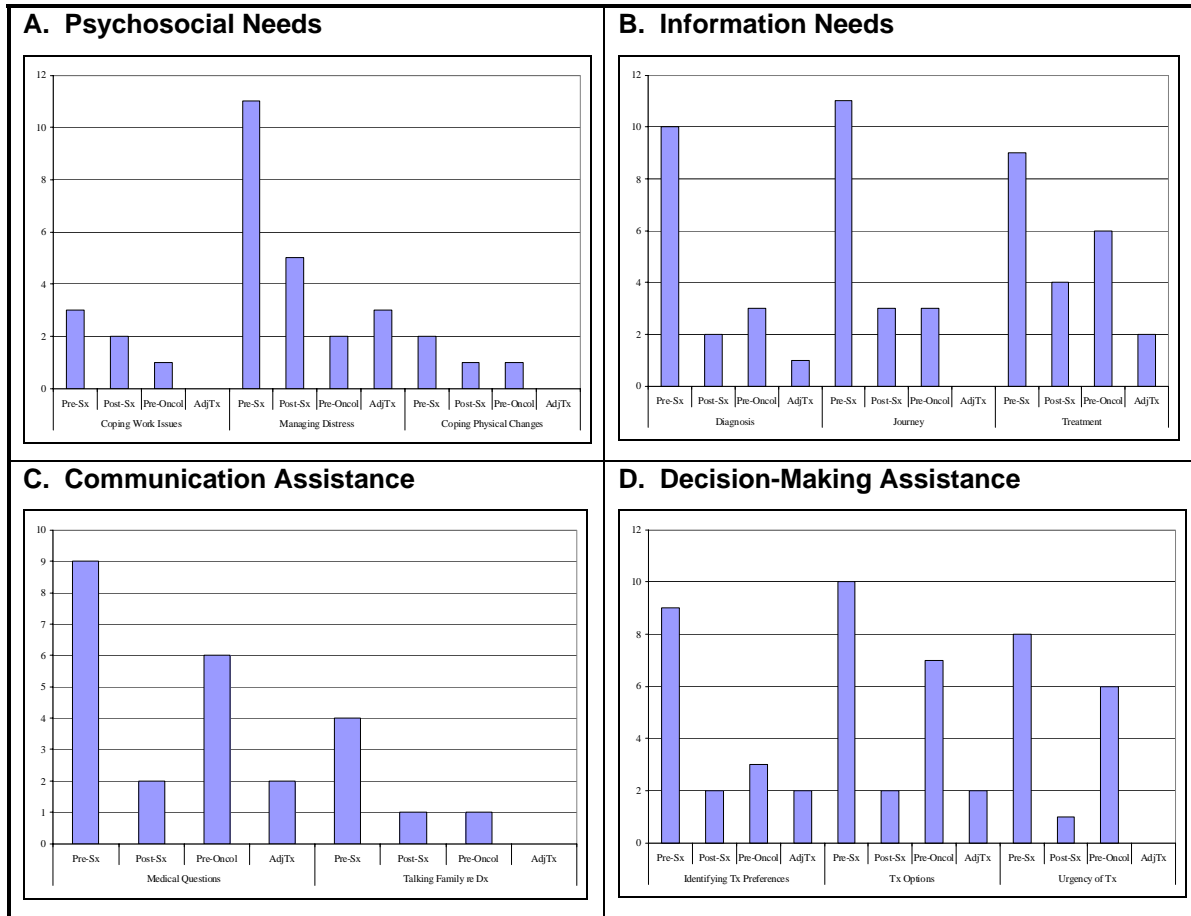
This questionnaire was intended to capture surgeons' perceptions of patients' level of informational and emotional preparedness for the consultation. Thirteen HCPQs were completed in total, all by surgeons in Victoria. This resulted in a 100 % response rate. Only two HCPQs were completed by oncologists in KB region, representing a very poor response rate.

## Patient Identification of Needs (PIN)

Navigators used the PIN with eleven patients during the pilot study. The patients who were seen four times were seen during all four phases identified by the team as most critical with regard to support: pre-surgery, post-surgery, pre-oncology visit, and during adjuvant treatment.

The first Navigation session, the pre surgical consultation, was always the longest, averaging 60 minutes in duration. Needs arising most often as requiring to be addressed were: psychosocial support, help with understanding medical information, help in communicating with others, help with decision-making, and practical support. Results are given in *Figure 1A-D*.

Figure 1: Patient Identified Needs



**Results**

Challenges to implementing the design were posed primarily by issues in coordination, integration and continuity within the different layers of health providers, and a shortage of time to conduct the pilot work. Recruitment was more difficult than expected, particularly in the KB region. One reason was the short time-window between family physician referral and surgical appointment.

The data presented here must be viewed with caution, since the pilot sample does not allow for strong conclusions. More studies are needed to test these questionnaires at a larger scale and with a controlled design. Despite the small sample, the findings from the feasibility study are encouraging.

**Positive results are:**

- The questionnaires had good acceptability, were easy to understand and required short time for completion;
- The response rates were good;
- These tools can be used for future studies to test reliability and validity.

In summary, despite the differences in the navigation programs and the backgrounds of the Navigators, both Navigators spent a similar amount of time with patients and provided similar services.

In both programs, patients' needs were most often identified as:

- psychosocial support,
- help with understanding medical information,
- help communicating with others, and practical support.

## Family Physicians

As part of the consultation process with other health care professionals, the team learned that many family physicians consider themselves as fulfilling a 'Navigator' function. Due to a number of factors, including lack of educational supports, patient volume, and the complexity of cancer care, however, many doctors cannot provide all the Navigation functions that their patients may find beneficial.

Therefore, family physicians were sampled to obtain an understanding of their perspectives on, and preferences about, the Navigator role, including how they would like to work with Navigators. In summary, these data indicate that the majority of physicians sampled do currently engage in some Navigator functions, but would value additional support of a cancer Navigator. Perceived barriers to doing more are insufficient time, and lack of easy access to needed *information and resources*.

*Most physicians (75%) would prefer to share navigation functions with a cancer Patient Navigator. 18.7% said they would prefer to delegate, and only 6.5% preferred to coordinate care themselves.*

The findings support the importance of the general practitioner's role, and indicate that family practitioners would prefer to share navigation responsibilities with other professional Navigators. To reiterate however, these findings represent a small sample of doctors, and may not be generally representative.

## V. Discussion

By providing a supportive context and listening ear, by providing appropriately-paced information relevant to the patient's immediate situation, and by helping the patient identify

gaps in necessary information and support, the Navigators observed in this study facilitated 'patient preparedness'. At the time of early diagnosis, 'preparedness' might lead to a medical decision and practical preparations for the circumstances of post-surgery. After treatment, 'preparedness' might involve finding a supportive community to help ease transition back to work and discovery of a new normality.

Both Navigators encouraged patients to use coping strategies that have worked for them in the past, offered additional strategies, and helped patients connect themselves to local resources and supports.

*Navigators aided patients in becoming more efficacious: to experience a greater sense of control, to be able to make informed decisions, and to care for themselves.*

Thus these constructs were highly salient to the work of the Navigators, and provided a meaningful theoretical framework for clarifying the intended outcomes and scope of the intervention.

Both Navigators were able to provide information and support as well as expedite patient access to resources. Differences in their approaches primarily reflected specific patient needs, and availability of local health services.

*Both Navigators fulfilled the function not only of increasing access and integration of health care services, but also of providing information and support both directly and indirectly.*

These are the essential characteristics of a facilitative Navigator model, and their flexible enactment demonstrates the model's strength.

## Conclusions

A conclusion of this study is that navigation should not be approached too narrowly or rigidly.

*Navigation work differs in diverse settings, and can be enacted by different professionals.*

*Furthermore, Navigators will differ in how they provide emotional and informational support, reflecting their professional training, their patient population, and the specific health-system context in which they operate.*

This flexible enactment should enable regional Health Authorities to appoint Navigators on the basis of local needs and personnel. It should also enable Navigators to develop their practice on the basis of needs, gaps, and their particular skills. However, Navigation should in all cases be systematic.

**The following core characteristics are recommended to structure future Navigation interventions:**

- Intervention should be time limited and targeted to high risk phases and service delivery gaps. Patient needs for information, support and practical help should be assessed.
- Intervention should have the goal of 'patient preparedness'.
- Information should be paced.
- Intervention should be supportive, but not psychotherapeutic.

In conclusion, a singular model of Navigation is not recommended, but Navigation work will be enhanced if the above features are explicitly developed and integrated into Navigation programs.

The study data must be viewed with caution, since the pilot sample does not allow for strong conclusions. More studies are needed to test these questionnaires at a larger scale and with a controlled design.

## **VI. Recommendations for Future Work**

To move Patient Navigation program development and research forward, the BCCA team initiated a national collaborative effort with an emphasis on implementation and integration of research and clinical practice, and bringing together program-developers, researchers and decision-makers from Nova Scotia, Quebec, Ontario, Alberta and BC. The plan is to identify common models, share assessment tools and

education materials, and identify challenges and opportunities for further development of Patient Navigation.

An initial meeting was held in the spring of 2005 under the auspices of the Canadian Strategy for Cancer Control (CSCC), Rebalance Focus Action Group. This group has accepted responsibility to work nationally by encouraging a collaborative effort in advancing work for patient navigation. A national approach is viewed as desirable despite the fact that navigation programs will be developed on a regional or provincial basis. Those interested in patient navigation have identified the importance of using common tools to forge ahead. Considering this approach a number of recommendations are made for future work.

### **Recommendation 1**

It is crucial that Navigation programs are developed in more communities according to the needs of patients, the existing strengths within communities and the financial resources of regional health authorities. Broad directives as to outcome, rather than rigid interpretation of process, will be most useful in ensuring flexible enactment, and best use of resources.

### **Recommendation 2**

One of the criticisms of instituting a professional Navigator role can be understood in the statement: *"rather than creating a role that fixes holes in the system, we should be fixing the system"*. Navigators can be catalysts for system change and should view their role as such. A single focus on patient needs without a broader awareness of possibilities for system change is likely to impede growth and implementation of Navigation approaches. When Navigators function as educators to physicians, as members of interdisciplinary teams, as community developers, they are adding value to their role and contributing to system change.

### **Recommendation 3**

Navigation programs need stable funding in order to provide ongoing, consistent, and expeditious care to all patients. The longer a Navigator is in the role, the greater is its potential value. Only with time do Navigators develop relationships with physicians and the community, and with providers of care and personnel in health authorities and regions.

#### **Recommendation 4**

Health authorities and the cancer centres need to work together, developing a common sense of the shared ownership of the programs. The Navigator should act to strengthen links between primary, tertiary, and Cancer Centre care. By establishing firm connections with family physicians, they facilitate more timely access during the initial diagnosis phase; by developing strong links with local cancer centres, they facilitate reliable access for patients returning to the community for adjuvant treatment or rehabilitation.

#### **Recommendation 5**

Navigators should be encouraged to use common patient assessment tools which serve two functions: directing the care plans of individual patients, and compiling a database documenting patient needs and system resources. This database would be available to improve services.

#### **Recommendation 6**

The creation of a national team or network should be supported for purposes of insuring communication between provinces and other jurisdictions to promote sharing of model development, approaches, data management and program evaluation in patient navigation. Consideration for funding applications to sustain such a team should be explored. A program of research should be pursued ideally through the development of a national research network.

